

# EUFASD 2016

12<sup>th</sup> - 15<sup>th</sup>  
September  
.....  
Royal Holloway,  
University of London

## FOURTH EUROPEAN CONFERENCE ON FASD

#EUFASD2016



Organised by the European FASD Alliance with  
collaboration of NOFAS-UK for the Training Day.



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In addition to those listed on the front cover, the following have also contributed:

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Fourth European  
Conference on FASD  
12 to 15 September 2016  
**Royal Holloway, University of  
London**

[www.eufasd.org](http://www.eufasd.org)

Conference chair: Raja Mukherjee

Organized by the European FASD Alliance

with collaboration of NOFAS-UK for the Training Day



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## Monday, September 12, 2016

Posters may be posted from 8:00 to 19:00. Please remove at end of day.

	Welcome
9:15 – 9:30	Raja Mukherjee, Susan Fleisher, Diane Black, Leopold Curfs
	Plenary Session 1: Where are we now?
	Session chair: Aurelijus Veryga, Lithuania
9:30 – 10:00	[1] Keynote: Ira Chasnoff, USA
	<b>40 years working with FASD. What has changed?</b>
10:00 – 10:30	[2] Keynote: Elizabeth Elliott, Australia
	<b>Fetal Alcohol Spectrum Disorder in Australia: from Fiction to Fact and to the Future</b>
10:30 – 11:00	[3] Keynote: David Townend, Netherlands
	<b>Legal and ethical questions posed by Fetal Alcohol Spectrum Disorder (FASD): responsibility, participation, and framing the debate</b>
11:00 – 11:30	<i>Coffee break and poster viewing</i>
11:30- 13:00	Parallel Session A
13:00 – 14:00	<i>Lunch and poster viewing</i>

	Plenary Session 2: Living with FASD
	Session chair: Marco Fiore
14:00 – 14:30	[4] Adults living with FASD: Lee Harvey-Heath and Claire McFadden
	<b>Personal Perspectives</b>
14:30 – 15:00	[5] Keynote: Lana Popova, Canada
	<b>Comorbidity associated with FASD</b>
15:00 – 15:30	[6] Keynote: Margaret Murray, USA
	<b>Thinking Globally and Acting Locally in Identifying, Treating, and Preventing FASD</b>
15:30 – 15:45	<i>Coffee break and poster viewing</i>
15:45 – 17:15	Parallel Session B
17:30 to evening	Ira Chasnoff Film : Moment to Moment

## Tuesday, September 13, 2016

Posters may be posted from 8:00 to 19:00. Please remove at end of day.

8:20 – 8:30	Opening
	Susan Fleisher
	Plenary Session 3: Recognizing the problem
	Session chair: Professor Barry Carpenter, CBE, PhD
8:30 – 9:00	[7] Keynote: Kate Fleming, UK
	<b>A critical review of what epidemiological studies have taught us about prenatal alcohol risk</b>
9:00 – 9:30	[8] Keynote: Paul Gard, UK
	<b>Low-dose chronic prenatal ethanol exposure alters serum aminopeptidase activity in adolescent mice</b>
9:30 – 9:50	[9] Katarzyna Dylağ, Poland
	<b>MRI findings amongst children with FASD</b>
9:50 – 10:20	[10] Keynote: Piyadasa Kodituwakku, USA
	<b>Comorbidity associated with FASD: a behavioural phenotype for FASD</b>
10:20 – 10:40	[11] Nina Kaminen-Ahola, Finland
	<b>Epigenetics of Fetal Alcohol Spectrum Disorders (epiFASD) project: Alcohol exposure during pregnancy alters DNA methylation and gene expression in human placenta</b>
10:40 – 11:10	<i>Coffee break and poster viewing</i>

	Plenary Session 4: Understanding the phenotype
	Session chair: Martha Krijgsheld, Netherlands
11:10 – 11:30	[12] Adoptive/foster parents: Sandra and Martin Butcher
	<b>Personal viewpoint: Lacking a post- diagnostic protocol for FASD in the UK parents struggle to fill that gap</b>
11:30 – 11:50	[13] Manon Spruit, Germany
	<b>Speech production disorders in children with FASD</b>
11:50 – 12:10	[14] Kieran O’Malley, Ireland
	<b>Clinical Phenotypes of of 30-35 children from Russia and Ukraine with NDPAE living in Ireland</b>
12:10 – 12:30	[15] Professor Barry Carpenter, CBE, PhD
	<b>Engaging Learners with FASD</b>
12:30 – 13:30	<i>Lunch and poster viewing</i>
13:30 – 15:00	Parallel Session C
15:00 – 15:30	<i>Coffee break and poster viewing</i>
15:30 – 16:30	Plenary Session 5: 5-min talks—What’s happening in my country?
	Session Chair: Penny Cook, UK
	[16] Romania: Teodora Ciolompea



	[17] Germany: Alison Frieling and Gisela Michalowski
	[18] Moldova: Dumitru Siscanu
	[19] Spain: Oscar Garcia Algar
	[20] Russia: Anait Marianian
	[21] Scotland: Maggie Watts
	[22] Israel: Yehuda Senecky
	[23] New Zealand: Kate Robertshaw
	[24] AFASAF, the young but active organization in Spain: Teresa Nuñez-Minguez, Montserrat Badia-Amate
	[25] South Africa: Leana Olivier
<b>16:45 – 17:30</b>	Business meeting; General Assembly of the Member Organizations
<b>19:00 – 23:00</b>	Gala dinner
	<i>Including presentation of poster prizes</i>

## Wednesday, 14 September 2016

8:20 – 8:30	Opening
	Leopold Curfs, Netherlands
	Plenary Session 6: More than just biology
	Session chair: Elena Varavikova, Russia
8:30 – 9:00	[26] Birth mothers: Samantha Marchant and Anne Russell
	<b>Personal experiences and stigma</b>
9:00 – 9:20	[27] Kathy Mitchell USA
	<b>Stamp out Stigma: How shame and blame hinder FASD prevention</b>
9:20 – 9:40	[28] Claire Coles
	<b>Prenatal alcohol exposure and transition to adulthood: Stress and resilience</b>
9:40 – 10:00	[29] Gerjo Kok, Netherlands
	<b>How to make social change for prevention of FASD</b>
10:00 – 10:30	<i>Coffee break</i>
	Plenary Session 7: The Way Ahead
	Session Chair: Thierry Maillard, France
10:30 – 11:00	[30] Elena Varavikova, Russia
	<b>Maternal ethanol consumption and FASD: A matter of health diplomacy</b>

<b>11:00 – 11:30</b>	[31] Mariann Skar, Eurocare
	<b>Preventing alcohol related harm to the unborn child at EU level</b>
	[31'] Miguel Del Campo, USA
	<b>Comprehensive evaluation of the fetal alcohol spectrum disorders in 83 children</b>
<b>11:30</b>	Announcement of Election Results: New Board for 2016 to 2018
<b>11:45</b>	Announcement of EUFASD 2018
<b>11:55</b>	Closing remarks
<b>12:15</b>	End

## Parallel Sessions A Monday morning

### **A1 [Room 1] [32] Focus on prevention campaigns for Fetal Alcohol Spectrum Disorders**

90-min workshop led by Gerjo Kok, Netherlands

### **A2 [Theatre] Supporting Adults with FASD**

Session chair Bérénice Doray, France

[33] Anne Russell, Australia **FASD and employment**

[34] Alanna Mihic, Canada **Sexual health promotion by care-providers of youth with fetal alcohol spectrum disorder: practices, barriers, and facilitators**

[35] Carmela Pestell, Australia **FASD and juvenile justice in Australia**

[36] Emma Weissblatt, UK **Clinical assessment of children and adolescents with complex neurodevelopmental difficulties and confirmed prenatal exposure to alcohol in a secondary care setting: an integrated service model and neuropsychiatric outcomes**

### **A3 [Room 2] Advances in diagnosis and medical management**

Session chair Magnus Landgren, Sweden

[37] Humberto Simões, Brazil **Auditory event-related evoked potential in schoolchildren exposed to alcohol during pregnancy: preliminary results**

[38] Eva Aring, Sweden **The 4-Digit Eye Diagnostic Code, a Tool for Eye Diagnostics in Fetal Alcohol Syndrome Disorders**

[39] Johanna M. H. Rau, Germany **Altered brain activity during response inhibition in female adults with FASD: a functional magnetic resonance imaging study**

[40] Michael Suttie, UK **A novel technique for the analysis of combined face-brain morphology and correlation with neurocognitive impairment in FASD**

[41] Pedro Coelho, Portugal **Pattern of Retinal Nerve Fiber Layer Thickness Loss in Fetal Alcohol Syndrome: A Spectral-Domain Optical Coherence Tomography Analysis**

### **A4 [Room 3] Social determinants**

Session chair Inyang Takon, UK

[42] Maria Xavier, Portugal **Pregnant women's perceptions of information about alcohol use during pregnancy: a qualitative pilot study**

[43] Daniela Fiorentino, Italy **Risk categories of alcohol consumption in a general population of pregnant women**

[44] Joanne Blake, UK **Documentation of maternal alcohol exposure during pregnancy and follow-up process for babies at risk of foetal alcohol syndrome**

[45] Gisela Michalowski, Germany **First Results of a Pretherapeutic Group for Adults with FASD and Risk of Addiction**

#### **A5 [Room 4] Biomarkers and Basic Research I**

Session chair Magdalena Borkowska

[46] Helen Howlett, UK **Prevalence survey of alcohol consumption at antenatal booking in pregnancy; comparing blood biomarker analysis to self-report**

[47] Valentina Carito, Italy **Prenatal ethanol exposure: cognitive and physiological effects in the offspring**

[48] Xavier Lieben Louis, Canada **Effect of docosahexaenoic acid (DHA) on DNA methylation in brain of rat fetuses prenatally exposed to alcohol**

[49] Oscar Garcia Algar, Spain **Segmental hair analysis to assess effectiveness of single session motivational intervention to stop ethanol use during pregnancy**

[50] Damien Bouvier, France **Biomarkers of Fetal Alcohol Syndrome in amniotic fluid: first results from rat model**

### **Parallel Sessions B Monday afternoon**

**B1 [Room 1] [51] Intractable Insomnia and Iron Deficiency in Prenatal Alcohol Exposure (PAE)**

90-min workshop led by Osman Ipsiroglu

**B2 [Theatre] Prevention I**

Session chair Patrizia Riscica, Italy

[52] Fiona Crawford-Williams, Australia **A public health intervention to change knowledge, attitudes and behaviour regarding alcohol consumption in pregnancy: A pilot randomised controlled trial**

[53] Stefania Bazzo, Italy **Using a visual questionnaire to investigate awareness and emotions of health professionals and pregnant women towards alcohol use and pregnancy. Findings from a comparative study in Northern Italy**

[54] Tatiana Balachova, USA & Russia **Effects of FASD education brochures on women's knowledge, attitudes, and alcohol use:outcomes in a randomized controlled trial**

[55] Nancy Poole, Canada **Preventing FASD in Canada: Closing the gaps between evidence and current practices**

[56] Roger Zoorob, USA **FASD prevention strategies in the primary care setting: A comprehensive, interprofessional method for implementation**

### **B3 [Room 2] Reaching the Professionals**

Session chair Neil Aiton, UK

[57] Heather Jones, Australia **Developing FASD educational resources for justice professionals**

[58] Jennifer Shields, Scotland **Professionals' confidence and knowledge of Foetal Alcohol Spectrum Disorder (FASD) within children's services in Scotland**

[59] Jolanta Terlikowska, Poland **Project of training socio-therapeutic community centers educators working with children with FASD**

[60] Gali Lackner, Israel **Medical students' knowledge about the damage to fetus due to in utero alcohol exposure: a cross sectional study**

[61] Denis Lamblin, France **The French National Academy of Medicine declares FASD prevention as a great national cause**

### **B4 [Room 3] Adult Outcomes**

Session chair Jan-Peter Siedentopf

[62] Joanna Buckard, UK **Outcomes for Adults with FASD in the UK- what's their narrative? A Qualitative pilot study**

[63] Emelie Gyllencreutz, Sweden **Ophthalmological findings in young adults with fetal alcohol syndrome disorders (FASD): a long-term follow-up study**

[64] Raja Mukherjee, UK **Neurodevelopmental outcomes in individuals with heavy prenatal alcohol exposure and a FASD diagnosis, with and without exposure to neglect: A natural experiment in patients seen in a national FASD diagnostic clinic. Initial findings**

[65] Jessica Wagner, Germany **Adults with Fetal Alcohol Spectrum Disorders: Health issues associated with a late FASD diagnosis**

[66] Jenny Rangmar, Sweden **Childhood placement in out of home care in relation to psychosocial outcomes in adults with FASD**

## **B5 [Room 4] Helping our children grow I**

Session chair Gro Lohaugen

[67] Carolyn Blackburn, UK **I'm going to be a superhero**

[68] James Fitzpatrick, Australia **The Lililwan\* Project: Neurodevelopmental outcomes and Fetal Alcohol Spectrum Disorders (FASD) prevalence in remote Australian Aboriginal children**

[69] Irina Volkova, Russia **Particularities of environing and personal alcohol consumption of bullying participants among Russian school-aged children**

[70] Teresa Jadczyk -Szumiło, Poland **Therapy program for children with FASD and their families**

[71] Deb Evensen, USA **Parents and teachers together can change the negative stigma of FASD and build a positive circle of support**

[72] Katarzyna Dyląg, Poland **Incontinence problems in children with FASD: a Polish study**

## **Parallel Sessions C Tuesday afternoon**

### **C1 [Room 2] [73] How to get your research published!**

90-min workshop led by Diane Black.

This is a unique opportunity for non-anglophone researchers to get training by an experienced teacher of academic writing courses. Includes 3 hours of coaching by e-mail and Skype. Gratis and limited to 12 participants. For more information or to sign up, mail to [d.m.black@rug.nl](mailto:d.m.black@rug.nl).

### **C2 [Theatre] Prevention II**

Session chair Joanna Buckard, UK

[74] Lori Vitale Cox, Canada **Reducing the prevalence of FASD primary and secondary disabilities using a community based approach to FASD prevention in an Atlantic First Nation**

[75] Stefania Bazzo, Italy **An international communication campaign to raise public awareness of Fetal Alcohol Spectrum Disorders. A feedback from participant organizations**

[76] Sandra Gonzalez, USA **FASD prevention in the U.S.: An innovative approach to systems change**

[77] Sylvia Roozen, Netherlands **Understanding Fetal Alcohol Spectrum Disorders (FASD) and maternal alcohol consumption during pregnancy**

[78] James Fitzpatrick, Australia **'Making FASD history' in Australia: Successful evidence-based, population-level programs of FASD Prevention, Diagnosis and Treatment in remote Australian communities**

### **C3 [Room 1] Helping our children grow II**

Session chair Ges Gregory, UK

[79] Sharon Dawe, Australia **Interventions for children with Fetal Alcohol Spectrum Disorders: where to next?**

[80] Claire Coles, USA **Improving neurocognition and behavior in children FASD: GoFAR, a metacognitive intervention**



[81] Valdemar Landgren, Sweden **Physical and intellectual development as well as psychiatric symptoms in young adults diagnosed with Fetal Alcohol Syndrome as children**

[82] Ana Hanlon-Dearman, Canada **Supporting Attachment in Preschool Children with FASD: A Descriptive Study Using the Circle of Security Home Visiting Program**

[83] Jane Thistlethwaite, New Zealand **Reaching and Teaching Learners with FASD, Implementing the Engagement for Learning Programme – A New Zealand Case Study**

[84] Raja Mukherjee, UK **Social communicatory deficits, autistic spectrum disorder and other neurodevelopmental consequences across the lifespan associated with prenatal alcohol exposure and FASD: Findings from the UK FASD National Specialist Behaviour Management Clinic**

#### **C4 [Room 3] Biomarkers and Basic Research II**

Session chair Katarzyna Dyląg, Poland

[85] Oscar Garcia Algar, Spain **Fetal Alcohol Exposure:relationship between ethyl glucoronide and maternal hair during pregnancy**

[86] Cheryl McQuire, UK **Early identification of risk for Fetal Alcohol Spectrum Disorders: a systematic review of biomarkers of prenatal alcohol exposure**

[87] Scott Parnell, USA **Synergistic actions of ethanol and synthetic cannabinoids during early gestation in a mouse model: Teratogenesis and potential mechanisms**

[88] Lesley Smith, UK **Exploration of alcohol consumption, antioxidants and fetal growth: Secondary Analysis of the Avon Longitudinal Study of Parents and Children (ALSPAC)**

#### **C5 [Room 4] Surveillance and screening**

Session chair Carolyn Blackburn, UK

[89] Katarzyna Okulicz-Kozaryn, Poland **FASD in biological and non-biological families in Poland**

[90] Peter Hammond, UK **Introducing computerised 3D face screening to the FASD clinic**

[91] Sarah Brown, Scotland **The development of the Prenatal Alcohol Investigation and Resource Service (PAIRS) in NHS Ayrshire & Arran**

[92] Bérénice Doray, France **Reunion Island, First French region to benefit from a specific Resource Center dedicated to the prevention, diagnosis, support and care of the persons afflicted by FASD**

[93] Christopher Steer, Scotland **The incidence of Fetal Alcohol Syndrome in Scotland. An enhanced passive surveillance study**

## List of Posters

Monday			
M1	Ges	Gregory	Identifying Children who are at Risk of Fetal Alcohol Spectrum Disorders in a Community Paediatric Setting.
M2	E Sharon	Brintnell	Expressing the Functional Profile of Adults Assessed for FASD
M3	Kelly D	Coons	"Well in Europe they drink all the time": Ontario health care students' attitudes regarding alcohol use during pregnancy
M4	Sharon	Dawe	Establishing an FASD assessment and diagnostic clinic: who we saw and caregiver's views
M5	Vicki	Russell	FASD and problem intractability
M6	Helen	Howlett	Alcohol screening in pregnancy: an opportunity for support and education?
M7	Lesley	Smith	Exploration of Dietary Patterns, Micronutrient Intakes and Heavy Drinking During Pregnancy: Secondary Analysis of the Avon Longitudinal Study of Parents and Children (ALSPAC)
M8	Laura Charlotte	Harrison Willis	Fetal Alcohol Spectrum Disorder: The Difficulties of Identification and Diagnosis of Adolescents and Adults with FASD
M9	Anuradha	Shetye	Fetal Alcohol Spectrum Disorder and external / middle ear problems - A retrospective audit to establish working together
M10	Maria	Xavier	Children prenatally exposed to alcohol -- a case study in north of Portugal
M11	Stefania	Bazzo	Evaluation of a multilevel and integrated program to raise awareness of the risks of prenatal exposure to alcohol in Italy
M12	Elena	Molchanova	Raising a child with FASD--experience of Russian parents
M13	Osman	Ipsiroglu	Prenatal alcohol exposure alters sleep patterns in young rats

M14	Marlene	de Vries	A case study from south Africa of a woman with multiple children with Fetal Alcohol Spectrum Disorders: alcohol use, social, and childbearing history
M15	Martha	Krijgsheld	The Fetal Alcohol Syndrome Foundation of the Netherlands
M16	Elizabeth	Henderson	Patterns and Prevalence of Alcohol Consumption In Pregnancy Using Infant Biomarkers

## Tuesday

T1	Anna-Susan	Marais	A Follow-up Study of the Epidemiology of Fetal Alcohol Spectrum Disorders in a Community in South Africa
T2	Belinda	Joubert	The role of fathers in pregnancies involving high-risk drinking mothers
T3	Carisa	Siemens	Life in four rural communities in South-Africa having the highest ever recorded prevalence of FASD
T4	Alison	Frieling	Living Accommodation for People Affected by FASD
T5	Alison	Frieling	FASD Deutschland e.V.--How our organisation works
T6	Alan	Price	Compounding effects of fetal alcohol spectrum disorders and early childhood trauma: A systematic review
T7	Anne	Koponen	Alcohol and/or substance abuse during pregnancy: effects on maternal welfare and developmental outcome of children -- a research plan
T8	Raja	Mukherjee	Exploring the experiences of birth mothers whose children have been diagnosed with Fetal Alcohol Spectrum Disorders: a Qualitative study.
T9	Raja	Mukherjee	Neurodevelopmental Disorder Associated with Prenatal Exposure to Alcohol (ND-PAE): A comparison of criteria against IOM and 4 Digit classification systems.
T10	Daniela	Fiorentino	The value of a comprehensive neuropsychological

			evaluation on treatment outcomes of a child with FASD: single case report
T11	Yadava	Campbell	The role of educational psychologists (EP) in supporting early years (EY) and primary school children with fetal (foetal) alcohol spectrum disorders (FASD) in the UK
T12	Laia	Martinez Ribot	Following a group of foster families until they get the diagnosis of Fetal Alcohol Syndrome Disorder
T13	Nuria	Gómez Barros	Psychiatric disorders in a sample of Russian adopted children with Fetal Alcohol Spectrum Disorder
T14	Magdalena	Borkowska	Case study of a child diagnosed with FASD-- educational and upbringing goals
T15	Humberto	de Oliveira Simões	T-ACE and AUDIT scores correlate with FAEEs concentrations in meconium

## **Conference Chairman: Raja Mukherjee**

### **Scientific Planning Committee**

Barry Carpenter (UK)

Leopold Curfs (Netherlands)

Marco Fiore (Italy)

Kieran O'Malley (Ireland)

Moira Plant (UK)

Elena Varavikova (Russia)

Aurelijus Veryga (Lithuania)

### **Local Planning Committee**

Inyang Takon

Ges Gregory

Penny Cook

Neil Aiton

Philippa Williams

Emilios Lemoniatis

Joanna Buckard

Carolyn Blackburn



The EUROPEAN FETAL ALCOHOL SPECTRUM DISORDERS ALLIANCE was founded in February 2011 to meet the growing need for European professionals and NGOs concerned with FASD to share ideas and work together. The EUROPEAN FASD ALLIANCE is a non-profit international organization registered in Sweden.

Our goals are

- To support the member associations in their efforts to improve the quality of life for all people with Fetal Alcohol Spectrum Disorders and their families
- To improve awareness of the risks of drinking alcoholic beverages during pregnancy.

The EUROPEAN FASD ALLIANCE will also act as a liaison centre

- To collate and disseminate information to its members
- To stimulate international collaboration on research projects on the origins, management and prevention of Fetal Alcohol Spectrum Disorders
- To encourage national associations to exchange and share their projects and experiences
- To foster the foundation and development of new national FASD Associations.

#### **The Board**

Diane Black (Netherlands)  
Katarina Wittgard (Sweden)  
Giorgie Petković (Croatia)  
Susan Fleisher (United Kingdom)  
Oscar Garcia-Algar (Spain)  
Martha Krijgsheld (Netherlands)  
Simona Pichini (Italy)  
Thierry Maillard (France)  
Philippa Williams (United Kingdom)

#### **The Scientific Advisory Council**

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Denis Lamblin (France)  
Ilona Autti-Rämö (Finland)  
Hans Spohr (Germany)  
Consuelo Guerri (Spain)  
Paul Peters (Netherlands)

#### **The Council of Lifelong Experts**

Lena Larsson (Norway)  
Donna Ross (Scotland)  
Lee Harvey - Heath (England)  
Karl Wittgard (Sweden)

[1]

## **40 years of working with FASD. What has changed?**

**Ira Chasnoff**

*NTI Upstream, Chicago, Illinois, United States*

The Biblical injunction against drinking alcohol during pregnancy is the first known reference to the harm that alcohol can cause for the developing child. Our understanding of alcohol's teratogenic effects has expanded enormously since that time, of course, but there remains a broad range of unknown facts and factors that challenge us to continue our work on behalf of children and families. This session will review the history of FASD, examine the past 40 years, and look toward future efforts, including prevention, that require our attention.



[2]

## **Fetal Alcohol Spectrum Disorder in Australia: from fiction to fact and to the future**

**Elizabeth Elliott**

*University of Sydney; The Sydney Children's Hospitals Network, Australia; National FASD Technical Network*

In 2000, fewer than 5 Australian publications on FASD existed in the medical literature, there was little clinical expertise, no parent support group and no diagnostic guidelines. I will provide an historical overview of advances made since then in addressing FASD in Australia. I will outline progress by clinicians and researchers in providing evidence to persuade authorities that FASD is in the realm of Fact, not Fantasy. I will outline the important role of NOFASD in supporting parents and of NGOs e.g. the Foundation for Alcohol Research and Education (FARE) in pursuing the FASD agenda. Data from the Lirilwan Project, which advanced knowledge about alcohol use in pregnancy and FASD in remote Aboriginal communities, will be presented, as will data from current birth cohort, animal, epidemiological, intervention and prevention studies in Australia. Government initiatives include the: Ministerial Council for Drugs Strategy Working Party on FASD; Parliamentarians for the Prevention of FASD; and the 2011 House of Representatives Inquiry into FASD (The Hidden Harms), which culminated in \$20 million from the Federal Government for an 'action plan' for FASD. This includes funding for services to pregnant women, a National FASD Hub, a National FASD register, a National FASD Technical Network, and an Australian Guide to the Diagnosis of FASD. Clinical and Research Networks, including the NHMRC Centre for Research Evidence (Reducing the Effects of Antenatal Alcohol on Child Health) and provision of targeted NHMRC funding for FASD research will be described. Through a collaborative national approach Australia has made great gains in a short time. However many challenges remain if we are to adequately support families living with FASD and prevent it from stealing future generations.

### [3]

## **Legal and ethical questions posed by Fetal Alcohol Spectrum Disorder (FASD): responsibility, participation, and framing the debate**

**David Townend**<sup>1,2</sup>, Sylvia Roozen<sup>2,3</sup>, Gjalte-Jorn Peters<sup>2,4</sup>, Gerjo Kok<sup>2,3</sup>, Ger Koek<sup>2,5</sup>, Jan Nijhuis<sup>2,6</sup>, and Leopold Curfs<sup>2,7</sup>

<sup>1</sup> *Department of Health, Ethics & Society, Maastricht University, The Netherlands*

<sup>2</sup> *Governor Kremers Centre, Maastricht University Medical Centre+, The Netherlands*

<sup>3</sup> *Department of Work and Social Psychology, Maastricht University, The Netherlands*

<sup>4</sup> *Faculty of Psychology and Education Science, Open University of the Netherlands*

<sup>5</sup> *Department of Internal Medicine, Maastricht University Medical Centre+, The Netherlands*

<sup>6</sup> *Department of Obstetrics & Gynaecology, Maastricht University Medical Centre+, The Netherlands*

<sup>7</sup> *Department of Clinical Genetics, Maastricht University Medical Centre+, The Netherlands*

FASD is becoming better understood in medical science, and there are increased attempts to address it in Law. These developments pose a number of ethical and legal questions that are not confined to FASD, but are common to many developments in personalised medicine (and, for example, the “participation society” in the Netherlands). They are issues about personal and collective responsibility, and about defining and requiring “doing the right thing”.

In this paper, we first explore recent developments in different jurisdictions to address issues relating to FASD in the Law. Thereafter, we will revisit questions about responsibility to the unborn child not from the perspective of managing the behaviour of mothers, but from the perspective of managing social expectations around alcohol. We consider the question of advertising, drawing comparisons with other health promotion and education programmes, particularly in the European Union. Finally, we consider the construction of the debate, and particularly the usefulness of ethics in demanding responsibility - in framing “doing the right thing”. We observe the contested nature of ethics, and present theories that address the process of framing ethical debate underpinning the operation of democracy - particularly discourse ethics, virtue ethics and ‘politeness’.

[4]

## **Adults living with FASD**

**Lee Harvey Heath and Claire McFadden**

## [5]

### Comorbidity of Fetal Alcohol Spectrum Disorder

**Svetlana Popova**<sup>1,2,3,4</sup>, Shannon Lange<sup>1,4</sup>, Kevin Shield<sup>5</sup>, Alanna Mihic<sup>2</sup>, Albert E. Chudley<sup>6</sup>, Raja A. S. Mukherjee<sup>7</sup>, Dennis Bekmuradov<sup>8</sup>, Juergen Rehm<sup>1,2,4,9</sup>

<sup>1</sup> *Social and Epidemiological Research Department, Centre for Addiction and Mental Health, Toronto, ON Canada*

<sup>2</sup> *Dalla Lana School of Public Health, University of Toronto, Toronto, ON Canada*

<sup>3</sup> *Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, ON Canada*

<sup>4</sup> *Institute of Medical Science, University of Toronto, Toronto, ON Canada*

<sup>5</sup> *International Agency for Research on Cancer, Lyon, France*

<sup>6</sup> *Program in Genetics and Metabolism, Children's Hospital, Departments of Pediatrics and Child Health and Biochemistry and Medical Genetics, University of Manitoba, Winnipeg, Manitoba, Canada*

<sup>7</sup> *FASD Specialist Behaviour Clinic, Surrey and Border's Partnership NHS Foundation Trust, Oxted, UK*

<sup>8</sup> *School of Occupational and Public Health, Ryerson University, Toronto, ON, Canada*

<sup>9</sup> *Epidemiological Research Unit, Klinische Psychologie und Psychotherapie, Technische Universität Dresden, Dresden, Germany*

**Objectives:** Current study aimed to (1) identify the comorbid conditions that co-occur in individuals with FASD, and (2) estimate the pooled prevalence of comorbid conditions co-occurring in individuals with Fetal Alcohol Syndrome (FAS).

**Materials and methods:** A systematic search for studies reporting on the comorbidity among individuals with FASD was conducted using multiple electronic bibliographic databases according to standardized international protocols (i.e., Preferred Reporting Items for Systematic Reviews and Meta-Analyses). All comorbid conditions were coded according to the International Statistical Classification of Diseases, tenth revision (ICD-10). To estimate the pooled prevalence of comorbid conditions found to co-occur in individuals with FAS, meta-analyses were conducted, assuming a random-effects model.

**Results:** Four hundred and twenty-eight comorbid conditions, which span across 18 (out of 22) chapters of the ICD-10, were identified to co-occur in individuals with FASD. Moreover, the results of 183 meta-analyses are reflective of the well-documented central nervous system damage caused by prenatal alcohol exposure, with specific conditions within the language, auditory, visual, and mental and behavioural domains having a pooled prevalence between 50% and 91% in individuals with FAS.

**Conclusion:** The high prevalence of comorbidity in individuals with FASD, especially when compared to the general population, highlights the importance of assessing prenatal alcohol exposure as a significant clinical risk factor for comorbidity.

[6]

## **Thinking globally and acting locally in identifying, treating, and preventing FASD**

**Margaret M. Murray**

*Director, Global Alcohol Research Programs, National Institute on Alcohol Abuse and Alcoholism, U.S. National Institutes of Health*

A new word "Glocal", has come into being to describe the idea of "Thinking Globally, Acting Locally." This concept was first used by environmental activists in the 1970's, subsequently spread to business and industry, and now is articulated in issues of public health. What does it mean for the FASD community? FASD has been identified in many countries throughout the world, and the health, development, and education of affected children and families has been the topic of a number of international conferences and activities. A global research consortia, CIFASD, funded by NIAAA, is focused on increasing understanding of FASD through building collaboration among scientists from many countries. The World Health Organization is conducting a prevalence study in very low income countries, has supported training of health care specialists in diagnosis, and has published guidelines on treatment of substance use disorders in pregnant women. How can global work on FASD be combined with local solutions to better identify, prevent, and treat the disorders resulting from prenatal alcohol exposure? How can working across communities, nations, and continents improve outcomes in all of these areas? This presentation will highlight some of the important work that is ongoing at global and local levels and suggest ways that, through working together, success can be accelerated.

[7]

## **A critical review of what epidemiological studies have taught us about prenatal alcohol risk**

**Kate Fleming**

*Liverpool John Moores University, Liverpool, United Kingdom*

That high levels of alcohol intake during pregnancy can cause damage to the fetus is no longer controversial. However, one of the most common questions posed within the professional communities dealing with children and families affected by fetal alcohol spectrum disorder, by alcohol policy makers, and particularly by women who are pregnant or considering becoming pregnant, is "What is the safe level of alcohol consumption during pregnancy?"

This session will provide an overview of the epidemiological studies that have tried to answer this question using traditional observational techniques particularly highlighting the limitations of these historic studies. Under consideration will be the absence of consistently robustly recorded information on prenatal alcohol exposure; the variety in outcome measures that render comparisons of these studies difficult; and the ability, or lack thereof, to control for confounding or mediating factors acting both prenatally and postnatally.

Further consideration will be given to some of the more recent methodological advances, such as Mendelian randomization, and a resurgence of group comparison designs to highlight additional ways of approaching answering the question "What is the safe level of alcohol consumption during pregnancy?"

[8]

## **Low-dose chronic prenatal ethanol exposure alters serum aminopeptidase activity in adolescent mice**

Paul R. Gard

*School of Pharmacy and Biomolecular Sciences, University of Brighton, Moulsecoomb, Brighton, UK*

Adolescent mice (3-6 months) produced from breeding harems receiving 5% ethanol via drinking water preconception and throughout pregnancy and lactation showed reduced exploratory behaviour in the novel object recognition test of learning and memory in both male and female off-spring, and in male off-spring abolition of the pro-cognitive effect of the endogenous neuropeptide angiotensin IV. In the elevated plus-maze test of anxiety-like behaviour the results indicated that prenatal alcohol exposure (PAE) had an anxiolytic effect in males but not females. Following the recent report that enzymes involved in the synthesis and action of angiotensin IV are altered in the plasma of patients with Alzheimer's disease, the current study explored the effects of PAE on serum aminopeptidase activity in adolescent mice.

Breeding harems received 5% ethanol via their drinking water preconception and throughout pregnancy and lactation. Off-spring then received tap-water following weaning (21 days). Post-mortem brain and serum samples were collected at 2 months of age and the activities of aminopeptidases (Ap) A, B and N, aspartyl aminopeptidase and insulin-regulated aminopeptidase (IRAP) were determined.

Measurement of the harem fluid consumption suggested that the ethanol intake in the current study equated to a human daily ethanol intake of approximately 10g, the equivalent of one bottle of table wine.

PAE decreased brain activity of ApN, aspartyl aminopeptidase and IRAP in male and female mice and ApB in female mice only. There was no change in ApA. Considering serum enzyme activity, IRAP activity was decreased in female offspring but increased in male offspring and ApA was increased in male offspring but unchanged in female.

It is recognised that plasma and serum activity of these enzymes differ between mice and Humans, and the apparent lack of correlation between brain and serum enzyme activity in mice requires further exploration. However these results indicate that aminopeptidase activity is altered in a mouse model of PAE, and that the changes correlate with demonstrated deficits in learning and memory. That the changes persist into adolescence, beyond the period of alcohol exposure suggests that the enzymes



may be a lasting peripheral /diagnostic marker of PAE or of behavioural deficit / neuronal damage.

[9]

## **Magnetic Resonance Imaging (MRI) findings among children with FASD**

**Katarzyna Dylag**

*Jagiellonian University Medical College/St. Louis Children Hospital, Kraków, Poland*

**Background:** The aim of the study was to analyze the findings in MRI of the brain amongst children diagnosed with fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) or alcohol related neurodevelopmental disorders (ARND). The issue has been studied in several researches previously but the experts agree that there is still few data on the MRI results in the group of younger children.

**Methods:** MRI results of 121 patients with either FAS or pFAS or ARND diagnosed with Canadian criteria were analyzed regarding the presence of abnormalities. The group consisted of 71 patients diagnosed with FAS, 33 diagnosed with pFAS and 17 diagnosed with ARND. The mean age of the patients was 8.09 years old, SD=4.04.

**Results:** In the total group of FASD patients 61.98% of the patients' MRI results were abnormal. The most common abnormality in MRI of the patients were demyelination plaques (incidence 23.14%) and corpus callosum narrowing (20.66%) as well as ventricular asymmetry (18.8%).

The demyelination plaques and corpus callosum narrowing were more frequent among children less than the age of 4 ((39.13% vs 19.39%;  $p=0.04$ ) and (47.83% vs. 14.29%  $p=0.00$ ) respectively). Among younger children multiple central nervous system abnormalities were observed more often than in the older age group (52.18% vs. 15.31%  $p<0.001$ ). Furthermore, in the analysis according to the specific diagnosis, among the patients diagnosed with FAS multiple anomalies were more common than in pFAS and ARND. Odds ratio for multiple changes per one year increase in age was 0.84 (95% CI 0.73-0.97),  $p=0.016$

**Conclusion:** In structural brain MRI of younger children multiple anomalies were found more frequently than among older children. Demyelination plaques and corpus callosum agenesis were more common in younger FASD patients than in older ones.

[10]

## **Co-morbidity associated with FASD: a challenge to defining a behavioral phenotype**

**P.W. Kodituwakku**

*University of New Mexico School of Medicine, Albuquerque, NM, USA*

It has long been recognized that children with FASD display a broad range of co-morbid conditions, particularly behavioral problems and emotional disturbances. Lemoine et al. (1968) reported that a majority of children with prenatal alcohol exposure showed hyperactivity, aggression, and language difficulties. A recent meta-analysis of the findings from 33 studies of FASD revealed 183 co-morbid conditions that co-occur in individuals with FASD (Popova et al, 2016), with 4 conditions having the highest pooled prevalence rates. These included disorders of peripheral nervous system and senses, conduct disorder, receptive and expressive language deficits and chronic serous otitis media. The prevalence rates of comorbid conditions in children with FASD are known to vary by age. Insecure attachment, irritability, and depressive symptoms stand out among the behavioral difficulties during infancy and early childhood. During their middle childhood, children with FASD have been observed to show signs of ADHD, oppositional defiant disorder, mood disorders, depression and anxiety (O'Connor & Paley, 2009). Researchers have found high prevalence rates of psychiatric problems and substance abuse among adolescents and adults with prenatal alcohol exposure (Streissguth et al., 2004). The fundamental question that remains unanswered concerns the causality of these co-morbid conditions. Most investigators assume that alcohol-induced brain damage leads to these conditions. On closer examination, however, children with prenatal alcohol exposure are often found to have complex prenatal and postnatal histories. In a recent survey, we found that a sizeable proportion of alcohol -exposed children had experienced toxic stress (neglect, exposure to violence, physical/sexual abuse) and had numerous genetic/epigenetic risk factors. Therefore, it is reasonable to suggest that multiple risk factors 'working together' (Kraemer et al., 2001) produce co-morbid conditions in individuals with FASD.

[11]

## **Epigenetics of Fetal Alcohol Spectrum Disorders (epiFASD) project:**

### **Alcohol exposure during pregnancy alters DNA methylation and gene expression in human placenta**

Heidi Marjonen<sup>1</sup>, Hanna Kahila<sup>2</sup>, **Nina Kaminen-Ahola**<sup>1</sup>

*<sup>1</sup>Department of Medical Genetics, Medicum, University of Helsinki, Finland, <sup>2</sup>Department of Obstetrics and Gynecology, University of Helsinki and Helsinki University Hospital, Finland*

Both genetic variation and environment affect the embryonic development, generating phenotypic differences between individuals. To clarify the epigenome's role as a mediator of the environment's effects on gene regulation, we have explored maternal alcohol consumption as environmental exposure. In our Epigenetics of Fetal Alcohol Spectrum Disorders (epiFASD) project we have collected biological samples immediately after birth from alcohol-exposed and control newborns. By revealing the alterations in gene regulation that lead to the variable phenotypic characteristics of FASD, it is possible to develop biomarkers. Early diagnosis enables appropriate support for development, which has an important role in the therapy of affected children.

We have started a pilot study with 30 alcohol-exposed and 50 control placentas. Due to alcohol-induced growth restriction in the phenotype of affected children, we have studied imprinted genes that control embryonic growth and development. In our preliminary work we have focused on changes in the epigenome and gene expression in *Insulin-like growth factor 2 (IGF2)/H19* locus. Interestingly, we have observed significant alcohol-induced changes in DNA methylation and gene expression in this locus in placenta.

[12]

## **Lacking a post- diagnostic protocol for FASD in the UK parents struggle to fill that gap**

**Sandra Butcher, Martin Butcher**

*Adoptive parents of an 11-year-old child with FAS, organisers of the East Hertfordshire and Area FASD Support Network, UK*

**Background:** Parents face a vacuum upon receiving an FASD diagnosis for their child. This session will provide healthcare and service providers an opportunity to "turn the table" and explore what the critical post-diagnostic period is like from the parents' perspective.

A recent journal article highlighted the lack of research into the lived experience of families with children with FASD. This session will offer an insight into one family's experience of raising an adopted child for 10 years, having received the FAS diagnosis two years ago.

Clinicians, educators, social workers and other professionals will gain an enhanced understanding of how parents react to and manage life after receiving an FASD diagnosis, including how parents manage with

- Absorbing the diagnosis without clear support systems in place.
- Overcoming confusion created by patchy understanding of FASD in the medical community which then impacts their ability to steer through multiple diagnoses, medication, access to various services.
- Helping the SENCO and providing information to schools where FASD is unknown/little understood. Struggling with decisions regarding the best educational setting with very little guidance.
- Researching and learning appropriate strategies for parenting and discipline for confusing and often extreme behaviours.
- Researching and accessing social care support that may be available but not adapted to FASD
- Becoming parent advocates and balancing these added pressures while trying to keep your own family afloat.
- Dealing with strains on relationships and fears of the future.

**Conclusion:** By gaining an increased understanding of the situation facing FASD affected families in that post diagnostic period and the steep learning curve families face with little support, clinicians and professionals will have an enhanced ability to provide support for children with FASD and their families.

## [13]

### Speech production disorders in children with FASD

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<sup>3</sup>*Faculty of Medical Science, Groningen University, The Netherlands*

In terms of cognitive functioning, fetal alcohol spectrum disorders have been associated with deficits in attention, learning, and executive functions, mental retardation, fine and gross motor difficulties, hearing disorders, and language and speech impairments. However, the speech production problems in children with FAS have not yet been described in detail.

The present study comprised a detailed investigation of phonological and speech-motor characteristics of the speech of children with FASD. By investigating commonalities and individual differences in phonological and speech motor development in children with FASD as compared to typically developing children, we aimed to identify the mechanisms underlying concomitant speech impairment in FASD.

Ten children aged 5.5–10.3 years (mean=7.2, SD=1.9) that were diagnosed with FASD by a specialized pediatrician and 25 typically developing children aged 4.1–8.7 years (mean=5.6, SD=1.4) participated in the study. Half of the children with FAS had a history of or still received speech therapy. Speech production, -perception, and oral-motor data were collected using standardized tests.

Results showed that the children with FASD were less intelligible and made more and more varied consonantal errors compared to typically developing children. Although the pattern of errors showed strong similarities with patterns that occur during normal development, the pattern of correlations with oral motor and auditory discrimination skills was very different in the group of children with FAS as compared to the typically developing children. Implications for diagnosis and treatment of speech production problems in children with FASD will be discussed.

[14]

## **Clinical phenotypes of 30-35 children from Russia and Ukraine with NDPAE living in Ireland**

Kieran D O'Malley

*Slievemore Clinic, Dublin, Ireland*

**Background:** Ireland has a long tradition of children being adopted both out and into the country. In the 1950s and 1960s a significant number of children were adopted privately through Catholic agencies to middle class homes in America. Witness the recent Oscar nominated 2013 film 'Philomena'.

In the 1990s Ireland began to privately adopt a significant number of children from countries such as Russia, Ukraine and Romania. The adoptive/ child location agencies were both in Ireland and Russia or Ukraine. There has been longstanding research, most notably from Rutter et al, 2011, on the Attachment Disorders and PTSD/ neglect related to inter-country adoption and early institutionalization of these children. However, it is also true that many of these children have been exposed to alcohol in pregnancy which creates a distinctive challenging Global Neurodevelopmental Disorder, NDPAE.

**Methods:** This is a retrospective clinical analysis of 30-35 children referred to a specialist psychiatric clinic (KOM) in Ireland for clarification of NDPAE diagnosis. The clinical characteristics presented are at the age of initial psychiatric consultation.

**Results:** The analysis will be by gender and age at time of clinical diagnosis. The clinical phenotype of NDPAE will be described in 6 dimensions: (1) Motor and or Sensory Disorder, (2) Disruptive Mood Dysregulation disorder, (3) Language Disorder, (4) Cognitive Disorder, (5) Facial Dysmorphology Disorder, (6) Growth Delay Disorder.

**Conclusion:** The sample age is 2 yrs to 18 yrs mainly boys. The preliminary findings will be presented which include the overlapping clinical phenotype presentation of NDPAE, as well as the prevalence of Early or Delayed onset PTSD related to early physical and emotional neglect in orphanage care in Russia prior to adoption in Ireland. There will also be an exploration of the quality of Mood Disorder in the children which is of a more melancholic variety, and may reflect familial loading and not just alcohol teratology. Finally, an exploration of violent risk tendencies which may relate to birth parent/father familial issues.



[15]

## Engaging Learners with FASD

**Barry Carpenter**

*Complex Learning Difficulties and Disabilities Research Project, UK*

*Universities of Worcester, Limerick and Hamburg and Adelaide*

The UK Government – funded Complex Learning Difficulties and Disabilities Research Project discovered that Engagement was the most effective approach for teaching children and young people with Complex Needs.

Within this national cohort, and the international validation group, were children and young people with Fetal Alcohol Spectrum Disorders . Recent studies have acknowledged those with FASD as learners with Complex Needs.

From this Research, the Engagement Profile and Scale (EPS) evolved as an evidence based tool for developing personalised approaches to assessment, teaching and learning. The validity of the EPS came through its multiple trials, in multiple schools with multiple teachers, across the UK and internationally.

Latterly, the EPS has been redesigned as the Engagement for Living Profile (ELP), to capture personalisation in daily living for adults with Complex Needs, including those with FASD.

Teaching children and adults with FASD brings many challenges in terms of the skills educators and therapists will need to design interventions that are meaningful and relevant to this new generation of people with Complex Needs. Mental Health, for example, is a known area of need in those with FASD of all ages, and our professional learning in this area has to be scaffolded from a basis of sound principles into meaningful practise.

Our repertoire of intervention approaches, built on the sound research principle of Engagement, must continue to change and diversify as children, young people and adults with FASD change and diversify. The answers will rest with the ability of the workforce to enskill itself from within, through systematic and deductive, evidence based initiatives, reported with rigour throughout the interdisciplinary community. All professions have a major role to play here if we are to preserve the intellectual integrity of our work, and our capacity to serve Society's most vulnerable children and adults, those with FASD.

[16]

## **Identification of risk behavior on girl students on Bucharest Romania during party night life, based on a questionnaire applied on student's campus subjects and bartenders from clubs around student's campus area**

**Teodora Ciolompea**, Mihaela Anca Iliescu, Mihaela Cojocaru , Ana Maria Florescu, Ilinca Negru

*Drug Addiction Treatment Centre Saint Stelian, Bucharest and NGO Ask Me, Bucharest , Romania*

**Background:** In 2010, 60% of girls between 15 - 19 years sexually active have never used contraception, according to EUROSTAT Romania study, on a sample of 1056 young women Incidence of fetal alcohol syndrome is estimated at 2-3 % cases per 1000 live births on rural communities in Romania where daily alcohol use is normal as well as in large urban areas.

In nearly all countries boys were drinking larger quantities than girls, but after 2007 drinking pattern changed in Romania where girls report drinking alcohol more than boys.

**Methods:** A retrospective study was conducted to examine risk behavior related to increasing percentage of women students abusing alcohol and unwanted pregnancies. A questionnaire was administered to 120 students from Bucharest and 24 bartenders from clubs around student campus. Different types of Coolers are the dominant beverage for the girls, accounting for 48% of the amount consumed on the last drinking day followed by 30% for spirits and 22% for wine.

On average, half of the students have been intoxicated at least once during their lifetime, to the point of staggering when walking, having slurred speech or throwing up. On average, heavy episodic drinking during the past 30 days increased on last two years we question compared to year 2007 from 35 to 43%, among girls included on our study.

Having used alcohol together with an oral contraceptive pill, was reported by 18.4% of the subjects.38% of the girls confirmed that are going on clubs and bars for dating partners and sex. They admit that lots of times due to alcohol abuse they forgot about contraceptive measures.

76% of the bartenders questioned reported that on last 30 days witness that majority of the young girls were drinking most of the time mixing beverages or doing binge drinking that lead them to acute alcohol intoxication.

**Results:** An upward trend (11.5%) for heavy episodic drinking throughout year 2207 to 2016 can be noticed among young female population on Capital city around universities campus.

[17]

## What is happening in my country? Germany

**Alison Frieling, Gisela Michalowski**

*FASD Deutschland e.V. Lingen, Germany*

FASD Deutschland e.V. is a non-profit parent support group that plays a key role within the German FASD network and acts as a kind of hub. Working to improve the lives of those affected by FASD means we are in touch with the lived experience but at the same time are in the extremely privileged position of being able to cooperate with FASD specialists and other experts from a wide range of professions.

Our main focus is on some of the most recent achievements, projects and events, some of which are still ongoing. Whilst these issues relate directly to Germany, we feel they also have implications for the international FASD community.

**(1) Diagnostics:** Following the release of the S3 Clinical Guideline for FAS in 2013 by The Association of the Scientific Medical Societies (**A**rbeitsgemeinschaft der **W**issenschaftlichen **M**edizinischen Fachgesellschaften or AWMF), the expert commission is now working on guidelines to diagnose pFAS and ARND. Conference work has now been concluded and the publication is expected in autumn 2016.

**(2) Politics:** In January 2016, FASD was the subject of a parliamentary hearing in Berlin. The Federal Health Committee discussed the life situation of people with FASD and asked what measures were needed to help improve their situation. One request was to establish a centre of competence at one of the larger universities to bring scientific research and services i.e. diagnostics and training opportunities for professionals under one roof.

**(3) A Special Project:** At the "Sonnenhof" Berlin a unique project has been developed - it's a clearing group for adults with FASD who also suffer from alcohol abuse. First qualitative interviews conducted for evaluation purposes have produced positive results.

"Major breakthroughs" don't happen overnight but they do encourage us to continue with routine work in the field of prevention, education and awareness and providing support to those whose lives are affected by FASD.

[18]

## Actual aspects of FASD issues in Republic of Moldova

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<sup>3</sup> Psycho-socio-pedagogical Center, General Directorate for Education, Youth and Sport, Chisinau

**Background:** In Republic of Moldova, one of the countries with tradition in producing quality wines, majority of the population considers alcohol consumption by women during pregnancy as one of the factors affecting maternal and child health. Some studies have found that, on average, about 7 percent of pregnant women consumed any alcoholic beverages (Moldova-Swiss Perinatology Project, 2012).

**Methods:** NGO "Progres prin Alternativă" in cooperation with the organization "Medecins du Monde", Municipal Clinical Hospital No.1, Republican Narcological Dispensary and Psycho-socio-pedagogical Center organized for the first time in 2015 a series of activities within the campaign "Too Young - To Drink". The event took place in several parts of the country and was widely publicized.

In a roundtable representatives of civil society, doctors, psychologists, pregnant women discussed various aspects of issues relating to the consequences of alcohol consumption during pregnancy. It was conducted a review of published studies regarding alcohol consumption by the population of Moldova.

**Results:** It has been found that the problem of consequences of alcohol consumption during pregnancy for future child development is actual for Moldova.

In the same time, it was found that national statistics do not provide certain data about the incidence of FASD.

Experts have noted difficulties in providing assistance to children with developmental disorders, including due to problems existing in working with their parents.

**Conclusion:** A comprehensive study of the situation regarding alcohol consumption by pregnant women and its consequences for child development is needed, to develop actions to prevent FASD, improving diagnosis and medical and psychosocial support for children with these problems. In this context, it is important the collaboration with specialists from other countries, including joint projects.

[19]

## What's happening in my country? - Spain

**Oscar Garcia-Algar**

Grup de Recerca Infancia i Entorn (GRIE), Institut Hospital del Mar d'Investigacions Mediques (IMIM), Barcelona, Spain

In Spain, alcohol consumption during pregnancy has been unnoticed and FAS diagnosis is uncommon. However in the only study in pregnant women based on alcohol detection in neonatal alternative matrices (meconium and maternal hair) in our country, 40% of pregnant women consume alcohol during pregnancy, but with a Mediterranean habit of consumption (not binge).

On the other hand, during the last 10 years a demographic phenomenon has occurred in our country: international adoption of children coming from East Europe countries, where consumption of high alcohol content beverages is almost universal in socioeconomic depressed people, also during pregnancy. Children from this environment are most of adopted children from these countries.

There are no official data about FASD in adopted children from these countries, but based on published from Russian orphanages and other countries in Europe, we can suppose that 30 to 70% of adopted children from East Europe countries may present FASD: that means about 5,000 children in Spain, most of them not diagnosed. Probably, they are going to collapse infantile psychological resources. This is a big problem for public health in our country.

[20]

## The problem of drinking alcohol during pregnancy and the health of newborns and infants

**Anait Marianian**, Natalia Protopopova, Lubov Kolesnikova

*Scientific Centre of the Family Health and Human Reproduction Problems; Irkutsk State Medical Academy of Postgraduate Education, Ministry of Health and Social Development of the Russian Federation, Irkutsk*

**Background:** The analysis of scientific researches shows that the issue of the use of alcohol (beer, dry wine, champagne), in small doses during pregnancy actually has been neglected for many years. So the problem has become quite urgent, especially in Russia. The aim of report is to raise the problem of the use of alcohol during pregnancy and its effect on the health of fetus and newborn babies.

**Method:** In order to determine the effect of alcohol on pregnancy and childbirth women and babies under research were divided into three groups. Group 1 (n=101) - (control group), Women who did not use alcohol throughout pregnancy. Group 2 (n=75) - little drinking women whose alcohol consumption during pregnancy has been less than 2 doses or 750 ml. Group 3 (n=33) - moderate drinking women whose alcohol consumption during pregnancy ranged from 3 to 11 doses (more than 750 ml to 3850 ml). *Methods of research of women:* surveys of pregnant women; clinical and laboratory examination on accepted standards; studying the system of «lipid peroxidation-antioxidant protection» of bioelement composition of blood; histological research of placenta; statistical analysis. *Methods of research of newborns:* clinical and laboratory examination on accepted standards; studying of the system of «lipid peroxidation-antioxidant protection» of bioelement composition of blood; additional methods of research for newborns in case of necessity: a) examination of neurologist, b) supersonic (examination) of brains, c) encephalography of brains; photographing children with confirmed (FAS and FASD); statistical analysis.

**Results:** The use of small amounts of low alcoholic beverages from 2 to 11 doses during pregnancy has significant effect on pregnancy, birth outcomes ( $p < 0,05$ ) and it can lead to inborn diseases and disorders of fetus. Even a small amount of alcohol consumed by women during pregnancy can cause serious metabolic changes in the body of newborns, in particular, it leads to an imbalance of «lipid peroxidation-antioxidant protection» and bioelement systems and congenital malformations ( $p < 0,05$ ).

**Conclusions:** Thus, the use of alcohol, even in small doses, during pregnancy can be extremely dangerous during pregnancy and for newborns health. Moreover it often leads to intellectual disorders (FAS) and inborn defects of fetus. It is necessary to pay and attract attention of specialists and researchers in different medical and social spheres that the problem has really become quite urgent, because with every year more and more newborns with various health and mental defects are born.



[21]

## Placing FASD prevention and awareness on the agenda in a remote and island setting

**Maggie Watts**

*NHS Western Isles, Stornoway, Isle of Lewis, Scotland*

**Background:** The Western Isles is an archipelago of 12 inhabited islands, 30 miles off the west coast of Scotland. A population of 26,700 is scattered across the islands, with a population density less than 9/km<sup>2</sup>.

Self reported alcohol use is low but alcohol-related hospital admissions are amongst the highest in Scotland and alcohol-related deaths have risen recently. The birth rate is low and, although screening for alcohol in pregnancy is in place, its use is patchy and almost no women are identified as drinking during pregnancy.

Children with an FASD diagnosis living in the Western Isles present challenges to the medical, social care and education workforces. Additionally there are families where FASD is a diagnosis under consideration.

**Methods:** Following Scottish work around prevention of FASD, the Outer Hebrides Alcohol & Drug Partnership determined to raise awareness of the consequences of prenatal alcohol exposure. From 2012 it participated in International FASD Awareness Day with activities around 9th September. These have been targeted at the general population and senior pupils to raise awareness of the potential impact of alcohol on the fetus.

In 2014 it took a deliberative stance to target professionals and combined alcohol messages with local action on the Scottish Framework for Sexual Health, placing a focus on increasing awareness of the use of long-acting reversible contraception in women of reproductive age, particularly post-partum. Alongside this was action from the Early Years Collaborative to raise awareness amongst early years professionals, including nursery, education and child and adolescent mental health staff.

**Findings:** The actions taken have identified an increased awareness of FASD amongst professionals. Links have been made with Scottish training and resources to provide peer support and encouragement as well as increase knowledge. Further work is needed to boost the confidence of professionals in assessing and managing people with FASD.

[22]

## What is happening in my country? Israel

**Yehuda Senecky**

*The Institute for Child Neurology and Development, The National FASD Clinic, Schneider Children's Medical Centre of Israel, Sackler School of Medicine, Tel-Aviv University, Israel Anti-Drug and Alcohol Authority Petah –Tikva, Israel*

Over the past decade, great and continues efforts were made in order to generate interest and raise awareness for FASD among the public, the medical community, politicians and the media.

Information on the risk of alcohol consumption during pregnancy and the potential damage caused to the future new-borns spreads slowly but consistently around the country. We work closely with the Israel Anti-Drug and Alcohol Authority and receive great support.

Our previous research showed that less than 10% of medical professionals in Israel believe they have adequate knowledge on FASD. We showed that alcohol consumption is considerably frequent among pregnant women in Israel, and that only few women received any formal education on the subject.

A recent survey we have conducted found that medical students are also unaware of the potential risk of alcohol consumption during pregnancy.

In 2014, we opened the first FASD clinic in the state, which was declared an official national clinic by The Ministry of Health. The clinic was also recently joined by a child psychiatrist.

We continue to spread the word in medical conferences, hospital staff meetings, medical journals, clinical guidelines and public media.

[23]

## What's happening in Aotearoa New Zealand?

**Kate Robertshaw**

Child Development Service, Hawke's Bay District Health Board, Hastings, New Zealand

### **Locally**

Our Child Development Service has a multidisciplinary team to evaluate child with complex neurodevelopmental presentations and since 2011 we have provided a FASD assessment pathway. Within our region we have engaged and provided education on FASD for professionals from health, education and social welfare sectors to build awareness and knowledge about FASD so that diagnoses made are understood by our community. We have advocated with our District Health Board to raise the profile of FASD as a key area to target preventative work through Health Promotion and primary and secondary care maternity services. We are developing a care coordination post to support post diagnosis care for families. We are partnering with Maori to ensure solutions are responsive and aimed at reducing the impact of FASD in Hawke's Bay.

### **Nationally**

The NZ Ministry of Health are developing a national FASD strategy which encompasses prevention, diagnosis and post diagnosis intervention and support. In December 2015 the government announced a 'First steps' funding package for FASD. First steps projects include: increasing FASD diagnostic capacity across NZ, providing education strategies for classroom teachers, prevention and awareness projects and establishing an FASD incidence study within an already established NZ longitudinal study. In addition, The Health Promotion Agency have highlighted FASD and have been running a targeted media campaign: 'Don't know, don't drink' to advise young women that alcohol is a risk to their baby *before* they know they are pregnant. This work is to continue with training for midwives on talking about alcohol and offering brief advice and getting a unified message across that there is no safe amount of alcohol in pregnancy.

[24]

## **AFASAF, the young but active organization in Spain**

**Teresa Nuñez-Minguez, Montserrat Badia-Amate**

*AFASAF, Barcelona, Spain*

Our young association is held in Barcelona but we have associates all over Spain. It was created, officialy, in Setember 2014, when a group of seven or eight families began a way in "Patronat de Cornellà", drinking a coffee. We don't have a large exerience, and FASD is quite unknown. Our first goal was to give a hand to the new families, listen to them and share experiences. In a short period of time we settled our ways for the future, such as

- appear in the media
- know as much as possible about FASD
- get in contact with other people from around the world
- AND prepare the future for our sons and daughters

Recently we have been in the Parliament to talk with polititians in order to change the laws to prepare schools, doctors, psychologists and society in general to smooth the future for people living with FASD.

As famílies, our main worry is the future, as everything must be done. So we look at other countries to see what are they doing.

[25]

**“DO YOU HAVE 3 MINUTES?”**

**Leana Olivier**

*CEO: The Foundation for Alcohol Related Research (FARR); Research Fellow:  
Department of Molecular Biology and Human Genetics, Faculty of Health Sciences,  
University of Stellenbosch; PhD student: Governor Kremer Centre, Maastricht University*

South Africa has the highest reported Fetal Alcohol Spectrum Disorder (FASD) and Fetal Alcohol Syndrome (FAS) prevalence rates in the world, ranging between 60/1000 to 270/1000 in some communities. Despite concerns regarding this public health challenge in South Africa very little is being done by government to address the problem. Based on research findings the Foundation for Alcohol Related Research has developed evidence based programmes to raise awareness and to prevent the condition in high risk communities. The Healthy Mother Healthy Baby Programme is one of these successful programmes and has now been refined to a model which primary health care professionals; social workers and teachers in the departments of Health; Social Services and Education can use in their day-to-day service delivery. The model is called “Do you have 3 minutes”. The presentation will focus on a brief background leading to the development of the model and will give an overview of the model which is currently being implemented with the funding and support of government in one district.

[26]

## **Birth mother story**

### **Samantha Marchant**

Samantha is the biological mother of a son with FASD. As an alcoholic she drank through most part of her pregnancy. She has stayed sober since her son was months old. Her son has many challenges due to FASD but one of the greatest challenges seems to be getting the world up to speed in understanding & accepting FASD. Samantha has 2 younger children who were not exposed to pre-natal alcohol. She tries to raise awareness of FASD and help her son to live the best life he can.

[27]

## **Stamp out Stigma: How Shame and Blame Hinder FASD Prevention and Treatment**

**Kathleen Tavenner Mitchell<sup>1</sup>, Pip Williams<sup>2</sup>**

<sup>1</sup> *National Organization on Fetal Alcohol Syndrome (NOFAS), USA*

<sup>2</sup> *European Birth Mothers Network, UK*

**Background:** Stigma and bias related to alcohol use by women, FASD, and those affected by FASD creates barriers that hinders FASD prevention, awareness and care. For women who are struggling with an addiction the embarrassment and perception of being judged by health care professionals can serve as a barrier to discussing their alcohol use and accessing treatment. Stigma associated with drinking during pregnancy is common, yet the reasons that women may drink while pregnant are not widely recognized or understood. Healthcare providers may not take the time to ask women about their alcohol consumption because they may believe they do not have the knowledge to support this kind of patient, that most addicts never get better anyway and believe there are no treatment options.

**Methodologies:** NOFAS has collected hundreds of comments on their social media sites that are blaming, shaming and judgmental towards birth mothers. In 2016 the Washington Post featured an article about NOFAS vice president, a birth mother of an adult daughter with FASD. The article was read by over 7 million people and trended on Facebook for a week. The comments on the Post site and other sites from around the world reflected the opinions of the general public. About 35% believe that anyone can stop drinking and that every mother knows not to drink while pregnant. NOFAS has also collected information from members of the Circle of Hope birth mothers network about why they drank while pregnant and their experiences with stigma.

**Results:** In 2015 the NOFAS Stamp out Stigma Campaign was launched. There are several initiatives of the campaign including working with universities, partners and government agencies to modify common FASD public health messages to non-stigmatizing language.

**Conclusion:** There are concrete actions and recommendations that can reduce the stigma experienced by birth mothers, their families and individuals with FASD and increase the chances of preventing FASD.

[28]

## **Prenatal alcohol exposure and transition to adulthood: stress and resilience**

**Claire D. Coles**, Mary Ellen Lynch, and Julie A. Kable

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**Background:** While it is evident that Prenatal Alcohol Exposure (PAE) impacts the developing brain and interferes with optimal adjustment in early adulthood, not all individuals are equally affected and some areas of behavior and adjustment are affected more than others. To support young adults and families in making the critical transition from adolescence to young adulthood it is necessary to better understand factors promoting resilience in this group.

**Methods:** In the Atlanta prospective longitudinal study of effects of PAE, adaptive function, entry into adult roles, mental health, substance use, and legal problems of 236 young adults were evaluated. Mothers' alcohol and drug use was established at recruitment prenatally and children were assessed at birth, during early adolescence and in their early 20's. Resilience was defined as successfully meeting developmental challenges in Educational and Vocational Achievement, Mental Health, Substance Abuse, Adaptive Functioning and Legal Issues. Physical, cognitive and social/environmental factors were assessed and Generalized Linear Regression used to identify factors that predicted more positive outcomes for this high risk group.

**Results:** Participants were predominantly African-American and low socioeconomic status. Physical characteristics (dysmorphic features, lower weight/ height) and cognitive deficits associated with PAE persisted but some exposed young people appeared to be "resilient" in the face of exposure and social stress. Overall, better outcomes were found for women, full term birth, authoritative parenting (warmth and supervision), and positive life experiences. Problematic outcomes were related to physical effects of PAE, negative life experience, personal and community violence, and using alcohol and drugs as an adolescent.

**Conclusion:** Effects of PAE are persistent into adulthood but more positive outcomes are possible with appropriate caregiving and access to support.



[29]

## How to make social change for prevention of Fetal Alcohol Spectrum Disorder (FASD)

**Gerjo Kok**<sup>1,2</sup>, Sylvia Roozen<sup>1,2</sup>, Gjalt-Jorn Peters<sup>1,3</sup>, David Townend<sup>1,4</sup>, Ger Koek<sup>1,5</sup>, Jan Nijhuis<sup>1,6</sup>, and Leopold Curfs<sup>1,7</sup>

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<sup>7</sup> Department of Genetics, Maastricht University Medical Centre+, The Netherlands

**Background:** Alcohol use during pregnancy is one of the leading preventable causes of intellectual or developmental disability. Fetal Alcohol Spectrum Disorder (FASD) is the non-diagnostic umbrella term used to characterize the full range of damage caused by prenatal alcohol exposure, varying from mild to severe, and encompassing a broad array of physical defects and cognitive, behavioural, emotional, and adaptive functioning deficits. This situation clearly warrants interventions for preventing FASD. As the complexity of intervention development is sometimes overlooked in health promotion, the field of FASD needs to use a systematic approach for developing evidence based behaviour change interventions, such as Intervention Mapping (IM).

**Method:** The IM framework is a six step systematic approach for designing, implementing and evaluating health promotion programmes. IM provides planners with a systematic method for theory and evidence-based decision making in each phase of developing a programme to influence changes in behaviour and environmental conditions.

**Results:** The first step in the IM process showed that current data remains insufficient of the existence of the problem and what it entails. The evidence for the next steps is now accumulated. The theory is already available to guide program planners to better decisions about behaviour change campaigns.

**Conclusion:** The Intervention Mapping framework is useful as a blueprint for designing, implementing, and evaluating an intervention for prevention of FASD.

[30]

## **Maternal ethanol consumption during pregnancy and FASD - Matter of Health Diplomacy**

**Elena A Varavikova**

*Central Research Institute for Public Health Organization and Information (CNIIOIZ),  
Moscow, Russia*

According to the World Health Organization Alcohol intake in the European Region is the highest in the world. Alcohol use during a woman's pregnancy can lead to severe mental handicap of her child. Numbers of Global, International and National organizations, and the WHO, could be in the Leading positions for the alcohol harm prevention. Effective International policy is an important key to the prevention of the alcohol consumption during pregnancy at the National level. Existing International and National Key players and related to FASD prevention agenda were analyzed. This analysis allowed to formulate some recommendations to influence National and International FASD prevention policies.

[31]

## Preventing alcohol related harm to the unborn child at EU level

**Mariann Skar**

European Alcohol Policy Alliance, Belgium

**Background:** The European Alcohol Policy Alliance (EUROCARE) is an alliance of non-governmental and public health organisations with around 60 member organisations across 25 European countries advocating the prevention and reduction of alcohol related harm in Europe. Member organisations are involved in advocacy and research, as well as in the provision of information and training on alcohol issues and the service for people whose lives are affected by alcohol problems.

The mission of Eurocare is to promote policies to prevent and reduce alcohol related harm. The message, in regard to alcohol consumption is “less is better.”

**Methods:** Eurocare has for the last 26 years been actively advocating for the prevention and reduction of alcohol related harm. Eurocare has a unique position of being a European organisation with committed members across Europe working specifically on one risk factor – alcohol. Eurocare’s main policy areas – such a price and taxation (increase in taxes and minimum unit pricing), regulation of marketing (including sponsorship and product placement), protection of young people (age limits and advertisement), comprehensive product labeling (ingredient listing and health information labels), work on chronic diseases (e.g. cancer) – all contribute to Member States efforts to reduce inequalities and create sustainable health systems.

Eurocare generates, disseminates and the facilitates exchange of best practices and capacity building in alcohol policy through its membership (61 members in May 2016) across 25 European countries, newsletters, website, events and cycle of policy debates. It is playing an effective role in civil dialogue processes at the EU level, through active participation in a number of established networks like European Health Policy Forum, DG Trade Civil Society Dialogue (TTIP negotiations), DG AGRI Civil Society Dialogue and DG Connect Pilot Community of Better Self- and Co-Regulation, and Better Internet for Children, as well as the expert group on prevention in OECD and work closely with World Health Organisation.

[31']

## Comprehensive evaluation of the fetal alcohol spectrum disorders in 83 children

Miguel Del Campo

*University of California, Department of Pediatrics, San Diego, California, USA*

**Introduction:** The Fetal alcohol Spectrum of disorders (FASD) is a complex group of diagnoses that include physical characteristics of FAS, neuropsychological (NP) impairment, and abnormal brain structure. Several diagnostic schemes have been proposed such as the IOM revised 2006, the Canadian Criteria, the Washington 4 digit score and the CDC criteria. We aimed to assess the contributions of physical, imaging and neurobehavioral components, using the novel diagnosis of Neurobehavioral disorder associated to prenatal alcohol exposure (ND-PAE, DSM-5). Although diagnoses within the FASD spectrum can be made in the absence of confirmation of maternal exposure for FAS and pFAS, this is not accepted in the absence of physical features (ARND or ND-PAE)

**Materials and Methods:** We evaluated 83 children (73 adopted from Russia or Ukraine), who were referred for cognitive or behavioural difficulties. Alcohol exposure was known in only 12 of them. We used standard IOM criteria for the physical diagnosis of FAS and partial pFAS, a complete battery of NP testing to assess for ND-PAE, ocular and neurologic exams and brain MRI in all cases. Arrays or molecular testing were performed in 5 cases.

**Results:** Among the 83 children, ten did not have evidence of FASD. Twenty-nine children had FAS and 19 pFAS. ND-PAE criteria were present in 14 additional children, with an overall FASD diagnosis in 62/83. Among these 14 children without confirmation of alcohol exposure, 3 had brain anomalies on MRI, 9 had high dysmorphology scores and all had NP anomalies within the 3 domains (cognitive impairment, self-regulation and adaptive functioning) suggesting ND-PAE.

**Conclusions:** Cognitive and behavioural problems in adopted children from Eastern Europe are very often caused by alcohol in pregnancy, but not always. The well-defined criteria for ND-PAE, eye and brain structural anomalies and the dysmorphology score all contribute to the diagnosis within the FASD spectrum, even in the absence of FAS (FIS PI12/01320).

[32]

## Focus on prevention campaigns for Fetal Alcohol Spectrum Disorders (FASD)

**Gerjo Kok**<sup>1,2</sup>, Sylvia Roozen<sup>1,2</sup>, Gjalt-Jorn Peters<sup>1,3</sup>, David Townend<sup>1,4</sup>, Ger Koek<sup>1,5</sup>, Jan Nijhuis<sup>1,6</sup>, and Leopold Curfs<sup>1,7</sup>

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**Discussion Leaders:** Prof. dr. Gerjo Kok, Prof. dr. David Townend, & Prof. dr. Leopold Curfs

**Workshop Purpose:** The aim of this workshop is to increase knowledge and provide you with the necessary tools for effective interventions related to alcohol consumption during pregnancy and FASD. In addition awareness for who is controlling the delivered message and the commercial aspects of campaigns will be discussed.

**Workshop Description:** The development of an effective prevention campaign is not easy. In various subjects people often instinctively make use of scary pictures. These so-called "fear appeals" to encourage people to stop drinking or discourage those who already drink are not effective. Despite the fact that the majority of people think it helps and politics continues to invest in these campaigns. It is important, in particular, to send out a positive message in which there are reference points to find how to act. A good approach (general strategy) is the Intervention Mapping methodology. A brief description of Intervention Mapping including the practical applications to secure effectiveness will be discussed.

**Necessitates:** All participants are invited to bring along their prevention campaign materials (e.g. posters) which are used in their own institute or country.

[33]

## Fetal Alcohol Spectrum Disorder and Employment

**Anne Russell**

Russell Family Fetal Alcohol Disorders Association, Queensland, Australia

**Background:** For adults with FASD there are many challenges but none as potentially critical as employment. For an adult with FASD who has likely experienced many 'failures' as a student at school, nothing can reduce the negative impact of that experience more effectively than a successful experience in the workplace. Unfortunately this rarely happens. Not only have I worked in the employment industry for almost 20 years, but I am also the birth mother of two adult children with FASD. My oldest son, Mick [ARBD] has been able to maintain employment from the outset when he began work at 15, however my youngest son, Seth [full FAS] has worked in many jobs over the last 17 years. I have seen what worked and what didn't and I believe that the majority of adults with FASD will not always have problems doing the job, but will almost always have problems with the day to day interactions between colleagues, supervisors and managers.

After discussing with other parents the trajectory of their adult children in employment, I have verified that this cycle happens to many adults with FASD in employment. I will also discuss the methods I used to try and pre-empt these issues. Unfortunately, I have never been able to pre-empt the eventual termination into unemployment.

This is not a research paper but one based on anecdotes, wisdom and practice-based interventions and models and the labour market.

- (1) Factors that must be present for a person with FASD to have the best possible opportunity for sustainable employment
- (2) Looking at jobs that might be appropriate for people with FASD in general
- (3) Methods of integrating a person with FASD into the workplace.

**Conclusion:** I have used features from my book titled Strategies for Employment Services Specialists.

[34]

## **Sexual health promotion by care-providers of youth with fetal alcohol spectrum disorder: practices, barriers, and facilitators**

**Alanna Mihic**<sup>1</sup>, Dionne Gesink<sup>1</sup>, Carol Strike<sup>1</sup>, Florence Large<sup>2</sup>

*1 Dalla Lana School of Public Health, University of Toronto, Toronto, Canada; 2Eagle Healing Lodge, Saddle Lake, Alberta, Canada*

**Background:** Living in a nurturing home and having access to disability services is associated with lower rates of inappropriate sexual behaviours among youth with FASD. This grounded theory study aimed to generate a substantive theory of how care-providers of youth with FASD practice sexual health promotion.

**Methods:** Individuals (19 women, 1 man) who provided one-on-one care to youth with FASD in a variety of care contexts in western Canada participated in a combination of semi-structured, audio-recorded group interviews and key-informant interviews. We used the constant comparative method of analysis to combine theory generation with systematic coding of emerging categories and socio-ecological determinants in data collected through theoretical sampling. Data collection continued until no new properties emerged and the theory achieved stable integration.

**Results:** Care providers' practice of sexual health promotion for youth with FASD is represented by the cycle 'caring today with an eye on tomorrow.' The practice involves (1) being aware and (2) addressing determinants. 'Being aware' illustrates how care-providers are observant of sexual health determinants existing at every socioecological level. 'Addressing determinants' showcases the numerous activities care providers engage in daily that promote sexual health in the lives of their children/clients with FASD. Care-provider activities are thwarted by lack of access and inability to exert power to initiate change at the community, institutional, and structural levels. Sustained and successful health promotion activities at the individual and interpersonal levels are facilitated by care-provider resilience characteristics.

**Conclusions:** Synergies in sexual health promotion for youth with FASD could be achieved through evidence-based program and policy reform that supports care-provider resilience and removes community, institutional, and structural barriers

[35]

## **FASD and juvenile justice in Australia**

**Carmela Pestell**, Carol Bower

*Telethon Kids Institute and University of Western Australia, Perth, Australia*

**Background:** There is substantial evidence that young people with FASD are more likely to engage with the forensic system than those without FASD. This has led to increasing concern within Australia regarding the forensic implications of FASD, given the neuropsychological sequelae can potentially affect all aspects of the court process, such as capacity to stand trial. Our research represents the first study of its kind within Australia to determine the prevalence rate of FASD amongst detained youth and respond to calls for improved understanding and management.

**Methods:** Assessment of young people in detention by a multidisciplinary team within a cross-cultural context utilising internationally accepted diagnostic criteria.

**Results:** To date over 70 young people have been assessed, and a wide range of neurocognitive impairments as well as comorbid diagnoses have been identified. In this presentation the core neuropsychological features of this cohort will be discussed, as well as related diagnostic and assessment issues including crosscultural factors and ethical considerations within a complex justice setting.

**Conclusion:** FASD and other neurodevelopmental impairments are common amongst young people in detention and have significant forensic implications impacting on management whilst in detention and on release. This presentation will provide a unique Australian perspective on this issue, and highlight recommendations for future clinical and research directions.



[36]

## **Clinical assessment of children and adolescents with complex neurodevelopmental difficulties and confirmed prenatal exposure to alcohol in a secondary care setting: an integrated service model and neuropsychiatric outcomes**

**Emma Weisblatt**<sup>1,2</sup>, Ges Gregory<sup>2</sup>, Alberto Danieli<sup>3</sup>

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<sup>3</sup>*IRCCS E.Medea, Polo di Conegliano (Treviso), Italy*

**Background:** Prenatal alcohol exposure is associated with neuropsychiatric difficulties, Foetal Alcohol Spectrum Disorder, (FASD) sometimes also with physical abnormalities (Foetal Alcohol Syndrome, FAS). A recent retrospective audit in community paediatrics in Peterborough, UK, (Gregory et al) found 3.5% of children with FAS or FASD; for those in care 27.2%. Many of the children have complex needs. We piloted a systematic, multidisciplinary clinical and developmental assessment clinic.

**Aim:** Systematically to assess clinical and developmental profiles of children with prenatal alcohol exposure with behavioural or developmental difficulties in a secondary care community setting.

**Method:** 20 children (14 male, 6 female) aged 6-16 years, with known prenatal alcohol exposure, were assessed by a multidisciplinary team including neuropsychiatrist, community paediatrician and psychologist. They received: medical assessment and investigations; WISC-IV; Conners ADHD screening questionnaire; Social Communication Questionnaire; ASD screen; BRIEF executive function questionnaire; neuropsychiatric clinical assessment.

**Results:** Learning difficulties were found in 6/14 children who had full WISC; all had impaired executive function. 7 had ADHD; 2 had ASD; 3 had affective disorders; 3 had conduct disorder; 3 were referred for inpatient assessment. Most had difficulties in multiple domains. Most had multiple risk factors for negative outcomes in addition to prenatal alcohol exposure. Feedback from families and social care staff was positive.

**Discussion:** Children who present with emotional, behavioural and neurodevelopmental difficulties following prenatal alcohol exposure have multiple and complex psychiatric and developmental diagnoses with high comorbidity. They may be in care and with other psychosocial disadvantages. Systematic assessment following screening allowed clear diagnosis and formulation facilitating prompt intervention and support for these children with complex needs.

[37]

### **Auditory event-related evoked potential in schoolchildren exposed to alcohol during pregnancy: preliminary results**

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**Background:** Sensory impairments are some of the reported morbidities in children exposed to alcohol during pregnancy. Although hypoacusia and hearing loss are frequently reported less is known about problems of the central auditory system. Auditory evoked potentials (AEP) can provide information about neural activity at cortical and sub-cortical level. This study aimed to investigate the cortical auditory function in schoolchildren lightly or moderately exposed to alcohol during pregnancy by means of AEP electrophysiological measurements.

**Method:** a cross-sectional study on an observational longitudinal cohort. The here presented preliminary results were obtained from the first 38 research participants (mean age = 14 years; males = 55,3%). Auditory event-related evoked potentials with the active electrode position in Cz and Pz were performed and the curve was analyzed in order to characterize P300 and other cognitive related potentials (latency and amplitude). The analysis was made by comparing groups of children according to their condition of alcohol exposure during pregnancy.

**Results:** The preliminary results showed a significant difference of the N2 component (rare stimulus condition) in the alcohol exposed group, manifested by a prolonged latency in both electrode positions. No significant difference between groups has been found for P300.

**Conclusion:** The prolonged latency of the N2 component in prenatally alcohol exposed children could indicate a delayed reception of the stimulus in the auditory cortex, which could be associated with preattentive difficulties and poor auditory discrimination.

[38]

## The 4-Digit Eye Diagnostic Code A Tool for Eye Diagnostics in Fetal Alcohol Syndrome Disorders

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<sup>3</sup>*Department of Pediatrics, Skaraborg Hospital, Skövde, Sweden*

**Background:** Previous studies have shown a high frequency of ophthalmological abnormalities in Fetal Alcohol Syndrome Disorders (FASD). However, there are no guidelines for ophthalmological examination in individuals with prenatal alcohol exposure. According to a 4-Digit Diagnostic Code, used worldwide, FASD can be divided into Fetal Alcohol Syndrome (FAS), Partial FAS (PFAS), Static Encephalopathy Alcohol Exposed (SE/AE) and Neurobehavioral Disorder Alcohol Exposed (ND/AE). Our purpose was to develop and evaluate an ophthalmological tool (*4-Digit Eye Diagnostic Code*), serving as a complement to growth deficiency, facial features, central nervous system structural/functional abnormalities, and prenatal alcohol exposure.

**Method:** Twenty-five children with FASD (*FAS n=9, PFAS n=6, ND/AE n=7 and SE/AE n=3*) and 25 age and sex matched controls were evaluated. Four ophthalmological digits were used: 1) visual acuity, 2) refraction, 3) strabismus/binocular functions, and 4) structural abnormalities. The magnitude of expression of each feature was ranked independently on a 4-point scale with 1 reflecting normal ophthalmological finding and 4 reflecting a strong presence of the most common abnormality found in children with FASD. We also tested the 4-digit eye code on 42 children with Attention Deficit Hyperactivity Disorders (ADHD) and on 78 children born Moderate to Late Preterm (MLP).

**Results:** Children with FAS had a total median score of 10: Visual acuity (2); Refraction (2); Strabismus/Binocular function (3) and Structural abnormalities (3). The total median score for children with PFAS and ND/AE was 9, for SE/AE and ADHD 5 and for MLP and controls the score was 4.

**Conclusion:** Our results are in consistence with our hypothesis that children with fully developed FAS have the highest score. This tool, based on the most common ophthalmological abnormalities previously found, may serve as a diagnostic help in FASD.

[39]

## **Altered brain activity during response inhibition in female adults with FASD: a functional magnetic resonance imaging study**

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**Background:** Executive dysfunction, particularly affecting inhibitory control and sustained attention, is a common finding in fetal alcohol spectrum disorders (FASD). Previous research has primarily focussed on such deficits in affected children and adolescents. Purpose of this study was to elucidate how inattention and impulsivity evolve in young adult subjects and to characterize the underlying neural mechanisms of impaired inhibitory control and attention in these more mature individuals.

**Methods:** We examined brain activity related to inhibition in a Go-/NoGo task using functional magnetic resonance imaging (fMRI). Female adults with histories of heavy prenatal alcohol exposure (n=19, 18–30y, Mdn=19.5y) and controls (n=19, 18–29y, Mdn=20.5y) were included. Individual fMRI data analyses were done by SPM8. Group-level whole brain analyses comprised a one-way ANOVA and post-hoc tests to assess group differences (FASD vs. controls) in brain activity in the differential contrast NoGo > Go as a measure of response inhibition ability.

**Results:** Mean response latency did not differ between both groups during Go trials. In contrast, error rates were significantly increased during Go trials in FASD subjects compared to controls (0.85% vs 0.08%, p=0.003), while NoGo error rates were comparable between groups. FMRI results revealed higher levels of neural activation predominantly in prefrontal areas in the FASD group compared to controls with parallel less involvement of parietal and temporal regions.

**Conclusion:** Adult FASD individuals exhibited deficits in attentive task performance only. Brain activity, however, in areas associated with inhibitory control as well as attention was altered. These findings might be indicators of compensatory neural processes in adults with FASD.

[40]

## **A novel technique for the analysis of combined face-brain morphology and correlation with neurocognitive impairment in FASD**

**Michael Suttie**, Leah Wetherill, Eric Kan, Elizabeth Sowell, Ken Jones, Sarah Mattson, Tatiana Foroud, Peter Hammond

*Nuffield Dept. Obstetrics and Gynaecology, University of Oxford, UK*

**Background:** Prenatal alcohol exposure damages the developing central nervous system and causes a variety of craniofacial effects depending on the timing of exposure. The individual morphological changes in the brain and the face are well documented, but few studies have explored correlations between them. The primary aim of this study was to develop novel techniques for the analysis of their combined shape variation, producing an objective evaluation of the morphological relationship between components of the face and structures of the brain. In addition, neurocognitive profile was introduced to determine relationships between combined face-brain structural effects and cognitive deficit.

**Methods:** Structural brain MRI and high-resolution 3D facial images were obtained through the CIFASD (Collaborative Initiative on Fetal Alcohol Spectrum Disorders) consortium of exposed (n=77) and unexposed (n=45) Caucasian children (age range; 6.8-17.7 yrs). By extending existing dense surface modelling techniques, we built joint morphometric shape models of individual regions of the face with surfaces of the corpus callosum and caudate nucleus. These joint models delineate the shape covariation of face and brain and enable statistical analysis of correlations between neurocognitive measures and joint face-brain shape variation in both unexposed and alcohol exposed individuals.

**Results:** (1) Shape correlations between facial features and brain morphology were determined. (2) Unexposed vs exposed discrimination accuracy for combined face-brain morphology was greater than for the separate face or brain structures. (3) Correlations between neurocognitive deficit and face-brain morphology were identified in alcohol exposed individuals.

**Conclusion:** The combined modelling of face and brain morphology enhances our understanding of the effects of prenatal alcohol exposure by delineating aspects that are less apparent when studied separately.

[41]

## **Pattern of Retinal Nerve Fiber Layer Thickness Loss in Fetal Alcohol Syndrome: A Spectral-Domain Optical Coherence Tomography Analysis**

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*Hospital Pedro Hispano, Matosinhos, Portugal*

**Background:** Optic disc hypoplasia is a common feature described in patients with fetal alcohol syndrome. Thus, we aimed to evaluate the optic disc morphology changes and the peripapillary retinal nerve fiber layer thickness in these patients.

**Material and Methods:** We performed spectral-domain optical coherence tomography in a cohort of 11 patients (22 eyes) with fetal alcohol syndrome and in an age-matched control group. We evaluated optic nerve head parameters (optic disc area and diameter, rim area, cup/disc horizontal and vertical ratios) and peripapillary retinal nerve fiber layer thickness.

**Results:** Mean optic disc area, rim area and optic disc diameter were, respectively, in fetal alcohol syndrome patients and control subjects:  $1.540 \pm 0.268$  and  $1.748 \pm 0.326$  mm<sup>2</sup>;  $1.205 \pm 0.286$  and  $1.461 \pm 0.314$  mm<sup>2</sup>;  $1.417 \pm 0.124$  and  $1.501 \pm 0.148$  mm ( $p < 0.05$ ). We found no significant differences between groups for cup/disc ratios. Mean retinal nerve fiber layer thickness was significantly lower in fetal alcohol syndrome patients ( $90.500 \pm 9.344\mu\text{m}$ ) as compared to controls ( $111.000 \pm 7.855\mu\text{m}$ ) ( $p < 0.0001$ ). Analysis showed a significant decrease in retinal nerve fiber layer thickness for the superior, inferior and nasal quadrants ( $p < 0.005$ ). The temporal quadrant showed no significant differences.

**Conclusion:** In addition to a smaller optic disc area/ diameter and rim area, we found a heterogeneous peripapillary retinal nerve fiber layer thickness loss in fetal alcohol syndrome patients with sparing of the temporal quadrant. Spectral-domain optical coherence tomography may be useful to determine the presence of fetal alcohol syndrome status.

[42]

## **Pregnant women's perceptions of information about alcohol use during pregnancy: a qualitative pilot study**

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Considering children prenatally exposed to alcohol present substantial challenges to parents, schools, and societies and considering minimum safe dose of alcohol during pregnancy is unknown, WHO, EU and different countries suggest zero consumption. Despite, research shows that there is a substantial number of women who continue to drink.

Taking into consideration that information is the base to make an informed decision about alcohol use during pregnancy, understanding the availability and quality of information available to pregnant women is an issue for research.

As far as we know, in Portugal no studies have looked at the pregnant women's perception of information about alcohol use during pregnancy. This work presents a qualitative pilot study, exploring attitudes of pregnant women regarding: (1) alcohol use during pregnancy; (2) knowledge about the impact of alcohol use during pregnancy; (3) accessibility and quality of information available.

Participants were 13 pregnant women recruited through snowball sampling strategies and at one public health center. After informed consent, in-depth interviews were conducted, transcribed and then thematically analyzed.

Only one participant continue to drink during pregnancy (social use). Pregnant women reported mixed messages and confusion about consequences of prenatal exposure to alcohol and about safe level of consumption, with implications on decision to drink during pregnancy. Mass media and relatives were mentioned as the most important sources of information about alcohol in general. Lack of consistent screening and information from healthcare professionals is other result, but some women recalled receiving advice not to drink alcohol during pregnancy (there is an abstinence official national guideline).

Evidence-based information is the base to make an informed decision about alcohol use during pregnancy. As this study showed, there are a number of limitations with accessibility and quality of information available, including for pregnant women. To ensure that all (pregnant) women are aware of alcohol recommendations for pregnancy, we underline the importance of the different professionals involved in healthcare arena, particularly within pregnancy care setting.

## [43]

### **Risk categories of alcohol consumption in a general population of pregnant women**

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**Background:** Identification of at risk pregnancies is essential for the prevention of FASD, as abstention from alcohol remains the unique way to avoid damages due to exposure to alcohol in uterus. This paper aims at identifying the prevalence of at risk pregnancies and describes a prevention protocol based on risk categories.

**Methods:** Women in the first trimester of pregnancy attending a prenatal visit in a major hospital in Rome (Italy) were interviewed about alcohol consumption, through a semi-structured interview. Women were grouped in four categories of risk: 1) no risk (no alcohol consumption) 2) mild risk (occasional consumption, no more than 1 drink per occasion and no binge drinking, defined as the consumption of three or more drinks in a single occasion) 3) moderate risk (from 5 to 7 drinks per week and no binge drinking); 4) high risk (more than 7 drinks per week and/or binge drinking)

**Results:** Among 172 women interviewed, 31,4% drank. Risk categories distribution was:

1. No risk: 68,0%
2. Mild risk: 29,1%
3. Moderate risk: 0,6
4. High risk: 2,3%.

Prevention strategies matching the risk categories are proposed:

1. Even if a woman do not drink, a verbal reinforcement of this behavior is recommended, along with the suggestion of passing information on the safest behavior to friends and relatives.
2. Women who drink, even if only occasionally, should be informed about the risks, as a safe threshold has not been identified yet: a single brief session has high chances to be effective.
3. Regular drinkers should be addressed by more structured counseling sessions.
4. A multi-professional approach is needed for heavy drinkers, including the referral for alcohol treatment.

**Conclusion:** As many women keep on drinking during pregnancy, the adoption of preventive measures is mandatory. Screening for alcohol consumption during prenatal visits should be routinely implemented by health professionals to allow the delivering of appropriate interventions, in order to diminish the number of alcohol-exposed pregnancies.



[44]

## **Documentation of maternal alcohol exposure during pregnancy and follow-up process for babies at risk of foetal alcohol syndrome**

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**Background:** Alcohol exposure to the foetal brain is known to impact upon neurodevelopment. The Consensus Statement 2013 developed by UK Healthcare Professionals and the FASD Trust highlighted the need for a clear clinical pathway to identify neonates at risk of foetal alcohol syndrome and to arrange developmental follow-up. This study aims to identify whether or not alcohol exposure in pregnancy was documented on neonatal discharge summaries and whether babies born to mothers with heavy alcohol use in pregnancy were referred for follow-up.

**Methods:** Retrospective study using electronic maternity records to identify mothers of babies born between 1<sup>st</sup> July 2013 and 31<sup>st</sup> December 2015 who were recorded as drinking alcohol at their pregnancy booking interview. 96 women were identified. 3 were excluded as the baby's NHS number had not been linked to the maternal record. Information gathered included maternal alcohol use during pregnancy (units per week), gestation and birth weight.

**Results:** Alcohol consumption during pregnancy in the 93 included women ranged from 0 to 40 units per week, median 1 unit per week. 28% women despite answering "Yes" to drinking alcohol were recorded as having an intake of 0 units per week. Of the 93 women's babies, 24% required admission to the neonatal unit.

Differences were found between alcohol documentation on the neonatal unit discharge summary (not recorded, none, social or heavy) and alcohol intake recorded at booking (units per week). 9% of the 93 babies received follow-up appointments for reasons such as prematurity. Only one baby was referred for follow-up specifically for a risk of foetal alcohol syndrome.

**Conclusion:** The study highlights the need for education of healthcare professionals involved in the care of women in pregnancy and new-born babies on the importance of early screening and identification of babies at risk of developing FAS. There is also a need to develop clear local protocols for follow-up of at risk babies.

[45]

## **First results of a pretherapeutic group for adults with FASD and risk of addiction**

**Gisela Michalowski and Alison Frieling**

*FASD Deutschland*

The development of a pretherapeutic group for adults with FASD and risk of addiction in a multidisciplinary team which aims to raise awareness of substance abuse disorders in the patients and ease access to facilities of addiction help will be presented.

Innovative for our multimodal, bifocal model project is (1) the weighting of impairment after severities, (2) the inclusion of caregivers by designing sessions for caregivers parallel and specific to the program and (3) the development of person-centered materials (flyers) to facilitate the transfer.

[46]

## Prevalence survey of alcohol consumption at antenatal booking in pregnancy; comparing blood biomarker analysis to self-report

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**Background:** Providing antenatal and postnatal care for women who drink alcohol in pregnancy is only possible if those at risk can be identified. We aimed to detect the prevalence of actual and self-reported alcohol consumption in pregnant women in the first trimester of pregnancy. We also compared the utility of self-report to blood biomarker analysis.

**Methods:** Routine blood testing is offered at the antenatal booking appointment (uptake 95%). 600 random blood samples were analysed by Helena Biosciences from each month of 2014 to illustrate any seasonal variation. We tested an aliquot (0.5 mL serum/plasma) of anonymised blood for Carbohydrate Deficient Transferrin (CDT), a validated marker of chronic alcohol consumption (normalising 2-4 weeks from the start of abstinence). Frequency of alcohol consumption during pregnancy is currently based on self-report. We collected data from medical records on women's reported alcohol consumption. We analysed and compared the self-reported alcohol consumption documented in the booking notes using the Audit-C alcohol screening tool of 600 randomly selected medical records.

**Results:** The percentage of women who reported drinking alcohol in pregnancy was 1%. This compared to 61% who reported consuming alcohol before pregnancy. The CDT results revealed an alcohol prevalence rate of 1.3% which corresponds with the self-reported alcohol in pregnancy results and current literature estimating a 1% prevalence rate of FASD births.

**Conclusions:** Most women screened antenatally at their booking visit using the audit C reported similar levels of alcohol consumption than were indicated by their blood biomarkers obtained at the same visit. However, CDT may not detect the low level drinkers. Therefore, further studies using additional blood biomarkers may be beneficial in detecting a more detailed drinking history.

[47]

## **Prenatal ethanol exposure: cognitive and physiological effects in the offspring**

**Valentina Carito**, Mauro Ceccanti and Marco Fiore

Prenatal ethanol exposure may induce marked cognitive and physiological deficits in the offspring. The damaging effects on offspring cognition and neurobiology due to maternal ethanol exposure during pregnancy and/or lactation have been widely established but recently also the role of the paternal alcohol exposure prior to mating begins to receive special attention. Both paternal and maternal alcohol exposure seem to induce long-lasting changes in brain regions inducing neuronal cell death in the offspring and affecting also the neurotrophin signaling pathways. Neurotrophins are molecules known to play a crucial role in the survival, development and function of nervous system. Among these, nerve growth factor (NGF) and brain-derived neurotrophic factor (BDNF) are prominent growth factors that play a critical role in the physiopathology of the brain and in the pathogenesis of developmental alcohol exposure. It has been shown in preclinical studies that alcohol exposure during pregnancy disrupts neurotrophin pathways that in turn affect brain cell growth and development but also paternal alcohol exposure may elicit changes on NGF and BDNF signaling. These NGF/BDNF changes were associated not only with anomalies closely related to the neurochemistry of the brain but also with behavioral alterations in the offspring, such as in memory and learning abilities and sensitivity to ethanol consumption. Hence, these results suggest that drinking ethanol in any form, before and during pregnancy, gives serious damage to the fetus and then the only indication is that both mother and father should quit drinking any kind of alcoholic beverages before conception and during gestation and lactation.

[48]

## Effect of docosahexaenoic acid (DHA) on DNA methylation in brain of rat fetuses prenatally exposed to alcohol

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**Background:** Fetal alcohol spectrum disorder (FASD) constitutes multiple effects and include physical, brain and central nervous system disabilities. Docosahexaenoic acid (DHA) levels are decreased in brain with chronic alcohol consumption and DHA supplementation may have a clinical benefit in FASD by mitigating adverse neuronal development. DNA methylation associated with alcohol exposure could be a potential mechanism through which genes involved in neurogenesis are suppressed during fetal stages. DHA has shown to affect epigenetic changes, such as DNA methylation and post translational histone modifications in neuronal cells, although its effect in alcohol exposed brain is not well known. Accordingly, the aim of this study is to test the beneficial effects of DHA supplementation in modulating DNA methylation in rat fetal brains exposed to alcohol.

**Methods:** 9-10 week old Sprague Dawley female rats received either ethanol 3g/kg body weight or dextrose twice a day by gavage. Pregnant rats were assigned to control and DHA diet groups. On G20 (gestational day 20), rats were terminated and brain tissues were harvested. DNA was isolated from fetal brain samples. DNA library was prepared by fragmentation, bead based enrichment of methylated fragments, adaptor ligation and amplification, emulsion PCR and sequencing on the SOLiD5500 platform.

**Results:** Data analysis showed that DNA methylation was significantly higher in alcohol+no DHA groups, when compared to control group. DHA administration reduced DNA methylation levels significantly. A number of differentially methylated regions DNA were identified for validation and gene expression analyses.

**Conclusion:** The results from this study show that DHA could mitigate alcohol exposure associated increase in DNA methylation in fetal rat brains. This finding could be extended to FASD settings.

[49]

## Segmental hair analysis to assess effectiveness of single-session-motivational intervention to stop ethanol use during pregnancy

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**Background:** This study aimed to test the effectiveness of single-session motivational intervention to stop ethanol use during pregnancy using segmental hair analysis of ethyl glucuronide to objectively verify drinking behavior before and after intervention.

**Methods:** 168 pregnant women attending Hospital del Mar (Barcelona, Spain) for antenatal visit were included in the study and randomly assigned to one of two conditions: single-session motivational intervention (MI; N = 83) or single-session educational control condition (ECC; N = 85). Ethyl glucuronide was measured in maternal hair divided into three segments of 3 cm each corresponding to the three different gestation trimesters by a validated liquid chromatography tandem mass spectrometry method. Concentrations of EtG < 7 pg/mg, between 7 and 30 pg/mg and ≥30 pg/mg in each segment were used to assess total abstinence, repetitive moderate drinking and chronic excessive consumption in the previous three months.

**Results:** About a third of pregnant women self-reporting no ethanol consumption during gestation showed hair EtG values corresponding to ethanol drinking. Single-session MI helped in decreasing alcohol consumption during pregnancy as assessed by lower hair EtG concentrations in 2nd and 3rd trimesters. However, it did not significantly increase complete abstinence in pregnant women who previously showed hair EtG compatible with ethanol consumption.

**Conclusions:** Pregnant women did not correctly self-reported ethanol consumption during gestation, while hair EtG was essential to correctly identify drinking patterns. Single-session MI was not enough to stop ethanol use during pregnancy. Interventions at any visit during pregnancy are strongly recommended.

[50]

## **Biomarkers of fetal alcohol syndrome in amniotic fluid: first results from rat model**

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**Background:** Fetal alcohol syndrome (FAS) is still today a clinical reality in France, concerning about 0.5 to 1 birth per 1000 per year. If the clinical diagnosis is easy when the FAS is typical, the lack of validated biomarkers in utero is a handicap for the detection and treatment of mothers during pregnancy and for the prevention of the negative consequences on the new unborn baby. These biomarkers may be useful due to the existence of one ultrasound sign during the first trimester: intrauterine growth restriction. If the ethanol abuse is known to alter the miRNA blood profile in some diseases related to alcohol as hepatitis, no data are known in the amniotic fluid (AF). Ethanol is also known to change the sialylation profile of certain glycoproteins such as transferrin.

**Methods:** Twelve pregnant rats (6 in control group versus 6 in alcohol group) were sacrificed for collection of biological samples (including maternal serum, AF, fetus for anatomical study), after exposing pregnant rats to alcohol (from J4 to J19) using pulmonary inhalation model. Our study investigated the change of the miRNA profile in AF and in maternal serum. N-glycan analysis was also performed in AF.

**Results:** Anatomical study of fetus validated the FAS animal model. Six specific miRNA of alcohol condition and amniotic fluid were highlighted. The N-glycan profile shows a decrease of sialylated oligosaccharides.

**Conclusion:** Our study presents potential biomarkers of fetal alcohol exposure in AF. These would help to establish a prenatal diagnosis of fetal alcohol disorders and allow early management of the mother and her child.

[51]

## **Is Iron Supplementation a 'Disruptive Intervention'? Sleep-wake behaviours and Iron Deficiency in Prenatal Alcohol Exposure (PAE) - from Animal Research to Clinical implications**

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Animal and clinical research over the last 20 years has indicated a complex and relatively unexplored interaction between sleep-wake behaviours, iron deficiency and FASD. This research is of particular relevance because traditionally the challenging/disruptive behaviours of children and youth with FASDs have been attributed to daytime-focused clinical explanatory models such as externalizing behaviours, e.g. attention deficit hyperactivity disorder (ADHD). Underlying sleep disorders, such as intractable chronic insomnia, or other biological mechanisms have not been investigated as possible causes of the challenging/disruptive behaviours associated with FASD. Consequently, targeting sleep as a first line therapeutic agent has not been investigated in a systematic fashion.

A common cause of intractable insomnia is Willis-Ekbom disease/restless legs syndrome (WED/RLS), which is a main differential diagnosis and/or comorbidity of ADHD. WED/RLS is associated with iron deficiency without anemia in the human and animal model of prenatal alcohol exposure (PAE). Iron deficiency – the most common nutritional deficiency of pregnancy – has been proven as a potent and synergistic modifier of FASD risk. The observed deficits in the iron deficient PAE animals include key diagnostic criteria of FASD,



showing that the iron deficiency alcohol interaction is selective and does not reflect generalized malnutrition. In the clinical setting, epidemiological data are missing and clinical recommendations are based on case series.

We are putting together the first puzzle pieces of complex pathways between nutritional status, biochemical mechanisms and clinical observations in animal and human research. We suggest focusing on iron status and sleep-wake problems as potential biomarkers in a novel explanatory model in FASD and iron deficiency research. Animal models are beginning to explore mechanisms underlying alteration in sleep-wake behaviors and frame the clinical research. On the clinical side, we are suggesting a participatory research concept to address the missing evidence via a bidirectional communication tool called a Sleep/Wake-Behaviour Application at the community level. Additional biochemical and brain imaging research, and neuropsychological tests will provide evidence at the specialist and research levels. Our goal is to catalyze clinical implementation of 'disruptive interventions' such as iron supplementation by collecting data in an orchestrated/structured way and providing the evidence.

#### **Speakers & Topics:**

- **Joanne Weinberg (15 mins):** Prenatal alcohol exposure and sleep-wake behaviours in the animal PAE-model
- **Susan M. Smith (15 mins; video presentation):** Prenatal alcohol exposure and iron deficiency in the animal PAE-model
- **Osman Ipsioglu (15 mins):** Iron deficiency, and WED/RLS as the differential diagnosis of ADHD in clinical practice
- **Sylvia Stockler (5 mins; video presentation):** Iron deficiency in clinical practice – how to read results
- **Alex Rauscher (5 min; video presentation)** Iron deficiency in the brain – new developments in MRI
- **Amy Salmon (15 mins):** Creation of participatory research project
- **Discussion & Q/A period**

#### **Objectives:**

- 1) To show the complex relationship between FASD and sleep-wake problems, and between prenatal alcohol exposure and iron deficiency.
- 2) To demonstrate best practice in iron status assessments and how brain iron can be assessed using MRI techniques.
- 3) To explore how a participatory research concept could be created to gather missing evidence and catalyze research.
- 4) To review objectives one through three in context of a collaborative North American and European exploratory research proposal.

[52]

## **A public health intervention to change knowledge, attitudes and behaviour regarding alcohol consumption in pregnancy: A pilot randomised controlled trial**

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**Background:** Improving knowledge about alcohol consumption during pregnancy may help to change social attitudes and ultimately reduce the number of pregnant women who continue to consume alcohol. This research aimed to evaluate the effectiveness of a public health intervention about alcohol consumption among pregnant women.

**Methods:** Pregnant women were recruited in second trimester. Participants were assigned to one of two treatment groups. Both groups completed an initial questionnaire assessing knowledge, attitudes, and practices relating to alcohol consumption during pregnancy. The intervention group then received a mocktail recipe booklet and were asked to share the information with their partner. The control group received standard antenatal care. A follow-up questionnaire was conducted four weeks post birth. The primary outcome measure was knowledge of the health risks associated with alcohol consumption during pregnancy. Secondary outcome measures included women's attitudes, their alcohol consumption and partner's alcohol consumption.

**Results:** A total of 161 participants were recruited (intervention=82, control=79). The findings suggest that the mocktail booklet was effective at improving knowledge ( $p < 0.001$ ; Effect size 0.80) and improving attitudes towards drinking during pregnancy ( $p = 0.017$ ; Effect size 0.43) in the intervention group compared to the control group. Although women in the intervention group were 30% more likely to abstain from drinking than in the control group (RR=1.3, 95% CI 0.97 – 1.75), this result was not statistically significant ( $p = 0.077$ ).

**Conclusions:** Knowledge regarding the effects of alcohol consumption as well as attitudes towards drinking significantly improved as a result of a mocktail recipe booklet. Using this intervention has the potential to reduce the percentage of women who continue to drink alcohol while they are pregnant and therefore improve outcomes for infants and children.

[53]

## Using a visual questionnaire to investigate awareness and emotions of health professionals and pregnant women towards alcohol use and pregnancy. Findings from a comparative study in Northern Italy

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**Background:** The Local Health Authority of Treviso, Italy, in 2008 started an ongoing local program to raise awareness of the risks of prenatal alcohol exposure, involving health professionals and the childbearing-aged population. To investigate the level of awareness of the problem five years after the start, a visual questionnaire was administered to a sample of professionals and pregnant women in the area of Treviso and to control groups in another area of Northern Italy.

**Methods:** The visual questionnaire depicted a pregnant woman drinking a glass of red wine during a party. Participants were asked to write three main things that they noticed, and to list three sensations aroused by the image. Post hoc analysis of responses was performed. Multivariate analyses by using logistic regression models was carried out to verify if there were independent effects of the variables investigated.

**Results:** Overall, 250 pregnant women and 189 professionals filled in the questionnaires.

Independently from the territorial area, both pregnant women and professionals who recognize the problem in the image ("pregnant woman who is drinking alcohol") had a significantly higher probability of recalling an ambiguous or negative emotion than respondents who have not noticed it (GOR 4.589; 95%CI 2.840-7.416;  $p=0.000$  for pregnant women, GOR 5.384, 95%CI 2.766- 10.478,  $p=0.000$  for professionals). Logistic regression model was good:  $P=0.004$ , Hosmer and Lemeshow Test's  $P=0.908$ , Cox & Snell  $R^2=0.205$ , Nagelkerke  $R^2=0.275$ . The dependent variable investigated was the recognition of the problem in the picture, coded as yes or not. Respondents who referred positive sensations towards the image have a lower probability of having noticed the problem ( $p=0.009$ ; ODDS 0.147; 95%CI 0.035-0.619).

**Conclusion:** recalling positive emotions towards the image was associated with a lower awareness of the issue "alcohol and pregnancy", while recognizing the problem was associated with expressing negative emotions.

[54]

## **Effects of FASD education brochures on women's knowledge, attitudes, and alcohol use: outcomes in a randomized controlled trial**

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*Nizhny Novgorod State Pedagogical University, Nizhny Novgorod, Russia*

**Introduction:** Although, a number of prevention strategies have been implemented, alcohol consumption during pregnancy continues to be a public health concern. Few studies collected information for formatting messages to educate women about effects of alcohol use during pregnancy. This randomized trial evaluated effects of different types of FASD education brochures knowledge, attitudes, and alcohol use in women of childbearing age.

**Methods:** 458 women of childbearing age were recruited at women's clinics in Russia and randomly assigned to receiving: a FASD education brochure with positive images and information stated in a positive way, positive group (PG); or a FASD education brochure with negatively presented information, negative group (NG); or a general health material, control group (CG). Face-to-face structured interviews assessed women's alcohol consumption, knowledge about FASD, and attitudes prior exposure to a brochure and at a one-month follow-up. A mixed-effects model analysis, quantile regression, Cochran-Mantel-Haenszel, McNemar's, and Fisher's tests were performed to model the outcomes.

**Results:** Participants in both PG and NG improved knowledge and attitudes at follow-up, while participants in CG did not. The proportion of at-risk drinkers decreased in PG significantly (by 11%), the change was not significant in NG and CG. The reduction in the number of drinks per day was the highest in PG followed by NG; the rate was lower CG. As indicated by risk ratio coefficients in all three study conditions, women who were at-risk drinkers at baseline were less likely to change their alcohol use at follow-up.

**Conclusion:** FASD education brochures improved women's knowledge and attitudes. The educational brochure that included positively framed messages and images had higher effect on women's alcohol consumption in this population.

[55]

## **Preventing FASD in Canada: Closing the gaps between evidence and current practices**

**Nancy Poole**, Rose Schmidt, Courtney Green and Natalie Hemsing

*BC Centre of Excellence for Women's Health and Prevention Lead, CanFASD Research Network*

**Background:** Over the past decade in Canada, health promotion and prevention specialists have been learning about how to prevent FASD, using multi-level and multi-sectoral engagement strategies. In the course of this work, they have created a four-part model of FASD prevention that includes: Level 1, awareness raising and health promotion; Level 2, conversations about alcohol with women of childbearing age; Level 3, specialized support for pregnant women addressing determinants of health; and Level 4 support for new mothers with alcohol-related concerns.

**Objectives:** To provide an overview of current promising FASD prevention efforts across Canada, to identify gaps relative to best practice, and to describe ideas gathered from Canadian researchers, service providers and government planners as to how to close the gaps and move FASD prevention forward in Canada.

**Methods:** In 2015, 50 community program providers, health service providers, civil servants and researchers participated in an online Delphi survey process, to: identify existing FASD prevention activities, programs and services across Canada, and collectively consider how to close the gap between evidence and practice.

**Results:** Promising Canadian practice related to: raising awareness, screening and brief alcohol interventions, specialized support for pregnant women with substance use and related health and social problems, and support for new mothers with alcohol concerns were described. Key areas for future action in research, policy and practice were identified.

**Conclusions:** This research combined best practice evidence from the literature with input from experts on how to close the gap between promising and current practice. Overall Canadian prevention programming reflects best practice as described in the literature, however there are many opportunities to improve scope and availability of education and interventions, and to integrate this work with other areas of health promotion with women, men and families. The results highlight the usefulness of Canada's four-part framework for FASD prevention, and inspire continuing and improved multisectoral action facilitated by the CanFASD Research Network.

[56]

## **FASD prevention strategies in the primary care setting: A comprehensive, interprofessional method for implementation**

**Roger Zoorob**

*Baylor College of Medicine, Houston, Texas, USA*

Risky alcohol consumption is a significant public health problem. Alcohol screening and brief intervention (SBI) programs have been shown to be effective in reducing harmful drinking; however, implementation of these programs in primary care has not been consistent. Women of childbearing age who drink and are not effectively using contraception may be at an increased risk for having a child affected by Fetal Alcohol Spectrum Disorders (FASDs). FASDs are a range of conditions that may occur when a woman drinks alcohol during her pregnancy. In the U.S., almost 50% of all pregnancies are unplanned. The time between conception and knowledge of pregnancy may extend into the second trimester, a critical period of time for fetal development.

The gap between research and practice is well established and implementation and sustainability of clinical programs to prevent FASD are no exception. Healthcare professionals are uniquely positioned to affect change when it comes to the universal adoption of FASD prevention strategies. This presentation will describe an interprofessional approach at developing, implementing, and evaluating FASD prevention strategies in healthcare systems, including the use of champions at all levels and scopes of practice. We will discuss the development of core online and practice-based curricula, an interprofessional practice manual, and post-implementation follow up with health systems to ensure the sustainability of the programs. We will also discuss barriers and facilitators that we have encountered over the course of piloting and successfully implementing SBI in primary care settings.

[57]

## **Developing FASD educational resources for justice professionals**

Heather Jones, Associate Professor Raewyn Mutch, Rochelle Watkins, **Carol Bower** and the Project Steering Group

*Telethon Kids Institute, The University of Western Australia, Perth, Australia*

**Background:** In 2011/2012 researchers from the Telethon Kids Institute surveyed Western Australian judicial officers, lawyers, corrective services staff and police on their Fetal Alcohol Spectrum Disorders (FASD) knowledge and attitudes and practice. This research identified what information was required by justice professionals and how this information should be delivered. The purpose of this project was to translate the research, by developing an educational intervention to prepare for the challenges facing judicial officers and lawyers so that they can:

- recognise cognitive impairments and possible FASD in young people engaging with the justice system whether as a victim, witness or offender
- identify legal implications
- consider referral for assessment if the disability is suspected
- consider decision making with respect to orders, sentencing and management

**Methods:** Cross sectional study using on-line survey methods, descriptive analysis of quantitative data and content analysis methods for qualitative data on justice professionals' knowledge, attitudes and practice. Collaboration with judicial officers, lawyers and community determined the content of the FASD educational resources and how these should be presented to this audience to develop an understanding of FASD and the legal implications for people engaging with the justice system.

**Results:** The resources included 6 videos, an on-line Continuing Professional Development module for lawyers and a FASD and Justice website.

**Conclusion:** The resources have been well received by justice professionals. The website has had international, national and state visits, high number of videos views visits and the module for lawyers has been made mandatory for many lawyers working in the Children's Court.



[58]

## **Professionals' confidence and knowledge of Foetal Alcohol Spectrum Disorder (FASD) within children's services in Scotland**

**Jennifer Shields**, James Anderson, Sarah Brown, Lorna Fulton

*NHS Ayrshire and Arran, Scotland*

**Background:** The assessment and diagnosis of Foetal Alcohol Spectrum Disorders (FASD) in the context of multidisciplinary teams in Scotland is a relatively new endeavour. Research indicates professionals working alongside individuals affected by FASD require increased knowledge of this condition. The assessment of FASD can be largely dependent upon professional groups being aware of the condition and confident in the process by which individuals can be formally identified, assessed and supported. Early identification of FASD is a protective factor that is associated with a reduction in associated adverse outcomes. Therefore increased knowledge and awareness of this condition among professionals should result in earlier assessment and better outcomes for these children.

**Methods:** A cross-sectional study including professionals (n=93) from a range of child health services (CAMHS, Community and Medical Paediatrics) was undertaken. An online questionnaire pertaining to professionals' confidence, knowledge and attitudes working with FASD was completed. Descriptive data was also collated in respect of professional group, current job role and length of service.

**Results:** (1) Professionals' rate their confidence and knowledge of FASD as low. (2) Professionals report not feeling confident taking a comprehensive history of prenatal alcohol consumption or completing an FASD assessment specific to their training (3) A large proportion of professionals report holding a case with suspected FASD whilst reporting not feeling confident case managing these individuals. (4) Professionals' reported a diagnosis of FASD as being more helpful to the family than to the child.

**Conclusion:** There is a significant gap in professionals' confidence and knowledge of FASD within child services. Further training and increased awareness of FASD is required.

[59]

## **Project of training socio-therapeutic community centers educators working with children with FASD**

**Jolanta Terlikowska**, Teresa Jadczak-Szumilo, Katarzyna Okulicz-Kozaryn, Krzysztof Brzózka

*The State Agency for Prevention of Alcohol-related Problems, Warsaw, Poland*

**Background:** In Poland functions a system of institutions involved in providing assistance to children from families with alcohol problems. It includes approx. 5.000 places of help where care is offered to 200.000 children. Unknown remains the percentage of children from this population whose mothers drank alcohol during pregnancy and who may be in consequence at higher risk for FASD. It can be assumed that the group is numerous, therefore professionals working in such institutions should have knowledge and skills required to support learning and development of children with FASD.

**Methods:** PARPA's experiences of implementing the 4<sup>th</sup> edition (years 2005-2010) of trainings for 80 socio-therapeutic community centers educators, were analyzed for changes in the training program, opinions of participants and implementers and deferred effects, i.e. participants' further activity regarding FASD in local communities.

**Results:** the substantive scope of the training programs and their duration was changing with the development of knowledge on the methods and opportunities to help children with FASD available in Poland and worldwide, and depending on the participants' needs. Implementers of the trainings were those directly involved in helping children with FASD, which is why they enriched the training program with their recently acquired knowledge, both theoretical and practical. This was especially true for methods of CNS stimulation and accommodation, as well as for routines introduced to lives of children with FASD.

**Conclusion:** In Poland the development of the system of help and support for children with FASD and their families can be based on existing institutions, which enables a significant extension of the scope of assistance without substantial financial investments in creating a separate infrastructure. Training programs should be subject to continuous evaluation and include new knowledge and needs of the participants, also regarding the supervision of their work.

[60]

## **Medical students' knowledge about the damage to fetus due to in utero alcohol exposure: a cross-sectional study**

**Gali Lackner**

*The Institute for Child Neurology and Development, The National FASD Clinic, Schneider Children's Medical Centre of Israel, Sackler School of Medicine, Tel-Aviv University, Israel Anti-Drug and Alcohol Authority, Petah-Tikva, Israel.*

**Background:** Previous study showed that the level of knowledge regarding FASD is extremely limited amongst medical professionals in Israel. We realize the importance of examining the level of awareness among the future generation of Israeli medical doctors. Based on the results of our study we believe we will be able to measure the need for enhancing the awareness of students destined to gain employment in key positions in the medical field, and in turn, conduct prevention efforts through them.

**Method:** A cross sectional study conducted among 592 Israeli medical students, from all five medical schools and all levels of training. A questionnaire was distributed through "Qualtrics" which is a web-based survey" regarding medical students knowledge about alcohol consumption during pregnancy and risk inflicted on the fetus.

**Results:** (1) a significant portion of the students did not exhibit sufficient knowledge (36%). (2) Most of the students were not aware of the prohibition on alcohol consumption during all stages of pregnancy. This was found to be significant ( $p=0.000$ ). (3) A significant correlation was found ( $R=0.107$ ,  $P=0.014$ ) between the level of training (clinical studies vs. pre-clinical) and the level of knowledge (sufficient ( $\geq 8$ ) vs. insufficient). (4) We have found a significant relation between the amount of exposure to the data about alcohol consumption during pregnancy and obtaining a sufficient grade in the questionnaire.

**Conclusion:** Medical students' knowledge about the damage to fetus due to in utero alcohol exposure was found to be insufficient and can be improved by increasing their exposure to the subject.

[61]

**The French National Academy of Medicine declares FASD prevention as a great national cause**

**Denis Lamblin**, Joelle Balanche, Patrick Chauvin

*SAF France, La Réunion, France*

This presentation will highlight:

- Recommendations made at the end of 2015 by the "Défenseur des Droits" (the Defender of the Human Rights) in his report : "Child with disabilities and child protection: child with double vulnerability".
- Recommendations addressed in March 2016 by the National Academy of Medicine following the hearing of French experts on FASD. For the defender, without screening, the role of early prevention is not properly fulfilled.
- How those two national recommendations should increase the development of concrete measures to facilitate the prevention of FASD.

[62]

## Outcomes for Adults with FASD in the UK- what's their narrative? A Qualitative pilot study

Joanna Buckard<sup>1</sup>, Raja Mukherjee<sup>2</sup>

<sup>1</sup> Red Balloon Training & Consultancy, 19 Wenlock Crescent, Chesterfield. UK

<sup>2</sup> National FASD Specialist behaviour clinic, Surrey and Borders Partnership NHS Foundation Trust, Oxted, UK

**Background:** Prenatal alcohol exposure can cause physical and neurobehavioural conditions known as Foetal Alcohol spectrum Disorder (FASD). These can lead to secondary disabilities as described by Streissguth (2004).

Streissguth reported that the risk for secondary outcomes such as mental health problems, inability to maintain work and trouble with the law, was increased if diagnosis had come late or if there was inadequate or inappropriate support. There continues to be limited longitudinal data that follows individuals with FASD examining outcomes in their lives and none in the UK. Where it does exist it does not offer the qualitative narrative of the experience that individual adults have faced in their journey with FASD.

**Method:** The purpose of this pilot study is to look at the long term outcomes for 4 individuals with FASD in the UK and whether the risk factors identified by Streissguth affected outcomes for the adults included in this study. An interview approach using a semi-structured questionnaire will be used to guide the interviews. 2 males and 2 females aged over 25 and diagnosed with FASD will be approached to participate. Contact initially by an online FASD forum and subsequently by arranged interviews. Participation will be voluntary and whilst this may introduce an inherent selection bias, for this pilot study to assess the approaches and allow refinement of the questions to be used in later studies, it is considered acceptable. Current interview themes have been developed through information provided by Foster Carers, feedback obtained from prior training and wider literature. Qualitative data will be analysed thematically.

**Results:** Data collection is currently ongoing and will be analysed prior to the conference. Data presented at the conference.

**Conclusions:** At this point conclusions cannot be drawn. To be presented at the meeting in London.

[63]

## **Ophthalmological findings in young adults with fetal alcohol syndrome disorders (FASD); a long- term follow-up study**

**Emelie Gyllencreutz**<sup>1,2</sup>, Eva Aring<sup>2</sup>, Magnus Landgren<sup>3</sup>, Leif Svensson<sup>3</sup>, Marita Andersson Grönlund<sup>2</sup>

<sup>1</sup>*Department of Ophthalmology, Skaraborg Hospital, Skövde, Sweden*

<sup>2</sup>*Institute of Neuroscience and Physiology/Ophthalmology, Sahlgrenska Academy at Gothenburg University, Gothenburg, Sweden*

<sup>3</sup>*Department of Pediatrics, Skaraborg Hospital, Skövde, Sweden*

**Background:** A previous Swedish study has shown correlation between ophthalmological findings such as low visual acuity (VA), subnormal binocular vision and small optic discs in children with Fetal alcohol syndrome disorders (FASD). The aim of this study was to analyze if these findings remained when the children turned 18.

**Method:** Sixteen young adults diagnosed with FASD at a mean age of 7.2 years in a study performed in 2000-2002 - underwent another ophthalmological examination in 2014 at a mean age of 21 years. Using a 4-digit eye diagnostic code, considering VA, refraction, strabismus/binocular functions and structural abnormalities, the results from the two examinations were compared. Each category was graded 1-4 depending on the severity in the ophthalmological exam. Maximum points given were 4+4+4+4.

**Results:** Mean score from the first examination was 9.2 points compared with 10.9 points in the second one. In ten cases the total score altered with 2 points or less. In the remaining six cases the score altered with maximum 5 points. In all these cases the score had increased, mostly because an abnormal optic disc was found more frequent in the young adults than in the young children.

**Conclusion:** The ophthalmological findings in children with FASD tend to remain or increase in a follow-up examination 12-14 years after they first were examined and diagnosed with FASD. An ophthalmological investigation could be a valuable tool as part of the diagnostic evaluation even in young adults suspected for FASD.

[64]

## **Neurodevelopmental outcomes in individuals with heavy prenatal alcohol exposure and a FASD diagnosis, with and without exposure to neglect: A natural experiment in patients seen in a national FASD diagnostic clinic. Initial findings**

**Raja A.S. Mukherjee**<sup>1,2</sup>, Penny A. Cook<sup>2</sup>, Sarah H. Norgate<sup>2</sup>

<sup>1</sup> *FASD Specialist Behaviour Clinic, 116-118 Station Rd East Oxted Surrey RH80QA, UK*

<sup>2</sup> *Division of Public Health, Salford University, Allerton Building, Salford, UK*

**Background:** The overlap between neglect and prenatal alcohol exposure is large. Studying this in humans in an experimental design is complex and in many cases unethical. In order to therefore establish the impact of each on cognitive development natural experiments are required to see the outcomes. Such a natural experiment occurred in the UK national FASD clinic where two groups became established, one with significant comorbid neglect and another with nil to minimal neglect.

**Methods:** Analysis of routine data from individuals aged 6 plus seen for confirmation of FASD diagnosis and assessment of wider neurodevelopmental conditions such as ASD, ADHD and underlying cognitive, communicatory and sensory processes. Categorical data were analysed using chi squared analysis. Further analysis is ongoing at the time of abstract submission.

**Results:** No significant differences were seen between the two groups on age, gender, ability to form attachments, FASD diagnoses, ASD diagnoses or ADHD diagnoses. The attachment difficulties may be more prevalent in girls who were neglected but the numbers seen in this group were low.

**Conclusions:** These findings would suggest that Prenatal alcohol exposure and a diagnosis on the FAS spectrum are affected neurologically and neurodevelopmentally, potentially independent of neglect. When taken alongside work from Scandinavia and America where it has been found that in people exposed to neglect with and without FASD that the neurodevelopmental issues were more common in the FASD group, it would suggest the prenatal exposure is impacting on neurodevelopmental presentations to a greater extent, while the psychological overlay may be related to the postnatal exposure. This has implications for interpretation of the effects of a common comorbid presenting factor.

[65]

## Adults with Fetal Alcohol Spectrum Disorders: Health issues associated with a late FASD diagnosis

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**Background:** An early FASD diagnosis has been described as a protective factor. However, many people with FASD were not diagnosed until adult age. Often, not the individual with FASD but a supportive key person aims at receiving a diagnosis. Therefore, people with FASD do not participate in decision making with regard to the diagnostic process and following interventions. The effects of a late diagnosis remain unclear, especially with respect to health related issues.

**Objectives:** In this study, the influence of subjective disease theories was investigated in individuals with FASD with a late diagnosis according to health related issues.

**Methods:** A sample of 15 individuals with FASD participated in this case study. Semi-structured interviews were conducted, transcribed and qualitatively analysed using thematic analyses. Data reduction, coding and analysis were facilitated by Maxqda qualitative data analysis software version 11. Additionally, several standardized questionnaires were used and combined to assess personality aspects (NEO-FFI), health issues (SF-36), handling of the disease (EFK) and emotion regulation (KATE, DEX).

**Results:** Health issues are crucially important in the life of individuals with FASD. Findings show that positive, neutral and also negative outcomes of a diagnosis are related to health related issues such as stress, relationship difficulties and emotion regulation. Support and further interventions are associated positively with the diagnosis. Negative outcomes included labeling and attributed disabilities. Overall, subjective disease theories play an important role in the acceptance of the diagnosis and participation in further interventions due to the FASD diagnosis.

**Conclusion:** It is important to include individuals with FASD participatory in the diagnostic process and planning of further interventions. Further participatory research is needed to investigate the barriers to gain further support and interventions.

**Questionnaires:** KATE, SF-36, NEO-FFI short version, DEX, EFK



[66]

## **Childhood Placement in Out-of-Home Care in Relation to Psychosocial Outcomes in Adults with Fetal Alcohol Syndrome**

**Jenny Rangmar**, Annika Dahlgren Sandberg, Marita Aronson, and Claudia Fahlke

*Department of Psychology, University of Gothenburg, Sweden*

**Background:** Even in adulthood the disabilities associated with FASD may have a major impact on life, but different environmental circumstances during childhood may also be influential. This study aimed to investigate placements in out-of-home care, and number of early separations from caregivers, related to psychosocial outcomes in adults with Fetal Alcohol Syndrome (FAS). Additional analyses were then done on a subgroup's cognitive development and mental health.

**Methods:** Data on education and living with biological parents or in out-of-home care were obtained from childhood medical records on 51 adults (43% women), mean age 32, all diagnosed with FAS. Adult psychosocial outcomes (e.g., highest completed education, economic status, care due to alcohol or illicit drug abuse, mental health, and conviction for crime) were obtained from national registers.

**Results:** No significant within-group differences related to the adult psychosocial outcomes were found. Psychiatric disorders, psychotropic drug prescriptions, and crime convictions were equally common, regardless of whether placement in care was early or late, or whether the participants had experienced few or many early separations.

**Conclusion:** We suggest that the findings illustrate the heterogeneity among individuals with FASD. Welfare authorities' decisions concerning special education and placement in out-of-home care should be tailored to each individual. Interventions from society are still needed for individuals with FAS over 22 years old.

[67]

## I'm going to be a Superhero

**Carolyn Blackburn**

*Early Child and Inclusion, Birmingham City University*

**Background:** The United Convention on the Rights of the Child (UNCRC) (articles, 2, 3, 5 12 and 19) stipulates that children have rights to non-discrimination, to have their best interests considered, to receive guidance from adults, to express a view, to have their views given due consideration/weight and to be safe. For researchers and educators, this means that children share power and responsibility for decision making, children are involved in decision making processes, children's views are taken into account and they are supported in expressing their views. These rights are conceptualised within the new Children and Families Act (2014) and revised Special Educational Needs Code of Practice (2014). This paper presents perspectives from children and young people with FASD about their education in mainstream and special primary and secondary education in England.

**Methods:** A mixed-methods case study approach was used for the study which explored the educational implications of FASD. Nine teachers, parents and children/young people were interviewed, following an initial survey with teachers. An action research cycle followed whereby teachers reflected on changed practice to develop teaching and learning frameworks. This paper will discuss data from interviews with children and young people that sought to explore their perceived successes and difficulties in education and aspirations for the future.

**Results:** The findings presented will discuss the areas in which children with FASD perceive both success and difficulty in education and their suggestions for educators about appropriate support. In addition children and young people's aspirations for the future will be discussed as well as the practicalities and difficulties involved in obtaining children's perspectives.

**Conclusion:** Children and young people with FASD have the right to express a view about their education. However, educators require training and professional development in order to elicit, understand and interpret the views that children and young people with FASD may express.

[68]

## **The Lililwan\* Project: Neurodevelopmental outcomes and Fetal Alcohol Spectrum Disorders (FASD) prevalence in remote Australian Aboriginal children**

**JP Fitzpatrick**, J Latimer, M Carter, J Oscar, H Carmichael Olson, BR Lucas, R Doney, C Salter, R Watkins, and EJ Elliott

*The Lililwan Project team. Sydney University and The George Institute for Global Health, Sydney Telethon Kids Institute, Perth, Australia*

**Objectives:** Aboriginal leaders in remote Western Australian communities, concerned about the impact of high levels of alcohol consumption in pregnancy, invited researchers to collaborate in The Lililwan Project with the objective to determine prevalence of Fetal Alcohol Spectrum Disorders (FASD).

**Methods:** Using active ascertainment, children born in 2002/2003, living in the Fitzroy Valley in 2010/2011, were identified (n=134). In interviews, 127 (95%) consenting caregivers provided social, biomedical and antenatal data including alcohol use, with birth outcomes derived from medical records. Interdisciplinary assessments were conducted for 108 (81%) children. Prenatal alcohol exposure was objectively quantified. FASD diagnoses (Fetal Alcohol Syndrome (FAS), partial FAS, and Neurodevelopmental Disorder – Alcohol Exposed (ND-AE)) were diagnosed using Canadian FASD Diagnostic guidelines with slight modification. Management plans were prepared for each child.

**Results:** Alcohol was used in 55% of 127 index pregnancies. Of women who drank, 87% drank at high-risk levels and 88% drank in the first trimester. In 108 children assessed, FAS or pFAS was diagnosed in 13 (120 per 1000 (95% CI 70-196), all with confirmed prenatal alcohol exposure. Of these, 69% had microcephaly, 85% had growth deficiency, and all had facial dysmorphism and CNS impairment in 3-8 domains. Using conservative diagnostic criteria, 8 more children were diagnosed with ND-AE. Overall FASD prevalence was 194 per 1000 (95% CI 130-280). Additional children considered at high risk for neurodevelopmental difficulties were referred for future evaluation.

**Conclusion:** FASD prevalence was higher than reported previously in Australia and amongst the highest worldwide. Alcohol use in pregnancy remains a major public health challenge throughout Australia, particularly in remote communities with high rates of alcohol consumption. Community-led initiatives for FASD prevention and FASD intervention must be supported.

\*Lililwan means 'all of the little ones' in Kimberley Kriol.

[69]

## Particularities of enviroing and personal alcohol consumption of bullying participants among Russian school-aged children

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**Background:** According to recent studies, alcohol consumption becomes widespread among young people in Russia. More than 60% of 11-24 year old responded to be drinking (Gorshkov, Sheregi, 2010). Effects of alcohol are well-known, and include not only damage to health and well-being of a particular person, but also negative social outcomes, such as criminal behavior, car accidents, and destructive/aggressive behavior. Aggressive behavior in teen ages can take form of bullying. The objectives of this study were as follows: (1) to study the frequency of drinking among school-aged children, (2) to understand if the alcohol consumption is connected to bullying behaviors, and (3) to estimate the influence of consumption in child's family and peer environment.

**Method:** The survey was conducted in secondary schools of Nizhny Novgorod region. The sample numbers 363 children of 6 to 11 grades (age 12-18), 187 boys and 176 girls. Bullying participants were revealed with a translated questionnaire developed by D. Olweus. Alcohol consumption was estimated with self-report answer sheet, containing questions on frequency of personal consumption, age of first experience, drinking behavior of parents and friends. The study was verified by Ethical committee of Saint Petersburg State University, and approved by schools where it was conducted.

**Results:** (1) 28% of respondents reported to drink alcohol from time to time, and 8% consume it once per month or more often. There is a correlation between frequency of personal drinking and a number of peers who drink. (2) Bullies were found to drink more frequently than victims and witnesses of bullying. (3) Victims are more likely to come from families where parents drink.

**Conclusion:** Alcohol consumption has several effects on bullying among school children in Russia. Drinking by parents may influence victims. Bullies themselves drink more often than others, and this behavior is supported by their peers.

[70]

## **Therapy Program for Children with FASD and their Families**

Teresa Jadczak -Szumiło, Agnieszka Palka, Grzegorz Palka

*Psychological Center, Żywiec, Poland*

For the last sixteen years, we have worked with FASD children and their families. We provide individual and group help: psychological workshops and therapeutic camps for children with FASD and their families. We support foster and adoptive families in the first place. The help program consists of neurodevelopmental stimulation and psychological programs for the family. The gist of problems with FASD children is the damage of CNS. Therefore, an important part of our program is stimulating children in this respect. Each child is given a tailored program of neurodevelopmental exercises that are to help in better reception and processing of stimuli, lead to maturity of motor developmental patterns, as well as to proper development of reflexive scripts. The program is based on neurodevelopmental diagnosis. To this end, we make use of evaluation protocols and the MNRI© therapy designed by Svetlana Masgutova. The program differs from other neurodevelopmental methods, as it takes the influence of HPA axis on the nervous system into account. We also conduct research on the effectiveness of the methods with FASD children. Family support encompasses workshops for families on stimulating children at home, educating on how to support FASD children at school and how to cope with their problems stemming from attachment and early childhood trauma. Ten people are involved in the realization of the program that is funded by EY Foundation.

[71]

## **Parents and teachers together can change the negative stigma of FASD and build a positive circle of support**

Deb Evensen and Jackie Lannon

Anchorage, Alaska, USA

**Background:** There was an urgent need, in our school district, to increase our capacity to successfully work with students facing the complex challenges of FASD. In order to do this, we needed to build an infrastructure that would increase the educators' understanding of brain differences while helping them implement practical strategies that work. Over the past 7 years, we have provided extensive training, developed a mentor program, a FASD think tank, and a parent support group.

**Methods:** We established a group of site-based specialists at the school level, teachers helping teachers, and a group of parents willing to talk about their children's struggles and challenges. The parents and educators work together to share resources that generate success for students at home, school, and in adulthood.

**Results:** We formed a parent support group where parents and educators come together on a regular basis to gain knowledge, share experiences, and learn from each other. Together we have created a proactive team. Our astounding results bring a promise of enhanced student outcomes and family relationships.

**Conclusion:** Parents and educators can teach and learn from each other. Together they solve previously insurmountable problems and create a pathway for student education and social success.

[72]

## **Incontinence problems in children with Fetal Alcohol Spectrum Disorders (FASD): a Polish study**

**Katarzyna Anna Dylag**<sup>1,2,3</sup>, Sylvia Roozen<sup>1,4</sup>, Katarzyna Przybyszewska<sup>2</sup>, Justine Niemczyk<sup>1,5</sup>, Alexander von Gontard<sup>1,5</sup>, Gerjo Kok<sup>1,4</sup>, and Leopold Curfs<sup>1,6</sup>

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<sup>4</sup>Department of Work and Social Psychology, Maastricht University, The Netherlands

<sup>5</sup>Department of Child and Adolescent Psychiatry, Saarland University Hospital, Germany

<sup>6</sup>Department of Genetics, Maastricht University Medical Centre+, The Netherlands

**Background:** Fetal Alcohol Spectrum Disorders (FASD) is one of the leading preventable forms of intellectual disabilities (ID). Not much is known about the topic of pediatric incontinence related to FASD, e.g. nocturnal enuresis (NE), daytime urinary incontinence (DUI) and fecal incontinence (FI). So far, incontinence problems have been examined among children with other specific syndromes such as Angelman Syndrome (AS), Rett syndrome, Prader-Willi syndrome, and Mowat-Wilson Syndrome (MWS). The aim of the present study is to investigate possible presence of incontinence among children and adolescents with FASD in a Polish cohort.

**Method:** Data from 53 participants, FAS (*n* 26), pFAS (*n* 14), and ARND (*n* 13) were evaluated (37 boys, mean age = 10.1 years) from an outpatient and inpatient centre for FASD in Poland. 205 parents/caregivers of children with FASD received the Polish version of the parental questionnaire: Enuresis/Urinary Incontinence.

**Results:** Preliminary results show that overall incontinence was present in 15% of children and adolescents with FASD (4 FAS, 2 pFAS, 1 ARND). 6% had nocturnal enuresis (2 FAS, 1 pFAS, 0 ARND), 8% had daytime urinary incontinence (4 FAS, 0 pFAS, 0 ARND), and 8% had fecal incontinence (2 FAS, 1 pFAS, 1 ARND). Scores on symptoms related to problems of the lower urinary tract (LUTS) ranged from 1 to 18 (mean = 5.3).

**Conclusion:** This is a first study to examine problems of incontinence among children and adolescents with FASD. Problems of NE, DUI and FI seem to be present in both children and adolescents with FASD. Further assessment of behavioral and psychological symptoms

associated with incontinence problems among children and adolescents with FASD are necessary for pediatric evaluation and clinical management.



[73]

## **Get your research published!**

**Diane Black**

*Chair EUFASD Alliance*

So you have done some great research! Do you know how to grab the attention of the editor, impress the reviewers, and communicate your message effectively? Do you know what shape a publication should be? Do you know the key components of an effective introduction? Do you know the surest way to get your paper rejected? Do you know the simple rules to construct graceful sentences in English? And do you know how to link sentences together for clear and flowing text?

This workshop will be presented by Diane Black, Ph.D., a native English speaker with 12 years of experience teaching courses in Publishing in English to Ph.D. students. Some basic principles will be covered in the short workshop, and participation also includes 3 hours of coaching with your paper by e-mail. Participation limited to 12. Only for nonnative speakers of English.

[74]

## **REDUCING THE PREVALENCE OF FASD PRIMARY AND SECONDARY DISABILITIES USING A COMMUNITY BASED APPROACH TO FASD PREVENTION IN AN ATLANTIC FIRST NATION**

**Lori Vitale Cox**

*Elsipogtog First Nation, New Brunswick, Canada*

**Objectives:** This presentation will discuss the development of a community and culturally based diagnosis, intervention and prevention model implemented in a First Nation after FASD prevalence of ~ 20% was established in 1999-2000. Was the community based model effective?

**Methods:** School age children attending a First Nation elementary school were assessed for FASD at two points in time- 15 years apart. In that 15 years period a community based service delivery model was implemented that included development of culturally based screening and diagnostic tools, access to community based diagnostic team, implementation of school interventions and an FASD mentoring and outreach program for pregnant and high risk women. The first group was followed longitudinally for 15 years after diagnosis and were screened for select secondary disabilities. In 2014-15 a second study was undertaken to track the level of secondary disabilities in the original cohort and to establish the present prevalence of FASD's in the community school.

**Results:** Overall FASD prevalence rates have dropped from approximately 20% to 12.5%. In 1999-2000 there was FAS prevalence in the community school of over 5%. In 2014-15 there was 0% FAS in the community school. There was no FAS diagnosis since 2005. There are also fewer siblings affected by FASD, Economically this means lifetime savings of millions of dollars for the community.

**Conclusions / Discussion:** Through an expanded community based model of prevention both the prevalence of FASD and severity of secondary disabilities associated with FASD can be shown to have been lowered. Despite these findings the prevalence rate of other FASDs continues to be higher than in the general population. Women continue to smoke cigarettes during pregnancy and there are much higher rates of pre-natal exposure to other drugs. Research indicates community based interventions have been effective but higher levels of outreach family support may be required.

[75]

## **An international communication campaign to raise public awareness of Fetal Alcohol Spectrum Disorders. A feedback from participant organizations**

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The communication campaign "Too Young To Drink" was launched on September, 9, 2014 by a network of organizations worldwide, coordinated by the EUFASD Alliance in collaboration with NOFAS. The aims were: to raise awareness of FASD among the general global population; to spread research-based information; to connect various entities all around the world, to share best practices and create the basis for future collaborations. The campaign applied principles of social marketing, basing on the concept of "value network" and on the theory of "holistic marketing". The campaign comprised digital and print materials, including a dedicated Website, a Facebook page and a Twitter profile. The launch consisted of a 24-hour, round-the-world action involving 53 organizations from 27 countries. The second edition, carried out in 2015, was joined by 76 organizations over 35 countries. After the launch of each edition, a survey was carried out with participant organizations to collect impressions about the campaign: 15 participants responded in 2014, 19 in 2015. The main strengths of the campaign were recognized to be the visual imagery; the fact that it was an international effort; the use of social media, the fact that it provided materials to motivate and initiate local campaigns, and helped to "start a global discussion on FASD." The main weaknesses were the lack of translations of the materials into all local languages, the secrecy required until the launch and the limited time available to organize the actions. Some partners recalled that some people from the medical community and from local partner organizations felt that the images could be perceived as too strong or unclear for sensitive targets.

Respondents expressed their interest in continuing to work together for future actions, to "sustain awareness and global interest for the issue", by maintaining the same motto and slogan for future editions and involving more organizations, big mass Media and public health agencies.

[76]

## **FASD prevention in the U.S.: An innovative approach to systems change**

**Sandra Gonzalez**

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Alcohol use during pregnancy can present significant preventable risks to prenatal and perinatal health. One of the most devastating long-term effects is Fetal Alcohol Spectrum Disorders (FASDs). Nearly half of all U.S. pregnancies are unplanned. Many women not aware of their pregnancy continue drinking well into their first and even second trimesters—critical periods of fetal susceptibility.

This presentation will describe the U.S. Centers for Disease Control and Prevention (CDC)-funded FASD Practice and Implementation Centers and National Partnerships initiative to prevent alcohol exposed pregnancies. Unlike previous efforts aimed at training individuals and groups of practitioners, the current project promotes activities that would result in sustainable change in practice behavior at the system level. The project specifically targets professionals from the fields of social work, family medicine, nursing, medical assisting, obstetrics, and pediatric practice. Each Practice and Implementation Center represents one or two health care disciplines and is partnered with a national professional organization in order to reach a wider, national audience.

This nationwide, interprofessional consortium has developed various training curricula, online courses, and supporting material such as training manuals to assist health care settings in implementing and sustaining FASD prevention programs. We will discuss these materials and ways that all members of the primary care team may be more involved in the prevention of alcohol-exposed pregnancies.

This initiative has taken an innovative approach at promoting the universal use of FASD prevention strategies for numerous health care professionals. Through increased training opportunities, a national focus on FASD prevention, and the promotion of systems-level practice change, this project will equip healthcare professionals with the necessary tools to reduce the incidence of FASD in the U.S. and worldwide.

[77]

## Understanding Fetal Alcohol Spectrum Disorders (FASD) and maternal alcohol consumption during pregnancy

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**Background:** Fetal Alcohol Spectrum Disorders (FASD) refers to a spectrum of disorders caused by prenatal alcohol consumption. Alcohol consumption during pregnancy and its interference with the development of the fetus and child is complex and highly variable. However, little is known regarding which alcohol consumption patterns most strongly predict FASD. The current study aims to provide the required evidence to estimate the FASD prevalence and identify which alcohol consumption patterns are most in need of intervention.

**Methods:** A systematic literature search on global FASD prevalence and related alcohol consumption was conducted in multiple databases up to August 2015, including PubMed, PsychINFO, PsychARTICLES, ERIC, CINAHL, EMBASE and MEDLINE. A query was generated and resulting hits were exported and screened by two independent screeners, after which results were extracted and (meta-) analyzed.

**Findings:** Global FASD prevalence estimates from included studies ranged from 0 to 176.77 per 1,000 live births. Substantial heterogeneity prompted meta-regressions, revealing geography as important moderator, and suggested cautious interpretation. Furthermore, studies lacked information to indicate when drinking during pregnancy becomes harmful for the unborn child. Also, a substantial variation in alcohol consumption measures was found, ranging from 'any consumption' to fine-grained specification of intensity and frequency. While precluded meta-analysis, this variation did enable development of guidelines for measuring alcohol consumption.

**Discussion:** FASD prevalence implies an urgent need for health promotion interventions addressing maternal alcohol consumption. To identify the most expedient target behaviors

for such interventions, we propose guidelines for studies examining maternal alcohol consumption patterns in relation to FASD.

[78]

## **'Making FASD history' in Australia: successful evidence-based, population-level programs of FASD prevention, diagnosis and treatment in remote Australian communities**

**JP Fitzpatrick**, J Oscar, M Carter, J Councillor, M Symons, K Bruce, B Wagner, R Walker, G Pearson

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**Objectives:** Australian Aboriginal communities documented the prevalence of FASD (194 per 1000 children), and prenatal alcohol exposure (PAE) (55% high risk drinking). In response a broad FASD strategy was implemented in two regions: Fitzroy Valley (FV) and Pilbara. Strategy aims are to reduce PAE, and deliver FASD diagnostic clinics and school-based treatment programs.

**Methods:** FASD strategies were implemented in the FV pop~4,500 (2008-2015), and Pilbara pop~60,000 (2015-2020). *Prevention* includes a) Mass media campaign and general health promotion activities b) Training of local health service providers to deliver targeted health promotion c) Support of pregnant women and their partners at-risk of alcohol use in pregnancy d) Postnatal support of women's social and emotional wellbeing. *Diagnosis* is delivered by PATCHES Paediatrics, a multidisciplinary outreach school-based FASD service. *Treatment* to improve self regulation/executive function is delivered through an RCT of the Alert Program, in nine schools in the FV (n~250 children) and six schools in the Pilbara (n~250 children).

**Results:** Alcohol use in pregnancy reduced from 65% in 2010 to 18% in 2015 (FV midwife data). Community awareness of FASD (95%), and intent of participants to stop drinking if pregnant (~80%) or to support others not to drink (~90%) has been documented in interviews with ~800 participants aged 18-80. FASD clinics are delivered throughout the Fitzroy Valley and Pilbara regions. The Alert Program pilot intervention (one school, n=24) improved caregiver/teacher-rated executive functioning using the BRIEF ( $p<.05$ ); and behavioural regulation SESBI ( $p<.05$ ) and ECBI ( $p<.05$ ). A further 14 schools will receive this intervention from 2016-2020.

**Conclusions:** It is possible to achieve FASD prevention, diagnosis and treatment within 5 years at a population/regional level. There is hope, and a roadmap for success for communities and governments seeking to address this complex public health issue.

[79]

## **Interventions for children with fetal alcohol spectrum disorders: Where to next?**

**Sharon Dawe**, Natasha Reid, Doug Shelton, Paul Harnett

*Brisbane, Australia*

**Background:** The consequences of prenatal exposure to alcohol are well documented. What is less clear is whether damage following prenatal exposure can be ameliorated.

**Methods:** We undertook a systematic review of all intervention trials reported since 1990 that focused on psychological treatment in order to inform our own efforts at developing interventions for children and infants with pre natal exposure to alcohol. Studies were identified from PsycInfo, PubMed, Scopus, Web of Knowledge, CINAHL, ERIC, The Cochrane Central Register of Controlled Trials, and gray literature. Two reviewers independently screened the title and abstract of each reference, and the methodological rigor of the included studies was assessed using the Effective Public Health Project assessment tool.

**Results:** 2962 studies were identified for title abstract screening, 32 met study inclusion criteria. The subsequent analysis of these studies highlighted (i) growing evidence for interventions that improve outcomes for early to middle childhood in particular and (ii) the importance of ensuring that interventions address both family functioning in addition to domain specific deficits found in children with FASD. This led to our current adaptation of the Parents Under Pressure (PuP) program.

**Treatment and conclusion:** The PuP program is a home-based program developed for complex families that addresses the quality of the caregiving relationship, parental affect regulation in addition to supporting optimal child outcome. The adaptation for children with FASD includes a focus on development of child emotional regulation through the use of mindfulness based strategies shared with parents and conducted both individually with the child and together with the parents. The detailed results of one family will be used to illustrate the changes found over the course of 20 sessions.



[80]

## **Improving neurocognition and behavior in children FASD: GoFAR, a metacognitive intervention**

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**Background:** Prenatal alcohol exposure impacts the prefrontal cortex and the behaviors and abilities regulated by this region of the brain. Problems are observed frequently in arousal regulation, self-regulation and adaptive function that negatively affect children and families. We addressed these problems through GoFAR, a multi-component intervention designed to improve self-regulation and adaptive living skills of children with Fetal Alcohol Spectrum Disorders (FASDs) by improving metacognitive control of emotions and arousal.

**Methods:** A 10-week intervention was implemented with children ages 5 to 10 diagnosed with a FASD. The program teaches a metacognitive strategy (FAR) to supports behavior regulation. GoFAR includes: 1) a computer game that instructs the child to use FAR in a virtual world; 2) parent behavioral regulation training; and 3) behavioral analog therapy sessions (BATS) where parent and child implement the FAR methodology with basic life skills. Families were randomly assigned to 1 of 3 groups: GoFAR Intervention, which received all components; Faceland Intervention, which received a different game, and Controls, which received no intervention.

**Results:** Relative to controls, participants in both intervention groups improved in externalizing behaviors problems, in a sustained attention on the Test of Variables of Attention (Attention Performance Index: Wald  $\chi^2(2) = 10.3$ ,  $p < .006$ ) and in parent report of negative affectivity ( $F(2, 23) = 3.5$ ,  $p < .046$ ,  $\eta^2 = .235$ ). The GoFAR group gained in domestic adaptive living skills ( $F(1, 24) = 5.1$ ,  $p < .033$ ,  $\eta^2 = .177$ ) relative to those in the FACELAND group. Thus, instruction in FAR, the metacognitive learning strategy, whether by computer or parent-child therapy sessions, resulted in significant reduction in negative affectivity and improvements in attentional regulation. Those in the GoFAR group who received FAR instruction both in the context of a computer game and in analog therapy sessions demonstrated the greatest gains in adaptive living skills.

**Conclusion:** Application of targeted behavioral interventions directed at deficits associated with FASD results in significant improvements in behavior, attention and adaptive functioning.

[81]

## Physical and intellectual development as well as psychiatric symptoms in young adults diagnosed with Fetal Alcohol Syndrome as children

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**Background:** In a previous report 71 children adopted from Eastern Europe were assessed 5 years post adoption to families in western Sweden. FAS was found in 21/71 (30%) children. A clinical follow-up was performed when grown up.

**Methods:** A physical examination, neurological, neuropsychiatric and psychological assessment was performed. The mini international neuropsychiatric interview (MINI), Adult ADHD Self-Report Scale (ASRS), Leiter-R IQ screener and the adaptive behaviour assessment system (ABAS) parental scale were used.

**Results:** 16 of 21 were obtained for follow up, 6 males, 10 females age 18-23, median age 20. Generally the cohort was low in weight and with a short stature. The head circumference was below the 50th centile in all cases and below the 3rd percentile in 7 cases. Lip-philtrum stigmata were still present in 14 cases. 9 cases exhibited dysdiadochokinesia. The non-verbal IQ-screening result a mean score of 62 in 14 individuals and 3 scoring above 71 but below 85. The assessment scale hand scored by adoptive parents showed a composite score of 71, with three individuals scoring above 90. 15/16 had ADHD.

MINI showed: Any depressive episodes 6/16, wherein 3 had attempted suicide. Any psychotic disorder 3/16, any eating disorder 3/16, mania 1/16, panic disorder 6/16, post traumatic stress disorder 7/16, general anxiety disorder 9/16, Agoraphobia 5/16, Social phobia 5/16, OCD 1/16. 6 reported occasional binge drinking, 1 alcohol abuse. 5 reported recurrent drug use, mainly cannabinoids. 7 were in contact with psychiatry, 6 treated with stimulants and 4 with antidepressants.

**Conclusion:** The diagnosis of FAS in children adopted from Eastern Europa entails in young adulthood growth inhibition, significant intellectual difficulties, ADHD in 90% as well as poor adaptation to everyday living. Already a wide array of psychiatric disorders was found, especially anxiety.

[82]

## **Supporting attachment in preschool children with FASD: A descriptive study using the circle of security home visiting program**

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**Background:** Research suggests that PAE increases the risk of insecure caregiver-child attachment and related negative child emotional behavioural outcomes. Research has also shown positive effects of attachment-focused interventions in preventing disrupted caregiver-child attachment relationships; however, such interventions have not been specifically adapted for children with FASD. This presentation will describe the implementation, challenges, and results of a community home-based attachment intervention, Circle of Security (COS), with young children affected by PAE, in Winnipeg, Canada.

**Methods:** This program used a home-based attachment model, Circle of Security. COS uses both graphic representations of attachment behaviors as well as videotaped interactions between the child and their caregiver, which are reviewed by the therapist who has established themselves with the caregiver as a secure base from which the attachment relationship may be explored. Preschool children and families who participated were referred to the FASD Outreach program for behavioural support and were on a wait list for intervention. Those who consented to participate in the program were randomized to COS or the standard behavioural support program. The intervention for each family took place over 9-12 month period.

**Results:** Twelve caregiver-child dyads completed the FASD adapted COS intervention. Children's ages ranged from 2-5 years. Results showed a significant reduction in parent stress that was maintained at 3-month follow-up. A clinically significant reduction in child behavioural issues was noted. Children showed increased ability to communicate their needs more effectively to their parent. Parents also showed an improvement in their ability to attend to their child's cues.

**Conclusion:** This research provides evidence of successful early behavioural intervention for preschool children affected by PAE and their families and provides evidence to inform future programming.

[83]

## Reaching and Teaching Learners with FASD, Implementing the Engagement for Learning Programme – A New Zealand Case Study

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*Positive Path International, New Zealand*

**Background:** Many educators believe that “the study of engagement has the potential to assist educators and therapists to maximise learning outcomes” and have focused on engagement as the foundation for effective learning in children with neurologically based complex needs including FASD. As Carpenter (2010, p. 5) states: Without [engagement], there is no deep learning, effective teaching, meaningful outcome, real attainment or quality progress. The purpose of this paper is to describe and illustrate the use of the Engagement for Learning Framework developed through the Complex Learning Difficulties and Disabilities (CLDD) Research Project (2009-2011) utilising a case study of a child with FASD situated in a New Zealand context.

**Methods:** In total, 95 educational settings and 224 students took part across three phases of research (November 2009-March 2011) comprising a resource development phase and two trial phases in mainstream and special schools. This research project also had a cohort of schools outside of the United Kingdom, including New Zealand involved in Phase 2. The researchers used an exploratory, multiple case study approach and action research methodologies.

**Results:** The resulting Engagement Ladder, Engagement Profile provided initial baseline information. The Engagement Scale enabled interventions specific to the student’s engagement across 7 indicator areas, from which data showed increases in engagement for similar proportions of the student cohort. Across the three phases, 81-85 per cent (mean: 83 per cent) increased their levels of engagement for learning, 2-9 per cent (mean: 5.3 per cent) showed no change, while 5.5-16 per cent (mean: 11.6 per cent) showed decreased levels of engagement. Descriptive data corroborated these scores.

This original research added value to existing work by developing resources for educators that enabled them to appropriately place students in preferred environments appropriate for their learning, using materials they related positively to, and interacting with people in a way suited to their learning style. Data from these aspects supported better use of activities adapted to encourage students’ engagement in the seven engagement areas (awareness, curiosity, investigation, discovery, anticipation, persistence and initiation). The

findings collated enabled educators to score learner engagement over time, add in new interventions, materials or adapt environments to support progress while collecting associated descriptive data. This paper will focus on one case study from New Zealand.

Conclusion – the engagement for learning materials have been generalised across a range of educational settings and resulted in improved measures of engagement for learning for children with FASD.

[84]

## **Social communicatory deficits, autistic spectrum disorder and other neurodevelopmental consequences across the lifespan associated with prenatal alcohol exposure and FASD: Findings from the UK FASD National Specialist Behaviour Management Clinic**

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**Background:** Prenatal alcohol exposure and FASD diagnostic criterion have recognised deficits in social communication as common findings. The relationship however with autism and wider autistic spectrum has continue to be debated. Whilst the prevalence of Autism in people with FASD has varied between different studies published to date, it is clear that social communication difficulties remain a core feature. Work conducted in the specialist behaviour clinic published in 2011 identified a strong relationship with an autistic spectrum disorder in a small sample of 21 people. In 2013 new criteria for autistic spectrum disorders were released in DSM V. These identified a spectrum of presentation for autism removing subcategorization. Also, a further criteria of Social Communication Disorder was introduced.

**Methods:** The specialist behaviour clinic offers a comprehensive neurodevelopmental assessment where each individual is assessed for a FASD diagnosis but also wider neurodevelopmental disorders such as ADHD and autism using specialist diagnostic tools. These findings are audited on a regular basis. Data is collected and analysed using SPSS.

**Results:** Whilst the 2015 audit is currently being completed and analysed, 2014 data completed on 82 individuals identified that just over 50% of those attending the specialist behaviour clinic met criterion for an autistic spectrum disorder using a specialist diagnostic tool (DISCO). Similar rates, although slightly lower, were seen with a validated screening tool for autism (SCQ) with around 44% meeting criteria for an autistic spectrum disorder. Evidence from a few case studies, who were reassessed, also would suggest in some the reduction in restricted patterns of behaviour, however the social communication deficit remains.

**Conclusions:** It has been recognised and presented previously the high percentage of overlapping ADHD, and from this clinic, autism in those people diagnosed with FASD and difficult challenging behaviours. This talk would firstly present updated clinical data regarding the diagnostic overlaps and discuss in the context of the most recent

diagnostic criterion identified in DSM V. The diagnostic and management implications will be discussed.

[85]

## **Fetal exposure to ethanol: relationship between ethyl glucuronide in maternal hair during pregnancy and ethyl glucuronide in neonatal meconium**

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**Background:** In recent years, fatty acid ethyl esters (FAEEs) and ethyl glucuronide (EtG) in meconium emerged as reliable, direct biological markers for establishing gestational ethanol exposure. We investigated whether EtG in maternal hair measured during the three trimesters of pregnancy correlated with EtG and FAEEs in neonatal meconium.

**Methods:** In a prospective sample of 80 mother-infant dyads from Barcelona (Spain), we measured EtG and FAEE in maternal hair segments and meconium samples using a validated UHPLC-MS/MS method.

**Results:** Fifty-eight (72.5%) women had EtG concentrations in the hair shafts  $> 7$  pg/mg in one or more pregnancy trimesters, and EtG and FAEEs in meconium samples were documented in 50 and 24 of their neonates, respectively. The best significant correlations ( $p < 0.0001$ ) were found between EtG concentration in the proximal 0–3 and 3–6 hair shaft segments corresponding to the last two pregnancy trimesters and EtG in neonatal meconium ( $\rho = 0.609$  and  $\rho = 0.577$ , respectively). Using the combination of EtG in meconium  $\geq 30$  ng/g and a median of EtG  $> 11$  pg/mg in maternal hair during the second and third trimesters of pregnancy, prenatal ethanol exposure could be predicted with a sensitivity of 85.7% and specificity of 73.7%.

**Conclusions:** This study provides evidence of proven fetal exposure to ethanol during the second and third trimesters of pregnancy by linking detection of ethanol biomarkers (EtG) in maternal hair segments and EtG in neonatal meconium.



[86]

## Early Identification of Risk for Fetal Alcohol Spectrum Disorders: A Systematic Review of Biomarkers of Prenatal Alcohol Exposure

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**Aim:** Diagnosis of fetal alcohol spectrum disorders (FASD) is often complicated by missing or unreliable information about alcohol exposure *in utero*. Objective measurement of prenatal alcohol exposure is essential to support FASD diagnosis and early intervention. Biomarkers have been advocated for use in universal screening programs but their validity has not been comprehensively evaluated. This study aimed to systematically review the validity of objective measures of prenatal alcohol exposure.

**Methods:** We systematically searched 13 electronic databases and supplementary sources between January 1990 and October 2015. Eligible studies provided data about validity of biomarkers within maternal and neonatal biological samples for the detection of prenatal alcohol exposure. Methodological quality was assessed using QUADAS-2.

**Results:** Twelve studies met inclusion criteria. Most (8) studies investigated objective measures of heavy prenatal alcohol exposure and included participants from high risk settings. Test performance varied widely for biomarkers in meconium (7 studies, sensitivity 4% to 100%, specificity 13% to 98%), maternal blood (4 studies, sensitivity 0% to 100%, specificity 79% to 100%), maternal hair (2 studies, sensitivity 19% to 85%, specificity 79% to 86%) maternal urine (2 studies, sensitivity 15%, specificity 97% to 100%) and biomarker test batteries (2 studies sensitivity 22% to 50%, specificity 56% to 97%). Placental biomarkers demonstrated 82% sensitivity and 83% to 94% specificity in one study. Methodological quality assessment suggested a high risk of bias within included studies due to the use of self-report reference standards and selective outcome reporting.

**Conclusions:** Current evidence is insufficient to support the use of objective measures for prenatal alcohol exposure screening in practice. Biomarkers in meconium and placental tissue may be the most promising candidates for future research and require validation in population based studies.

[87]

## **Synergistic actions of ethanol and synthetic cannabinoids during early gestation in a mouse model: Teratogenesis and potential mechanisms**

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**Background:** Synthetic cannabinoids (SCB) are increasingly common drugs of abuse with potencies far greater than THC. We have recently shown that the SCB, CP-55,940, can induce birth defects involving the face, eyes and brain at acute dosages as low as 62.5  $\mu\text{g}/\text{kg}$ . These defects are similar to a comparable ethanol (EtOH) exposure, a known inhibitor of sonic hedgehog (Shh) signaling, and given the frequent co-abuse of ethanol and cannabinoids, we sought to determine their combined teratogenicity.

**Methods:** Pregnant mice were exposed to a moderate dose of EtOH and/or either a moderate or low dose of CP-55,940 on their 8<sup>th</sup> day of pregnancy (beginning of neurulation and comparable to the end of the third week in humans). EtOH was administered via two ip injections of 1.4 g/kg, four hours apart. CP-55,940 (25 or 250  $\mu\text{g}/\text{kg}$ ) was administered either alone or with the first EtOH injection. Just prior to birth, the fetuses were examined for the presence of birth defects, and incidence and severity of eye defects was quantified. Additionally, an *in vitro* cell assay assessed if CP-55,940 might inhibit the Shh pathway.

**Results:** At 1.4 g/kg, EtOH slightly increased the incidence of ocular abnormalities beyond that in controls (6% above control), while 250  $\mu\text{g}/\text{kg}$  CP55,940 increased the incidence 34% above controls. When administered together, the incidence of ocular defects increased to 49%, illustrating a synergistic effect. The low dose of SCB (25  $\mu\text{g}/\text{kg}$ ) was not significantly teratogenic; however, when administered with ethanol, the two drugs together increased the incidence of eye defects ~12% above controls. In the *in vitro* assay, CP-55,940 inhibited the Shh pathway, suggesting a possible mechanism by which it interacts with ethanol.

**Conclusion:** EtOH and SCBs have synergistic actions in inducing birth defects and may work together to inhibit the Shh signaling pathway, a key signal for normal brain and face development. These findings may help elucidate pathogenic mechanisms of FASD.

[88]

## Exploration of alcohol consumption, antioxidants and fetal growth: Secondary Analysis of the Avon Longitudinal Study of Parents and Children (ALSPAC)

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**Background:** Being born small-for-gestational-age (SGA) is associated with a range of adverse outcomes through infancy and into adult life, including increased risk of neonatal morbidity and mortality, and type-2-diabetes and cardiovascular disease. Alcohol and maternal micronutrient intakes are both independent risk factors for poor fetal growth, and evidence from animal models suggest that dietary antioxidants may modify the relationship between antenatal ethanol exposure and harm to offspring. The aim of this study was to explore whether dietary antioxidants modify the relationship between antenatal alcohol consumption and fetal growth in a sample of pregnant women from the UK.

**Methods:** A secondary analysis of data from ALSPAC was conducted. Women provided details of alcohol consumption and binge drinking at 18 weeks gestation, dietary data were gathered using an FFQ at 32 weeks gestation, and birthweight and gestational age at birth were taken from hospital records (n=11,715). Binary logistic regression models and likelihood ratio tests were used to explore relationships between alcohol consumption and the intakes of antioxidants (vitamin C, E and carotenoids). Regression models were adjusted for maternal age, ethnicity, parity, smoking, education and socio-economic status.

**Results:** After adjustment for confounders, the odds of giving birth to an SGA infant was significantly higher for women who reported binge drinking, if they were in the lowest quartile (Q1) for vitamin E intake (OR=2.03, 95%CI=1.37-3.00; p<0.0001),

compared to women in other quartiles (OR=0.83, 95%CI=0.59-1.17; p=0.31). For vitamin C and carotenoids odds ratios were similar for women in Q1 compared to all other quartiles.

**Conclusion:** Low intakes of vitamin E during pregnancy may increase the risk of fetal growth restriction in women who engage in binge drinking during the first 18 weeks of pregnancy.

[89]

## FASD in biological and non-biological families in Poland

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**Background:** The prevalence of Foetal Alcohol Spectrum Disorders (FASD) is significantly lower among children in biological families than in orphanages, foster care or adoptive families. This latter population is also much better recognized because most studies include individuals from non-birth families. The main objective of this study was to estimate the scale and compare characteristics of FASD in biological and non-biological families in Poland.

**Methods:** The study based on an active case ascertainment approach indicated the prevalence of FASD not lower than 2%, including 0,4% of Foetal Alcohol Syndrome among general population of 7-9 year olds in Poland. Data were re-analysed in order to compare FASD rates and functioning of children with FASD living with biological parent(s) (N= 258, 97% of the sample) or with other caregivers (3%).

**Results:** Among children recognized as at risk for FASD, 86% lived with biological parent(s). Children from non-biological families scored lower on IQ, visual-motor integration, cognitive flexibility measures and presented more externalized problem behaviours than children living with birth parent(s). There were no other differences between two groups.

**Conclusion:** Children living with biological parent(s) are rarely referred for FASD diagnosis in Poland, but the results of our study suggest that FASD recognition in foster care and adoptive families is just a top of the iceberg. However, FASD in biological families is an extremely sensitive issue, requiring in-depth ethical consideration of potential benefits and threats, especially for birth mothers.

[90]

## Introducing computerised 3D face screening to the FASD clinic

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**Background:** The face is a focus of the dysmorphology examination when assessing the effects of prenatal alcohol exposure. Palpebral fissure length (PFL) and head circumference can be measured well with appropriate training. Objective evaluation of the philtrum and upper lip is more challenging. Previously, we showed methods developed in CIFASD for analysing 3D face photographs. With the availability of hand-held 3D cameras, computerised face screening is now a realistic prospect. We report on our experience of introducing such novel technology and techniques to a FASD clinic.

**Methods:** The camera requires left, front and right views to produce a 3D face photograph. We tested the single front view to assess PFL and philtrum smoothness, and full face for more detailed analysis. A heat map of surface curvature depicts prominence of the pillars, and depth of vertical groove, of the philtrum to delineate smoothness. Using 4 eye landmarks, PFL% is calculated. With more landmarks, the philtrum heat map can be normalised against matched controls and the volume of the philtrum groove computed. Classification of a face is possible using CIFASD controls and diagnosed individuals.

**Results:** The hand-held camera is easy to use but capture of 3 views in series is challenging with less co-operative children. A single front view can determine PFL and assess philtrum smoothness. More detailed analysis requires a full face image.

**Conclusion:** The hand-held 3D camera is relatively easy to incorporate into clinic workflow. With relatively little clinical intervention, PFL and philtrum smoothness are assessable on the spot. Comparison with previously diagnosed individuals requires more interaction with the software that is best undertaken when formalizing the assessment.

[91]

## **The development of the Prenatal Alcohol Investigation and Resource Service (PAIRS) in NHS Ayrshire & Arran**

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**Background:** The assessment and diagnosis of Foetal Alcohol Spectrum Disorder (FASD) in the context of multidisciplinary teams is a relatively new undertaking within NHS Scotland. Following training delivered by the FASD Centre, Manitoba; which was commissioned by the Scottish Government, NHS Ayrshire & Arran sought to integrate learning into clinical practice.

**Developments:** Since this innovation, the team based within Ayrshire Central Hospital, Irvine were granted funding by the Scottish Government to deliver an assessment, diagnostic and intervention service for children affected by FASD. Rainbow House is a Child Development Centre based in Ayrshire Central Hospital, which was established to provide the children of Ayrshire and Arran with a multi-disciplinary approach to the diagnosis and support of neuro-developmental difficulties and chronic health conditions. CAMHS is also located on site and provides a neurodevelopmental assessment service for children with additional mental health needs. Together we have an excellent base from which to focus on the assessment and the diagnosis of FASD. Our FASD team currently comprise Consultant Paediatricians, an FASD Team Co-ordinator, Clinical Psychologist, Assistant Clinical Psychologist, Speech & Language Therapy and Occupational Therapy.

**Outcomes:** To date the service has provided assessment (and in some cases a diagnosis) of FASD for over forty children. FASD awareness training has also been delivered to almost one thousand participants. Developing pathways span prenatal and postnatal services onto universal and specialist services across all agencies. With the ongoing support of the Scottish Government and specialist advisors, we hope to continue to develop our service and welcome feedback from those who are also striving to meet the needs of this client group.

[92]

## **Reunion Island, first French region to benefit from a specific Resource Center dedicated to the prevention, diagnosis, support and care of the persons afflicted by FASD**

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On the 1st of January 2016, in Reunion Island, an Action Plan of prevention and follow-up of those afflicted by FASD has been initiated. Its purpose is to gather the strengths of the island to develop primary, secondary and tertiary actions of prevention islandwide. To this end, Reunion Island will be equipped with 2 diagnosis centers, one covering the north and the other one the south of the island.

At the head of the system, a resource Center will promote, coordinate and evaluate all actions developed in the island.

It will also direct and support the research and regional and international cooperation.

For many years this project has been longed for by professionals and families to care for the children, adolescents and adults. It will benefit from the support of the State through different services (ARSOI, MILDECA, Pr efecture), and from the region and the department councils.

This presentation will highlight:

- Why the establishment of this first FASD Resource Center is for France a major step in acknowledging this issue especially for adolescents and adults.
- How this pilot project will mobilise all forces in this french region in close cooperation with national and international experts.
- How this collective mobilisation islandwide can quickly be evaluated, shine in other French regions and be of help internationally.



[93]

## The incidence of Fetal Alcohol Syndrome in Scotland: an enhanced passive surveillance study

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**Background:** The reported prevalence of Fetal Alcohol Syndrome (FAS) varies considerably and has not been extensively investigated in W. Europe. The SCOTPSU undertook a five year FAS surveillance study of children diagnosed under 6 yrs. of age commencing in January 2010, preceded by FAS national and local educational and awareness raising events.

**Methods:** Paediatric Specialists across Scotland were contacted by e-mail monthly and invited to notify and detail any recently identified cases of FAS, exhibiting *full* clinical features as defined by Institute of Medicine (IoM) criteria. Returns were collected, collated and analysed.

**Results:** 41 cases of FAS were reported over a period of 60 months, with a majority identified under the age of 1 year. This represents a maximum birth prevalence of 0.19/1000 live births. The mean maternal age was 32 years (mean gestation at delivery 36 weeks). Co-occurring maternal substance misuse and cigarette smoking were commonly reported. Less than one third of FAS babies remained in the care of their biological parents. Significant neurodevelopmental deficits were common as well as a number of reported congenital abnormalities. A range of treatment and support services were being utilised, particularly social support and community child health teams.

**Conclusions:** This study identified the expected range of developmental impairments caused by pregnancy alcohol exposure in FAS and demonstrated an association with pre-term delivery, cigarette smoking and drug mis-use. Significant family and social burdens were identified along with considerable utilisation of a range of professional and support services. The birth prevalence reported is low compared to most international studies and likely to represent an underestimate. To address the challenges associated with early recognition and diagnosis a national clinical assessment pathway has been established; a FASD Diagnostic (SIGN) Guideline is also in preparation.

[M1]

## Identifying children who are at risk of Fetal Alcohol Spectrum Disorders in a community paediatric setting

**Geraldine Gregory**

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**Background:** The prevalence of Fetal Alcohol Spectrum Disorders, (FASD), in the UK population is currently unknown. Looked After Children (LAC) are a particularly vulnerable population of children where the likelihood of prenatal alcohol and substance exposure is higher than the general population. Community Paediatricians who work with challenging families, LAC, and who act as Medical Advisors for Adoption Services have a unique overview of the unmet needs of this group of vulnerable children. It has become apparent in recent years that there is an increasing number of children presenting with complex behaviour difficulties, where a history of exposure to alcohol and drugs prenatally is found if this is specifically looked for. This information is vital in planning assessment of the child.

**Method:** Two simple audits of children seen by a community paediatrician are described. The first audit documented the number of children seen during a period of two and a half years, between April 2010 and August 2013, where there was a clear prenatal history of alcohol exposure. This audit also identified how many of children may have FAS or FASD. The second audit reported on children put forward for adoption during a 12 month period, from January to December 2013.

**Results:** This audits reported a history of prenatal exposure to alcohol and or drugs in 55 out of 160 (34%) children seen for health assessments as LAC, and in 34 out of 45 (75%) children seen for medical assessment prior to adoption.

72 children not previously identified were considered to fulfil criteria for a diagnosis of FAS or FASD following these audits.

**Discussion:** Children with FAS and FASD continue to be unrecognised as the opportunity to identify the risk factors is often missed. The long term impact of parenting an affected child needs to be understood by carers and professionals, with access to appropriate assessment, management and support. Commissioners need to be adequately informed in order that appropriate services can be funded.

## [M2]

### Expressing the functional profile of adults assessed for FASD

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**Introduction:** The research on adults with fetal alcohol spectrum disorders (FASD) is limited and is focused on the prevalence and general descriptions of impairments such as executive functioning, impulsivity, and emotional regulations. Correctional and Justice Systems sites have received greater attention than community settings. With the documented costly impact of FASD on health and social systems globally more sensitive data on daily functioning profiles begs attention for the planning and delivery of supportive community services.

**Objective:** To present the results of a secondary analysis of the daily functioning of 74 adults assessed for FASD in a Canadian province, most whom have a justice profile and to present an occupational therapy format for integrating diagnostic test results with lifestyle patterns to guide the selection and structuring of community services.

**Approach:** A interactive format with participants will explore the commonalities of the issues presented with those found in other jurisdictions and application of proposed collaborative programming strategies.

**Findings:** Health, social performance patterns emerged which support using community navigators, having supportive residences with 24-hour staff, connecting individuals with Primary Health Care (PHC), using individualized work placements and implementing inclusive community development strategies to mobilize local resources.

## [M3]

### **"Well in Europe they drink all the time": Ontario Health Care Students' Attitudes Regarding Alcohol Use during Pregnancy**

**Kelly D. Coons<sup>1</sup>**, Shelley L. Watson<sup>2</sup>

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<sup>2</sup> *Psychology Department, Laurentian University, Sudbury, Ontario, Canada*

Compared to other groups, midwives demonstrate better knowledge of FASD, but some midwives believe that infrequent consumption of alcohol during pregnancy does not pose significant risk to the fetus or the mother. Family physicians and OB/GYNs indicate that one or more drinks per week or per occasion is likely safe for pregnant women. These findings demonstrate that healthcare providers may not be following the recommendation that no alcohol consumption during pregnancy is the safest option. However, limited research has examined healthcare students and their knowledge, attitudes, or self-efficacy regarding FASD. 30 healthcare students in their final two years (medical, nurse practitioner, and midwifery students) have completed two quantitative questionnaires regarding FASD. 18 students participated in a narrative vignette and a semi-structured interview, which were analyzed using Thematic Analysis. While almost all students recognized that no alcohol consumption during pregnancy is the best recommendation, many students discussed exceptions to this recommendation (e.g., "low" or "moderate" consumption; "light" drinking for special occasions) and highlighted that "we don't know what level is safe". Participants compared alcohol consumption during pregnancy in Canada to the "normalized drinking patterns" that they perceived to occur across Europe. The belief that "there is no known safe level" during pregnancy and that the research is "not clear" was discussed by all participants. Participants reflected that they require further education about FASD in order to care for individuals with FASD and support primary prevention. If healthcare professionals are ill-informed about the risks of prenatal alcohol exposure, professionals may be increasing their patients' risk of having a child with FASD. By understanding the attitudes of healthcare students, and their knowledge deficits, these gaps can be targeted and addressed in FASD prevention programs.

## [M4]

### **Establishing an FASD assessment and diagnostic clinic: Who we saw and caregiver's views**

Natasha Reid, Doug Shelton, **Sharon Dawe**, Judith Warner, Katrina Chamberlain, Brisbane Australia.

**Introduction and Aims:** The effects of prenatal exposure to alcohol are wide-ranging and pervasive in nature. In response to growing concerns about the lifelong disabilities, the first Australian multi-disciplinary assessment and diagnostic team for Fetal Alcohol Spectrum Disorders (FASDs) in young children was established in 2012 as part of the Queensland Child Health Service (Gold Coast). The current paper provides (i) an analysis of 29 cases with diagnostic and demographic characteristics of the children and their families and (ii) the views of caregivers on their experience and the consequences for their children.

**Design and Methods:** A case file review was undertaken of 29 consenting families documenting current and historical findings from clinical assessments. Of these, ten families provided in depth interviews that were subsequently transcribed using NVivo 10 for thematic analysis.

**Results:** There was considerable diagnostic heterogeneity with the majority of children having received at least one diagnosis in addition to an FASD. The qualitative analysis identified three major themes: a desire for future support for their child; an ongoing concern that FASD was not recognized as a disability across school and related settings; that the formal assessment process provided validation for caregivers, that they felt respected and understood by the clinical team during this process.

**Discussion and Conclusions:** These findings highlight concerns of caregivers, emphasizing both the importance of diagnostic services and the need for provision of further support beyond diagnosis for a child diagnosed with a FASD.

[M5]

## Fetal Alcohol Spectrum Disorder and problem intractability

Vicki Russell

*University of Tasmania*

**Background:** The science of fetal alcohol exposure has rapidly advanced over the past four decades from the initial association of fetal anomalies with high risk maternal alcohol use to a contemporary, albeit controversial, prevention message of abstinence during pregnancy. Despite Efforts to date have not significantly reduced alcohol consumption by pregnant women, the outcome is complex, ambiguous and intractable. FASD can be conceived as a 'wicked problem' and the objectives of this study were to explore why this is so.

**Methods:** A three-country comparison utilised a multiple method qualitative approach to data collection including semi-structured interviews with key stakeholders to draw out similarities and differences. A conceptual model of agenda building with particular attention to the phases of specification and expansion within different agenda building patterns enabled examination of the relative influences on FASD as a public policy process. Using a network approach to wicked problem resolution some conclusions are made about how FASD might be better managed.

**Results:** The research found that FASD is a wicked problem with preferred problem solutions reflecting the interests of public policy decision makers with the consequences of (1) suppression of the problem; and (2) little improvement for individuals and families who live with FASD. In all three countries, a shift in the pattern of agenda building from an 'outside initiative' pattern to an 'inside initiative' conceptual pattern of agenda building enabling governments to control entry to the public agenda.

**Conclusion:** Whichever way FASD is, however, viewed, value systems and power dynamics are at play. This means fetal alcohol exposure and FASD are embedded with conflict and, therefore, are essentially contested. Competitiveness is at the heart of wicked problems and relieving tensions to find common ground can facilitate acceptance that problem formulation and finding solutions are mutual.

## [M6]

### **Alcohol screening in pregnancy: an opportunity for support and education?**

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**Background:** Providing antenatal and postnatal for women who drink alcohol in pregnancy is only possible if those at risk can be identified. However screening, either by questionnaire or biomarker analysis, will only be helpful if women feel comfortable with the screening method used. We aimed to conduct a survey of pregnant women and their partners to investigate self-reported beliefs and practice regarding drinking during pregnancy and the acceptability of screening using biomarkers.

**Methods:** Pregnant women and their partners attending a range of antenatal clinics in North East England were asked to complete a short survey regarding their alcohol consumption in pregnancy, their beliefs about safe levels of alcohol in pregnancy and whether they would be happy to have their blood or their babies meconium analysed for alcohol biomarkers. Data analysis used a mixed (quantitative and qualitative) approach.

**Results:** Of 171 women surveyed, 153 (89.5%) felt pregnant women should abstain, although only 70 (40.9%) reported not drinking in pregnancy. Of 96 women who reported drinking in pregnancy and reported when they stopped, all but 6 (6.3%) stopped drinking when they found out they were pregnant. Of women and partners who recorded an answer, 87.2% said they would consent to blood biomarker analysis. Confusion over what level of alcohol is safe and using screening as an opportunity for education and support emerged as a key theme from thematic analysis.

**Conclusions:** Most women viewed screening for alcohol in pregnancy positively, although its acceptability in the small number of women at high risk is unclear.

[M7]

## Exploration of Dietary Patterns, Micronutrient Intakes and Heavy Drinking During Pregnancy: Secondary Analysis of the Avon Longitudinal Study of Parents and Children (ALSPAC)

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**Background:** Alcohol intake and inadequate maternal nutrition are associated with adverse fetal outcomes; potential mechanisms being interactions with DNA methylation and oxidative stress (OS). Binge and heavy alcohol intake are typically associated with lower fruit and vegetable, and higher processed and fried meat intake compared with intake in people consuming lower levels of alcohol or abstaining. The study aims were to determine relationships between maternal micronutrient intakes, dietary patterns, and alcohol consumption during pregnancy.

**Methods:** A secondary analysis of data from ALSPAC was conducted. Women (11,457) provided details of alcohol consumption and binge drinking at 18 weeks gestation and dietary data were gathered using an FFQ at 32 weeks gestation. Linear regression models were used to explore relationships between alcohol consumption and dietary intakes during pregnancy.

**Results:** After adjustment for confounders, drinking > one drink per day (first trimester) was associated with lower intakes of folate and vitamin B6, and increased adherence to the 'Processed' ( $\beta=0.19$ , 95%CI=0.03, 0.34;  $p<0.05$ ) and 'Confectionery' ( $\beta=0.14$ , 95%CI=0.07, 0.20;  $p<0.0001$ ) dietary patterns. Binge drinking during pregnancy was associated with significantly lower mean daily intakes of folate, vitamin B6, vitamin C and vitamin E, and greater adherence to the 'Processed' dietary pattern ( $\beta=0.12$ , 95%CI=0.04, 0.19;  $p<0.001$ ), compared to women who did not report binge drinking.

**Conclusion:** Women who report drinking in potentially harmful patterns may be putting their baby at increased risk of adverse fetal development due to greater adherence to dietary patterns associated with lower intakes of micronutrients involved in DNA methylation and OS.



[M8]

## **Fetal Alcohol Spectrum Disorder: The Difficulties of Identification and Diagnosis of Adolescents and Adults with FASD**

**Laura Harrison & Charlotte Willis**

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Individuals with Fetal Alcohol Spectrum Disorder (FASD) often present in childhood with a range of learning and behavioural difficulties. A characteristic set of facial features may present in cases of Fetal Alcohol Syndrome (FAS), the more severe end of the FASD spectrum. However, if individuals with FASD are missed during childhood, identification and diagnosis becomes increasingly difficult due to factors such as the disappearance of the unique facial features with age, dramatically varying manifestations of the syndrome and the overlap with other disorders, such as ADHD. In addition there is a lack of education about FASD among clinicians and other agencies, such as social services and the police. Worldwide, there is also a lack of consensus regarding diagnostic criteria and none targeted specifically at identifying FASD in adolescents and adults, which means that a significant number of patients with FASD are potentially undiagnosed. Diagnosis is extremely important as it allows them to access the help and support they need, which can reduce the adverse outcomes associated with this condition.

Our research examines the presentation of FASD in adolescents and adults and the difficulties of identification and diagnosis in this age group. We review the current guidelines and recommend that, in order to develop a clear set of diagnostic criteria for this age group, further studies are essential into the presentation and epidemiology of adolescents and adults with FASD. A screening programme could then be implemented to increase identification of undiagnosed individuals. Specific factors that are more prevalent in individuals with FASD, such as comorbid psychiatric disorders, conflict with the law and placement in foster care, together with prenatal alcohol exposure, could be used to statistically determine an individual's likelihood of having FASD. Our prototype screening questionnaire is an example of how this could be developed.

## [M9]

### **Fetal Alcohol Spectrum Disorder and external/middle ear problems: a retrospective audit to establish working together**

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**Background:** Fetal Alcohol Spectrum Disorder (FASD) encompasses the clinical conditions of Fetal Alcohol Syndrome (FAS) and Alcohol Related Neurological Disorder (ARNND). There is recognition of a link between fetal alcohol syndrome and middle ear disorders, but this is based on a small number of studies. The main objective of this retrospective audit was to establish the middle ear profile of children diagnosed with FASD. An attempt has also been made to enhance multidisciplinary working to provide safe and good clinical care of patients diagnosed with FASD.

**Methods:** Patients were identified from an existing updated database. The database included children who had undergone a diagnostic assessment to confirm the diagnosis. Twenty nine patients, with a male: female ratio of 18:11 was identified. Information on physical examination, audiometry and tympanometry was obtained. Outcome measures: 1) External and middle ear pathology on physical examination. 2) Pure tone audiometry and tympanometry results were noted. Hearing loss  $\geq 20$  dbHL in each frequency tested was considered to be clinically significant.

**Results:** Age range: 18 months to 14 years. None had external ear abnormalities. A total of 2 (16.6%) patients had a mild temporary conductive hearing loss due to middle ear effusion and 1 (8.3%) patient had moderate mixed hearing loss and received interventional support in the form of hearing aids to assist with hearing. A total of 17 (58.62%) did not have any contact with Paediatric Audiology or ENT service.

**Conclusion:** The prevalence of temporary conductive hearing loss in this group is only slightly higher than that of the general population. A significant proportion of patients did not have any contact with the Paediatric Audiology / ENT service. It is speculated that, if these children had been referred to these services for assessment, the prevalence of temporary hearing loss would have been higher. Children with FASD have multiple medical needs along with learning difficulties. Hence early detection of hearing difficulties and intervention is vital.

## [M10]

### **Children prenatally exposed to alcohol – a case study in north of Portugal**

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Alcohol use during pregnancy is a worldwide significant public health problem. Obtaining accurate information about prenatal alcohol exposure is particularly important because of the risks for negative neonatal and later neurobehavioral outcomes, ranging from subtle developmental problems to fetal alcohol syndrome. The purpose of this poster is to present the developmental characterization of a group of children prenatally exposed to alcohol, born at a Hospital of North of Portugal between 2005 and the first 6 months of 2009, and discuss difficulties of detecting prenatal alcohol exposure.

Analysis of paper medical records allowed identification of 13 children. Their parents were contacted by members of the research team from the hospital's staff and informed consent was obtained. At the moment of the first contact, children had a mean age of 38.79 months (14 to 62 months). Emotional and behavioral problems were studied by use of Achenbach's Child Behaviour Checklist (CBCL) and general development and language, motor and social development and cognition were assessed using the Griffiths Mental development Scales (0-2 and 3-8 years). Socio-demographics characteristics were assessed by caregiver interview.

All children scored below the normative mean for their age (problems in language area, mobility and autonomy). Externalizing and internalizing results (CBCL) were comparable to nonclinical normative sample (USA and Portugal). Results obtained with CBCL and GNDS showed notorious inter-individual variation. 61.5% mothers report not to currently consume alcohol.

Prenatal exposure were under-diagnosed but adequate diagnosis is critical to early intervention. We defend use of adequate screening and report strategies and that a non-punitive/collaborative work between the different professionals involved in health care arena is necessary. We hope that this kind of work represents an alert and a step to error prevention in detection of prenatal alcohol exposure.

## [M11]

### **Evaluation of a multilevel and integrated program to raise awareness of the risks of prenatal exposure to alcohol in Italy**

**Stefania Bazzo**<sup>1</sup>, Giuseppe Battistella<sup>2</sup>, Patrizia Riscic<sup>2</sup>, Giuliana Moino<sup>2</sup>, Francesco Marini<sup>2</sup>, Mery Bottarel<sup>2</sup>, Giuseppe Dal Pozzo<sup>2</sup>, Mara Padovan<sup>2</sup>

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**Aims:** Alcohol consumption is widespread in Italy and has important cultural and economic connotations. In the area of Treviso (North-East Italy), alcohol consumption during pregnancy is culturally accepted. In 2008, the Local Health Authority of Treviso started a multilevel and integrated program to raise awareness of the risks of prenatal alcohol exposure. The program, which is still ongoing, consisted of an action-research experience involving local health professionals, and a communication campaign targeted to the childbearing-aged population. The aim of the study is evaluate the efficacy of the program, in terms of awareness of the problem, five years after the start.

**Methods:** A comparative study was performed in 2013. Surveys using semi-structured self-report questionnaires were carried out among professionals and pregnant women in Treviso, and among control groups in another area of Italy (Verona). The questionnaires investigated awareness and opinions about alcohol and pregnancy, as well as sources and kind of information provided and received.

**Results:** Health professionals in Treviso, who had been exposed both to the action-research experience and to the campaign, showed a more rational approach to alcohol than colleagues in the control group, and were more aware and sensitized about the risks of alcohol consumption during pregnancy (70% vs 56%,  $p=0,038$ ). Physicians and midwives had a higher probability of having advised pregnant women to abstain from alcohol in Treviso. Pregnant women in Treviso, who had received information through the campaign and from professionals, had a higher probability of having received only correct advice about the issue, but did not show significant differences in the perception of the problem, compared with Verona (48% and 55%,  $p=0,252$ ).

**Conclusions:** The integrated program performed in the Treviso area was effective in increasing awareness and improving attitudes among healthcare professionals, compared with the control group.

## [M12]

### **Raising a child with FASD - experience of Russian parents**

**Elena Molchanova**

*Parent, Moscow, Russia*

My husband and I adopted a girl with FASD in September, 2012. By the time we already had two children, few years of experience as volunteers in Baby House and I was studying Methods of education for children with special needs in Pedagogical University. According to physiological researches parents and a child need from 1 to 3 years to adopt to each other. In our case, it was about three years and a half. It was really difficult period of time for all the family. But every day step by step we all become more happy.

Our adopted daughter was born on 33th week of pregnancy, her weight was 1kg 340 g, she had many different problems with health from her first days, including FASD. She also had two years experience of living without parents in Russian Baby House, got special medical treatment for brain development every three months.

I started to communicate with our future daughter when she was 10 month old. And she became a part of our family at 2 years 2 months. Her speaking experience by the time was about 10 words, her behavior was as a child of about one years old - so we called her "Running Newborn".

During four years we are studying information about FASD and try to do our best to help our daughter. And she has a great progress in brain development and behavior features. Thanks to special kindergarden, neuropsychology specialists, wise advices of Diane Black, our parents' help we became calm and happy family with three lovely daughters. But we don't stop - we continue to study to understand our daughter's needs. And I will be glad to share our achievements with the Conference participants.

[M13]

## **Prenatal alcohol exposure alters sleep patterns in young rats**

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Sleep is essential for development, physical and mental health in all children, and therefore sleep problems in children with neurodevelopmental disorders, such as fetal alcohol spectrum disorders (FASD), compound the challenges they already face. In this study, sleep was investigated in a rat model of FASD. Pregnant dams were fed either a typical pelleted diet (Control, C), a liquid diet with 35% of the calories derived from ethanol (Prenatal Alcohol Exposed, PAE), or a liquid control diet calorically matched to the PAE group to compensate for decreased consumption (Pair Fed, PF). After weaning, the offspring were housed in pairs, and were filmed twice in their home cages for the entire 12 hour light cycle, immediately after weaning, at 22-25 days of age, or during the early pubertal period, at 35-36 days of age. This approach aimed to elucidate natural sleep patterns by investigating sleep in the rats' home environment without disruptions. The videos were manually scored for many different outcomes relevant to sleep. We found that the PAE group showed a number of deficits in sleep pattern when compared to controls, including taking longer to fall asleep, spending less time asleep and more time awake, and spending more time in transition between awake and asleep states. These results suggest that there is an effect of prenatal alcohol exposure on the developing brain that affects the neural circuitry involved in regulating the sleep-wake cycle. Furthermore, the dysregulations of the sleep-wake cycle can be observed through non-disruptive filming of the rats in their home cages. Currently, we are investigating the creation of an automated video scoring program to replace the manual scoring of these sleep videos.

## [M14]

### **A case study from South Africa of a woman with multiple children with Fetal Alcohol Spectrum Disorders: alcohol use, social, and childbearing history**

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**Background:** Certain communities in the Western Cape Province of the Republic of South Africa have been involved in epidemiology research on fetal alcohol spectrum disorders (FASD) for two decades. The rates of FASD have been reported to be the highest of any general populations in the world. As such there are many cases of children with FASD that have been diagnosed through various prevalence study samples, special intervention and prevention projects, and other research initiatives. Furthermore, the characteristics and experience of the mothers of children with FASD have also been researched extensively.

**Methods:** Presented in this poster will be a summary of specific findings regarding maternal alcohol use, childbearing history, and the social circumstances of one mother who has given birth to multiple alcohol-exposed children over the past 15 years. Furthermore, the outcomes of her children will be described to highlight a pattern of life which is all too common in some of these communities.

**Results:** The study mother has had 10 children since 1991 in nine pregnancies (one set of twins), and at least three of the pregnancies resulted in premature births. Only the last-born child is in her custody, the oldest child is in jail, and eight are in foster care with their grandmother. At least four of her children have been involved in various samples of the epidemiology research and each received a formal diagnosis on the continuum of FASD. Furthermore, all of her children are reported to have learning problems, and several have documented behavioral problems. Data will be presented on specific alcohol consumption patterns for several of the pregnancies and associated with specific child outcomes. During her last pregnancy, the mother reported drinking an average of 4.4 (standard unit) drinks per day, 3 to 4 times each week, and 7.9 drinks per day once or twice each week, a pattern which was reported to be quite consistent for each trimester.

**Conclusion:** Much can be learned about maternal risk factors and patterns of life and alcohol use from case like this that result in negative child outcomes.



[M15]

## **The Fetal Alcohol Syndrome Foundation of the Netherlands**

**Martha Krijgsheld**

*Foetaal Alcohol Syndroom Stichting, Nederland*

The FAS Foundation of the Netherlands was founded in 2002 by three parents of children with FASD. Our goals were to raise awareness of FASD and to support parents raising children with FASD. At the time, there was no diagnostic clinic and FASD was little recognized in the Netherlands. Our first activities included the following: a website, an e-mail group for parents, a newsletter, developing the first educational folder for midwives to use in counseling clients, and holding the first national conference. As awareness of FASD grew in the Netherlands, several diagnostic clinics were started and our activities expanded. Now, 14 years down the road, there are several diagnostic clinics in the Netherlands, professionals and parents are much more aware of FASD, and the Health ministry has recently held a first inquiry into the seriousness of the problem in the country.

We continue to give training sessions in schools, universities and hospitals; for workers in alcohol and drug addiction agencies; and for youth care and foster care organizations. Increasingly, we are asked to provide tailored sessions built around an individual child or adult, involving family, teachers, social workers, psychologist, etc. In addition to our open Facebook group, we also support a Facebook group for adults with FASD and one for birth mothers; have developed a set of short films with accompanying educational folders various professional groups (dentist, physiotherapist, etc.); hold annual family weekends; and provide books and literature in the Dutch language for parents and professionals.

## [M16]

### **Patterns and prevalence of alcohol consumption in pregnancy using infant biomarkers**

Elizabeth Henderson, Helen Mactier and David Tappin

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Foetal Alcohol Syndrome (FAS) is the most common, preventable cause of learning difficulties in the UK. FAS has lifelong implications on individuals and their families, including shortened life expectancy. The national impact of FAS includes health, education and judicial costs.

FAS is under diagnosed, in part because little is understood about the prevalence of alcohol consumption in pregnancy. Therefore it is difficult to direct and assess the effects upon alcohol consumption in pregnancy of public health legislation and education.

Biomarkers of prenatal alcohol exposure have potential to provide more accurate assessment of alcohol exposure during pregnancy compared to maternal self report. Fatty acid ethyl esters (FAEEs), produced by esterification of free fatty acids, and ethyl glucuronide (EtG) a direct metabolite of ethanol, are laid down in fetal meconium from 16 weeks of pregnancy onwards. Meconium analysis after birth may detect cumulative second and third trimester maternal alcohol consumption.

Phosphatidylethanol (PEth) is a high sensitive, direct biomarker of alcohol, accumulated in the cell membrane of red blood cells. It has a half life of 4-5 days; measured on dried blood spot cards PEth may reflect alcohol consumption in late pregnancy.

[T1]

## A follow-up study of the epidemiology of Fetal Alcohol Spectrum disorders in a community in South Africa

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**Background:** This community in the Western Cape Province of the Republic of South Africa was first involved in epidemiology research on fetal alcohol spectrum disorders (FASD) in 1997. The rates of FASD in this community have consistently been among the highest of any general population in the world. The overall characteristics of the children with and without FASD in this community and their mothers have been described in four previous publications. This study adds current data to follow-up on the status of FASD in this community.

**Methods:** Presented will be the detailed case control findings from a community-wide, in-school study of all consented (72%) first grade-learners enrolled in 2010 and their mothers. Dysmorphology exams and final diagnoses were made using revised U.S. Institute of Medicine criteria. Children (n=406) entered the third tier (final diagnostic assessment) of the study via random selection and/or growth deficiency ( $\leq 25^{\text{th}}$  centile on height, weight, or head circumference). In tier 3, all participants were assessed on five cognitive and behavioral measures, and their mothers were interviewed about alcohol use, childbearing history, socioeconomic status, health status, and demographic traits.

**Results:** The 846 consented children were effectively delineated and categorized by the specific IOM diagnostic categories on both physical traits (growth and minor anomalies) and cognitive/ behavioral measures. Mothers of children with FASD were significantly more likely to report drinking before, during, and after the index pregnancy, to binge with 3 or more or 5 or more drinks per occasion. During the index pregnancy, mothers of children with FAS reported drinking an average of 7.5 drinks per drinking day and 16.5 ( $\pm 1$  SD of 23.2) drinks per week, most of them drinking only on weekends (2 - 3 days per week). While controlling for two measures of socioeconomic status, the number of drinks per drinking day and drinks per week correlated most highly with head circumference ( $r = -.293$  and  $-.306$  respectively,  $p < .001$ ) and total dysmorphology score ( $r = .302$  and  $.313$ ,  $p < .001$ ). Cognitive and behavioral measures were less correlated with drinking. Mothers of

children with FASD were significantly older; smaller in height, weight, Body Mass Index, and head circumference; higher parity; and lower in educational attainment and income.

**Conclusion:** The prevalence of FASD remains high in this community. The rate of FAS in the 2010 cohort was 59 – 79 per 1,000 children and total FASD was 170 – 233 per 1,000 or 17% to 23%.

[T2]

## The role of fathers in pregnancies involving high-risk drinking mothers

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**Objectives:** In the Western Cape Province of South Africa a subculture of binge drinking is an important contributory factor to the prevalence of Fetal Alcohol Spectrum Disorders being the highest documented in the world. There is growing awareness of the importance of the role of fathers during pregnancy in taking co-responsibility with mothers in bearing healthy babies. Research into Case Management (CM), as a method of indicated prevention, has shown that support and encouragement of the mother during pregnancy can reduce weekly and problematic drinking. In this study we investigated the role of the father in providing support and influencing drinking habits of the mother during pregnancy.

**Materials and methods:** An indicated prevention study used CM and motivational interviewing to help high-risk pregnant women to abstain from alcohol or drink less. Fathers of unborn babies were targeted for primary prevention to help them understand their role during the index pregnancy with the emphasis on reducing their drinking and improving their behavior towards their partners.

**Results:** Where male partners of women in CM reduced their drinking or drank apart from their partner, reduced stress levels and fewer violent episodes were reported. In such instances women reported that they also decreased their alcohol use or abstained from use. Details on this change in drinking behavior will be presented in this poster presentation.

**Discussion:** A pregnant woman's alcohol consumption can be significantly influenced by her partner's drinking habits. As a result men should be an import target for efforts to prevent FASD.

## [T3]

### Life in four rural communities in South-Africa having the highest ever recorded prevalence of FASD

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**Background:** An epidemiological study conducted in the general populations of four rural communities of the Western Cape Province (WCP) in South Africa revealed the highest prevalence of FASD ever recorded. The rates of FAS were 93 – 128 per 1,000 and total FASD were 182 – 259 per 1,000 or 18.2% to 25.9%. These communities are more rural/remote and have populations with lower socio-economic status than previously studied.

**Methods:** Consent was sought for first grade pupils to participate in the study. After consented children were weighed and measured to determine if they met inclusion criteria, they were then examined by pediatric geneticists/dysmorphologists, subjected to cognitive and behavioural testing and maternal risk factor interviews were conducted. All of the research was designed to provide a final diagnosis of FASD on the continuum of the U.S. Institute of Medicine criteria. The maternal risk interviews provided a way to determine exact levels of antenatal alcohol exposure, elicit significant distal maternal risk variables, and ultimately to understand the lives and hardships of women living in these rural communities.

**Results:** Women in these rural communities are confronted with daily struggles such as growing up in households where alcohol abuse and domestic violence are the norm. They are frequently exposed to unemployment or harsh working conditions, limited access to medical services, are often the sole provider for extended families and frequently fall victim to physical, emotional and sexual abuse. These challenges create a feeling of hopelessness where alcohol use is seemingly the only escape. The primary or proximal maternal risk factor for FASD is alcohol consumption. Other significant, distal maternal risk factors include low bodyweight, body mass, education and income, and high gravidity, parity, and age at birth of the index child. The context of life for alcohol using women in rural and small town communities will be discussed in detail in this poster presentation.

**Conclusions:** Women living in these communities with very high FASD rates are exposed to daily struggles. Their alcohol use and other challenging conditions contribute to difficulty with childbearing and child development.

[T4]

## **Living accommodation for people affected by FASD - A survey carried out by our organisation**

**Alison Frieling, Gisela Michalowski, Katrin Lepke, Ute Spreyer**

*FASD Deutschland e.V. Lingen, Germany*

**Background:** Many members of our NGO are parents and caregivers of people with FASD and have first-hand experience in trying to find suitable accommodation for their children as they get older.

**Methods:** An anonymous survey (20 questions) was started to find out (1) Where adolescents and (young) adults with FASD live (2) How they fare in the various types of accommodation available (3) How difficult it is to find accommodation and (4) What is needed to make accommodation suitable for people with FASD. The minimum age was set at 14. The questionnaire was made available on our website as a file that could be downloaded. The survey was launched in September 2014 and is still running. 39 replies have been evaluated to date.

**Results:** Living with children with FASD can be challenging in a family setting, it can become *impossible* during puberty or later. Various forms of supported or sheltered accommodation are available but hardly any housing programmes cater for the needs of a person with FASD. Facility "hopping" and homelessness are real issues that confront even those people who have been diagnosed and officially qualify for assistance from the department of health and social services.

**Conclusion:** Children with FASD grow into adults with FASD (!); finding suitable living accommodation proves to be one of the most daunting challenges facing (legal) guardians. The level of care and support needed - often 24/7 is not generally available in existing accommodation programmes.

New forms of accommodation must be developed as soon as possible. The needs of people with FASD must be made clear and communicated to the decision-makers. Every conceivable effort must be made to prevent any more people with FASD from "slipping through the net".

Life on the streets or time in jail should not be part of anyone's life story and certainly not a foregone conclusion on the grounds of a disability that is simply not understood.



[T5]

## **FASD Deutschland e.V. - How our organisation works**

**Alison Frieling, Gisela Michalowski, Katrin Lepke**

*FASD Deutschland e.V. Lingen, Germany*

**Background:** Our NGO has no paid staff; we are all volunteers and by highlighting the achievements of the last decade we would like to encourage others either to become involved or to continue their work supporting those affected by FASD.

**Methods:** (1) A list of important events and achievements in chronological order from the official registration of the organisation (then called FASworld Deutschland) as an NGO in March 2005 until today. (2) A review of our work and a glimpse into the future.

**Results:** An organisation with "humble beginnings" has developed into a recognised and respected initiative where all strings come together. FASD Deutschland has a central role within the FASD network in Germany and also operates at international level.

**Conclusion:** Parents and carers of people with FASD experience first-hand what it means to **live** with the disability i.e. the problems encountered in everyday life. Whilst experience serves as a sound basis for understanding the needs of those affected, that alone is not sufficient to improve the lives of people with FASD. These needs must be communicated to those involved in decision-making and that can be challenging! In Germany we have unique constellation of experts from a wide range of professional backgrounds working together with families at grass roots level in **one** network. Together we can make a difference!

[T6]

## **Compounding effects of fetal alcohol spectrum disorders and early childhood trauma: A systematic review**

**Alan Price**, Penny A. Cook, Sarah Norgate, Raja Mukherjee.

*University of Salford, Manchester, UK.*

**Background:** Fetal alcohol spectrum disorders (FASD) and incidents of early childhood trauma such as neglect and abuse are characterised by markedly similar cognitive and behavioural deficits. The rate of these issues presenting together is thought to be high (Coggins et al., 2007), but this combination has not been well studied. The question remains to what extent these factors compound each other and lead to more severe deficits, and in which domains these deficits might present.

**Methods:** We conducted a systematic review of eight databases and reference sections which initially returned 463 records. From these, 45 full papers were screened, resulting in six relevant articles. Two of these were descriptive studies whose value was deemed worthy of inclusion for background information, while the remaining four articles featured comparisons. Two of these were the work of a team in the United States who compared patients (aged 6-16years) with history of trauma and FASD, to patients with just trauma. The two remaining studies were the product of a team in Finland, who conversely compared patients (aged 1-15 years) with FASD and trauma, to patients with just FASD.

**Results:** The American studies focused on speech and language, but also assessed memory, attention, motor skills, and behavioural issues. Both of these studies found that FASD and trauma together were associated with greater deficits than trauma alone. The Finnish studies found that behavioural and emotional problems were more strongly associated with FASD and trauma, than with just FASD.

**Conclusion:** These findings suggest that early childhood trauma and FASD have compounding effects in multiple areas, and more research is urgently required to investigate the full range of deficits, especially in the domains of executive functioning, social cognition and peer interaction.

[T7]

## **Alcohol and/or substance abuse during pregnancy: effects on maternal welfare and developmental outcome of children – A research plan**

**Anne M. Koponen**, Hanna Kahila, Taisto Sarkola, Mika Gissler, Erja Halmesmäki, Ilona Autti-Rämö

*Finland*

**Background:** In Finland, approximately 6% of pregnant women have alcohol and/or substance abuse problem. These women are in high risk for physically and mentally endangering themselves and their children. This study investigates 1) welfare of women with alcohol/substance abuse problem identified during pregnancy and 2) welfare and overall developmental outcome of their children.

**Methods:** A register-based retrospective case-control study using two cohorts:

1. Cohort 1992-2001

A 15-24-year follow-up of pregnant women with identified alcohol and/or substance abuse problem (n=524) referred to three special antenatal clinics in Helsinki metropolitan area for pregnancy follow-up, and their children (n=638), and matched control mother-child dyads (n=1792). Data from medical records are linked with register data collected from several mandatory national health and social welfare registers.

2. Cohort 2002-2011

A 4-14-year follow-up of similarly collected data.

**Results:** The earlier, 6-15 years follow-up of the first cohort showed significant long-term morbidity, mortality and loss of productivity among the study group women, and 114-fold risk of violent and accidental death compared with controls. The exposed children needed a lot of mental and behavioral healthcare services and psychosocial support, and many were placed in out-of-home care. The pregnancies and deliveries of buprenorphine-using women were uneventful but severe NAS and need for morphine replacement therapy was seen in 57% of the newborns. A high number of sudden infant death occurred.

**Conclusion:** A further follow-up of mothers and children is needed. The new cohort shows possible changes in substance abuse.

[T8]

## Exploring the experiences of birth mothers whose children have been diagnosed with Fetal Alcohol Spectrum Disorders: a Qualitative study

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**Background:** Fetal alcohol spectrum disorder (FASD) is an umbrella term for a range of conditions that may occur in an individual whose mother drank alcohol during pregnancy. There has been little research into the experience of birth mothers of children with FASD and no published work of this kind in the UK. This is in contrast to a number of studies that have been conducted on foster/adoptive parents. In light of the recent publication in the UK of a mixed methods study on adoptive carers it is timely to conduct research on birth mothers in the UK.

**Aims:** The study seeks to explore the experiences of birth mothers following a diagnosis of FASD in their children.

**Method:** An interpretive phenomenological analytical approach was used to generate themes from individual semi-structured interviews of 5 women who are birth mothers of children with FASD.

**Results:** Four themes were identified. *To blame or not to blame* captures the tension the mothers experience when considering the cause of their child's condition. *Life is a series of battles* describes the struggles the women experience. *On a crusade with a renewed sense of purpose* captures the process of transformation that occurs. *What helps* describes the internal and external factors which help the mothers cope.

**Conclusion:** FASD is often described in the literature as being completely preventable with the implication that it is the mother's fault because they drank alcohol during pregnancy. However a statement like this fails to portray the complexities of the phenomenon of women drinking during pregnancy. Life is difficult for the women for a number of different reasons yet a sense of hope is present. The mothers have a renewed sense of purpose to do the best they can for their child and to raise awareness of FASD. Understanding their experiences can help service providers better meet the needs of parents and children affected by FASD.

[T9]

## **Neurodevelopmental Disorder Associated with Prenatal Exposure to Alcohol (ND-PAE): A comparison of criteria against IOM and 4 Digit classification systems**

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**Background:** Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE) was proposed as a diagnostic formulation intended to capture the range of mental health problems occurring in alcohol-affected individuals with a history of prenatal alcohol exposure. The proposed criteria for the disorder are reviewed as well as various factors considered in the development of the disorder and its associated criteria. To date these criteria remain in development. This paper presents an audit of cases comparing NDPAE to IOM and 4Digit categories.

**Methods:** An audit of cases seen in the UK National specialist FASD behavior clinic is completed every two years to identify cases and trends seen. The clinic uses the Canadian approach to diagnosis but therefore allows the cases to be recoded against the 4 digit classification system and also linked to IOM codes. Following the development of DSMV and in preparation for a proposed paper to EJMG, a reaudit of the 2104 caseload was made to identify the ability to map NDPAE to cases seen and to also compare these to other diagnostic systems.

**Results:** 82 people were included in the 2014 audit with 73 of those meeting a FASD diagnostic code. Of that group 72 (87.8%) were able to be mapped to the new diagnostic code. When comparing to the other diagnostic methods most cases also mapped across to the different diagnostic the main difference appeared for FAS Alcohol unknown.

**Discussion:** NDPAE is a useful category that appears to map well across to current criteria. It does have limitations and may not be as easy to implement in less specialist services with less resource. These and other issues will be discussed during the presentation.

## [T10]

### **The value of a comprehensive neuropsychological evaluation on treatment outcomes of a child with FASD: single case report**

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<sup>2</sup> Department of Pediatrics, University "La Sapienza", Rome, Italy.

**Background:** The term "fetal alcohol spectrum disorders" (FASD) denotes the broad spectrum of morphological changes and functional deficits seen in children exposed to alcohol prenatally. The notion of a continuum highlights the variability with which the disorder occurs, and the different response that individuals can have various treatments. The neuropsychological assessment is an important first step towards developing the treatment that better suits the needs of the affected children.

**Methods:** Ivan (not his real name), a six years old child, was born in Russian Federation but has been adopted by an Italian family at the age of 4. Once in Italy, a partial FAS diagnosis was made. He was evaluated to get information on cognitive, emotional and behavioral functioning. It was assessed parenting stress too. The baseline and follow up evaluation after six months of treatment were done using the following tests: GMDS-ER, VMI, CBCL, TEC and PSI. The rehabilitation project involved sessions of cognitive-neuropsychological therapy to improve: behavior of work, receptive and expressive communication, strategies visual search, hand-eye coordination and motor skills', attention and executive functioning, emotional regulation and social problem solving. The improvement of the behavioral and cognitive functioning of children and parental support were the goals of treatment.

**Results:** The data were analyzed using trend analysis. Significant improvements were observed in domains subject to treatment.

**Conclusion:** Our study illustrates how a comprehensive assessment can be used to define the best treatment plan for that individual.

[T11]

## **The role of educational psychologists (EP) in supporting early years (EY) and primary school children with fetal (foetal) alcohol spectrum disorders (FASD) in the UK**

**Yadava Campbell, Kathleen Tyldesley**

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**Background:** Whilst there are currently no reliable estimates for incidence of FASD in the UK it is hypothesised that EPs and educational settings are likely to be dealing with the effects of FASD (Westrup, 2013). There is no literature known to the current researchers documenting the role UK EPs may be playing in supporting EY and primary school children with an FASD. The objectives of this study are as follows (1) To identify how UK EPs are contributing to the identification and assessment of FASD in EY and primary school children (2) To identify what support, strategies and interventions UK EPs recommend to educational settings or conduct through direct involvement and how these relate to best practice guidelines (3) To examine EP practice in one local authority (Salford) with a suspected high rate of incidence of FASD (4) Produce a prototype toolkit for EPs working in educational settings.

**Method:** Preliminary study has been conducted in which three UK EPs with experience of FASD-related casework were interviewed and data analysed using thematic analysis (Braun & Clark, 2006; 2013). Findings from the former along with data from an expert reference group made up of healthcare and education professionals (e.g. paediatrician, EY practitioner, SENCo, specialist EP, CAMHS worker) and scrutiny of the literature will inform the construction of an exploratory questionnaire to be administered nationally to UK EPs. Qualitative data collected from the survey will be analysed by thematic analysis. Quantitative data collected from the survey will be treated descriptively and analysed for correlational relationships over variables such as EP experience and service type. A nested, descriptive case study will be undertaken to examine the Salford context for identification and intervention.

**Outcomes:** Produce guidance in the form of a prototype skeletal tool-kit to be adapted for learning needs of educational psychology services in local authorities and EP service providers.

## [T12]

### Following a group of foster families until they get the diagnosis of Fetal Alcohol Syndrome Disorder

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**Objectives:** We aimed to determine how much information about prenatal alcohol exposure, Fetal Alcohol Syndrome Disorders (FASD) or other developmental diagnoses was provided to the adoptive families before and during the adoptive process.

**Methods:** A cohort of 78 adopted children from Vall Hebron and Sant Joan de Deu Hospitals with cognitive or behavioural impairments and/or clinical suspicion of FASD were included in our study. Multidisciplinary evaluation led to a diagnosis within the FASD spectrum (or not) using the Institute of Medicine (IOM) criteria as well as the new DSM-V category 'Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)'. A standardized questionnaire was filled by the 78 adoptive families. Information and diagnosis regarding the diagnosis of FASD before and after the adoption was recorded.

**Results:** Out of the 78 adoptive families, 62 (79.49%) answered the questionnaire. Drinking alcohol during pregnancy was disclosed in 31 cases (50%), and a diagnosis of FAS/FASD was not given to any child. Preadoptive oral and written information was considered overall scarce for 34 families (54.84%) and the brief medical reports of adoptive children provided to the families were considered inaccurate for 49 (79.03%). Pre adoptive consultations with local physicians identified a specific diagnosis in 4 cases (6.45%) and none were diagnosed as possible FASD. In Spain, FASD was mentioned by psychiatrists, psychologists or geneticists in 40 cases (64.52%) but only 18 (29.03%) were given a definite diagnosis of FASD.

Our multidisciplinary team granted diagnoses to 50 (80.65%) children within one of the FASD categories: 21 (33.87%) had FAS, 23 (37.1%) partial FAS and 6 (9.68%) had ARND.

**Conclusion:** The information on FASD and alcohol consumption in pregnancy provided during the adoption process need to be improved. In addition, under recognition of the phenotypes among providers in Spain suggest poor knowledge of the FASD spectrum.



## [T13]

### Psychiatric disorders in a sample of Russian adopted children with Fetal Alcohol Spectrum Disorder

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**Objectives:** We aimed to determine the presence of psychiatric disorders in children affected within the fetal alcohol spectrum disorder.

**Methods:** A cohort of 78 adopted children from Vall Hebron and Sant Joan de Deu Hospitals with cognitive or behavioural impairments and/or clinical suspicion of FASD were included in our study. Multidisciplinary evaluation led to a diagnosis within the FASD spectrum (or not) using the Institute of Medicine (IOM) criteria as well as the new DSM-5 category 'Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)'. A psychiatric interview was conducted and administered semistructured interview "Schedule for Affective Disorders and Schizophrenia in School-Age Children (K-SADS). This diagnostic interview assesses past and current episodes of psychopathology in children and adolescents according to DSM-IV.

**Results:** Our multidisciplinary team granted diagnoses to 50 (80.65%) children within one of the FASD categories: 21 (33.87%) had FAS, 23 (37.1%) partial FAS and 6 (9.68%) had ARND. The most prevalent psychiatric disorder was attention deficit hyperactivity disorder followed by anxiety disorders and oppositional defiant disorder. Moreover approximately half of the children had difficulties in emotional control and a third in difficulties in social relationship and behavioral control.

**Conclusion:** Prenatal exposure to alcohol appears to be a risk factor for the development of psychiatric disorders, even before adulthood.

## [T14]

### Case study of a child diagnosed with FASD--educational and upbringing goals

**Magdalena Borkowska**, Jolanta Terlikowska, Krzysztof Brzózka, Katarzyna Okulicz-Kozaryn

*The State Agency for Prevention of Alcohol Related Problems, Warsaw, Poland*

**Background:** Fetal alcohol spectrum disorder (FASD) is a relatively poorly understood health problem which hampers recognition and effective help. Understanding the spectrum of deficits related to alcohol exposition in prenatal life, children should receive special and adequate treatment during their lifespan. The tested child had extensive congenital central nervous system damage which was superimposed with an unfavorable postnatal home environment.

**Methods:** Qualitative analysis of the study case is the starting point for reflection on the difficulties of diagnosis and consequences of FASD diagnosis for the continued functioning of the child at home and at school.

**Results:** The diagnosis of FASD brought intensive and interdisciplinary activities that significantly improved the functioning of the child. The diagnosis also helped to receive the judgment of disability, which helped to gain admittance to necessary services (etc. social, medical, educational).

**Conclusion:** FASD can't be cured but it can be prevented. It is also possible to improve the educational achievements and development, however, the condition for its effectiveness would be early diagnosis and consistent, systematic and intensive treatment.

## [T15]

### **T-ACE and AUDIT scores correlate with FAEEs concentrations in meconium**

Fabiana Spinetti dos Santos<sup>1</sup>, **Humberto de Oliveira Simões**<sup>3</sup>, Bruno Spinosa De Martinis<sup>2</sup>, Erikson Felipe Furtado<sup>3</sup>

<sup>1</sup> *Faculdade de Ciências Farmacêuticas de Ribeirão Preto, Universidade de São Paulo, Brazil*

<sup>2</sup> *Faculdade de Filosofia, Ciências e Letras de Ribeirão Preto, Universidade de São Paulo, Brazil*

<sup>3</sup> *Faculdade de Medicina de Ribeirão Preto, Universidade de São Paulo, Brazil*

**Introduction:** Fatty acid ethyl esters (FAEEs) in meconium have been reported to be potential biomarkers of fetal exposure to alcohol. In this study, we correlate maternal alcohol use with concentrations FAEEs (E16, E18, E18:1 and E18:2) in meconium.

**Methods:** A total of 160 mother/infant dyads were recruited from a public low-risk obstetric unit in the city of Ribeirão Preto, Brazil. The mothers were retrospectively interviewed about the quantity and frequency of alcohol consumption during trimester before pregnancy and during the three trimesters of pregnancy. The questionnaires T-ACE and AUDIT were employed as screening instruments for alcohol use. 160 meconium samples were collected from these neonates and analyzed by gas chromatography coupled to mass spectrometry.

**Results:** The sum of four FAEEs concentrations were above 600 ng/g in 30.6% (49) of all sample. E18:2 was detected at the highest levels, followed by E18:1 and E16. The better correlations were obtained between FAEEs concentrations and T-ACE, AUDIT scores (correlation ranged between  $\rho=0.185$ ,  $p=0.0194$  and  $\rho=0.345$ ,  $p<0,0001$ ). The amount of alcohol consumed per occasion was also significantly correlated with FAEEs concentration, mainly with E18:2 and sum of 4 FAEEs. In regarding to exposure period, the better correlations were found for the maternal self-report drinking about the trimester before pregnancy and first trimester of pregnancy.

**Conclusions:** The E18:2 and sum of 4 FAEEs could be potential biomarkers of fetal alcohol exposure. The finding that FAEEs concentration in meconium is more correlated to amount of alcohol consumed per occasion suggests that ingestion of high levels of alcohol in a short period generates a greater FAEEs accumulation in meconium. And the better correlations for the maternal alcohol report about preconception and first trimester of pregnancy suggest a greater openness of mother to report her alcohol consumption in these periods.



## Foetal Alcohol Spectrum Disorders: Diagnosis, Behaviours, Strategies, Support

What: EUFASD Continuing professional training day

When: Thursday, 15 September 2016

Where: Royal Holloway, University of London, Egham,

Surrey, TW20 OEX

Who: Paediatricians, GPs, Psychiatrists, Psychologists, Geneticists, Midwives, Teachers, Social workers, Parents and Foster carers

Organized by the EUFASD Alliance and NOFAS-UK.

*The Royal College of Paediatrics and Child Health has approved this activity for CPD in accordance with the current RCPCH CPD Guidelines. For attendees following a credits-based approach to CPD, this activity carries up to 5 CPD credits.*

8:30 - 9:30	Arrival and new registrations
9:30 - 9:40	<b>Welcome</b> Raja Mukherjee
9:40 - 10:20	[Tr1] Ken Warren <b>FASD: A History Spanning Five Centuries</b>
10:20 - 11:00	[Tr2] Ed Riley <b>Prenatal alcohol exposure: The impact on brain and behavior</b>
11:00-11:30	<i>Coffee Break</i>

11:30 – 13:00	Workshops Round 1
13:00 – 14:00	<i>Lunch</i>
14:00- 15:30	Workshops Round 2
15:30 – 16:00	<i>Coffee Break</i>
16:00 – 16:20	[Tr3] Philippa Williams, Kathy Mitchell, Anne Russell <b>Information + Intervention + Support = Better Futures for All</b>
16:20 – 16:50	[Tr4] Professor Sir Al Aynsley-Green Kt. <b>Getting effective political action for alcohol in pregnancy - insights from Canada and England</b>
16:50 – 17:00	<b>Closing</b>

## Workshops Round 1

Room 1	[Tr5] Helen Oakwater <b>How consequences of maltreatment and neglect overlap with FASD symptoms</b>
Room 2	[Tr6] Jan de Vries <b>Guidance for teens and young adults in their relationships, including discussion on sexuality</b>
Theatre	[Tr7] Ira Chasnoff <b>Behavioral and Educational Interventions for Children and Adolescents with FASD</b>
Room 3	[Tr8] Miguel Del Campo <b>Identification and significance of physical features in FASD</b>

## Workshops Round 2

<b>Room 3</b>	[Tr9] Piyadasa Kodituwakku <b>Cognitive behavioral profile in children with FASD</b>
<b>Room 4</b>	[Tr10] Joanna Buckard <b>Fostering and adoption for children with Foetal Alcohol Spectrum Disorder (FASD)</b>
<b>Theatre</b>	[Tr11] Eva Akins <b>Navigating the education system with a child with FAS, knowing your rights and what to do when things go wrong</b>
<b>Room 1</b>	[Tr12] Carolyn Blackburn <b>Educating children and young people with FASD</b>
<b>Room 2</b>	[Tr13] Heike Hoff-Emden <b>The Physician as Key manager in the FASD Network</b>

### Learning Aim

This study day will help delegates learn to recognize and manage Foetal Alcohol Spectrum Disorders in accordance with their professional backgrounds.

### Learning Objectives

1. To improve the recognition of neurocognitive and behavioural difficulties in children with FASD.
2. To have better understanding of holistic management framework for children with FASD.
3. To understand the consequences of delayed diagnosis of children with FASD.

Speakers for Training Day on September 15, 2016, at Royal Holloway, Egham, Surrey

Main lectures
<p><b>Raja Mukherjee</b>, MBBS, MRCPsych, PGdip EPP, PhD            Consultant Psychiatrist and Lead Clinician for National FASD Specialist Behaviour Surrey and Borders Partnership NHS Foundation Trust</p>
<p><b>Kenneth R. Warren</b>, Ph.D.            Senior Advisor for FASD            National Institute on Alcohol Abuse and Alcoholism            National Institutes of Health (NIH)            Bethesda, MD, USA</p>
<p><b>Edward P. Riley</b>, Ph.D.            Distinguished Professor of Psychology            San Diego State University, San Diego, California, USA</p>
<p><b>Pip Williams</b>            Founder &amp; Executive Director of UK &amp; European Birth Mother Network            EUFASD Alliance Board Member and Co Founder of FASD UK social media support group supporting over 870 families            London, UK</p>
<p><b>Kathleen Tavenner Mitchell</b>, MHS, LCADC            Vice President and Spokesperson            National organization on Fetal Alcohol Syndrome (NOFAS)            Washington, D.C., USA</p>
<p><b>Anne Russell</b>            Executive Officer            Russell Family Fetal Alcohol Disorders Association   rffada            Cairns, QLD, 4870, Australia</p>
<p><b>Prof. Sir Al Aynsley-Green Kt.</b>            Professor Emeritus, University College London            Founder, Aynsley-Green Consulting</p>
Workshops
<p><b>Helen Oakwater</b>, B.Ed (Hons)            Founder FAB Parents: Coach, Trainer, Author            6 Richfield Road, Bushey, Hertfordshire WD23 4LQ</p>
<p><b>Jan de Vries</b>            Registered psychologist, child/youth psychology, educational psychologist            ZO! zorgoplossingen, Leeuwarden, the Netherlands</p>
<p><b>Ira J. Chasnoff</b>, MD            Professor of Clinical Pediatrics            University of Illinois College of Medicine            President, NTI Upstream            Chicago, Illinois, USA</p>
<p><b>Miguel del Campo</b>, MD, PhD            Associate Professor, Pediatrics            Division of Dysmorphology and Teratology, Center for Better Beginnings            Department of Pediatrics, University of California San Diego,</p>

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**P. W. Kodituwakku, Ph.D.**  
Professor  
Departments of Pediatrics and Neurosciences  
The University of New Mexico School of Medicine  
Albuquerque, New Mexico  
USA

**Joanna Buckard, BSC PGCE**  
Specialist FASD Trainer  
Red Balloon Training  
Chesterfield, UK

**Eva Akins**  
LLB Bachelor of Laws with First Class Honours.  
Postgraduate Legal Practice Course (LPC)  
Education Lawyer  
Associate | Russell-Cooke LLP  
Bishop's Palace House | Kingston Bridge | Kingston-upon-Thames | Surrey | KT1 1QN UK

**Dr. Carolyn Blackburn, PhD, FHEA, PGCert Special and Inclusive Education**  
Senior Research Fellow, Early Childhood and Inclusion  
Centre for the Study of Practice and Culture in Education  
Faculty of Health, Education and Life Sciences  
Birmingham City University

**Dr. Heike Hoff-Emden**  
Pediatric, Psychotherapist, Socialmedicine and qualification in EMDR, Chief doctor in social pediatric  
centre, Leipzig, Germany  
[Dr. med. H. Hoff-Emden  
FÄ für Kinder- und Jugendmedizin  
Psychotherapie - Sozialmedizin  
Leitende Ärztin  
SOZIALPÄDIATRISCHES ZENTRUM LEIPZIG /social pediatric centre  
Delitzscher Straße 141  
04129 Leipzig



[Tr1]

## **FASD: A History Spanning Five Centuries**

**Kenneth R. Warren**

*National Institute on Alcohol Abuse and Alcoholism, NIH, Bethesda, MD USA*

For most of the 20<sup>th</sup> century alcohol was considered to be a substance which did not pose a risk to the embryo or fetus. This belief was so ingrained that the use of very high dose alcohol was introduced in the middle 1960s for the treatment of threatening premature labor. The viewpoint on alcohol's safety in pregnancy began to change in 1973 with the publication of research findings identifying the fetal alcohol syndrome (FAS) and subsequently fetal alcohol spectrum disorders (FASD). Scholars then began to look back to see whether any evidence of the risks posed by alcohol to the fetus had been observed in earlier history. This analysis revealed several historical time points, among them the early 18<sup>th</sup> century London gin epidemic, when alcohol was noted to be placing the fetus at risk. In the middle of the 19<sup>th</sup> century a temperance movement emerged in continental Europe, the U.K., Canada and the U.S. which among other behaviors, encouraged total abstinence from alcohol. In the early 20<sup>th</sup> century the success of temperance campaigns had resulted in the establishment of prohibition (laws against production and/or consumption of alcohol) in Russia, Canada, the U.S. and several European countries including Norway, Finland, and Iceland. Public reaction to prohibition in the long run was negative which led to overturning prohibition in all implemented countries by the early 1930s. The negative backlash toward prohibition resulted in rejection of much of the knowledge on the health effects of alcohol that had existed before prohibition including that related to alcohol and pregnancy. Rejection of pre-prohibition knowledge resulted in a forty-plus year amnesia which has impacted public health and the provisions of services for those affected by prenatal alcohol.

[Tr2]

## **Prenatal alcohol exposure: The impact on brain and behavior**

**Edward P. Riley**

*San Diego State University, San Diego, California, USA*

Shortly after the identification of FAS it became clear that the developing brain was impacted by prenatal alcohol exposure. Early autopsies reported diffuse CNS disorganization, including microcephaly, migration errors, and, corpus callosum, basal ganglia, and cerebellar anomalies. However, magnetic resonance imaging (MRI) has indicated specific alterations in brains of individuals exposed prenatally to high doses of alcohol with and without a diagnosis of FAS. In early studies, reductions in specific areas of the cerebrum, the cerebellum, basal ganglia, and corpus callosum were noted. More recently, relative white matter hypoplasia has been observed and diffusion tensor imaging (DTI) studies suggest that white matter pathways are disorganized in FASD. Most recently, functional MRI (fMRI) has exposed changes in brain function in FASD during tests of spatial working memory, attention, verbal learning and memory, and response inhibition. Typically, increased frontal activation has been observed, although decreased activation has been observed in brain areas thought to mediate certain aspects of the tasks (e.g. caudate during response inhibition tasks). This may indicate inefficient neural networks or some form of compensation. Importantly, the changes in behavior and cognitive function seen in individuals with prenatal alcohol exposure are consistent with the functional and structural brain changes. Behaviorally, these individuals have executive function deficits, attention and motor problems, and various learning and memory deficits. Additional research will help to elucidate the relationships between brain changes and functional outcomes and hopefully lead to better intervention strategies.

[Tr3]

## **Information, Intervention and Support: Better Futures for All**

**Philippa Williams<sup>1</sup>, Kathy Mitchell<sup>2</sup>, Anne Russell<sup>3</sup>**

<sup>1</sup> *UK & European Birth Mum Network – FASD*

<sup>2</sup> *NOFAS, USA*

<sup>3</sup> *Russell Family Fetal Alcohol Disorders Association (rffada), Australia*

Birth mothers to children with an FASD bring a unique and valuable perspective to the field of FASD. This international panel of women will provide over 60 years of combined experience both working in the field of FASD and FASD prevention, along with an innate understanding of the familial and systemic issues that arise in families living with FASD.

[Tr4]

**Getting effective political action for alcohol in pregnancy –  
insights from Canada and England**

**Professor Sir Al Aynsley-Green Kt.**

## [TR5]

### **HOW CONSEQUENCES OF MALTREATMENT AND NEGLECT OVERLAP WITH FASD\* SYMPTOMS**

**Helen Oakwater**

It's not just the womb experience which can be toxic. What happens to a child afterwards can also have a dramatic effect.

If the post birth experience was negative due to maltreatment and/or neglect it can compound the problems created in-utero through maternal drug and alcohol abuse. This legacy of trauma (pre and post birth) impacts brain formation, all the body systems and is difficult to unravel.

Sometimes when so many symptoms overlap, a diagnosis of a condition such as FASD (or ADHD, ADD OD, etc) can stop parents and professionals considering additional root causes. Often its tough to see beyond the child's presenting behaviour and the existing diagnoses.

However we know "the body keeps the score" (Bessel Van Der Kolk) and trauma is stored as a sensory memory.

Sometimes a child's reaction seems disproportionate to the current situation. What if the presenting behaviour is the result of an old toxic sensory memory being stimulated? A reminder of gnawing hunger or an angry face which meant "pain is coming"? These memories are unconscious, deep and easily retriggered.

For some adopted and fostered children their early experiences result in hyper vigilance, poor executive functioning skills, impaired impulse control, lack of cause and effect thinking - all very similar to symptoms in FASD and other 'conditions'. These intertwined components are hard to unpack, yet understanding them provides another dimension to caring for children who have experienced multilayered trauma.

Helen Oakwater has a reputation as an engaging and inspiring speaker. In her presentation she will explore trauma triggered behaviour, its roots, causes and some strategies for living with these complex children. The session will be interactive and offer practical ways to manage the child and yourself in the moment (now) and in the long term (future proofing).

\* FASD = Foetal Alcohol Spectrum Disorder

## [Tr6]

### **Guidance for teens and young adults in their relationships, including discussion on sexuality**

**Jan de Vries**

*ZO!-zorgoplossingen, Leeuwarden, the Netherlands*

In the workshop the participants (parents and professionals) will have an opportunity to share experiences. Participants will therefore have an active role. We will try to learn from the experiences of each other in dealing with the relationships and sexual behavior of teens and young adults. We speak about the vulnerability and how we can protect them, with respect for their own development and privacy. Jan presents some facts about sexual behavior of teens and young adults between 12-25 years old in The Netherlands. He also briefly presents a method developed in Belgium, for parents and workers to talk with and teach children and teens about sexually (un-)acceptable behavior.

[Tr7]

## **Behavioral and Educational Interventions for Children and Adolescents with FASD**

**Ira Chasnoff**

*NTI Upstream, Chicago, Illinois, United States*

This workshop will focus on the structural and functional changes that occur in the fetal brain due to prenatal exposure to alcohol and how the exposure impacts the child's long term behavior, learning, and social outcomes. Based on this information, the program will present the core components of a model of educational interventions and behavior management that parents and professionals should consider when addressing the needs of the alcohol-exposed child.

[Tr8]

## Identification and significance of physical features in FASD

**Miguel Del Campo**

*Division of Dysmorphology and Teratology, Center for Better Beginnings  
Department of Pediatrics, University of California San Diego, San Diego, California, USA*

The fetal alcohol syndrome was initially described as dysmorphic phenotype with several characteristic minor malformations that were apparent in multiple children with cognitive and behavioral manifestations, born to alcoholic women. Since then, the physical features of FAS have been the most specific marker of the condition. Growth deficits, small head circumference and the three cardinal facial features (short palpebral fissures, smooth philtrum, narrow and linear vermilion of the upper lip) are the hallmark of the physical impact of alcohol exposure during pregnancy. Even in the absence of known exposure to alcohol during pregnancy, the presence of this physical phenotype can today lead to a diagnosis of the Fetal alcohol Syndrome (FAS) according to most widely used diagnostic criteria for the condition.

Much has been learnt in 40 years of research on FASD. Many other minor malformations than the 3 facial diagnostic features are characteristic and associated with FASD. Most reflect alterations in craniofacial development dependent on the impact of alcohol in brain development, other reflect altered early movement in utero. Human studies and animal models have been used to replicate these physical features and understand their pathogenesis, the time in pregnancy when they occur, and their association to the cognitive and behavior characteristics of these patients. We now know almost all infants within the FASD spectrum have some differences in craniofacial morphology and other physical findings that suggest alcohol exposure. Identification of the physical features of FASD is essential for the correct diagnosis of the condition, since the main differential diagnoses for intellectual disabilities are genetic syndromes and other teratogen exposures.

The different diagnostic systems (IOM, Hoyme criteria, 4 digit code, Canadian guidelines...) have approached the significance of the physical features in different ways, and no universal and reliable guidelines for the diagnosis of the conditions of FASD have yet been established. This fact makes even more important to master the correct identification of these features, to understand the significance of these physical features and to assess the needs for genetic testing or other evaluations in these patients.



[Tr9]

## **Cognitive and behavioral profiles of FASD**

**P.W. Kodituwakku**

*University of New Mexico School of Medicine, Albuquerque, New Mexico, USA*

The majority of children with FASD do not display clinically discernible morphological anomalies. This presents a serious diagnostic challenge because some cognitive and behavioral problems seen in children with FASD are also found in children with other neurobehavioral disorders, particularly those with ADHD and conduct disorder. Therefore, the question whether children with FASD show a unique profiles of cognitive and behavioral problems has received considerable attention over the past 40 years. Neuroimaging studies and basic science research have revealed that prenatal alcohol exposure is associated with alterations in specific brain regions. These observations have led investigators to hypothesize that children with FASD may have unique patterns of cognitive and behavioral changes corresponding to those neuroanatomical alterations. To find such changes, researchers have systematically gathered cognitive data by means of neuropsychological tests and behavioral data through parent or teacher-rated questionnaires. Given that the study of intermediate-level functions (endophenotypes) has proven to be fruitful in the study of neurogenetic disorders such as Williams syndrome and Turner syndrome, some investigators have probed elementary cognitive processes such as eyeblink conditioning and fear conditioning in children with FASD. It is believed that such elementary processes reflect alcohol-induced brain damage more accurately than complex neuropsychological measures because they "measure something closer to the site of damage". Therefore, the task of defining the cognitive-behavioral profiles of FASD boils down to answering three main questions: do children with FASD display a unique profile of elementary cognitive functions? ; do children with FASD display a unique profile of neuropsychological test data? ; and do children with FASD display a unique profile of behavioral observations? In this presentation, I will summarize the latest findings related to these questions and discuss their implications for the development of intervention programs for children with FASD.

## [Tr10]

### **Foetal alcohol spectrum disorder (FASD) in fostering and adoption**

**Joanna Buckard**

*Red Balloon Training and Consultancy*

- How many looked-after children may have been exposed to alcohol prenatally?
- What FASD is and how to recognise if a young person may be affected
- The process of getting a diagnosis and the long-term needs of the affected young person
- Overlapping disabilities and misdiagnosis
- Identifying and meeting the additional support needs of children with FASD and their foster carers and adopters
- Why FASD should be at the fore during the adoption and fostering process

[Tr11]

## **Navigating the education system with a child with FAS, knowing your rights and what to do when things go wrong**

**Eva Akins**

*Russell-Cooke*

The daughter of an alcoholic mother, sister to siblings with severe mental and physical health problems and having made the journey from exclusion to education lawyer; Eva knows a thing or two about cultivating resilience.

Parent to children with neurodevelopmental conditions, she has also learned (the hard way) that what usually serves as 'good enough' parenting for a typical child is nowhere near sufficient when it comes to a child with complex needs. This is often most acutely felt in little understood conditions like Fetal Alcohol Syndrome Disorder.

Whilst school may be the 'best years of our lives' for some, sadly this is rarely the reality for children with special educational needs and disabilities. Their parents in turn soon learn that getting your child's needs properly identified and securing the provision to meet them can be anything but straightforward. More often than not, it involves a relentless and at times overwhelming struggle with an under-resourced and seemingly hostile system.

Good enough or even 'outstanding' school provision for a typical child is unlikely to be successful for a child with FASD. Significant adjustment and additional support is required. Eva seeks to empower parents and concerned professionals with the knowledge they need to navigate the complex terrain of the special educational needs system. In this session she will provide: an overview of how the SEN system should be operating within the framework the Children and Families Act 2014 and SEN Code of Practice 2015; outline your child's rights under the Equality Act 2010; and explain what you can do when things go wrong. This will be followed by a Q & A session.

**[Tr12]**

## **Educating children and young people with FASD**

**Carolyn Blackburn**

*Faculty of Health Education and Life Sciences, Birmingham City University, UK*

The range of learning difficulties and disabilities associated with children and young people who are prenatally exposed to alcohol has been highlighted as an emerging but little understood area of special educational needs. Including children and young people with FASD in any educational setting presents challenges as well as opportunities for educators. Children and young people with FASD often have strengths of a practical nature and these can be used to develop appropriate pedagogy. However, challenges are posed in relation to the uneven and inconsistent learning profile of individuals with FASD, their socio-emotional vulnerability and often hidden needs. This is compounded by co-existing conditions such as mental health problems and early adverse experiences.

This workshop will discuss these opportunities and challenges in light of the Children and Families Act and revised Code of Practice and present a framework of teaching and learning strategies which have been trialled with educators and other professionals and aligned with international evidence.

## [Tr13]

### **Physician as Key manager in FASD Network** **The critical role of medical specialists within an FASD network**

**Heike Hoff-Emden**

*Sozialpädiatrisches Zentrum Leipzig (Social Pediatric Centre), Leipzig*

#### **Tasks:**

- Coordinate and initiate treatment; help organise support teams, particularly important during life events
- Provide long-term medical support after the diagnosis
- Assess the necessity for medication
- Discuss coming to terms with the disability, provide support and discuss coping mechanisms
- Hold seminars for those affected by FASD (children/adolescents and their care givers)
- Advocate for services and support
- Help find suitable schools, jobs and accommodation; provide assistance in matters relating to guardianship
- Help prepare for the transition to adulthood

## Speaker information



### **Eva Akins**

Eva is an associate solicitor in the children and education team specialising exclusively in education law. Ranked in Legal 500 as 'highly recommended' and working within an 'excellent' team she has won praise for her 'client care, attention to detail and expertise'. Eva is also ranked by Thomson Reuters as a "Super Lawyer". It is Eva's first-hand experience of parenting children with special needs that fuels her passion for this area of legal work. She has a real understanding of what a struggle it can be to navigate this complex area of law. In her spare time Eva volunteers for national charity IPSEA and assists in running Richmond ADHD support group.



### **Carolyn Blackburn**

Carolyn has undertaken research on the educational implications and educator perspectives of the effects of prenatal exposure to alcohol and is widely published in this area. She is lead author of the first UK text on the education of children and young people with FASD and a co-editor of an interdisciplinary text on FASD. Carolyn teaches professionals from diverse disciplines on the subject and has talked about her research in the UK, Turkey, Moldova, Stockholm, the Netherlands and New Zealand. Carolyn is a Board Member of Eurllyaid and an editorial board member of *Infants and Young Children*. She is a 2015 Churchill Fellow.



### **Joanna Buckard**

Joanna has been working in the FASD field for 13 years. Recognising a need for effective FASD training, she set up Red Balloon Training and Consultancy in 2008 to specialise in FASD. She is a qualified Health and Social Care lecturer and has a social care background. She has delivered training to various children and families social workers, fostering and adoption teams, paediatricians, foster carers, family support workers, residential social workers, teachers, inclusion teams, midwives, doctors, psychologists and many more. She has spoken at various conferences throughout the UK, taken part in and consulted on 2 FASD films, co-written an FASD booklet for midwives, written an FASD booklet for GP's and presented academic posters at international FASD conferences. She has spoken in the House of Commons at the APPG on FASD. She has also arranged Pregnant Pause Events working with members of the public and students to raise awareness about FASD. You tube films were made about these which went viral.

She has been interviewed on ITV news, quoted in newspapers, Midwives Magazine and in an FASD book.



### **Ira Chasnoff**

Ira J. Chasnoff, M.D., an award-winning author, researcher and lecturer, is President of NTI Upstream and a Professor of Clinical Pediatrics at the University of Illinois College of Medicine in Chicago. He is one of the nation's leading researchers in the field of child development and the effects of maternal alcohol and drug use on the newborn infant and child. Dr. Chasnoff led the development and operation of a laboratory preschool classroom to develop specific interventions for children prenatally exposed to alcohol and other drugs and developed a model Head Start Family Service Center for children and their families at risk from drugs and the drug-seeking environment. In addition, Dr. Chasnoff and his research team were one of five national sites conducting research into the integration of behavioral health interventions into primary health care services for high-risk children and their families, and from 2002 - 2009, Dr. Chasnoff led work funded by the Centers for Disease Control and Prevention as one of four national centers conducting research into innovative treatment for children with Fetal Alcohol Spectrum Disorders. Dr. Chasnoff's most recent work focuses on community approaches to the integration of behavioral health services into primary health care for women and children and the impact of child welfare system policies on the occurrence of co-occurring mental health disorders in children who have been exposed to alcohol and illicit drugs. Dr. Chasnoff received his medical degree from the University of Texas Health Science Center at San Antonio, which in 1991 awarded him its first Distinguished Alumnus Award. He is the author of numerous articles in the research literature and has authored ten books including *The Mystery of Risk*, which explores the biological and environmental factors that impact the ultimate development of alcohol- and drug-exposed children and presents practical strategies for helping children reach their full potential at home and in the classroom.



### **Miguel del Campo**

Miguel del Campo, MD, PhD, is a medical geneticist at Rady Children's Hospital-San Diego and an associate professor at UC San Diego. After graduating from the Universidad Complutense de Madrid in Spain, Dr. del Campo went on to complete additional training at the Hospital Universitario La Paz and the Universidad Autonoma de Madrid. He followed this training with a fellowship in genetics and

dysmorphology at the University of California San Diego, a Ph.D. in pediatrics from the Universidad Autonoma de Madrid, and postdoctoral training at the Salk Institute for Biological Studies.

Dr. del Campo cares for patients with dysmorphic, genetic, and teratologic conditions and his current research interests include: Fetal Alcohol Syndrome Spectrum disorders (FAS), limb defects and HOX signaling pathways, Williams syndrome, autism, prenatal diagnosis through comparative genomic hybridization, and Marfan syndrome and other connective tissue disorders. Additionally, he actively participates in various national and international organizations as well as support groups for parents with children with genetic disorders and FASD disorders. His latest research involves the description of the phenotype of the Zika Virus Embryopathy.



### **Elizabeth Elliott**

Elizabeth Elliott AM is a Distinguished Professor in Paediatrics and Child Health in the Sydney University Medical School; Consultant Paediatrician at the Sydney Children's Hospitals Network at Westmead; a National Health and Medical Council of Australia (NHMRC) Practitioner Fellow; and Chair of the National Fetal Alcohol Spectrum Disorders Technical Network, convened by the Australian

Government Department of Health. She has been involved in clinical services, research, advocacy and policy development regarding Fetal Alcohol Spectrum Disorders (FASD) in children and alcohol use in pregnancy for over 20 years, is Head of the NSW FASD clinic and Co-Director of a Centre for Research Excellence on harms from alcohol in pregnancy (REAACH). She was a Deputy Chair of the Intergovernmental Committee on Drugs Working Party on FASD; a Member of the NHMRC committee to develop Australian Alcohol guidelines (2009); Member of the group to develop World Health Organization guidelines for identification and management of alcohol misuse during pregnancy (2014); and Member of the group to develop an International Charter for the Prevention of FASD.



### **Kate Fleming**

Dr Kate Fleming is an epidemiologist with broad reaching methodological expertise, particularly in the analysis of large datasets. She is presently Senior Lecturer in Public Health Intelligence and Statistics at the Public Health Institute of Liverpool John Moores University. Previously Kate was an Assistant Professor in the Division of Epidemiology and Public



Health, University of Nottingham and an active member of the UK Centre for Tobacco and Alcohol Studies.

Kate's research interests have focussed on the epidemiology of gastrointestinal diseases, particularly liver disease and alcohol harm, and complications of pregnancy leading naturally to a present research focus on alcohol in pregnancy. Kate has taught epidemiology, research methods and statistics across undergraduate, postgraduate and continuing professional development courses and has successfully supervised a large number of students including doctoral students examining alcohol harm utilising existing data sources.



### **Paul Gard**

Paul Gard is Professor of Experimental Therapeutics at the University of Brighton. He obtained his Joint Honours B.Sc. degree in Pharmacology and Psychology from the University of Nottingham, before undertaking a PhD studying the endocrine basis of post-partum depression and pre-menstrual syndrome at the University of Aston, in collaboration with the Department of Obstetrics and Gynaecology, Birmingham Medical School. During his time at Brighton, he has undertaken extended sabbatical periods as a visiting senior lecturer in pharmacology, at the School of Pharmacy, Central Institute of Technology, Wellington, New Zealand and as a visiting Researcher at the Laboratorium voor Moleculaire en Biochemische Farmacologie (MBFA), Vrije Universiteit, Brussels, Belgium. His research focusses on the brain renin-angiotensin system and in particular the effects of drugs such as ACE inhibitors and angiotensin receptor antagonists on learning and memory in conditions such as dementia and foetal alcohol spectrum disorders.



### **Piyadasa Kodituwakku**

Piyadasa Kodituwakku, Ph.D. is a professor of pediatrics and neurosciences at the University of New Mexico School of Medicine, USA. The focus of his research over the past 25 years has been on the delineation of neuropsychological and behavioral profiles of children with prenatal alcohol exposure. He has investigated a broad range of cognitive abilities (e.g. executive functions, language, memory, motor skills) in children with FASD from South Africa, Italy and various communities in the US (mostly Native American). He has also conducted collaborative research to identify the neural correlates of cognitive disabilities in alcohol-affected children using neuroimaging methods such as

magnetoencephalography and functional MRI. He is currently interested in the study of neuroplasticity induced by motor training and music training in children with FASD.



### **Kathleen Mitchell**

Kathleen Mitchell, MHS, LCADC, is currently the Vice President and International Spokesperson for the National Organization on Fetal Alcohol Syndrome. She has a Master of Human Services (MHS) degree and is a licensed clinical alcohol and drug counselor (LCADC) with over thirty-two years of experience as a national educator, author, clinician, and lecturer. She was an adjunct faculty member of the Georgetown University School of Medicine and Northwestern School of Medicine teaching the NOFAS FASD Selective. She has served on many expert panels including the special committee of the World Health Organization (WHO) developing guidelines for the identification and management of substance use disorders in pregnancy, the U.S. National Task Force on Fetal Alcohol Syndrome, and serves on the American College of OB-GYNs (ACOG) and the American Academy of Pediatrics (AAP) FASD Champion Committees. She founded an international birth mother mentorship program, the Circle of Hope (COH). Ms. Mitchell serves as the project officer on several government projects including the National Institutes of Health (NIH) Consortium Initiative on Fetal Alcohol Spectrum Disorders (CIFASD). She assisted the writers of NBC's Law and Order; Special Victims Unit to create an episode about FASD: "Choices." She has provided media interviews for: The Doctors (CBS), NBC's Later Today Show, NBC's Real Life, Self Magazine, The Daily News, Glamour Magazine, BBC Radio, National Public Radio and the Washington Post that was viewed by over 8 million readers and caused FASD to trend on Facebook as the #6 topic for days.



### **Margaret M. Murray**

Dr. Murray is Director of the Global Alcohol Research Program, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health. Dr. Murray directs NIAAA's efforts in international research collaboration spanning each of the Institute's priorities in biomedical, epidemiological, prevention and treatment research. This includes serving on U.S. Science and Technology Committees, NIH and government wide initiatives in global health, and representing NIAAA to multilateral organizations such as the World Health Organization, the Organization for Economic Cooperation and Development and National Academies of Science committees. She is primarily responsible for facilitating

collaborative relationships at the individual institute and scientist level. Dr. Murray is a member of the Institute of Medicine's Forum on Global Violence Prevention.

In 2014, Dr. Murray was assigned to represent NIAAA on the Coordinating Committee for Collaborative Research on Addiction at the NIH, or CRAN.

Dr. Murray is also responsible for the Institute's research translation initiatives in health professions education. She is co-author of A Medical Education Model for the Prevention and Treatment of Alcohol-Use Disorders, a twenty module curriculum and faculty development course for medical school faculty in the primary care specialties. The model has been translated into five languages and implemented in eight countries. She led the development of a model curriculum for social work educators, A Social Work Education Model for the Prevention and Treatment of Alcohol Use Disorders that is currently being disseminated and tested by NIAAA, and is also involved in a similar project in nursing education.

She has published in the areas of screening and brief intervention for alcohol use disorders in primary health care settings, evaluation of international faculty development programs and homelessness and alcohol and drug problems.

Dr. Murray received a BA degree in English from St. Mary's College of Maryland, a public honors college. She holds PHD and MSW degrees in social policy from Catholic University in Washington, DC and certificates in epidemiology and biostatistics from Johns Hopkins University School of Public Health.

Dr. Murray served as adjunct faculty in the graduate Social Work program at the Catholic University of America and Howard University where she taught courses in the history of Social Welfare Policy in the United States.



## **Helen Oakwater**

An adoptive parent, professional Coach and Trainer; Helen Oakwater is the author of "Bubble Wrapped Children: How social networking is transforming the face of 21st century adoption". Since adopting a sibling group from the UK care system in 1992, Helen has worn a variety of professional hats. She was a member of the Adoption UK Trustee Board, the Government Adoption Task Force and two adoption panels. She has personal experience of parenting traumatised children, mentoring parents and has trained thousands of parents and professionals in trauma triggered behaviour. Her mission is to help people understand the legacy of childhood neglect and maltreatment, melt trauma and futureproof children.



### **Svetlana Popova**

Svetlana Popova, MD, PhDs, MPH is a Senior Scientist of the Institute for Mental Health Policy Research at Centre for Addiction and Mental Health, The Pan American Health Organization (PAHO)/World Health Organization (WHO) Collaborating Centre. She is also Associate Professor of the Dalla Lana School of Public Health, Epidemiology Division and Factor Inwentash Faculty of Social Work, University of Toronto. Dr. Popova's research focuses on FASD, substance abuse and disease burden, and evidence-based policy development. Dr. Popova led the study on estimation of burden and economic cost of FASD in Canada, supported by the Public Health Agency of Canada. Currently, she is a leading investigator of a large multi-country international study on estimating global prevalence FASD guided by the WHO and the National Institute on Alcohol Abuse and Alcoholism. Dr. Popova is also collaborating on the WHO Global Burden of Disease studies on alcohol consumption as a risk factor for burden of disease.



### **Edward P. Riley**

Edward P. Riley received his Ph.D. in Psychology in 1974 from Tulane University and did a postdoctoral fellowship at the Center for Alcohol Studies, Rutgers University. He is currently a Distinguished Professor of Psychology and the Emeritus Director of the Center for Behavioral Teratology at San Diego State University. He has authored close to 300 scientific papers and reviews, primarily on the effects of prenatal alcohol exposure. He served as Chair of the U.S. National Task Force on FAS/FAE from 2000-2004 at the request of the U.S. Secretary of Health. He is a Past-President of the Research Society on Alcohol (RSA), the Fetal Alcohol Study Group of the RSA, the Behavioral Teratology Society, and the International Society for Biomedical Research on Alcoholism. He has served as a member of the U.S. National Institute on Alcohol Abuse and Alcoholism Council and as a member of the Behavioral and Social Advisory Council of the ABMRF/The Foundation for Alcohol Research. He served on the Expert Panel for the U.S. Substance Abuse and Mental Health Service Administration's FASD Center for Excellence and previously served as Chair of this advisory group. He has received numerous awards for his scholarship and contributions to the alcohol field, including the RSA Distinguished Researcher Award, the National Organization on Fetal Alcohol Syndrome Research Recognition Award, and most recently the Frank Seixas Award from the RSA. His work on FASD has been funded continually since 1978 by the National Institute on Alcohol

Abuse and Alcoholism. He currently directs the Collaborative Initiative on FASD, an international, multisite consortium funded by NIAAA.

## **Elizabeth Anne Russell**

Anne founded the Russell Family Fetal Alcohol Disorders Association (rffada) Australia in 2007 after realising that there needed to be direct support for parents and carers living with diagnosed or undiagnosed FASD. Anne has kept the organisation running for almost 10 years without any funding from the government and only through the generous donations of the organisation's supporters. The rffada supports several Facebook sites and works directly with parents, foster carers, foster organisations, disability organisations and others to provide training, support and information. This is all done at no cost to the consumer. The rffada lobbies government, develops submissions, keeps up with the latest research and has the unique advantage of knowing FASD from different perspectives – that of a birth mother, a researcher, the author of several books on the subject and co-author of several academic papers on aspects of FASD. Lastly, the rffada was the first organisation in Australia to make training on FASD publicly available.



## **David Townend**

Professor David Townend (1966) is an academic lawyer and legal philosopher focusing on issues in health and life science governance. His interest in FASD is in the way that society protects individuals and the way that society interprets responsibility and rights in different situations. His theoretical work in relation to legal philosophy is about the interaction of norms - the relationship between legal norms and other societal norms, particularly ethics and manners. He is particularly interested in the collectivist pre-conditions for liberalism, and in 18th century Politeness; about how individuals exercise choices. His substantive legal work is about the construction of the concepts of privacy, property and public interest; data protection, particularly in relation to health research and large data set research; the regulation of health and life science research; patient rights, and particularly cross-border patient rights in the EU; and, human rights, particularly the rights to health and to access cultural and scientific benefits in society.

David is Professor of Law and Legal Philosophy in Health, Medicine and Life Sciences at Maastricht University, NL (Faculty of Health, Medicine and Life Sciences, and in the CAPHRI Care and Public Health Research Institute). He is a member of the Governor Kremers Centre in the University. He is also a Visiting Professor of Health Law at the

University of Lincoln, UK, and an external member of Durham Centre for Ethics and Law in the Life Sciences at Durham University. Prior to his work in Maastricht, he worked in the Faculty of Law and Sheffield Institute of Biotechnological Law and Ethics at the University of Sheffield. His Ph.D., *The Politeness of Data Protection: Exploring a Legal Instrument to Regulate Medical Research Using Genetic Information and Biobanking*, was awarded cum laude at Maastricht University. He was, from 2012-14, a member of ESBAC (the Emerging Science and Bioethics Advisory Committee) of the UK Department of Health. He is currently a member of the Global Alliance for Genomics and Health (GA4GH) working group on Regulation and Ethics, chairing task teams on Ethics Review Equivalence, and on Data Protection.



### **Jan de Vries**

Jan de Vries, MSc, is a registered child-youth psychologist and educational psychologist. He works in a small practice in the North of the Netherland, ZO!-zorgoplossingen. He is a specialist in working with attachment disorders, ASD, ADHD and now also FASD. And thereby, he works a lot with adoption and foster care children and adults.

Since his work in the late 90's in Therapeutic Foster Care, FASD has his focus. In that time it was a completely ignored and not identified handicap in The Netherlands. He experienced difference with particular children, but couldn't find information about it. During a EU study trip to Polen in 2003 he recognized particular behavior and physics of children in foster-families. Polish foster parents told him about FASD. Around this time the FAS Foundation of The Netherlands also began with there work and provided information. Since than there is a frequent contact between the FAS Foundation and Jan. Recently Jan is, together with Dianne Wesseling, Sandra Knuiman and the FAS Foundation, developing a course in The Netherlands for psychologists and pediatricians about diagnosing and guiding people with FASD.

Jan is married and has 2 adults sons.



### **Kenneth R. Warren**

Kenneth R. Warren, Ph.D., is currently a Senior Advisor for Science and Operations within the National Institute on Alcohol Abuse and Alcoholism (NIAAA) a part of the U.S. National Institutes of Health (NIH). Having joined NIAAA in 1976 he served in many positions including Director of the Office of Scientific Affairs from 1984 to 2007, Institute Deputy Director from 2008 to 2015, and

Institute Acting Director from 2008-2014. Throughout the course of his career at NIAAA, Dr. Warren has served as the leader of the Institute's research and policy efforts on alcohol and pregnancy, including his continuing service as the chair of the U.S. government's Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders. A graduate of the City College of New York, Dr. Warren earned his doctorate degree in Biochemistry from Michigan State University in 1970. He entered into the field of birth defects in 1972 when he served as a postdoctoral fellow at the Mental Health Research Institute of the University of Michigan pursuing research on the sphingolipid storage diseases underlying specific birth defects. Dr. Warren has received many awards over his career including being placed into the Tom and Linda Daschle Hall of Fame of the National Organization on Fetal Alcohol Syndrome (NOFAS), and the NOFAS Excellence Award, the Lifetime Achievement Award from the Research Society on Alcoholism (RSA), a Special Recognition Award from the International Society for Biomedical Research on Alcoholism, the Henry Rosett Award from the FASD Study Group of RSA, and many other awards from the United States Public Health Service and the NIH.

### **Pip Williams**

Pip Williams is the mother of two adult sons with Fetal Alcohol Spectrum Disorder (FASD). In 2010 she founded the UK & European Birth Mother Network - FASD and has worked for the last 12 years to help raise awareness and to help birth mothers and families living with FASD. Pip delivers training throughout the UK. She is a Board Member of the EUFASD Alliance and Co - founder of FASD UK a facebook group which supports over 900 families and adults with FASD.



European Conference  
Fetal Alcohol Spectrum Disorders

# EUFASD 2018

24<sup>th</sup> – 26<sup>th</sup> September

Ramada Hotel Berlin, Alexanderplatz

- 3 Day conference followed by 2 day German Symposium
- For all Professionals and other associated with FASD
- To increase understanding about FASD
- Keynote presentation from international experts
- On-site accommodation available to book

Further information:

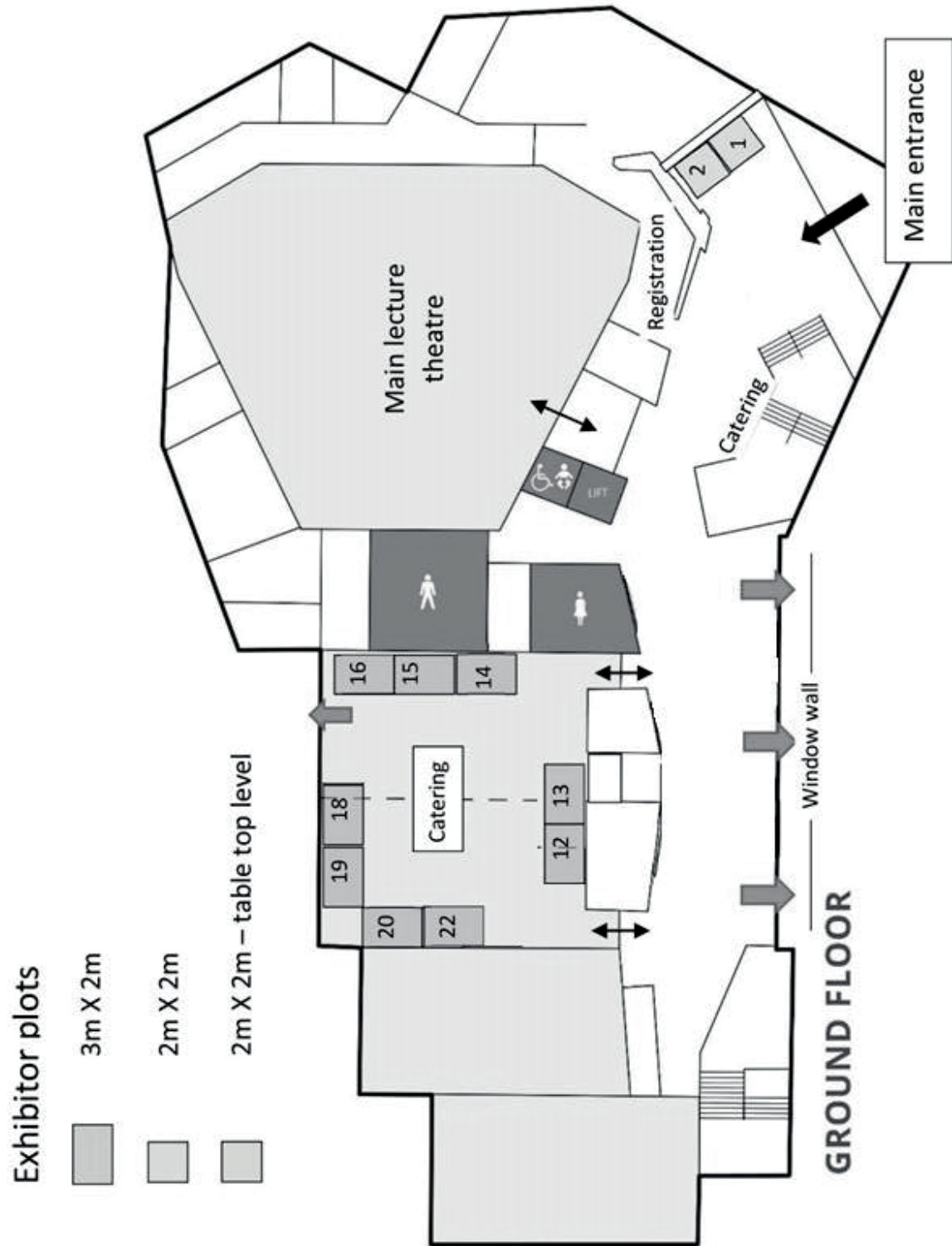
[www.eufasd.org](http://www.eufasd.org) or [www.fasd-deutschland.de](http://www.fasd-deutschland.de)

EUROPEAN  
FASD  
ALLIANCE

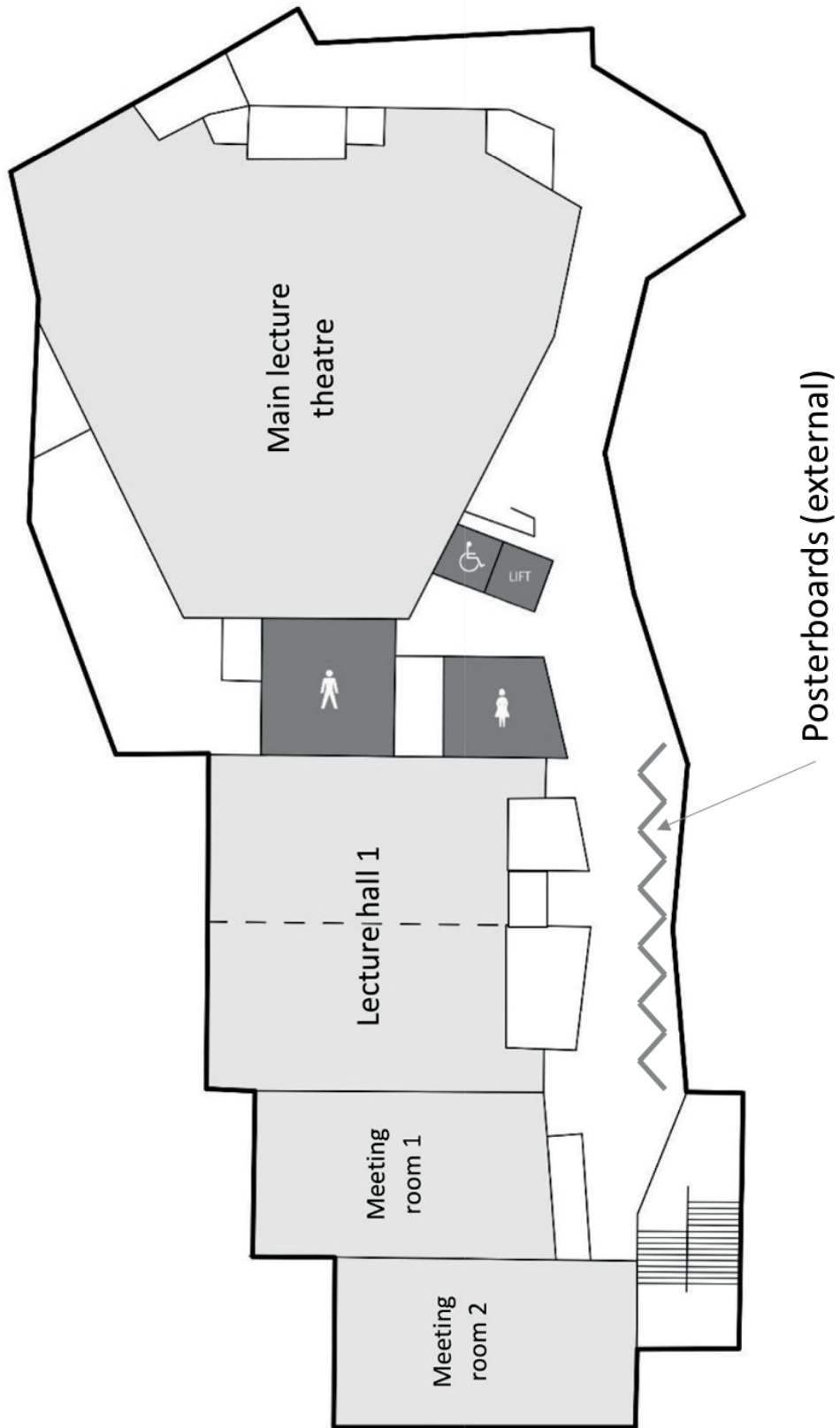
*fasd*  
Deutschland  
aufklären • beraten • helfen



# Windsor Building Ground Floor



# Windsor Building First Floor





# ROYAL HOLLOWAY

## LOCAL RESTAURANTS



**A** – Megna Tandoori, St Jude's Road, Englefield Green  
<http://www.megna.uk.com/>

**B** – Sopranos Restaurant (Italian) – St Jude's Road, Englefield Green  
<http://sopranostakeaway.co.uk/>

**C** – Mango Chutney (Indian) – St Jude's Road, Englefield Green  
<http://www.mangochutneyindianrestaurant.co.uk/>

**D** – The Happy Man (Pub) – Harvest Road, Englefield Green

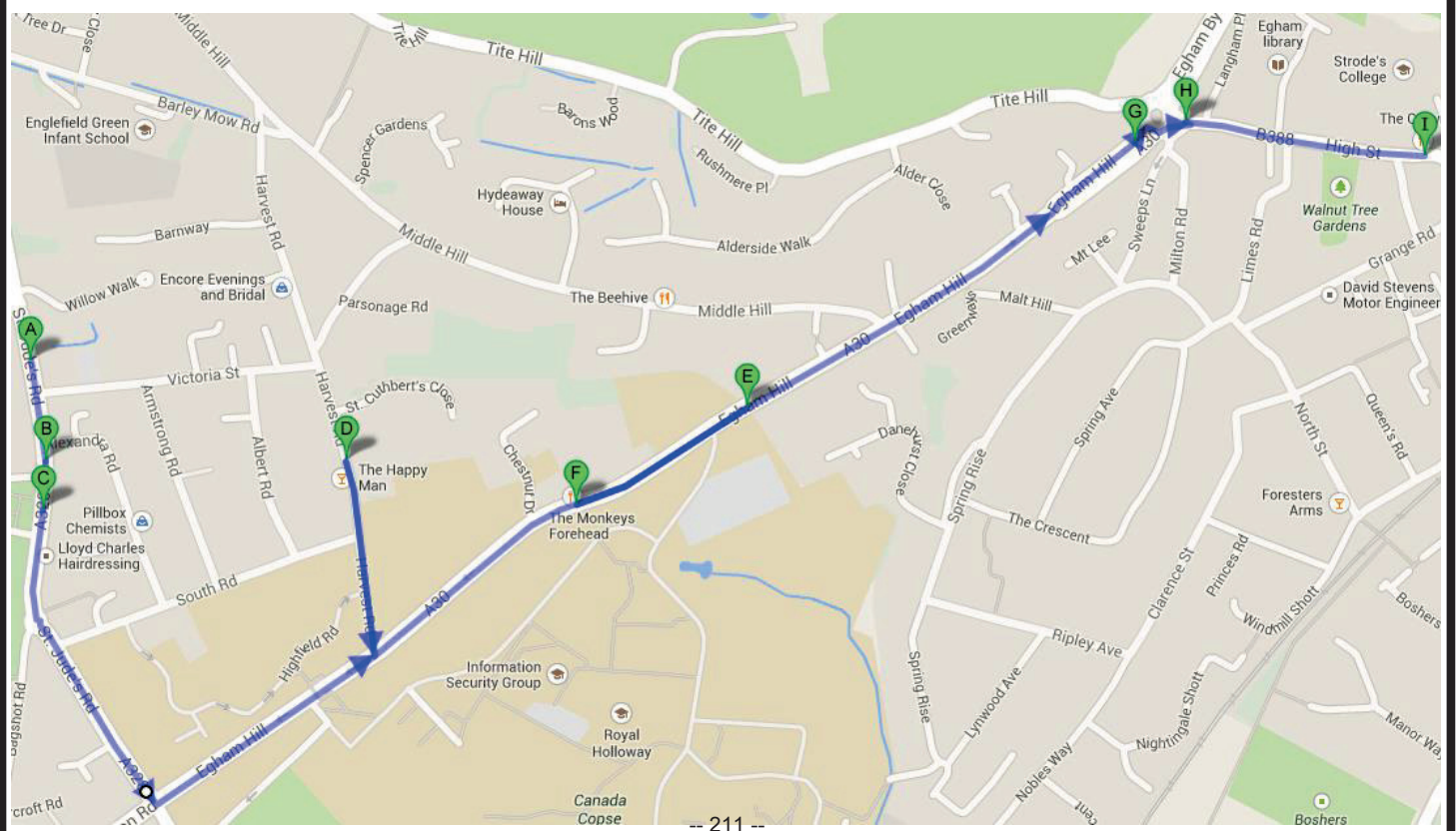
**E** – Royal Holloway Campus, Egham Hill, Egham

**F** – The Monkey's Forehead (Pub), Egham Hill, Egham  
<http://www.monkeysforehead.co.uk/>

**G** – Prezzo Restaurant (Italian), Egham Hill, Egham  
<http://www.prezorestaurants.co.uk/restaurant/egham>

**H** – Loch Fyne (Fish & Seafood), High Street, Egham  
<http://www.lochfyneseafoodandgrill.co.uk/locations/egham>

**I** – The Crown (Pub), High Street, Egham  
<http://www.crownegham.co.uk/>



# POPULAR LONDON SITES



British Museum: London's famous British Museum hosts artifacts from prehistoric to modern man, including the Rosetta Stone



Science Museum: Take a fascinating look the major scientific advances of the last 300 years at the Science Museum



National Gallery: See one of the greatest collections of European painting in the world in the National Gallery



Victoria and Albert Museum: See 3,000 years worth of amazing artefacts from many of the world's richest cultures at the Victoria and Albert Museum



Natural History Museum: Meet the dinosaurs, experience an earthquake simulator and explore the new Darwin Centre at London's Natural History Museum



Tower of London: Discover the secrets of 900 years of royal gossip at the historic Tower of London



Tate Modern: Housed in the former Bankside Power Station in London, Tate Modern is Britain's national museum of modern art



National Maritime Museum: One of the greatest maritime museums of the world with nautical displays and more



London Eye: See more than 50 famous London landmarks in 30 minutes on the Coca-Cola London Eye - the world's highest observation wheel



Madame Tussauds: Come face-to-face with some of the world's most famous faces at Madame Tussauds and interact with your favourite celebrity



Bus Tours

### Getting to Royal Holloway:

Situated in Egham, Surrey, Royal Holloway is a short drive from the M25, 7 miles from Heathrow and just 40 minutes by train from London. Full details of alternative travel methods and routes can be found here <https://www.venue.royalholloway.ac.uk/getting-here/>



### Things to do in/near Egham <http://www.touruk.co.uk/surrey/Egham.htm>:

- ❖ [John Battleday Waterski](#) - A great place for an exciting and active day out.
- ❖ [Valley Garden](#) - Considered by some to be the finest woodland gardens in world.
- ❖ [Royal Holloway Collection](#) - An outstanding collection of Victorian Art.
- ❖ [The Royal Lodge and Cumberland Lodge](#) The Royal Lodge dates from the 17th century, and is 3 miles south of Windsor Castle at the centre of Windsor Great Park.
- ❖ [Spelthorne Museum](#) - Discover the history of Staines and the local district.
- ❖ [Chertsey Museum](#) - A local museum covering the borough of Runnymede.
- ❖ [Runnymede Meadow](#) Explore the riverside site where the Magna Carta was signed.
- ❖ [Salter's Steamers](#) - Enjoy a trip on the River Thames.
- ❖ [The Savill Building](#) - The unique visitor centre is the gateway to the Royal Landscape. Covering 1,000 acres of landscaped gardens, lakes and woodland.
- ❖ [Virginia Water Lake](#) - Originally just a small stream, this large lake was created in 1753 by William, Duke of Cumberland, a Ranger of the Windsor Great Park.
- ❖ [Windsor Great Park](#) - Dating from the 13th century, the 4,800 acres of deer park and Crown Estate originally formed the hunting ground of Windsor Castle.
- ❖ [Thorpe Park](#) - One of the UK's premier theme parks.
- ❖ Windsor Castle – short taxi ride (15 mins - 8km). Price £20 for taxi. Typical visit lasts 2-3 hours  
<https://www.royalcollection.org.uk/visit/windsorcastle>



### Eating out in Egham:

### Getting to London from Royal Holloway:

- There are frequent rail services between London Waterloo via Clapham Junction and Richmond to Egham (35 – 40 minutes, cost £11 return off peak) You can change at Clapham Junction for London Victoria. Please be aware that there is also a slow service that runs via Hounslow, which increases the journey time to and from Waterloo by roughly twenty minutes. Or Taxi to central London - Egham taxi company 0044 1784 434484 - Cost from about £45
- Getting to Egham station: head north-east on Egham Hill, at the roundabout take the 3<sup>rd</sup> exit on the High Street, turn right on Station road, turn left onto School Lane.
- You might want to buy an Oyster Card (a smartcard which can hold pay as you go credit, Travelcard and Bus & Tram Pass season tickets. <https://tfl.gov.uk/fares-and-payments/oyster?cid=oyster>.)

### Things to do in London:

Visit one of the many museums, galleries, theatres, parks or just browse the shops: <http://www.visitlondon.com/>



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