

# First European Conference on FASD

## Fetal Alcohol Spectrum Disorder: Growing Awareness in Europe

3 to 5 November 2010

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

Conference chair: Diane Black

organized by:



## Contents

Program	3
Posters	10
Local Planning Committee	13
Scientific Planning Committee	13
Abstracts Wednesday opening session	14
Abstracts Wednesday evening session	17
Abstracts Thursday morning plenary session I	28
Abstracts Thursday morning plenary session II	32
Abstracts Thursday Parallel Session A	36
Abstracts Thursday Parallel Session B	42
Abstracts Thursday Parallel Session C	47
Abstracts Thursday Parallel Session D	52
Abstracts Thursday Parallel Session E	57
Abstracts Thursday Parallel Session F	63
Abstracts Thursday Parallel Session G-H	67
Abstracts Friday	70
Abstracts posters	73
List of presenters	114
Rolduc floorplan	120

# PROGRAM

3 to 5 November 2010

## WEDNESDAY 3 NOVEMBER

- 15:00 and on Arrival of guests and registration
- 17:30 Dinner buffet in the 'Grote Eetzaal'
- Plenary meeting in Aula Minor  
Theme: What is the state of affairs in Europe?
- 19:00 **Opening**, Diane Black, FAS Foundation of the Netherlands, Conference Chair  
Chair: Martha Krijgsheld
- 19:10 Paul W. J. Peters, Senator of the States-General of the Netherlands:  
**Recognition, Detection and Prevention of Alcohol related Developmental Disorders.**
- 19:30 Michel Craplet, Chairman Eurocare:  
**Why does it take so long to recognize FASD?**
- 19:50 Vladimir Poznyak, Coordinator, Management of Substance Abuse, WHO  
**Prevention of FASD: a call for a global action**
- 20:10 **What is happening in my country?**  
  
Representatives from various countries give 5 minute overview of what is happening in their countries:  
  
Finland (Ilona Autti-Rämö)  
Netherlands (Diane Black)  
UK (Susan Fleisher)  
Poland (Magdalena Borkowska)  
Belgium (Bernard Dor)  
Israel (Yehuda Senecky)  
Croatia (Giorgie Petković)  
Italy (Simona Pichini)  
Sweden (Katarina Wittgard)  
Germany (Veerle Moubax)  
France (Denis Lamblin)
- 21:00 End  
Guests can mingle in Foyer or Cellar bar

## THURSDAY 4 NOVEMBER

7:30 Breakfast served until 9:30 in the 'Grote Eetzaal'

8:00 Optional morning walk--weather permitting  
Posters up all day

### Plenary meeting in Aula Minor Theme: What's new in Europe?

8:40 Welcome

8:45 Plenary Session I

#### Chair: Marjolein Beltz

Peter Hammond (UK)  
**3D facial analysis in fetal alcohol syndrome**

Christina Chambers (USA)  
**Preliminary data from a longitudinal study of alcohol-exposed pregnancies in Ukraine**

Miguel Del Campo (Spain)  
**Physical phenotype and cognitive deficit in prenatal exposure to alcohol (PEA) and the Fetal Alcohol Syndrome (FAS)**

Joanne Rovet (Canada)  
**Children with Fetal Alcohol Spectrum Disorder show atypical fMRI activation of the hippocampus on memory tasks**

10:05 Questions and discussion

10:15 Coffee break

10:45 Plenary Session II

#### Chair: Nickie van der Wulp

Simona Pichini (Italy)  
**Assessment of prenatal exposure to ethanol by meconium toxicology: results of an Italian multicentric study**

Reinhold Feldmann (Germany)  
**The Fetal Alcohol Syndrome Questionnaire (FASQ)**

Anne Maarit Koponen (Finland)  
**Socio-emotional development of children with FASD in long-term foster family care - a qualitative study in Finland**

Joy Ellis (Sweden)  
**Team Haga: cross-disciplinary specialist care for substance-abusing pregnant women and their infants in Gothenburg, Sweden**

12:05 Questions and discussion

12:15 Lunch buffet in the 'Grote Eetzaal'

13:30 First round parallel sessions

### A. Prevention, prevalence, public education I

#### Chair: Ken Warren

Ab Aaldriks (the Netherlands)  
**Continuous care for addicted pregnant women and their children**

Stefania Bazzo (Italy)  
**Project "Kambio Marcia - In attesa, cambia": A Research and Prevention project to raise awareness on the FASD issue in the area of the Local Health Unit 9 Treviso, Veneto Region**

Malgorzata Klecka (Poland)  
**FASD children and their families: therapeutic dilemmas**

Kathleen Tavenner Mitchell (USA)  
**Reaching women of child-bearing age: Facilitating a best practice FASD prevention media campaign**

Rianca den Ouden (the Netherlands)  
**Tools for a structural approach to alcohol use and abuse during pregnancy**

Michela Morleo (UK)  
**Alcohol related harm and under-reporting of Fetal Alcohol Spectrum Disorders**

### B. Improving recognition and medical management

#### Chair: Rudi Kohl

Raja Mukherjee (UK)  
**Autism and autism-like features in people diagnosed with FASD**

Primavera Spagnolo (Italy)  
**Fetal Alcohol Spectrum Disorders in Italy: clinical delineation of Italian children**

Oscar Garcia-Algar (Spain)  
**Assessment of prenatal exposure to ethanol by meconium toxicology: results from a survey in Barcelona, Spain**

Kelly Nash (Canada)  
**Canadian neurobehavioural screening tool for Fetal Alcohol Spectrum Disorders**

Leif Svensson (Sweden)  
**Multidisciplinary team approach recognizes more cases of FASD**

## C. The latest research from lab and clinic

Chair: Edu Mulder

Netta Fulga (Canada)

**The use of hair FAEE analysis to identify mothers at risk of having children with FASD**

Marco Fiore (Italy)

**Early exposure to ethanol or red wine and long-lasting effects in aged mice.  
A study on nerve growth factor, brain derived neurotrophic factor, hepatocyte growth factor and vascular endothelial growth factor in a FASD mouse model**

Sheila Pons-Vásquez (Spain)

**Structural and functional changes in the visual system related to ethanol abuse during pregnancy.**

Vincenza Bianchi (Italy)

**Variations and accuracy of carbohydrate-deficient transferrin during pregnancy**

Pascal Burger (Germany)

**Determination of fatty acid ethyl esters (FAEE) in meconium from 602 newborn for detection of maternal alcohol abuse**

## D. Ethical issues and the justice system

Chair: Leopold Curfs

Ilona Autti-Rämö (Finland)

**Ethical evaluation of a screening programme for alcohol abuse during pregnancy**

J. Boonekamp (the Netherlands)

**Ethical aspects of coercive interventions in early pregnancy in order to prevent or reduce risks for FASD**

Liam Curran (Ireland)

**Illicit Drug and alcohol use during pregnancy as a child protection issue  
-- multidisciplinary views**

Miguel Del Campo (Spain)

**FASD and adoption -- ethical issues**

Jessica Wagner (Germany)

**Different perspectives on FASD and the legal system**

15:00

Coffee break

15:30

Second round parallel sessions

## E. Prevention, prevalence, public education II

Chair: Ed Riley

Nickie van der Wulp (Netherlands)

**Intervention for prenatal alcohol use and the role of midwives**

Layla Mirzaei (Sweden)

**Do children from orphanages in Brazil and Eastern Europe differ in their frequency of FASD?**

Raja Mukherjee (UK)

**Knowledge of FASD in UK general public and healthcare practitioners**

Peggy Murray (USA)

**Reaching health professionals to improve identification, treatment, and prevention of FASD**

Daniela Fiorentino (Italy)

**Drinking and smoking behavior during pregnancy and association with health professionals recommendations**

Philipp Nordhues (Germany)

**The prevalence of the Fetal Alcohol Syndrome (FAS) in foster children**

## F. Management of FASD from childhood to adulthood

Chair: Susan Fleisher

Hannah Schmidt (Germany)

**Evaluation of the FAS "First Aid Box"**

Osman Ipsiroglu (Canada)

**FASD & Sleep: an epidemiological concept for international comparisons**

Sara Stevens (Canada)

**Investigating the socioemotional profiles of children with Fetal Alcohol Spectrum Disorder and children with prenatal cocaine exposure**

Åse Fagerlund (Finland)

**Adaptive behavior in children and adolescents with FASD**

## G. Political and legal approach to FASD: a round-table discussion

Chair: Thierry Maillard (France)

Members of round-table: Ruth Ruiz (EU), Denis Lamblin (France)

## H. Psychiatric review of first 100 clinic-referred patients with FASD & their families in Ireland (2006-2010)

Limited to 25 participants.  
In-depth discussion with a family living with FAS and presentation of data from Ireland, led by Dr Kieran O'Malley.

## I. Diagnosis of FASD using the 4-digit code

Limited to 25 participants.  
Intensive workshop on diagnosis of FASD, led by Rudi Kohl, Pediatrician.

17:00 End of parallel sessions

### Poster sessions

Presenters: please stand by your posters during the following times:

17:15-17:45 Even-numbered posters

17:45-18:15 Odd-numbered posters

19:00 Gala dinner in the 'Grote Eetzaal'

Presentation of Poster Prize

Evening: Guests can mingle in the Foyer or Cellar Bar

## FRIDAY 5 NOVEMBER

7:30 Breakfast served until 9:30 in the 'Grote Eetzaal'

8:00 Optional morning walk--weather permitting

**Reminder:** Please turn in your room key before 10:00

Plenary meeting in Aula Minor

Theme: Looking ahead to the future

Session Chair: Dianne Wesselink

8:40 Welcome

FASD: impact on individuals, family, society

8:45 Prof. Hans Spohr, DRK-Kliniken Westend, Berlin:  
**Fetal Alcohol Syndrome in Adulthood**

9:05 Family panel: Rob Wybrecht, Philippa Williams, Tracey Hayter

10:05 Questions and discussion

10:15 Coffee break

10:45 **Looking to the future**

Session Chair: Inge van Balkom

Ken Warren, NIAAA

**The Future Emerging from FASD Research: Impact on Identification, Prevention and Treatment**

Dag Rekve, World Health Organization

**FASD and the global strategy to reduce the harmful use of alcohol**

Marjatta Montonen, European Commission, DG Health & Consumers

**EU Alcohol Strategy: Prevention of foetal alcohol harm as priority theme**

12:05 Questions and discussion

12:15 Simona Pichini

**Announcement of 2nd European Conference on FASD**

12:25 **Closing remarks**, Diane Black

12:30 End. Lunch packets to take along as guests leave.

## Posters

1. S. Vichi (Italy)  
Modulation of liver and brain CYP2E1 mRNA expression in CD1 mice exposed in utero to red wine or ethanol
2. M.E. Raats (the Netherlands)  
Awareness to malice
3. J. Rangmar (Sweden)  
A retrospective register study on psychosocial functioning in adults with fetal alcohol syndrome
4. M.L. Ojeda (Spain)  
Selenium supplementation as an effective antioxidant to ethanol exposed pups
5. Svetlana Popova (Canada)  
Prevalence of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder in European countries: a systematic literature review
6. Jessica Wagner (Germany)  
Executive functioning (EF) in children and adolescents with FASD. A paired comparison of two groups of 15 children and adolescents with and without FASD matched according to their age, IQ and living standards
7. Sylvie Kruchten (Canada)  
Experiences of a FASD/CDBC key worker at the Simon Fraser Society for Community Living in British Columbia
8. Cécilia Lafosse (France)  
About 155 adults exposed to alcohol in utero: presentation of our study
9. Rosanna Mancinelli (Italy)  
Evidence-based, multidisciplinary approach to the study of FASD: an Italian current experience
10. Kathleen Tavenner Mitchell (USA)  
Creating a circle of hope: the Women in Recovery summit model
11. Stefania Bazzo (Italy)  
Alcohol consumption by pregnant women in the Treviso area (Veneto Region, Italy): results of a screening activity
12. G.P. Dolan (UK)  
A systematic review of continuous performance task research in children prenatally exposed to alcohol
13. Silvia Ceccanti (Italy)  
The effects of ethanol exposure during pregnancy in pediatric surgery: a review
14. Carolyn Blackburn (UK)  
Facing the challenge and shaping the future for students with FASD
15. Diane Black (the Netherlands)  
Nutrition for children with FASD
16. Donna Debolt (Canada)  
Building promising practice in child welfare service for individuals with FASD
17. Felicia Demchuk (USA)  
Investigating the impact of prenatal alcohol exposure on the social-emotional, academic, and adaptive functioning of internationally adopted children
18. Raja Mukherjee (UK)  
Behavioral management strategies in people with FASD: lessons from a national referral clinic
19. Raja Mukherjee (UK)  
Carers experience of looking after a child with FASD in the UK
20. Åse Fagerlund (Finland)  
Risk factors for mental and behavioral problems in Fetal Alcohol Spectrum Disorders
21. Simona Pichini (Italy)  
A survey of Italian neonatologists knowledge regarding awareness of maternal ethanol use and the diagnosis of FAS and FASD
22. Katarina Wittgard (Sweden)  
Do you recognize Eric?
23. L. Tarani (Italy)  
Different strategies for FASD's diagnosis: two cases in comparison
24. Lesley Smith (UK)  
Feasibility of screening for risk drinking in pregnant women
25. Sandra Knuiman (the Netherlands)  
FASD in children adopted from Poland
26. Sara Stevens (Canada)  
Face processing in children with fetal alcohol spectrum disorders
27. Inyang Takon (UK)  
A survey of paediatricians knowledge and practice in the diagnosis and management of Foetal Alcohol Spectrum Disorders -- A UK survey
28. Inyang Takon (UK)  
Diagnostic dilemma -- Foetal Alcohol Spectrum Disorder or Pierre Robin Sequence -- case history
29. Inyang Takon (UK)  
Epilepsy in Children with FASD--case report
30. Suvi Vaarla (Finland)  
FASD project in Finland (2008-2011)

31. **Osman Ipsiroglu (Canada)**  
Differentiating restless legs syndrome (RLS) as a cause of circadian rhythm sleep disorders (CRSD) in children with FASD: video studies in the home setting--using optical flow to quantify movements
32. **Osman Ipsiroglu (Canada)**  
Differentiating restless legs syndrome (RLS) as a cause of circadian rhythm sleep disorders (CRSD) in children with FASD: video studies in the home setting--commercially available lowcost equipment
33. **Osman Ipsiroglu (Canada)**  
FASD & Sleep: an epidemiological concept for international comparisons
34. **Wybrecht, Barbara (USA)**  
FAS Prevalence and Effects
35. **Titti Huseby (Norway)**  
Focus on protecting children from FASD through prevention, harm reduction and treatment during pregnancy
36. **Maria Falcón (Spain)**  
Ethyl Glucuronide and Ethyl Sulfate In Human Placenta and Fetal Tissues; Potential Biomarkers of Maternal Alcohol Intake During Pregnancy
37. **Lucilla Manganozzi (Italy)**  
An observatory on newborns with microcephaly
38. **Nancy MacKay (Canada)**  
Fetal Alcohol Spectrum Disorder Prevention: Canadian Perspectives
39. **Mary Johnston (Canada)**  
Early Primary School Outcomes Associated with Children's Prenatal Exposure to Alcohol and Tobacco from the Better Beginnings, Better Futures Study
40. **Mary Johnston (Canada)**  
Development of a model to determine the economic impact of Fetal Alcohol Spectrum Disorder (FASD) in Canada
41. **Reetha Parthiban (Canada)**  
A Systematic Review of Literature and Data on Alcohol Use by Canadian Women of Childbearing Age: Identifying Policy and Program Implications

Conference Chair: Diane Black, the Netherlands

## Local Planning Committee

Diane Black, Board, FAS Foundation of the Netherlands

Martha Krijgsheld, Board, FAS Foundation of the Netherlands

Harold de Cuba, Board, FAS Foundation of the Netherlands

Meriyane Schippers, volunteer worker, FAS Foundation of the Netherlands

## Scientific Planning Committee

**Ilona Auttti-Rämö**  
Helsinki, FINLAND

**Leopold Curfs**  
Maastricht, THE NETHERLANDS

**Miguel Del Campo Casanelles**  
Barcelona, SPAIN

**Thierry Maillard**  
Saint-Louis, FRANCE

**Raja Mukherjee**  
Oxted, UK

**Simona Pichini**  
Rome, ITALY

**Edward Riley**  
San Diego, California, USA

**Hans-Ludwig Spohr**  
Berlin, GERMANY

**Kerstin Strömland**  
Göteborg, SWEDEN

## ABSTRACTS OPENING SESSION WEDNESDAY

Recognition, detection and prevention of alcohol related developmental disorders

Paul W. J. Peters

Fetal alcohol syndrome disorder between taboo, science and action

Why does it take so long to recognize FASD?

Michel Craplet

FASD has been suspected since a long time as we can see in the work of some writers reflecting the popular good sense. In spite of early research since the beginning of the 20th century, it is only in 1968 that a French pediatrician published the evidence with a study of 127 cases. This news was disseminated around the world only in 1973 after a publication concerning 5 cases in the most important English medical journal.

The author studies the resistance and finally the emergence in France of a first policy action 40 years after the scientific evidence. In most of the countries, information of the general public and education of health professional remains poor. It can be explained by the general taboo on alcohol problems, the complexity of this case and special difficulties of this theme. Many confusions have been made between FASD and problems arising from the drinking of (both) parents outside pregnancy and the supposed hereditary transmission. The fear of putting all the responsibility of the problems on women is another difficulty, especially in some communities such as popular classes and the first inhabitants of Northern America.

The author will insist on the fact that Information can progress only through a comprehensive approach and if prevention avoid the use of stigmatisation, guilt and fear.



## Prevention of FASD: a call for a global action

Vladimir Poznyak

## ABSTRACTS EVENING SESSION WEDNESDAY WHAT IS HAPPENING IN MY COUNTRY

### FASD in Finland

Ilona Autti-Rämö

Only 10 percent of fertile aged women are abstinent in Finland and several obstetric units have founded special outpatient clinics for pregnant women with alcohol or substance abuse.

The consequences of prenatal alcohol exposure have been studied in several studies in Finland. In 1982 a prospective follow-up study on 82 children born to pregnant women with alcohol abuse was instituted. It showed that the longer the alcohol exposure the poorer the outcome, the cognitive deficit could not always be diagnosed before school age and nearly all children with FAS were taken into custody. 77 children and adolescents with FASD have been studied as part of the CIFASD study. The results from this study emphasize the need to search for minor and major malformations and abnormalities of vision, hearing and cognitive development whenever FASD is being suspected. A study on FASD children taken into custody revealed that the foster parents and the children are not getting the necessary psychosocial support. An ongoing register based study analyzes the long-term outcome of women with alcohol abuse during pregnancy and their offsprings in regards to morbidity and mortality.

A proposal to have a warning label on alcohol containing bottles got strong support from health care professionals. The proposal was unfortunately turned down by the government. Recently a proposal for involuntary care of pregnant women with alcohol or substance abuse has raised vivid discussion and a debate about the incidence of FASD in Finland has started - once again.

## FASD in the Netherlands

Diane Black

Ten years ago, FASD was hardly mentioned in the Netherlands. Doctors routinely advised pregnant women that "one glass can't hurt." In 2002, the FAS Foundation was created to counter this misconception. In 2005, the Health Council of the Netherlands published an official advice stating that women should not drink during the conception period, pregnancy or breastfeeding.

There are now several organizations actively informing professionals and the public about alcohol and pregnancy, including STAP and the FAS Foundation, as well as three active FAS policlinics for diagnosis and support.

The FAS Foundation has a website; supports an e-mail group for parents of children with FAS; provides books and other materials in the Dutch language; and gives presentations to schools, social workers, midwives, and other professional groups. Awareness of the dangers of alcohol during pregnancy is growing, though we still have a long way to go in this country.

## Getting FASD On The Radar In The UK

Susan Fleisher

Though the odd appearance of children of Alcoholic Women was debated in the English House of Commons in 1834, the issue dropped off the radar until the first studies were done in Scotland and England in the 1980's (independent of the studies in France in the 1960's and in the US in 1973). Since then Britain has become the leading country for binge drinking and interest in the issue of prenatal alcohol exposure has increased. There have been 3 debates in the House of Lords and in 2007 the change in the UK Department of Health Guidelines recommending "no alcohol in pregnancy" and the first UK FASD medical publication by the British Medical Association. Now, after the founding of three UK FASD Charities, numerous television programmes, and the initiation of more FASD studies, fewer doctors, teachers and social workers are saying, "Fetal Alcohol Spectrum Disorder. . . What is that?"

The UK has come along way. The UK still has a long way to go.

## Pregnancy with NO Alcohol Nationwide Education Campaign

Magdalena Borkowska

- Main message to woman and society at large: I don't drink to my baby's health! Foetal Alcohol Syndrome and other defects resulting from foetus' exposure to alcohol is 100% preventable. All you need to do is to abstain from alcohol use during pregnancy.
- Campaign Tools: TV and radios spots billboards and city lights, printed educational materials, press articles and TV programmes, campaign website [www.ciazabezalkoholu.pl](http://www.ciazabezalkoholu.pl), local debates and conferences, basic training for doctors, nurses, midwives and social workers.

### **Educating specialists:**

- Providing basic training to doctors and medical services.
- Training child therapists who work in sociotherapeutic centers - basics of the therapy treatment.
- Organizing conferences and providing funding for training courses or scientific conferences devoted the FASD. They include national as well as regional conferences.

### **Public education:**

- FAS Picnic on FAS DAY a form of attracting women to the idea of refraining from drinking during pregnancy.
- Educational program "I am taking the responsibility" addressed to high school students.
- A photo exhibition entitled Fascinating Children created during a two week therapeutic camp for FAS children and foster parents. For the last four years it has been shown in many Polish cities.

### **Cooperating with others and research:**

- Cooperating with the team of experts on FASD, doctors, a psychiatrist, a psychologist, a health-care promotion professional, representatives of foster families organizations and PARPA professionals.
- PARPA carries out FAS research and cooperate with other institutions: opinion poll regarding alcohol consumption in Poland, interdisciplinary research regarding FAS children etc.

### **PARPAMEDIA publishing house:**

- PARPAMEDIA publications devoted to prevention of alcohol consumption by pregnant women and to helping FAS children. Publications are distributed to local municipalities and other institutions.

## FASD in Belgium

Bernard Dor

## Israeli women's awareness and knowledge regarding alcohol consumption during pregnancy

Yehuda Senecky MD, Neta Weiss, Stavit A. Shalev, Dan Peleg, Dov Inbar, Gabriel Chodick, Eliezer Shalev, Avinoam Shuper

**Background:** Fetal alcohol spectrum disorder (FASD) is a range of disabilities caused by gestational exposure to alcohol. In the United States FASD is the leading cause of preventable mental retardation and developmental disabilities. In Israel FASD has never been examined systematically. In our previous research we discovered that the knowledge regarding the risk and potential damage of fetal exposure to alcohol is extremely limited among medical professionals in Israel.

**Objectives:** To determine the awareness and knowledge of women regarding alcohol consumption during pregnancy and its attendant risks, the information they received during pregnancy from various medical professionals, and their own habits of drinking during the current pregnancy.

**Methods:** A cross-sectional study among post-labor women was conducted in three large hospitals in central and northern Israel. Women were asked about alcohol consumption prior and during pregnancy as well as other health behavior practices such as smoking and diet.

**Results:** A total of 3815 participated in our study (82% Jewish, mean age 30.4y). Over 15% of the Jewish women reported consumption alcohol during pregnancy, and 0.8% admitted to binge drinking during third trimester. Nearly one-third of the secular Jewish participants reported knowing of pregnant women who drink alcohol. In addition, 75% of the participants received no formal instruction regarding alcohol consumption during pregnancy, but 72% thought pregnant women should not consume any alcohol during pregnancy.

**Conclusions:** Alcohol consumption is a considerably frequent among pregnant women in Israel, with major differences between ethnicities. Only few women had received any formal education on alcohol consumption during pregnancy.

## Prevalence of maternal alcohol consumption in pregnancy and fetal alcohol syndrome in Croatian schoolchildren

Giorgie Petković, Ingeborg Barišić

In this study we present the prevalence of fetal alcohol syndrome (FAS) and partial fetal alcohol syndrome (PFAS) in a sample of Croatian schoolchildren and prenatal alcohol consumption among their mothers.

This investigation included schoolchildren in an urban centre attending 1st to 4th grade elementary school and their mothers who volunteered to participate in this project. The study involved the maternal interview and clinical examination of children. The questionnaire for the maternal interview consisted of 29 questions and included information on alcohol consumption during pregnancy. For FAS diagnosis we used the revised Institute of Medicine (IOM) diagnostic criteria and evaluated the presence of the cardinal features of FAS/PFAS, which are growth deficiency, microcephaly, short palpebral fissure length, smooth philtrum and thin upper lip. The clinical part of the study was performed blinded to all information regarding maternal interview.

Out of 912 mothers, 575 (63.04%) participated to the interview. Prenatal alcohol consumption was admitted by 15.47% and binge drinking by 3.13% of interviewed mothers.

We evaluated 466 (51.09%) children for FAS/PFAS. The observed prevalence of FAS is 3 children and of PFAS is 16 children among 466 students and the estimated prevalence of FAS is 6.44/1000, of PFAS 34.33/1000 and overall prevalence of FAS/PFAS 40.77/1000.

This study is the first epidemiologic study of FAS/PFAS in Croatia.

## A survey of Italian neonatologists knowledge regarding awareness of maternal ethanol use and the diagnosis of FAS and FADS

S. Pichini, F. Vagnarelli, S. Pedori, L. Ambrosetti, R. Spoletini, R. DiGiovannandrea , R. Pacifici , P. Zuccaro

There are no Italian statistics on ethanol consumption during pregnancy. Usually, gestational drinking habit is investigated by generic questions included in the maternal interviews at prenatal visits. It is also probable that eventual fetal ethanol syndromes and fetal ethanol spectrum disorders are under diagnosed by physicians. To evaluate neonatologists awareness of gestational drinking patterns and their experience, knowledge and confidence with respect to the diagnosis of FAS and FADS, a multiple choice anonymous questionnaire was e-mailed to neonatologists registered in the mailing list of Society of Italian Neonatologists.

Preliminary results on 43 completed questionnaires are currently available. With respect to the epidemiology of the problem, around half of the respondents considered that the %pregnant women consuming ethanol in any time, daily or problematically during pregnancy is unknown since no systematic study has been carried out in Italy up to now. Only 50% responders declared that they ask pregnant women information on ethanol consumption during prenatal visit and report in hospital medical records. Pregnant women at risk of problematic ethanol consumption were disclosed by their previous clinical history (45% responders) or by measuring a biomarker, which in the majority of cases was serum gamma glutamyl trans peptidase. Conversely, not a single respondent could list a neonatal biomarker of prenatal exposure to ethanol and even if 95% neonatologist of this survey declared that FAS and FADS are identifiable syndromes, they believe that both are underdiagnosed and 72% responders admitted not to feel confident about diagnosing FAS and FADS.

## FASD in Sweden

Katarina Wittgard

It is estimated that 385 000 children in Sweden live in families where one or both parents are drinking unhealthy amounts of alcohol. One target area for the EU's alcohol strategy is how we can protect children, young people and unborn children from the harm caused by alcohol. Although many positive forces are working for this target there is not much focus on the children who actually are injured, those with FASD.

The FAS-association has been established in Sweden for ten years to support families whose children have alcohol related birth defects. The association is creating networks and disseminates information to the public as well as working towards politicians and other decision makers.

There is an ongoing work in a clinic western Sweden to build a national team for examining and diagnosing children with alcohol-related birth defects under the leadership of Dr. Magnus Landgren.

## What is happening in Germany?

Veerle Moubax

The official number for the prevalence of FASD in Germany is 10.000 births per year of which 4.000 newborns are diagnosed with full FAS. Warning labels on alcoholic beverages are not mandatory. Public awareness about FASD is on the rise because year round coverage in the mass media. In April of this year one major national campaign against alcohol consumption during pregnancy was started in Berlin by the Center for People Born With Damages Resulting from Alcohol.

There are 2 major diagnostic centers: one in Berlin and one in Münster. Major efforts are made by these centers to increase knowledge about FASD and train other teams in diagnostic work. Goal is a network of diagnostic centers spread all over Germany. In view of this goal, FASworld organizes its yearly conference on FASD each year in a different federal state.

Recommendations for therapy now are more based on brain elasticity, addressing sensory issues, problems with attachment and coping with traumatic experiences. At this time, we have 2 rehabilitation centers, we feel comfortable with, sending children with FASD to. Nevertheless, finding respite possibilities for overwhelmed parents is still an ongoing endeavour. There are 2 homes for adults with disabilities, one in Berlin, one near Münster, successfully taking on adults with FASD.

FASworld Germany is a national based support group, that provides a 24/7 support group online, 17 regional support groups and a yearly caregiver training with children's program. We raise awareness through publications, trainings and our yearly conference on FASD.

## France: FASD prevention is a priority

Denis Lamblin

In 2006 the French government decided to tackle the problem of FASD prevention and to make it a public health priority. Four new laws were approved which aim at prevention during pregnancies. These French Public Health Laws have provisions for information in schools, the training of health professionals, public awareness campaign through bottle labeling, and sensitization campaigns on the dangers of alcohol during pregnancy. In 2007 following a pilot experiment in the Reunion Islands, the French Health Ministry requested a mission to monitor how FASD prevention is organized in 9 French areas. From these observations, we have been able to highlight the factors supporting and hindering prevention. A set of recommendations has been forwarded to the National Health Director to better support FASD prevention in France. In 2008 FASD makes demands on different medical specialties: perinatology, addiction, psychiatry, pediatrics ...), but also the social, medico-social, legal system and the education ... The synergy between these different skills seems to be the key of FASD prevention.

3D facial analysis in fetal alcohol syndrome

Peter Hammond

Preliminary data from a longitudinal study of alcohol-exposed pregnancies in Ukraine

Christina Chambers, Lyubov Yevtushok, Natalya Zymak, Svetlana Onishenko, Carl Keen, Jan Uriu-Adams, Andrew Hull, Wladimir Wertelecki, Kenneth Jones, and the Collaborative Initiative on Fetal Alcohol Spectrum Disorders

Infants of women who consume alcohol in pregnancy are at risk for Fetal Alcohol Spectrum Disorders (FASD), which are characterized by a specific pattern of structural abnormalities, growth deficiency, and neurobehavioral impairment. Challenges in identification, early intervention and prevention of FASD are many, and include difficulty in diagnosing affected infants leading to missed opportunities for early intervention. Although maternal alcohol exposure is necessary for the induction of FASD, not all similarly exposed infants are affected. This suggests that other factors, such as maternal nutritional status, may play a role in susceptibility. In addition, recent animal studies have suggested that supplementation with a B vitamin, choline, may represent a promising treatment for some of the neurobehavioral impairments associated with FASD.

In an ongoing longitudinal study in selected regions of Ukraine, we have screened over four thousand pregnant women in their first or second trimesters for current and early pregnancy alcohol consumption.

From this group, we have recruited pregnant women who report moderate to heavy alcohol consumption and minimally exposed comparison women. To test the feasibility of improving early diagnosis, repeated 2D prenatal ultrasound measurements of brain growth are collected, and local geneticists and pediatricians perform targeted newborn physical exams that are subsequently validated by an expert diagnostician. In addition, local clinicians have been trained to administer two modes of neurobehavioral testing at 6 and 12 months of age.

To test hypotheses related to nutrition, as part of a randomized clinical trial (RCT), women in the sample are randomized to receiving a prenatal vitamin/mineral supplement with or without additional choline, or to receive standard of care.

Maternal plasma samples collected at enrollment and again in the third-trimester are analyzed for minerals, methyl-donor nutrients, vitamins, and several indices of oxidative stress and inflammation. Preliminary data analyses suggest that specific prenatal ultrasound measures are both correlated with alcohol exposure and are predictive of facial features of FASD.

Preliminary data also suggest that local clinicians can be trained to accurately diagnose FASD. Furthermore, selected measures of maternal nutritional status at baseline are associated with greater quantities of reported maternal alcohol consumption.

Results of the RCT await accumulation of the full sample size.

## Physical phenotype and cognitive deficit in prenatal exposure to alcohol (PEA) and the Fetal Alcohol Syndrome (FAS)

Miguel Del Campo, Sarah Mattson, Ed Riley, Christina Chambers, Kenneth L. Jones

**Objective:** To determine whether there are associations and correlations between the presence and severity of the physical features characteristic of FAS and the degree of cognitive impairment. This could result in a potential use of the physical phenotype as markers for "prediction" of IQ.

**Methodology:**

**Design:** This is a retrospective study ascertaining 61 patients with high prenatal alcohol exposure that have consulted a reference clinic for FAS during the years 1995-1999.

**Setting:** The study was performed at the Dysmorphology Unit and the California Teratogen Information Service of the University of California in San Diego and the Department of Psychology, San Diego State University.

**Patients:** Sixty one patients were included in this study, all having had prenatal alcohol exposure (PEA) greater than 5 drinks per week, as well as complete physical dysmorphology exams and neuropsychological evaluations.

**Interventions:** Standardized physical dysmorphology examination and neuropsychological testing including age-appropriate Weschler scales IQ testing.

**Outcome measures:** Outcome measures included FSIQ and its verbal (VIQ) and performance (PIQ) components. Statistical methods included calculation of the mean and standard deviation for each variable representing the physical features of FAS. For qualitative variables, IQs were compared using, Kruskal-Wallis or Mann-Whitney U test. For quantitative variables correlation studies with IQ were performed using Pearson correlation coefficient. Multivariate analysis included multiple linear regression studies and regression tree models. Sensitivity and specificity were calculated for each variable to determine its impact on "prediction" of IQ.

**Results:** Variables that showed statistically significant associations with lower IQ were: ptosis, smooth philtrum and linear upper lip, abnormal hand creases and "the hockey stick" crease. Variables that showed statistically significant correlations with IQ variation were: height, head circumference, upper lip and philtrum smoothness scores, as well as the number of these physical diagnostic criteria. Multiple linear regression analysis identified head circumference and the hockey stick crease as the variables with significant multivariate correlation with IQ variation. Regression trees allowed stratification of the variables as potential predictors of cognitive outcome. A "predictive score" for the physical examination was proposed.

**Conclusions:** The presence and severity of the physical features of FAS in patients with PEA is associated with the severity of the cognitive deficit in a retrospectively assessed population with high alcohol exposure. Microcephaly and the hockey stick crease can be considered higher impact markers of a lower IQ; postnatal growth retardation, abnormal palmar creases, and smooth philtrum and vermilion boarder of the upper lip can be considered lower impact markers of cognitive impairment. The remaining findings of the physical exam, some of which are important FAS diagnostic criteria, are not significant markers of cognitive outcome. A score for FAS is proposed according to this study that could be used to predict outcome in children with PEA and physical features characteristic of FAS. Several other studies conducted within the frame of the International consortium for FASD (NIAAA-NIH), in Finland, Russia, South Africa, support the correlation among the physical features and the severity of the cognitive impairment. A review of these studies will be performed and speculation on whether the physical exam in newborns and infants can predict cognitive outcome will be made. Counseling of the families regarding prognosis and the need for early intervention and therapies can benefit from the conclusions of a precise physical exam.

## Children with Fetal Alcohol Spectrum Disorder show atypical fMRI activation of the hippocampus on memory tasks

Joanne Rovet, E. Sheard, S. Wheeler, J. Skocic

Prenatal alcohol exposure leads to impaired associative memory ability. In our work, adolescents with fetal alcohol spectrum disorder (FASD) show structural hippocampal abnormalities that predict their poorer associative memory performance. In addition, recent functional magnetic resonance imaging (fMRI) evidence using a passive viewing paradigm reports children with FASD are less likely than controls to activate the hippocampus on a verbal paired associates paradigm. The present study attempted to extend these findings using an event-related fMRI design and both verbal and visual memory tasks.

**Methods:** 19 10-14 year olds with FASD and 21 typically developing controls received two same-day scanning sessions. Before each, they learned a series of novel word pairs or picture locations and during scanning, were assessed for stimulus recognition. The verbal associates paradigm required them to form sentences during training by linking novel word pairs and then in the scanner, distinguish old from new word pairs. The object-place task involved viewing pairs of objects in different grid locations and then during scanning, indicating whether pairings or object locations were new or old.

**Results:** On the verbal task, controls activated both hippocampi, whereas FASD activated only the left hippocampus. On the object-place task, controls activated the left hippocampus in the objects condition and right hippocampus in the locations condition, whereas FASD activated right hippocampus in the objects condition and neither hippocampus in the locations condition.

**Conclusions:** Children with FASD recruit different neural resources than non-exposed controls in order to successfully remember newly learned information, thus signifying altered hippocampal function.



Assessment of prenatal exposure to ethanol by meconium toxicology: results of an Italian multicentric study

Simona Pichini, L. Morini, F. Vagnarelli, P. Biban, G. Rapisardi, M.R. Elicio, F. Raimondi, M. Bisceglia, E. Marchei

The prevalence of prenatal exposure to ethanol in five Italian towns was estimated by neonatal meconium testing of seven fatty acid ethyl esters (FAEEs: palmitic, palmitoleic, stearic, oleic, linoleic, linolenic and arachidonic esters) and ethylglucuronide (EtG). Indeed, both meconium FAEEs and EtG have been established as reliable, direct biological markers for establishing in utero exposure to ethanol. A total of 336 meconium samples were obtained from neonatal wards of five public hospitals: Verona in the north-east, Reggio Emilia in the middle-east, Florence in the centre, Naples in the south and Crotona in the south-west of the peninsula. Meconium biomarkers were measured with a liquid-chromatography tandem mass spectrometry methodology and the results categorized using the internationally established cut-off of 2 nmol/ g total amount of seven FAEEs and 2 nmol/g EtG, to differentiate heavy maternal ethanol consumption during pregnancy from occasional or no use at all. On the basis of the above reported cut-off, all the samples from Verona, Naples and Crotona showed biomarkers values under the above-reported cut-offs, while 5% samples from Florence and 10% samples from Reggio Emilia presented values above those cut-offs. Positivity to neonatal biomarkers of exposure appeared to be related to socioeconomic and ethnic characteristics. The accurate assessment of fetal exposure to ethanol, through the objective measurement of biomarkers in meconium can provide the basis for appropriate treatment and clinical and neurological follow-up of exposed newborns. This is particularly important in case of fetal alcohol spectrum disorders (FASDs) since up to now no epidemiological population-based study has examined, in terms of relative risk, the association between prevalence of FASDs and gestational alcohol exposure.

The Fetal Alcohol Syndrome Questionnaire (FASQ)

Reinhold Feldmann, H. Scheffner

**Objective.** Diagnosis in Fetal Alcohol Syndrome (FAS) still is insufficient and inadequate. Diagnostic criteria based on physical, particularly facial features like a small upper lip or small palpebral fissures fall far short to identify the FAS. Symptoms in FAS are predominantly not somatic but behavioural and emotional.

**Methods.** A questionnaire including 38 items presenting social, behavioural and emotional problems of children and adolescents was administered to parents of children and adolescents with FAS. Additionally the questionnaire was answered by parents of children with mistakable diagnoses (ADHD, Autism, Attachment Deficits).

**Results.** In the questionnaire, the total score of children and adolescents with FAS was higher than the total scores of children with other diagnoses. In a discriminant analysis the questionnaire classified 92% of the patients correctly according to their diagnose.

**Discussion.** The Fetal Alcohol Syndrome Questionnaire (FASQ) is a new additional tool not only for a professional differential diagnosis. The FASQ, moreover, allows to diagnose those three in four FAS patients who show no facial features at all.

## Socio-emotional development of children with FASD in long-term foster family care

a qualitative study in Finland

Anne Maarit Koponen, M. Kalland, I. Autti-Rämö, R. Laamanen, S. Suominen

**Aim:** To study the socio-emotional development of children with FASD (n=34, aged 0-15 years) in long-term foster family care.

**Methods:** A theme analysis on the data gathered from foster parents by questionnaires and interviews. In addition, information given by social workers was utilized. Children taken into custody at birth were compared with children, who had lived their first years of life with their biological parents.

**Results:** Compared with children taken into custody at birth, children who had lived with their biological parents had faced more traumatic experiences, had more placements and were placed at an older age into long-term foster family care. They were reported to have more socio-emotional problems and to be more difficult to foster. In both groups children had somatic and neuropsychological disabilities caused by prenatal alcohol exposure but in the second group neuropsychological problems, especially concentration and hyperactivity problems, were more severe. In addition, children who had lived with their biological parents showed multiple and serious behaviour and attachment problems and developmental delays in the beginning and during the placement. These problems were difficult to cure even though family care improved the development of all children in the study. In some cases meetings with biological parents after placement caused fear and insecurity for children and increased their behaviour problems.

**Conclusion:** Traumatic experiences in the first years of life during the rapid brain development form a major risk for the later development of children with FASD.

## Team Haga: cross-disciplinary specialist care for substance-abusing pregnant women and their infants in Gothenburg, Sweden

Joy Ellis, Antonia Reuter

Sweden's comprehensive, free-of-charge antenatal and paediatric health care services have almost 100% attendance and high credibility among women and families. Local antenatal care routines in western Sweden now entail a first visit to a midwife within one week after positive pregnancy test and very early AUDIT screening and narcotics/nicotine/medication counselling for all pregnant women. Since 2007, Team Haga serves Greater Gothenburg's substance-abusing pregnant women and their infants with specialist antenatal and paediatric care.

**Goals:** protect the fetus from substance-abuse effects, support women to stop abuse and to stay substance-free after delivery.

**Team members:** midwives, paediatric nurses, social worker, psychiatric nurse, gynaecologist, paediatrician, psychiatrist, assistant nurse.

Women are referred by antenatal care centres, substance abuse facilities, social services or the criminal justice system and some come on their own initiative. During pregnancy, women see midwives weekly and most are tested for narcotics/alcohol regularly. Team conferences determine individualised care and support for each woman and follow-up for infants/women. Extensive collaboration with social services, psychiatry and the paediatric health care system is essential. Long-term follow-up is often required.

**Challenges:** psychiatric morbidity complicates many cases; no designated resources for care/support of fathers-to-be (majority are substance abusers); varying knowledge of perinatal substance abuse aspects among social workers; some substance-abusers are unmotivated to attend Haga.

**Results:** Most of Team Haga's patients stay substance-free during pregnancy, and no cases of FASD or other serious neonatal effects of substances have been diagnosed so far.

## THURSDAY PARALLEL SESSION A

### Continuous care for addicted pregnant women and their children

Ab Aldriks

Since the end of 2007 BoumanGGZ and the GGD have a program in the region of Rotterdam to follow and treat addicted women who are pregnant or want to become pregnant. The aim of the program is to obtain abstinence during the pregnancy, to support the women to prepare them for the coming parenthood, and to protect the unborn child for the negative effects from the addiction and the unhealthy lifestyle of the mother. After the child's birth the mother and child will be followed for at least one year by the nurses of the program and by the pediatrician. If necessary the child can be placed under custody directly after birth or later during follow-up. Women can participate on voluntary basis, but the judge has the possibility to oblige women to enter the program.

In the session we will present the details of the program, divided into women addicted to alcohol or drugs. We will present the results of the program, such as number of women entered in the program divided into voluntary and obliged, co-morbid psychopathology of the women, number of abortions and births and number of children who have been placed out of the home, etc.

### Project "Kambio Marcia - In attesa, cambia": A Research and Prevention project to raise awareness on the FASD issue in the area of the Local Health Unit 9 Treviso, Veneto Region

Stefania Bazzo, P. Riscica, G. Moino, T. Codenotti, F. Marini, G. Battistella, Domenis L. Czerwinsky

The project, started in 2008 and still ongoing, is a team work of researchers and health professionals working at the University of Trieste and at the Local Health Unit in Treviso. The main purpose of the project is reducing the harm done by alcohol consumption during pregnancy and breastfeeding, even at low doses. It comprises two main areas of interest:

1. a preparatory research area investigating both attitudes of health professionals in regards to alcohol use and alcohol consumption by women in their fertile period, during pregnancy and breastfeeding. In this area, pilot education interventions are also performed targeting this population group;
2. an information-education area aiming at fostering the involvement of the whole community in the prevention of alcohol related risks and harms during pregnancy and breastfeeding, for the protection of the unborn and born children.

The entire project is designed and implemented on the basis of two important principles:

- Prevention and awareness interventions must be anticipated by preliminary investigations on the extent of the problem and on the level of knowledge on FASD, as well as on the related opinions and attitudes of people living and working in a specific area of intervention;
- Prevention on FASD includes not only short-term actions targeting pregnant women, but also actions for the general population living in the community, particularly health professionals, pregnant women' partners/family members, and long-term actions targeting young people, which represent the future parents.

#### Research area

Four population groups have been included:

1. Health professionals working in the field of pregnancy and in children issues
2. Pregnant women
3. Adolescents aged 14-15
4. 20-year old young people

The general aim of each of the four surveys is to identify opinions, attitudes and behaviours related to alcohol consumption during pregnancy and to FASD. The results will allow the identification of key issues to be taken into consideration when planning FASD prevention actions in the community.

#### Information-education area

Actions in this area include:

- establishing a network of public and private institutions/organizations which can be involved in the activities at different levels;
- designing a social marketing campaign of the issue of FASD prevention aiming at raising awareness of the local community
- creation of information materials
- dissemination of prevention messages
- experimental education intervention targeting women during pregnancy and breastfeeding
- evaluation of the results

## FASD Children and their families: therapeutic dilemmas

Malgorzata Klecka, Malgorzata Janas-Kozik

Children with disorders caused by prenatal exposure to the alcohol present variety of symptoms showing dysfunctions in different developmental areas: motor, sensory and psychological. Those disabilities have direct impact on emotional functioning FASD children.

FASD children live in a specific condition so called „sensory deprivation“ showing extreme need for the stimuli for their senses. In many cases strange behaviors of children are the form of auto stimulation. Most of FASD children in Poland live in foster homes and adoptive families. Lack of understanding for FASD behaviors result often with the rejection of a child. To help those families living with FASD children we develop FAStryga program („fastryga“ in English means „baste“, „connect“).

The basis of the diagnostic process which goal is to establish therapy proposal for the family in Fastryga program is:

1. Detailed medical, developmental and life history of a child.
2. Neurodevelopmental profile (for example: sensory and motor testing, attachment style assessment)
3. Metabolic functions evaluation.
4. Assesment of psychological condition of the whole family (biological, foster or adoptive) and support.

Many of our patients have a tragic life history: were abandoned, rejected, abused, found in plastic bags in a garbage, experienced that the world around them is cruel. Anyway they survived, some of them found support in new families or in different kind of institutions. Living with FASD children is not easy for many people. We try to help them to understand what FASD really is and develop therapeutic tools to make theirs lives happy. We want to share with you our experience and present some FASD children histories and our efforts to help them.

## Reaching women of child-bearing age: facilitating a best practice FASD prevention media campaign

Kathleen Tavenner Mitchell

This workshop will provide an overview of a successful FASD prevention media campaign that targeted women of child bearing age that resided in Washington, D.C., U.S.A. (NIAAA-NOFAS, 2004). Participants will receive an overview of the steps used to develop the campaign. A social marketing framework model guided the process which included identifying the target market, testing the messages and materials, identifying media outlets, pretesting and assessing effectiveness of the campaign.

## Tools for a structural approach to alcohol use and abuse during pregnancy

Rianca den Ouden, M. Postel, J.L. Thijs

In the past years, the message that drinking alcohol during pregnancy is not good for your baby has become more and more generally accepted. Tactus AddictionTreatment and the FAS-Foundation made efforts to provide good information for women who are pregnant or try to become pregnant, and also for midwives and gynecologists, in line with the opinion of the WHO.

But what if the answer to the question "Do you drink alcohol?" is "Yes, I do" and we have to deal with mothers who can not or will not stop drinking during pregnancy? What is the best way to implement early intervention methods, treatment and even juridical interventions?

Tactus developed a prevention program for professionals that provides tools for a structural approach to alcohol use and abuse during pregnancy. The intervention spectrum of Mrazek and Haggerty (1994) was used as a guide for illustrating the available outreaching methods for prevention and care. Information and results from the Tactus study 'Pregnancy and alcohol' (2007) illustrated the need for a outreaching approach. 36% of the mothers does not get any information about alcohol and pregnancy during her pregnancy and 25% of the women said the information was not sufficient.

From training courses for professional workers to appropriate intervention techniques such as outreaching care and motivational interviewing and special projects for Children of substance Misusing Parents, all of the appropriate aspects in the methodical assistance of pregnant moms will be pointed out. Tactus thinks the interests of the unborn child can be served better if there's also proper care for their pregnant mothers who struggle with alcohol problems.

## Alcohol-related harm and under-reporting of Fetal Alcohol Spectrum Disorders

Michela Morleo, Kerry Woolfall

**Background:** Despite an escalation of alcohol related harm in the UK, current intelligence surrounding Fetal Alcohol Spectrum Disorders (FASD) and related disorders are limited. It is only by understanding prevalence and characteristics of at-risk groups that effective services and interventions can be developed. The study used Hospital Episode Statistics to estimate prevalence and explore whether known geographical patterns of alcohol related harm are reflected in the reporting of FASD and related disorders in England.

**Methods:** Retrospective analysis of hospital admissions data (1 April 2002 to 31 March 2008)

**Sample:** 949 patients admitted with FASD-related conditions: O35.4, maternal care for (suspected) damage to fetus from alcohol; P04.3, fetus and newborn affected by maternal use of alcohol; and Q86.0, fetal alcohol syndrome (dysmorphic). 322,161 women admitted due to alcohol-related conditions.

**Results:** The number of fetal alcohol syndrome admissions has increased significantly over time (from 126 in 2002/03 to 293 in 2007/08;  $p < 0.001$ ); however no such change was identified in admissions for fetus and newborns affected by maternal use of alcohol or damage to the fetus from alcohol. Only for fetal alcohol syndrome was a statistically significant variation identified in regional rates ( $p < 0.001$ ), with the North West having the highest level of harm. However, region of residence was not recorded for 40% of cases for fetus and newborn affected by maternal use of alcohol. Established regional rates of admission for alcohol-related conditions in women aged 15-44 years old were not associated with admission rates for FAS-related conditions.

**Conclusions:** Geographical variations of alcohol related harm were not reflected in the prevalence of FASD-related conditions, suggesting under-reporting. With incomplete datasets, intelligence systems are severely limited which hampers efforts to develop targeted interventions. In order to tackle this, improvements to intelligence systems, practitioner awareness and screening are essential.

Autism and autism-like features in people diagnosed with FASD

Raja Mukherjee

**Introduction**

The relationship between FASD and other neurodevelopmental disorders continues to be explored. Whilst setting up a national clinic it was decided to look at the relationship between FASD and Autism using a behavioural phenotype approach to FASD.

**Methods**

21 Consecutive cases attending a national FASD service were assessed using the 4 digit code for FASD and then also other standard measures for neurodevelopmental outcomes including Autism. The data was also compared to a nested case control group of people who were part of a general neurodevelopmental clinic run on the same principles prior to the clinic becoming purely a FASD clinic. Data was entered and analysed using SPSS version 16.

**Results**

76% of the group diagnosed with FASD also met diagnostic criteria using the gold standard methods for childhood Autism. Further the type of ASD presentation was not the classic Autism seen in terms of social functioning. Differences between groups became evident during comparison in the nested case control series.

**Discussion**

These results suggest in a clinic population there is evidence for prenatal alcohol being strongly associated with ASD presentations. The clinic is limited by referral and severity. These results warrant further exploration of this area of work.

Fetal Alcohol Spectrum Disorders in Italy: clinical delineation of Italian children

Primavera Spagnolo, M. Ceccanti

**Introduction:** In Italy, drinking habits are distinctive, since in rural areas daily consumption of "moderate" or slightly increased amounts of wine, always with meals, is widespread. Thus, this pattern allowed for an opportunity to evaluate the effects of daily "moderate" drinking on the FASD prevalence.

**Aims:** Our purpose is to report on the clinical features of one of the largest cohorts of clinically diagnosed children with FASD in Europe, thereby delineating the clinical spectrum of FASD in Italian children.

**Methods:** Primary schools in the Lazio region were randomly selected and recruited. Five hundred forty-three children received parental permission to participate in a 2-tiered, active case ascertainment screening process. Dysmorphology assessment and psychological development and behavior evaluation were used to determine potential assignment into a FASD category, according to revised IOM criteria (Hoyme et al., 2005).

**Results:** As expected, the FASD group scoring lower in height, weight, and head circumference. Four children in the FASD group (18%) were assigned a diagnosis of FAS; 17 (77%) of partial fetal alcohol syndrome (PFAS); and 1 of ARND. Fifty percent of children with FAS and 36% of those with PFAS exhibited all 3 cardinal facial features. The overall dysmorphology score was significantly different for the FASD group (12.5) and controls (3.3).

**Conclusion:** Children with FASD in Italy are similar to those with FASD elsewhere in the world. However, the overall dysmorphology score, although was elevated among Italian children with FASD, differs significantly from dysmorphology scores estimated in other racial and ethnic groups.

## Assessment of prenatal exposure to ethanol by meconium toxicology: results from a survey in Barcelona, Spain

Oscar Garcia-Algar, S. Pichini, L. Morini, X. Joya, B. Friguls, S. Martinez, O. Vall

The prevalence of prenatal exposure to ethanol in three subsequent cohorts of infants born in Hospital del Mar, Barcelona, Spain was estimated by neonatal meconium testing of seven fatty acid ethyl esters (FAEEs: palmitic, palmitoleic, stearic, oleic, linoleic, linolenic and arachidonic esters) and ethylglucuronide (EtG). Indeed, both meconium FAEEs and EtG have been established as reliable, direct biological markers for establishing in utero exposure to ethanol. A total of 276 meconium samples were obtained in three different periods between 2008 and 2009. Meconium biomarkers were measured with a liquid-chromatography tandem mass spectrometry methodology and the results categorized using the internationally established cut-off of 2 nmol/g total amount of seven FAEEs and 2 nmol/g EtG, to differentiate heavy maternal ethanol consumption during pregnancy from occasional or no use at all. On the basis of the above reported cut-off, the 83 and 119 samples collected in 2008 showed an alarming prevalence of 45% fetal exposure to maternal ethanol. Conversely in the 74 samples collected in 2009, prevalence decreased around 20%. It has to be noticed that the studied cohorts included mother-newborn pairs from Hospital del Mar, located in an urban area with low socioeconomic status and a high percentage (more than 40%) of immigrants. Positivity to neonatal biomarkers of exposure was indeed related to socioeconomic and ethnic characteristics. This study, which highlights a high prevalence of ethanol consumption during pregnancy by a low socio economic status cohort, may serve as an eye opener for Europeans, that gestational alcohol exposure is not endemic only in areas outside Europe.

## Canadian neurobehavioural screening tool for Fetal Alcohol Spectrum Disorders

Kelly Nash, Joanne Rovet, Gideon Koren

**Background:** In most cases of Fetal Alcohol Spectrum Disorder (FASD), the pathognomonic facial features are absent making diagnosis challenging. Furthermore, because FASD is often comorbid with Attention Deficit Hyperactivity Disorder (ADHD) and Oppositional Defiant/Conduct Disorder (ODD/CD), children with FASD may be improperly diagnosed and receive poorly tailored treatment. Since access to psychological testing is typically limited in remote areas, other diagnostic methods are needed.

**Objectives:** To determine if a characteristic behavioural phenotype distinguishes children with FASD from typically developing children, children with ADHD, children with ODD/CD, and use this information to create a screening tool for FASD diagnosis. **Methods:** Parents and caregivers completed the Child Behavior Checklist (CBCL), a standardized tool for evaluating children's behavioural problems. Data from 56 children with FASD, 50 children with ADHD, 60 children with ODD/CD, and 53 typically developing children were analyzed. Receiver Operating Characteristic (ROC) curve analyses of the 118 CBCL items determined sensitivity and specificity of different item combinations.

**Results:** Items reflecting hyperactivity, inattention, lying and cheating, lack of guilt, and disobedience significantly differentiated children with FASD from controls., Items reflecting acts young, cruelty, no guilt, lying or cheating, steals from home, and steals outside differentiated FASD and ADHD. Acts young differentiated FASD from ODD/CD. These items were used to construct a FASD screening tool, having strong sensitivity and specificity.

**Conclusions:** Our findings identifying the behavioural characteristics differentiating children with FASD from typically developing children children with ADHD, and ODD/CD have the potential for development of an empirically derived screening tool for FASD.

## Multidisciplinary team approach recognizes more cases of FASD

Leif Svensson, Magnus Landgren, Kerstin Strömblad

We performed a multidisciplinary study on children adopted to Sweden from East European countries with a team representing neuropediatrics, psychology and ophthalmology (Landgren et al. Pediatrics 2010). Among the 71 children FASD was found in 52%, FAS in 30%, attention deficit/hyperactivity disorder in 51%, mental retardation in 23% and ophthalmological pathology in 78%. Based on the experience from this study the same multidisciplinary approach using the same methods is now being used for children with a suspicion of FASD referred to the Department of Pediatrics, Developmental Neurology, Mariestad, Skaraborg Hospital, Skövde, a center for diagnosing children with neurodevelopmental disorders. Our experience is that since it became known that there is a possibility to refer suspected cases of FASD from different parts of Sweden to the unit, more children with FASD are being recognized and also that the number of referrals is increasing. We therefore recommend that a multidisciplinary team representing neuropediatrics, psychology and ophthalmology collaborate in diagnosing children with FASD in order to give the children an appropriate educational and social help and support.

## THURSDAY PARALLEL SESSION C

## The use of hair FAEE analysis to identify mothers at risk of having children with FASD

Netta Fulga, Katarina Aleksa, Joey Gareri, Gideon Koren

FASD is the most prevalent cause of neurocognitive handicap among North American children. A serious challenge in diagnosis is the need to document excessive maternal drinking during pregnancy. Maternal and paternal alcohol abuse in the perinatal period affect the likelihood of fetal exposure to alcohol and hence the occurrence of FASD.

The objective of the study was to document the use of the fatty acid ethyl esters (FAEE) test in hair, as a biomarker of excessive alcohol use by parents in an at-risk population for FASD, and to quantify the prevalence of alcohol abuse in this population.

Hair samples of parents of at-risk children were submitted for FAEE analysis by Children's Aid Societies in Canada. FAEE was extracted from hair and analyzed by gas chromatography-mass spectrometry (GC-MS). Positive levels for excessive drinking were ascertained using a cut-off level of 0.5 ng/mg.

Results showed that the rate of positive hair samples for excessive drinking was 33.3% (n = 324). The majority of samples (62%) had FAEE levels above the exclusion of strict abstinence (0.2 ng/mg) and 19% were highly positive (above 1.0 ng/mg). Among pregnant women, 18% tested positive and 39% had FAEE levels above 0.2 ng/mg.

The high rate of positive FAEE results demonstrates that the FAEE hair test corroborates the clinical suspicion of alcohol abuse in parents of children at-risk for FASD. Our results suggest that FAEE hair analysis may be a powerful tool in detecting heavy alcohol use in the perinatal period.



Early exposure to ethanol or red wine and long-lasting effects in aged mice. A study on nerve growth factor, brain derived neurotrophic factor, hepatocyte growth factor and vascular endothelial growth factor in a FASD mouse model

Marco Fiore, Rosanna Mancinelli, Mauro Ceccanti

Prenatal ethanol exposure produces severe changes in brain, liver and kidney throughout mechanisms involving growth factors. These molecules regulate survival, differentiation, maintenance and connectivity of brain, liver and kidney cells. Despite the abundant available data on the short and mid-lasting effects of ethanol intoxication only few data show the long-lasting damage induced by early ethanol administration. The aim of this study was to investigate changes in nerve growth factor (NGF), brain derived neurotrophic factor (BDNF), hepatocyte growth factor (HGF) and vascular endothelial growth factor (VEGF) in brain areas, liver and kidney in a FASD mouse model. 18-month-old male mice were exposed perinatally to ethanol at 11 vol.% or to red wine at same ethanol concentration. We found that ethanol per se elevated NGF, BDNF, HGF and VEGF measured by ELISA in brain limbic system areas. In the liver, early exposure to ethanol solution and red wine depleted BDNF and VEGF concentrations. In the kidney, red wine exposure only decreased VEGF. In conclusion the present study shows that, in aged mice, early administration of ethanol solution induced long-lasting damage at growth factor levels in frontal cortex, hippocampus, liver but not in kidney. Otherwise, in mice exposed to red wine significant changes were observed in the liver and kidney but not in the hippocampus and frontal cortex. The brain differences in ethanol-induced toxicity when ethanol is administered alone or in red wine may be related to compounds with antioxidant properties present in the red wine.

Structural and functional changes in the visual system related to ethanol abuse during pregnancy

Sheila Pons-Vásquez, K. Strömland, C. Galbis-Estrada, M.D. Santos-Agulló, O. Alvarez-Barrachina, M.D. Pinazo-Duran

**Purpose:** The eye is a sensitive marker of the adverse effects of alcohol and drugs. We have shown that methamphetamine, cocaine or alcohol are major teratogenics for the developing visual system. Herein we deal with studying the effects of pre- and postnatal ethanol exposure on the visual system in children and experimental rats.

**Methods:** Children with FAS were ophthalmologically examined to assess morphological-functional parameters (visual acuity, ocular fundus photographs and image analysing)(n=30). Juvenile wistar rats were fed a liquid diet containing ethanol (5%w/v;n=20;EG) or isocaloric carbohydrates (n=20;CG) during gestation and lactation. Their offspring was obtained at 21st gestational day, and the postnatal days 5, 10 and 15. Eyeballs and optic nerves were obtained and processed to morphological, morphometrical and immunohistochemical approaches. Data were statistically processed.

**Results:** Typical facial features in children were epicanthus, short palpebral fissures, indistinctive philtrum, short upper lip, and uni or bilateral blepharoptosis. Retinal fundus changes ranged from discrete to severe malformations, mainly the optic nerve hypoplasia and increased tortuosity of retinal vessels. More than half of the affected children had visual impairment, which was <0.2 in 12% of them. In rats, the eyeball, retinal and optic nerve size, ganglion cell and optic axons density were significantly lower in the EG than in the CG ( $p < 0,001$ ). Glial and myelin developmental markers were significantly reduced in the retina and optic nerve from the EG vs the CG.

**Conclusions:** Comparison of the results from the children and animals strongly suggests that similar teratogenic mechanisms are responsible for the alcohol damage in utero to the eyes and vision.

## Variations and accuracy of carbohydrate-deficient transferrin during pregnancy

Vincenza Bianchi, Alessandra Ivaldi, Alessia Raspagni, Carlo Arfini, Matteo Vidali

Contrasting data are available on the diagnostic accuracy of Carbohydrate-Deficient Transferrin (CDT) during pregnancy. These differences may depend in part on how CDT was evaluated and expressed. Here, we report on variations in CDT levels in pregnant women using an HPLC candidate reference method (Helander et al., CCLM 2007).

Alanine Aminotransferase (ALT), Aspartate Aminotransferase (AST), Gamma-Glutamyltransferase (GGT), Mean Corpuscular Volume (MCV), Serum Transferrin, urine and serum Ethyl glucuronide (EtG) and CDT% (% of disialotransferrin, cut-off 2.0%) were measured in 65 women, self-reporting as non-alcohol abusers, at different stages of normal pregnancy (gestational weeks: median 28, IQR 8.5-32.5).

AST, ALT, GGT and MCV were respectively 19 IU/L (IQR 16-23), 15 IU/L (IQR 12-21), 8 IU/L (IQR 5-11) and 86.5 fL (IQR 82.7-90.4). Recent alcohol consumption was excluded in all women by undetectable serum and urine EtG. CDT% and Transferrin were 1.4% (IQR 1.1-1.6%, min-max 0.5-2.0%) and 377 mg/dL (IQR 313-423, min-max 221-681). Transferrin was associated with CDT% ( $p < 0.001$ ) and gestational week ( $p < 0.001$ ). Interestingly, CDT% was highly correlated with gestational week ( $r = 0.75$ ,  $p < 0.001$ ), even after controlling for transferrin (partial correlation  $r = 0.64$ ,  $p < 0.001$ ). Significant differences in CDT% were also evident between women grouped for pregnancy trimester (I: 1.0%, 0.9-1.1; II: 1.3%, 1.2-1.4; III: 1.6%, 1.4-1.7; ANOVA  $p < 0.001$ ; Trend Analysis  $p < 0.001$ ). Three women had CDT% close to the cut-off (1.9, 2.0, 2.0).

CDT is independently associated with gestational week. The diagnostic accuracy of CDT for alcohol abuse may be limited in pregnant women and the effect of gestational week should be considered.

## Determination of fatty acid ethyl esters (FAEE) in meconium from 602 newborn for detection of maternal alcohol abuse

Pascal Burger, P.A. Fasching, F. Pragst, U. Reulbach, M.W. Beckmann, J. Kornhuber, T.W. Goecke

**Objective:** With a new method for determination of fatty acid ethyl esters (FAEE) and ethyl glucuronide (EtG) in meconium we diagnosed alcohol abuse in the last months of pregnancy in the frame of a broader study of the University Clinic Erlangen.

**Material and Methods:** FAEE and EtG were determined in 602 samples of about 1g meconium in a maternal health evaluation study for detection of gestational alcohol consumption. For interpretation, the concentration sum of five analyzed esters CFAEE (via GC-MS) was evaluated using a cut-off of 500 ng/g for prenatal alcohol abuse. For EtG (via LC-MS-MS) the cut-off was 300ng/g.

**Results:** Although all participating mothers declared their alcohol consumption being of less than one unit per day, from the 602 meconium samples 43 had a CFAEE at least 500ng/g, between them 12 samples with CFAEE of at least 5000ng/g. 38 samples were positive (more than 300ng/g) for EtG. There were 33 cases both FAEE- and EtG-positive. 7.1% of the mothers in this sample were identified as alcohol abusers - at least during the last months of their pregnancies - by objective biochemical parameters of alcohol metabolism.

**Discussion:** Alcohol abuse during pregnancy is dramatically underreported - which is objectively proven in this sample as well. The damaging consequences of prenatal alcohol consumption, like FASD with all its facets (mental retardation, failures in organ development etc.) are widely known and undesired by society. When asked, most mothers answer according to social standards and negate alcohol consumption although there is a high number of actual users.

Ethical evaluation of a screening programme for alcohol abuse during pregnancy

Ilona Autti-Rämö

**Background:** Sensitive methods to screen for drinking during pregnancy have been under research. However, little has been discussed about the ethical criteria that have to be fulfilled prior a screening programme can be implemented.

**Method:** The criteria for a screening programme presented by Wilson and Jungner (WHO 1968) and by the Danish council of ethics have been compiled and used by the Working Group for Screening at the Ministry of Social welfare and Health in Finland to evaluate existing and proposed screening programmes. An eclectic approach to conduct an ethical analysis of a screening programme has been developed at the Finnish Office for Health Technology Assessment. The various ethical concerns on a screening programme for alcohol abuse during pregnancy were elicited using 1) the criteria for a screening programme and 2) a cross tabulation of stakeholders and situations with and without screening.

**Results:** During the evaluation several problematic issues were identified which will be presented in detail.

**Discussion:** Ethical evaluation is a continuous process that tries to understand the prevalent moral values and behavioural models of society. Each profession creates its own ethical rules and regulations that are the basis for their profession; these combine knowledge, experience, and commitment to ethically acceptable goals. For a screening programme the general criteria have to be fulfilled as well. With the help of an in-depth framework, it is possible to capture the wide consequences that implementing a new health technology has on individual citizens, the health care system and society.

Ethical aspects of coercive interventions in early pregnancy in order to prevent or reduce risks for FASD

J. Boonekamp, R. Berghmans, W. Dondorp, G. de Wert

Today most scientists agree that, of all substances taken during pregnancy, alcohol causes the most and most severe harm to the child. Given this knowledge, pregnant women should be counseled to abstain as much as possible from alcohol intake during pregnancy. But what if women are unable or unwilling to take their responsibility towards their future child and continue drinking? There is a growing consensus that society's responsibility to protect children from serious harm should not be regarded as starting only with the birth of the child. However, there is less agreement on the implications of this, also with regard to measures affecting pregnant women's autonomy and privacy. To what extent and under what conditions is it acceptable to use forms of pressure or coercion on pregnant women with the aim of protecting their future children? Answering this question requires a consideration of the effectiveness, proportionality and subsidiarity of those measures: do they work?; is the infringement of the woman's autonomy proportional to the harms that can thus be avoided?; is it clear that no less intrusive approaches are available? The (legal) view that coercive measures can be acceptable only after the fetus has reached viability is problematic in the light of the fact that serious damage will already be done in the early stages of pregnancy. We argue that where the health of the future child is clearly at stake, legal and ethical principles do not rule out taking effective measures of coercion already in the beginning of pregnancy.

## Illicit drug and alcohol use during pregnancy as a child protection issue -- multidisciplinary views

Liam Curran

This Irish study examined the views and explored the experiences of fourteen professionals who deliver services to pregnant women, some of whom use alcohol and illicit drugs during pregnancy. Ireland is unique within international jurisdictions due to the Constitutional protection it affords the unborn under Article 40.3.3 of the Constitution (Bunreacht na hEireann 1937). However, the unborn may suffer harm as a result of drug and alcohol habits during pregnancy in the form of FAS/FASD. The study sought professional views from three key areas of service delivery to these women, and posed the question; "Is parental consumption of drugs and alcohol in pregnancy a child protection concern for them as professionals?"

The study reviewed the relevant literature, looking at international developments in the field of drug and alcohol use/misuse during pregnancy. It looked at the issues of legislation, policy and procedure. It examined the practice of multidisciplinary interprofessional work in this emerging area of social care practice.

The study was undertaken by adopting qualitative techniques of semi-structured interviews with the professionals concerned.

The findings demonstrate that there is a significant level of concern among professionals engaged in the services studied. Concerns were expressed about the lack of clarity and procedure, the ad hoc service structures and the lack of clarity on the rights of the unborn.

The study makes seven key recommendations for future consideration and deliberation.

## FASD and adoption -- ethical issues

Miguel Del Campo

Among adopted children, particularly from Russia and other Eastern European countries, FASD is a frequent cause of mental retardation and physical features of FAS. However, the evidence of prenatal exposure to alcohol is rarely reflected in the medical reports shown to the future adoptive parents, and neurological problems and developmental delays are usually attributed to other causes such as perinatal asphyxia, intracranial hypertension, cerebral palsy, institutionalisation or others. Even in the face of a clear physical phenotype, and with the evidence of alcohol exposure, the risks are not clearly explained to the family and the firm diagnosis of FAS is almost always absent. In addition, private and governmental adoption agencies do not appear to be aware of this diagnosis. Even though risks to the health of the adopted child seem to be thoroughly explained regarding other diagnosis, FASD is rarely identified as a major health issue. Considering most of the other medical diagnoses are most of the time inaccurate and not based on any firm evidence, whereas FASD is not an identified risk, we believe parents are commonly unaware of the major risks to the health of the children they are going to adopt. Later, when the children clearly show problems that are not transient and go far beyond the consequences of institutionalisation, the families feel betrayed and manipulated, as they were not given the appropriate information.

There are several studies that identify a very high prevalence of FASD in Russian and Ukrainian Orphanages, and alcoholism is a well recognised problem among youth in some countries, and clearly related to unwanted pregnancies. Perinatal counseling for alcoholic women is mostly nonexistent or inefficient, and formal recognition of the potential consequences in the offspring is not made. The identification of severe development problems once in the adoptive families can lead to problems and dysfunction in the adoptive family, and occasionally maladjustment of the adoptive family that can lead to rejection of the child or other major problems.

We believe this is an issue that should be brought to the attention of the organisations involved in adoption of both the countries where the exposed children are born and those of the adoptive parents. FASD should be recognised as a major health issue for international adoption, and great efforts should be made to achieve accurate diagnoses and provide appropriate counseling to the families.

We are performing interviews to parents of children with FASD, in order to identify discrepancies among the medical records of the children and the real diagnoses causing their delays, as well as the feelings and consequences of this previously unrevealed cause of cognitive impairment for these families.

## Different perspectives on FASD and the legal system

Jessica Wagner

“Sure, I committed the crime. Can I go home now?” A behavior like this is not uncommon to people with fetal alcohol spectrum disorders (FASD). But it still leaves us – and not only the police officer – helpless in a way. People with FASD are suffering from many deficits including cognitive-behavioral deficits and neurodevelopmental deficits because of their massive brain damage.

Executive functioning – which is often used as a synonym for acting and planning – plays a major role with respect to questions of autonomy and responsibility. Deficits in acting and planning and a higher ‘suggestibility’ may lead people with FASD to a higher involvement in delinquency.

Therefore, it is very important to discuss FASD in the legal system.

Based on questions which arise from diagnosing and counseling people with FASD and their families various implications should be taken into consideration.

Different positions from three perspectives will be presented: neuropsychological/neuro-scientific approaches, philosophical-ethical questions, and juridical aspects. Definitions of guilt, responsibility, freedom of will and freedom of action will be discussed with regard to FASD. Additionally, case studies will be pointed out. Further consequences as well as the usefulness of European guidelines should be discussed. European court decisions should be collected for more analyses.

## THURSDAY PARALLEL SESSION E

### Intervention for prenatal alcohol use and the role of midwives

Nickie van der Wulp, W. van Dalen, C. Hoving, H. de Vries

In the Netherlands, it is estimated that 35% to 50% of the pregnant women continue to drink alcohol even when they know they are pregnant. How is it possible that so many pregnant women cause danger to their unborn child? Do they know how dangerous alcohol is for the foetus? Has anyone told them?

Dutch midwives assist over 75% of the pregnant women; for approximately 35% of the pregnant women, a midwife is the only medical person involved with the pregnancy. Therefore, midwives play an important role in communicating with pregnant women about health issues. The Royal Dutch Organization of Midwives (KNOV), the professional association of midwives representing 98% of the midwives, recommends women not to use alcohol during pregnancy. Do midwives pass on this advice to their clients?

STAP and the University of Maastricht develop an intervention to reduce alcohol use during pregnancy. Part of this project is a qualitative research using the I-Change Model (De Vries et al., 2003) in order to find out what advice midwives give to their clients about the use of alcohol. In this session, we present the set up of the intervention and the most important findings of the qualitative research. This research shows that midwives generally have the intention to advise their clients not to drink any alcohol, but this advice does not reach all of the clients. Lack of knowledge about the effects of alcohol during pregnancy appears to be the main reason for this.

## Do children from orphanages in Brazil and Eastern Europe differ in their frequency of FASD?

Layla Mirzaei, Liana Ventura, Carlos Brandt, Ana Elisabeth Moura, Keila Fontes, Bruna Ventura, Marcelino Bandim, Kerstin Strömmland

A study of children from orphanages in Eastern Europe [Landgren et al Pediatrics 2010] adopted to Sweden showed that 30 % had FAS, 52% FASD, 51% ADHD and 78% had ophthalmological findings.

In order to study the conditions among children staying in orphanages in South America we have started a project using similar methods as those for the East European children. A multidisciplinary team involving pediatrics, neuropsychiatry, psychology and ophthalmology examine children in an orphanage in Recife, Brazil. Information is being gathered on the family situation, use of alcohol and drugs and the reason for being placed in the orphanage.

Up till now, approximately one hundred children have been examined. The preliminary results show that most children were abandoned because of violence and abuse of alcohol and drugs of the parents, especially the mothers. Growth retardation including small head circumference, facial features typical for FAS, poor vision and strabismus have been found. Some children have cognitive and behavioral defects as ADHD, mental retardation and autism. A few cases of FAS have been detected.

When comparing the children from Eastern Europe and the preliminary data from Brazil, our impression is that the Brazilian children do not suffer from as severe physical and functional deficits, especially FAS, as those from Eastern Europe. However, it has to be taken in consideration that the adopted children came from several orphanages, while in Brazil only one orphanage is being studied.

## Knowledge of FASD in UK general public and healthcare practitioners

Raja Mukherjee

### Introduction

Despite FASD being the most common cause of developmental disability and with reported prevalence rates of 1-3 % it remains a hidden disorder and is underrecognised. In order to develop education strategies in the UK and to guide policy regarding diagnosis and management, it was considered important to establish a baseline level of knowledge of FASD in the UK.

### Methods

A Mixed methodology project was conducted using a mixture of quantitative questionnaires developed by the lead researcher, as well as a series of focus groups. A large sampling frame was developed across the country and with different professional and non professional groups to gauge the current understanding of FASD and Alcohol in the UK. Quantitative data was analysed using PAWS(SPSS) version 18 and qualitative data using NVivo.

### Results

The data is currently being collected and will be ready for dissemination by September 2010.

Reaching health professionals to improve identification,  
treatment, and prevention of FASD

Peggy Murray

Drinking and smoking behavior during pregnancy and  
association with health professionals recommendations

Daniela Fiorentino, Giovanna Coriale, Philip A. May, Mauro Ceccanti

Retrospective data about drinking and smoking habits of 977 mothers of first graders enrolled in an in-school prevalence study of FASD in Lazio Region (Italy) is presented. Data was gathered through a semi-structured interview regarding lifelong health, alcohol and tobacco use at present, during the three trimesters of the indexed pregnancy, before it, and health recommendations received by professionals.

The main results showed that 60% drank before pregnancy and 26% during. Tobacco was used by 37 % before and 12% during. While 70% quitted smoking once pregnant, a significant lower percentage stopped drinking (56%). Gynaecologists suggested not to drink to 25% of respondents and not to smoke to 37%, to moderate alcohol intake to 10% and to smoke less to 7%, while 65% and 56% of respondents did not receive any advises respectively regarding alcohol and tobacco. Among drinkers who were advised not to drink, 25% kept on drinking during pregnancy, while when advised to drink less a significant higher percentage (68%) kept on drinking. Similarly, among smokers, 29% kept on smoking once pregnant when advised not to smoke, compared to a significant higher number of women that kept on smoking when advised to reduce the number of cigarettes (76%).

These results suggest that, even if women quit smoking slightly more than drinking during pregnancy, in Italy information about alcohol and tobacco use is not often included among health recommendations, whereas simple advises showed to be effective in reducing both alcohol and tobacco use.

## The prevalence of the Fetal Alcohol Syndrome (FAS) in foster children

Philipp Nordhues, M. Weischenberg, Reinhold Feldmann

**Objective.** The prevalence of the Fetal Alcohol Syndrome (FAS) is still unknown. This holds true for a majority of European countries. FAS related prevalence data for a population are difficult to generate. Studies have to focus on children with a high risk of FAS. Our study was to identify the prevalence of FAS in foster children.

**Methods.** A questionnaire including 38 items presenting social, behavioural and emotional problems of children and adolescents (FASQ) was administered to the collectivity of foster parents in three regions of North West Germany: a rural region, a mixed region and a major city.

**Results.** More than 270 foster families answered to the FASQ. The response rate was 50% with 65% in the rural area and 44% in the city, resulting in data of 275 foster children. Total FASQ scores that indicate a FAS were reported in 19.5% of the children.

**Discussion.** The prevalence of FAS in foster children may indicate the total prevalence in children if we hypothesize that children of alcohol abusing mothers are taken out of their homes and live with a foster family.

## THURSDAY PARALLEL SESSION F

### Evaluation of the FAS "First Aid Box"

Hannah Schmidt, M. Fietzek, R. Feldmann

**Objective.** Daily living with a FAS child may be stressful and conflict laden. The typical social and emotional problems of children and adolescents with FAS require suitable answers from parents and siblings. The FAS patient is in need of daily instruction and support. Parents and siblings need adequate information to understand the shortcoming due to FAS they face in the affected family member.

**Methods.** A "First Aid Box" was designed including instructions for children (e.g. icons demonstrating sequences of action) and information for parents (e.g. addressing typical social and emotional situations that require an appropriate parental reaction). In a randomized, controlled cross over study the First Aid Box was administered to 72 families with a FAS child.

**Results.** Both the instructions for children and the information for parents helped to cope with daily life situations that are arduous due to the forgetfulness and mood changes of FAS patients.

**Discussion.** The First Aid Box is a valuable tool to support children with FAS and to ease life in families with FAS children. An online (download) version of the First Aid Box is in planning stage.



## FASD & Sleep: an epidemiological concept for international comparisons

Osman Ipsiroglu, J.E. Jan, C. Loock, J.P. Collet

Children with FASD are high-risk for developing sleep disturbances or sleep disorders. Clinical day or night time symptoms may not be clear enough to be recognized as sleep-related by parents or physicians and may remain unreported. Results of clinical assessments and research suggest that screening studies would be helpful in triaging patients for further clinical sleep assessments. In collaboration with parents and professionals, using qualitative interviews, we have developed a screening tool which helps to assess the significance of sleep challenges as well as the consequences of sleep deprivation on perceived daytime wellbeing. The main elements of the survey include the BEARS sleep screening algorithm (Owens 2003), Family Ecology Assessment (Lucyshyn 1997) and Quality of Life, assessed with a Likert scale. The survey is anonymized, but in order to organize the results by geographic location the first three digits of postal codes are requested. The information collected from the surveys in Canada will be used to design tailored sleep programs/services across the Provinces.

We are presenting our screening tool and study design in order to conduct an international epidemiological survey. This presentation is geared towards health researchers but open to other professionals and family members.

## Investigating the socioemotional profiles of children with Fetal Alcohol Spectrum Disorder and children with prenatal cocaine exposure

Sara Stevens, Kelly Nash, Rachel Greenbaum, Joanne Rovet

Ongoing work in our lab has shown significant deficits in socioemotional processing in children with FASD. However, we do not know if prenatal exposure to other teratogens contributes to similar deficits. The present study compared sociobehavioral characteristics of children with FASDs (mean age 9.8) versus prenatal cocaine exposure (PCE; mean age 10.7) relative to normal controls (NC; mean age 9.7). Parents and teachers completed CBCL, TRF, and SSRS questionnaires; children were assessed using Saltzman-Benaiah's (2007) Social Cognition task and MNTAP, a test of emotion processing. On the CBCL and TRF, impairments were reported in FASD relative to NC on Total and Externalizing Problems. Parents rated FASD as more impaired than PCE on Total, and PCE as more impaired than NC on Externalizing. On the SSRS, parents rated FASD lower in Social Skills and higher in Behavior Problems than PCE and NC, and PCE higher in Behavior Problems than NC. Teachers indicated lower Social Skills and higher Behavior Problems in FASD than NC, and higher Behavior Problems in PCE than NC. On Social Cognition, FASD performed more poorly than NC on False Beliefs and more poorly than NC and PCE on Display Rules. On MNTAP, FASD had poorer performance than NC on Affect Match and Prosody Congruence, and PCE performed more poorly than NC on Affect Match. These results show children with FASD differ from PCE in sociobehavioral functioning and emotion processing, with FASD being more severely affected. Overall, prenatal exposure to different teratogens contributes to unique patterns of sociobehavioral deficiency.

## Adaptive behavior in children and adolescents with FASD

Åse Fagerlund

### Objective:

Children and adolescents with Fetal Alcohol Spectrum Disorders (FASD) have been described with extensive adaptive problems in daily life. Difficulties comprise of communication, socialization and daily living skills important for an upcoming independent adult life. It remains unclear to what extent these difficulties might be explained by a generally lower IQ level and thus not specific to the FASD diagnosis. With the aim of delineating a specific profile for individuals with FASD it is important to compare them with IQ matched groups of children with other developmental diagnoses.

### Methods:

In the present study a group of children and adolescents with FASD (n=73, age range 8-20) was compared to an IQ matched contrast group of children with learning disorders (LD, n=30) and a normal control group (n=40) on a measure of adaptive behavior (Vineland Adaptive Behavior Scales, VABS). VABS is a well-known scale measuring adaptive behavior in communication, daily living skills and socialization.

### Results:

The results indicated that the FASD group fared significantly less well than both the LD and NC groups on adaptive behavior overall, both on an adaptive behavior composite score ( $p<0.0005$ ) as well as on subscales of communication ( $p<0.0005$ ), daily living skills ( $p<0.0005$ ) and socialization ( $p<0.0005$ ). (The FASD group received the lowest scores, followed by the LD and then the NC groups.)

### Conclusion:

Despite matched IQ levels, children with FASD show greater difficulties overall on measures of adaptive behavior than children with learning disorders. In order to develop appropriate support and intervention a special neurobehavioral profile for FASD differentiated from other groups of developmental disorders is important.

### Acknowledgements:

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## THURSDAY PARALLEL SESSIONS G - H

### Political and legal approach to FASD: a round-table discussion

Chair: Thierry Maillard

Members of round table: Ruth Ruiz, Denis Lamblin

## Psychiatric review of first 100 clinic-referred patients with FASD & their families in Ireland (2006-2010)

Led by Dr. Kieran O'Malley

This paper/workshop will present a descriptive analysis of the first 100 patients seen in psychiatric consultation, in 2006 to 2010, since my return from North America. The patients were all clinic-referred and were seen in both the Public Health Care System in Belfast, namely the National Health Service(NHS), and the Public Health Care System in Dublin, the Health Service Executive (HSE). It will also incorporate clinic-referred private consultation patients seen from all over the Island of Ireland who have been seen in either Dublin or Belfast medical consultation offices. The age of this Study Sample ranges from birth to young adulthood, but as well identifies potential transgenerational FASD in grandparents. The paper will focus on increasing the recognition of the developmental psychiatric presentation of patients with FASD, and will review multi-system and multi-modal management strategies utilised from babyhood through childhood and to young adulthood. As well, it will include early examples of involving adult and child mental health care/ social service teams in 'joined-up planning' for patients and their families with FASD. Finally, it is planned to introduce a young adult with FAS who has Aspergers Disorder symptomatology and include her long term foster parents in the discussion.

## Diagnosis of FASD using the 4-digit code

Led by Rudi Kohl

## ABSTRACTS FRIDAY

### The Future Emerging from FASD Research: Impact on Identification, Prevention and Treatment

Kenneth R. Warren, Ph.D.  
Acting Director  
National Institute on Alcohol Abuse and Alcoholism

The U.S. National Institute on Alcohol Abuse and Alcoholism (NIAAA) has actively supported research and prevention activities on fetal alcohol spectrum disorders (FASD) over nearly its entire 40 year history. These efforts have played a major role in bringing worldwide public attention to this public health problem. Despite the many accomplishments to date, there are many important issues that impede further advancement in the prevention of FASD and the treatment of those affected. NIAAA has focused its attention on these issues and defined them as research challenges. They include improving the ability to recognize women who are high risk drinkers, or who are alcohol dependent, both before and during pregnancy, through the development of new biomarkers. Also included are studies to identify children with FASD disabilities at an early age to foster early educational and skills interventions. This includes use of advanced technologies such as computer-aided 3-D facial recognition. Basic science on alcohol actions on the brain is also included for the purpose of developing new therapeutic interventions. NIAAA is fostering research on educational interventions for FASD affected children, and testing new individual-oriented and community-oriented prevention activities to decrease the extent of alcohol use in pregnancy. Through these efforts is striving to reduce the extent of FASD in the U.S. and worldwide, and enhancing global public health.

### FASD and the global strategy to reduce the harmful use of alcohol

Dag Rekve, World Health Organization

## EU Alcohol Strategy:

### Prevention of foetal alcohol harm as priority theme

Marjatta Montonen

Although alcohol-related harm has been long since recognised at EU level as a public health challenge, and alcohol as an important determinant of health, the first EU strategy focussed specifically on alcohol-related harm was only launched in 2006. In this Strategy, protecting young people, children and the unborn child is the first priority theme for action. The Strategy was outlined in a Communication from the Commission on an EU Strategy to support Member States in reducing alcohol-related harm, which was endorsed by the Council and the Parliament as well as other EU institutions. Although there may be slight differences in preferred approaches to dealing with alcohol-related harm, there is clear consensus on the priority themes and aims for work across countries and sectors, whether through action by the Commission, Member States, the civil society or wider stakeholders. One of the specific aims under the first priority theme is to reduce exposure to alcohol during pregnancy, thereby to reduce the number of children born with Foetal Alcohol Disorders. We are now four years into the Strategy, which is running till the end of 2012. The presentation looks at achievements so far related to the reduction of alcohol-related risks in pregnancy and at areas where further progress could be made.

## Abstracts posters

### 1. Modulation of liver and brain CYP2E1 mRNA expression in CD1 mice exposed in utero to red wine or ethanol

S. Vichi, R. Mancinelli, M. Fiore, L. Aloe, M. Ceccanti, S. Gemma

Contribution of genetic factors as the presence of allelic variants for those enzymes involved in ethanol metabolism such as cytochrome P4502E1 (CYP2E1) in developing FAS has been suggested by animal models and molecular epidemiological studies. Oxidative stress products generated by CYP2E1 during ethanol biotransformation participates to adverse effects of alcohol exposure, by promoting lipid peroxidation and severe damages to DNA and proteins.

At moderate alcohol doses, CYP2E1 is responsible only for about 10% ethanol oxidation, but its contribution becomes relevant at high alcohol doses after heavy consumption, when alcohol dehydrogenase is saturated and in chronic alcohol abusers. Aim of this study was to evaluate alterations in CYP2E1 expression in CD1 mice due to pre- and post-natal chronic exposure to ethanol solution or red wine at equivalent alcohol concentrations. Overall, prenatal exposure to ethanol appeared not to significantly influence the hepatic CYP2E1 expression in mice, likely due to the limited exposure coming from mother. An induction was evidenced at postnatal day 8 after wine-treatment, which could be due to components other than ethanol per se, or a different absorption kinetic may be hypothesized when ethanol is ingested as wine component. CYP2E1 induction was observed in cerebellum in ethanol mice group sacrificed 8 days after birth, but not in wine group. The CYP2E1 up-regulation was in this case attributable to ethanol per se. The different ethanol effect on CYP2E1 expression seems to come out depending on the form in which alcohol is assumed (ethanol vs red wine) and on the target organ.

## 2. Awareness to malice

M.E. Raats, A.J. Schneider

The Erasmus MC is partaking in a treatment programme (KetenZorg) in which all addicted mothers are being closely followed and supported to stop their alcohol intake.

We'd like to present a case of alcohol consumption by a pregnant woman, resulting in the birth of a child with a partial FAS. Although the patient abstained from alcohol after week 15, the child was severely afflicted. Before contacting her gynaecologist at week 15 she was following a psychotherapeutic treatment. After this time the patient followed psychotherapeutic treatment with strict controls of her alcohol intake. This case shows that public education for patients and health care workers is necessary in the prevention of FAS.

## 3. A retrospective register study on psychosocial functioning in adults with fetal alcohol syndrome

J. Rangmar, M. Aronson, A. Dahlgren Sandberg, C. Fahlke, A-S. Lindqvist, K. Strömblad

Few studies focus on psychosocial functioning in adults with fetal alcohol syndrome (FAS). A previous follow-up study of Swedish children with FAS showed that they had severe problems with social relationships and education, problems that remained throughout childhood.

The aim of this register study is to further investigate the past and present social and psychosocial demographics of these children who now are adults (n = 79, mean age 29 [18-49 years], 37 % women and 63 % men). A Swedish longitudinal integrated database for health insurance and labour market studies (LISA by Swedish acronym) is used for this purpose. Examples of data that will be utilized from the database LISA are employment, income (e.g. parental leave, unemployment, labour market activity, rehabilitation, early retirement, social assistance), place of residence (county, municipality, parish and property) and highest level of education. Obtained data will be compared to a gender and age matched comparison group, also retrieved from the database LISA.

Preliminary results show that almost 30 % of the adults with FAS had been subjected to the Swedish enforcement authority and the Social services. Moreover, about 70 % of the individuals had been regularly in contact with the Swedish public employment services. The results indicate that FAS have a major impact on the adult daily life, especially on social and psychosocial demographics.

#### 4. Selenium supplementation as an effective antioxidant to ethanol exposed pups

M.L. Ojeda, K. Jotty, F. Nogales, M.J. Delgado, M.L. Murillo, O. Carreras

Ethanol consumption affects maternal nutrition and antioxidant status together with the future health of their progeny. Selenium (Se) is a trace element with antioxidant activity. The aim of this paper is to study the relationship between alcohol, selenium, gestational parameters and oxidative stress in breastfeeding rat pups exposed to ethanol during gestation and lactation. We have also studied how a Se-supplemented diet among mothers could prevent these disorders in the pups.

**Method** Pups of 21 days were randomised into four groups: Control group (C), Alcohol group (A), Alcohol Selenium group (AS) and Control Selenium group (CS). Alcohol was supplied to their mothers for 13 weeks (induction, reproduction, gestation and lactation periods). The selenium-supplemented diet contained 0.5 ppm as selenite. We determined milk, serum and liver Se by graphite-furnace atomic absorption spectrometry. We measured hepatic glutathione peroxidase (GPx) activity by a spectrophotometric method in liver.

**Results** In the liver of pups, exposure to ethanol provoked a decrease in selenium and GPx activity, however despite A pups consumed less Se via milk, they had higher serum Se levels. Gestational parameters were also affected by ethanol exposition, and at the end of lactation A pups showed the lowest cranium-caudal longitude and body weight. Administering Se with alcohol balances these parameters.

**Conclusion** These results suggest that selenium could be effective in neutralising the damage of ethanol consumption during gestation and lactation in pups since it repairs selenium levels in liver as well as GPx activity, improving the "fetal programming" process.

#### 5. Prevalence of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder in European countries: a systematic literature review

Svetlana Popova, Jayadeep Patra, Jürgen Rehm

##### Objectives

The primary objective of this study is to use the world literature to estimate the prevalence rates of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) in European and other countries of the world, which is then to be followed by a comparison of the prevalence rate in European countries with other countries and the overall prevalence rates of FAS/D.

##### Method

A systematic literature review of existing studies concerning the frequency of FAS/D was conducted. A pooled-estimation technique was used to estimate overall FAS/D birth prevalence and prevalence for all age groups.

##### Results

Birth prevalence and prevalence for all age groups of the FAS/D in European countries will be reported and compared with other countries and the overall prevalence rates. Prevalence estimates of FAS/D will also be provided for "populations at risk" and compared to general populations. It is expected that the prevalence rates will vary, depending on country, population and method of surveillance.

##### Conclusion

FAS/D should be identified as an important Public Health problem in European countries, as well as around the world. Different research methods of estimating prevalence and incidence used in the reviewed studies will be identified (e.g., passive surveillance, clinic-based studies, and active case ascertainment) and their strengths and weaknesses will be discussed.

**6. Executive functioning (EF) in children and adolescents with FASD.**  
 A paired comparison of two groups of 15 children and adolescents with and without FASD matched according to their age, IQ and living standards

Jessica Wagner

Executive functioning (EF) in children and adolescents with FASD. A paired comparison of two groups of 15 children and adolescents with and without FASD matched according to their age, IQ and living standards.

In this study, specific neuropsychological tests and a special questionnaire were used to evaluate EF in general and in specific EF domains such as planning, selective inhibition, cognitive flexibility, concept formation and rule breaking.

Alcohol-exposed children were deficient in their overall EF performance as indicated by the overall BADS score as well as specifically impaired in planning, selective inhibition and rule breaking.

No differences could be found with regard to cognitive flexibility, concept formation and self-assessment.

The results demonstrate that children and adolescents with FASD are more impaired in EF even when they are compared to a control group with same age, IQ and living standards.

**7. Experiences of a FASD/CDBC key worker at the Simon Fraser Society for Community Living in British Columbia**

Sylvie Kruchten

In 2003 the Canadian province of British Columbia (BC) released a Strategic Plan to address Fetal Alcohol Spectrum Disorder (FASD), the first such comprehensive plan in Canada. This Plan identified 5 priorities: diagnosis and assessment, public awareness, early intervention and prevention, life long support, and research and evaluation. Within this context, the BC Ministry of Children and Family Development implemented throughout the province in 2005/2006 a family support program called the "Key Worker and Parent Support Program".

The goals of this program are:

- \* to maintain and enhance the stability of families of children/ youths with FASD and/or Complex Developmental Behavioural Conditions (CDBC) in order to improve the children's long-term outcomes;
- \* to increase the knowledge of families and professionals about the brain-based nature of the developmental-behavioural conditions, leading to the affected children and youths experiencing more success and less frustration
- \* and to foster and improve access to a network of support for the families.

The program is based on an understanding of FASD as a brain-based disability, leading to ways to develop effective supports for children and youths. The program uses a family-centered approach, a cultural safety framework, and a strength-based practice.

Standardized training was provided to all key workers. The program allows for regional program delivery and implementation.

We will describe our experience implementing this program in our agency. We will review the different roles of a key worker: support of the families during and after assessment, education, assistance to access family support, education, health and community services, support of the caregivers in advocating for their child, case manager, and facilitator of parents support group for caregivers (adoptive, birth parents, foster parents and grandparents).

Finally we will present some of the challenges faced by this program in 2010, after 5 years.



## 8. About 155 adults exposed to alcohol in utero: presentation of our study

Cécilia Lafosse

The consequences of a fetal alcohol exposure in adulthood are not very well known yet. Only a few study report the same neurological impairments and social difficulties to adults exposed to alcohol during prenatal stage.

155 children born over a eleven months period in the early 80s at maternity hospital Paul Gellé in Roubaix -France - and exposed to variable levels of alcohol consumption during pregnancy were examined at birth then followed up until 4 years old of age. 47% were exposed to the equivalent of 1 glass of alcohol or less per day, 32% to a rate of 1 to 3 glasses per day and 21% to more than 3 glasses per day. The development of these children was studied particularly with regard to psychomotor and neurological items.

Our aim is to study the becoming of the se 155 subjects now aged of 24 or 25 especially through professional, social and medical aspects.

## 9. Evidence-based, multidisciplinary approach to the study of FASD: an Italian current experience

Rosanna Mancinelli

A successful example of evidence-based, multidisciplinary research about gender differences and teratogenic effect of alcohol drinking is presented. Experience started in 2004 in Istituto Superiore di Sanità (ISS)-Rome with the collaborative project ISS-NIH "Woman, health, alcohol: risks and damages from alcohol in different woman ages. The role of abuse markers" (to RM). This is a gender-focused research promoted by ISS and performed in collaboration with NIH- NIAAA, University "Sapienza"-Rome, and National Research Council (CNR) researchers with well stated expertise. Clinical studies on alcoholic patients, and animal studies about foetal alcohol spectrum disorders (FASD) were included. Clinical studies concern Biochemistry (clinical biomarkers); Immunology (innate immunity and autoimmunity); Nutritional and environmental factors (vitamins, oligo-elements, metals); Genetic factors (polymorphisms of CYP2E1, GSTs, and neurotransmitters). Animal studies concern biochemical (e.g. growth factors) and neuro-behavioural researches. Teaching is a significant part of the project. In 2007 started the Course "Woman and child health: clinical and experimental aspects of alcohol exposure" and in 2010 is the fourth edition. Until now, this is the first and unique Course in Italy about multidisciplinary research on alcohol related diseases in woman and in the dyad mother-fetus (FASD). More than 30 scientific papers have been produced, but the most significant result is the spreading of awareness among health operators, obtained thanks to the work of all the researchers involved in this challenge. This Italian collaborative experience may be suggested as an holistic model for the clinical approach to alcohol related problems including FASD, and for planning evidence-based prevention strategies.

## 10. Creating a circle of hope: the Women in Recovery summit model

Kathleen Tavenner Mitchell

Reaching women at high risk for an alcohol exposed pregnancy with education about FASD is essential to FASD prevention. With support from the government, NOFAS hosted a series of Hope for Women in Recovery Summits across the United States (2004-2008). The model was designed to educate policy makers, addiction professionals and the women they serve to educate them about basics of FASD and the long-term implications for individuals, families and systems of care. This best practice model targeted women who were being treated in addiction centers, their administrative and counseling staff, and policy makers. Since many of the women who attended the Summits had already given birth to children that had been exposed, they were provided with resources for FASD assessments and service providers. Empowerment was the underlying theme of the Summit model, and the term Warrior Mom was coined to remind women of their strengths. The presenters were primarily birth mothers of children with FASD, and provided hope and encouragement for the participants. In this workshop participants will review the steps that were taken to plan, implement, and evaluate a Hope for Women in Recovery Summit. Participants will each receive a Women in Recovery Summit Manual.

## 11. Alcohol consumption by pregnant women in the Treviso area (Veneto Region, Italy): results of a screening activity

S. Bazzo, P. Riscica, G. Moino, T. Codenotti, G. Battistella

The results of a screening activity targeting pregnant women in the Treviso area are presented here. This study represents the fourth phase of the FASD prevention and awareness project called "Kambio Marcia: mamma beve bimbo beve". (free English translation: "Change: mother drinks, child drinks").

The study has a double purpose:

- to identify the prevalence of women drinking alcoholic beverages during pregnancy;
- to contextualise opinions and habits related to alcohol use in a wider frame work of the individual's health and wellbeing, both in general and specifically for pregnant women.

During April and May 2010 a self-administered survey will be performed with the whole population of pregnant women at any stage of their pregnancy, who are monitored by health professionals in hospitals in the given time period. Alcohol use will be measured by using AUDIT-C screening test. It is foreseen that at least 200 pregnant women will be tested in this study, whose results will be available by October 2010 at the latest. The results will be used as key references in designing and implementing education strategies targeting pregnant women.

## 12. A systematic review of continuous performance task research in children prenatally exposed to alcohol

G.P. Dolan, D.H. Stone, A.H. Briggs

**Aim:** The aim of this study was to review systematically, research investigating an association between the continuous performance task (CPT) in children and exposure to alcohol in utero, in order to identify any evidence of a specific deficit in performance.

**Methods:** Seven electronic databases and three websites were searched. Papers were selected in accordance with specific inclusion criteria and scored in terms of the methodological quality using the Newcastle-Ottawa score. Marked methodological heterogeneity limited the validity of any statistical meta-analysis and a descriptive synthesis was performed instead.

**Results:** A total of 14 papers were identified for inclusion. There was no consistent evidence of any association between prenatal alcohol exposure and correct responses, reaction time, commission or omission errors during CPT testing. Apparent trends in the reported results, however, suggest that a potential effect might have been missed.

**Conclusion:** Identifying a specific profile of CPT performance may assist in the detection and management of attention deficits amongst children with prenatal alcohol exposure. Future research with more consistent measures of exposure and outcome is, however, required before any valid generalizations about CPT performance can be made.

## 13. The effects of ethanol exposure during pregnancy in pediatric surgery: a review

Silvia Ceccanti, Marco Fiore, Denis Cozzi, Mauro Ceccanti

**BACKGROUND:** Fetal Alcohol Spectrum Disorders (FASD) is an embryopathology related to maternal alcohol drinking. To date the attention was focused on the deleterious effects of this exposure on the neural cells, considered the specific target of ethanol teratogen effects, which include typical craniofacial dysmorphism, growth and mental retardation. Few data are available on the anomalies induced in other organs.

**AIM:** We provide an overview of papers reported in literature on the systemic malformations resulting from fetal exposure to ethanol.

**METHODS:** An extensive search of the literature from 1975 to 2009 using the PubMed database was carried out. We included both case reports of patients with diagnosis of FAS and clinical or experimental case-control studies on the effects of prenatal exposure to ethanol. We considered only anomalies reported in 2 or more case reports, or those supposed to be ethanol exposure related by case-control studies.

**RESULTS:** We were able to find 48 case reports describing a wide spectrum of disorders, including: pediatric tumors(9), genitourinary anomalies(19), extra hepatic biliary atresia(2), diaphragmatic hernia(1), and CCAM(1). Finally recent case-control studies found an effect of prenatal exposure to ethanol on the etiology of neuroblastoma, diaphragmatic hernia and delayed intestinal maturation.

**CONCLUSIONS:** This heterogeneous spectrum of disorders suggests that ethanol has as target not only the neural cells. Interestingly several abnormal changes in FASD involve regions colonized by cell lineages derived from neural crest cells. We suggest to investigate about prenatal ethanol exposure in children with this pathologies in order to prove or disprove a real cause-effective involvement.

## 14. Facing the challenge and shaping the future for students with FASD

Barry Carpenter, Carolyn Blackburn

Children with FASD will present with a unique set of learning needs that can make it difficult for many teachers to know how best to support them. In the UK, little is known about FASD and the approaches that may be helpful in educating children affected, and there is currently no government guidance on this.

Teachers and teaching support staff will undoubtedly meet children with FASD in their classrooms. They need to know how to respond to their learning needs effectively, enable them to maximise their potential, improve their life chances and take their places alongside their mainstream peers as citizens (DfES, 2004; HM Government 2004).

The difficulties that these children face in the classroom epitomise that much-used phrase 'complex needs' (Dittrich and Tutt 2008, Carpenter 2009). Their unusual style of learning and their extreme challenging behaviour is out of the experience of many teachers and, as there is significant shortfall in guidance for teachers on how to educate children with FASD in the UK, teachers find themselves 'pedagogically bereft' (Carpenter 2009).

In response to this emerging area of Special Educational Needs (SEN), the FAS-eD Project will investigate best practice in educational approaches for children affected by FASD with the objective of securing an effective school workforce that raises educational standards and improves children's life chances. This Project will underpin innovative and exploratory research, whose findings will inform teachers at primary and secondary level and be of interest and value to those engaged in initial teacher training and continuing professional development.

## 15. Nutrition for children with FASD

Diane Black

FASD is more than "just" brain damage. Prenatal exposure to alcohol also damages the digestive tract, pancreas, liver, and kidneys. Children with FASD often have difficulty chewing or swallowing. Digestion is then further impaired by reduced secretion of digestive enzymes, and uptake of nutrients may be poor in the compromised intestines. The damaged liver and kidneys may not function optimally to filter the blood, thus affecting health and mental well-being. Another dietary problem common in children with FASD is self-limitation of the diet to a few foods which do not provide well-balanced nutrition. Due to these dietary problems, children may suffer from food intolerances or allergies, and they are at risk for nutritional deficiencies.

Malnutrition plays a role in the genesis of FASD, and good, adapted nutrition can play a role in improving the mental and physical health of persons with FASD. Research has shown that nutritional deficiencies of a pregnant mother play a role in the development of typical FASD damage, and that nutrient supplementation can prevent some damage. A recent report has shown that one nutrient, choline, improves mental functioning in rats even after birth, thus opening the possibility that nutritional supplements might improve brain function in our children. In some cases, genetic factors or poor absorption of nutrients leads to a higher-than-normal requirement for nutrients. Although these factors have not been subject to scientific investigation in children with FASD, many parents find that their children respond dramatically to extra supplementation of vitamins, minerals, and essential fatty acids.

## 16. Building promising practice in child welfare service for individuals with FASD

Donna Debolt

In previous research (2005), the University of Calgary found significant outcomes in relation to improved placement stability and caregiver relationships, in addition to reduced risk behaviours in children and adolescents with FASD in foster care and residential/group care services.

These positive initial results led Children and Youth Services (CYS), through the Research and Innovation Branch, to establish a FASD Community of Practice Research Project to evaluate the promising practices on a larger scale. Participants from child welfare regions in Alberta agreed to recreate the research and provide the practice community with definitive case management best practice in the service delivery to individuals with FASD within Child Protection.

It is well understood that there is significant prevalence of FASD in that service delivery system. The CoP approach is critical in building common understanding and expertise in FASD and case management while providing participants from the participating regions the opportunity to share ideas and practice-based experience as the project progresses. Building on the capacity of the Casework Practice Model of Assessment, Collaboration and Engagement, this Research Project will support the evolution of thorough assessment, collaborative case planning and service provision to achieve desired child, youth and family outcomes. The FASD CoP Research Project began on April 1, 2009 and is scheduled to be in place for 18 months until September 20, 2010.

## 17. Investigating the impact of prenatal alcohol exposure on the social-emotional, academic, and adaptive functioning of internationally adopted children

Felicia Demchuk

Hundreds of thousands of social orphans have been adopted into families from foreign countries, including Russia and Ukraine, which have high levels of documented alcoholism. Social orphans have multiple risk factors, including prenatal exposure to alcohol, which contribute to poor outcomes. Although these children present with multiple risk factors, many studies indicate that most of these children appear to be resilient over time though there is evidence that this group is over-represented in certain special needs areas.

Prenatal exposure to alcohol is a variable that has a negative impact on outcomes of children who have been exposed. Yet, in previous research, prenatal exposure to alcohol has been consistently ignored as a variable in studies of children who have been internationally adopted from Russia or Ukraine. Prenatal exposure to alcohol must be considered in the study of outcomes for this population in order to measure a critical variable impacting the identification, treatment, and appropriate interventions needed to help this population achieve more positive outcomes.

The research question for this study is: why do individual children present with resilient outcomes in the areas of social-emotional behavior, academic, and adaptive behavior functioning while others present with what appears to be irremediable damage, in spite of the fact that many of their pre-adoption histories and post-adoption family environments are comparable? The study is designed to evaluate the relationship between prenatal alcohol exposure risk and pre-adoption placement risk to resilient outcomes in the areas of social-emotional behavior, academic and adaptive behavior functioning during latency age.

## 18. Behavioral management strategies in people with FASD: lessons from a national referral clinic

Raja Mukherjee

### Introduction

Clinical management strategies in people with FASD are still under-researched. A link between the psychological findings and the psychiatric disorders remain confusing and unclear. We attempted in the national referral clinic to try and bridge these two areas.

### Methods

Detailed analysis of clinical measures used in a national referral clinic including Developmental behaviour checklist, Vineland Adaptive behaviour Schedule and single item analysis of ADHD criteria were conducted. Data was analysed using SPSS version 16.

### Results

Children and adolescents with FASD show behaviours that using single item analysis links to psychological findings in cortical functioning. Inattention and distractability were the most consistent findings. Differences between our group and previous studies were also seen.

### Discussion

It is possible using the techniques used in our clinic to look at behaviours at an individual level correlating both the behavioural presentations and the psychological research. Without this approach the subtleties of individual differences can be lost.

## 19. Carers experience of looking after a child with FASD in the UK

Raja Mukherjee

### Introduction

FASD is recognised to be associated with behavioral and learning deficits. Despite this it appears in the UK to be a condition that is poorly understood. Anecdotal feedback from carers suggested there are struggles obtaining help from social services, local education authorities and health in order to best meet the needs of affected individuals. In order to better understand this it was decided to study scientifically the experiences of carers regarding the care of these individuals.

### Methods

A Mixed methodology project was conducted using a mixture of qualitative focus groups and quantitatively the Adibin Parental Stress index to gauge the experiences and difficulties faces in raising a child with FASD in the UK. A large sampling frame was developed across the country with a series of meetings held in the UK. Quantitative data was analysed using PAWS (SPSS) version 18 and qualitative data using NVivo.

### Results

The data is currently being collected and will be ready for dissemination by September 2010.

## 20. Risk factors for mental and behavioral problems in Fetal Alcohol Spectrum Disorders

Åse Fagerlund

**Objective:** To examine the risk and protective factors associated with the mental and behavioral problems of children and adolescents following prenatal alcohol exposure.

**Method:** A total of 73 children and adolescents were assessed for internalizing, externalizing, and total behavior problems using the Child Behavior Checklist. Linear regression models were used to determine the effects of diagnostic and environmental risk and protective factors on behavior, while controlling for age, sex and IQ.

**Results:** Length of time spent in residential care was the most pervasive risk factor associated with internalizing, externalizing and total mental and behavioral problems. A low dysmorphology score was related to more internalizing and total problems.

**Conclusion:** The results underscore the need to consider the postnatal environmental circumstances of children with fetal alcohol spectrum disorders in predicting outcome. Consistent with an attachment model of development, presence of close and persistent relationships may be of particular importance for improved outcomes in children with FASD. More attention should be focused on children with fetal alcohol spectrum disorders with lower dysmorphology scores and their special risk profile.

## 21. A survey of Italian neonatologists knowledge regarding awareness of maternal ethanol use and the diagnosis of FAS and FASD

S. Pichini, F. Vagnarelli, S. Pedori, L. Ambrosetti, R. Spoletini, R. DiGiovannandrea, R. Pacifici, P. Zuccaro

There are no Italian statistics on ethanol consumption during pregnancy. Usually, gestational drinking habit is investigated by generic questions included in the maternal interviews at prenatal visits. It is also probable that eventual fetal ethanol syndromes and fetal ethanol spectrum disorders are under diagnosed by physicians. To evaluate neonatologists awareness of gestational drinking patterns and their experience, knowledge and confidence with respect to the diagnosis of FAS and FASD, a multiple choice anonymous questionnaire was e-mailed to neonatologists registered in the mailing list of Society of Italian Neonatologists.

Preliminary results on 43 completed questionnaires are currently available. With respect to the epidemiology of the problem, around half of the respondents considered that the % pregnant women consuming ethanol in any time, daily or problematically during pregnancy is unknown since no systematic study has been carried out in Italy up to now.

Only 50% responders declared that they ask pregnant women information on ethanol consumption during prenatal visit and report in hospital medical records. Pregnant women at risk of problematic ethanol consumption were disclosed by their previous clinical history (45% responders) or by measuring a biomarker, which in the majority of cases was serum gamma glutamyl trans peptidase. Conversely, not a single respondent could list a neonatal biomarker of prenatal exposure to ethanol and even if 95% neonatologist of this survey declared that FAS and FASD are identifiable syndromes, they believe that both are underdiagnosed and 72% responders admitted not to feel confident about diagnosing FAS and FASD.

## 22. Do you recognize Eric?

Swedish FAS Association

The poster "Do you recognize Eric" is used to in a personal way raise awareness of the costs of FASD, the cost for the society as well as the personal costs for the affected individuals. The poster is supplemented by a leaflet. Available also in Swedish.

## 23. Different strategies for FASD's diagnosis: two cases in comparison

L. Tarani, M. Fiochi, L. Manganozzi, N. Liberati, S. Ceccanti, M. Ceccanti, G. Coriole

Fetal Alcohol spectrum disorder (FASD) is permanent brain damage caused by maternal consumption of alcohol during pregnancy. In utero exposure to alcohol can have numerous effects: it may include physical, mental, behavioural and learning disabilities.

The diagnostic process is complicated by the variability of the syndrome expression, therefore multidisciplinary team approach is needed.

Signs and symptoms of FASD are:

- 1) characteristic facial anomalies (short palpebral fissures, flat philtrum, thin upper lip)
- 2) pre or/and post natal growth delays
- 3) signs of brain dysfunction (microcephaly, language delay, learning disabilities...).

We present two cases of clinical verified FASD detected by two different diagnostic strategies. One 5 years-old baby came to us for a growth delay, additionally presenting all major criteria for FASD diagnosis, including pathognomonic facial malformations. Other genetic disorders that could lead to features of FASD were verified. During the following interviews the mother admitted an alcohol abuse during her pregnancy.

The other 6 years-old child was adopted from Russia, and presented major and minor clinical FASD signs. According to the statistical high average alcohol consumption in this country and the clinical presentation, we hypothesized an elevated alcohol exposure risk of his mother. In conclusion due to mother's reticence to admit fetal alcohol exposure, particular doctor sensitiveness is needed to detect the maternal behavior and the suggestive clinical signs of FASD.



## 24. Feasibility of screening for risk drinking in pregnant women

Lesley Smith, Ethel Burns

**Background:** Whilst many women either stop or reduce their alcohol consumption once they know they are pregnant, a significant minority continue to drink at potentially harmful levels [1-6]. About 10% UK women exceed recommended drinking levels while pregnant; about 2% binge drinking or drinking heavily [1]. Clinical guidelines recommend routine screening for antenatal alcohol consumption, but offer no clear guidance to midwives how to do this [7]. Research has suggested that screening with short questionnaires is effective for identifying women with problem alcohol use [8].

**Objectives:** Determine feasibility of screening using short alcohol questionnaires. Obtain estimates on the prevalence of different drinking patterns in pregnant women using AUDIT and T-ACE alcohol screening questionnaires.

**Design:** Cross-sectional survey.

**Setting:** Two antenatal clinics in SW England. Both cover a diverse population in terms of ethnicity, social class and deprivation and a mix of urban, small town and rural settings.

**Participants:** Women at least 18 years old who are attending either clinic for their initial antenatal appointment (11-14 weeks gestation). Non-English speakers were excluded.

**Questionnaires:** AUDIT and T-ACE alcohol screening questionnaires self-completed by the woman in the clinic.

**Sample size:** We invited 505 women to take part, and 408 questionnaires were returned.

**Main findings/results:** The study data are currently being analysed, and results will be presented. We will provide data on the demographic profile, obstetric characteristics and prevalence of different alcohol drinking patterns using these screening questionnaires on a representative sample of pregnant women in England.

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## 25. FASD in children adopted from Poland

Sandra Knuiman, Catharina H.A.M. Rijk, René Hoksbergen, Anneloes L. van Baar

**Background:** Annually, 300 to 400 Polish children are adopted internationally. Prior to adoption, most of these children have been exposed to circumstances which may harm their development. Prenatal alcohol exposure appears to be an important factor. In our research project, the background and functioning of Polish adopted children are investigated, with special attention for Fetal Alcohol Spectrum Disorder (FASD). This poster presents the incidence of maternal drinking, FASD and behavioral problems.

**Method:** Dutch families of 133 children adopted from Poland (69 boys, 64 girls, age 8.7 years [sd 2.8; range 2.8-15.2], age at adoption 3.0 years [sd 1.6; range 0.4-6.8]) took part in this study. FASD indicators were assessed through a parental report. The Child Behavior Checklist was used to determine behavioral problems.

**Results:** Maternal drinking was reported for 54% of the adopted children; 16% reported no knowledge of alcohol abuse. FASD was diagnosed in 20% of the cases. In addition, adoptive parents suspected FASD for 28% of the children. Parents of Polish adopted children reported a higher incidence of behavioral problems than a norm group, with significantly more scores in the clinical range (39% vs. 10%). Children with (suspected) FASD display significantly more behavioral problems than children without such diagnose or suspicion.

**Conclusion:** First results show a high risk for FASD and a high incidence of behavioral problems for Polish adopted children. A more elaborate FASD diagnose is needed, to disentangle to what extent behavioral problems are related to FASD or result from early-life deprivation before adoption.

## 26. Face processing in children with fetal alcohol spectrum disorders

Sara Stevens, Kelly Nash, Joanne Rovet

Faces are one of the most important stimuli people process daily, and within the face, the eyes are fundamental for attention and social cognition, including theory of mind and affect processing. Children with FASD are shown to have poor face memory, as well as emotional processing. However, the specific aspect of face processing that shows the most deficit in FASD is unknown. The present study sought to investigate face processing in FASD and typically developing controls (TDC). Twenty-five children with FASD (mean age 10.31ys) and 13 TDC (mean age 10.28ys) completed two face processing tasks: 1) Face Processing (Bruce et al., 2000) explores different aspects of face processing (Expression, Gaze, Identity, Speech Sound); 2) Gaze/Arrow Cuing (Driver et al., 1999) evaluates how gaze and arrow cues facilitate attention by having the cue direction congruent or incongruent to a peripheral target. Reaction time, accuracy and cuing effects (benefit of congruent over incongruent cues in the cuing task) were calculated. Results showed that for Face Processing, the FASD group had slower reaction times on Expression, Speech Sounds and specific Identity subtests, and poorer accuracy on one Speech Sound subtest, compared to TDC. For Gaze/Arrow Cuing task, the FASD group had poorer accuracy for both cues, than TDC. The FASD had a larger cuing effect for both cues, indicating a greater benefit from congruent cues and increased difficulty disengaging from incongruent cues. Overall, FASD show weaknesses in processing different aspects of faces, which may underlie their social cognitive deficits, including theory of mind and affect processing.

## 27. A survey of paediatricians knowledge and practice in the diagnosis and management of Foetal Alcohol Spectrum Disorders -- A UK survey

Inyang Takon

Paediatricians regularly assess and manage children with complex difficulties some of whom may have FASD however FASD remains largely underdiagnosed.

**Method:** A questionnaire survey was carried out to assess the knowledge and practice of Paediatricians regarding FASD. A 19 item questionnaire was circulated through email survey to Paediatricians in the Eastern region of England. Questionnaires were also administered to Paediatricians attending an ADHD study day. The period of survey was 2 weeks.

**Results:** 45 completed questionnaires in total were received. 74% of respondents were Consultant Paediatricians with 29% being hospital Paediatricians and 55.6% being Community Paediatricians. 69% of respondents had received direct or indirect referrals for FASD assessment. Most of the referrals were received from Social Services (32%) with 25% being from GP's. 19% of respondents have referrals from multiple sources. 55.6% of respondents referred patients for assessment to other professionals; with referrals to Geneticist forming 40% of all referrals. 35.6% of respondents did not regularly take a history of alcohol use from the mother. 42% of Paediatricians were slightly confident in assessing children with FASD. 62% of Paediatricians reported they had not been trained in assessing FASD. 97.8% of respondents felt it was important for Paediatricians to be trained in assessing FASD whilst 91% of respondents felt FASD was of Public Health Significance. 82.2% of Paediatricians indicated they do require further training on assessing FASD.

**Conclusion:** There is need to improve the Training and skills of Paediatricians in the United Kingdom in assessment and management of children with FASD.

## 28. Diagnostic dilemma -- Foetal Alcohol Spectrum Disorder or Pierre Robin Sequence -- case history

Inyang Takon

Foetal Alcohol Syndrome can present with diagnostic challenges for the clinician. Facial malformations are not uncommon in FASD.

NB was born at 37 weeks gestation to a 25 year old single mother. Mum was a chronic alcohol abuser and also took heroin, methadone and non prescription drugs. NB was very small at birth and her weight and head size were below the 0.4th centile. NB was dysmorphic at birth and had thin upper lip and absent philtrum. She had a cleft of her hard palate, small chin and was fed through a nasogastric tube.

NB was irritable after birth, she had breathing difficulties and had withdrawal symptoms requiring treatment for methadone withdrawal. NB was seen by the cleft palate team and felt to have Pierre Robin Sequence. Follow up by the Cleft palate team continued with plan to have surgery when NB's weight was optimal. NB was subsequently discharged to foster care.

NB remained highly irritable and fractious, had difficulty with sleeping and her weight, height and head circumference continued on the lower centiles. She was developmentally delayed at her 6 month review. NB was reviewed by the Paediatrician who felt that NB's facial features were in keeping with Foetal Alcohol Syndrome and further referral to a Geneticist was made. NB was confirmed as having FAS with facial abnormalities. It was however felt that NB's complex difficulties were secondary to a combination of Chronic Drug and Alcohol Abuse, Poor maternal nutrition resulting in significant growth retardation.

## 29. Epilepsy in children with FASD--case report

Inyang Takon

Children with FASD have an increased risk of having neurobehavioural and neurocognitive difficulties. These difficulties arise as a result of the CNS dysfunction from the teratogenic effect of alcohol on the developing brain.

Children with FASD are also at risk of developing Epilepsy however this is less well reported, particularly in the United Kingdom.

A recent study amongst Children attending an FASD clinic in Canada showed a high prevalence of Epilepsy of 5.9% and prevalence for a seizure disorder being 17.7%.

AB is a 3 yr old girl who developed early onset seizures at age 1 year. AB had vacant spells during the day and subsequently developed generalized tonic clinic seizures. AB had facial asymmetry with dysmorphic features and a notable squint. She had significant motor problems, was hyperactive and had impaired social and communications skills. AB had an EEG which was abnormal although her MRI was normal.

AB was treated with anticonvulsants which she did respond to but she has continued to have several seizures in a day needing a combination of medication. Further assessment showed significant history of maternal alcohol use in pregnancy. AB was felt to have significant features of FASD on further review and referred to the Geneticist.

There is a need for Paediatricians and Neurologists managing Children with Epilepsy and Seizure disorders to be aware of the contribution of FASD as a risk factor for Epilepsy particularly where no other definite cause has been found.

### 30. FASD project in Finland (2008-2011)

Suvi Vaarla

The Finnish Association on Intellectual and Development Disabilities (FAIDD) has launched the FASD awareness project that runs from 2008-2011. The emphasis on this project has been on FASD children and adolescents.

#### Starting point

Annually 600-1000 children affected by alcohol during pregnancy are born in Finland. There is no patient organization that would promote their interests in Finland, and the service system has not always been able to fulfill their needs. Adolescents with FASD find it especially difficult to get proper support at school or in the transition from school to adult life.

#### Social research

Our research explores the attitudes of social and health care professionals towards FASD and other moral-ethical perspectives of the subject. Negative attitudes towards FASD can influence for example children's access to clinically assessment and how the subject is discussed in day care and school. The research report will be published in 2011.

#### Raising awareness

The project includes regional activities in some parts of Finland. The project has participated in public discussion about FASD and alcohol related issues. One of the main goals has been to raise awareness about the phenomenon. We have also produced a brochure and a poster suitable for preventive work, as well as a book about FASD.

#### Peer support groups

The project has arranged two peer support groups for young FASD adults, for the first time in Finland. In the groups, young adults have been able to meet other young people in the same situation.

### 31. Differentiating restless legs syndrome (RLS) as a cause of circadian rhythm sleep disorders (CRSD) in children with FASD: video studies in the home setting--using optical flow to quantify movements

A.V. Barbosa, F. Chan, A. Black, J. Maurer, J.E. Jan, O.S. Ipsiroglu, E. Vatikiotis-Bateson

**Background:** RLS is a "disorder characterized by disagreeable leg sensations that usually occurs prior to sleep onset and that cause an almost irresistible urge to the move the legs" and can cause difficulties falling asleep and maintaining sleep. Video studies may be helpful for the diagnosis of RLS among children who have difficulties expressing sensations associated with RLS.

**Objective:** To develop software that quantifies different types of movements during sleep, as captured on video.

**Methodology:** After a qualitative analysis of the child's sleeping positions and movements during sleep, video files are analyzed using Optical Flow. Optical Flow computes horizontal and vertical pixel displacements between consecutive frames of a video. It is possible to define regions of interest (e.g. legs) and determine the amount of motion (over time) within each region separately.

**Results:** Magnitudes and frequency of movements are plotted on a time graph before and after falling asleep. Movements are plotted showing magnitude and frequency for the chosen sequences. The program can analyze specific regions of interest with respect to each other.

**Conclusion:** The optical flow analysis enables us to quantify RLS related movements as one cause of CRSD.

**Source of Funding:** Victoria Foundation, Telethon Award Competition 2007

### 32. Differentiating restless legs syndrome (RLS) as a cause of circadian rhythm sleep disorders (CRSD) in children with FASD: video studies in the home setting--commercially available lowcost equipment

F. Chan, A.V. Barbosa, E. Vatikiotis-Bateson, A. Black, J. Maurer, J.E. Jan, O.S. Ipsiroglu

**Background:** Children with FASD have a higher prevalence of CRSD; thus a description of what happens before falling asleep is significant. RLS, a "disorder characterized by disagreeable leg sensations that usually occur prior to sleep onset and that cause an almost irresistible urge to the move the legs," can cause difficulties falling asleep. Video studies may be helpful for the diagnosis of RLS among children who have difficulties expressing sensations associated with RLS.

**Objective:** To develop a reliable, inexpensive video monitoring solution that can be sent out via courier for home-based video studies.

**Methodology:** Various software and hardware options were explored with the following criteria. Hardware: infrared camera, low physical bulkiness/weight, portable, durable, cost effective, memory and power capacity for at least 8 hours of continuous audio/video recording. Software: synchronized audio/video, live time-stamp, smooth/continuous frame rates, low video artifacts, automatic splitting into multiple smaller files (to prevent file loss with system failure, and expedite file synchronization and viewing of recorded video).

**Results:** Our solution was to use a netbook/laptop to store video data and power a commercially available USB infrared security camera (total = \$500). All equipment fits into a case (2.8 kg total) with dimensions 34x30x10cm. The internet connection enables remote access from the research lab to facilitate home setup. We also developed a test setting for analyzing strength and weakness of video recording programs.

**Conclusion:** We developed a portable, inexpensive, and cost-effective solution to perform video sleep studies that produce consistent good quality videos.

**Source of Funding:** Victoria Foundation, Telethon Award Competition 2007, UBC Summer Student Scholarship 2010

### 33. FASD & Sleep: an epidemiological concept for international comparisons

O.S. Ipsiroglu, N. Carey, R. Houben, F. Chan, J.E. Jan, J. Owens, J. Lucyshyn, J.P. Collet

**Background:** Children with FASD are at high-risk for developing sleep disturbances or sleep disorders. Parents and physicians may not recognize day or night time symptoms to be related to sleep, and these symptoms may be unreported. Results of clinical assessments and research suggest that screening would be helpful for triaging patients for further clinical sleep assessments.

**Objective:** To develop an algorithm and a survey which assesses day and nighttime symptoms, behaviour, wellbeing, and family situation is applicable for a national and international epidemiological study.

**Methods:** Qualitative interviews with birth/adoptive/foster parents (n=8); key workers (n=4); social workers (n=2); PhD/MD (n=3); interviews were recorded, transcribed and analyzed.

**Results:** We developed an algorithm which we used as a screening tool to assess the significance of sleep challenges as well as the consequences of sleep deprivation on perceived daytime wellbeing. As a second step, we adapted the main elements of this algorithm for an online survey. The survey protects anonymity; however in order to organize the results by geographic location, the first three digits of postal codes are requested. The information collected from the surveys in Canada can be used to advocate for tailored sleep programs and services across Provinces.

**Conclusions:** We are presenting our screening tool and study design in order to conduct a national and international epidemiological survey.

**Source of funding:** Victoria Foundation

### 34. FAS Prevalence and Effects

Helga V. Toriello, Vivian Valdanis, Stephen Pastyrnak, Anthony Ritchmeier, Barbara Wybrecht

The experience of one FASD Diagnostic Clinic, showing high numbers of children with Adverse Childhood Experiences, family histories of mental illness, especially depression and bi-polar disorder and a variety of behavior and learning problems. In order to develop the best treatment/intervention approach, each co-occurring diagnosis must be addressed. This poster may seem somewhat controversial but we know that all challenging behaviors are not related to prenatal alcohol exposure. Without a complete diagnosis of all co-occurring disorders, the proper support and treatment cannot be provided and could even be detrimental to the child and family.

### 35. Focus on protecting children from FASD through prevention, harm reduction and treatment during pregnancy

Frid Hansen

#### NORWAY

#### FOCUS ON PROTECTING CHILDREN FROM FASD THROUGH

- \* PREVENTION
- \* HARM REDUCTION
- \* TREATMENT DURING PREGNANCY

#### NATIONAL GUIDELINES

Alcohol free pregnancy is recommended by The Norwegian Directorate of Health

#### INFORMATION

##### THE BEST POSSIBLE START

Advice for those planning or expecting a child

The national guidelines imply that doctors and midwives give information to all pregnant women about the risks of damage to the child caused by alcohol, and recommend an alcohol free pregnancy. The Norwegian Directorate of Health has published this brochure in Norwegian, Lappish, English, Spanish, Polish and Russian.

[www.helsedirektoratet.no/gravid](http://www.helsedirektoratet.no/gravid)

#### SCREENING

TWEAK is a prenatal screening test for risk drinking during pregnancy.

The Directorate of Health recommends that doctors and midwives use this test on all pregnant women, in order to detect and prevent use of alcohol that may damage the child.

#### LEGISLATION THAT MAKES POSSIBLE DETENTION WITHOUT CONSENT DURING PREGNANCY

Social Services Act - Section 6-2a

Pregnant substance abusing women can be detained without consent during pregnancy if their substance abuse makes it overwhelmingly likely that the foetus may be harmed and voluntary assistance is insufficient.

The main intention behind this act, which implies compulsion, is to protect the unborn child and prevent/reduce substance related damages. Furthermore, the pregnant woman is offered treatment in order to be able to take care of the child after birth - if possible.

#### TREATMENT DURING PREGNANCY

On a voluntary basis

Detention without consent under the Social Services Act

For further information, contact:

Borgestadklinikken, Norway

A treatment center and center of expertise for problems related to substance abuse during pregnancy and in families with young children.

[info@borgestadklinikken.no](mailto:info@borgestadklinikken.no)

[www.borgestadklinikken.no](http://www.borgestadklinikken.no)

### 36. Ethyl Glucuronide and Ethyl Sulfate In Human Placenta and Fetal Tissues; Potential Biomarkers of Maternal Alcohol Intake During Pregnancy

L. Morini, M. Falcón, S. Pichini, O. Garcia-Algar, O. Vall, P. Danesino, A. Groppi, A. Luna

Toxicity of ethanol during first trimester of pregnancy in humans is well known, but toxic mechanisms and ethanol effects on the placenta and the fetus development are not yet fully clarified. Toxicokinetics of ethanol and materno-placental and fetal metabolism during early pregnancy could be useful for a deeper understanding of Fetal Alcohol Spectrum Disorder. The aim of this study was to develop a method for the direct determination of ethyl glucuronide (EtG) and ethyl sulfate (EtS), in placental and fetal human tissues, as potential biomarkers of ethanol exposure during the first trimester of pregnancy.

**Methods:** Placental and fetal tissues samples were obtained from women undergoing voluntary termination of pregnancy at 12th week of gestation. After addition of D5-EtG and D5-EtS as internal standards, samples were deproteinized with acetonitrile, centrifuged and diluted 1:10 in bidistilled water. Then an aliquot was directly injected in a LC-MS/MS system, operating in negative polarity and in MRM mode, by monitoring two reactions for each analyte. A LOD of 3 and a LLOQ of 5 pg/mg were reached for both metabolites and a six-point calibration curve ranging from 5-1000 pg/mg was used for quantification purposes.

**Results:** The method was fully validated and applied to 24 placenta-fetal tissue samples. Two out of 24 cases tested positive for EtG and EtS for both placenta and fetal tissues (Table).

	Case 1	Case 2		
	Placental tissue	Fetal tissue	Placental tissue	Fetal tissue
EtG pg/mg	122.2	33.2	1305.8	391.0
EtS pg/mg	50.7		under the LLOQ	

**Conclusion:** For the first time an analytical method was set up and validated for the determination of EtG and EtS in placental and fetal tissues. Preliminary results suggest that these metabolites are present in both tissues of pregnant women and can be further evaluated as specific markers in the diagnosis of alcohol intake during pregnancy.

### 37. An observatory on newborns with microcephaly

Luigi Tarani, Alberto Spalice, Lucilla Manganozzi, Martina Fiochi, Marzia Trivelli, Mauro Ceccanti

In utero exposure to alcohol can have numerous adverse effects on a developing fetus. These effects represent a spectrum of structural anomalies and neurocognitive and behavioral disabilities that have recently been termed fetal alcohol spectrum disorders. Children, at the most severe end of this spectrum displaying the complete phenotype of characteristic facial anomalies, growth retardation and developmental abnormalities of the central nervous system, are defined as having fetal alcohol syndrome. While FAS is the most readily clinically recognized form of FASD, other categories within the continuum of adverse effects due to prenatal alcohol exposure are becoming better defined. These include partial fetal alcohol syndrome, alcohol-related birth defects and alcohol-related neurodevelopmental disorder. We selected 108 newborns (52 male, 49 female, 4 twin male, 3 twin female) with cranial circumferences < 10 centile, born at Policlinico Umberto I Rome between July 2009 and December 2009 (total = 936). Every neonate will be included in a yearly follow-up program: 1 pediatric examination 2 neurological examination to evaluate the psychomotor development 3 if necessary, magnetic resonance imaging to confirm reduction in brain volume and central nervous system disorganization, specific structural abnormalities 4 food frequency questionnaire to evaluate dietary practices during the pregnancy. Because FASD is one of the main cause of preventable mental retardation and represents a major public health concern, early recognition of at-risk children is important for initiating interventional strategies. The aim of this observatory is to educate practicing about the recognizable phenotypes of FASD in order to accurately identify these children and implement the most appropriate management plans.

### 38. Fetal Alcohol Spectrum Disorder Prevention: Canadian Perspectives

Holly Mackay and Nancy Poole

**Objective:** This is a prevention model based on the collaborative efforts between the Government of Canada and women's health experts who identified the need to develop a model for a multifaceted and multilevel response to improve Canada's capacity to prevent Fetal Alcohol Spectrum Disorder.

**Methods:** Different sectors are identified to deliver four levels of prevention including, but not limited to: community based prevention specialists and advocates, health care and other service providers, prenatal outreach and care providers, addictions and mental illness treatment providers, postpartum care providers.

**Results:** The prevention activities span general and specific practices that assist women to improve their own health and the health of their babies, with support from family, support networks, services and community. This model describes activities in community settings that are found to be effective in delivering FASD prevention. The model includes four levels of prevention:

- public awareness and community development strategies;
- health promoting discussions between women of childbearing years and service providers;
- provision of specialized, holistic pregnancy outreach services; and
- support for new mothers in the post partum period.

**Conclusion:** This model provides examples of the four levels of prevention in action, as identified by prevention specialists from across Canada. It also highlights what we have learned from the delivering prevention activities and programs over time.

### 39. Early Primary School Outcomes Associated with Children's Prenatal Exposure to Alcohol and Tobacco from the Better Beginnings, Better Futures Study

Mary Johnston, Ray Dev Peters, Kevin Parker

#### Objectives

The analysis of data from the Better Beginnings, Better Futures Study demonstrates the relationships between prenatal exposure to alcohol and nicotine separately and in combination on developmental outcomes in young children over the first four years of primary school.

#### Methods

Measures in five domains of child development outcomes were analyzed: general development, cognitive development/ academic performance, social/emotional functioning, physical health, and behavior problems. Analyses were designed to determine whether prenatal exposure to alcohol and/ or nicotine may have differential effects on these aspects of children's functioning during the early primary school years. The analyses were carried out on a longitudinal data set comprised of over 400 children.

#### Results

The results indicated that children whose mothers reported high-risk alcohol consumption during pregnancy showed negative outcomes on measures of school performance and behaviour problems and that those outcomes were accentuated in children whose mothers also reported smoking during the pregnancy.

#### Conclusions

These findings support other studies indicating that prenatal alcohol use does affect the outcome of children and that negative effects are compounded by smoking. It highlights the need for further studies involving the effect of prenatal use of multiple substances on children's outcomes.



#### 40. Development of a model to determine the economic impact of Fetal Alcohol Spectrum Disorder (FASD) in Canada

Mary Johnston

##### Objectives

The need for data illustrating the significant economic costs of FASD was identified by experts from a policy and program perspective, e.g., public health, education, justice, corrections, social welfare and others. As the incidence of FASD internationally is estimated to be 9 in 1000 live births, this model may be of use in other countries.

##### Method

The Government of Canada hosted the first National Roundtable with representation from the cross-jurisdictional and cross-sectoral partnerships to identify the components and their interactions necessary to calculate the cost of FASD.

##### Results

This overview of the Economic Impact Model provides highlights from the development of the methodology for calculating the economic impact of FASD on society and includes a systematic review of literature on the economic impact of FASD, studies relating to general costs of FASD, costs in the correctional services system, and data from a study of the costs of children in care with FASD.

##### Conclusions

Based on a report published in 2009 (Stade et al), the annual cost of FASD in Canada for individuals aged 0 to 53 years was \$5.3 billion. This data did not include the costs of children in care of child protection services, special education, costs to the justice system and other elements. A more complete cost estimate, including all affected systems, is important in identifying potential intervention points and the cost-benefit of various interventions.

#### 41. A Systematic Review of Literature and Data on Alcohol Use by Canadian Women of Childbearing Age: Identifying Policy and Program Implications

Reetha Parthiban

**Objectives:** The Government of Canada commissioned a review of the literature and data on Canadian women's alcohol consumption patterns and trends.

**Methods:** A review was conducted on Canadian literature and data associated with women of childbearing age (i.e., 11-55 years of age) alcohol use. This study followed a multi-systemic approach that incorporated sociological perspectives, ecological systems perspectives, social constructionism and bio-psychosocial perspectives.

**Results:** This review provides data from 10 national, 10 provincial and 1 territorial study. One aspect of the study looked at binge drinking (5+ drinks on one occasion). Recent national studies of adult female binge drinking observed a range from 13% (2005 Canadian Community Health Survey and 2004 Canadian Campus Survey of undergraduates) to 21.5% (2004 General Social Survey), indicating a slight upward trend in risky drinking patterns among females.

**Conclusion:** Comparing surveys over time and between regions is challenging because of inconsistent measures and a lack of data with a gender perspective. The review, however, indicates a change in the pattern of women's alcohol use and presents details summarizing the drinking patterns and the background determinants.

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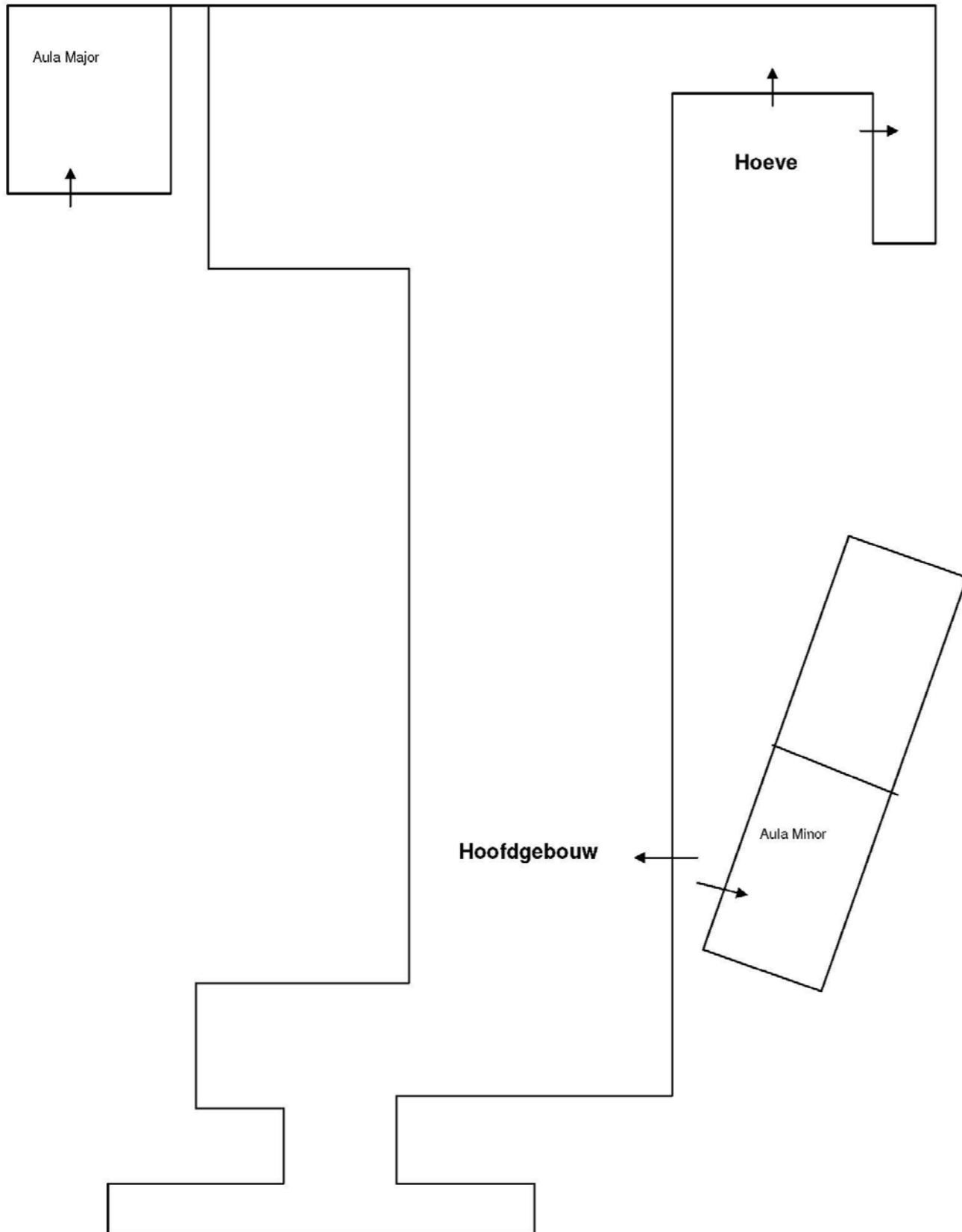
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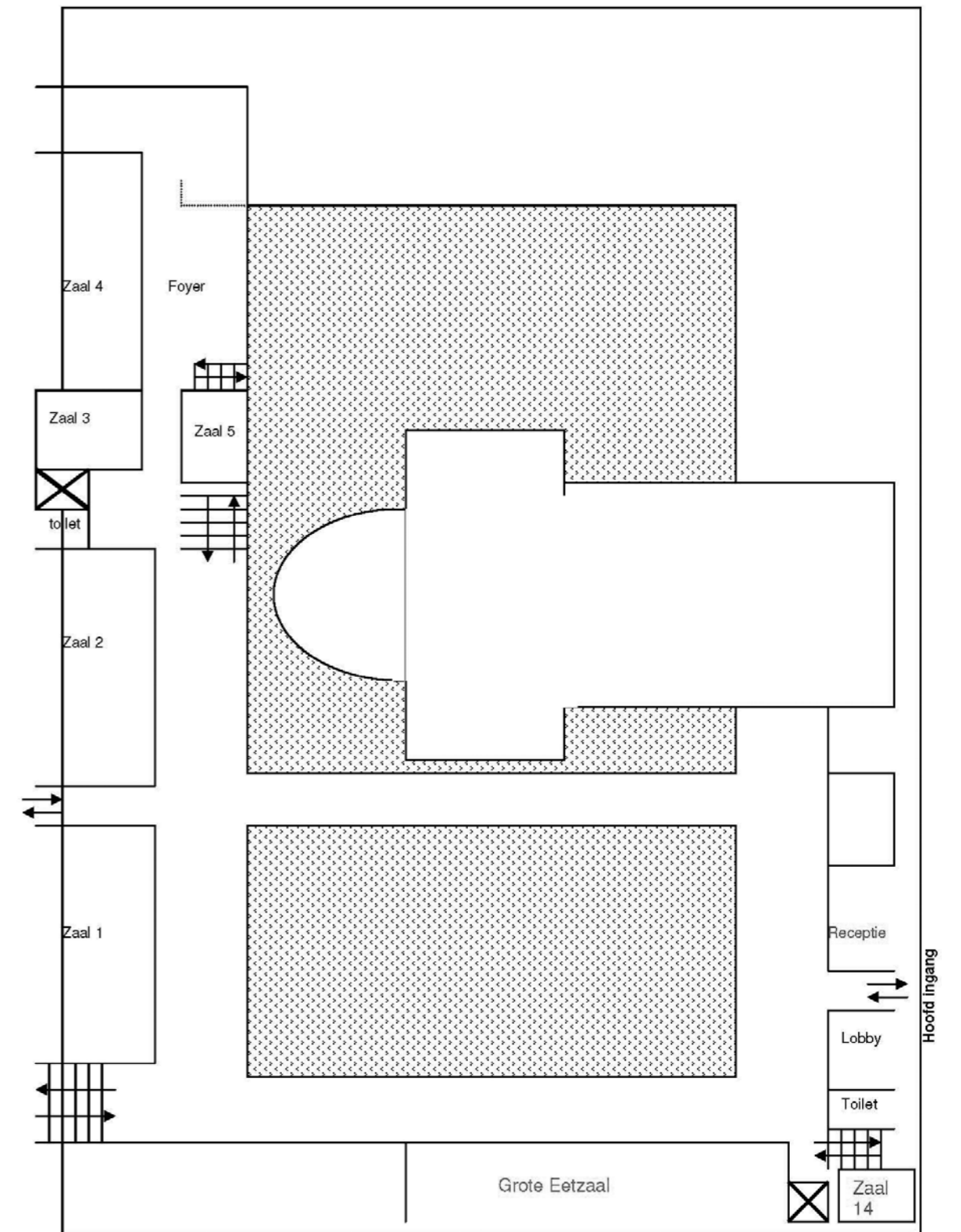
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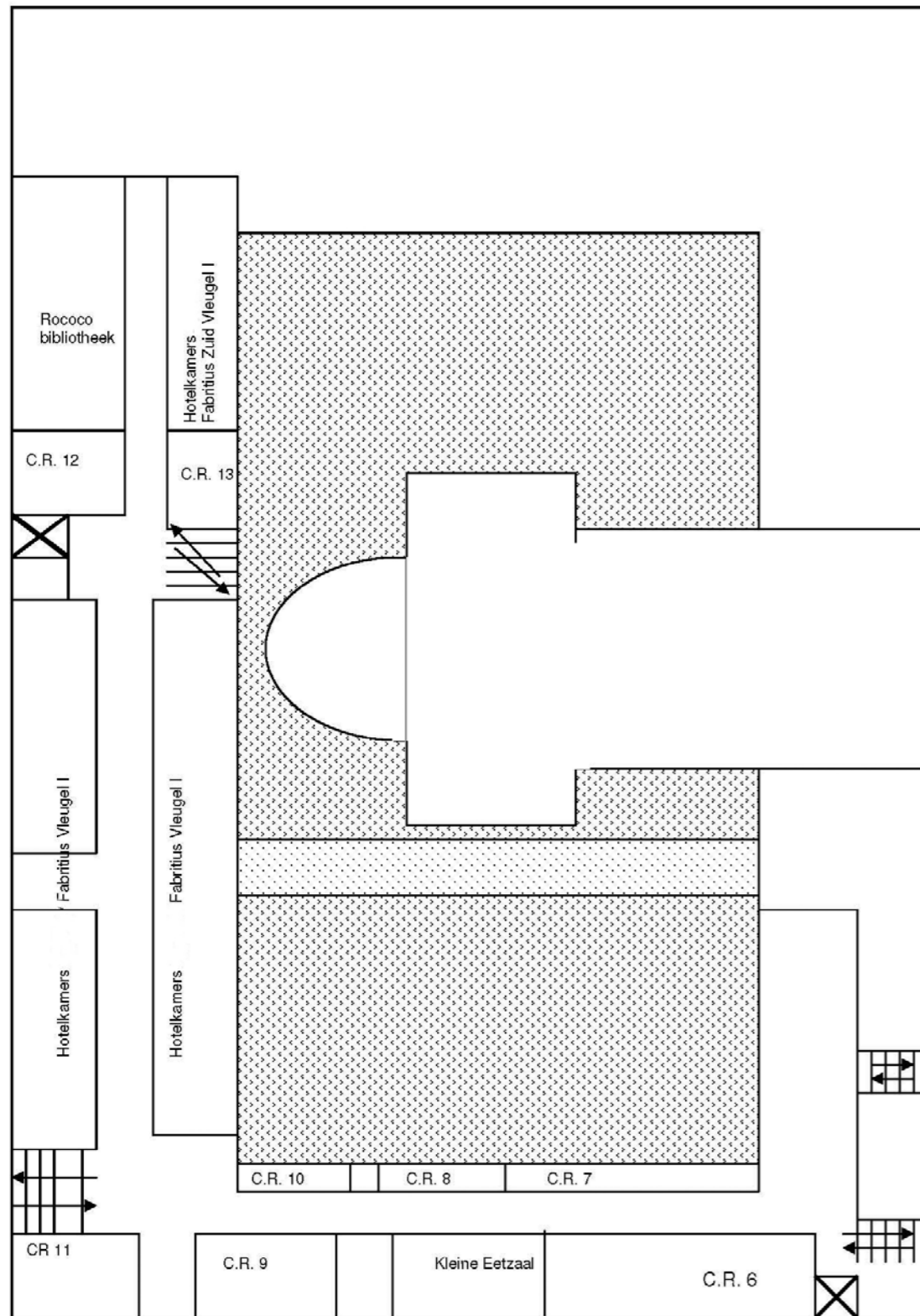
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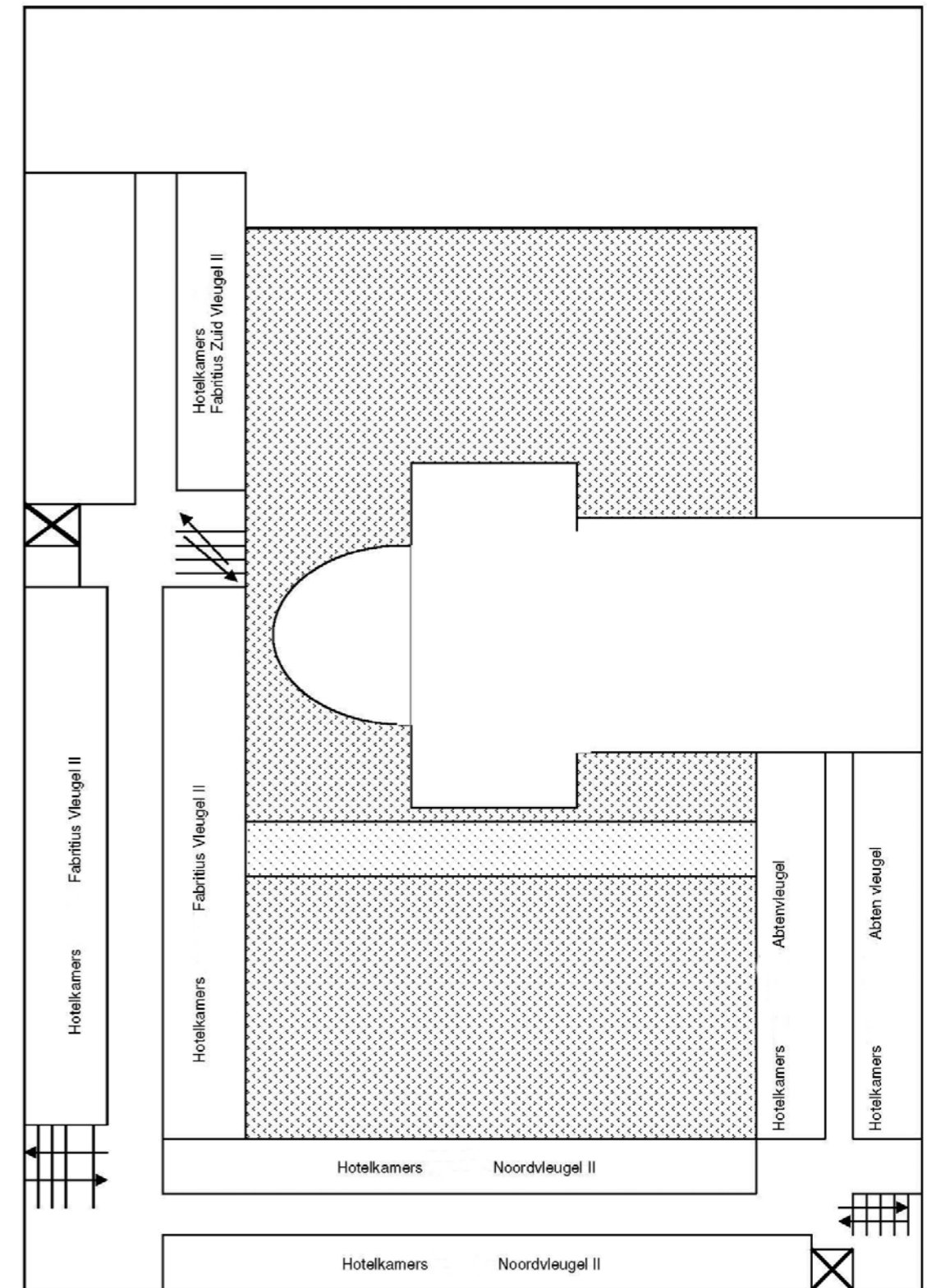
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