



The 5th European Conference on FASD was held from 24 to 26 September, 2018, in Berlin. There were 249 attendees from 26 countries including Finland, Spain, Denmark, Slovak Republic, Canada, Brazil and Australia. The program book with all abstracts is now available at http://www.eufasd.org/EUFASD_2018/Program_book_EUFASD2018.pdf.

Monday sessions

The opening lecture, presented by Dr. Thierry Maillard, presented an overview of the life of Dr. Lemoine, whose publication on abnormalities in children of alcoholic mothers appeared 50 years ago.

The morning session was devoted to questions of prevention, with special focus on evidence-based prevention, highlighting successful programs among aboriginal communities in Australia and South Africa, as well as prevention research in Canada.

The morning closed with a rapid fire series of 5-minute updates from Romania, Spain, UK, Scotland, France, Slovenia, Poland, Australia, Finland, and the Slovak Republic. For more detail, see Appendix 1.

In the afternoon, there were two rounds of parallel sessions, covering topics including assessment of neurocognitive function, secondary disorders, prevention, guidance of adults with FASD, physical growth and traits, diagnosis, and raising and educating children with FASD.

Tuesday sessions

Tuesday morning began with several talks on biology of FASD. In a keynote lecture, Prof. Michael Kobor highlighted the emerging role of epigenetics in fetal alcohol spectrum disorder, including the interface between environments and the genome in the context of the origin of disease concept, the studies illustrating how early life adversities can become embedded into our genome, and recent epigenetic signatures of human fetal alcohol spectrum disorder.

In a second keynote lecture, Dr. Miguel Del Campo showed that overall contributions of MRI and EEG to the diagnostic clinical evaluation and management of FASD justify their use in the clinic.

Then Luis Castillo described the development of an expert App tool using last mobile technologies for the first screening assessment by health care workers in front of children with a risk or suspicion of FASD. The sessions continued with lectures on sleep, the ADEF Helsinki research project, and FASD in the youth justice system in Australia.

The Tuesday afternoon session was opened by Dr. Pietsch, Speaker for the Federal Drug Commissioner. Then we viewed a short film prepared by German adults with FASD, and heard the moving story a young Dutch woman who lives with FASD. The viewpoint of an adoptive mother was presented, too. Further we heard stories from professionals from South Africa, Scotland, and the UK.

The last plenary sessions on Tuesday were about interventions, including the use of the ICF framework for understanding the needs of persons with FASD as well as learning about educational and behavioral interventions for children and youth.

The afternoon closed with parallel session on topics including interventions, legal issues, supporting carers, training professional and prevention.

Gala dinner

The gala dinner was held on Tuesday evening. During the course of the dinner, various prizes were awarded. The top poster prize went to the German adults with FASD for their poster depicting the the FASD tree that shows the positive and negative effects of the FASD.

The second poster prize was awarded to Fiona Burslem from Scotland, for her poster on Communicating Brain Domains. Lifetime achievement awards were presented to Kenneth Warren, Edward Riley, and Hans Spohr recognizing their work and invaluable support of the EUFASD Alliance over the years.

Wednesday sessions

Wednesday morning opened with a keynote lecture by Prof. dr. Hans Spohr with reflections on the difficulty of FASD to be accepted as a diagnosis. In the second keynote, Dr. Kenneth Warren gave a historical overview of the missed clues in the recognition of the effects of prenatal alcohol exposure. Finally, Prof. Arjan Bos addressed the issue of stigma and how to fight it.

After the coffee break, we heard from Prof. Ed Riley on the activities of CIFASD and from Mariann Skar on policy developments and action at EU level. There followed several short presentations on the importants of networks, at the local, national and international levels.

During the closing ceremonies, the new Board was announced (see below) and the site of the 2020 conference was announced: Arendal, Norway. To be held 14 to 16 September 2020.

Scholarships



(left to right)

Marcella Broccia is a doctor and Ph.D. student from Denmark. She says it has been a huge opportunity to meet other people with the same passion. The knowledge is very supportive, and she will go home inspired by everything she heard and by the people

she met. Gabi Mitrani, an adoptive mother from Israel, is very grateful for the opportunity to come and to tell her story. When she found out that her son had FAS everything in her life changed. Suellen Baggio is a PhD student from Brazil. She works with zebrafish and FASD. Her work is shown in a poster presentation. She has been learning so much!

Newly elected Board (to sit from January 1, 2019 until December 31, 2020)

Chairperson: Diane Black (Netherlands)

Assistant chairperson: Gro Løhaugen (Norway)

Secretary: Thierry Maillard (France)

Assistant secretary: Magdalena Borkowska

Treasurer: Katarina Wittgard (Sweden)

Assistant Treasurer: Theresa Millqvist (Sweden)

Board members general:

Jon Skranes (Norway)

Oscar Garcia-Algar (Spain)

Philippa Williams (UK)

Martha Krijgsheld (Netherlands)

Simona Pichini (Italy)

Gisela Michalowski (Germany)

Teodora Ciolompea (Romania)



Appendix 1: Summary of 5-minute talks

The problem of awareness and interventions related to fetal-alcohol syndrome was presented by several countries like Romania, Spain, Netherlands, United Kingdom, Scotland, France, Slovenia, Poland, Australia, Finland and Slovak Republic. During the plenary session of the first Congress day: What's Happening in my country? Representatives of these countries described the initiatives undertaken in the recent years.

Specifically:

Teodora Ciolompea of Romania in her intervention "Benefits of a new prevention and intervention program for population at risk for FASD" presented a multi-focus program that combines an awareness campaign to reduce alcohol use during pregnancy with professional training for medical staff and social services to introduce a community clinical prenatal and neonatal screening protocol and medical follow-up after birth at least for the first year of life for the newborns exposed to alcohol during pregnancy.

Spain, in the person of Oscar Garcia-Algar, reported on "Foetal Alcohol Spectrum Disorder (FASD) in adopted children from East Europe countries in Spain" describing the prevalence of FASD between children adopted from East Europe countries (Russia and Ukraine) in Barcelona (Spain) across prospective, observational, multidisciplinary, cross-sectional, cohort study proving that FASD was common in children adopted from orphanages in East Europe countries.

Martha Krijgsheld in "What's happening in the Netherlands" explained that they tried to spread awareness by continually building up networks and expanding knowledge of FASD in the Netherlands. They have trained a group of volunteers to give information and lessons in schools, adoption organizations, foster caregivers and other groups of interested people. Moreover, they support special groups, including parents of children with FASD, adults with FASD, and birth mothers. They have a lively Facebook account with a lot of interaction and good information about FASD and in 2017 they introduced a FASD pass, a special card for (young) adults to help them explain FASD in complicated situations.

In the United Kingdom, a local assessment pathway for FASD was set up in Brighton and Hove in 2016. Michelle Bond in "Establishing a local assessment pathway for FASD within a Community Child Development Service" explained that the Washington 4-digit code (Astley SJ et al.) was used as the assessment method for FASD. Pediatricians and a psychologist from the service underwent online training and a clinical pathway was established. Documentation of the four key areas for FASD diagnosis was improved for children assessed as part of the pathway. The time taken to reach diagnostic formulation was also improved and outcomes were clearer.

A different strategy was instead adopted in Scotland, as Sarah Brown commented in “What’s Happening in My Country – Scotland, UK” where a whole population approach has been adopted, aimed at reducing consumption, supporting affected families and communities, and improved treatment and support for alcohol-related issues. Within local health boards FASD-specific initiatives were increasing e.g.: pre-pregnancy and pregnancy advice services; appointment of a FASD Program Manager driving service development in prevention, identification, diagnosis and support.

In France, a network of neuropsychiatrists able to diagnose the disease was created. The same steps were taken to create a network of psychiatrists to support adults with FASD. Catherine Metelski in “FASD: What is happening in France?” explained that six regional antennas had also been created to foster closer contacts between our members and local professionals. Regular conferences had been held to raise awareness among professionals: school teachers, medical doctors, but also job centres, the Police, and the Justice System. Moreover, the Ministry of Health has announced steps to increase the visibility of the logo on alcohol containing bottles and two Resource Centers have been created for diagnoses and support.

In their speech “What’s happening in Slovenia?”, Matej Kosir and Marjetka Hovnik-Keršmanc informed the audience that NIPH carried several key messages regarding alcohol exposure in pregnancy or during breastfeeding through traditional and social media, stands in larger cities, calls to health professionals and students, video campaigns etc. Main activities were focused on information and awareness campaigns in media, particularly social media (2014-2017), conducting surveys among health professionals and women of childbearing age. Several conferences, workshops and lectures have been conducted in previous years by NIPH for health professionals and students, women of childbearing age and staff in restaurants, bars and pubs as well.

“Looking for the agreement on the Polish guidelines for diagnosis of Fetal alcohol spectrum disorder” was the intervention of the Polish Katarzyna Okulicz-Kozaryn. The State Agency for Prevention of Alcohol Related Problems (PARPA) in cooperation with the Warsaw Medical University and St Louis Children's Hospital in Krakow initiated the project aimed at reaching the professionals’ agreement on the standards for FASD diagnosis in Poland. The process of agreeing on the Polish standards will consist of several steps, starting from the elaboration of the questionnaire to collect experts' opinions on the quality of each recommendation, completing the list of stakeholders to be questioned and looking for the experts consensus.

In the presentation “My Country 5 Minute Update—Australia” Elizabeth Elliott provided a status report on achievements relating to FASD in Australia. Advances in prevention, diagnosis, clinical management and non-clinical interventions was noted, gaps identified and

future directions outlined. The main key initiatives included: the establishment of a national website - FASD Hub Australia; an information repository for health professionals, researchers, policy makers and families; the establishment of a National FASD Register and the establishment of an Australian Centre of Research Excellence. Despite significant progress in addressing FASD in Australia, significant needs remain particularly in capacity to provide diagnostic and clinical services and support for individuals across the lifespan.

Sari Somer, FASD Coordinator of FAIDD, in “Support groups for young FASD Adults” explained to the audience that in Finland support groups for young adults with FASD have been organized since 2009. Young adults have profited a lot from support groups that they have helped them to move on with their lives, look to the future, face adulthood challenges and reach dreams. Because of the excellent results, Sari Somer hoped that support groups for young FASD adults will be a permanent part of the foster care system in the future.

The last speaker Šebeková Veronika in her speech “Multidisciplinary teams platform and screening algorithm indicating the presence of FASD by preschool children in the system of early intervention in Slovak republic” specified that unfortunately Slovak specialists are not yet trained in screening, prevention, and at moment they are unable to coordinate mediation of interventions with other professionals, so there is an urgent need to network early (0-7 yr.) intervention actors into active childcare with the FASD in Slovakia.