Mednarodni strokovni simpozij

na temo

»Spekter fetalnih alkoholnih motenj (FASD): kako ga preprečevati, prepoznati in obravnavati«

četrtek, 11. april 2019

Zdravstvena fakulteta Univerze v Ljubljani,

Zdravstvena pot 5, Ljubljana

08:00 Registracija udeležencev

09:00 Uvodni nagovori

09:10 Spekter fetalnih alkoholnih motenj (FASD) – trenutno stanje na področju problematike in mednarodnih pristopov preprečevanja, prepoznavanja in obravnavanja FASD
***Diane Black**, Evropsko združenje EUFASD*

09:40 Kognitivna funkcija in komorbidnost pri FASD
***Gro Løhaugen**, Bolnišnica Sørlandet, Oddelek za pediatrijo, Arendal (Norveška)*

10:25 Koraki Slovenije na poti preprečevanja izpostavljenosti otrok alkoholu pred rojstvom in zmanjševanju s tem povezane škode
***Marjetka Hovnik Keršmanc**, Nacionalni inštitut za javno zdravje (NIJZ) (Slovenija)*

10:45 *Odmor*

11:15 Vzgoja otrok s FASD – zgodba rejniške matere
***Martha Krijgsheld**, Fondacija FAS-stichting (Nizozemska)*

11:35 FASD v programih zdravljenja zasvojenosti: primer iz Bukarešte
***Teodora Ciolompea**, Bolnišnica Saint Stelian, Center za diagnostiko in zdravljenje zasvojenosti z drogami, Bukarešta (Romunija)*

11:55 Biomarkerji za odkrivanje izpostavljenosti alkoholu pred rojstvom
***Simona Pichini**, Nacionalni center za zasvojenost in doping, Nacionalni inštitut za zdravje, Enota za analitično farmakotoksikologijo, Rim (Italija)*

12:15 Vključevanje skupnosti v preventivo in podporo
***Thierry Maillard**, SAF Ocean Indien, Saint-Louis (Francija)*

12:35 Razprava

12:45 *Kosilo*

13:45 - 14:45 Paralelni sekciji A

A1 Prepoznavanje (diagnosticiranje) oseb s FASD
***Jon Skranes**, Bolnišnica Sørlandet, Oddelek za pediatrijo, Arendal (Norveška)*

A2 Podpora družinam pri vzgoji otroka s FASD
***Jan de Vries**, ZO!, Leeuwaarden (Nizozemska)*

15:00 - 16:00 Paralelni sekciji B

B1 Obravnava otrok s FASD v zdravstvu
***Oscar Garcia Algar**, Hospital Clinic Barcelona (porodnišnica), BCNatal, Enota za neonatologijo, Barcelona (Španija)*

B2 Na dokazih temelječa preventiva FASD
***Sylvia Roozen**, Univerza v Maastrichtu, Maastricht (Nizozemska)*

16:00 Zaključna plenarna razprava (vodi **Matej Košir**, Inštitut UTRIP)

16.30 Zaključek simpozija

Sofinancer dogodka:

REPUBLIKA SLOVENIJA
MINISTRSTVO ZA ZDRAVJE

FETAL ALCOHOL SPECTRUM DISORDER (FASD) – BASIC INFORMATION

Oscar Garcia-Algar[1], Simona Pichini[2], Diane Black[3]

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Introduction

The knowledge of the dangers of alcohol consumption during pregnancy is not a new issue, as shown by the fact that even the ancient Greeks and Romans had a rudimentary awareness of the association between maternal alcoholism and abnormal development (Brown et al. 2018). The physical and behavioral archetypes of more than 100 children of women who drank during pregnancy were then well documented by Lemoine in 1968 (Lemoine et al. 2003), with definitive diagnostic criteria to indicate the fetal alcohol syndrome (FAS) condition published by Jones in 1973 (Jones et al. 1973). Thereafter, several thousand articles on the effects of prenatal alcohol exposure among human subjects and animal models have been produced and underscored that the adverse effects of alcohol on a developing being comprise a spectrum of structural anomalies and behavioral and neurocognitive disabilities, most accurately termed fetal alcohol spectrum disorders (FASD). In 1996 the terms alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) were proposed to describe different outcomes associated with a history of maternal alcohol exposure – defined as substantial regular intake or heavy episodic drinking – validated by clinical or animal studies (Stratton et al., 1996). Thus, FAS is not a single entity but represents the most severe form of a spectrum of disorders, known as FASD. Recent animal models, used to study the effects of various regimens of alcohol administration, have resulted in remarkable phenotypic similarities with the features of FASD in humans, including distinctive craniofacial alterations, stunted growth and behavioral abnormalities (Petrelli et al. 2018). They have shown that clinical severity after *in utero* ethanol exposure correlates either with the developmental stage (timing exposure) or with the dose and the frequency of exposure (acute versus chronic exposure). FASDs are probably the result of complex gene-environment interactions that alter gene

expression patterns, especially during development; even if the first trimester is considered the most vulnerable period, the fetal damage might occur throughout all gestation.

Epidemiology

FASD can be considered as the commonest preventable cause of acquired mental disability; it has been observed in all societies in which women drink alcohol during pregnancy, and constitutes a serious problem for the individual and society, in terms of human suffering, lost productivity and medical and social monetary costs.

At present, there are no systematic data on ethanol consumption during pregnancy and consequent fetal exposure to this toxin in any European country. Most of the research on the prevalence of FAS and FASD comes from North America. State-based estimates of the prevalence of FAS in the United States vary from 0.3 to 1.5 per 1,000 live-born infants, whereas the highest prevalence of FAS worldwide was reported in a wine-growing region in the Western Cape province of South Africa with a FAS prevalence of 40.5 to 46.4 per 1,000 children aged 5–9 years in one community in Western Cape (Roozen et al. 2016). In Europe, studies have shown that a substantial number of physicians feel that they lack the training to diagnose FASD (Vagnarelli et al. 2011).

Regarding drinking in pregnancy, several European studies have reporting alarming figures, for example, up to 45% in Barcelona (Garcia-Algar et al. 2008). In a Russian study, over 50% of women in one area were at risk for an alcohol-exposed pregnancy (Balachova et al. 2012).

Furthermore there have been several local studies on prevalence of FASD in Europe. A field study aimed to assess the prevalence of FAS and FASD by retrospective cohort study, was carried out in a restricted area of Rome province and reported a striking FAS and FASD prevalence of 0.37 and 2.3% in examined children, respectively (May et al. 2006). The most recent Italian National Surveys on use and abuse of alcohol show that the percentage of women of childbearing age who declare daily intake of any alcoholic drink is around 7% between 18 and 44 years of age, while that of risky consumers, those who declare to exceed the daily

ethanol dose of 20 g is 6.8 at 18–24 and 4.6% at 25–44 years of age (Vagnarelli et al., 2011). It is thus conceivable that a significant number of women who are not only problem drinkers but also social drinkers with high ethanol consumption and are of child bearing age will not refrain from ethanol drinking during pregnancy and may give birth to an infant *in utero* exposed to this toxin.

Other prevalence studies have been carried out in Croatia and Poland. In Zagreb, Croatia, Petković et al. (2013) found prenatal alcohol consumption was admitted by 15.47% and binge drinking by 3.13% of interviewed mothers. Four hundred sixty-six schoolchildren were evaluated for signs of FAS or partial fetal alcohol syndrome (PFAS) using revised Institute of Medicine (IOM) diagnostic criteria. Nineteen students had features consistent with FAS or PFAS. Full FAS was found in 3 children and PFAS in 16 children among 466 students, based on 51% participation rate. The estimated prevalence of FAS was 6.44/1000, of PFAS 34.33/1000 and overall prevalence of FAS/PFAS 40.77/1000. A similar active case ascertainment study in Poland found an overall rate of at least 2% of FASD (Okulicz-Kozaryn et al. 2017).

FASD is more prevalent in some particular groups. For example, among adopted children from East Europe countries, prevalence of FASD has been shown to be about 50% in Sweden (Landgren et al. 2010) and in Spain (Andreu-Fernández 2018). Furthermore, a Canadian study showed that youths with FASD were 19 times more likely to be incarcerated than the general population (Popova et al. 2011).

Diagnostic criteria

Early diagnosis and treatment are indeed crucial for a better developmental outcome and in the meantime allowing prevention of additional cases of FASD in the family, through antenatal counseling and care services. Several sets of diagnostic criteria are in common use, including the 4-digit code of Astley et al. (2013) and the so-called Canadian criteria of Chudley et al. (2005).

In the 4-digit code criteria of Astley et al., scores are given to codify the magnitude of expression of the four key diagnostic features of FASD: (1) growth deficiency, (2) the FAS facial features, (3) central nervous system (CNS) structural and functional abnormalities, and (4) prenatal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FASD feature and 4 reflecting a strong "classic" presence of the FASD feature.

Other commonly used guidelines are those of Hoyme H.E et al, who proposed a practical clinical approach to diagnosis of FASD, reviewing the 1996 Institute of Medicine Criteria of the National Academy of Sciences. These guidelines were updated in 2016 (Hoyme et al. 2016).

Establishing the history of alcohol consumption is one of the most difficult issues in diagnosing FAS, since the pregnant woman who consumes alcohol is not always easily identified. Patients usually are not forthright about their drinking habits nor are they necessarily able to recall the precise quantities and timing of their drinks. The challenge for the physician is to identify women who are drinking alcohol during pregnancy since, in the absence of a specific biomarker to detect alcohol exposure, the history remains pivotal in the diagnosis. A systematic drinking history is thus essential and should be obtained by a skilled interviewer from all patients, during the initial history and in subsequent prenatal care, since most problem drinkers cannot be identified by appearance or by socioeconomic characteristics.

As far as the clinical diagnosis is concerned, full-blown FAS denotes a specific pattern of malformations and minor anomalies of the face, prenatal onset of growth deficiency (length and/or weight) that persists postnatally and neurocognitive deficits with a confirmed history of maternal alcohol abuse during pregnancy. The classical dysmorphic facial features of FAS include a rather flat midface with short palpebral fissures, a low nasal bridge with short nose, and long smooth or flat philtrum with a narrow vermillion border of the upper lip.

In the most severely affected children, FAS can be diagnosed at birth; however, the characteristic physical features are most pronounced between eight months and eight years of age. Presenting as small-for-gestational-age babies, but with microcephaly in the neonatal period, they continue to grow poorly and often are admitted to hospital for evaluation of

“failure to thrive”. They may be described as jittery or tremulous babies, a feature that often results in confusion with drug withdrawal symptoms; however, these neurologic abnormalities persist and, in addition to developmental delay and mental retardation, such children often have poor coordination, and may be tremulous and sometimes hyperactive in later life.

Approximately 80% of children with FAS also have microcephaly and behavioral abnormalities. Neuropathologic examination often shows abnormalities of neuronal migration, hydrocephaly, absence of corpus callosum, and other midline anomalies, as well as cerebellar abnormalities. As many as 50% of affected children also exhibit hypotonia, decreased adipose tissue and other identifiable facial anomalies, such as maxillary hypoplasia, cleft palate, and micrognathia. Cardiac defects (especially atrial and ventricular septal defect), hemangiomas, eye (microphtalmia) or ear abnormalities, joint anomalies and a variety of dermal and skeletal abnormalities are also common.

FASD must always be a diagnosis of exclusion. Since the face of FAS is the result of a non-specific effect of ethanol teratogenesis altering growth of the midface and brain, children exposed to other embryotoxic agents such as solvents, hydantoin, phenobarbital, trimethadione, valproic acid, or with maternal phenylketonuria display common similar phenotypic effects on facial development, impaired growth, a higher frequency of anomalies, and developmental and behavorial abnormalities. Many genetic syndromes have some of the clinical features of FAS, and children with other genetic and dysmorphic syndromes are born as frequently to women who abuse alcohol as they are to other women in the general population. Therefore, a diagnosis in the FASD continuum should not automatically be assigned to a child with disabilities, merely because his or her mother drank alcohol during the pregnancy. A careful examination by a trained dysmorphologist and/or specific genetic testing may be necessary.

Biomarkers

When a diagnosis of FASD is suspected, it is necessary to look for the related congenital malformations with a cerebral MRI, a cardiac and abdominal sonography, and also to exclude a chromosomal disease with a karyotype analysis.

As prenatal exposure to ethanol has been considered one of the principal diagnostic criteria (or the principal itself) for FAS and FASD, an early postnatal investigation of several biomarkers in meconium, besides clinical and neurological follow-up of exposed newborns, has been suggested.

In recent years, fatty acid ethyl esters (FAEEs) in meconium have emerged as reliable, direct biological markers for establishing gestational ethanol use and consequently prenatal exposure to alcohol (Pichini et al. 2012). Following maternal intake, ethanol crosses the placenta and FAEEs are formed by esterification of ethanol with endogenous free fatty acids via a non-oxidative pathway with the help of FAEE synthase. The newly formed metabolites (FAEEs) are excreted in meconium. The total amount of seven FAEEs (palmitic, palmitoleic, stearic, oleic, linoleic, linolenic and arachidonic acid ethyl esters) equal to or above 2 nmol/g meconium has been the accepted cut-off to differentiate heavy maternal ethanol consumption during pregnancy from occasional use or no use at all.

There are two other direct phase II metabolites of ethanol: ethyl glucuronide (EtG) and ethyl sulphate (EtS) formed by ethanol conjugation with glucuronic acid and by the transfer of a sulfuric group from 3′-phosphoadenosine-5′-phosphosulfate to ethanol accomplished by the mitochondrial UDP-glucuronosyltransferase and sulfotransferases. Recently, the presence of of EtG and EtS was demonstrated in meconium and their usefulness as alternate biomarkers of prenatal exposure to maternal ethanol has been proposed.

The EtG cutoff value between drinking and non-drinking pregnant women has been set to 2 nmol/g of meconium, whereas a cut-off value for EtS does not exist for the so far low number of positive samples.

On the basis of the above reported cut-offs, a 2012 pilot study, carried out in seven neonatology wards along the Italian peninsula, showed an overall prevalence of newborns prenatally exposed to maternal ethanol of 7.9% with a range of exposure going from 0% in Verona to 29.4% in Rome (Pichini et al. 2012).

Supporting persons with FASD over the lifespan

Raising children with FASD poses a significant burden on families due to attachment disorders, poor sleep of the children (and thus the parents, too), difficult behavior, failure to learn from experience, etc. (Domeij et al. 2018). Many children with FASD must be placed out of their homes, and may move from foster family to foster family (Lange et al. 2013). Special education and therapies are often required, for example, play therapy, speech therapy, physical therapy, specialized dental and orthodontic care, etc. As the teenager transitions to adulthood, plans must be made to support the adult with FASD (Lynch et al. 2015). Many need supervised living in a group home, and a supported workplace. Even adults with a higher IQ have trouble managing their time and their finances, so continued assistance is needed. An early diagnosis and creation of an appropriate support network are crucial to a successful and happy life for persons with FASD (Streissguth et al. 2004).

Prevention

Drinking during pregnancy has many causes. Some women drink socially, and do not realize the dangers posed to the fetus. Others may use drink as a means to escape their problems. Still others are confused by conflicting advice in books, from friends, and from the internet. Many well-meaning approaches to prevention may raise fear, confusion, and anger, and contribute to stigma against the drinking woman. Best evidence currently suggests that women need good information and also support/empowerment to refrain from drinking in pregnancy. The support of the partner, family and friends is crucial (Roozen et al. 2016).

Conclusion

Drinking during pregnancy carries serious risks. Evidence-based prevention policies can help to reduce the numbers of babies born with a FASD, and good support can improve the quality of life of persons living with FASD and their policies. To reach these goals, it is important that doctors, therapists, teachers, social workers and policy makers be aware of FASD.

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PREDAVATELJI / PREDAVATELJICE

Diane Black

Dr Diane Black is the adoptive mother of three children with Fetal Alcohol Spectrum Disorder. She was one of the founders of the European FASD Alliance in 2011 and has been Chairperson since that time. The goals of this nonprofit organization are to support member associations in various European countries in their efforts to prevent FASD and improve the quality of life of persons living with FASD. She is a member of the board of the Fetal Alcohol Syndrome Foundation of the Netherlands, whose activities include a Dutch-language website, newsletters, distribution of folders to professionals for use in counseling pregnant women, and maintaining a Dutch-language mail group for parents of children with FASD. She is also one of the founders of FASD Global. One of her main interests is the role of nutrition in management of FASD. She has given presentations on this topic, and started an e-mail discussion group on Nutrition for FASD. She holds a Ph.D. from Purdue University (1986), and previously held various positions as researcher at the University of San Diego, Hoefer Scientific (San Francisco), INSERM (Strasbourg) and Marion Merrell Dow Research Institute (Strasbourg). She speaks fluent English, Dutch and French.

Gro CC Løhaugen

Gro Løhaugen is a clinical neuropsychologist and Head of the regional resource centre for children with prenatal alcohol and/or drug exposure, Department of Pediatrics, Sørlandet Hospital, Arendal, Norway. This Center is the first of its kind in Norway and assesses children aged 0-18 years with suspected brain injury after exposure to alcohol and/or illicit drugs during fetal life. We use a multidisciplinary approach based on the 4-digit-diagnostic-code in diagnosing FASD. The Center has until now evaluated about 170 children. Løhaugen also works at the Department of Research at Sørlandet Hospital and mentor several PhD students. Her research areas have been clinical studies of early brain development combining neuroimaging and multidisciplinary clinical assessments of preterm born children with very-low-birthweight in a lifetime perspective as well as the effect of cognitive training on working memory function across the lifespan.

Marjetka Hovnik Keršmanc

Mag. Marjetka Hovnik Keršmanc, zdravnica, specialistka javnega zdravja, je svojo poklicno pot kot mlada raziskovalka pričela na Inštitutu za varovanje zdravja RS na področju spremljanja umrljivosti prebivalcev v Sloveniji, kasneje pa je svoje delo usmerila predvsem v epidemiološko spremljanje rabe alkohola, pripravo in izvajanje preventivnih programov na področju zmanjševanja in preprečevanja tvegane in škodljive rabe alkohola. Od leta 2001 do leta 2014 je bila zaposlena na Zavodu za zdravstveno varstvo Kranj kot nosilka področja promocije zdravja, delovala pa je na celotnem področju socialne medicine, analitike in promocije zdravja. Po reorganizaciji leta 2014 je zaposlena na Nacionalnem inštitutu za javno zdravje na območni enoti (OE) Kranj. Dve leti je vodila nacionalno strokovno skupino za alkohol, še naprej pa se aktivno vključuje v spremljanje pivskega vedenja prebivalcev, raziskovalno delo in pripravo publikacij ter izvaja aktivnosti za zmanjševanje tveganega in škodljivega pitja alkohola ter zmanjševanje posledic škodljive rabe alkohola na regijski in nacionalni ravni, še posebej aktivno na področju alkohola in nosečnosti. V letih 2013 in 2014 je skupaj z drugimi regijskimi strokovnjakinjami razvijala projekt Alkohol in nosečnost, ki je bil osnova tudi za nadaljevanje in širjenje dela na tem področju v slovenskem prostoru. V okviru OE Kranj deluje še na drugih področjih: spremljanje zdravja prebivalcev, preventivni programi in promocija zdravja. Je snovalka preventivnih programov, zdravstveno vzgojnih gradiv ter avtorica strokovnih in laičnih

člankov ter prispevkov s področja javnega zdravja. Vključena je tudi v raziskovalno in pedagoško delo. Devet let je sodelovala z Medicinsko fakulteto v Ljubljani kot asistentka pri predmetu socialna medicina. Na Fakulteti za zdravstvo Angele Boškin sodeluje kot visokošolska učiteljica pri predmetu Javno zdravje in osnove promocije zdravja.

Martha Krijgsheld

Martha Krijgsheld is the fostermother of 4 children with FAS in the age of 23,20,10 and 8 years old. She is one of the founders and the chairperson of the Dutch FAS Stichting (since 2002) whose activities include a Dutch-language website, newsletters, distribution of folders to professionals for use in counseling pregnant women, and maintaining a Dutch-language mail group for parents of children with FASD, facebook group for adults with FAS, developes brochures etc for eduation and better parenting skills. She gives presentations and lessons about FAS in general and about her own experiences with raising children with FAS in the Netherlands. She is a member of the board of the EUFASD Alliance. She studied biology, and music In Groningen. She speaks Dutch, English and German.

Teodora Ciolompea

Teodora Ciolompea is a General Director of the Centre for Diagnosis and Drug Addictions Treatment, Saint Stelian, Bucharest, Romania from 2016. She is also a Medical Expert at the National School of Public Health, Management and Professional Development in Bucharest. She

is M.D., specialist in prevention and treatment on drug abuse, training in drug abuse research through NIDA (USA) through Hubert Humphrey Fellowship Program at John Hopkins University 1999 – 2000. Master in Health Promotion and Health Education through Valencia School of Public Health 2004. Key qualifications: (a) Technical assistance: to the Ministry of Health, Public Health Authorities, National Institute of Public Health - related to design and implementation of health care reform (delivery and organization of services), quality assurance, monitoring and evaluation of national health programs (5 years coordinator of the National Program for Mental Health and Drug Addiction Treatment, 3 years National Coordinator of the Stop Smoking Program); Collaborate each year to elaborate the National Country Report regarding drug abuse in Romania for EMCDDA in Portugal. Expert of Ministry of Health assigned to write the Annual Country Report on Drug Addiction and Related Diseases for UNO on 2004, 2005, 2006; assistance to non-governmental organizations and health services providers-related to organizational management, capacity building, human resources management, quality management; (b) Teaching at postgraduate level in the fields of Health Promotion, Drug Abuse Prevention and Treatment; project management, evaluation of health services programs, management of the GP practice; (c) Research in the fields of drug use and misuses in Romania (national research regarding harm reduction activities, assessment of HIV and hepatitis C number of patients among IV drug users; GYTS, GATS and ESPAD studies in Romania) health needs assessment, health care organization and finance, evaluation of health services and programs; (d) Collaborative work with international organizations/experts on projects related to health sector (World Bank, PHARE, USAID, UNICEF, etc.); (e) project management, curriculum development and organizational development activities in local or international projects; (f) Member on EUFASD board since 2016.

Simona Pichini

Simona Pichini is an Italian Pharmacotoxicologist working at the Italian National Institute of Health. She is the Head of Analytical Pharmacotoxicology Unit, National Centre on Addiction and Doping. She is an expert of pharmacokinetics and toxicokinetics of drugs, drugs of abuse and doping agents in conventional and non-conventional biological matrices. She is one of the international experts in monitoring ethanol exposure biomarkers in newborns, children, adults and pregnant women in correlation with clinical outcomes. She is the Italian representative at

the EUFASD Alliance, the European association studies of the effects of alcohol during pregnancy from 2010 and the Head of the Scientific Group SIFASD: Italian Society for the study of fetal alcohol spectrum disorders. She is the adoptive mother of a FASD 24 years old boy. She speaks English, Spanish and Portuguese.

Thierry Maillard

Dr Thierry Maillard is a physician and addictologist in Reunion Island, French overseas department in Indian Ocean, near Madagascar. Member of the French Society of Alcohology (SFA), he has been involved in FASD prevention since 1995, with a prevalence thesis[1] on the island. Then, he created a network, Reunisaf[2], to support professionals and families, and coordinate the care path. This model received the price "Bien Traitance" from the Academy of Medicine in 2005 and has been called to develop in France. Thierry Maillard proposed his presentations in various international conferences; he taught at the University of Reunion Island and organized trainings on alcohol and pregnancy. He is currently president of the NGO, SAF Ocean Indian[3], in the Indian Ocean (Mauritius, Madagascar, Reunion, Mayotte and Seychelles) and working to set up, with the local stakeholders, the tools for Mothers and children accompaniment.

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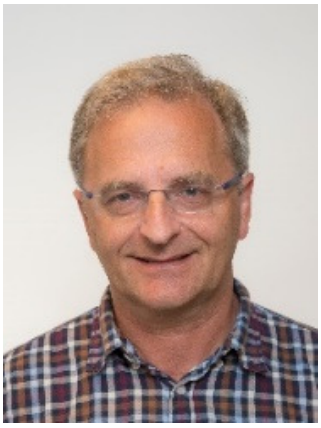
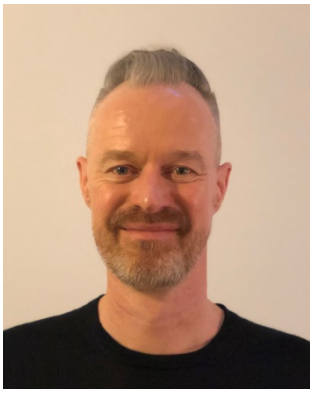
[2] Prevention of the set of disorders caused by Fetal Alcohol in Reunion Island. Archives de Pédiatrie 2008, Vol.15, N°5, 513-5
[3] www.safoceanindien.org

Jon Skranes



Jon Skranes is a pediatrician and Head of Department of Child Neurology and Rehabilitation at the Sørlandet Hospital, Arendal, Norway. He is also a Senior Consultant at the Regional Competence Center for children with prenatal alcohol/drug exposure at Sørlandet Hospital. This Center is the first of its kind in Norway and assesses children aged 0-18 years with suspected brain injury after exposure to alcohol and/or illicit drugs during fetal life. We use the 4-digit-diagnostic-code in diagnosing FASD. The Center has until now evaluated about 170 children. Skranes also holds a position as a Professor in Child Neurology at the Norwegian University of Science and Technology (Department of Clinical and Molecular Medicine Faculty of Medicine and Health Sciences) in Trondheim, Norway. His research area has been clinical studies of early brain development combining neuroimaging and multidisciplinary clinical assessments of preterm born children with very-low-birthweight in a lifetime perspective.

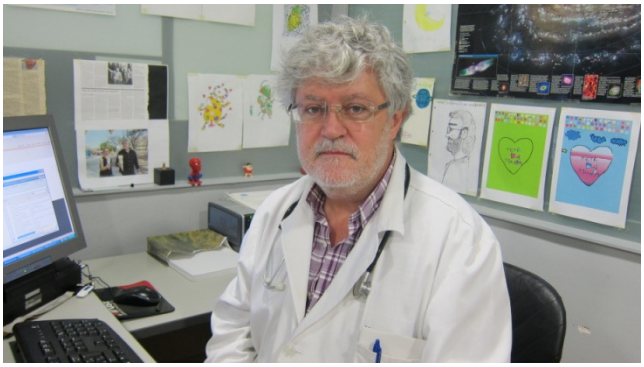
Jan de Vries



Jan de Vries MSc is a child psychologist. Since 2008 he is the head psychologist of the clinic ZO! in Leeuwarden, Netherlands. Prior to this he worked as a social worker and psychologist in child protection-care, foster care, a residential treatment center, a trauma centre for sexual abuse and domestic violence, and a child psychiatry clinic. Additionally, he also researches on attachment therapy intervention (Vrije University Amsterdam & ZO!). ZO! is an organization for

child and youth healthcare that specializes in attachment problems and FASD. So far, ZO! is the only clinic which provides long term support for children and youth with FASD in The Netherlands. Together with clients and their families they explore forms of support.

Oscar Garcia-Algar



Dr Oscar Garcia-Algar is the Head of Neonatology Unit at Hospital Clinic-Maternitat, Barcelona, Spain, and Associated professor of Pediatrics at University of Barcelona, Spain. At present he is the responsible of a prematurity research group included in a Spanish research network: Red SAMID. From a long time, he is the director of a research group (GRIE) about prenatal and postnatal exposure to substances of abuse, including alcohol. The group has active research projects in clinical, basic and animal models research lines, including the only FASD clinics in the country, the only study about prevalence of FASD, the only therapeutic candidate clinical assay (with an antioxidant), edited clinical guidelines about FASD for parents and schools, and the design of a App for diagnosing FASD.

Sylvia Roozen

Dr Sylvia Roozen is a researcher at the Governor Kremers Centre (GKC) of Maastricht University Medical Centre (MUMC+), the Netherlands. Her work is aimed at improving health promoting programs with special emphasize on the topic of Fetal Alcohol Spectrum Disorders (FASD). She addresses, among other topics, the following FASD-related research topics: a framework for a systematic intervention approach, FASD prevalence, alcohol consumption and psychosocial

determinants, etiology and pathogenesis, incontinence as one of the common neglected problems for clinical management, and stigma related challenges. She is appointed as coordinator of the Maastricht University Medical Centre multidisciplinary working group on FASD including the disciplines of Intellectual disability, applied psychology, Gynecology and Obstetrics, and Law and Philosophy. Author of the knowledge synthesis on FASD (together with prof. dr. Gerjo Kok and prof. dr. Leopold Curfs). She furthermore coordinates an international consortium aimed at FASD prevention and management. For this topic, she is also consultant for the Dutch Government and the German Government (Saarland).

ABSTRACTS

FASD – Current State of Knowledge and International Approaches to Prevention

Diane Black, European FASD Alliance (EUFASD)

No amount of alcohol is safe during pregnancy

Alcohol reduces fertility, increases the risk of miscarriage and causes brain damage and birth defects. Prenatal exposure to alcohol can cause cognitive damage, learning disorders and mental retardation, as well as behavioral disorders such as ADHD and autism. Poor motor coordination is common. Difficulty with judgment and understanding social situations contributes to long-term outcomes such as unemployment, psychiatric illness, and criminality. Even moderate drinking or a single binge can cause permanent damage. The severity of the damage depends on factors such as the level of exposure, the developmental stage of the fetus, and nutritional status of the mother.

FASD: Fetal Alcohol Spectrum Disorder

FASD is an umbrella term covering a range of birth defects and brain damage resulting from prenatal exposure to alcohol. The term FASD is not used as a clinical diagnosis, but encompasses diagnoses such as Fetal Alcohol Syndrome (FAS) and related disorders. FAS is diagnosed when a child shows retarded growth, a specific pattern of minor facial anomalies and neurological damage. Children who do not show all the features of FAS may receive a diagnosis of partial FAS, Fetal Alcohol Effects, Alcohol-Related Neurodevelopmental Disorder, or Alcohol-Related Birth Defects. All persons with FASD have lifelong cognitive, social and behavioral disabilities.

Prevalence of FASD

The prevalence of FASD has not been studied in all areas of the world. Diagnosis requires special medical expertise, so many cases are missed or misdiagnosed. In Canada, Italy, and the United States estimates of prevalence of FASD range from from 30.52 to 47.13 per 1,000. A study in Croatia found the prevalence of FAS is 6.44/1000, and overall prevalence of the full spectrum was 40.77/1000.

Prenatal exposure to alcohol is a cause of social inequality

Children with FASD are more likely to grow up in foster care, and youth with FASD are 19 times more likely to be incarcerated than youth without FASD. Adults with FASD have a high risk of

low educational achievement, broken relationships, and unemployment. Prenatal exposure to alcohol has thus been termed a “poverty trap.”

Prevention

There is no cure for FASD. The incidence of FASD can be reduced by public information campaigns, support of pregnant women, and clear preconception advice.

Stigma

Women who have given birth to a child with FASD are often blamed for having harmed their child. The reality is that many women do not receive correct information about drinking in pregnancy, and that our society encourages women to drink to have fun and relax. Thus prevention is a very complex problem.

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Cognitive function and comorbidity in FASD

Gro Løhaugen, Bolnišnica Sørlandet, Oddelek za pediatrijo, Arendal (Norveška)

Neuropsychological deficits are prevalent in children with FASD even without cognitive impairment indicating the need for comprehensive cognitive assessment. The most common neuropsychological challenges are deficits in attention/executive functions and language. These deficits will affect the child’s ability to function in school and present as learning disorders. In patients with FASD, there is a high incidence of comorbidity. Fagerlund et al. reported that the main risk factor for secondary psychiatric problems in children with FASD was time in residential care as well as the absence of dysmorphic features, supporting the need for assessing the whole spectrum of fetal alcohol disorders, not only FAS. Prevalence of attention

deficit hyperactivity disorder (ADHD) is especially high in children with FASD. In a Norwegian study, 86% of children with FASD and 100% of children with prenatal psychotropic drug exposure fulfilled the diagnostic criteria for ADHD. Other common comorbid psychiatric conditions are attachment disorder and behavior problems. In addition, problems with sleep, nutrition and regulating emotions are frequent, adding to the burden for both child and family. Several studies have reported deficits in adaptive behavior among children with FASD. Adaptive behavior is the effectiveness or degree to which individuals meet the standards of personal independence and social responsibility expected for age and cultural group. A comparison of patients with FAS/pFAS and other forms of FASD revealed that all had adaptive behavior deficits with scores more than 2 SD (standard deviations) below age-appropriate levels. Adaptive behavior does not seem related to cognitive level in children with FASD. Therefore, assessment of adaptive behavior should be included for all children with FASD to address the need for health and community services.

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Koraki Slovenije na poti preprečevanja izpostavljenosti alkoholu pred rojstvom in zmanjševanja s tem povezane škode

Marjetka Hovnik Keršmanc[1], Maja Roškar[1], Tadeja Hočevar[1], Matej Košir[2], Vislava Globevnik Velikonja[3] in Jan Peloza[4]
[1] Nacionalni inštitut za javno zdravje; [2] Inštitut Utrip; [3]Univerzitetni klinični center Ljubljana, Ginekološka klinika; [4] Inštitut za mladinsko participacijo, zdravje in trajnostni razvoj

Razširjenost pitja alkohola med ženskami v rodni dobi v Sloveniji

V Sloveniji večina odraslih žensk vsaj priložnostno pije alkoholne pijače, pitje alkoholnih pijačah pa je razširjeno že med mladostnicami in mladimi odraslimi. V starostni skupini od 25 do 34 let je delež abstinentk najnižji, hkrati pa v tej skupini najizraziteje narašča delež žensk, ki pijejo tvegano. To je še zlasti zaskrbljujoče, saj gre za starostno obdobje, kjer je porodov največ. Bolj spodbuden je podatek, da po letu 2012 med mladimi ženskami (25-34 let) upada odstotek tistih, ki se pogosto opijajo. Anketa med obiskovalkami šole za bodoče starše na Gorenjskem je

pokazala, da pije alkoholne pijače vsaj enkrat v času nosečnosti več kot tretjina nosečnic ter, da jih kar 40 % ocenjuje pitje manjših količin alkohola v nosečnosti kot varno. Pregled preventivnih programov in aktivnosti, ki so ga opravili pri MOSI, pa je pokazal, da v Sloveniji primanjkuje programov, ki bi bili namenjeni tej problematiki.

Prepoznava potrebe po intenzivnejšem delu na področju zmanjševanja škode zaradi izpostavljenosti alkoholu pred rojstvom

Vse navedeno kaže na nujnost informiranja in osveščanja žensk v rodni dobi in širše javnosti glede tveganja, ki ga za še nerojenega otroka predstavlja materino pitje alkohola v nosečnosti in takrat, ko še doji otroka. Intenzivnejše delo v Sloveniji na področju alkohola in nosečnosti se je pričelo s projektom »Alkohol in nosečnost«, ki je potekal v letih 2013 - 2014 na Gorenjskem, vodil pa je takratni Zavod za zdravstveno varstvo (ZZV) Kranj (danes OE Kranj NIJZ). V projektu so se povezali in sodelovali ginekologinja in porodničarka, pediatrinja, strokovna delavka v šoli za bodoče starše iz lokalnega zdravstvenega doma ter strokovnjaki javnega zdravja z NIJZ. Cilj projekta je bil zaščita še nerojenih otrok in dojenčkov pred škodljivimi učinki alkohola. V okviru projekta so potekale naslednje aktivnosti: ocena stališč bodočih staršev do pitja alkohola v nosečnosti in poznavanja njegovih škodljivih učinkov na plod; strokovno srečanje za zdravstvene delavce na Gorenjskem; informiranje splošne javnosti glede tveganja, ki ga za še nerojenega otroka predstavlja materino pitje alkohola v nosečnosti in takrat, ko še doji otroka.

Aktivnosti, ki jih danes v Sloveniji že izvajamo

Le-te potekajo na več področjih:

a) Spremljanje epidemiološke situacije na področju pivskega vedenja žensk v rodni dobi ter prepoznanih primerov FASD v okviru redne nacionalne statistike, ocena trenutnih praks ginekologov glede svetovanja opuščanja pitja alkohola med nosečnostjo v letu 2017.
b) Senzibilizacija in motiviranje zdravstvenih delavcev in sodelavcev za rutinsko odkrivanje alkoholu izpostavljenih nosečnosti in svetovanje ženskam v rodni dobi glede pitja alkohola in nosečnosti ter motiviranje drugih deležnikov (strokovnih delavcev na centrih za socialno delo, bodočih delavcev v strežbi alkohola, predstavnikov nevladnih organizacij in mladih) za promocijo nosečnosti brez alkohola (dogodki na tematiko alkohola in nosečnosti, prispevki o alkoholu in nosečnosti na drugih konferencah in strokovnih srečanjih ter v strokovnih publikacijah). Trenutno v Sloveniji potekata dva projekta, ki med drugim naslavljata tudi področje alkohola in nosečnosti (Skupaj za odgovoren odnos do pitja alkohola - SOPA, Prepoznavanje ranljivih žensk v obporodnem obdobju – PODN).
c) Osveščanje splošne javnosti o nezdružljivosti pitja alkohola in nosečnosti ter kje v primeru težav iskati pomoč. To najintenzivneje poteka okoli Dneva FAS. Ta dan smo v Sloveniji prvič obeležili 9. septembra 2014 s ključnim sporočilom: »V nosečnosti ni varne alkoholne pijače, ni varne količine alkohola in ni varnega časa za pitje alkohola. Abstinenca je najboljša

odločitev za žensko, ki je noseča, lahko postane noseča ali doji otroka.«. Od takrat dalje širimo to sporočilo vsako leto preko medijev, objav na družbenih omrežjih, na stojnicah po regijah, pozivov zdravstvenim in drugim strokovnim delavcem, ki prihajajo v stik z bodočimi starši. Pri tem se povezujemo deležniki iz zdravstva, nevladne organizacije (Mladinska zveza brez izgovora Slovenija in Inštitut Utrip). Za širjenje sporočila uporabljamo tudi zloženko *»Za najboljši začetek«* in plakat *»Za naju brez alkohola, prosim!«*, spletno stran www.zdaj.net (zavihek Bodoči starši) ter video spot *»Nosečnost brez alkohola« (slednjega nam je v uporabo predal Direktorat za zdravje Norveške).*

Slovenski pristop je med primeri dobrih praks na področju preprečevanja škode zaradi izpostavljenosti alkoholu v nosečnosti v svoji publikaciji leta 2016 prikazala tudi Svetovna zdravstvena organizacija.

Nekaj priložnosti za še uspešnejše delovanje na področju preprečevanja in zmanjševanja izpostavljenosti alkoholu pred rojstvom v Sloveniji:

- epidemiološka raziskava o razširjenosti pitja alkohola med nosečnicami in njihovimi partnerji v Sloveniji;
- presejanje na alkohol naj bo rutinski postopek pri vsaki zdravstveni obravnavi žensk oz. družine v rodni dobi;
- priprava strokovnih smernic za naslavljanje alkohola in nosečnosti v ginekološko-porodniški stroki;
- vključevanje vsebin o škodljivosti pitja alkohola v času nosečnosti v učne načrte študijskih smeri s področja zdravja in medijskega sporočanja;
- vključevanje tovrstnih vsebin v programe promocije zdravja in preventive za mladostnike in mlade odrasle;
- usmeritev pozornosti na tveganje za alkoholu izpostavljene nosečnosti v sklopu obravnav na centrih za socialno delo in na zavodih za zaposlovanje;
- razširitev ozaveščenja o problematiki na še druge stroke (novinarji) in deležnike, ki imajo lahko pomembno vlogo pri spreminjanju odnosa do pitja alkohola (npr. frizerji, duhovniki, gostinski delavci,…) ter pridobiti mlade kot promotorje;
- okrepiti zavedanje, da k zdravemu razvoju še nerojenega otroka pomembno prispeva tudi očetov odnos do alkohola, prav tako odnos bližnjih oseb in celotne družbe.
- Za zmanjševanje sekundarnih posledic izpostavljenosti alkoholu pred rojstvom pa je pomembno boljše prepoznavanje otrok s FASD in multidisciplinren pristop k takim posameznikom.
- V Sloveniji bomo tudi v prihodnje delovali v luči tega, da bi vsakemu otroku omogočili čim boljši začetek. Poseben izziv vidimo predvsem v tem, kako obstoječe programe in aktivnosti ovrednotiti, kako vzpostaviti mrežo različnih deležnikov, ki bodo zastavili in izpolnjevali cilje za naprej.

Raising children with FASD--a story from a foster mother

Martha Krijgsheld, Dutch FAS Foundation and, foster mother (The Netherlands)

In 1997, the first child with FAS came into our family. He was two years old then. He had a diagnosis, very rare in those days in the Netherlands. His younger brother was born in 1998 and joined his brother. He was diagnosed a few months later. We love them very much, but we also struggled with health, sleep, growth, retardation, behaviour, lying, stealing, and worries about independant living etc. In 2009, a three-month old baby with FAS joined the club and a year later his newborn brother too. No child with FAS is the same, and on the other hand, they are very similar in the approach to managing their difficulties.

Improving treatment outcomes for drug addict patients that may also have FASD

Teodora Ciolompea, Bolnišnica Saint Stelian, Center za diagnostiko in zdravljenje zasvojenosti z drogami, Bukarešta (Romunija)

Background

Individuals with an FASD are a largely hidden population that frequently need mental health and substance abuse treatment, but majority of them, entering on medical care services will not be recognized as having this diagnosis. The neurological impairments expressed by individuals with FASD typically lead to high-risk behaviours, such as alcohol/drug abuse or an increased possibility to get into high-risk situations. There are a few potential explanations for the high prevalence of substance use among individuals with FASD: a biological/ genetic vulnerability ; tendency to use substances to self-medicate; difficulties with impulse control . Patients with co-morbid substance use and mental disorders have a more complicated trajectory of service use, including higher rates of relapse and readmission to addiction treatment.

Actual situation in Romania

FASD is not mandatory included in medical curriculum. Therefore, physicians are not trained to detect or treat this medical condition. Another major problem is the fact that in the DSM classification of mental disorders, there is no code for FASD. Furthermore, not having a code for FASD, means is not useful to be added on medical documents because the health insurance house is not paying medical services for something that is not recognized as a diagnosis. Medical staff is not trained and not encouraged to study about FASD since their work can`t be quantified and reimbursed by health insurance houses. Another important aspect we are facing is the extreme specialization on physician’s common practice (a requirement of health insurance system – that also sets that some bureaucratic boundaries between medical

specialties) that reflects on the difficulty of having a correct diagnosis for a patient with FASD because this syndrome is a mixture of neurology and psychiatric symptoms. Therefore, in order to be diagnosed with FASD, one patient needs to be consulted by 2 different specialists on 2 separate clinics. Many patients got 2 different treatment during lifetime, one for neurologic and one for psychiatric issues leading rarely to a good treatment outcome. Only by recognizing the disability of FASD and modifying systems of care, we can improve outcomes for clients.It is not uncommon for a client with FASD to be unsuccessful and sometimes terminated from drug addiction treatment. Others are getting a double psychiatric diagnostic (addiction and depression/ anxiety disorder/ sleep disorder/ mood disorder/ obsessive-compulsive disorder). Since psychiatrist are not thinking that those patients may have a neurological damage due to FASD and not only a psychiatric issue, this mixture of psychiatric medication, more and more complicated over the years, is not showing a good outcome, for patients or even worsen their daily life. Recognizing the disability of FASD and understanding that the patient "can't" perform, rather than "won't" perform, immediately changes the way that patient should be treated. Understanding the complexity of drug addiction and FASD on same patient can help the doctor to modify and adjust the treatment for each patient, and so treatment outcomes could improve. These individuals need structure, support and understanding. If psychologists could better understand the typical behavioral profile of a client with FASD, and how to work according to their lifelong disability on cognitive, behavioral, emotional and social skills they could improve the ability to predict future behaviors of their patients and give to them what thy really need , meaning a lifelong transitional and behavioral support.

Substance-using women are commonly asked at admission to drug addiction center about substances of abuse, including marijuana, ecstasy, cocaine and heroin, but extremely rare about their drinking problems even though alcohol produces by far the most serious neurobehavioral effects on their newborn children. Another common lack of information comes by the fact that no doctor is interested to find out more about the family history of drug and alcohol abuse of their patients. When we start to ask, we found out that more than 50% of substance abuse patients were having at least one family member (father or mother) with alcohol, tobacco, medication or illegal drugs misuses as far as they can remember from their early childhood.

Conclusions - what can be improved

The time spend by a new patient on the addiction center should be used by the medical staff to start a **more comprehensive clinical exam and to try to diagnose the patients that may be affected by FASD**. So, is recommended that the doctors and psychologists to be trained and use a correct diagnosis for FASD using the Canadian guidelines that are accepted and considered easier to be applied on daily practice. Drug addiction may continue to be diagnosed using DSMIV/ ICD 10 criteria and severity of addiction by European Addiction Severity Index (EuropASI), a multidimensional clinical and research instrument. The primary use of this tool is

to provide basic diagnostic information on a client prior, during and after treatment for substance use-related problems, and for the assessment of change in client status and treatment outcome. Problems Assessed:Medical status, Chemical use (alcohol / drug use), employment/support ,Family / social relationships, Legal status, Psychiatric / psychological status Completion Time: 30 - 45 minutes for a skilled and trained technician.

Neurological impairments must be evaluate by a neurology doctor and a MRI exam to be done to all patients at risk for FASD before starting or changing or adding more psychiatric medication to a patient that has a difficult medical outcome. Concerning the patient, this treatment time must be used like an opportunity to learn more about FASD.

New topics for CBT should be introduced for individual and group therapy in addition to the traditional topics, such as:

- health benefits for drug abuse women to use an effective contraception method
- drinking while pregnant - consequences for personal health and the new born child. An essential goal for women with FASD must be to increase their knowledge of the effects of prenatal alcohol exposure and a treatment goal must be no use of alcohol during pregnancy.
- coping with the difficult issues around mothering and parenting
- facing daily concerns raised by their problems in judgment, memory and social skills
- identify the seemingly irrelevant situations on their daily lives that can lead them to drug use or law problems because those patients are typically naïve and are easily led into this kind of situations.

Additional social services to be added on treatment center for FASD patients:

- support them to complete the social assistances files to benefit from social security income,
- offer them some basic legal assistance for the most common issues they are facing during lifetime, support them to enter to the Medical Health Insurance system for people with different disabilities or with no income.
- assist them with housing, vocational, educational and, legal recreational activities.

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Biomarkers for detection of prenatal alcohol exposure

Simona Pichini, Nacionalni center za zasvojenost in doping, Nacionalni inštitut za zdravje (Italija)

The deleterious effects exerted by prenatal ethanol exposure result in physical, mental, behavioural and/or learning disabilities included in the term fetal alcohol spectrum disorder (FASD), whosemost severe form, including morphological abnormalities, is defined as fetal alcohol syndrome (FAS) . Objective assessment of exposure to ethanol at both prenatal and postnatal stages is essential for early prevention and intervention. Since pregnant women tend to miserreport alcohol drinking, a number of biological markers have been proposed and evaluated for their capability to highlight gestational drinking behaviour and consequent intrauterine exposure to alcohol.

These biomarkers include classical biomarkers (albeit indirect) of alcohol-induced pathology (mean corpuscular volume (MCV), gamma glutamyltransferase (GGT), aspartate aminotransferase (AST) and alanine aminotransferase (ALT)) acetaldehyde-derived conjugates, and finally derivatives of non-oxidative ethanol metabolism (fatty acid ethyl esters (FAEEs), ethyl glucuronide (EtG), ethyl sulphate (EtS) and phosphaditylethanol (PEth)). Since ethanol itself and acetaldehyde are only measured few hours after ethanol intake in conventional matrices such as blood, urine and sweat, they are only useful to detect recent ethanol exposure. In the past few years, the non-oxidative ethanol metabolites have received increasing attention because of their specificity and in some case wide time-window of detection in non-conventional matrices from the pregnant mother (oral fluid and hair) and fetus-newborn (neonatal hair, meconium, placenta and umbilical cord).

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Fetal Alcohol Spectrum Disorders: from collective awareness to public health policies in Madagascar

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Alcoholism is a scourge, which don't spare developing countries. One of **the most serious repercussion** is the adverse effects of alcohol on the developing human caused by maternal consumption of alcohol during pregnancy: Fetal Alcohol Spectrum disorders (FASD). Children at the severe end of the spectrum have been defined as having Fetal Alcohol Syndrome (FAS), a characteristic set of **physical abnormalities and alcohol induced mental impairments**. Maternal prenatal alcohol use is one of the leading preventable causes of birth defects and considered **the most common non-hereditary cause of mental retardation**. However, FASD is not just a childhood disorder; it increases the risk for later alcohol, tobacco and drug dependence in adults (secondary disabilities, Ann Streissguth).

Mothers are not all suffering from alcoholism but **they drank at the wrong time**, sometimes it was during a binge drinking! Estimates of the prevalence of FASD in developed countries are nearly 1% live birth. But how much in our countries? How many women are still drinking during pregnancy? More than 30 % of pregnant had declared to keep drinking and **5,36 % alive babies were diagnosed having Fetal Alcohol Syndrome** in the biggest maternity of Antananarivo. This might be only the top of the iceberg! Despite ancient references to the adverse effects of alcohol on the offspring of drinking women, more recent references provide insight into **the lack of recognition of the teratogenic effects of alcohol.**

FAS was not a public health problem in Madagascar before … Before we knew! This presentation, first, will discribe the size of the problem posed by drinking in pregnancy. The second part of this presentation attempted to suggest that formulating appropriate advice or knowledge to professionals, to politics would create a dynamic of awareness with immediate and adapted responses for that population at risk. Madagascar becomes aware, it could happen in our countries!

How to diagnose fetal alcohol spectrum disorder

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The term FAS was introduced in 1973 as a description of children with a common pattern of face deformities and alcohol-dependent mothers. Since then, FAS has achieved a diagnostic code (i.e. Q86.0) in the International Statistical Classification of Diseases and Related Health Problems, version 10 (ICD-10, 1994). How to diagnose FAS/FASD is controversial, and at least four different diagnostic systems are currently in use in Canada and the United States. Recently, one of the most recognized systems, the 4-Digit Diagnostic Code System, has been extensively validated. In 2013, German FAS guidelines were published based on literature reviews, but no clinically evaluated guidelines exist from Europe. Each diagnostic system has its advantages and challenges, and no common agreement exists regarding which one to use. In this lecture, the primary focus will be on the assessments performed by the neuropediatrician to be able to make the diagnosis FASD, with emphasis on the 4-Digit Diagnostic Code System. Common for all diagnostic systems are the need to assess growth parameters like length and weight (at birth and current measures), look for facial features typical for FAS, assessment of CNS structure and function, and the degree of alcohol exposure. The clinical neuropsychologist will contribute to the CNS functional evaluation by assessing IQ, attention/executive functions, language, learning/memory and visual-motor function. The medical doctor has to evaluate any differential diagnoses and the need for supplemental medical examinations such as genotyping and sensory examinations (vision and hearing). EEG should also be considered as the prevalence of seizures is 3%–21% in children with FASD, compared to 0.32%–0.55% in the general population. In addition, the indication for performing brain MRI and expected structural findings will be discussed.

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Supporting families who raise children with FASD

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Parents who are raising a child with FASD experience a lot of stress (Mohammed et al, 2018). Yates et al. (Yates, Obradović & Egeland, 2010) reports that parental stress leads to less sensitivity and ineffective parenthood. Parental stress predicts a more negative quality of parenthood for example, harsh discipline and an authoritarian style (Abidin, 1992; Kim et al., 2013; Yates et al., 2010). Not only children with FASD need support, but also their caregivers (Paly et al 2006).

So raising a child or youngster with FASD is a challenge. Generally, schools and surroundings often have no substantial knowledge about FASD. Caregivers struggle themselves a lot. Supporting involved parties in the child's environment can make a big difference for them and the victim with FASD.

For interventions, it is important to notice the following:

1. The primary effects caused by FASD. These are behaviors caused by underlying brain differences (Malbin, 2002).
2. The secondary effects caused by FASD. These are responses to chronic failure and frustration, such as the effects on emotions, self-esteem and behavior (Malbin, 2002).
3. The support system itself. The support system is essential for the functioning and wellbeing of the person with FASD. It is important to strengthen the capacity and resilience of caregivers, siblings, friends, schools, and work environments etc. In order to educate and support them how they can provide backup to the person with FASD. In addition, how caregivers can take care of themselves while simultaneously provide care and support to their child with FASD.

In this workshop, we will explore what help supporting families require in raising children with FASD. Furthermore, we will explore how to facilitate formal and informal networks. We will see the importance of good information, collaboration with schools and others, the importance of working in a non-judging manner and finding unexpected solutions together. We will see how frustrating it can be for healthcare and social workers to work with children with FASD and their surroundings, but that it can also be challenging and joyful.

In this workshop, we will discuss the theory described above, as well as clinical experiences, video-interviews with Dutch parents and teachers about what helped them and discuss experiences and questions from the participants in the workshop.

'The key to successful formal and informal networks is understanding behaviors from a brain-based perspective. Understanding is the cornerstone for acceptance and acceptance is essential for relationships.' Community Living British Colombia (2011).

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Medical management of FASD

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Ethanol is the most important teratogen agent in humans. Prenatal alcohol exposure can lead to a wide range of adverse effects, which are broadly termed as fetal alcohol spectrum disorder (FASD). The most severe consequence of maternal alcohol abuse is the development of fetal alcohol syndrome, defined by growth retardation, facial malformations, and central nervous system impairment expressed as microcephaly and neurodevelopment abnormalities. These alterations generate a broad range of cognitive abnormalities such as learning disabilities and hyperactivity and behavioural problems. Socioeconomic status, ethnicity, differences in genetic susceptibility related to ethanol metabolism, alcohol consumption patterns, obstetric problems, and environmental influences like maternal nutrition, stress, and other co-administered drugs are all factors that may influence FASD manifestations.

Recently, much attention has been paid to the role of nutrition as a protective factor against alcohol teratogenicity. There are a great number of papers related to nutritional treatment of nutritional deficits due to several factors associated with maternal consumption of alcohol and with eating and social disorders in FASD children. Although research showed the clinical benefits of nutritional interventions, most of work was in animal models, in a preclinical phase, or in the prenatal period. However, a minimum number of studies refer to postnatal nutrition treatment of neurodevelopmental deficits. Nutritional supplementation in children with FASD has a dual objective: to overcome nutritional deficiencies and to reverse or improve the cognitive deleterious effects of prenatal alcohol exposure. Further research is necessary to confirm positive results, to determine optimal amounts of nutrients needed in

supplementation, and to investigate the collective effects of simultaneous multiple-nutrient supplementation.

Despite public health efforts to reduce or eliminate alcohol consumption during pregnancy, i.e., specific public health programs or clinical guidelines, an important number of pregnant women continue to consume alcohol. The adequate strategy for FASD prevention remains ethanol abstention, but effective and evidence-based interventions and treatment against ethanol damage are needed to ameliorate adverse consequences in children who are affected by FASD. More interesting than the symptomatic treatment of clinical disorders due to neurodevelopmental deleterious effects of prenatal alcohol exposure is specific neurovedelopmental disorder treatment. Recently, much attention has been paid to the role of nutrition as a protective factor against alcohol's teratogenicity.

Developing Evidence-Based Health Promoting Programs for Fetal Alcohol Spectrum Disorders (FASD)

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Background: The complexity of intervention development is sometimes overlooked in health promotion. This is for sure the case concerning FASD. Evidence-based health promotion intervention aimed at the field of FASD is a complex process (Roozen et al., 2016). The complexity lies within an in-depth description of interventions and their development. The field of FASD needs to use systematic approaches for adapting evidence based behavioural interventions (Roozen, Kok, and Curfs, 2017). Lessons can be learned from a framework that has been applied in various other health promoting fields; namely Intervention Mapping (IM; Kok et al., 2016). IM provides planners with a systematic method for decision making in each phase of developing a programme to influence changes in behavioural and environmental conditions. The aim of this interactive presentation is to provide participants with evidence-based insights and tools for systematic development of effective interventions related to alcohol consumption during pregnancy and FASD prevention. In addition, awareness for the various sources of alcohol related messages and the commercial aspects of campaigns will be discussed.

Workshop Activities: The development of effective prevention campaigns is not easy and the complexity is often overlooked. Program planners often do not use a systematic approach and choose methods intuitively versus derived from evidence. For example, scary pictures are often used in health promotion to discourage unhealthy behavior. These so-called "fear appeals" to discourage behaviors such as drinking during pregnancy, are ineffective. A better approach is to send out positive messages that deliver new and valid arguments, increase social support

and improve people's skills. In order to do so, program planners benefit from using a planning strategy or framework such as Intervention Mapping. A brief description of Intervention Mapping will be discussed, including practical applications to secure effectiveness.

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