

# Clinical Phenotypes of Russian adopted children & adolescents with NDPAE living in Ireland

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Dr. Kieran D. O'Malley MB BAO BCh DABPN  
Child & Adolescent Psychiatrist,  
Slievemore Clinic, Dublin.

President Elect Intellectual Disability Section RSM, London.

# Conflict of interest

- I am not receiving funding from industry, drug companies or research companies.
- I am not receiving financial support for this academic talk.
- I receive yearly royalties on book ADHD and FASD published by Nova Science Publishers, NY
- No member of my family or relatives are receiving funding from industry related to this talk, or has shares in a company related to this talk.
- I do not have shares in a company related to this talk.

# Learning Objectives

1. To describe the clinical phenotypes of a case series of Russian adopted children and adolescents with Neurodevelopmental Disorder Prenatal Alcohol Exposure, NDPAE, DSM 5 code 315.8 living in Ireland.
2. To describe the medical Alcohol Related Birth Defects, ARBD, associated with NDPAE present in this case series.
3. To describe the gaps in Systems of Care services for these Russian adopted children and adolescents with NDPAE.

# The history of adoption in Ireland

- In 1950s and 1960s Irish children were privately adopted to American and UK parents, and were considered 'Irish' at adoption and subsequently in the USA & UK.
- All these adoptions were Closed, with mostly young single, poor mothers having no further contact with their children, and done mainly through the aegis of the Catholic Church mainly through the nuns. There was usually no information on the birth father. (See 'Philomena' 2013 Oscar nominated film, & recent 2016 UTV show on the re-unification of a 48 year old daughter with her Irish birth mother who was a school girl 13 years old when she gave birth).
- In the late 1990's and throughout the 2000's Irish parents have privately adopted children from Russia and Ukraine ( and Romania). These are Closed adoptions done mainly through private agencies. Russian birth mothers are mostly single and poor, and the children are considered 'Irish' when adopted into Ireland. The information on the birth fathers indicates that many are soldiers in the Russian army.

# Inter- country adoption services in Ireland

- There are no formal Pre- Adoption agreements regarding health , education or special needs for Irish adoptive parents in Ireland.
- There are no Post- Adoption agreements with Irish adoptive parents for continuing medical, education or special needs support in Ireland.
- There is no provision for a ‘ special needs child’ as a particular category of inter -country adoption .
- There is no ‘official ‘ recognition of the prevalence of FASD or NDPAE in the Russian children adopted into Ireland.
- Irish adoptive parents suffer chronic stress in the parenting of these undiagnosed children with NDPAE, as they are commonly told that all the problems are ‘ parent –driven’ i.e. Insecure Attachment Disorder. So the child’s problems/ challenging behaviours are implicitly ‘their fault’.

# Ireland's legislative approach to vulnerable children and learning disability

1. Ireland has still not signed the European or United Nations Charter of Rights for Children.
2. If / When Ireland signs the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) it will have “the dubious distinction of being the last nation of the European Union to do so”. (Sarah Lennon, Inclusion Ireland, Irish Times August 11<sup>th</sup> 2016).

# Case series : Sample Size and demographics

- Number : 22
- Gender : male 17, female 5
- Age range : 2 ½ years to 19 years ( age at assessment)
- Ethnic group: Russian 19, Ukrainian 3 (\* Romanian 8)
- Early adoption ( under 5 years of age) : 17  
Late adoption ( over 5 years of age) : 5

# Clinical Phenotypes of NDPAE in case series

## Psychiatric Disorders.

- ADHD : 12
- ADD :7
- Mood Disorder: 6
- ASD/SCD: 7
- PTSD: 7
- Conduct Disorder/ Antisocial Behaviour; 3\*
- Alcohol Abuse/Dependence: 3
- Identity Disorder : 3

# Neurological problems in NDPAE case series

- Developmental Co-ordination Disorder ( including truncal and gait ataxia): 11
  - Sensory problems: 8
  - Seizure disorder: 2
  - Sleep problems : 6
  - Microcephaly : 7 (4)
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- Bonthius et al 1992, 2005 , Roebuck et al 1998, O'Malley & Barr 1998, O'Malley 2014, \*Irwin & O'Malley 2015

# Alcohol Related Birth Defects, (ARBD) in case series

- Low weight /Failure to Thrive : 5
- Anaemia: 5
- Dysmorphic face: 9 (fleeting)
- Heart problems: 5
- Kidney problems: 2
- Skeletal problems: 1
- Eye problems: 3
- Ear problems : 2
- Chest problems: 4

# Prevalence of psychiatric disorders co-occurring with Developmental Disorders ( intellectual disability)

- Rutter et al 1970, 9-11 years old, 38.9%
- Corbett et al 1979 , > 15 years old, 47%
- Gilberg et al 1986, range 40-60%
- Einfeld & Tonge, 1996, range 40-60%
- Streissguth et al 1996 , range 90 to 94% ( FASD)

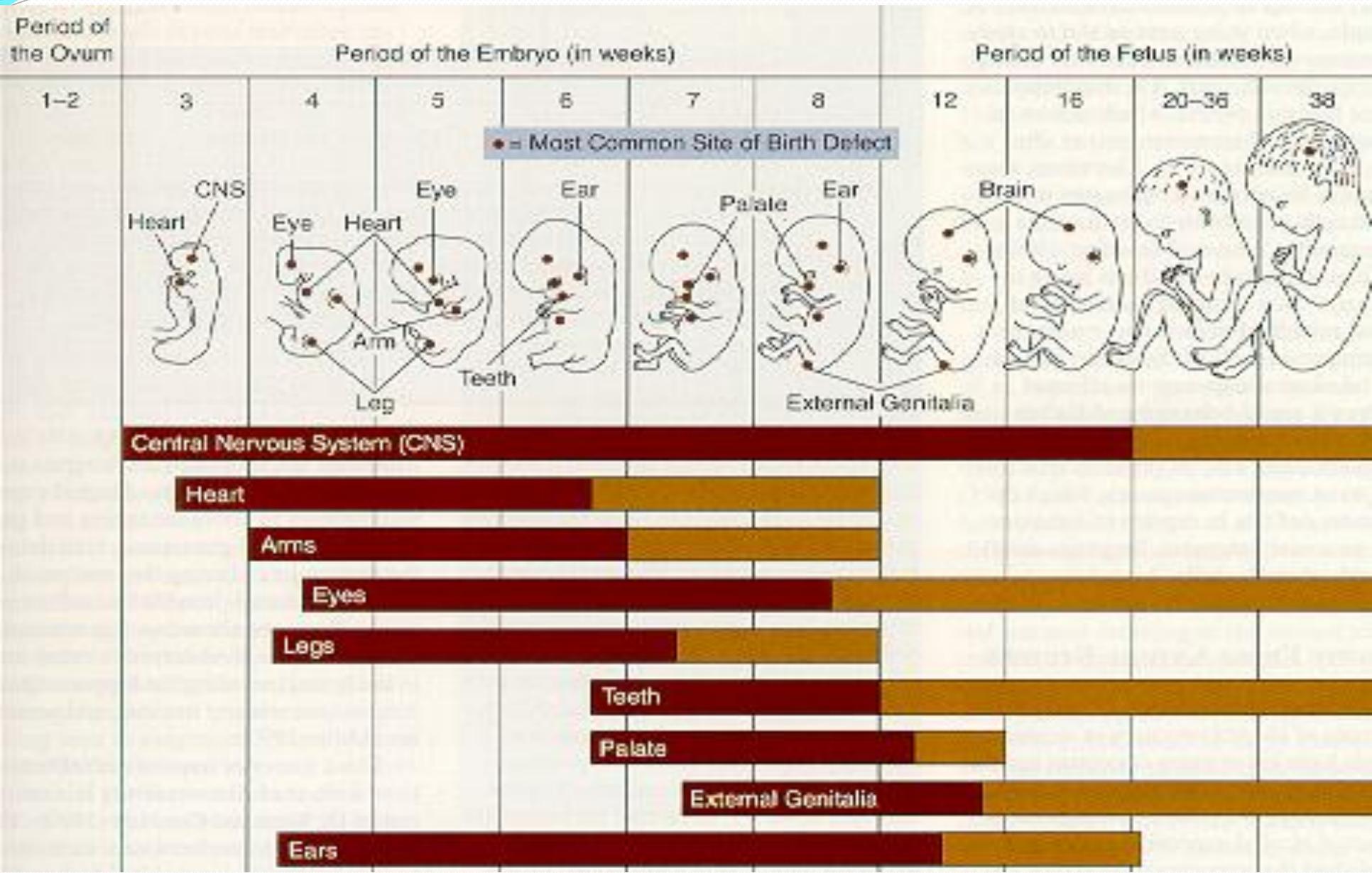
# Probable psychiatric developmental trajectory of NDPAE (from general clinical experience).

Psychiatric Disorders appear from infancy/early childhood

- Regulatory Disorders become ADHD
- Regulatory Disorders become Mood Disorders
- Regulatory Disorders become a mixture of ADHD & ASD
- ADHD becomes Mood Instability
- ADHD becomes Intermittent Explosive Disorder/ Conduct Disorder
- ADHD increases impulsive suicidal risk
- ADHD or Mood Instability predate Alcohol Dependence

O'Malley 2014, 2016

# Development of the Embryo



# **The teratogenic neurotoxicity of alcohol continues throughout the whole of pregnancy .**

- 1. The Brain /CNS, is the most vulnerable organ, and differing neurotoxic effects continue as the foetus develops throughout the whole of pregnancy.**
- 2.The global physical growth of the foetus is effected at different periods in the pregnancy , mainly by teratogenic neurotoxic alcohol exposure in the first trimester.**
- 3.\*Prenatal alcohol exposure does not just cause a neurodevelopmental disorder , but has an epigenetic effect on the development of the whole body.**

Stratton et al 1996, FADU, University of Washington, Seattle, 1997, DSM 5 2014, Nguyen & Riley 2014,O'Malley 2016

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- The effect of prenatal alcohol exposure leaves a legacy for coming generations which is seen in ethnic groups across the world .

# Fetal Programming

## 1. Barker's Hypothesis:

“Biological factors acting during prenatal life are associated not only with the development of common adult cardiovascular and metabolic disorders, but also with neurobehavioural abnormalities and behavioural disorders.”

Lester & Padbury 2009

## 2. Alcohol Epigenetics , Haycock 2009

## 3. Also the concept of 'Environmentally Induced Developmental Disorders'

Sage Handbook of Developmental Disorders, 2011

# Can the epigenetic effect of prenatal alcohol exposure programme the brain to induce alcohol craving?

Animal research going back over 40 years has shown the relationship between prenatal alcohol exposure and postnatal alcohol craving.

Could sugar craving be related to prenatal alcohol exposure and predate alcohol craving?

(The prevalence of Diabetes has been shown for many years to be 4 to 5 times higher in Native American and First Nations populations than Caucasian population).

Researchers have shown higher prevalence of alcohol dependence in young adults with FASD (NDPAE), higher than just by family history of alcohol alone.

# An analysis of alcohol craving risk in adolescents adds to the clinical picture

International Study; Trinity College, Dublin, Dr Hugh Garavan, with University of Vermont, USA

- Abnormality in orbito-frontal cortex on shown in brain imaging studies to underpin alcohol/ addictive craving in adolescents.
- Prenatal alcohol exposure has been shown to increase alcohol craving in animal and human studies going back over 40 years with effect on developing prefrontal cortex and nucleus acumbens, transcription protein , Delta Fos B, linked to CdK5 gene.
- Is there a biological vulnerability to this alcohol craving risk which could link it to the prevalence of NDPAE?

Nestler 2002, O'Malley 2003, 2014



# Do Russian children have a genetic / epigenetic susceptibility to Alcohol and /or NDPAE ?

1. Drinking patterns in Russian women indicate a substantial risk for alcohol – exposed pregnancies. The study reported high levels of alcohol consumption in non- pregnant , child-bearing, women irrespective of their knowledge of FASD or NDPAE. \*( not unlike Ireland).

2. One scientific study analysed alcohol metabolism enzymes in 3 groups
- a. Mothers who have children with FAS,( NDPAE with dysmorphic and growth features)
  - b. Children with FAS ( NDPAE with dysmorphic and growth features)
  - c. Controls

The variability of these enzymes showed the importance of alcohol metabolism in FASDs/ NDPAE.

(further research has pointed out the differential genetically determined rates of alcohol metabolism in different patient populations)

3. As well it has been shown in the USA that there are higher rates of FASD/ NDPAE in African Americans and Native Americans than non- Hispanic Whites.

# Systems of care issues related to Russian children with NDPAE

- Ireland has no trans-cultural medical or psychiatric services so foreign born Russian children have little access to culturally sensitive and/or culturally competent medical or educational services. So alienation and identity issues are a potential problem.
- Well-meaning Irish adoptive parents of Russian children tolerate/ minimise their challenging behaviours because of the 'shame/stigma' of having a child with possible acquired brain injury.
- Although alcohol has a central role in the society, Ireland is still the only European country that does not 'officially' recognize FASD or NDPAE. So it is not a notifiable medical disorder and remains essentially a 'hidden' disorder.

# Systems of Care issues, cont.

- Professor Michael Rutter and colleagues have done painstaking work on the influence of institutionalisation and trauma on adopted Russian (and Romanian) children, but have traditionally minimized the influence of prenatal alcohol exposure & NDPAE on these infants.
- FASD or NDPAE are both a 'diagnosis of exclusion' for out-patient child psychiatry CAMHS service and HSE government in-patient services in Ireland. This means the Irish adoptive parents are mainly left to their own devices regarding ongoing therapy.
- \* However, a senior public health medical officer from Cork, Dr. Doireann O'Keeffe, has recently organized the 1st multidisciplinary FASD special interest group in Ireland which is meeting October 12<sup>th</sup> 2016. So green shoots may be appearing..!

# An approach to Challenging Behaviours in NDPAE can be applied to these Russian children

- A common entry point to diagnosis or management of NDPAE ( and Psychiatric Developmental Disorders in general).

Three principles:

1. Applied Behavioural Analysis (environmental impact on behaviour)
2. Developmental factors ( i.e. motor & sensory, cognitive, language/ social communication , mood dyregulation)
3. Co-morbid Psychiatric/Medical/Addictive Disorders

O'Malley 2003, Professor Tony Holland, Cambridge, ( SSBP mtg. Leuven) 2012

# References, O'Malley Talk, London 2016

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