Report Of The Committee of the Brick Lane Branch of the United Grand Junction Ebenezer Temperance Association

‘Your committee have pursued their grateful labours during the past month, and have the unspeakable pleasure of reporting the following additional cases of converts to Temperance.’

‘Betsy Martin, widow, one child, and one eye. Goes out charing and washing, by the day; never had more than one eye, but knows her mother drank bottled stout, and shouldn’t wonder if that caused it (immense cheering). Thinks it not impossible that if she had always abstained from spirits she might have had two eyes by this time (tremendous applause). Used, at every place she went to, to have eighteen–pence a day, a pint of porter, and a glass of spirits; but since she became a member of the Brick Lane Branch, has always demanded three–and–sixpence (the announcement of this most interesting fact was received with deafening enthusiasm).’

“The intoxicants consumed were in the form of beer, whisky, and rum; as a rule the patients drank any sort of liquor they could get.”

Mortality of Infants of Female Inebriates. – Amongst the 100 women of our series, twenty were able to give details of female relatives also of drunken habits, who had had children. Of these 120 female inebriates were born 600 children, of whom 265 (44.2 per cent.) lived over two years; 335 (55.8 per cent.) died under two years, or were dead-born.

“….. of the children comprised in our series, 219 lived beyond infancy, and of these nine, or 4.1 per cent., became epileptic.”

“…..this primary influence of alcohol is due in part to the permanent effects of the poison on the maternal organism, inducing a transmissible degenerate condition; in part to a direct toxic action on the embryo, owing to continued excesses during pregnancy and lactation.”

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Fetal Alcohol Syndrome & Fetal Alcohol Spectrum Disorders - The Modern Era.


“Les enfants des parents alcooliques : anomalies observees a propos de 127 cas” (Quest Medical. 25.476-482 )

- Described abnormal physical and behavioural patterns in the offspring of women who drank heavily in pregnancy.

Paul Lemoine (1917-2006) later reflected – “…..the 127 cases of a modest paediatrician from Brittany did not create any interest, whereas 8 American cases became immediately convincing ! ….” (also notes Jacqueline Rouquette’s earlier unpublished thesis from Paris in 1957)
Jones K.L and Smith D.W. 1973
“Recognition of the Fetal Alcohol Syndrome in Early Infancy”
(Lancet 2. 999-1001)

The first of three papers describing a typical pattern of facial dysmorphism, growth restriction and developmental delay in 8 children. The first clinicians to utilise “Fetal Alcohol Syndrome / FAS”

Dave*:- “So Ken, what do you think of this?”

Ken:- “Not much Dave”

Dave*:- “This is the most important thing I have ever seen!” 😊

“Alcohol and the fetus in the West of Scotland”
Beattie J, Day R, Cockburn F and Garg R A
BMJ. 1983. 2nd July. 287.17-20

- 40 cases of FAS between 1971-1981

“Further prospective research is urgently needed to define the origins and extent of the problem of the fetal alcohol syndrome in the UK so that appropriate resources can be allocated for education, intervention and prevention”
Subsequently...

Streissguth A.P and O’Malley K 2000 (Seminars in Clinical Neuropsychiatry 5(3):177-90) introduce the umbrella term “Fetal Alcohol Spectrum Disorder (FASD)”

“FASD” acknowledges that around one in ten children and young people damaged by pregnancy alcohol exposure has typical facial features of FAS, but the rest don’t, whilst still demonstrating evidence of brain and organ damage; they are all within a “SPECTRUM”.

This population on assessment show a range of physical, mental, behavioural and/or learning difficulties with life long implications and very variable prognosis and frequent “secondary disabilities”.

FASD DIAGNOSTIC SYSTEMS * (!):

• Centres for Disease Control (CDC); Bertrand et al. 2005
• Institute of Medicine - Revised (IOM); Hoyme et al. 2016 (previously 1996/2005)
• Four Digit Code; Astley 2006 (original 2000)
• DSM 5 ( “Neurodevelopmental disorder associated with prenatal alcohol exposure.” ) APA 2013
• Canadian (Revised); Cook et al. 2016 (original 2005)

(* See BMA Board of Science “Alcohol and Pregnancy. Preventing and managing Fetal Alcohol Spectrum Disorders. ”February 2016; Now SIGN Guideline 2019 supports - Canadian Guideline)
Descriptor Categories: (n.b. growth criteria no longer applied)
- FASD ‘with sentinel facial features’
- FASD ‘without sentinel facial features’
- ‘At Risk for FASD’

Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population in 2012
Global prevalence of alcohol consumption in pregnancy
Popova et al 2017

Top 5 countries % consumption
- Ireland 60.4
- Belarus 46.6
- Denmark 45.8
- UK 41.3
- Russia 36.5

*UK PREVALENCE of FASD 20-50/1000 POPULATION (2-5%)*
SIGN GUIDELINE 156 (2019) - 32.4 per 1,000 (95% CI 20.0 to 49.0) (~ 3.2%)
The actual figure may be higher – see biomarker studies.
Strategies to reduce Alcohol Harm in Scotland over the last Decade

2009

Changing Scotland’s Relationship with Alcohol:
A Framework for Action

2018

e.g.
• PH awareness campaigns
• Price (MUP)
• Marketing
• Availability
• ABI’s
• Preconceptual care

Scottish Government supported Strategies targeting Pregnancy alcohol exposure and harm

Awareness Raising and Training:-

- On Line FASD e-Learning modules (NES 2013/2019) – upgrade due
- Outreach Clinician Training from Winnipeg Manitoba (2013/16/19)
- National FASD Clinician’s Forum (2015, et seq.- biannual)
- National FASD Care Pathway (2016, Dr. Patricia. Jackson et al.)
- SIGN Guideline 156 (2019 Drs. Patricia Jackson, Helen Mactier, Jennifer Shields, Sarah Brown et al.)
Other Measures:-

- **Awareness Raising / Liaison** – education, social work, third sector, preconceptual health care ("Ready Steady Baby" initiative), justice

- **Research:-**
  1. Scottish Paediatric Surveillance Unit Enhanced Passive FAS Surveillance Study of FAS in under sixes (2010-2014) 41 cases in 60 months (Neil McIntosh, Forrester Cockburn, John McClure, Maggie Watts)
  2. Alcohol Biomarker Study (Meconium Alcohol Ester) (Abernethy et al. 2017/18)

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Pregnancy alcohol exposure and Meconium Alcohol “Biomarkers”

**Fatty Acid Ethyl Esters, - “FAEE’s” (and Ethyl Glucuronide levels)**
Reflect Fetal Alcohol Alcohol Exposure from around 20 weeks to term
Determining the pattern and prevalence of alcohol consumption in pregnancy by measuring biomarkers in meconium

Carolyn Abernethy, Karen I McColl, Gill Cooper, Donna Farren, Fabio Viscarola, Helen Macdonald

ABSTRACT
Objectives: To investigate the feasibility of determining the patterns and prevalence of alcohol consumption in pregnancy by measuring ethanol biomarkers in meconium.

Design: Retrospective cohort study.
Setting: Princess Royal Maternity Hospital, Glasgow.
Population: Random sample of neonates born at 36-37 weeks gestation at the Princess Royal Maternity Hospital, Glasgow.
Methods: Fetal meconium was collected for biomarker analysis. Ethanol biomarkers (ethanol, ethyl glucuronide, ethyl acrylate) were screened using gas chromatography. Data was compared with alcohol consumption at booking.

Results: 125 mother and babies were enrolled. Median gestational age was 37 weeks. Ethanol was detected in 9% of meconium samples. Ethanol was detected in 7% of meconium samples. Ethanol concentrations were highest in the first week of pregnancy. There was a significant association between maternal smoking and detection of ethanol biomarkers in meconium. There was no association between maternal age, parity, smoking status, birth weight or head circumference.

Conclusions: Fetal meconium is a potential tool for determining the patterns and prevalence of alcohol consumption in pregnancy.

Recent Scottish Meconium Biomarker Study, Published 2018.

Abernethy C. et al. 2018 Princess Royal Maternity Hospital, Glasgow. (Inner City, Northern and Eastern Suburbs of Glasgow)

- N = 235 mother and babies
- Analysis of Fetal Meconium Fatty Acid Ethyl Esters and Ethyl Glucuronide

Results
- Data suggests 40% of pregnancies in this study population were exposed to alcohol.
- Significant & potentially harmful* quantities in 15%
- No association between biomarkers and age, ethnicity, parity, postcode, smoking status, birth weight or head circumference

= 1 in 7 pregnancies

(* >2 drinks (3.5 units) per day or binge drinking of >5 (8.75 units) drinks per occasion)
We will also increase our support for children and families affected by Fetal Alcohol Spectrum Disorder (FASD). Over the next year, we will work to set up a third sector hub that will focus on both preventing instances of FASD arising in the first place and supporting families following diagnosis.

"IMPROVING OUR POPULATION HEALTH" : ...............
Alcohol facts and figures

- Patterns of alcohol use in women have changed significantly over the past 30 years
- Alcohol has become more affordable and more available
- 73% of alcohol sold through supermarkets and other off licenses

Affordability of alcohol

Long term trend

In the UK since 1980 alcohol has become 64% more affordable.

Statistics on Alcohol, England 2018
Alcohol facts and figures

- Patterns of alcohol use in women have changed significantly over the past 30 years
- Alcohol has become more affordable and more available
- 73% of alcohol sold through supermarkets and other off licenses

Drinking by annual income

Higher earners were more likely to drink alcohol.

79% of those earning over £40,000 drank alcohol in the last week compared to 47% of those earning up to £9,999.

Statistics on Alcohol, England 2018

Alcohol facts and figures

- In 2015 wine sales in Scotland reached their highest level for over 20 years

Type of drink amongst those drinking more than 8/6 units

Normal strength beer was the most popular choice for men, while wine (including champagne) was most popular with women on the heaviest drinking day in the week before interview.

Statistics on Alcohol, England 2018
**Drinking Culture**

- Women ‘binge’ drink to levels which would be teratogenic to a fetus - a binge is classified as 6 units of alcohol in one sitting
- 46% of pregnancies in the UK are unplanned/ambivalent (Wellings et al 2013)
- The UK has the 4th highest rate of drinking in pregnancy in the world (41.3%, 32.9–49.3%)  
  *The Lancet Global Health 2017*

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**Alcohol guidelines - pregnancy**

The new guidelines bring the rest of the UK in line with Scotland:

**The CMO guideline states that:**

- If you are pregnant or planning a pregnancy, the safest approach is **not to drink alcohol at all**, to keep risks to your baby to a minimum.
- Drinking in pregnancy can lead to long-term harm to the baby, with **the more you drink the greater the risk**.
- Despite this many pregnancies are alcohol-exposed
• Alcohol can destroy brain cells and damage the nervous system and other organs.
• Prenatal alcohol exposure inhibits both neuronal production and neuronal migration, processes which are crucial for development.
• Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

American Institute of Medicine Report to Congress, 1996
Connectivity

• Alcohol affects
  – Neuronal migration
  – White matter myelination
• “10-second children in a 1-second world”
  • Takes longer to ‘lay down information’
    – Patience required
    – Different techniques
    – Expectations
• Expressive language often better than receptive

Functional Imaging

<table>
<thead>
<tr>
<th>Less connections</th>
<th>Work Harder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>ARND  FAS</td>
</tr>
<tr>
<td>FAS</td>
<td></td>
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Diffuser Tensor Imaging studies (CIFASD)
Functional MRI

Images used with permission of Dr Edward Riley & the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD).
A spectrum of lifelong acquired brain injuries:

- Congenital abnormalities in the structure, size, growth and/or function of the brain and central nervous system.
- Difficulties with development, learning and/or behaviour.
- *May not be detected at birth but can become apparent later in life and carries lifelong implications*
- Vast majority:
  - ‘Patchy profile’
    - Academic difficulties
    - Social difficulties
    - Behavioural problems
    - No growth deficits/no facial features
    - Not microcephalic

What is FASD?

Alcohol is most common cause of developmental disability in the western world

- FASD 2-5% + of population (3%……)
  - Autism 1%
- England – population 66.5 million
  - 13.9m children and young people (<18 years)
    - 400,000 children and young people affected (3%)
- Greater London – population 8.8 million
  - 2.1m children and young people (<18 years)
    - 63,000 young people affected
    - Conservative estimate
  - 1 child in every class of 30…….
Fetal Alcohol Syndrome

NOT ALL CHILDREN WILL HAVE FACIAL FEATURES

THIS DOES NOT MEAN THAT THEY HAVE NOT BEEN AFFECTED BY ALCOHOL
High prenatal alcohol exposure

• What amount confers risk?
  – No known safe amount
  – Maternal factors (weight, health, liver function)

• Canadian Guidelines
  • ≥7 standard drinks/week (1 standard drink = 1.7 units UK*)
  • ≥4 or more drinks on 2 occasions

• DSM IV
  • ‘more than minimal exposure to alcohol during gestation, including prior to pregnancy recognition’
  • ‘minimal drinking is 13 drinks a month, with no more than 2 drinks on the same occasions’
  • Binge – 6 units
High prenatal alcohol exposure

- What amount confers risk?
  - No known safe amount
  - Maternal factors (weight, health, liver function)

4 digit code

- >100mg/dL weekly alcohol (6‐8 beers in a 55kg woman) = 6‐8 standard drinks/week

Canadian Guidelines

- ≥7 standard drinks/week
- ≥4 or more drinks on 2 occasions

DSM IV

- ‘more than minimal exposure to alcohol during gestation, including prior to pregnancy recognition’
- ‘minimal drinking is 13 drinks a month, with no more than 2 drinks on the same occasions’

Factors which can mitigate effects

- Nutrition and metabolism
- Health and concurrent drug use
- Mother’s Age
- Stage of pregnancy
- Pattern of Drinking
  - “Binge culture”
- Paternal Factors

Pre-natal alcohol exposure does not always = FASD
Lifestyle conversation

• Thinking back, can you remember how many weeks you were when you knew you were pregnant?
• What was your life like before you were pregnant?
  – Were you working? At college?
  – Were you happy?
  – Were you generally healthy? Were you on any medications?
  – Were you out much?
    • When you were out, can you remember how much would you have to drink?
    • Would you have anything to drink before you went out?
    • How many drinks would you usually have in a day/week/month?
• Was it a planned pregnancy? Were you taking folic acid?
• How was your pregnancy- Did you keep well? Did you have any concerns?
• Do you remember if you drank any alcohol during your pregnancy? Either at the beginning or the end of your pregnancy?
• What about any drugs and/or smoking?

Nine brain domains affected by FASD

➔ ‘Patchy’ cognitive profile with a disorganised brain
➔ 3 or more affected domains indicates CNS impairment
➔ Highly variable from individual to individual
➔ FASD is a whole body diagnosis
What you see is NOT always what you get: *an example profile*

Neuropsychological profiles differ significantly from individual to individual

- Age may not correlate with functional ability in key areas of their life
- Individuals may function well in some domains, yet need significant support in others.
- Building up a strengths profile of every individual is key

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**Prognosis if not accurately understood......**

**As they grow older they can experience:**

- Social difficulties in relating to their peer group
- Difficulties with educational attainment
- Mental health issues
- Unemployment
- Dependent living
- Addiction issues
- Homelessness
- Involvement with criminal Justice
- Become vulnerable adults
  - likely to experience future trauma
What if we do nothing?

Study of 500 adults with FASD

- 94% mental health problems
- 23% received in-patient care for mental illness
- 79% experienced unemployment
- 60% of those over 12 years had trouble with the law
- 35% of adults experienced dependant living
- 35% overall had alcohol and drug problems
- 35% of adolescents had been in prison for a crime
- 45% engaged in inappropriate sexual behaviour
- 43% had disrupted school experiences (e.g. Dropped out)

Streissguth, Barr, Kogan, & Bookstein (1996)

Successful Outcomes

- Early identification and diagnosis provides a crucial window of opportunity:
  - To educate
  - To provide early intervention
  - To link with resources
  - To facilitate successful transition to adulthood

Diagnosis and early intervention is known to improve outcomes

(Streissguth 2004, Burd et al 2003)
Factors contributing to better outcome are known

– Providing diagnosis at young age
– Guarding from violence and abuse
– Stable and supportive home environment

References

What is the point of the diagnosis?

• Misclassification
  – Inappropriate care and assessments
  – Increased risk of mental health issues
  – Risk in future pregnancies
  – Costly
What is the point of the diagnosis?

- **Misclassification**
  - Inappropriate care and assessments
  - Increased risk of mental health issues
  - Risk in future pregnancies
  - Costly

Post-Diagnosis

- Diagnosis alone does not improve outcome
- Appropriate interventions
- Education
- Support
- Goals
- Improve outcome
- Requires collaboration
The importance of collaboration: parent and caregiver views

- Having to, “fight to be heard,” prior to MDT assessment, and finally feeling “heard” by the team
- Facing “stigmatisation” & having their parenting doubted.
- Assessment process helped them, and others, to understand their child
- Hope that the understanding will enable their child to achieve their potential and prevent emotional distress

The importance of collaboration: professionals’ views

- Professionals clearly felt that MDT assessment helped them make sense of the unique profiles of each child
- Feeling, “informed but not yet empowered,” to work with affected individuals.
- Strategies were highlighted as an area where education wanted to collaborate with clinicians
What does collaboration look like?

Collaboration can take many forms and it relies on forging new relationships

- Training professionals from diverse disciplines to improve expertise and confidence
- Mainstreaming FASD assessment and diagnosis rather than creating specialist services
- Creating new pathways – e.g. Edinburgh’s MDT incorporating educational psychology
- Third sector relationships – e.g. Adoption UK’s FASD Hub (now including support for birth parents)
- Creating resources to empower parents, caregivers, educational professionals and more
Any Questions?

Thanks to:
- NHS Ayrshire and Arran
- Scottish Government
- FAAST team members
  - Old and new!