



APPG on Foetal Alcohol Spectrum Disorders
AGM and Roundtable Discussion

**Clinical Commissioning Groups:
Failing to Implement Government Policy Regarding FASD?**

Thursday, 9 May 2019

4:00 – 6:00 pm

Committee Room 15

Government policy recognises the importance of early interventions for those with Foetal Alcohol Spectrum Disorders and states it is the responsibility of local CCGs to commission these services. Then Health Minister Steve Brine stated in January that Government has 'not an ounce of complacency' in addressing FASD. A new report from the National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) uses responses from Freedom of Information requests to all CCGs and NHS Trusts to draw attention to the glaring mismatch between government policy regarding FASD services and on-the-ground realities. Discussion will include a consultant paediatrician who will explain the challenges of working to support those with FASD when the local CCG has no commissioned services, a father of a child with FASD who also works for a CCG and most critically, the experience of an adult with suspected FASD who has been battling for five years to seek access to a diagnosis who will discuss the impact that delay has had on her life. Roundtable participants will include other officials from relevant departments seeking to improve services and stakeholders involved with other charities and organisations from the FASD UK Alliance seeking to raise awareness and provide support for those with FASD. The first UK screening prevalence study, released at the end of 2018, showed that this brain-based neurodevelopmental disorder resulting from exposure to alcohol in the womb may affect more than 6% of the UK population. It is a hidden disability that affects every constituency throughout the UK.

4:00 – 4:30 **AGM – Update and Election of Officers**
Bill Esterson, MP, Chair

4:30 – 5:30 **Moving Beyond Complacency:
The Need for Change Regarding CCGs & FASD**
Sandra Butcher, Chief Executive
Martin Butcher, Lead Author

The challenge of seeking a diagnosis
Nyrene Cox, Adult with undiagnosed FASD
Member, National FASD Advisory Committee

Diagnostic challenges in assessing FASD – Paediatrician's perspective
Dr Inyang Takon, Consultant Paediatrician
MBBS, MPH, MSc (Lond), MRCPCH, FRCPCH, FWACP

A father's insights into navigating the system
Richard Clements
*Father to child with FASD who works for a CCG as a Primary Care Manager with
responsibility for long term conditions*

5:30 – 6:00 Discussion and next steps

RSVP: info@nofas-uk.org

Questions? Sandra Butcher, NOFAS-UK, 07920 747 560