BPSU Surveillance of Fetal Alcohol Syndrome
Commences in October 2018

Fetal Alcohol Syndrome (sometimes known as FAS) is a rare condition which occurs when the developing baby is exposed to alcohol in the womb. Alcohol can cross the placenta into an unborn baby's bloodstream. The exposure of an unborn baby to alcohol can then affect the development of the brain, leading to challenges in learning and development. Alcohol can also affect the development of other parts of the unborn baby's body, particularly the face.

In the UK and Ireland we currently know little about the exact numbers of babies and children affected by Fetal Alcohol Syndrome and the services they require to support them throughout their childhood. The aim of the study is to answer both these questions and ultimately improve the treatment and support we can provide to babies, children and families affected by Fetal Alcohol Syndrome.

This study is not investigating Fetal Alcohol Spectrum Disorder.

**Duration:** BPSU surveillance will be undertaken for 13-months commencing in October 2018.

**Case definition:** Any child < 16 years old newly diagnosed with FAS in the last month based on the presence of all three of the following clinical features:

1. Facial features*: Smooth philtrum; Thin upper lip; Short palpebral fissures
2. Poor growth: In utero < 10th centile for gestational age; Postnatal – FTT
3. Structural or functional brain abnormality: Head circumference < 10th centile or microcephaly with increasing age; Abnormal brain scan; Developmental delay / learning difficulties; Abnormal neurological signs.

A history of maternal alcohol use during pregnancy is not required for reporting and cases may be reported if this is uncertain or unknown.

* Please refer to palpebral fissures and philtrum guide at [www.rcpch.ac.uk/sites/default/files/2018-10/palpebral_fissures_and_philtrum.pdf](http://www.rcpch.ac.uk/sites/default/files/2018-10/palpebral_fissures_and_philtrum.pdf)

**Reporting Instructions:** Please report any cases of babies or children under 16 years of age meeting the surveillance case definition of FAS whom you have seen in the last month in the UK or the Republic of Ireland from October 2018.

**Website:** [www.rcpch.ac.uk/bpsu/fas](http://www.rcpch.ac.uk/bpsu/fas)

**Funding:** This study is being funded by the Sir Halley Stewart Trust with matched funding from Public Health England.

**Ethical approval:** This study has been approved by London - Camden & Kings Cross Research Ethics Committee (REC reference: 17/LO/1020; IRAS project ID: 212510); HRA Confidentiality Advisory Group (reference: 17/CAG/0161); and the Scottish Public Benefit and Privacy Panel (1718-0262).

**Support group:** National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) ([http://www.nofas-uk.org/](http://www.nofas-uk.org/))

**Further information:** If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

Dr Kathryn Johnson,
Leeds General Infirmary Great George Street, Leeds LS1 3EX

**Email:** leedsth-tr.bpsu.fas@nhs.net

V1 23102018