BPSU Surveillance of Severe Microcephaly in the UK & Ireland (SSM-UKI)

Commences in October 2017

Microcephaly describes a baby with a ‘small head’, who has experienced poor head growth before or after birth. Severe microcephaly is defined by the World Health Organization (WHO) as a head circumference more than 3 standard deviations (<-3SD) below the mean for age and sex. This rare condition may be associated with abnormal brain structure or neurodevelopment, and with disability, although some babies will develop normally. Many different causes of microcephaly have been described, including genetic disorders, exposure during pregnancy to environmental toxins, certain drugs, malnutrition or infection. Two important infections in the mother that may cause microcephaly are rubella (German measles) and Zika virus.

This study will find out how many UK babies are born with microcephaly each year and how seriously this affects their health and development, including any problems with hearing and vision. It will provide a better picture of the support these babies and their families currently receive. This will allow us to make sure the right services are available to meet their future needs and improve outcomes. Importantly, through comparison with congenital anomaly registers, the study will also explore the best ways to monitor future changes in the frequency of microcephaly.

**Duration:** BPSU surveillance will be undertaken for 13 months, commencing 1st October 2017.

**Reporting case definition:** Commencing 1st October 2017, please report any child seen in the UK or Republic of Ireland in the last month who meets the case definition below.

Any live born child aged up to and including 12 months of age who:
- has been diagnosed with microcephaly in the past month,

and / or is noted to have a head circumference that is:
- more than three standard deviations below the mean (<-3SD) for gestational age and sex, or below the <0.4th percentile for age and sex.

Use your standard growth chart.

Excluding: Please do not report babies with anencephaly.

**Website:** www.rcpch.ac.uk/bpsu/microcephaly

**Funding:** Great Ormond St Hospital Children’s Charity

**Ethical approval:** East of Scotland REC (17-ES-088); CAG (17-CAG-0126); Public Benefit & Privacy Panel, Scotland (1718-0184)

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

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