BPSU Surveillance of the Incidence, Management and Early Outcome of Congenital Ichthyosis
Commences in November 2018

Ichthyosis is a group of skin diseases with abnormally thick, scaly skin. It affects the whole body. Some types of ichthyosis are more severe compared to others. Historically such babies died at birth but they can survive with modern treatments.

Babies with ichthyoses are very rare. There is no proven correct treatment so practice varies. Some babies are kept in the neonatal intensive care unit for weeks whilst others receive care within a more normal setting. Babies may suffer from unnecessary medical interventions.

Our study will establish the number of new cases and early death rates. We will record key treatments, complications and age on discharge from hospital. Ultimately, we aim to improve care for children and families with severe ichthyosis, reducing misconceptions about the disease, variation in practice, and avoidable deaths.

Duration: BPSU surveillance will be undertaken for 2 years commencing in November 2018 with a follow-up questionnaire at 12 months.

Case definition: Any suspected cases of severe congenital ichthyosis in live newborn or still-born babies born in the UK and Ireland between 1st November 2018 and 31st October 2020. This includes babies with collodion membrane (a shiny film covering the skin) or harlequin ichthyosis (thick scales encasing the babies’ body).

Reporting Instructions: Please report any child seen in the last month who meets the case definition in the UK or the Republic of Ireland from November 2018.

Website: www.rcpch.ac.uk/bspu/ichthyosis

Funding: Great Ormond Street-SPARKS research grant V4518.

Ethical approval: The study has been approved by West Midlands - Black Country Research Ethics Committee (reference: 18/WM/0211); HRA Confidentiality Advisory Group (reference: 18/CAG/0105); and Public Benefit and Privacy Panel for Health and Social Care (PBPP) approval in Scotland (PBPP reference: 1819-0098).

Support group: Ichthyosis Support Group (www.ichthyosis.org.uk)

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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