

BPSU Surveillance of Behçet's syndrome in children and young people <16 years of age in the UK and ROI Commences in May 2015

(Short Study Name: Behçet's syndrome)

Behçet's syndrome is a rare condition which can cause inflammation in many parts of the body. In particular, it can cause repeated attacks of mouth and/or genital ulcers (sores), which can sometimes occur with skin rashes, tiredness, joint pains, tummy pains, headaches or eye problems. Behçet's syndrome can affect children and young people although we do not currently know how many children and young people are affected in the UK.

The purpose of this study is to establish the current UK incidence and prevalence of Behçet's syndrome and to describe the burden of disease in children and young people under 16 years of age in the UK and ROI.

Duration: BPSU surveillance will be undertaken for 25 months, commencing in May 2015 with follow-up one year later.

Case definition: Paediatricians and Dermatologists please report any child seen in the last month (new AND follow-up cases) who meet the following case definition in the UK or the ROI.

Children and young people <16 years of age who have 2 of more of the following features not explained by an alternative diagnosis:

- Oral aphthous ulceration
- Skin involvement defined as erythema nodosum, pustulosis, folliculitis or acneiform lesions
- Positive pathergy test (skin prick test)
- Eye involvement (defined as uveitis and/or retinal vasculitis)
- Genital ulceration
- Family history of Behçet's syndrome in a biological parent or sibling
- Vascular involvement: arterial or venous thrombosis, thrombophlebitis and/or aneurysm
- Neurological involvement suggestive of Behçet's syndrome

Website: www.rcpch.ac.uk/bpsu/BHT

Funding: Behcet's syndrome society (from funds raised by the Worshipful Company of Horner's), Alder Hey Children's Charity and the study investigators.

Ethical approval: This study has been approved by NRES Committee – NRES North-West Liverpool East (REC reference: 15/NW/0035; IRAS project ID: 163430) and has been granted Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0103).

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

Dr Clare Pain, Consultant Paediatric Rheumatologist, Department of Rheumatology, Alder Hey Children's NHS Foundation Trust, Eaton Road, Liverpool L12 2AP

Tel: 0151 282 4521 Email: <u>clare.pain@alderhey.nhs.uk</u>