



## BPSU Surveillance of Sydenham's chorea Commences in November 2018

Sydenham's chorea (SC) is a movement disorder, which can occur in children and adolescents that is often accompanied by emotional and behavioural symptoms. The condition is associated with prior infection with the bacteria streptococcus. In Western Europe SC is considered a 'rare disease'; but little is known about how frequently the disorder now occurs in the UK and the Republic of Ireland (ROI). We plan to study the numbers, characteristics, management and outcomes of new cases of SC aged between 0 and 16 years in the UK and ROI.

**Duration:** BPSU surveillance will be undertaken for 25 months, commencing in November 2018 with a 12-month and 24-month follow-up until November 2022.

**Case definition:** According to the Jones criteria for Acute Rheumatic Fever, Sydenham's chorea is defined as "purposeless, involuntary, nonstereotypical movements of the trunk or extremities, often associated with muscle weakness and emotional lability". Sydenham's chorea is typically of acute or subacute onset, meaning that chorea reaches a peak within days or weeks rather than months. The Jones criteria include the differential diagnoses which must be excluded in order to confirm a diagnosis of Sydenham's chorea – these are listed on the notification form. Chorea is frequently a clinical diagnosis. It is important to note that laboratory confirmation of streptococcal infection provides supportive evidence of SC, but absence of such evidence does not preclude clinical confirmation. Cases may be either:

- **Suspected:** cases presenting with chorea with acute or subacute onset, but where no diagnosis of SC has yet been made
- **Confirmed clinically:** cases where a new diagnosis of SC has been made, with chorea presenting with acute or subacute onset, and lack of clinical or laboratory evidence of an alternative cause as defined by the Jones criteria

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

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

**Funding:** This research is supported by the Paul Polani Award from the Royal College of Paediatrics and Child Health / British Academy of Childhood Disability, and by the Sydenham's Chorea Association

**Ethical approval:** This study has been approved by London Bloomsbury REC (REC reference: 18/LO/0760) and has been granted Section 251 HRA-CAG permission (CAG Reference: 18/CAG/0086). This study has been granted Public Benefit and Privacy Panel for Health and Social Care (PBPP) approval in Scotland (PBPP reference: 1819-0077).

**Support group:** Sydenham's Chorea Association (<http://sydenhamschorea.org.uk/>)

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

Dr Tamsin Newlove-Delgado  
University of Exeter Medical School, College House, St Luke's Campus Exeter EX2 2LU  
**Tel:** 01392 726083 **Email:** [t.newlove-delgado@exeter.ac.uk](mailto:t.newlove-delgado@exeter.ac.uk)