



An Update on Research supported by Sydenham's Chorea Association (SCA)

Modern illness or a thing of the past? Surveillance study of childhood/adolescent Sydenham's chorea in the UK and the Republic of Ireland

(Principal Investigators, Dr Tamsin Newlove-Delgado & Dr Oana Mitrofan, University of Exeter)

This study involves an ambitious collaboration between the SCA and experts in neurology, psychiatry, cardiology and public health, a mix of NHS and university researchers based in Dublin, Exeter, Glasgow, London and Newcastle. The study aims to fill the gap in scientific knowledge of the current pattern of SC in the UK and Ireland. Over a period of 1-2 years researchers will collect anonymised information relating to all children and young people referred to paediatricians with new diagnoses of SC or referred to child and adolescent mental health services with a history of SC. The study will provide information on the range of symptoms together with some data on the course of SC and their treatment experience. It will also raise the profile of SC in the UK and Ireland.

The resources of the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatric Surveillance System (CAPSS) enable this research to reach paediatricians and child psychiatrists working in all health settings across the UK and Ireland. Paediatricians and child psychiatrists receive a monthly reminder asking them to report children with SC. The paediatric surveillance launched in Nov 2018 and will continue for up to 2 years. Psychiatrists are being contacted for one year only from May 2019.

There have already been more cases reported than initially expected, with a geographical spread across the UK. The most common neurological features reported so far were gait disturbance, problems with speech, and loss of fine motor skills. The majority also presented with emotional and/or behavioural symptoms, with the most common being emotional lability (rapid mood swings), anxiety and problems with attention.

More details of these studies can be found on the BPSU & CAPSS websites;

<https://www.rcpch.ac.uk/bpsu-study-sydenhams-chorea>

<https://www.rcpsych.ac.uk/improving-care/ccqi/research-and-evaluation/current-research/studies-relating-to-capss>

Future Plans:

If sufficient funding is achieved the surveillance projects may lead on to further qualitative and mapping studies. These would allow researchers to produce a more detailed picture of the experience of children, families and clinicians dealing with the challenges of SC.

Neuropsychiatric Complications in Sydenham's Chorea

(Principal Investigator, Dr Mallika Pudukollu, University of Glasgow)

A description of the course of the movement disorder and associated psychiatric difficulties in twelve children and young people affected by neuropsychiatric aspects of Sydenham's chorea (SC), who had been seen in the Glasgow Paediatric Neurosciences service. This study brings together their accounts of their illness and motor function recovery, sometimes with continuing symptoms or relapses, together with the occurrence of psychiatric symptoms over time. Highly detailed interviews covering each individual's lifetime experience and brief neurological tests have been completed and analysed. A scientific paper has been drafted for publication and the findings have been drawn together as an MSc thesis, lodged in the Glasgow University Library.

Neuro-Immunology Pilot Study:

A proposed study, to obtain information from blood tests on patients and families interviewed in the study of Neuropsychiatric complications, could not be taken forward for various reasons.

Dr Michael Morton, University of Glasgow