CHILDHOOD/ADOLESCENT SYDENHAM'S CHOREA IN THE UK AND IRELAND

A BPSU/CAPSS SURVEILLANCE STUDY
Summarised by Dr Michael Morton (May 2025)

We supported the first prospective surveillance study to find out how frequently Sydenham's chorea was diagnosed in the UK and Republic of Ireland. Surveillance used established systems, which made monthly contact with paediatricians and child and adolescent psychiatrists to ask them to report if they had seen children with Sydenham's chorea.

In 24 months, starting in 2018, 40 children with new diagnoses were identified from reports made by general paediatricians in the UK. No children were reported in Ireland and psychiatrists reported none. With about 1 new case every 2-3 weeks, and around 15 million children in the surveillance area, Sydenham's chorea is very rare.

The children's mean age was 9 years, and 60% were female. The majority were judged as 'moderate' or 'severe' chorea (72% and 14% respectively). However half of children had severe impairment due to chorea for at least one of the functions of hygiene, handwriting, dressing, speech, walking, and handling utensils. In addition to chorea, their most common neurological features were loss of fine motor skills, walking problems, and speech difficulties.

Emotional and/or behavioural symptoms were very common in this early stage of the illness. Emotional lability (rapid mood swings) was seen in 76%, anxiety in 51%, tics in 37%. More unusual features included episodes of confusion with visual hallucination.

Only 12% were described as having carditis (heart involvement) but 17% didn't get an echo examination of the heart, so it is hard to know the true number.

Most children (76%) were admitted to hospital, with a mean length of stay 6 days (up to 22). Only 30% saw a neurologist.

Almost all children had evidence of prior streptococcal infection, and were prescribed antibiotic courses of varying duration, but only 23% were started on long term antibiotics to protect them in future.

Half of the children were treated with anticonvulsant and/or neuroleptic medication (aiming to reduce symptoms of chorea) and a quarter received immunotherapy (aimed at the treating the underlying disease process). Half were referred to occupational therapy or physiotherapy and just 14% were referred to psychology.