



## **BPSU Surveillance of Severe Paediatric Chronic Fatigue Syndrome or Myalgic Encephalitis (CFS/ME) in UK and Republic of Ireland Commences in February 2019**

Children with chronic Fatigue Syndrome or myalgic encephalitis (CFS/ME) have persistent disabling fatigue for at least 3 months. The fatigue is made worse by activity and is not relieved by rest. Children with CFS/ME have other symptoms including muscle aches, headaches, and poor concentration.

Children with severe chronic fatigue syndrome or ME are only able to leave their house occasionally (if at all). They have severe fatigue and often severe pain and many require help with daily activities such as eating and washing. At the moment, we do not know how often children develop severe CFS/ME or what treatment they receive. This means the NHS cannot organise treatment for them.

In this study, we will ask every children's doctor in the UK whether they have seen a child that month with severe CFS/ME. We will then ask the doctor about their symptoms, how disabled they are and how long they have been unwell. We want to know what treatment children with severe CFS/ME get and we will ask doctors what treatment children were offered and what treatment they received. We also want to know whether children with severe CFS/ME get better and we will go back to doctors after a year to find out what happened to children in terms of treatment offered and whether they got better (or not).

**Duration:** BPSU surveillance will be undertaken for 13 months commencing in February 2019 with a 12 month follow-up until February 2021.

**Case definition:** Children aged 5 to 16 years who has been given a clinical diagnosis of CFS/ME with fatigue that is so severe that they are unable to attend school for more than one hour a week during the last 6 weeks of the school term.

### **Notes:**

- If a child has had CFS/ME for a long period of time, they should be reported when the paediatrician becomes aware that they are not attending school.
- School includes hospital school but not home tuition.
- If a paediatrician is providing assessment during the school holidays or shortly after the school holidays, they should consider whether the child is able to attend school for more than one hour (or do a similar activity) during the last 6 weeks.

**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 February 2019.

**Website:** <http://www.rcpch.ac.uk/bpsu/CFS>

**Funding:** The study is funded by The National Institute for Health Research (Senior Research Fellowship, SRF-2013-06-013) and a grant from the Royal United Hospitals Bath NHS Foundation Trust.

**Ethical approval:** This study has been approved by South West – Central Bristol REC (REC reference: 18/SW/0051) and has been granted Section 251 HRA-CAG permission (CAG Reference: 18/CAG/0051). Public Benefit and Privacy Panel for Health and Social Care (PBPP) approval in Scotland is awaited.

**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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