

SCT Encephalitis Lethargica Research BICMS/QMUL: 2010 update

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EL Surveillance Programme

The EL surveillance program was set up in 2007, with the support of the Sophie Cameron Trust. The aim of this is to monitor all reported UK cases of EL, and to gain specific information on these cases. There are two arms to this study; the paediatric surveillance programme commenced in December 2007, and the adult surveillance programme commenced in April 2008.

As of October 2010, we have been informed of 13 confirmed EL cases in the UK, 9 of these were paediatric cases. Many of these are still awaiting informed consent and have not yet been entered on the database; in several cases informed consent has not been obtained and it has not been possible to obtain further observation. The number of confirmed cases is low, and the number of cases reported via the surveillance program included a number of retrospective cases; however, the initial diagnosis and reporting of EL cases (and therefore the number of cases reported) depends on the awareness of the condition.

Research Programme

A research programme to investigate the functional significance of ABGAs has been supported by a grant from the Sophie Cameron Trust. This currently supports the PhD project of Priya Dua, which started in October 2008. The main focus of Priya's work is to establish a working model to study Encephalitis lethargica and related post-streptococcal movement disorders. In particular this tests the role of streptococcal infections and the functional significance of anti-neuronal antibodies studied in the previous project. A progress report is attached to this report.