

WILSON'S DISEASE SPECIAL INTEREST GROUP (SIG): ANNUAL REPORT 2018-19

This annual report covers the period 1 September 2018 to 31 August 2019.

Membership

The BASL Committee appointed an initial SIG Lead to serve for one year, Dr Bill Griffiths, Consultant Hepatologist, Addenbrookes Hospital, Cambridge. Dr Griffiths was subsequently elected as SIG lead for the period November 2018 to November 2020.

At the time of writing this report, there are 117 individuals included in the member database. 56 (48%) are BASL members and 61 (52%) are non-members.

Meetings

One meeting of the SIG was held during 2018-19 - 14 February 2019, London, 24 participants. A second meeting is planned for 29 November 2019 in London (Queen Square).

Key achievements

The SIG continues to grow, with welcome Psychiatry input, along with strong patient representation from the UK Wilson's Disease Support Group (WDSG). Specialist Centres for Wilson's Disease have been established via the requirement for oversight of trientine use (now under NHSE specialised commissioning as of April 2019). Three paediatric and 12 adult sites for this purpose have been identified in England, with further sites likely to come on board. All sites have clear multidisciplinary working. The SIG is currently developing these sites into 'Centres of Excellence' for the care of patients with Wilson's Disease, with a view to a fully commissioned specialised service in time. The SIG is also establishing standards of care for monitoring of patients with Wilson's Disease in the UK, as these are lacking in current guidelines and there is clear variability. There are exciting developments in the laboratory with new copper assays.

In terms of research, the NIHR adopted CROWD study is in process, which is examining neurological biomarkers and genetic correlation. A UK-US detailed phenotyping study has also been adopted. A novel NIHR proposal is in development and the SIG is interfacing with Pharma regarding a number of drug trials. Database work has accelerated with the appointment of a fellow working with Public Health England (PHE) - there will be considerable research output from this and initial abstracts are in preparation. PHE (specifically NCARDRS) is cross-referencing various data sources including clinical, HES, mortality, prescription, genetic and laboratory copper analysis. This will build up a real understanding of the disease, outline the unmet needs and provide a registry going forward.

Further information

Please visit the SIG webpage at <https://www.basl.org.uk/index.cfm/content/page/cid/31>.