



UK CJDSN ANNUAL REPORT 2023 [September2022-November2023]

CHAIRMAN'S SUMMARY

The Management Committee:

Professor Richard Knight (Chair), Andy Tomaso (Treasurer), Anita Tipping (Secretary), Beth Marsh (Coordinator), Professor Simon Mead, Annette Beal, Dr Kate Dahill, Brian Marsden, Margaret Leitch, Lisa Denton, Sean Horstead, Lizzie Hill and Dr Diane Ritchie (co-opted).

Our Coordinator, Beth Marsh, is now well established in her role, and has been developing and extending what we offer as a support organisation.

Our last Family Day was again face-to-face and again in St Anne's College, Oxford. This has proved a successful venue. However, in line with our policy of considering holding the meetings in different regions, we have decided to hold the 2025 meeting in Chester. The evening meal before the main meeting day has proved to be a good idea; we intend to continue this and to encourage more families to attend it. We decided that it was better to hold our AGM on a separate day from the FSM and it will be held on-line on 08.11.23.

We have continued with digital meetings for the Management Committee. The Committee has a new co-opted member: Dr Diane Ritchie.

We have continued to develop our digital communications and provisions, through our website, email, Facebook and Twitter. Our website promotional video has been updated. The Information/Fact sheets are being updated progressively and will be in digital format only but copies can be downloaded and printed for those who want or need a printed format. We have decided to produce a Quarterly, rather than Annual, Newsletter, and to publish this on our website (copies can be downloaded and printed where necessary). The Helpline continues, with calls back to those who leave messages out of usual hours.

We have continued a series of on-line support groups. A decision was made to have these on a quarterly evening basis, covering 4 topics:

Sporadic CJD, Inherited Prion Disease, Iatrogenic/Acquired CJD and Former Carers. These have proved to be successful, providing useful support for the attendees.

We continue to strengthen our previous connections with other organisations. Liaison with the NPC/NCJDRSU (especially their nursing staff) is very important. Our links with the CJDISA (the CJD International Support Alliance) are valuable; this organisation is reforming and new country members are joining. Beth attended the Prion 2023 Conference and was able to meet with the Directors of the CJDISA. We also became a member of Genetic Alliance UK this year and hope to use this as a way of increasing our reach within the rare disease community and raise awareness.

Our finances are in a good state but donations and fundraising remain vital. Details are given in the Coordinator's and Financial reports. We have approved a number of care grants since the last report, supporting families where health and social care are unable to cover costs.

We continue to provide small research grants, when funding allows. Two new grant recipients presented their intended projects at the FSM in Oxford (15.09.23).

**Richard Knight,
Chair, CJDSN Management Committee,
November 2023**