



UK CJDSN ANNUAL REPORT 2024 [September2023-November2024]

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

Our Coordinator, Beth Marsh continues to develop and extend what we offer as a support organisation.

Our last Family Day was held on the campus of the University of Chester, following our consideration of holding meetings in different regions; it proved to be a good venue and a successful meeting. The evening meal before the main meeting day was well-attended and all agreed it was a good arrangement that we should continue. We are deciding on a venue for the 2025 meeting. Our AGM will again be held on-line on 18.11.24.

We have continued with digital meetings for the Management Committee.

We have continued to maintain and develop our digital communications and provisions, through our website, email, Facebook and Twitter. The Information/Fact sheets are subject to regular review and updating produced in digital format, although 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; essentially a 'digest' of things posted on our website during the relevant period.

The Helpline continues, with calls back to those who leave messages out of usual hours.

We have continued our series of on-line support groups which receive positive feedback from 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 2024 Conference and presented to the conference attendees, along with others representing the CJDISA.

We continue as a member of Genetic Alliance UK and Beth has been accepted as a mentee in the 2024-5 Beacon for Rare Diseases Patient Group Mentoring Programme, enabling her to engage regularly with a experienced Rare Disease charity leader.

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, and plan another call shortly.

**Richard Knight,
Chair, CJDSN Management Committee,
November 2024**