

UK CJDSN ANNUAL REPORT 2022 [November 2021-September 2022]
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 and Lizzie Hill.

This has been the first year that our new Coordinator, Beth Marsh, has been in her role. She has settled in extremely well, not only continuing the excellent work of our previous coordinator (Gill Turner), but also developing and extending what we offer as a support organisation.

This has also been a year, for all of us, in which we have gradually emerged from the Covid restrictions, into more normal life arrangements. Our last Family Day/AGM was face-to-face and so is this one. We have been considering locations and venues other than our long-standing Birmingham hotel. Last year's meeting was in a hotel in Manchester and this year, we are using a college in Oxford. We will review this year's meeting and continue to consider the best arrangements for future meetings.

We have continued with digital meetings for the Management Committee, but have not yet decided if there might be benefit from reinstating at least some face-to-face meetings. The Committee has welcomed three new members: Lisa Denton, Sean Horstead and Lizzie Hill. We have a good balance of professional and family members with a range of useful skills.

We have continued to develop our digital communications and provisions, through our website, email, Facebook and Twitter. We are considering a change of website platform. 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.

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

As a new development, we ran a series of regional on-line peer-support groups. Groups for the North East, North West, Midlands, South East and South West of England were attended with excellent feedback.

We have strengthened our previous connections with other organisations and started to develop new one. Liaison with the NPC/NCJDRSU (especially their nursing staff) is very important. Beth has met with the Cure CJD Campaign and developed our links the CJDISA (the CJD International Support Alliance). Beth has arranged to attend the Prion 2022 Conference and participate in a CJDISA Family Meeting there.

The CJDSN has applied to join the Genetic Alliance UK; being accepted into this wider network of organisations would help to increase our reach 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 had a second call for research grants. One grant was awarded and the researcher will attend the meeting in Oxford to explain briefly their intended work. A researcher who received funding in the first call, will present results of their work at the same meeting. We plan to have a further call for researchers at some point in the next few months.

**Richard Knight,
Chair, CJDSN Management Committee,
September 2022**