

AGM of the CJD Support Network

8th November 2023

Via Zoom at 1800hrs

Present: Beth Marsh, Prof Richard Knight, Andy Tomaso, Anita Tipping, Annette Beal, Eileen Orr, Dr Diane Ritchie, Lizzie Hill, Margaret Leitch, Eve Buckland, Andrew Takoushis, Alice Groux

Apologies: Prof Simon Mead, Lisa Denton, Paul Buckland

1.0 Approval of the 2022 FSM/AGM minutes

The minutes were reviewed and the minutes were deemed to be true by Andy and seconded by Annette.

2.0 Chairman's Annual Report

Prof Knight welcomed everybody. A summary of the Network's annual activities was given.

The Network has strengthened its collaboration and has fostered a close working relationship with the CJD International Support Alliance (CJDISA).

The Network has a new website, www.cjdsupport.co.uk replacing the former www.cjdsupport.net. There is an indication that the new website is working well for us in view of the figures collated since its launch. The digital media platforms have also been recently updated. Followers on X and the Facebook page have dipped a little however, there is a significant increase in number of followers to our Facebook group.

The Network is continuously engaging with its members in trying to improve how best we can serve and help families caring for their loved ones with prion disease through the helpline, peer group online support, annual FSM/AGM, care grant and collaboration with other like-minded charities.

We are trying to hold the Family Support Meeting (FSM) at a different place each year. We were in Oxford this year and next year the FSM 2024 will be held in Chester. Details will be posted on our website in due course.

Current CJDSN factsheets have all been updated and are posted on our website. They can be downloaded for information and dissemination.

The Network has awarded 2 research grants this year.

Care grants have been given to families in need where the local authority is not able to provide. Between 3-4 care grants have been awarded this year.

The CJDSN can be reached by phone through our helpline service and e-mail to admin@cjdsupport.co.uk. We also have the social media platforms that the members and to an extent the public can use to get in touch with the Network.

3.0 Financial report

Accounts from 1st April 2022 to 31st March 2023

Income	£59,995.16
Other Income	£1,094.00
Total Income	£61,049.16
Expenditure	£34,720.72
Net profit for the year	£26,328.44
Reserves	£200K+

The Network remains in a healthy financial position. We continue to grow which allows us to run the Network for 3 years. The new website costs £3860.00. It is a one-off payment which also included the updating of the Network's digital social media platforms. This amount is not a recurring payment.

The 2 research grants awarded this year are still outstanding and yet to be paid for. **Action: Andy**

Andy thanked Lisa and Beth for their support. Andy has reported that there has been a marked increase in income since Beth has taken the role of the Network's coordinator.

The yearly account will be collated in due course. The account will be reviewed by the committee members, signed off by Richard and will be posted to the Charity Commission. **Action: Richard/Andy**

4.0 Coordinator's report

Beth is on her 2nd year as the coordinator of the CJDSN. Her priority mission strategy is engaging with other like-minded group, keep raising the CJDSN profile, develop online group support, support people in fundraising, plan for more informal peer group meeting, collaborate and establish a close working relationship with the CJD International Support Alliance are just few of Beth's innovative ideas to take the Network forward.

Beth is looking at creating audio factsheets, continue collaborating with other groups regarding fundraising activities, meet with the genetic group more frequently, review and update the criteria required for a care grant in view of today's rising cost of living crisis.

She has informed the committee that we have a place in the London Marathon this year.

Beth has also reported that she met up with Alice Groux, a CJDSN member. Alice will be helping Beth regarding ideas for a fundraising and awareness activities.

The coordinator's report will be posted on the website in due course.

5.0 Election of Officers

The incumbent committee members were elected in-block, proposed by Andrew Takoushis and seconded by Annette Beal. Dr Diane Ritchie is now officially a co-opted member of the committee.

6.0 AOBs

The Network's Constitution was last reviewed in 2012. It has been agreed by the committee that it needs to be reviewed in due course to reassure the Network is working within its constitutional parameters and keeping to its purpose.

The meeting finished at 1830hrs.