

CJDSN AGM Minutes Virtual Meeting

13th November 2020

Via Zoom

Present: Andy Tomaso, Beth Marsh, Prof. Richard, Prof Simon Meade, Brian Marsden, Annette Beale, Anita Tipping, Lisa Denton and Megan Marsh,

Apologies: No names submitted

Richard welcome everyone for attending the virtual meeting.

1.0 Annual report of the CJD Support Network

The year's overview of the CJDSN's activities and use of the Network's funds are itemized on the report.

Also included are, why the in-person Family Support Meeting is important, the importance of the Network's digital and social media platforms as a means of communication and support to those who needs it, the decision to hold "on-line meetings for families" as an alternative and temporarily replace the FSM with a series of talks (via zoom) on given topics, followed by Qs & As.

The talks so far presented are

1. The Diagnosis Process
2. Talking about Grief and Loss
3. Genetic forms of CJD and Risk in Families

The talks are all recorded, available to the CJDSN members to see and can be accessed via "you-tube".

Also included, is Richard thanking Gill's commitment and her hard work in developing the CJDSN from its inception to the present day. On behalf of the Network and the committee, Richard has also posted a tribute to Gill on the Network's website.

2.0 Approval of last year's (2019) FSM/AGM CJDSN minutes

The minutes were proposed true by Andy and seconded by Annette.

3.0 Financial Report

Historically, the CJDSN has received a grant from the Department of Health (DOH) for £30,000 per annum to develop the helpline, its core values, education and support strategies. The grant ceased in 2010. Currently, the Network's income relies mainly on donation and fundraising.

£30-35K is earmarked to run and meet the cost of the Network annually. We aim to have enough funds to run the Network for 3 years.

Year-end Financial Report

Total income	£45950.84
Expenditure	£55299.17
Net Profit	-£9349.17
Current Reserve	£154K

Financial Report up to November 2020

Income	£27K
Expenditure	£
Net Surplus	£12K+

Currently our income from fundraising events are on the low side while in-memoriam donation remains high.

Andy is anticipating the net surplus to grow as the Network is not currently paying a coordinator's salary.

3.1 Separate 2nd Bank Account

Earlier in the year, a separate second bank account for the Network's current reserve was brought up and discussed. Andy did look into other accounts and reported that the Charity Account Foundation (CAF) is a slightly better account than the other accounts he's looked into. Gill was looking into the CAF prior to her resignation. To date we have not progress about the account where Gill has left off.

Today that separate bank account was again brought up by Richard. Nothing was decided and Andy will further look into this in due course. **Action: Andy**

Richard has suggested, if we continue to generate a good income, maybe we should think about another research work to be undertaken.

3.2 Lisa Denton

Since Gill's retirement, Lisa, Andy's secretary, has been doing most of the administrative work left by Gill which takes 2-3 hours per week to do. Andy has confirmed that she is paid £15.00 an hour.

4.0 Election of Officers

Prior to the election of officers, Richard asked if there are new names put forward for election and who might want to step down from their posts. No names were submitted.

The incumbent committee members were re-elected en-bloked. Proposed by Brian and seconded by Annette.

5.0 Helpline

Since Gill's retirement the helpline had been manned by the committee members in turn.

Over the 5 weeks of helpline rotation, 7 calls were received which is relatively low. This was discussed and the committee had agreed this could be due to a shift of activities by using more of the Network's digital and social media platforms instead of the helpline.

Richard thinks people are not quite isolated when getting information. Information and support can be had from the National Surveillance Unit Edinburgh, the Prion Clinic, the helpline, the website, FB and twitter.

6.0 On-line Talks for Families

It was reported that all 3 sessions of the talks proved to be popular among the CJDSN members. This was evident by the increase in number of attendees from one session to the next.

As the sessions were recorded it was noted and reported that there are plenty of people looking at the recordings.

Ms Megan Marsh expressed her appreciation for the Network's way of keeping in contact with the CJDSN members while the Covid-19 restrictions are in place, by holding 3 sessions of on-line family meetings via zoom.

7.0 AOBs

Discuss the coordinator's post on the next meeting.

Presentation of the research works by Dr Mok and Dr Nihat. Simon suggested maybe in 6/12 time when all the findings are collated.

Kate has taken in charge of the Network's e-mail@CJD.supportnetwork. Andy thanked Kate for allowing us to have a breathing space for taking this on until a National Coordinator is appointed.

Andy is having a certificate done for Gill and to be signed by Richard. It will be circulated to the committee to see before being sent to Gill.

The next meeting is yet to be announced. Richard will send a doodle poll in due course.

The meeting finished at 1835hrs.