

## **AGM 2024 of the CJD Support Network**

**18<sup>th</sup> November 2024**

**Via Zoom**

**Present:** Beth Marsh, Prof Richard Knight, Andrew Takoushis, Martin Glavan, Ian Cogbill, Helen Turner, Dr Kate Dahill, Margaret Leitch, Dr Diane Ritchie, Brian Marsden, Jessica Carsen, Serena Hill, Anita Tipping (13)

**Apologies:** Prof Simon Mead, Andy Tomaso, Sean Horstead, Dr Lizzie Hill, Carol Parrott (5)

Prof. Knight welcomed everybody for attending the Network's AGM.

### **1.0 Approval of the CJDSN 2023 AGM**

The minutes were reviewed and were deemed accurate. Proposed by Andrew Takoushis and seconded by Kate Dahill.

### **2.0 CJDSN 2024 Annual report- Prof Richard Knight (Chairman)**

Beth, our Network's coordinator continues to develop, extend and raise awareness what the CJDSN has to offer as a support organization.

### **2.1 FSM**

The 2023 FSM (family support meeting) held at the University of Chester proved to be a success and the venue was rated very good. The evening meal held before the FSM was well attended and all agreed it was a good arrangement and it should continue. The venue for the 2025 FSM is yet to be decided.

The Executive Committee (EC) meetings are held via digital technology. The EC continues to maintain and develop our digital communications through our website, email, Facebook and Twitter now known as X.

Information/factsheets are subject to regular review and updating. They are produced in digital format which can be downloaded and printed. Hard copies can also be printed and sent to those who want or need them. The CJDSN Newsletter is produced quarterly rather than annually. The Newsletter is a "summary" of activities, events posted on our website during the relevant period.

## **2.2 Helpline**

The Helpline continues, with calls returned to those who left messages out of the usual hours.

Our on-line peer group support meetings have received positive feedbacks from attendees. Beth will be posting more dates for the on-line peer group support meetings in due course.

## **2.3 Connections to other organizations**

Our connections with other organizations continue to strengthen. Our link with the CJDISA (CJD International Support Alliance) is stronger and valuable. The CJDISA is developing and new country members are joining. Beth attended the Prion Conference 2024 in Shanghai, China.

The CJDSN continue as a member of Genetic Alliance UK. Beth has been accepted as a mentee in the 2024-25 Beacon for Rare Diseases Patient Group Mentoring Programme allowing her to regularly engage with an experienced Rare Disease charity leader.

## **2.4 Finances**

The Network's finances are in a good health. Donations and fundraising remain vital to continue our work as a support organization. The EC has approved a number of care grants since the last report, supporting families where health and social care are unable to meet the costs.

We continue to provide small research grants and plan to call for another in due course.

## **3.0 Coordinator's report**

Beth gave a brief overview of her report to the management committee held on 05.09.24 which will be posted on the CJDSN website in due course.

## **3.1 Activities**

To increase the offer of "in person meetings" Beth has organized the first CJDSN informal "in person meeting" in Dewsbury held during the International CJD Awareness Day, on 12<sup>th</sup> November 2023.

Another meeting of the same aim was held on 9<sup>th</sup> November 2024 held in Edinburgh. Both meetings were open to all. Each meeting welcomed 15-20 attendees and positive feedbacks from each meeting were received.

Other activities explored with the help of volunteers included a walking group meet up and on line “craft and chats” which unfortunately were less attended. Beth would like to thank Kate Errington and Dave Richardson for initiating these ideas.

In terms of raising the CJDSN profile, Beth links with other like-minded organizations, i.e the CJD International Support Alliance and the UK and International Rare Disease Community. Beth on behalf of the CJDSN, participated in an international online campaign for rare disease day in February 2024 and Beth is now a mentee in a mentoring scheme for rare diseases leaders.

Beth attended and spoke at the Prion Diseases Conference in Shanghai, China in October this year and Beth has joined the board of the CJD International Support Alliance.

### **3.2 Continuing areas of focus**

Areas Beth will be focusing this year includes re-confirming our vision and mission and developing strategic aims centred around information, support and connection.

Fostering support and input from non-Executive Committee Volunteers which has led to the development of a new factsheet “For Local Professionals” initiated by Libby Critchley and our “Fundraising Guide” which was developed in collaboration with Alice Groux and launched in January 2024. Beth extends her thank you to the many people who were willing to be featured in this guide.

Continuing our close relationship with the prion nurses in London and Edinburgh to establish a referral system whereby, with consent, client’s details are passed on to Beth for her to reach out to them.

### **3.3 Looking to the future**

Beth will be focusing on consolidating the growth of the Network seen over the recent years and this includes

1. Encouraging and managing formal membership of the charity.
2. Refining and sustaining our outreach telephone support processes.
3. Further develop our audio and video resources.
4. Establishing a clear and manageable programme of events for the next 12 months.

### **3.4 Strategic aims and supportive processes**

During the development of the Network's strategic aims, key performance indicators were included to help measure how we are doing in working towards our vision. More detailed information on our strategic aims and the identified key performance indicators will be shared with the members via our website in due course.

Within the report Beth acknowledged the key processes that are vital for these aims to be achieved as well as information on activities in each area from September 2023-2024. This includes the compassionate and committed governance of the EC, the innovation of our volunteers, the dedication and hard work of our fundraisers.

### **3.5 Spreading the message and collaboration with the Alzheimer's Disease Society**

There are various ways that we and the wider community strive to raise awareness about CJD, Prion Disease and the Network amongst the relevant groups.

In the report, Beth highlights our expanding activities held during International CJD Awareness Day on 12<sup>th</sup> November. This year, Beth reported that the Network took part in the campaign run by the CJDISA helped and supported by volunteers, Ian Cogbill, Libby Critchley, Dave Richardson, Alice Groux as well as Prof. Mead and Prof Knight for their contributions to our UK specific resources for this year's campaign and helped Beth to identify and reach out to like minded organizations to help us spread our message.

Joining the CJDISA campaign led to the collaboration with the Alzheimer's Disease Society and other like-minded organizations resulting to our contents reaching an audience of nearly 1 million people on the day. To maintain the impetus, Beth will be working with our volunteers on how we can increase our reach next year.

Finally, Beth would like to thank everyone who have helped and supported her in her role in taking the Network forward and from strength to strength.

#### **4.0 Financial report**

CJDSN accounts from 1<sup>st</sup> April 2023 to 11<sup>th</sup> March 2024

Income	£88062.86
Other income	£1437.00
Total income	£89499.86
Expenditure	£81382.24
Profit before taxation	£8117.62
Operating profit	£6680.62
Current account 11.03.24	£13143.94
Reserves 11.03.24	£212769.19

Our financial accounts for the year end March 2024 are in the process of being prepared for submission to the Charities Commission.

Our income for year end March 2024 increased by approximately £40K in comparison with year end March 2023.

Notable income comes from Gifts and Donations of around £28.5K and the biggest in-memoriam donations for a year was almost £51K.

The Network is in good financial footing at year end March 2024 and our three years operational cost is comfortably met.

The forecast for 2024-2025 looks positive and income from Gifts and Donations remains buoyant. The Network has also received a large cash donation which has taken our cash reserves to well over £400K.

The Network gratefully acknowledge and thank all those who generously donated and fundraised for us over the years.

#### **5.0 Election of officers**

Annette Beal and Lisa Denton have stepped down from their posts and Prof Knight thanked them for their work and invaluable support to the Network. Every member of the executive committee, management committee and co-opted members were each proposed for re-election and seconded by the members.

Chairman	Prof Richard Knight
Treasurer	Andy Tomaso
Secretary	Anita Tipping
Mgt. Committee	Beth Marsh (co-ordinator)
	Prof Simon Mead
	Dr Kate Dahill
	Margaret Leitch
	Dr Diane Ritchie
	Brian Marsden
	Sean Horstead
	Dr Lizzie Hill
	Andrew Takoushis

A new member standing for election is Andrew Takoushis who was proposed by Dr Kate Dahill and seconded by Helen Turner.

## 6.0 AOBs

Martin asked if we use twitter now X as a digital platform. Only one member is known to use it. So far CJDSN has not had any misinformation posted on X. We'll stay on the course until changes happen.

Andrew inquired about the review of the Constitution. This has come about due to a query of how many co-opted members we could have on the management committee. We need to have the wording right that any changes made is within the law of the Charities Commission. **Action: Beth**

The meeting finished at 1825hrs. The next EC meeting will be on 04.12.24 from 1700hrs – 1830hrs.