

# Annual report of the CJD Support Network Nov. 2020 – Nov. 2021

Report date: 10.11.21

## 1 Year's overview

### 1.1 Funding outcomes April 2020 - March 2021 (Financial year)

A breakdown of our funding can be seen in the financial report. We are very grateful to the members, families and friends of the network who provided us with this funding.

The funding over this period enabled us to provide our usual activities:

1. To run a helpline to provide practical and emotional support for all stakeholders (including responding to 'helpline' emails)
2. Provide written and audio information to families and professionals
3. Maintain our website at [www.cjdsupport.net](http://www.cjdsupport.net) and reply to website emails
4. Maintain other digital platforms, such as Facebook & Twitter.
5. To be an information conduit between public affected by CJD and professional research and service providers to ensure their views are taken into account in all decision making.
6. To provide Support Grants to families.

## 2 Activities

### 2.1 Helpline

During the period under review the CJDSN helpline has received calls from families affected by all types of CJD, those who have been told they were at heightened risk of developing CJD, worried well and professionals seeking information. The number of calls has fallen over the last year or two, perhaps reflecting the support given by the NPC and the NCJDRSU, but also, no doubt, reflecting increasing use of digital means of contact. On average, we now receive only around 1-2 calls/week.

Following Gill Turner's retirement from her role as Co-Ordinator, the committee members have manned the helpline on a rota basis. The helpline will be taken over by our new co-ordinator from November 2021 onwards. We have decided to run the helpline during the day, with a promise to return calls in relation to any messages left overnight.

### 2.2 Website

Our website provides written, audio and video information on CJD. Visitors have used the website to send emails. These were from people affected by CJD asking specific questions about issues surrounding the disease.

During the year we have kept the web information current and up to-date with recent developments in issues surrounding CJD.

### 2.3 Facebook And Twitter

We have continued to use Facebook and Twitter as means of communication and support. The restricted-access Facebook page has allowed families to share

experiences and give advice, as well for committee members to post replies to queries.

## **2.4 Newsletter**

Our last Newsletter was published in July 2019. We have discussed the role of the Newsletter in the light of increasing use of our website and other digital platforms. We have decided to continue with a quarterly Newsletter but to publish this on our website and to print out copies to send to those who wish to have a print copy, rather than produce a separate fully print version.

## **2.0 Covid-19**

### **2.1 Committee Meetings**

Covid-19 situation has impacted on our activities, as it has for everyone. Firstly, our committee meetings shifted to ones conducted in person to virtual on-line meetings, via a zoom account. The situation is under constant review. Our first face-to-face committee meeting for some time will be held in Manchester, the day before our Family Support Meeting. This has resulted in some saving of costs (transport etc). We will consider how many face-to-face meetings we should undertake and how many to leave in a virtual setting.

### **2.2 AGM & Family Day**

The AGM is normally held at our annual Family Day. Sadly, we had to cancel the Family Day arranged for November 2020. The 2020 AGM was a virtual one held on Nov13th 2020. The loss of an in-person Family Day is a real one, given the importance of people meeting and sharing their experiences; we are very pleased to reinstate this day in Manchester in November 2021. The cancellation of the 2020 meeting involved a small financial loss relating to the booking, but this was unavoidable.

### **2.3 On-Line Meetings for Families**

We decided to replace the Family Day with a series of on-line (zoom) Family Support Meetings. These consisted of a short talk on a given topic, followed by an open Q&A session.

We held 3 such virtual meetings in the year covered by the last Annual Report:  
09.09.20 The Diagnostic Process; 10.10.20 Talking about Grief and Loss;  
11.11.20 Genetic Forms of CJD and Risk in Families

We held a further meeting on 22.06.20 on nursing and care for CJD.

The talks given at these meetings were recorded and are available for CJDSN members & families to watch.

We will consider holding other such meetings as an adjunct to our annual Family Support Meetings.

### **3.0 Our New Co-Ordinator: Beth Marsh**

Gillian Turner, our previous national coordinator was involved in CJD support for some 23 years and retired in September 2020. A great many families will have reason to be grateful to her, as indeed are the whole CJDSN management committee. Our website contains a tribute to her work and commitment over the years. I am sure everyone wishes her well in retirement.

The Covid situation, with the Lockdown, meant that we could not give a proper farewell to Gillian, but the committee have invited her and her husband, David, to an evening meal on the eve of our Family Support Day.

Members of the committee have been very helpful in covering her various roles, including manning the helpline in rotation, whilst we sought a replacement. We are very pleased that Beth Marsh has taken on the role from November 2021.