

THE CJD SUPPORT NETWORK
ANNUAL REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31st MARCH 2021

Associates House
118a East Barnet Road
New Barnet
Hertfordshire
EN4 8RE

TRUSTEES

Prof. Richard Knight (Chairman)
Andrea Tomaso (Treasurer)
Anita Tipping (Secretary)

BANKERS

Lloyds Bank Plc
1 Claremont Road
Surbiton
Surrey KT6 4QS
Sorting code 30-98-62

REGISTERED CHARITY NUMBER

1097173

INDEPENDENT EXAMINER

Weaver-AFS Ltd
Associates House
118a East Barnet Road
New Barnet
Hertfordshire
EN4 8RE

THE CJD SUPPORT NETWORK

REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31st MARCH 2021

The Trustees are pleased to present their report together with the financial statement of the charity for the year ended 31st March 2021.

Legal and Administration information set out on the front page of this report.

STRUCTURE, GOVERNANCE AND MANAGEMENT

The CJD Support Network is governed by an independent constitution and administered by an executive committee.

The officers and other members of the committee are elected annually at the Annual General Meeting and there are currently three trustees.

OBJECTIVES AND ACTIVITIES

To support patients and their carers affected by Creutzfeldt Jakob Disease and all human prion diseases by the provision of information, advice and support and to advance scientific and medical education and research in topics related to Creutzfeldt Jakob Disease and all prion diseases.

ACHIEVEMENTS AND PERFORMANCE

The Network continues to be the principal charity for Prion disease and maintains good links with both the Centres of Excellence in the UK. We have been providing emotional and practical support to families affected by all forms of CJD and to those who are informed that they are at higher risk of CJD through secondary transmission i.e. blood transfusion and surgery instruments now for over 20

In the period of this report we have responded to numerous helpline calls and agreed 3 care grants to families in need through caring for a loved one with all forms of CJD.

In September 2020, our National Co-ordinator, Gill Turner, announced her retirement. Gill was involved in the CJD Support Network since its inception, and her dedication and professionalism has helped the Network grow into the position we are in today. We thank and acknowledge the excellent service she has given us, and are well aware of the help she has personally given families over the years, testament to this being the numerous messages of thanks and best wishes conveyed to Gill directly from family members who have benefitted from Gill's knowledge, experience and compassion. Whilst we undertook a search for Gill's replacement, the helpline and support service we provide continued thanks to the commitment of our committee members on a

Due to the Covid-19 pandemic, we were unable to host our annual family support day in November 2020. This was a great disappointment as historically, these days provided a great deal of support to families and loved ones. It was therefore decided that we would instead host a series of online support events as follows:

- 9th September 2020, 'The Diagnostic Process' (led by Prof. Richard Knight)
- 10th October 2020, 'Talking About Grief and Loss' (led by Dr Kirsten Moore and Jill Walton)
- 11th November 2020, 'Genetic Forms of CJD and Risk in Families' (led by Prof. Simon Mead)

During each event, an expert speaker gave a presentation before leading a Q&A session during which attendees could ask questions themselves, or submit them anonymously via a chat

We have continued to update our website with relevant information and news we feel is of use to anyone who wishes to find out more about CJD and how we can offer support.

The charity is also a member of the international support network for this disease and is often approached by families in European countries and worldwide, including those where no support

FINANCIAL REVIEW

Despite the Covid-19 pandemic, we are pleased to report that it has been another positive year for the Network. Whilst our income from sponsored fundraising events understandably diminished during the pandemic due to government imposed restrictions, we continued to receive great support from many individuals.

Our main source of income during this financial year came from In Memoriam donations totalling amazing £41,430. General donations totalled £7,239 and we were grateful to also receive £7,493 via Gift Aid reclaim. Our total income totalled £57,230 which was up on the £44,252 from the year

Our expenditure for the year was £17,570 which allowed us to enjoy a very healthy surplus for the year of £39,659.

The time, effort and donations contributed by everyone is very much appreciated and we will endeavour to ensure that we continue to make the best use of all the monies raised. It continues to be the policy of our Charity to maintain sufficient reserves to safeguard against any future fluctuations in income and expenditure so the Network may continue operating as long as possible.

PLANS FOR THE FUTURE

The Network always considers its main purpose to be for the support of patients and carers affected by Creutzfeldt Jakob Disease and increasingly also those at risk through secondary transmission. Our priority will be to maintain our services in the present economic climate.

Prof. Richard Knight
Chairman

Signed:

Richard Knight

THE CJD SUPPORT NETWORK
INDEPENDENT EXAMINER'S REPORT

Independent examiner's report to the trustees of CJD Support Network

I report to the trustees on my examination of the accounts of the CJD Network (the Trust) for the year ended 31 March 2021.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act;
2. the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

David Wilkinson FCMA CGMA
Weaver-AFS Ltd
Associates House
118a East Barnet Road
New Barnet
Hertfordshire
EN4 8RE
Date:

THE CJD SUPPORT NETWORK

STATEMENT OF ASSETS AND LIABILITIES at 31st March 2021

	2021		2020	
	£	£	£	£
Current Assets				
LloydsTSB Current Account		6,363		5,745
LloydsTSB Savings Account		192,997		153,956
TOTAL ASSETS LESS LIABILITIES		199,360		159,701
THE FUNDS OF THE CHARITY				
Restricted funds		1,709		1,709
Unrestricted funds		197,651		157,992
TOTAL CHARITY FUNDS		199,360		159,701

Approved by the Board of Trustees on ____ October 2021 and signed on its behalf

Signed by

Richard Knight

Prof. Richard Knight
Chairman

Andy Tomaso

Andy Tomaso
Treasurer

THE CJD SUPPORT NETWORK STATEMENT OF FINANCIAL ACTIVITY
INCOME & EXPENDITURE ACCOUNT FOR YEAR END 31ST MARCH 2021

		2021		2020	
		Unrestricted Funds £	Restricted Funds £	Unrestricted Funds £	Restricted Funds £
Income					
	Pen sales	0		0	
	Gift Aid Reclaim	7,493		1,562	
	Gifts & Donations	7,239		8,468	
	Give As You Earn	264		386	
	In Memoriam	41,340	0	8,303	1,709
	Interest Income	41		80	
	Raffle income	0		2,035	
	Dinner FSM	0		340	
	Sponsored Fundraising Events	852		23,078	
	TOTAL INCOME	57,230	0	44,252	1,709
Expenditure					
	Bookkeeping	240		240	
	Caring Grants	1,300		925	
	Committee Meetings	0		78	
	Energy Cost Contribution	0		0	
	Family Support Meeting	0		4,859	
	Fundraising Expenses	36		147	
	Insurance	700		681	
	Membership Fees	324		562	
	Microsoft software for computer	0		96	
	Mobile Phone/Internet	586		1,024	
	National Co-ordinator	11,460		18,492	
	New Website costs	43		0	
	Newsletter Printing	0		776	
	Office Supplies	106		189	
	Postage & Delivery	526		664	
	Research Grant	10		12,213	10,072
	Promotional Material	0		0	
	Software	815		477	
	Stationery	0		103	
	Telephone	576		597	
	Training & Development	0		0	
	Travel/Committee	0		1,455	
	Travel/Co-Ordinator	0		799	
	Website maintenance	850		850	
	TOTAL EXPENDITURE	17,570	0	45,227	10,072
Excess of expenditure over income		39,659	0	(975)	-8,363
Balance brought forward 1st April 2020		157,992	1,709	158,967	10,072
BALANCE CARRIED FORWARD 31ST MARCH 2020		197,651	1,709	157,992	1,709