

THE CJD SUPPORT NETWORK

England & Wales · Charity number 1097173

Details

Status Registered

Legal form Other

Registered 2003-04-23

Register [View on the Charity Commission register](#)

Contact

Address C J D Support Network
Associates House
118a East Barnet Road
New Barnet
EN4 8RE

Phone 08007747317

Email admin@cjdsupport.co.uk

Website www.cjdsupport.co.uk

Activities

Objects: 1. TO RELIEVE PERSONS AND THEIR CARERS AFFECTED BY CREUTZFELDT JAKOB DISEASE AND ALL HUMAN PRION DISEASES (CJD* FOR THE REST OF THE CONSTITUTION) BY THE PROVISION OF INFORMATION, ADVICE AND SUPPORT. 2. TO ADVANCE SCIENTIFIC AND MEDICAL EDUCATION AND RESEARCH IN TOPICS RELATED TO CREUTZFELDT JAKOB DISEASE AND ALL PRION DISEASE (CJD*) INCLUDING, BUT NOT EXCLUSIVELY BY THE PROVISION OF CONFERENCES, TRAINING, WORKSHOPS AND TALKS.

Activities: To provide accessible, plainly written CJD information, advice, emotional and practical support for patients, carers, professionals and those at risk through secondary transmission. Promoting good quality care, support and interagency co-operation. Linking families with similar experience.

Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£260,541	£38,640	-	-
2024-03-31	£101,052	£83,728	-	-
2023-03-31	£61,299	£34,990	-	-
2022-03-31	£35,269	£44,070	-	-
2021-03-31	£57,230	£17,570	-	-

Trustees

Name	Role	Appointed
Richard Sydney Godfrey Knight	Chair	2017-11-18
Andrew Paul TAKOUSHIS		2025-11-24
Bethan Rose Marsh		2025-11-24
Daniel Michael Schonberg		2025-11-24
Dr Diane Louise Ritchie		2025-11-24
Elizabeth Amy Hill		2025-11-24
Katherine Dahill		2025-11-24
Professor Simon Harvey Mead		2025-11-24
Sean Kevan Horstead		2025-11-24

THE CJD SUPPORT NETWORK

England & Wales - Charity number 1097173

Accounts

THE CJD SUPPORT NETWORK
ANNUAL REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31st MARCH 2025

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

TRUSTEES

Prof. Richard Knight (Chairman)
Andy 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

Not Just Numbers Ltd
5 Carrwood Park
Selby Road
Leeds
West Yorkshire
LS15 4LG

THE CJD SUPPORT NETWORK
REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31st MARCH 2025

The Trustees are pleased to present their report together with the financial statement of the charity for the year ended 31st March 2025.

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 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 almost 30 years.

Beth Marsh has continued in her role as our National Co-ordinator and continues to bring great passion, enthusiasm and skill to the role. In the period of this report, we have responded to numerous helpline calls and agreed eight care grants to families in need through caring for a loved one with all forms of CJD. We once again hosted our Family Support Day in September 2024 in Chester. The Family Support Day gives families the opportunity to meet with other families who have experience with CJD, and also provides information from presentations given by expert speakers. We received a lot of positive feedback from attendees.

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 is available.

FINANCIAL REVIEW

We were the generous recipients of many donations throughout 2024-25, with major contributions from general Gifts and Donations totalling over £172,000 and In Memoriam donations totalling just under £56,000. Our overall income for year ending March 2024 was just over £260,000. Our expenditure for the year was £38,640. As a result, we showed a financial surplus for year ending March 2024 of just over £214,000.

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.



RSG Knight

Signed on 29 January 2026 @ 10:58

Prof. Richard Knight
Chairman

Signed:

THE CJD SUPPORT NETWORK – CHARITY NO 1097173
INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31ST MARCH 2025

Independent Examiner's Report

I report to the trustees on my examination of the accounts of the CJD Support Network charity ("the Trust") for the year ended 31st March 2025.

Responsibilities and basis of report

As the charity's trustees, 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

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Chartered Institute of Management Accountants.

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

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting 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 to enable a proper understanding of the accounts to be reached.

Signed



D A Whitaker
Signed on 28 January 2026 @ 21:58

Deborah Whitaker ACMA CGMA
Not Just Numbers Ltd
5 Carrwood Park
Selby Road
Leeds
West Yorkshire
LS15 4LG

Date:

**THE CJD SUPPORT NETWORK STATEMENT OF FINANCIAL ACTIVITY
INCOME & EXPENDITURE ACCOUNT FOR YEAR END 31ST MARCH 2025**

	2025		2024	
	Unrestricted Funds £	Restricted Funds £	Unrestricted Funds £	Restricted Funds £
Income				
Member Subscriptions	145		130	
Fundraising Item Sale	13		1,028	
Gift Aid Reclaim	9,576		6,650	
Gifts & Donations	172,159		21,104	
Give As You Earn	470		803	
In Memoriam	56,404		57,960	
Interest Income	4,136		2,300	
Merchandise	1,112		0	
Research donation	380		0	
In memoriam (Restricted for reasearch)	0	300	0	
Raffle income	0		1,157	
Dinner FSM	0		260	
Sundry incom	0		220	
Sponsored Fundraising Events	15,847		9,441	
TOTAL INCOME	260,241	300	101,052	0
Expenditure				
Accountancy	648		672	
Caring Grants	2,159		3,635	
Family Support Meeting	7,087		5,529	
Fundraising Expenses	2,481		2,342	
Gifts	135		0	
Insurance	929		902	
Legal & Professional	0		295	
Membership Fees	-10		668	
Mobile Phone/Internet	229		180	
New Website costs	0		46	
Office Supplies	30		12	
Postage & Delivery	694		600	
Printing	189		0	
Prion Conference	750		259	
Promotional Material	215		0	
Raffle expenses	120		76	
Research Grant	0		48,500	
Salaries employers nic and employers pension	19,109		17,094	
Software	810		597	
Telephone	549		390	
Travel/Committee	398		564	
Travel/Co-ordinator	1,241		766	
Website maintenance	878		600	
TOTAL EXPENDITURE	38,640	0	83,728	0
Excess of expenditure over income	221,601	300	17,325	0
Balance brought forward 1st April 2024	232,484	1,709	215,159	1,709
BALANCE CARRIED FORWARD 31ST MARCH 2025	454,085	2,009	232,484	1,709

THE CJD SUPPORT NETWORK

STATEMENT OF ASSETS AND LIABILITIES at 31st March 2025

	2024		2024	
	£	£	£	£
Current Assets				
Other debtor	0		0	
LloydsTSB Current Account	13,198		21,318	
LloydsTSB Savings Account	443,140		213,004	
		456,338		234,322
Current Liabilities				
Other taxes and social security costs		(244)		(129)
TOTAL ASSETS LESS LIABILITIES		456,094		234,193
THE FUNDS OF THE CHARITY				
Restricted funds	2,009		1,709	
Unrestricted funds	454,085		232,484	
TOTAL CHARITY FUNDS		456,094		234,193

Approved by the Board of Trustees on ___ January 2025 and signed on its behalf

Signed by



RSK Knight

Signed on 29 January 2026 @ 10:58



A Tomaso

Signed on 29 January 2026 @ 06:03

Prof. Richard Knight
Chairman

Andy Tomaso
Treasurer

THE CJD SUPPORT NETWORK

England & Wales - Charity number 1097173

Accounts

THE CJD SUPPORT NETWORK
ANNUAL REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31st MARCH 2024

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

TRUSTEES

Prof. Richard Knight (Chairman)
Andy 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 2024

The Trustees are pleased to present their report together with the financial statement of the charity for the year ended 31st March 2024.

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 25 years.

Beth Marsh has continued in her role as our National Co-ordinator and continues to bring great passion, enthusiasm and skill to the role. In the period of this report we have responded to numerous helpline calls and agreed 8 care grants to families in need through caring for a loved one with all forms of CJD.

We once again hosted our Family Support Day in September 2023 in Oxford. The Family Support Day gives families the opportunity to meet with other families who have experience with CJD, and also provides information from presentations given by expert speakers. We received a lot of positive feedback from attendees.

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 is available.

FINANCIAL REVIEW

We were the generous recipients of many donations throughout 2023-24, with major contributions from general Gifts and Donations totalling over £21,000 and In Memoriam donations totalling just under £58,000. Our overall income for year ending March 2024 was just over £101,000. This included approximately £1150 raised from our annual fundraising raffle.

Our expenditure for the year was £83,728. Research grants totalling £48,500 were awarded in the year. Other expenditure was broadly in keeping with previous years. As a result, we showed a financial surplus for year ending March 2024 of just over £17,000.

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:

RSG KNIGHT



THE CJD SUPPORT NETWORK
INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31ST MARCH 2024

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 2024..

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; or
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: 20 January 2025

**THE CJD SUPPORT NETWORK STATEMENT OF FINANCIAL ACTIVITY
INCOME & EXPENDITURE ACCOUNT FOR YEAR END 31ST MARCH 2024**

	2024		2023	
	Unrestricted Funds £	Restricted Funds £	Unrestricted Funds £	Restricted Funds £
Income				
Member Subscriptions	130		130	
Fundraising Item Sale	1,028		422	
Gift Aid Reclaim	6,650		3,452	
Gifts & Donations	21,104		16,464	
Give As You Earn	803		122	
In Memoriam	57,960		29,931	
Interest Income	2,300		379	
Raffle income	1,157		454	
Dinner FSM	260		640	
Sundry incom	220		0	
Sponsored Fundraising Events	9,441		9,305	
TOTAL INCOME	101,052	0	61,299	0
Expenditure				
Accountancy	672		528	
Caring Grants	3,635		1,395	
Family Support Meeting	5,529		5,250	
Fundraising Expenses	2,342		2,346	
Insurance	902		836	
Legal & Professional	295		0	
Membership Fees	668		713	
Mobile Phone/Internet	180		367	
National Co-ordinator	0		0	
New Website costs	46		3,860	
Office Supplies	12		120	
Postage & Delivery	600		419	
Prion Conference	259		657	
Raffle expenses	76		164	
Research Grant	48,500		0	
Salaries and employers nic	17,094		17,003	
Software	597		514	
Telephone	390		149	
Travel/Committee	564		494	
Travel/Co-ordinator	766		147	
Website maintenance	600		27	
TOTAL EXPENDITURE	83,728	0	34,990	0
Excess of expenditure over income	17,325	0	26,309	0
Balance brought forward 1st April 2023	215,159	1,709	188,850	1,709
BALANCE CARRIED FORWARD 31ST MARCH 2024	232,484	1,709	215,159	1,709

THE CJD SUPPORT NETWORK

STATEMENT OF ASSETS AND LIABILITIES at 31st March 2024

	2024		2023	
	£	£	£	£
Current Assets				
Other debtor	0		162	
<hr/>				
LloydsTSB Current Account	21,318		6,312	
LloydsTSB Savings Account	<u>213,004</u>		<u>210,394</u>	
		234,322		216,868
Current Liabilities				
Other taxes and social security costs		(129)		0
		<hr/>		<hr/>
TOTAL ASSETS LESS LIABILITIES		234,193		216,868
		<hr/>		<hr/>
THE FUNDS OF THE CHARITY				
Restricted funds	1,709		1,709	
Unrestricted funds	<u>232,484</u>		<u>215,159</u>	
TOTAL CHARITY FUNDS		234,193		216,868
		<hr/>		<hr/>

Approved by the Board of Trustees on 15th January 2024 and signed on its behalf

Signed by

Prof. Richard Knight
Chairman

RSG KNIGHT

RSG KNIGHT



Andy Tomaso
Treasurer

THE CJD SUPPORT NETWORK

England & Wales - Charity number 1097173

Accounts

THE CJD SUPPORT NETWORK
ANNUAL REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31st MARCH 2023

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

TRUSTEES

Prof. Richard Knight (Chairman)
Andy 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 2023

The Trustees are pleased to present their report together with the financial statement of the charity for the year ended 31st March 2023.

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 25 years.

Beth Marsh has continued in her role as our National Co-ordinator and continues to bring great passion, enthusiasm and skill to the role. In the period of this report we have responded to numerous helpline calls and agreed 5 care grants to families in need through caring for a loved one with all forms of CJD.

We hosted our Family Support Day in September 2022 in Oxford. The Family Support Day gives families the opportunity to meet with other families who have experience with CJD, and also provides information from presentations given by expert speakers. We received a lot of positive feedback from attendees.

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 is available.

FINANCIAL REVIEW

We were the generous recipients of many donations throughout 2022-23, with major contributions from general Gifts and Donations totalling over £16,000 and In Memoriam donations totalling just under £30,000. Our overall income for year ending March 2023 was just over £61,000. This included approximately £450 raised from our annual fundraising raffle.

Our expenditure for the year was £34,990. Other expenditure was broadly in keeping with previous years. As a result, we showed a financial surplus for year ending March 2023 of just over £26,000.

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:



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 2023.

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; or
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 FINANCIAL ACTIVITY
INCOME & EXPENDITURE ACCOUNT FOR YEAR END 31ST MARCH 2023**

	<u>2023</u>		<u>2022</u>	
	Unrestricted Funds £	Restricted Funds £	Unrestricted Funds £	Restricted Funds £
Income				
Member Subscriptions	130		120	
Fundraising Item Sale	422		271	
Gift Aid Reclaim	3,452		2,215	
Gifts & Donations	16,464		11,106	
Give As You Earn	122		791	
In Memoriam	29,931		17,058	
Interest Income	379		18	
Raffle income	454		1,308	
Dinner FSM	640		120	
Sponsored Fundraising Events	9,305		2,262	
TOTAL INCOME	61,299	0	35,269	0
Expenditure				
Accountancy	528		336	
Caring Grants	1,395		2,780	
Family Support Meeting	5,250		3,165	
Fundraising Expenses	2,346		1,706	
Insurance	836		754	
Membership Fees	713		0	
Mobile Phone/Internet	367		683	
National Co-ordinator	0		0	
New Website costs	3,860		0	
Office Supplies	120		1,493	
Postage & Delivery	419		11	
Prion Conference	657		0	
Raffle expenses	164		142	
Research Grant	0		24,990	
Salaries and employers nic	17,003		7,078	
Software	514		533	
Telephone	149		185	
Travel/Committee	494		214	
Travel/Co-ordinator	147			
Website maintenance	27		0	
TOTAL EXPENDITURE	34,990	0	44,070	0
Excess of expenditure over income	26,309	0	(8,801)	0
Balance brought forward 1st April 2022	188,850	1,709	197,651	1,709
BALANCE CARRIED FORWARD 31ST MARCH 2023	215,159	1,709	188,850	1,709

THE CJD SUPPORT NETWORK

STATEMENT OF ASSETS AND LIABILITIES at 31st March 2023

	2023		2022	
	£	£	£	£
Current Assets				
Other debtor	162		0	
<hr/> LloydsTSB Current Account	6,312		4,742	
LloydsTSB Savings Account	<u>210,394</u>		<u>186,015</u>	
		216,868		190,757
Current Liabilities				
Other taxes and social security costs		0		(198)
		<hr/>		<hr/>
TOTAL ASSETS LESS LIABILITIES		216,868		190,559
		<hr/>		<hr/>
THE FUNDS OF THE CHARITY				
Restricted funds	1,709		1,709	
Unrestricted funds	<u>215,159</u>		<u>188,850</u>	
TOTAL CHARITY FUNDS		216,868		190,559
		<hr/>		<hr/>

Approved by the Board of Trustees on ___ January 2024 and signed on its behalf



Prof. Richard Knight
Chairman



Andy Tomaso
Treasurer

THE CJD SUPPORT NETWORK

England & Wales - Charity number 1097173

Accounts

THE CJD SUPPORT NETWORK
ANNUAL REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31st MARCH 2022

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

TRUSTEES

Prof. Richard Knight (Chairman)
Andy 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 2022

The Trustees are pleased to present their report together with the financial statement of the charity for the year ended 31st March 2022.

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 years.

In the period of this report we have responded to numerous helpline calls and agreed 6 care grants to families in need through caring for a loved one with all forms of CJD.

In November 2021, following the retirement of our National Co-ordinator, Gill Turner, in September 2020, we were delighted to welcome Beth Marsh as our new National Co-ordinator on a part-time basis. Beth was already well-known to us a committee member previously, and has brought great passion, enthusiasm and skill to the role.

We were also delighted to be able to host our Family Support Day in November 2021 in Manchester following 2020's postponement due to the Covid-19 pandemic. The Family Support Day gives families the opportunity to meet with other families who have experience with CJD, and also provides information from presentations given by expert speakers. We received a lot of positive feedback from attendees.

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 is available.

FINANCIAL REVIEW

We were the generous recipients of many donations throughout 2021-22, with major contributions from general Gifts and Donations totalling £11,106 and In Memoriam donations totalling £17,058. Our overall income for year ending March 2022 was £35,269 This included £1,308 raised from our annual fundraising raffle drawn at our Family Support Day in November. Our income was down on the previous year by £21,961

Our expenditure for the year was £44,070. This included a research grant payment that although had been awarded in our financial year ending March 2019, was paid in this financial year. Other expenditure was broadly in keeping with previous years, notwithstanding the reduction in overall salaries paid as we did not have a full time National Co-ordinator in place. As a result of the one-off research grant expenditure, we showed a financial loss for year ending March 2022 of £8,801

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

Richard Knight

Signed:

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 2022.

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; or
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 FINANCIAL ACTIVITY
INCOME & EXPENDITURE ACCOUNT FOR YEAR END 31ST MARCH 2022**

	<u>2022</u>		<u>2021</u>	
	Unrestricted Funds £	Restricted Funds £	Unrestricted Funds £	Restricted Funds £
Income				
Member Subscriptions	120		0	
Fundraising Item Sale	271		0	
Gift Aid Reclaim	2,215		7,493	
Gifts & Donations	11,106		7,239	
Give As You Earn	791		264	
In Memoriam	17,058		41,340	
Interest Income	18		41	
Raffle income	1,308		0	
Dinner FSM	120		0	
Sponsored Fundraising Events	2,262		852	
TOTAL INCOME	35,269	0	57,230	0
Expenditure				
Accountancy	336		240	
Caring Grants	2,780		1,300	
Family Support Meeting	3,165		0	
Fundraising Expenses	1,706		36	
Insurance	754		700	
Membership Fees	0		324	
Mobile Phone/Internet	683		586	
National Co-ordinator	0		11,460	
New Website costs	0		43	
Office Supplies	1,493		106	
Postage & Delivery	11		526	
Raffle expenses	142		0	
Research Grant	24,990		10	
Salaries and employers nic	7,078		0	
Software	533		815	
Telephone	185		576	
Travel/Committee	214		0	
Website maintenance	0		850	
TOTAL EXPENDITURE	44,070	0	17,570	0
Excess of expenditure over income	(8,801)	0	39,659	0
Balance brought forward 1st April 2021	197,651	1,709	157,992	1,709
BALANCE CARRIED FORWARD 31ST MARCH 2022	188,850	1,709	197,651	1,709

THE CJD SUPPORT NETWORK

STATEMENT OF ASSETS AND LIABILITIES at 31st March 2022

	2022		2021	
	£	£	£	£
Current Assets				
<hr/>				
LloydsTSB Current Account	4,742		6,363	
LloydsTSB Savings Account	<u>186,015</u>		<u>192,997</u>	
		190,757		199,360
Current Liabilities				
Other taxes and social security costs		(198)		
TOTAL ASSETS LESS LIABILITIES		<u>190,559</u>		<u>199,360</u>
 THE FUNDS OF THE CHARITY				
Restricted funds	1,709		1,709	
Unrestricted funds	<u>188,850</u>		<u>197,651</u>	
TOTAL CHARITY FUNDS		<u>190,559</u>		<u>199,360</u>

Approved by the Board of Trustees on ___ January 2023 and signed on its behalf

Signed by

Richard Knight

Prof. Richard Knight
Chairman

Andy Tomaso

Andy Tomaso
Treasurer

THE CJD SUPPORT NETWORK

England & Wales - Charity number 1097173

Accounts

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 to 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				
<hr/>				
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

Andy Tomaso

Prof. Richard Knight
Chairman

Andy Tomaso
Treasurer

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

	<u>2021</u>		<u>2020</u>	
	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