CJD SUPPORT NETWORK

Newsletter

Issue 32
Autumn 2022

Charity no. 1097173 CREUTZFELDT-JAKOB DISEASE SUPPORT NETWORK NEWSLETTER

Greetings from the Coordinator

Welcome to the 32nd issue of the CJD Support Network Newsletter. As ever, since our last issue we have continued to offer listening, support, information, and caring grants to those affected by CJD in the UK.

On page 2, you will find an article on our annual Family Support Meeting, which took place on 9th and 10th September, including feedback from some of our wonderful attendees. Following this, on page 3, you will find a report on my experience of attending 'Prion 2022' as well as an article on our first round of online support groups which were held in August.

Page 4 features an introduction to our three new committee members, Lizzie, Sean and Lisa and to a newly appointed clinical nurse specialist at the National CJD Research and Surveillance Unit (NCJDRSU) in Edinburgh, Juli Jose.

The research article for this issue (page 5) takes us back to the challenges of lockdown with an article from Dr Neil Watson, formerly of the National CJD Research and Surveillance Unit (Edinburgh), on his work evaluating the use of telehealth for clinical assessments and contact with families.

As we look to the upcoming International CJD Awareness Day (12th November), on page 6 you will find information on how we are marking the day and how you can get involved, as well as pictures and stories of members of the network and how they have been raising awareness.

On pages 7-8 we showcase some of our fabulous fundraisers, without whom we could not continue our work. This section also details exciting news about our recent partnership with 'Run for Charity'.

In our personal stories section (pp.9-10) you will find touching accounts from Carole, who lost mum Elsie in 1973, and Sally who lost her dad Peter in 2015. A gentle reminder that if you are affected by any of the themes in this newsletter, we're here for you at support@cjdsupport.net and on **0800 774 7317**.

Finally, on page 11 we introduce the CJD International Support Alliance and its two current co-chairs. The CJD Support Network is proud to be part of the alliance and work together with our international colleagues.

As I approach a year in my role, I cannot express how proud I am to be part of this network, to represent the incredible people in it, and to have the opportunity to work with the committee to help ensure that appropriate care and support is available.

Beth

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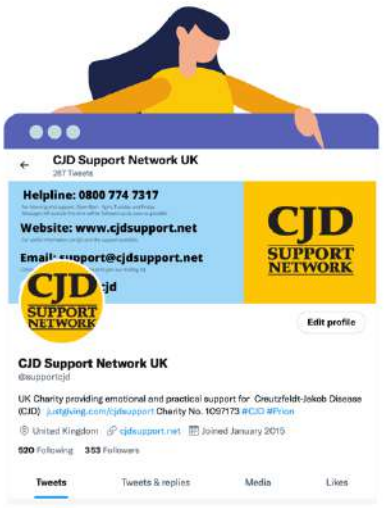

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Twitter: @supportCJD

Join the discussion in our closed group

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Click HERE to join our mailing list and receive future newsletters via email.

Network News

2022 Family Support Meeting (FSM)

On 9th & 10th September we welcomed fifty-five family members and professionals to our FSM, which took place at St. Anne's College, Oxford. Those who opted to join us on Friday shared in an evening meal. On the Saturday, we heard from Dr Hatice Kurudzhu (NCJDRSU) who gave an overview of prion disease, and research presentations from CJDSN research grant recipients Dr Diane Ritchie (NCJDRSU) and Dr Tze How Mok (NPC). Click **here** to access further information on their research which featured in our summer 2022 newsletter. Prof Simon Mead (NPC) gave an update on treatment research. Time was made for more informal discussions through the day and an anonymous Q&A session with national experts. Visit the 'FAQ' section of our website or click **here** to see the answers to the questions asked during the anonymous session.

Questions were answered, and tears were shed, alongside plenty of laughs, hugs and new friendships built as we came together to support, and be supported by, one another. As a committee, we would like to thank everyone who came along and made the weekend such a supportive one, as well as those who provided feedback, which will help us to ensure future meetings continue to be as valuable as possible for attendees. We are already busy planning the FSM for 2023 and hope to be able to announce more details on this in our next Newsletter.

Members of the CJD Support Network Committee

I found the whole weekend comforting, educational, protected & protective, warm, friendly, nurturing and could feel the relief at being with people who just understood.
FSM 2022 Attendee

As I was a first- time visitor, I didn't know what to expect and was quite anxious about joining in. But I was soon put at ease and everybody made me feel welcome and included.
FSM 2022 Attendee

It's been so helpful to learn more about this awful and extremely rare disease, speak to professors with any questions we have, and meet other families who really understand what we've been through.
FSM 2022 Attendee

Network News

Prion|2022
13-16 September
Göttingen, Germany

Beth Marsh,
CJDSN National Coordinator

This year, the world's largest research congress on prion and protein misfolding diseases – Prion 2022 – took place in Gottingen, Germany. At this conference, researchers, students, postdoctoral fellows, clinicians and policy-makers from the neurological and prion fields gathered to focus on what can be done collaboratively to work towards discoveries, diagnostics and treatments.

I had the privilege of attending the conference and it was extremely encouraging to hear about how much work is being done to further our understanding of prion disease internationally. On the final day of the conference, a session on 'Therapeutic perspectives in prion disease' really demonstrated the drive and passion with which researchers are seeking to find ways of tackling this devastating disease.

As part of the scientific programme, a session on international support was hosted by Suzanne Solvyns, director of the CJD Support Group Network (Australia) and co-chair of the CJD International Support Alliance (CJDISA; see page 11 for an article on the CJDISA).

I had the honour of speaking during this session, representing the voice of UK families. I thanked the scientists and clinicians for their continued dedication to understanding prion disease and finding a treatment, and emphasised how important their work is.

The conference featured a 'European CJD Family Workshop' which was attended by family members from countries including the UK, Australia, Belgium and Germany. During the family workshop, our chair Professor Richard Knight gave an extremely clear and accessible overview of prion disease. Further talks were given by Professor John Collinge (UCL), Professor Brian Appleby (USA), Dr Peter Hermann (Germany) and Professor Ruth Gabizon (Israel).

I was extremely proud to represent our network at Prion 2022, connecting with support colleagues from around the world and helping to remind scientists and researchers of the importance of their work and the people whose lives they are working to change.

Online Support Meetings

Throughout August, we hosted our first series of online support meetings. Thank you very much to all who took part, below are some of the feedback comments:

What did you find beneficial about the group?

"There was a real empathy and a desire to listen to each person's experiences."

"The ability to talk freely without having to explain the basics of CJD. The knowledge the others have walked the same path ahead of me and learned to cope"

"A sense of belonging."

Whilst most of those who provided feedback felt the regional aspect of the meetings was positive, a number of people commented that they weren't sure it was necessary. On this basis, we plan to host a further series of sessions in the New Year (dates TBC) with a mix of regional and non-regional groups available as follows:

Northern Ireland
Scotland and NE England
North Wales and NW England
South Wales and SW England
SE England
Current Carers
Genetic prion disease
Sporadic CJD
Acquired/Iatrogenic CJD

Dates for these meetings will be sent to our mailing list and publicised on social media once they are agreed. For queries, contact support@cjdsupport.net

Network News

National CJD Research & Surveillance Unit (NCJDRSU) welcomes new Clinical Nurse Specialist

The NCJDRSU has welcomed new Clinical Nurse Specialist Juli Jose to their team. Juli says:

"I am a qualified dual graduate nurse with extensive experience in the nursing field. Before joining the NCJDRSU team, I was working in the community as a Dementia Specialist Nurse, and I have experience in working in Neurology and Medicine of Elderly departments.

My aim is to provide evidence-based quality care to all the patients who have been diagnosed with the fatal degenerative disease, CJD, and to provide support to their loved ones to the best of my best ability. I believe working with Dementia patients and their families has given me opportunity to have a solid understanding of the disease pathophysiology. It has also enlightened me to understand the importance of providing practical and emotional support to individuals, families and professionals concerned with all forms of CJD. I am willing to provides support, education and training to professionals concerned with CJD as I believe it will help the patients to have better experience while being cared for."

We wish Juli all the very best in her role, and welcome her as part of our wider network.

We are pleased to announce that we have joined Genetic Alliance UK, a national alliance of over 200 patient organisations, supporting those affected by rare and genetic conditions. Being part of this network will help us to increase our reach and raise awareness of CJD. To learn more visit https://geneticalliance.org.uk

We are also pleased to announce that we have partnered with 'Run for Charity' to offer charity places in events across the country. On page 10 you will find details of the key races we are offering places in, with discounted registration fees. If you would like to sign up, follow the appropriate link or visit our website (www.cjdsupport.net or click **here)** for more info.

Introducing our new committee members

At our AGM, which took place as part of the Family Support Meeting on 10th September in Oxford, we welcomed three new committee members. We are pleased to introduce Lisa, Lizzie and Sean to the network:

Lisa Denton has been involved with the network since 2020. She provides invaluable support to the network, assisting with the organisation of the family support meeting and supporting our treasurer, Andy. Lisa says:

"I am very proud to be involved in this charity thanks to Andy introducing me to the committee and happy to help in any way I can."

Lizzie Hill is a PhD student at the MRC Prion Unit in London studying the role of a genetic risk factor, syntaxin-6, in prion disease. She has been with the network since 2021 as a volunteer helping with the newsletter and fundraising, she says:

"Through attending the family support days, I have developed a strong personal commitment to help those affected by prion diseases, which was why I wanted to join the committee."

Sean Horstead is HM Area Coroner for Essex. Sean lost his mother Gillian to sCJD in 2020. Sean wrote a beautiful poem in his mother's memory which was published in our last newsletter. Visit our website or click **here** to read the issue.

The MRC Prion Unit at UCL is holding an open day on Tuesday 29th November 2022.

Capacity is limited and therefore places must be reserved by no later than Friday 15th November.

For more information, to RSVP, or to be added to a list to receive information on the next open day, please contact Sarah Mazdon: **020 7679 5036** or s.mazdon@nhs.net

Research

CJD during the pandemic: a novel use of telehealth

Dr Neil Watson – National CJD Research and Surveillance Unit, University of Edinburgh

Back in March 2020, COVID-19 rates were rising fast in the UK. At the National CJD Research & Surveillance Unit (NCJDRSU) we were faced with difficult decisions around how to safely continue our work, providing timely diagnostic assessments and supportive care to all affected by CJD in the UK. Travelling across the UK was no longer a safe option, but we decided early on that we would continue receiving referrals and providing high quality assessments and support.

We were aided in our time of need by colleagues leading motor neuron disease (MND) clinical care and research trials in our base site, the Centre for Clinical Brain Sciences, University of Edinburgh. They had been using a secure video conferencing platform endorsed by the NHS, the Near Me platform, to perform remote assessments of MND patients. This is a form of telehealth, a term which also includes phone-based assessments. The MND Nurse Consultant for Scotland, Judith Newton, set us up with Near Me accounts. It was intuitive and easy to use.

We had a lot of questions to consider. How could we adopt our surveillance model to telehealth, without losing any of what we gain from in-person assessments? And how would CJD patients and their relatives find this platform? We deal with a highly sensitive subject: we interview patients and families during an incredibly difficult time, and confront lots of challenging topics: would people find video- or phone-based interviews acceptable? Would we still be able to provide the same level of support and empathy over a screen or speaker?

We performed our first assessments in mid-March, a week ahead of the UK-wide lockdown, immediately after we ceased travelling, keen not to miss any opportunities to assess patients. Things went as smoothly as they could have. It soon became apparent that COVID-19 was here to stay, and it would be some time before we returned to in-person interviews. As we adjusted to the 'new normal' we set up a formal telehealth suite, and decided to study the new model to see how it was performing. The results were published in Journal of the Neurological Sciences in November 2020.

By the time of the study, we had interviewed 52 patients, the majority by Near Me. We were able to perform rapid assessments, in 3 cases on the same day as the referral from the regional hospital site, which was a major advantage of the development – this would have been impossible to do when travelling for in-person visits. Given the devastatingly short prognosis in CJD, time matters – and it turned out that the new method saved an average 2 days waiting time before our assessments.

Part of what we do on our visits includes a detailed neurological examination of patients – so how did this work with telehealth? In most situations we were able to work with local clinicians to perform video examinations. This wasn't always possible: for example, some sites had limited internet signal, and some patients were in their own homes rather than hospitals. Nevertheless, if we couldn't perform video examinations, we received detailed reports from local neurologists' assessments, allowing us to secure the diagnosis from afar.

As for users' experiences, feedback from a survey we sent out was encouraging. Respondents felt that telehealth enabled prompt interviews and gave plenty of time for discussions and questions. Only one felt the sound and video quality were inadequate, and unfortunately, they had experienced problems with local signal connections. For others, things went smoothly, and the survey indicated people felt it was an appropriate way to deliver our interviews.

So where do things now stand? The landscape of COVID-19 has changed enormously in the last 28 months. The NCJDRSU team now perform many in-person assessments, but still use telehealth in some situations, often as an adjunct to in-person assessments, for example in individuals nearing the end-of-life and where delays for travelling would be unacceptable. In other situations, for example more complicated cases with unclear diagnoses, in-person assessments might be more suitable. Remote assessments are also a sustainable option when considering the environmental impacts of frequent air and rail travel, and have proven valuable during recent frequent travel disruption and strikes.

If you are a patient, or relative, and you are offered a telehealth interview, please do ask the NCJDRSU staff member what this involves. We are always happy to provide information on how things will work, including what you'll need equipment-wise and how to best set up your room. Please do also get in touch with the Support Network, many of whom have gone through the same process and can help to guide you.

Raising Awareness

In this section of the newsletter, we provide awareness raising updates and showcase some of the fantastic awareness-raising that members of our network have been doing.

International CJD Awareness Day

As many of you will already know, the 12th November 2022 is International CJD Awareness Day, a day when we come together with our friends across the world to raise awareness of CJD.

To mark the day, we will be drawing our 2022 raffle. If you would like to buy tickets, or encourage friends and family to buy tickets and raise awareness in the process, please feel free to follow or share this link: **www.justgiving.com/campaign/CJDSNraffle2022**

In addition, we will be putting together an 'in memoriam' video to raise awareness and honour the memory of loved ones. If you would like us to include a photo of your loved one, please send it to support@cjdsupport.net by 7th November 2022.

We will also be hosting a takeover of the Genetic Alliance UK twitter account **@GeneticAll_UK**, sharing posts throughout the day to raise awareness of CJD to their 15.4k followers. As part of this, we will also be creating content which all are welcome to share via social media to raise awareness. Keep an eye on our website for this!

Finally, we still have awareness raising items available to purchase for just £1 each (plus p&p) including pens, badges and wristbands. These can be worn and used on 12th November 2022, and all year round, to raise awareness at home, work, and school. Please email support@cjdsupport.net for details of how to buy items.

A* for Awareness

Bertie Wood's aunt Jay Blundell, who passed away with sporadic CJD at the age of 55, was a great mentor to him. As a tribute to his aunt, when receiving outstanding grades in his A-Levels, Bertie took the opportunity to raise awareness of CJD through an article in his school paper and the Harrogate Advertiser. A huge congratulations to Bertie on receiving his results and taking the opportunity to raise vital awareness of CJD. Click **here** to read the full article.

Paula Sutton is using her CJDSN badge to raise awareness of CJD in memory of her beloved mum, who passed away with sCJD on 21st October 2022.

Fundraising Stories

In this section of the newsletter, we showcase some of the fantastic fundraisers who support us to continue our work. A huge **thank you** to all who have supported us in this way.

Birthday Fundraiser for CJD

December 2021

Melissa Oram lost her mum, Isabelle Oram-Louwage, to CJD in December 2020. For Melissa's birthday in 2021 she set up a fundraising page, asking that people donate to the CJD Support Network. Melissa's friends and family donated a fantastic £600 in total, a wonderful tribute to Isabelle who passed away at the young age of 51. Isabelle is greatly missed by her two daughters, her mum and her husband.

Pete's Great North Run

September 2022

This year, Peter Grime pushed the Great North Run in his everyday wheelchair, completing the course in a fantastic 2h2min. Pete raised an amazing £878 in memory of his friend Paul Crimes' father-in-law, John Cook, who passed away with sporadic CJD in February 2022.

The 'Dream Team'

June 2022

In memory of their wonderful colleague, Emma Broughton, who passed away with CJD in 2018, the 'Dream Team' (Matt, Claire, Natalie and George) completed the biannual Samworth Charity Challenge this year. Running a half marathon through the Brecon Beacons before cycling 50km back over the mountains and finishing with a 15km kayak around a mountain lake. The group raised a fantastic £2,340 for the CJD Support Network.

2022 Raffle Tickets now available!

Tickets for this year's raffle are now available at £1 each or £5 for a book of six. Contact us if you would like to buy or sell tickets.

Prizes

2 x Tickets to a Tottenham Hotspur Premier League match

Spa day for two

Necklace and earrings

£50 Cash

And many more!

Click **HERE** to buy tickets

Fundraising Stories

In this section of the newsletter, we showcase some of the fantastic fundraisers who support us to continue our work. A huge **thank you** to all who have supported us in this way.

Rebecca's Great North Run

September 2022

The mother of Rebecca's dear friend Kadie, Jo Buttress, passed away with sporadic CJD in March of 2021, just 2 weeks after diagnosis. As a tribute to Joanne, Rebecca took part in the Great North Run this year, raising a fantastic £260 for the CJD Support Network.

Kadie and her beloved mum, Jo, at her graduation.

Rebecca wore a CJDSN shirt to raise awareness as she ran.

Interested in fundraising?

We can support you with ideas, merchandise and much more! Contact support@cjdsupport.net or call **0800 774 7317** for more info.

Get moving for the CJD Support Network!

We are proud to have partnered with 'Run for Charity' to offer discounted places in a number of events across the country. Follow the links below to take part in any of these events and raise money and awareness for CJD. Use the links below or visit www.cjdsupport.net to get signed up and get moving for the CJD Support Network!

Manchester Marathon
16 April 2023
Click **HERE** to Sign up

Edinburgh Marathon Festival
27-28 May 2023
Click **HERE** to Sign up

5k Inflatable Series (For all the family!)
Various dates
Click **HERE** to find your local event

The **Personal Stories** section of the Newsletter provides an opportunity for network members to write and read about shared experiences. Please be mindful that this may include sensitive content. If you require further support with any of the themes raised, we are here for you at **support@cjdsupport.net** and on **0800 774 7317**.

Personal Story: Carole Parrott

Carole's mum, Elsie

My mum, Elsie, was born on 25th June 1916. She was an ordinary, kind, and homely person who was happy with her lot. In her youth, she worked for a dressmaker in Great Portland Street, London. She was interested in clothes and fashion and was always smartly turned out. My mum was married to my dad, Jim. My dad retrained as a butler in the late 1960's and so the family moved to a flat near St James Palace and clarence house that came with his new job. My mum was only a home cook, but soon became involved with cooking at dinner parties for dad's employers, whose guests were often from other parts of the world and so traditional British fayre was usually requested.

Around the end of April 1973 she began to show differences in her behaviour and outlook. Neither mum, nor her GP, had any idea why this was happening. My dad's employer kindly arranged for mum to visit his GP as a private patient as often as was needed. Various tests and scans were carried out, including some at the 'Maida Vale Hospital for Nervous Diseases' which has since closed. I can still recall the serious faces of the doctors as they told us it was a 'brain problem'.

Days went by and my mum's communication and physical got worse, her expression had changed to a constant frown. Mum was eventually admitted to the National Hospital in Queen's Square and dad and I visited every day. – she was deteriorating rapidly. At the end of one visit, we walked back to the car and dad suddenly stopped and turned to me and said "She's not coming out of there Carole". Not quite understanding this I phoned the private GP who informed me that it was true, nothing could be done. The GP said there was no cure for this 'condition' and that it was like 'searching for a grain of sugar on a sandy beach'.

I was faced with a dilemma – I was booked to go on holiday to Spain just a few days later and wondered 'should I go or not?'. My dad said I should, mum wouldn't want me to miss out. I visited her in hospital the afternoon before I flew. I chatted away to her, saying I'd send a postcard, bring her back a gift, all to no response. Although up to the point I was leaving she hadn't spoken or moved, as I leaned over to kiss her cheerio I felt her hand gently close around me on my back.

I returned from my holiday on the 3rd of June to find out that mum had passed away on the second. I later learned that I had been the last person to see her conscious, she had been in a coma when my dad arrived the night of my last visit. Though we'd had a few weeks of knowing the outcome, Dad, my brother Pete, and I were still devastated. Mum would have been 58 on her birthday just a couple of weeks later.

When we received mum's death certificate it stated 'pneumonia and CJD' – what was this 'CJD'? None of us had ever heard of it. Later, amidst the BSE crisis, the phrase 'Mad Cow Disease' became associated with it which was horrible for us as a family.

To this day, I don't know what type of CJD mum had. Since she passed away, I have attended one of the CJD Support Network's meetings and in December 1999, I attended a memorial service at St Martin in the Fields arranged by the network. The names of people who had passed were read out, I still have the list (below). I have stayed up to date with the work of the CJD Support Network as a member of their mailing list, and have recently purchased some of their branded items to bring awareness to this devastating illness.

A MEMORIAL SERVICE

St Martin-in-the-Fields
Trafalgar Square

Sunday 12th December 1999
6.30 PM

Remembering all the people who have died with Creutzfeldt-Jakob Disease especially:

PAMELA BEYLESS
ELIZABETH BOTTLE
ADA BROADHURST
DEENA BUCK
GRAHAM BYRNE
NINA NADINE CADWALLADER
SUSAN CAREY
GRACE SINCLAIR CASSIDY
ELSIE FRANCES CHISLETT
MICHAEL JOHN CONNOR
BILL COOK
LYNNE COOLE
EDITH MARCIA CONNELL
LISA CROWE
STAN DAVIS (DUNNETT)
GLEN DAY
NIGEL DENTON
DR CLIVE ANDREW DEVALL
HARRY DULLAGE
RONALD EAST
ELWYN EVANS
DOREEN FARNELL
STEVEN PHILIP GOLDE
MARTIN GRIFFIN
ANDREW HAIG
MARIANNE LOUISE HARVEY

CJD SUPPORT NETWORK

*The CJD Support Network would like to thank Carole for sharing her family's story. If you would like to share your experiences in our newsletter, please do get in touch **0800 774 7317**.*

If you require support with any of the themes raised in the newsletter, we are here for you at **support@cjdsupport.net** and on **0800 774 7317**.

Personal Story: Sally Snape

My dad Peter Nolan was born in 1940 to a hard-working, impoverished family in Wythenshawe, Manchester. As a young man he worked hard, becoming a nuclear construction engineer and volunteering overseas – first in Kenya teaching English and later returning to Ethiopia as a civil engineer.

He married my mum and had four children with her, before moving to be with my now step-mum, Wendy, and her three children in 1985. Eventually, my dad left the nuclear industry to re-train as an actor at the Bristol Old Vic but he never quite achieved the fame he sought. When he was 70, he went on a six-month solo trip to India which he loved – whilst there he started writing a book called his 'Adventure before Dementia'.

In October 2014, when he was 74 and still working on various projects such as the odd acting job and directing at his local theatre group, dad began to suffer with mobility issues. Walking was becoming more difficult and he began needing the support of a wall behind him if standing. He developed extreme tiredness, anxiety and trouble sleeping. Dad was losing weight and unable to remember family friends, however the GP continued to diagnose his symptoms as those of stroke. As a nurse, I found this frustrating as hemiplegia is usually left or right sided and this didn't fit at all with what my dad was experiencing.

In February 2015, my dad was admitted to hospital after a neurologist who had seen him previously was shocked at the progression of his symptoms and immediately admitted him. By this point, he was unable to speak. Despite this, we could see that he was trying to smile, to communicate to us that everything was fine – I'm so glad that he knew we were there. Dad had a lumbar puncture and we received the diagnosis of CJD two days before he died on 21st February 2015. I am still coming to terms with what happened but am grateful for the opportunity to tell my story.

*The CJD Support Network would like to thank Sally for sharing her family's story. If you would like to share your experiences in our newsletter, please do get in touch. If you would benefit from further support, we are here for you at **support@cjdsupport.net** and on **0800 774 7317**.*

Sally's dad, Peter Nolan

Peter, during his time volunteering in Kenya.

In this issue, we are pleased to introduce the CJD International Support Alliance. An alliance of patient associations across the world who are dedicated to ensuring that the educational, social, emotional, spiritual, and practical needs of those affected by prion disease are met in their respective countries.

The CJD International Support Alliance (CJDISA) connects people with patient associations in their own country, who provide support with information in partnership with their group of 'Friends and Advisors' who are professionals and experts in prion disease. The Alliance also assists in the development of new patient associations around the world.

The CJDISA began in 2006 when a small group representing patient associations came together at the 4th CJD Foundation Family Conference in Washington DC. The founding members, CJD Foundation USA, CJD Insight USA, CJD Support Group Network (CJDSGN) Australia and the CJD Support Network Japan were joined by CJD Support Network UK shortly thereafter. That year, Florence Kranitz (CJD Foundation USA) and Suzanne Solvyns (CJDSGN) became co-chairs of the CJDISA. Florence spoke at the 2006 Prion conference opening ceremony in Turin, Italy, and the following year the CJDISA welcomed the newly formed Italian Association of Encefalopatie of Prion as a member.

During the early days of the CJDISA, representatives from various countries would meet as an international alliance at CJD Foundation conferences in the US to share ideas and offer support to new patient associations. The conferences continue to be a networking hub for families keen to create patient associations and offers alliance members the opportunity to present as a panel and share the progress, ideas for support and fundraising.

In 2009 the CJDISA welcomed CJD Foundation Israel, established mainly to support families affected by genetic CJD, and the French association which was formed by parents who had lost children to iatrogenic CJD due to human pituitary growth hormone treatment (hGH). In 2011, a patient association was established in Mexico and, the following year, a CJD patient association was formed in Germany. In 2014, the alliance welcomed representative from Chile and since this time have seen the development of groups in Canada, Brazil, India, Spain, New Zealand and most recently Pakistan.

The CJDISA consists of 15 patient associations covering 14 countries. Co-chairs Deana Simpson and Suzanne Solvyns work tirelessly to further the aims of the alliance. As several colours have come to represent prion disease charities around the world, for instance, purple in the US, orange in Australia and Yellow in the UK, the CJDISA logo brings together these colours to symbolise international unity. To learn more about the CJDISA, visit their website at: www.cjdisa.com

Suzanne Solvyns was treated in the mid-1970s in Australia with human pituitary gonadotrophin (hPG). In 1991, she was listening to the radio when she heard a news story stating that women receiving this treatment were at risk of having been treated with batches containing prions. In 1992, Suzanne was sent a letter and had a phone call from a gynaecologist confirming that she had in fact been treated with a contaminated batch. Four women who were treated with hPG had recently died of iatrogenic (medically acquired CJD), two of whom had received the same contaminated batch.

Suzanne went on to become the New South Wales coordinator of the CJD Support Group Network (CJDSGN) which was set up in Australia for those at risk who had received hPG treatment. Suzanne later became the director of the CJDSGN which expanded in 2004 to support genetic and sCJD families. Suzanne continues to work tirelessly to support individuals and families affected by CJD across Australia in her role as director of the CJDSGN, and internationally in her role as co-chair of the CJDISA.

Deana Simpson is the founder of CJD Insight, a patient association in the US dedicated to those affected by inherited prion disease. Deana's family are affected by genetic CJD, she lost her mother in 1998. This was Deana's first exposure to the disease and was devastating. Deana is a nurse by training but had not come across the disease. Seeing the challenges faced by families affected by genetic CJD, including complex questions and decision around genetic testing and having children, Deana wanted to make a difference in providing support to those impacted by prion disease and educate clinicians across the care continuum on the importance of understanding this disease.

Deana's family have lost 22+ family members over the last seven generations, she has personally lost four cousins in only the last 2 years. Deana continues to work as a dedicated advocate and advisor in her role supporting those affected by familial prion disease, as well as providing global support in her role as co-chair of the CJDISA.

Management Committee

The CJD Support Network Committee is made up of individuals with a personal or professional interest in CJD. The Management Committee works to advance the aims of the CJD Support Network, in the interest of our members.

Prof Richard Knight, Chair, is a Clinical Neurologist at the NCJDRSU in Edinburgh

Prof Simon Mead is a Neurologist working at the National Prion Clinic, London.

Brian Marsden joined the committee after losing his wife to sCJD in 2017.

Anita Tipping, Secretary, is a registered nurse, RSCN, whose son David died of iCJD through growth hormone injections.

Annette Beal works in a care home; she lost her husband to sCJD in May 2017.

Margaret Leitch is a National Care Co-ordinator and Senior Nurse at the NCJDRSU in Edinburgh.

Andy Tomaso, Treasurer, lost his mother Carmelina to genetic CJD in 2007.

Dr Kate Dahill works as a junior doctor. She lost her aunt to sCJD in 2012.

Beth Marsh, National Coordinator, lost her father to sCJD in 2016.

Sean Horstead is HM Area Coroner for Essex. Sean lost his mother Gillian to sCJD in 2020.

Lizzie Hill is a PhD student at the MRC Prion Unit, London.

Lisa Denton works with our treasurer, Andy, and has been supporting the network since 2020.