THE CURE

CJD

CAMPAIGN

CASE FOR SUPPORT

THE CURE CJD CAMPAIGN

Mark was a remarkable, vital man.

Mark was a remarkable, vital man. He was larger than life, extremely fit, healthy and had a keen sense of humour. We had an unbreakable connection and that rare thing – great love.

We could take on anything together, but when we received the diagnosis, “I’m sorry, it is sporadic CJD”. Those few words floored us. It was devastating. I knew what CJD was.

We were about to face the worst possible challenge and we knew exactly how it would end.

The most amazing man I have ever known would die in a matter of weeks; at 56 years old it was about thirty years too early. And there was nothing we could do. Nothing.

When we received the diagnosis I said to Mark, “We don’t deserve this”. Mark replied, “Nobody deserves CJD”. He was right.

Nicola, whose beloved partner, Mark, died as a result of Sporadic CJD.

Diagnosis: 14 June 2017 **Death:** 12 August 2017

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Creutzfeldt-Jakob Disease (CJD)

Creutzfeldt-Jakob Disease (CJD) is a rare, degenerative, fatal brain disorder caused by the malfunction of a naturally occurring protein.

The normal prion protein is thought to play a role in the transport of messages between brain cells.

However, in prion diseases, the normal prion protein becomes faulty and forms clumps or chains which build up and destroy brain tissue. This results in the progressive loss of normal brain functions.

The human immune system produces antibodies to fight infection caused by viruses and germs, as the system recognises them as abnormal. However, because prions are made up of the body's own proteins, the immune system does not recognise them as a problem and therefore, does not make antibodies to destroy them.

CJD usually leads to death within one year of onset of illness, and often much sooner.

There are three types of CJD:

1. **Sporadic** — Sporadic CJD occurs at random in the population as an unlucky chance event.

2. **Inherited** — Inherited CJD is caused by a faulty gene passed down in families.

3. **Acquired** — Acquired CJD is caused when a person is infected with prions from an outside source, such as transplants.

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There is no treatment or cure for CJD.

Yet.

The Cure CJD Campaign

The Cure CJD Campaign was established in 2016 by a group of individuals impacted by the disease to raise funds to support the work of the Medical Research Council (MRC) Prion Unit at University College London (UCL).

World-leading research at the MRC Prion Unit at UCL developed an antibody treatment called PRN100, designed to stop prions from malfunctioning.

Positive results were shown in laboratory testing.

As the millions of pounds it would take to conduct a full regulated trial of PRN100 were not available, the first goal was to treat a few patients with PRN100.

> And so, the Campaign's fundraising target was set:
>
> **£100,000 towards the treatment programme.**

The money was raised quickly with matching funds provided by the University College London Hospital (UCLH) Biomedical Research Centre, and further support from the JP Moulton Foundation.

Between 2018 and 2019, PRN100 was offered to the selected patients at UCLH in the groundbreaking first-in-human treatment programme.

The results of the treatment programme are now published online in *The Lancet Neurology (April 2022, Vol 21 Issue 4 pp. 342-354).*

However, more vital research needs to be conducted to further advance PRN100. The Campaign formed a Committee in December 2018 with the intention of moving into a second stage and achieving greater impact.

As of July 2022, almost

£900,000

has been raised for research costs since the establishment of the Campaign.

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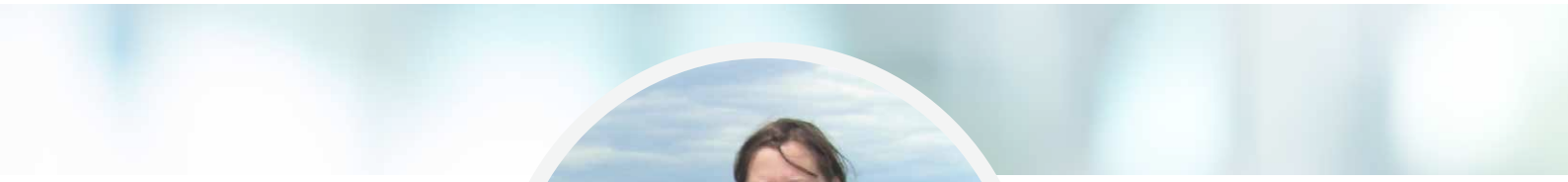

My sister, Diana.

My sister, Diana, passed away in September 2016: she had the inherited form of CJD and like her mother and two uncles, died at the age of just 46. I did not inherit the faulty gene and I felt guilt. Why her? Why not me?

After she passed away, I set up the Diana Camidge Foundation with the sole purpose of raising money for the Cure CJD Campaign – to date we have generated £50,000, which is testimony to the impact Diana made in her short life on those who knew her.

I joined the Cure CJD Campaign in late 2016. I am committed to continue raising funds through the Diana Camidge Foundation and supporting the work of the Campaign as a Committee Member.

Nobody should have to suffer as Diana and others did at the hands of this disease. From a very quiet start in a relatively short space of time, the Campaign has managed to raise a significant amount due in large to people who have tragically been impacted by this terrible disease. What makes this all the more noteworthy is that everyone on the Committee is a volunteer and I am proud to be one.

John, whose younger sister, Diana, died as a result of Inherited CJD.

Diagnosis: 9 April 2016 **Death:** 4 September 2016

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I pray that other families will not have to face a loss like ours.

There was no hope when my wonderful brother, Shane, was diagnosed with CJD.

Then we discovered that a promising antibody therapy was in development, but that these antibodies would not be ready for human use in time for us, it was devastating.

My brother will always be in my heart. He is missed so much.

For the future, I pray that other families will not have to face a loss like ours.

It gives me comfort knowing so much amazing work is taking place in the Prion Unit in London to find a treatment for this terrible disease.

Jacqueline, whose brother, Shane, died as a result of Acquired CJD.

Diagnosis: 10 May 2011 **Death:** 18 February 2012

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"Without charities, the UK would not be the world leader in medical research that it is today."

- Association of Medical Research Charities

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Funding of The Cure CJD Campaign

Funds have been raised through the support of generous fundraisers and donors, predominately people whose lives have been impacted by the disease. But that alone will not result in the level of funding needed to advance the research to find a viable treatment.

Anyone who has seen the impact of CJD on someone they love could not fail to be motivated to do something. Every Committee member has seen first-hand what this disease does and found themselves powerless against it.

Love cannot save people from CJD, but research to help find a treatment or cure could. The Campaign is committed to raising funds to support the MRC Prion Unit at UCL, and hopes that one day others will not be powerless in the face of CJD.

We know this may take years, but our commitment will not wane.

A full clinical trial is the ultimate goal, and the Campaign has set out to provide whatever support it can to help make this a possibility. The vast amount of groundbreaking UK research in this field has made significant strides to understand prion diseases and has already shown real progress.

This research and progress must be harnessed to complete this important journey to one day find a viable treatment or cure.

Nobody should experience CJD.

The cost of conducting a full clinical trial will cost **between £7 – £8 million.**

Some of the costs associated with the journey to a viable treatment are:

One research support technician	One clinical nurse	One clinical research fellow	One clinical trial project manager	Transportation costs of patients to clinical research facilities
£30,000 - £40,000 PER YEAR	£40,000 - £50,000 PER YEAR	£50,000 - £60,000 PER YEAR	£60,000 - £90,000 PER YEAR	£100,000 PER YEAR

The Campaign has supported a fraction of these costs to date, but much more is needed.

With your help, we can do more. You can make an impact in the fight against this disease.

CJD took my mum so quickly and brutally.

CJD officially came into our family's life in April 2020 when an autopsy report confirmed that was what my mother had died of. However, rewind six months to October 2019 and that's when CJD dealt its first brutal blow. We just had no idea that's what it was at the time. My mum had fallen and broken her leg, and woke up from the general anaesthetic very confused with what the doctors believed was "delirium" at the time. However, four weeks later my mum continued to deteriorate instead of improve – never regaining the ability to walk, and her "delirium" was being described as early onset dementia.

By December, she was unable to feed herself, and by March, she was dead. It was without doubt one of the worst, most traumatic and terrifying experiences of my life as I watched my beautiful strong mum disappear in front of me. And the doctors couldn't understand what was happening – no diagnosis could be offered.

A friend had suggested testing for CJD, having previously known someone who had died as a result of it. Unfortunately, the doctors at my mum's hospital refused to consider testing for a probable diagnosis while she was alive. When she died, I insisted on an autopsy and asked them to test for it. I was almost relieved to get the diagnosis. Finally, we had some answers.

The impact CJD has had on our family can never fully be explained and I think we are all still struggling to understand what happened. CJD took my mum so quickly and brutally – but for our family, this grief has been compounded by the fact that we didn't know what was happening to her. I argued with doctors, nurses, geriatricians, and neurologists, always fighting to try and get an answer and understand what this meant for my mum. I was told my mum had at least 10 to 15 years left – she died five weeks later. This haunts me to this day, as I feel we had the time to say goodbye taken away from us. If she had been diagnosed, we would have taken her out of the hospital and had her at home. I would have given up work and been with her every hour of every day to nurse her myself, had her around her favourite things at home, and in her garden with the sounds, smells and sights she knew and loved.

This is why our family wanted to support the Cure CJD Campaign – to try and get vital research into this disease, a disease so many of the medical community never knowingly encounter. I never want another family to go through what we did – watching someone slip away at such a rapid speed with no one understanding why, and not being able to offer support to the family while their whole world implodes.

On the first anniversary of my mums passing, family and friends did a virtual (in line with COVID-19 restrictions) triathlon to raise money for the Cure CJD Campaign and I am so proud of what we achieved in memory of my amazing mum. Because this disease is so rare and so little is known about it, I believe it is more important than ever to get as much research as possible into it with the hope we can eventually fight back.

Laura, whose mother, Audrey, died as a result of Sporadic CJD.

First indication: 9 October 2019 **Death:** 8 March 2020

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Working together

The Campaign is developing a closer relationship with the CJD Support Network, the UK charity providing practical and emotional support for all strains of CJD, to find ways we can work together and raise awareness of this disease. You can play a role in supporting the Campaign in its vision and be a vital part of the fight to achieve something monumental in medical history.

With your support, we will be closer to finding a cure and saving the lives of people like Mark, Diana, Shane and Audrey.

You could be someone's miracle.

To make a donation online please visit:
www.justgiving.com/campaign/cureCJD
or contact us about other ways to give

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Fundraising:
www.curecjd.org/fundraising-ideas-and-support