CJD SUPPORT NETWORK

Helpline +44 (0)1630 673973

www.cjdsupport.net

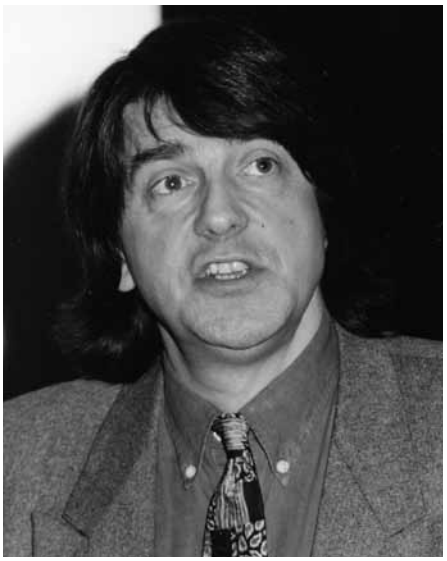
Newsletter

Issue 21
April 2012

CREUTZFELDT-JAKOB DISEASE SUPPORT NETWORK NEWSLETTER

Letter from our new Chairman

Professor Richard Knight



Welcome to this issue of the CJD Support Network newsletter – my first one as Chairman! I have been associated with the Network and a member of the Executive Committee for some time but have taken on the Chairmanship following Dr Angus Kennedy, who has stepped down because of his increasing other commitments.

I and the Committee would like to thank Angus, on behalf of ourselves and, of course yourselves, for the time and effort he has put in over the years. He has set me an excellent example of Chairmanship and I will try my best to do the job as well as he did.

As an independent charity, in an uncertain financial climate with resultant changes in income, we have had to review our financial situation carefully. Following detailed consideration, Gillian Turner, our National Co-ordinator, has decided to work for the Network on a part-time basis, rather than a full-time one. However, this change will not affect the core activities of the Network. The Network remains strong and is in a good position. We still have Gillian's vital expert services; her great experience will remain available to us and other committee members will contribute cover for the 24 hour Help Line (as they have done in the past when Gillian has been on leave).

This letter is an opportunity to thank Gillian and the other committee members who have given their time so willingly. All committee members contribute a great deal but we should perhaps express particular thanks to our Treasurer (Andy Tomaso) whose role is demanding and pivotal especially in these financially difficult times.

The Network remains strong and is a good position to continue its provision of those core services that we feel essential: the availability of someone on a phone 24 hours a day, the provision of information booklets, leaflets and newsletters, the maintenance of our website and the Annual Family Conference Day. Those of you who attended the last Family Day in November in Birmingham felt it was a very successful occasion.

This year has also marked the Network's further incursion into the modern information world, with the production of a podcast (see our website www.cjdsupport.net); we hope this will prove a useful way of giving others an insight into what we do and its importance to those directly or indirectly affected by this terrible illness of CJD.

The oganisation belongs to you, of course; your contributions to this newsletter and any views or reactions you have to the Network's activities, or other matters related to CJD, are of great importance. Please let us hear from you about anything you feel the committee, or others, need to know or do something about.

As our funding circumstances have changed, we have become increasingly dependent on individual contributions and fundraising events. Many of you have been extraordinarily generous or active (or both!) in the last year and this has been an enormous benefit to the Network. Thank you!

If any of you would like to consider fundraising in the coming year, we would be extremely grateful and can offer practical advice and support. If you would like to consider becoming involved in our activities and even possibly joining the Executive Committee – please contact Gillian.

We look forward to another year of successfully fulfilling our core aim – providing help and support to individuals and families ■

With best wishes,
Richard Knight

Our website

www.cjdsupport.net

In 2011 we had over 60,000 unique visitors to our website. It is recognised as an up-to-date and reliable source of information about CJD, written in plain language. All our information sheets and newsletters can be viewed or downloaded from the website.

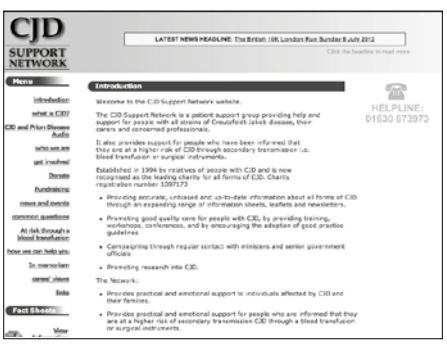
Audio presentation

As well as written information, the website includes an audio presentation narrated by TV's Dr Hilary Jones. In this presentation, he introduces and explains aspects of the various strains of the disease and discusses causes, symptoms, diagnosis and treatment. He also answers some frequently asked questions and explains the availability of further information and support.

Podcast

Our latest project has been to produce a video podcast illustrating the role and benefits of the Network to patients and carers. The podcast includes interviews with families who have been affected by CJD and is introduced by a doctor whose husband died of sporadic CJD. We are most grateful for the help of the families who took part in the making of this podcast.

The audio and podcast presentations, factsheets and newsletters can be accessed via the main menu on the left of the website home page.



Family Support Meeting 2011

Our annual family support meeting was held on International CJD Day, Saturday 12 November 2011, at the Burlington Hotel, Birmingham.

The meeting was well attended and from the letters we have received from families who attended it was an enjoyable and informative day.

Speakers at the meeting included Prof Richard Knight, Prof Bob Will, Dr Simon Mead, Judy Kenny and Gillian Turner.

Summaries of their talks can be seen in this newsletter.

Keep the next date free

We do hope you will be able to join us at the 2012 Family Support Meeting. This is provisionally scheduled for 3 November. Further information will be distributed nearer the date.

In Memory

Heartfelt thanks to the friends and families of those below for the donations received in 2011. You gave a total of £10,707

Peter Willoughby	Warwick Nixon	Mark Templeman
Paul Phillip Hope	Tony Swain	Dean Burrell
Leslie James Creber	Della Scribbins	George Herbert Read
Mary (May) Messer	Kathleen Lucy	Stuart Hanslow
Marje Hutchinson	Peter Gatens	Linda Young
Robin Lawson	Mick Golding	Ann Redfern
Stephen Bryant	Stanley Cozens	Michael Harvey
Audrey Collin	Julian Bailey	Nick Taylor
Peter Hardy	Colin Robinson	Mr Lovelock

We would also like to say a big thank you to all those fundraisers in 2011 that ran marathons, organised coffee mornings, asked for donations instead of birthday and anniversary presents, gifts from employers and much much more. You all helped to raise a further £8,888.

We would like to assure you that every penny is used to support families affected by all strains of CJD.

CJD figures from the CJD Surveillance Unit in Edinburgh

The number of deaths of definite and probable cases in the UK

YEAR	SPORADIC	IATROGENIC	FAMILIAL	GSS	VCJD	TOTAL
2009	79	2	3	5	3	**92**
2010	84	3	6	1	3	**97**
2011	82	3	9	2	5	**101**
2012*	11	0	0	0	0	**11**

*As at 8 March 2012

Total of definite or probable vCJD cases (dead and alive) in UK **176**

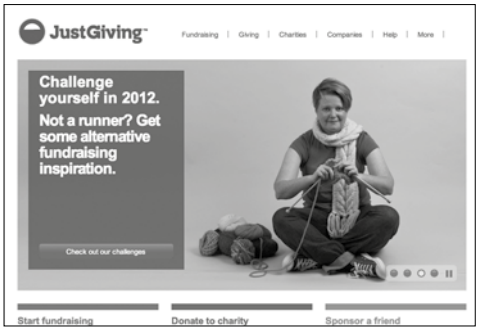
The CJD Support Network no longer receives funding from the Department of Health and relies completely on income donated or raised by members, friends and the public. We welcome all donations, however small. To make a donation online logon to **www.justgiving.com/cjdsupport**

How to make your own fundraising web page

Through **www.JustGiving.com** you can easily set up your own webpage for your fundraising.

If you plan to raise money to support the Network and its work, perhaps through an event such as a run or a coffee morning, or just to collect 'In memoriam' donations, a good way to do this is online through JustGiving. This makes it easy for people to donate (they can even do it through a text from a mobile phone) and if they are a taxpayer, the Network can receive over 25% extra from each donation at no cost to the giver. Donated money is transferred directly to the Network each month, with a list of who it is from.

To set up a JustGiving webpage is very easy, basically you just follow their instructions. To start:



1. **Log on to www.justgiving.com**
2. **Click Fundraising in the top menu – then Make your page**
3. **Then follow the online instructions.**
4. **Once you have made your page you can go back at any time and edit almost all of it. You can change the text, add pictures and videos and enable giving by Text.**

You can find more detailed instructions on our website via the fundraising link at www.cjdsupport.net

Good luck with your personal web page and fundraising. If you have any problems, or would like us to set up a web page for you, please email gturner@cjdsupport.net or phone 01630 673 993 and we will be pleased to help.

Andy's bike ride

by Andy Tomaso

On Sunday 24th July 2011, 'Team CJD' cycled 60 miles from London to Cambridge to raise money for the CJD Support Network.

The team managed to complete the journey in around six hours, aided by frequent stops at pubs throughout the Essex and Cambridgeshire countryside. A fantastic £4,000 was raised, which has been put towards funding our all important Family Support Days over the next couple of years.

A big thank you goes out to Sam Richardson and her family. Sam was unable to take part in Team CJD's London-Cambridge bike ride in July, but very kindly staged a garden party at her house the weekend before to raise funds. A great barbecue, a TV style 'Gladiator' challenge and lots of games and competitions meant that several hundred pounds were raised on the day. This money was donated to Team CJD's cause. Once again, a massive thank you to Sam and all her family who gave up their house, and their time, so generously on the day.

The team from left to right are: Steve Dupoy, Matt Partridge, Rob Bloomfield, Claire Tomaso, Andy Tomaso, Rob Stoddart and Dave Jones. (Not included in picture – Liz Lea)

Experian Robin Hood Marathon and Half Marathon

by Mike Hutchinson

On bright, slightly blustery Sunday 11th September 2011, roughly 12,000 eager runners competed in the Experian Robin Hood Marathon and Half Marathon in and around the city of Nottingham, starting and finishing at the impressive 'Festival of Running ' site on the banks of the river Trent.

In and amongst the crowd of enthusiastic, athletic (and not so athletic) competitors waiting behind the starting line before the start of the race, three figures stood out unmistakably in bright yellow CJD Support Network running vests. Just outside the security lines marking out their section, their support team (including a fourth yellow vest) stood giving a last minute pep talk to the determined, if frankly, a bit underprepared, athletes.

The four yellow-vested men made up the Hutchinson family, including dad Richard, and his three sons Michael, David and Stephen. All four were out to raise money for the CJD Support Network in memory of wife and mum Marje Hutchinson, who passed away in January 2011 from sporadic CJD and in thanks for all the help, advice and information provided by the Network during a very difficult time for the family.

Pretty quickly the runners, Richard, Michael and David, aided and supported by Stephen and a team of girlfriends and family members, were warmed up and ready to go. Months of training in wind, rain, and in some cases even dragging a bewildered Springer spaniel along, had been building up to this moment and the boys felt ready as ever to get out on the track.

Slowly, finally, the pack ahead

Runners in the Experian Robin Hood Marathon and Half Marathon

began to move and with that, the Team Hutchinson Robin Hood Half Marathon had begun.

For Mike and Dave, the two younger members of the running team, the race started strongly, with the two-hour pace setter kept in sight. For Richard, the pace was set a bit more steadily, as the runners passed through Nottingham city centre.

Later, the track wound its way through the greenery of Nottingham University, before diverting round and into Wollaton Park. Thanks to one or two much needed drinks points, the Hutchinson boys were still going strong, now spread out in age order with David at the front, Michael in the middle, and Richard resolutely bringing up the rear.

At last, the final corner came into sight, and the runners were greeted enthusiastically by the thousands of people packed into the festival site. The first triumphant yellow vest crossed the finishing line after 2 hours and 7 minutes, collecting his medal just as the second Hutchinson also crossed the threshold.

The two younger runners then waited patiently for the last Hutchinson to come into sight. Would he make it? Would he have collapsed somewhere along the track, or just stopped for a cappuccino at the Cafe Nero on Angel Row?

Eventually, the last yellow vest appeared, crossing the finishing line and so bringing the Hutchinson Half Marathon to a winning end.

Thanks to the efforts of their family and friends, who have been nothing but endlessly supportive and caring over the past year, the Hutchinson family managed to raise over £3,000 for the CJD Support Network, at a time when every penny raised for the charity really counts.

Richard, Michael, David and Stephen would like to thank everyone at the Support Network for all their efforts to help those affected by CJD, and would also like to thank their other support network, the

family and friends whose love and help has kept the family going through some difficult times over the past year.

Running in the Robin Hood Half Marathon was a fantastic experience for everyone involved, and for anyone thinking of competing in a half marathon on behalf of the charity, the Hutchinsons would like to heartily recommend it (with plenty of training, of course). See you on the track.

British 10K London Run

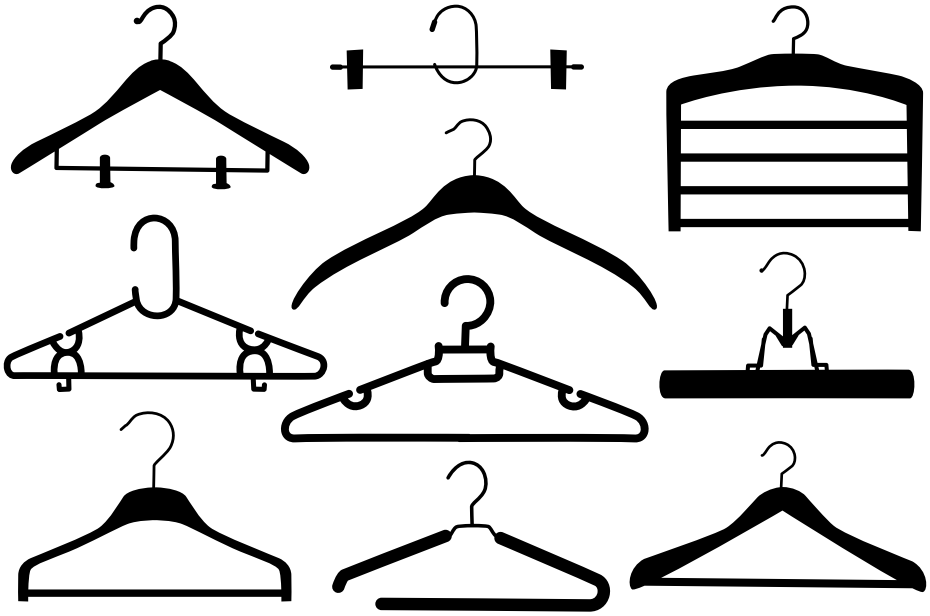
The 12th anniversary British 10K London Run is scheduled to take place on Sunday 8 July 2012, just a few weeks before the opening ceremony of the London Olympic Games. With the Olympic Relay Torch arriving in London on 24 July, only 16 days after the British 10K London Run, and with much of the race route being used for both men's and women's Olympic marathons, this is an ideal opportunity to experience this unique event.

The CJD Support Network has six places in this run, if you are interested in taking part and think you can raise loads of money for the charity please contact Gillian Turner.

Thanks to everyone who has donated and fundraised for the CJD Support Network. We do appreciate your efforts. All money raised goes directly to supporting patients and families affected by this terrible disease.

An easy and fun way to raise money

Clothes swap



by Jean Bailey

Have you ever wanted to raise some money in a fairly easy way... without having a coffee morning?

Try this if you do…

You borrow a fold-away clothes stand and get two friends to offer to make fresh sandwiches on the day of your swap – three types is enough and don't forget the vegetarian option. Make in advance, or again, get your friends to make, cakes (say, six different ones).

You then send out an invitation to family and friends asking them to come to your home around lunchtime on the chosen day and bring with them five items of good clothing (including belts, shoes, handbags, hats, jewellery etc) hangers too, if they have any spares, as it makes it much easier to display the clothes.

They also need £10!

For their £10 donation, each person gets tea or coffee, a sandwich (freshly made of course), some cake, and five different items of clothing to take home.

The whole thing takes two to three hours and, theoretically, you should have no clothes to take to the charity shop the next day. Stress to everyone that the clothes or items they bring need to be good quality and make sure there are places for people to try things on, with mirrors if possible.

My family and I have had two swaps in the last year and raised over £500.

We can even help you with a downloadable invitation. Just let us know your details (name and address plus date and time of clothes swap and any other important info) at least a week ahead and we can include them in your flyer.

All you have to do then is download, print and photocopy.

Contact Lucy Roberts at satsuma_dog@yahoo.co.uk or phone 0117 951 0992 and she'll be happy to make you a bespoke flyer to print or email to your friends.

The diagnosis of sporadic CJD

Prof Richard Knight
Consultant Neurologist and Director of the National CJD Research and Surveillance Unit

Prion diseases exist in three main forms: genetic, sporadic and acquired. The commonest form is sporadic CJD (sCJD) which is the most common overall human prion disease (although still rare at around 1 to 2 people affected per year in a million population).

The typical presentation of sporadic CJD is that of a rapidly progressive dementia (loss of memory and other cognitive function) often along with ataxia (co-ordination and balance impairment), visual symptoms and myoclonus (involuntary jerky movements).

This most often affects middle-aged and elderly people and the rapidity of progression is surprising and alarming, with an average illness duration, from onset to death, of around only four months. The preliminary routine medical investigations (such as blood tests, simple X-Rays and even CT head scans) are typically normal.

About 80% of sCJD patients fit this overall profile, which, with experience, is relatively readily recognisable. However, the diagnosis of sCJD is often made late from the point of view of the patient and one often hears something of this form: 'When I read about sCJD, my relative's story was typical-why couldn't it have been diagnosed earlier?'

It is, of course, important to recognise that the retrospective view is always easier than the prospective one. Looking back from the diagnosis, one can indeed see that the illness has followed a characteristic line, but starting with the initial symptoms and working forwards, there were in the beginning, a number of different possible diagnoses that had to be considered and explored. If one follows a maze from the start to the centre, leaving a trail behind one, it is easy to retrace one's steps along the trail and see the correct path, but one has to find it from amongst the various options when one first enters the maze.

Specifically, there are quite a few possible causes of a rapidly progressive dementia with ataxia, in middle aged people and most of them are much more common than sCJD. Some of them are also treatable (whereas this is not so for sCJD). The consideration and investigation of these other causes takes time.

The process is complicated by a number of factors, including:

- sCJD is rare (and, therefore, of course, an inherently unlikely diagnosis);
- it is fatal and untreatable (and so clinicians like to be reasonably sure about the diagnosis before making it);
- there are atypical forms of the disease;
- there is no validated simple disease-specific clinical diagnostic test.

Tests such as the EEG (electro-encephalogram – recording of the brain's electrical activity), the brain MRI scan and the 14-3-3 protein test on the CSF (cerebro-spinal fluid obtained by lumbar puncture) provide support for the diagnosis but none of the abnormalities found in sCJD are absolutely specific to sCJD.

Prion diseases, like sCJD, involve a change in structure of the normal brain prion protein to an abnormal form (hence the name 'prion diseases'); tests related to this fundamental protein change should be more specific and could therefore allow earlier and even more accurate diagnosis. One test under development for sCJD is the RT- QuIC (real-time quaking induced conversion) test on cerebrospinal fluid (CSF). The basic idea is that CSF should contain some of the abnormal, disease-related prion protein, but it is known that it is generally present in very low amounts in sCJD, so we cannot reliably detect this using our standard detection methods.

RT-QuIC uses a method that aims to amplify the amount present to a level where it can be detected. To date, preliminary assessments of this test suggest it will be very sensitive (correctly diagnosing most cases of sCJD) and very specific (being positive only very rarely in other diseases). It requires a lumbar puncture (to provide the CSF) but this is a routine investigation in most people presenting with a rapidly progressing brain illness. However, more assessment is needed and this is ongoing in the laboratories of the NCJRSU (Surveillance Unit). It is so far a test that is limited to sCJD but it might be developed for other forms of prion disease ■

A blood test for variant CJD

Dr Simon Mead – Neurologist, National Prion Clinic

A blood test for variant Creutzfeldt Jakob disease (vCJD) has been an important goal of medical research laboratories and companies around the world for many years. It has been very difficult to achieve because the infectious agent (germ) causing vCJD, known as a prion, has unique features that mean that the sensitive methods doctors normally use to detect the presence of a germ (detecting the body's antibody response to the germ or the germ's own genetic material) do not work.

The Medical Research Council (MRC) Prion Unit, working with the NHS National Prion Clinic (www.nationalprionclinic.org) at the National Hospital for Neurology and Neurosurgery (NHNN) in London, has developed an entirely new type of test following a number of years of intensive research. The test is at an early stage but is able to correctly identify the large majority of patients with symptoms of vCJD and has not yet given any false results in patients with other brain diseases or in healthy individuals. We think this is an important breakthrough and it raises a number of issues which need to be carefully considered. Details of the test have been published by the leading medical journal, *The Lancet*, on 3 February 2011.

This brief article describes why a blood test is important, how the test works and how to approach us at the National Prion Clinic to inquire further about this test. It is important to be cautious about this news, because although the results so far are very encouraging, we want to go on to look at blood samples from much larger numbers of healthy people and those with other brain diseases to get a better idea of how specific the test is in practice. This will be vital before a version of this test could be considered to routinely screen healthy blood donors.

Why is a blood test important?

vCJD (as with other forms of CJD) tends to be diagnosed only when the patient has had the disease for some time and has developed symptoms that are associated with extensive damage to the brain. A simple blood test gives us an opportunity to make the diagnosis at a much earlier stage. While at present we do not know of any treatment effective in stopping progression of these diseases, an early diagnosis does avoid the need for other tests and gives the patient and their family a clear answer. This enables them to make the best use of their time together and spend less of this precious time in hospital. Experimental drugs to stop or slow down the disease progression are being developed at the MRC Prion Unit and elsewhere, with a view to clinical trials in the next few years. We would want to try such treatments at the earliest stage before irreversible brain damage has occurred.

It is now known that vCJD can be passed on by blood transfusion. Several vCJD patients had been blood donors before they developed symptoms of the disease. To date, three individuals who had received blood transfusions from such donors have themselves developed and died from the disease. A further individual, who had also received prion infected blood, died of unrelated causes but showed evidence of prion infection at autopsy examination.

A future development of our blood test may allow us to screen donated blood and further increase the safety of blood transfusions. Also it may in the future allow individuals who have been exposed to vCJD infection to find out if there is evidence that the infection has taken hold in their body. Considerable further research will need to be done, first to find out how specific the test is when tested on large numbers of health donors and to understand how good the test will be at detecting infected blood from healthy individuals rather than those with the established disease.

How well does the test work?

As with any other blood test, the test involves taking a small blood sample from a patient. A small sample of this blood is mixed with special metal beads to which the rogue prion proteins stick tightly. These are then washed to remove the normal prion protein and other blood components that would interfere with the test. Finally, the amount of rogue prion protein attached to the beads is measured using antibodies we have developed, that bind very tightly to the prion protein.

The test was applied to a number patient samples including from patients with vCJD, those with sporadic CJD, other neurological diseases that might be confused with vCJD and a number of healthy blood donors. As vCJD is a rare disease, only relatively small numbers of samples were available for this testing. All samples were given code numbers and the scientists carrying out the test in our laboratory did not know which sample was which. We were able to try the test on 21 samples from different vCJD patients. 15 of these 21 patient samples (around 70%) were shown to be positive by the test. So far, all samples from other neurological diseases or healthy blood donors have tested negative but only relatively small numbers of these have been looked at so far. We are testing larger numbers of samples now.

What happens now and how is the test going to be made available?

We are ready to use the test to assist with diagnosis of patients who are suspected of having vCJD or other diseases that might be mistaken for vCJD. Working with neurological colleagues to begin to use the test will also help us get more information on the test itself and hopefully lead to further improvements and understanding of its usefulness. A request card needs to be completed by referring doctors. While we are working to increase the throughput of the test, at this stage it remains relatively labour intensive and we will attempt to return results at the earliest opportunity. ■

The work of the CJD Incidents Panel

Professor R G Will
National CJD Research & Surveillance Unit
Edinburgh

Dr N Connor
CJD Section
Health Protection Agency

The UK CJD Incidents panel was established in 2000 on behalf of the UK Chief Medical Officers, in order to advise all those bodies responsible for the provision and delivery of health care on how to manage incidents involving potential transmission of CJD between patients. Particular areas of concern include the risk of transmitting infection between individuals through contaminated surgical instruments, blood transfusion and the transplantation of organs and tissues.

The background to the setting up of the Incidents Panel is that CJD is known to have been transmitted in the past from one person to another via hormones derived from human pituitary glands, grafts of the brain lining (dura mater) and rarely, corneal grafts, brain electrodes and neurosurgical instruments.

There have been only four cases in which CJD has been transmitted through infected neurosurgical instruments and three of these occurred in the 1950s. The last UK case was in the 1970s. Despite the long period since the last case, health authorities in many countries remain concerned about the potential risk from instruments used in the brain or other tissues of a patient and then reused on another case. Such incidents continue to happen, for example in recent years in Canada, the USA and Australia. Concern about the risk of transmitting CJD have been increased by the identification of 4 instances in the UK in which variant CJD infection has been transmitted through blood transfusion.

A CJD incident occurs when a patient with CJD or who is at risk of CJD is found to have undergone a medical procedure at some time in the past and other patients may have been put at risk, for example through exposure to surgical instruments.

These incidents are often identified by public health doctors who routinely obtain information on the medical history in recently diagnosed cases of CJD, or by infection control teams working in hospitals. If there is a potential risk of transmission, information is then passed to the CJD Incidents Panel. For surgical instruments an assessment is made of the potential risk. This depends on a number of factors, including the type of surgery and how long ago this took place.

In sporadic and variant CJD the tissues that are judged to contain high levels of infectivity are the brain and related tissues and operations on the back of the eye. The spinal ganglia and the lining of the nose are medium infectivity tissues in all forms of CJD, while in variant CJD additional tissues judged to be of medium infectivity are the tonsil, appendix, lymph nodes and some other gut tissues. In sporadic CJD the period of infectivity is assumed to be 8 years before the symptoms began and in variant CJD infection is assumed to have started in 1980.

If an operation on medium or high infectivity tissues has been carried out on someone who developed CJD, the local doctors try to trace the instruments used and who they were subsequently used on. With high risk operations the first 10 patients operated on after the procedure on the CJD case are included in the group to be contacted, while with medium risk operations, the first two patients are contacted. If there is doubt about the diagnosis of CJD the surgical instruments are taken out of use until the diagnosis is established and if this is found to be CJD the instruments are destroyed, or may be retained for the sole use of that patient. Because of the variation in type of surgery and the timing of surgery, together with whether instruments can be identified, each surgical incident has to be assessed individually, although over the years precedents have been established that in most cases make it easier to reach a decision about what action is required.

When a CJD incident occurs some people may have been put at increased risk of being infected with CJD either through contact with surgical instruments or because they have received blood or blood derivatives from a person who later developed variant CJD (there is no evidence that sporadic CJD is transmitted through blood transfusion).

People who are exposed to 1% or greater risk of infection with CJD are considered to be 'at risk for public health purposes'. As a precaution people who are 'at risk' are advised not to donate blood, organs or tissue and to tell doctors and dentist if they are to have surgery. They are also asked to tell their family in case they need emergency surgery. The assessment of risk is based on many assumptions and the 1% threshold is aimed at reducing the risk of transmitting CJD to another person.

It cannot be used to predict whether someone who is exposed will actually develop CJD. The CJD Incidents Panel is clear that being classified as being 'at risk for public health purposes' should not adversely affect the standard of care given to people by the health services.

Since 2000, 141 people have been identified as being 'at risk' of CJD through exposure to surgical instruments. In addition 67 people have been judged to be 'at risk' through receiving a blood transfusion from a person who later developed variant CJD. Other groups have been told they are 'at risk'; including haemophilia patients (over 3,000) and those who have donated blood to people who later get variant CJD. Apart from the 4 variant CJD infections linked to blood transfusion and probable infection in a haemophilia patient, there is no evidence so far that any other people who have been judged to 'be 'at risk' have gone on to develop CJD.

One important consideration is the anxiety and worry that may be caused by informing people that they are at greater risk of developing a fatal and untreatable neurological disease, but this has to be balanced against the possibility that CJD can be transmitted accidentally in the course of medical treatment. The CJD Incident Panel has a lay chair and the membership includes representatives from a wide range of medical disciplines, ethicists, experts on legal matters and a representative from the CJD Support Network. The decisions that are made by the Panel are always carefully considered in the light of scientific evidence with the aim of protecting public health and informing people that they are 'at risk only when this is justified ■

Deryck John Kenny

By his wife, Judy

To understand the dreadful change that occurred in Deryck during the course of his final illness, vCJD, I feel I must first paint a picture of this happy vibrant man.

Deryck was a larger than life character who grasped life by the hand and embraced it. Despite having had major invasive surgery to fuse C5 and C6 to prevent progressive paralysis in 1988, and a radical prostatectomy in 1996 for cancer (this was when he received the contaminated blood which was to kill him six and a half years later), he bounced back and enjoyed a very happy, busy life.

This man of mine was the eternal optimist. He saw the funny side of every thing and lived life to the full. He was Santa Claus to the children at Christmas and the teller of wonderful stories at all times, I think some of them tall. During his years as a Royal Marine his nickname had been Smiley and that was his natural expression.

Following his retirement he did not let grass grow under his feet. He had always wanted to work with wood, so taught himself to carve both with and without a lathe. He began to write for pleasure and I have a collection of the most wonderful stories that he wrote. He painted both with water colours and on glass; he made and painted pewter model soldiers. That was when he wasn't tending his beloved garden, or cooking up extremely tasty concoctions in the kitchen.

I first became aware of changes in Deryck about June of 2002. He complained of generally feeling unwell and this normally outward looking, optimistic man began

Deryck Kenny (30 November 1933 – 24 October 2003)

to be introverted and to loose his confidence and social skills. On a visit to the Eden project he, normally so gregarious and sociable, felt awkward in the hotel, not wanting to interact with other guests and experiencing feelings of inadequacy.

In the August he was to go on a wood carving course, something he loved and had taught himself since retiring. Due to work commitments I was unable to accompany him. He found it difficult to mix with the other mature students, even though he was staying in the same pub over night, and rang me constantly for reassurance. He said on his return 'I am never going away without you again'.

Over the course of the next few months his behavioural changes developed insidiously. During this time he had a recurrence

of his prostate growth with accompanying treatment and I am afraid most things were blamed on this. He appeared to be depressed – something entirely new to him, but attributed to his physical relapse.

In November whilst attending the christening of his godson's twin girls (the godson was the baby he had delivered on the lounge floor, when he had popped round to see if Wendy was ok whilst Mick was at work), he failed to say hello to anyone in the church, not even to Mick, the twins grandfather and his best friend whilst in the marines. He came home with the cards and presents.

By this time this active, outgoing man was depressed tired and lethargic and experiencing transient symptoms. For a period of some weeks he complained that all his food tasted salty, even when I stopped adding salt during cooking. He then felt his eye sight was deteriorating and had trouble watching the TV and complained of pain in his eyes. He would complain of abdominal pain for a few days, then that would pass. He developed a tremor in both hands requiring me to cut his food for him. This disappeared after a couple of weeks. But the thing I remember most during all this was his constant need for reassurance and to know where I was at all times.

Deryck was to drive the car for the last time on 13th January 2003 when he took the car for a run to charge the battery, whilst I was asleep (I worked nights). He got lost on roads that he had known all his life and it terrified him.

This did nothing for his state of mind and he seemed to withdraw into himself.

We had a little dog of which he was very fond and he began falling whilst walking her. His mobility worsened. He was walking with a stick and falling with alarming regularity.

During this time he had regular appointments with his urologist who investigated him with CAT scans, blood tests, MRIs etc all proving to be negative.

It is difficult to say when exactly Deryck became dependant physically and mentally as it seemed to change almost daily and I just accepted the deterioration and dealt with it. I would take him for walks around the cemetery at the end of the road at first using sticks then a Zimmer frame trying to improve his mobility. He would watch the same DVD day after day as presumably he had forgotten that he had watched it the day before and the one before that.

I just accepted the deterioration and dealt with it

The meaningful conversations and discussions that we used to have, became a thing of the past and the most important problems would be how to cope with everyday life as his abilities receded.

His short term memory came and went, one day seeming not too bad, the next not remembering where I had said I was going, panicking, trying to find me and falling yet again.

Because of his altered mental state, he was being treated for depression, but I think he was more frustrated with himself and frightened than depressed. Things changed so quickly he would wake up one morning with lower abdominal pain so bad that he required a morphine derivative and five days later no mention of pain.

His balance became worse and worse and he was falling all the time but seemingly unaware of the last fall so would try and stand or walk minutes after being sat down. I would come home from night duty to find him on the floor not knowing how long he had been there. And so after a domiciliary visit from a geriatrician he was admitted for assessment and rehabilitation, and strangely enough, he who would not let me out of his sight was quite happy to be admitted.

During the time he spent in hospital his cognitive ability seemed to improve slightly. He walked with a Zimmer but did not seem to fall so often, he was able to shower himself and function on a level greater than he had at home. His memory was still poor and he would ring me when I was supposed to be sleeping wondering why I was not with him at the hospital; and he would wander the hospital corridors with his Zimmer frame looking for me, but he was not unduly distressed and accepted all the tests philosophically, including a lumber puncture.

After a day visit home he was discharged on the 29th May 2003 with a diagnosis of postural hypotension and with the social workers involved. This meant me installing a stair lift, and them finding him a place at a day centre twice a week so that I could have a couple of days sleep after night duty.

He fell out of bed the first night home which required a visit to A&E to have his head sutured. Once home he quickly lost a lot of his independence, maybe due to the limited space in a family home as opposed to the spaciousness of the ward, maybe because of the speed of the damage occurring in his brain.

He only managed the day centre four times. He fell in the toilet and they requested that we fetch him and said they were unable to deal with him.

By the 20th of June I was at my wits end. Deryck fell several times a day, however careful I was. His memory was so bad now that it was almost not worth telling him what was happening. After a home visit from his GP a domiciliary visit was arranged from a care of the elderly consultant. And on the 24th he was admitted to hospital, first to the acute hospital where his care was anything but satisfactory and from there to Christchurch Hospital where he spent the rest of his life.

It became very noticeable whilst on ward G3 how his behaviour had changed. Because of his constant falling, one of the sisters came up with the idea of him using a wheel chair without foot plates. He propelled himself with his feet, which stopped him trying to stand. This gave him renewed mobility. Unfortunately he would use it too try and get on to the balcony to see if I was coming, also to visit the ladies' bays – wholly inappropriately – and something which they did not appreciate. This was very much out of character. He would also purloin the ward post and hide it in his bed. He had always had a mischievous character but not I think one that would sanction this behaviour!

As it became apparent that rehabilitation was not an option, he was moved to J ward under the care of a consultant who specialised in Parkinson's however this was ruled out. Sporadic CJD was muted but an EEG appeared to dismiss this.

Deryck was now experiencing myoclonic jerks, sometimes so violent that he permanently had sores on his shins and ankles due to scraping these areas on the cot sides. We tried all sorts of things to prevent this: padded tubi-grip bandages thick socks, but nothing helped.

His eyes now seemed to express fear constantly when awake, and only relaxed when either Alison or myself was with him. The ward staff, all of whom he should have known and been comfortable with, appeared to frighten him and he was terrified of the doctors. This, my stoical Royal Marine, who never made a fuss about anything and in his right mind would accept whatever treatment was suggested.

An example of this; he acquired a virulent infection (UTI) and required to be cannulated for IV antibiotics and fluids. Alison and I arrived on the ward as the registrar was attempting to cannulate him, he was frightened, agitated and trying to resist both doctor and nurse. We were able to calm him down and Alison popped the cannular in with no fuss; that didn't mean that he wouldn't remove the drip when we not there.

The joy I would feel to get him to eat a child's portion

By August Deryck had lost so much weight he was having to be fed and only then with small amounts. I would take in yoghurts, rice puddings, stewed fruit and custard, and you wouldn't believe the joy I would feel if I managed to get him to eat a child's portion. He still spoke at times but it was becoming less and less.

Every day that it was possible (only the rain would prevent me) I would take him out in a wheel chair, either around the extensive hospital grounds or down to the local shops, or around the massive cemetery where there were lots of birds and flowers. The last day I was able to do this was on the Tuesday before he died on the Friday.

Deryck seemed to be able to assess situations if they had enough meaning almost to the end of his illness. On September 22nd just one month before he died we took him into Christchurch to the Priory. The British Legion were holding a service and a band of the Royal Marines were to march from the Legion to the Priory; Deryck sat in a wheel chair with his green beret on his lap (there was no way he could wear it he had lost so much weight). He attempted to sit straight in his chair and return the salute that the Marines seeing his beret gave him. However he was unable to maintain that awareness and was rather noisy and agitated during the service.

Following this outing, other than the soul destroying search for an EMI (elderly mentally ill) nursing home bed, only to be told ten days before he died that he could remain in hospital, there was no sudden change in his condition, he just stopped eating slept more and more and faded away.

There would be brief glimpses just for a short time of the old Deryck. On one occasion walking with him in the wheel chair, Alison was hungry so bought chips from the chip shop, he reached up and took a chip and then helped her eat them possibly eating about six chips after days of eating nothing.

On October the 3rd out of the blue he suddenly lifted his head looked at me and said 'let's go home', heart breaking enough but his face by this time was not showing any emotion, he now neither smiled frowned or had any change in his expression, just the constant fear in his eyes.

Wednesday 22nd was the first day we didn't get Deryck out of bed and by Thursday he had slipped into a coma, I sat with him all that day and night and the following day; and at 6.30pm on Friday 24th October 2003 – with Alison, friends, Annie our little dog and myself around him – he quietly stopped breathing ■

My wonderful husband

Rita King

My husband, Tony King, was looking forward to his retirement and lost his life to Sporadic CJD on 24th June 2011 at the age of 64 years. He was a very active, caring person who loved his family and was respected by so many people and was a very fit and healthy man until this terrible disease took his life.

The symptoms began during December 2010. He was complaining of discomfort in his left leg which we thought was sciatica. The weakness started to affect his right leg which was slightly uncomfortable and also started suffering with fatigue. This was completely out of character as he was always so active.

He was taking medication for cholesterol and during February 2011 I heard on the news that these particular statins had a very bad side effect so he made an appointment to see the doctor. She examined him and took various blood tests and immediately took him off the statins and arranged to see him in a month's time. Towards the end of March his symptoms became worse, weakness in legs, restlessness at night complaining of cramps and muscle spasms, twitching and hand tremors. He started to lose balance and became very confused after cat-naps. We went back to the doctor at the end of March and she referred Tony to a neurologist consultant, as she felt the weakness in his legs had become worse. This appointment was arranged for 28th April 2011. During this time he carried on working, he seemed quite happy and was communicating normally with everyone.

At the beginning of April he became quieter which was very concerning as he was normally a very loud and vibrant, outgoing person. The weakness in his legs was now causing a problem, he kept falling over and hurting himself, but this didn't seem to bother him he just laughed as if it hadn't happened to him. He had tremors in his hands when he was asleep and began to become agitated and confused.

I felt this was not normal and contacted the doctor to try to arrange to see the consultant sooner. The doctor agreed that Tony was deteriorating and contacted the consultant to bring the appointment forward to April 7th.

Tony started making strange comments, if we went out food shopping he would say why are we here we have already been this morning? It was like déja vu. My son would take him trout fishing, which was his passion, but he would lose his balance and stumble. He began to fight in his sleep and became paranoid, thinking other people were in the house. When I told him the next morning he would laugh it off as if it never happened.

On April 7th we went to see the consultant. Tony drove the car and became confused not knowing which hospital it was (although we had been there many times before), I had to keep telling him the directions and he became quite aggressive. The consultant thoroughly examined him and did a mental aptitude test which I thought Tony did very well. He was smiling and communicating like his normal self. The consultant didn't really know what was wrong but assured us it wasn't a brain tumour. We felt that this was very good news and felt very relieved.

The consultant arranged a MRI scan for 19th May 2011 and he had some more blood tests. Tony drove home and seemed very relaxed. He carried on working and on April 19th I asked the doctor to sign him off work, as I felt his concentration had got worse and was worried about his driving and his legs were becoming weaker.

His memory got worse, he kept thinking he had to go to work and still got up at the usual time of 6.00 am, he forgot that he had been signed off. He frequently

Tony King

asked what day and time it was, but he forgot as soon as he we told him. We had to hide the car keys which made him very annoyed, so we had to make excuses.

During the time from April 20th to the day of his MRI 19th May, he became rapidly worse. I was working part time and Tony was at home on his own, he seemed quite content, but very confused. He would ring me several times in the afternoon forgetting that I was at work. He would go out for a walk and fall over. He had no coordination and couldn't use a walking stick. Every time he tried to get up from the armchair he would lose his balance and fall. This was nerve racking.

I now realised that Tony couldn't be left alone even though he could move around slowly and go up and down the stairs I thought that he could fall and seriously injure himself, so I decided to take annual leave to be with him. Things started to get really bad, he was falling more often, at one time falling backwards and cutting his head, I called the emergency doctor. His speech became very slurred. We were all beginning to panic as we didn't know what was wrong, we researched the internet but nothing connected as to what was wrong. We went back to the doctor and she was very concerned that he had deteriorated so rapidly, so she arranged for the appointment with the consultant to be brought forward to the 26th May 2011.

It was the day of the MRI, 19th May 2011. Tony said he wasn't looking forward to this, but he was chatting quite

normally and seemed very calm. That evening he became very agitated and disorientated which was quite disturbing. During that week he completely lost the use of his legs. It was so difficult to move him especially at night putting him to bed, he was a dead weight. It was a struggle in every way. He began to hallucinate which was very scary. It was very frightening to see him like this as no-one knew what was happing to him and why. We thought perhaps there was a chemical imbalance and still very much believed this was the effects of the statins causing these problems. We had nothing else to relate to.

May 26th 2011 we all went to see the consultant and were given the devastating news that he had sporadic CJD and the prognosis was only a few weeks to live. This was just unbelievable – what was this disease! Tony actually asked the consultant if there was any medication and was told that there was no cure and no medication and that there was no treatment for this terrible disease.

We were all in disbelief; we never thought for one moment that he would die. He was still eating normally and seemed very content throughout all this. One week later Tony was admitted to the John Radcliffe in Oxford where he had a spinal fluid biopsy and a brain scan. He didn't seem to be aware of what was happening and was still smiling – he always had a fear of hospitals. Within a week he couldn't talk, only managing to mumble and communicated by gesturing with his hands. Two weeks later he was transferred to the hospice, where deteriorated rapidly. He couldn't swallow and spent most of the time sleeping. Tony sadly passed away 24th June 2011.

We now realise why he deteriorated so rapidly. We never thought for one moment he would die. In hindsight perhaps it was a blessing that we thought it was the statins as we thought the situation could be reversed and he would be okay. If we thought he was dying I don't think we could have coped the way we did. It was all a terrible shock; we still can't come to terms with this dreadful disease ■

My Mum and the thing I can't pronounce – Creutzfeldt-Jakob Disease

Claire Hewitt (Whitbourn)

Seeing my Mum Catherine ill, was very hard to accept at the time, I was 25 and I am an only child. It had always been just me and Mum, my parents are divorced. Up until then I had spent my whole life being looked after by my Mum – coughs and colds, hay fever, grazed knees, chicken pox and sprained ankles – she had taken care of it all.

My Mum prided herself on the fact that I held the record at school for having the least days off due to sickness and she mirrored this at work. I thought I was invincible before Mum, no one had ever died in our family – I still have both sets of grandparents and had never experienced what it was like to lose someone close.

I got married in July 2008, I look back at our wedding photos and see how happy we all were, Mum with her newly fixed Turkish teeth – the first time she had ever smiled properly at a camera. I look at that day and wonder if I will ever feel that happy again, I was so blissfully unaware of what was about to happen, ignorant to the world around me, selfish even.

It was around January 2009 when I realised that something was very wrong with Mum, but she had been suffering a while before that. In October 2008 she began to complain that she couldn't sleep. She had a bad dose of flu and we put it down to the fact she was stressed out with various things going on in her life. The insomnia carried on throughout the illness, she saw various doctors and sought out different herbal remedies but nothing seemed to even touch it.

We spent Christmas day at Mum's – what was always a great experience had turned into one big stress – Mum was tired and irritable and she seemed disorientated. The day felt weird, it sounds horrible, but my Christmas presents were pretty bad that year – and some of them were strange. Mum usually gave me a list of things she wanted every Christmas but this year she had told everyone the same things and ended up with very similar presents from everyone! This may not sound weird to you but Mum was meticulous when it came to things like that.

We met for lunch on New Years Day and Mum had an unusual glow in her cheeks, I was so relieved to see her smile again and look so healthy, I thought that that was the start of her recovery. After Christmas and New Year I met with her for dinner – she was still driving at this point. We walked to the restaurant and I talked and talked, she starred at me blankly and nodded and just kept asking me what the time was over and over again. We finished our meal and walked back to where we were parked – Mum was clinging on to me for dear life, she couldn't walk straight and she stumbled several times. I watched her drive away and though 'this is not right, something is seriously wrong here.'

On St. Valentine's Day my husband and I popped round to see Mum on our way out to lunch, she was totally unaware of what day it was – most unusual for Mum being a single lady! And it took her a long time to open the electric gate to her flat for us to drive in. I still look up at that window when I pass by and see her trying to open the gate.

Mum told us how she had tried to wash her hair and had scalded her head because she couldn't work out the hot tap, we laughed along with her, but inside I was devastated.

We had an appointment with her doctor, who referred Mum to a neurologist – the appointment was ages

away and in the meantime all we could do was wait. Mum became increasingly unable to look after herself and I was visiting her twice a day to make sure she was ok. I got her up, helped her brush her teeth and fed her. I even had to bath her and take her to the toilet. Everything for Mum was scary, getting in the bath, washing her hair, she would scream because she thought she was drowning. She cried when I tried to shave her legs and I had to find super human strength to lift her out of the bath when she got stuck because she could lift her legs out and balance at the same time – from then on it was showers together!

We finally saw the neurologist who referred her to the Royal London hospital – It would take three weeks to get her a bed and I pleaded with him to speed up the process as Mum lived on her own and we just couldn't cope with looking after her.

We ended up calling an ambulance one night when Mums friend found her sitting at the end of her bed with her dressing gown folded up in her arms – she didn't know where she was or what to do, she just couldn't comprehend what was happening to her. This time, she stayed in hospital until she was transferred to the Royal London. Previously she had been admitted to hospital and then discharged because they didn't know what was wrong with her – I had a phone call saying 'your mother is in outpatients waiting to be picked up' I rushed over and found her sitting in a chair with her bag next to her, not knowing what was going on and whether someone was coming for her – God know how long she had been there.

They thought she had had a stroke – Mum cried when she heard this, little did she know it was much worse, they even accused her of being drunk!

After Mum arrived at the Royal London, everything happened very quickly, we visited her and I remember the look on her face when we walked in she was absolutely ecstatic that we had even turned up 'I'm so glad you are here' she said, as if I would be anywhere else!. She would forget that people had visited her and cried a lot because she didn't know what was going on.

The next day, when I visited her, she was in a coma-like state – we would never speak again. I remember during this visit I left my husband with Mum while I spoke to the doctor – he said that she held his hand and looked him deep in the eyes – as if to say 'look after her.'

I sometimes think that Mum could hear me talking to her and sometimes she understood. She would stare at me with her cool blue eyes and once when my husband and I visited she made a loud noise when we said goodbye – I don't think she wanted us to go. It broke my heart to see her like that, she was such a beautiful, independent and proud women, never a hair out of place and she still looked beautiful in her hospital bed. Fantastic skin, not a wrinkle in sight.

Another time I visited, Mum had a seizure right there in front of me – she opened her eyes wide and began to moan as if she was petrified it was like she was having a bad dream.

I had a meeting with the consultant. I knew it wasn't going to be good news, I had come around to the fact that the Mum I knew wasn't coming back. When he told us it was CJD I had no idea what he was talking about, he told me Mum had a month and then just left the room. One of the hardest things I have ever had to do was to tell my Mum's best friend the news, it was heartbreaking. Mum never knew what was wrong with her, we never got the opportunity to discuss it. I never got the chance to see how she felt about it, it all happened so quickly.

Over the next month I visited as much as I could. By this time I had done my research and was keen to find out the type of CJD. I looked up my grandfather and discovered he had died some years ago – his death certificate stated 'encephalitis' – I researched what this was and realised that it was very similar symptoms to CJD. He was also from Poland – where genetic CJD is more common. I just knew it was genetic CJD and when the doctor confirmed this two months after Mum died, it was no surprise.

Mum died on 10th April 2009. I had a call at 1AM from the hospital and believe it or not had the best nights sleep I had had in four months – it was like she was at rest now, no more pain, no more suffering.

I miss Mum every day and shortly after her death I became pregnant, I have a beautiful baby boy and every time I look at him I remember Mum. So now it's my turn – do I get the test? Do I find out if my fate is the same as Mums? Do I tell my son about heaven Nana and how she died? Will my son have the gene? I am still so angry about our position, so frustrated at the fact that my wonderful family might have to go through it all again with me. My gorgeous husband will have to pick up the pieces again and he just doesn't deserve it.

I am so grateful that we have each other and we still have a life together, you never know what's around the corner, life is short and unfair and it's hit me hard to learn it. I'm not sure if I have even accepted that Mum has gone yet and I don't know when that will happen, I still think of her in the dark at night before I go to sleep and hope that soon those thoughts will be positive memories rather than horrible memories of her illness.

I hope that doctors can become more aware of this disease and be able to diagnose it sooner – this would save the families a lot of heartache and worry. More support is needed for carers of people with this disease, especially for those who live on their own. Mum lived in a penthouse flat with no lift – we couldn't even take her outside because we couldn't get her down the stairs. It was very, very hard and I wouldn't wish it on my worst enemy. ■

The story of the CJD Support Network (so far)

Gill Turner

The start

The CJD Support Network was originally formed in 1994 as part of the Alzheimer's Society, in response to pressure from families and carers contacting them for more information and awareness about CJD.

vCJD discovered

In 1994 CJD was a very rare disease and little understood but in 1995 when vCJD was discovered CJD became a very high profile disease. To cope with the increasing numbers of contacts, the Alzheimers Society applied to the Department of Health for funding to employ a national CJD co-ordinator.

National co-ordinator

In 1996 Gillian Turner was recruited as national CJD co-ordinator, working from home but under the umbrella of the Alzheimer's Society.

The role of the Network

Gillian's first tasks were to run a 24-hour helpline and establish what was needed. This was determined as:

- information about CJD
- awareness raising amongst professionals
- guidelines for professionals
- ensuring that patients and families were at the centre of planning
- consistent care
- someone to talk to
- peer support.

The network identified that accurate information on CJD was needed, written with lay people in mind. With the help of our colleagues at the National CJD Surveillance and Research Unit we developed a series of factsheets on each strain of CJD, a booklet on Prion Disease and more.

During this time it became obvious that social workers were struggling with CJD. In 1997 we opened a dialogue with the directors of social services which resulted in Derrick Biggs being appointed as link person to work with us. Our first joint piece of work was to develop CJD national guidelines for social workers. We also worked with the Queen's Nursing Institute to develop information and nursing guidelines for CJD.

These guidelines created many calls from health professionals, asking about guidelines for them. We were pleased when the Department of Health agreed to write guidelines for health workers, which were published in 2000.

Public awareness

The network grew and in 1996 Gillian arranged the first CJD conference at Warwick University. This attracted over 300 delegates and 39 film crews from all over the world.

In 1999 we organised the first CJD Memorial Service at St Martin in the Fields with a memorial role of 44 and again in 2002 with a memorial role of 63. Both services attracted a full congregation and it showed how important it was to bring families together.

International CJD Day (12 November)

At the 2002 service we launched 12 November as International CJD Day. I am pleased to say that this day has been recognised as CJD Day since 2002 and is now marked in different ways around the world by our sister organisations.

Family support meeting

Each year we host a family support meeting. We have held them in various parts of the country, but Birmingham seems to attract the most members. It is heart warming to see families mixing, sharing experiences and making friends.

A national voice

We felt it was important also to have a voice on national committees for CJD and were pleased when in 2001 we were asked for a representative to sit on the CJD Incidents Panel and this was followed by membership on other important committees. Since this time we have ensured that patients and their families are at the centre of all discussions.

Independence

In 2003 our Department of Health funding was uncertain and the Alzheimer's Society decided it was time to let go of the CJD Support Network. Dr Angus Kennedy, Gillian and a few hard working committee members decided that the network was still important and, with the help of the Alzheimers Society it became an independent charity in 2003 which today has a membership of over 400.

Funding and the future

Although it has been hard at times, with funding uncertain, the CJD Support Network continues to flourish. We were extremely grateful to the Department of Health who continued to fund us from 1995 to 2011. However all good things come to an end and we have started 2012 being solely funded by public donations.

In 2011 we received 559 calls to our helpline and supported 55 new families with information and emotional support.

We continue to represent the CJD community on several important government committees and we help and work closely with CJD Support Networks in America, Australia, Japan, France, Italy, Mexico and Israel. We are also very grateful for the support of our CJD colleagues in the UK, including the National CJD Research and Surveillance Unit, the MRC Prion Clinic and the Department of Health ■

CJD Support Network

Management Committee 2011

Professor Richard Knight, Chair Richard is a Consultant Neurologist at the National CJD Research and Surveillance Unit in Edinburgh

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

Andy Tomaso, Treasurer
Andy's mother Carmelina died of Genetic CJD in 2007

Sarah Tomkins
Sarah's late husband Edward died of sporadic CJD

Roger Tomkins
Roger's daughter Clare, died of vCJD

Alison Kenny
Alison's father died as a result of a contaminated blood transfusion. She is a RGN, nurse practitioner

Jean Bailey
Jean is a retired human biology lecturer. Jean's husband, Julian, died recently of sporadic CJD

Judy Kenny
Judy's husband, Deryck, was the first person to die of vCJD through a blood transfusion. Judy is a retired nurse

Derrick Biggs is our social services adviser and an operations manager with Cambridgeshire Social Services. He is the Association of Directors of Social Services link person for CJD

Dr Andrew Smith
Andrew is a Senior Lecturer in Microbiology at Glasgow Dental School

Malcolm Young
Malcolm's wife Linda died of Sporadic CJD

Dr Simon Mead
Simon is a neurologist working at the National Prion Clinic

Gillian Turner
CJD Support Network co-ordinator

Can you help us this year to raise money?

Due to the present economic climate it is very difficult to attract grants, so fundraising by members and their families is even more necessary to maintain the work of the network. If you have any ideas or you would like help to arrange a fundraising activity, please contact Gillian Turner (see below).

The CJD Support Network was established in 1995 by relatives of people who have died with CJD and is now recognised as the leading charity for all forms of CJD. Our aims are:

- To offer support to individuals and families concerned with all forms of CJD.
- To offer support to people who have been told they are at a heightened risk of CJD through blood and surgical instruments
- To provide emotional support for carers and to link families with similar experiences of all forms of CJD..
- To offer small care grants for families in need whilst caring for a family member with CJD.
- To provide accurate, unbiased and up to-date information and advice about all forms of CJD.
- To provide a national helpline on all forms of CJD.
- To promote good quality care for people with all forms of CJD.
- To promote research into all forms of CJD and the dissemination of research findings.
- To develop a public response for all forms of CJD

Membership

Becoming a member of the CJD Support Network adds to our strength and enables you to take a full part in the decision-making process and the work of the Network. If you would like to become a member of the CJD Support Network and receive free regular copies of our newsletters and any other information we produce, please send £10 annual membership to the CJD Support Network, PO Box 346, Market Drayton, Shropshire TF9 4WN. Please make cheques payable to *CJD Support Network*. However, if you are caring for someone with CJD and would appreciate free membership, please tick this box ☐

Name ..... Title .....

Address .....

..... Postcode .....

Telephone ..... Email .....

I am caring for someone with CJD: ☐ at home ☐ in residential care

I am: ☐ a concerned relative/friend ☐ former carer ☐ professional ☐ interested

Contact: Gillian Turner, CJD Support Network, PO Box 346, Market Drayton TF9 4WN
Telephone 01630 673993 · Email gturner@cjdsupport.net · Website www.cjdsupport.net
Charity number 1097173