CJD SUPPORT NETWORK

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www.cjdsupport.net

Newsletter

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CREUTZFELDT-JAKOB DISEASE SUPPORT NETWORK NEWSLETTER

A sponsored walk with a difference

By Clare Morris

Six members of families affected by different forms of inherited prion disease met on the 26th June 2010 to make a journey along the Thames between Westminster and Hampton Court and raise money for the CJD Support Network.

Our primary purpose was peer support in the context of a journey chosen as symbolic of what is needed by people at risk and their families: companionship and understanding in order to mitigate against the isolation often felt by people who have inherited prion disease in their lives, from all perspectives.

The intention to walk was more than a little ambitious, particularly on such a hot day, so we took a boat from Westminster pier to Hampton Court, where we then had lunch and travelled back to Waterloo by train, where we made our goodbyes – until the next time.

This idea was conceived by a group of people who felt their needs were different because they are aware they carry the gene that will cause the disease sooner or later in their life.

Interestingly, during the initial meeting they expressed a wish to involve their spouses. So this gathering involved other family members too; spouses and people who have tested negative, because the experience affects everyone in your family whether they themselves are at risk or not. What became very clear was that the need for emotional support is an issue that is separate from the need for information about the disease, developments in understanding and the important role of taking part in research to develop treatments.

I have a longstanding relationship with all those who took part in our 'journey for support'.

Initially I was under the impression that some members would want private discussions with me at some point during the day, but his was not the case.

On occasions, I initiated conversations I knew to be important to individual people and other people picked up where they had left off at previous meetings. The need to discuss personal struggles was never prescribed, but took place organically, as it arose during the course of the day. This was interspersed with comments about the places we were passing, and the commentary from our skipper on the boat. The informality of the context meant people could tune in and out of discussion as they wished, which was important to all of them.

Much of discussion developed from a central theme; the what, how, where and when of support. It was felt that other diseases such as MS had a much more developed support network than that for prion disease. The structure in which I developed events during my work at the National Prion Clinic was validated and the nature of a group that would be supportive to people at risk and their families elaborated:

- It is important to have a regular but not frequent meeting, in order to feel less isolated but not constantly reminded. Long periods might go by without the issue of risk being in the forefront of their mind, but knowing there is a structure and network to tap into, is of benefit in itself.
- Informal events, such as this, away from a hospital or formal setting, were felt to be useful and the suggestion was that twice a year would be ideal.
- The inclusion of spouses and children was felt to be very important; the whole notion of support in managing, what is a family issue and providing a context in which people could control the amount they actively discussed.
- The role of hearing other people's conversations and comments was felt to be just as important, as well as coming to know people in a wider respect.
- Respect for privacy and confidentiality was likewise felt to be crucial. The role of a meeting enables a coming together in the context of respect for each other's privacy and different positions in the rollercoaster that living with risk can be. This issue was out

Sponsored walk with a difference, continued from front page

in the open from the outset of the 'gene positive' group and, despite exchanging numbers, all members prefer to meet in this way rather than intrude on each other's lives

- It would be helpful to be able to call someone with an understanding of the issues as and when needed. The role of a counsellor on the end of the telephone was discussed; however the need to fund this was understood.

The outcome of the day

- We raised over £1400 for people at risk of inherited prion disease and their families.
- In the light of families wishing to continue meeting and develop this service, I am looking into writing a research application in order to make this possible.
- The plan is to hold yearly, possibly twice yearly events and to rotate venues among participants.
- We have set a date for our next journey: Saturday 25 June 2011. This will take place either in Dorset or Boston, Lincolnshire.
- We wrote this article for the newsletter and hope to hear from others who would like to participate in future events, and maybe even generate more sponsorship of this important cause.

More information about the experience of cognitive impairment and feedback from those who took part in the journey can be found on my website: www.livingwithdementia.uk.com/file/risk.html

If you are interested in taking part in next year's event please email Clare at **clrmrrs@me.com**

Keep us informed

Insurance and mortgage discrimination

From time to time we get calls to the helpline regarding difficulties experienced in obtaining insurance and mortgages due to CJD risk. We would like to identify the extent of these problems so we can take any necessary action.

If you or your family have had problems in obtaining insurance or mortgages, or have suffered any similar discrimination as a result of your or your family's connection with CJD, please let me (Gillian Turner) know. You can contact me by phone, email or letter (my contact details are on the back page of this newsletter).

In memory

Heartfelt thanks to the friends and families of those below for the donations received in 2010. You gave a total of £11,000.

Julian Bailey
Alan Bedford
Brenda Bosley
Ann Erskine
Linda Fanning
Mr Gupta
Dawn Hales
Deryck Kenny
Edward Peduzie
Jennifer Perry
Christine Ann Masie Plant
Colin Robinson
John Shelley
Trevor William Smith
Trevor Stevens
Nick Taylor
Alan Tittensor
Linda Young

We would also like to say a big thank you to all those fundraisers in 2010 that ran marathons, organised a clothes swop day, asked for donations instead of birthday and anniversary presents, gifts from employers and much much more. You all helped to raise over £9,000.

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
2007	64	2	9	1	5	**81**
2008	88	5	2	3	1	**99**
2009	78	2	3	5	3	**91**
2010	72	2	5	1	3	**83**
2011*	11	0	1	1	1	**14**

*As at 9 March 2011

Total of definite or probable vCJD cases (dead and alive) in UK **175**

Family support meeting

The CJD Support Network attracted over fifty family members to the annual family support meeting, held at the Burlington Hotel, Birmingham on the 19th November 2010.

Chairman of the Network, Dr Angus Kennedy welcomed everyone to the meeting and explained that we had decided to change the format a little this year by inviting eminent speakers on CJD to talk about a variety of issues that regularly come up on the helpline.

The most frequently asked question is about diagnosis, so we asked Prof. Richard Knight Director and Consultant Neurologist at the National CJD Surveillance Unit to explain the diagnostic process, the reasons for delays and testing for CJD.

Another issue that is the subject of many calls is about post-mortems and whether it will delay funerals. So we asked Neuropathologist Prof. James Ironside to give a talk on post mortems and their findings. At our request, James has worked very closely with many undertakers, to clarify uncertainties around infection control and funeral practices.

Dr Simon Mead then gave an up-date on the cohort study which was being conducted by the National Prion Unit. Many of our members have agreed to be part of the study.

This was followed by an open questions and answer session, where our speakers' panel were asked some very interesting and challenging questions.

The Annual General Meeting followed, chaired by Angus Kennedy. He gave a talk on the Network's work over the past year. He said we were very grateful to a family member who had funded today's meeting and the family support meeting last year.

He thanked people for raising money with a variety of sponsored events and that he hoped for another kind sponsor for the next year's family day.

Dr Kennedy said that he had been Chairman for the past ten years and found it a great privilege. It had been agreed that due to pressure of work, Richard Knight would now be joint chair. He thanked Gillian for the enormous amount of work she did so efficiently. He said that the committee ran well and thanked the Prion Unit and the National CJD Surveillance Unit for their help and support.

The network's project for 2011 was to make a podcast about the network.

Minutes of the last year's AGM were circulated and agreed.

Andy Tomaso explained he had only been treasurer since April – he thanked Mike Curtis for handing over the up to-date accounts. Copies of the financial report were distributed and Andy gave details of the network's financial position. He said that 2010 had been the best in the history of the CJD Support Network for money donated from sponsored events and donations in memoriam. He spoke of the need for another good year in 2011 in view of the fact that the network had lost its Department of Health funding.

The network's committee for 2011 were accepted en bloc and are listed on the back page.

We all had an enjoyable lunch before the afternoon session began.

Following on the morning's look at the most common areas of questions asked on the helpline, Prof John Collinge gave a talk on pre symptomatic treatment and an up-date on treatment studies.

The need for a reliable safe blood test is often the basis for many calls so we asked Dr Phillip Minor to talk on blood test development and evaluation of tests.

All the speaker's talks were very interesting and prompted many questions to the speaker's panel as well as other questions from family members.

Angus Kennedy summed up the day saying he hoped it had been helpful and informative. He thanked all the speakers and we enjoyed a cup of tea before travelling home.

If you would like to attend our next family support meeting this will be on Saturday 12 November 2011. November 12th is International CJD Day so we hope it will be a very special family support meeting. Please contact Gillian Turner either by telephone or email to register your interest.

Research update

Prototype blood test for vCJD

The CJD Support Network welcomes the news announced in The Lancet that a prototype blood test for vCJD has been developed at the MRC Prion Unit.

Prof John Collinge said that the development of a blood test to detect vCJD infection has been a major scientific challenge but one that is important both for early diagnosis of this disease in patients and for development of a screening test that may detect silent infection in healthy individuals. The latter is of important with respect to estimating the number of infected carriers in the UK population and to reduce risks of accidental transmission of infection through medical and surgical procedures including blood transfusion.

[www.thelancet.com Vol 377, 5 February 2011]

Our one in a million…

By Tracey Massey

We lost my beautiful big sister, Linda Fanning in November 2009.

For us, her family, it started off with noticing that something wasn't quite right and there seemed to be certain words Linda would 'forget' or not be able to pronounce quite right. She had been under some stress with one thing and another and at the end of February 2009, unbeknown to most of us at the time, she had a 'funny turn' whilst hairdressing. Linda kept it from us all except for her husband Vince and her daughter-in-law Nicky. Nicky works at the West Middlesex Hospital and Linda asked her to arrange for an appointment to have an MRI scan after this incident. Thinking back we assume that Linda herself knew something was wrong after she had this 'turn'.

Linda had the MRI scan in March 2009 which came back clear. It was put down to stress and after seeing her GP in May, Linda was diagnosed with depression and prescribed Prozac.

In early June her youngest son Adam married. At the wedding we could see that Linda was far from right and still deteriorating despite being on Prozac. Having been a hairdresser all her life, she had arranged to do the bridesmaids' hair for the wedding, but she seemed uninterested. There were lots of guests at the wedding who had not seen her in a while saying that she didn't look well. Linda was always happy and smiling and in her younger days she had been a dancer and still loved dancing. She barely got out of her chair and hardly spoke to anyone. When she did get up to dance I was practically holding her up. Both my brother and I noticed that she seemed to be 'staring into space' and really wasn't herself.

Two weeks later her daughter-in-law Nicky took her back to see her GP to see if there were more tests that could be done, but the GP responded with 'just up the dosage on the Prozac'. At that point all of us wanted to go to see Linda's GP and tell her 'IT'S NOT DEPRESSION'. She was still getting worse. We knew her and could see that it was more than that. It was so frustrating.

At the end of July 2009, after continually begging Linda's GP, it was arranged for her to have another MRI scan and the results showed up some irregularities. She was given a hospital appointment, but it fell on a date when she was going to be on holiday in Ireland with her husband Vince and youngest daughter Kate, so the appointment was re-scheduled for 5 November. This seemed a ridiculous delay seeing she was still getting worse. Again, her daughter-in-law Nicky stepped in and the appointment was bought forward.

Linda saw a neurologist on 7 September 2009. She had an EEG a week later. Another appointment on 24 September led her to be admitted to Charing Cross Hospital four days later, where a lumbar puncture was performed.

On the Tuesday morning we were told she had tried to 'escape' from the hospital and had been restrained and sedated because she was 'fighting' with nurses and security. We all rushed up to Charing Cross and I know I will never forget how she looked. She was terribly bruised where she had been restrained and her face looked terrified – it will be etched on my memory forever. I know that our Mum cannot forget that terrible memory.

Two days later we had the worst confirmed – Linda had CJD and she wasn't going to make it. Of all the things we thought might be wrong we didn't expect that. We were not even sure what it was.

We saw Dr Kennedy and other specialists from Edinburgh on Friday 2 October and had the disease explained to us and were told that Linda only had 'weeks' to live. We were told what to expect, but it was impossible to imagine what we were about to go through. Watching someone you love become so helpless and fade away in front of you is not easy to put into words and we would have all given everything we had to keep her, but there was nothing anyone could do.

Linda was moved to West Middlesex Hospital where she deteriorated further. She could no longer feed herself or go to the bathroom. She would back away from us and not recognise her own children. It was heartbreaking. With the help of family and the CJD 'care package', Vince took Linda home. She began to go through the various stages that we had been told about and went down hill very quickly. She was only at home for a week.

Linda went into Princess Alice Hospice on 28 Wednesday October. She was hardly conscious and we were told she would not last the weekend. We all spent these days by Linda's side and Vince and her Mum stayed at the hospice 24/7 until 5 November 2009 when we lost her to CJD. She was only 56 years old.

She died on the day she would have had the appointment for the MRI scan which confirmed CJD. Had it not been bought forward we would not have had any idea what she had actually died of. Unfortunately, as far as it stands at present, we still do not know what caused Linda to contract CJD.

For me not a day goes by without me thinking of Linda and all my family live in hope that one day we will have an answer to the question.

Genetic CJD and me

By Sarah

I was 13 years old when my father died of genetic CJD.

At the time we thought it was Multiple Sclerosis, as this was the diagnosis given, or perhaps a brain tumour because of the speed of the illness.

My father's car had been hit by a drunk driver in the days when you did not wear a seat belt. He had a slight head wound and was badly bruised, but within six months of this accident he was a broken man, twisted and tormented, unable to speak, in a vegetative condition. I remember well his vivid nightmares – something that scared me a lot at the time, as I also had vivid dreams and could relate to his piranha fish swimming in front of him. My Dad was nursed at home by my mum, as she had been a nurse before having us four children. Dad was just 47 when he died in 1972.

It was the mid 80s when I first started to have mobility problems along with dizziness and falling episodes. Having always been a tomboy and 'Mrs Builder', I found loosing my self-control and strength very hard.

My elder sister Susan also started to display worrying symptoms. It was at the time that variant CJD was in the news a lot. She was having severe memory problems, typical of Alzheimers and because of her shaking, query Parkinson's disease. Susan was able to explain that our father, his mother and sister had all died in their mid 40s, 'going mad', as it was put at the time. Finally she was seen by Professor Rosser at the Prion Clinic in London and a blood test was taken.

It was a couple of months later that Susan collapsed and was taken to our local hospital in a comma. It was here that we had the sad truth about the family history confirmed. Faxes were sent between London and our local hospital and the doctor covering my sister's case told our mother that we had the inherited gene P102L.

Unlike our father, Susan lived on for a further three years slowly slipping from us in a tormented world of her own. She died on 6 May 2001 having endured the illness for a good six years.

Four days later I had a heart attack and missed her funeral, but I am still here!

I had been tested in 1997 and found to be carrying the gene. By this time I was disabled myself. Living with this illness has been a long hard road to travel along. Many of my 'battles' have been because of the many health problems I have had and the refusal by the NHS to treat me as a normal person, often flouting their own Department of Health Guidelines in their refusal of treatment.

This started with dentistry problems. I needed a root treatment and despite being under the local special needs dentist and being sent to the London Dental Hospital twice, no one could treat me. This went on for 18 months and I was in pain for the whole of this time. Two MPs, from each of the main political parties, came to see me at home, but they could not help me. If my local hospital won't take advice from the Prion Unit, or accept their own government guidelines and your MP can't help – where do you go? Thankfully, there are sensible souls in this world and my husband's private dentist finally stepped in to treat me and has continued to see me every three months since this time.

Sarah kindly knitted this 'little golfer' which was presented to the winning junior girl at the Colin Robinson Memorial Golf Tournament organised by Tim Gibbons in memory of his brother in law Colin who died of Sporadic CJD.

More recently I have had great battles with the NHS to get a simple sigmoidoscopy (short camera examination in the bowel) and endoscopy (camera examination down the throat). At last I have been tested and prodded, to find that I have Diabetic Gastroporisis, (tummy unable to process food anymore). So a liquid diet, low fibre and small portions. My diabetes is steroid induced, from a week's course of intravenous steroids I was given when they thought I had MS. Again it took nearly two years to get to the bottom of the problem, in which time I had gall stones and passed them, as no one wanted to operate. Neither did I want an operation, come to that. I just wanted to be treated as a normal person and not a 'leper'. The additional stress of not being treated had effects on me with angina, but also caused considerable stress for my husband.

What do I achieve by telling you part of my tale of living with this illness?

Well, life has been a battle, but I am told I am unusual to still be here with such clarity, while my body fails me. Perhaps that is because I am a fighter. I do believe in being tested for the gene, although my husband's view would differ, given all the medical hassle I have had. It is your loved ones that bear the brunt of this illness. For my husband, the endless times the ambulance has been called, having an angina attack again, or having collapsed on him. He has to pace the corridor, wondering if I will survive my latest problem, wondering

continued over/…

if I will get the treatment I deserve, just to be treated the same as a normal person in the street.

For me, my glass is always half full. I do believe that the more that is known about Prion illness, the more the barriers will come down. I do believe that in time, there will be medication to slow the illness. You only have to look at the improvements for Alzheimers and Multiple Sclerosis. I also have faith, that the hassles I have experienced over dentistry and surgery issues, will be reduced as more is known about the illness. It took over a year, but I did have carpel tunnel surgery on both hands, having originally been told that it could not be done because of the cost of disposal of the instruments.

I also believe strongly that you must NEVER give in.

I do have a tremendous amount of pain, but decided from the beginning I was going to keep pushing myself. I knit every day, making funny clowns and teddies for different charities. I find the knitting eases the pain in my arms and shoulders. I make mistakes, but just undo the work and start again, accept that my concentration has wondered and try to laugh at it. I keep a 'memories' album to remind me of what I have made and where possible a photo of the children's happy faces as they cuddle my toys and if possible the amount raised for different charities. When you are unable to pursue one hobby due to your health decline, find another way of doing something, as I have. From once doing upholstery, sewing and embroidery, to now knitting smaller items.

I am unable to walk through fields with my neighbour's dogs, but can race off down the street in my electric wheelchair, or pram as I like to call it, still feeling the wind against my face. One advantage of my pram was when attending a vintage motorcycle meeting; we met John Cooper, a famous British motorbike rider from the '60s. He befriended us, giving us tickets to the Festival of 1000 Bikes vintage motor bike meeting. There he introduced us to Agostini an even more famous racing rider of this era. I now have a photo of me with Agostini and John Cooper to look at every day, something that would not have happened if I was a normal person wondering through the paddock of bikes. I cherish these simple new adventures in my pram, of meeting people like John Cooper, rather than dwelling on what I have lost. The odd whiff of Castrol R just takes you right back to the old days, no matter what your condition now.

It has been difficult to accept the changes we have had to make as a couple. For example, accepting having carers in for me and knowing that I need 24 hour care now. However, we are now used to the system of our carers, who are from the charity Crossroads. Our carers have helped stimulate me tremendously. I look forward to them coming and it has helped my husband to be able to cut off and indulge in his hobby for a short time without worrying about me. I do feel very alone with this illness and afraid of the future, but I am determined to face it, fighting as best I can. Defiantly embracing the need to having carers has eased this fear of being alone.

I would like to be able to challenge the stupid bureaucrats that refuse me treatment through the NHS, but I am no longer able to cope with the stress of an argument, or put the words together, but I hope one day they get to feel what it is like to be on the other side of the fence, being refused treatment and feeling like a leper, helpless to do anything about it.

But I shall keep fighting – and look forward to Professor Collinge's team finding that magical mix to slow this illness or stop it in its path.

John Shelley

20 April 1947 – 12 January 2010.

As told by daughters Angie and Mindy, and his partner Donna

Our Dad was a hardworking, generous and thoughtful man who was loved and respected by all who knew him. Dad always made sure us three children had everything we needed and took us on many great holidays.

Sadly our mother and brother were tragically taken from us and Dad never really came to terms with this, although he tried to be strong for his girls. Years passed and Dad and his partner Donna moved to Worcester with their two dogs, but still commuted back to Birmingham everyday for work.

In the beginning of November 2009 Dad's voice and hands seemed to be

The UKHCDO (United Kingdom Haemophilia Centres Doctors' Organisation) has informed the Haemophilia Society that some people at a particular haemophilia centre had been told that they were 'at risk of vCJD for public health purposes', when they are in fact not at risk.

A number of patients were wrongly identified as having UK plasma donated blood-products between early 1999 and 2001and were consequently informed in 2004 that they were at risk of vCJD for public health purposes.

This was a mistake, because these particular patients had been treated with UK manufactured blood products made from US plasma which was deemed to be safe. Between 1999 and 2001, batches of UK manufactured (BPL) blood products made from either British or American plasma were in use at

shaky and he was unable to get his words out. We then discovered his manager was concerned as Dad's personality had changed, showing sings of agitation, aggression and forgetfulness.

On November 11th Dad went to hospital and was admitted. What we experienced in the next four weeks was sheer hell. He had many horrendous hallucinations which left him frightened and confused and we would be called up to the hospital on many occasions in the early hours to calm and reassure him. The peculiar thing was when he was hallucinating he was able to walk and speak normally, but when he was in a calm state he could not do either, Throughout the four weeks Dad had a total of seven falls which left him bruised and anxious as to what was wrong with him. Dad's condition varied and we never knew what to expect from one day to the next. One day he could wash eat and walk and the next he couldn't – it was heartbreaking.

Dad endured many tests including MRI, EEG and CT scans, lumbar punctures and various blood and urine tests. All these came back normal, except for the lumbar punctures which showed a high protein level and one blood test was still to come back. On the fifth week Dad's symptoms slightly improved to the point where he was discharged, while waiting for the result of the remaining blood test.

On 17 December Dad went home to Worcester, where for the next 12 days his condition was much the same as it was in hospital, but then he deteriorated dramatically and on 30 December he was admitted to his local hospital where they recognised that he needed specialist treatment.

Dad was transferred to Birmingham to a neurological ward on 1 January where he was given medication to alleviate his symptoms. He improved slightly and we stayed in the hospital with him. One of the nights we stayed, Dad made us laugh so much, he had such a funny sense of humour we will always hold that memory dear.

On 5 January Dad slipped into a coma, unable to speak and oblivious to everything around him. We were devastated. On that same day Dad's condition was diagnosed and we were told there was no cure and it was terminal. We were heartbroken, all hope was gone.

A week to the day after Dad was diagnosed, with us and his grandson around him, he took his final breath. After all he'd been through, he was finally at rest.

'At risk' status changes for some individuals living with a bleeding disorder

the same time. These could be told apart only by their batch numbers, hence the confusion.

According to the UKHCDO, this error may have occurred in other haemophilia centres around the UK, though it is suspected that the number of affected patients is likely to be small. All haemophilia centres have been asked to check their past batch number records to see if people registered with them are affected. To ensure diligence, all haemophilia centres will be carefully cross referencing with others to identify everyone affected by this problem. Due to the complexity of this arrangement, it may take some time before centres are in a position to contact patients to discuss the situation with them.

This can only affect you if you were only ever treated with BPL plasma products between 1999 and 2001.

If you were, then it is more likely to affect you if:

- You are only treated very infrequently.
- You have von Willebrand's disease (treated with 8Y), very infrequently treated mild haemophilia A and B, factor XI, factor VII or Antithrombin deficiency.

It will definitely not affect your vCJD status if:

- You were treated with any BPL plasma derived product between 1980 and 1999.
- You have not already been told you are 'at risk' or have been told you are not at risk.

It is therefore very unlikely that any frequently treated patients for severe haemophilia A or B will be involved and the UKHDCO suspect that a relatively small number of patients may have been misinformed about their vCJD 'at risk' status.

Editor's note: An interesting review article, written by Prof J W Ironside, appeared in Haemophilia (2010), 16 (Suppl. 5) 171-180 Variant Creutzfeldt-Jakob Disease.

CJD Support Network

Management Committee 2011

Dr Angus Kennedy – Joint Chair
Consultant Neurologist

Professor Richard Knight
Richard is a Consultant Neurologist at the National CJD Surveillance Unit in Edinburgh

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

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

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

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

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

Francesca Certo
Francesca's family is affected by GSS

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

Gillian Turner – CJD Support Network co-ordinator

Malcolm Young – Malcolm's wife Linda died of Sporadic CJD

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

CJD SUPPORT NETWORK
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