

THE JEREMY WILLSON CHARITABLE TRUST

COMPENSATION PAYMENTS

IN OCTOBER 2000, The Secretary of State announced the Government would pay compensation to the victims of variant Creutzfeldt-Jakob Disease (vCJD) and their families.

Details of the scheme were announced in October 2001, when £67.5 million was set aside for up to the first 250 cases. The Government says it will review the scheme if the total exceeds 250.

For more information about the trust go to www.cjdtrust.co.uk

'A positive impact on

New variant Creutzfeldt-Jakob Disease is a rare, deadly disease that saps the life from its victims in a matter of months after first symptoms appear. To date, only 158 people in the UK have died from vCJD. One family from Maidstone spoke exclusively to **Helen Wagstaff** about how they are turning the tragedy of their son dying from vCJD into something more positive for the future.

JUST 10 months before new variant Creutzfeldt-Jakob Disease (vCJD) claimed his life, Jeremy Willson was climbing one of the highest mountains in North America.

At the time he made the 11,249-ft climb, in May 2005, the devastating illness had already started irreversibly changing Jeremy.

The bright, athletic, former Maidstone Grammar School boy had been experiencing severe psychological problems, which his doctors diagnosed as depression.

Despite being a brilliant geologist who was achieving great things in Houston, Texas, with employer Shell, he was struggling to make simple decisions.

However, Jeremy refused to give in and defiantly continued with his love of mountaineering.

According to his family this spirit and determination was typical of Jeremy. "He was incredibly active in work and play," said his twin brother Matt. "He would suddenly announce he was off to somewhere like Peru for a few days and then just go.

"Our parents would say to him, 'slow down, you've got your whole life to do these things,' but that was not the case. In a way it now makes sense."

Jeremy's vigour for life was one of the reasons the Willsons, from Tudor Avenue, Maidstone, decided that rather than just mourning their beloved son and brother, they would do something positive to celebrate his life.

vCJD has claimed the lives of 158 people in the UK. It is linked to BSE (known as Mad Cow Disease) and has symptoms similar to Alzheimer's, which take hold rapidly.

After Jeremy's diagnosis, the family was awarded compensation from the Government.

"None of the family wanted the money. How can you compensate



■ Jeremy climbing Mount Hood in Oregon

for losing a brother and son?" explained Matt. "Originally we were going to give it as a lump sum to charity."

However, rather than simply donate the money, the Willsons decided to set up a charity to help others who share Jeremy's passions in life.

The Jeremy Willson Charitable Trust (JWCT) aims to hand out more than £10,000 in annual awards and individual grants through The Royal Geographical Society, Maidstone Grammar School and other similar organi-

sations and groups. These grants and awards will help disadvantaged athletes achieve their goals, geologists carry out independent, ground-breaking expeditions and the conservation of, and improved access to, mountain and ocean environments in the UK and overseas.

Each cause has been selected by parents Nick and Tricia and brothers Matt, Simon and Tom, in tribute to Jeremy.

Formative

Although still in its formative stages, the JWCT is hoping to make its first awards later this year.

A website is being designed and a launch newsletter has already been sent to interested parties.

Matt said: "Jeremy grabbed life with both hands and achieved more in his short 30 years than most would in a lifetime.

"He inspired and encouraged others to achieve things they thought were not possible.

"The Jeremy Willson Charitable Trust has been set up so that Jeremy can continue to have a positive impact, in a small way, on other people's lives."

■ If you would like to donate to the JWCT there are a number of ways to do so: you can set up a direct debit or make a one-off donation via www.justgiving.com/jwct/donate or www.cafonline.org

You can also support an event being run in aid of the JWCT, or set up your own fund-raising activity. Details on www.justgiving.com/jwct/raisemoney

For more information about the JWCT e-mail jeremywillsonct@yahoo.co.uk

Variant CJD: The facts

Variant CJD was first reported in 1996.

Since its discovery 158 people have died from vCJD in Britain.

Worldwide there have been 198 known cases of vCJD; of these 165 of the cases are from the UK. 12 of the victims are still living.

No cases of vCJD have been seen with symptoms that began before 1994.

The initial symptoms of vCJD are similar to those of depression; mood swings, memory lapses, fatigue, irritability, sleep problems, withdrawal from social activities, lack of interest in life, and neglect of personal hygiene

There is no proven therapy or cure for any of the forms of CJD. Treatment is based entirely upon reducing symptoms through the use of drugs, and trying to keep the person as comfortable as possible.

According to the World Health Organisation vCJD has affected younger patients with an average age of 29. It has a relatively long duration of illness, around 14 months and is strongly linked to exposure, probably through food, to Bovine Spongiform Encephalopathy (BSE) or Mad Cow Disease as it is commonly known.

For more information visit www.cjd.ed.ac.uk

Source: vCJD Surveillance Unit at Edinburgh University, NHS Direct and World Health Organisation

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other people'



■ Jeremy lived life to the full, as an athlete, climbing with his twin brother Matt, and climbing Mount Hood in the Cascades, Oregon

Adventurous life cut tragically short

JEREMY Willson was born in Maidstone in 1975.

Along with twin brother Matt, he grew up with parents Nick and Tricia, and his other brothers Simon and Tom, in Tudor Avenue, Maidstone.

He attended St Paul's Infant School and North Borough Junior School in Peel Street, Vinters Boys' School in Huntsmans Lane and Maidstone Grammar School in Barton Road.

Throughout his school career, Jeremy excelled both academically and athletically, running for GEC Avionics and later Bristol University.

He was also a keen Scout at St Paul's Scout Group in Sandy Lane and a hockey player for both MGS and Sutton Valence Hockey Club.

After leaving school, his lust for adventure shone through when he travelled to Indonesia with the Project Trust, before going to Bristol University to study geology, followed by an independent geological expedition to the Andes in northern Argentina for seven months.

Jeremy's career took him first to Den Haag, Holland, for two years, before he took up a post as exploration geologist for Shell in Houston, USA.

Work with Shell took him to remote regions of the world including Pakistan, Chile and Nigeria.

Jeremy lived his life to the full, throwing himself into travel, mountaineering, athletics and other out-



■ Jeremy Willson, third from left, with his family

door pursuits. He loved life and was determined to get the most out of every day. But this life was to be cut tragically short.

The first indication something was wrong came in early 2005.

Initially, small things started to change. He suffered problems with his balance and started finding it difficult to make decisions.

Doctors diagnosed depression but, by June 2005, Jeremy's condition had deteriorated so much he was forced to leave the USA and return to Maidstone.

By this point, Jeremy was unable to even book his own flight.

Back home, Jeremy was cared for by his family, as medical experts performed test after test to find out what

was wrong. Each day the condition worsened, with co-ordination, memory and awareness ebbing away.

"It makes you realise how fragile your mind is," said Matt Willson. "Take, for example, cleaning your teeth. It is a whole series of individual actions that you don't realise you are doing. If even one of these actions is missed out or is in the wrong order, then the whole process collapses.

Devastating

"Jeremy's memory went quite quickly. He wouldn't remember what he had for breakfast, but for quite some time he could still remember the height of Mount Everest."

In September 2005, doctors gave the Willsons the devastating news

Jeremy was most likely suffering from new variant CJD.

By that time, he was not well enough to comprehend what was happening to him.

In just seven months he had gone from an active, outgoing person to one who had lost his ability to walk, remember, eat or speak.

Jeremy died in March 2006. More than 400 people, many from other countries, attended his funeral at All Saints' Church in Maidstone.

At the funeral, his father Nick said: "Jeremy was an inspiration to us all and it will be a fitting memorial to him if we all leave here with determination to follow his example and live life to the full."

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