In memory of our daughter Judith

It is hard to believe that this time last year life was good. In January 2010 we were an average family who had recently celebrated Christmas and five family birthdays, one of which was my 80th birthday. On 15th July 2010 our lives changed forever when we lost our first born, Judith Anne, to Creutzfeldt-Jakob Disease.

Judith was a pharmacist, married with three adult children and a 2yr old grandson. She owned and operated a Pharmacy in Ulverstone, Tasmania and had over 30 years experience in her profession. In 2008 her pharmacy was named Australia's best pharmacy/natural health store in the Australian Small Business Champion Awards. She was chair of the Australian Association of Consultant Pharmacists from 2008 until last year; she was also chair of the Guild's Women and Young Pharmacists' Committee. In 2008 the Federal Health Minister appointed her to serve on the External Reference Group of the Government's National Primary Health Care Strategy. In 2002 Judith won the Telstra Business Women's Award for Tasmania. Shortly before her death she was awarded honorary life membership of the Pharmacy Guild of Australia. She was only the 3rd woman to be so honoured in more than 80 years of Guild history.

My husband and I had been down to Tasmania in late April 2010 to visit and there was no indication that there was a problem with her health. We saw her again in late May at her grandson's 2nd birthday party, and to us she seemed fine. She had been troubled with back soreness; however x-rays showed that there was no problem for her to be concerned about. Judith had recently been prescribed new glasses, but was not happy with them and intended to return to the optometrist to have them checked.

On 22nd June 2010 we learnt that Judith was not well, she had been anxious, a little forgetful, and had become unsteady on her feet. She had been to see her GP and it was thought that she was suffering from stress due to her heavy work load, and so rest and medication were ordered for her. I was concerned that it may be a brain tumour or something more serious, and encouraged her to ask for further tests. This she did, and an appointment was made with a Specialist Physician for Tuesday 29th June. Following this consultation specific tests were conducted, this was when Prion was first suggested as being a possible cause of her illness.

None of our family had ever heard of this disease and we all immediately turned to the internet to obtain the information we so desperately needed. The enormity of this disease was overwhelming for us and the implications devastating.

During this time I had been talking to Judith each day on the phone and she was bright and chatty as usual, although a little forgetful. I had already arranged to fly to Tasmania on 30th June to support her and to see her condition for myself. With this new development uppermost in my mind, I was extremely apprehensive as to how I would react on seeing my daughter. I was terrified that I would not be able to control my emotions and succumb to the fears that were fast overwhelming me. However on seeing her I had only thoughts of being there with her, determined that we would share the good and the bad times together. Strangely it seemed to be the normal thing to do.

When I first saw Judith she was walking with a jerky leg movement and holding onto the wall and then the bench in order to support herself. She greeted me with her usual beautiful smile and we made light of her unsteadiness. Judith's husband had been doing the cooking and we enjoyed a glass of wine that night with our evening meal. We discussed the visit to Launceston Hospital as they were to leave at 8 am the next day. On rising the following morning she had forgotten all about the trip. On mention of the appointment at the hospital, she asked me if it was for more tests and at what time were they to leave. It turned out to be a long day for her as they arrived home just before 10 pm, she was very tired.

Each day during my stay her condition deteriorated and she became more restless, due in part to the involuntary movements of her arms and legs. She became increasingly more anxious that no diagnosis was forthcoming, and that there had been no improvement to her health. However she was enjoying her food, though it would take her a long time to finish her meal. Early on the morning of the 4th July 2010 I found Judith in the bathroom in a trance like state. I was unable to move her or get any response from her. The family were taking turns at sleeping with her as she was rising frequently during the night to go to the toilet and walk around the house. At times when she became excited her voice would be raised and her demeanour would become very intense. She became more dependent on her family to help her dress, toilet and feed her. It was here in Tasmania that I had my last reasonable and coherent conversation with my daughter.

On 5th July 2010 Judith left her home in Tasmania to come to St. Vincent's Hospital in Melbourne. She was no longer capable of independent movement and was confined to a wheelchair. Her husband and children travelled with her to Melbourne, the cargo lift was required to transfer her onto the plane.

On arriving in Melbourne the following day I realised how much my daughter had deteriorated in just 24 hours. Her conversation was limited, and then it was mainly in response to questions or comments made by those present. While in hospital she experienced some panic attacks which were distressing to us all. At St. Vincent's tests were organised under the direction of CJD specialists. A lumbar puncture test was performed as well as a MRI. These tests were positive to CJD.

When it was clear that further treatment would not be of any benefit, it was decided to transfer Judith to Palliative Care. She spent 5 days in hospital, and then another 5 days in Palliative Care. Her deterioration was rapid. During her last days she was unable to eat or drink, and she had great difficulty in swallowing .Over these 10 days her husband and three children were on roster to be with her at all times.

In the early hours of Thursday 15th July 2010 our courageous daughter found peace.

We take comfort from the fact that Judith's progression was quick and her suffering limited to a short period of time. We understand that many other suffers can endure long periods of illness. As CJD manifests symptoms like many other diseases, this can lead to misdiagnosis. We will be forever grateful for the health care our daughter received, both here in Melbourne and in Tasmania. All doctors and medical staff involved were professional, diligent and compassionate. At such a traumatic time in our lives we were grateful to have such prompt and expert medical care.

We have been ably supported by the CJD Support Group with information about this rare and fatal disease. This, as well as personal contact with an informed and compassionate person on the national support helpline, has been much appreciated. Reading case histories of CJD victims has been pertinent to us gaining some understanding of this disease and its consequences. I hope reading Judith's journey will do likewise for others. As there was no way to rule out a genetic cause for Judith's illness both my husband and I have been genetically tested for this insidious disease. Our tests were found to be negative.

The government of Tasmania will award a $5000 annual scholarship in recognition of Judith's contribution to pharmacy and the community. It will help provide for a student from the North-west coast who wishes to study Pharmacy at the University of Tasmania.

Of course we are very proud of all Judith achieved in her life. However, what is most important to us is that she has always been a loving and much loved daughter, sister, aunt, wife, mother and grandmother.