

November 2000

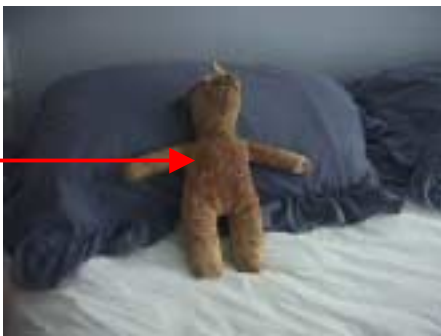
Dear Donor Family

I have written you so many letters in my mind, and yet I still don't know how to start this letter, or what to say. Ever since I first was told about needing a Liver Transplant, the family of the donor have been constantly in my thoughts. After the 14th August 2000 that family became you. I am so very very sorry that you have suffered this loss.

When I think of you, I am in awe that at a time of such personal sorrow and grief, you made the decision to donate your loved one's organs. This is such an amazing gift, and I don't know how you had the strength to do this, when I imagine you were in shock. Thank you so much for your decision. I am humbled by the size of this gift. You have given me life, through this gift. Together with the expertise of the New Zealand Liver Transplant Unit, your gift of your loved one's liver has allowed me to dream of a future again. I celebrated my 34th birthday in October; this birthday was one no one in my family expected me to live to see, until I received my donor liver.

I understand that your Transplant Co-ordinator has told you that your loved one's liver went to a 33 year old female who had had a long-term illness. Well, I want to tell you about your liver's new home.

Teddy
has a
new liver
too!



The Liver
is here.



My Family

I am the eldest of two daughters (no sons). We are pakeha New Zealanders. On my Mother's side we came to New Zealand in the early 19th Century as Anglican missionaries. On my Father's side, his Father emigrated from England in the early 20th Century, and became an Orchardist. Currently I live alone, with a cat.

My Illness

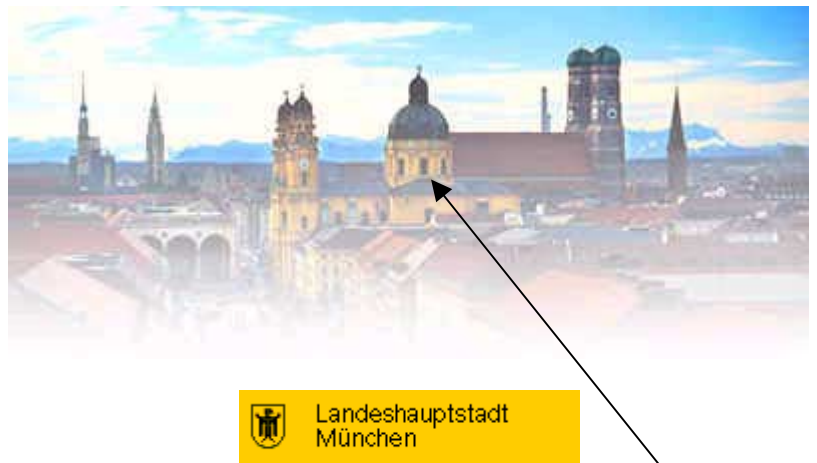
I was born with Wilson's Disease. This is a genetic disorder where I was born without the Enzyme that metabolises copper. I am not very good at explaining the medical side of things, but there is plenty of information on the Web.

"Wilson's Disease is transmitted as an autosomal recessive disease, which means it is not sex-linked (it occurs equally in men and women). In order to inherit it, both of ones parents must carry a gene which each passes to the affected child. Two abnormal genes are required to have the disease. The responsible gene is located at a precisely known site on chromosome 13. The gene is called ATP7B."¹

¹ <http://www.wilsonsdisease.org/aboutwilsons.html>

I was ill off and on from about 4 years of age. This was getting worse and worse, so that by the time I was 7, I was dying. I was admitted to hospital, where numerous tests were done over a number of weeks, and finally, shortly after my 8th birthday, the diagnosis was made. I was started on a drug called Penicillamine, which chelates or binds the copper so that it can be excreted. I eventually returned to school, and until I reached University, I was monitored by Specialists, but was able to live a relatively normal life, provided I took the drugs daily. Over the course of a number of years my spleen enlarged and this developed into a severe problem, with oesophageal varices, and required the removal of my spleen during the Christmas vacation between Stage 2 and Stage 3 at University. (I have a B.A. in Art History and German Language and Literature).

Raphael,
The Sistine Madonna.
1512-14



My favourite city of all time. The Cathedral in the background is my favourite church – the Theatinerkirche.

At this stage the surgeons also did a spleno-renal shunt to divert the blood through the left kidney, owing to the liver being scar-tissue and badly cirrhotic from my earlier liver failure at 7. 16 months later my family saw me off to Europe, where I spent 6 months backpacking alone around West Germany and Switzerland. This was certainly the way to re-train stomach muscles (I have a 19" splenectomy scar), as when I left I couldn't even lift my pack on, but had to find a park bench, place the pack on it, and shrug my way into the harness.

In all the time that I knew I had Wilson's Disease, I never knew that (1) my liver could fail twice, (2) that I could have a Liver Transplant or (3) that the Penicillamine and the Splenectomy were not a long-term solution.



SIMPSON GRIERSON
LAW

In 1998 I left the large Law Firm where I had worked for over 6 years and moved to a new position within a national IT Firm. At the same time I had commenced my 3rd University qualification, which entailed evening lectures, study groups and lots of homework.



Over the next months I had difficulty climbing up the hill to the office, and felt I was getting really unfit and putting on weight. I left the IT Firm for another Law Firm in November 1999, just after my exams, (I still have one paper to go to complete this qualification), and

continued to work late into the evenings, and felt very tired all the time. This I put down to lifestyle. I was doing a lot of national flying at the time, and the increased oedema I attributed to elevation. I had also commenced "Adult Learn to Swim" classes last November at the local pool, and I got an ear infection. This, after numerous visits to the GP, antibiotics and eardrops, had still not cleared up.

The weekend that the Auckland Museum was re-opened by the Prime Minister, my boyfriend and I went there and wandered through from the Official Opening until 3pm. At that stage, I said to him that I just couldn't walk another step, because my legs were so swollen (fluid was leaking out the pores) that I had to go home and lie down. That Sunday I went to the Emergency Doctor. I wondered if maybe I was anaemic, as I was looking jaundiced and pale. I had blood tests done, but still flew to Wellington on business on Tuesday and Wednesday. Arriving back Wednesday evening I remember distinctly the odd feeling that as I looked out the window at Auckland, there was not a single landmark that I could recognise, which was most disconcerting, as I have flown into Auckland countless times. I also couldn't find my car, even though it was parked outside the Terminal, and I spent 10 minutes looking for it. I don't even remember driving home. Once I got home I had no energy to even get my briefcase ready for the next day. I went straight to bed. I woke up at about 3am, as I was shivering with cold, and couldn't breathe. I was so so cold, and I had no energy at all. I was desperate for a blanket, and I couldn't reach one or get out of bed and make a hottie or anything. It took about 5 minutes for me to gather enough strength to reach the phone next to me, and ring my mother (who didn't answer), my boyfriend (who didn't answer) and then my brother-in-law (who, as a Doctor, had to answer) told me to immediately call an ambulance. By the time I got to A&E I was running an extremely high fever and I was in Resuscitation. I had my briefcase and cell-phone, still expecting to go to work that morning – however I haven't seen my office since that day.

NEW ZEALAND LIVER TRANSPLANT UNIT

At this stage I was transferred to the **New Zealand Liver Transplant Unit**, where the specialists fought valiantly to isolate the acute infection (staphylococcus from the ear, in my ear and blood) and treat it, and then started to deal with the chronic liver failure. I presented with unusual side effects. The liver damage had caused massive pressure in the heart and lungs, with right heart failure and tri-cuspid valve leakage and pulmonary hypertension. The liver also had a blocked portal vein.

At this stage, the options were (1) do nothing (short life span), (2) liver transplant (heart and lungs made this not survivable), and the talk was of a lung-liver transplant, or a heart-lung-liver transplant. The specialists needed to reduce the pressures to make me operable. The Greenlane and NZLTU specialists gained funding from the Health Funding Authority for a trial of a drug called "iloprost" which was started in early July to reduce the pressures through dilating the veins. Eventually the NZLTU decided to assess me for transplantation (before that I was too ill to be considered), and this occurred late July, with the added complication arising that my superior mesenteric vein (used by the surgeons if the portal vein is not available to attach the donor liver to) was not available. They had to hope that if they operated, that they could find the splenic vein, which had already been used as a shunt to the kidney.

I am attaching here some excerpts from e-mails that my boyfriend wrote to my friends and family, keeping them informed. I am enclosing part of the first one as well as ones relating to the time of the transplant, as for over 4 months we did not expect me to be able to have a Liver Transplant.

DATE: Sunday, 26 March 2000 10:23
SUBJECT: xxx poorly

I am not sure if you will have heard the news, but xxx was admitted to hospital on Thursday with liver failure. For a while it looked as though she would not last long, and even now she is not nearly out of danger, although she has stabilised. She has a few complications, and did have a serious fever, so has not really had a good time of it.....

DATE: Friday, 11 August 2000 14:01
SUBJECT: xxx Update

This is a very belated update, as you will see, and I must apologise to those who have known about some of the many developments but not had actual news.

Since the last update, xxx's tests have been completed. During the week we had both good and bad news, and at one point there was some real doubt as to whether the transplant could proceed at all. However, shortly after this low point, a solution to the apparent difficulties appeared, and xxx was listed for a liver transplant almost two weeks ago. She is still on the Iloprost, and still therefore feeling very weak and suffering head and back pains for much of the time, but at least now has a real goal in sight.

The transplant is subject to no more urgent case being in front of her anywhere in the region [much of Australasia] and also to a real high quality liver becoming available. This could take anything up to 12 weeks, although clearly could come at any time before then.....

DATE: Tuesday, 15 August 2000 13:32
SUBJECT: xxx Update - Transplant news

I have just come from the Auckland Hospital, and as I write this xxx is in surgery. Last night [Monday] around 7.30pm [NZ] xxx was unexpectedly called by the transplant team to be told that they had a suitable liver available!

Needless to say there followed a hectic couple of hours getting things ready and getting to the hospital. The surgery was initially scheduled to start at 5am today [Tue 15th] but she eventually went into theatre around 7.15.....

DATE: Tuesday, 15 August 2000 16:05
SUBJECT: xxx update - all going well

The latest from the theatre is that all is progressing well.

The new liver is in and it appears to be working already. The pressure in the heart is dropping, which is very good news, and right now they are sewing her back up again. It seems she may be out of the operation sooner than expected, perhaps as soon as 4.30!.....

DATE: Wednesday, 16 August 2000 11:19
SUBJECT: xxx Update

xxx woke up yesterday evening, and was very aware of her visitors, although largely unable to communicate due to the high number of attachments - drains, probes, drips etc., that she has everywhere.

Her blood pressure is already dropping, which is seen as very good news, and other vital signs are good.

Around 4am this morning there was a scare over some internal bleeding and she was taken back into theatre. After a 2 hour operation it has been announced that the problem, which is not too uncommon, had been identified and fixed, and she was sewn back up again. Right now she is back in intensive care, where her Mother is waiting for her to wake up....

DATE: Thursday, 17 August 2000 21:12
SUBJECT: Brief xxx Update

Just a short note to say that I have just come from the Intensive Care Unit and all is going extremely well. xxx has been sitting up in bed all day, and has not stopped smiling since she first woke up. She is very happy to be alive, and extremely grateful for all the goodwill flowing in from everyone.....

What I remember most was waking up in Intensive Care while they were doing an Ultrasound on me, and my new liver. Although I was too tired to open my eyes, and the tube down my throat meant that I could not talk, I was so happy that I had this new liver, and that I was alive. Before the operation, I had discussed my funeral arrangements with my Mother, and the scariest moment of my life was when I had to leave her and my boyfriend down in the preparation room, as they wheeled me through those doors, into the theatre. I waved and thought, would I ever see them again, and was my last waking moment of life going to be of the theatre table.

In the theatre I was able to see the view of Rangitoto, and see one of the surgeons all dressed up, but I didn't see the liver before it went into me. I know it is big and healthy, because I feel wonderful. I have never had colour in my lips or cheeks, but the first thing my Mother commented on was had the nurses been putting make-up on me in Intensive Care. Three months later, and I still get a pleasant shock when I see my pink cheeks and lips, and I say "Thank you, liver" as I give it a pat.

It is the most amazing, incredible feeling to be alive. I can't begin to describe what having this liver means to me. I have just the most thankful feeling within me all the time, that I am alive to be able to pat my cat, talk to my friends, see the beautiful spring flowers, take a gentle walk, read, do tapestry, etc.

I try to put myself in your position, and I know that what I imagine can't even come close to what you are experiencing with your loss. I hope that I can empathise, as for most of this year I was dying, and knew that I didn't have long to live. My family feels deeply for your loss. I just hope that you can realise what a totally amazing thing your gift of your loved one's liver has meant to me and my family. Thank you for this precious gift.

I am trying hard to be a very good patient. I feel that I have a real responsibility to cherish my liver, and live as healthy and good a life as possible, for me, my liver, you and the NZLTU. I do not smoke or drink alcohol, and never have. I am a vegetarian. I am going to Physio three times a week, and once the Physio stops, I intend going to the Gym. The doctors are delighted with my progress. The problems I had in my heart appear to have been fixed with the new liver, so that it is only the lungs that we are still working on, with a drug that I take by nebuliser 5 times a day.

I am looking forward to a completely normal new life, with a hopefully normal life expectancy. This is only thanks to the gift of your loved one's liver. I would be dead now, if it wasn't for your generosity.

Thank you – Thank you – Thank you

As we get closer to Christmas, I imagine that this time of year will be very hard for you. Families coming together, but this year you have a big absence. This part of your loved one, living still in me, makes me want to give you such a big hug.

Lots and lots of hugs and thanks from your loving recipient (and my very grateful cat too).