

Hepatic Happenings

Volume 3, Number 1
April 2002

Consulting Editor:

Val Honeyman,
NZLTU
E-Mail:
valh@adhb.govt.nz

Editor:

Bethli Wainwright

Please e-mail or mail
contributions to the
Editor:

Bethli Wainwright

5A Eyre Street
Henderson Heights
Auckland
NEW ZEALAND

E-Mail:
ptoli@ihug.co.nz

Phone:
(09) 836-7107

**This issue has been
sponsored by Jack
McCleary, Caregiver
of a liver recipient.**

**Next issue is due
mid-June 2002 - if
there is a new
Editor!**

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This issue is dedicated to the memory of Noelle, a woman of inspirational courage, endurance and tenacity, who, after two liver transplants, finally succumbed to illness and died on the 31st December 2001.

29th Oct 1951 - 31st Dec 2001

I hope you have all had a great Christmas and New Year, and that your New Year's resolutions remain unbroken! I wish you all health and happiness. I would like to apologise for the lack of a "Hepatic Happenings" newsletter towards the end of 2001. This was owing to the pressures of full-time work (which I have been in since the 13th August 2001). I am not able to continue doing this newsletter in the long term when working full-time, so if there is a volunteer to take over, or offer assistance, I would love to hear from you!

This would best suit someone who is working part-time. It can be done from outside of Auckland, as any attendee at recipients' meetings can post or e-mail the report to you. I can make available the postal list and e-mail list to a new Editor.

I look forward to hearing from someone soon!

Celebrating liver transplant anniversaries from September 2001 to February 2002 are:

- (1) Carmen S, September. 1 year.
- (2) Brian E, September. 2 years.
- (3) Susan R, September. 5 years.
- (4) Pam R, October. 2 years.
- (5) Michael S, November. 1 year.
- (6) Marion B, November, 2 years.
- (7) Valerie K, November. 2 years.
- (8) Frank G, November. 2 years.
- (9) Lynda B, December. 2 years.
- (10) Graeme R, December. 1 year.
- (11) Robert L, January. 3 years.
- (12) Grant G, January. 2 years.
- (13) Paul H, January. 2 years.
- (14) Maureen F, January. 1 year.
- (15) Robert I, January. 2 years.
- (16) Ronette D, February. 4 years.
- (17) Richard M, April. 4 years.

Congratulations everyone!

Reminder: If you want details on the *Hepatitis C Resource Centre*, call their toll-free number 0800-22HEPC (0800-224-372).

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Liver Transplant Group:

Meeting in 7B's Patient Lounge on Wednesday 5th September 2001

Eleven liver transplant recipients and caregivers attended this meeting, facilitated by Ron Benjamin with the assistance of Val.

Recipients and caregivers shared news of their current situations and condition, with some incidental discussion. Once again, the importance of networking was brought up, with reference to not only current recipients and their caregivers but prospective ones as well. Once again, the importance of a list of contacts arose, in order to facilitate such networking.

Mention was made of caregivers having begun a Resource Pack to assist the Liver Team and social worker in smoothing the arrival of prospective recipients and caregivers. At this stage it is chiefly for discussion and development. Details will soon be forwarded to those concerned.

Notes taken by John R.

Notes were taken with the permission of all attendees at this meeting, on the basis that what was reported would not identify speakers, and would concentrate on general themes.

Meeting in 7B's Patient Lounge on Wednesday 19th September 2001

The meeting was facilitated by Ron Benjamin, and was attended by Dawn and eight liver transplant recipients and caregivers. The meeting began as usual with a round of the group, each person relating their current state of health and progress. A main point that was raised was our vulnerability to damage to the abdomen by impact including such wide-ranging risks as fall injuries from horse-riding or water skiing and kick injury from milking cows. The greatest risk is from damage to delicately sutured tissues such as bile ducts and blood vessels.

The initial draft of the Transplant Group's **Resource List** was introduced. This was drawn up by transplant recipients, their caregivers and others, to provide vital information for prospective recipients and caregivers. A wide range is covered, from 24-hour food sources to WINZ benefit requirements.

The following items arose from discussion:

- ◆ Local accommodation options - for those who arrive on short notice.
- ◆ Link Bus tickets last the whole circuit, for the day of purchase.
- ◆ Queen Street's Information Centre by the Civic Theatre is a good resource for all caregivers and family.
- ◆ Telecom's 0800 number 'ring home' arrangement is the best arrangement for out-of-towners.
- ◆ A Community Services Card is very worthwhile if you are eligible. See your GP.
- ◆ The Peoples Centre contact details should have been on the list.
- ◆ If your house will be unoccupied, see your phone and power companies about reduced charges.
- ◆ Auckland Library requires out-of-towners to show them a letter addressed to you at your Auckland address, otherwise costs will be \$60.
- ◆ A good local trip is the Fullers ferry to Devonport. Leaves the Ferry Building, water's edge at the very end of Queen Street.
- ◆ The Maritime Museum is free. Quay Street at the Americas Cup Village entrance.
- ◆ Caregivers of local liver transplant recipients are a valuable resource for

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**Liver Transplant
Group**
continued

- understanding company and local trip possibilities.
- ◆ Add contact phone/fax numbers of key recipient group members to the list.
- ◆ The Resource List may also be handy for someone else out of town.

Notes taken by John R.

Notes were taken with the permission of all attendees at this meeting, on the basis that what was reported would not identify speakers, and would concentrate on general themes.

Meeting in 7B's Patient Lounge on Wednesday 3rd October 2001

This meeting was attended by five liver transplant recipients and caregivers and facilitated by Ron Benjamin. After a brief circuit of catching up with each others' health and progress, the attendees spent the rest of the time looking around the group's website, <http://www.livers.org.nz>, not directly from the internet but from a duplicate stored on a transplant recipient's computer brought along for the session.

An item that came up in the early discussion was common agreement between the two recipients on the problems of periods of low energy when little is done other than rest and basic activities, interspersed with periods of normality when energy levels return with an urge to take action and do things that would not otherwise be contemplated. There was also mutual agreement that liver biopsies were not a fun thing.

Notes taken by John R.

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Meeting in 7B's Patient Lounge on Wednesday 7th November 2001

Ron Benjamin was absent, attending a "Liver Transplant Social Work" conference in Chicago, so this meeting was facilitated by Carol Blair, another Social Worker. There were 8 attendees as well as Val, the Liver Transplant Co-ordinator. The big news was that the Liver Unit has now done 102 liver transplants!

A chatty meeting with much involved participation, including caregivers. After an initial round of "who we are and where we are at", discussion developed into relating pre-op and post-op events, some of which were fairly gruesome. Talk moved on to financial problems associated with the transplant situation. It was good news for some to hear that there is Harold who assists with transplant families and helps set up benefits.

The helpfulness of the Hepatic Happenings newsletter was discussed. Mention was made that recent transplants have some access to back copies, or access to some copies, via the Liver Team. Summer is more or less upon us. Dawn mentioned a few meetings ago that our main risk from skin cancer involves ears and LIPS. Also that it is better to sunblock AND cover up, including brimmed hats, than to just sunblock.

Notes taken by John R.

Notes were taken with the permission of all attendees at this meeting, on the basis that what was reported would not identify speakers, and would concentrate on general themes.

Meeting in 7D's Patient Lounge on Wednesday 20th March 2002

This meeting was facilitated by Ron, with the assistance of Val, and was attended by 20 liver transplant recipients, caregivers, or those awaiting transplantation. It was an education session taken by Dr. Ed Gane on Liver Disease in New Zealand and Indications for Transplant, and what to expect after transplant - long-term.

The New Zealand Liver Transplant Unit is now over 4 years old. 115 transplants have now been done in Auckland.

What causes Liver Disease in New Zealand?

What causes people to be listed for transplant?

- (1) Elective Liver Transplant is for those patients with chronic conditions, which have developed over time. (The audience for this talk all had Elective Liver Transplants).
- (2) Acute Liver Failure - you would be in DCCM, and have only a couple of days to live. The most common cause of this is Hepatitis B and non-A non-B Hepatitis.

A pie chart was displayed which showed the main causes for chronic liver transplant in New Zealand.

- Hepatitis B - 40%
- Hepatitis C - just under 20%
- Auto-immune Hepatitis - around 5%
- Primary Sclerosing Cholangitis - 10%
- Wilson's Disease - not much at all - but your Editor's reason!
- Cryptogenic - 10%
- Alcohol - 10% (less in New Zealand than around the world).
- Budd Chiari - not much at all.
- Tumours -
- Primary Biliary Cirrhosi - 5%

In Europe and Australia most transplants now are for Hepatitis C. In the Asia/Pacific region most transplants are for Hepatitis B. Hepatitis B is caused by a virus, and will be eradicated within 20-30 years.

Cirrhosis

When you developed Cirrhosis (for the majority of transplantees who did), you probably noticed increased tiredness, listlessness, and you would have found it difficult to do a full day's work. You probably also developed jaundice. Liver cancer usually develops in Cirrhosis, but occasionally occurs in livers without cirrhosis.

What happened in New Zealand before the New Zealand Liver Transplant Unit was formed?

The first New Zealand transplant was in 1986, and the patient was transplanted in the United Kingdom. After that, transplant recipients (133 in all) were more frequently done in Australia than in the United Kingdom, until our own New Zealand unit opened.

A graph was shown titled: ***Annual number of New Zealanders over 14 years old who have been assessed for and undergone liver transplantation***

(performed at the NZLTU since 1998).

Between 1986 and 1992 less than ten people were transplanted each year.

1993 = 10
1994 = less than 10
1995 = 10
1996 = 11
1997 = 13
1998 = 13
1999 = 26
2000 = 33
2001 = 36

In 2002 the New Zealand Liver Transplant Unit has a contract to transplant 39 adults. The New Zealand Liver Transplant Unit is the second largest unit in Australasia. Sydney's unit is slightly bigger. Dr Gane trained for 5 years at the Kings unit in the United Kingdom, where they do just under 200 transplants per year.

Children can now be transplanted at the Starship hospital. Before now, all the children were sent to Brisbane for transplant.

Hepatitis B does not re-occur. 38 people have been transplanted with Hepatitis B with no recurrence. Hepatitis C always comes back. There is no vaccine against it. Researchers are now aiming to prevent it coming back and want to be able to treat it with new treatments (rather than transplants).

A big advance for Hepatitis C is the research into protease inhibitors - tablets. These are still a couple of years away, but will make the situation safer for Hepatitis C transplantees. Currently those with Hepatitis C have to have injections for 1 year post-transplant.

The New Zealand Liver Transplant Unit works closely with the Australian units. There was a question from the audience whether New Zealand shared livers with Australia. We don't share the livers unless we have to. The New Zealand donor rate is reasonable, and it is an adequate rate for Cirrhosis and liver cancer but not for acute liver failure. For example, if there is someone in Australasia with acute liver failure and only a couple of days to live, livers are shared, and this works both ways. This patient goes to the top of the list in all the clinics, and it means for us that our pool of 4 million potential donors is expanded to 27 million potential donors. New Zealand also offers a liver from a blood group where there is no one in New Zealand currently waiting for a transplant in that group. It works as a round-robin situation. Specialists from the Australasian liver units meet every couple of months. In America there is the UNOS (United Network of Organ Sharing), which achieves a similar result.

New Zealand liver transplant recipients come from Bluff to Kaitia with highest numbers from Auckland, Bay of Plenty, Hawkes Bay, Wellington and Southland.

What the New Zealand Liver Transplant Unit expect after Transplant

People who, when on the waiting list, were very sick (with severe liver failure), will notice a bigger more rapid improvement than those on the waiting list who were relatively well.

At transplantation:

You are usually off work, dependent on your family and the hospital, malnourished, and weak. Your thinking may be fuzzy - you can no longer sleep well at night.

After the transplant:

You are on many drugs, which will affect you. Drugs such as Prednisone can make you high, depressed or produce mania (Editor. I'm sure I had all three!). Tacrolimus and Cyclosporin can produce a whole range of feelings and mood effects. It can take 6-12 weeks for this to improve. Lots of research has been done on Quality of Life post-transplant. Most people would regain close to near normal health by 6-12 months. As Cirrhosis causes severe Protein Caloric malnutrition (like the Sudanese children with Kwasiorkor) it takes time to return to a state of normal nutrition. People with Cirrhosis lose muscle owing to malnutrition. However, as at the same time we typically have oedema (fluid retention), we do not appear as malnourished as we are. (Ed. I looked fat, until 15 litres of fluid was Frusomided away!!). Protein muscle takes more than one year to come back. Normal nutrition doesn't come back until at least one year post- transplant.

We were told that immediately after the liver transplant operation we put on several kilos of water, as anaesthetists have to pump in lots of water to keep our blood pressure stable.

Around the world, obesity after transplantation is a problem with liver transplant recipients. Pre-transplant we have a high metabolism and we lose protein very rapidly. We generally have protein supplement drinks such as Ensure Plus to supplement our diets. As we recover after our transplants, we have a scaled down metabolism. Obesity can become a real problem after transplant. We may also notice changes in our reaction to temperature, as when we were malnourished, we would generally have felt the cold more.

How soon should we start to feel well and resume our normal occupation and activities at home?

It is advised that we shouldn't return to full-time work until six-twelve months post-transplant in general. This also depends on individual circumstances, such as how sick were you before and after, and any complications. Many feel well enough at three months post-transplant, some take a lot longer. It is important to return to work from a therapeutic angle - a resumption of normal life, as well as for financial reasons.

Quality of Life

It is expected that your quality of life will improve post-transplant. What is meant by Quality of Life? Psychologists have objective measures and do "fill in the box" surveys. These look at mood, strength, relationships with other people etc. Surveys are divided into the physical domain and mental functioning, and there is a complicated scoring system. One commonly used is the SF36. Dr. Gane has access to materials such as the Quality of Life study done in North America by the *Liver Transplantation Journal*. Categories include General, Daily Activities, Sexual Functioning, Physical Health, Social Functioning and Psychological Health. The study suggests that there is overall improvement but not universal, not 100% improvement.

Most people who are very ill before transplant should notice improvement in strength and mood post-transplant. This is a gradual improvement over time. For example, at one week there would be no improvement, at six months you should

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continued

show marked improvements, and after one year you should have definite improvements. Employment is only a crude indicator of the quality of the recipient's life. About 2/3rds of recipients return to their previous occupation and about 1/3rd do not. Duration of life and quality of life are both improved. However it is not possible to answer the question as to the expected length of life. Transplant operations are now more refined and sophisticated than in the past, and the drugs are better, so life expectancy is longer. There are patients who were transplanted 25 years ago who are still alive today. Quality of life is a subjective experience. Huge improvements have been made in the last decade with liver transplantation. In the earlier days of transplantation, the recipients were required to stay on many immune-suppression drugs for their lifetimes, whereas now it is just one drug. The two main immuno-suppressants used are Cyclosporin and Tacrolimus. Sirolimus is the newest immuno-suppression agent, if Cyclosporin and Tacrolimus do not appear to be working - Sirolimus is added.

Liver transplant researchers are actively working towards the 'Holy Grail' of transplantation - "tolerance", when the body accepts the new liver with no need for immunosuppression. There are ways to try and develop tolerance, but at the moment this is possible in only a small number of people. At ten years post-transplant the researchers have tried to work out who the few people are who are tolerant naturally after this time period. Scientists are developing ways in the labs to develop tolerance and fool the immune system. Sir Roy Calne visited the New Zealand Liver Transplant Unit recently. He was in New Zealand at the request of Dr Bob Elliot, doing Diabetes research. Sir Roy is well known for having started the first European Liver Transplant Programme in 1968. [Editor: his work is mentioned at http://www.novartis-transplant.com/medpro/symposia/milestones_in_TX.html - in Milestones in Transplantation (according to drug company Novartis)]. Sir Roy did the second Liver Transplant in the world, in Cambridge, in 1964. He has always had an interest in developing tolerance. Tolerance is a huge field of research at the moment. It is possibly attainable within a decade or so. The Kupfer cells in the liver from the recipient replace the Donor Kupfer cells shortly after the transplant has occurred. Kupfer cells get rid of the antibody cells in the liver. The liver is called a 'privileged organ'.

[Editor: the audience was very grateful to Dr Gane for this presentation, and it would be great if this was an annual event!]

Notes taken by Bethli W and checked and amended by Dr. Gane.

Quality of Life Before and After Heart, Lung and Liver Transplant: Results Summary

Sarah Beilby, Dr. Rona Moss-Morris & Liz Painter.

Those of us who contributed towards a research study last year should now have received a [Results Summary](#) in the mail. Results included:

"...this study found that post-transplant patients reported superior physical well-being compared with pre-transplant patients. Psychological well-being was also better in post-transplant patients, although there did not appear to be much difference in social functioning before and after transplantation. No differences in quality of life were found between the heart, lung and liver transplant groups in either the pre- or post-transplant samples. Post-transplant patients were found to report poorer physical well-being, general health and social functioning when compared with the New Zealand general population. Of particular interest however, is the finding that post-transplant patients reported higher vitality and mental health scores than the New Zealand general population."

Further information from the Faculty of Medical and Health Sciences, University of Auckland. Phone (09) 373-7599.

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Diary

An article about the 1st Liver Transplant recipient in Melbourne, Australia.

Big Louis IS DEAD. I found out only yesterday, because the last time I went to the Clinic I didn't meet any of the people who might have told me, which can happen when you're down to three-monthly visits. He might have died as long as five months ago. It's odd to discover you have been orphaned for months without knowing it. Louis was the first person to receive a liver transplant at the Unit when it started at the Austin Hospital here in Melbourne in 1988. Units were already working in Brisbane and Adelaide, but he was our first. They'd tried transplanting livers long before that, but everybody used to die, so they gave up for a while, but in the early 1980s they began again. What had changed the odds were better operating techniques and yet another miracle drug, this one called Cyclosporin. Cyclosporin controlled rejection without damaging the patient too much. It came into use only in 1989, so Louis must have survived his first few months without it. The Unit must have been proud of him.

So Louis was Number One. The last one, operated on about a week ago, is Number 301. I am Number 108, from April 1994. We write our history in the old-fashioned way here: dates and numbers matter in this long, thin, accidental family I have joined. We care about lines of descent, too, so Louis was our grandfather. He was a big, slowmoving Frenchman or Belgian in his late sixties who couldn't or wouldn't speak English. He would sit peaceably in the waiting room on his too-small chair, one large hand on each knee, and exude the mild benignity of an elephant, or perhaps a bishop. It was good to see him slowly moving up the corridor ahead or lying back in the padded chair for the routine blood test.

The family has no politics or class, and prior relationships are erased on entry. Because humans happen to be endowed with two kidneys and only one is necessary for life, a friend or kinsman might surrender the other to a specified donee, as Kerry Packer's helicopter pilot recently did to his employer in a blare of ambiguous publicity, but even our richest man couldn't buy himself a liver. 'Living cadaver' transplants, as they're called - liver, heart, lungs - are done democratically, in designated public hospitals, with public patients queued according to need. We are nonetheless selective; there are no honorary members. The only way into the family is through the operation. People on the waiting list aren't supposed to meet us post-transplant people except for the one selected by the Unit to be their counsellor or 'next friend'. This segregation might be no more than a way of ordering the doctors' time between re and post-transplant duties, but I suspect it is also policy. People on the waiting list panic easily. They need to know some things, but not others, and they haven't learned to trust the medicos, who naturally want to control the information flow so that no one gets muddled or demoralised.

We sometimes meet, however. Before my transplant I was waiting by the Unit's lift, shaking, yellow, cradling my distended belly in my arms (with advanced liver disease the abdomen swells grotesquely), when a slender Indian woman standing in the corridor was suddenly beside me, holding my shaking hand in her steady warm ones and saying, 'You'll be all right. I promise you, you will be all right. It is only three months for me and look, already so well! And today I am off to Sydney to be with my husband! They are letting me go to Sydney!' The lift doors opened, she pulled my head down and kissed me firmly on the forehead, pushed me inside, and I saw her blessing me through the closing crack as I slid through the floor.

Months later, after my own transplant, I felt a similar surge of affection for a yellow, wasted man trying to cradle his swollen belly in exactly the same place: the little hall by the lift outside the Liver Transplant Unit's offices. I shared her impulse but lacked her courage. I didn't speak. Guilt lived with me until I came

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across the man in the surgical ward after his transplant, transformed back to his original form: a small, tough Scot with a spiky ginger moustache, cheerfully remembering 'the little Asian-looking fella' he had once been.

A handful of pre-transplant people are terrified or suspicious or downright paranoid about the whole business, which can easily seem surreal, and then someone who has been through it is allocated to calm them. One woman I was sent to see sat huddled in a blanket in her hospital bed, persuaded that the doctors had not the least concern for her welfare and were intent on experimenting on her body. Another woman, startlingly beautiful even in her flattened state, was incandescent with rage at the unseemly eruption of the physical melodrama which had plucked her from the world and sequestered her in a tiny blue-curtained tent (she kept her bed curtains furiously drawn). She had festooned the tent with what looked to be hundreds of cards, communiques from her lost life. She finally acquiesced, I think largely because I described the process of the alternative, death. Then she died anyway.

Most people on the waiting list die. Australia has a very low donor rate, one of the lowest in the world, which used to surprise me. I thought a bunch of secular humanist hedonists like us would be easy givers, and suspected that the influx of migrant families with strong religious backgrounds explained the low rate. That seems not to be the case: provided the correct rituals are followed (naked candles in intensive care if required), those families tend to be generous. Perhaps the hedonism is the problem. Perhaps we refuse to think about death because we believe it is the end, and there can be no previous discussion, with everyone being agreed they will live forever. Then families lurching under the impact of grief are asked to allow a loved one's body to be, as they think of it, pillaged. That is why the recent scandals in Britain about the unauthorised taking of organs for research distress me. They will make people even less ready to think about the simple realities, so even more people will die prematurely.

For the lucky few who enter the family the benefits are multiple. For example: the worst thing about being seriously ill is the loneliness. You know that nobody, not your doctor nor your husband nor your best friend, can imagine what it feels like, especially in its more trivial manifestations: how your left calf will clench and tremble for no reason, how dread comes sliding smoothly out from behind the water jug. Your new family knows. They will say: 'It was my right leg used to do that, quiver like a mad thing. And in the small of your back, like a big vibrator buried in your spine, do you get that?' And you say, with relief, 'Yes I do,' and the loneliness is less lonely, and you also know there will be someone eager to listen when you need to talk about fluttering muscles, inexplicable tastes in the mouth, inexplicable tears. The doctors might give you a brisk explanation as to the why of it, but they can't help you find the words to describe how it feels.

In the Clinic I found again the radiantly chaotic social world I thought I had lost when I left primary school and began a lifetime of picking and choosing friends and associates. The studious egalitarianism of the Australian national health system serves up a marvellous mix of genders, ages, classes and ethnic origins. As it turns out my betters had told me but I never really learned the greatest of these is class. People I would never have met, never glanced at, never even seen in my ordinary life as a middle-class academic of Anglo ancestry were now sitting next to me for a couple or more hours at a time, waiting their turn. Gloria, for example. She would be up by 4.30 a.m. to come into Clinic from her distant outer suburb, where I had never been, its name no more than a sociological tag for deprivation and disorder. She didn't have to leave quite so early, but she dreaded being late and seeming less than grateful. She would get home again

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by mid-afternoon, to deal with her two small children and her superbly unco-operative husband. The drugs had happened to work in her to produce a soft flow of surplus flesh. Most of us had had our adventures with our protein bodies, but no one else billowed with flesh as she did. She had also become chronically breathless and uncertain of her balance, and now she was a diabetic, which sometimes happens. You can't fool with bodies without some unintended consequences. Gloria would sit with her pretty hands in her matron's lap and the face of a pretty girl lost somewhere in her wide one, and when she saw me she would direct a vague smile somewhere past my right shoulder and pat the seat she had been keeping beside her. As far as I could discover (she spoke little and softly) she was at once desperately shy, shamed by her shyness, and shamed by her flesh. She was also determined to be stoical, which is why she needed a friendly presence beside her. Some husbands and wives always came to the clinic with their spouses and acted as talking chiefs for them, thereby re-enacting a way of being married I had forgotten about, but Gloria had to get through everything alone.

Pat wasn't shy, just scary. He looked as if he had been rough-carved out of a chunk end of redgum; a long bristle of red hair ran right down the middle of his big bare skull; and his arms, and for all we knew all of him, were blue with tattoos, most of an embarrassingly intimate nature. No one was game to talk to him for a while, but I thought he could scarcely turn on a grey haired old granny, or not in the Unit's waiting room, and one day sat next to him. He had been, as he looked and in his own description, 'a very bad lad', deeply into illegal substances, violence, motorbikes and alcohol. Then at 28 he discovered he had ruined his liver and that he might well die soon and unpleasantly, and immediately after that some well-spoken strangers in white coats were ready to try to give him another chance, provided he mended his ways. So he did.

He gave up drink, drugs, even smoking, and now when he went to the pub to see his mates he drank lemon squash. He'd also sold his motorbike: if he wanted to go anywhere he walked or rode his push-bike or took a train. He lived in a suburb where train-travel was quite peaceful, provided you were built like a tree. He was translucently proud that his 13 year old son was building his first machine in the garage - he'd done the same when he was 13 - but he himself was through with them. Motorcycles were too dangerous, now that his body didn't belong exclusively to him. He had tried to throw his life away, and it had been given back to him. He would not throw it away again. What was most noticeable about Pat - what I privately thought rare and noble about him - was his refusal to moralise from his experience. He was utterly free from the middle class urge to preach. This had been his personal lesson, and he had learnt from it. He's still going well.

Most arguments against transplants make me angry, like those made by fastidious people who do not suffer from a terminal disease and who find the notion of brain death too complicated or the whole idea of transplantation of organs too aesthetically distasteful to be contemplated, while here we are in our various bodies, walking around enjoying ourselves. We are the argument for it. Of course, our situation is a touch precarious. Given the chronic shortage of donors, what being accepted onto the waiting list for a transplant most feels like is being snatched out of a turbulent river and hoisted up onto a rickety suspension bridge. You know you would surely have died in the water, but you still don't feel too safe. But soon the people ahead of you on the bridge are turning to hug you, cheering you on, and telling you the quivering and rocking is normal, the vertigo is normal, everything is normal and you will be, indeed you already are, fine. Over the next few weeks or months you meet more of your new

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continued

family, and sooner or later they'll point to a slow-moving shape up ahead, and say: 'that's Louis. He's Number One.' And now Louis is gone and we turn and clutch each other, because without his weight the bridge is trembling.

Inga Clendinnen

Originally published in the London Review of Books, 19 July 2001.

Helpful Hints

Antiseptic gargle - Betadine

Sometimes you will find that you are getting a sore throat. One treatment, maybe two, of Betadine should be enough to stop a sore throat in its tracks. Its effect is dramatic, though less so when we are aware that it is a variation on the iodine which is painted over skin before operations. Find it at any chemists. You can get an equally effective iodine antiseptic cream made by the same people, for minor infections which, for us, can be more serious than we may realise.

E-mailed in from a Liver Recipient to share - Source Unknown

Imagine there is a bank that credits your account each morning with \$86,400. It carries over no balance from day to day. Every evening it deletes whatever part of the balance you failed to use during the day. What would you do? Draw out every cent of course!!!

Each of us has such a bank. Its name is TIME. Every morning it credits you with 86,400 seconds. Every night it writes off as lost, whatever of this you have failed to invest to good purpose. It carries over no balance.

Each day it opens a new account for you. Each night it burns the remains of the day. If you fail to use the day's deposits, the loss is yours. There is no going back. There is no drawing against "tomorrow". You must live in the present on today's deposit. Invest it so as to get from it the utmost in health, happiness and success! The clock is running. Make the most of today.

- To realise the value of ONE YEAR, ask a student who failed a grade.
- To realise the value of ONE MONTH, ask the mother who gave birth to a premature baby.
- To realise the value of ONE WEEK, ask the editor of a weekly newspaper.
- To realise the value of ONE DAY, ask the daily wage labourer with kids to feed.
- To realise the value of ONE HOUR, ask the lovers who are waiting to meet.
- To realise the value of ONE MINUTE, ask a person who missed the train.
- To realise the value of ONE SECOND, ask a person who just avoided an accident.
- To realise the value of ONE MILLI-SECOND, ask the person who won a silver medal in the Olympics.

Treasure every moment that you have, and remember that time waits for no one.

Yesterday is history.

Tomorrow is a mystery.

Today is a gift ... that's why it's called the PRESENT!!!

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Recent Research:

Liver resections in Auckland 1998-2001: mortality, morbidity and blood product use, by John McCall, Jonathan Koea, Kerry Gunn, Michael Rodgers and John Jarvis. *The New Zealand Medical Journal*, Volume 114 No 1144, 23 November 2001, pages 516-519.

This article reviews the recent liver resections done at Auckland Hospital from January 1998 to May 2001. Liver resection is used to treat problems such as colorectal liver metastases.

Thanksgiving Services 2002

There will be two services of Thanksgiving this year. These will be in Auckland and Wellington.

Auckland: Sunday April 21st, at 11:30 am.

Holy Trinity Cathedral, Parnell. Lunch follows - RSVP's required.

Wellington: Sunday June 9th, at 12 midday.

Saint Peter's Church, corner of Willis and Ghuznee Streets, Wellington. Lunch follows - RSVP's required.

If you have not been to one of these services before, they are very moving occasions when we get to hear stories from Donor families and recipients (of all organs), and light a candle in memory of our own Donor and their family.

Noelle's Funeral Service, Christchurch.

It was a sad morning 6th January 2002 attending Noelle's funeral in Christchurch. The funeral service was a very moving and refreshing one. You came away with a truly peaceful feeling. There wasn't a minister, as the family all gave a wonderful insight into the memories that they would hold dear to them about the wonderful person that Noelle was for each of them. It was then opened for friends and colleagues of Noelle's to come forward and give their own memories. There were photos of Noelle around the chapel and a board with photos from early childhood to represent her life-time.

For those of us who had the pleasure of meeting and becoming a friend of Noelle's in the time that she was in Auckland. We know what a wonderful warm and kind person she was and the strength and courage she showed through this time when needing to have two Liver transplants and the complications that followed for her.

The feeling of Noelle's love, strength and courage for life came through with each new memory given at the service. The family praised and thanked the dedication and friendships from the Liver team and nursing staff to the new friends that came into Noelle's and their lives in this troubled time.

Karen and Murray, Christchurch.

Gossip:

- Dawn Keenan has replaced Ralph as one of the two National Transplant Donor Co-ordinators.
- Margaret Johnston is Dawn's replacement. Margaret has previously been the Clinical Nurse Specialist for liver transplants, working on Ward 7B.
- We now have two Registrars - Dr John Perry and Dr Shiraz Hassen. Dr Davis Orr, last year's Registrar, has moved over to Middlemore.

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Feedback from the Website -
<http://www.livers.org.nz>

One of the liver transplant recipients who has her story on the website, has been receiving e-mails from around the world, from others who have also had liver transplants. She has forwarded them to us for sharing. You may also wish to write and publish your story on our website, please feel free to do so, and forward (by e-mail or post) to the Editor, contact details on page 1 of this newsletter.

E-mail 1:

Hi You'all

I am writing from and small town in North Carolina. I am sitting here with a pager on my hip waiting for a call from the Veterans hospital in Virginia. My liver was badly damaged during that bad time in Vietnam. I have been looking for information and more so hope in getting through this bad time in my life. Its been a long road and you are the first person I have shared this with except my family. Your story has given me new hope. As you know this is a hard time, waiting and praying that you have a future. I am so glad to hear the words of hope and future in your words. I have been very worried about my future if I survive this procedure. I just wanted you to know your words have helped. If it's okay I will let you know how everything works out.

All the best

Ray A.

E-mail 2:

Dear ***

I just stumbled upon your story while looking for information on Wilson's Disease. I was curious to see how things have progressed in its treatment. You see, ten years ago this July, I received the liver of a 32 year old man due to my total liver failure from Wilson's. It is the inability of the body to use the copper it needs and excrete the remainder. I was only on "the list" 36 hours. I felt compelled to write when I read how you enjoy going to the gym! Since my transplant, I have completed college, been teaching 3rd grade for six years, and start most days with a 4-6 mile run and weights before school--at my local gym! I also run in 5 and 10K's about once a month, and a friend and I want to do a half marathon in August. I take 5mg Prograf and 4mg Prednisone, and Acyclovir and an occasional Bactrim as preventatives. I hope you continue to enjoy a healthy happy life with your new liver!

Sincerely,

Linda S.

E-mail 3:

Hello ***,

I just came across the New Zealand Liver Transplant Recipients' website and I read your story and found it very interesting and quite familiar. I am a middle-aged (55) man living in Stockholm, Sweden with my wife and four kids. I was liver-transplanted in September 1988 as about number 40 here in Sweden. So I'm a bit of a veteran. There has not been any real trouble during all these years. I am working full time as an engineer, and I have been travelling quite a bit. Mostly here in Europe but also to Kenya and Thailand. So, as you know, there is really very few things you can't do as a transplanted person.

Good luck and my very best regards

Arne

We have also recently received an e-mail from a New Zealand father of a six month old girl with liver disease, who is very keen to increase the donor rate of all organs in New Zealand. Below is part of his e-mail:

"...Anyway, to cut a long story short, I have emailed every MP in NZ and some of the top people in the health authority to try and promote, and get more organ

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Feedback from the Website -
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continued

donors (not just livers) I have enclosed a text version of what I have sent them just so that I don't duplicate everything in this e-mail. In a week or two I will then follow it up with letters to them all. After that I would like to send everyone of them a video. (I am a video technician so can do a few hundred copies) Do you have a recommendation of what would be best to send to them? I currently have "*Kill or Cure*" and "*The Right Decision*"....".

If you would like to contribute ideas, or assist him in his work, please contact him by e-mail at givelife@xtra.co.nz or contact the Editor, who has full contact details.

Here is the text of the letter...

Organ Donation in New Zealand

Dear Minister,

I am the father of a six month old daughter who will, due to liver disease need a liver transplant at some stage.

Whilst researching her condition I discovered that New Zealand has one of the worst organ donation rates in the civilised world. Only Poland and Greece are worse!

In an effort to save more lives and improve the quality of life of many more I have had meetings with the National Transplant Co-ordinators at Greenlane Hospital in Auckland, to 'think tank' ways around this problem. This applies to 'all' organs and not only the liver.

The funding and cost to improve the situation is minimal, as the system is already in place. I am not another 'charity' asking for money, I am asking for more... the gift of life.

Rather than go into a lot of detail, I will outline some facts and a possible solution. Though as a parent, and not knowing who, or how I should be going about 'changing the system' I hope you will be able to pass this onto the relevant persons, or, steer me in the right direction! I would make myself available for any discussions that you may wish me to attend on the subject.

First a few facts:

Last year New Zealand was 'given' 9 livers by Australia. We get these on a rotational basis AND ONLY if there are no suitable recipients available at the time in Australia, basically their rejects.

In the UK & USA you can get a free donor card that you carry in your wallet/purse indicating that you want to be a donor, this at least lets your family know your wishes. The only way to be a donor in NZ is to have it on your Drivers Licence. This excludes anyone under the age of 15 and non-drivers automatically.

If you do not add it to your drivers licence when first gained, then change your mind and want to add it later, you have to go through the whole procedure and cost of obtaining a new drivers licence. (How many people are liable to do that?)

Organs can only be kept for up to 12 hours from death. Consider that a liver transplant takes approx 7 hours (& transport from Australia....)

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Feedback from the Website -
<http://www.livers.org.nz>
continued

So why are we begging off other countries? Only 50% of NZ driving licence holders have agreed to organ donation (NZ has a rate of 10 donors per million of population) and out of those 10 only one would be a 'possible' suitable donor, 'if' his (her) family agreed to the donation (even if you are a registered donor, after you die, your family can (and do) override your wishes. Then of course there is the tissue matching etc. One organ donor can save the life, or improve the quality of life for up to 15 people. On major transplants, the success rate can be as good as 95% unfortunately 40% die whilst waiting for a suitable donor.

Solutions?

Only two that we decided were viable (if you have more suggestions please let me know!)

We introduce a donor card similar to the UK/USA system to COMPLIMENT the current Driving Licence System. These would be available at the counters of banks/post offices etc?

Arrange that people could go on the LTSA organ donation database by application, currently they can not do this unless they are a driver. The costs involved would be advertising/education of the scheme.

I would be grateful for your help and comments on the above, and hope we can move this forward. Please contact me for any comments at:

<snip>

Regards
Andy (givelife@xtra.co.nz)

14th April 2002: Andy writes:

"I have had a few more positive emails/calls from some MP's and now hope to try and get the press involved, again any suggestions that your readers may have please let me know at givelife@xtra.co.nz".

He has also sent a copy of a Press Release for us to publish in the Newsletter about why Spain is the best in the world at organ donation, compared with New Zealand at 10.6 donors per million of population.

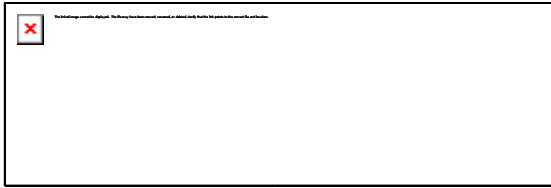
Barcelona Blanca Miranda, head of the National Transplant Organization (ONT), announced recently that the organ donation rate in Spain reached 31.5 donors per million in 1998, an 8% increase over 1997. Miranda said the next goal is to achieve 33 donors per million in 2000, along with a 15% increase in the rate of donations within the next 3 years.

The ONT was founded as a Ministry of Health-based group about 10 years ago by Rafael Matesanz, MD, who is currently general director of Spain's National Health Service and president of the Transplantation Commission of the European Council.

In 1997, Spain had 29 organ donors per million, double the average rate for other European countries and seven donors per million higher than the United States. Then, in 1998, for the first time, it surpassed 30 donors per million, a figure many experts had considered an impassable barrier. Today, the country leads the world in organ donations and stands in sharp contrast with other European countries, particularly the United Kingdom, where the decrease in organ donations has been a matter of concern.

Along with the increase in Spanish donations, the rate of family refusals for donation 30% in 1990 continues to decline. The figure is currently 18%, one of the world's lowest. The northern regions of Spain register the highest donation rates, with 44.2 donors per million in Cantabria, 43.1 in the Basque Country, 38.8 in Catalonia, and 38.5 in Navarra.

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Feedback from the Website -
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continued

In 1998, the rate of solid organ transplantations increased concomitantly. The overall rate went up by 9%, with extrarenal organ transplantation increasing most. Currently, 4000 people in Spain are waiting for kidneys and 300 are waiting for livers. About 115 need new hearts and 60 require new lungs.

CLUES TO SUCCESS

In Spain, any person is a potential donor if he or she has not previously expressed a contrary will. If the person has never talked about the issue, this is also interpreted as an implicit authorization for organ removal.

A large contribution to people's positive attitudes about organ donation in Spain is the popular image of the ONT, which is responsible not only for coordinating transplant services and providing guidance for health care professionals but also for providing information to the public and the media. Because both positive and negative messages may affect people's willingness to donate organs, the organization tries to minimize the impact of "bad news" and maximize the transmission of "good news" about transplantation.

Several strategies are followed in an attempt to harness the power of mass media and improve the general level of information about transplantation. According to ONT officials, possibly the most important group that needs to receive appropriate information are health care professionals themselves, in particular those responsible for identifying potential donors or approaching their grieving relatives. Most of these professionals are not directly involved in the transplantation process, but they are vital to obtaining the organs. Miranda and her ONT team believe the support of this group is so essential that rather than simply being the focus of communication strategies, like the public, they must be involved in developing these strategies. Such a strategy allows them to have full confidence in the content of the messages and be willing to pass them on to other health care workers and the public.

Because the ONT believes that information must be transmitted in a clear, concrete, fair, and trustworthy fashion, the group has always practiced a clear and coherent policy based on a 24-hour transplantation "hot line," continual availability to and easy access for journalists, and periodic meetings with communication experts aimed at educating the media and emphasizing the lifesaving aspects of transplantation.

NEW ROYAL DECREE

In recent months, the ONT, in collaboration with the Ministry of Health, Ministry of Justice, and others, has developed a new decree on organ donation and transplantation that notably updates the existing one of 1980. The new royal decree, which must be approved by the government within the next 3 months, includes substantial modifications, mainly involving legal concepts of brain death, removal of organs after sudden cardiorespiratory arrest, live-donor donation (of a kidney or part of a liver or pancreas), and confidentiality (no data will be given to recipients of organs from dead donors, and recipients and live donors must reach mutual agreement on the procedure).

Until now, organs could be removed only after certification of brain death and brain death had to be established by means of two electroencephalograms performed 6 hours apart. The new decree will make it possible to diagnose brain death by means of other more scientifically rigorous and objective tests, such as blood flow measurement tests.

But the most important innovation will be the inclusion as potential donors of people who die of sudden cardiorespiratory arrest or asystole (eg, those involved in road accidents). The General Council of the Judicial Power approved these innovations on March 9.

Officials of the ONT have recently criticized the increasing use of the media by relatives of prospective transplantation recipients who appeal directly to the public. Miranda said that these appeals are self-defeating, because they make it seem that the system is not effective, which in turn provokes anxiety among patients on waiting lists. Donors, she explained, do not appear sooner because of public appeals but because "there is a death, a donation, and an organization that makes donation possible."

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