

Hepatic Happenings

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Queen's Service Medal to liver transplant recipient Lorraine from Taumarunui, for services to the community. More in next issue! http://www.gg.govt.nz/honours/queensbirthday	

From the Editor...

The last issue of *Hepatic Happenings* was sent out in **April 2002** (Volume 3, Number 1) and I did not expect to produce any more. This new issue comes as a result of my January-February 2010 research tour of the South Island, interviewing liver transplant recipients about their transplant experiences. I was surprised to discover that old issues of *Hepatic Happenings* are still referred to, and that there appeared to be a demand for this newsletter to be re-started.

For those of you to whom this newsletter is new, I wrote/edited, printed and distributed seven issues between late 2000 and early 2002, which can still be viewed online at <http://www.livers.org.nz/Newsletter/Newsletter.htm>. I commented in my last issue that:

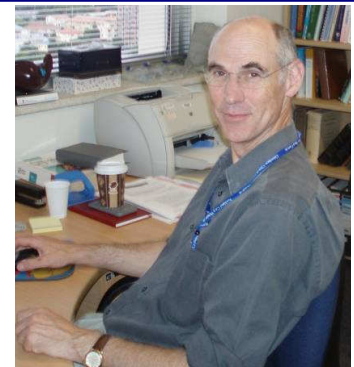
"I am not able to continue doing this newsletter in the long term when working full-time, so if there is a volunteer to take over, or offer assistance, I would love to hear from you!"

In the absence of volunteers, and with the assistance of Val Honeyman, I will attempt to produce two issues a year (June and December) if liver transplant recipients and their caregivers/families find it useful. Any feedback and **contributions are welcomed!** Regards

Bethli (recipient #62)

Farewell to liver transplant surgeon Dr. John McCall - off to Dunedin!

John McCall joined the Liver Transplant Unit as a transplant surgeon in 1998, after returning from the Kings College Liver Unit in London. Over the next 12 years John was an invaluable member of the team, introducing innovative procedures to increase donor liver availability. This included splitting adult donor livers to provide liver grafts for two recipients, both a child and an adult. John also led the live donor liver transplant programme, whereby a relative or friend donated a part of his or her liver to the recipient. Since 2002, 41 live donor transplants have been performed and



Auckland remains the only centre in Australasia which performs live donor liver transplantation. John also built up a large multidisciplinary Liver Cancer Clinic which now sees and manages almost all cases from around New Zealand – now over 120 cases per annum. Finally John has supervised a number of important research projects within the University and Hospital departments and has been successful with several HRC grants. John has decided to move to Dunedin with his wife Jenny, who has been appointed as Professor of Community of Medicine at the University of Otago. He has an academic appointment at the Medical School and will continue to be very active in clinical and basic research. Adam Bartlett, who has recently returned from two years training at the Kings College Liver Unit, has been appointed as the replacement liver transplant surgeon at the NZLTU. Adam also has a strong research background. For the meantime, John will continue to return to Auckland to help with live donor liver transplants.

By Dr. Ed Gane, Hepatologist, NZLTU

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Hepatic Happenings

Who's Who in the NZLTU

Stephen Munn	Clinical Director/Transplant Surgeon
Ed Gane	Hepatologist
Peter Johnstone	Transplant/Hepatobiliary Surgeon
Motohiko Yasutomi	Transplant Surgeon
David Orr	Hepatologist
Rachael Harry	Hepatologist
Adam Bartlett	Transplant/Hepatobiliary Surgeon
William Hecker	Transplant Surgeon
Margaret Johnson	Senior Transplant Co-ordinator
Val Honeyman	Transplant Co-ordinator
Barry Harrison	Transplant Co-ordinator
Karyn Lowe	Clinical Nurse Specialist
Ranjuka Ubayasiri	Transplant Surgical Fellow
New in June 2010	Liver Registrar
New in June 2010	Liver Registrar
Lucy Mills	Clinical Nurse Specialist
Katrina Ames	Charge Nurse Ward 71
Ron Benjamin	Social Worker
Cindy Penny	Social Worker

The **DECEMBER 2010 ISSUE** will profile new transplant surgeon **Dr. Adam Bartlett** and new part-time Social Worker **Cindy Penny**.

John McCall, Live Donor Surgeon
Bridget Faire, Shared Care Hepatitis Nurse
Faye Manu, Research Co-ordinator
Vicki Cochrane, Research Co-ord.
Carla Hooijkaas, Research Co-ord.
Bill Abbott, Research Scientist
Kathy Oliver, Team Administrator
Denny Wood, Team Admin (Mondays)
Rose Fernandes, Liver Scheduler
Andrea Pugh, Liver Referrals

By Kathy Oliver, Administrator, NZLTU

Liver Transplant Coordinators

Bethli invited us to write a few words about what a normal day/week entailed for the transplant co-ordinators. PHEW!!! would be the best description of an average day.

Every day starts with the paper round at 08.00 – when the current inpatients are discussed and any outpatient concerns. The transplant co-ordinator who is on-call will also attend the ward round with the team.

Alexander Graham Bell has a lot to answer for as a usual day sees lots of phone calls for the co-ordinators – whether its calls to or from patients, booking appointments, notifying staff of admissions, etc.

There may be patients to see either on the ward (post transplant education) or patients to review in the liver unit. Wednesday is clinic day – a busy day for everybody – we love catching up with all the patients that we haven't seen for a while – great to see everybody looking well.

Friday is the busiest day of the week with Selection Conference in the morning and patients to see in the afternoon. The waiting list is also compiled and distributed on a Friday afternoon – Barry manfully attends to that duty.

Most weeks there are new patients being assessed and we try to ensure that the week flows smoothly for them.

At any given time of the day there can be a donor referral. A busy time for the whole team – but the best part of the transplant co-ordinators job – the phone call informing the recipient that the wait is over.

Although there is a structured start to each day with the ward round, no two days are ever the same – you never really know how the day will unfold – the unpredictability of the job is what probably appeals to our quirky natures!

By Val Honeyman, Liver Transplant Co-ordinator, NZLTU

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Hepatic Happenings

Anniversaries - January – June, 2010

Celebrating 10 years post-transplant are...

1. Paul H, January
2. Bob I, January
3. Grant G, January
4. Basil A, February
5. Nadia E, February
6. Murray W, May
7. Oliver P, May



*Congratulations
everyone!*



By the end of May 2010, the New Zealand Liver Transplant Unit has already undertaken 26 liver transplants for the year, and three of these were living donor liver transplants. They are very busy!

Questions and Answers

Question: From the caregiver of a liver transplant recipient

How do doctors approach New Zealand families to ask them to donate the organs of their deceased loved ones?

Answer: From Dr. Stephen Streat, Specialist, Critical Care Medicine and Clinical Director, Organ Donation New Zealand.

Doctors in New Zealand do not 'ask (families) to donate the organs of their deceased loved ones' – they 'discuss organ donation with families'. This discussion involves the family, an intensive care doctor and an intensive care nurse. It is not a 'request for organs'. The role of the doctor is to ensure that every family is given the opportunity to donate organs and tissues in circumstances where this is possible, that families have all the information that they need and that they are supported in making the decision which is right for them. This is considered best practice in New Zealand and Australia (see websites below). Organ donation is not 'required' or 'expected' or 'always the right choice for everyone'. The content of the discussion is varied and wide-ranging, reflecting the differing concerns of each family. In New Zealand in 2009, 69% of families who had organ donation discussed with them agreed to donate, notably more than the 49% of New Zealand drivers who answer 'yes' in response to the question 'Would you be willing to donate organs in the event of your death?'

- 1) <http://www.clinicalguidelines.gov.au/browse.php?treePath=&pageType=2&fldglrID=1313&>
- 2) http://www.anzics.com.au/downloads/doc_download/128-the-anzics-statement-on-death-and-organ-donation-third-edition
- 3) <http://www.adapt.asn.au/>

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Recent research on liver transplantation

As you can read from the list below, the specialists in the **New Zealand Liver Transplant Unit** are still doing research and publishing their results in a range of medical journals around the world. This is a small selection of their output between 2005 and 2009.

Bartlett, A. S. J. R., **McCall, J. L.**, Koea, J. B., Holden, A., Yeong, M.-L., Gurusinghe, N., et al. (2007). **Liver resection for hepatocellular carcinoma in a hepatitis B endemic area.** *World Journal Of Surgery*, 31(9), 1775-1781.

Gane, E. (2005). **Liver transplantation in chronic hepatitis B.** *The Medical Journal Of Malaysia*, 60 Suppl B, 88-89.

Gane, E. J. (2008). **The natural history of recurrent hepatitis C and what influences this.** *Liver Transplantation: Official Publication Of The American Association For The Study Of Liver Diseases And The International Liver Transplantation Society*, 14 Suppl 2, S36-S44.

Marui, Y., **McCall, J.**, **Gane, E.**, Holden, A., Duncan, D., Yeong, M.-L., et al. (2005). **Liver transplantation for hepatocellular carcinoma in New Zealand: a prospective intent-to-treat analysis.** *The New Zealand Medical Journal*, 118(1217), U1532-U1532.

Wilde, J., Chin, S., Johnston, P., **McCall, J.**, **Munn, S.**, Nixon, C., et al. (2007). **Paediatric liver transplantation in New Zealand: the first 5 years.** *The New Zealand Medical Journal*, 120(1260), U2679-U2679.

If you want to read one of these articles (above) you should be able to request this as an inter-library loan from your local public library. They should be able to source an abstract from *Medline* for you at no charge. If you have access to the internet, you can also look at the **New Zealand Medical Journal** online at <http://www.nzma.org.nz/journal/> (website address accurate at 23 March 2010). This website provides free access to the full-text of articles older than six months, and to all abstracts. You can also search (no charge) all issues from 2002 onwards. A recent example of an article by the Liver Transplant Unit from this journal is....

[Live donor liver transplantation in New Zealand: a report on the first 20 cases](#)

13 February 2009, Volume 122, Number 1289

["Authors](#)

John McCall, Margaret Johnston, Barry Harrison, Ian Dittmer, Ron Benjamin, Yvonne Fullerton, Andrew Holden, Kerry Gunn, Peter Johnston, Ed Gane, David Orr, Simon Chin, Helen Evans, Stephen Mouat, Stephen Munn.

[Abstract](#)

Background: Liver transplantation (LT) is established treatment for adults and children with acute or chronic liver failure, however there are insufficient donor organs to meet demand and 14% of New Zealand patients have died waiting or were de-listed due to deterioration whilst on the waiting list. Live donor liver transplantation (LDLT) offers an alternative graft source that enables timely transplantation, but also carries the risk of morbidity and mortality for the donor.

[Aim](#)

To report the initial experience with LDLT in New Zealand.

[Methods](#)

Review of donor and recipient outcomes for the first 20 cases.

[Results](#)

129 potential live liver donors were assessed for 68 recipients. Donors were evaluated according to a multi-step protocol including independent donor advocacy. Twenty LDLT were performed on 7 adults and 13 paediatric recipients using 5 right lobe, 2 extended left lobe, 2 left lobe, and 11 left lateral section grafts. Five donors (25%) experienced postoperative complications, none of which were life-threatening. Four recipients had acute liver failure and 16 had chronic liver disease including one retransplant. There was a high rate of recipient biliary complications (40%) but graft and recipient survival is 100% to date.

[Conclusion](#)

LDLT has been successfully introduced in New Zealand with good donor and recipient outcomes."

Retrieved from <http://www.nzma.org.nz/journal/abstract.php?id=3459> on 23 March 2010.

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Hepatic Happenings

Profiling...Dr. Michael J. Burt, Consultant Gastroenterologist, Christchurch Hospital

Dr. Michael Burt writes...

I don't really know why I decided to do medicine but apparently I chose this while at high school and I am pleased with having made that decision. I was born in Dunedin and did all my undergraduate study there. **Ed Gane** and John Wyeth were both in my medical class. I did not like the pre-clinical years as I felt a lot of it was nonsense with little relevance to the real world. At one stage I thought about leaving but did an additional research degree between my 3rd and 4th years and then really enjoyed my clinical training. When I qualified, I moved to Christchurch and have spent most of my working life at Christchurch Hospital.



Part of Christchurch hospital

<http://www.cdhb.govt.nz/cwh/images/cwhnightshot2005.jpg>
retrieved 23 March 2010.

I liked being a house surgeon as it was good to move between the different specialities and it was fun to work at small hospitals like Ashburton where, as the only doctor on duty, you had to be fairly resourceful and learn quickly.



Dr. Michael Burt

http://www.chmeds.ac.nz/departments/medicine/m_burt.htm retrieved 23 March 2010.

At one stage I planned to do surgery but found the physician type approach to medicine more to my liking. I was surprised to pass the FRACP Part I (specialist exam) at the first attempt and decided that gastroenterology seemed attractive. As soon as I started gastroenterology I developed my interest in liver disease which continues today.

I worked in Brisbane between 1993 and 1996 where I completed a PhD in the genetics of the iron loading disorder haemochromatosis. In 1996 I was appointed as consultant at Christchurch Hospital and have been there ever since. My clinical interests are broad and although I enjoy liver disease I also am a general gastroenterologist and do a lot of "luminal" work including endoscopy.

The most stimulating and exciting part of my work is helping to look after **liver transplant patients**. I have cared for approximately **20 transplant recipients** and it is rewarding getting to know them and their families so well and to see someone who is incredibly sick come back to be a fully functioning independent person.

Although I have an extensive research background including two research degrees and 50 published papers I decided to leave academic medicine some years ago as I did not like the mindless university bureaucracy. My main activities revolve around direct patient care and my goal is to continue to improve the gastroenterology service we offer in Christchurch through my administrative role as Clinical Director. I am also very involved and committed to the teaching of students and supervision of advanced trainees in gastroenterology.

Outside medicine I am a keen walker and trumper and relax in the weekends by walking in the hills with friends and no cell phones. My wife is a nurse who I met 33 years ago at high school (yes tragic or wonderful - you chose) and I have three children who tell me what to do. I have just turned 50 and celebrated by spending 3 weeks in the wilds of Western Tibet with three old school friends trekking around remote mountains at high altitude.

Interviewed by Murray and Karen (Recipient and Caregiver), Christchurch

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Hepatic Happenings

Memoirs and biographies by/about liver transplant recipients

These are books that the Editor has purchased (or been given) in the course of her research into the lived experience of liver transplantation in New Zealand. Most have been purchased from www.amazon.com or www.amazon.co.uk. Your local library should be able to access these for you through inter-library loan.

- Ahmed, M.** (1999). *Surviving liver diseases: Life with a liver transplant*. London: MegaZette.
- Anjoubault, A. C.** (1995). *Racing against time*. New York: Barclay House.
- Casey, R. P.** (1996). *Fighting for life: The story of a courageous pro-life democrat whose own brush with death made medical history*. Dallas: Word Publishing. (*Governor in the USA*)
- Chalmers, M.** (1995). *Extra time: A story of a liver transplant*. Ashburton: M. A. Chalmers. (*New Zealander*)
- Clendinnen, I.** (2000). *Tiger's eye: A memoir*. New York: Scribner.
- Darling, R. S.** (2006). *Coma life: Touch me. Talk to me. I'm here*. (4th ed.). [California?]: J&W Publications.
- Hagman, L., & Gold, T.** (2001). *Hello darlin': Tall (and absolutely true) tales about my life*. New York: Simon & Schuster. (*Yes, JR from Dallas*)
- Kavanagh, K. H.** (2002). *Neither here nor there: The story of a health professional's experience with getting care and needing caring*. In N. L. Diekelmann (Ed.), *First, do no harm: Power, oppression and violence in healthcare*. Madison: The University of Wisconsin Press.
- Klug, C., & Jackson, S.** (2004). *To the edge and back: My story from organ transplant survivor to Olympic snowboarder*. New York: Carroll and Graf Publishers.
- Kuhn, P.** (2008). *Will I live, will I die?* Florida: SeaStory Press. (*Memories from coma included*)
- Maier, F., & Maier, G.** (1991). *Sweet reprieve: One couple's journey to the frontiers of medicine*. New York: Crown Publishers. (*Newsweek Editor, deceased*)
- McCarty, B. C.** (2002). *Time shared: The miracle of transplant*. College Station: Virtualbookworm.com Publishing Inc. (*Author is on Facebook*)
- Murray, P. S.** (2007). *Hit the ground running! An insider's guide to surviving Hepatitis C, liver transplant and beyond*. Arden: When Pigs Fly Books.
- Parr, E., & Mize, J.** (2001). *Coping with an organ transplant: A practical guide to understanding, preparing for, and living with an organ transplant*. New York: Avery, a member of Penguin Putnam Inc.
- Yomtoob, P., Yomtoob, L., & Wepler, D.** (2005). *The gift of life 2: Surviving the waiting list and liver transplantation: The inspirational story of one man's triumph over terminal liver disease: A guide for transplant patients and their families*. Deerfield, Illinois: Rainbow International Press.

Book Review: Extra Time: A story of a liver transplant, by Margaret Chalmers (1995)

Margaret Chalmers is a woman born and brought up in mid-Canterbury, who trained as a primary school teacher at Dunedin Teachers' College, married, had three children, and at the age of nearly 30 was diagnosed with ulcerative colitis; later diagnoses included sclerosing cholangitis, cirrhosis and portal hypertension. Eventually her advanced liver disease with frequent bleeding from oesophageal varices (varicose veins in the gut) led to frequent stays in hospital. This book is the story of her liver transplant experience with the Brisbane Liver Transplant Service in 1989, nine years before the New Zealand Liver Transplant Unit commenced work.

Margaret portrays the reality of New Zealanders required to go overseas. Being a foreigner, when asked who is the Prime Minister (checking for the intellectual deterioration with end stage liver disease) and responding with the name of the New Zealand Prime Minister - not the Australian Prime Minister; being away from friends and family. She touches on the work her family and friends did to fundraise for the costs of the operation and care, only partly funded by the New Zealand Government. I was privileged to meet Margaret twenty-one years after her transplant, in Ashburton February 2010. She is looking wonderfully well, and is an inspiration.

This book was published privately by the author. Limited copies are available (at no charge) from myself.

By Bethli (recipient), Auckland.

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Traveling the world after a liver transplant

Since I had my transplant seven years ago (3/3/2003) I have been very lucky to have led a near normal life. I am very thankful to my Donor for having looked after their liver as I have had no illness relating to it. And of course thanks to the wonderful Team.

I have been fortunate to travel overseas at least seven times since transplant. My story is to reassure those who are waiting, or who have already had a liver transplant, that this is possible.

The most important thing is to have full Medical Insurance and be honest with them and tell them you have had a transplant. I have found only two insurance companies that would cover me.



Wendy and son in Disneyland, USA

One is **Mike Henry Travel**¹ and I have used them twice but just recently found them to be more expensive than the other that is offered by having a **Gold Visa Card**. I had to ring them to speak to their agent and it cost me \$100 to have the extra cover for anything that may happen relating to my transplant.

I also got a Letter from Dr. Ed Gane to say I was fit and well to travel and that I would be carrying medications – and if needs be they can be listed here. This obviously helps with going through Customs at all destinations or you may have to explain what the drugs are for.



Wendy and friend in Hong Kong

I have traveled to the USA, Cook Islands, South Africa and Australia and I've never had any issues. I wear a watch with New Zealand time as I leave home and take my medications on New Zealand time and then adjust as I reach my destination. So if it's morning and night that I take them here in New Zealand then I do the same in the country I am staying in. Or it gets too complicated trying to take them through the night etc.

Remember it is very important to carry your medications with you on the plane – luggage gets lost and you don't want to be without your meds!!

Common sense has prevailed when it comes to eating and drinking water. I never eat from street stalls or such eateries. I never drink tap water or from water jugs on tables. I'm very aware of the surroundings of any restaurant I go to. I can't eat shellfish as I've become allergic to that since I've had my transplant so I don't take risks around what foods I eat.

In all having had a transplant has never affected my desire to travel and I encourage all of you if you can, do so and relax and enjoy.



Wendy and friend, Table Mountain, Sth Africa

By Wendy (recipient), Auckland.

¹ Mike Henry Travel no longer insures any liver transplant patients - most recently some of the recipients have found http://www.healthandtravel.co.nz/health_Leisure_Travel.cfm a helpful website. Val, NZLTU, June 2010.

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Roxanne's story - one year post-transplant



"He aha te mea nui o te ao?

He tangata! He tangata! He tangata!

What is the most important thing in the world?

It is people! It is people! It is people!"

detected a tumour and I would be referred back to Gastroenterology at Greenlane Hospital. My doctor gave me the news and I was just devastated. It dawned on me that my lifestyle had caused my condition and I was solely the author of my own demise; anger, frustration and regret began to set in. I thought to myself if I can beat 8 years surviving in the sex industry, I'm sure I can beat this.

My support person and I attended my first appointment with the Liver Transplant unit with Dr Ed Gane, I was so nervous! And it felt like I was about to meet God himself! He was so good in explaining everything to me, I also met my transplant co-ordinator, you know when you think you've met an angel? Well that was Val, I count her as a dear friend. I had to go through a week of intense pre-transplant assessment and at the end of it, I was told I met the criteria for being placed on the waiting list, I was so relieved! I was diagnosed in August '08, placed on the list by September. While on the list I had the TACE procedure done, where they inject a form of chemotherapy beads into the liver via the artery in the groin. The procedure doesn't hurt, you are awake all the time and they administer a "calming drug" into you to relieve pain and anxiety, it's just absolute heaven! This is to ensure the tumour(s) don't grow while you're on the list otherwise surgery may not be an option.

My operation drew closer and I got the first call on Wednesday 5th March to come into the hospital at 4am, if you please! I was so afraid and filled with dread. "Was I going to come out alive?" I thought. We went to the hospital and you're admitted to ward 73, the nurses prepare you for the operation, the call came through that the donor liver was a no go, so we went home. The following Wednesday I got the call again. The donor liver was approved and I was wheeled into theatre crying! There were so many clinicians in the theatre, monitors equipment and such, the theatre looks like something out of Star Trek, truly impressive and you realise you are in good hands. Gas mask on and you're out like a light.

You wake up in DCCM (department of critical care medicine): my whanau were around me and it was so reassuring to see them, I wasn't dead! I spent the next 24 hours there and was cared for by a lovely nurse. Later I was transferred back to ward 73, in a private room of course! Nothing second class for this girl! The staff in the surgical wards are just marvellous to say the least and they know their stuff! I met four fellow liver transplant patients there and made friends with them and we went through Physiotherapy together, we had a commonality between us and you develop a friendship with them that is almost like family. I was discharged nine days later from ward 73 and sent home. I visit the liver clinic every three months now. It is very important you take your pills as directed by the Doctors! Don't miss them otherwise you could end up back in the hospital. People! Make sure you take a good moisturizer to the hospital otherwise you'll end up with snake skin luv! And drink heaps of water too. I'm now 1 year post transplant; I have a lot to be thankful for. I've had no complications thus far. I swore to my donor that I would not dishonour them; that was important to me as a Maori woman, that I should not return to my old ways. Each day I thank God for having mercy on me, allowing me to live a full life. I hope life and God is as kind to you as it/He was to me, when you're feeling down and alone don't be disheartened, there is always the light at the end of the tunnel and it feels good!

Arohanui, Roxanne xoxox

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