Vol.5 No.1 Newsletter December 2011

Hepatic Happenings

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ODNZ – the first port of call

ORGAN DONATION NEW ZEALAND (ODNZ) IS A NATIONAL SERVICE THAT WAS ESTABLISHED IN AUCKLAND IN 1987 WHEN HEART TRANSPLANTATION COMMENCED AT GREEN LANE HOSPITAL.

ODNZ's primary responsibility is to co-ordinate the donation of organs and tissues from deceased donors in New Zealand for transplant units in New Zealand (and sometimes Australia) and tissue banks in New Zealand. ODNZ also provides education for health professionals - the general public and transplant recipients often speak at these education sessions as their stories are inspiring and positive.

The team at ODNZ consists of three donor co-ordinators, two part-time medical specialists, a communications advisor and a team administrator.

A donor co-ordinator is available 24-hours a day to receive referrals of potential donors. Following a family's agreement to donation, the donor co-ordinator requests medical information about the donor and liaises with the transplant units and tissue banks.

The donor co-ordinator organises all aspects of organ or tissue retrieval.

Following the donation, the donor co-ordinator provides information and support for the family of the donor and, for some families, this support is continued for a number of years.

Janice Langlands, donor co-ordinator and team leader, says that what makes ODNZ special is being able to meet and have ongoing contact with the generous families who have donated in the midst of their own personal tragedies.

"There is so much variation in one day-providing support for families, providing education for health professionals and the public, dealing with media enquiries and building relationships; and working with large numbers of health professionals throughout New Zealand and Australia," says Janice.

"Working for ODNZ isn't just a job – you have the opportunity to make a difference to a family at one of the worst possible times in their lives. We are also able to assist health professionals with a process which always occurs in extremely sad circumstances."

ODNZ is also responsible for organising the annual Thanksgiving Services. These services are held in Auckland each year and in Wellington and Christchurch on alternate years. There is also a service held in Dunedin every second year. The services are an opportunity for donor families and recipients to gather and remember those who gave them the gift of life.

The mother of a teenage boy who died 16 years ago attended a service in Auckland for the first time in 2010. She said: "I was overwhelmed by the attendance of both recipients and donor families and I found it incredibly moving."

Transplant recipients are able to write anonymously to their donor families through the transplant co-ordinators. It can be difficult to find adequate words to convey gratitude but it is important to remember that this correspondence will be hugely appreciated by most donor families.

> Your family will also be asked for their agreement so this is why it is important to have a conversation with them about your wishes.

Many people don't realise that organ donation can only happen when a person is on a ventilator in an intensive care and has fatal brain damage. Less than 1% of all deaths happen this way.

Along with your liver, you can donate your heart, lungs, kidneys and pancreas. Tissue donation – heart valves, corneas and skin – can occur in many more circumstances.

Many people tick "yes" to becoming a donor on their driver's licence form. This is an indication of what you want. Your family will also be asked for their agreement this is why it is important to have a conversation with them about your wishes.

www.donor.co.nz
donornz@adhb.govt.nz
(09) 630 0935

Editor's note: ODNZ are very grateful for offers from people willing to distribute information pamphlets about organ donation.

Editorial

Welcome to this 2011 issue of Hepatic Happenings, our annual roundup of goings-on in the New Zealand Liver Transplant Unit. The forum was the idea of Bethli Wainwright who, up until the previous issue, edited this newsletter. Sadly, we lost Bethli this past Christmas. She passed away on Christmas morning 2010, leaving an infectious legacy of enthusiasm for the work of the Unit and an almost completed post-graduate research thesis on the "lived experience" of liver transplantees in New Zealand. Bethli's supervisors assured her prior to her passing that her thesis will be completed and published and made available on the Auckland University of Technology's website where it will serve a most valuable role in the ongoing work of the Unit. Bethli's sister, Kylie delivered a moving eulogy at Bethli's service and it is contained in this newsletter together with a summary of the thesis.

Bethli was also informed that her nominee for an MBE – Professor Ed Gane – would receive this honour in the 2011 New Year's Honours List. I am certain everybody who has had direct – or even indirect – involvement with him will understand what a worthy recipient he is. Congratulations from us all Dr Gane.

It's been a busy and fulfilling year for the NZLTU and here we are again, Christmas 2011. We all have much to be thankful for and to that end, let us celebrate Christmas with the best possible incentive.

– Lyn (recipient #87)

Hine-Ahu-One gown designed by Christopher Huia Woods

Riding for New Zealand

Earlier this year Greg Hampton rode at the New Zealand Master Games, earning three gold and one silver medal in track cycling. No mean feat for anyone. But also consider that Greg Hampton is a liver transplantee .

In August 2009, over 2,000 people from 50 countries travelled to Australia's Gold Coast to compete in the 17th World Transplant Games. It brought the biggest ever number of competitors to a festival which celebrates renewed life through organ donation and transplantation. It is remarkable indeed to realize that every athlete at the Games has received a life-saving organ and has returned to a healthy life.

Greg Hampton, centre, takes gold

Among the 50 strong New Zealand contingent from New Zealand was cyclist Greg Hampton from Thames who received a new liver in June 2000. One year later, a critical workplace accident saw him rushed back into the liver transplant unit with a punctured pancreas. It was after recovery from that second event that he realized how much he was missing his pre-transplant sporting pursuits. "I followed my son into the sport of cycling, albeit as a spectator for the first couple of years," says Greg. "When I did try out the bike for myself it was a slow start. Twenty kilometers was a long ride then. But I found a mind and body in coalition are an amazing tool. Determination, good advice, planning and progressive training allowed me to rebuild my physical fitness to the point where I felt I could take on a competitive sport again."

Over time, twenty kilometers became fifty, then one hundred. Soon Greg was racing with the Morrinsville Wheelers and his average speeds improved to the point of allowing him to be competitive in his age group. For competitive, read winning. "I've had a few wins and trophies along the way at club and local level and early on contested the Waikato Bay of Plenty Cycling Champs in which I was placed second in my age group. Next stop, the Games!"

Greg had been riding for just three years when he was selected to represent New Zealand.

Greg was competing in the 50 – 59 age group. Previously at these Games, the cycling medals have been keenly contested and the winning rides dominated by Europeans.

The two cycling events on offer at the World Games were "surprisingly" short, being restricted to the 5km time trial and the 20km road race but Greg anticipated the speeds and intensities would be high. As he found, they were. Nonetheless, he came away from the Games with two gold medals – one each for the time trials and the road race in his age group. But as he reflects, "when I lined up for my first event at the World Transplant Games, it represented much more than a mere sporting challenge on a world stage. I was competing with the awareness that I had already faced the greatest challenge - a life saving liver transplant."

Back on the Catwalk

At age 52, designer Christopher Huia Woods of Tauranga took second place in the Traditionally Inspired category at this year's Westfield Style Pasifika Fashion extravaganza.

At the end of 2007 Christopher had just completed a Masters degree in Art and Design at the Auckland University of Technology when his liver disease was diagnosed. "The transplant was like a rebirth," he says, "not only physically but spiritually. The hardest thing for me has been the re-introduction to daily life."

His first undertaking, post transplant, was the creation of a gown worn by Miss New Zealand as our national costume for the Miss World Show in South Africa. And his most recent piece of work has been the gown created for Style Pasifika *Hine-Ahu-One* (pictured)

Christopher also freelances as a hair designer ("another passion") but is currently setting out to create a collection for 2012 Fashion Week which, as he says, will hopefully generate huge sales!!

"To all my fellow recipients – Stay Well"

Did you know...

In 2010 the Unit performed:

- 84 liver transplant assessments.
- 41 liver transplants in 41 patients.
- 12 were children
- 15 were female
- 26 were male
- 6 were live donor recipients – all 6 were for paediatric.
- All patients survived

In 2011 the Unit performed 44 liver transplants

Live donors - 8
(6 adult to child & 2 adult to adult)

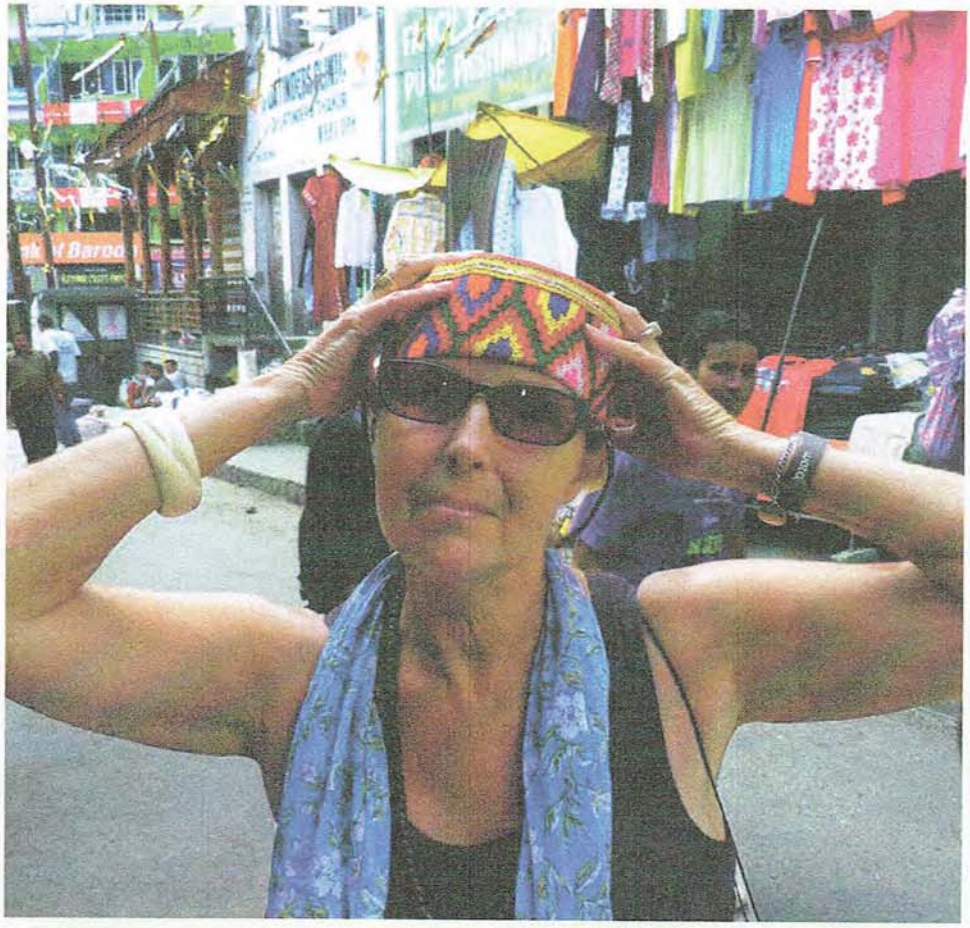
Survival statistics in New Zealand are:

- 1 year – 96%
- 5 year – 89%
- 10 year – 81%

Survival statistics in the USA are :

- 1 year - 93%
- 5 year - 85%
- 10 year - 76%

Since 1998 the NZLTU has performed 481 transplants.



Felicity Spencer-Goodwin in India

A Year in India

EVERYTHING IS POSSIBLE
SAYS TEACHER
FELICITY SPENCER-GOODWIN

In 2009 I had a liver transplant. In 2010 I won a secondary teacher's study award for the following year. This allowed me a year away from the classroom to further my qualifications.

E-learning, distance learning or on-line learning (call it what you will) is a modern day miracle. E-learning allows you to study from wherever you choose. I chose India.

Armed with a laptop, 3 kgs of text books and a year's supply of tacrolimus, I left New Zealand to complete my year's study in that exciting, colourful country. Crossing the highest land crossing in the world at Khardung La on the India/Pakistan border by motorcycle was the fulfillment of a long dream. Sab Kutch Melega. That translates as Everything is Possible, and I realise now that with the help of Team Transplant, everything is.

I return to New Zealand before Christmas to spend this festive season with my 5 year old grandson who, thanks to the "team", I now get to watch grow up and develop.

Thank you Team Transplant for making everything possible and giving me back my life.

TEN

REFLECTIONS ON THE TEN YEAR MILESTONE
BY LYN LOATES

Josh the grandson turned 10 in March. He was proud and excited to have reached this milestone – the entrée into double digits. As the family cake baker I attempted a cake worthy of this event. Josh said to me on the day, "It's hard to believe I'm 10. It's so cool."

Yes, it was cool. And I said to Josh - a respectable time later, "You know, it's going to be my 10th birthday in May. May 27th in fact." He laughed, of course. "Ten! More like six lots of ten," which was generous of him I thought. So I explained that on 27 May it would be 10 years since I received a new liver to replace my old sick one, and that if I hadn't got a new liver I wouldn't be here to bake cakes and do other things that grandparents do.

I'm sure it was difficult for him to comprehend the magnificence of this event. Sometimes it's difficult for me as well. To be so sick, and then by the generosity of an unknown donor and by the powers of science and fantastic surgeons and physicians, to eventually be so well – to continue to be well ten years on actually defies my expectations.

During the first three years post transplant I spent many days, weeks, amounting to months in hospital. It was ward 7B then, housed in the old building and not nearly as comfortable as the bright new ward 71 in which transplantees now reside. But it became familiar, almost a second home – it was in fact said in jest (I hope) by Stephen Munn that I should take up residence in the basement! Suffice to say that following a massive rejection post transplant, a cornucopia of complications ensued. For a long time I seem to have been surrounded by all manner of liver sick people – some who strode through the transplant procedure like Trojans, never to look back, and thankfully by far the majority of transplantees fall into this group. There were of course others who struggled and staggered through all manner of setbacks. But I don't think I ever saw a person give up, such was the optimism and positivity imbued in patients by the team of ward 71. Really, we New Zealand liver transplantees are so lucky to be surrounded by a truly magnificent team.

Initially it was my ambition to reach one year. Having done that, it became three, then six years I was aiming for, and every year after that was going to be a bonus. The sheer notion of what I call the bonus years has increasingly inspired me to achieve things I could not do when I was ill. My career has been as a journalist, in writing in all manner of modes. It's what I love. In my

Lyn Loates celebrating 10 years

8th year post transplant I had my first novel *Butterscotch* published here in New Zealand, and in my ninth year a children's illustrated story *Christmas Delicious* published in New York. And speaking of New York, I finally got there in 2009– a life's ambition fulfilled. I couldn't have done that before.

Of course science and medications are advancing all the time. Therefore those of you awaiting transplant now have much improved chances of a long life span post transplant and it may be that 20 years or 30 may be the milestones we aim for. Luck and love to you all. #87

Bethli Vivienne Wainwright 1966-2010

We're pleased to reprint here a passage from Bethli's Life Sketch as presented at her funeral service by her sister Kylie Burling. Bethli's was an extraordinary and indeed, inspiring, life. Space prevents us from publishing the entire article; it is however available for reading on www.livers.org.nz/recipients. Her thesis is available on the academic website aut.researchgateway.ac.nz/handle/10292/2536

At precisely 2am on 23rd March 2000 Bethli made a phone call to her sister and brother-in-law, Dr Fraser Burling. She was freezing cold and wanted Fraser to come over to her home to find a blanket for her. He asked where it was. She said "it's on the end of the bed" to which he replied, "If you cannot reach a blanket on the end of the bed, CALL AN AMBULANCE!" Such was Bethli's respect for his medical knowledge that she did just that, but such was her ignorance of the severity of her condition that, probably only 48 hours from dying, she took her work bag to hospital with her. Fraser was working at the same hospital and early next morning went to see her for himself and promptly sent her to Auckland hospital's liver team.

The next five months were a day by day battle for survival with the amazing team in the New Zealand Liver Transplant Unit as her army, fighting unceasingly for her life...

Bethlic had experienced the intensive care unit at 20 with her splenectomy, so she had a good idea of what to expect after her liver transplant. In her typical organized manner, she sat down with the family and worked out all the questions she might want to ask when she had a tube down her throat and unable to speak. She put

it all in a checklist format, printed it off double sided and laminated it for protection, put a hole in one corner for a string to go through to tie to her bed; then asking the nursing staff to ensure it would be with her when she came in to ICU. It worked brilliantly for all situations bar one: when she managed to ask for a piece of paper and a pen, she found she could not write intelligibly – firstly because of the tremors caused by the anti-rejection drugs, and secondly because no one had given her glasses to her! Her communication card was the talk of the ICU for weeks, if not months, afterwards.

Bethli realised that she had a legacy to leave the world because those who have received transplants have a lived experience like no other she began producing a doctoral thesis on the lived experience of liver transplant recipients in New Zealand. Her health issues caused some interruptions but she was still working on it right up to her death.

From the results of the thesis she wanted to publish books to be given free to all prospective transplant recipients in order to prepare them for life post-transplant. All the information currently given to patients is from a medical point of view. These books are going to tell the stories of past transplant recipients to future recipients. Such was her belief in the need for these books, and her diligence in collecting all the relevant information, that her family will produce these on her behalf, in her memory and honour.

Bethli's Legacy

The Thesis: The Lived Experience of Liver Transplant Recipients in New Zealand

By late 2010, Bethli Wainright had completed the research and writing of her thesis.

During the early part of this year, Bethli's two supervisors, Professor Marilyn Waring and Associate Professor Ed Gane put together a team of academics to complete the thesis in order that it could be submitted for examination. Each person on the team had an important role, some looking at cohesion of presentation, some at content, others at polishing or editing. The result was a completed thesis presented for examination in the middle of the year. Bethli had completed the research and writing and all that remained was to tie it together and review it. Everyone did their very best to honour Bethli and her research. On 22 August this year it was confirmed that Bethli's thesis had been awarded without any amendments necessary . She graduated posthumously with a Ph.D. this December. Her mother Robin and her sister Kylie accepted the honour on Bethli's behalf.

Professor Ed Gane, Robin Wainwright, Dr Marilyn Waring and Kylie Burling accepting Bethli's Doctorate.

The thesis will be published in book form and electronically on the Auckland University of Technology's website, and the electronic access will be free to the public. The location is aut.researchgateway.ac.nz/handle/10292/2536

Last year Bethli wrote an article for the SITES Journal, published by the University of Otago, as there was to be a special issue on organ and xeno transplantation. This article was published in September, in Vol. 8, No. 1, 2011. The data for that article was based on preliminary findings from the interviews, and is entitled: "Liver Transplant Recipients' Reflections on Organ Donors and Organ Donation: A Preliminary Analysis."

Where to from here? The next step is to prepare some of the data for other journal articles that Bethli intended to write, and to prepare the booklets that will be given to future liver transplant recipients by the New Zealand Liver Transplant Unit, free of charge.

Thank You Day

On March 8 2012 transplant recipients around New Zealand will be saying thank you. Thank you to their donor, donor family, health professionals, support people, employer- anyone who has helped them on their transplantation journey.

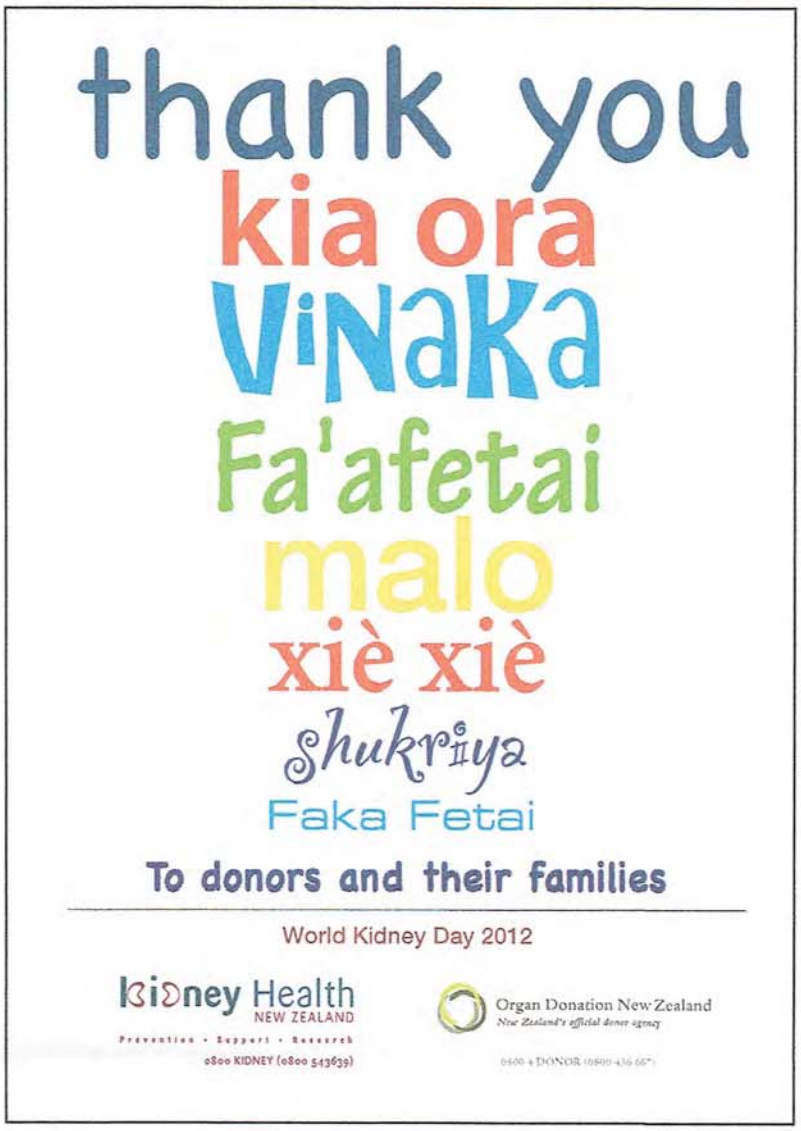
Organ Donation New Zealand (ODNZ), in conjunction with Kidney Health New Zealand is organising the Thank You Day which will take place on World Kidney Day 2012. The theme for Kidney Awareness week next year is transplantation and organ donation (of all organs- not just kidneys).

If you would like to take part in the Thank You Day. ODNZ will send you a package containing a t-shirt, a packet of freesia bulbs (generously donated by Oderings) and a card. The idea is for you to plant the bulbs in your community on 8 March- your local community centre, school, library etc.

ODNZ will help you organise this and will also contact local media so they can attend the planting, take a photo and have a chat about why you're giving something back to the community. ODNZ will also provide you with some information about organ donation and some tips on speaking with the media.

Contact ODNZ's communications Advisor Melanie Selby if you are interested in being involved in the Thank You Day.

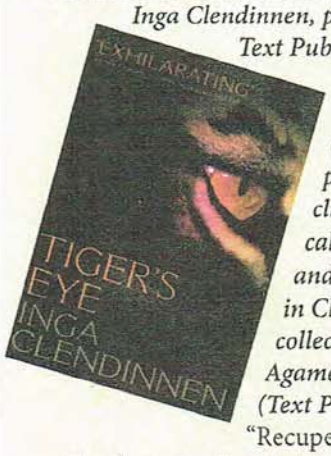
Email: mselby@adhb.govt.nz
or phone (09)630 0935



BOOKCASE

OBSERVATIONS FROM AN AUSTRALIAN LIVER TRANSPLANT SURVIVOR

The piece is extracted from the book Tiger's Eye, a memoir by Australian transplantee Inga Clendinnen, published by Text Publishing in 2001. The full essay covering her experience as a post transplant clinic attendee is called Big Louis and is published in Clendinnen's collection of essays Agamemnon's Kiss (Text Publishing 2001)



"Recuperating patients attend a post-transplant clinic, at first twice-weekly. On my first day I sat, nervous and deferential, on the edge of my chair, uncertain what to do, how to behave, feeling at once haughty and excluded. By morning's end I had been recruited into a society of a distinctive kind.

We are not really friends. We know too little of each other's lives beyond the hospital to be friends. What we are is comrades. We are like Roman veterans meeting back in the city between stints on the frontiers, serving in different camps, with the deprivations various, the natives differently troublesome, but sharing a knowledge incommunicable to all those others – family, lovers, friends – who know nothing of life on the frontier. The great dividers of class, occupation, faith, ethnicity, sex, age, have no authority here. The senior veterans command a touch more deference, that is all.

Not everyone is a member. Those people who, catapulted into sudden illness and emergency surgery, catapult as swiftly back to health do not belong. The children are not members. Prolonged debilitation seems to be a pre-condition for membership, and then experience of the slow, lurching waltz of recovery, step forward, step sideways, step together, step. We know that for us 'health' is an artificial condition…We know that today is as contingent as tomorrow.

I think that is what we share. I cannot be sure because we do not talk about such things. We are content in one another's company, but I do not know if anyone felt and feels quite as I do, thought and thinks as I do.

I am back. That is how it seems to friends: the person they knew, the voice, the manner, the little box of social tricks, is back. And so she is. Except now I know more of the processes which made her and therefore know her to be a fiction: a thing made out of idiosyncratically angled experiences and an obstinate habit of writing.

Late in the year of my transplant operation my husband and I built a house on an island in Far North Queensland – my third beach house. We built it… partly to mark a break with the past."

Tigers Eye
By Inga Clendinnen
Text Publishing
ISBN:9781786495550
240pp
Available from:
www.textpublishing.com.au

ANNIVERSARIES

10 YEARS

David	15-Jan-01
Maureen	26-Jan-01
Darren	01-Feb-01
Andrew	07-Feb-01
John	25-Feb-01
Pio	31-Mar-01
Beverley	13-Apr-01
Roger	20-Apr-01
Jong	28-Apr-01
Stephen	10-May-01
Iani	22-May-01
Lyndsay	27-May-01
Nicholas	24-Jun-01
Elma	27-Jul-01
Bruce	11-Aug-01
Ronald	11-Aug-01
Amanda	15-Aug-01
Abdul	07-Sep-01
John	01-Oct-01
Raoa	25-Oct-01
Brian	18-Nov-01
Te Kapo 1	9-Nov-01
Anitimomi	17-Dec-01
Robert	28-Dec-01
John	29-Dec-01

5 YEARS

Lisiate	28-Jan-06
Bong	10-Feb-06
Frederick	20-Feb-06
Steven	12-Mar-06
Richard	27-Mar-06
Lazarus	27-Mar-06
Sitini	28-Mar-06
William	07-Apr-06
Teresa	18-Apr-06
Deng	17-May-06
Nicola	19-May-06
Michael	03-Jun-06
Howard	13-Jun-06
Paulo	21-Jun-06
Sine	25-Jun-06
Tarsem	04-Jul-06
Jorden	04-Jul-06
Leighton	17-Jul-06
Robert	15-Aug-06
Teia	29-Aug-06
Carol	31-Aug-06
Jillian	01-Sep-06
Kenneth	07-Sep-06
Moreh	19-Sep-06
Nilesh	01-Oct-06
Colin	04-Oct-06
Lorraine	10-Oct-06
Sine	11-Oct-06
Noeline	12-Oct-06
Nget	29-Oct-06
Tracy	12-Nov-06
Teresia (tracey)	13-Nov-06
Theresa	11-Dec-06

How, Why, When... Those Things We Want to Know

Q When is my next blood test due:

A Your doctor/nurse should have discussed with you at your last clinical appointment how often you will require to have blood tests. Initially you will be having blood tests at least once a week. As you improve the time between bloods tests increases and by the end of one year you may possibly only require a blood test once a month. Eventually tests may drop to every two months (but only if your doctor agrees!)

Blood tests are an important indicator of your health and can reveal a lot of information to the doctor.

- Liver function Tests (LFTs) will indicate if there is rejection, infection in your bile ducts or recurrent disease in your liver.
- Kidney Function (Creatinine) will indicate how well the kidneys are working and if they are being affected by your anti-rejection medication.
- Full Blood Count (FBC) looks at your levels of haemoglobin (anaemia), platelets and white blood cells which fight infection.

The amount of most anti-rejection medications is determined by measuring how much is in your blood. If your level is too low you may be at risk of rejection; if it is too high you may be more at risk of an infection.

Of course blood tests only give us a preliminary indication of the way things are for you. Depending on these results, you may require further investigations.

For the majority of people these blood tests are merely "wellness checks" to ensure everything is going smoothly and may indicate the occasional fine tuning such as a change in immunosuppression dose.

Q When Can I Go Back to Work?

A One of the primary aims of having a liver transplant is to make you well again so that can live a normal life. Most patients who have had a liver transplant will be ready to return to work/school/study within about 3 months after their transplant, regardless of occupation. If possible, it is advisable for you to return to work/school/study on a part time basis, allowing yourself time to recover and build up stamina. After 3-6 months most people will be back to normal activity levels. If you are concerned about the timing of your return to work, discuss this with your doctor.

Q Can I travel overseas?

A The NZLTU team are thrilled to hear of patient's prospective travel. However, it is important that you are well and stable at the time you plan to travel. We ask all transplant recipients not to travel overseas for the first 12 months. After that time, provided all is well, you are free to travel. If you are unsure whether it is safe for you to travel, ask advice from your transplant physician.

It is imperative that you have travel insurance for all overseas travel and that you declare your pre-existing medical conditions. If you have problems finding travel insurance, please contact one of the NZLTU transplant co-ordinators as other patients have passed on useful information in this regard. (If you DO find good travel insurance, please let us know so that we can inform other patients).

Depending on where you are travelling to you may require vaccinations or preventative medications. You may need to discuss your requirements with a travel doctor.

ANNIVERSARIES

A special mention to Ngaire who celebrated 11 years this year and who we inadvertently failed to mention in last years Big 10.

Memo

NB – It is important that you do not receive any live vaccines.

PS It is essential that you send the NZLTU a postcard!

Pharmacy Update

SARAH FITT, CHIEF PHARMACIST, ADHB, COVERS POTENTIAL PITFALLS OF ALTERNATIVE THERAPIES

Complementary and alternative therapies have become a popular healthcare approach and the use of herbal medicines in particular is increasing. Despite a lack of good-quality evidence to support their efficacy and tolerability, many people perceive herbal medicines to be entirely safe because they are "natural".

In NZ, herbal medicines are not regulated as medicines but as dietary supplements and therefore manufacturers of these products are not required to provide quality, efficacy, or safety data before marketing. This can lead to potential problems such as adulteration (inclusion of toxic metals or conventional pharmaceuticals), misidentification of herbs, substitution of other herbs and incomplete labelling. Studies are lacking in areas relating to safety of herbal medicines such as active constituents, metabolites, pharmacokinetics, pharmacology, toxicology, adverse effects, effects of long term use, interactions, use in specific age groups, contraindications, and warnings. In addition, most herbal medicines are not standardised, therefore there may be variation in constituents among different batches and brands. This may not only cause differences in efficacy when changing from one brand (or batch) to another, but may also influence the range of adverse effects and interactions.

Herbal medicines may be associated with serious adverse effects, which are often unreported. In addition, there is an indirect risk that a herbal medicine without demonstrated efficacy may compromise, delay, or replace an effective form of conventional treatment. It is therefore important that if you are thinking about taking any herbal medicines that you discuss it with the NZLTU team first.

Don't forget to order your prescriptions at your monthly checkups

Potential adverse effects of frequently used herbal preparations.

	Herbal Medicine	Claimed Use	Adverse effects
	**Milk thistle** Silymarin is a mixture of flavenoids extracted from the milk thistle plant.	Mode of action is unknown but has anti oxidative and anti-fibrotic properties	▪ Generally well tolerated
	**Echinacea** (*Echinacea* spp.) Part used: rhizome, root	Antiseptic, antiviral and peripheral vasodilator properties Immunostimulant	▪ Most common adverse effect is unpleasant taste. ▪ Allergic reactions including anaphylaxis have occurred, but thought to be more common in atopic individuals.[9] ▪ **Should not be taken by individuals who are taking courses of immunosuppression.**
	**Ginkgo** (*Ginkgo biloba*) Part used: leaf	Dementia, conditions associated with cerebral vascular insufficiency, memory loss, concentration	▪ Mild side effects include nausea, headache, gastrointestinal side effects and rarely allergic reactions. Larger doses can cause lack of muscle tone and weakness. ▪ A few cases of spontaneous intra-cranial bleeds, post op bleeding, subdural haematoma. Isolated reports of bleeding in elderly patients. ▪ Some concern that gingko seeds & excessive amounts of gingko leaf extract may be associated with seizures
	**Kava** (*Piper methysticum*) Parts used: rhizome, root, and stem	Used to treat anxiety disorder, stress, insomnia, and restlessness	▪ Parkinsonian-like adverse effects ▪ Liver toxicity is of particular concern. More than 68 reports of liver toxicity with use of kava products. ▪ Long term use may lead to addiction, tolerance and acute withdrawal after abstinence ▪ Dry, flaky skin with long-term use
	**St Johns Wort** (*Hypericum perforatum*) Part used: Herb	Used for depression, anxiety, heart palpitations, mood disturbances	▪ Commonly reported side effects are gastrointestinal symptoms, dizziness, confusion & tiredness/sedation ▪ Mania and hypomania also reported. ▪ Insomnia, vivid dreams, restlessness ▪ Photosensitivity particularly in fair-skinned individuals.
	**Valerian** (*Valeriana officinalis*) Part used: Rhizome, Root	Used as a sedative for insomnia and anxiolytic for restlessness and anxiety-related sleeping disorders	▪ Impairment of performance following ingestion of valerian. ▪ Occasionally causes dry mouth, vivid dreams, and morning drowsiness ▪ Possible liver toxicity

Tour De Force

NEW ZEALAND'S LIVE DONOR LIVER TRANSPLANTATION PROGRAMME IS UP THERE WITH THE BEST.

In an ideal world of liver transplantation, there would be no reason to subject healthy people to potentially life-threatening surgery for the procurement of transplantable organs. But as any liver transplantation professional will tell you, their environment is far from ideal. With a growing discrepancy between the supply of deceased donor organs and the need for organ replacements, the number of transplantation units which perform live donor transplantation is increasing internationally.

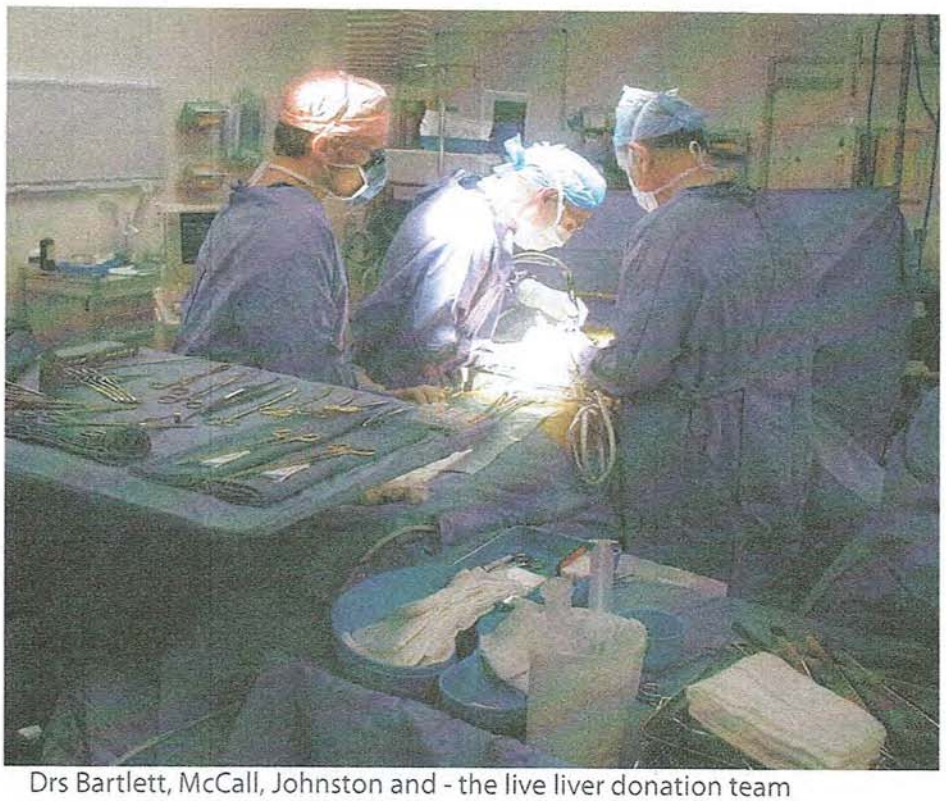
The first successful live donor liver transplant was performed by Dr Russell Strong in Brisbane in 1987 when a mother donated part of her liver to her 17 month old son. It would be ten years later when Professor Steven Munn performed the first cadaveric liver transplant in New Zealand at the newly opened (1997) New Zealand Liver Transplant Unit at Auckland Hospital. Two years later, the possibility that the Unit's service should include Live Donor transplantation was proposed.

The Unit had the expertise. Professor John McCall was highly experienced at liver resection surgery, the skill required over and above the skills of cadaveric transplantation. McCall himself was hesitant, he says. It was too soon, he claimed. His primary concern then, as now, was "risk to donor". Unlike cadaveric transplant where risk to recipient is the unique consideration, here paramount regard must be given to donor safety and cannot be compromised, regardless of the implications for a recipient.

By generality, the risk to a live donor can be ten times that to a kidney donor. So it was not a procedure he would undertake without first exploring the plethora of research evolving throughout the world. It took McCall two years of study and observation of centres internationally before he felt confident in "offering a programme that was as close to perfect as possible."

The results from the Auckland Unit have traditionally been excellent. In comparison to Australia which has five transplant units, 45 of the 60 live liver transplants performed in the whole of Australasia to date have been performed by the Auckland Unit.

In recent years two more hepatic surgeons from the Unit joined the Live Donor Liver transplantation team. Dr Peter Johnston, and latterly, Dr Adam Bartlett have come on board. McCall, now resident in Dunedin, believes the additional expertise means that the programme remains in excellent hands. However, he says, the existing two to three surgeons will probably represent the maximum number of surgeons working in this specialized field in New Zealand. "New Zealand will always have a modest requirement [for liver transplantation] and the resources required to undertake just one live donor transplantation are comparatively great," McCall says.



Drs Bartlett, McCall, Johnston and - the live liver donation team

The differences between cadaveric transplantation and live donor transplantation are considerable. In live donor transplantation ethical issues are more complex. Here, says McCall, risk is borne by one individual for the benefit of another". So there have to be tight rules. It's crucial to establish, first off, that the donor is fully informed and exercising a free choice. In desperate situations things can go awry if there are not good processes in place to ensure the absence of coercion. And in such situations coercion can come from all sides, even from those who are well intended.

> "...paramount regard must be given to donor safety and cannot be compromised, regardless of the implications for a recipient"

McCall says that the established protocol in both Australia and New Zealand is to accept family members or close personal friends as donors. No donor over 60 is accepted, partly because of the liver's lessening regenerating ability. Any underlying disease that would increase the risk to the donor is an exclusion criterion. Alcohol intake is required to be minimal and a body mass index greater than 30 is a contraindication to donation.

Some would-be donors decide against proceeding when they become fully aware of what they would be letting themselves in for and many are declined for medical reasons.

Ultimately, blood and hepatic compatibility are crucial to the outcome. The anatomy of the liver is quite variable from person to person and the hepatic arteries, portal veins, hepatic veins and bile ducts are all required to match up for a transplant to be successful. Liver mass is also important. There has to be enough for the recipient and enough left behind in the donor to ensure complete recovery. That means a 60kg woman, for example, could not donate to an 80kg man. As in deceased donor transplantation, it is possible to cross the ABO blood barriers but this can increase recipient risk and is only done under certain circumstances. On the issue of how much of a donor liver is required: donation to a child may require just 20 – 30% of a donor liver whereas donation to an adult may require up to 65% of a donor liver. The risk to the donor increases with the amount of liver removed, with a risk of death of about 1:1000 up to about 1:300 (based on international figures). There are many variations between these two examples but as a rule of thumb, the greater the resection the greater the risk. Exact risk factors are difficult to quantify since no reliable international registry exists.

It's easy to see then, why the donor assessment process is necessarily exhaustive. It is performed independently from the recipient's assessment by a team of people entirely responsible for the welfare of the donor. The team includes a co-ordinator, a liver surgeon, an independent physician who understands transplantation but is not

responsible for the transplant recipients, a psychiatrist and a social worker. Other people such as radiologists are involved in particular aspects of the assessment.

On the other side, a similarly formed team assesses the potential recipient. "In a small unit like ours, it's a big call on our resources," McCall says, "and on average we assess 5 or 6 potential donors for every live donor transplant performed."

So, it is only after the transfer of detailed information between the donor assessment and recipient assessment teams that the final decision can be made.

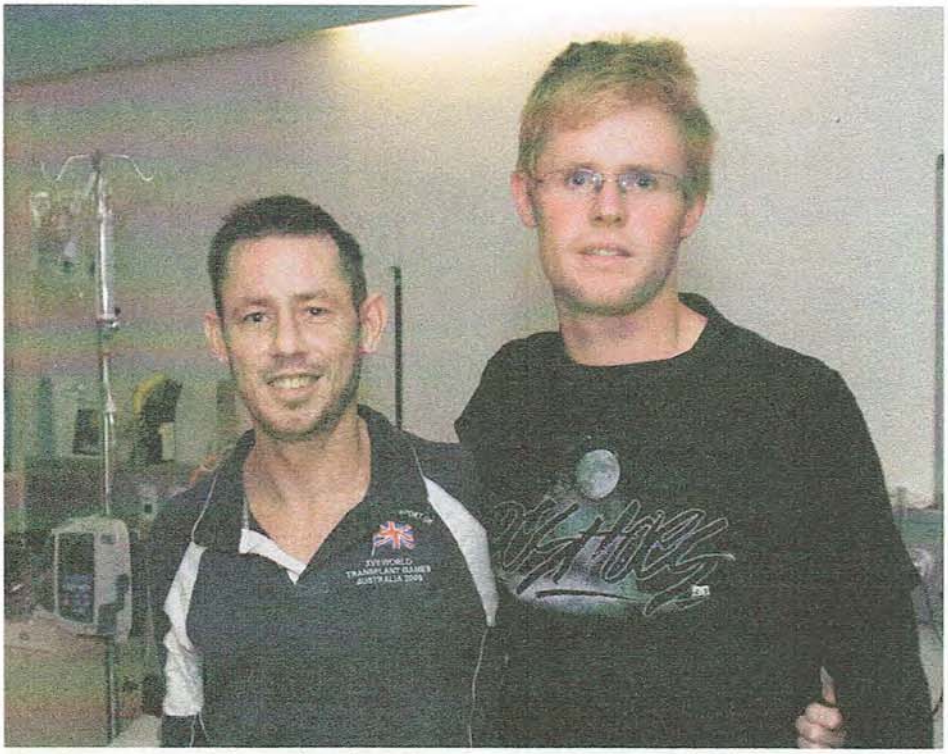
Here in New Zealand, the decision to perform live donor liver transplantation is based on a very careful analysis of both donor and recipient outcome. Having decided to undertake the live donor programme, McCall recalls how the team built in all the safety checks and balances and set conservative selection criteria so that there were no unnecessary risks. "That's the way we designed the programme," he says, with certainty.

And definitely there are some potential advantages over cadaveric transplanations. Importantly, it optimizes the timing of transplantation and frees patients from waiting lists. Preservation time is minimal in live donor transplants and so less ischemic damage is sustained by the liver. Live donations are by definition healthy and therefore the quality of the organ is much better. There is no doubt that live liver donation is a life saving therapy.

The New Zealand Liver Transplant Unit treats 50% of recipient children by live donation. "Deceased donor livers are pretty sporadic for kids in our country," says McCall. "Live donation is a very good option for kids and is the backbone of our paediatric liver transplant programme."

Currently New Zealand leads Australia in the tour de force of live liver donation and the results achieved to date have been outstanding by international standards.

Professor John McCall



Brothers Jason (left) andMark Dellow

Brotherly love

MEET THE 45TH LIVE LIVER DONOR TRANSPLANTATION DUO.

Seven years ago, Jason Dellow underwent a lung transplant as a result of advanced Cystic Fibrosis. Consideration was given at the time to a combined transplantation of lungs and liver, an infrequently performed operation in patients with CF. In Jason's case liver disease was not considered advanced enough for surgeons to undertake the combined operation. However, following the lung transplantation, Jason's liver began to deteriorate more rapidly than could normally have been expected. Immunosuppression drugs were implicated in the decline, hastening the pulmonary hypertension disorder, subsequently causing encephalitis in the brain. In October this year his health was failing to the point where waiting for a donor liver was a poor option.

Several months earlier, Jason had received a general letter from the Liver Transplant Department asking potentially suitable patients to consider the prospect of live liver transplantation. Immediately, Jason's younger brother Mark Dellow stepped in, offering to become his brother's live donor. "I didn't hesitate," says Mark. "We're a very close family. I read as much information as I could find on the procedure and actually the risks were not as bad as I thought they might be." There was no pressure from Jason," he says, and provided our livers were compatible, I just wanted to go for it."

Jason says, "I was surprised and I was scared, not for myself but for Mark. And honestly, words can't express ...."

Mother Jean Dellow says she and her husband had no say in the matter. "It was entirely their decision. They're both strong minded, independent boys. But I won't say it wasn't hard, having two sons in the frame at the same time. No, it was definitely very hard."

Jean says, however, that Jason's response to the earlier lung transplantation gave her some confidence. As a part of recovery from that surgery, patients were encouraged to walk progressive distances, including, ultimately, climbing part way up One Tree Hill beside Greenlane Hospital where lung transplants were performed. Within a short period of the operation, Jason told his mother he had decided to climb to the top and with his characteristic determination he did. Not only that, his was the quickest time recorded among lung transplant patients at that time.

On 25th October this year, 60% of Mark's liver was removed by Dr Adam Bartlet in a five and a half hour operation. Jason received his brother's gift in a longer operation performed by Dr Peter Johnson.

The Dellow brothers both say the procedure turned out far better than either of them had hoped for. Both intend to return to work, Mark (27) to his job as a commercial fisherman based in Warkworth in about two months time; Jason (31) to his Auckland based sales job. Optimism is plentiful among the Dellow family and the brothers are keen to publicise both the wonders of live liver donation and the sheer professionalism of the team. "Put it this way," says Jason, grinning, "I wouldn't want to have my transplantation done anywhere else!"

Liver Transplant Group

SUPPORT GROUP PRE AND POST TRANSPLANT

The Liver Transplant Group, an education and support group for patients and their support people, both pre and post liver transplant, has been meeting since February this year. The first four sessions on diet and nutrition, liver disease and future developments/research, liver transplant surgery, and demystifying blood tests and radiological procedures were well attended with 20-25 people meeting each month.

Sessions over the past six months have covered the following topics:

- *Medications pre and post transplant*
- *What to expect in DCCM and Ward 71*
- *Donor issues and the role of the donor coordinator*
- *Lifestyle changes post transplant*
- *Exercise and relaxation pre and post transplant*
- *Emotional and psychological issues around transplantation*

Lectures scheduled for 2012 are listed in diary dates on page 5

Meetings are held in the Ward 71 Meeting Room on the first Wednesday of each month from 1.00-2.30pm. They are facilitated by the New Zealand Liver Transplant Unit's social workers Ron Benjamin and Cindy Penny.

For further information on meetings call Ron Benjamin 021 835 604

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IN MEMORY OF
BETHLI WAINWRIGHT

Professor Stephen Munn, Mr Peter Johnston, Tien-Huey Lim, Margaret Johnston, Barry Harrison, Carla Hooijkaas, Kathy Oliver, Dr Rachael Harry, Professor Ed Gane, Val Honeyman (Obsc), Janine Smillie, Lucy Mills, Ron Benjamin, Cindy Penny. Absent Dr David Orr, Mr Adam Bartlett., Angelle Lockie, Denny Wood and Moto Yasutomi.

From the 15th floor

It's been another busy year for the Liver Transplant Unit. By December the Unit had completed 44 transplants for 2011 making this the largest number of transplants performed in any year since the Unit's inception in 1998.

Despite the "busyness" we've all managed to get up to other things. There have been weddings, births, sporting indulgences, holidays and conferences and awards.

Margaret's eldest daughter was married in April. She looked beautiful as did Margaret in her Mother-of-the- Bride outfit. Margaret has also become a golf aficionado, playing every weekend. In fact several transplants have been organized from the golf course! She attended a Liver Transplant conference in Canberra in June.

Kathy, our team support, has been mother of the bride twice. Both her eldest and middle daughters were married in April with just two weeks between the weddings! And her youngest daughter gave birth to a baby girl in October giving Kathy her first granddaughter.

David Orr, one of our hepatologists, became a father for the second time this year with the birth of a baby son in September.

Ron, our chief social worker has returned from a wonderful holiday on the Greek Isles. We're pleased to report that he was recently presented with an award from ADHB for "outstanding, significant and consistent contribution to the social work profession and to ADHB".

Lucy, our Nurse Specialist on the ward gave a presentation on liver disease at the New Zealand Gastroenterology Conference in November and won several awards for h presentation.

Barry has continued his marathon runnir His last race of the year was the Sar race where hundreds of santas gather at the start line at Auckland's Viaduct. August Barry attended an internatior Transplantation/Organ Donatio Conference in rainy Glasgow and took t opportunity to see his family in Englan His mum, bless her, sent him back to with a case full of goodies.

Val has been busy painting her house wi bribed assistance from her teenagers. S attended an international liver conferen in San Franciso in November which Stev Ed, Rachael and Sarah – our pharmacist also attended.

But the staff member with the bigge year is **Ed.** It began with the presentatic of an MBE from the New Year's Honou List. Then in November he was award the prestigious HRC Beavan Medal f excellence in translational research. H particular research investigates wheth better surveillance can prevent liv cancer and death in Maori with chron Hepatitis B virus infection and explor how the research translates into clinic practice. We're all extremely proud of hir

The co-ordinators wish you all a mer Christmas (though not too merry!) and tl best of things for the New Year. (Val ar Margaret will be on call over Christmas ar the New Year).

– Val Honeyman