

# Hepatic Happenings

## NZTLU in its 15th Year

### AND THE NUMBERS SPEAK

**With 15 years and 500 liver transplants now recorded, the progress of the NZTLU is a national success story. More, in the field of organ transplantation, it is an international success story.**

Its success is largely due to an "innovative" and "self sacrificial" (says Professor Stephen Munn) team. The team has grown from the original lineup in 1998 and with that growth has come new expertise in both medical and surgical disciplines and therefore notable outcome improvement. In this area, the NZTLU is at least on par with the best in the world. Perhaps the numbers tell the story.

After competitive tendering, the tender group from Auckland was awarded the contract for liver transplant assessments and transplants in New Zealand. The contract allowed 33 assessments per year and in the first year of service, 1998, 22 of those assessed people were transplanted. 15 years on, between 80-90 a year are assessed. That represents a total of 980 people. Around two thirds of those people have been listed as patients for transplant. 144 of those have subsequently been de-listed, some because they have recovered sufficiently, the majority because they have died of disease progression while on the list. The Unit has achieved 1 year survival rates of 96%, 5 years 89%, 10 years 81%. 9 babies have been born to transplanted mothers.

On the down side, there is an increasing gap between demand and supply of donor organs. It is common now for patients to wait a year – more, for their transplants.

And while 15% will be removed from the list because of disease progression, our national requirements are far from being met. Our population donates around 9 deceased livers per million per year. This pales in comparison to Europe – say, Spain where 30 – 40 organs are donated per million population.

There are two mutually important approaches to the problem; increase donor supply; reduce demand for transplant. Both are being implemented. "We are now using marginal donors," says Dr Ed Gane. "We're using donors we would not have used 10 years ago.

**...the need for donated organs will not pall. The NZTLU needs everyone to know that.**

Older donors, obese donors, donors who have Hepatitis C (to recipients who suffer from Hepatitis C) and donors who previously suffered from Hepatitis B." Due to dramatic progress in preventative treatment and also the introduction of potent oral anti-virals, the majority of Hepatitis B sufferers are cured and whereas Hepatitis B once formed the bulk of transplant indications, it is now only sufferers of acute Hepatitis B and liver failure who are transplanted.

New surgical innovations include the use of non-heartbeating donors (people who have not reached brain death criteria) and increasingly, split livers. Live donor transplant now accounts for 10% of transplantation.

The two growing trends in liver disease are Hepatitis C and Fatty Liver. Hepatitis C causes 50-60% of transplant referrals. It's a world wide health burden and it's growing fast. Not so long ago it was estimated that by 2030, the annual

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## Editorial

We're celebrating two milestones for the NZLTU this year - the 500th liver transplant and the 10th birthday of the Starship Children's Hospital transplantation service.

New Zealand came comparatively late to the field of on-shore liver transplantation. In 1986 several of our patients had been sent to both UK and the US – the costs being borne either independently or by non-government charitable support. By the early to mid-90s a percentage of us were receiving transplants in Sydney and Brisbane.

Even so, there was an evident problem of under-referral, partly because we lacked a centralised hepatology service to determine candidacy. That became one of several compelling reasons why New Zealand should create an on-shore service.

The New Zealand Liver Transplant Unit was finally instigated at Auckland Hospital in 1997. The first transplant took place in February 1998, the 500th in July 2012. The NZLTU is recognized as producing among the highest long term survival rates in the world.

This issue of Hepatic Happenings acknowledges the success of our service, of our team in all its disciplines. I say "our" advisedly. Most of us who have been connected with the Unit feel we have a vested interest in it. I think we're proud of it and grateful to be part of it. Well done team.

**Lyn (recipient 87)**



# Presenting the Theatre Crew



Charge nurse Robyn Grant (right) and her Level 8 OR Vascular Transplant Team

Courtesy ODNZ

***Robyn Grant is the charge nurse for Level 8 Operating Room (OR) vascular transplant team and has been a member of the liver transplantation team for almost 15 years. She notes that she's been known to leave a whole trolley of groceries in the supermarket because of the need to get to Auckland City Hospital, an action that underlies the urgency of a transplant situation.***

Her team of 20 or so nurses all volunteer to be part of the team as it is the sort of 24/7 job that requires them to be on call during days off and therefore impacts on family and social life and is indisputably very tiring for the nurses themselves.

Some of the team also travel to assist with the organ donor retrieval operation. Being part of this team means taking it in turns to be available 24 hours a day, and requires them to get to Auckland City Hospital within two hours of receiving the phone call informing them that a retrieval operation will be taking place somewhere in New Zealand. Often this involves flying to a donor hospital in a small plane with the donor co-ordinator and surgeon. (If a heart/lung retrieval

is also taking place there will be a second nurse, two surgeons and an anesthetist travelling).

The nurse is responsible for taking the surgical instruments and equipment needed by the surgeon and the fluids and chilly bins required for the storage of the abdominal organ.

At the donor hospital the nurse will work with the donor hospital OR staff to set up the Operating Room, then scrub for the retrieval operation.

Those in the liver transplant team at level 8 OR are also rostered to be on call for three to four days per week. This team includes two anesthetic technicians. These two people plus three nurses have about six hours prior knowledge that they are required and are notified by the liver transplant co-ordinator of the time the transplant will begin.

Robyn Grant says of her team, "they are a dedicated and committed group who support each other. They enjoy making a difference. Knowing there is going to be a good outcome for the patient is what makes it all worthwhile. I'm really proud of the team and what is achieved," she says.

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## 15 years for NZLTU

numbers attending NZLTU with Hepatitis C could be up to 200. But again, there have been dramatic changes at NZLTU. A treatment of oral antivirals as used for HIV have been shown on trial to offer a 95% cure rate of Hepatitis C after only 12 weeks of treatment.

"We believe in the next 10 years the demand for transplant due to Hepatitis B and C will largely drop" says Dr Gane.

New challenges may arise from:

- long term complications relating to immunosuppression in long survival post transplant patients
- The epidemic of non-alcoholic steatohepatitis (NASH)
- Increasing numbers of people with liver cancer

So, the need for donated organs will not pall. The NZLTU needs everyone to know that.



# Starship Enterprise

THE CAPTAIN OF PAEDIATRIC, GASTROENTEROLOGY AND HEPATOLOGY REPORTS

*In February 2012 we celebrated our 10th anniversary with an education day for liver transplant families at Butterfly Creek, organized by the Kids Foundation. Butterflies were released to recognize each liver donor and the small number of children who did not survive their transplants. But to see so many healthy children living normal lives after transplantation and to hear them tell their stories was a truly heart warming experience for our transplant team.*

Following the success of NZLTU which served adults and children over 7, the service was expanded to include all children in 2002 and the first transplant under the new extended contract was on 5th February 2002. At the time of writing, we have now performed 84 transplants. Our survival rates are among the best in the world with over 96% alive and well at 5 and 10 years post transplant. In fact we have refined our protocols over the years in response to these survival rates being so good. We are now able to focus on keeping the children as healthy as possible and minimizing the possible complications from their long-term medications. The reasons children need liver transplants are different to adults. Over half of the children we see have been born with a condition called biliary atresia in which the bile ducts draining bile from the liver into the intestine are not properly formed. This results in very early liver disease. Others have metabolic or genetic problems and about 1 in 10 of the children we transplant have acute liver failure, usually of unknown cause.

Post transplant the rates of technical complications are higher than for adults and return visits to the operating theatre are often needed. Due to the small size of blood vessels and bile ducts, leaks and blockages are not uncommon. Infections (due largely to immature immune systems) can be problematic - Epstein-Barr virus (EBV) is a real concern and



requires very close monitoring as it can lead to post transplant proliferative disease (PTPD) which can in turn lead to cancer. But most children are remarkably resilient and return to good health relatively quickly. We continue to monitor them closely. We are primed to look out for potential kidney damage for instance. Also we have learnt from our overseas colleagues that children can have mild developmental problems after transplant, especially with concentration and subjects which require complex reasoning such as maths. We react to any early signs of such problems by liaising with educational services and developmental specialists.

You will see in this issue an article by Dr Rachael Harry outlining a new initiative called the Young Persons Clinic. This provides for children once they leave the paediatric clinic, headed towards the adult service. Its creation confirms the number of children going through our system and the degree to which we continue to oversee recipients. Also, children are now offered transplantation for a greater number of diseases and we need to adapt to this need. A major challenge is not having access to enough small-sized livers from deceased donors. Our surgeons have shown increasing

innovation by reducing the size of whole livers, splitting livers between two recipients and where possible using live donors. In 2011 we performed the first ABO incompatible transplant – in other words the donor and recipient have different blood groups. While this type of transplant would not be tolerated by adults, it is tolerated by very young children because their blood group antibodies have not yet fully developed. We have so far used this technique in three babies under age 1 and they have done extremely well.

It has been a great honour for me to work with the Starship team for the last 8 years and lately as Head of Department. I pay thanks to each one of the people involved with the service. My particular thanks to my fellow paediatric gastroenterologists – Simon Chin, Stephen Mouat and Jonathan Bishop. The transplant surgeons, Stephen Munn, Peter Johnston and Adam Bartlett, our nurse specialists – Cate Fraser-Irwin and Karyn Sanson, The transplant co-ordinators – Margaret Johnston, Barry Harrison and Lucy Mills. Also to Dr Alison Wesley who was head of department in the beginning.

Dr Helen Evans, Head of Paediatric Gastroenterology and Hepatology, Starship Hospital.



# Catching up with....

## Ronette Druskovich– Liver Recipient No. 1

*The first thing I knew about my liver transplant was a couple of weeks after it happened. My liver failure was very quick and I was incredibly lucky that the NZ Liver Transplant Unit had just opened and that a liver became available. That was almost 15 years ago.*

Since that time I have moved from Auckland to Wellington and more recently to Australia. Changing hospitals always comes with a bit of uncertainty but

that's nothing a bit of persistence and a telephone cannot fix. The NZ hospital system is much more efficient than what I've experienced in Australia! Sometimes the drugs may be slightly different and the way you have to collect your prescriptions is different but strangely, clinic appointments seem to be the same wherever I've been.

A couple of years ago I became a trustee for Lions Liver Transplant House so I manage to remain connected with the team in Auckland and also give a bit back in a very small way.

### **Date of transplant**

20 February 1998 (I was 26 years old)

### **Reason for transplant**

Acute liver failure – unknown virus

### **Surgeon**

Professor Munn

### **Support person**

I didn't have one pre-transplant, but afterwards, my mum.

### **How long were you in hospital?**

Approximately 1 month

### **How long were you on the waiting list?**

A few hours, maybe... I was in a coma.

### **What things got you through your post operative period?**

Focusing on getting my life back and working out how to do that.

### **What was the best thing your friends/family contributed to the situation?**

My mother picked me up from home every day for most of that year, she fed me and drove me everywhere and early on basically did everything for me.

### **What was the first real change you noticed in yourself post transplant?**

Having had acute failure I was the opposite of most patients. Early on I was VERY TIRED, ALL THE TIME, I was absolutely hopeless at everything. This was rather frustrating but I improved, back then the energy improvement seemed quite slow, looking back it was probably fast, all

things considered. It took me less than 3 months to be back at work but about 3 years before I could play a decent game of football.

### **What did you first want to eat after your transplant?**

I wasn't particularly interested in food for quite some time post transplant (which is surprising for those who know me).

### **How has your life changed?**

I am living the life I had always expected for myself and I do not limit myself in any way.

### **Have you written or plan to write to your donor family?**

I wrote to my donor family a few times in the first while.

### **What are you doing with yourself these days?**

I am a fully qualified lawyer presently practicing in Australia, I like to travel (the Pacific, Europe, Asia, North America, South America and South Africa post transplant so far), I am still playing football (just), I cycle regularly, I recently started playing the mandolin, I am a member of the Yellow Fever (Wellington Phoenix) and an active All White's supporter, I like to see live music – Byron Bay Blues festival earlier this year. Basically I do everything time and money allows me to do.

### **What are your plans for the future?**

I do have an issue with long term planning. I can't tell you where I will be living or what I will be doing in 5 years from now, but I am planning to:

- Complete the Conquer Cancer 200km 2 day cycle in WA next year;
- See the Kimberleys in the upper North West of Australia ASAP;
- Go to the FIFA World Cup in Brazil in 2014;
- See India, Tibet and Nepal by the end of 2016;
- Be a good Mandolin player; and
- Reduce my shoe purchasing habit.





## Our 500th Recipient is...

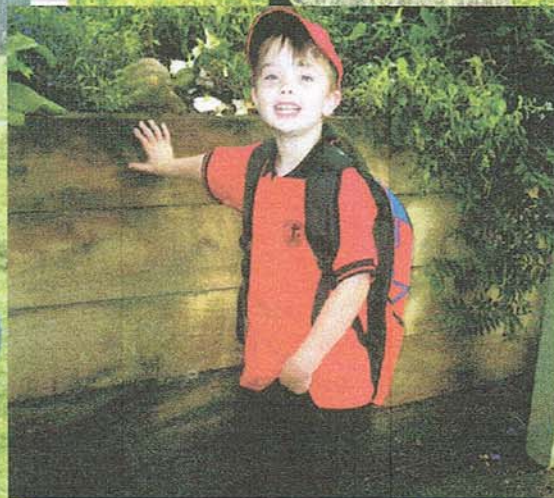
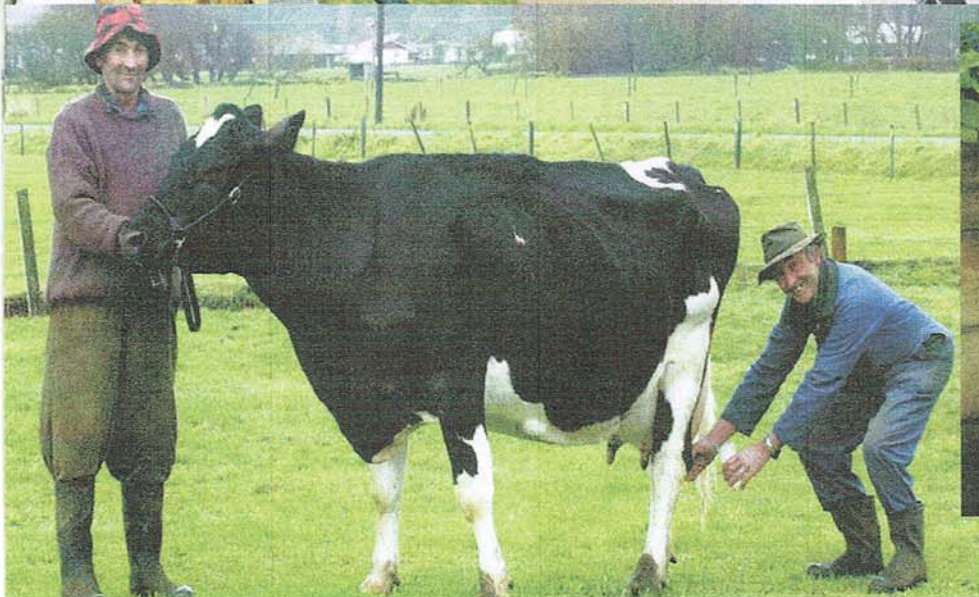
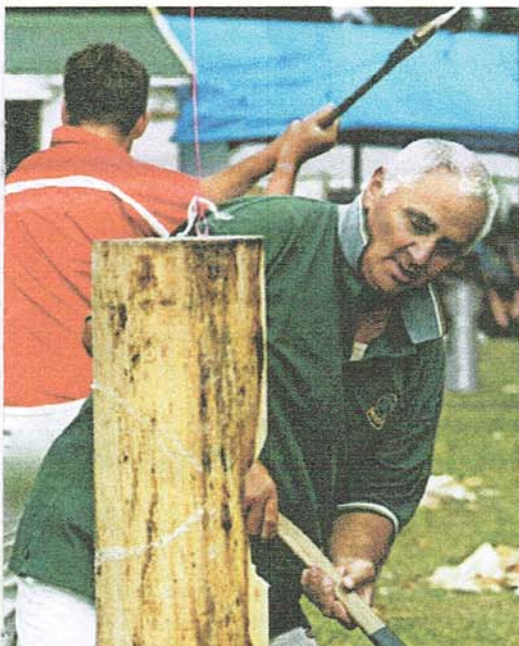


### Tony Buckley of Waikato

Tony received his new liver on July 10 this year following 9 months on the waiting list. He was 52 and suffered from cancer of the liver. "I never actually felt very ill," he says. "My joints and muscles were quite sore and I thought it was old age catching up. But I've improved incredibly since the transplant. I'm less sleepy, less vague and have tons more energy". He spent just one week in hospital and has

recently bought a business - Busy Bees Services Waikato - as a franchiser of commercial cleaning franchises and is now able to do some physical work training franchisees. He's also back on his treadmill, "three or four times a week now, running up to 6kms.

## Some of the other 498 enjoying life





# To our daughter's donor, thank you

BY YOKEHAR LEE

*Our daughter Julia was 2.5 years old when she was diagnosed with Hodgkins disease, a form of lymph node cancer. While considered in remission, she experienced acute liver failure at 4.5 years old, due to what the doctors deemed a virus.*

The events that transpired are sometimes a blurr, other times stark. My husband and I will never forget the call we received from her surgeon Dr Stephen Munn, mid transplant, that when the transplant team opened her up they found traces of cancer in her. Transplant was suspended while the team sought expert advice on whether to give her the new liver. Thankfully, the experts see cancer as an "eminently treatable disease," in Dr Munn's words.

A new liver does take its time to adapt to a new environment. Providing a home to a liver is akin to settling an alien in a human home. In Julia's case she had chronic liver rejection a few months post transplant. She has also had a series of bile duct infections which have meant a series of interventions including a bile duct reconstruction.

Julia has given us other scares along the way, contracting chicken pox while she was around 6 years old and more recently a gastro-bug which took almost six weeks to shake off, causing her to miss a few weeks of term 2 at school.

We are always mindful that she still has days of unexplained symptoms such as "I feel sick" or "I feel like throwing up". When something in her is hurting there is always cause for concern. No parenting book can tell you when to react and when not to. You develop a balancing act somewhere between gut instinct and practicality and hope you get it right.

For the past nine years we have tried as much as possible not to treat Julia



Yokehar Lee and her daughter Julia

as a "transplant child". We try to normalize her life, encouraging her to do as many sports as possible. We count ourselves lucky that Julia has many natural abilities hence, as we tell her, we have high expectations of her to excel at whatever she does. But most of all, we hope she will



develop a deep sense of empathy and compassion for all beings.

By June 2013 Julia's new liver will no longer be so new. It will be a decade old and she has transformed from a determined little child into a normal, trying 14 year old. She has her own hopes, fears and trepidations. She already worries about her scars, feels short changed for not being able to drink, and thinks about the places in the deepest jungles or highest mountains where she may not be able to track due to the high risk presented.

But for most of the time she is just a really fun-loving, social teen who has stalked Justin Bieber, snorkled in the South China Seas and looks forward to doing her big OE.

Our journey as a paediatric liver transplant family is probably no more curious than any other cases experienced by many families at Starship who have walked down the same path – that of an overbearing sense of doom into the transformative power of hope that comes with a liver transplant.



# Adequate words

ADVICE FROM ORGAN DONATION NEW ZEALAND (ODNZ)

**While many organ and tissue recipients wish to communicate their thanks to their donor family, writing the letter can be a daunting experience. A card may be an easier option and carry the same sentiments.**

In either case we encourage you to wait at least three months post transplant before writing. This gives you time to recover, feel well and less stressed.

In writing, you may wish to:

- Thank your donor family and recognize the death of their own family member
- Talk about yourself and your family, how your transplant has changed your life, mention plans you now have for the future.

Use respectful and sensitive language, remembering that the family is coming to terms with their loss. Simply sign the letter or card with

"from your grateful recipient" or similar.

Please do not include identifying information (name, where you live or work, or phone numbers). All correspondence is reviewed and will not be sent if such information is contained.

When you have finished writing, place the letter or card in an unsealed envelope. On a separate sheet, write your full name and date of transplant. Send both to your Transplant Co-ordinator.

Your communication will be forwarded to your donor family via your transplant team and ODNZ. If your donor family indicates they are not ready to receive your correspondence, it will be held by ODNZ until the appropriate time. You will be informed if this is the case.

While some donor families may choose to respond to your correspondence, some may not. Don't take this personally. You may find that some families respond even years later.

**NB Your transplant team and ODNZ do not facilitate meetings between transplant recipients and donor family members. Confidentiality is maintained to protect the privacy of all involved.**



## BOOKCASE

### More Than a Footnote

The story of Organ Transplantation in Australia and New Zealand  
by Brian D Tait

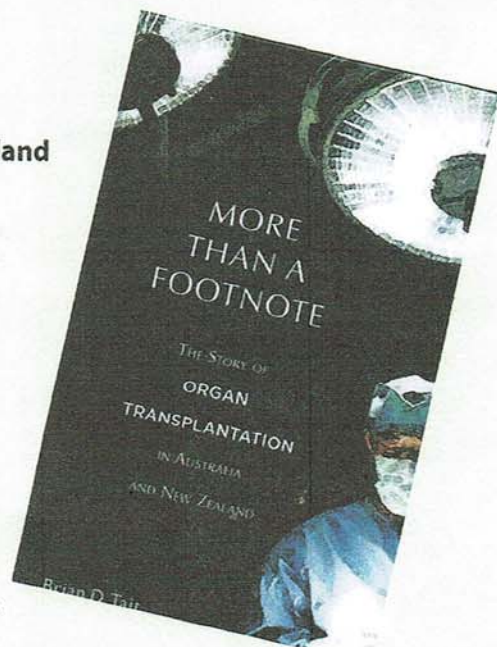


**Rather than a broad international account of organ transplantation, Dr Brian Tait, Senior Research Fellow in Transplantation Services at the Australian Red Cross Blood Services catalogues its progress in his area of the world. It has been published this year as "More than a Footnote".**

It certainly is that. As suggested in the Foreword, the book is "rich with stories about the trials and tribulations of the early days" and "authoritative in explaining the remarkable number of original discoveries (in our two countries). Much of the successes are due to collaboration and common will between the range of disciplines – interhospital, interstate and trans-Tasman. The advent and advances of the New Zealand Liver Transplant

Unit are touched on less vigorously than those of Australia. Professor Stephen Munn's chapter, however, is an assiduous summary of how our Unit evolved. He is one of a raft of contributors; they comprise, at the least, researchers, co-ordinators, technicians, surgeons, patients, all of whom write of their contributions to the history.

Undoubtedly there are more scientific tomes on the subject. This, I think, is aimed at professional health observers, but pleasingly is also accessible to the reader interested to understand how far and how fast transplantation has come in the pantheon of life saving therapies. It goes some good way to answering the who, how, when and why's of the matter.



More Than a Footnote

The Story of Transplantation in Australia and New Zealand

Brian D Tait

Australian Scholarly Publishing Pty Ltd,

567pp

\$A69.65



## ANNIVERSARIES

### 10 YEARS

Transplant No.	Name
110	Daniel
113	Jaimee
114	Paul
115	Margaret
116	Michael
117	Barry
118	Shirley
120	Bruce
121	Susan
122	Kamrul
123	Robert
124	Rebecca
125	Moepai
126	Vincent
128	Grant
130	Robin
131	Matlyn
133	Michael
134	Eileen
135	Mori
136	Morein
137	Summer
139	John
141	Don
142	Wiremu
144	John
145	Rosemary
146	Philip



### 5 YEARS

289	Tevy
290	Kelly
292	Julia
293	David
294	Lara
295	Michael
296	Maria
297	Clinton
298	August
299	Linus
300	Rita
301	Heather
302	Hamish
303	Ivamere
304	Claire
305	Joanne
306	Stephen
308	Bruce
309	Anthony
310	Chris
312	Emma
313	Tangata
314	Philippa
315	Gurdial
316	Bella
317	Crystal
318	Cushla
319	Mia



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

**Q** When will life return to normal?

**A** The term "normal" is relative! Taking immunosuppression medication for the rest of your life and ongoing follow up with the transplant team may not be considered normal by some. However, we expect that you would be able to resume an active lifestyle, return to work or study, travel and enjoy life after your transplant.

Every individual is different. Post-transplant requirements and complications vary from person to person. We aim for you to return to a normal lifestyle as soon as possible, ideally 3-6 months after your transplant. Talk to your transplant coordinator if you have any questions.

**Q** Why do I need to be extra vigilant about sun protection?

**A** Long-term immunosuppression medication increases a person's risk of developing cancer, particularly skin cancer. You should:

- try to keep out of direct sunlight, particularly between 10am and 2pm (11am and 3pm daylight saving),
- cover up as much as possible and always wear a hat,
- no sunbathing or using a sunbed,
- use a good sunscreen.

Marine Blue lotion is an SPF 30+ sunscreen that is available on prescription for people with severe photosensitivity, such as immunosuppressed patients post-transplant. Ask your transplant doctor, coordinator or GP.



Signs of possible skin cancer need to be checked by a doctor as soon as possible. These include:

- Any sore that does not heal, where on the body.
- Any change in the colour or size of a freckle or mole.
- Any sort of skin lesion that changes over a period of time, especially if the borders become irregular.
- Any patch of skin that is consistently itchy for a period of time.

## Did you know...

### 500 transplants means:

187 female recipients

313 male recipients

86 were children

414 were adults

### It took:

131885 minutes of surgery

Or 2198 hours

Or 91.5 days

### You spent:

61610 days waiting for a transplant

Or 169 years

### You were in hospital for:

7844 days immediately after your operation

Or 21 years

### You needed:

1944 units of blood

...because you're worth it!



# Show Your Cards

SARAH FITT NZLTU PHARMACIST

**The Pharmaceutical Subsidy Card (PSC) allows the cardholder and named family members to pay a lower amount on government prescription charges.**

The purpose of the card is to help people who face high prescription costs. There is no income testing for the PSC. The PSC is also known as a Safety Net Card, Prescription Subsidy Card, Exemption Card or Discount Card.

## What do I get from a PSC?

A family unit with a PSC will receive no further \$3 prescription charges for the rest of the year starting from the date when the PSC is issued and until the following 31 January. The card does not cover herbal remedies, supplements that are not classified as medicines, or medicines that you can buy over the counter (that is, without needing a prescription).

## Who is entitled to a PSC?

Any member of a family unit, usually the primary caregiver, will hold the PSC.

A family unit can mean:

- A married (or de facto) couple, with one or more dependent children or

- A married (or de facto) couple, with no dependent children or
- One person with or without children.

## Where and how can I get a PSC?

As a service, your pharmacist will automatically keep a prescription count for you. If your partner or children have different names, you



should make sure the pharmacist knows when a family member picks up a prescription. Your pharmacist will issue a PSC once a family unit has paid for 20 subsidised prescription items since 1 February of any year.

If you go to a different pharmacy

from your usual pharmacy keep your receipts and show them to your usual chemist so they can add them to your PSC record.

If you don't have a usual pharmacy keep all your receipts for prescriptions for your family. When you get to 20 items, take them into a pharmacy and ask them for a card.

## Does it cost me anything to get a PSC?

Pharmacies do not charge for this service.

## What should I do with the card?

Keep it in a safe place. If you always go to the same pharmacy, they should be keeping a record for you, so you might not need to take it with you when you get a prescription. If you visit a different pharmacy, take the card and present it with your prescription.

Government prescription charges are made up of several different parts and can be very complicated. If you have any questions about the charges you pay, please talk to your usual community pharmacist.

# What's 4C?

**What is important about that number? It's the item number on your driver licence that registers your wish to be a donor.**

An enterprising group of Public Relation Students at University of Waikato won an assignment which asked groups to develop campaigns to heighten donor awareness.

Their 4C phrase was mounted on

billboards, posters, T-shirts and was plugged on radio. Inevitably, the response from everyone was "What's 4C?" What a stroke of brilliance.

Other groups came up with campaigns around the words "Have the Talk" "Spill the Beans" and "Have you told your mum yet? Any or all of the phrases are worth their weight in the drive for more organs.

# 4C.

[whatis4c.co.nz](http://whatis4c.co.nz)



# HOW TO DEAL WITH TEENAGERS...

## THE NZLTU'S NEW INITIATIVE

**Currently there are over 40 young people in New Zealand now aged 14 plus, who have had liver transplants in childhood. Some were transplanted in Brisbane prior to the advent of our own liver transplant unit, the majority though, will have been transplanted at Starship Hospital. Given that most juvenile transplants are performed before age 10, these young people and their families have remained under the care of Starship's paediatricians for much of their lives.**

But as young people hit their mid teens with its attendant problems they're required to move from the familiar environment of Starship into the quite demanding structure of the adult service. Each year, of course, the numbers build. Most young people, possibly 50%, are well adjusted and cope fine with this transition. Some, though, struggle with the process and don't engage well with the adult service from the get go.

Which is why in February this year, a new service arrived on the Liver Transplant block. The Young Persons Liver Clinic. This clinic tries to smooth the journey between paediatric and adult care for young people with liver disease or who have had liver transplants. This is the joint work of paediatric and adult services and is led, from the adult services side, by hepatologist Dr Rachael Harry.

Since her arrival in 2009 Rachael received growing numbers of referral letters from paediatric gastroenterologists at Starship and the problems of transition became apparent. "In the first instance," says Rachael, "you have a situation of the patient not wanting to leave Starship. You also have a situation of parents having to pull away from the people who have supported them so well and kept their child well for possibly many years. It's not intended

that the patient should be abandoned, but actually, that's the way it can feel."

Traditionally, there has been no framework to educate the patients and families about the differences between the two services – the highly assisted service of paediatrics and the self-sufficient approach required of adult patients.

Therefore the idea of the Young Person's Liver clinic is to introduce young people and their families to the adult setting with paediatricians still present and involved in their care. That way, it's hoped



Donatello, Dr Rachael Harry and Dr Helen Evans

that the patients and their families will develop trust in the adult service ahead of transfer.

Since February, the team has held monthly clinics at the Greenlane Outpatient Centre. The team comprises Rachael, two Starship gastroenterologists – Helen Evans and Stephen Mouat, adult nurse practitioner Margaret Johnston and Cate Fraser-Irwin, paediatric nurse specialist. On board also are psychologist Lucy Robinson and NZLTU Chief social worker Ron Benjamin. During an hour long appointment the patients will meet with two doctors, followed by a session with two nurses. Social and psychological services are included as required. The team has undertaken training in engaging teenagers with the help of the centre for Youth Health in Papatoetoe. As Rachael finds it, "there's a whole lot of information out there about how to engage teenagers in managing their own health and it's important we learn about it."

Part of the initiative is that the paediatricians now begin to steer young patients towards independence from Starship at age 12-14 when they start to attend some clinics on their own and slowly become familiar with adult patient requirements: - the responsibilities of taking their own medications, filling scripts, booking and confirming appointments, knowing how to recognize symptoms, who to call if they feel unwell. These skills are built on in the transition years.

Of particular concern are those young patients in the far flung reaches of the country who are under the post-operative care of local paediatricians. In theory, the New Zealand Liver Transplant Unit – both adult and paediatric arms – provide an over-arch for the care of all patients who have received liver transplants. However when a young person transfers from paediatric to adult care outside Auckland there has been no formal system to ensure this continues. The creation of this clinic is intended to overcome the vagaries of the system. As a result of the initiative, the NZLTU now has a data base of all child transplantees in New Zealand and they can be followed more closely.

The Young Persons' Liver Clinic is still in its infancy but the team hopes it will grow in stature and success. "We're feeling our way," says Rachael. "Of course we'd like to think that if we give teenagers the right information they could process that and come up with good decisions. That they're going to take their tablets regularly (non-adherence to medication is common among adolescents), they won't drink alcohol, they'll take appropriate precautions with sex. Of course, it's not always like that. But for sure, if you don't give them appropriate information, they can't make appropriate decisions. I don't think the education we are trying to provide is the answer to everything, but it forms a basis, at least."



# Game on

**The 19th World Transplant Games 2013 are to be hosted in the South African city of Durban. Recipients of organ transplants from more than 55 countries will compete in 13 different sporting codes aiming to win Gold, Silver or Bronze medals for their countries.**

Sports represented in Durban include Badminton, Bowling, Cycling, Golf, Lawn Bowls, Road Race, Squash, Swimming, Track & Field, Table Tennis, Tennis and Volleyball.

The World Games are held every two years and there is a Winter World Transplant Games event in the intervening year. The next Winter games, the 9th, is to be held from 12th to the 17th January 2014 in the resort of La Chapelle d'Abondance in Haute-Davoie, France. The Winter Games includes the Nicolas Cup a ski event for child transplantees.

There are also regional events such as the Australian National Transplant games held recently in Newcastle, NSW at which our local team performed so well.

At the last World Games held in Göteborg, Sweden in 2011 the New Zealand team of 13 athletes won 8 medals - 2 Gold, 2 Silver and 4 Bronze.

Athletes compete by gender and by age groups: (18-29), (30-39), (40-49), (50-59), (60-69) and (70+). Juniors compete in events designated as junior events by gender in the following age groups: (5 years and under), (6-8), (9-11), (12-14) and (15-17).

The games are intended to help raise awareness of the importance of organ donation worldwide. The athletes competing in the World Transplant games are living proof of the life affirming gift that organ donation represents.

19th World Transplant Games 2013  
You can get more information from the New Zealand Transplant Games Association at

[www.transplantnewzealand.org.nz](http://www.transplantnewzealand.org.nz)  
or see the World Transplant Games Federation site at [www.wtgf.org](http://www.wtgf.org).



## WORLD TRANSPLANT GAMES DURBAN 2013



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## PLAY ON GUYS

**A team of six transplant recipients won an impressive number of medals at the Australian Transplant Games in Newcastle, NSW this year.**

The games took place from September 29 to October 6 and offered 24 events for transplant recipients. Donor families and live donors are also invited to compete in selected supporter events.

New Zealand's team took home nine gold, seven silver and seven bronze medals. Team Manager Sheryl Power said they were delighted with their effort. "We really enjoy competing in both the Australian and the world transplant Games and after a lot of hard work we were proud to come home with an impressive tally of medals."

The New Zealand team was the inaugural winner of the International Shield presented to the most successful visiting



Ross Forrester, Dave Swarbrick, Bryan Eckersl, Alan Power, Sheryl Power (Team Manager) Gr Hampton. Missing: Ken Newlands

country team per competitor (senior and juniors)

Next year a team of recipients will be competing in the World Transplant games in Durban, South Africa.

Care to join them?

Courtesy ODNZ





Dr Mahendra Naidoo (registrar), Dr Estella Johns (Registrar), Jen Chesbrough (Nurse Specialist), Dr Muhammad Asim (Transplant Surgical Fellow), Sarah Fitt (pharmacist), Barry Harrison (Transplant Coordinator), Ron Benjamin (Social Worker), Val Honeyman (hidden) (HCC Coordinator), Karen Lowe (nurse specialist), Kathy Oliver (Team Administrator), Dr David Orr (Hepatologist) Front: Margaret Johnston (Nurse Practitioner), Dr Rachel Harry (Hepatologist), Professor Ed Gane, Mr Adam Bartlett (surgeon), Mr Peter Johnston (surgeon).

## Hepatic Happenings

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### Consulting Editor

Margaret Johnston

margj@adhb.govt.nz

### Editor

Lyn Loates

tinlid@extra.co.nz

### Design

Jude Woodside

Jude.woodside@gmail.com

Contributions for 2013 issue welcome.

Please send to:

Hepatic Happenings

c/o NZLTU

P.O. Box 8395

Symonds Street

Auckland City 1150

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## From the 15th floor

***I can't believe how quickly this year has gone. It has been highlighted by the milestone of the 500th liver transplant and the celebration of 10 years of paediatric liver transplantation in New Zealand. We are extremely lucky to have many of the original staff from the time of the first transplant in 1998 in all departments of the NZLTU. It's a real thrill to know that so many people's lives have been saved and changed through the kind donation of the liver donors either live or deceased.***

The team on the 15th floor have been managing an exciting time between the hard work.

2012 has meant a change of role for Val Honeyman. There has been a growing need for a dedicated Nurse Specialist to oversee the care of the patients who have liver cancer. Val has sadly (for Barry and Margaret) moved from the transplant coordinators office to a little way down the corridor to take up this long needed role. She has just returned from a 21/2 week trip to Vancouver, New York, Boston and Singapore visiting hospitals, and attending conferences. A wonderful opportunity for her to ensure those who have liver cancer are getting the best care possible.

We have been fortunate to have Lucy Mills change her role from Nurse Specialist on Ward 71 to fill Val's position. Lucy, Barry Harrison and Rachael Harry keep us all very tired

on the 15th floor with them talking about which run they are doing next and what training they are doing. Barry has completed two marathons this year in the record time for the Liver Transplant Unit (3hr 31min)! Rachael and Lucy are excelling in half marathons and the local tri-series (again with NZLTU record times).

Ed Gane has once again had a very successful year with respect to his results on research into the treatment of Hepatitis C (see article). We are extremely lucky to have Ed's expertise in this unit ensuring that the NZ Hepatitis C patients are getting the most up to date treatment and best of care.

2012 is the year of babies/pregnancy. Karyn Lowe, the Nurse specialist on Ward 71 gave birth to her 2nd child Amelia in April and Adam Bartlett's partner gave birth to their first child Sophia in June, both beautiful wee girls. Stephen Munn, Peter Johnston, Kathy Oliver and Margaret Johnston are all expecting grandchildren early in 2013, the first for Steve, Peter and Margaret. Jen Chesborough who has replaced Lucy on ward 71 is also expecting her first child early next year. Exciting times for us all, lots of show and tell photos!

From all of us in the NZLTU we wish you and your families a very Merry Christmas and Happy 2013.

Margaret Johnston