

# Hepatic Happenings

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## The man who ran for his daughter's life

**Over the past months a man in full military kit and a 20kg pack on his back has been seen pounding the early morning pavements of Northcote. He's David Cave and in fully laden mode, completed the recent 42km Auckland Marathon in a foot blistering 5hrs 30 mins. He and two buddies ran for Starship Foundation and through [fundraiseonline.co.nz/militarymarathon](http://fundraiseonline.co.nz/militarymarathon), have raised \$4,230.00. Great effort, we say.**

David is a New Zealand Defence Force youth instructor. He's also father of two daughters, one of whom, Madison, was diagnosed with *biliary atresia* (bile duct blockage) at 6 weeks in 2011. It was made clear to David and

his wife Kelly that without transplant, Madison was not expected to survive more than a year. David donated part of his own liver to save Madison's life. There were complications, a second transplant was required. The liver transplant team fast tracked a suitable liver from Australia and within a short nine days Madison had received a second transplant. However, the road to Madison's recovery has been bumpy. She has had to fight severe rejection, pneumonia, low platelet count and recurring infections. She has proved her true fighting spirit and despite astonishing setbacks, is now doing well. "But you know what," David reflects. "We're the lucky ones. Our kid came home."

David Cave has become one of many parents to benefit from the efforts of the fund raising organization, Starship

Foundation. The Foundation's contribution to Starship Childrens Hospital is immense and without equal in New Zealand. Fundraising enterprises sprout from all corners of our society. Of his own effort, David says "It's been about mental fitness and putting one foot in front of the other. My knees are shot to pieces... but no matter what I go through it's nothing in comparison to kids like Maddy."

Now David Cave intends to run the gruelling *Marathon des Sables* on behalf of Starship Foundation. It covers 200km of the Sahara Desert and is reputed to be one of the most trying tests of human character on earth. He is keen to hear from anyone who could help his fund raising efforts and make the feat possible.

(courtesy: Fairfax New Zealand News)

# Editorial

There is something exciting on the horizon and thanks to the unreserved efforts of Dr Ed Gane and his team, it's on its way to a liver transplant unit near you.

We're referring here to a new oral antiviral drug Sofosbuvir, much of the development of which took place here, in conjunction with the NZLTU. Its approval is now a mere formality and it will soon be used in the treatment of Hepatitis C with - it is anticipated - astonishing effect. Here in New Zealand, 400 Hepatitis C sufferers - both pre and post transplant - took part in the clinical trials and 90% of those have been cured with 12 weeks or less of the drug.

This is a major step internationally for the treatment of the Hepatitis C virus and it deserves major accolade. Dr Gane's summary of the development

takes pride of place in this issue of *Hepatic Happenings*.

However, for many of us in the liver transplant family, personal achievements carry their own excitements. This year, for example, teenager Matthew Mokoroa who was transplanted in 2005 set two world records in his age group for cricket ball throwing and shot put at the 19th World Transplant Games in Durban. He earned two gold medals for the team. And David Cave, father of and donor for baby Madison ran like a trooper to honour his daughter's life. This year also, Wendy Duff received the medal of the New Zealand Order of Merit in the New Year's Honours List. Wendy was transplanted in 2003 following primary liver cancer and respiratory disease but soon carried on her unstinting service to Autism

New Zealand which organization nominated Wendy for this special honour.

Our "family" is stocked with people who, on the back of second chances, pick up the baton. Travel, education, new and secondary careers, sport, creative pursuits - the opportunities available when one becomes well are again within reach, and often seized with renewed determination and vigour. You'll see a couple of examples within.

Come to think of it, those first steps taken by any transplantee following surgery may also be the most winning steps a person can take. For all of us - the patient, the care giver, the family, the donor family, the medics and the staff - those small steps can herald a big new life. And that's just got to be exciting.

## Thank you Dr Tom

**Fifty years ago Dr Thomas E. Starlz performed the world's first liver transplant at the University of Colorado.**

Four years later he performed the first successful liver transplant. Then, in 1980, he brought the field a step forward by introducing the anti-rejection medications, anti-lymphocyte globulin and cyclosporine which became the accepted immunosuppression regimen given to patients with a liver, kidney or heart transplant.

Nine years on he introduced the anti-rejection medication FK-506 (tacrolimus) which markedly increased survival rates for liver transplants and led the way to other successful types of organ transplants including pancreas, lung and intestine.

For most of his career Starlz led a team of transplant surgeons at the University of Pittsburgh School of Medicine. Now 87 years old he devotes his time to research and remains active as professor of surgery at the University's Thomas E. Starlz

Transplantation Institute. Starlz, known as The Father of Modern Transplantation, is the world's most cited scientist in the field of

clinical medicine.

Dr Thomas E. Starlz MD, PhD





# Direct Acting Antivirals herald breakthrough in Hepatitis C treatment

NZLTU is the only transplant centre outside USA and Spain involved in these ground breaking studies

**Hepatitis C is now the leading indication for liver transplantation and is responsible for 40-70% of adult transplants around the world.**

The hepatitis C infects the new liver at the time of transplant surgery and this can result in rapid re-development of cirrhosis, often within 5 years. Because of this, people transplanted for hepatitis C have worse outcomes and shorter survival than those transplanted for other liver diseases.

Up till now there has been no safe and effective treatment to use before or after liver transplantation. Interferon is not effective, is poorly tolerated and sometimes causes severe rejection.

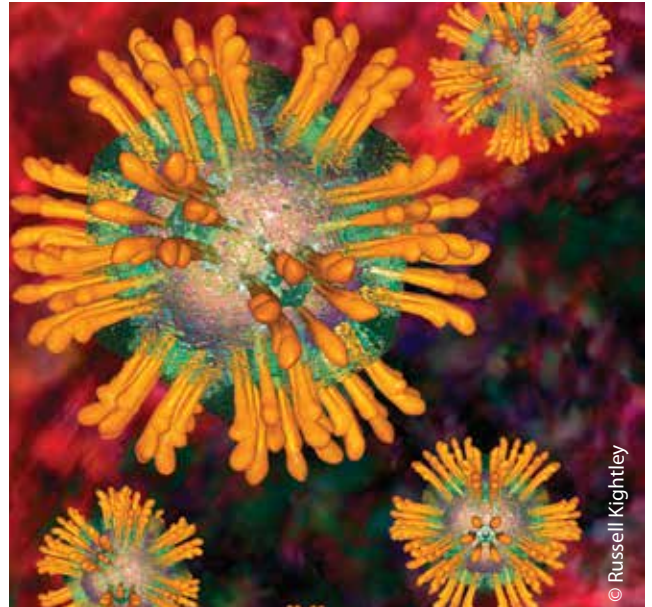
Therefore there has been great excitement surrounding the recent development of combinations of new, better tolerated oral **direct acting antiviral** (DAAs) which, when used in combinations, completely remove the need for interferon and ribavirin.

Three DAA combinations have entered global registration

studies. These are made by Gilead, AbbVie and BMS. All three regimens achieved greater than 95% cure in Phase II studies after only 12 weeks treatment.

**Sofosbuvir** is the most advanced in clinical development and is likely to be approved in early 2014. Much of the development of Sofosbuvir took place here in New Zealand. To date, more than 400 New Zealanders have been treated with Sofosbuvir in the ELECTRON study, more than 90% of whom have been cured with 12 weeks or less of tablets.

The first trials of these “interferon-free” DAA combinations have started in people with “end-stage hepatitis C” who are on the waiting list for liver transplantation. The preliminary results suggest this treatment will prevent the virus infecting the new liver after transplantation which should improve wellbeing and survival. As well, successful treatment



The Hepatitis C virus

before transplant may lead to recovery of liver function and rescue many people with liver failure who would otherwise require liver transplantation. Early results from the first trials of these DAAs in liver transplant recipients with recurrent HCV infection have demonstrated that these are safe and effective after transplantation. There are almost 150 liver transplant recipients at NZLTU with recurrent HCV infection all of whom will benefit from successful treatment with these new oral therapies.

*Ed Gane*

## Current HCV treatment

Current antiviral therapy for HCV is limited by poor efficacy and tolerability especially in patients with HCV GT1. Pegylated interferon (PEG) plus ribavirin (RBV) has significant side-effects, must be administered for up to 48 weeks and cures less than half of patients. These limitations mean less than 1% of HCV+ New Zealanders are treated each year.

The addition into the mix of recently approved first generation protease inhibitors (bocepravir and telepravir) - oral drugs which target specific steps of HCV replication - has shortened the duration of treatment from 48 to 24 weeks in almost 50% of patients. Similar improvements in efficacy are observed in previous non-responders to PEG/RBV. But these improvements in efficacy are offset by the reduced tolerability of the triple therapy. The triple therapy is not only associated with specific toxicities

but requires a strict and inconvenient application regime.

Our biggest dilemma is whether to commence immediate treatment with bocepravir or wait until the interferon-free oral DAA combinations become available. Although all HCV+ transplant

recipients are eligible for PHARMAC-funded Pegylated interferon plus ribavirin, we suggest most should now wait until the all-oral treatments become available within the next 1 – 2 years.

Current HCV treatment regime: pegylated interferon and ribavirin



# Happy Anniversary



John  
Robert  
Mata  
Maurice  
Alan  
Jun  
Ken  
Ronette



Lois  
Christopher  
Rene  
Teyah-Mere  
Lorraine



Peter  
Noel  
Ketisemani  
Irene  
Taiai  
Anne  
Angus  
John  
Sean  
Garry  
Kirsty  
Barry  
Gary

Joanne  
King-Hon  
Edward  
Julia  
Tristram  
Ellen  
Cho-Ching  
Mark  
Toma  
Teimouraz  
Judith  
Naziah  
Pieter  
Ronald  
James  
Wendy  
Rex  
Brady

Amanda  
Hok  
Jorge  
Fononga  
Jesse  
Neville  
Kirsty  
Mirianne  
Helena  
Abdi  
Darryl  
Ken  
Sandra  
Richard  
Raymond

Anna  
Jonathan  
Dennis  
Sharleen  
Blake  
Sophie  
Barry  
David  
Robert  
Feng  
Lynda  
Maia  
Anthony  
Joanne



# This Lady Deserves a Medal

**When Wendy Duff was wheeled into theatre for transplant surgery in 2000 she reckoned her luck was in. She'd been diagnosed with primary liver cancer, the tumour was growing but still small enough for a liver transplant to be viable and a liver had become available within a few months.**

So when she woke up in ICU feeling unusually well she was elated. Wendy is a busy person, a formidable achiever and among her first thoughts, there in ICU, was that there were things to do and she'd get over this small hurdle in no time flat.

But the unpalatable truth was, the transplant hadn't happened. During pre-op preparations, a previously undiagnosed condition – Pulmonary Arterial Hypertension was diagnosed. The tumour had been temporarily staunched, but the PAH had to be successfully treated before transplantation could be considered.

With no definitive, affordable treatment available to her in New Zealand, Wendy Duff was soon on a plane to the United States to attend a medical conference on PAH. There she learned of an attested treatment. In some countries Sildenafil, commercially known as Viagra, was being used in conjunction with other medications to treat PAH. Wendy returned with a tape recording of the conference session and persuaded the NZLTU to apply for a special authority on her behalf. In conjunction with the nebulising drug Iloprost, she was able to bring the PAH under control.

After two years of successful treatment, but with the tumour re-growing, Wendy had her transplant in 2003. She had continued with her daily work as an accounts executive with an Auckland manufacturing company up to the day before the transplant. There were no



Wendy Duff receives her MNZM from Governor General Sir Jerry Matapara

complications. Three months later she was back in the office as if nothing had happened. She's still there, always grateful to have had the surgery, but it does not occupy a predominant place in her mind.

What does predominate is her voluntary work for Autism New Zealand. Back in 1996 when her son Elliott was two, Wendy could find nobody in New Zealand who could give a definitive diagnosis of her son Elliott's disability. Wendy took him to Brisbane to meet with Professor Tony Attwood, internationally pre-eminent in spectrum disorders. Attwood confirmed autism and Wendy's interest was ignited. It's for her work with Autism New Zealand that Wendy received a MNZM in the 2013 New Years' Honours List.

Neither primary liver cancer coupled with respiratory illness nor a subsequent liver transplant has interrupted Wendy's determination to progress services for this section of our disabled community.

Last year she stepped down from a 12 year stint on the Board of Autism

New Zealand having presided as Chair since 2007.

She is acclaimed for progressing many of the services in New Zealand, particularly for her role in seeing providers of respite care extend residential services to people up to 21 years. Yet there are still no day programmes available to many autism sufferers in the post-education age group who remain home bound and unmotivated, sometimes to the destruction of families.

So Wendy, still a member of the Auckland committee and a member of the Disability Support Services Consumer Consortium (under the umbrella of the Ministry of Health), refuses to lie down, continues to push passionately for service improvements. She implies she is a thorn in the Ministry's side. "But there's a continual fight to be fought," she says. Likely as not, the unflinching Wendy Duff MNZM will be on the winning side.

# The highs and lows of herbal remedies

There is a general belief that **Complimentary and Alternative Medicines (CAMs)** are “natural” and therefore harmless. This, coupled with the increasing desire for a “natural” lifestyle, has resulted in expanding use of CAMs. This is particularly seen among people with chronic disease, those wanting to prevent the effects of aging and those wanting more autonomy and involvement in their own health.

In Australia, almost half the adult population use a natural supplement, with public spending on complementary medicines being an estimated figure of four times the patient contribution for all pharmaceutical medications. In a recent local study (Ryan et al), the majority of people attending HCV clinics in the Auckland region were taking at least one CAM.

Under the Medicines Act, most herbal remedies in New Zealand are exempt from licensing. They are classed as dietary supplements under the Food Act, but there is limited regulation. Because of this, potential problems with CAMs include the risk of contamination with toxic substances such as heavy metals or pesticides/herbicides. Herbal medicines are frequently adulterated with prescription medicines to increase

efficacy. Common examples include diabetes remedies which contain anti-diabetic medicines; rash creams which contain steroids; arthritis remedies which contain aspirin or steroids; potency remedies which contain Viagra. Other possible problems include interactions with conventional medicines and direct toxicity, including hepatotoxicity (i.e. liver injury). Note: It may not be possible to identify actual contents of products.

The most common and most serious hepatotoxic ingredient found in CAMs in New Zealand is the kawakawa plant (Maori pepper tree). The root of this plant is a common ingredient of traditional Polynesian medicines often used by Maori and Pacific Islanders. Kawakawa is a close relative of Piper methysticum, the plant from which kava is made. Kava is used to treat anxiety, stress, epilepsy, infections and many other conditions. Almost 100 cases of severe liver toxicity (including acute liver failure and death) have been attributed to kava and it is now banned in many countries including Switzerland, Germany and Canada. In New Zealand, consumption of tea brewed from the kawakawa root has been linked to severe liver failure and death in several patients, most of whom had underlying chronic liver disease.

However, most CAMs are safe and

some may benefit people with chronic liver disease.

Garlic is a common ingredient of CAMs and is a strong antioxidant which can directly scavenge free radicals. In addition to potentially ameliorating the liver damage caused by hepatitis, it can reduce blood pressure and cholesterol and may help build up resistance to infections.

Ginseng improves immunity by enhancing natural killer cell function and may reduce the long-term risk of cancer.

Milk thistle contains *silymarin* which has strong anti-oxidative and anti-fibrotic properties which may slow the progression to cirrhosis.

St John's Wort contains *hypericum perforatum*, which has antidepressant properties. However, it should NOT be used in patients post liver transplant because it reduces the effectiveness of the immunosuppression medication.

It is important to remember that the risk of liver toxicity from any medicine (both prescribed and complementary) is much higher in someone with a transplanted liver. For this reason, any patient who has had a transplant should always discuss any CAM with their doctor or pharmacist, before starting a new therapy.



**Kawakawa**



**Comfrey**

## Short list of known hepatotoxic CAMs available in New Zealand

|                   |                                   |
|-------------------|-----------------------------------|
| Kawakawa bush tea | Acute hepatitis and liver failure |
| Kava              | Acute hepatitis and liver failure |
| Black cohosh      | Acute hepatitis and liver failure |
| Germander         | Slow fibrosis and cirrhosis       |
| Chapparral        | Slow fibrosis and cirrhosis       |
| Comfrey           | Acute jaundice                    |
| Skull Cap         | Chronic hepatitis                 |
| Shark cartilage   | Chronic hepatitis                 |



**Germander**



**Kavakava**



**Black Cohosh**



**Skullcap**



# Eating Well for Health

## Dietician Rosalind Poole explains the importance of eating well post-transplant

**Improvement in surgical techniques, management of infectious complications and immuno-suppression has led to excellent long-term survival rates in liver transplant recipients. As a result we are becoming increasingly aware of the role nutrition and lifestyle play in optimising liver health and reducing complications after transplant.**

Many patients will know from experience that malnutrition is closely related with severity of liver disease leading up to transplant, often requiring a diet high in calories and protein. The presence of ascites in cirrhotic patients can also make BMI measurements irrelevant pre-transplant. However, good nutrition and weight management following transplant are just as important.

Patients may find that their weight begins to increase after the first few months of transplant. This can be due to a combination of factors: medication (steroids), feeling better with improved liver function, no dietary restriction (e.g. low sodium), better appetite, liver working efficiently, keeping to high protein/high energy food.

Unfortunately research shows that obesity within one year of transplant is becoming more common.

Obesity in the general population is often publicised as one of the most significant public health challenges of the 21st century. Less widely known is that the burden of disease caused by obesity is largely related to the “Metabolic Syndrome.”

Metabolic Syndrome (MS) is defined as the presence of dyslipidemia (eg: high cholesterol), obesity, glucose intolerance (raised blood sugars/diabetes), and hypertension (high blood pressure). MS has become a major health concern worldwide and is considered to be the cause of the current epidemic of diabetes and cardiovascular disease.

Following liver transplant, the prevalence of MS is estimated to be 44-58%. Left untreated, MS can lead to non-alcoholic fatty liver disease (NAFLD), increased cardiovascular disease, or a more rapid progression



to fibrosis in those transplanted for cirrhosis. Therefore early recognition, prevention and treatment of MS components (diabetes, obesity and hypertension) are vital for ALL liver transplant patients.

The good news is that if we achieve and maintain a healthy weight through good nutrition and regular exercise we can significantly reduce, eliminate or prevent the negative effects of MS and its complications from occurring. Good nutrition is achieved by eating a variety of foods from the four main food groups (breads and cereals, fruit and vegetables, lean meat and legumes, and

low fat dairy/soy products) to maintain your ideal weight.

It is important that as soon as you begin to near the “healthy BMI range” you follow a healthy eating plan, just like that recommended for everyone. This will reduce your risk of obesity, heart disease and high blood pressure.

**If your weight is already beyond the healthy range, then following a plan like the one below will also help you to maintain your present weight and possibly reduce it:**

1. Eat regular meals (ie. breakfast, lunch & dinner).
2. Do not continue your high energy/high protein diet.
3. Cut down on fatty foods.
4. Eat plenty of fresh vegetables – choose a variety of colours.
5. Always use lean meat, chicken and fish, and keep portions small.
6. Avoid sugary beverages such as fruit drinks, juices and fizzy drinks.
7. If you have high blood pressure, maintain your low sodium diet.
8. Enjoy regular exercise, aim for 30mins/day.

### Understand your risk

#### Obesity or Abdominal Obesity:

BMI > 30kg/m<sup>2</sup>

#### or Waist circumference:

>102cm in men

>88cm in women

#### Dyslipidemia:

Serum triglycerides >2.0mmol/L

HDL Cholesterol <1.0mmol/L

#### Insulin resistance or diabetes:

HbA1c > 41mmol/molHb

#### High blood pressure:

> 130/85 mm/Hg

\*Steroid medication can exacerbate these symptoms.

# WHAT WE'RE DOING NOW

Three recent liver transplantees share what they're doing with their lives now

## Roisin King

**“Why do you want to do Outward Bound?” was the most regularly asked question and to be honest I didn’t have an answer that justified my decision.**

**Except this. I had a liver transplant in June 2011 (autoimmune or unknown virus) and tried very hard to reach the conclusion that life is short, not to be wasted and get back to living a life worth living.**

At the time of booking Outward Bound what I really wanted to do was outdoor sports, prove to myself and the people around me that I am not fragile. After all, in late April 2011, I had turned banana yellow and in June was flown to Auckland. Within a week I was on the critical list with 24 hours before my poor liver gave up but not my brain and I had kicked in the willpower to survive. Well that is what our family history now records. A liver from Australia at the last minute and a world-class liver unit probably had more to do with it!

So you see Outward Bound felt like the challenge I needed to kick start living for me. I booked in for the “Aspire” course, designed for people recovering from illness, or at least people who are less than optimally fit.

The Aspire course runs over 8 days and mostly involves sailing, canoeing, high ropes and climbing. There is a 24-hour period sleeping rough; it turned out to be a highlight. The base camp at Anakiwa in the Marlborough Sounds is a dream and the food is amazing. The coaches and equipment are top notch.

Bearing in mind that Outward Bound grew its reputation as a discipline for kicking teenagers into shape, there can be an assumption that people who attend the courses have a small comfort zone and need to be shaken out of it; that we are all soft, scared to put our toes in the water. I beg to differ. Who knew I could get through a night on a clipper, dog tired, the entire crew snoring (reminding me of nights in hospital).

I won't lie. I found being thrown in to the Outward Bound challenges very uncomfortable. But I also learned a couple of “take-homes” that



I believe will prove valuable in my approach to life in general.

There are lots of options on what you can do post transplant to challenge yourself. Outward Bound is one of them. I'd like to say that whatever



Roisin King

you do, do something because as a transplantee you'll discover life is short, not to be wasted and you need to get back to living a life worth living. But after Outward Bound I would add be kind to yourself. Sounds better eh!

### Outward Bound offers:

- An 8 day Aspire course costs \$2320.00 (includes everything)
- A 21 day course for fit people

Sponsorship is available in some cases.

Contact 0800 688 927

## Mia Fakin

I have always longed to travel the world and as an ardent Anglophile and art history nerd I've been particularly keen on visiting the UK and Europe. During my illness it was a goal I looked forward to achieving once I was better. This year my dream finally became a reality when I moved to London in March and began my overseas experience.

Living in London has been an exhilarating and challenging experience so far. It's been a joy discovering all the history, culture and fun this city has to offer.

After a couple of months exploring and acclimatising to my new home I settled into a routine work and home life and began contemplating some new adventures further afield.

I planned to take a short holiday during a break in temping assignments and settled on Bruges as the destination for my first sojourn into Europe, and it has been the highlight of my trip so far.

I sought a retreat from the hectic metropolis and with its calm, friendly atmosphere, Bruges more than delivered. Wandering around the city I felt almost transported back in time. With its charming canals and well-preserved Gothic medieval architecture, the city's historic centre is a picturesque delight.



In my four days in the compact, walkable city I took in as much as possible.

The imposing Belfort that towers over the Markt square and beautiful churches such as the Onze-Lieve Vrouwekerk (Church of Our Lady) and the Basilica of the Holy Blood offered intriguing glimpses into the city's rich history. My visit to the Groeningemuseum and its wonderful showcase of Flemish art from the Primitives to the Expressionists was another particular highlight.

I enjoyed the boat tour along the canals that provides another perspective of the city, and a peaceful stroll around the tranquil environs of the Begijnhof and the Minnewater Lake.

The city looks even more magical at night, especially in the beautifully lit and lively Burg and Markt squares. Though touristy, the Markt is the perfect spot to dine, relax and people watch in the evening.

Belgian food was another joy. I indulged in delicious waffles, chocolate, ice cream and far too many frites to



Mia Fakin soaking up the atmosphere in Bruges

mention. Also, any city that celebrates its food history with museums dedicated to chocolate and fries is definitely my kind of place.

I was sad to leave Bruges but thrilled to have experienced it. My list of must-see European destinations grows

constantly but the history, art and culture of this medieval Belgian city was the best introduction to the wonders of Europe I could have hoped for. I can't wait to see where my adventures take me next.

## Donatella Odisho

**Just months out from her second liver transplant in two years, 16 year old Donatella's new goal is to help younger teenagers realize they should make the most of their lives.**

After three tough years in which she was diagnosed with an acute form of the rare Wilson's Disease, underwent a live organ donation at age 14 within 72 hours after being rushed to hospital and a second transplant in May this year following eventual failure of that liver - and that's without counting the 100+ hospital procedures in-between, this girl reckons she knows the value of life.

"This year I was lucky enough to be invited to be an official contestant for Miss Junior New Zealand 2014," Donatella says. Hundreds of girls aged 10 – 17 applied to participate, 60 were chosen and in April next year the winner will be announced. Director of MJNZ, Collette Lochore advises "At MJNZ there is no spray tanning, no big poufy hair, no ridiculous heels, no "go-go" juice, no stage mums, no tantrums..." She goes on to say that her competition is not about appearance, rather it's about Beauty with a Mission. And that appeals to Donatella Odisho. She's looking forward to the two month

workshop beginning in February in which contestants will be coached in life skills and development of self-esteem with the aim of encouraging future women leaders. In the MJNZ Pageant in Auckland next April, finalists will then be judged on charity and community involvement, public speaking abilities, attitude, talent, sport and the "feeling fab" factor.

Meantime the selected contestants have each chosen a charity that motivates and inspires them and they have initiated fundraising efforts for their particular cause.

Donatella has chosen The Kids Foundation (founded 1987) as her charity. It was this organization that supported her and her family during her time in hospital. "They checked on me and made sure my (correspondence) school subjects weren't behind," she says. Now she wants to repay them. She has just resumed study at Papatoetoe High School. Ultimately she wants to train as a physiotherapist but



Donatella recovering from her 2nd transplant

currently, she says, "My future is to make people proud, most of all the people who were around me, the people who saw me at my worst."

*(Wilson's disease is caused by excess copper in the body tissues. It affects 1 in 30,000 people. 8 have been transplanted for the disease since NZLTU began. Also known as hepaticolenticular degeneration).*

*Picture courtesy Richele Louisson photography*



# BOOKCASE

Title: *Cutting for Stone*,

By: Abraham Verghese

Publisher: Vintage, 2010

**I happened upon this capacious novel earlier this year when I had to read it for the book group to which I belong. At first glance it was not a book I would have chosen. The title “Cutting for Stone” was a mystery in itself**

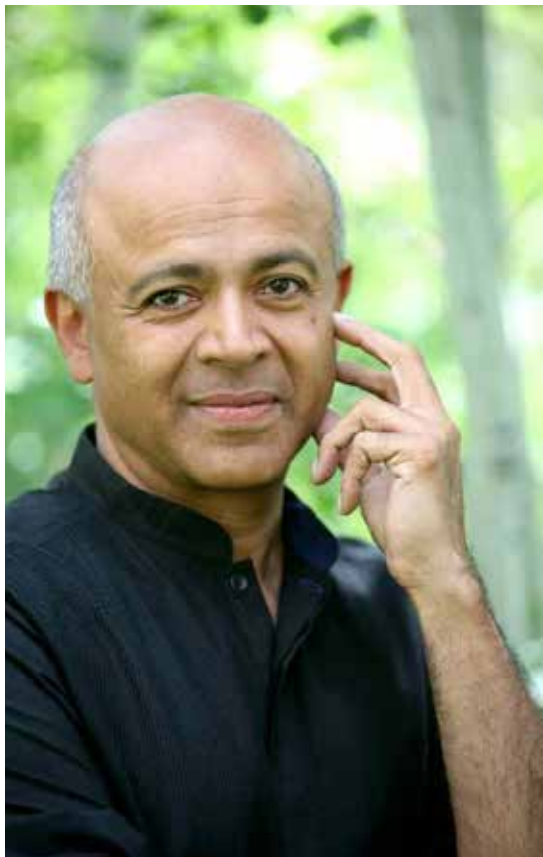
The book follows the life of two skull-conjoined twin boys, born in 1954 to a nun in an Ethiopian Mission Hospital and an unproven father, largely absent from the pages but hauntingly present in spirit. The nun dies of complications during the twins’ birth, but there is professional expertise on hand which sees the twins successfully separated shortly thereafter. The doctors responsible for their survival raise the twins amid the political turmoil of northeastern Africa.

Though spiritually connected, the twins pursue increasingly separate lives. Both

enter medicine and become successful surgeons in differing disciplines and different countries.

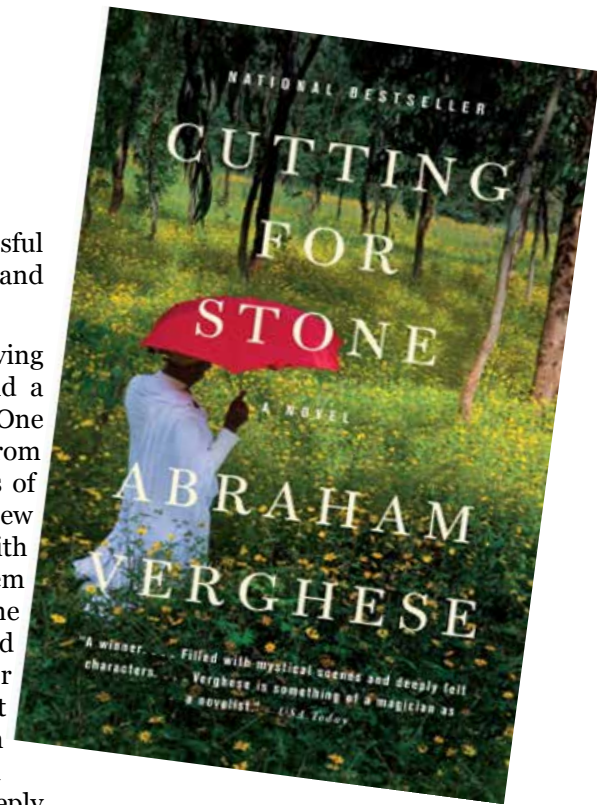
The story threads seamlessly, weaving in a multitude of back-stories and a hefty agglomeration of detail. One particular ingredient leapt out from the mix. The author’s descriptions of surgery, vivid enough, says the New York Times Reviewer that those with weaker stomachs may find them disturbing. She goes on to say, “One would, I suppose, be ill advised to use this novel as a textbook for liver transplantation...but it might almost be possible”. Take from this that liver transplantation circa late 20th century America is deeply and probably accurately addressed. I suspect I took more interest in this aspect than the average reader might.

Abraham Verghese, MD, MACP, is Professor for the Theory and Practice of Medicine at Stanford University School of Medicine and Senior Associate Chair of the Department of Internal Medicine. Indian by birth, Verghese studied at Madras Medical College and arrived at Stanford via Tennessee, Texas and finally Boston University School of Medicine. In his first spell at Boston he saw the early signs of the forthcoming AIDS epidemic and later in Tennessee was involved in the second epidemic. It was through his caring for AIDS patients in an era when little could be done, helping them through their early and painful deaths that he became known as a hero of medical humanities. His insights formed from his relationships with the suffering were intensely transformative; they became the basis for his first book, *My Own Country: A Doctor’s Story*.



Dr Abraham Verghese, MD, MACP

He studied at the Iowa Writer’s



Workshop at the University of Iowa where he earned a Master of Fine Arts degree in 1991.

Of *Cutting for Stone*, he says, “I wanted the reader to see how entering medicine was a passionate quest, a romantic pursuit, a spiritual calling, a privileged yet hazardous undertaking. It’s a view of medicine I don’t think too many young people see in the West because, frankly, in the sterile hallways of modern medical-industrial complexes, where physicians and nurses are hunkered down behind computer monitors, and patients are whisked off here and there... that side of medicine gets lost.”

No autobiography this, but like all writers, he has grabbed from his own reality. He poses plenty of puzzles as his characters search for their own truths. Thankfully, the reason for the title becomes manifest half way through the book. And thankfully, truth of the twins parentage is unfurled towards the end. It may have been a most unsatisfactory ending otherwise.

A tour de force by a remarkable man.

Lyn Loates



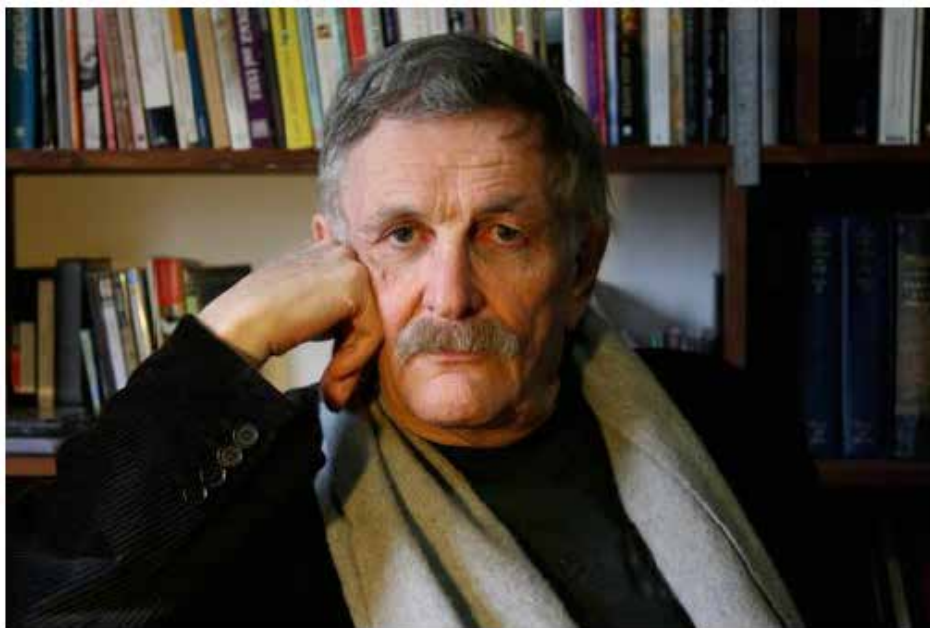
# The Dinner Party

## What one man did to raise donor awareness

Paul Cox, Dutch by birth, migrated to Australia in the mid 60s as a stills photographer and has gone on to become one of that country's most prolific and individualistic filmmakers. His two stand out documentaries have been *Vincent: The Life and Death of Vincent van Gogh (1987)* and *the Diaries of Vaslav Nijinsky (2001)*.

But as a liver transplantee, his newest contribution to both the documentary film industry and the need to raise donor awareness arrived two years ago in the form of *The Dinner Party*.

As guests arrive at his home we hear his voice over..."Almost a year ago on Christmas Day I was summoned to the Austin Hospital and received a transplant of the liver. I was given that great gift of life. Tonight I want to celebrate my donor's life and my miraculous survival. I have invited a few of my fellow recipients for Christmas dinner [at my home]. There are not many of us. A fairly exclusive club I would say. None of us would have lived without the miracle of transplantation and we're very grateful to be alive. It seems easier now to be forgiving and kind, to be more generous and loving. But we find ourselves in a world that moves too fast, a world that doesn't even have the time to contemplate our gratitude. It's marvelous to slow down, to share a moment with people that feel and understand. The body heals but the mind doesn't heal that easily. How can one



Paul Cox, film maker and transplantee

get used to miracles?

As a way of documenting his own experiences, Cox arranged and filmed a pre-Christmas dinner party on 18 December 2010. Here he hosts seven fellow liver transplantees of varying ages and cultures. The film follows the round table conversations of these diners, all of whom had different experiences in the run up to transplant, and a variety of experiences in the aftermath. As the director promised, the discussions are "raw, unguarded and insightful". Probably they answer every question you ever wanted to ask. Cox comments: "For us it was a very healing experience and many viewers have told us how moved they were to see how the recipi-

ents cope. The American Liver Foundation has been promoting it for some time and according to my friends, has received some million hits."

The film was screened as a free event during the 2013 Donate Life initiative

ILLUMINATION FILMS, SAVAGE FILMS  
THE AUSTIN HOSPITAL and the ORGAN AND TISSUE AUTHORITY  
present

### *The Dinner Party*



A film by Paul Cox

"How can one get used to miracles?"

This film has been made as a resource for the health community.  
We encourage you to utilise this film in your work and give us some feedback.

INFORMATION BOOKLET

August 2012



in Australia but the goal is to ensure wide exposure and use of the film in the organ and tissue donor community.

You can see *The Dinner Party* by downloading *The Dinner Party* by Paul Cox on <http://vimeo.com/47145572>. Recommended.

# Starship Enterprise



## Paediatric Liver transplant team

Back row left to right: Andrew Day, Stephen Mouat, Simon Chin, David Wilson, Amin Sheikh. Front row left to right: Jon Bishop, Robyn Agnew, Jo Knappstein, Kim Herbison, Amy Kostrzewski, Helen Evans, Karyn Sanson, Cate Fraser-Irwin and Lucy Robinson

**Clinical Nurse Specialists Cate Fraser-Irwin and Karyn Sanson will be familiar faces to the liver transplant children and their families and what a vital role in our team they play! Achievements from Cate and Karyn over this year have been spectacular.**

Firstly, they embarked on a major overhaul of the patient resources, namely a new printed booklet on liver transplantation for families and an electronic educational resource for nursing staff throughout New Zealand. These resources were launched to coincide with the 10th anniversary celebrations of the Starship liver transplant service. The strength of these resources is the result of robust consultation and collaboration.

### Whanua support

An important aim of the Starship team is to try to manage children with liver disease in their own communities, close to their sustainable whanau supports. However this needs to be balanced by the need for timely transfer to Starship when things are not going so well. This can be a fine balance and

can cause stress both for families and medical teams close to home.

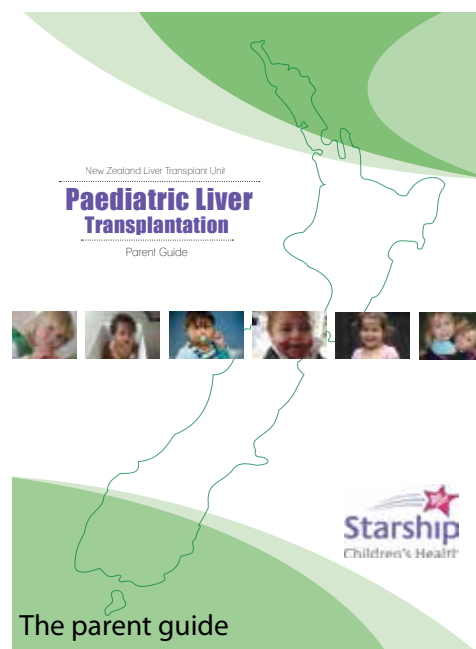
Our patient group is small and so many nurses outside Starship will rarely encounter a child with liver disease. This was the topic Karyn chose for her Masters degree thesis. She undertook a painstaking survey of paediatric nurses around New Zealand who currently help manage liver children closer to home. Key questions included where do they seek information, what information they would find helpful and how they want to access information. The result is a Web-based resource critiqued by peers from around New Zealand. Feedback on the usefulness of this document has been excellent. We are proud of Karyn and delighted to see her awarded her Masters degree.

### Parent guide

The parent guide to paediatric liver transplant was developed by Cate in collaboration with families and the Starship medical team. Samantha Sutherland, mother of Lara, was co-editor and she provided the energy to ensure our new improved family resource was completed "this century". Families who have been through liver transplant have been very generous with their honesty and words of

encouragement for families about to embark on the liver transplant journey. To see photographs of the children pre and post transplant is wonderfully rewarding for us but for families going through the trauma of transplant assessment, they are truly inspiring.

These new resources were generously sponsored by the Kids Foundation who support children with liver disease. Their input helped the final product be visually appealing, modern and very





professional. The design is now “ours” and will be used in future departmental resources. The team intends to develop disease-specific information including biliary atresia, portal hypertension, Alagille syndrome and many others.

## Up and Away

We have recently moved to our newly refurbished ward. This follows months of planning and a long time in a temporary ward. However, the result is nothing short of amazing. The old 26B was designed over 21 years ago and was tired and run-down. Back then liver transplantation was non existent in New Zealand. Consequently, when we began performing transplantation, 26B had limited ability to house an ever-growing number of paediatric liver transplant recipients in single rooms.

The new ward consists ONLY of single rooms, most with their own bathrooms. The space is bright, airy, modern, clean and crisp. Gone are the pastels, the carpet, the dingy playroom and the tiny



A new patient gives the new look ward the once over

parent lounge. Now it’s colour blocks, friezes, wall mounted TVs, a bigger drug preparation area, a huge parent lounge and playroom and some quiet rooms for families to go when it all gets too much. The paediatric liver team is happy in their new home, but nowhere

near as pleased as the children and their families, some of whom literally shed tears of joy when they saw it for the first time.

## Captured

Meet the people essential to our team but whose faces you may not readily know. Maybe you have heard their voices on the phone or read the letters they send, or you have heard about them from staff. These people perform vital roles and deserve as much recognition as those on the frontline. We thank them all for assisting us in our goal of providing first class treatment to children with liver disease.



Ward 26B Familiar faces

(left to right) Bex, Jody, Laure, Chrissie and Nirmala



Daystay team

Left to right Tizzle, Marion, Sarah and Juliet



Starship radiology

Sandra B, Vanessa & Sandra G



# Familiar faces



Rosalind Poole, Dietician



Colette Kennedy, Radiologist



Linda Peters, Ward Clerk



Sili Lio, Catering



Peliese Tipelu & Sabina Bibi, Healthcare assistants



Winifred Ho, Physiotherapist





## From the 15th floor

From the left: Margaret Johnston (Nurse Practitioner), Katrina Ames (Charge Nurse, Ward 71), Judy Huang (Liver Registrar), Ed Gane (Hepatologist), Chris Cederwall (Liver Registrar), Kathy Oliver (Team Support), Oonagh Lithgow (Hepatoma Nurse Specialist); Jen Chesborough (Clinical Support Nurse); Jane Biddulph (Research Nurse); Amy Cole (obscured) (Research Nurse), Rachael Harry (Hepatologist), Stephen Munn (Transplant Surgeon, Director of NZLTU), Ron Benjamin (Social worker), Faye Manu (Research Nurse), Adam Bartlett (Transplant Surgeon), Barry Harrison (Transplant Coordinator), Michelle Singh (Pharmacist), Anthony Phillips (Donor surgeon).

### **I can't believe another year has gone by. All of us at the NZLTU hope that 2013 has been a good year for you.**

2013 has been a reasonably quiet year with respect to personnel changes. Val Honeyman resigned from her role as Hepatoma Nurse Specialist and has taken up an exciting new role at Middlemore Hospital as lead Nurse Coordinator for the Cancer team. We miss her and her Scottish sense of humour. Oonagh Lithgow has replaced Val. Oonagh has a wealth of nursing experience and was most recently a nursing tutor at AUT.

In the Co-ordinators office we were lucky to have Lucy Mills for a 1 year relieving position. Sadly Lucy has now moved on. She has been replaced by Fionna Burgess. We are extremely lucky to have Fionna in the team. She has 20+ years nursing experience at Auckland City Hospital, eight of those as the Charge Nurse in Neurology.

Dr Dominic Ray-Chaudhuri (Hepatologist) and Professor John McCall (Surgeon) joined us for three months while David Orr and Peter Johnston were on sabbatical leave during the year. As many of you will remember Prof. McCall was one of our original transplant surgeons. David and Peter have now returned from their sabbaticals.

On a sad and happy note – sad because Lyn Gillanders and Kerry McIlroy who have been fabulous dieticians since the start of the liver transplant unit in 1998 have now moved to other positions

within the Auckland Hospital dietetic department. Both Lyn and Kerry have been friend and, at times, foe to many of you in the pre and post liver transplant phase but despite this we have all been incredibly lucky to have had their expertise for this long time. On the happier note, Lyn and Kerry have been replaced by Ros Poole. Ros comes with experience in transplant and has worked overseas for the past few years. We are fortunate to have her.

The exciting staff news for 2013 was Adam Bartlett's (surgeon) wedding to Annabelle. Many NZLTU staff travelled to Dunedin to attend the wedding. This was a grand affair with the reception at Larnach Castle.

Also, Jen Chesborough (Nurse Specialist) gave birth to a gorgeous son, Paddy, in April. She has just returned from maternity leave and is back on ward 71.

Last year Hepatic Happenings featured the introduction of a Young Persons Clinic. This clinic was set up to ensure a smooth transition for patients from the paediatric to adult services. Dr Rachel Harry continues to be the driving force in this clinic, and has herself completed a post graduate certificate in youth health and has become the project manager for the ADHB youth services. The clinic has approximately 25 patients either still in the clinic or who have progressed on to the adult services, and is proving very successful for these young people.

The NZLTU continues to be active in research. We were fortunate earlier in the

year to have several places on a clinical trial of Sofosbuvir and Ribavirin for people with post transplant Hepatitis C recurrence. These are interferon-free regimens. The trial medicines were tolerated well and each of the participants is now in the follow up phase. In the coming months we are aiming to commence enrolment for a new study including post-transplant recipients with Genotype 1 Hepatitis C. During this year a substantial number of patients have been enrolled in a weight loss trial under the direction and management of Dr David Orr. We expect first results to be available next year.

Live liver donation continues to save lives and ensure our transplant numbers grow. We will be performing the 50th live liver transplant later this year. We are forever grateful for the courage of our live liver donors.

The NZLTU has been operating now for over 15 years. Liver transplantation is a fantastic operation and has given most of the recipients a chance for a normal life, and opportunities that would have otherwise been lost. Without the courage of the donor families and live liver donors we would not have a liver transplant programme in NZ. The generosity of donation should never be forgotten.

**We wish you all a very happy Christmas and especially to stay well in 2014.**

Margaret Johnston

## Keeping Score

To date the NZLTU has performed:

- 1010 transplant assessments
- 545 transplants in 520 patients
- 96 paediatric transplants in 93 patients\*
- 49 live donor transplants

This year to 8 October 2013 the NZLTU has performed:

- 28 liver transplants
- 3 were live donor transplants
- 11 were for paediatric patients\*

*\*paediatric describes patients aged 16 and under*

### Hepatic Happenings

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**Contributions for 2014 issue welcome.**

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Hepatic Happenings would benefit from any sponsorship or financial contribution to printing costs of this annual publication. If you or your company feel inclined to help with a small donation, please contact Margaret Johnston at above address.

## We like the message.

This graphic was originally designed to promote New Zealand's participation in the forthcoming 2014 London Marathon because, for the first time ever, our Starship Foundation had secured a limited number of places for the popular race. But interest was so overwhelming that the general international ballot closed off just hours after opening with just a handful of places being awarded to our country's hopefuls. At this point there remains a waiting list. Applicants wanting to run for Starship Foundation comprised not just locals but people from around the world who had specific interest in our Starship Hospital. Starship Foundation's Sarah Woodhams confirms the huge success of this project and that the Foundation will be an official fundraiser for the 2015 event which has the reputation of being one of the most exhilarating races on the marathon calendar. And for the Starship Foundation which supports over 120,000 young Kiwi patients each year, the race certainly helps make miracles happen.

For more information:  
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