

Hepatic Happenings

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Consulting Editor:
Val Honeyman,
NZLTU

Editor:
Bethli Wainwright

Please e-mail or mail
contributions to the Editor:

Bethli Wainwright
5A Eyre Street
Henderson Heights
Auckland
NEW ZEALAND

E-Mail:
ptoli@ihug.co.nz

Phone / Fax:
(09) 836-7107

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Introduction:

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Sanitarium has decided to

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I am delighted that Sanitarium has decided to sponsor both this issue and the June issue of this Newsletter. If you want information about their product range, or you have other queries, you can e-mail them at enquiries@sanitarium.co.nz.

The first of the Caregivers' Meetings has already been held this year, and I know from my principal caregiver who attended this, that it was a useful and helpful meeting. There is a brief report below.

We are also very fortunate to have a Donor Family share their story. They have met the recipient of their son's liver, and you can read about this on page 2.

I hope you enjoy this issue. Stay healthy and take care!

Liver Transplant Caregivers Group:

On the evening of Tuesday February 13th, the first meeting of the Liver Transplant Caregivers Group was held at the NZLTU, Auckland Hospital, with thirteen caregivers present, plus Ron Benjamin, the NZLTU Social Worker, as facilitator. There was a wide cross-section of caregivers, ranging from those still waiting to those of several years, which made for a very interesting evening. Many topics were aired, among which diet, difficulties facing those from out of Auckland, and the differences caring for husbands / wives / children were included. All in all, a very helpful and supportive meeting, and we look forward to the next one.

Notes taken by Robin Wainwright.

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

The next meeting of the Liver Transplant Caregivers Group is on Tuesday April 10, New Zealand Liver Transplant Unit, 10th Floor, Auckland Hospital, from 7:00 - 8:30 pm.

Anniversaries:

Celebrating liver transplant anniversaries in March and April are:

1. Richard M, April. 2 years.
2. Ken T, April. 3 years.
3. Jane P, April. 2 years.
4. Josephine E, April. 2 years.

Congratulations everyone!

From a donor family - the story of Nicholas Green:
© Reg Green 2001

One warm night in September 1994 in southern Italy a vivacious 19-year old, Maria Pia Pedala, was dying of liver failure. Her brother had died of a liver disease, her mother was dead too. The family were gathering to face yet another devastating blow.

But that same night my son, seven year old Nicholas, was dying too from a bullet fired in an attempted robbery. Nothing could save him and for Maggie, my wife, and me life will never be the same again. But Maria Pia did wake up and when she did she had a new liver.

She recovered quickly and when Maggie, my wife, and I saw her four months later it was impossible to tell that she had been so desperately ill. Then, in the full bloom of womanhood, she was married and more than two years ago she had a baby, a boy, whom they have called Nicholas, a whole life that would never have been, and so far the livers of mother and son are working perfectly. When I saw her last, a few months ago in Rome, she was pregnant again, and now she has another beautiful baby, a girl this time, Alessia.

All this came from a decision that was so obvious to us that neither Maggie nor I can remember which one of us suggested it first. The doctors had told us that in Nicholas' brain, which had been so full of colourful fancies and high ideals, there was no longer any activity.

Obviously we would have done anything to keep Nicholas alive, however badly injured, to put our arms round him, take him home and nurse him. But that option was not open. His brain, which had been so full of colourful fancies and high ideals, was now quite dead. So we did the only thing we could do that would bring some good out of this dreadful affair. It was a decision that turned out to have momentous consequences we could never have dreamed of.

Even the initial results were far more than we imagined: there were seven recipients of his organs, two of them going blind, the others dangerously ill. All seven are now living full productive lives.

But in addition the donations seemed to take Italy by storm: the Prime Minister asked to see us, we were flown home in the President's own aircraft, schools, streets and the largest hospital in Italy have been named for Nicholas. Best of all organ donation rates have more than doubled so that literally thousands of people are alive today who would have died.

Nicholas' story quickly went to all corners of the world -- we've been told of news coverage in Nepal and Kuwait, Russia and Argentina -- and to this day we still get letters from people who say their attitude to organ donation has been changed by what they've heard.

Maggie and I regard it now as our life's work to write, make speeches, produce videos and give interviews to let it be known that thousands and thousands of people, many of them children, some just babies, die every year because donation rates everywhere are too low. I can't believe that we cannot cure this problem if enough people know of the suffering that a refusal to donate causes.

The Green family has two websites: <http://www.nicholasgreen.org> and <http://www.nicholaseffect.com>.

Liver Transplant Group:

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

Twenty-one adults and one child attended.

Meeting start time will change from 11:30 to 12:30, beginning from the next printing of the pamphlet. This may ease some of the pressure in Clinic, as some patients arrange their appointments to coincide with group meeting days.

Matters connected with the Department of Critical Care Medicine

Reference was made to the "non-verbal" DCCM communication card. Its recent first trial failed as the card was mislaid and the patient involved could not communicate effectively. DCCM staff thought the patient was hallucinating when "writing in the air" was attempted. **[Editorial Note: Give this card to your principal caregiver, who can pin it to you when they visit you immediately post-transplant].**

Some patients appreciated the opportunity to orient themselves with DCCM by doing a pre-operative tour, and recommended it for others in the future.

Further to the subject, several caregivers found the DCCM situation -

- a) confusing because of the east/west wing arrangement and moveable partitions, and
- b) upsetting because of the mayhem involving distressed family members in the waiting room and cubicles.

Returning to the community after leaving hospital

Transplant patients and their caregivers returning to the community related stress from the load of communicating progress and health status with a large number of family and friends while trying to adjust to the new situation. One patient found refuge by 'escaping' to the local library every day. Another caregiver eased the load by sending out letters. Others found it very helpful to arrange a family spokesperson to cover the task.

Caregivers' experiences

Caregivers brought up the subject, and patients agreed, that it is hard but important for caregivers to learn not to "wrap patients in cotton wool".

Important to know

Some transplantees were unaware of the danger of contact with soil bacteria. This subject and the "dos and don'ts" of food preparation are covered in the Nutrition Services publication "**Eating For Liver Transplant Patients**".

Also some transplantees were unaware that it may be necessary for them to have antibiotics prior to Dental work being carried out. It is best to contact the NZLTU to find out if you require antibiotics or not.

There was support and recommendation for a complete ward checklist to be adopted.

Notes taken by John Russell.

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

Meeting in 7B's Patient Lounge on Wednesday 21st February 2001

This meeting was attended by 12 people and facilitated by Ron Benjamin. This was the first of the guest speakers for the year. The Pharmacist, Sarah Fitt, from the NZLTU at Auckland Hospital, presented on drugs, their side effects and general concerns relating to medications. Mention was

made of the new trial drug Sirolimus, for those who can't tolerate Tacrolimus or Cyclosporin. She finished her talk with general recommendations.

- Avoid sunlight and use a Factor 30 sunblock if outside.
- Avoid herbal remedies / nutritional supplements / over the counter remedies. Discuss all these with the NZLTU first.
- Be careful with cough and cold remedies / pain relieving gels. These can often contain high levels of aspirin / paracetamol, which may increase the levels of your immunosuppressant drug in your blood.
- When flying take **at least** one weeks supply of all medications in your hand luggage.
- Avoid live vaccines, the main one being Yellow Fever.
- In general, try to keep at least two weeks worth of all medications at home. There can be supply problems for New Zealand, especially with Tacrolimus.

Remember... NEVER stop taking your medications!

Notes taken by Bethli Wainwright.

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

This meeting was attended by 16 people and facilitated by Ron Benjamin with the assistance of Val Honeyman. This was the six month anniversary of these meetings and Ron asked for a general indication as to how useful these meetings were. Responses were all positive, and included our abilities to learn from each other's experiences, a non-intimidating environment where it was easy to ask questions and exchange information, and the positive benefits from seeing people transplanted in advance of ourselves, and how well they were doing - positive benchmarking.

There was group discussion relating to specific causes requiring transplantation, and the exchanging of specific experiences. This focussed on Hepatitis B and Liver Cancer.

Notes taken by Bethli Wainwright.

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

Meeting in 7B's Patient Lounge on Wednesday 21st March 2001

This meeting was attended by 18 people, and facilitated by Ron Benjamin with the assistance of Dawn. There was a wide-ranging discussion on the topics of organ retrieval practices and ethics, organ donors and raising awareness of organ donation. This included comment on the number of people who die while waiting for an organ - about 15% for Australasia. There were also recipient issues discussed to do with applying for jobs post-transplant and whether prospective employers should be informed of our transplant status or not, and obtaining travel and health insurance. People had various experiences to share - in particular with travel insurance. As a competitive market, obtaining travel insurance did not seem to provide too many hurdles once past the first year post-transplant.

Notes taken by Bethli Wainwright.

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

Education Session: April 18, 2001 at 12:30pm.

Ron Benjamin would like to remind us that the Liver Transplant Group meeting on the 18th April 2001 is an Education Session. **Kerry McIlroy, Dietitian**, will be taking this session entitled "**Nutrition in Transplantation**".

Thanksgiving Services - advance notice:



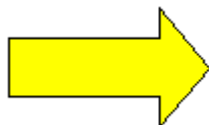
There are special church services for donors and recipients of transplant organs in Auckland and Christchurch each year. This year the **Thanksgiving Services** will be held on the following dates:

Auckland: Sunday April 29th at 11:30 am
Holy Trinity Cathedral
Parnell

Christchurch: Sunday June 10th at 12:00 noon.
Christchurch Cathedral

All are welcome to attend these services.

QUESTIONNAIRE - For Liver, Heart and Lung Transplant recipients:



NOTICE

Val Honeyman, Liver Transplant Co-ordinator, would like to alert us to a questionnaire that will be posted to everybody in April.

The questionnaire has been developed to ascertain the quality of life for patients after Transplant. All liver transplant patients and heart and lung transplant patients will receive one. It is 11 pages long and should take 20 minutes to complete. It is not compulsory to complete the questionnaire. It is entirely voluntary.

The questionnaire will be sent out by Sarah Beilby, a student at Auckland University. If you need any further information please do not hesitate to contact Val, at the New Zealand Liver Transplant Unit. **E-Mail** ValH@ahsl.co.nz

Internet Sites:

The Transplantation Society of Australia and New Zealand, Inc.

<http://www.racp.edu.au/tsanz/index.htm>

This site is designed for scientists, doctors, transplant coordinators and research students interested in all forms of transplantation, not just liver transplants. There is an annual meeting. This year, the

Nineteenth Annual Scientific Meeting of the Transplantation Society of Australia and New Zealand will be held at the Australian Academy of Science, Canberra, ACT, 4th - 6th April 2001. One of the two convenors is Professor Stephen Munn, of the New Zealand Liver Transplant Unit. The site has information including awards and fellowships available to professionals researching in the transplantation area, Organ allocation protocols (see <http://www.racp.edu.au/tsanz/oapmain.htm>) and also a discussion of xenotransplantation owing to the shortage of human donor organs. It also includes a diary of forthcoming events and conferences, including:

Joint Meeting of the International Liver Transplantation Society, European Liver Transplant Association and Liver Intensive Care Group of Europe-LICAGE.

11th -13th July 2001

Berlin, Germany.

Also on this site is a report from the President, Mauro Sandrin, about the *18th International Congress of the Transplantation Society* that was held in Rome in August 2000. This is reported in the February 2001 Newsletter, and can be seen at http://www.racp.edu.au/tsanz/nl_feb01/pres.htm. This congress had over 4000 participants from 60 countries! This conference also included the first visit of Pope John Paul II to a scientific meeting that promoted organ donation. The Pope addressed the Congress with a clear, positive statement of the Catholic Church's view on transplantation. His speech included the acceptance of brain death, an endorsement of organ donation and recognition of xenotransplantation as a possible source of organs.

Cookery Corner:

Yummy Cheesecake

This is a great cheesecake recipe, which you can make if you are going to make and eat it in your own home. If I take it somewhere, I make sure that I serve myself first, and don't return for seconds. Be careful because it is not cooked.

Base

Crush 1 and a ½ packets of superwine biscuits (or other plain biscuits of your choice) and place in a medium sized mixing bowl. Melt 300gr of butter and add to the crushed biscuits. Mix well. Place this mix into a greased dish of your choice, for example a flan dish. Press the mix firmly to the base and sides of the dish. Place the dish in the fridge so that the base can harden.

Filling

In a blender mix 1 tin of sweetened condensed milk with 250 grams of cream cheese. In a bowl whip 300 ml of cream. Add ½ cup cup of the whipped cream and 3 ounces of lemon juice (or the juice of two juicy lemons) to the mix in the blender and blend well, for at least 1 minute.

Pour this mix into the dish with the biscuit base. Place back in the fridge and chill for 2-3 hours. Serve the same day with the remainder of the whipped cream and fruit of your choice. This recipe can be frozen.

Recent Research:

The *New Zealand Medical Journal* of the 23rd March 2001 has an Editorial by Dr. Ed Gane, *Hepatologist, Auckland and Middlemore Hepatitis Clinics and the New Zealand Liver Transplant Unit, Auckland*, titled "*Current management of hepatitis C in New Zealand*". The exact citation for this article is: **NZ Med J 2000;114:101-2.**

This editorial informs us that there are now almost 25,000 New Zealanders infected with the hepatitis C virus (HCV). There have been no cases of transfusion acquired infection since blood donor testing

was introduced in 1992. More than 90% of new cases have arisen from intravenous drug use. Dr. Gane writes that:

"The numbers of HCV-related deaths or transplants in New Zealand will more than double by 2010 (to 60 per annum)."

This editorial also discusses the need to prevent the infection, which would include appropriate public health strategies including teenage drug education programmes. Dr. Gane concludes by stating that:

"Chronic HCV is an important public health problem in this country. Until the arrival of an effective vaccine, needle exchange programs and increased awareness of the risks of intravenous drug use remain the most important preventative strategies. Antiviral therapy is the only means of reducing morbidity and mortality in those already infected. The improved efficacy and tolerability of ribavirin and pegylated interferon means that cure has become a realistic goal in the majority of patients."

Liver Transplant Web Page:



Watch out for a **Press Release** on the **19th April 2001**, when this site will be launched. We are launching one week prior to the Thanksgiving Service at Auckland Cathedral, in order to generate some donor awareness in the media. Any recipient or caregiver experiences would be appreciated by Easter at the latest!

Letters to the Editor:

It is nice to hear your comments and opinions. Recently received was a note from **J. E.** saying:

"I enjoy reading about the topics discussed at the meetings as living out of Auckland I am not able to come to meetings."

And from **P. R.**

"Thank you for the informative news letters. You are providing an excellent, needed service."

Thank you for your feedback!

If you want to raise a point or ask a question, whether **medical** for the NZLTU to comment on, or **lifestyle** etc, for other recipients or caregivers to comment on, remember to post or mail your letters to the Editor, contact details on page 1.

Being a Nurse on Ward 7B, by Lisa Craig

Ward 7B is a unique ward, compared to other wards at Auckland Hospital, which is due to the diverse range of patients on the ward at any one time. This involves liver and renal patients, urology, surgical and, orthopaedic patients, all in varying stages of health, thus 7B is a very interesting place to work. The most interesting, challenging, scary, and rewarding specialty of the ward are our transplant patients. For all new staff it is the transplants that are both fascinating and formidable, as liver

transplantation and also combined renal and pancreas transplantation are both relatively new in New Zealand.

I started as a new graduate on 7B in January 1998, and it was March that year that the first liver transplant was performed in New Zealand. This was a very exciting time to be a nurse on the ward, ground breaking stuff for little New Zealand, but I have to confess I was petrified of looking after a 'transplant recipient'. As I'm sure you are aware we have now done 78 transplants, and I have a memory of the experience of each person and have cared for most recipients at one point in time. Over the past three years, I have come to favour caring for the transplant patients, as well as those awaiting a transplant, and patients undergoing various difficult surgical procedures.

Caring for transplant recipients and their families is both challenging and rewarding, for many different reasons. Firstly it challenges ones medical knowledge and skills. The nursing care involves the constant monitoring of patients for changes in their condition, as well as signs and symptoms of complications which must be acted on immediately to prevent a deterioration of the patients health, which may occur dramatically. Communication skills must also be primed to ensure effective communication with the transplant recipient and their family. Using communication skills, education regarding self monitoring and lifestyle after transplant may be taught at a pace and level appropriate to each patient and their family.

Providing support to the patient and their family is a major role of the job. As a nurse, I feel honoured by the rapport that is established with transplant recipients and their families and the trust that is extended to me at this time of transition and coping with life after a transplant. It is always in my mind the bravery, and strength possessed by our patients and their families during the transplantation process, as there is so much to deal with, ie the surgical trauma and the feeling immediately post transplant which Professor Munn assimilates to getting run over by a Mack truck, the effects of the drugs on both body and mind, and learning about adaptations to lifestyle. It is this nurse-patient rapport that is the most rewarding aspect of the job.

To summarise, I see my role as a transplant nurse as one of being a support person, a liaison between the medical team and patient (and their family). A person who can provide safe care, guidance and education. A lot of skills are required to gain insight and a holistic perspective of the unique experience of the transplant patient and their family during such a dynamic life experience. However in the role of a nurse, I have also learnt much from each person I have cared for, as everyone has amazing life experiences to share and learn from.

I would like to thank all the people I have worked with, both patients and medical colleagues. I appreciate all the experiences and learning I have gained from you all. I will miss you, and think of you frequently from the northern hemisphere. Goodbye, good health and good luck. **Lots of love from Lisa.**

Pam Robinson's *Spiritual Bits and Pieces*:

© Pam Robinson, March 2001

[Editor: Pam is aware that responses to this article could be varied, she has included her contact details at the bottom of the article.]

One and a half years post liver transplant I feel extremely good, fortunate, happy and invigorated with life. I hadn't dared to hope for such amazing results from a transplant and the associated drugs. For years an area of specific interest to me has been the spiritual realm. This is my experience of spiritual liver transplant happenings.

In our society we are not generally taught how to die or what to do at death. Shock and confusion usually occur especially at accidents and sudden deaths. The soul's spirit may stay at the place of death, wander off or follow their body. At death we need to know to look up to the bright light and go towards the peace. After transplantation the donor spirits are usually present to communicate with

and are often angry at dying. They attach easily to organ recipients in a new relationship, their unhappy state unrecognised and ignored. Recipients feel the donor's presence and emotions then wonder, "What is wrong with me?" Communication and discussion with the donor's spirit about the situation is usually all that is needed. A request may exist. I tuned into my donor, had a deep discussion about our new relationship and promised to return the ethereal liver when I die. I directed the donor up to the light and we contentedly parted for now.

Shock and trauma or bad experiences cause people to retreat from reality where they live feeling light and carefree but don't really experience life. This is where I was after the operation until I saw myself looking vacantly from a mirror and made the effort to bring myself into the "*Here and Now*." Integrating energies of my body and the donor liver took me ages to work out. I experienced low energy and related problems. The liver is an organ of vitality and with a healthy new one I just had to tune into it to feel energised.

One of the side effects of Tacrolimus is moving into a somewhat depressed state that gives a dark horrible feeling and creates sleeping difficulties. My dreams were in black and white and my psychic abilities were impaired. A remedy of herbal rosehip, three drops ten minutes after tacrolimus keeps me buoyant.

A homoeopathic remedy used for colitis worked deep in my body and on the transplanted liver, healing its childhood diseases. Later I shook in shock and agony feeling the anguish of some happening from the liver's cell memory. It was painful until it was cleared by my aura healer.

Wishing you all well, Pam Robinson

E-mail Paiawa@actrix.gen.nz
Phone 09 432 2862

Helpful Hints:

Sun Screen

All liver transplant recipients have to be sun-aware, as the anti-rejection drugs cause us to be more prone to skin cancers. It is beneficial for liver transplant recipients with a Community Services Card to get sunscreen prescribed. (The sunscreens are only partially subsidised, but it still makes a difference). For those recipients without a card, the supermarket would be the best option.

Currently the following can be prescribed:

- Cream 50g Aquasun 30+
- Cream 100g Elizabeth Arden Suncare
- Cream 100g Hamilton Sunscreen
- Cream 100g UV Tripleguard SPF 15+
- Lotion 125ml UV Tripleguard SPF 15+
- Ointment 14g RV Paque
- Lotion 125ml Le Tan SPF 15+
- Lotion 125ml Aquasun 30+
- Lotion 125ml Aquabloc 30+
- Lotion 300ml Le Tan SPF 15+

This item has been contributed by Lisa, 7B Nurse, Auckland Hospital.



The bristles of these toothbrushes are made of antibacterial material. This may assist our efforts to avoid infection. Our Liver Team recommends a course of antibiotics before and after dental work, including "just a clean", which may be an even greater risk than normal dental treatment.

This brush was discovered in supermarkets a few days after reading an internet article that recommended replacing toothbrushes after two to three months.

Some recipients recommend placing the head of your toothbrush in a cup of boiling water for 15 minutes, once a week.

This item contributed by Liver Recipient #27

Psst....here's the Goss!

- ***Wedding Bells!***

Our very own Dawn, Liver Transplant Coordinator, gets married to Rodney on the 6th of April on Waiheke Island. Dr.Gane, Prof.Munn, Kathy and Val are attending in their glad rags. Rodney is a very keen sailor and members of Team New Zealand and Prada will also be attending. Dawn's sister and brother will be coming from the UK.

- ***The Pitter Patter of Tiny Feet...***

Rumour has it that Dr. Gane and his wife are expecting their first child mid-April.

That's all for this issue! Stay healthy, and enjoy life!