

The Alfred Hospital

Lung Transplant Service

Clinic Newsletter – March 2012

NEWS FROM THE LUNG TRANSPLANT CLINIC TEAM

So far 2012 has been a busy year in the Transplant Clinic, with a lot of moving of offices, welcoming of new staff, and following the trend of recent years, a steady and constant stream of transplants being performed.

LUNG TRANSPLANT HQ

We have now set up our new dedicated Lung Transplant Service HQ office on Level 5, and all of the lung transplant clinics are now held there also. The changes and movement in the Clinic have also seen **A/Professor Bronwyn Levvey** commence her new role as Lung Transplant Nursing Team Leader, and we have welcomed **Kelina Attard** as a newly appointed transplant nurse. Kelina joins **Emilie Beattie** and **Rani Martin** to form our clinic nurse team. Kelina comes to us from a background of nursing for Hospital in the Home, Oncology/Haematology, Midwifery, and she has relieved in our clinic in the past as well. She has been nursing for 12 years, spending the past 8 years at The Alfred. The new 'HQ' office is also home to **Lauren Mitchell** and **Yvonne Cristiano** (Research Nurses in Lung Transplant), and **Sheridan Misso** (PA / Admin Support).

Please see the back page for a cut out card listing our updated contact details.

NEW STRATEGIES AND SERVICES

New strategies are being implemented such as our updated contact numbers and email address, and a more formal involvement of our clinic nurses with ward 5East is aimed towards providing patients with a smoother transition from inpatient to outpatient status post-transplant. In the near future we plan to distribute a patient satisfaction survey seeking feedback and information to assist us in implementing changes and improving our service to the transplant community, and we will welcome your input.

NEW MEDICAL STAFF AND STAFF ABSENCES

Dr Miranda Paraskeva has joined the Team and is now seeing patients in Clinic. She will be seeing patients on a Monday morning, as Judy Morton had done in the past, as well as seeing patients Wednesdays and Fridays. We also are pleased to advise that **Dr Nursh Harun** (our Registrar in 2011) will be joining us as a Consultant all day Mondays. **Dr Dominic Keating** has accepted a role as Consultant in the Cystic Fibrosis Service, however will still have a Wednesday afternoon session in Transplant Clinic. **Dr Sameer Kaul**, **Dr Melinda Wilson** (Registrars) and **Dr Sarah Rotstein** (Intern) are also working with the Team this year.



Above: A/Prof Bronwyn Levvey, Nursing Team Leader
Below: Emilie Beattie, Rani Martin & Kelina Attard



Above: Lauren Mitchell & Yvonne Cristiano, Research Nurses in Lung Transplant.

Do you have a suggestion for a topic you would like to have covered in a future newsletter?

We welcome you to forward your ideas: lungtransplant@alfred.org.au



PRESCRIPTION REQUESTS

If you find that you require a prescription before your next appointment, we ask that you give the Clinic staff at least 24 hours notice, as we are not always able to obtain a script at short notice.

If you are a country patient and require a script to be filled and posted to you, please advise us as early as possible (before medication runs out). If you are taking a 'simple' medication which can be obtained from your GP, it may be appropriate to obtain such scripts from them if this is convenient.

Pharmacy Hours at The Alfred:

M-F 8:30am-5:15pm; (Weds 9am-5:15pm)
Pharmacy is closed on weekends

Please phone Clinic on 0417 046 210 or 9076 2867 with requests.

For non-urgent requests:

lungtransplant@alfred.org.au



PHARMACY NEWS

CHANGES TO SOME THE COST AND QUANTITY OF SOME SPECIALISED TRANSPLANT MEDICATIONS

by Steve Ivulich, Lung Transplant Pharmacist

As you may be aware, there have been some changes to the prescribing of medications through the Pharmaceutical Benefits Scheme (PBS) from the 1st March 2012. The Government has changed how some more expensive medications are funded and this has implications for how some of the medications used by the Lung Transplant unit are supplied.

The only medications that will be affected by the changes are **Tacrolimus, Cyclosporin and Valgancyclovir**.

Quantity changes

A set quantity of medication, regardless of the dose will now be supplied.

For example, 200 capsules of Tacrolimus 1mg will be supplied whether the dose is 1mg twice daily or 4mg twice daily whereas previously the exact quantity required for the month would have been supplied. This can result in either an over or undersupply of medications dispensed so you should take care that you have adequate supply until your next clinic appointment. Five repeats can be given for each of these items.

Pharmacy will make every effort to ensure that adequate supplies of medication are dispensed until the next outpatient visit but it is also important that you monitor your existing supplies of medications at home to prevent any shortages.

Patient charges

The other difference will be for charges to the patient if multiple strengths are required. Previously, patients were charged ONE dispensing charge for each medication regardless of how many different strengths are given.

For example, a 6mg dose for Tacrolimus (requiring 5mg and 1mg capsules) a patient would have previously been charged \$5.80 for a concession script or \$35.40 for a general patient. The changes will now require a patient to pay for each strength dispensed. This is consistent with the current practice for other PBS medications such as azathioprine (50mg and 25mg tablets) or warfarin (1mg and 5mg tablets).

The changes introduced by the government will not affect other important medications used by the lung transplant unit that are hospital funded (eg. Mycophenolate, Everolimus, Sirolimus) and these prescriptions will be written and supplied as per the previous system.

The new system will not have any impact on postage of medications for regional patients. Outpatient's pharmacy will continue to post medications when required in emergency situations.

If you have any questions regarding these changes please ask any member of the Lung Transplant team.

Please feel free to send us an email at lungtransplant@alfred.org.au to join our mailing list.
We often email out general information, updates and information regarding Clinic contact over holiday periods.

TRAVEL POST-TRANSPLANT

Many patients will plan a holiday when they feel well enough post-transplant. Here we discuss some of the issues to be aware of, and how we can help you to have a safe and happy holiday.

TRAVEL INSURANCE is something that many people who have a chronic health issue will purchase to protect them in the event they become unwell while away from home. We recommend that, depending on where you travel to, you discuss the need for insurance with your travel agent at the time of booking. If you are advised to purchase insurance and need paperwork completed by the Clinic, we advise that you send this to us as soon as possible and allow at least two weeks for it to be completed. Some countries have reciprocal rights with Australia and may negate the need for further health insurance when traveling, but this must be discussed with your travel agent.

VACCINATIONS should be discussed with the Clinic to ensure that you are up to date with any necessary vaccines, and also that you are aware of any vaccine which you are unable to have (e.g. live vaccines).

MEDICATIONS You will need to ensure that you are traveling with enough medication to last the duration of your holiday, and for the days immediately after you arrive home. Having to seek and purchase additional medication (especially internationally) can be costly, therefore is best avoided where possible. If you need to take a medication at a specific time each day and are traveling to a different time zone, some patients find it useful to keep one watch on 'home time' and stick to it.

TRAVEL LETTERS We are happy to complete travel letters outlining your medical history and medications for any travel, however require at least two weeks notice to complete this. If you are coming in to Clinic to have a check up and to request a travel letter, please also email or phone Sheridan in advance (please phone 9076 2867 or email lungtransplant@alfred.org.au) advising of your letter request and the date you are coming in to Clinic, to ensure that the typing of your letter is prioritized and the avoid delays in getting the letter to you in a timely manner.

AWARENESS OF WHERE TO GO FOR ASSISTANCE when traveling in Australia and overseas is very important. The Clinic can supply you with the contact information for transplant centres throughout Australia and internationally. If you advise us of where you are traveling, we can print you a tailored contact list to take with you in case of emergencies. As there is a member of the transplant team on call 24/7, any other site treating you in your travels will always be able to speak to a member of our team to assist in your care.

SAFETY IN CHOOSING HOLIDAY DESTINATIONS is something you can discuss with the Doctors and Nurses in Clinic. There are some travel destinations which due to issues with the water supply and food contaminants, or lack of specialist medical facilities may be deemed risky for transplant patients. You are able to discuss these issues in Clinic at your review, or we also welcome enquiries via email or phone which we can follow up and get back to you regarding.



Left: Kaye Hayne resting during a 10km walk including 1000 steps at Ingleton Falls, Yorkshire Dales, England. Kaye and her husband David have travelled overseas three times since Kaye's transplant in 2006.



Above: Chris Walley and his wife recently enjoyed a holiday which took in, amongst other sights, Singapore, Munich, Austria and France. They drove around 2000km through Europe in 14 days!

Chris' list of things that impressed him in his travels:

- 1. Ride in WW2 "Lancaster" bomber.(see picture above)*
- 2. Arriving 6am Frankfurt (after 14 hr flight), driving French car on right hand side of road with Dutch speaking GPS, on ultra fast (150+ k) German Autobahns !!*
- 3. Several long narrow lane road tunnels (up to 15k), with big trucks either side at 80k.*

*Have you enjoyed a holiday, adventure or other exciting experience (weddings, new additions to the family, new career) post-transplant?
We would love to hear your stories and receive pictures to share in future newsletters.
If you have something to share,
please email us at:
lungtransplant@alfred.org.au*

Phone: 9076 2867 or 0417 046 210 - Email: lungtransplant@alfred.org.au

Have you seen the Quit campaign's advertisements featuring Mick and his battle with Emphysema?



Above: Mick in the Quit ads which are frequently shown on TV to raise awareness of the dangers of smoking.

Many of you will have seen the Quit ads featuring a gentleman speaking of the effect Emphysema has had on his life and family, showing him struggling at home and talking of how limited and restricted his life had become due to his lung disease. Upon seeing the ad, I am sure many of you may have asked yourself, 'I wonder what happened to Mick'.

Well, we are pleased to report that Mick is enjoying a new lease on life after undergoing a lung transplant in 2011.



Above: Mick today, smiling again following his lung transplant.

Mick says "I'd like to thank the team at The Alfred for everything and for making me smile again by being able to breathe easily".

Thank you to Mick and his family for sharing his story and allowing us to share this happy update.

SUPPORT AND THE TRANSPLANT COMMUNITY

The Victorian Heart Lung Transplant Trust is a fantastic organisation dedicated to creating a community and support network for transplant recipients, those awaiting transplant, carers, family, friends and anyone supportive of the cause. The Trust organise regular events such as BBQ's and fundraising, and produce a fantastic and informative newsletter. If you haven't already, we would encourage you to visit the HLTTV website at www.hlttv.org.au and consider joining this great initiative.



Heart & Lung Transplant Trust (Vic) Inc.

DONATELIFE – SUPPORT AND RESOURCES

DonateLife offer a wonderful range of resources for many aspects of transplantation, as well as opportunities to be involved as a volunteer, in raising awareness and support for donation, offering a wealth of information and organising fantastic events to raise awareness and allow recipients and donor families to have a voice and offer their thanks.



DonateLife Book of Life

Read stories of hope about organ and tissue donation written by everyday Australians.



<http://www.donatelife.gov.au> or phone 1300 133 050



Lung Transplant Service Contact Details

Appointments / general enquiries:
9076 2867

Nursing/Medical enquiries:
0417 046 210

Non-urgent enquiries:
lungtransplant@alfred.org.au

