

coming events

Patient Events 2009

Wednesday - June 24th
Patient Meeting, Tauranga/BOP

Wednesday - July 22nd
Coffee Meeting, Auckland
Starship Hospital

Friday - July 31st
AGM, Auckland LabPlus, Including
seminar to update patients on
CVID genetic testing program

Wednesday - September 30th
10 Pin Bowling Meeting,
Auckland

Wednesday - October 14th
Coffee Meeting, Auckland
Starship Hospital

Tuesday - November 2nd
Patient Meeting, Christchurch

Details of exact times and venue
locations are on the invitations
sent to all local members

Swine Flu Update

The 'Swine Flu' influenza virus has been very much in the news over the last month;



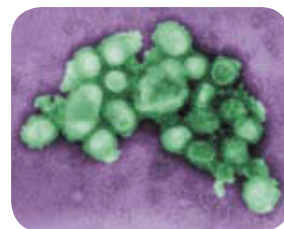
As the current story unfolds it has raised many questions for IDFNZ members. Although this potential pandemic is cause for general concern, we can be assured the virus in question poses no threat to the safety of plasma-derived medicinal products. In this edition of In Touch, Dr Peter Flanagan from the New Zealand Blood Service updates members on the background to this virus and precautions being taken by NZBS. Plasma donations are not accepted from donors that

show symptoms of the flu such as fever, a cough or general pain (people with the flu are contagious when they have symptoms; after their symptoms have gone, they are no longer likely to infect others). No case of influenza transmitted by transfusion has been reported in the scientific literature. In a global pandemic however, if significant numbers of plasma donors showing symptoms of the flu were to be deferred, it is possible that, over time, supplies of donated plasma might be affected and this could eventually reduce the supply but not safety of immunoglobulin products.

Meanwhile our medical panel are recommending members follow MOH guidelines and updates found at:

<http://www.moh.govt.nz/pandemicinfluenza>
or phone healthline on: **0800 611 116**

More information can be found at:
<http://www.who.int/csr/disease/swineflu/en/index.html>
and <http://www.cdc.gov/swineflu/index.htm>



Medical Transport Services

Travelling to and from medical and other appointments can be very challenging if you are unwell or caring for sick children. Health coordinator Tracey Cornwall has researched information on transport options for families based in Auckland who do not have access to a private vehicle and are unable to access public transport due to health or other reasons.

MANUKAU EAST PATIENT SHUTTLE SERVICE

Door to door shuttle bus for all of the community to Boatany Clinic, Manukau Superclinic and Middlemore Hospital. For appointments between 10am and 3pm. Call **0800 ME PATIENT (0800637284)** for timetable and bookings. Total fare for return trip \$10 patient with community services card or accompanying adult. \$20 for patient without community services card.

DIAL A RIDE - 09 625 5599 Email - dartran@xtra.co.nz

Transport services for people who cannot access public transport or have a disability. They cater for all travel needs, leisure, social, work, medical, education, clubs, tours, trips, single passengers or groups. Operating hours 7.30am - 4.30pm The office is open until 7pm for bookings. Prices at time of enquiry: \$3 flagfall, 80c per km for 1 person, \$1.30km for 2 people. No charge for caregiver. Ask for a quote prior to using this service.

RE-LI-ON-US - 0800 025 999 OR 09 278 5999

Re-li-on-us assist customers from Orewa to Bombay with transport for all occasions including medical appointments and social occasions. They provide both wheelchair and non wheelchair accessible transport across

the greater Auckland region. They also provide a pickup service for those in urgent need of prescribed medicines or who cannot leave the house or make it to the pharmacy. They will also deliver parcels if needed. This service operates 24/7. When booking say you are a member of IDFNZ/ KIDS and ask for prices prior to accessing the service.

ST JOHN'S HEALTH SHUTTLE - WEST AUCKLAND ONLY 0800 000 606

Contact the above number to see if they operate in your area. The service operates Mon-Fri from 8am - 5.30pm. They provide transport for medical, hospital, specialist appointments, treatment at clinics, transport to and from minor day surgery. To ensure a vehicle is available please give 24 hours notice. Prices up to 10km - \$5, from 10-20km - \$7.50, and over 20km - \$10. All drivers are first aid trained.

TOTAL MOBILITY SCHEME

To be eligible for this scheme a person must be able to show they cannot access public transport in a safe and dignified manner which may include a physical, sensory, neurological, intellectual, psychiatric, psychological or other impairment. Contact Tracey 0508 300600 for more information on this service.

MINISTRY OF HEALTH - NATIONAL TRAVEL ASSISTANCE

Patients can also check out the Ministry of Health website to view the current rules for eligibility to claim travel assistance for travel to publicly funded specialist appointments

Recent Events

Patient Member Events around the country

Auckland members enjoyed a visit to Auckland Zoo with IDFNZ; a networking meeting and family picnic with time afterwards to explore the Zoo as a family.

A behind the scenes visit to Air New Zealand Engineering Services was made available to both Auckland and Christchurch members. This was certainly a unique experience, it was fascinating to learn what goes on behind the scenes, to have a guided tour of so many different aircraft and to enjoy wonderful hospitality. A great day out for all attending. Thank you to Grant Stone of Air New Zealand for organizing this opportunity.



Wellington members chose to meet at Bowlands Porirua, they enjoyed bowling together followed by an opportunity to talk together and to staff / board members over a coffee afterwards.

PID Seminars

IDFNZ held a PID and Blood Safety information seminar on February 14th with some excellent New Zealand guest speakers involved. This event was targeted at patients receiving gamma globulin treatment and was attended by members from all across the country. The information transfer and subsequent networking from these meetings has been excellent value. Many thanks to Professor Rohan Ameratunga, Dr Peter Flanagan of NZBS, Dr Richard Steele, Dr Jan Sinclair, Dr Miriam Hurst, Dr See-Tarn Woon and Sancha Vos, for giving freely of their time and expertise and supporting IDFNZ.

Transplant Members

Auckland - A special meeting was held with Scott Large, a New Zealand member who underwent a successful double Liver - Bowel transplant in 2003, sharing his experience with prospective bowel transplant families. This was a very touching event, a rare opportunity

to ask first hand all of those burning questions that arise when families face such a rare and daunting treatment option. We would like to thank Scott for his time and for being willing to share so openly.

The coffee meetings at Starship hospital continue on a quarterly basis, all transplant members are welcome to attend, especially those hospitalized for long periods - come along for a break with others who understand what you are facing.



The highlight of the February meeting was guest speaker Susan Cato-Symonds from Starship Information Centre, updating members on free services available to them at Starship. Parents were able to enjoy the talk and talk to Susan as the children were playing in the Ronald MacDonald playground nearby.



Auckland liver clinics are taking place most Thursday mornings at Starship - Tracey Cornwall has been asked by the hospital staff to be available onsite during this period so that families can touch base with her before or after appointments.

Other Centre's -Tracey will also be visiting other hospitals around NZ alongside the Liver / Gastro outreach clinic team and so will be able to catch up with liver patients around the country face to face.

Whangarei members were able to meet Tracey in April for the first of their scheduled meetings.

Christchurch members will have their opportunity on May 25th, both at the outreach clinic and for an IDFNZ lunchtime meeting planned for the same day.

Our Services

Bookings for holiday homes

Booking Fee has increased to \$40 from 1st June 2009 as a result of increased costs.

We encourage families to book up to 12 months ahead to avoid disappointment. Bookings may also be possible at short notice for emergency situations or families from out of Auckland requiring overnight accommodation to attend hospital appointments. please do not hesitate to ask.

Booking forms are available on the website or call Christine Jenden on free phone 0508300600and leave a message for her to call you back; Christine works part time and will respond within 5 working days.

Family grants and vouchers

The Foundation continues to help members with hospital parking, prescription costs, hospital meal costs and the like. A grant application form is available on our website or contact Tracey Cornwall 050830060 to request a friendly needs assessment meeting.

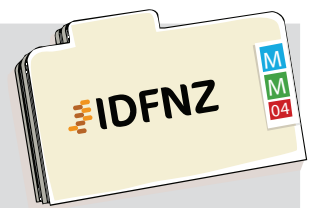
Medic Alert Bracelets - Limited offer!

We still have a small number of bracelets available free to patient members. These are assorted sizes and will require engraving with medical details by the family. Write to us with your wrist size if you are interested.

We have had some feedback that bracelets have been too large in some cases; these were donated to us so all we can suggest is they are either taken to a jeweler to see if they can be altered, or else set aside until a child patient 'grows' into the bracelet.

Medical Matters

Influenza A H1N1 and Immunoglobulin Products



The recent emergence of this new strain of influenza raises a number of questions for blood services and for regular recipients of blood products.

Fortunately a considerable amount of time and energy has been devoted to planning for an influenza pandemic during the last few years and so for once answers to these questions are already available.

Influenza A is an enveloped virus. The World Health Organisation has provided information on the natural history of the infection. This indicates that the incubation period, the period between exposure to the virus and onset of symptoms, for the infection is generally one week. People become infectious about one day before the onset of symptoms. Influenza virus may be present in the blood stream. This is believed to occur only when the patient has symptoms. Infectivity generally declines within a week of the onset of symptoms and is followed by recovery. It is noteworthy that no case of influenza transmitted by transfusion has been reported in the scientific literature.

Blood Services use a combination of methods to assure the safety of blood products. Firstly donations are only collected from healthy people – donors with symptoms of a cold or influenza type illness are not accepted. The likelihood of influenza entering the blood supply is therefore small. There is currently no

test available for screening of donations nor in reality do we need one based on the information we know about the virus. The manufacturing processes used to produce Immunoglobulin products do however include specific steps that inactivate any virus that might have been present in the donated blood or plasma. CSL Bioplasma products all contain at least two such steps - enveloped viruses, including Influenza, are readily destroyed by these processes thus assuring their ongoing safety.

During the last few weeks NZBS has been working closely with the Ministry of Health on this issue. The Ministry and Regional Public Health teams are identifying 'at risk' individuals and asking them not to donate for a period of 2 weeks following their return from risk countries if they are well and for 4 weeks if they have had symptoms possibly suggestive of Swine flu. We will continue to monitor the situation closely and introduce any additional measures if required.

The main risk to blood services from influenza relates to a sudden increase in the number of cases. This will likely reduce the availability of donors and will also impact on NZBS staff. The real risk therefore relates to our ability to continue to collect enough blood and plasma to meet clinical requirements. For a number of reasons this is unlikely to impact on the supply of immunoglobulin products;

- * Firstly NZBS always keeps at least 4 months supply of all fractionated products in New Zealand. Current supplies are above this level.
- * Secondly because we normally manufacture a pool of plasma every two months there is

always a further 2 months of product in the manufacturing pipeline in Australia, and

- * Thirdly we also keep enough plasma at CSL in Melbourne to enable us to respond quickly in the unlikely event that a problem were to occur that required a batch of product to be withdrawn. Currently we have well over 10 tonnes of plasma at CSL – this is enough to meet a further 2 months of clinical requirements.

Given the above NZBS is confident that we will be able to meet all clinical requirements even if an influenza pandemic arises that is sufficiently serious to disrupt our routine collection and manufacturing programme. One further area that NZBS is investigating is the ability to collect 'convalescent plasma'. This involves collecting plasma from people who have recovered from the influenza strain. This will contain high levels of specific antibody and might be useful in the treatment of severe cases of the disease. This type of product might be particularly beneficial for people with immunodeficiency disorders.

NZBS is currently busy updating its pandemic plan. This will ensure that we are confident in our ability to continue to supply adequate amounts of safe product if the current situation were to deteriorate.

Dr Peter Flanagan, National Medical Director, New Zealand Blood Services



World Day of Immunology 29th April 2009

Tracey Cornwall represented IDFNZ in an exhibition by immunology staff at Auckland Hospital to mark world day of immunology.

This was an opportunity to raise awareness of all aspects of the immune system, and in particular for IDFNZ a reminder of those people affected by immune systems that do not work optimally, the treatments available to them and new research taking place here in New Zealand. Many thanks to Sanchia Vos for organizing this event.

Upcoming Events

World Blood Donor Day 12th June 2009 – "It takes all types"



World Blood Donor Day is an annual event celebrated worldwide to create awareness about the need for safe blood for transfusion and the importance of blood donation.

For the New Zealand Blood Service (NZBS) it is also an opportunity to thank Kiwi blood donors for their dedication and to remind people about the importance of donating blood regularly. It is therefore a major event on the NZBS calendar, with the hope it will result in new people contacting NZBS to make an appointment to donate as well as encouraging current donors to donate regularly.

This year's theme is "it takes all types" and the event will be marked in New Zealand on Friday 12 June.

IDFNZ is pleased to be able to support NZBS with some of our patient members receiving IVIG / SCIG treatment, speaking out to express their gratitude and share their stories to show blood donors what a difference they have made.

World Blood Donor Day 12th June 2009 – "It takes all types"

This edition of **Intouch** was sponsored by The Mt Wellington Trust.

The IDFNZ is a not for profit organisation dedicated to supporting New Zealanders of all ages diagnosed with Primary Immune Deficiencies (PID's). IDFNZ provides education for PID's, PID lobbying and advocacy services, and ongoing medical and scientific research.

The Kids Foundation is the welfare arm of IDFNZ caring for PID children, teenagers and their families, as well as bone marrow and liver transplant children. The Foundation offers members practical, emotional, medical and social support.



The Kids Foundation
key immune deficiency support

Web www.idfnz.org.nz Freephone 0508 300 600 Fax 09 523 5551 Email info@idfnz.org.nz Post PO Box 75-076 Manurewa, Manukau 2243



Razz-Ma-Tazz Annual Appeal 2009

KIDS Foundation is proud to announce that this year's Annual Appeal will be based on hosting Razz-Ma-Tazz - A fun filled variety show featuring the amazing award winning American family entertainers David Kaplan and Sylvester the Jester. Shows will be hosted for the free entertainment of local special needs and disadvantaged children made possible by the loyal support of local businesses supporting this community cause. KIDS Foundation will benefit from all profits made from these shows using these funds to continue the support services that we offer PID and transplant patient members in these regions. We are confident this new show will appeal to all members of the family. Show locations and dates are as follows:

Sunday August 16th – Auckland.

Monday August 17th – Hamilton.

Wednesday August 19th – Wanganui.

Thursday August 20th – New Plymouth.

Friday August 21st – Palmerston North.

Saturday August 22nd – Wellington.

Tuesday August 25th – Nelson

Friday August 28th – Christchurch

Saturday August 29th – Timaru.

Sunday August 30th – Dunedin.

Monday August 31st – Invercargill.

Wednesday September 2nd – Whangarei



Special Appeals



To learn more about some of our current special appeals please visit the links on our website www.idfnz.org.nz. Donations towards these special causes can be made easily on line with full tax receipts emailed back.

Family Conference

IDFNZ is pleased to announce the next family conference will be held in Auckland July 16th – 18th 2010.

Overseas speakers will include Professor Luigi Notorangelo from Boston and Dr David Gills from Brisbane.

The event will mark 21 years of supporting New Zealand families affected by PID's.

Registration forms will be available to members in November.



CSL Bioplasma

The Foundation is pleased to acknowledge an unconditional education grant from CSL Bioplasma which is to be used for our new GP PID education program being released soon across New Zealand.



Thanks to Pub Charity for supporting our transplant services, enabling the Foundation to print and distribute a new range of educational resources for patients and medical professionals.

Our Supporters

A special thank you to all of our loyal sponsors and supporters who make the work of the Foundation possible.

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The New Zealand Transplant Support Trust
Octapharma Ltd
Lotteries Auckland
The Pacific Sports and Community Trust
Trinity Foundation
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COGS Manukau
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Supporters of Circus Quirkus and Spellbound
Plus the many loyal individual donors who choose to give to IDFNZ and KIDS Foundation.