

coming events

Patient Events 2011

Saturday June 18th
Special Members Meeting
2.15pm, Auckland Botanical
Gardens

Sunday July 3rd
Maritime experience
Voyager Museum,
Auckland.

Tuesday 19th July
Dunedin, Supernan/Choc Hunt

Wednesday 20th July
Invercargill, Kidszone Festival

Monday 25th July
Auckland MERC Youth event

Saturday 13th August
Wellington, Ten pin bowling/
superstrike

Razzmatazz 2011

Saturday 20th August
Invercargill Civic Theatre

Tuesday 23rd August
Queenstown, Memorial Hall

Wednesday 24th August
Dunedin, Town Hall

Thursday 25th August
Timaru, Theatre Royal

***Friday 26th August**
Christchurch, venue tbc

Tuesday 30th August
Nelson, Trafalgar Centre

Saturday 3rd September
Wellington, TSB Arena

Sunday 4th September
Palmerston North, College of
Education

Monday 5th September
New Plymouth, TSB Showplace

Thursday 8th September
Hamilton, Founders Theatre

Saturday 10th September
Auckland, Logan Cambell Centre

Monday 12th September
Whangarei, Forum North

Please visit our website for further
details, some details may change*

Raising Awareness

Raising Awareness of Primary Immunodeficiencies.

The new global PI Awareness week and World Day of Immunology were successfully marked across New Zealand due to the efforts of many willing volunteers.

IDFNZ would like to convey a huge **THANK YOU** to the following organisations for their help in providing resources and setting up of IDFNZ / PID information stands to promote this important message :
Auckland Public Hospital, Auckland Labplus ,
Auckland Starship Hospital, Starship Information Centre, Hamilton Hospital, Invercargill Hospital, Wellington Children's Hospital, New Zealand Blood Service Donor Centre's at Epsom, Manukau ,
Auckland North Shore, Waikato, Tauranga, Wellington, Napier, Christchurch, Dunedin, Nelson and Manawatu . The Royal New Zealand College of GP's, Lion Foundation, Pub Charity Inc and our own IDFNZ Board members and volunteers around the country.



Another important day for your diaries:
NZBLOOD
Te Ratonga Toto O Aotearoa
JUNE 14th
World Blood Donor Day 2011

Blood Donors Save The Day

IDFNZ is proud to support New Zealand Blood Service and give heartfelt THANKS to the heroic blood donors across New Zealand touching the lives of our PID patients every day.

We can all play a part in assisting NZBS achieve its goals of reaching new donors for the coming year...

World Blood Donor Day (WBDD) is celebrated across New Zealand on 14 June each year in thanks to volunteer blood donors for their life-saving contribution. For the NZBS, it also serves as a critical annual campaign to highlight the constant need for more blood donors.

Under the theme 'Blood Donors Save the Day', this year the NZBS is asking people to help 'save the day' for fellow Kiwis in need of blood and blood products by 'saving a day' to donate blood. Choose just one special day in the coming year - your birthday, an anniversary or other memorable day - to commit to making a blood donation and you'll help save lives.

The number one goal of our media activity is to inspire action - we want more people to become blood donors.

NZ Blood Service:

The New Zealand Blood Service (NZBS) is a not-for-profit Crown organisation responsible for the collection, processing, testing and storage and distribution of all blood and blood products in New Zealand. Via voluntary and non-remunerated blood donations from individuals around the country, NZBS provides the constant supply of precious blood and blood products to our health services, which are used to save thousands of lives.

Our People

Adriaan Bosch -New Board member, appointed December 2010



Kia Ora, my name is Adriaan Bosch and I live in the Far North at Wainui bay in the Whangaroa district, I have been an IDFNZ member for some years now as a PID patient. I thought I may have something to offer the foundation and after much thought applied for one of the vacant positions on the board. I have been involved in community work for many years following my children's growth through different sports, Yachting was interesting with logistics of getting a dozen sailing dinghy's to regattas from Taupo to Taipa I also sat on the Kerikeri Cruising club centre board committee for three years, Kaeo rugby club senior committee had my services for ten years as their secretary, and some of you may remember the two floods that devastated our clubrooms on televisions Close Up, my job there was to price and purchase the two insurance claims, I also ran every electrical wire throughout the two story building when it was being rebuilt, but that's in the past I resigned from the Rugby club to put my efforts into IDFNZ. I am a active Coastguard member in Whangaroa and hold two Skippers ticket's, I really enjoy getting out on the ocean and waterways fishing and scuba diving, work is at a place called Imerys Tableware at Matauri Bay where we mine a white Kaolin clay which we process and bagged to send export to places all over the world, it's a one off mine in New Zealand producing some of the purest white clay in the world, used in Porcelain and Bone chinaware. As you can see I live a fairly normal life and the once a month (IV) seems to keep me active, all though I still need to be mindful of keeping clear of every day infections. I hope my term on the board brings rewards to our members and I can see by our board's agenda that the next few year's building blocks will benefit many members long into the future.



Blood Donors Save the Day - cont.



Primary Immune Deficiencies and the NZ Blood Service

Demand for blood products is growing rapidly each year. The demand for Intragam P used by many members of IDFNZ is growing at 8% per year. To meet this ongoing need, a core focus for the NZBS in 2011 is to collect 30% more plasma donations by apheresis (cell separation machine). NZBS is well on the way to meeting this target. In order to increase plasma donation NZBS recruits people who are already blood donors. These donors need to be replaced and World Blood Donor Day is one way we can communicate the need for more donors.

Key Messages NZBS are using for this year's WBDD campaign are:

- Thank you to the generous blood donors that help 'save the day' for thousands of Kiwis with the life-saving gift of blood.
- World Blood Donor Day is a reminder to make your next appointment to donate, or consider becoming a blood donor.
- Help 'save the day' for fellow Kiwis in need of blood and blood products by 'saving a day' to donate blood. Choose just one special day in the coming year - your birthday, an anniversary or other memorable day - to commit to making a blood donation and you'll help save lives.
- Donating blood is easy and convenient to make a part of your everyday life.
- Red blood cells only last 35 days and platelets last just 5 days. The NZ Health Service relies on regular blood donations to save lives every day.
- We always need more new donors to help meet demand and keep pace with natural turnover.
- There is no alternative for patients in need of blood or blood products - blood donors save lives. (One donation can potentially save three lives!)

Did you Know?

To keep up with New Zealand's need for blood and blood products, the NZ Blood Service must collect 3,000 donations per week (around 148,000 units per year)

Around 42,000 people needed blood or blood products last year to help save their life, yet only around 4% of the eligible population currently donate blood

The donor database has to sustain a turnover of around 20,000 people every year (as regular donors retire, become ineligible and so on, they must be replaced)

Visit www.nzblood.co.nz or phone 0800 GIVE BLOOD to find out more or to register to donate. You can make an appointment up to three months in advance.

To make an appointment or to find out more about blood donation call 0800 GIVEBLOOD (0800 448 325) or go to www.nzblood.co.nz

Invitation from IPOPI to Participate in an International Patient Needs & Outlooks Survey

IDFNZ is a national member organisation of IPOPI, the International Patient Organisation for Primary Immunodeficiencies. IPOPI serves to link together individual PID patient groups from around the world. IPOPI has committed to undertake a global survey of individual PID patients and has forwarded the following invitation to individual IDFNZ members to participate:

Dear IDFNZ members

We are currently conducting a market research survey to identify the needs and wants of PID patients and carers and would like YOU as a member, to take part. The survey will allow us to gain a clearer understanding of the current state of play in relation to your views to help provide opportunities to refine and relate differently to the developing needs of Members.

This online study is being conducted by Bryter, an independent opinion research

company. Bryter's full privacy policy is available online (<http://www.bryter-research.co.uk/Privacy.htm>): we can assure you that your individual responses will be completely anonymous and reported only at an aggregated level.

We would very much value your response. The survey will take 25-30 minutes to complete and can be completed by entering the following link into your browser:

www.pi-survey.net

Please try to complete the survey as soon as possible.

Many thanks in advance for your time and help with this important study. If you have any technical problems with the survey itself, please contact laurence.olding@bryter-research.co.uk

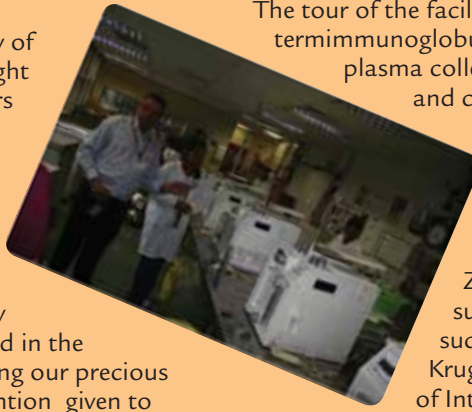


The Board of IDFNZ encourages all members to take the time to participate in this survey.

IVIG / SCIG Patient Meeting – New Zealand Blood Service

The Patient meeting held at New Zealand Blood Service on World Day of Immunology April 29th was a highlight for everyone attending. Our members were greeted with a very warm welcome, given very comprehensive and informative talks, an interesting tour of the facility and treated to an enjoyable lunch.

The information gathered was very valuable, it was good to hear directly from the specialists the steps involved in the collection, screening and fractionating our precious plasma products; the care and attention given to assure safety, compliance and supply was evident.



The tour of the facility allowed our PID patients on long term immunoglobulin treatment the opportunity to see plasma collection actually taking place and to meet and chat with some of the regular donors. It brought home for everyone the very personal nature of this generous 'gift' which is truly 'vein to vein'.

We would like to thank Dr Peter Flanagan and Paul Hayes of New Zealand Blood Service for their ongoing support and for making this event the success it was. Thanks also to Tamlyn Kruger of CSL for updating us on Production of Intragam P, and our own Sandi Field for all of the organising behind the scenes.

Regional Patient Meetings

Other Patient Events held since April include a morning tea meeting for our transplant patients at Starship hospital – thank you to everyone who participated in the survey regarding the new Patient centre, your enthusiasm is appreciated.

Sandi was also able to bring together patient members in Hamilton and Christchurch for the first time this year. These regional meetings are a wonderful opportunity for local families to get to know other members living nearby, sharing information and experiences and generally building a strong network. For our Christchurch members this was the first meeting since the recent earthquakes – it was heartening to see everyone so positive and strong after such a nightmare experience. Dealing with the challenge of chronic health conditions certainly builds character and coping mechanisms making our families in some ways more prepared than the average in dealing with the unexpected. We applaud you for coping so well with this incredible additional stress.

Circus Quirkus

Our annual Circus Quirkus was hosted in Gisborne and Napier this year with hundreds of local medically fragile and special needs children attending. The show was excellent with its unique blend of international family entertainers. Thanks to the Infinity Foundation and all of our regular business supporters for making this a success.



Patient News

WINZ Sickness Benefit Changes - Keeping Up to Date

Adult Patient members receiving WINZ support need to keep up to date with recent changes. We refer to the following information from WINZ: Work and Income (WINZ) offer a range of assistance to support you and your family when you need it. To see if you are eligible to receive support through WINZ contact them on 0800 559 009 or visit their website www.workandincome.govt.nz

Sickness Benefit - Changes

WINZ is changing the way they work with disabled and sick people on a Sickness Benefit. The focus is on what people can do, instead of what they can't, with the goal of helping people into work if they're able to. From the 2nd May 2011 WINZ will be making three main changes to the Sickness Benefit.

These changes are:

1. People receiving a Sickness Benefit who have been assessed by Work and Income as able to work at least 15 hours a week, will need to start looking for part-time work. This assessment will be based on information provided in the Work Capacity medical certificate along with what the client and other experts tell WINZ.
2. When people start receiving a Sickness Benefit, their first medical certificate will be valid for a maximum of four weeks. They will need a second medical certificate for the next four weeks and then a new medical certificate every 13 weeks after that. This extra information early on will allow WINZ to work more closely with people to determine if they are capable of doing some work and what work would be most suitable. It will also help WINZ determine the right assistance the person should be getting.
3. People who have been on a Sickness Benefit for 12 months or longer will need to come in for a review after every 12 month period. This is to ensure that people are getting the right assistance and support to help them get into work as quickly as possible.

People won't lose their benefit if they do not get a job, but they may have it reduced or stopped if they don't actively look for one. Work must be suitable to each person's particular situation.

If you are on a Sickness Benefit and have any questions regarding the changes please contact your WINZ Case Manager or the call centre on 0800 559 009.

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

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 PID Bone Marrow and Liver Transplant children. The foundation offers members practical, emotional, medical and social support.

IDFNZ
Immune Deficiencies Foundation
of New Zealand



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

Support IDFNZ by partnering with Aon for your insurances

IDFNZ have teamed up with Aon New Zealand, to provide an opportunity dedicated to helping you as a supporter improve your insurance coverage and support IDFNZ at the same time. The process is really simple, it works by you contacting Aon (craig.graves@aon.co.nz) and for each insurance policy placed for you, IDFNZ will automatically receive a donation**. To insure your Business, Home, Contents, Motor Vehicle or Travel, simply contact Craig Graves at Aon per the IDFNZ contact form available on our website www.idfnz.org.nz.

Benefits of insuring with Aon

- Customer focused
- Dedicated support
- Unequaled Risk and Insurance services
- Tailored policy wordings
- Innovative products and services
- Aon is the leading insurance broker to the corporate, public, primary, manufacturing and transport sectors



The process is simple:

1. Email the completed IDFNZ contact inquiry form to Craig Graves on craig.graves@aon.co.nz or contact him c/- (09) 486 9756
2. Provide your current insurance requirements
3. Receive Aon terms and policies
4. Appoint Aon and automatically have a percentage of your premium donated to IDFNZ upon receipt of payment

** **A percentage of income earned by Aon will be donated to IDFNZ.**

About Craig...

Hi my name is Craig Graves and I have worked in the insurance industry for more than 11 years now, over that time I have come to realise that insurance is not just a bill people receive on an annual basis but in times of grief, disaster, etc. it is something that can truly assist you (if only from a monetary perspective). Whilst it won't bring back an individual, rebuild the exact same house or building, or return your great grandmother's heirlooms; it does allow for some comfort in overcoming the situation.

My wife and I have two children and whilst our youngest spent 8 weeks in intensive care at birth, we are fortunate that both children are healthy today, I believe, as does my company - Aon New Zealand, that in donating a percentage of our income from each insurance policy purchased by both the members and supporters of IDFNZ, we can do a little to assist you with your needs through IDFNZ's various services and resources.

"You can have everything in life that you want if you are prepared to help even one person get what they want"

Smith & Smith - Giving back update

Staff members of Smith & Smith branches across the country are competing to raise funds for IDFNZ KIDS Foundation. We are thrilled to hear we have such a creative and determined group working on our behalf and look forward to reporting on some of their efforts as the year progresses. Meanwhile we give Thanks to Smith & Smith corporate for their generous donation of \$15,000 towards our Patient Centre Building fund.



Chairman Judith Dickson receiving a mighty cheque from Greg Liddington of Smith & Smith

Razz-Ma-Tazz 2011 Update

Our much-loved, Kids Foundation RazzMaTazz shows are happening around the country throughout August and September. This year we are again hosting shows at 12 locations to provide a fun night out for thousands of special needs children/ families such as our own; they also help to raise valuable public awareness of our cause, and raise much needed funds as part of our Annual Appeal.

The Foundation would like to thank all local businesses and Trusts who regularly support the Foundation and make these events possible in their local community.

Visit www.razzamatazz.co.nz to see more about the wonderful performers.

Patient Survey Update

Many thanks to patients and caregivers who took the time to complete our survey - we have had an encouraging response so far and are currently analysing the data. Cut off date for late responses is 30th June. We hope to report back with the results next newsletter.

Thanks also to the Transplant patients who agreed to complete our more in depth Patient centre survey - we are still working our way through these interviews, but the response so far is overwhelmingly positive. We really appreciate your willingness to support us.

2011 Supporters include

Smith & Smith®
The Freemasons Charity
The Freemasons Mangere Lodge 330
Commonwealth Serum Laboratories Ltd (CSL)
COGS
The New Zealand Transport Support Trust
Octopharma Ltd
The Mount Wellington Foundation Ltd

Four Winds Foundation Ltd
Oxford Sports Trust
Circus Quirkus Appeal
The Perry Foundation
The Lion Foundation
The Pelorus Trust
The Endeavour Community Trust
Sovereign Sunshine

Razz Ma Tazz Appeal Supporters
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