

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.

**IDFNZ**  
Immune Deficiencies Foundation  
of New Zealand

**Ki Kids**  
Foundation  
for immune deficiency support

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## Spellbound

Our major fundraising event this year is called "Spellbound" a show full of fun, laughter and comedy.

This event allows us to give many children, teenagers and families, who are dealing with illness or disabilities, a special day out and a chance to forget about their daily difficulties. Business's throughout New Zealand supporting our Appeal make this event possible. The proceeds the Foundation receives by hosting these events help us to provide the valuable and comprehensive program of services for patient members. See the events page for details of show times and venues.

A huge thank you to all businesses sponsoring these events which will benefit thousands of New Zealand special children as well as the Foundation.

## Our Supporters

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

The Remuera Lions Club  
Immune Deficient Teen Trust  
Pub Charity Inc.  
The Trillian Trust  
The Southern Trust  
Commonwealth Serum Laboratories Ltd CSL  
South Auckland Charitable Trust  
The New Zealand Children's Transplant Support Trust  
The Trusts  
The Century Foundation  
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The Trinity Foundation  
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The Oxford Sports Trust  
The Winton and Margaret Bear Trust  
The Bay Foundation  
The New Zealand Community Trust  
The Pacific Sports & Community Trust  
The Southern Victoria Trust  
The Green Thistle Trust  
The Mt Wellington Trust  
Trust House  
The Auckland Airport  
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The Mangere Bridge Sports and Cultural Trust  
Sponsors of the KIDS Foundation Wishlist Appeal  
Sponsors of the KIDS Foundation Circus Quirkus Appeal  
Sponsors of the KIDS Foundation Spellbound Appeal

## Supporters of the Foundations Repite Care Program

### In Auckland ... 'Lions Den' provides much needed sanctuary

Kids Foundation members are set to benefit from our latest brand new purpose-built holiday home at Red Beach just north of Auckland. The holiday home - aptly named the Lions Den - was formally handed over to the Kids Foundation by the Remuera Lions Club in late May. Totally funded by the Lions Club of Remuera it will provide respite for families who deal with the every day stress of living with PIDs. Kids Foundation chairman, Stephen Baxter, says the new holiday home provides an ideal opportunity for families to have "time out" together. "Providing them with an opportunity to have a holiday in a wonderful location will give much needed time out for both children and their parents. "Now thanks to Remuera Lions and the support of and Pinewoods Motor Camp management and board they can relax close to one of the best beaches on the North Shore in a holiday home equipped down to the last detail."



Joshua Baxter and Mischa Tattley trying out the Lions Den



Members of Remuera Lions Club handing over the Lions Den to the Foundation

### ...and for our Wellington and Lower North Island Families...

A further holiday home has been made possible by the generosity of Trusts such as The Southern Trust and Pub Charities Inc. to serve all Foundation members, but in particular those within easy traveling distance of Otaki. This home sleeps a family of eight comfortably and will be a huge asset for local members of the Foundation.



Wellington Respite Holiday Home, Otaki Beach. Sponsored by The Southern Trust and Pub Charities Inc



**IDFNZ** **Intouch**  
Immune Deficiencies Foundation  
of New Zealand

JULY 2007

## coming events

### BI Annual Patient Conference

Friday 20th July - Sunday 22nd July  
Saturday 21st July Liver Transplant Day  
Vaughan Park, Auckland

### AGM

Sunday 22nd July  
Vaughan Park, Auckland

### Spellbound 2007

Tuesday August 14th, 6pm  
Forum North, Whangarei.

Saturday August 18th, 2pm  
Great Lake Centre, Taupo.

Sunday August 19th, 1pm & 4pm  
Logan Campbell Centre, Auckland.

Monday August 20th, 6pm  
Founders Theatre, Hamilton.

Tuesday August 21st, 6pm  
Massey University, Palmerston North.

Thursday August 23rd, 6pm  
Trafalgar Centre, Nelson.

Saturday August 25th, 1pm & 5pm  
Theatre Royal, Christchurch

Sunday August 26th, 2pm  
Theatre Royal, Timaru

Tuesday August 28th, 6pm  
Civic Theatre, Invercargill

Thursday August 30th, 6pm  
Regent Theatre, Dunedin

Saturday September 1st, 2pm  
Wanganui Collegiate, Wanganui

Monday September 3rd, 6pm  
TSB Events Centre, Queens Wharf, Wellington

## Fighting the Stress of Chronic Illness

The Foundation is committed to fight this ongoing battle.

It is well known that chronic or long term illness means the patient has to adjust to the demands of the illness and the therapy used to treat the condition. There may be additional stresses, since chronic illness might change the way a person lives, sees themselves and relates to others. Chronic or long term illness and its treatment pose special problems for the person. It takes time to learn how to live with the physical effects of the illness, deal with the treatments, make sure there is clear communication with doctors and maintain emotional balance of both the individual and the wider family unit. All of this without even touching on the added stress caused by the financial cost of any chronic condition; juggling jobs, childcare, and travel to and from hospitals for a sick member of the family is draining for all concerned.

An interesting study looking at effects of illness on PID children revealed that whilst all chronically ill children are found to be at risk of behavioral and emotional difficulties, those with PID, suffering multiple chronic conditions and complicated medical regimens, suffered a higher frequency of concerns. Children receiving intravenous immunoglobulin or immunomodulatory treatments were also reported to have more problems than children not receiving them.\* It is logical to deduce that this increase in stress is also reflected on the rest of the family unit supporting the PID patient.

### The Foundation seeks to help members cope with stress by offering practical help:

Providing Information and seminars - Thus helping to understand the condition, to know more about treatments and therapy available. Providing family matching and meetings to enable individuals to mix with others facing similar challenges, as well as access to the expertise of our medical panels.

This year we are pleased to announce our second National Family conference in Auckland which will help with all of these aspects of support. Remember our Health Coordinator is available to everyone to answer specific questions and provide information at any time.

### Providing Respite Care - The

Foundation is now in the position of having three respite holiday homes in the North Island that are available for any of our families to use. Rest and recuperation, time out as a family, can help recovery from illness and strengthen families to cope with ongoing stress. We hope to provide an even wider network of these quiet havens which will allow families to escape on a regular basis.

The facilities are modern and hygienic, fully self contained and within easy travel distance. These are lasting gifts for use by all of our current families and by generations yet to come. They are available to adult patients as well as families - give yourself something to look forward to!



Long Bay, location of July Patient Conference



\*Child and caregiver psychosocial functioning in pediatric immunodeficiency disorders. *Annals of Allergy Asthma Immunol.* 2006;96:298-303

## Our People

Vicki Tattley



I have been part of IDFNZ for the last 11 years, from when we were informed that our middle child, Aidan had an immune problem. This was all new to us and we were most grateful to discover IDFNZ who then supported us through the critical period of adjustment parents have to make when finding out that their child has a "medical condition". When Aidan was a little older I joined the board of IDFNZ to 'give back' something to an organisation that upheld us at a difficult time.

Living with immune deficiency changes your life; Forever. We acknowledge that Aidan's immune deficiency is a milder form; however it still brought about changes in our families life. Small things that other people take for granted - in the 90's McDonalds was a favourite place for children, with their fun playgrounds etc. For us however McDonald's playgrounds were potentially places where we might inadvertently put Aidan at 'more risk' of sickness, therefore a visit to one was a treat, followed by a period of waiting - hoping no bugs had been picked up. Stomach bugs were a nightmare for us as they seemed to linger forever (and even now still do) a lot longer than for the 'average' child. Aidan has had a few trips to Starship by ambulance when he presented with symptoms similar to meningitis - he was so ill that we were transported quick smart. Once at Starship, the stress continued as obviously there are lots of sick children in hospital with many different illnesses. Luckily meningitis was soon ruled out, it was merely another bug hitting extremely hard - (Aidan can and still does appear well one minute and can have a raging temperature the next

and produce all the meningitis symptoms); however, then we were constantly alert for whatever other infections we were at risk of being exposed to in Starship as he recovered. We have been known to keep our children in the car at 'After hours' Doctors so that we only take them in when it is their turn rather than expose them unnecessarily to more bugs. This all sounds rather 'over the top', however a little preventative medicine in the form of avoidance pays dividends.

We present a different type of picture to the more acute PID conditions which are obviously life threatening and may require bone marrow transplants, or the children who require regular and lifelong transfusions of blood products. Nevertheless, ours has been an ongoing, chronic disability which is constant and wearing; affecting all aspects of normal 'living' for the whole family.

Our other children have shown symptoms but not as severe as Aidan. Aidan's immune system appears to be stabilising now, however we are ever vigilant and careful. He still suddenly becomes ill and we still have him closely monitored by our very supportive GP.

Our children do not make any big deal over their immune problems. We try to let them lead the same lives as their peers. We just have a different set of precautions. Thankfully our children have all been able to be actively involved in many different sports at different levels. It has always been the aim of the Foundation for those suffering from immune deficiencies that they integrate into society as much as is practicable, and to lead as normal a life as possible. Who is to say what is "normal" anyway? Each and every family will have some sort of issue to deal with - our families, we hope, with the support of the foundation can carry on to achieve whatever goals they set.

## Recent Events

### PID PATIENT SEMINARS

During 2006 the Foundation ran a series of PID health seminars reaching out to medical professionals and members around the country. The following areas were covered:

Dunedin, Christchurch, Wellington, Tauranga, Gisborne, Palmerston North, and Auckland. The information transfer and subsequent networking from these meetings has been excellent value.

### TRANSPLANT COFFEE MORNINGS

A series of casual coffee meetings at Starship hospital have been quite successful with groups of liver families meeting together in a relaxed atmosphere. These are now a regular event and we are exploring new venues and ideas for this group.



## Medical Matters

### CVID RESEARCH



IDFNZ is excited to announce that final approval has been given to the team at LabPlus Auckland under Dr Rohan Ameratunga, to start their research into Common Variable Immune Deficiency (CVID).

This is a project to try and identify the genetic abnormalities that cause this condition. There have been recent advances in this area but there is much more that needs to be researched to enable this disorder to be better identified and diagnosed correctly. Due to the large variation of symptoms and abnormalities,

CVID has up till now often been a diagnosis of exclusion, that is, if it doesn't fit into any other diagnosis it must be CVID!

If the genetic abnormalities causing the deficiency can be identified then the diagnosis can be made with certainty and will hopefully reduce the often long wait between onset of symptoms and diagnosis. This will then help to reduce some of the damage done to the body as it struggles to fight infection by enabling immunoglobulin therapy to start much earlier.

The project is now underway - If you have CVID and are interested in being part of this research we invite you to register your interest by completing the following form and sending to Sarah Perry by fax (04 232 9511) or post to PO Box 51-111 Tawa Wellington

If accepted into the project you will receive a full report at its conclusion. If you have any questions please contact the Health Coordinator on either free phone 0508 300 600 or info@idfnz.org.nz

### World Health Organization Essential Medicines List

Great news! It is now officially confirmed that immunoglobulin has been reinstated on the "Model List of Essential Medicines". Well done IPOPI who worked hard on this project.

## Our Services

### BOOKINGS FOR HOLIDAY HOMES

We are now taking bookings for all three holiday homes, we encourage families to book as far ahead as possible. Bookings are also possible at short notice for emergency situations please do not hesitate to ask.

Booking forms are available on the website or call Christine Jenden on freephone 0508300600 ....and leave a message for her to call you back to discuss your needs.

### 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.

Sarah Perry is the first point of contact - please feel free to contact Sarah on free phone 0508300600 or fax your completed form to 04 232 9511 and she will call you back to discuss your needs.

### ENCOURAGING SPORT AND EXERCISE

The Foundation continues to offer grants for swimming lessons to encourage youngsters who may have missed out due to chronic illness; apply for the September term now. Contact Chris Jenden on free phone 0508300600 and she will call back to discuss your needs.

Youths suffering from bronchiectasis are also being offered financial assistance with other sports or exercise activities which will assist their health conditions. These will be on a case by case basis and written applications should be sent to Sarah Perry PO Box 51-111 Tawa, Wellington.

## USANA New Zealand

### Health Company Supporting Primary Immune Deficiency Patients

Special thanks to staff and Management of leading Albany based health and nutritional supplement company USANA New Zealand for supporting the Foundation. With a special interest in helping people achieve optimum health, they have chosen the KIDS Foundation as a special beneficiary and have raised over \$3422; USANA New Zealand manager Marissa Penfold has asked that the Foundation use these funds to provide 'care packs' for hospitalized members to be of practical assistance during hospital and lift their spirits towards recovery.



USANA manager Marissa Penfold handing a cheque over to Vicki Tattley