



## coming events

### May - June 2005

#### Kids Foundation/IDFNZ Annual Appeal

Donations to PO Box 75-076, Manurewa

### June - July 2005

#### Movie Madness Film Festival

See [www.idfnz.org.nz](http://www.idfnz.org.nz) for venues and details. Free tickets from support staff 0508 300 600.

### Friday 15th July, 2005, 6pm

#### IDFNZ/Kids Foundation AGM

Auckland Public Hospital, 3rd floor, Labplus building. Anyone outside Auckland wishing to link by teleconference please contact Sarah Perry at 0508 300 600 to arrange.

### August 31 - September 4, 2005

#### ASCIA Meeting - Queenstown.

See [www.allergy.org.au](http://www.allergy.org.au) for registration costs and details.

### September 9-11, 2005

#### IDFNZ Family Conference

Vaughan Park, Long Bay, Auckland. Early-Bird registration by 31st May 2005 to enter draw for family helicopter ride.

Registration forms and details enclosed.

### Free First Aid Courses

#### Meditrain Ltd

NZQA qualification  
For information, phone Graham on (09) 636 1377, or visit [www.meditrain.co.nz](http://www.meditrain.co.nz) for details.

# Family Conference

## a first for Foundation

2005 is set to be a very special year for IDFNZ members with the launch of the first ever PID Family Conference for all patient members and their families.

To be held from Friday September 9th to Sunday September 11th 2005 at the Vaughan Park Retreat Centre, Long Bay, Auckland, the conference will offer members a comprehensive PID education programme including specialist sessions with international experts, as well as fun relaxing events for all the family.

IDFNZ General Manager, Janet Simons, says the conference is a real achievement for the Foundation and an absolute must for all members to attend.

"Members should diary the conference dates now and make a special effort to attend this first ever family conference. As well as having the opportunity to learn about the latest developments in the

management and treatment of PID, attendees will get to question the experts, network and enjoy 'time out' with friends and family.

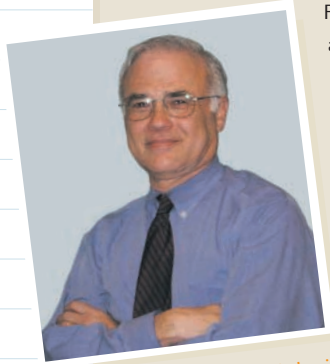
"Most importantly, the conference has been heavily subsidised by the Foundation, and as a result, it will cost members next to nothing to attend. So instead of paying the actual cost of the weekend which is in excess of \$500 per person, registration has been set at only \$30 per family to encourage as many families as possible to come along.



The Vaughan Park Retreat Centre

And for \$30, families will receive two nights free accommodation, free meals, entry to all conference sessions and children's events, as well as free entry and transport to Rainbow's End on the last day. Families outside Auckland can also apply for assistance to fund their travel to Auckland for this not to be missed event," said Janet.

Early-bird registration by the end of May will put those families registering into a special draw for a free family helicopter ride over Auckland. For more information about the Family Conference please refer to page four of this newsletter, check our website on [www.pidsnz.co.nz](http://www.pidsnz.co.nz) or contact your support IDFNZ coordinator.



PID expert Jerry Winkelstein

# our people

Just what the doctor ordered...



...A fair dinkum kiwi summer holiday! The soggy tents are hanging in the garage and I've just dosed the kids with antibiotics for bronchitis. Some summer! Then Michele from KIDS phones me, and offers me a week in the Foundation's Summer bach in Mangawhai.

It takes me all of 20 seconds to say "yes, please" and 3 days later we're off up North in search of summer.

The bach is at the Riverside campsite, which is beautifully kept and run by Lorraine who is just dynamite. It's on the estuary which offers safe, shallow swimming at high tide and a small sandy beach at low tide. We'd only been there an hour and the kids were already in the water!

The bach is really a 'house for a mouse'; it's tiny but incredibly well designed, ample storage space, adorably decorated and, well, just perfect! Every time I thought "if only there was a ...", there'd be one - this place has everything! Microwave, electric toaster, jug, electric frying pan, all kitchen tools, towels, bedding, vacuum cleaner - the works. Imagine our surprise when we find a shower bigger than the shower at home, with a removable handset so you can shower sandy, salty children easily. There's a stereo with CD player, and even a television.

Best of all, Michele and Janet had equipped the bach with games, and we played "Pass the Pigs" amidst gales of

laughter, and chess, draughts, pick up sticks, ludo - you get the picture!

The kiddies rooms are small with great timber bunk beds - you can actually sit up on the bottom bunk - with massive storage drawers for toys and clothes underneath. The bedsprads caused great delight - dinosaurs in one room and Snazzy Sister covers in the other!

The weather took pity on us, and the sun came out for our entire week. The kids' chests cleared, their faces took on a rosy sheen and their teeth gleamed in permanent smiles.



Mangawhai offers a massive variety of summer activities. We went to the surf beach, where you can swim between the flags and boogie board, or if you go to the left you can boogie board down the enormous sand dunes, which the kids infinitely prefer!

Then there's the estuary at the campsite for swimming, which offers a rope swing to the left of the beach; at high tide the kids swung right out and dropped into the water. They also held boogie boards for each other and "water skied" while holding on to the rope! Down at the estuary proper there's another

beach with lovely swimming, which is also great for floating sticks when the tide is running, you can have some exciting competitions.

A short drive from the bach is Te Arai point, a must visit during your stay. There's a white sand surf beach to the left, and a deep, protected swimming lagoon to the right. A short walk over the headland (only 20 feet high) takes you to a shell collecting beach with the most interesting rock pools in N.Z. Take a bucket and a net...

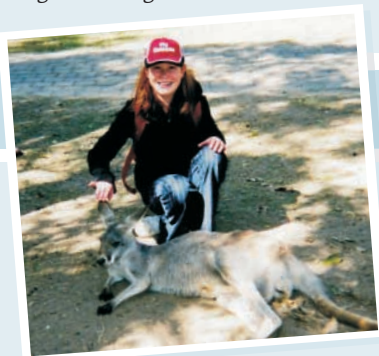
From the back of the campsite is a mangrove walk, which goes for 2 hours to a wildlife reserve stocked full of oyster catchers and other birds. And there's an inland salt water pool which is awesome to swim in. Wear shoes and watch out for oyster shells in the entire estuary.

The campsite rents kayaks and lifejackets, so the kids explored the estuary - right out under the bridge and into the mangroves, and it's never more than 6 feet deep even 400 metres out!

When we weren't at the beach - or eating ice creams - the kiddies were on the trampoline next to the bach, a massive hexagonal one (and there's another one for kids 10 and over near the beach), or playing in the enormous grassy play area right next to the bach.

A week later the kids are healthy, happy and relaxed, and so am I. We can't express our gratitude to KIDS for such a fabulous week - you made our summer holidays. Thank you.

By Ngao Merrick



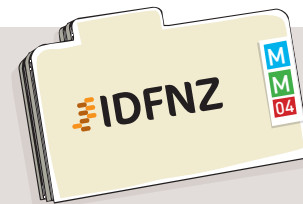
## Emily Win heads to Brisbane's Gold Coast

Visits to Movie World, Currumban Wildlife Park, Sea and Dream worlds were all part of a 'to dream' for holiday given to Emily Win of Waikenae by Koru Care with some assistance from the Kids Foundation. Emily

had a wonderful time and listed patting a Kangaroo and seeing some baby Kangaroos at Currumban Wildlife Park, and the seal show at Sea World as being among some of the special highlights of the trip.

# medical matters

## Immunisation and Primary Immune Deficiencies



By Sarah Perry - RcompN Support Coordinator and member of the IDFNZ Medical Panel

As the number of immunised children in NZ continues to fall, those parents with children diagnosed with primary immune deficiencies are faced with the ever-increasing risk of their child falling victim to one of the list of serious diseases that is currently covered by the immunisation policy in this country.

At the very heart of the problem is the fact that many parents are being persuaded to opt out of the immunisation schedule by what is often misleading and unsubstantiated information, and they believe they are acting in the best interests of their child.

Unfortunately, the reality is not quite so simple. Every year, for example, many

children are admitted to hospital with whooping cough, measles and meningitis and some of these children are damaged beyond repair by these illnesses. Sadly too, some will die. So the reality is that as the number of children immunised drops, these illnesses will become more and more frequent along with their devastating effects.

So what should a parent with a child living with a Primary Immune Deficiency (PID) do when faced with this issue? The first thing to do is to discuss the issues with your Paediatrician or immunologist as their advice will be specific to your child and his or her particular form of PID. However, as a general rule the guide below from the Ministry of Health Immunisation Handbook 2002, pages 21 – 22, can be used.

Parents should also note that children with a primary or secondary immune deficiency may not respond adequately to an immunising agent. Specific serum antibody titres should be determined to guide future

management of exposure and vaccine. Another important vaccine that should be considered for all PID children is the annual influenza immunisation, but only in and after consultation with the child's specialists.

The bottom line is that immunisation is important for the whole community if we are to maintain our first-world health standards. And, for Primary Immune Deficient children, immunisation is particularly important to ensure that potentially preventable harmful and deadly illnesses are kept well under control. So please talk to your general practitioner or practice nurse about individual vaccines, and talk to your family members, friends and neighbours about the importance of everybody being immunised – after all it's our children's lives that are at stake!

Please note that while there may be a small charge from the medical treatment for treatment, PID children are entitled to a fully subsidised vaccine.

Category	Specific immune Deficiency	Vaccine Contraindications	Effectiveness and Comments	
Primary	B Lymphocyte (Humoral)	X-linked & common Variable immune Deficiency	Live bacterial Vaccines, MMR, and varicella	Effectiveness of any Vaccine dependent on humoral response is doubtful: IVIG interferes with response to live vaccines
		Selective IgA Deficiency	None	All vaccines probably effective: vaccine response may be attenuated
	T Lymphocyte (cell mediated and humoral)	Severe combined	All live vaccines <b>ab</b>	Effectiveness of any Vaccine dependent on humoral or cellular response is doubtful
	Complement	Deficiency of early components (C1,C2,C3,C4)	None	All routine vaccines probably effective; pneumococcal & meningococcal recommended
		Deficiency of late components (C5-9) properdin, factor B	None	All routine vaccines probably effective; meningococcal vaccine recommended
	Phagocytic function	Chronic granulomatous disease, leukocyte adhesion defect myeloperoxidase deficiency	Live bacterial vaccines <b>b</b>	All routine vaccines probably effective; consider influenza vaccine
Secondary	Malignant neoplasm, transplantation/ immune suppressive or radiation therapy	Live viral and bacterial depending on immune status <b>ab</b>		Effectiveness of any Vaccine depends on degree of immune suppression

**KEY:** IVIG: intravenous immunoglobulin MMR: measles, mumps and rubella BCG: Bacille-Calmette-Guerain (for TB) **a** Live viral vaccines(MMR, varicella) **b** Live bacterial vaccines (BCG & Ty21a Salmonella typhi)

## Swedish Treatment Model worthy of consideration

Thanks to N.Z. Lotteries sponsorship in 2004, six foundation members (2 patients, 2 nurses and 2 immunologists) attended parallel conferences held by the European Society for Immunodeficiencies (E.S.I.D.) and International Nursing Group for Immunodeficiencies (N.G.I.D.) in Versailles, France. N.G.I.D. attendee Sarah Perry, RcompN Support Co-ordinator and Member

of the IDFNZ Medical Panel, said the conference provided a wealth of information about recent advances in treatment of PID and the highlight was a Swedish Study.

“This study, which was presented by a senior professor of nursing from Sweden, looked at what kind of quality of life patients receiving Immunoglobulin therapy could expect. In

Sweden the “norm” is for patients to be trained to do their own (or parents for their children) subcutaneous Immunoglobulin therapy and the study showed that a significant number of patients had a much higher quality of life once established on home subcutaneous therapy. We should consider this model,” she said.

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

**The Kids  
Foundation**  
key immune deficiency support

Web [www.idfnz.co.nz](http://www.idfnz.co.nz) Freephone 0508 300 600 Fax 09 523 5551 Email [info@idfnz.co.nz](mailto:info@idfnz.co.nz) Post PO Box 75-076 Manurewa, Auckland

## news in brief

### Your Personal Organiser for 2005

Thanks to a Lion  
Foundation grant, all

patient members should now have received a free medical diary. An invaluable tool, the diary will help members to consolidate and coordinate all their medical appointments and notes in one place. Keeping a record of treatments and medical discussions can be a valuable aid in managing PID.

**Computers for KIDS** Child patient IDFNZ members struggling with their school

work due to repeated periods of being hospitalised can now apply to the Foundation for a loan computer and printer.

The Computers for KIDS initiative has been made possible thanks to the generosity of the Century Foundation. Adult PID patients may also be eligible for computers. To apply for the computers members should approach the support staff.

**Still Time to Get into the Swim of Things** While the best of summer is now over and autumn is just weeks away, it is never too cold, or too late to learn to swim.

For those wishing to 'splash out' - sponsored swimming lessons are available from the NZCT in four locations around Auckland. For further information, members should contact the IDFNZ support staff.

### Remember to Ask for Assistance!

When confronted by a medical problem, illness and or hospitalisation, it is easy to forget sometimes that there are a range of financial aids available to patient members. For example, hospital parking and cafeteria vouchers, St Johns Membership and epipens are all available in deserving cases and it is just a case of asking support staff.

## cause champions

### Respite Holiday Home a reality thanks to caring businesses



Thanks to major sponsors the ASB Trust and Southern Trust, chronically ill patient members can now enjoy what many healthy Kiwis often take for granted - 'time out' recuperating at the beach, swimming, walking, or simply gazing out to sea.

Designed to accommodate the whole family (6-8 people), the brand new IDFNZ Respite Mobile Holiday Home is based at the Riverside Campgrounds at Mangawhai Heads, roughly one and a half hours drive north of Auckland. Just a short walk to the water, the home will offer members a peaceful and memorable holiday. To book, simply contact IDFNZ Board member Michele Kay-Sharman.

In addition to the support of the major sponsors, special thanks goes to IDFNZ Board

members, Michele Kay-Sharman and David Hilliar for designing and 'fitting-out' the new home, Loraine Hartley (Riverside)

for financial support, and in association with her special team of helpers, the on-going care of families staying at the holiday home.

The Foundation is also grateful for the assistance of Brian Keeley and Clint Small of Leisurebuilt Industries, for the unit design, discounts and on-going assistance, as well as the many local businesses that have assisted.

"Having a Respite Holiday Home available for chronically ill members has been a dream of the Foundation for many years and it is wonderful to see it become a reality," said Michele Kay-Sharman. "It will we hope, become a place that holds very special memories for a lot of our members for many, many years to come".

### Cause Champions 2004-2005

ASB Trust  
The Southern Trust  
The Trillian Trust  
The Century Foundation  
NZCT  
Pub Charity  
NZ Children's Transplant Support Trust  
The Trinity Foundation  
The Lion Foundation  
NZ Lotteries  
COGS  
The Royal Oak Trust  
Scottwood Trust  
The Endeavour Trust  
South Auckland Charitable Trust  
The Mt Wellington Trust  
The United Way  
The Pelorus Trust  
The Waitakere Trust  
The Sunshine Charity Shop  
Our Wishlist sponsors



Special thanks to the Mt Wellington Trust for funding towards this edition of In Touch.

The IDFNZ and the Kids Foundation run solely on donations and fundraising. If you wish to become involved by making a financial contribution to the Foundation, please contact us on 0508 300 600.