

coming events

August 7

Children's Pantomime

Beauty and the Beast
Logan Campbell Centre
For tickets contact Carol Hadwin
0508 300 600

August 7 & 8 and 28th & 29th, 8.30am to 5pm

Four Day Self-Discovery & Life Skills Workshop

Run by the Kiwi Family Trust,
it is for people over 12 years,
Auckland.
Venue to be advised and lunch
is provided. Free to teachers,
caregivers and holders of
Community Services Card.
For bookings or information
contact Jenny 0508 543 375, or
email jenny@kiwifamilytrust.org.

Free First Aid Courses

Meditrain Ltd in association with Polytechnics.

For Community Groups
and individuals New Zealand
wide. Recognised NZQA First Aid
Qualification.
For information, phone Graham
on (09) 6361377.

Foundation forges bright new future with a **Brand New Look!**

After fifteen years in operation, the Foundation is modifying its direction to better meet the needs of members with Primary Immune Deficiency (PID) conditions.

Building and harnessing Pacific Rim and global alliances are central to the new direction, with the goal being to strengthen the Foundation's financial, scientific and medical resources.

Foundation Chairperson, Stephen Baxter says he is excited with the new plan and the

opportunities that will flow from teaming up with patient organisations internationally.

"The reality is that we are a relatively small organisation, representing a relatively small group of people, with a relatively

rare condition, in a small country at the bottom of the globe. To better serve our members, we must reach out across the world and develop partnerships with organisations such as, the Immune Deficiency Foundation (IDF) in America – organisations which have significant funding, medical and scientific resources.

"International organisations such as the IDF can assist us in a series of ways. For example, they can help us through contacts with global health companies to raise our funding base and progress medical and

scientific research into PID in New Zealand. In addition, the Foundation can share more closely in global medical and scientific developments, as well as those focusing on the welfare and caring of patients," he said.

The first step in the process was to review the Foundation structure to assess its effectiveness in terms of meeting an increasing array of sometimes conflicting objectives. At the present time the Foundation has a raft of roles, such as caring for members, fund-raising as well as, supporting medical and scientific research. The review found that the existing structure would be more effective if it was divided into two entities, the parent organisation, or the Immune Deficiencies Foundation of New Zealand (IDFNZ), the original name chosen in the late 1980s, and the Kids Foundation.

While both entities will be tasked with caring for members with PID, IDFNZ will focus on educating the public and health professionals about PID, lobbying key Government and medical organisations, promoting PID medical and scientific research in New Zealand, and forging new alliances with patient organisations around the Pacific Rim. On the other hand, the Kids Foundation will take primary responsibility for the day-to-day, practical, financial, emotional, medical and social support of members and their families, bone marrow transplant children and immune compromised liver transplant children. Fund-raising will be shared by both entities, with IDFNZ spearheading medical and scientific approaches, while the Kids Foundation focuses on the more public appeals.



With the change in the structure of the organisation, the next task was to take a fresh look at how it presented itself publicly, and in particular its logo. Not only did the organisation need to contemporise its public face after more than fifteen years, it also needed to reflect the dual entities of the IDFNZ and Kids Foundation in a way that would make them more effective in achieving their separate objectives, while still being clearly connected. To this end, graphic design company Gardyne Design was commissioned to create some suggestions.

Two exciting and refreshing logo designs were chosen. For the new face of the IDFNZ, a more corporate medical and scientific professional look was needed, but with a contemporary edge. The corporate feel is captured in the use of the IDFNZ letters with the ladder of orange and brown rectangular spots on the left, symbolising the genetic DNA chain, central to PID medical and

scientific research. The strong and eye-catching colours are then carried into the



THE NEW BRANDS

new Kids Foundation logo to ensure that the two logos work together.

However the designer's brief for the Kids Foundation was different. Here, the look

had to be positive and modern, appeal to all age groups (children, teenagers and adults – both the general public and members) and echo the Foundation's function – Key Immune Deficiency Support. This change makes it clear that the people the Foundation cares for includes children, teenagers, adults and families, and not just kids.

“We hope everyone is as excited as we are about our plans and fresh new look. In the 15 years since the inception of the Foundation, we have made a lot of progress and learnt a lot of lessons, but we know that to continue providing members with the quality of care they need, change is essential. And yes, we may be small, but engaging in PID research is one way we can offer our members hope for a positive future,” said Stephen.

our people

PID plays second fiddle in family of musos



He's nineteen years of age, works full-time, plays guitar, bass, drums and mandolin, sings, has his own rock band called 'Hollowed', is a member of an Irish Band called 'Sidhe' and is currently rehearsing for a University of Canterbury musical production. His name is Christopher Rattray, and yes, he is very, very passionate about music.

Indeed, you could say that music runs in the family's veins. Younger brother James who is in his final year at Cashmere High School, plays trumpet and is a member of the school Stage Band, Concert Band and a small jazz group called 'Subtle Undertones'. He plays bass guitar and sings,

is a member of a Rock Band called 'Overdrive', recent winner of the Christchurch Smokefreerockquest Regional Finals and works at two jobs after school.

From their musical achievements and sheer passion for life, it would be hard to pick Christopher and James for PID patients. However, both have a PID condition called x - linked agammaglobulinaemia which means they are susceptible to bacterial infections such as, bacterial pneumonia, ear and skin infections, and both receive monthly I.V.I.G. infusions.

Their successes are therefore all the more awesome and an example to all!

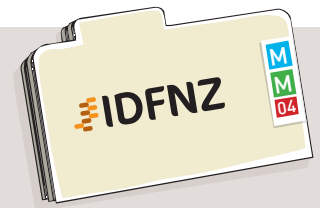
The path to diagnosis for Christopher and James was, like it is for a lot of families, not a straightforward one. Christopher was diagnosed at four and half years, after being very ill for around two and half years. By the time he was hospitalised he had pneumonia, was anaemic and weighed considerably less than a normal healthy child of his age. Just as he was diagnosed, James started to display the same PID symptoms.

For mother Willy and father Pete, while finding out what was wrong with their two boys afforded them some relief, they were devastated and felt a certain amount of grief.

“You always think, “why us?” And, what have we done to deserve this? Worse still, we didn't know what to expect and just what kind of life our boys could expect to have. Heading into the unknown is a scary thing. But the good news is, our boys have and are achieving, and are enjoying an extremely full life. We are very grateful,” says Willy.

medical matters

PID genetic testing and research breakthrough



Thanks to an IDFNZ 2003 initiative, for the first time ever in New Zealand, PID patients will get easier access to family genetic tests and research related to specific PID conditions that predominate in this country.

The establishment of more routine genetic testing for PID began as the result of a market research project spearheaded by IDFNZ to establish the feasibility of setting up a genetic testing laboratory, and the allocation of funding for the research by the Lion Foundation. Dr Karen Snow-Bailey was

responsible for the feasibility project and her work identified significant gaps in the services provided to PID adults and kids.

As a direct consequence of the information gathered by Dr Snow-Bailey, the Auckland District Health Board (A Plus) has agreed to make laboratory space available for genetic testing and to employ a senior tenured full-time scientist. A completely new position, the scientist will undertake molecular diagnostic work and conduct PID research. The position is currently being advertised nationally and internationally, and it is hoped that a suitable candidate will be found shortly, so that genetic testing and research can begin.

IDFNZ would like to recognise the support given to this initiative by Associate Professor Rohan Ameratunga who has driven the project from conception, and will continue to be responsible for its on-going management. Thanks must also go to 'A Plus' staff and management, in particular, Dr Kitty Croxson, Don Mikkelsen and Tony Barker of Labplus, and Fiona Ritsma, General Manager of support services, Auckland Hospital. Thanks too to the IDFNZ Patron Bishop John Paterson for his fundraising encouragement and the Lion Foundation Jazz Bar for its sponsorship of this very important project.

New international scientific advisory panel

To ensure on-going support for the new genetic testing facility, and in particular PID research, IDFNZ has formed an International Scientific Advisory Panel.

The Panel will oversee the research program, manage the research fund allocation, and actively raise finance by, for example, applying for research grants, and seeking corporate sponsorship.

A leading international PID expert, Professor Jerry Winkelstein M.D. will chair the Panel. Professor Winkelstein

is the Eudowood Professor of Paediatrics and Director of the Division of Immunology, Department of Paediatrics at Johns Hopkins University School of Medicine, Baltimore, Maryland. His clinical expertise is in PID conditions and his research has been on the genetics and clinical significance of the complement system.

Introducing Wellington's new clinical immunologist



After eleven years working at Sydney's Liverpool Hospital, Dr Richard Steele has returned to his city of birth, Wellington, to take up the role of Clinical Immunologist.

At Wellington Hospital, Dr Steele will specialise in allergy related illnesses, autoimmune diseases, H.I.V. and primary immunodeficiency conditions. Additionally, he has been employed as a general physician, and as a qualified pathologist, will be responsible for

autoimmune and primary immunodeficiency laboratory testing. Richard's most recent role on leaving Sydney's Liverpool Hospital, was as the Staff Specialist in Immunology, General Medicine Immunopathology and Chemical Pathology. He was also a Conjoint

Senior Lecturer in Medicine at the University of New South Wales, Australia.

While Richard's formal training in immunology started eight years ago, he has cared for patients with PID (mostly adult) throughout his career and studied the condition extensively. Like other PID specialists, he is keen to see better PID testing services and facilities available and more awareness among health professionals and the public.

Originally qualified at the University of Otago, Dunedin, Dr Steele is married with two children. He lists his family, music (composition and playing guitar, saxophone and keyboard), computing, reading and sport (soccer and tennis) as his primary interests.

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.



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news in brief

IDFNZ collaborates with IDF

Last month, the Foundation Chairperson Stephen Baxter and General Manager Janet Simons travelled to Baltimore Maryland, USA to meet with sister organisation the Immunodeficiency Foundation (IDF). The meeting was very positive, specific areas of collaboration were identified for future discussion and a lot of information was shared.



IDFNZ announces family conference at AGM

The 2004 annual general meeting was held in June with members in Wellington and Auckland linked through teleconferencing. As well as reviewing the 2003 highlights and achievements, initiatives such as the organisation's new brand and logos, and the New Zealand based PID genetic testing project were launched. The Board made a commitment to host the first ever IDFNZ family conference in September 2005.

cause champions

Manawatu businesses boost Movie Madness 2004



There's more to Manawatu business people than meets the eye – it seems they are kind and generous, as well as, canny commercial operators.

Thanks to this group, the Foundation's 2004 Appeal was launched in Palmerston North in June, and over 1000 special needs children were treated to a round of Film Festival Movie Madness. Running for eight weeks, the Appeal will also be held in the Wellington and Auckland regions.



The Foundation thanks local businesses and cinemas for making these events possible and special thanks go to all the volunteers helping out behind the scenes at each event.

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

Cause Champions: April, May, June, and July 2004

The Trillian Trust

Pub Charity

Endeavour Trust

New Zealand Community Trust

The Southern Trust

Mt Wellington Trust

South Auckland

Community Trust

The United Way

The Lion Foundation

The Royal Oak Trust

The Sunshine Charity Shop



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.