

coming events

Sat 26th and Sun 27th November

Magic Show

Auckland Show grounds

Sat 26th November

Special Xmas Party

Christchurch
Westpac Centre

Mon 28th November

IDFA Patient Meeting

12pm - 2pm
Royal Prince Alfred Hospital
Kerry Packer Education Centre Building
Missenden Road
Camperdown

Sat 3rd December

Special Xmas Party

10.30 - 2.30pm
Auckland Show grounds

Snow White pantomime

4pm
Auckland Show grounds
Logan Cambell Theatre

Sun 4th December

Wellington IDFNZ/KIDS Foundation

Christmas Ten Pin Bowling
Petone Bowling

Sat 10th December

Special Xmas Party Hamilton
Mystery Creek

Sat 17th December

Special Xmas Party Wellington
Queens Wharf

Sat 17th December

**IDFNZ/KIDS Foundation Auckland
Xmas Party**
Rainbows End, Auckland

Family Conference 05

Our first IDFNZ Family Conference was an outstanding success.

Over 100 delegates registered for this conference, far exceeding our expectations, these were a mixture of PID patients and guardians, as well as medical professionals with a special interest in PID. Unfortunately some late registrations had to be declined as we had exceeded the venue capacity.

All delegates were rewarded with up-to-date information on all Primary Immune Deficiencies, their diagnosis and treatment. We were privileged to hear from a wide range of speakers with special expertise in this field. We were sorry that Professor's Jerry and Marilyn Winkelstein visiting from Johns Hopkins Hospital in Baltimore, USA were called away urgently to attend to a sick relative, however we were at least able to enjoy their presentations thanks to Associate Professor Rohan Ameratunga and Sarah Perry standing in.

We were also privileged to hear from Professor Hans Ochs who took us all on an interesting journey into the past introducing us to the pioneers in PID research and diagnosis, and comparing today's situation for PID patients to that of 50 years ago. The impact of now everyday medicines such as antibiotics has been amazing for these patients, as well as advances in bone marrow transplants. In more recent times the advent of more effective test methods and understanding of the immune system has also enabled better diagnosis and treatment. The future clearly lies with gene therapy with very encouraging results from overseas.

We must thank Dr See-Tarn Woon for a very clear and understandable presentation of genetic testing for PID conditions in New Zealand. This is a very complex subject for non medical professionals and yet she was able to make everyone feel that they had a good understanding. The work being done in



New Zealand is very exciting and is directly benefiting our members. Associate Professor Rohan Ameratunga was able to expand on this topic and explain the future potential for gene therapy. Doctor Peter Flanagan gave an update on the safety

of immunoglobulin and explained the process of collecting and fractionating blood products such as Intragam Pand Normal Immunoglobulin used for IVIG and Subcutaneous infusions. This was complimented by Pauline Brown talking about subcutaneous treatment as an option for New Zealand patients. CSL also provided CD's featuring a virtual tour of their Intragam P Fractionation process.

We were also able to consider the psychological impact of PID's as a group of chronic conditions affecting both the patient and their immediate family. Dr Louise Webster and Associate professor Marilyn Winkelstein gave a wealth of information to consider on this subject that benefited all.

The third day of the conference was centred on hearing from the PID patients and parents, of what PID has meant to them. Some very brave members were willing to share their personal experiences with the group and by doing so made a very real

difference for all listening. Our thanks to Jane Baxter, Michele Kay-Sharman and Bronagh Quinn for allowing us into their most private lives and for sharing all their hard earned strategies for coping with the devastating effects of PID on everyday life.

Sarah Perry was able to build on these presentations and to give more understanding of why chronic illness has this effect. Sarah was also able to suggest some excellent resources available to families and as our Information Officer, can follow up with specific requests for information and/or family matching. All attendees were also able to take away with them an excellent resource of Rain, Hail or Shine, published by Skylight. A copy of this is available in our library for others wishing to borrow it.

More photographs of the conference can be seen on the IDFNZ website. Some of the papers presented are also available on the website, and a selection of some of the presentations are available on DVD for anyone interested that was unable to attend.

(Please contact Sarah for these).

As well as the valuable information gained at conference, there was also a unique opportunity to meet other

patient members and be able to form friendships. Living with PID is a challenge for all but by having contact with others facing similar issues, one can feel strengthened and have a more positive outlook for the future.

The weekend ended with an IDFNZ family outing to Rainbows End—this was enjoyed by adults and children alike. Whilst the adults were busy in conference, the younger

members were busy having fun with a very busy 3day program that included activities such as a helicopter ride across Auckland, visits to Kelly Tarltons, The Sky tower, The Maritime Museum and sailing around Auckland Harbour, visiting dinosaurs at the Museum, rock climbing and archery. Whilst having fun the youngsters were also forming friendships and learning from each other. They also enjoyed a talk on the immune system and learnt a little about PID. The trip to Rainbows End was a finishing touch!



our people

Disney World



We just couldn't believe it when Janet rang us a day in April, to ask if we would like to travel to America for a conference. It turned out that the USA National IDF conference was to be held in Disney World of all places! We were just over the moon with the news.

After many weeks of arranging the details for the week in America, which was all kindly done by Janet, we were on our way. The boys were so excited. For weeks they had anticipated the plane trip, imagined America and dreamed about Disney World. For us as parents of 3boys, 2of which have the PID condition CGD, it really was a wonderful opportunity to meet other parents and listen to acclaimed speakers at the conference.

Early Tuesday morning, with the long trip behind us, we were suddenly part of a country where everything appeared to be done on a bigger scale. A special bus took us to our next destination, the hotel, which would be our home for the next week.

It was certainly impressive! In our hotel room, after every switch and tap was tried and tested and all that could be investigated was, thoroughly, by the boys, we all plonked down on the beds and slept for 2hours (fortunately our 13month old as well). The first day flew by with swimming in the hotel pool, trying to figure out what Disney World parks to go to and just trying to find our feet in the haze of jetlag.



Martin 9, Alexander 13 months and Erik 11

The next two days, Wednesday and Thursday, we were able to see all the amazing things in Disney World with our own eyes and not just in brochures. We chose to go to the MGM Studio's the first day and Epcot was our second day choice. What an experience it was! So many things to see and do, it was almost 'visual overload'. We used the days to the utmost, going back to the hotel only when our feet just couldn't do any more

walking or when the boys' tongues were dragging on the ground.

Then was the conference—the real reason for our trip. With over 1200people attending, it was huge. People from all over America were represented, us being the only family from overseas. It was very well organised. The two older boys attended the special youth programme

and the little one was looked after in the crèche provided. That left us free to attend all sessions and listen to many of the speakers. Some sessions we attended separately, so we could benefit from more than one speaker. The information was invaluable and talking to other parents with children with CGD was encouraging and made us realise that we are part of a larger group, although that group may seem very small here in New Zealand.

The conference was ended with a visit to one of the Disney World parks and a stunning fireworks display.

So we came to the end of our tremendous, very unexpected, very exciting and very

valuable trip of a lifetime! Early Sunday morning, the bus was there to pick us up at our hotel, this time to drop us off at the airport. Many, many hours later, we were back in our own living room, with a happy

cat purring around our feet and a treasure chest full of memories. Thank you IDFNZ!

medical matters

New appointments



We are thrilled that Professor Hans Ochs has agreed to join the IDFNZ International scientific panel, adding further PID expertise.

The panel is chaired by Professor Jerry Winkelstein, a fellow American, giving IDFNZ a truly International foundation of knowledge and experience. Professor Hans Ochs is the Professor of Paediatrics, the University of Washington, and Seattle. He graduated from the Medical School, University of Freiburg, Germany, in 1961 and one year later was awarded a Doctor of Medicine. After rotating internships in Germany and in Toledo, he joined the faculty of the Department of Paediatrics, University of Washington School of Medicine in 1973.

Dr. Ochs has devoted his research activities to the study of Primary Immune Deficiency Disorders (PID). His early investigations focused on the abnormal cellular and humoral immune responses of PIDDs and the use of IVIG in the treatment of antibody deficiency disorders. More recently, he investigated the

genetic and molecular basis of PIDD. He has participated in the discovery and study of ADA deficiency as one of the causes of SCID. He has been responsible for the identification of a number of the genes responsible for several genetically distinct PIDD, including CD40ligand as the cause of X-linked Hyper IgM Syndrome, and the finding that the mutations of WASP cause Wiskott-Aldrich Syndrome/X-linked thrombocytopenia, mutations of Rag 1/Rag 2 as the cause of Omenn Syndrome, mutations of FOXP3 are associated with IPEX. Recently, together with French and Japanese investigators, he also observed the mutations of Uracil-DNA glycosylase affecting isotype switching and the somatic hypermutation, causing the clinical phenotype of hyper IgM syndrome.

IDFNZ sponsors the ASCIA 2005 conference in Queenstown

The Australian Society of Clinical Immunology and Allergy (ASCIA) is the peak professional body of Clinical Allergists and Immunologists in Australia and New Zealand. The Organisation held its annual conference in Queenstown this year, featuring leading International speakers on Primary Immune Deficiencies and attracting over 240 delegates with a professional interest in Immunology from Australia and New Zealand.

IDFNZ supported this event by sponsoring overseas speakers as well as having an information stand. We used the event to familiarise the medical specialists with our

services and to launch new overseas divisions to serve Australia, the Pacific Islands and South East Asia. These divisions were launched under the umbrella of IDF Asia

Pacific—a working relationship between ourselves and IDF USA to improve the diagnosis, care and treatment of PID patients in the Asia Pacific Region. The purpose of the relationship is to

encourage the development of new National Patient Organisations in this region.

IDF Australia, IDF Pacific and IDF Asia are the names of these new groups, more details

can be seen on our website. The registration of medical professionals and all patients is now well underway. The next step will be to establish committees to coordinate the

fundraising and patient events. In 2006 IDFA is planning to host a series of PID patient seminars in New South Wales, Queensland and Victoria.

IDFNZ would like to acknowledge the help and support of the ASCIA committee in the support of this

initiative and assisting in publicising these new divisions to PID patients.



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

news

Swimming lessons

Apply now to be considered for free 2006 swimming lessons funded by IDFNZ at Hilton Brown swimming schools around Auckland. Application forms available on the IDFNZ website or phone 0508 300 600. (Limited places available so be quick!)

Need a good holiday?

IDFNZ is now taking bookings for our holiday home located at Mangawhai Heads. Application forms are available on the IDFNZ website or phone 0508 300 600.

IDFA Patient Meeting

An informal meeting to learn more about IDFA and plans for patient support/events and fundraising in 2006. To be held at Sydney, Royal Alfred Hospital, Monday 28th November 12pm - 2pm. If you live locally we would love to meet you! For those outside of Sydney there will be other opportunities in 2006 which we will publicise early in the New Year.

Avian Flu Plan

Have you thought through the impact of a pandemic for your family? The IDFNZ medical panel has drafted a useful checklist which may be useful for members to refer to when preparing a personal readiness plan. See our website for details.

cause champions

2005 movie madness campaign

A huge thank you everyone who supported this campaign. Deserving children across New Zealand enjoyed a special trip to the movies over the last few months as a result of your support, with all profits benefiting KIDS Foundation.

Thankyou for your generous support

Grants have been gratefully received from the following organisations:

Trillian Trust, Lion Foundation, Trinity Foundation Ltd, CSL Ltd, New Zealand Children's Transplant Support Trust, Pub Charities, COGS, Pelorus Trust, South Auckland Trust, NZ Community Trust, ARA Lodge 3481c, Auckland Confederation of Billiard Sports, The Whitehouse Tavern Trust, The Charity Shop, University of Otago and East Tamaki Trust.

Taradale Intermediate School

The pupils of Taradale Intermediate also deserve a special mention for donating the proceeds of their recent Mufti Day to KIDS Foundation.



Photos taken at the first IDFNZ conference.

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.