



coming events

Patient Events 2011

Jan 29

Rock climbing and glow in the dark mini golf, Tauranga.

Feb 19

Mangawhai Heads, BBQ/Patient meeting

Feb 11

Liver group coffee morning

Feb 12th

Freemason Presentation Auckland

Feb 23rd

Coffee Meeting , Starship Hospital

April 29

World Day of Immunology, Auckland Patient meeting - NZ Blood Service , plus various displays at hospitals around New Zealand.

Visit our website for more details.

dates to remember

February 28

Jeans for Genes

April 29

World Day of Immunology

Visit www.idfnz.org.nz for details

Close of year Message from our Chairman

From the speech given to attendees of the Auckland Xmas Party

Welcome to you all, it is great to see so many of our patient members and their families with us today. This year we celebrated 21 years of assisting the immune deficiency community. I would like to take this opportunity to pay tribute to the very many dedicated men and women who have willingly given so much of their time, over the years, to build Kids Foundation/IDFNZ into the thriving organization that it is today.



We have had a very busy and exciting year - one of the main highlights was certainly the annual family conference which was held over 3 days in July and which was combined with our 21st birthday celebrations. We were fortunate to attract both international and national speakers of a high calibre. The conference was very well-attended with a mix of PID and TXP patients, families, and speakers and the accommodation at Vaughan Park was at full-capacity. A

large contingent of Board Members, their families and other volunteers ensured that the proceedings ran smoothly and we are indebted to these people for their help. We held our AGM on the final day of conference and this was also well-attended. I was also pleased to observe the continued support of our Transplant members and enjoyed meeting so many of you at the conference. We have all followed closely the overseas transplants of both Aria and Matisse whom I am sure you will all know - wouldn't it be wonderful to see these 2 families here at next years Xmas party?



As you are aware we rely heavily on the generosity of a large number of supporting individuals and organizations who, year after year provide us with the funds which enable us to improve the services we provide to patients and their families. These are too numerous to list, but I would like to thank all who have supported our Annual Appeal in the last year and a special mention to Steve Grousfky of Nova Systems Ltd who kindly sponsored such a wonderful rocking horse we were able to raffle.

We are especially grateful to the Mangere Masonic Lodge and Freemasons Charity for their very generous donation of funds which will enable us to purchase eight new SCIG pumps for patient members.

The engine room of organisations such as ours is the Board and the administration. We have been extremely fortunate, over the years, to have had the support of many remarkable minds and talents, without which we would definitely not be where we are today. No organisations of our type however, stay still and we have had several changes over the last year. I would like to thank two long standing Board members who have stood down since the last AGM - Stephen Baxter and Associate professor Rohan Ameratunga. Professor Ameratunga will continue to chair the Medical and Scientific panel. Both have made huge contributions to IDFNZ over the many years they have served and we are most grateful for their unstinting efforts.

This year our administration team has been boosted with the appointment of Sandi Field our new National Support Coordinator. Sandi comes from a needs assessment and nursing background and with the skills and experience she brings to this position has greatly strengthened our support services.

The Board also gained Dr Shannon Brothers who joined the Board as a member of the Medical Panel. Dr Brothers brings extensive experience in the field of pediatric immunology.

I want to thank all of the Auckland Board members and staff for their huge effort this year, especially in organizing and running the family conference and 21st birthday party - no small task. Thanks also to our wonderful medical speakers for giving so generously of their time and knowledge.

Now for some new information as we look towards a promising New Year...

Firstly I would like to thank all of the members who kindly volunteered their time and skills and applied for the newly vacant positions on the Board. It was good to see so many of you willing to take a turn It is my pleasure to announce our two newest Board members ..Adriaan Bosch and Nick Metson. They both come with unique and differing skill sets which will enrich our Board performance and a first-hand history/knowledge of living with PID, themselves or a family member. Coming from Northland and Wellington they also give a greater geographical spread of Board members throughout New Zealand.

We have other members who have agreed to volunteer to assist the Board with some special projects we are planning for next year – these are Samantha Sutherland (from Auckland), Katie Brown (from Whangarei) and Melissa Rouse (also from Auckland) .

2011 will be a very challenging year with what will possibly be our most exciting project to date....I would like to announce that we are committing to fundraising to build a New Patient and Family Centre here in Auckland . We are launching this project officially in the New Year with a text appeal, but have already made some wonderful progress with a design company called Creative Arch agreeing to draw up free concept plans for us.

We have set up a fundraising webpage for this project if anyone can think of ways to help with this please let us know– every dollar will help with such a huge target we have to raise.

We have some more special news to share with you, I am pleased to announce that the new Patient Centre project has already attracted its first major sponsor - Smith & Smith Glass Ltd .

Firstly, my Sincere thanks to the Smith &Smith senior managers Mark Morgan (Operations Director), David Coyle (North Shore Branch Manager) and Saji Pappen (Manukau Branch Manager) who have given up precious family time to be here today to meet you all today , working very hard for us behind the BBQ. What a splendid display of commitment to the community. It is now my pleasure to welcome and introduce Greg Liddington, HR Director of Smith &Smith to the stage today to meet you all and explain first-hand about how Smith & Smith plan to support IDFNZ in the coming year.

(We plan to interview Greg and publish full details of this pledged support in our next newsletter for those members not at the meeting.)

Wishing all members a Happy New Year.

Judith Dickson, Chairman IDFNZ.

Medical Matters

2010 combined ESID/ IPOPI /INGID Conferences



The 2010 combined ESID/ IPOPI /INGID Conferences were held in Istanbul, Turkey.

6th-9th October . NZ had representation in all three streams of this combined event .

The following report is from Susie Lester, Paediatric Nurse Specialist, Immunology /Allergy Starship Children's Health, sponsored by IDFNZ.

I was very honoured & privileged in early October 2010 to attend the bi-annual, XIV ESID (European Society for Immunodeficiencies) meeting in the centre of Istanbul, Turkey. Istanbul has been proclaimed the European capital of culture for 2010 & is an exciting mystical city, with a wonderful history. The venue was the Istanbul Exhibition & Convention Centre, a modern and impressive building.



This meeting was also the XI meeting of the International Patient Organisation for Primary Immune Deficiencies (IPOPI) and the IXth meeting of the International Nursing Group for Immunodeficiencies (INGID).

The ESID scientific meeting focuses on the most recent developments in the field of primary immune deficiencies & was composed of lectures, workshops, oral presentations & symposiums. IPOPI focuses on optimal treatment & care of PID patients. Patients and families are able to attend this meeting. The INGID meeting focuses on the challenges of nursing patients with primary immune deficiencies.

It was very exciting being at a conference where there was an opportunity to mainly focus on nursing but there was also the opportunity to all attend any of the ESID lectures and symposiums as well. There were nurses from Europe, Scandinavia, Turkey, United Kingdom, USA, Canada and one from Australia & me from New Zealand. There were about 70 nurses registered for INGID this year.

INGID ran educational sessions on the immune system on day one & four scientific sessions each day. The presentations were of very good quality and there was ample opportunity for questions and discussions. One of the most

impressive speakers we had was Bobby Gaspar from London speaking on advances in diagnosis & treatment of PID, including gene therapy research.

INGID presentations included nursing research, advances in paediatric nursing & home therapy, stress & coping for children, families and for nurses, protocol development. I particularly enjoyed a networking workshop on the third day, where we divided into round table groups to work on nursing issues. I was part of the roundtable on home therapy (subcutaneous & intravenous). Together we were all passionate about doing our best for the children we nurse with immune deficiencies. There was only one other nurse from our "down under", a nurse from Western Australia.

My overall impression from this conference is that New Zealand is certainly keeping up with current medical and nursing knowledge & management of primary immune deficiencies. This is in spite of the reality that New Zealand has less health dollars to spend than many countries especially some such as the Scandinavian countries. Of particular interest to me is the concept of home therapy particularly subcutaneous infusion of immunoglobulin at home, which has been popular overseas for sometime. Infusions are usually twice a week & are managed by the child/family allowing them to infuse the immunoglobulin around busy household schedules. We at Starship are very enthusiastic about this and are encouraging more of our children & families to consider this as an option. It is a great alternative to having to come to hospital for intravenous infusions every 3 or 4 weeks. Levels of immunoglobulin in the body seem to stay quite stable with this method of infusion. Some counties such as Denmark are able to use very expensive pumps, especially designed for subcutaneous immunoglobulin infusion. We now have available to us a syringe pump which is also very good, the Niki T34 which is small & portable & very easy to use. Several of the children I look after are using this pump & finding the home subcutaneous infusions very successful. My Western Australian colleague & I will stay in touch and share ideas. We both hope to return to ESID in Europe in 2 years time. Maybe then we can present to our colleagues from around the world how we are progressing with our home therapy "down under".

Finally, I would like to acknowledge the support & assistance of some people who enabled me to attend this wonderful conference. Firstly, thanks to the board of IDFNZ for their generous assistance with my registration for attending ESID.

Also thanks to my husband Peter who gifted me his air points for my return trip to Istanbul. Lastly, thanks to our wonderful Turkish friend Ergin Imre who funded my stay in Istanbul at the Marina Inn along with my husband & his sailing crew. **Continued back page**

Attended by over 180 people over a 3 day period this event was certainly a highlight for 2010. Huge thanks to all of the speakers, volunteers and attending families who made this a success for IDFNZ. Check out the photographs on our website.



Sandi Field reports back on some recent patient events she has attended around the country:

DUNEDIN/INVERCARGILL

In October I was able to go to Dunedin and Invercargill for the first time to meet with some of our members. The one way system in Dunedin provided some amusement as my son (who was my navigator) and I got looks of "oh my goodness a tourist" from Dunedinites as I tried several times to go up a one way street the wrong way! However we managed to navigate our way around this beautiful city without any major hiccups found our way to St Clair where we enjoyed wonderful company, scrumptious food and a laugh.

WELLINGTON

Christmas came early to our Wellington families this year with a BBQ lunch at our Otaki Holiday Home in November. Santa arrived in a Mercedes convertible - top down - and to the delight of the kids did a lolly scramble then handed out small gifts from his Santa sack. Riley and Lucas made some wonderful decorations to go on our tree. The day was perfect, the company delightful and the food BBQ'd to perfection. Thank you to Judith for getting the Christmas tree and tinsel, Ali for organising the food, John for manning the BBQ and Santa (you know who you are ...) for donning the red suit.

AUCKLAND

The Rainbows End Party was attended by over 300 members. It was wonderful to see so many of our families making the effort to come out on a rather cold and rainy day. It was a fitting way to end 2010, with sponsors, patients and families coming together for a few hours of entertainment and visit from Santa. Thank you to Christine for organising such a great event with your many volunteers helping behind the scenes. A special thank you to the staff of Smith & Smith for helping with our BBQ - it was great to see such hands on commitment to the community, our families were very touched.

We set off early the next morning to Invercargill and drove through some lovely countryside. Ten Pin Bowling became the battle of the sexes. The girls were mighty opponents but the boys came out the winners on the day. Again the company was terrific and the atmosphere relaxed with some gentle teasing between the teams.

Thank you Laura and Bronagh for your support finding suitable venues .



Thank you to all members who supported these events by attending.

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

New Face book Connection for Transplant Patients

Kate Manson is mum to Alice, now 1. Alice was diagnosed with Biliary Atresia and at four-months-old underwent live liver transplant surgery. Kate has set up face book page with the hopes that she and the others who have joined her on face book will be able to offer support to families who have a child or a family member that has been diagnosed with this disease and who are pre or post liver transplant. If you would like to join Kate please go to [facebook.com](http://www.facebook.com/profile.php?id=689246059) and search for 'biliary atresia/liver transplant New Zealand' or enter <http://www.facebook.com/profile.php?id=689246059>

Special Appeals



**Support the IDFNZ KIDS Foundation
Patient Centre Appeal**

SMS KIDS to 469 to donate \$3 or click to Donate online



This special community project will benefit all patient members of IDFNZ and KIDS Foundation. Please take time to read about it on our website. By simply texting a \$3 donation members are able to signal their support for this exciting new facility'. Please pass on this message to friends and colleagues looking for a good cause to support.



Our annual appeal has now begun in Napier and Gisborne – each year hundreds of community minded businesses support the Foundation hosting Circus Quirkus- a family friendly variety show. The event allows these businesses to directly benefit local children suffering from serious illness and disabilities, as well as benefiting the work of IDFNZ KIDS Foundation with PID and liver/ bowel transplant children across New Zealand. This year the Board have once again made Matisse Reid the major beneficiary of this, our members have been closely following Matisse's progress undergoing a multi organ transplant in the U.S.A.

Thank you to participating businesses for your loyal support.



2010 combined ESID/ IPOPI /INGID Conferences *Cont.*

In addition to sponsoring Susie, IDFNZ also sent delegates to the IPOPI meeting. David Hilliar attended as the 2010 NZ Board nominee standing for election onto the IPOPI board. Although unsuccessful in the election, David was able to experience for himself the power of being part of a worldwide network of patients, medical professionals and scientists

all coming together to focus on Primary Immune Deficiencies. Meeting patients and representatives from sister NMO'S from around the world stimulated ideas and new relationships for the future.

IPOPI attendees: Tracy Brew (IDF Australia), Janet Simons (IDFNZ), David Hilliar (IDFNZ) Dr See-Tarn Woon (Auckland Labplus).



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