

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.

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fundraising champions



There has been a lot of energy and activity over the last few months as members and supporters work on fundraising towards the new Patient and family centre. Here are some of the initiatives underway that all members and supporters can help with:

Glen Wallis is a Wellington member and Ford Car enthusiast. He has organised his fellow car club members of the New Zealand FPV & Tickford Owners' Club Inc. To create and print a wonderful calendar to raise funds for the IDFNZ KIDS Foundation Patient Centre Appeal. So all you car enthusiasts seeking the ultimate Xmas gift for friends and family - visit www.trademe.co.nz and search for FORD CHARITY CALENDAR to purchase online. Be sure to leave a message of encouragement on the Q&A section.

Enistic New Zealand have made available to the Foundation the new Bye Bye Standby power saving device which offers convenience of remote control, genuine power savings on your power bill and financially benefits IDFNZ KIDS Foundation. Every home needs one of these gadgets! All proceeds go towards our Patient Centre
Buy online (see below) or order from info@idfnz.org.nz.

Everlea Group NZ Ltd have been long term supporters of IDFNZ KIDS Foundation - they have recently launched a new affordable vehicle GPS device into the New Zealand market allowing real time, online tracking of cars, boats and other valued assets. Recently featured by Gadget man on the TVNZ Breakfast show (Nov 9th), every Trakie sold generates a donation for the Foundation - so as well as being a 'must have' device they are also helping Patient Centre Appeal. Both of the above products can be purchased online www.everlea.co.nz

Smith & Smith Ltd continue their heroic support of the Foundation with a fundraising challenge to each of their nationwide branches. Friendly competition is an effective motivation!



And there is more to come...ALL 4 GOOD is a new school fundraising campaign we will be launching in 2012 - watch out for details early in the New Year. This is an opportunity for all member families to support the Foundation by promoting this event in their local schools. A new Patient fundraising group is also being organised for 2012 - with the aim of joining together to maximise all fundraising opportunities made available to the Foundation and generating new ideas and initiatives to make our vision of a new Patient and Family Centre a reality.

Swimming Lessons



We still have spare places commencing February for Hilton Brown Swimming lessons.

If you are interested please contact Christine 0508300600 or email office@idfnz.org.nz.

coming events

Patient Events 2012

January 25th
Youth Outdoor Event MERC

February
Auckland Coffee Meeting

March
Christchurch clinic / Boatshed meeting

April 29th
World Day of Immunology

Please visit our website for further details. Invitations are being mailed out to patient members by staff in the next few weeks.*

Coming Soon...



Christmas Message

from Vice Chairman Vicki Tattley.

Vicki addressed the 360 attendees of the children's Christmas party at Rainbows End December 10th.

Another year has passed with what seems to have been amazing speed, with many events over the period. These included PID Awareness, Youth Patient Events at MERC, an Auckland maritime museum visit and harbour cruise, patient meetings in all the main regions, not to mention the various shows - Razz Ma Tazz, Circus Quirkus, Magic Show and Pantomimes. We have continued to offer practical support in many ways, be it in the form of Hospital parking/pharmacy vouchers and meals, family medical assistance grants, medical diaries, medic alert bracelets, advocacy and patient visits to name just a few.

World day of Immunology saw us highlight this with NZBS Patient event, including a tour and information seminars. We had representation at Auckland Home Show, RNZNCGP Conference, ASCIA, and Paediatric Society of NZ Conference, and we are progressing with new literature and information to form school education resources. We continue to support CVID research, genetic testing and have seen more scientific papers published.

We undertook a patient survey which has given us direction for future planning for the Foundation. Thank you to all those who took the time to participate, and also a very big thank you to the Board and staff members who ably compiled the results for us. Our holiday homes continue to be well patronized and we believe these continue to be a real asset to our families.

It is fitting when mentioning all the events etc that we take the time to give sincere thanks to our sponsors and supporters, without whom we could not achieve what we do. We receive support in many shapes and forms and I cannot possibly list individually, however I would like to specifically thank Greg and the crew from Smith and Smith Glass who came on board with us last year have continued to be generous in their support, including a significant donation for our patient center. Thanks also to our support staff for their continued hard work and loyalty. To my fellow board members I give sincere thanks for your commitment and the hours that you all so freely give to guide this organization to grow and achieve our goals.

Last year at this time we launched the idea of the Family Patient Centre - it is the biggest project we have taken on and is obviously going to take time to make happen, but we have got the ball rolling, with a couple of generous donations and we look forward to increasing this fund to realize our dreams.

It has been a tough year for many New Zealand families with Pike river and the Christchurch Earthquakes. I think everyone has been touched in some way by these tragedies. Our thoughts go out to all of these families. The sad loss of our wee battler Aria Mac Donald also touched many of us this year, and I know so many of our other member families are facing ongoing medical challenges - my thoughts and prayers are with all of you. I wish you all a safe and Merry Christmas and may the New Year be good for each family individually and collectively as a Foundation.



2011 Supporters include

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The Pelorus Trust
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Our People

Samantha Sutherland, Board member



Hello, my name is Samantha Sutherland, and I am privileged to be the first transplant patient representative on the IDFNZ Board, in this newly created position.

I first heard about the Kids Foundation when my baby daughter Lara was placed on the waiting list for a liver transplant in 2007. Lara was born with biliary atresia, a rare liver condition where the bile ducts are missing, effectively the liver slowly stops working as bile builds up and damages it. The journey before and after transplant is fraught with distressing medical challenges, long hospital stays and plenty of emotional stress as you watch your child deteriorate and suffer.

When the Kids Foundation stepped in with meal vouchers, parking vouchers and a warm friendly smile, we were so grateful. Although we live in Auckland, we are on the far outskirts and the financial costs of

twice daily commuting and meals were a burden. My children are also able to enjoy just being normal kids at the Rainbows End Christmas party each year too, even if Lara has sometimes arrived there straight from hospital!

When I was living up at hospital with Lara, I made a list of goals for the next few years ahead and one of them was to give back somehow to the foundation that has kindly supported us. I was really excited therefore to apply and be accepted as a board member. So far I have been able to work on a patient survey about the services IDFNZ provides, help out at a Razzmatazz show and am currently working with our nurse specialist to update the transplant manual which will be an amazing resource for transplant patients and their families embarking on this huge journey. As a parent of a transplant child who has had a very rough ride in her first five years I feel very excited to be able to represent transplant patients and their families and their needs.

...Lara's story is published on the KIDS Foundation website in the member's stories section.



Medical Matters

SCIG Pumps

PID members will be aware that there have been some significant changes in the Subcutaneous Immunoglobulin pumps (SCIG) adopted by district health Boards over the last two years. For many years the Graseby 16A pumps were used for SCIG infusions, these were finally retired in 2010 and alternative pumps were issued. Unfortunately the initial replacement pumps (Alaris) were problematic and had to be withdrawn. The most recent approved replacement pumps are the Nike T34 and Nike T34L. IDFNZ is pleased to be able to assure members and health professionals that we now have a good supply of these new model pumps available to loan to suitable patients. Please contact Sandi – support@idfnz.co.nz if you would like to inquire about this new equipment or have old model pumps you would like to return to the Foundation.

IDFNZ would like to acknowledge the Trillian Trust for assisting with recent pump acquisitions



Update on our Patient and Family Centre

Fundraising



It is always daunting to start a new project of this scale from zero! We have been blessed however with some amazing and generous contributions to this project over the last year. We have broken the project into stages, commencing with securing suitable land. We are pleased with the encouraging results to date and further funds pledged from activities underway now. No contribution is too small – you can all make a difference by getting behind this venture.

Survey results

Thank you to all who participated in the recent survey, your feedback has been very helpful. Responses came from a good cross section of our membership, representing the experience of families undergoing various kinds of transplant in the USA, Australia and Auckland as well as some families awaiting transplant at that time.



There was overwhelming support for a patient and Family centre being a "great goal" for the organisation and that the Boards understanding of the specific needs is realistic and worth pursuing.

Typical comments included...

"..Wish this had been available when (they) had to relocate To Auckland from Wellington.."

"..There is a need for this",

".. It is very comforting to have a 'clean' place to stay during uneasy times",

" .. A place to stay where people have some understanding of your situation...."



The families responding had endured post transplant hospital stays from 4 – 6 months duration. (This doesn't include any pre transplant hospital admissions – which in some cases doubled this time away from home. One Christchurch family spent a full 12 months living at Auckland hospital).

Post transplant, the Auckland based patients typically were discharged home earlier than non Auckland patients, but were required to commute for daily and eventually weekly hospital clinic appointments as follow up. One particular patient had undergone 3 separate transplants. All agreed that this was a very stressful time and being away from home was difficult. They felt "isolated and vulnerable".

Recent Patient Events

Outdoor Adventure

On the 10th October 2011 a group of our Auckland youth members (7-15) joined me for a cold but fun day at Sir Peter Blake Marine Education & Recreation Centre (MERC) Long Bay.

The team challenge started the day off with right amount of confidence building and laughs. Groups were required to work together to conquer various activities that were a blend of physical and cognitive challenges.

Our older youth members scaled the heights to experience a unique view of the Hauraki Gulf from the top of a very tall Norfolk Pine. Whilst our younger youth members had fun challenging each other on the climbing wall.

Archery proved to be more difficult than it looked for some and yes I heard some good excuses as to why arrows weren't going where they were supposed to!

The day was so successful that we are planning repeat the experience on the 25th January 2012.

IDFNZ/KIDS Foundation would like to thank Aotearoa Sports Foundation for their generous grant making these events possible. Sandi Field



Proximity to the hospital was identified as being paramount, with 93% of responses favouring a radius of 30km or less. It was acknowledged that cost and land availability however, would be factors in selecting the final site.

Privacy was also important, a "Private family living space", "Sometimes people just need to be by themselves", "I am a private person didn't want to listen to other peoples issues when dealing with my own grief", "...a private space is essential".

This is understandable given the long period living on the hospital ward / using communal facilities. The concept of having 3 bedrooms – to fit parents, recovering patient and visiting siblings/grandparents etc, was also supported by an overwhelming majority. "This would be great for larger or extended family. It is important that they are part of the healing process".

Access to an adjacent garden and outdoor living space was also identified as being desirable, especially for families with younger children needing child friendly space to unwind.

It was clear that families wanted somewhere where they could function as a family, have independence and live as 'normally' as possible.

In response to our questions probing the benefits of the IDFNZ office facilities being located adjacent to the self contained family accommodation, there was again very strong support, with particular mention of access to – Internet services, Information resources, Transport assistance to hospital /shops/schools/church etc, and the easy access of meeting rooms for family meetings. Access to support staff advice and information was also seen as being beneficial. Those

with young children expressed an interest in a possible crèche service. A careful balance between the need for privacy and easy access to support services was clearly communicated.

Comments included:

"It is important to have ongoing emotional and medical support especially early on however families need their own space to heal", "Allow families to heal as needed but have support as required", "The closer to support services the better", "A lot of support is needed initially post transplant". Need for 'Peace of mind' (that medical and support services were nearby), was a recurrent theme as vulnerable families adjust and recover and heal.

Your responses have been very helpful – allowing a clearer understanding and focussing of our project committee as it works on the challenges of fundraising, finding a suitable site and the final design features of the complex. Many respondents also offered to share their personal stories to promote our project and to assist with fundraising – we will certainly follow up on these generous offers which will benefit future transplant families.

If any other members or supporters would like to assist with fundraising for this project, or know of suitable land coming up for sale or lease – we would love to hear from you.

