

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.

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

 **IDFNZ**
Immune Deficiencies Foundation
of New Zealand



The **Kids**
Foundation
key immune deficiency support

Two important new ways that members and supporters can reduce their own expenses while supporting KIDS Foundation:

Introducing the **NEW Bye Bye Standby®** Energy Saving Starter Kit

How to Use

Simply plug an electrical device into the Bye Bye Standby® Smart Socket, and this will enable you to take that device off standby when it is not in use - either by using the remote control or the switch on the socket itself. By combining with a 4-way extension lead, you can control up to four appliances with one Smart Socket. The kit is easy to extend by adding further Smart Sockets or other items from the Bye Bye Standby range. The remote control can be used to operate up to six different groups of devices independently or to switch everything off or on at once (e.g. when you leave the house / go to bed).



Buy now for \$45 (inc gst)

Place your Order Now:

Call 0508300600

Email : info@idfnz.org.nz

PO Box 75076, Manurewa, Manukau 2203

Features

- Wireless remote control
- On/Off function
- Group control (enables multiple devices/lights to be controlled at once)
- Operable control distance – up to 30m
- For indoor use only

NZ safety standards

- Voltage: 240VAC/50Hz
- Maximum load: 3000W (13A)
- On/off indication: LED
- Remote range: up to 30m
- Battery type: 12VDC/MN21

Save energy - Save costs – save the environment – Help NZ medically fragile children

AON NEW ZEALAND INSURANCE BROKERS

Since our last newsletter Insurance costs have skyrocketed for all consumers. Please remember the special arrangement we have with AON insurance broker Craig Graves – passing on competitive quotes to our members/ supporters and rewarding IDFNZ with a cash donation for all policies signed. As your family and business insurance policies come up for review we ask you to check out this generous offer.

The process is simple:

1. Email the completed IDFNZ contact inquiry form (available on our website) to craig.graves@aon.co.nz or call him direct 09 4869756
2. Provide your current insurance requirements
3. Receive Aon terms and policies
4. Appoint Aon and automatically have a percentage of your premium donated to IDFNZ upon receipt of payment.

2011 Supporters include

Smith & Smith®
The Freemasons Charity
The Freemasons Mangere Lodge 330
Commonwealth Serum Laboratories Ltd (CSL)
COGS
New Zealand Children's Transplant Support Trust
Octopharma Ltd
The Mount Wellington Foundation Ltd
Four Winds Foundation Ltd
Oxford Sports Trust
Circus Quirkus Appeal

The Perry Foundation
The Lion Foundation
The Pelorus Trust
The Endeavour Community Trust
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Constellation Trust
Eleanor May Pharazyme Trust

Francis Henrietta Muter Trust
The Infinity Foundation
The Southern Trust
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Our People

IDFNZ Board



The AGM in August was held at the beautiful Auckland Botanical Gardens. Board elections took place as part of this event with your new Board confirmed as : Judith Dickson (Wellington) Chairman, Vicki Tattley (Auckland) Vice chairman, Nick Metson (Wellington) , Ali Coombes (Masterton), Laura Hannah (Nelson), Samantha Sutherland (Auckland), Adrienne Bosch (Kaeo), Katy Brown (Whangarei), David Hilliar (Auckland)Treasurer, Janet Simons (Auckland) Secretary and Dr Shannon Brothers (Auckland) Medical Panel representative.

Shania's trip to Queenstown



Earlier this year IDFNZ/KIDS Foundation nominated one of our Christchurch patient members, Shania (15) and her mum, for the 2011 'Ticket for Hope' Queenstown event funded each year by Cure Kids. A wonderful all expenses paid weekend experience in New Zealand for 15 children who live with a life-threatening illness. Shania's application was successful and she enjoyed a very special weekend.

You can read about Shania's fun weekend exploring Queenstown and look at more of her photos on our website www.idfnz.org.nz.



"Mum and I had an awesome trip to Queenstown. We have never experienced anything like that in our life. We will never forget this trip – it will be one of my best memories. Thank you for making it possible." Shania.

Medical Matters

Measles Epidemic- Message from our Nurse Specialists



As most members will be aware there is a measles epidemic in the Auckland community due to falling rates of immunisation; this can pose a significant threat to our immunosuppressed / immuno-deficient patient groups (these patients are considered high risk); Our nurse specialists are presently reviewing each patient's history to establish those who are immune versus non-immune .

Parents should be alert to the symptoms of measles and contact their GP / clinical specialist team should they suspect exposure. Recommendations via the Starship Measles Clinical guideline:

Patients with a weakened immune system should not receive the MMR vaccine unless recommended by your child's specialist. However, it is important that their family and close contacts are immunised against measles to help protect them. All immune competent

Summary Characteristics of Measles

1. The virus is spread by breathing in virus-containing droplets or by touching contaminated surfaces
2. The virus grows in cells in the back of the throat and lungs. Symptoms appear after 2-12 days
3. Infected person has a fever lasting two to four days, followed by a cough, runny nose and red, watery eyes



4. A rash, lasting five to six days, appears about the face and head, spreading through the torso to the hands and feet
5. The virus can be transmitted from four days prior to and four days after the appearance of the rash.

siblings and Parents (born after 1969) who have not had 2 doses of Measles containing vaccine should be immunised with MMR; a rash developing 6-12 days post vaccination is not infectious as long as there has been no other exposure to a child with Measles.

Exposure constitutes:

Exposed persons are defined as those who enter the same room or work-space as a person who has Measles infection within 2 hrs of the infected person leaving.

Treatment post exposure:

Your clinical team will need to be notified of the exposure at the earliest opportunity. Immunoglobulin will be offered for exposed patients if considered necessary by your clinical team (to be administered within 6 days of the initial exposure).

EpiPen and EpiPen Jr have a new look!!



The new look EpiPen and EpiPen Jr are oval in shape to make it easier to grasp and handle. Due to the shape being 'flatter' the new look EpiPen and EpiPen Jr is easier to read. The needle end is a bright orange in colour and extends upon use so the needle remains protected. The safety cap is now an easy to see blue.

There is no change in the process of using the new look EpiPen and EpiPen Jr it is just the look that has changed.

The motto for the new look EpiPen and EpiPen Jr is "blue to the sky orange to the thigh" – catchy and easy to remember!

Even the container to store your new look EpiPen and EpiPen Jr has had a makeover – instead of unscrewing the cap you just need to flip it open.

The Epiclub Reminder Program is a free service where members are sent a reminder to renew their prescription before their EpiPens are due to expire. If you are interested

in signing up to Epiclub you can either do so online at www.epiclub.co.nz or complete the Epiclub registration from inside your new EpiPen box or call 0800 620 620.

If you are at risk of anaphylaxis please ensure that you have an up to date anaphylaxis action plan signed by your doctor with you at all times. These action plans can be downloaded from www.allergy.org.au

EpiPen is one of a range of portable adrenaline autoinjector treatment devices for emergency use by patients. In New Zealand there are now two brands of adrenaline autoinjectors (Anapen and EpiPen), and each of these is also available in a Junior version. As Anapen and EpiPen products have different administration techniques, only one brand should be prescribed per individual, and their ASCIA action plan for anaphylaxis must be specific for the brand they have been prescribed. In our next newsletter we will be outlining current options available to patients in more detail. Meanwhile, for information on Anapen go to www.analert.com, and for EpiPen information go to www.epiclub.com. Useful information about these devices can also be found on the Allergy NZ website: www.allergy.org.nz.

Thanks to a generous grant from the First Sovereign Trust - IDFNZ Patient members are eligible to apply for family grants towards the cost of one of these adrenaline devices each year - contact support staff for details.

ASCIA , Darling Harbour Sydney September 1-6th



The Australasian Society of Clinical Immunology and Allergy (ASCIA) is a professional medical organisation, comprised predominantly of Clinical Immunologists, Allergy Specialists and Immunology Scientists.

The 22nd Annual Scientific Meeting of ASCIA was held at the Sydney Convention and Exhibition Centre, Darling Harbour in September. The ASCIA 2011 scientific program included a record number of 9 international speakers, more than 40 Australasian speakers and chairs, 75 posters and 9 Clinical Grand Round (CGR) presentations

IDFNZ have been part of the ASCIA conference for many years. We were pleased to have the opportunity again this year to have a display stand in the patient support area at the conference.

Vicki Tattley and Sandi Field attended the conference

on behalf of IDFNZ and were able to make good use of this opportunity – updating themselves with latest information presented at the seminars, communicating the work of IDFNZ to medical professionals attending, and valuable networking and collaboration with other patient groups present such as IDFA our Australian sister group.

All in all this was a very busy and productive week for our delegates – Many thanks to ASCIA for supporting the work of IDFNZ and sponsoring our attendance at this important event.

In 2012 the 23rd Annual Scientific Meeting of the ASCIA will be held in New Zealand at the Wellington Convention and Exhibition Centre. IDFNZ is looking forward to assisting with the hosting of this event and has committed to sponsoring one of the key International speakers. We will also be linking this with a series of talks to medical professionals around New Zealand



– more news on this next newsletter.

Royal New Zealand College Of General Practice(RNZCGP)Conference Auckland, September 1st -4th.



The RNZCGP is the professional body which provides training and ongoing professional development for general practitioners and rural hospital generalists, and sets standards for general practice.

The Annual Conference for General Practice is the premier event in the College calendar. In 2011 it was jointly held between the RNZCGP and General Practice New Zealand (GPNZ). It is considered to be the premier venue for collegial, local, national and international networking.

The Conference provides an academic programme involving

a national forum and scientific curriculum along with the presentation of recent research.

The Langham Hotel in Auckland was the venue for The 2011 RNZCGP Conference and IDFNZ was thrilled to be given the opportunity to have a stand at this prestigious event. IDFNZ Staff and volunteers were able to distribute information to raise awareness of our organization and the rare medical conditions we offer information and support for- lifting our profile to the 650 delegates who attended.

IDFNZ would like to thank and acknowledge the support given by RNZCGP.

.....More about ASCIA 2011 from our PID Nursing Specialists

Janice Capstick, Clinical Nurse Specialist and Simone Stephens, Research Nurse from adult Clinical Immunology and Allergy Services, Auckland City Hospital attended the 22nd Annual Scientific Meeting, Australasian Society of Clinical Immunology and Allergy (ASCIA) in Sydney, Australia.

This ASCIA meeting included the Allergy and Immunology Update day for nurses and allied health professionals which comprised of a number of relevant updates on this year's topic of allergy. As members of the ASCIA nurses committee we were able to participate in consultation, review and feedback of nursing policies regarding allergy and immunology care in Australasia. Educational resources for nurses and patients were discussed and to have ongoing development. On behalf of the New Zealand Clinical Immunology and Allergy Group (NZCIAG) nurses committee we updated the ASCIA committee regarding the nursing practice policies currently being established in New Zealand.

Attendance at the three main conference days offered us opportunities to update our knowledge and reassurance that our current practice is in line with international standards of practice. We submitted two posters, the first displaying data for the interim report regarding the current clinical trial of subcutaneous immunoglobulin replacement therapy. This report established the continued efficacy for using subcutaneous product as a form of treatment. There is likely to be NZ registration for use of the subcutaneous products in early 2012. The second poster reviewed antibiotic usage following negative penicillin challenges in our day ward.

Overall we found this conference to be supportive of our learning and ongoing professional nursing development. We can continue to incorporate relevant new information gathered into our current practice. It was a good opportunity to renew relationships with immunology health professionals in Australia. The ASCIA 2012 scientific meeting is to be held in Wellington and we all looking forward to participating in the organisation and events around hosting this conference.

By Janice Capstick and Simone Stephens

Razzamatazz 2011

Thank you to our Sponsors for making this possible - touching the lives of so many of our brave children

Special mention to :

International Entertainment Ltd
Smith & Smith Ltd
Navman Technology NZ Ltd
Harroways Ltd
Contact Energy Ltd
Mainland Foundation
The Southern Trust
The Infinity Foundation
The Endeavour Trust
and all of those Annual Appeal supporters that regularly sponsor our special needs children.

coming events

Patient Events 2011

Monday October 10th
MERC Youth Patient and sibling event - Auckland

Monday October 31st
Clinic/Lunch Meeting
Christchurch

Sunday November 6th
Xmas BBQ Meeting
Wellington

Wednesday November 23rd
Liver Group Coffee Meeting
RMH- Auckland

Saturday December 10th
Childrens Xmas Party
Auckland

TBC
Patient Meeting
Dunedin/Invercargill

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

Weird & Wonderful

Community support for IDFNZ KIDS Foundation

Razzamatazz 2011 has been another successful and uplifting event for the Foundation as it toured 13 New Zealand locations.

Headlined by the fantastic visual comedy and high-tech silliness of the ever popular Marty Putz and Co, combined with the amazing penguin jugglery of Jeremy Ansley, this year's charity show was the best yet.

Canadian born, Marty Putz, with his youthful style and infectious enthusiasm offers a unique brand of physical and visual comedy. Marty is committed to helping KIDS Foundation and really enjoys engaging with the audience, always happy to mingle with his young New Zealand fans after each show. His humour is infectious!

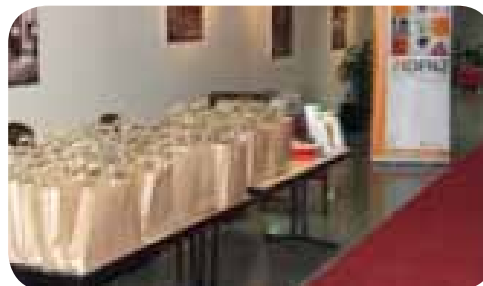
Our thanks to the audiences for showing their appreciation of KIDS Foundation and the Razzamatazz show by purchasing our unique Marshmallow shooters, bow and Mallowes and Marshmallow guns - new unique merchandise which serve as a memento of the show and allow the marshmallow fun to continue at home! These items can now be purchased online at www.mcshooter.co.nz - perfect Xmas gifts, with proceeds benefiting KIDS Foundation.

We would also like to thank the IDFNZ staff, members and volunteers that helped behind the scenes of each show - your support is greatly appreciated. Special mention to Smith & Smith Auckland volunteers who ran a marathon Sausage sizzle during the 3 Auckland shows selling over 1200 sausages to raise funds for KIDS Foundation!

The Foundation would especially like to thank each of the wonderful businesses and individual sponsors around New Zealand who make this annual event possible. By the end of the 2011 tour thousands of special children and their families had experienced the pleasure of live theatre featuring these amazing international performers.



Happy faces were a feature of every audience



These special Whangarei Razzamatazz show bags were prepared by Katy and Adrianne



Marty working his magic