

## VALUED BOARD MEMBER, NICK METSON STEPS DOWN



**Deborah and Nick Metson**

A referral to the KIDS Foundation founder many years ago saw the start of a long association between Nick Metson and his wife Deborah and KIDS – one that has sadly just come to end as a result of Nick's growing work commitments. The Foundation's vice chairman for the last four years and long standing Wellington KIDS member and representative, Nick will be increasingly involved in his company's overseas expansion, especially into Asia and the Middle East. Nick is the International Commercial Manager for Airways Corporation, a New Zealand company providing navigation and air traffic control services in New Zealand and overseas. While no longer a KIDS board member, Nick will however continue in his role as the PIDS Teenagers Trust chairperson. The Metson's involvement with the Foundation started with the birth of their son Alexander (now 16 years), and continued through the births of Louis (aged 13) and George (eight years). After a series of paediatrician and

immunologist visits, all three were diagnosed with a transient PID condition that improves with age. True to diagnosis, they are today enjoying increasingly good health.

While Nick has been heavily involved with the Foundation for many years, he would describe the association as a 'family affair' and one that significantly changed their lives, particularly in the early days.

*"I wasn't the only one involved with the Foundation, my wife Deborah also contributed a great deal as the Wellington Co-ordinator for many years and only recently left the position. In the end, it was a family decision and one we all benefited from. Back at the start, when we were just getting to grips with the fact that Alexander had a PID condition, it was, to say the least, a daunting prospect. Learning about the Foundation, getting access to appropriate resources and meeting others in a similar situation really made a difference for our family and we went onto to really value the friends we made in KIDS," said Nick.*

Fellow Wellington Board Member Judith Dickson says she and others will miss Nick in so many ways – his wonderful way with people, ever cheerful nature and business skills.

"Nick's motto was "just get on with it" and this applied whether we were on those ghastly Wellington 'take off' and 'landings', or taking a business decision at a board meeting. He also had a wonderful way of getting his message across without

getting off-side with people – his dry sense of humour and self effacing demeanour all helped. And underpinning it all, were his strongly held values and commitment to family," she said.

## NEED TO KNOW!

### **KIDS Foundation Capital Weekend**

- Labour weekend 23-28th October  
El Rancho Waikanae

### **More FM Xmas party**

- Auckland 30th November  
Auckland Zoo

### **Special Radio Network Xmas parties this year are as follows:**

- Auckland 7th December  
Auckland Showgrounds
- Wellington 20th December  
Queens Wharf
- Christchurch 6th December  
Westpac Centre
- Hamilton 14th December  
Mystery Creek

All shows are 11am – 2.30pm, tickets will be distributed by support staff as available.

### **KIDS Foundation Xmas Parties**

- Auckland 6th December Kiwi Valley
- Wellington Juniors 30th November  
Tawa Pool
- Wellington Adult/Teens 4th December  
Lighthouse Theatre

Invitations will be posted out by support staff – remember to RSVP.

*continued over page >*

## “FROM VEIN TO VEIN SEMINAR”

### New Zealand Blood Expert infuses Intragam Patients with knowledge

Dr Peter Flanagan, National Medical Director of New Zealand Blood Service presented an exceptional seminar on blood safety to a group of 40 Intragam recipients and parents in Auckland. “The patients had traveled from as far a field as Dunedin, Christchurch, Wellington and Napier to hear Dr Flanagan speak. It is the first time the Foundation has held a meeting focusing on blood products and the feedback from members was very

positive.” said General Manager, Janet Simons. “We are privileged to have Dr Flanagan as a member of our medical panel, he was able to present very technical information in a very understandable manner”.

Dr Flanagan has a unique background; born in the UK, He moved to New Zealand in November 1998 to take up his current position. Trained in General Medicine and Haematology He Then moved into the field of Transfusion Medicine. He became a consultant in Transfusion Medicine in 1989 and has a particular interest in blood safety and quality systems whilst in the UK he had a

senior role in policy development relating to Blood Safety within the English National Blood Service. He was the Chairman of the UK BTS Standing Committee on Transfusion Transmitted Infection (SACTTI), was closely involved in the development of strategies in the UK to implement nucleic testing of blood donations and also the introduction of measures to reduce the risk of transmission of variant CJD by transfusion.

The Foundation is committed to patient education and plans to host regular meetings for this group.

## News all Positive at Annual General Meeting!

Reports of an event filled year (e.g. Winkelstein Seminars) and a good financial position dominated the Foundation’s Annual General Meeting held on July 28, 2003. While long-standing member Nick Metson stepped down as the Vice Chair, the Rev. Stephen Baxter (Chair), Dr Rohan Ameratunga (Vice

Chair), David Hilliar (Treasurer), Janet Simons (Secretary), Vicki Tattley, Michele Kay-Sharman, Dr Jan Sinclair, Judith Dickson and Ali Coombes continue into their second year of a three year term in office. Printed Annual Reports, including full audited accounts will be mailed to Foundation members shortly.

## Foundation Fields New Library Service!

Finding ‘credible’ information about a range of PID conditions can be a daunting task for even the most capable of among us, but this is all about to change with the introduction of a new information service. Free to families nationwide, it will be run by Sarah Perry who will source, store and distribute information as well as, research specific topics. KIDS General Manager Janet Simons says the service will take the stress out of getting ‘up-to-date’ and ensure that members have access to the very best specialist medical texts. Texts can be booked out online through the KIDS website on [www.pidsnz.co.nz](http://www.pidsnz.co.nz) (includes a booklist) and Sarah can be contacted either online or, free phone on 0508 300600.

## Liver Transplant Children Cared for by KIDS

Children undergoing a liver transplant at Starship Hospital will now be cared for by the KIDS Foundation following the announcement of a new partnership with the New Zealand Children’s Support Trust (NZCTST). While the Trust will continue to

fund the care (on-going social services and family contacts) provided by the KIDS Support Co-ordinator, the new association is a rational response to a shared set of circumstances said Janet Simons.

“Liver transplant children are cared for in the same ward as PID children receiving Bone Marrow Transplants and both face similar challenges due to the long term use of immune suppressant drugs. It makes sense then for the two organisations join forces,” she said.

## KIDS to Have Capital Time!

A group of KIDS children are set to have a capital time over Labour Weekend when they head to El Rancho at Waikanae.



Visits to Te Papa, Carters Observatory, Nga Manu Nature Reserve and Southwards Car Museum are all part of the package as well as, taking a scenic helicopter trip, horse riding and mini golf. This action packed weekend has been made possible through Trillian Trust and the Diplomats Ball Committee funding. For details and registration forms check the KIDS website on [www.pidsnz.co.nz](http://www.pidsnz.co.nz).

## Trillian Trust Key Sponsor for 2003 KIDS Camp

The Trillian Trust has once again agreed to sponsor KIDS Foundation by being our major sponsor of this years KIDS camp. The Trillian Trust has granted \$22,000 towards the camp.



## OVERWHELMING GENEROSITY FROM DIPLOMATS

Last edition we reported on the success of the Ambassadors Benefit Ball. The Ball committee has since hosted KIDS Foundation Board members to a cocktail party at which a cheque for \$98,000 was presented to the General Manager. The size of the donation was a wonderful surprise for the Foundation and will go towards providing services and events such as Respite holidays for families, support services, and the 2003 KIDS Camp.



## A Ray of Sunshine for KIDS Foundation



Henderson locals may be familiar with the "Sunshine Shop" – an opportunity shop with a difference. This business has been set up and managed by a group of local residents. These volunteers donate their time and energy on an ongoing basis in order to raise funds for charities. KIDS Foundation was supported by this group on two occasions last year and has recently been presented with a further cheque for \$1500. This ongoing support is wonderful as it allows the Foundation to continue its work with families. This years donation is tagged for the Auckland Xmas party event to be held in December. Representatives of the Sunshine Shop have been invited to come along to the party to meet some of our members.

## Big Red Bin Benefits KIDS!

Members will have seen them around the city before, in car parks and outside their local supermarkets, but now they are taking on a new role – helping the Foundation raise funds for member services. They are the new KIDS Foundation red clothing recycling bins – just the place for used clothing, 'bric a brac' items and other fabric household items! KIDS General Manager Janet Simons said that members could assist by placing all their used clothing in the bins and in other ways. "Agreeing to have a bin on a business site or persuading the local church or school to 'host' a bin would be helpful," said Janet. For further information about the red clothing bins, please call KIDS free phone 0508300600.

### OTHER CAUSE CHAMPIONS:

CENTURY FOUNDATION  
 ENDEAVOR TRUST  
 TRUST HOUSE  
 ROYAL OAK TRUST  
 ARA LODGE  
 PUB CHARITY INC  
 SOUTH AUCKLAND CHARITABLE TRUST  
 MT WELLINGTON TRUST  
 THE TRINITY FOUNDATION  
 SUNSHINE SHOP  
 WISHLIST SPONSORS  
 TRILLIAN TRUST

## MEDICAL MATTERS

### Kids Chairman reports on Immune Deficiency Foundation (IDF) 2003 Conference

This year, the International Patient Organisation for Primary Immune Deficiencies (IPOPI) sponsored IPOPI Trustee and Chairperson of the KIDS Foundation of New Zealand, the Rev'd Stephen Baxter to attend the 2nd National IDF Conference. Held in Baltimore, Maryland USA, the conference brought together individuals and families affected by immune deficiency diseases (PID) as well as physicians, nurses, industry and government representatives who play a part in the treatment and management of these diseases. Over 1300 people attended the conference. Stephen Baxter commented that the major drug companies were

well represented at the conference and indeed had made a substantial commitment to the PID community. "While we often struggle here to obtain significant sponsorship to meet members' needs, it was nevertheless pleasing to see the strong relationship between the IDF and drug companies. This year for example, the IDF received US \$1,000,000 sponsorship from FFF Enterprises with substantial contributions from other drug companies also," he said. The IDF was founded in 1980 by parents of primary immunodeficient children and their physicians. At the time, there were few treatments for many PID diseases. There were no educational materials for parents, no public advocacy, and little research being done. For more than 20 years the IDF has worked on these issues and made real progress.

*continued over page >*

### IDF Day on Capital Hill!

On Day one of the conference, attendees travelled to Washington DC to meet with members of Congress, their aides and others on Capital Hill, as part of a comprehensive lobbying campaign to discuss important policy issues regarding PID.

IDF Public policy focuses on:

- Advocating for safe and adequate blood supply
- Ensuring access to quality health care for PID patients
- Increasing funding for medical and scientific research

Stephen Baxter said he was very impressed with the IDF lobbying effort, especially the high level of organisation, preparation and perseverance.

"I think that we can learn from IDF about lobbying for the rights of members and we should not be shy about putting the PID case to government. We have nothing to lose and everything to gain.

However, like the IDF it is important that lobbyists are well briefed and are provided with all the material they need to be effective," he said.

Some of the talking points for the IDF Day on Capital Hill included, improving Primary Immune Deficiency Disease Research by awarding and fully funding the NIH Primary Immunodeficiency Disease Network at a level of \$12.8 million in the fiscal year 2004, providing general information on PID diseases and sharing personal experiences of PID.

Other hot topics facing the PID community include blood safety and public health, for example, the West Nile Virus. As the summer mosquito season begins PID patients are at greater risk of complications from a bite from this mosquito and there is a concern that Immune Globulin Intravenous (IGIV) could be tainted with the Virus. Post September 11, there is the added concern about smallpox and vaccines, and in more recent times SARS (Severe Acute Respiratory Syndrome). The IDF supports simple public health measures including education to guard against these potential threats to PID patients.

For anyone interested in the IDF and its work in the United States, log onto its website at [www.primaryimmune.org](http://www.primaryimmune.org) or for conference papers E-mail: [idf@primaryimmune.org](mailto:idf@primaryimmune.org)

## OUR PEOPLE

### Webmaster William Wright Puts KIDS Online



These days if you aren't online and don't have a website, there's a very real danger that your messages will simply not be heard. That's why William Wright's

contribution to the KIDS Foundation as the Webmaster for [www.pidsnz.co.nz](http://www.pidsnz.co.nz) is such an important one!

A software developer for the New Zealand Racing Board, William Wright has spent the last five years, in his spare time managing and updating the KIDS Website. As an adult PID Patient he is the perfect candidate because he knows what it is like to have PID.

William was diagnosed with CVID in November 1997 at the age of 38 after suffering from chronic sinusitis problems for over 12 years. He was also found to be in the early stages of bronchiectasis (left lung). As with other PID patients, William's journey to diagnosis was a long one with a series of wrong turns. There was a long history of taking antibiotics (he was

prescribed most brands), a brush with surgery, an attempt at alternative treatment and then onto a medical specialist. That was when things got a lot better for William - his condition was diagnosed and he started Intragam treatment. Knowing what it's like coping with PID, William was keen to assist the Foundation spread the word. "One of the difficulties the Foundation faces is the very rarity of PID. That's why we have to take every opportunity possible and use all the communication tools available to us to explain to everyone just what PID is about. Being on the internet is so important for KIDS in terms of building profile in an increasingly global and wired world."

"While having a website is important, it is also critical to ensure that the information is updated, and equally important, there is a regular supply of fresh new material or stories to encourage repeat visits. This is where I would make a special plea to members to come forward with their personal stories for the site. And, if anyone has any suggestions about how the

website could be improved, these would be most welcome," said William.

Based in Wellington, William is married to Judy and has two healthy teenage sons. In addition to acting as the Foundation's webmaster, William served a term as a board member and is a moderator for the PIDS-Australasia mailing list. Members with suggestions for the website or keen to post their stories should contact Janet Simons.

*Kids*  
**FOUNDATION**

A ray of sunshine

[www.pidsnz.co.nz](http://www.pidsnz.co.nz)

#### Contact the Kids Foundation

PO Box 75-076, Manurewa  
Auckland

Freephone 0508 300 600

Fax (09) 523 5551

email: [kids1987@nznet.gen.nz](mailto:kids1987@nznet.gen.nz)

*Photography by Susanna Burton*