

The IDF is a not for profit organisation dedicated to supporting Australians of all ages diagnosed with Primary Immune Deficiencies (PID's). IDF provides education for PID's, PID lobbying and advocacy services, and ongoing medical and scientific research.

The Immune Deficient Kids Foundation is the welfare arm of IDF caring for PID children, teenagers and their families. The Foundation offers members practical, emotional, medical and social support.



Our People *Cont*



from Pg 2 with his JRA starting to improve – he had been on 8 Aspirin a day for the pain and swelling! Unfortunately, Rory, who still had his cold, also developed JRA. When he was retested he was found to be suffering from what was now called XLA – X Linked Agammaglobulinaemia – and commenced IVIG in mid May, 1987. Callan was born a couple of weeks later! He was diagnosed at 5 months of age! Three boys in the one family with XLA!

Life was very busy as the boys grew up. Holly came along just after Floyd's 6th birthday. From February 1987 onwards, we had 4 weekly trips into the hospital for IVIG, then 3 weekly, and occasionally 2 weekly. All 4 children had extensive swimming lessons, as this was good for their chests – not always good for their GI tract though, as they often succumbed to GI infections, which occasionally hospitalised them. Floyd was a top swimmer, always going through to the state finals with school, and 3 times being nominated as District Swimmer of the Year while at school. They also participated in most sports – tennis, cricket, netball, basketball, athletics, Surf Life Saving at Portsea SLSC – but not football or soccer as every time they were drenched in the cooler months they ended up with pneumonia!

We have had numerous admissions for pneumonia; countless visits to paediatric immunologists, eye specialists, gastroenterologists and thoracic physicians, physiotherapists, occupational therapists, psychologists, psychiatrists, social workers and counsellors; and many days missed at school! Family holidays have been interrupted for treatment, or because of illness – having IVIG has not prevented them having bouts of pneumonia at times – Floyd's last admission was in September last year! We also implemented twice daily physiotherapy, increasing it to 3 times a day with an infection, which is still every now and then. As they grew older they were encouraged to use a Flutter device or a CPAP mask, so that I didn't have to physically do the physio for them.

Rory was granted a wish with the Starlight Foundation in 1997 to visit the home of Ferrari – he has always been mad about them. So we spent a week in Italy as guests of Best Western in Bologna, visiting Ferrari's head quarters in Marinello – that is another story, but a great one! From Italy we went to the UK for 2 weeks to visit my family – we were too close to them not too! My sister didn't want to have children with XLA, so she had been referred to Dr Helen Chapel in Oxford. Dr Chapel was wonderful – she put me in touch with a doctor in Sydney.

The Immunologist in Sydney, who I took the boys to in early 1998, refined their care and I went back to the Immunologist at RCH with a plan of action! We increased their trough levels of IgG, and increased the frequency of their infusions. This hasn't made them completely healthy, but it has made a huge difference to their overall health.

These days the boys are all under the care of adult Immunologists – 2 at the Royal Melbourne, and 1 at The Alfred here in Melbourne.

As a mother, life has been hard in many ways raising and caring for my 3 sons and my daughter, who has an Auto Immune Disorder which causes her much pain at times. As far as I am aware, I am the only mum with 3 boys with XLA in Australia, and 1 of only a handful in the world. There was constant illness in our home – occasionally I even succumbed! Sometimes I do get worn down. But I strongly believe in being a survivor. I have been involved in a couple of small support groups for people affected by PID, and I am a member of the Victorian IVIG Users Group.

Late last year I was invited to become a board member of the IDFA – Immune Deficiency Foundation of Australia. I look forward to working with the other board members and advancing the knowledge of PIDs here in Australia, as well as continuing to support those affected by these disorders.

Do you know what allowances you are entitled to?

In each magazine we will highlight a government allowance and indicate the circumstances it is paid. Please always check with your nearest Centrelink (www.centrelink.gov.au) as each payment is individually assessed and not everyone will qualify for each allowance.

Carer Allowance is a payment available to parents or carers who provide daily care and attention for adults and children with a severe disability or medical condition. This is paid fortnightly and is not income or asset tested. You must be an Australian resident to qualify. You will need a doctor's or health professional's report to help establish eligibility. It may be paid in addition to some other payments.

coming events

February:
IDFA Board meeting Vaughan Park, Auckland

14-16 November 2007
18th ASCIA Annual Scientific Meeting
Fremantle, W.A.

Saturday 17th November
Family Conference Day
Fremantle, W.A.

Razz-Matazz

24th March, Canberra

25th March, Hobart

27th March, Launceston

Circus Quirkus

June 10th, Cairns

16th June, Toowoomba, Queensland

20th June, Newcastle, NSW

21st June, Penrith, NSW

3rd July, Burnie, Tasmania

10th July, Moe, Victoria

Establishing International Awareness and support for PID patients across the Asia Pacific Region

Immune Deficiency Support For All Australia!

Welcome to the first Australian newsletter! This is the end result of a year of hard work by a few dedicated people to enable the Foundation to establish a real presence throughout Australia. IDFA now has member representation in all states except for the Northern Territories. October 2006 saw the setting up of the first Australian led board. For the IDFNZ board members who have been giving of their time and enthusiasm on the Australian and New Zealand boards, this was an exciting step forward! Meetings were held in NSW, Victoria and Queensland where small groups of families met together, which for some was the first time they had met with others living with the same condition.

We also acknowledge the support and encouragement received from a number of medical staff, specifically Dr Jane Peake Brisbane, Dr Sean Rimminton Sydney, Dr Jo Smart and Dr Karl Bleasel Melbourne. We also wish to thank all the other immunologists around the country who

have signed patient application forms! Looking forward we are now starting to develop some regional support networks; fundraising is going well and this year sees the start of new campaigns in Tasmania and then hopefully the Southern and Western states; more local meetings will be organised; A conference day is being planned, to be held in November in Fremantle to coincide with the ASCIA medical conference. Along side these formal events there is still available the one-on-one telephone calls, emails, and information from Sarah Perry the Health Coordinator. The toll free number (+641800465849) is there for you to use if you need someone to talk to.

Here's to another exciting and productive year!



Our People IDF Staff



Profile of Michael Daniels, Sydney, NSW:
Michael is the Secretary to the Board for IDFA.

I was pleased to be asked to be the Secretary for IDFA as I am very hopeful that IDFA will succeed in Australia in a similar way to IDFNZ in New Zealand. I am a chemical engineer who has worked at the same company for 27 years and I am not sure if

this is admirable or not. My wife (Anne) and two of three sons (Martin and Jeremy) discovered they had CVID in 1994 and this began a long involvement in support groups. Initially Anne was the driving force and I would help but as Anne's career in research (molecular genetics) became more involved I spent more time in the support

Cont. Pg 2

Our People, Our Stories

IDF Staff



from Pg 1 side of things. Over the years I have been involved with submissions to government, attendance at forums, attempts at fundraising etc. I have also spent time with Soccer Clubs, Before and After School Committees and P & C meetings.

We live in Sydney but have a preference for



the country over the city and spend a lot of time about 4 hours west of Sydney near Mudgee in a minimalist shed on 700 acres of bush. The other interests that seem to have stayed with me over the years are riding a bicycle, looking at the night sky and observing natural things.

Michael and Jeremy Daniels

Our Story. From Ruth Taylor in Melbourne, Victoria

Ruth is one of the new Australian board members

Where do I start? I am a single mother of 3 sons, Floyd, Rory and Callan, and a daughter, Holly. The boys are now aged 19-23 and Holly is 17. My story really starts in late September 1986, just before Floyd's 3rd birthday! After 2 and 1/2 years of repeated illnesses, including multiple, extreme ear infections, abscesses all over his body, whooping cough at 6 months of age, continuous gastroenteritis, pneumonia, spending more time in hospital than out, and a diagnosis of Juvenile Rheumatoid Arthritis, (JRA), at 28 months of age, Floyd was finally diagnosed with Agammaglobulinaemia. Luckily (???), I knew what it was as I had trained as a Registered Nurse in the UK in the mid 70s.

At this time we were living in Sydney, with only new friends for support, but some of them were excellent, and one family I still keep in touch with! My own family is in the UK - I had immigrated to Australia in 1977.

Floyd was commenced on IM Immunoglobulin as the Immunologist felt that that was what was needed! I didn't know that IVIG existed as it hadn't in the 70s! 10mls twice a week into his buttocks by my GP, (who was excellent), when he was skeletal! Not nice, for him or me. And, unfortunately no improvement in his health either - but we persevered. Floyd's father, Rory, then 19 months old, and I, were all tested. Rory was IgA Deficient, but this is quite common in the general community - 1 in 500 these days! At this stage, Rory was healthy other than having had Measles, Mumps and Rubella after being immunised for MMR at 15 months of age, and having a continuous cold!

Early in 1987, when I was 5 months pregnant, we moved back to Melbourne. Floyd was transferred to the care of the Royal Children's Hospital and Dr Don Robertson, who commenced him on Intragam, (IVIG), at once. Within 2 months there was a huge improvement in Floyd's overall health, ▶ Cont. Pg 4

Recent Events

Melbourne Family Meeting

The first family meeting in Australia was held at the beginning of July in Melbourne. It was an informal gathering over afternoon tea of both parents and adult patients with a short presentation on IDFA followed by general discussion and sharing of experiences. This was an exciting start to the foundation's role in supporting families across Australia. The next meeting will be in NSW at the national conference in Manly with a further meeting booked for Brisbane at the end of October.

We hope that as we make more contacts in each state we can slowly start to build a great network of people across the country that can actively provide support and encouragement to each other.



Brisbane Family Meeting

Another successful patient and family meeting was held at the end of October for families in and around Brisbane, with some travelling down from the Gold Coast! It was a great time to chat and catch up on what had been happening over the year with IDFA with Janet Simons giving a brief overview of where we are at across Australia. There then followed a brief look at the types of families joining the organisation with a discussion led by Sarah Perry on some of the issues facing families and patients in Queensland.

We were also very appreciative of Dr Jane Peake taking time out from her busy schedule to join in the meeting along with her two delightful daughters! The afternoon tea disappeared quickly as did the time.

We would like to thank Marie Turner and the staff of the Ronald MacDonald House, Herston, for allowing us to use their facilities to hold this meeting. We look forward to the next one!

Medical Matters



IVIg Therapy Update

In the last few years there have been a number of changes around the often sticky area of immunoglobulin therapy. For the first time we have imported large quantities of IVIg (Intravenous immunoglobulin) that is not sourced from Australian plasma (Supplied as Octagam). This can be distributed to people under the same arrangements as Intragam P, the Australian product made by CSL.

We have emphasized that as long term users we should not be presented with a different IVIg when turning up at the hospital for the infusion. However, the idea of having a choice of IVIg products and another supply that can ease the pressures of excessive demand and production disruptions is definitely something that needs to be thought through. We also need to think about whether we support the use of IVIg from non-volunteer donors (i.e. donors who are paid for their donations).

Another issue to consider is whether we should sacrifice our self sufficiency and import IVIg that may come from countries where there are people who, for various reasons, cannot get access to that IVIg. While considering these and other issues I was invited to work with Philippa Kirkpatrick (ASCIa PID register) to prepare a submission to the Plasma Fractionation Review Committee. This committee was formed by the government as a result of a condition of the US Free Trade Agreement that came into being a few years ago. Apparently the Australian government had to carry out a review of the state

From the Fact Files

Did you know?

- 77 percent of patients treated with IGIV are over the age of 18.
- Nearly one in ten PID patients is over the age of 65

IDF USA Survey published 2003

(For the full results of this the biggest survey of PID patients see the website www.primaryimmune.org)

of plasma collection and production of plasma blood products. One of the main products is immunoglobulin (Intragam P). A brief summary of our submission is that we acknowledged the difficulty to keep supply and demand balanced. We stated that our preference is for IVIg to be produced from plasma collected in Australia and that we should aim for self sufficiency.

We also acknowledged that the competition that has arisen following the allowed distribution of Octagam in Australia has had some benefits but that the amount imported should be strictly controlled and monitored and not be allowed to eliminate the local production of IVIg. Following our written submission we were asked to present in person to the committee. Philippa prepared and presented a very compelling presentation which together with questions lasted for an hour. We heard that the committee was very impressed. The result of the review is to be published in early 2007. We hope that the outcome does not adversely impact on our local product.

- Michael Daniels

Manly Conference Day Sept '06

The first national conference day was held in Manly NSW to coincide with the annual ASCIA (Australasian Society Clinical Immunology and Allergy!) conference.

This was a fantastic first event with over 80 people registering representing NSW, Victoria, Queensland, ACT and South Australia. The day saw a mixture of presentations from both medical professionals and members. The sharing of stories and situations was a big part, especially over morning tea and lunch.

The feedback was very positive from everyone canvassed and we hope that this year's meeting will be as successful.



morning tea time!



The registration stand manned by Michelle Kay-Sharman, (NZ board member), Judith Dickson (AU & NZ Board member) and Vicki Tattley (NZ & AU Board member)



question & answer time