

Australian Family Weekend

Sea World Resort Gold Coast Queensland

The inaugural IDFA Family weekend took place on the 11-13th September 2009.

21 families (almost 100 people) with school aged PID children came together to the Sea World Resort on the Gold Coast Queensland to meet for the first time as a family PID group.

The weekend was a mix of social and workshop activities which proved to be a great success with participants. New friendships have been forged and planning is already taking place for the next family get together.

The workshops on Saturday for children and young adults consisted of a number of age specific groups for both PID patients and siblings.

The teenager PID group worked with a very experienced workshop leader, and through creative posters, explored the effect PID had on their life and how they dealt with these challenges on a daily basis. The teenage siblings group shared their understanding of the nature of PIDs, followed by some very involved discussions about how PID affected their family, along with discussions on their hopes and concerns for the future for their sibling. Both groups came together at the end of the day for a combined session. Many new friendships were formed and email addresses exchanged.

The parents were treated to both medical and social welfare presentations throughout the day. Doctor Jane Peake, Chair of the IDFA Medical Advisory Committee, proved very popular as always with her presentations on the latest updates in PID.

The day at Sea World on Sunday started early, with a private guided tour of the shark enclosure for the IDFA group before the park opened. When Sea World opened later that morning, everyone headed back in to make the most of the beautiful day, enjoying the rides, shows and sea creatures with new found friends.

Some comments from a few of the parents:

"It was also great to meet other parents dealing with similar situations and heartening when they extended their hand in friendship and support."

"Perhaps the icing on the cake for us though was that our son who is 13 and has CGD collected email addresses and Facebook contacts for several other boys. Just to realise he is not the only one and in fact that some others are much worse off was important for him."

"The whole weekend was so well run, the workshops were fantastic, the speakers – especially Dr Peake – were really good. If only there had been more time! All the parents are so hungry for information and it was fantastic to speak to other parents and kids about our shared and different experiences."



Some Ideas from the Siblings Group on how they can help their brother or sister....

- Visit them in hospital when they are sick
- Do things with them that they can do, take them places they can go
- Remind them to take their medication
- Not annoy them when they are sick
- Remind them of good times when they're not feeling well
- Let them know they are so much more than their illness

Some ideas from the Siblings Group on how their family can support them....

- We worry too – let us know it'll be ok
- Let us know what's happening
- Tell me more about the physiological side of the illness so I can explain it better to other people.

Some things the Siblings Group want their brother or sister to know...

- You are really brave!
- We hope you get better
- Don't worry, someone will always be there for you

And their parents....

- You do a great job
- Don't stress, it'll be cool
- We're watching out for him too
- Keep helping her as much as possible, thanks!

IDFA
Immune Deficiencies Foundation
Australia

InTouch

JANUARY 2010

Establishing international awareness and support for PID patients across the Asia Pacific Region

IDFA Board Update

Hello. I am the new Chair of the IDFA Board, and thought that this newsletter article was a good opportunity to introduce myself, and the other members of the IDFA Board.

My name is Adam Friederich, and I have been on the IDFA Board for just over 12 months now, having joined the Board in late 2008.

I initially got involved because I have a primary immune deficiency (PID) myself (I have common variable immune deficiency, first diagnosed many years ago when I was 18). I think it's important to offer support and assistance to people, particularly when a PID diagnosis is first made. If only IDFA had been around when I was told I was immune deficient!

I also got involved because thought that I had some skills I could offer to the IDFA Board – I have been actively involved in community and not-for-profit organisations in Canberra (where I live) and nationally for the past 20 years, and this has included taking on senior Board roles such as Finance and Audit Chair, Deputy Board Chair and Board Chair positions. Through this experience, and my paid work with the Commonwealth public service, I think I have developed a good understanding of governance processes, Board decision-making and financial management.

I only recently became Chair of IDFA – at the November 2009 annual general meeting. This AGM saw several long-standing members of the Board retire, including our previous Chair, Michael Daniel, as well as Stephen Baxter, David Hey, Janet Simons and Ruth Taylor. I'd like to extend my thanks to Michael and the other retiring board members for their work on the Board. While their names may not be that familiar to many of you, they have been instrumental in setting up IDFA over the past few years.

After the AGM, we have six members on the IDFA Board. As well as me, there are:

- **Tracy Brew** (Board Deputy Chair) – Tracy lives in Queensland, has a child with a PID, and has worked with a range of community organisations



- **Lara Alexander** (Chair of Finance & Audit Committee) – Lara lives in Western Australia, and has a strong professional background in financial management
- **Dr Jane Peake** (Chair of Medical Advisory Committee) – Jane lives in Queensland and is a paediatric clinical immunologist at the Brisbane Children's Hospital
- **Dr Karl Beasel** – Karl lives in Victoria and is a clinical immunologist at the Royal Melbourne Hospital
- **Trevor Lowe** – Trevor lives in Victoria, has a child with a PID, and has a strong business background.

The Board will next be meeting in January 2010, when we will be considering IDFA's strategic priorities. I hope to give you an update on this in our next newsletter.

Adam Friederich
Board Chair

BECOME MORE INVOLVED IN THE FOUNDATION'S WORK

IDFA is calling for expressions of interest from people who wish to become more involved in the Foundation's work.

Opportunities to help out the Foundation include being involved with state and national events, committees and board positions.

Please send your expression of interest for the role you may be interested in, along with an outline of your skills, to Cathryn Baker General Manager IDFA PO Box 149 Stroud NSW 2425 or email gm@idfaustralia.org

STOP PRESS!

Please note IDFA has new 1800 numbers and post box details!

Telephone: 1800 100 198

Fax: 1800 100 714

Postal: PO Box 149 Stroud NSW 2425

IDFA
Immune Deficiencies Foundation
Australia

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

Web www.idfaustralia.org Freephone 1800 100 198 Fax 1800 100 714 Email info@idfaustralia.org Post PO Box 149 Stroud NSW 2425

Our people, our stories

JOY WILLIAMS, IDFA Support Services officer



Medical Matters



I started with IDFA in March this year, in the newly developed Support Services Officer role. I moved to Melbourne early this year with my partner Matt, from my hometown of Gisborne New Zealand, a lovely little city on the east coast of the North Island.



It has been fantastic to meet so many children, adults and families at patient meetings over the last few months, and I hope to meet many more of you in the upcoming months

I left a job in public health management, having spent the last 3 years working with children and families who had developed chronic health problems due to inactivity and poor diet.



Joy conducting the Sea World workshop

The Support Services role appealed to me straight away. I love working with people, especially when it involves working towards a common goal to improve quality of life. I have a background in Psychology and Education which has given me the knowledge to build on this passion. Although I started the job with limited knowledge of PID, I am currently studying towards a Master of Nursing Science at the University of Melbourne, and as I go, I am vastly building my knowledge of immunodeficiency – sometimes by the day it seems! It has been fantastic to meet so many children, adults and families at patient meetings over the last few months, and I hope to meet many more of you in the upcoming months. Please feel free to email or call at any time, whether it be for further information, support or just to have a chat if things are feeling a little overwhelming.

ANZADA update

The ANZADA (Australia and New Zealand Antibody Deficiency Allele) Study, a collaboration of Australian Immunologists, coordinated by Dr Matthew Cook, has recruited almost 200 patients with primary antibody deficiency. As many of you will know already, it is the aim of this study to uncover new mechanisms to explain antibody deficiency diseases (including CVID). The investigators are performing state of the art genetic analysis at Australian National University and cellular studies at ANU and Westmead Hospital in Sydney in order to elucidate the genetic and cellular mechanisms of antibody failure. They hope that these studies will improve diagnosis for immune deficiency, reveal new strategies for treatment, and improve our overall understanding of the immune system.

Chief investigators Matthew Cook (Director of Immunology at Canberra Hospital) and David Fulcher (Director of Immunopathology, Westmead Hospital in Sydney) were successful in obtaining a major grant (\$525,500 over 3 years) to support the ANZADA study from the National Health and Medical Research Council of Australia (NHMRC). The award of this prestigious grant is very important news for PID research in Australia.

How to get involved

The ANZADA investigators are seeking to recruit as many patients as possible from all parts of Australia. Enrolment involves completing a consent form. After this, your clinical details will be recorded, a blood sample will be taken, and a spit sample will also be taken (DNA is extracted from the spit). All details are held securely and are only accessible to the chief investigator of the study. The aim of the study is to determine the causes of antibody deficiency, but if discoveries are made on particular samples, this information will be made available to you and your doctor.

So far, the team have identified genetic variants thought to be responsible for antibody deficiency in about 6% of patients enrolled, with many additional variants under intensive investigation.

Patients can get involved in several ways:

1. Ask your Immunologist to complete the paper work at your next consultation.
2. Contact us directly (in the first instance, via our study nurse, Anastasia.wilson@anu.edu.au; or chief investigator matthew.cook@anu.edu.au)
3. Contact Cathryn Baker for further information gm@idfaustralia.org



Dr Matthew Cook presenting at the IDFA National Patient Conference

31 Recent Events

WA

Dr. Richard Loh gave an engaging talk on immunodeficiency and the use and regulation of IVIg in Australia.

NSW

Dr. John Zeigler spoke on PID research recently presented at an international conference and plans for a new immunology diagnostic centre in Sydney.

QLD

Dr David Gillis spoke about the physiological causes of different PIDs and their effect over the lifetime.

VIC

Dr Jo Douglass spoke on her research into the transition from paediatric to adult health care for PID patients and Linley Beilby from the Australian Red Cross Blood Service spoke about the production and regulation of IVIg.

SA

ASCIA – IDFA hosted a booth at the ASCIA conference in September 2009. Our thanks to ASCIA for their continued support of IDFA over the past 4 years.



Joining IDFA is easy and free – why not join now and enjoy member benefits right away!

Go the website to download a membership form or email support@idfaustralia.org

Not sure if you are registered? Email IDFA and we can confirm your member status right away!

Health professionals – helping PID patients to access support

IDFA has a range of counselling & support services, information pamphlets and patient membership registration forms that we can provide to health professionals for your PID patients. Just drop a note to our Support Services Officer Joy Williams on support@idfaustralia.org or call her on 0403251855

