

Chairman's Report 2006

IDFA

The Immune Deficiency Foundation of Australia (IDFA) has come a very long way in what I believe will prove to be a historic first year. I look back with a great sense of achievement, admiration for those who have dedicated themselves to IDFA's progress, and a clearer sense of what needs to be achieved in the years to come. One message stand out: individuals affected by Primary Immunodeficiency Diseases (PID) in Australia will greatly benefit through the support IDFA has to offer.

IDFA in its first year has already been able to provide services to people affected by PID and has embarked on its campaign to raise awareness of PID across the country. People who join IDFA are provided benefits which include provision of diagnosis-specific information packs, regular newsletters, access to a medical advisory panel, access to a family matching service, invitations to local patient meetings, free IDFA conference attendance and free tickets to shows including 'Circus Quirkus'.

On September 6, 2006 IDFA held its Inaugural Patient Conference at the Manly Pacific Hotel in Sydney. This was exceptionally well attended. We heard moving personal stories, with people reporting feelings of isolation, stigma, and the difficulties of struggling to cope with the daily burden of chronic disease but also stories of courage and triumph despite adversity. Real concern was expressed about safety and choice in antibody replacement therapy. Those people most affected by changes in this important therapy appear to be the least likely to be consulted, and education strategies accompanying change has been inadequate. There was widespread disappointment about the current ability of the medical and allied health professions to deliver adequate diagnostic and therapeutic outcomes to people affected by PID. However the overall feeling was one of excitement and encouragement as people were, for the first time, introduced to others with similar experiences to their own and the conference was seen as a celebration of how far IDFA has come and how IDFA will positively impact on the lives of people affected by PID into the future.

The Patient Conference itself started the journey of developing a collective voice. Submissions have been developed and delivered to the Federal government at both the Plasma Fractionation Review and the review of National Criteria for Use for Intravenous Immunoglobulin (IVIg). As a measure of the emergent influence of IDFA, we were delighted to host Stephanie Gunn from the National Blood Authority, who had the opportunity to hear for the first time the voices of those most affected by government policy in this area.

IDFA has not materialised by magic, but by skill, teamwork, and plain hard work. IDFA owes its existence to the success of IDF in New Zealand (IDFNZ). IDFNZ has grown over many years into a world leader among patient organisations in PID. This has been achieved by a solid corporate structure and professional diligence, subsequently rewarded by success in fundraising. Using this model, IDFA was registered as a company limited by guarantee on 15 December 2005, and became a registered charity and deductible gift recipient. The constitutional objectives of the organisation are uniquely dedicated to supporting the needs of individuals of all ages affected by PID, their families and health care providers. The Board comprises an initial mix of IDFNZ Board Members and Australian Directors designed to establish a

foothold in Australian professional life. IDFA has been approved for membership of the International Patient Organisation for Primary Immunodeficiency (IPOPI).

Of all the achievements of the first year the success of fundraising is the most important. This has been a consequence of, among other things, an excellent contractual arrangement with International Entertainment. International Entertainment have been able to draw corporate and personal sponsorship contributions from the community in Australia on behalf of IDFA and the Immune deficient KIDS Foundation. On behalf of IDFA I would like to convey our sincere thanks to all contributors and in particular to International Entertainment. I will like to thank all businesses and individuals across Australia who have supported IDFA through fundraising campaigns and without who, IDFA would not be in existence.

IDFA owes a great debt of thanks to certain key personnel. I would like to single out three people in particular. Rev Stephen Baxter and Janet Simons from IDFNZ have been essential in developing the vision for what can be achieved in Australia and driving that vision through manifest difficulties to position IDFA securely in Australia. Philippa Kirkpatrick has achieved remarkable successes by her enthusiastic dedication to essentially carry the Australian arm of the executive in its first year. In addition, IDFA has drawn heavily on the skills and dedication of David Hilliar, Sarah Perry as our Health Coordinator, all company Directors as well as Michael Daniel and other members of previous and existing patients support groups in Australia.

IDFA must now move on to a critical transition phase in securing its future. Delivering on the extraordinary potential of the current situation will require the achievement of four key milestones.

1. IDFA must secure and expand the fundraising base in Australia, the success of which will underpin all future achievements of the organisation
2. IDFA must harness the skills and leadership of local individuals affected by PID, and in so doing, move to being a fully Australian patient-led organisation. This will require a skilled and resourced local executive office.
3. IDFA needs to deliver material benefits to all people affected by PID
4. IDFA needs presence in all States and territories of Australia and to develop, like IDFNZ, a strategy of care for our international neighbours.

IDFA must look forward with energy and purpose. One day, however, it will be appropriate to look back on this first year and consider the foundations of its subsequent achievements. For those who have contributed, your efforts will benefit people affected by PID in enduring and important ways. I celebrate your dedication and achievements.



Sean Riminton
Chairman