

IDFA National Conference Report

Who we are: IDFA is the peak patient body supporting patients, carers and families from Australia affected by Primary and Secondary Immunodeficiencies.

Event: Immune Deficiencies Foundation Australia (IDFA National Conference – “there’s more to me than my immune deficiency”

The Immune Deficiencies Foundation Australia (IDFA) National Conference 2019 was held at the Novotel Hotel, 200 Creek Street Brisbane on the 13-14 April 2019.

The aims of the conference were to educate, engage and support people affected by Immune deficiencies. The IDFA concept was to explore the concept “there’s more to me than my immune deficiency” and address the Medical, Practical, Educational, Social and Emotional needs of patients and their partners/carers/families affected by both Primary and Secondary Immune Deficiency. 108 Patients and Carers attended.

The purpose of the congress was to explore the concept “*there’s more to me than my immune deficiency*” and to address the medical, practical, educational, social and emotional needs of patients and their partners/carers/families affected by both primary and secondary immune deficiency.

The conference hosted over 100 patients and carers who participated in thirteen medical sessions with eight immunologists, three genetic researchers, a clinical nurse consultant, a national blood authority representative, IDFA carers advisor, IDFA board members and staff. Beyond this the conference provided medical and practical information about PIDs regarding manifestation, diagnosis, pathology, genetics, treatments and research. They also addressed transition, bone marrow transplants, lung disease, sexual health and Australian research.

Reaching beyond the medical sessions the conference also offered four inclusive workshops about patients, carers, families and sexual health and discussed other issues relevant to participants such as family, genetic diagnosis, depression and anxiety. IDFA also addressed social, emotional, psychological needs while providing practical advice, coping skills and discussion forums. The national conference ended with a great masquerade dinner, offering the participants a chance to be “*more than their immune deficiency*”.

Conference Outcomes:

- **Did it make a difference?** Yes, patients and carers greatly benefited from the conference
- **How well did we do it?** Very well – the participants want another meeting in the next year with more emphasis on individual patient and carer concerns!
- **How much did we do?**
 - Facilitated 13 Medical Sessions Speakers included 8 Immunologists, 3 Genetic researchers, Clinical Nurse Consultant, National Blood Authority Representative, IDFA Carers advisor, IDFA Board Members and Staff.
 - Facilitated 4 inclusive workshops about patients, carers, families and sexual health
 - Provided medical and practical information about primary immune deficiencies, their manifestation, diagnosis, pathology, genetics, treatments and research
 - Addressed Transition, Bone marrow transplants, Lung Disease, Sexual health, Australian Research Addressed issues relevant to participants – family, genetic diagnosis, sexual health, depression, anxiety
 - Addressed social, emotional, psychological needs and provided practical advice, coping skills and provided discussion forums
 - Addressed carer needs and issues in separate carer session
 - Provided social interaction for patients and carers through the Conference Masquerade Dinner, breaks and Workshops



IDFA National Conference 2019

"there's more to me than my immune deficiency"



108 IDFA members attended from every State except the Northern Territory. 2 Representatives from CSL also attended.

The greatest number of attendees were patients.





Feedback:

The feedback was mainly very good,

Staff and Board

ANSWER CHOICES	RESPONSES
Extremely helpful	75.00%
Very helpful	25.00%
Somewhat helpful	0.00%
Not so helpful	0.00%
Not at all helpful	0.00%

Speaker feedback

ANSWER CHOICES	RESPONSES
Excellent	40.00%
Very good	55.00%
Good	5.00%
Fair	0.00%
Poor	0.00%

Education, engagement and support

ANSWER CHOICES	RESPONSES
I feel more educated about immunodeficiency	78.95%
I made new friends	73.68%
I learned skills and coping strategies	26.32%
I feel more supported by IDFA	42.11%
I would attend another IDFA Event	89.47%
I am more aware of what IDFA does	57.89%



Comments:

"We felt like part of the family and were so happy to be a part of the conference".

"Thank you so much for all the time and effort it took to hold such an event. The people with IDs are better off because of the work you do".

"It is very valued, making CVID sufferers feeling less isolated, also supporting carers. A great event, thanks for organizing it. Brisbane is a great location"

Areas to improve:

But there are areas still to improve on for the next Conference! Patients want more interaction with each other, and workshops that are strategy focussed. It appears that State based Meetings are more appropriate for our membership's current needs.

Feedback on areas to improve:

"Perhaps more discussion and practical suggestions for carers in terms of actual strategies they could take away and apply to their own lives".

"Perhaps some time could be allocated to connecting people from the same state (apart from the opportunity to talk at meal breaks). For example, perhaps tables could initially be state based to encourage people to meet/chat with others from their state".

"A little too much scientific data, need more informal sessions".

"The guest speakers were great!! I think next time we need a respiratory specialist and a gastroenterologist. Gut health and respiratory are the 2 major issues with PID and there were lots of discussion around these topics. More group activities, interaction and/or workshops would have been wonderful".

Overall, it was a great conference!

Overall Event rating

ANSWER CHOICES	RESPONSES
Excellent	50.00%
Very good	50.00%
Good	0.00%
Fair	0.00%
Poor	0.00%

IDFA sincerely thanks DSS, CSL Behring and Shire for their sponsorship of this event.

Report by,



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BUDGET

IDFA recorded a loss of **-\$24,491.97** for the conference.

Verification of funding			DSS	Shire Funding	CSL	Other sponsors
Expenditure item	Numbers		Funding ex GST	Funding ex GST	Funding ex GST	
			\$10,000.00	\$20,000.00	\$30,000.00	\$9,432.66
People with a disability (patients)	51	Actual Cost (ex GST)	Costs ex GST	Costs ex GST	Costs ex GST	Costs ex GST
Accommodation		\$10,849.54	\$2,731.86	\$4,000.00	\$3,000.00	\$617.68
Travel		\$7,258.89	\$2,906.37	\$2,000.00	\$2,000.00	\$908.18
Registration		\$6,327.78		\$2,500.00	\$3,500.00	\$827.78
Dinner		\$5,379.04		\$2,000.00	\$3,000.00	\$879.04
Material/promotion/other		\$2,716.03		\$1,000.00	\$1,000.00	\$67.94
Project Management, Governance & Quality Assurance		\$14,134.10		\$1,000.00	\$4,500.00	
Carer/support person	57					
Accommodation		\$9,754.60	\$2,346.42	\$0.00	\$0.00	\$6,920.02
Travel		\$5,588.05	\$2,015.35	\$1,000.00	\$2,000.00	\$0.00
Registration		\$7,072.22		\$2,000.00	\$3,000.00	\$ 1,330.83
Dinner		\$6,011.87		\$2,000.00	\$2,000.00	\$ 1,181.81
Material/promotion/other		\$3,035.57		\$1,000.00	\$2,000.00	
Project Management, Governance & Quality Assurance		\$15,796.94		\$1,500.00	\$4,000.00	
			\$10,000.00	\$20,000.00	\$30,000.00	\$9,432.66
TOTALS PATIENTS & CARERS	108					
Accommodation		\$20,604.14	\$5,078.28	\$4,000.00	\$3,000.00	\$6,920.02
Travel		\$12,846.94	\$4,921.72	\$3,000.00	\$4,000.00	\$0.00
Registration		\$13,400.00	\$0.00	\$4,500.00	\$6,500.00	\$1,330.83
Dinner		\$11,390.91	\$0.00	\$4,000.00	\$5,000.00	\$1,181.81
Material/promotion/other		\$5,751.60	\$0.00	\$2,000.00	\$3,000.00	\$0.00
Project Management, Governance & Quality Assurance		\$29,931.04	\$0.00	\$2,500.00	\$8,500.00	\$0.00
		\$93,924.63	\$10,000.00	\$20,000.00	\$30,000.00	\$9,432.66
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Totals	Income	\$69,432.66	\$10,000.00	\$20,000.00	\$30,000.00	\$9,432.66
Totals	Expenses	\$93,924.63	\$10,000.00	\$20,000.00	\$30,000.00	\$9,432.66
	Surplus/Loss	-\$24,491.97	\$0.00	\$0.00	\$0.00	\$0.00

