

Immune Deficiency Foundation of Australia

Raising awareness & supporting people affected by immune deficiencies in Australia



Annual Report 2016-2017

Christine Jeffery, Executive Officer

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Immune Deficiencies Foundation Australia

IDFA supports people affected by Primary (genetic) and Secondary (caused by disease, treatment or autoimmune disease) Immune Deficiencies in Australia. IDFA is committed to raising awareness about primary immune deficiencies and improving quality of life for patients and their families.

Chair Summary

Dear all,

Over this last financial year, IDFA has continued to work closely with its members, the medical community and sponsors, maintaining the focus on promoting a 'Patient-Centred Model of Care' and a 'Community-Centred Model of Care'.

This year, IDFA made an important decision, announcing that it is extending its support and advocacy activities to include patients with Secondary Immune Deficiency, resulting from chemotherapy treatments, haematological malignancies, renal or gastrointestinal immunoglobulin loss, organ transplant, infectious diseases and corticosteroid as well as immunosuppressive medication. With help from our supporters and members, we are looking forward to extending our support to a larger community.

Once again, we have organised this year the National Conference, held from the 8th to the 10th July, including 23 sessions and 126 patients, carers, family members, sponsors and supporters. The feedback was excellent and a big 'thank you' to our speakers, sponsors, staff and volunteers who contributed to the event's success.

Our focus on increasing awareness was reflected in the intense campaign over the World PI Week, 22-29 April. This year, we have launched our new mascot: MaggiePi to bring out the message that "PI is not always black and white". In addition, we have launched the '10 warning signs' and four videos featuring young adult IDFA members, Teal and Zoe.

2016/17 has been a year of consolidating and re-evaluating our objectives and strategy to better position our organisation in delivering members services such as: advocacy, education, practical and emotional support.

Our membership has continued to grow, and our statistics show that new members learned about the organisation, mainly through the internet, other IDFA members and immunologists.

We are currently working to improve our website where members can find useful updates and information about travelling with PI, transitioning to Intragam10 as well as events, fundraising and supporting IDFA through donations.

On behalf of the Board, I would like to express our gratitude to all the members, volunteers and staff for their continued support and dedication to IDFA. Their enthusiasm and energy in organising trivia nights, school fundraising events, Blackmore Bridge run, and sale of merchandise have raised much needed funds.

Also, on behalf of the Board, I would like to thank our corporate sponsors, Shire, CSL Behring and Grifols who have continued to provide valued support for events, education and resources.

Best regards,

Lara Alexander

Board Chair
IDFA Board of Directors

Finance and Audit Chair Summary

The main feature of 2016/17 was the National Conference, held in Sydney in July 2016. This event had a significant effect on the financial results, delivering additional grant and donation revenues and associated expenses.

The conference income had been received during the 2015/16 year, and placed on the Balance sheet to be recognised in the Income Statement in the appropriate financial year in which the event took place.

Profit and Loss

- Gross Profit, ie net income from International Entertainment (Professional Fundraiser): last year \$180,730, this year \$172,565 (4.5% reduction)
- Other Income: \$199,882 this year, and increase of \$146,542 from last year, due to funding received for the National Conference
- Total costs were \$370,120, an increase of \$118,951 from last year due to conference costs. Operating costs were flat year on year.

The net result was a profit of \$4,546.

Balance Sheet

- Comparison of 2016/17 balance sheet to 2015/16 shows reductions in Cash, Prepayments and Deferred Income resulting from provisions made for the conference.
- Inventory relates to the IDFA awareness Pin. As the Pins are sold the value will be depleted.
- Net assets have grown by the net income for the year of \$4,546 from \$192,119 in 2015/16 to \$196,665 this year

Additional details on the financial performance of the organisation are available in the audited Financial Statements.

CATH BAMPTON

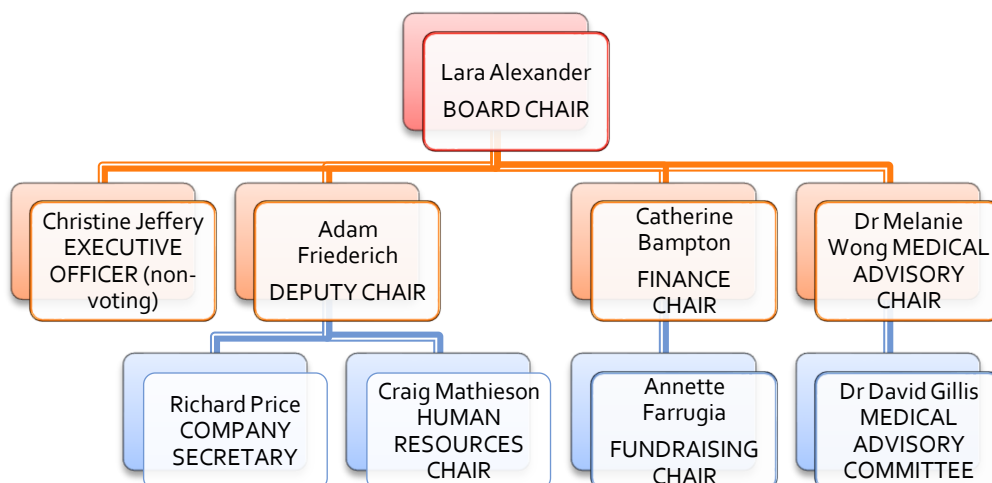
Chair, Audit and Finance Committee

IDFA Board of Directors

Governance

Board of Directors 2016-2017

IDFA is governed by a Board of nine Directors, with one non-voting member, Christine Jeffery the Executive Officer.



Information on Directors

LARA ALEXANDER

Special responsibilities: Chair

Qualifications: CPA, BA Econ Studies (Hons)

Experience and expertise: Lara has worked in the NFP sector for over 15 years, working in various senior management and executive roles with organisations such as St John Ambulance, Cancer Council, Save the Children, Bethesda hospital and more recently in the Aged Care sector with Presbyterian Care Tasmania. Lara's expertise is predominantly in finance and budgeting, management, human resources, payroll and fundraising.

ADAM FRIEDERICH

Special responsibilities: Deputy Chair

Qualifications: Grad Cert (Mgmt), Grad Dip (Sc, Com), CIII Public Sector Admin, CIII Public Sector Qual Mgmt, BSc (Hons)

Experience and expertise: Adam has 20 years' experience with not-for-profit boards, and has been a board member or office bearer with numerous NFP organisations. He is regularly involved as a patient representative on Commonwealth Government health-related committees and working groups, and is experienced at effectively representing and advocating for health consumer views. Adam also has more than 15 years' experience working with the Australian Public Service, where his responsibilities focus on governance issues, such as strategic and business planning, performance reporting, and financial and HR management. Adam has a Primary Immune Deficiency.

CATHERINE BAMPTON

Special responsibilities: Finance Chair

Qualifications: CPA, Bachelor of Commerce (Hons)

Experience and expertise: Catherine is an accountant with over 20 years' experience in both public and private sectors, across all aspects of financial management. Her experience extends beyond accounting to strategy development and operational management. Catherine has a primary immune deficiency.

RICHARD PRICE

Special responsibilities: Company Secretary

Qualifications: BEng (Mining, Hons), MSc (Mineral Economics), M AusMIMM

Experience and expertise: Richard is a mining engineer with 10 years' experience in the mining industry and 5 years' experience in financial services. Richard has a Primary Immunodeficiency (PID) and lives in Perth.

DR MELANIE WONG

Special responsibilities: Medical Advisory Committee Chair

Qualifications: MBBs (Hons), PhD, FRACP, FRCPA

Experience and expertise: Senior staff specialist, Department of Allergy and Immunology, The Children's Hospital at Westmead, Director of the Immunology Laboratory and Head of the Immunodeficiency Service, President Elect, Australasian Society of Clinical Immunology and Allergy (ASCIA), Chair, Allergy and Immunology Foundation of Australasia (AIFA)

DR DAVID GILLIS

Special responsibilities: Director

Qualifications: MBS BS (1st class Hons), FRACP, FRCPA

Experience and expertise: David is an Immunologist with 27 years' experience in the clinical management of primary immunodeficiency in adults. He is also a pathologist with extensive experience in the testing for primary immunodeficiency. David was a previous chairperson of the primary immunodeficiency committee of ASCIA and was chairman of the South Australian IVIG Users Group for many years.

ANNETTE FARRUGIA

Special responsibilities: Director

Qualifications: PLA's in First Aid, Anaphylaxis, Managing multiple Projects, Performing CPR, Managing Workplace Bullying

Experience and expertise: Annette is a Student Teachers Assistant and has been working in the Education Department for more than 18 years. She has extensive administration experience in the Government sector. Over the years, Annette has acquired knowledge in First Aid, Anaphylaxis, CPR and managed projects such as workplace bullying and OH&S. Through her extensive experience in Fundraising she has achieved many goals. Annette has a family history of X-linked Agammaglobulinaemia (XLA) and has a son with this condition.

CRAIG MATHIESON

Special responsibilities: Director

Qualifications: Grad Dip Bus Admin, Dip Building

Experience and expertise: Craig has over 30 years' experience in running small to medium business. The nature of small business means that he has hands on experience in sales, administration, HR, strategic and financial planning and WPH&S. Craig is a graduate of the AICD Diploma Course for Directors and has served as a Director on various small businesses as well as not for profits.

CHRISTINE JEFFERY

Special responsibilities: Director (non voting), Executive Officer

Qualifications: Adv Dip Bus Mgmt, Cert IV in Training & Assessment, SA Sustainability

Experience and expertise: Christine has 20 years' experience in Management and 10 years' experience in Education & Training. Christine joined the IDFA Board in 2011 and became Executive Officer in 2012. Christine is also Treasurer of IPOPI (International Patient Organisation for Primary Immunodeficiencies). She has an adult daughter with complex immune and autoimmune diseases.

Staff

In 2015-2016, IDFA employed:

- 1 full time staff member, Christine Jeffery - Executive Officer (EO)
- 1 part time staff member, Chloe Appleton - Member Support
- 1 part time staff member, Emma Joseph - Communications and Health Promotion

Industry association

IDFA is proud to be associated with:

- | | |
|--|---|
| <ul style="list-style-type: none"> • ASCIA (Australasian Society of Clinical Immunology and Allergy) • IPOPI (International Patient Organisation for Primary Immunodeficiencies) • Arthritis Australia • NBA (National Blood Authority) • CPI (Centre for Personalised Immunology) • WEHI (Walter and Eliza Hall Institute) • Garvan Institute • CHF (Consumer Health Forum) • Genetic Alliance Australia • Livewire | <ul style="list-style-type: none"> • IDFNZ (Immune Deficiency Foundation New Zealand) • ARRC (Autoimmune Research & Resource Centre) • Australian Immunological Alliance • Leukaemia Foundation • Australian Red Cross • Thalassaemia Society of NSW • Mastocytosis Australasia • HAE Australasia • GARDN (Genetic and Rare Disease Network) • RVA (Rare Voices Australia) • Beyond Blue |
|--|---|

Blood Donors and the Red Cross

IDFA is grateful to all blood donors. Immunoglobulin (made from plasma) is the main treatment for our members.



International Campaigns

IDFA participates in:

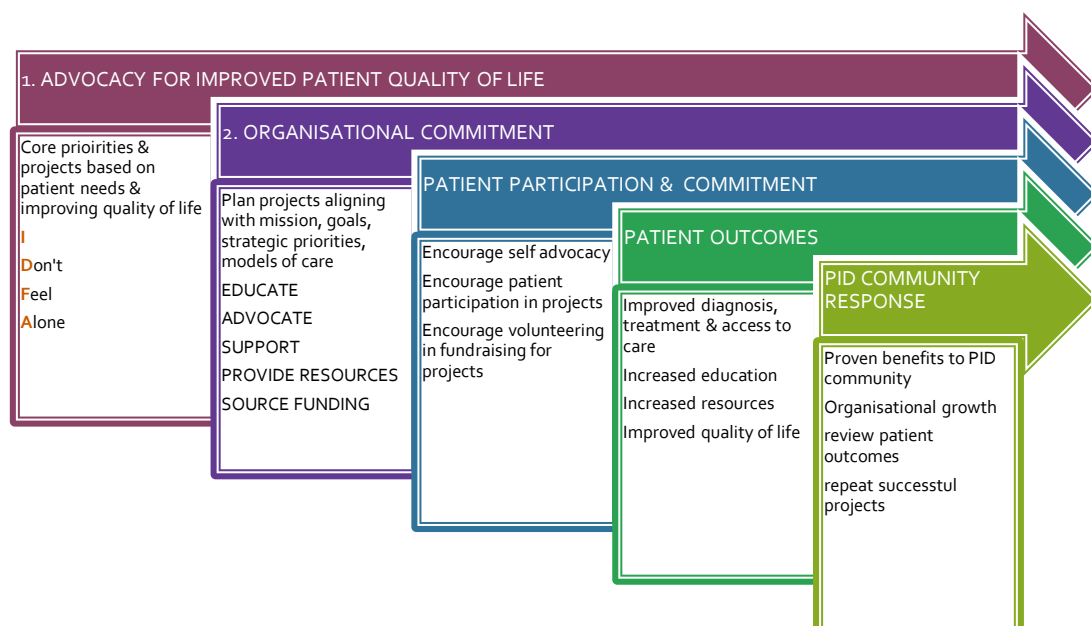
- Rare Disease Day (26 Feb)
- World PI Week (22-29 April)
- World Immunology Day (29 April)
- Yellow Day (27 March)
- International Plasma Awareness Week (October 8 -14)
- Giving Tuesday (IDFA "gives back" to patients supporting Xmas get-togethers)
- IPIC (International Primary Immunodeficiency Congress)
- IPOPI (International Patient Organisation for Primary Immunodeficiencies) Congress
- ASCIA Conference



Models of Care

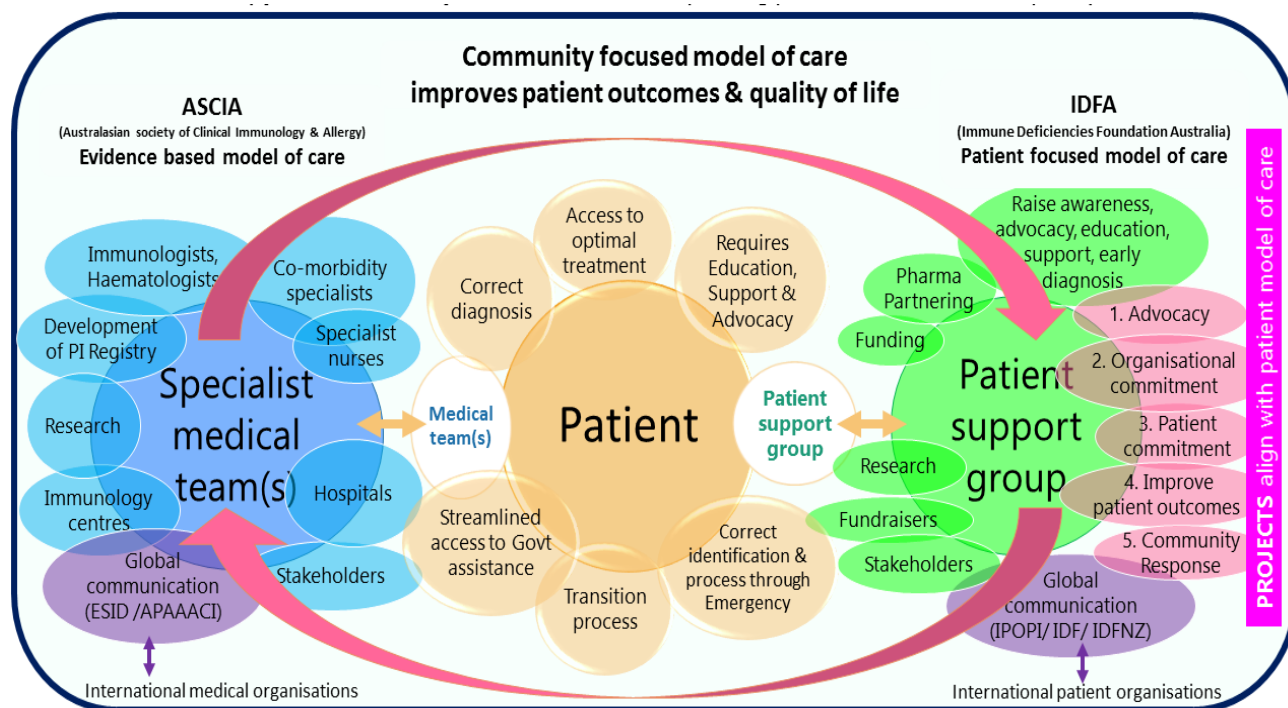
Patient focused Model of Care

IDFA's model of care is a framework that establishes how IDFA advocates to improve patient quality of life. It aligns with our Mission, Strategic Priorities and Goals. IDFA's Projects are developed based on the Patient focused Model of Care.



Community Focused Model of Care

IDFA'S Community focused model of care encompasses evidence based and patient focused national and international communities dedicated to improving primary immune deficiency patients' quality of life.



Member Services

- Advocacy
- Education
 - Patient meetings
 - Biennial National Conferences
 - Resource Packs
- Resources
 - Member Resource pack worth \$95 (free)
- Connecting members through events
 - Giving Tuesday
 - Patient get togethers
- Practical support
- Emotional support

Strategic Plans

Vision

A future where Primary Immune Deficiencies are diagnosed early, communities are more aware of the signs and symptoms of PID, and those affected by PID feel supported.

Mission

To promote an understanding of Primary Immune Deficiencies; link members, their families and medical professionals; and advocate for a better quality of life.

Goal

To achieve our Mission via:

Awareness We work to increase PID awareness in the general and medical community.

Membership We acknowledge that unity is strength and our aim is to reach and support those affected by PID.

Advocacy We publicly promote initiatives that will improve quality of life for those affected by PID.

Values

Our members We can all learn something from someone, and those affected by PID have a story worth listening to.

Courage PID can get you down but we get back up together.

Strength Sometimes, just getting through the day can be tough. We understand.

Education Through events and resources we continue to increase our knowledge of PIDs.

Engagement and Collaboration We seek to involve PID affected individuals, families, medical professionals and the wider community.

Determination Our members, volunteers and staff work tirelessly to give those affected by PID a better quality of life.

Strategic Priorities

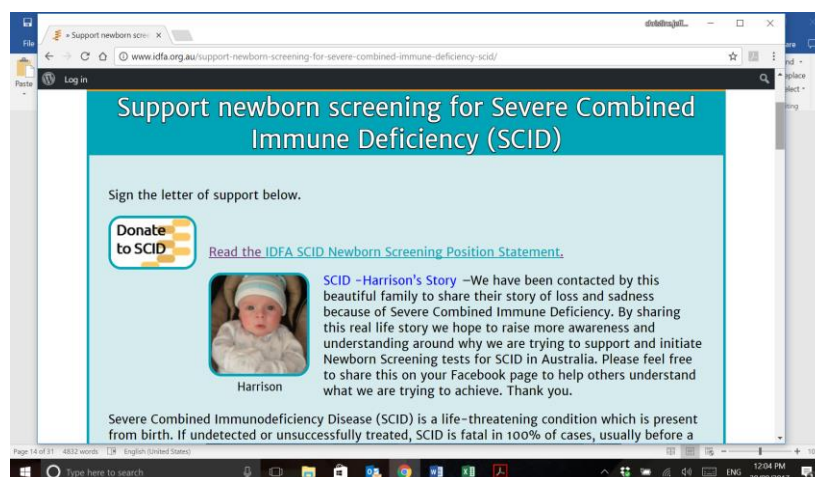
1. Promote early diagnosis by being more visible in the medical community.
2. Promote community awareness of the signs and symptoms of PID.
3. Be recognised as the Australian peak patient body for primary immune deficiencies.
4. Support patients and families affected by PID.
5. Advocate the best outcomes for PID patients to improve quality of life.
5. Streamline business processes to ensure maximum efficiency.
6. Become more sustainable by increasing by increasing financial capabilities.

Strategic Priorities -Achievements 2016-2017

Promote early diagnosis by being more visible in the medical community

SCID Newborn Screening campaign

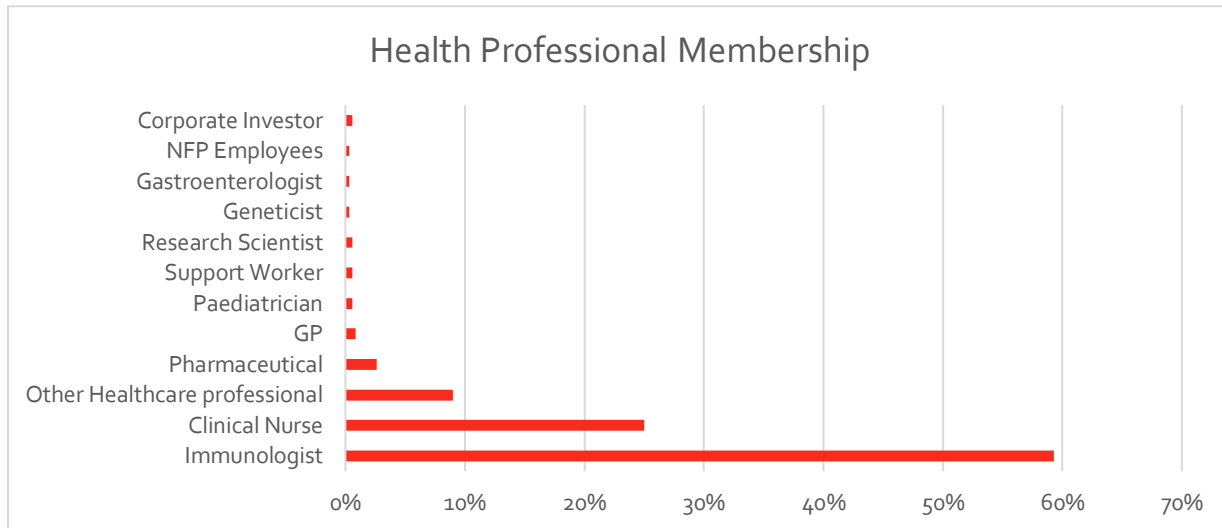
- IDFA launched the Newborn Screening for SCID campaign this year.
- Collected over 700 signatures online
- \$750 funds raised



IDFA is very grateful for the brave story told by Harrison's family.

Medical community awareness

- ❖ Continued attendance at medical conferences national and internationally: PPTA, ASCIA, IPOPI
- ❖ Continued visibility of medical related groups and boards IUG, NIGAC, HCA, AGSA, GARDn, Immunological Alliance, IPOPI



Promote community awareness of signs and symptoms of PID

Community awareness

FUNDRAISING AND VOLUNTEERS

IDFA have a very small group of volunteers. We would like to thank:

- | | | |
|--------------------------|---------------------------------|-----------------|
| ○ Blackmores Bridge run: | ○ Penrith Trivia Night | ○ Pen sales |
| ○ Ruth Currey | ○ Emma Joseph & Damir | ○ Jenny Tyrrell |
| ○ Cath Bampton | ○ Christine & Andrew Jeffery | ○ Morning Tea |
| ○ Chloe Appleton | ○ Chloe Appleton & Stuart Smith | ○ Debbie Nies |
| ○ Emma Joseph | ○ Jo & Phil Smith | |
| ○ Penrith Bunnings BBQ | ○ School Fundraising | |
| ○ Emma Joseph | ○ Emily and Gail Dixon | |
| ○ Jamie Watman | ○ Shan Spiers | |
| ○ Christine Jeffery | | |
| ○ Andrew Jeffery | | |
| ○ Mike Jeffery | | |
| ○ Elise Jeffery | | |



IDFA is very grateful for our small but enthusiastic fundraising team!

Support patients and families affected by PID

Resources



Three new and six PID specific IPOPI pamphlets were added to the Member resources this year:



TeleConnect

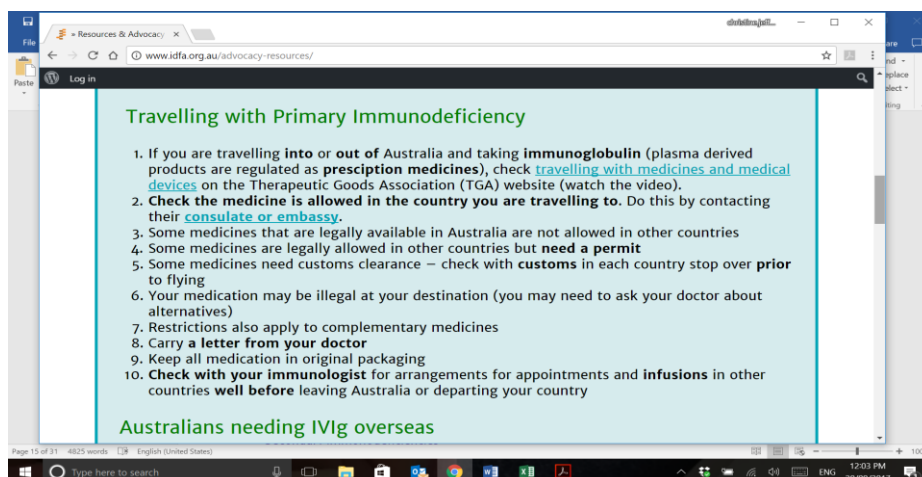
TeleConnect teleconferences continue linking patients from all areas to discuss topics of interest to PI patients.

Platinum sponsor: Shire

Website education

The IDFA website has added some new pages on topics of interest to PI patients:

- Travelling with PI
- World PI Week
- New transitioning to Intragam10
- Addition of credit card facilities for donations



Secondary immunodeficiencies

IDFA is delighted to extend its support and advocacy activities to include patients with Secondary Immune Deficiency. This will include in the first instance, community members and other patients requiring immunoglobulin replacement therapy. As we continue to grow and with the help of our members and supporters, we are looking forward to being able to offer our services to a larger community.

Secondary Immune Deficiency caused by a decrease in antibodies occurs most commonly as a consequence of chemotherapy, haematological malignancies, renal or gastrointestinal immunoglobulin loss, organ transplantation, infectious diseases and corticosteroid, anticonvulsant or immunosuppressive medications, e.g. Rituximab (RTX). Secondary Immune Deficiency can be a consequence of:

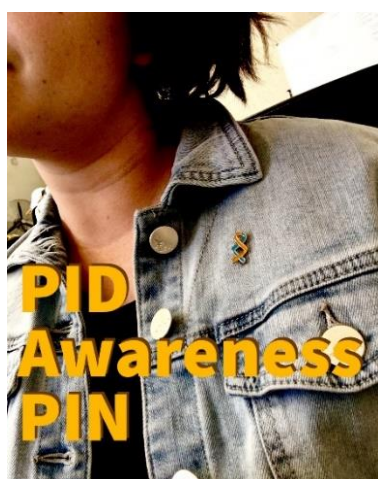
- Chronic Lymphocytic Leukaemia
- Multiple Myeloma
- Non-Hodgkin Lymphoma
- Good's Syndrome
- Any lymphomas or cancers of the lymph nodes or immune system
- Protein Losing Enteropathy
- Lymphoreticular Malignancy
- Antibody Deficiency due to treatment for Autoimmune Disease using chemotherapy-like reagents (e.g.SLE)

Advocate the best outcomes for PID patients to improve quality of life

Merchandise

AWARENESS PIN

The IDFA Primary Immune Deficiency Awareness Pin is the only symbol of Primary Immune Deficiencies worldwide. This year, IDFA sold 211 and gave away 82 in medical promotions.



Platinum sponsor: Grifols

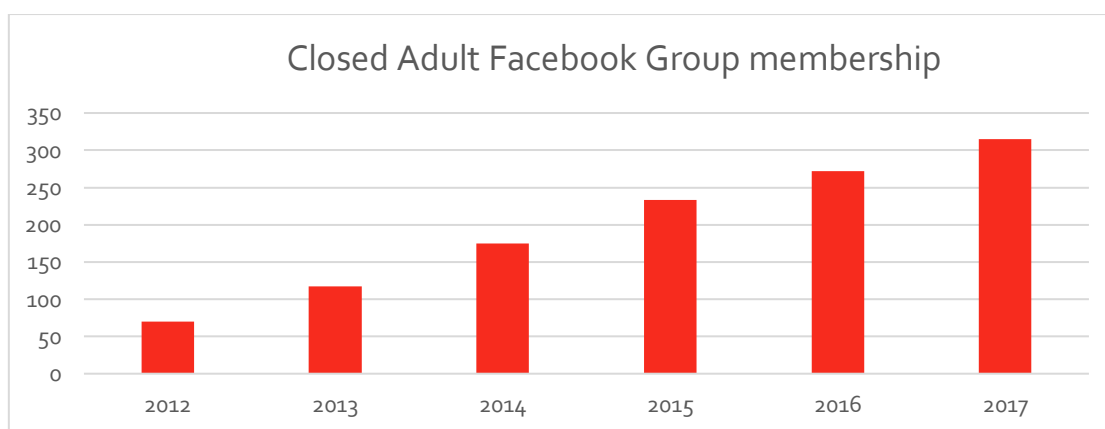
Community education

Social media:

IDFA has a Facebook page, LinkedIn Page, Twitter and Instagram accounts

IDFA has 2 closed face book groups:

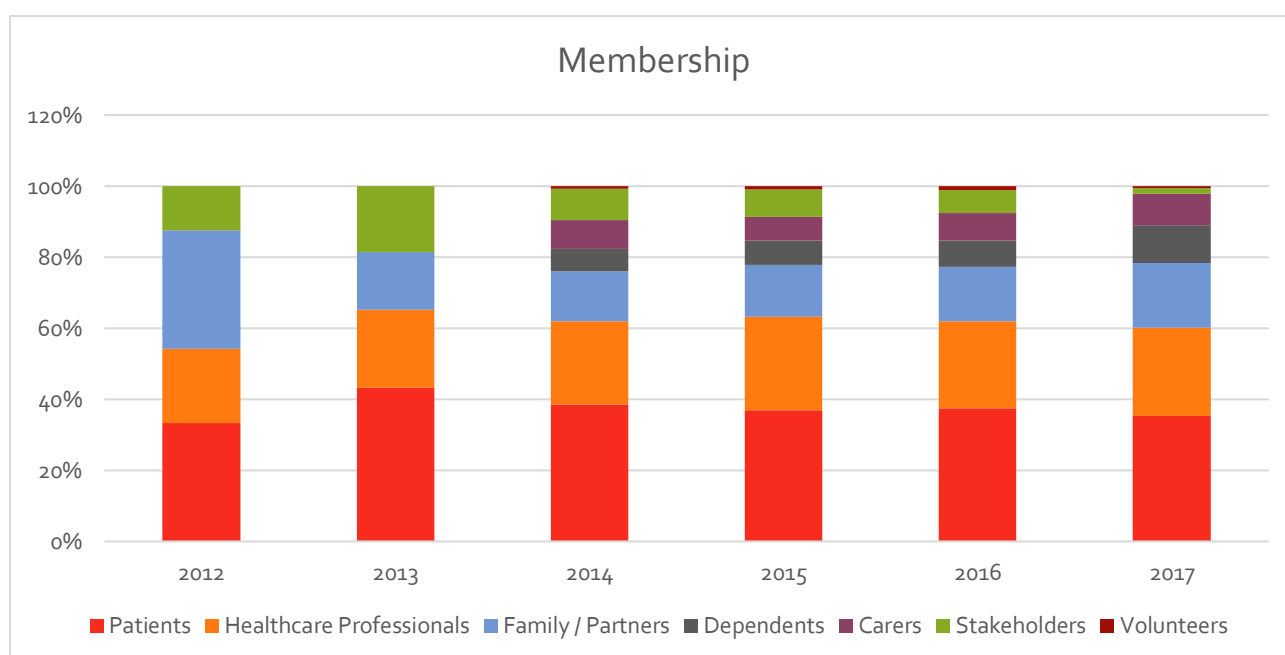
- ❖ Adults - closed page
- ❖ YAMS - Young adult members closed page



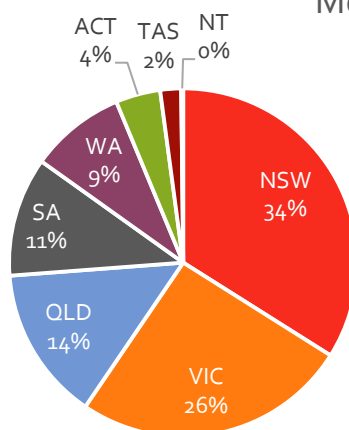
Database information

As our database continues to grow and diversify, we are still in need of a professional database.

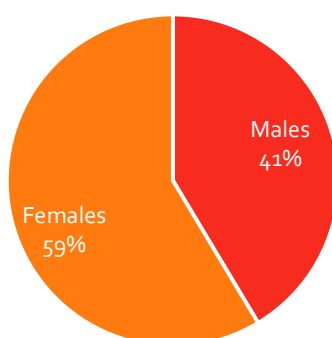
MEMBERSHIP



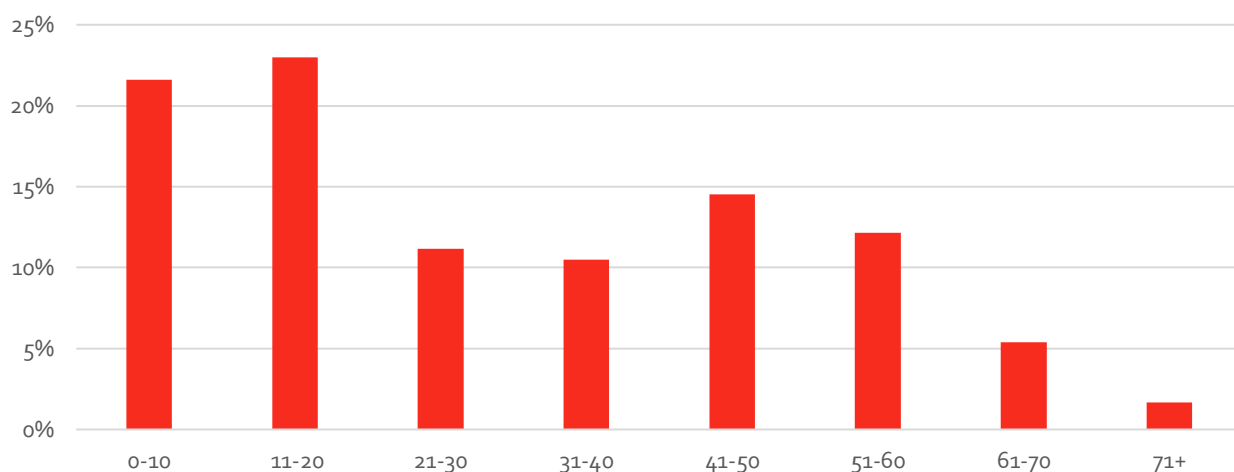
Membership by State



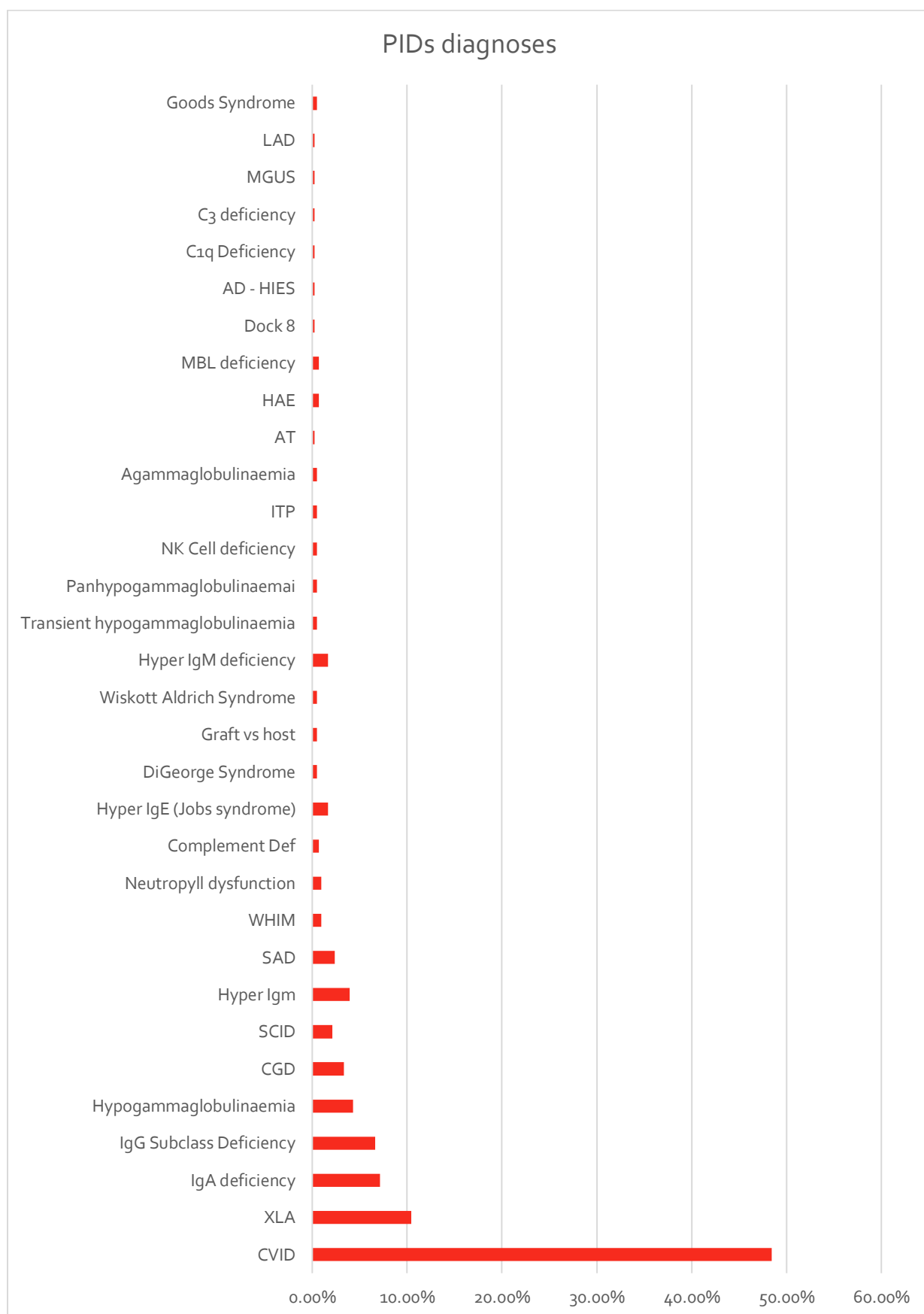
Patient Gender

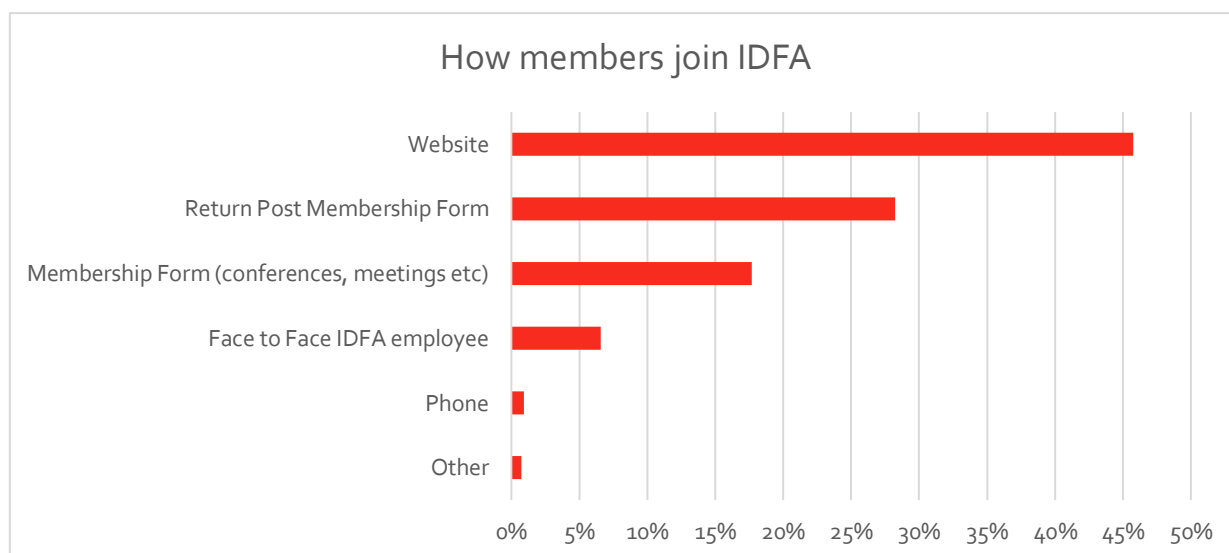
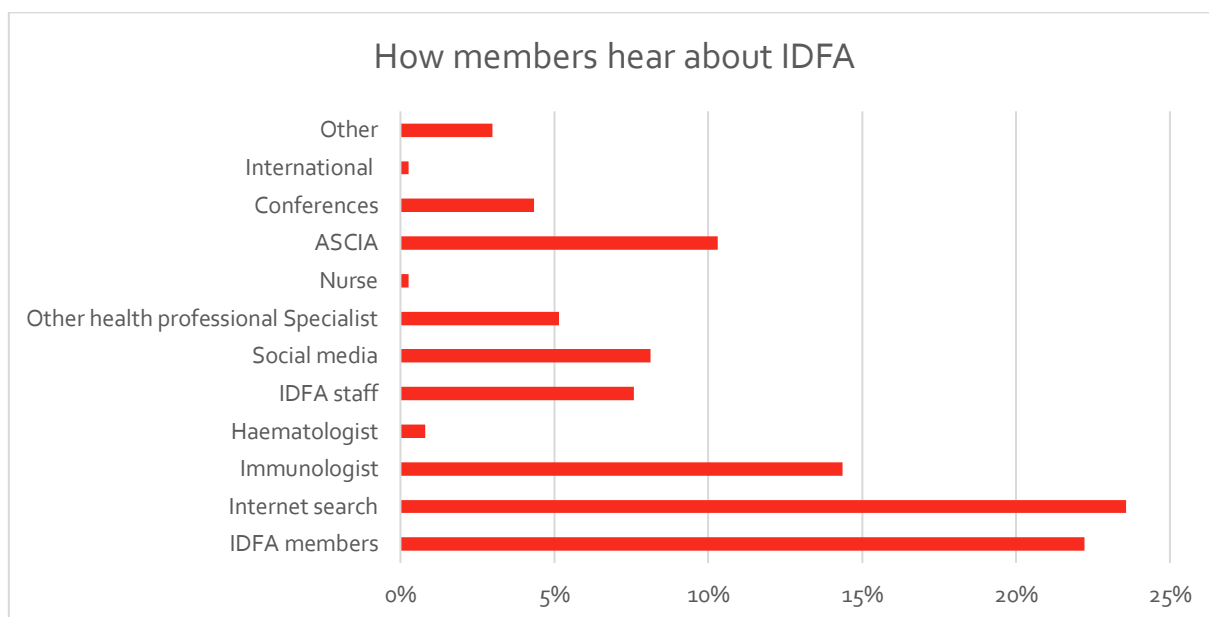


Patient Ages



Primary Immune Deficiency Diagnosis





Maintain our recognition as the peak body representing Australians affected by PID

July National Conference

The Immune Deficiency Foundation of Australia held it's 2016 National Conference at Darling Harbour on 8-10 July. 126 Patients, carers, family members and stakeholders attended. The 3 day conference featured international guest speaker Dr Nizar Mahlaoui from the Necker Institute Paris. Dr Mahlaoui spoke about X-Linked Agammaglobulinaemia, Chronic Granulomatous Disease and also Granulomatous Disease in Common Variable Immune Deficiency.

There were 23 Sessions and several interactive workshops about Antibody deficiencies, Advances in diagnosis and Treatments, Fatigue, Autoimmunity, Genetics, and Practical guides for patients & carers.

Speakers also featured prominent Australian Immunologists and Researchers Dr Melanie Wong, Dr David Gillis, Professor Matthew Cook, Professor John Ziegler, Dr Vanessa Bryant, Dr Charlotte Slade ; guest speakers Anastasia Wilson, Clinical Nurse Educator Canberra Hospital, Dr Marline Squance (Autoimmune Resource and

Research Centre), Michael Stone (National Blood Authority); Tanielle Stackman (young adult patient), Richard Price (Board Chair), Christine Jeffery (Executive Officer), Chloe Appleton and Emma Joseph (IDFA Patient and Advocacy Support).

The Conference also featured the launch of IDFA's Primary Immune Deficiency Awareness Pin and our advocacy campaign to have Newborn Screening for Severe Combined Immune Deficiency or SCID (the 'bubble boy' disease) added to the Guthrie screening test done at birth.

There was Karaoke, face painting, a photo booth and games on Friday Fun night and Fireworks at the conference dinner! Patient feedback was it was our best conference to date !



Platinum Sponsor: Grifols

Gold Sponsor: CSL

Silver Sponsor: Shire

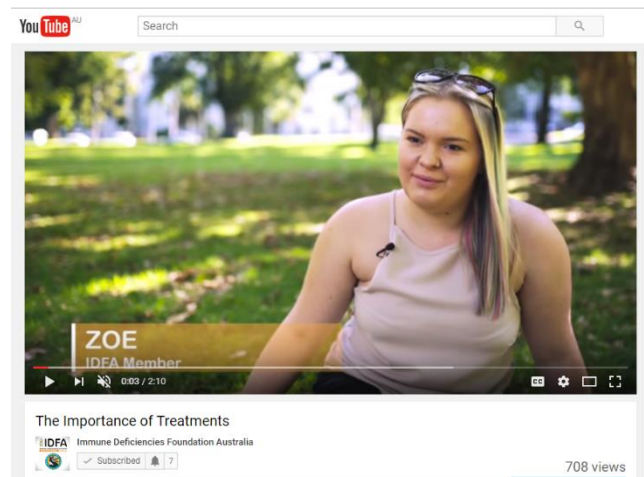
Other Sponsors; Department of Social Services

Thanks to: Novotel Darling Harbour, AtPrint Penrith

IDFA would like to thank the Hey family for their generous donation which allowed us to live stream the Conference Sessions.

World PI Week

- Launched new PI mascot -Maggie.Pi and Pi slogan "PI is not always black and white"
- Launched new 10 warning signs
- Launched 4 Videos featuring IDFA young adult members Teal and Zoe focusing on:
 - Teal Chapman – story of CGD
 - World PI Week
 - 10 Warning Signs
 - Importance of Treatments
- IDFA members Gail and Emily Dixon created awareness and raised over \$2,500 in QLD with their massive school and media campaign
- Patient representatives distributed new 10 Warning signs posters in their infusion centres and GP offices



From left to right: Emily and Gail Dixon, Al, Bridge and Spida from the Gold FM team, Rev Chad Rynehart and Stuart Marquette the Lindisfarne Anglican Grammar School Principal.

Platinum sponsor: Shire

IDFA would like to thank Emily and Gail Dixon for their hard work in promoting World PI Week, PIDs and IDFA

Peak body representation

- ❖ Staff and Board are representatives on State, Federal, International groups, regulatory bodies, rare disease groups and Immunoglobulin (Ig) committees
- ❖ Adam Friederich is a representative on the NIGAC Committee (National Immunoglobulin Advisory Committee) and several other health related Boards and committees
- ❖ Dr Melanie Wong is the Chair of AIFA and is a representative on many medical Boards and committees
- ❖ Christine Jeffery is the Treasurer of International Patient Organisation for Primary Immunodeficiencies (IPOPI) and also involved in other immunoglobulin and allied health Boards and Committees.

Increase financial capabilities to facilitate growth

Increase financial resources for core requirements and projects

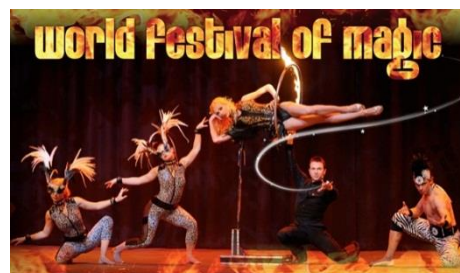
Financial Resources: Professional Fundraiser – International Entertainment

To assist us in Fundraising, International Entertainment run shows for IDFA. Purchasing tickets for the shows provides opportunities for those who are sick, have a disability or impoverished and their carer to enjoy a great afternoon of entertainment and fun! These shows include Razzamatazz, Circus Quirkus and World Festival of Magic. Tickets are \$55 ea or \$110 for a child and their carer. They are tax deductible. By purchasing tickets to a show, sponsors enable children and families whose lives are difficult due to illness, disability or poverty, to have a great few hours of fabulous entertainment.

IDFA members attend these shows and are very grateful to those who purchase tickets. International Entertainment run 3 types of shows:

1. World Festival of Magic

[World Festival of Magic](#) has been touring Australia since 1988. It features the great Illusionist Michael Boyd. The show features acts of interactive magic, acrobatic cyclists and circus acts. The IDFA show is run in WAGGA WAGGA



2. Razzamatazz

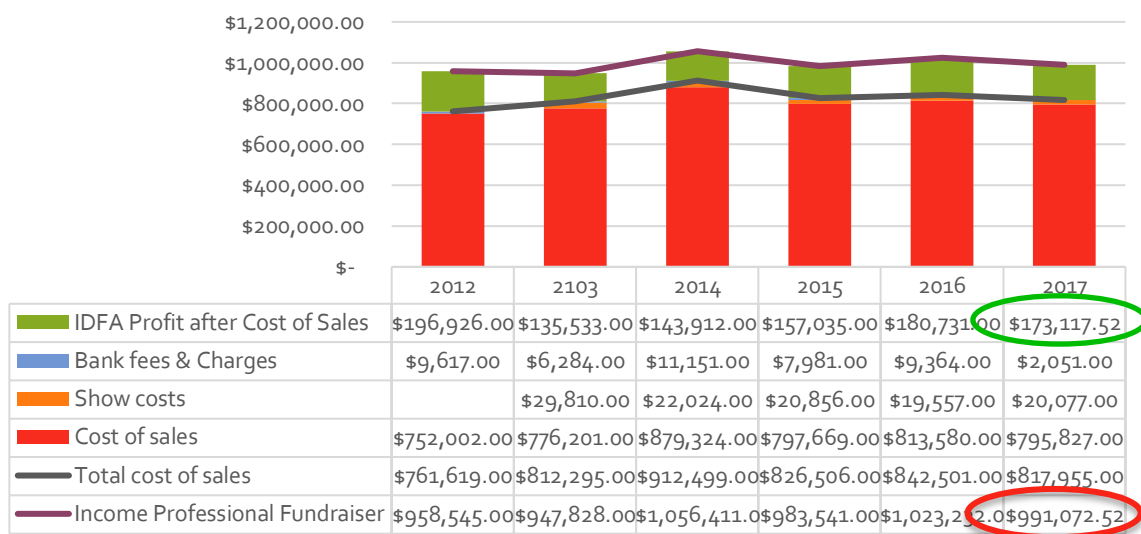
[Razzamatazz](#) has been touring Australia since 2008. It is a mix of circus, magic, comedy and dazzling dancers in spectacular costumes. It is a great variety show and fun for everyone. The show runs for about 1 hour with no interval. The IDFA shows are run in: CANBERRA, MELBOURNE and PENRITH



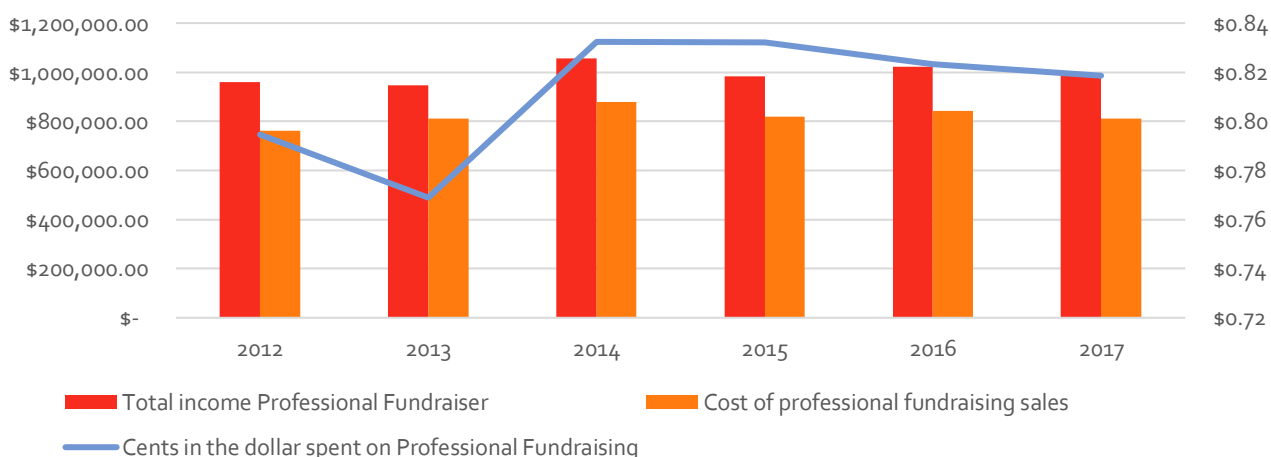
3. Circus Quirkus

[Circus Quirkus](#) has been touring Australia since 2002. It is a contemporary take on traditional circuses of ages past. It is an eclectic and entertaining mix of Circus acts brought to you from all over the world. Internationally renowned Clowns, Jugglers, Acrobats, and more deliver funny, hugely engaging and sometimes death-defying acts of unbelievable skill. The IDFA shows are run in CAIRNS, TOWNSVILLE, LISMORE, TOOWOOMBA, MACKAY, NEWCASTLE, BENDIGO and BURNIE.

Professional Fundraiser Income, Cost of Sales & Profit after Cost of Sales



Cents in the dollar spent on Professional Fundraising



Major Sponsors

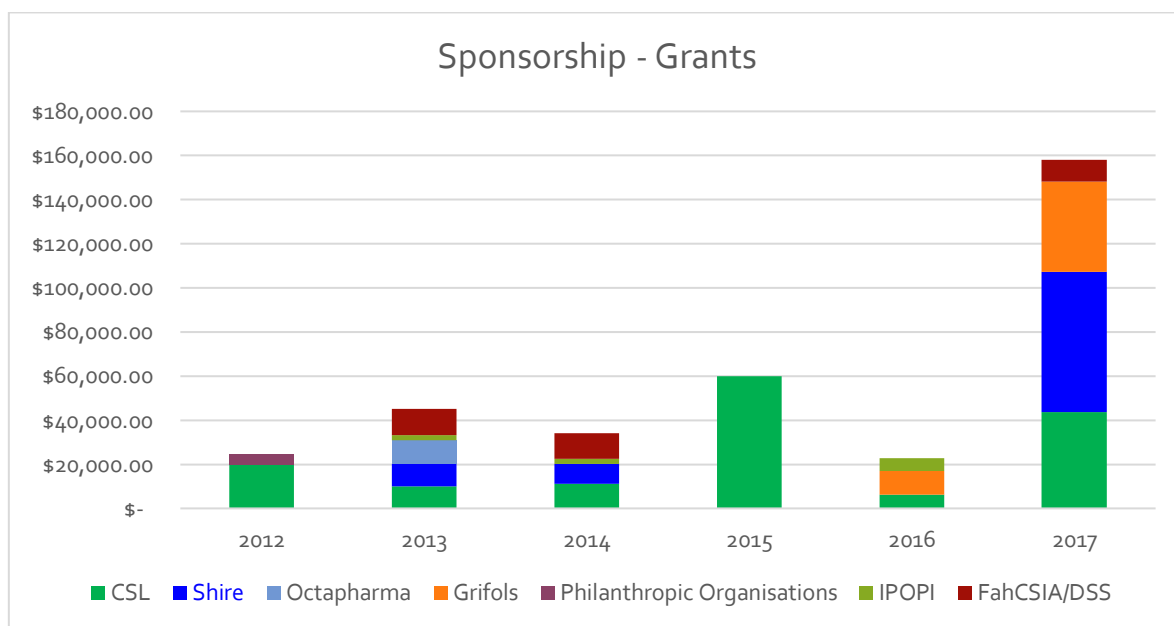
IDFA's major sponsors for 2016/17 were:

- ☐ Platinum - Shire
- ☐ Gold - CSL Behring
- ☐ Silver - Grifols



Pharmaceutical Companies and Grants

Due to the changes in Immunoglobulin supply, there are only two pharmaceutical companies that supply blood products IDFA patient's use - CSL Behring and Grifols. However Shire has continued their support of IDFA into 2016-17 which has been extremely encouraging. As IDFA receives no government funding, the support of the pharmaceutical companies is pivotal to supporting our membership growth and services. IDFA also lodges many grant applications (government and philanthropic), including international grants through IPOPI.



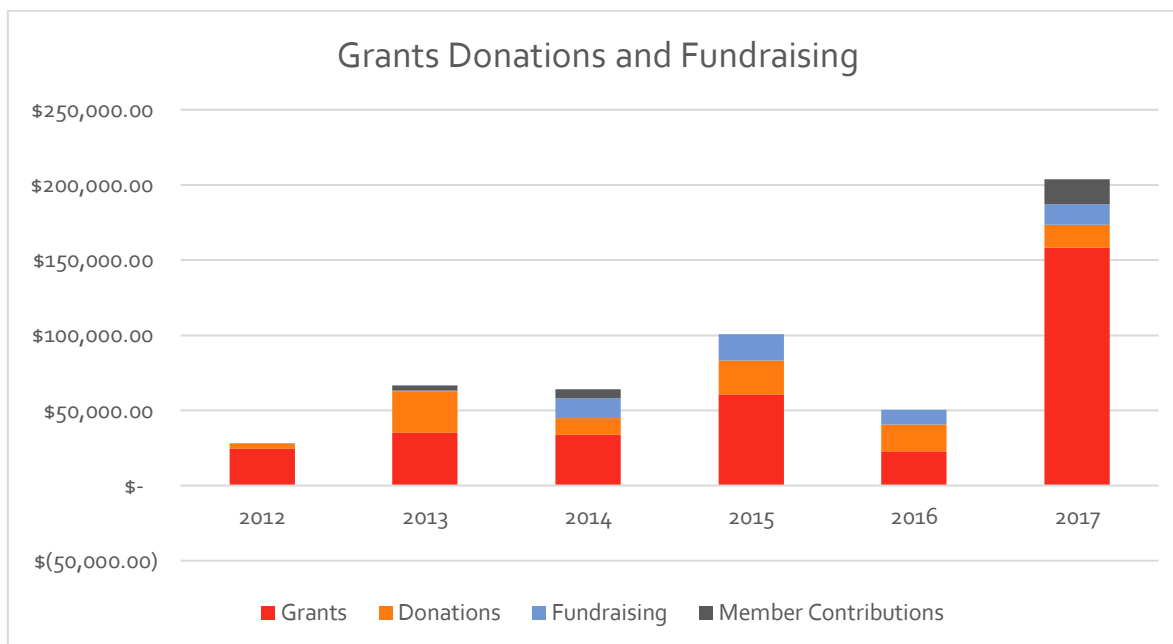
Other Sponsors and Donors

- AtPrint
- Tweed Heads Public School
- Terranora Public School
- Lindisfarne Anglican Grammar School
- Lower Mountains Rotary Club
- Nepean Rotary Club
- Tyrrell Family
- Mathieson family
- Young family – in memoriam of their mother
- GoFundraise platform
- Sharon Heathfield – Sharon has made and donated many beautiful quilts to IDFA patients. A patient herself, this gift has brought much joy to IDFA members of all ages



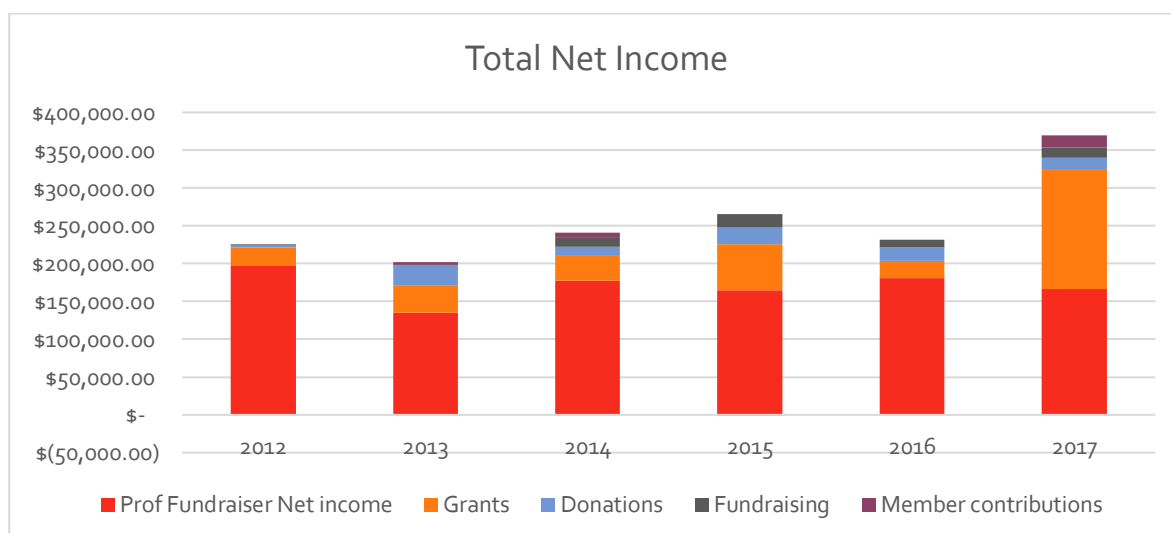
IDFA truly values our donors and thanks you for your kind donations.

Other Income



Summary of total net income

Although financial reporting includes the total income received, the net figure to IDFA is most important and contributes a "true" picture of income received. Although sales have increased, the cost of sales has also increased.



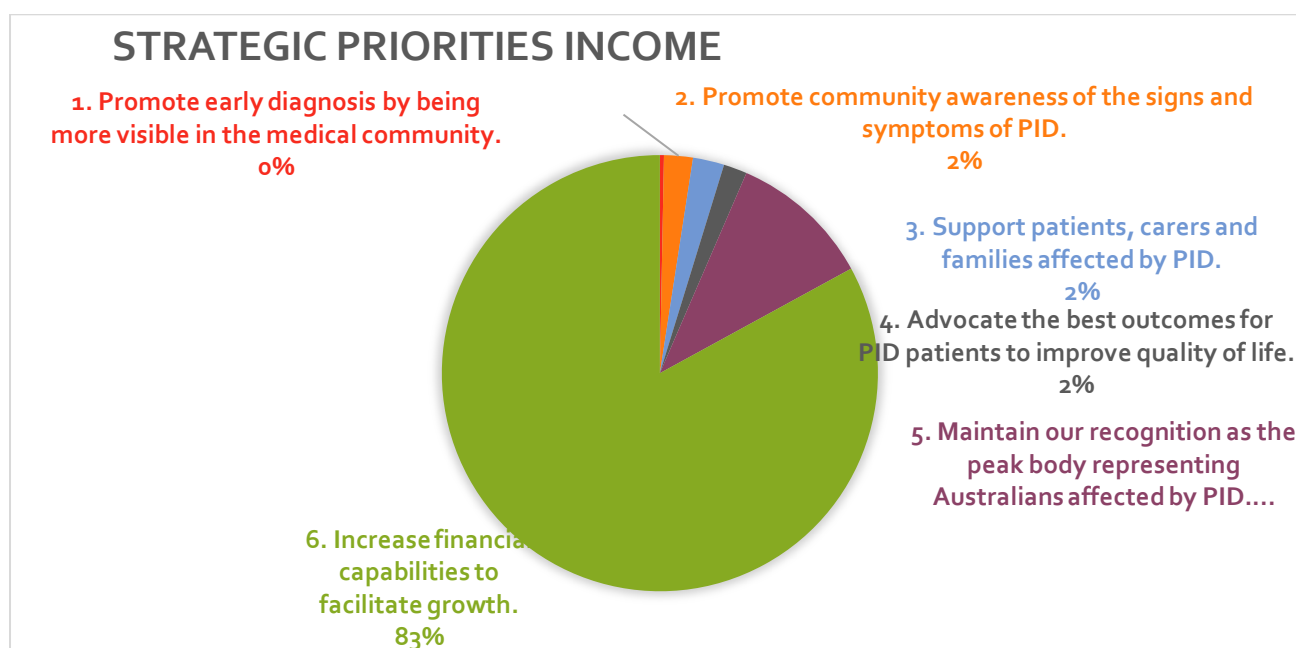
Operational Benchmarks

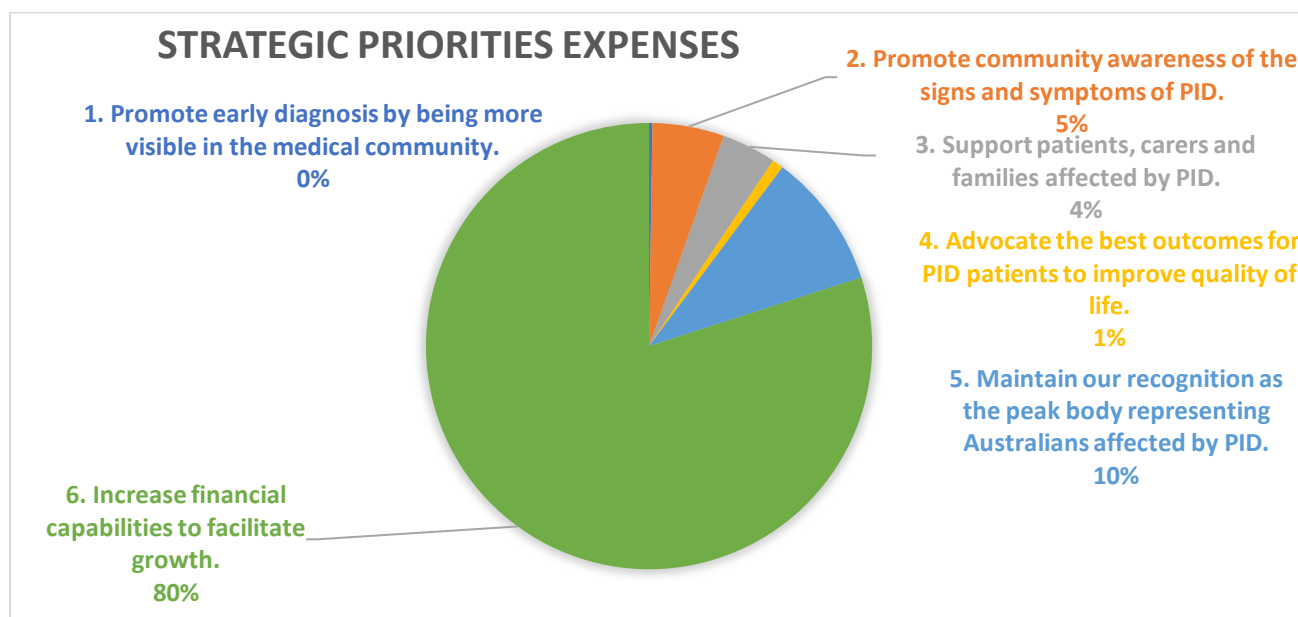
These ratios measure the performance of each activity.

Operational benchmarks

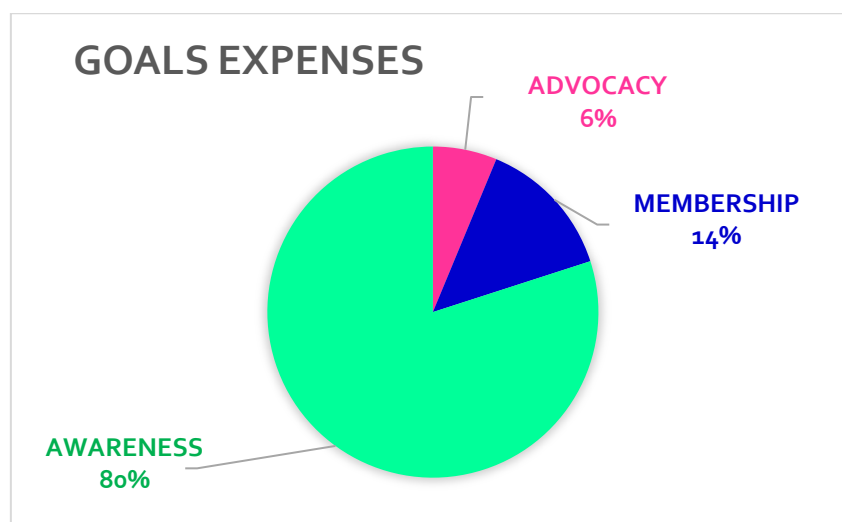
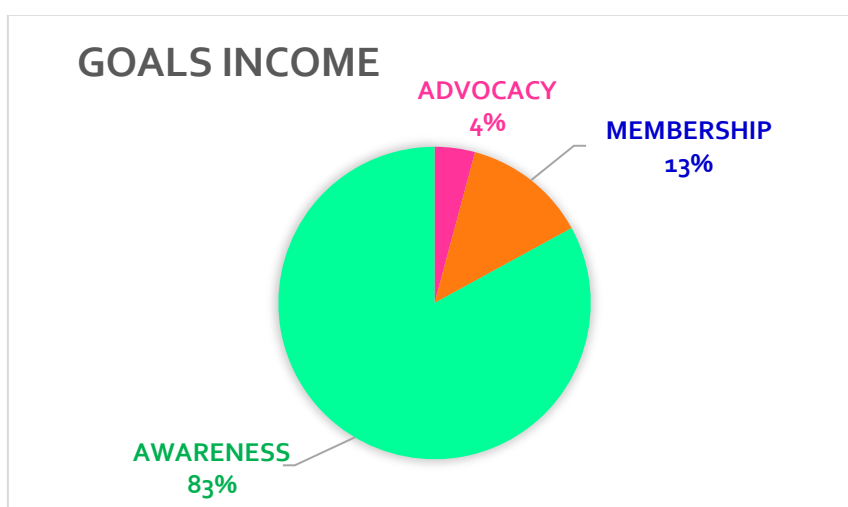
Activity expense benchmark	International Entertainment Shows
Fundraising expenditure divided by	\$818,508.00
Fundraising income	\$991,073.00
Fundraising expense ratio =	83%
Activity expense benchmark	Projects
Fundraising expenditure divided by	\$141,362.00
Fundraising income	\$174,550.00
Fundraising expense ratio =	81%
Activity expense benchmark	Fundraising
Fundraising expenditure divided by	\$2,316.00
Fundraising income	\$27,037.00
Fundraising expense ratio =	9%
Activity expense benchmark	IDFA Merchandise
Fundraising expenditure divided by	\$444.00
Fundraising income	\$109.00
Fundraising expense ratio =	407%
Activity expense benchmark	IDFA PIN
Fundraising expenditure divided by	\$443.00
Fundraising income	\$2,110.00
Fundraising expense ratio =	21%

Income and expenses reflected as IDFA Strategic Priorities

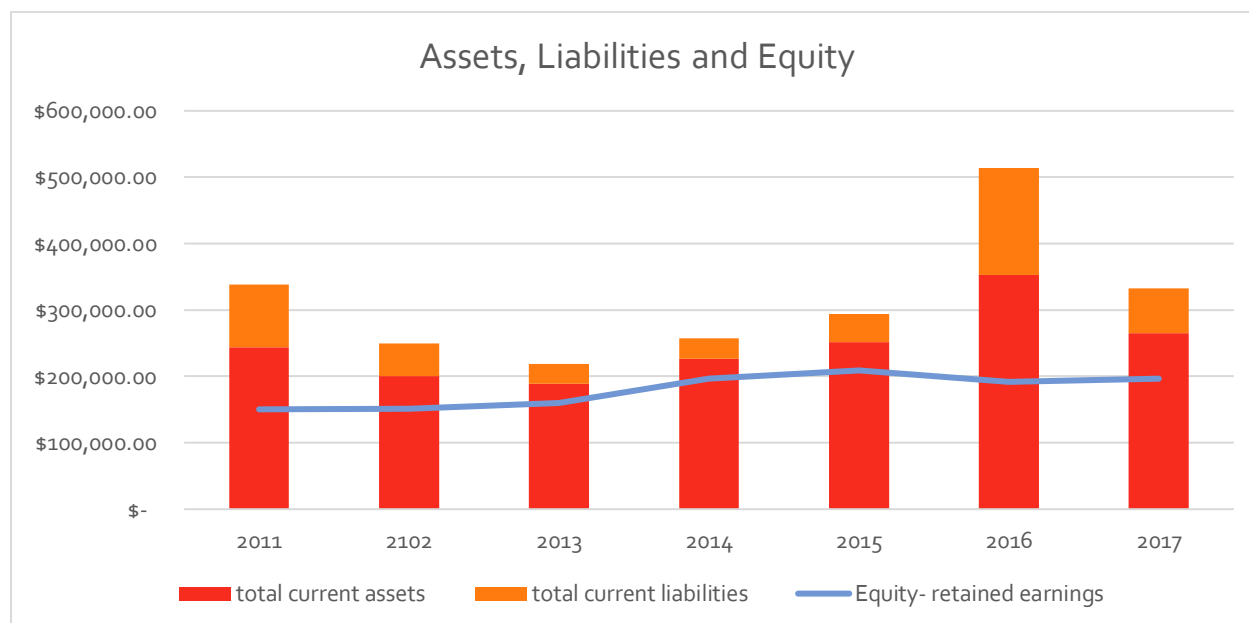




Income and Expenses reflected as IDFA goals



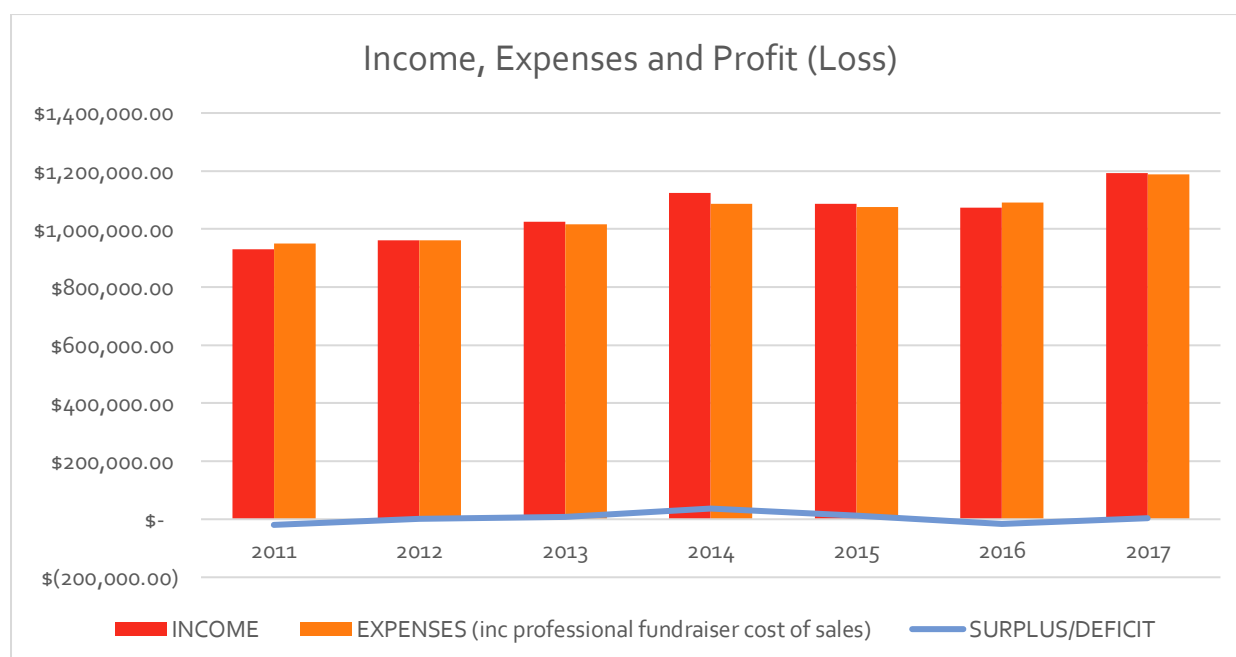
Statement of financial position - assets, liabilities and equity



End of year surplus/deficit

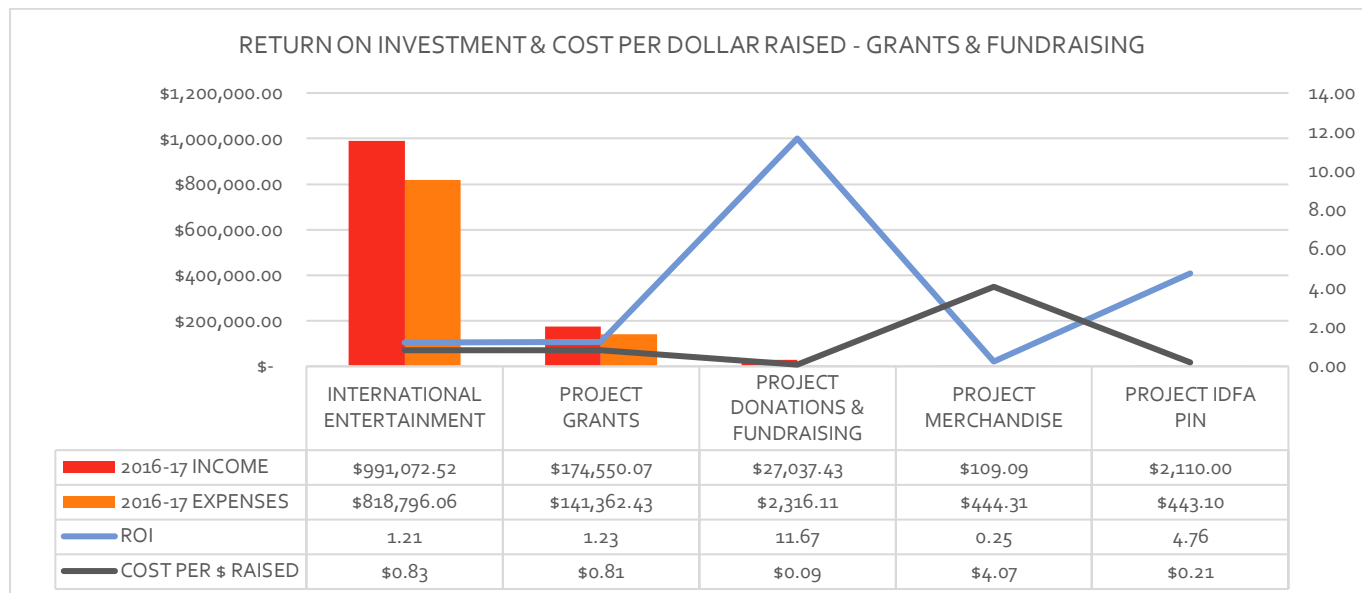
IDFA experienced a profit of \$4546 in 2017. This can be attributed to:

- ❖ The increase in grants raised
- ❖ Preparation for the Biennial Conference in July focused grants for early 2016-17 year
- ❖



Return on investment

The ROI summarises whether IDFA is achieving its objectives and making an appropriate return on the funds it raises and receives.



Growing Through Change

By adopting both a “patient” focus and “business management” focus, IDFA has implemented successful strategies to achieve KPIs for 2016-2020.

IDFA is still experiencing rapid growth and change. IDFA is seeking innovative ways of growth by utilising financial and human resources. IDFA will continue with:

- Increasing Member resources
- Focus on business management
- Innovative growth plan
- Collaboration with industry, regulatory bodies

Strategic priorities moving forward 2018-2020

The strategic priorities for 2018-2020 remain:

1. Promote early diagnosis by being more visible in the medical community.
2. Promote community awareness of the signs and symptoms of PID.
3. Be recognised as the Australian peak patient body for primary immune deficiencies.
4. Support patients and families affected by PID.
5. Advocate the best outcomes for PID patients to improve quality of life.
5. Streamline business processes to ensure maximum efficiency.
6. Become more sustainable by increasing by increasing financial capabilities.

2017-2018 will focus on:

1. Increasing financial capabilities
2. Holding State patient meetings
3. Advocating, raising awareness and funds for a SCID newborn screening pilot in NSW with a long-term focus of implementing SCID newborn screening in every State
4. Advocating for optimum treatment for patients to achieve the best quality of life
5. Advocating for recognition of Primary Immunodeficiencies by Centrelink and NDIS
6. Improving the database
7. Improving the website

Report by

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Support our advocacy campaign to have newborn Screening for Severe Combined Immune Deficiency (SCID, the "bubble boy" disease) added to the Guthrie heel prick test, to prevent further infant deaths from this disease. [SIGN OUR PETITION](#)