

# Immune Deficiencies Foundation Australia

*Raising awareness & supporting people affected by immune deficiencies in Australia*

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"I Don't Feel Alone" - By IDFA Members



## 2017-2018

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 our 'Patient-Centred Model of Care'.*

*We organised this year the YAM JAM Youth Conference, held from the 23<sup>rd</sup> to the 24<sup>th</sup> June, in Melbourne. The feedback was excellent and a big 'thank you' to our speakers, sponsors, staff and volunteers who contributed to the event's success.*

*As a result a new IDFA Resource was developed for use on social media, conferences and the website – our "I Don't Feel Alone" music video and soundtrack <https://www.youtube.com/watch?v=CLkyaB75JeQ>*

*We also held State Patient meetings in Sydney Brisbane, Adelaide and Canberra, with excellent speakers and members learning more about immune deficiency and treatment.*

*Our focus on increasing awareness was reflected in the intense campaign over the World PI Week, 22-29 April, emailing over 1,000 awareness cards to GP's and Healthcare Professionals.*

*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.*

*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 BBQs, 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 and CSL Behring who have continued to provide valued support for events, education and resources.*

*Best regards,*

*Lara Alexander*

*Board Chair*

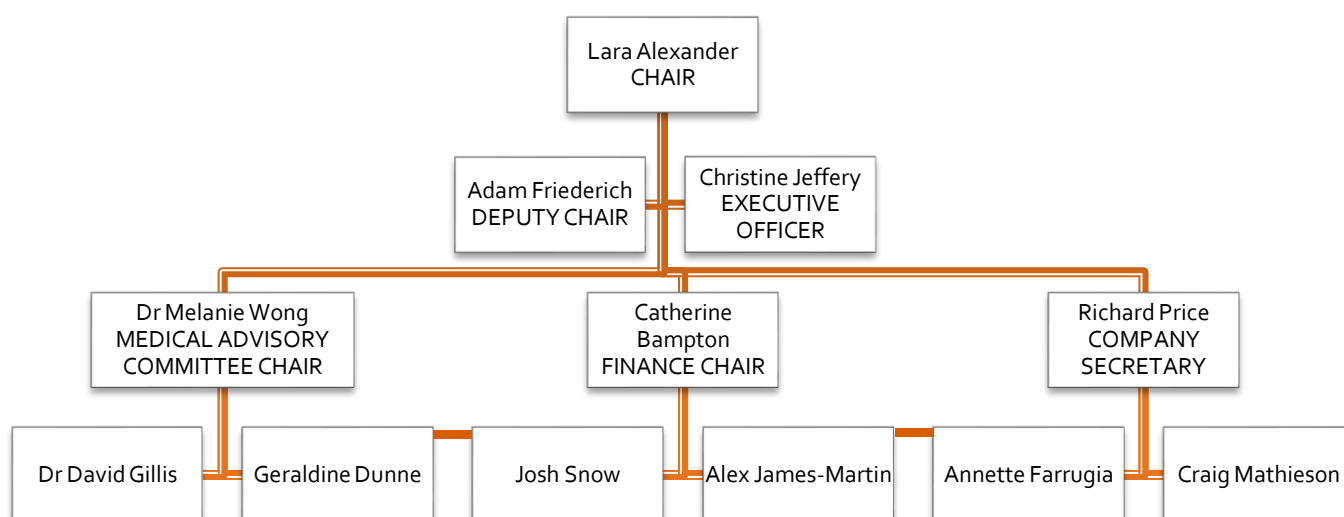
*IDFA Board of Directors*



## Governance

### Board of Directors

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



### Staff

In 2017-2018, IDFA employed:

- 1 full time staff member, Christine Jeffery - Executive Officer (EO) [christine.jeffery@idfa.org.au](mailto:christine.jeffery@idfa.org.au)
- 1 part time staff member, Chloe Appleton - Member Support [chloe@idfa.org.au](mailto:chloe@idfa.org.au)
- 1 part time staff member, Emma Joseph - Communications and Health Promotion  
Emma Joseph resigned in 2017 and in 2018 an additional 2 part time staff were employed:
- Emma Little Stakeholder & Business Development & Secondary Immune Deficiencies [emma.little@idfa.org.au](mailto:emma.little@idfa.org.au)
- Janessa Catto – Community Outreach and Development [janessa.catto@idfa.org.au](mailto:janessa.catto@idfa.org.au)

### Office volunteers

In 2017-2018, IDFA had 2 office volunteers:

- Lyn Torckler - Mondays
- Maria Pirovic – Tuesdays

### University of Western Sydney intern

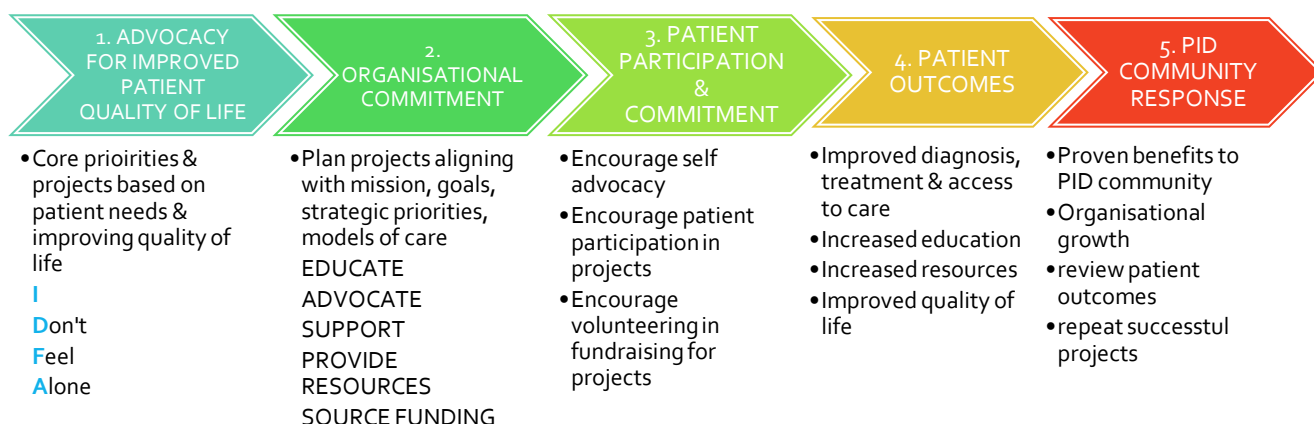
- Lauren Stevenson



## Model 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.



## Strategic Priorities

### VISION

A future where immune deficiencies (primary and secondary) are diagnosed early, communities are more aware of the signs and symptoms of immune deficiencies, and those affected feel supported

### MISSION

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

### GOALS

#### ADVOCACY

#### MEMBERSHIP

#### AWARENESS

### STRATEGIC PRIORITIES

1. Advocate the best outcomes for patients to improve quality of life.

3. Support patients, carers and families affected.

5. Promote community awareness of the signs and symptoms of IDs.

2. Promote early diagnosis by being more visible in the medical community.

5. Maintain recognition as the peak body representing Australians affected.

6. Increase financial capabilities to facilitate growth.



## Values

**Our members:** We can all learn something from someone, and those affected by immune deficiencies (primary and secondary) have a story worth listening to.

**Courage:** Immune deficiency 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 immune deficiencies.

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

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

## Member Services

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

## Achievements

### GOAL: ADVOCACY

**STRATEGIC OBJECTIVE: 1. Advocate the best outcomes for PID patients to improve quality of life**

#### OUTCOMES

IDFA is working towards the following advocacy outcomes:

- ❖ Australia to implement newborn screening for SCID (Severe Combined Immune Deficiency)
- ❖ Organise State SCID NBS petitions to support State NBS pilots & advocate for national screening
- ❖ An increase in range and continuity of immunoglobulin (Ig) products
- ❖ The provision of immunoglobulin to all patients that need it (rather than those that fit the “criteria”)





- ❖ SCIg (subcutaneous immunoglobulin) availability to all patients at no/reduced cost (including pumps and consumables)
- ❖ Provide patient and family support to Secondary Immune deficiency patients
- ❖ Develop and Maintain Primary and Secondary immunodeficiency resources

Letters have been written to Health Minister Greg Hunt MP and the National Blood Authority (NBA) and meetings were held with Michael Stone from the NBA and Dr William Smith, Chair of ASCIA, raising our concerns about:

- ❖ the criteria for receiving immunoglobulin in Australia
- ❖ the difficulty in availability of SCIg treatment in Australia
- ❖ the costs of SCIg treatment to patients in Australia
- ❖ the tender process for immunoglobulin which sees patients change products every 4 years.

*We are also pleased that the NSW pilot for newborn screening for SCID  
(Severe Combined Immune Deficiency) has started!*

#### PROJECT: NATIONAL ROADSHOW MEETINGS

Four Patient Meetings were held in 2017-2018. Three patient meetings were held as part of our 'Beyond Hospital Walls' series in Brisbane, Adelaide and Canberra. The meetings included the latest information on immune deficiencies from specialists, practical support guides, resources and a chance to meet other patients.

- ❖ Sydney – Garvan Institute
- ❖ Brisbane
- ❖ Adelaide
- ❖ Canberra



Canberra



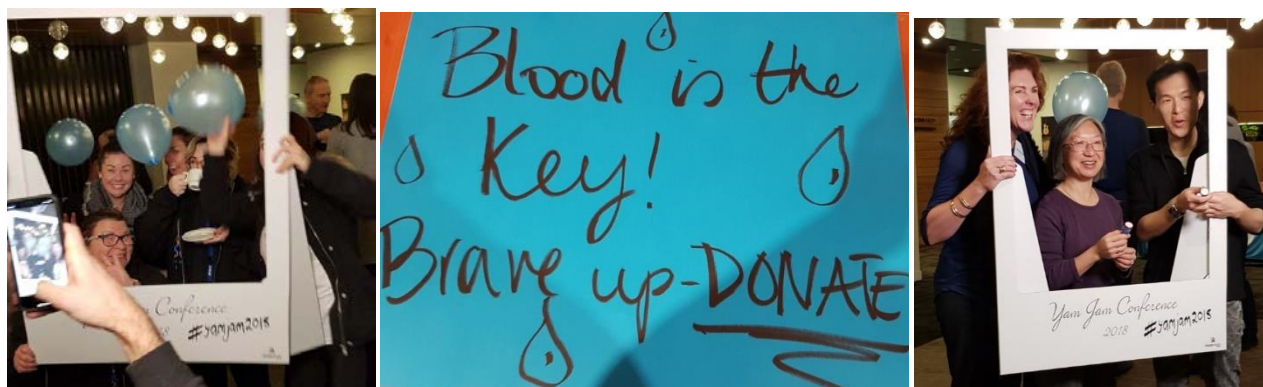
Sydney



## PROJECT YAM JAM

IDFA held our very first Young Adult (YAM JAM) Conference in Melbourne on June 23-24. The event was attended by over 30 patients and friends/partners and guest speakers. We were thrilled to have Dr Melanie Wong, Dr Frederick Lee and Ms Geraldine Dunne attend as our specialist speakers, as well as Adam Friederich and Emily Regan attend as our Carer Support specialists.

The weekend was a huge success with many attendees expressing their gratitude for the support, encouragement and inspiration along with some much-needed fun and time out. It was an example of the IDFA mantra 'I don't feel alone' which is so vital for connecting people and ensuring that each person's journey is supported.





## THE 'IDFA MUSIC VIDEO'

One outcome from the YAM JAM was the [IDFA Music Video](#). The words were written by the YAMS and the video features Imogen Abba, Tokana Hennequin, Christopher Bowd and Ben Johnson on vocals, YAMS and staff on chorus and the YAM JAM dancers and scenes from the conference. The video will be a valuable resource going forward for awareness campaigns and showcasing IDFA to gain funding and support for the work we do. We hope you enjoy it as much as we did making it.  
[Click here](#) to view on the IDFA YouTube channel.

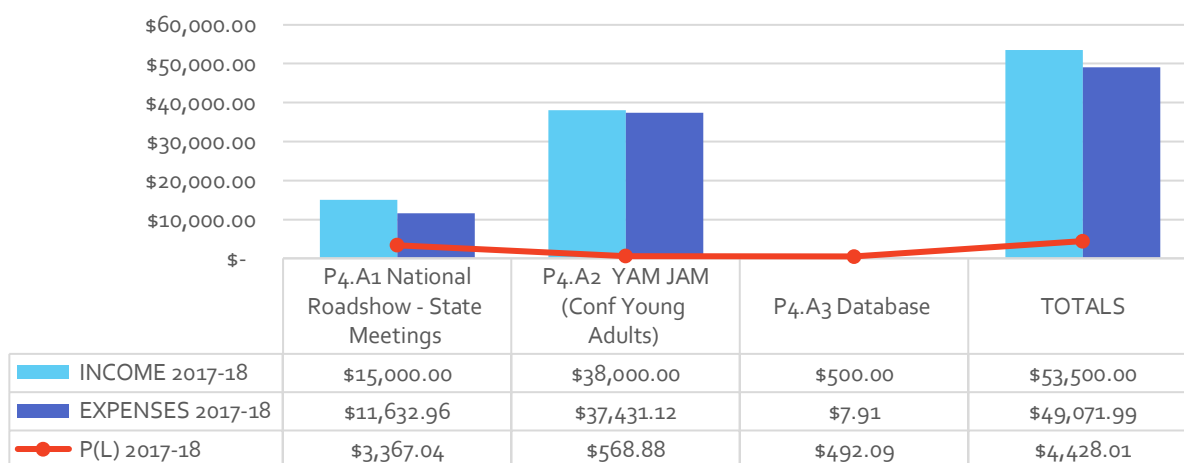


## PROJECT: DATABASE

As our database continues to grow and diversify, we are still searching for an appropriate professional database.



## ADVOCACY - PROJECTS PROMOTING QOL

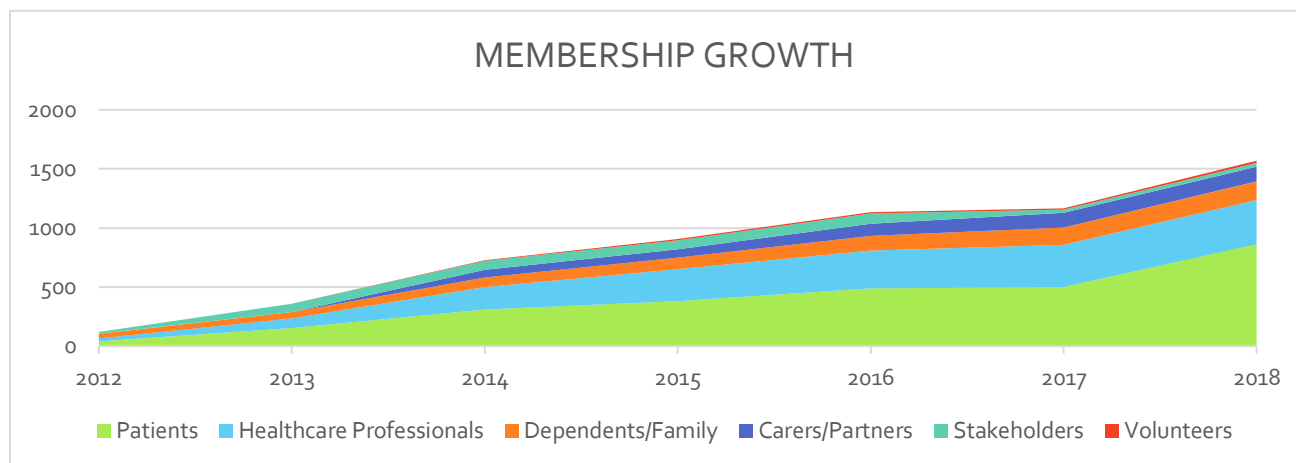


## PROJECT: MEMBERSHIP GROWTH

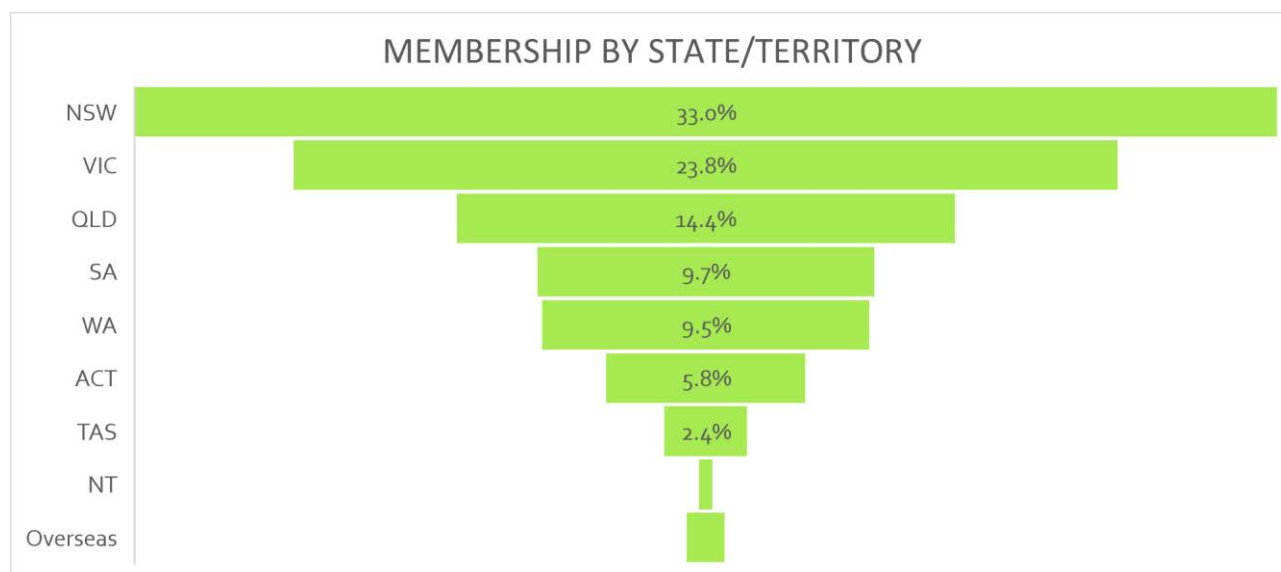


Patient locations around Australia

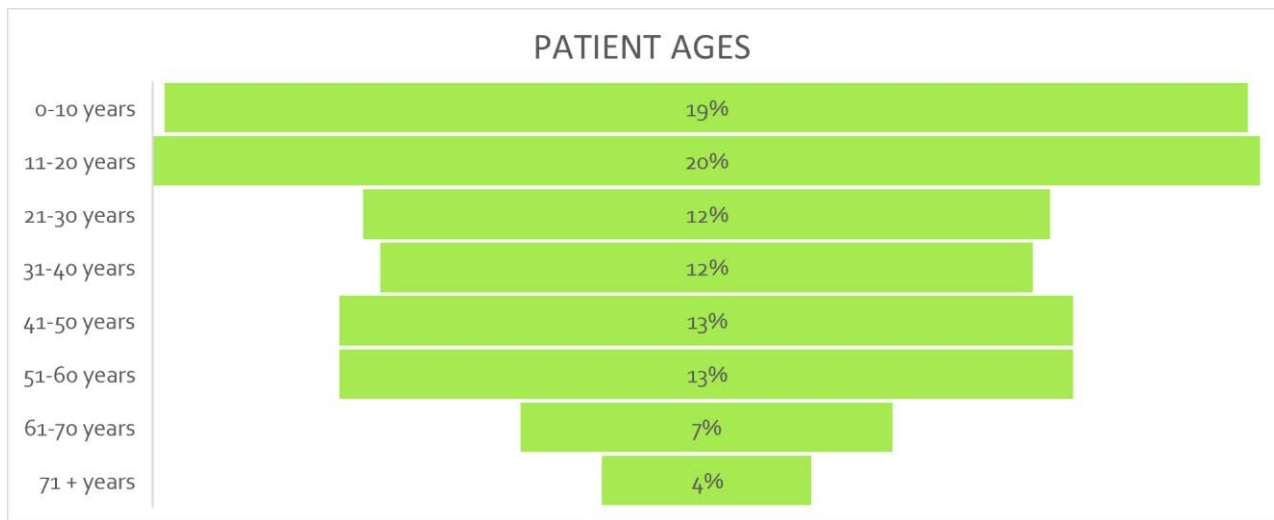
## MEMBERSHIP COHORT GROWTH



## MEMBERSHIP BY STATE

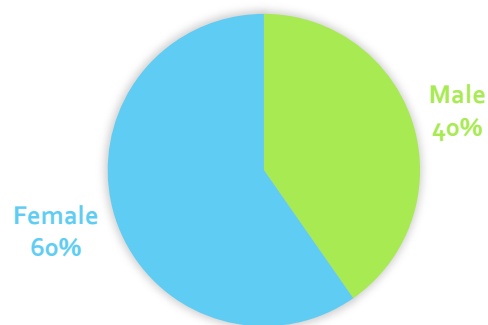


## PATIENT AGES

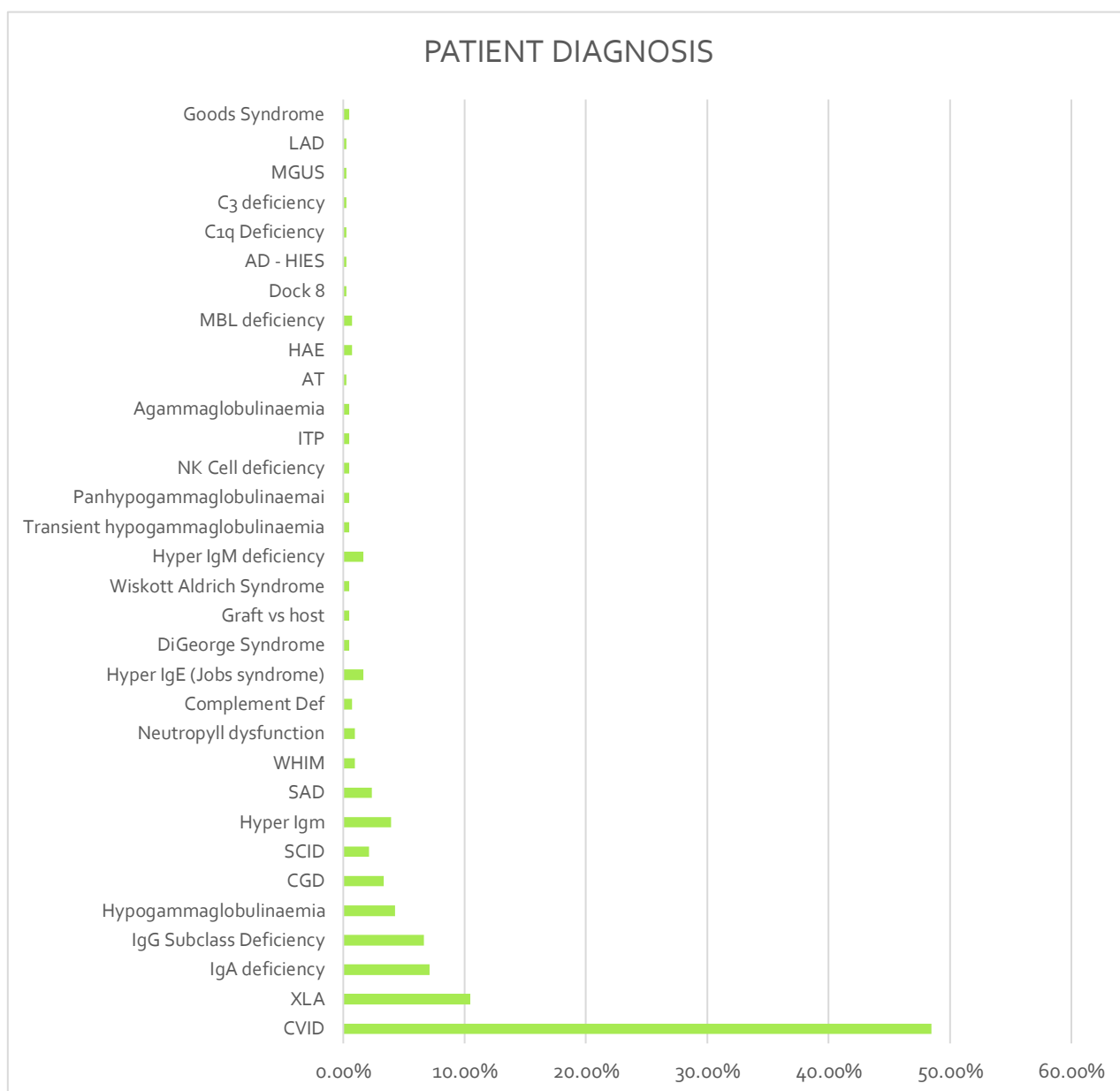


## PATIENT SEX

### FEMALES/MALES



## PRIMARY IMMUNE DEFICIENCY DIAGNOSIS



## STRATEGIC OBJECTIVE: 2. Promote early diagnosis by being more visible in the medical community.

### PROMOTE EARLY DIAGNOSIS

#### PROJECT: SCID NEWBORN SCREENING CAMPAIGN

IDFA continued our newborns screening campaign with:

- ❖ Letters to the Health Minister
- ❖ Petitions
- ❖ Signatures

*IDFA is very grateful for the brave story told by Harrison's family on our website.*



## PROJECT: MEDICAL COMMUNITY FORUMS

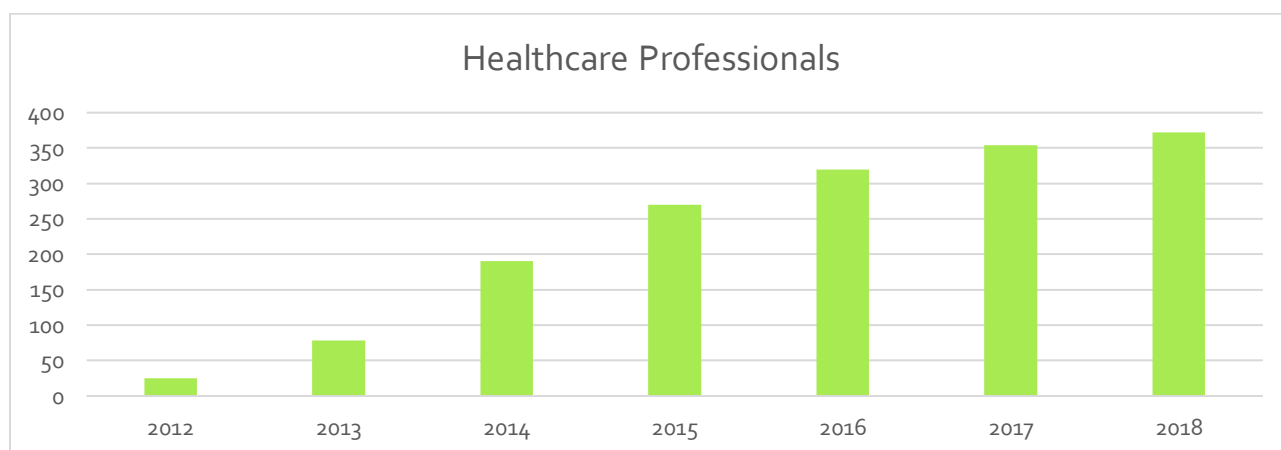
- ❖ Continued attendance at medical conferences national and internationally: PPTA, ASCIA, IPIC,
- ❖ Continued visibility of medical related groups and boards IUG, NIGAC, HCA, AGSA, GARDn, Immunological Alliance, IPOPI
- ❖ Continued growth of healthcare professional members

## LAUNCH OF THE JEFFERY MODELL FOUNDATION (JMF) RESEARCH CENTRE MELBOURNE

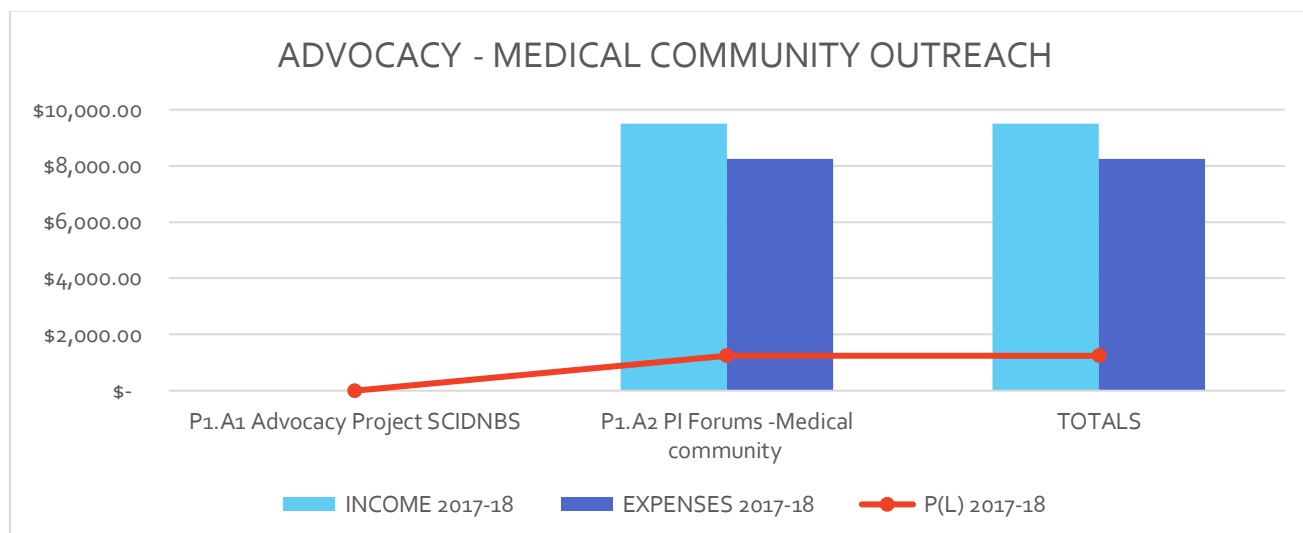
June saw the opening of the Jeffery Modell Foundation Centre for Immunodeficiency in Melbourne, a partnership between 5 hospitals, 2 universities and research centres. IDFA co-hosted the event with Chloe Appleton presenting on behalf of IDFA while two of our members Tara Flannery and Camile Condon showed real courage in presenting their patient stories.



## MEDICAL COMMUNITY MEMBERSHIP







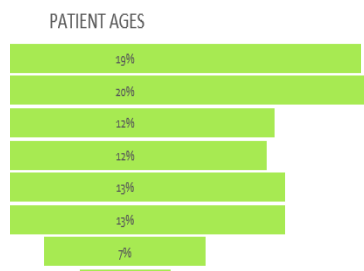
## GOAL: MEMBERSHIP

### STRATEGIC OBJECTIVE: 3. Support patients, carers and families affected

#### PROJECTS SUPPORTING THE IMMUNODEFICIENCY COMMUNITY

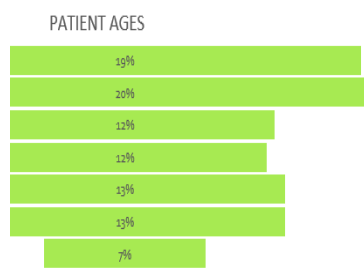
##### PROJECT: TELECONNECT

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



##### PROJECT: WEBSITE EDUCATION

IDFA is building NEW website to be launched in 2018. We thank Bruce Saunders for all his work designing it.



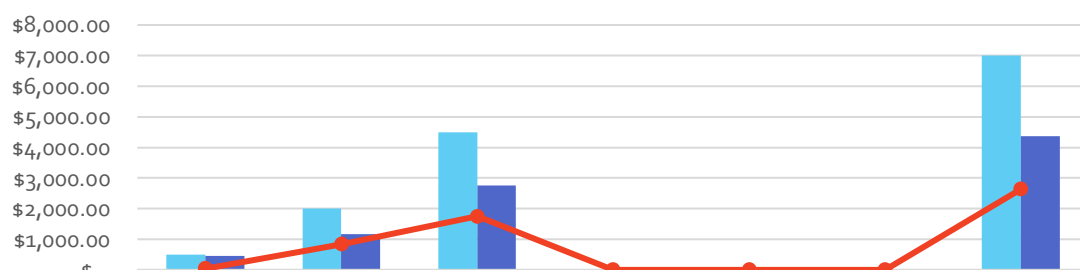
## PROJECT: SECONDARY IMMUNODEFICIENCIES

IDFA is delighted to extend its support and advocacy activities to include patients with Secondary Immune Deficiency. 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)



### MEMBERSHIP- PROJECTS SUPPORTING ID COMMUNITY



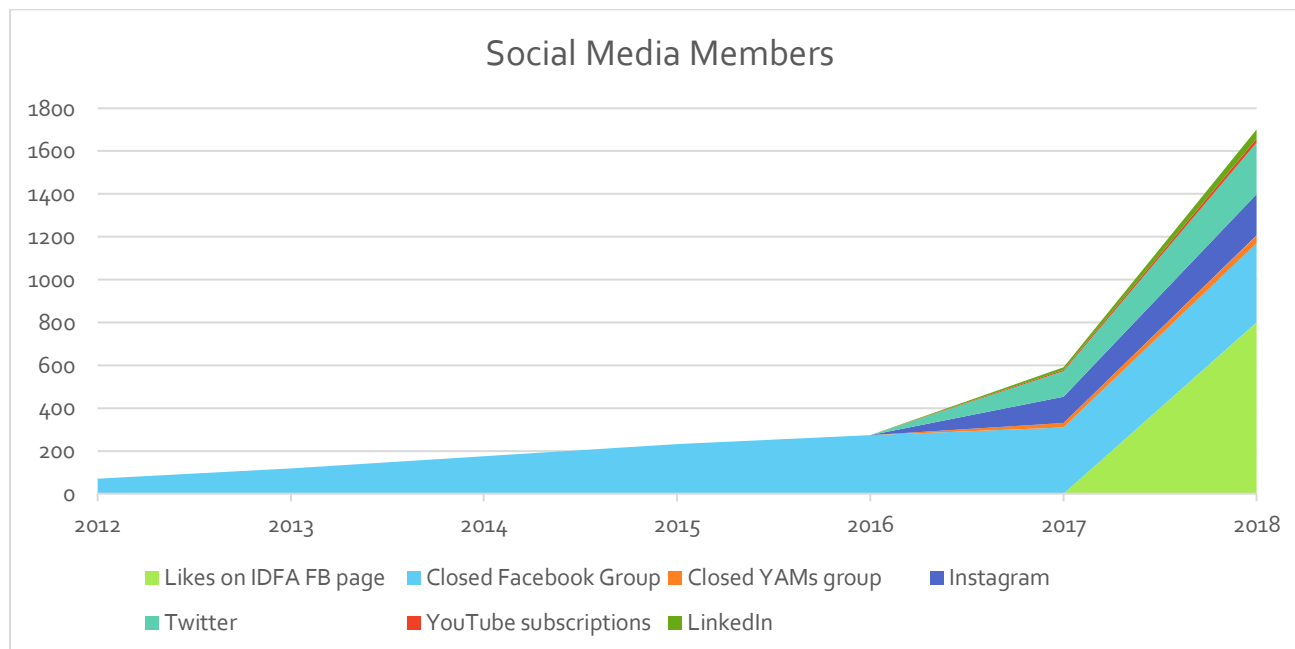
|                  | P3.M2 TeleConnect | P3.M3 Website Education | P3.M4 Secondary Immune Deficiencies | P3.M5 Family Camp | P3.M6 Specific Event (RD Conf) | P3.M7 Research Project | TOTALS     |
|------------------|-------------------|-------------------------|-------------------------------------|-------------------|--------------------------------|------------------------|------------|
| INCOME 2017-18   | \$500.00          | \$2,000.00              | \$4,500.00                          | \$-               | \$-                            | \$-                    | \$7,000.00 |
| EXPENSES 2017-18 | \$451.55          | \$1,164.00              | \$2,749.66                          | \$-               | \$-                            | \$-                    | \$4,365.21 |
| P(L) 2017-18     | \$48.45           | \$836.00                | \$1,750.34                          | \$-               | \$-                            | \$-                    | \$2,634.79 |



## SOCIAL MEDIA

**Social media:** IDFA has 2 closed face book groups:

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



IDFA have our own YouTube channel - **Subscribe today!**

## STRATEGIC OBJECTIVE: 4. Maintain recognition as the peak body representing Australians affected

### COMMUNITY RECOGNITION

#### 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.



## INTERNATIONAL CAMPAIGNS

IDFA participates in:

- ❖ Rare Disease Day (26 Feb)
- ❖ World PI Week (22-29 April)
- ❖ World Immunology Day (29 April)
- ❖ International Plasma Awareness Week (October 8 -14)
- ❖ Plasma Awareness Week (October 8-12)
- ❖ How is your day? Plasma awareness campaign
- ❖ Giving Tuesday (IDFA “gives back” to patients supporting Xmas get-togethers)
- ❖ ASCIA Conference
- ❖ IPIC (International Primary Immunodeficiency Congress)
- ❖ IPOPI (International Patient Organisation for Primary Immunodeficiencies) Congress



## INDUSTRY ASSOCIATION

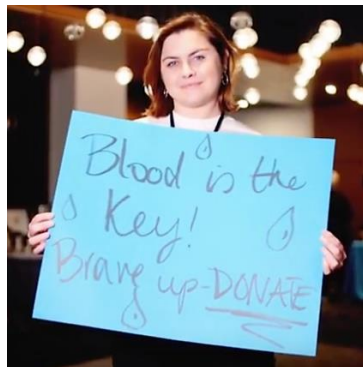
IDFA is proud to be associated with:

- ❖ ASCIA (Australasian Society of Clinical Immunology and Allergy)
- ❖ IPOPI (International Patient Organisation for Primary Immunodeficiencies)
- ❖ IDFNZ (Immune Deficiency Foundation New Zealand)
- ❖ NBA (National Blood Authority)
- ❖ CIRCA (The Clinical Immunogenomics Research Consortium Australia)
- ❖ CPI (Centre for Personalised Immunology)
- ❖ WEHI (Walter and Eliza Hall Institute)
- ❖ PPTA (plasma proteins therapeutic association)
- ❖ Garvan Institute
- ❖ CHF (Consumer Health Forum)
- ❖ RVA (Rare Voices Australia)
- ❖ Genetic Alliance Australia
- ❖ JMF (Jeffrey Modell Foundation)
- ❖ ARRC (Autoimmune Research & Resource Centre)
- ❖ Australian Immunological Alliance
- ❖ Arthritis Australia
- ❖ Leukaemia Foundation
- ❖ Lymphoma Australia
- ❖ National Disability Insurance Agency (NDIA)
- ❖ Thalassaemia Society of NSW
- ❖ Mastocytosis Australasia
- ❖ HAE Australasia
- ❖ GARDN (Genetic and Rare Disease Network)
- ❖ Beyond Blue
- ❖ Livewire
- ❖ Australian Red Cross
- ❖ Carers NSW
- ❖ Royal Flying Doctor Service
- ❖ Volunteers Australia
- ❖ Outer west local health district
- ❖ Cancer Council
- ❖ Centrelink
- ❖ University of Western Sydney



## BLOOD DONORS AND THE RED CROSS

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



## PEAK BODY EVENTS

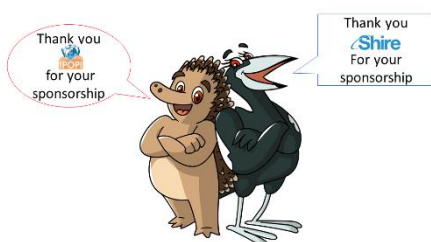
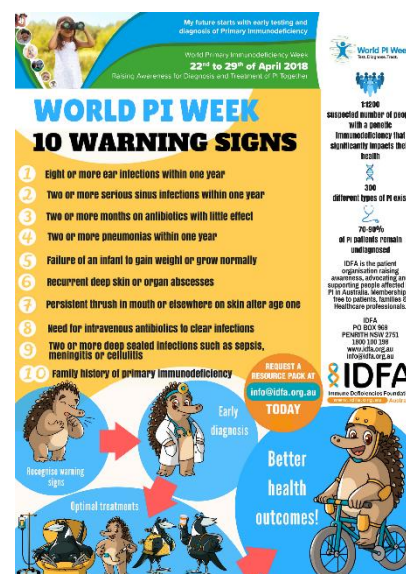
### PROJECT: WORLD PI WEEK

WORLD PI WEEK 22-29 APRIL 2018:

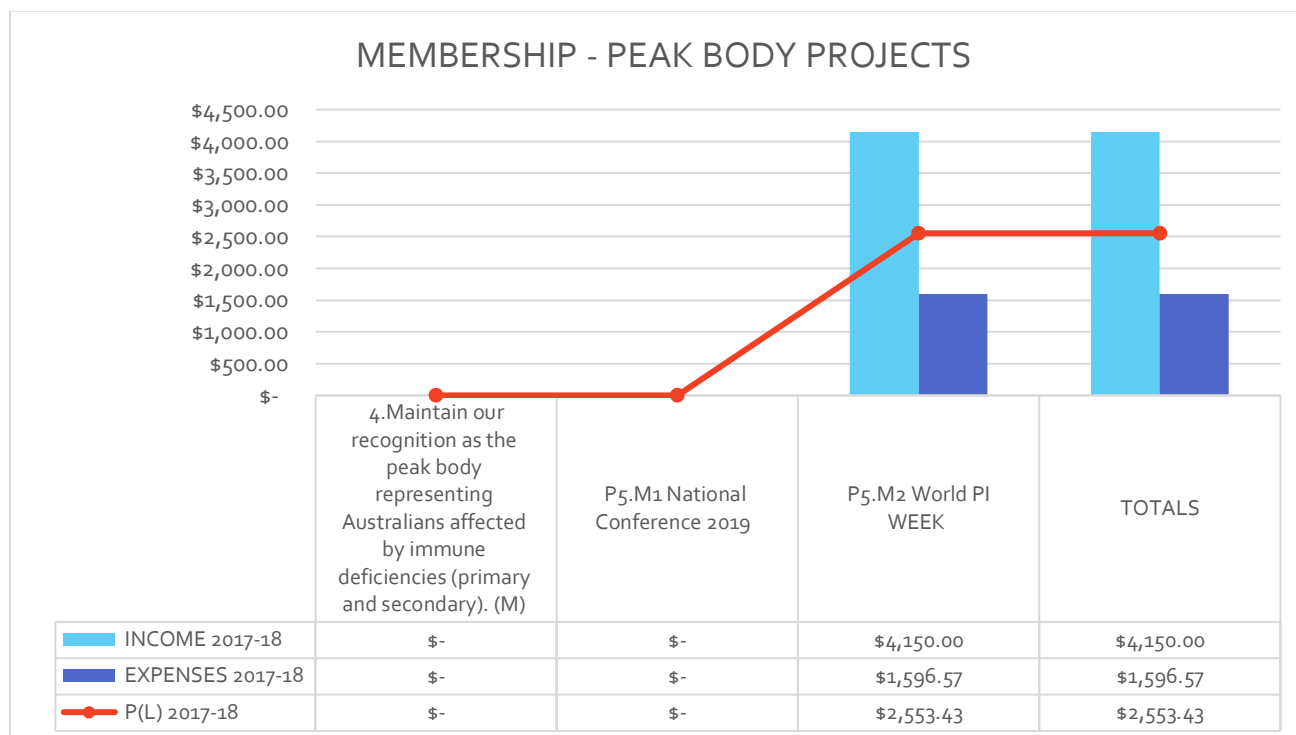
Over 1,000 Warning Signs cards were sent to GPs, Respiratory Physicians, Immunologists and other specialists.

Many posters were distributed to GPs and infusion wards by members.

We had an amazing response from our members for World PI Week this year with over 30 members getting involved by either sharing their story, contacting local media, writing to local members, holding events, selling pins or all of these combined! A huge thank you again from all of us at IDFA for your efforts. IDFA had several events reported in the World PI Week Report. We hope World PI Week 2019 can be even bigger!







## GOAL: AWARENESS

**STRATEGIC OBJECTIVE: 5. Promote community awareness of the signs and symptoms of IDs.**

### COMMUNITY OUTREACH AND EDUCATION

#### PROJECT: COMMUNITY FORUMS

During 2017-2018:

Christine:

- ❖ spoke at a Carers meeting in Wagga,
- ❖ attended the APSID (Asia Pacific Society for Immunodeficiencies) Congress in Chongqing China,
- ❖ attended the PPTA (Plasma Proteins Therapeutics Association) meeting in Washington DC.
- ❖ Susan Templeman MP – Meeting
- ❖ **Read all Reports** at [www.idfa.org.au](http://www.idfa.org.au).

Janessa:

- ❖ Catherine King MP – Shadow Health Minister Breakfast Policy Forum
- ❖ Susan Templeman MP – Meeting
- ❖ Jeffrey Modell Foundation – Launch of the Centre for Primary Immunodeficiencies Melbourne
- ❖ Genetic Alliance Quarterly Leadership Meeting - Garvan Institute

Emma:

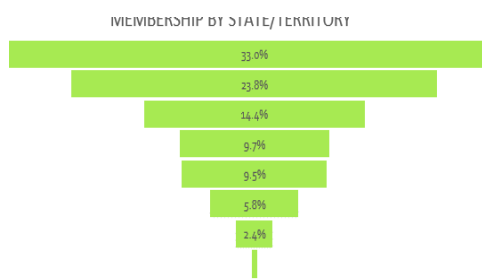
- ❖ Carers NSW
- ❖ Lymphoma Australia
- ❖ Royal Flying Doctor Service



- ❖ Volunteers Australia
- ❖ Outer west local health district
- ❖ NSW Dept Education and Training
- ❖ VIC Dept Education and Training
- ❖ Rare Voices Australia
- ❖ Engaged various National Primary Healthcare Networks
- ❖ Caitlan Bannister – Centre for personalised immunology

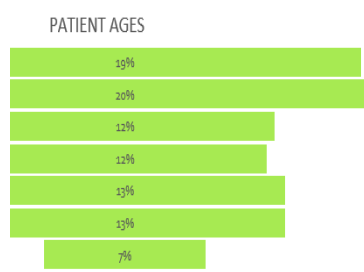
Chloe:

- ❖ Continued her work supporting our members and patients through listening, supporting and practical assistance



## PROJECT: RESOURCES

IDFA have published five new booklets – Secondary Immune Deficiency, Allergies, Infections, Psychological Support and IDFA Strategic Plans. [Order here.](#)

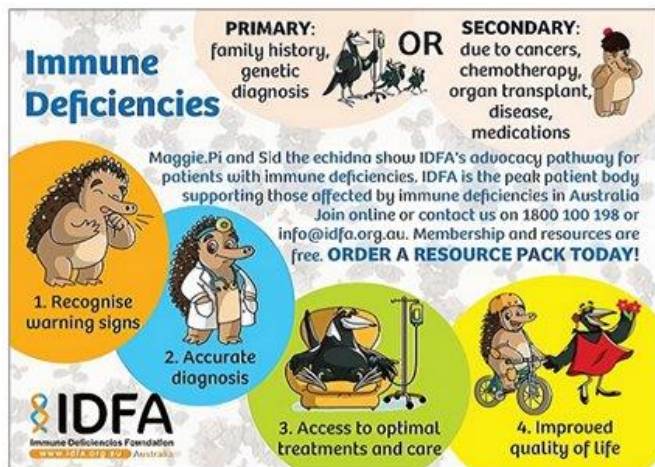


## PROJECT: COMMUNITY EDUCATION

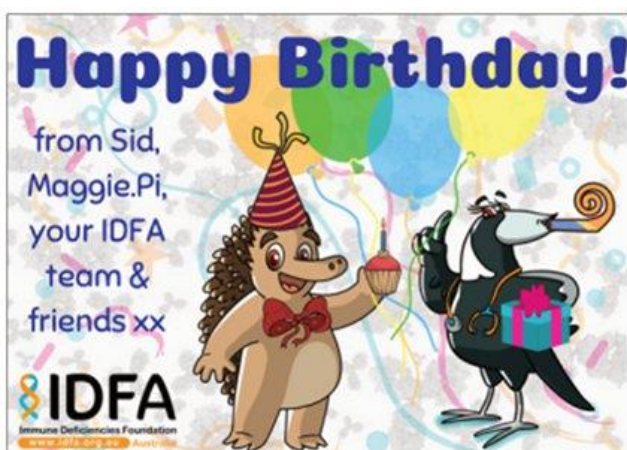
As well as meeting with the community, simple resources such as postcards and posters have been developed for Community education.



- ❖ Healthcare Professionals – postcards, magnets and resource kit



- ❖ Members – thank you card for blood donors, get well cards, birthday cards, resource kits



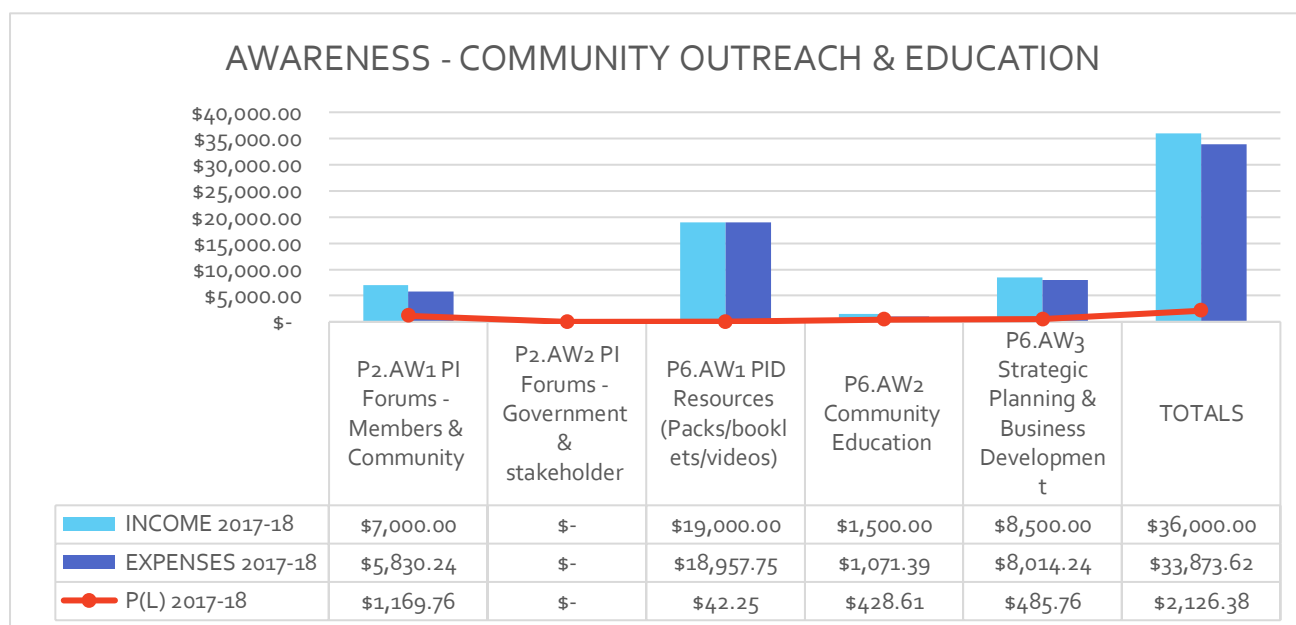


- ❖ Stakeholders – strategic plans booklet, resource kit



## PROJECT: STRATEGIC PLANNING

The Board met in February at the Office to review, develop and discuss IDFA's strategic plans. The Strategic priorities and Constitution were updated, and discussions were held about upcoming projects.

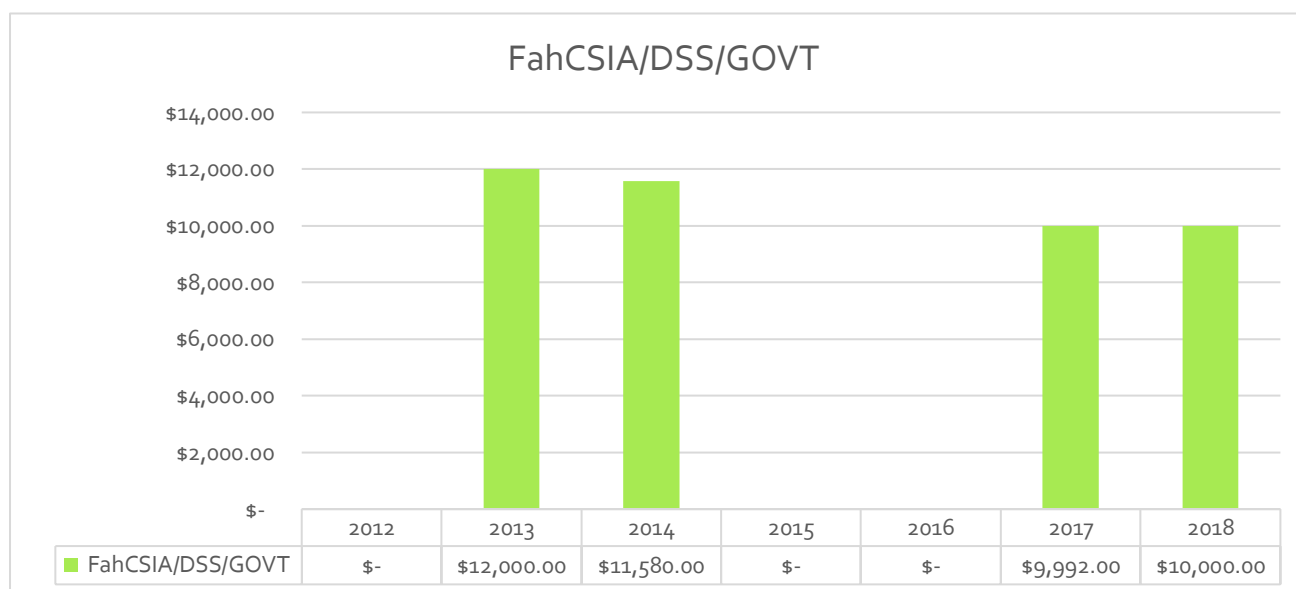


## STRATEGIC OBJECTIVE: 6. Increase financial capabilities to facilitate growth.

### FINANCIAL CAPABILITIES: GOVERNMENT FUNDING

IDFA receives no regular government funding.

This year IDFA were successful in receiving the National Disabilities Conference Funding from Community Grants.



### FINANCIAL CAPABILITIES: GRANTS

#### MAJOR SPONSORS

IDFA's major sponsors for 2017-2018 were:

- ❖ Platinum - CSL Behring
- ❖ Gold - Shire

**CSL Behring**

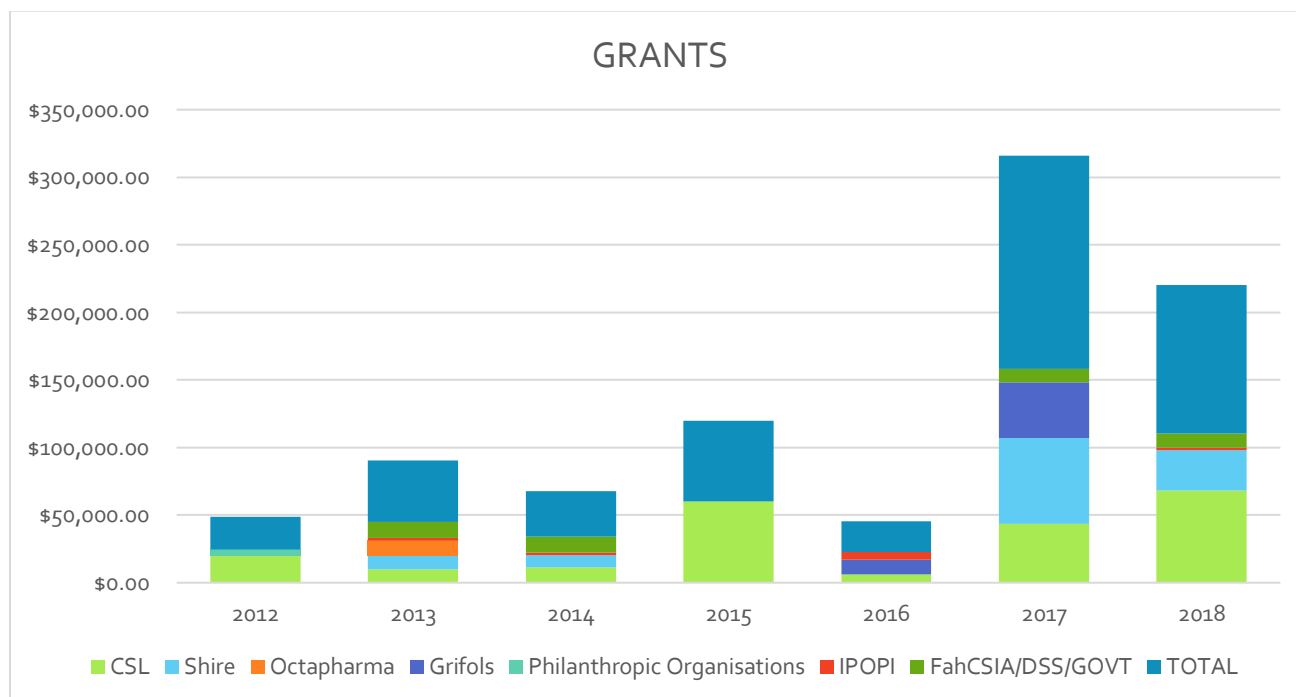
**Shire**

#### 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 2017-2018 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.





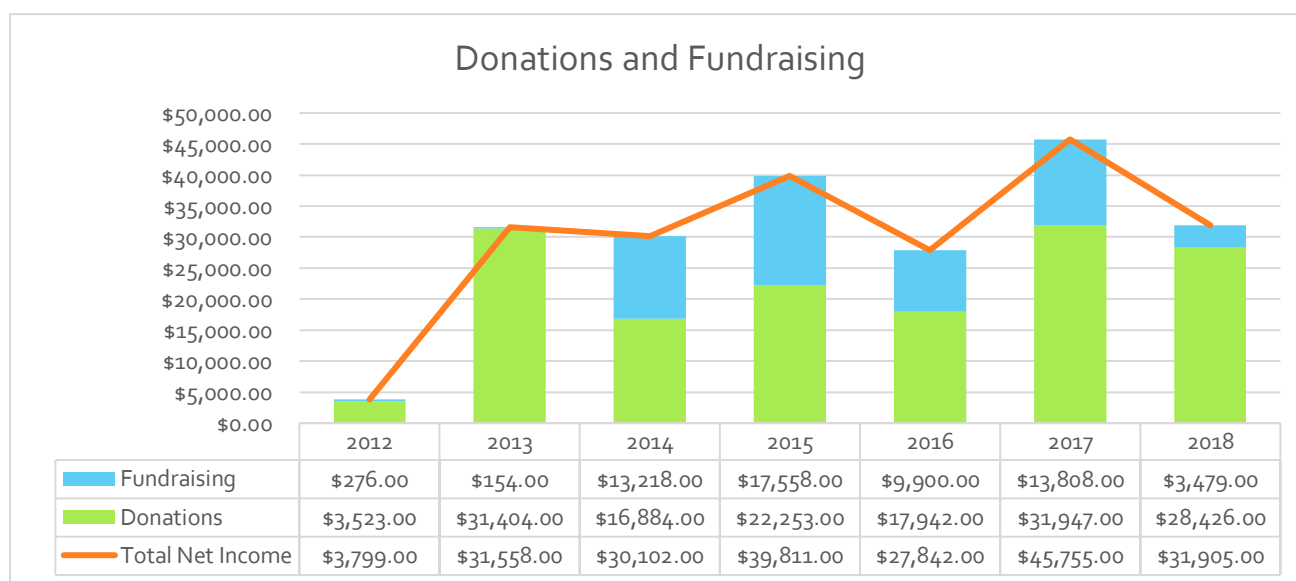


Other sponsors included:

- ❖ DSS
- ❖ IPOPI
- ❖ DPM Computers
- ❖ Nepean Rotary



### FINANCIAL CAPABILITIES: DONATIONS AND FUNDRAISING



## FUNDRAISING AND VOLUNTEERS

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

- Blackmores Bridge run:
  - Ruth Currey
  - Cath Bampton
  - Chloe Appleton
  - Emma Joseph
- Penrith Bunnings BBQ
  - Andrew Jeffery
  - Craig & Julie Mathieson and family
- School Fundraising
  - Emily and Gail Dixon continued their World PI Week Zebra School campaign raising \$1908



- 10-year-old **Quinn Williams** (NSW) raised money and awareness about CVID at his local primary school in support of his mum Anita who was diagnosed with CVID four years ago. He raised \$564 in 3 days through selling stationary, pins and wristbands and presented at his school assembly. Well done Quinn!!



### Quilt raffle

- Sharon Heathfield and her quilting group donated 3 beautiful quilts to be raffled for World PI Week and raised \$530
- World PI Week morning tea
  - Michelle Bowen raised over \$250
- Hughes history book ACT
  - Jenny Tyrrell (over \$1,000)



- Flea's paddle
  - Felicity (Flea) raised \$5,646 on her NSW paddle.



Thank you also to the following volunteers who distribute Immune Deficiency Education Kits and posters to medical centres, hospitals, GPs and Immunology practices:

- Cheryl Cullen
- Jeanette Kavanagh
- Jenny Tyrrell

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



#### OTHER SPONSORS AND DONORS

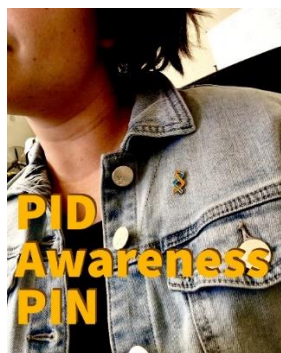
- AtPrint
- DPM Computers
- Rotary Club of Nepean
- Mathieson family
- GoFundraise platform
- Sharon Heathfield – Sharon has made and donated many beautiful quilts to IDFA patients. A patient herself, this gift has brought much joy to IDFA members of all ages



## FINANCIAL CAPABILITIES: 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.



### OTHER MERCHANDISE



## FINANCIAL CAPABILITIES: PROFESSIONAL FUNDRAISER CORPORATE PARTNERSHIP

### 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 \$60-\$65 ea or \$120-\$130 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

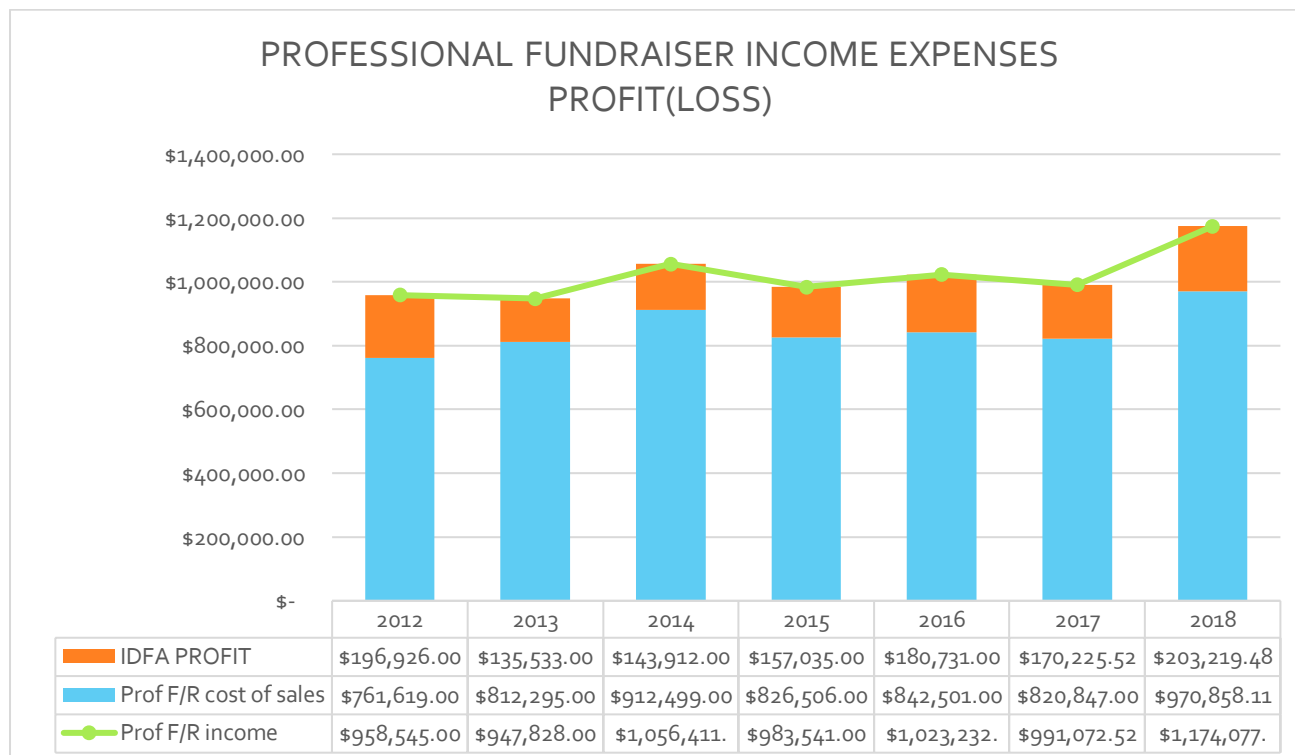
**Razzamatazz** has been touring Australia since 2008. It is a mix of circus, magic, comedy and dazzling dancers in spectacular costumes. It is a great variety show and fun for everyone. The show runs for about 1 hour with no interval. The IDFA shows are run in: CANBERRA, MELBOURNE and PENRITH

## 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.



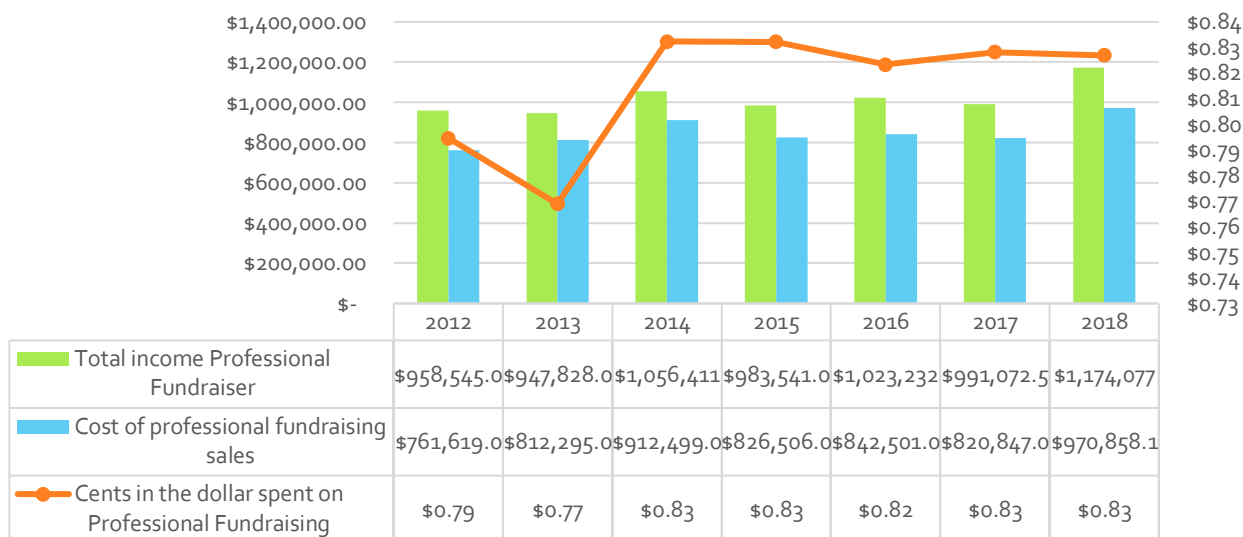
## Expenditure - Professional Fundraiser cost of sales





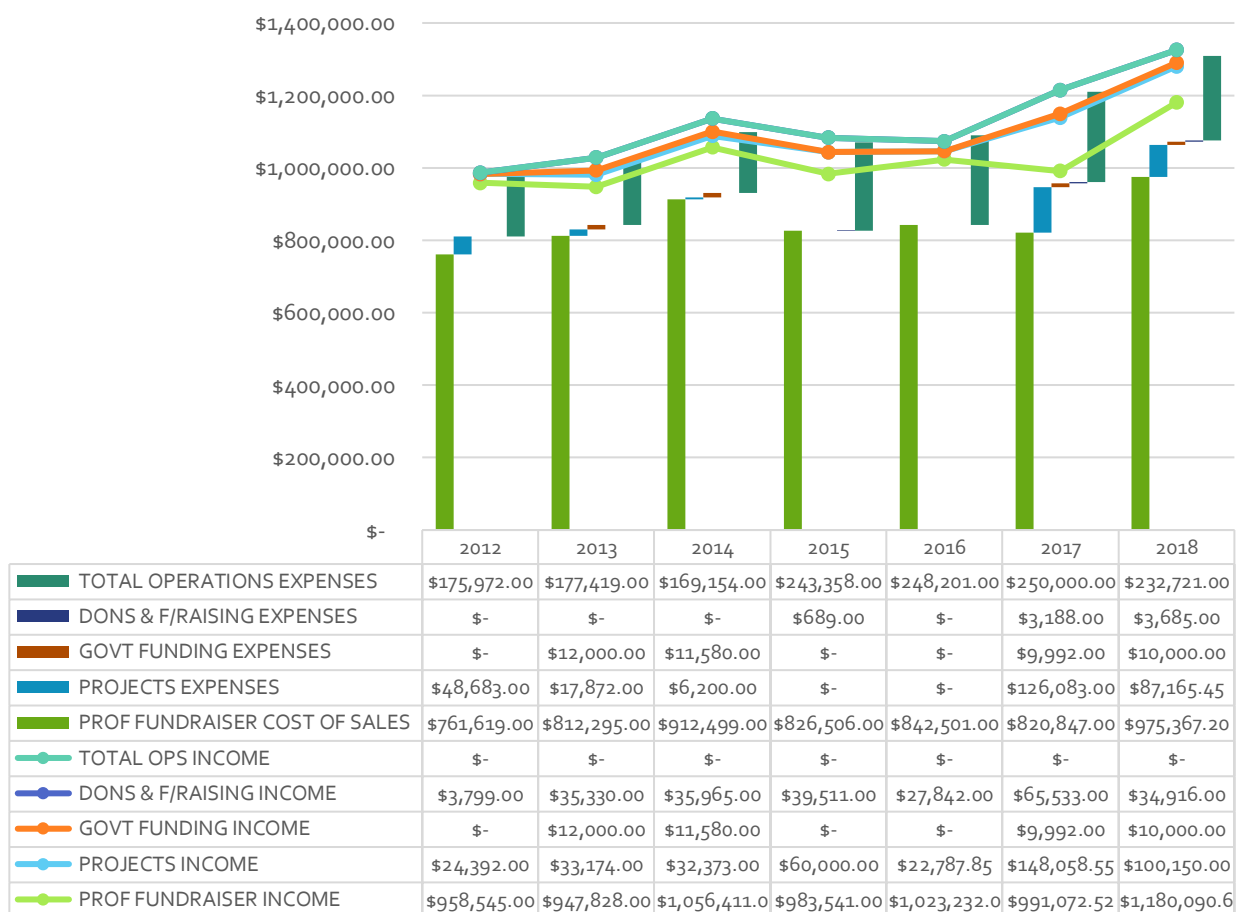
## Expenditure – Cents in the dollar spent on fundraising with professional fundraiser

### Cents in the dollar spent on Professional Fundraising



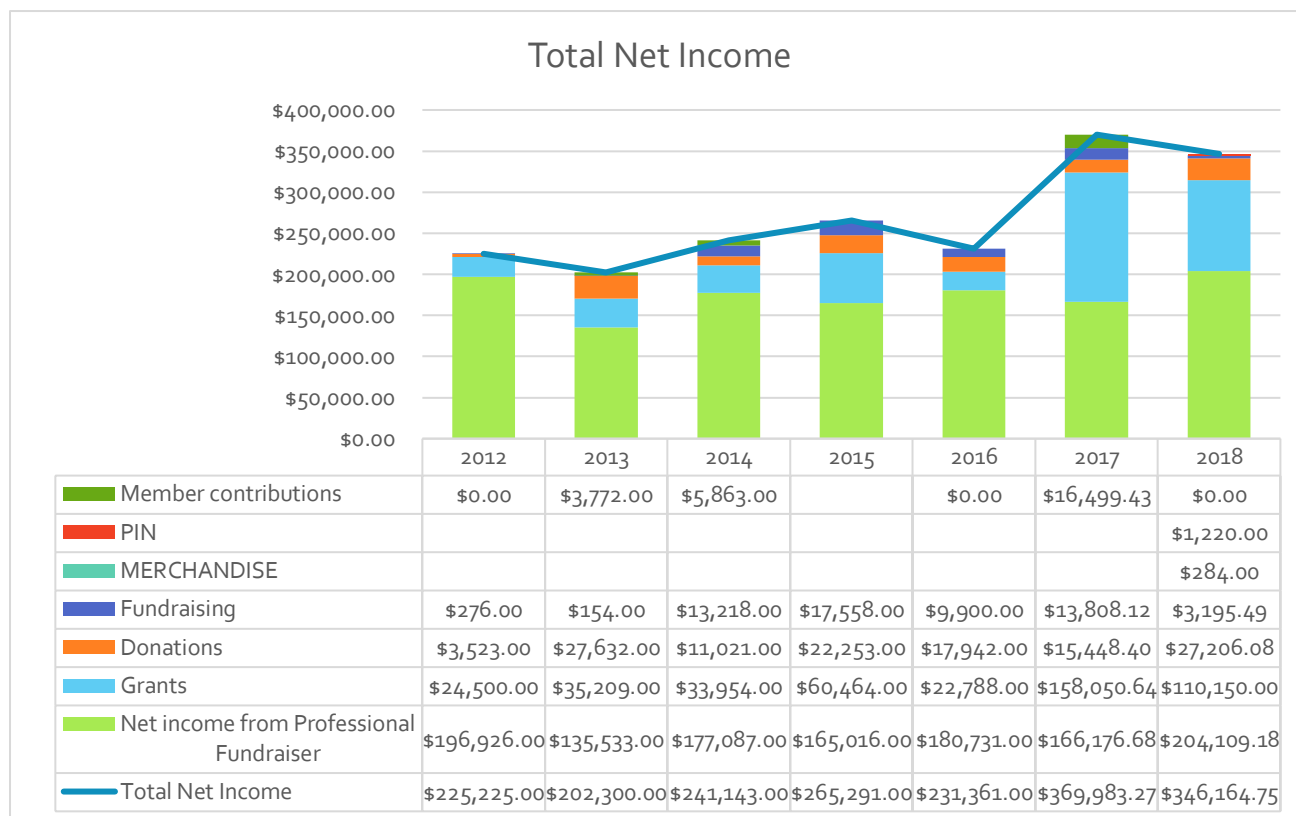
## Summary of Income and Expenses

### INCOME & EXPENSE SUMMARY

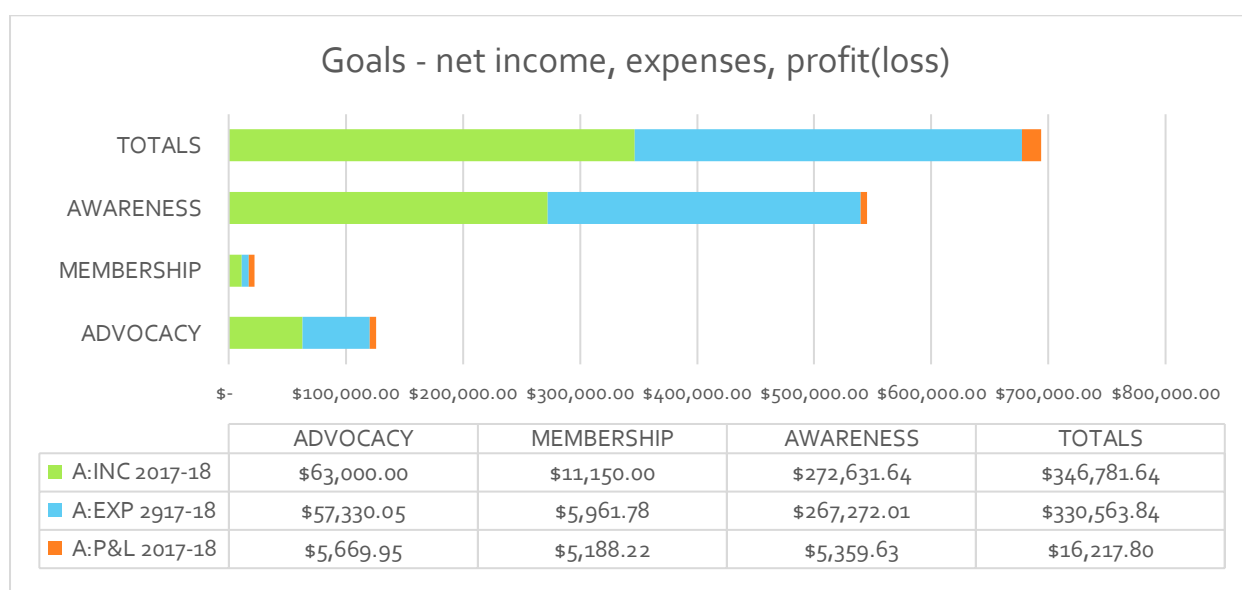


## Summary of total net income

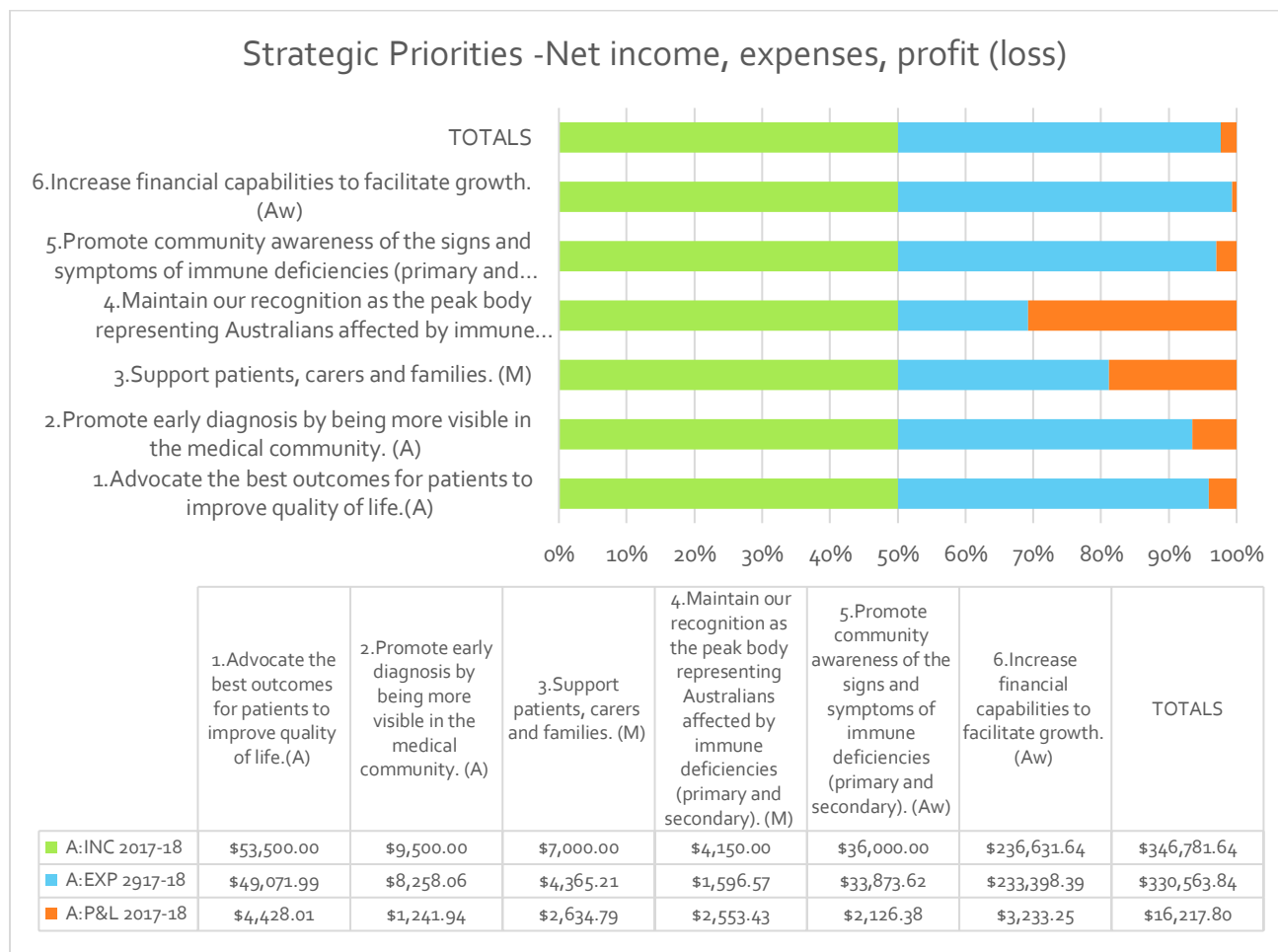
Although financial reporting includes the total income received, the net figure to IDFA is most important and contributes a “true” picture of income received. Although sales have increased, the cost of sales has also increased.



## Income and expenses as goals



## Income and expenses as strategic priorities



## Operational Benchmarks

These ratios measure the performance of each activity.

### Operational benchmarks

#### Activity expense benchmark - Projects

Fundraising expenditure divided by Fundraising income =  $\frac{\$20,029.14}{\$20,500.00} = 98\%$

#### Activity expense benchmark - Professional Fundraiser

Fundraising expenditure divided by Fundraising income =  $\frac{\$970,858.11}{\$1,174,077.59} = 83\%$

#### Activity expense benchmark - Projects

Fundraising expenditure divided by Fundraising income =  $\frac{\$97,165.45}{\$110,150.00} = 88\%$



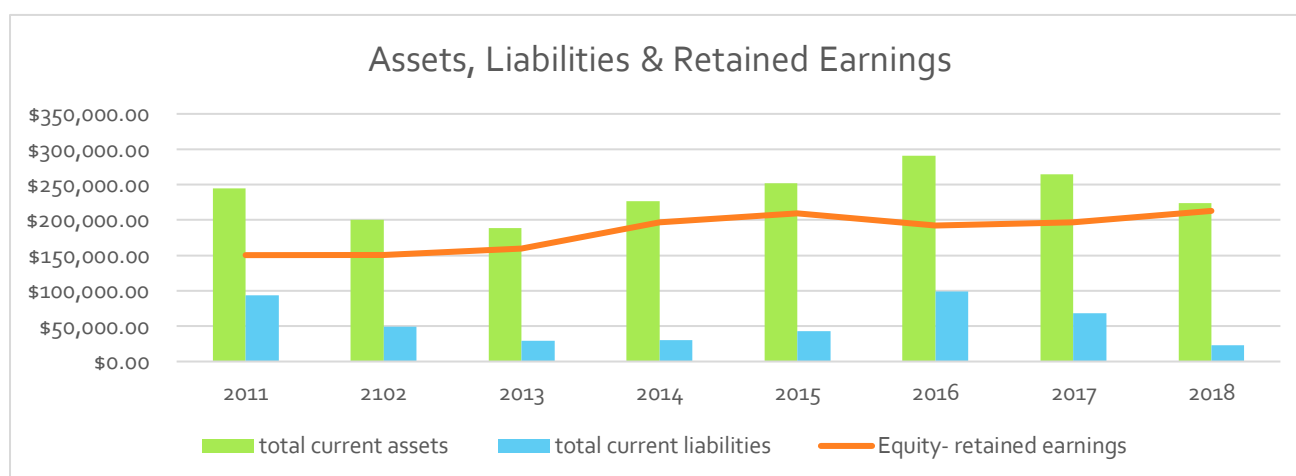
### Activity expense benchmark - Fundraising & Donations

|                                    |             |
|------------------------------------|-------------|
| Fundraising expenditure divided by | \$2,702.69  |
| Fundraising income                 | \$30,401.57 |
| Fundraising expense ratio =        | 9%          |

### Activity expense benchmark - Merchandise & PIN

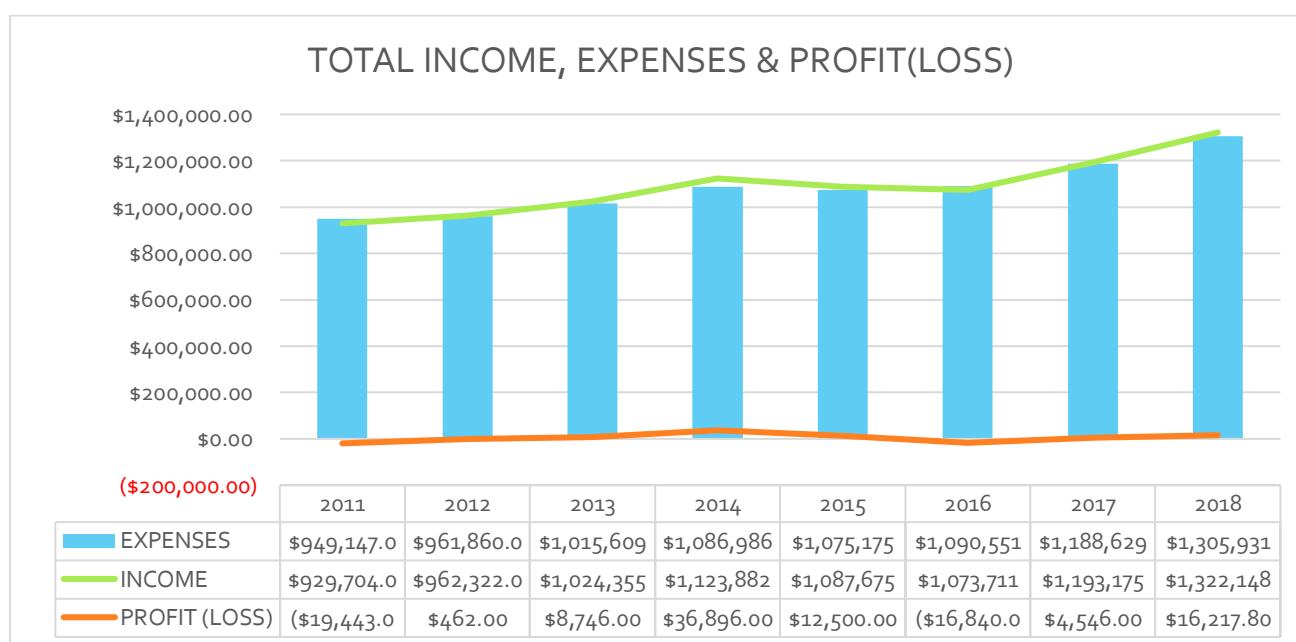
|                                    |            |
|------------------------------------|------------|
| Fundraising expenditure divided by | \$614.30   |
| Fundraising income                 | \$1,504.00 |
| Fundraising expense ratio =        | 41%        |

## Statement of financial position – assets, liabilities and equity

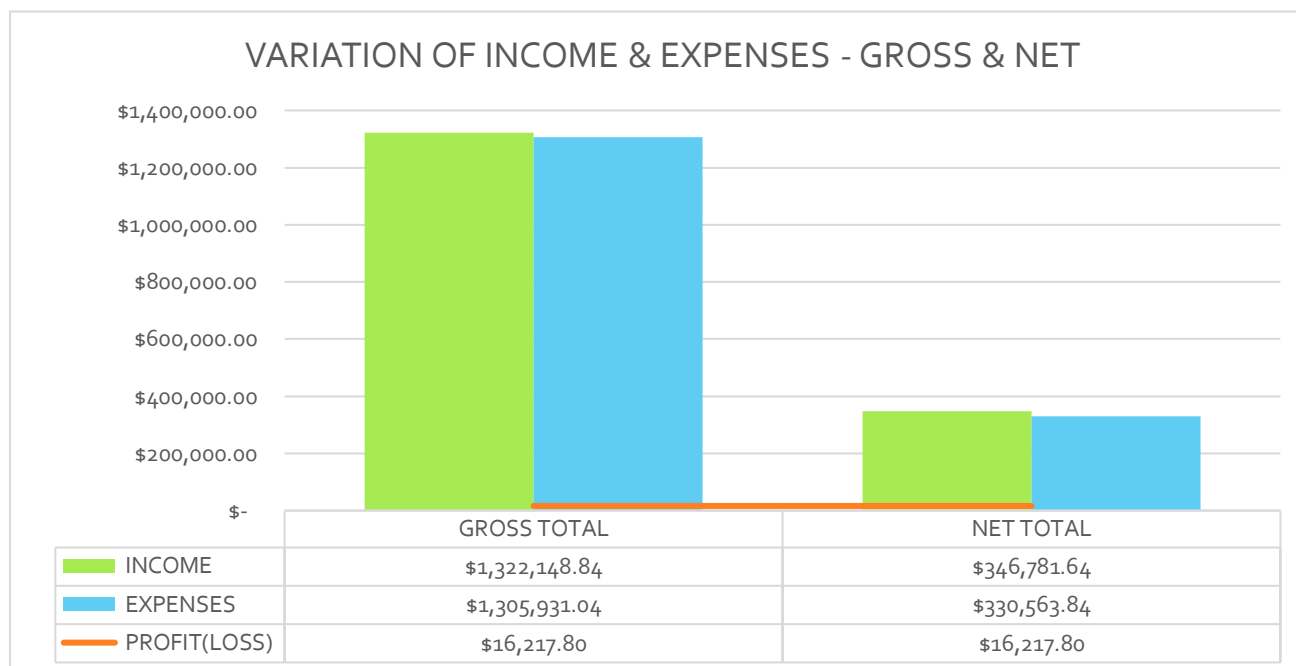


## End of year surplus/deficit

IDFA delivered a profit of \$16,218 in 2017-2018.

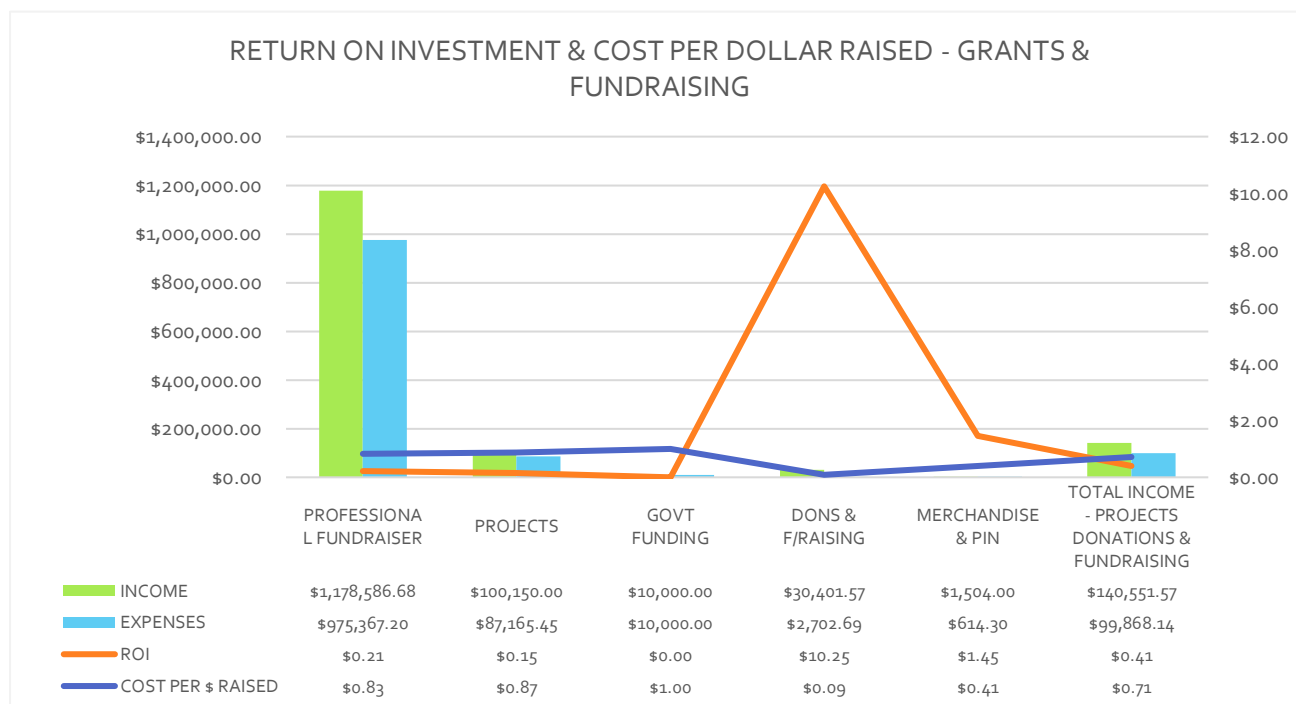


Given the high Cost of Sales from Professional Fundraising, IDFA's Income, Expenses and Profit(Loss) are better portrayed using the gross income from Professional Fundraising.

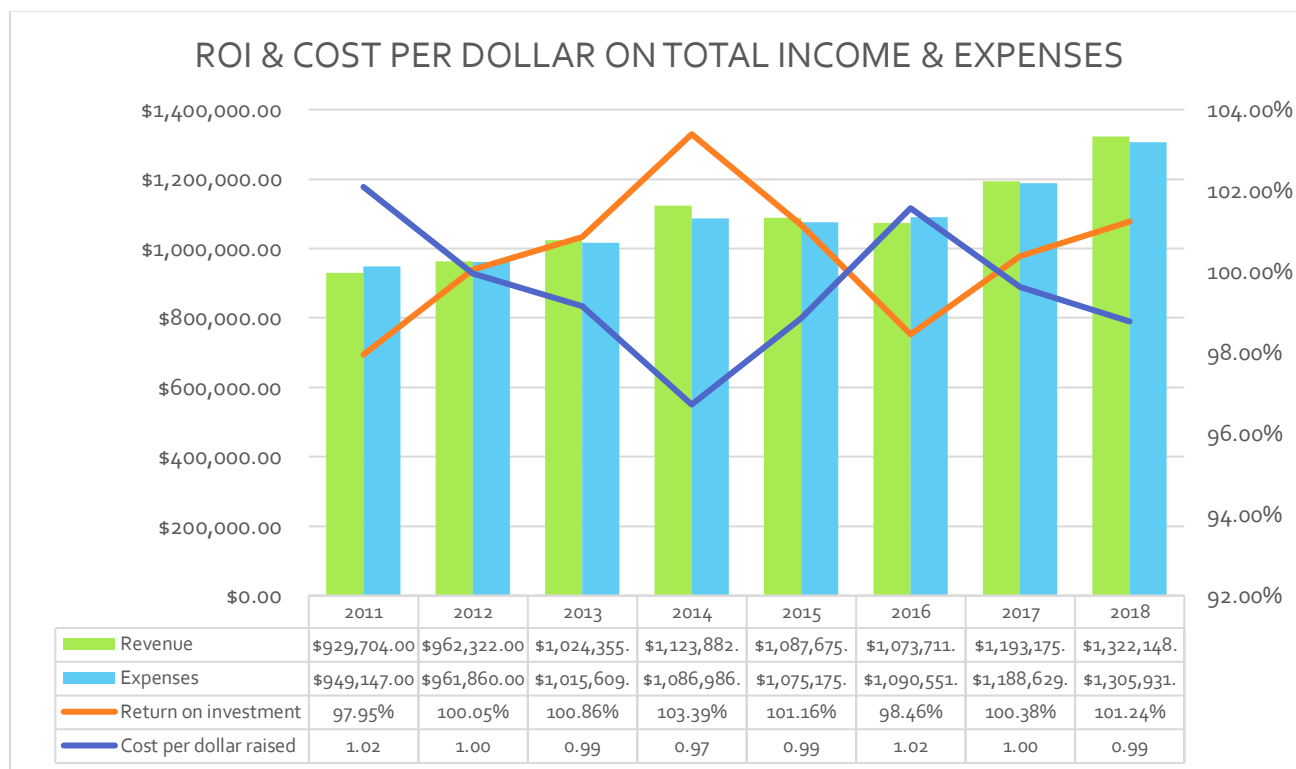


## Return on investment

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 2017-2018.

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:

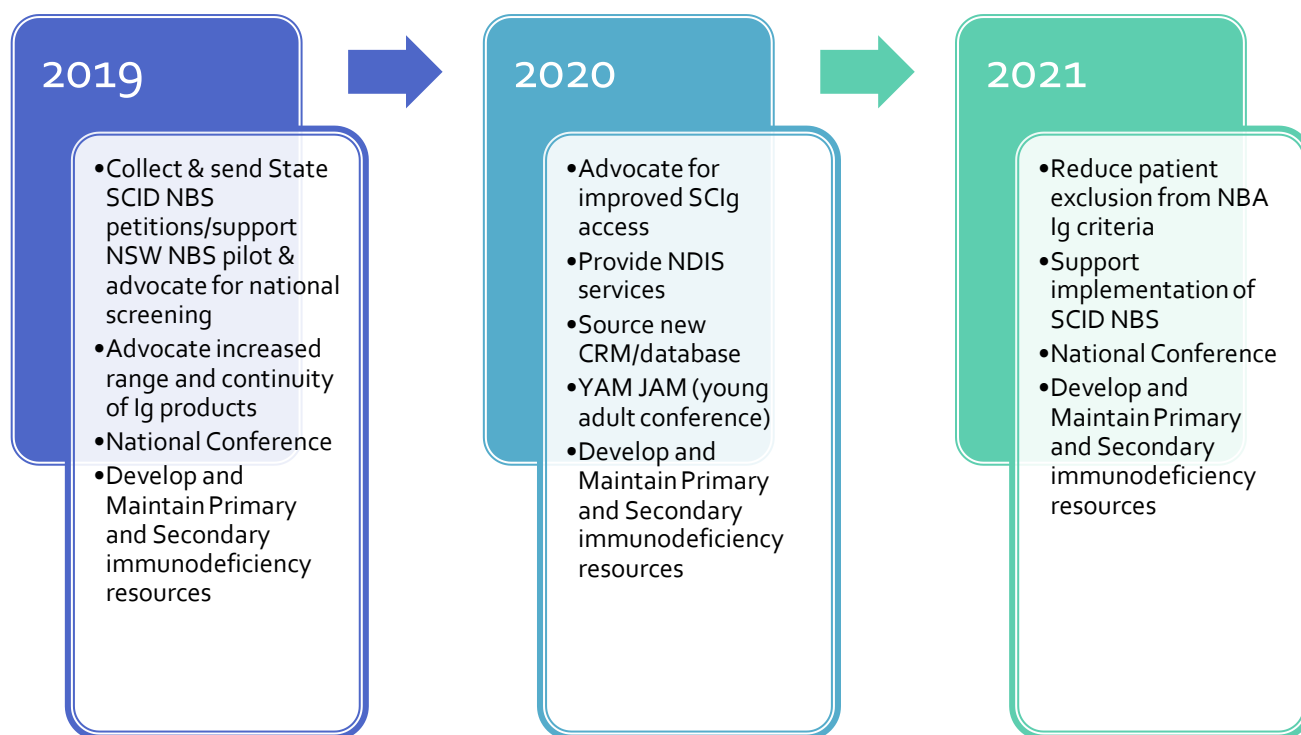
- ❖ Increasing Member resources
- ❖ Focus on business management
- ❖ Collaborating with industry, regulatory bodies and stakeholders

## Strategic priorities moving forward 2019-2021

2018-2019 will focus on:

- ❖ Increasing financial capabilities
- ❖ National Conference
- ❖ 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
- ❖ Advocating for optimum treatment for patients to achieve the best quality of life
- ❖ Advocating for recognition of Primary Immunodeficiencies by Centrelink and NDIS
- ❖ Seeking a CRM to replace the current database
- ❖ Launching a new website





Report by

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