The Immune Deficiencies Foundation Australia

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- Member stories for the IDFA Storybook

Financial Highlights

IDFA made a small profit of $10,055

Operating Highlights

IDFA has demonstrated our commitment to improving quality of life for patients and families through our Objectives of Advocacy, Membership and Awareness. We thank our sponsors, donors and volunteers for making our work possible.

Membership growth

IDFA has nearly 1800 members, consisting of patients, carers, healthcare professionals and stakeholders.

Looking Ahead

In 2019-2020, IDFA will:

- address young adult issues by holding a YAM JAM in 2019-20.
- address junior issues by holding a JPID Activity in 2019-20.
- build on Carers support.
- continue outreach to GPs and other healthcare practitioners.
- seek new and innovative ways to raise funds to support our current programs.
- Refurbish our database and website.

As the membership growth over the past few years has been vast, IDFA will make significant improvements to systems, social media, the website and operations in the next few years.

Christine Jeffery
CEO, Immune Deficiencies Foundation Australia

COMPANY PROFILE

IDFA is the Peak Patient Body supporting, educating and advocating for people affected by **Primary** (genetic) and **Secondary** (caused by cancers, disease, chemotherapy, other treatments or organ transplants) **Immune deficiency diseases** in Australia.

IDFA is committed to raising awareness about Immune Deficiencies, supporting, educating and advocating for improved quality of life for patients, their carers and family members.

Maggie.Pi and Sid the echidna show IDFA's advocacy pathway for patients

STRATEGIC PLANS

Vision

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

Mission

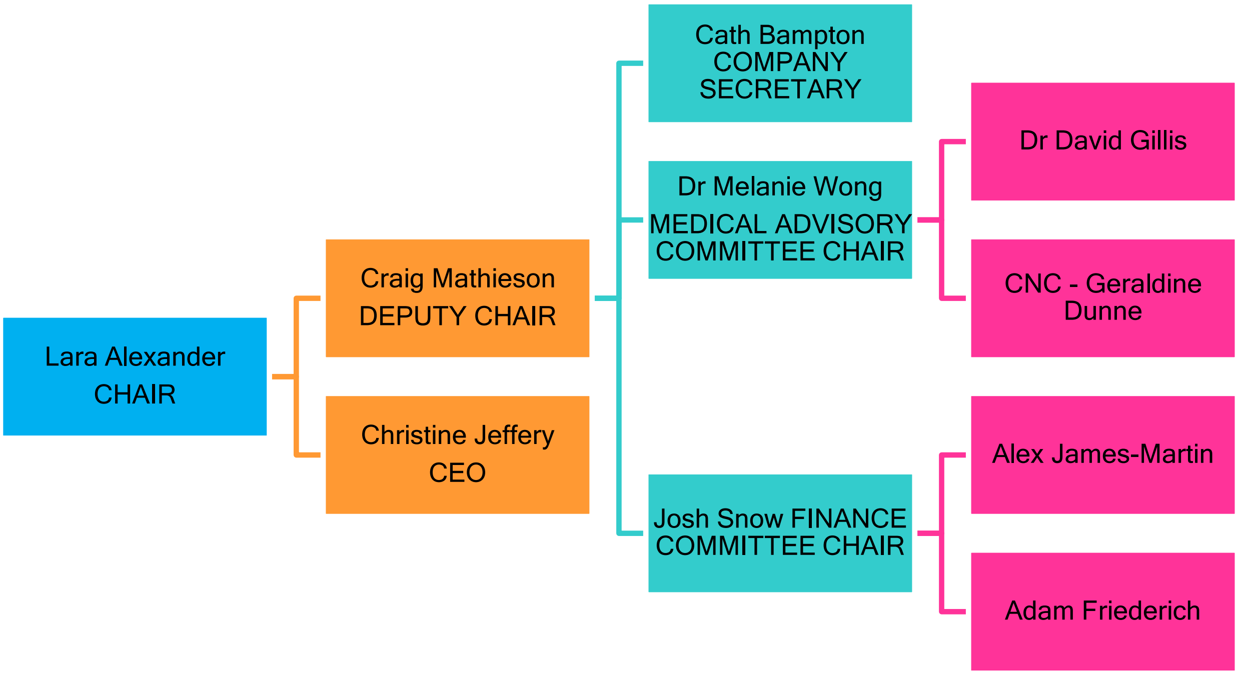
To promote an understanding of immune deficiencies (primary and secondary); link members, their families and medical professionals; and advocate for a better quality of life.

Goals and Strategic Priorities

OBJECTIVES	PRIORITIES
Awareness: We work to increase awareness of immune deficiencies (primary and secondary) in the general and medical community.	1. Advocate the best outcomes for patients to improve quality of life.(Advocacy) 2. Promote early diagnosis by being more visible in the medical community. (Advocacy)
Membership: We acknowledge that unity is strength and our aim is to reach out and support those affected.	3. Support patients, carers and families. (Membership) 4. Maintain our recognition as the peak body representing Australians affected by immune deficiencies. (Membership)
Advocacy: We publicly promote initiatives that will improve quality of life for those affected.	5. Promote community awareness of the signs and symptoms of immune deficiencies. (Awareness) 6. Increase financial capabilities to facilitate growth. (Awareness)

GOVERNANCE

IDFA Board



Two well-loved Board Members resigned this year:

Annette Farrugia and **Richard Price.**

We thank them for their enthusiasm and participation on the Board, and their continuing commitment and support of IDFA and our patients.

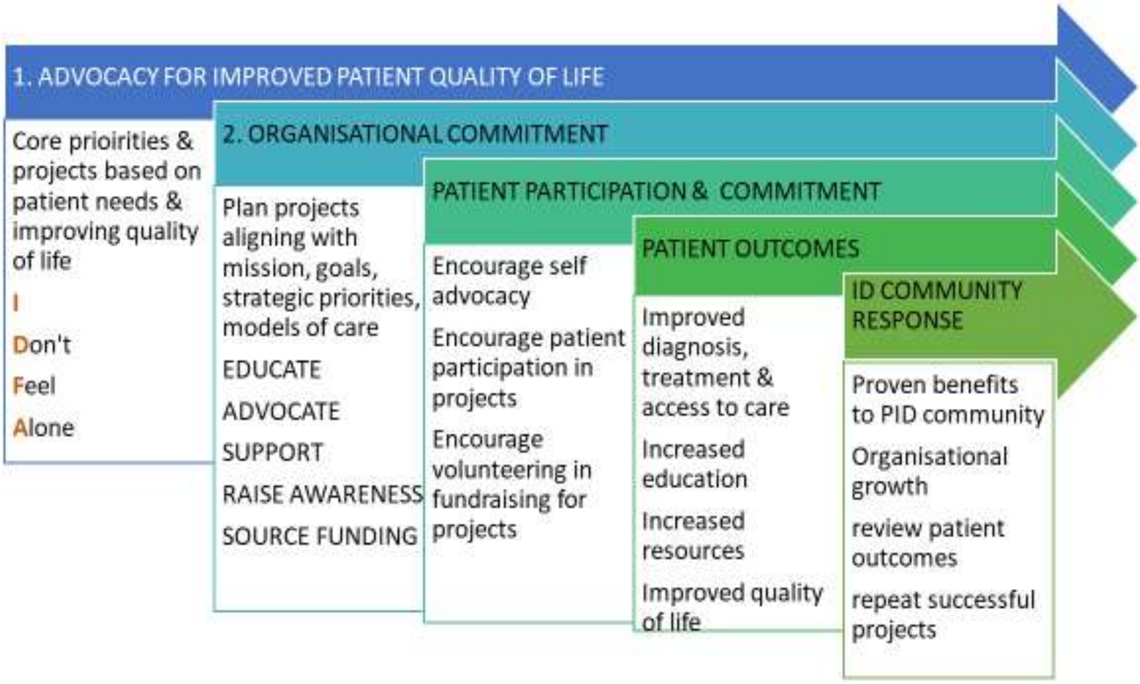
Staff

In the year 2018-2019, IDFA employed:

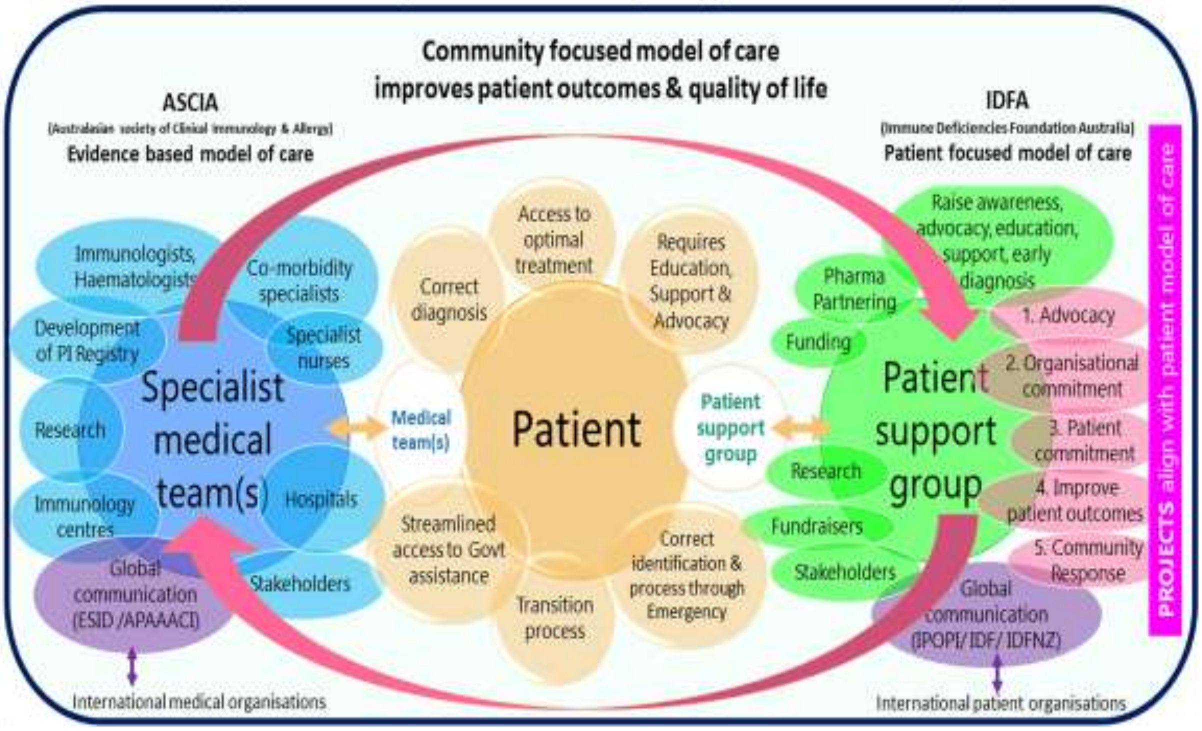
- Christine Jeffery, CEO (FT)
- Chloe Appleton, Member Support (PT)
- Janessa Catto, Community Outreach (PT, resigned Dec 2018)
- Emma Little, Stakeholder and Business Development (PT, resigned Dec 2018)
- Maria Pirovic, Carers and Communications (PT, joined staff Feb 2019)
    - Office Volunteers: Maria Pirovic (2018), Lyn Torkler (2018, 2019)
    - University of Western Sydney Intern: Ashriya Prasad

MODELS OF CARE

Patient focused model of care

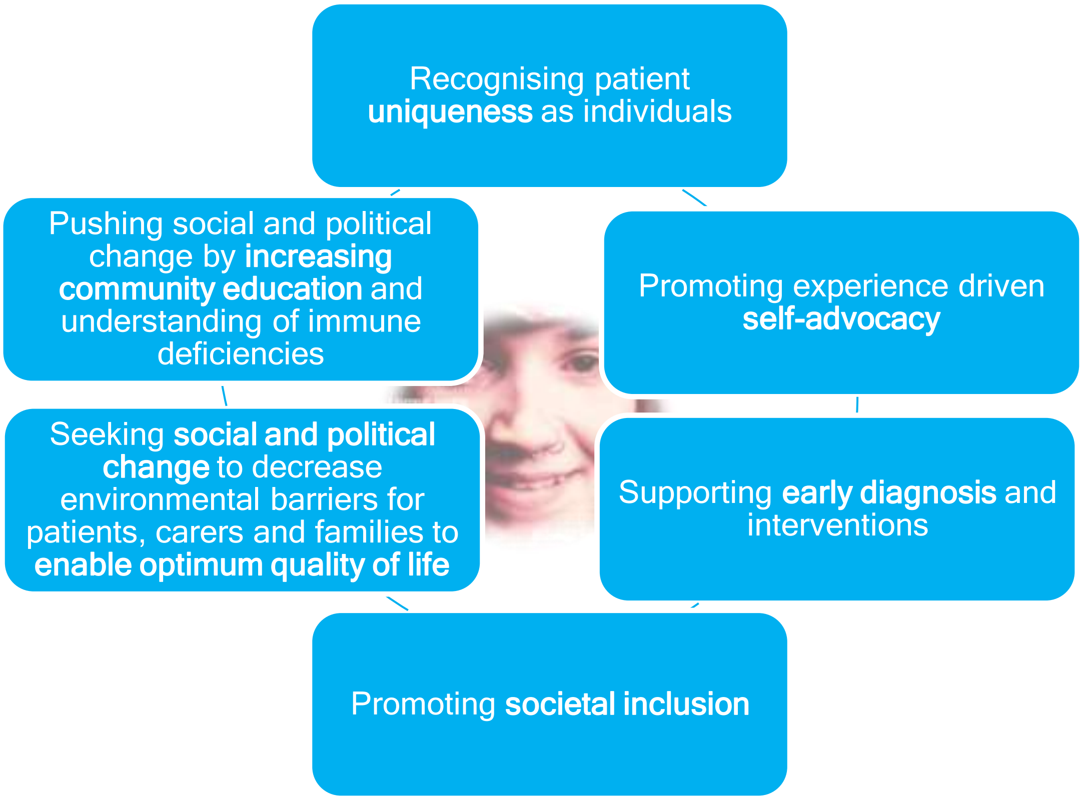


Community focused model of Care



Social model of disability

IDFA’s social model of disability promotes a holistic societal acceptance of immunodeficient patients.



Recognising patient **uniqueness** as individuals

Promoting experience driven **self-advocacy**

Supporting **early diagnosis** and interventions

Promoting **societal inclusion**

Seeking **social and political change** to decrease environmental barriers for patients, carers and families to **enable optimum quality of life**

Pushing social and political change by **increasing community education** and understanding of immune deficiencies

Severe Combined Immunodeficiency.

SCID. The "bubble boy" disease.

SCID took the life of our first son, Zakariya, at 15 months of age in 2014. He went undiagnosed for 13 months. He never made it to his transplant date, which was delayed due to the unavailability of a matched donor.

We isolated our second son, Ismaeel, from birth until he was 2 years old; we converted our home into a bubble, kept him inside and away from other people to protect him from the risk of virus or illness. We washed hands and sanitised and sterilised everything. All. Day. Long. We isolated ourselves so we wouldn't bring any germs home. Our daughter didn't go to school or see other kids for a year and I didn't leave the house, except for hospital visits.

We didn't spend time searching for a donor this time. Ismaeel’s dad donated his cells. A haplo 50% matched transplant was risky, but we had no other option. The processed cells were given as an infusion to Ismaeel at 3 months of age. *We want to raise awareness of the need for bone marrow donors, particularly from non-Caucasian backgrounds as they are severely under-represented on the bone marrow donor registries.*

It has been a long, challenging journey. We have learnt now that his immune system has not fully reconstituted- as of last winter he started monthly immunoglobulin infusions (IVIg) to boost his immune defence. *We are so thankful for all the blood and plasma donors that make his IVIg infusions possible. Newborn screening in Australia for SCID is a MUST!* Both of my sons' newborn screening blood sample cards were used to validate the trial tests for SCID newborn screening. If they help in any way to turn newborn screening for SCID to a reality and that, in turn helps other children be diagnosed early and treated in time- then they are already part of a legacy that is bigger than us.

Javeria

IDFA
Immune Deficiencies Foundation
www.idfa.org.au Australia

“We are so grateful to see Ismaeel grow and thrive, and feel very blessed watching him approach his 4th birthday”

In loving memory of Zakariya

PROFESSIONAL NETWORKS

- International Entertainment (a professional fundraiser)
- ASCIA (Australasian Society for Clinical Immunology and Allergy
- IPOPI (International Patient Organisation for Primary Immunodeficiencies - CEO Vice President)
- ESID (European Society for Immunodeficiencies)
- IDF USA (Immune Deficiency Foundation USA)
- CHF (Consumer Health Forum) - IDFA Chair is on CHF Board
- IDFNZ (Immune Deficiency Foundation New Zealand)
- NBA (National Blood Authority)
- NIGAC Committee (National Immunoglobulin Advisory Committee)
- Ministry of Health NSW
- AIFA (Allergy and Immunology Foundation Australasia)
- 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
- RVA (Rare Voices Australia)
- APON (Australian Patient Organisation Network)
- Genetic Alliance Australia
- JMF (Jeffrey Modell Foundation)
- Australian Immunological Alliance
- National Disability Insurance Agency (NDIA)
- GARDN (Genetic and Rare Disease Network)
- Beyond Blue
- Livewire
- Australian Red Cross
- Carers NSW
- Centrelink
- University of Western Sydney

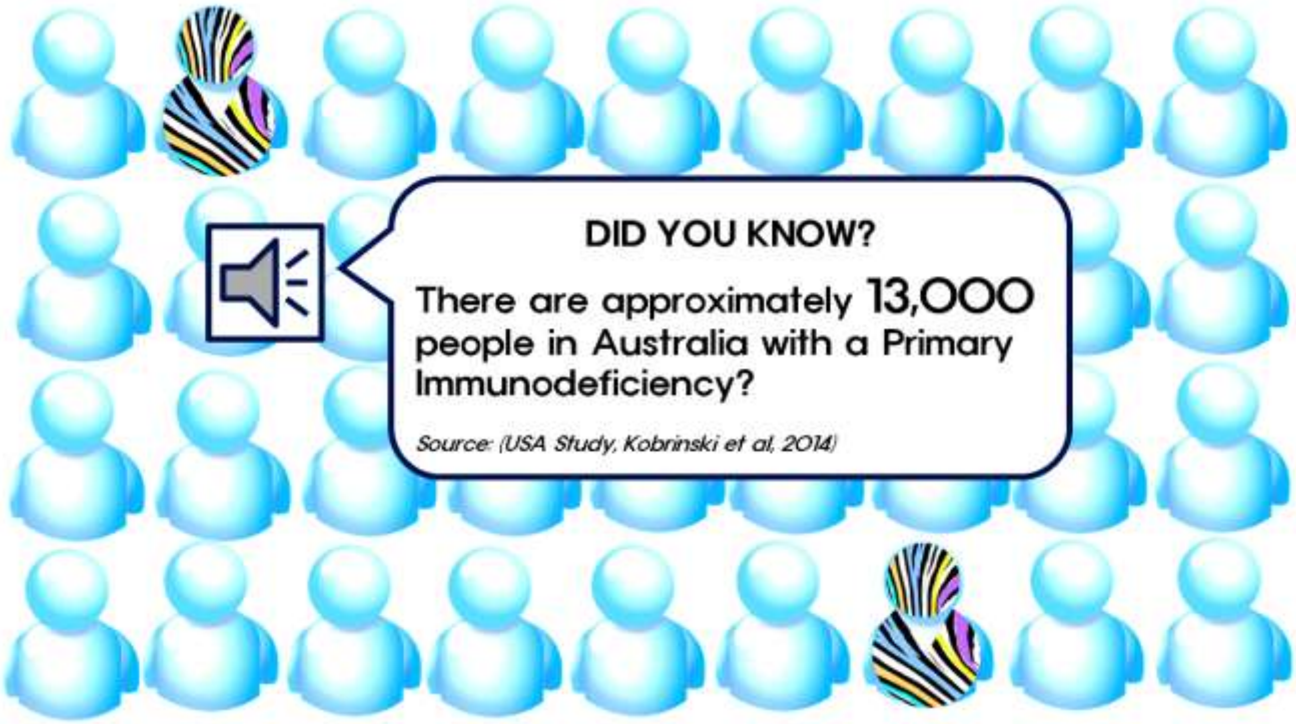
Other Patient Organisation Networks

- HAE Australasia (Hereditary Angioedema)
- ARRC (Autoimmune Research & Resource Centre)
- Arthritis Australia
- Leukaemia Foundation
- Lymphoma Australia
- Thalassaemia Society of NSW
- Mastocytosis Australasia
- Volunteers Australia
- Outer west local health district
- Cancer Council

IMMUNE DEFICIENCIES

Primary Immune Deficiency

- **Primary Immune Deficiencies (PIs)** – relatively new field of diseases (50 years)
- Individually they are **"rare diseases"**
- Over 430 **genetically** diagnosed – majority **no cure**
- **Genetic**: Caused by **defects in the genes** that control the immune system
- People with PIs are born missing some or all the parts of the immune system.
- There is **no cure** for the majority of PIs.
- PI is a **life-long disease requiring life-long treatment**
- The World Health Organization has identified **more than 400 PIs**, ranging from extremely rare (**severe combined immunodeficiency affects one individual in 60,000**) to the more common **selective immunoglobulin A (IgA) deficiency**, which occurs in approximately **one in 500** individuals.
- PI affects at least **10 million people worldwide**
- PI can affect anyone, regardless of age, sex, ethnicity
- Severity varies depending on whether one or several parts of the immune system are affected
- It is estimated that **70 – 80% of PIs remain undiagnosed globally**



DID YOU KNOW?

There are approximately **13,000** people in Australia with a Primary Immunodeficiency?

Source: (USA Study, Kobrinski et al, 2014)

Secondary Immune Deficiency

This is Immunodeficiency caused by:

Malignancy

- Haematological malignancies
- Multiple Myeloma
- Non-Hodgkin’s lymphoma and
- Chronic Lymphocytic Leukemia

Organ transplantation

Other diseases

- Good's Syndrome
- Any lymphomas or cancers of the lymph nodes or immune system
- Protein Losing Enteropathy
- Lymphoreticular Malignancy

Medications

- Corticosteroid, anticonvulsant or immunosuppressive e.g. Rituximab (RTX)
- Chemotherapy

Aging and malnutrition

- Several immune functions become less efficient with aging.

Infectious agents

- Many bacterial, viral and parasitic agents compromise host immune functions

Symptoms of immune deficiency

The main symptom of immune deficiency is increased susceptibility to infections. Particularly the:

- Upper respiratory tract
- Lungs
- Middle Ear
- Sinus
- Skin

These infections can also be in unusual places.
They often require several courses of antibiotic or hospital admission.

People with immune deficiencies also experience a range of comorbidities, such as autoimmune diseases of the bowel, endocrine system and skin.

Treatment – Immunoglobulin replacement

The treatment for most immunodeficiency diseases is **immunoglobulin** replacement therapy (IgRt). This is made from human plasma.
Immunoglobulin replacement therapy is given via intravenous (IVIg) or subcutaneous (SCIg) infusion.

- **Immunoglobulin (Ig) is a lifesaving, lifelong treatment**
- The **World Health Organisation List of Essential Medicines** lists **human immunoglobulin** as a treatment for Primary immune Deficiencies
- Immunoglobulin (Ig) is made from **human plasma**
- Ig **MUST** be considered in a different context to drugs which have generic options as it is a **biological** and **cannot be replaced by a generically derived product**
- Igs have different components and manufacturing processes, so **one brand may suit a patient better than another**
- Australia imports nearly 50% of plasma products **(over 2million grams)**
- To receive immunoglobulin in Australia, a patient must meet the Criteria set by the National Blood Authority.

Treatment – Other

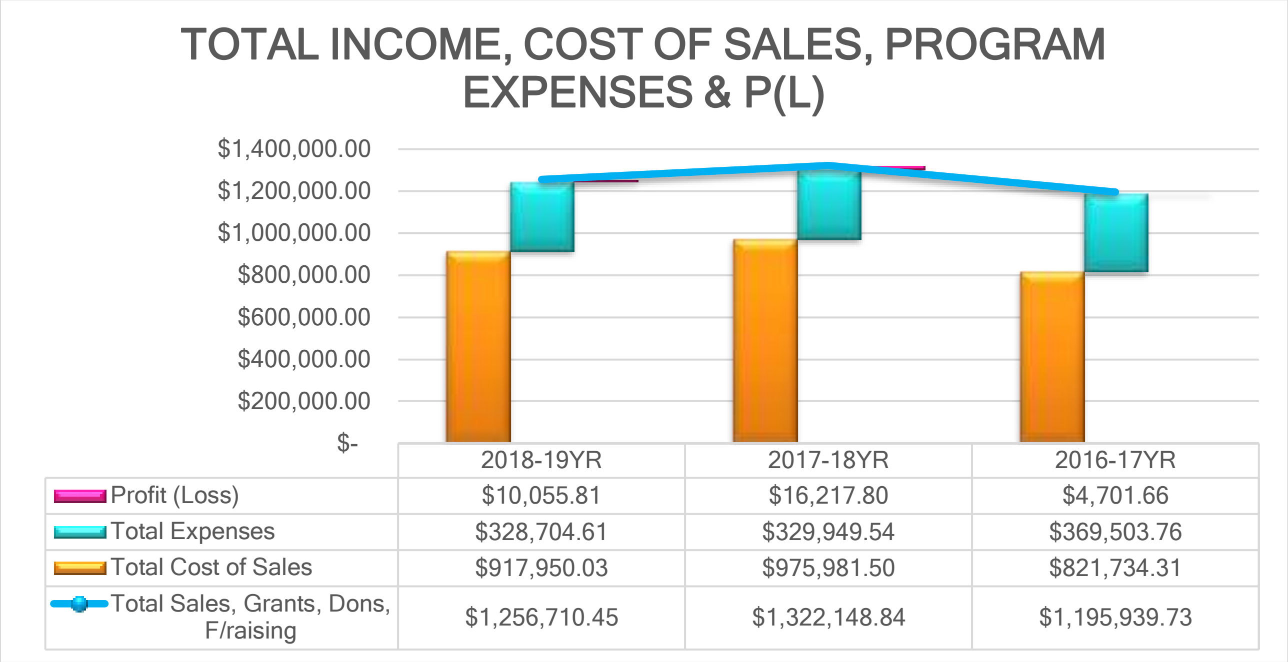
- Gamma interferon injections
- Hematopoietic Stem Cell Transplantation (HSCT)
- Bone marrow transplant
- Gene therapy (new)
- Granulocyte colony-stimulating factor (G CSF)
- Prophylactic antibiotics
- Corticosteroids

FINANCIAL STATEMENTS

IDFA made a small profit of $10,056 in the financial year 2018-19.

Income, COS, Expenses, P(L)

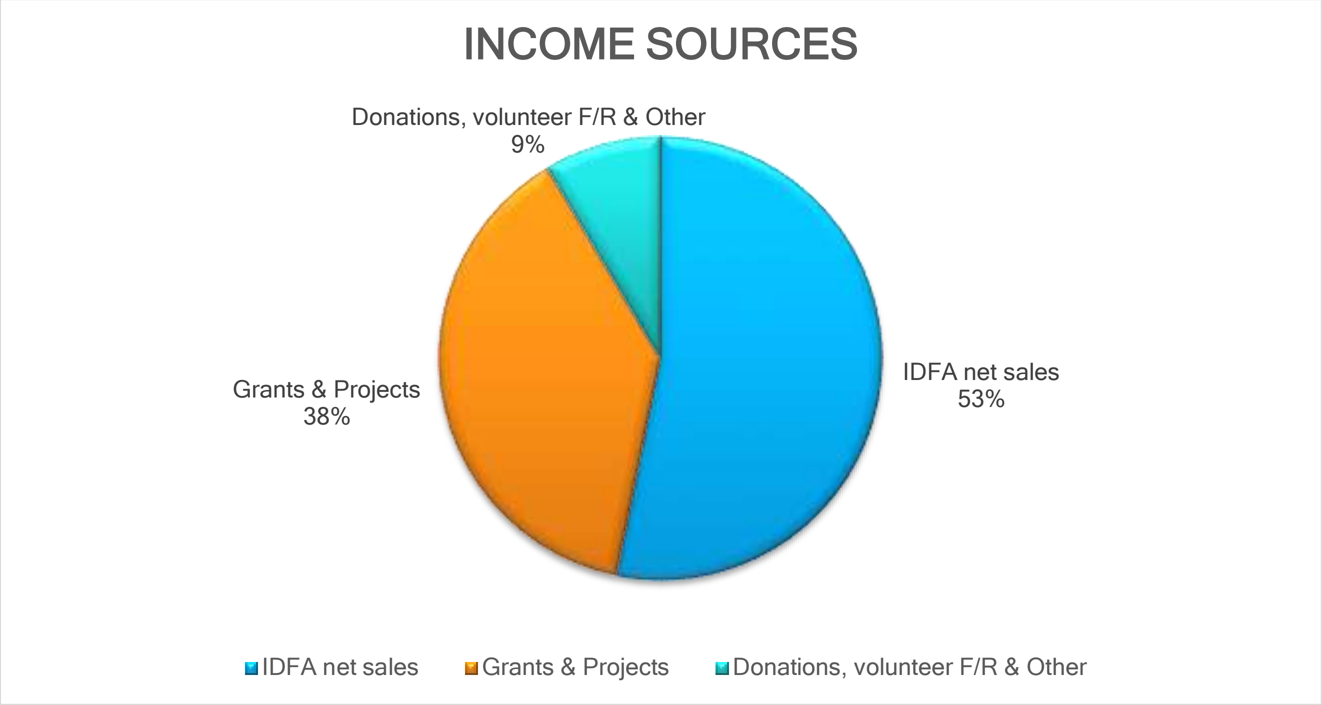
Annual comparison of the Sales Income, Cost of Sales and IDFA net profit from Sales.



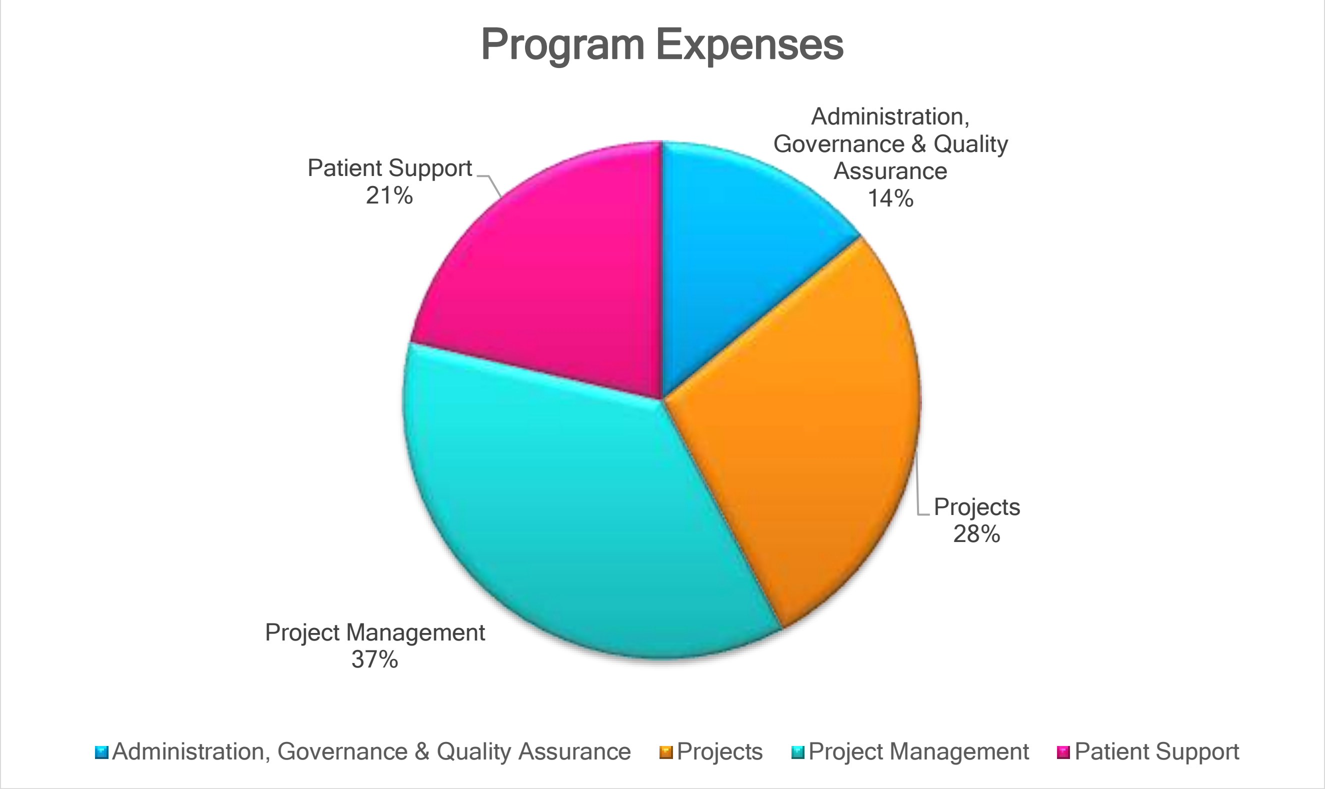
	2018-19YR	2017-18YR	2016-17YR
Profit (Loss)	$10,055.81	$16,217.80	$4,701.66
Total Expenses	$328,704.61	$329,949.54	$369,503.76
Total Cost of Sales	$917,950.03	$975,981.50	$821,734.31
Total Sales, Grants, Dons, F/raising	$1,256,710.45	$1,322,148.84	$1,195,939.73

IDFA’s Audited Financial Statements can be viewed at http://www.idfa.org.au/financial-reports/

Income Sources 2018-2019



Expenses 2018-2019



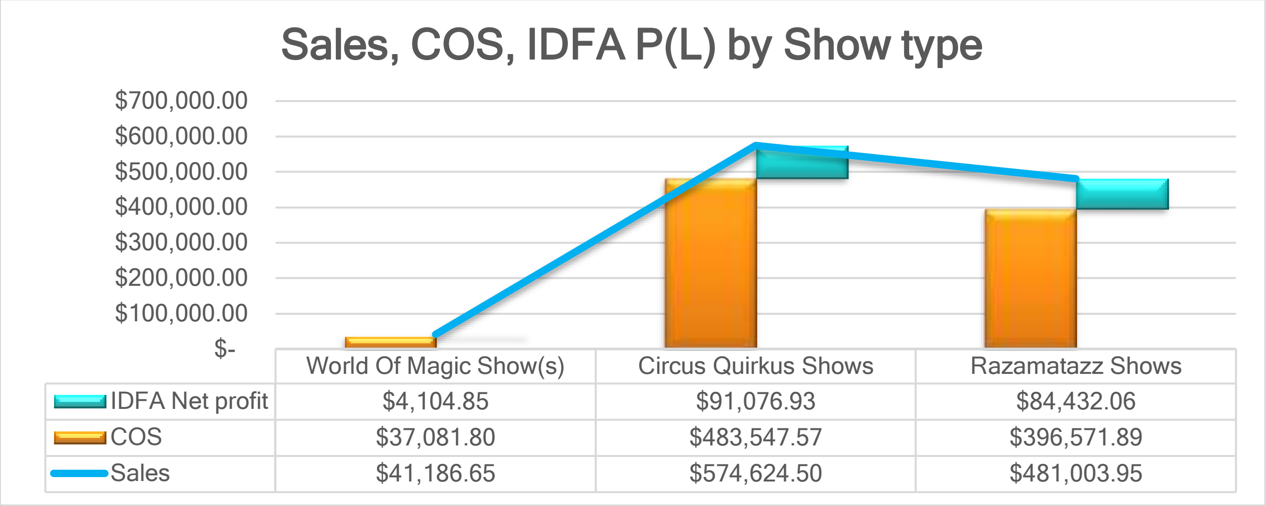
SALES

IDFA fundraises through our Corporate Partner, International Entertainment.
IDFA also fundraises through selling the ID Awareness Pin and Merchandise through volunteers and online.

SOURCE	SALES	COST OF SALES	IDFA PROFIT	IDFA NET PROFIT %
Professional Fundraiser – International Entertainment (IE)	$ 1,096,815.10	$ 917,201.26	$ 179,614.00	16.38%
IDFA PIN and Merchandise sales income	$ 1,314.46	$ 748.77	$ 565.00	42.98%
TOTALS	$ 1,098,129.56	$ 917,950.03	**$ 180,179.00**	**16.41%**

International Entertainment Shows

International Entertainment are a Professional Fundraiser and fundraise on IDFA's behalf by selling tickets to Shows – World of Magic, Circus Quirkus and Razzamatazz. These tickets are distributed to chronically ill and underprivileged children and their carers to attend the show. IDFA holds 13 shows throughout NSW, Victoria, Queensland, Tasmania, South Australia and the ACT.

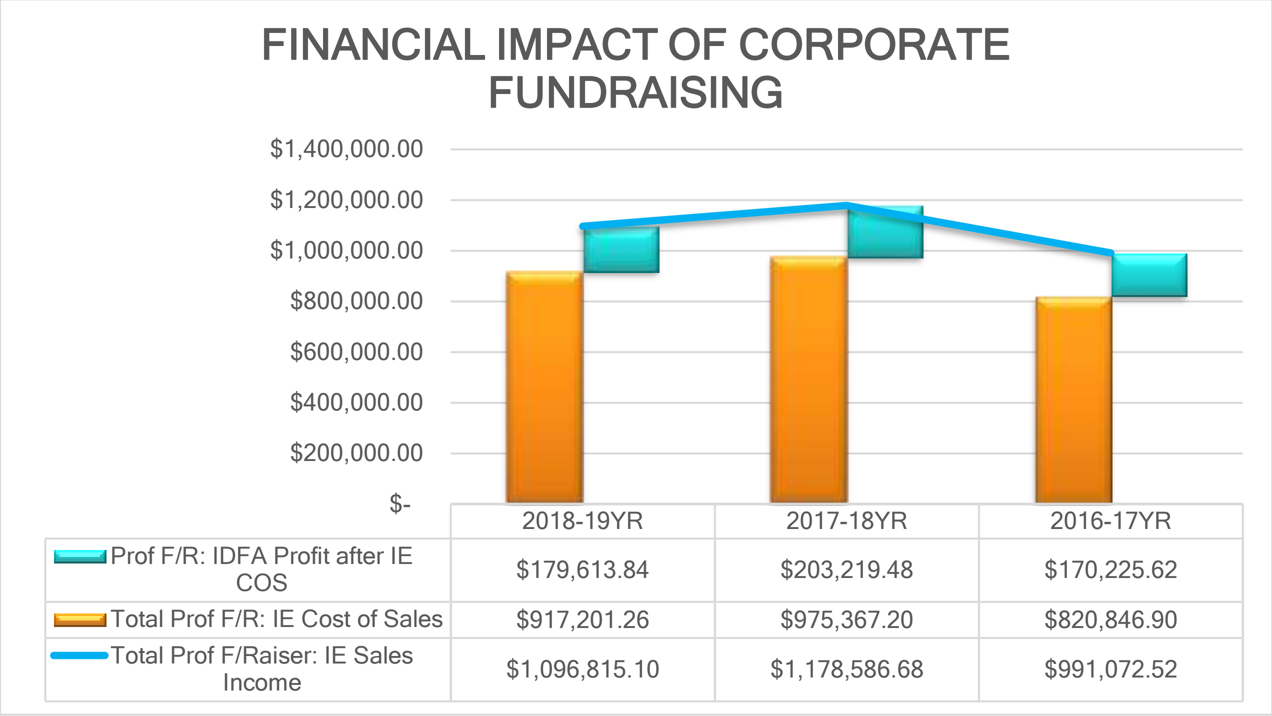


	World Of Magic Show(s)	Circus Quirkus Shows	Razamatazz Shows
IDFA Net profit	$4,104.85	$91,076.93	$84,432.06
COS	$37,081.80	$483,547.57	$396,571.89
Sales	$41,186.65	$574,624.50	$481,003.95

Financial Impact

Financial Impact Corporate Fundraising Sales	% +/- on prev year	2018-2019	2017-2018
Total Prof F/Raiser: IE Sales Income	-7%	$1,096,815.10	$1,178,586.68
Total Prof F/R: IE Cost of Sales	-6%	$917,201.26	$975,367.20
IDFA Net profit from Sales	-13%	$179,613.84	$203,219.48

% decrease due to reduced income on previous year



	2018-19YR	2017-18YR	2016-17YR
Prof F/R: IDFA Profit after IE COS	$179,613.84	$203,219.48	$170,225.62
Total Prof F/R: IE Cost of Sales	$917,201.26	$975,367.20	$820,846.90
Total Prof F/Raiser: IE Sales Income	$1,096,815.10	$1,178,586.68	$991,072.52

Community Impact

Community Impact	% +/- on prev year	2018-2019	2017-2018
Number of chronically ill children & their carers attending the shows	-8%	18,069	19,538
Number of Shows	-8%	13	14
Number of projects supported by IDFA Net profit from IE Sales	0%	25	25

% decrease due to reduced number of shows

Beneficiaries

A total of ***18,069*** *chronically ill and disadvantaged children and their carers attended the IDFA Shows this year!*

Thank you to all the businesses and individuals who sponsored tickets!

Dear IDFA,

Thank you for the tickets. We loved the magic!

IDFA Merchandise


The ID Awareness Pin can be ordered online at: http://www.idfa.org.au/idfa-products-for-sale-2/idfa-pid-awareness-pin/

Merchandise can be ordered online at: http://www.idfa.org.au/idfa-products-for-sale-2/

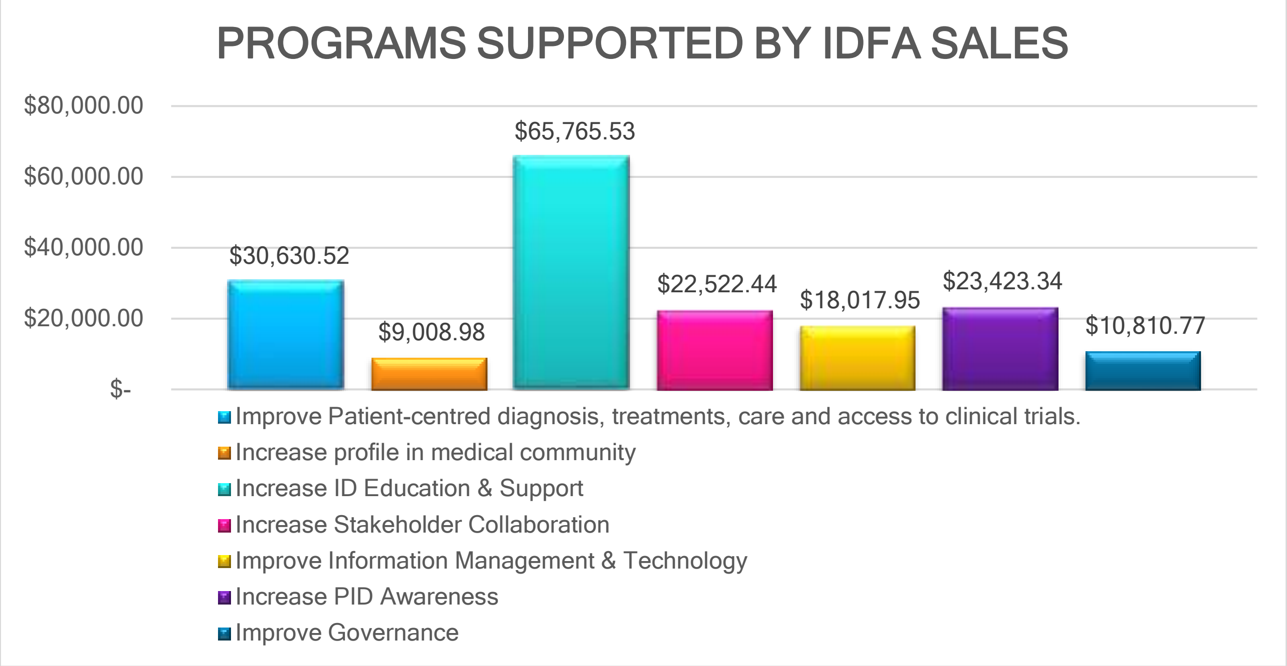
Financial Impact	% +/- on prev year	2018-2019	2017-2018
IDFA Pin and Merchandise Sales	-13%	$1,314.46	$1,504.00

% decrease due to reduced income on previous year

Programs supported by IDFA Sales

IDFA's projects and activities are divided into seven Programs:

1. Improve Patient-centred diagnosis, treatments, care and access to clinical trials.
2. Increase profile in medical community
3. Increase ID Education & Support
4. Increase Stakeholder Collaboration
5. Improve Information Management & Technology
6. Increase PID Awareness
7. Improve Governance



Strategic Priorities supported by IDFA Sales

IDFA's programs are encompassed in six Strategic Priorities

1. Advocate the best outcomes for patients to improve quality of life
2. Promote early diagnosis by being more visible in the medical community
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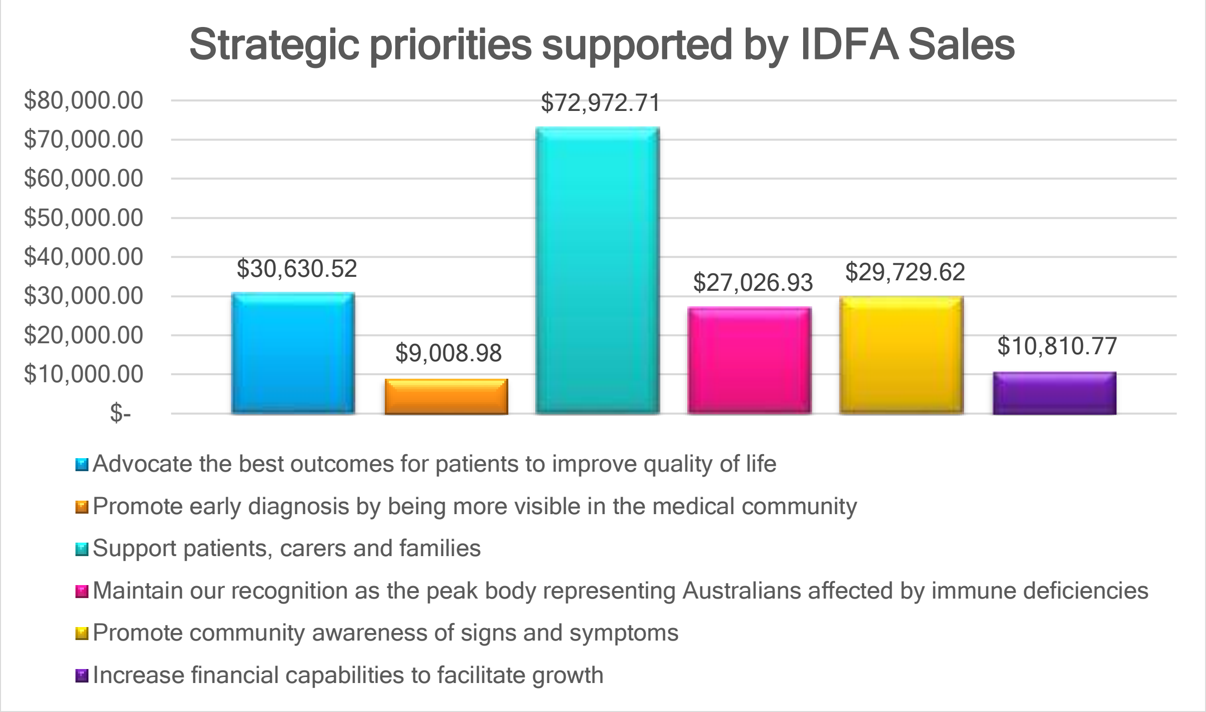
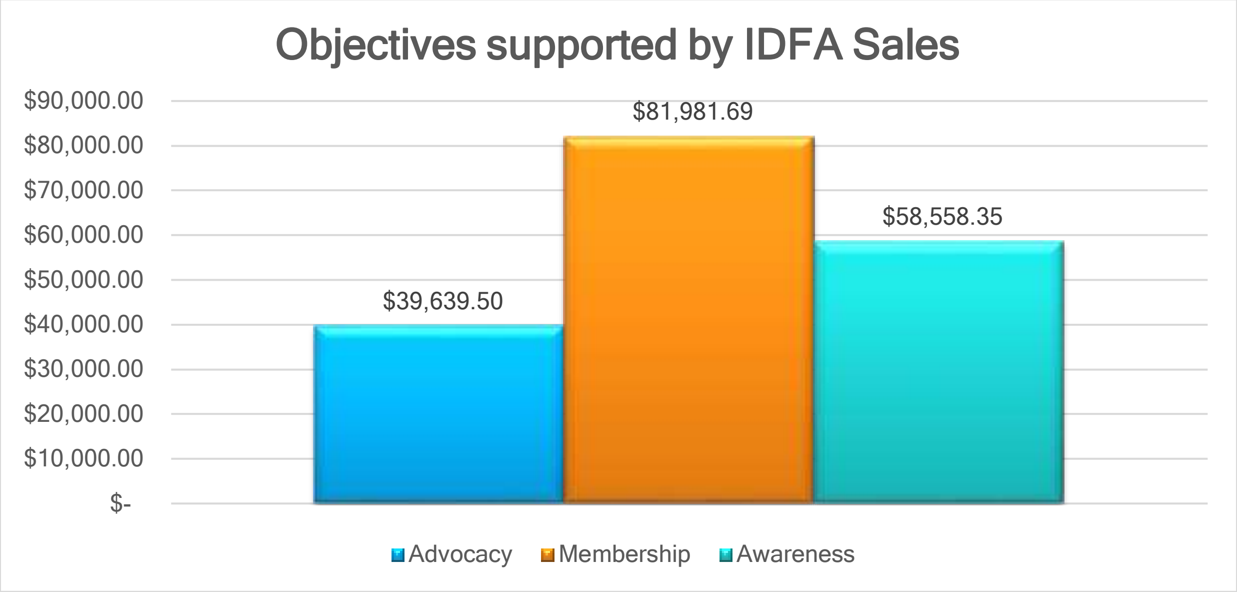
4. Maintain our recognition as the peak body representing Australians affected by immune deficiencies
5. Promote community awareness of signs and symptoms
6. Increase financial capabilities to facilitate growth



Objectives supported by IDFA Sales

IDFA's Strategic Priorities underpin the three main objectives of the organisation:

1. Advocacy
2. Membership
3. Awareness



Financial Impact IDFA Sales	% +/- on prev year	2018-2019	2017-2018
Total Prof F/Raiser: IE Sales Income	-7%	$1,096,815.10	$1,178,586.68
Total Prof F/R: IE Cost of Sales	-6%	$917,201.26	$975,367.20
Prof F/R: IDFA Profit after IE COS	-13%	$179,613.84	$203,219.48
IDFA Pin and Merchandise Sales	-14%	$1,314.46	$1,504.00
TOTAL IDFA NET SALES	-13%	$180,928.30	$204,723.48

% decrease due to reduced income on previous year

Community Impact IDFA Net Sales	% +/- on prev year	2018-2019	2017-2018
Total members supported by IDFA Net Sales	8%	637	590
Total value per member	-18%	$235.84	$287.16
Total member value	-11%	$150,274.48	$169,351.98

% decrease due to membership increasing and income decreasing

Beneficiaries

637 members were supported by IDFA net sales income.

Thank you to International Entertainment, our corporate fundraising partner and all those businesses and individuals who bought tickets to IDFA shows!

GRANTS AND SPONSORSHIPS

IDFA seeks grants and sponsorships from a variety of sources to support our patient programs.

Diamond Sponsor (Corporate Partnership): International Entertainment

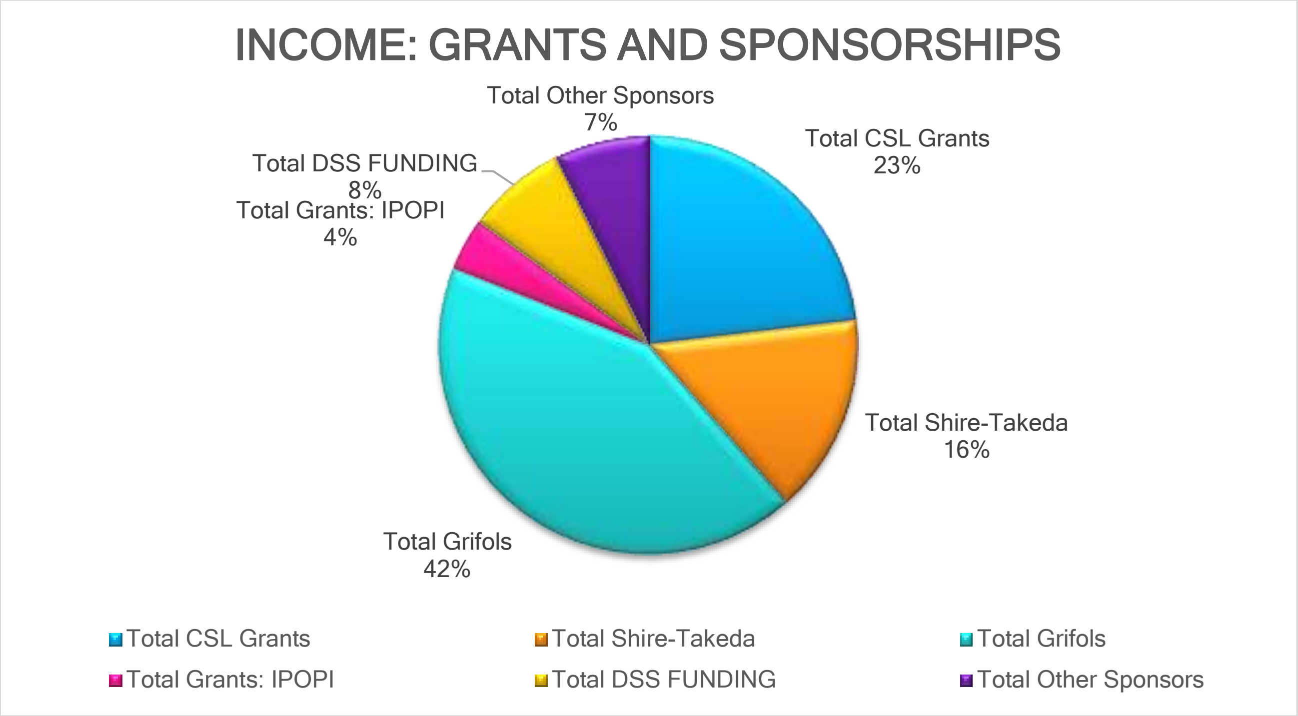
Platinum Sponsor: GRIFOLS

Gold Sponsor: CSL Behring

Silver Sponsor: Takeda - Shire

Bronze Sponsor: Department of Social Services, Australian Government

Iron Sponsor: IPOPI



Programs supported by Grants and Sponsorships

IDFA’s projects and activities are divided into seven Programs:

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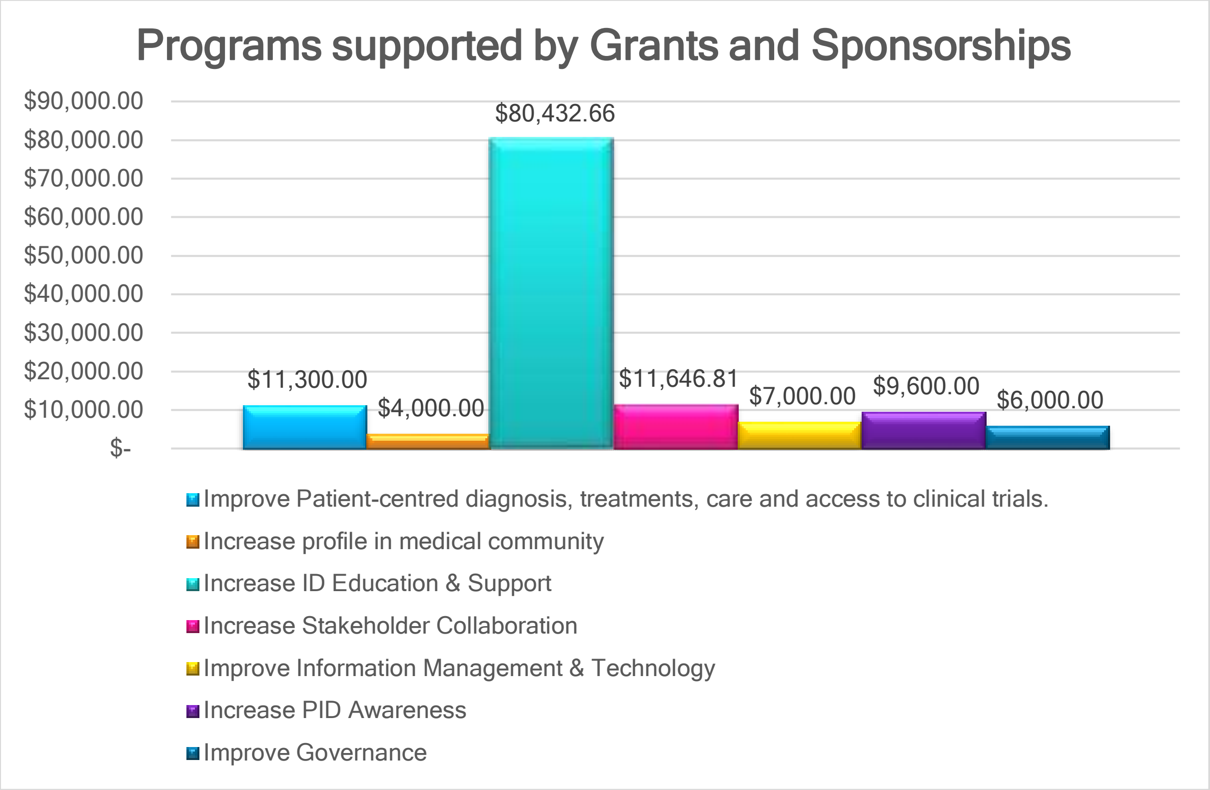

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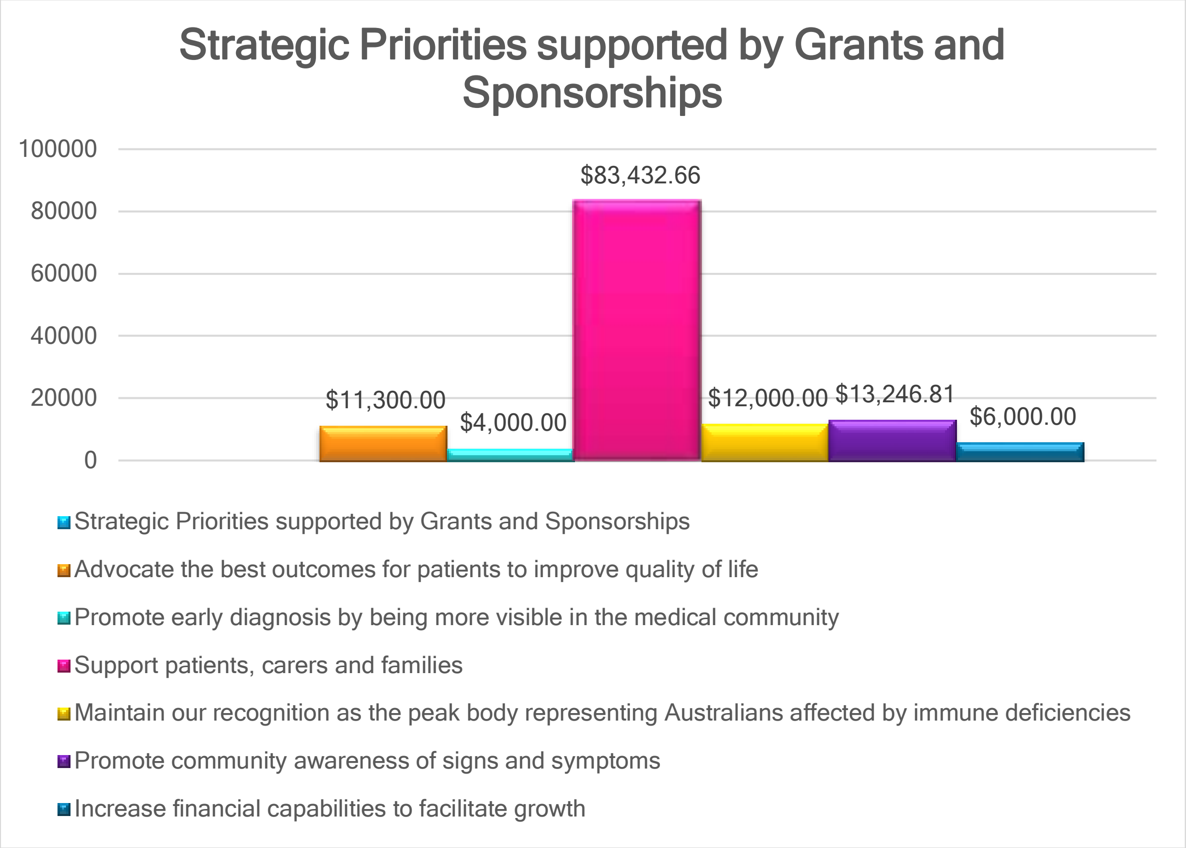

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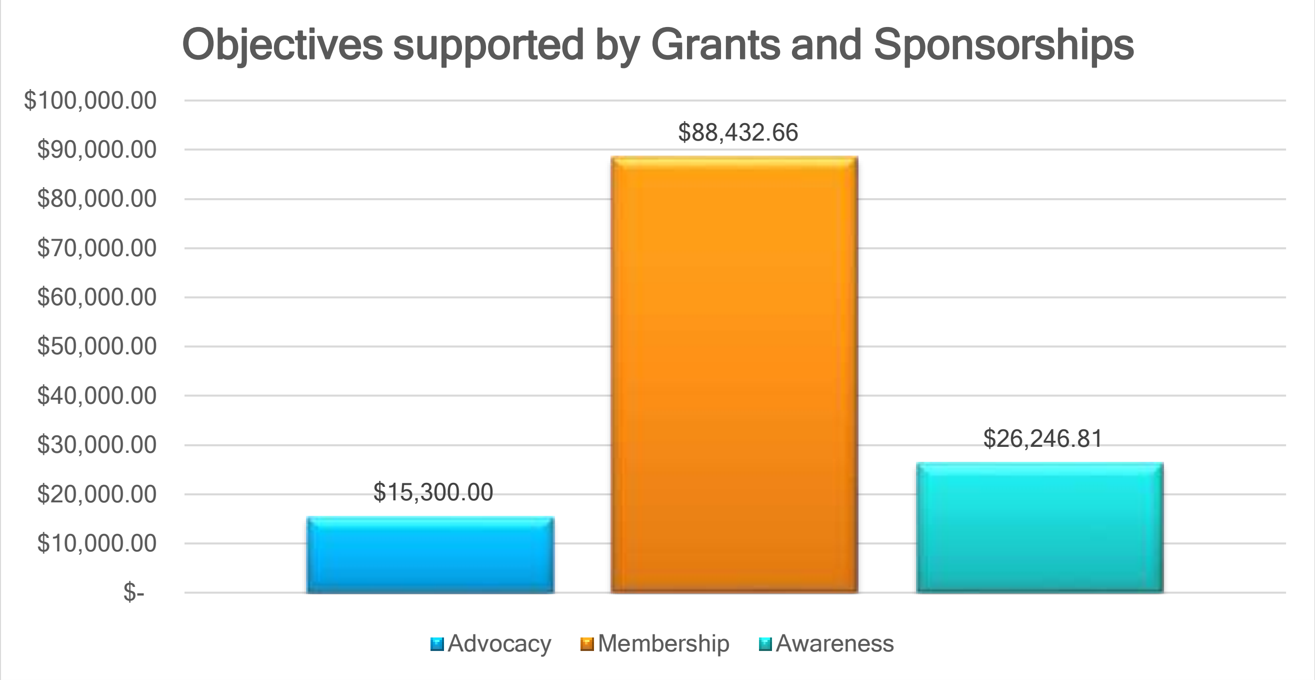


Financial Impact Grants and Sponsorships	% +/- on prev year	**2018-2019**	**2017-2018**
Total CSL Grants	-127%	$30,000.00	$68,000.00
Total Shire-Takeda	-50%	$20,000.00	$30,000.00
Total Grifols	100%	$55,000.00	$-
Total Grants: IPOPI	59%	$5,246.81	$2,150.00
Total DSS FUNDING	0%	$10,000.00	$10,000.00
Total Other Sponsors	100%	$9,432.66	$-
TOTAL GRANTS AND SPONSORS	15%	$129,679.47	$110,150.00

% decrease due to reduction in grant amount from previous year

Community Impact Grants and Sponsorships	% +/- on prev year	**2018-2019**	**2017-2018**
Total members supported by Grants and sponsorships	43%	459	320
Total value per member	-32%	$235.84	$344.59
Total member value	-2%	$108,156.42	$110,150.00

% decrease due to membership increasing and income decreasing

Beneficiaries

459 members were supported by our grant sponsors.
Thank you to our grants and sponsorship partners!

DONATIONS, VOLUNTEER FUNDRAISING AND OTHER INCOME

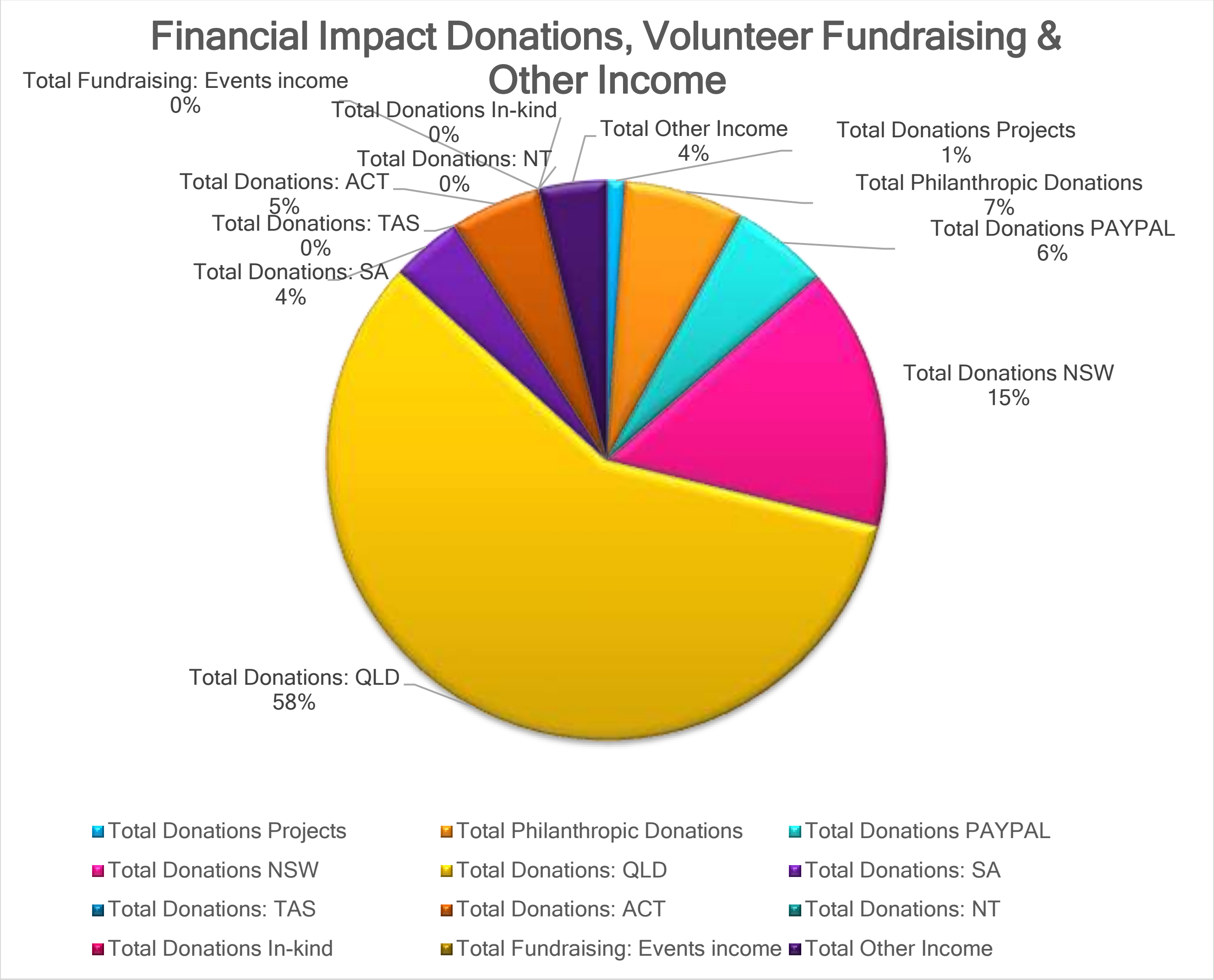
IDFA would like to thank our very valued volunteers who continue to fundraise for IDFA.

- Sharon Heathfield
- Jenny Tyrrell
- Cath Bampton
- Ruth Currey
- Luke Currey
- Cheryl Cullen
- Craig and Julie Mathieson
- Gail Dixon
- Emily Dixon
- Abbey Jones
- Tayla West

We would also like to thank:

- Grill'd Penrith
- Perpetual
- Warmhearts Quilt group
- Burdekin Patchwork and Quilters Guild
- Vodafone
- Lindesfarne Grammar
- Tweed Heads Public School
- Trifaro family
- SyncorSwim

Thank you to our volunteer fundraisers! We thank you for your enthusiasm, commitment and support of IDFA and our patients.



Programs supported by Donations, Volunteer Fundraisers & Other Income

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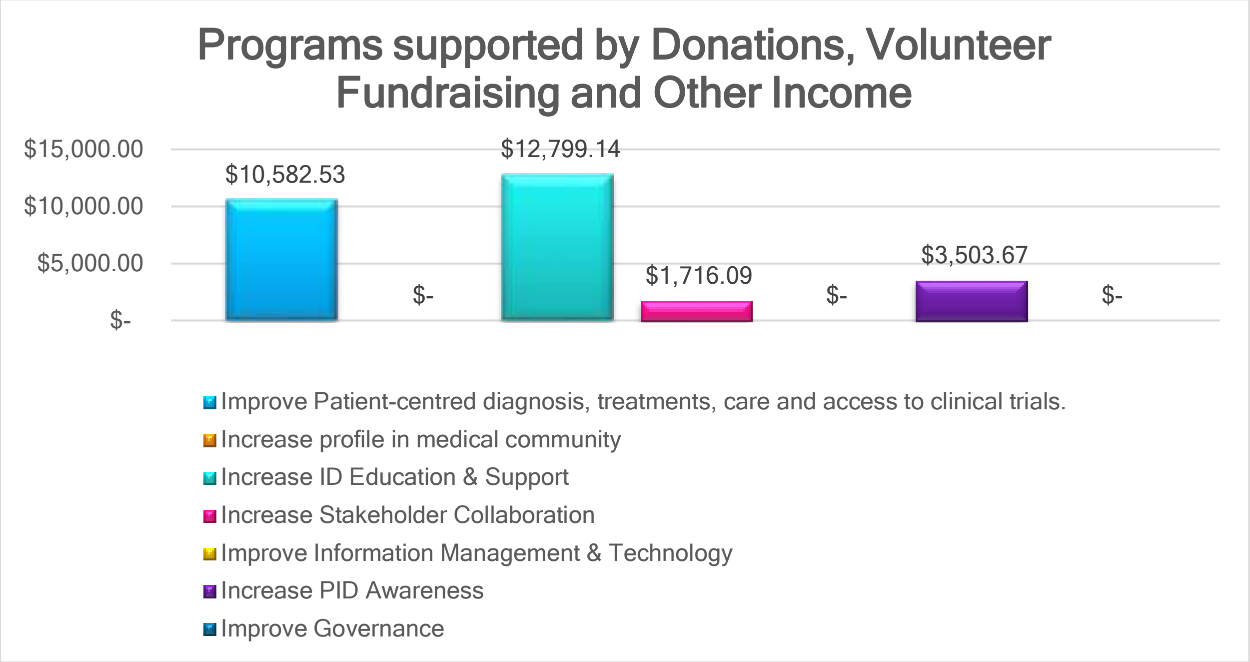

Strategic Priorities supported by Donations, Volunteer Fundraisers & Other Income

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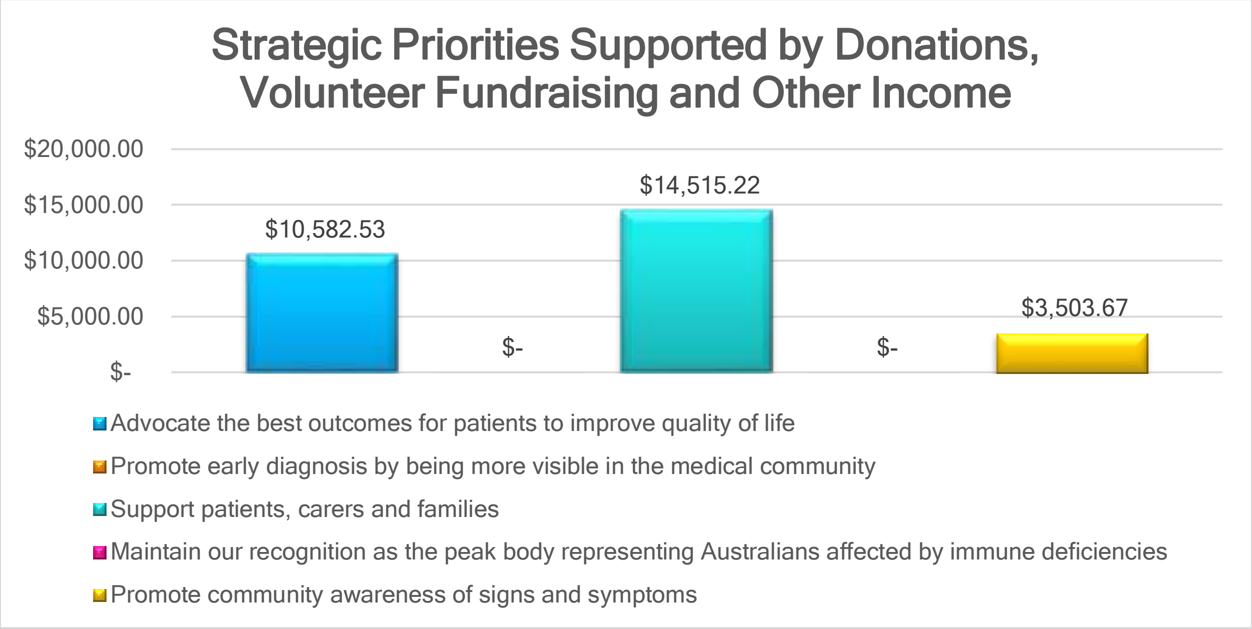

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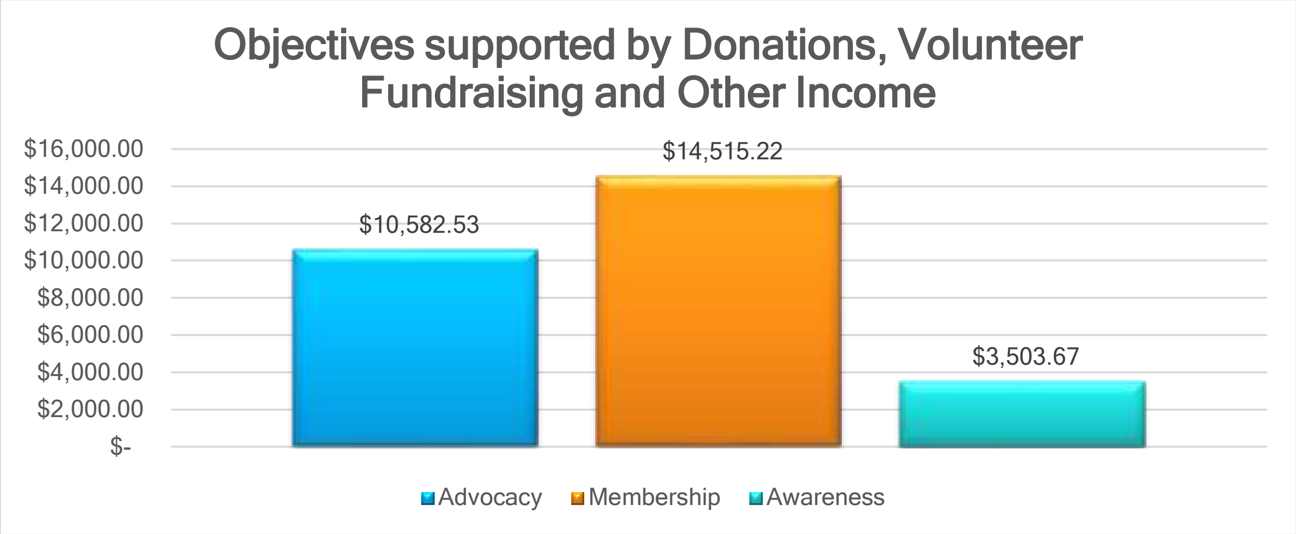


Financial Impact Donations, Volunteer Fundraising & Other Income	% +/- on prev year	**2018-2019**	**2017-2018**
Total Donations Projects	100%	$300.00	$-
Total Philanthropic Donations	100%	$2,000.00	$-
Total Donations PAYPAL	100%	$1,602.00	$-
Total Donations NSW	-215%	$4,362.58	$13,756.63
Total Donations: QLD	54%	$16,612.35	$7,569.45
Total Donations: SA	55%	$1,170.00	$530.00
Total Donations: TAS	0%	$-	$-
Total Donations: ACT	-44%	$1,500.00	$2,155.00
Total Donations: NT	0%	$-	$-
Total Donations In-kind	0%	$-	$2,995.00
Total Donations Income	2%	$27,778.93	$27,206.08
Total Fundraising: Events income	0%	$-	$3,195.49
Total Other Income	-34%	$1,122.49	$1,506.59
Total Donations, Volunteer Fundraising & Other Income	-10%	$28,901.42	$31,908.16

% decrease due to reduced income on previous year

Community Impact Donations and Volunteer Fundraising	% +/- on prev year	2018-2019	2017-2018
Total members supported by Donations and Volunteer Fundraising	8%	102	93
Total value per member	-18%	$235.84	$287.16
Total member value	-11%	$24,104.62	$26,590.51

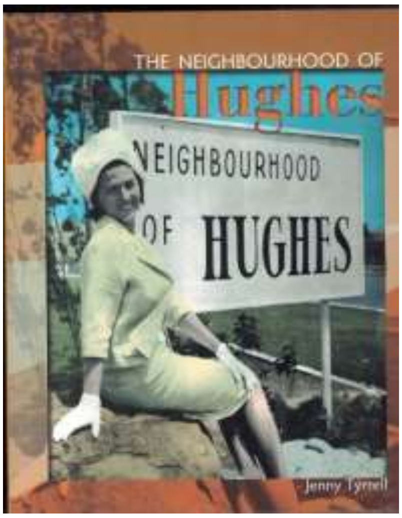
? *% decrease due to membership increasing and income decreasing*

Beneficiaries

102 members were supported by donations and IDFA volunteer fundraisers. Thank you to our donors and fundraisers!

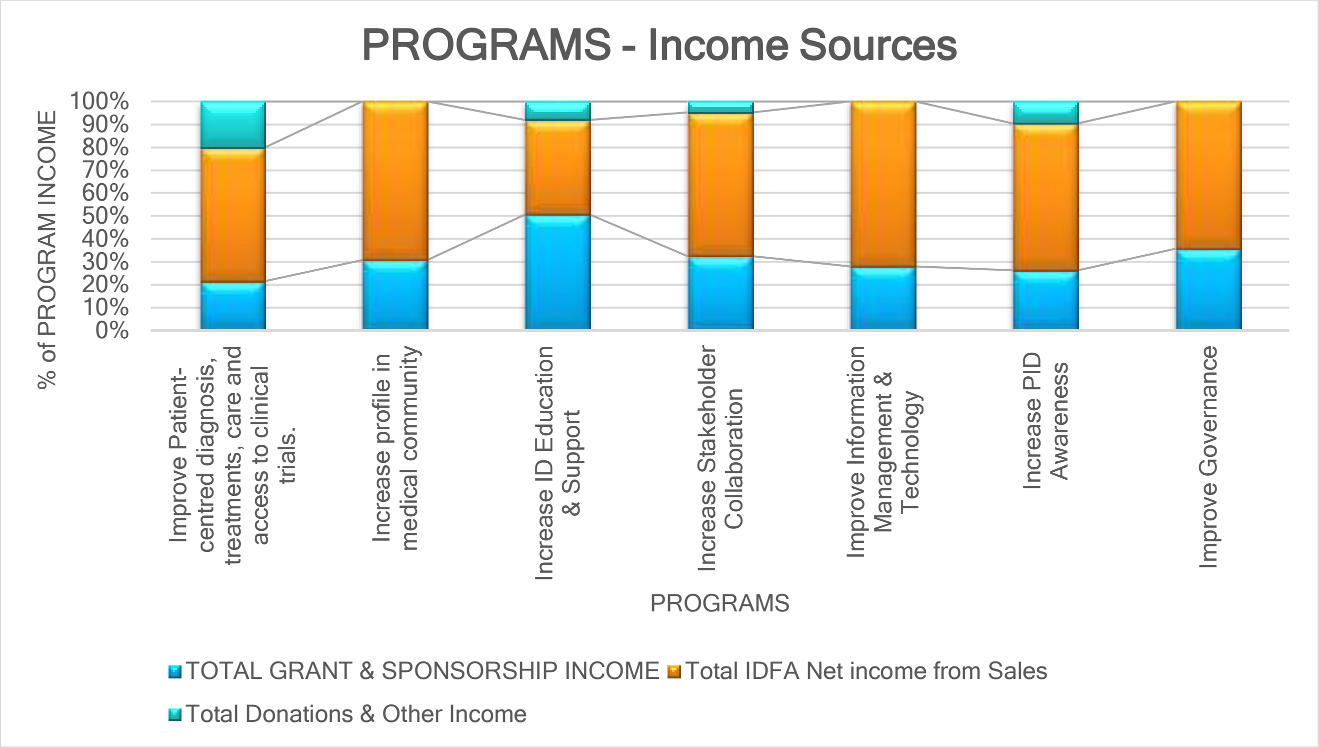
IDFA member **Jenny Tyrrell** donated **$1500** from the sale of her book “The Neighborhood of Hughes” to IDFA.

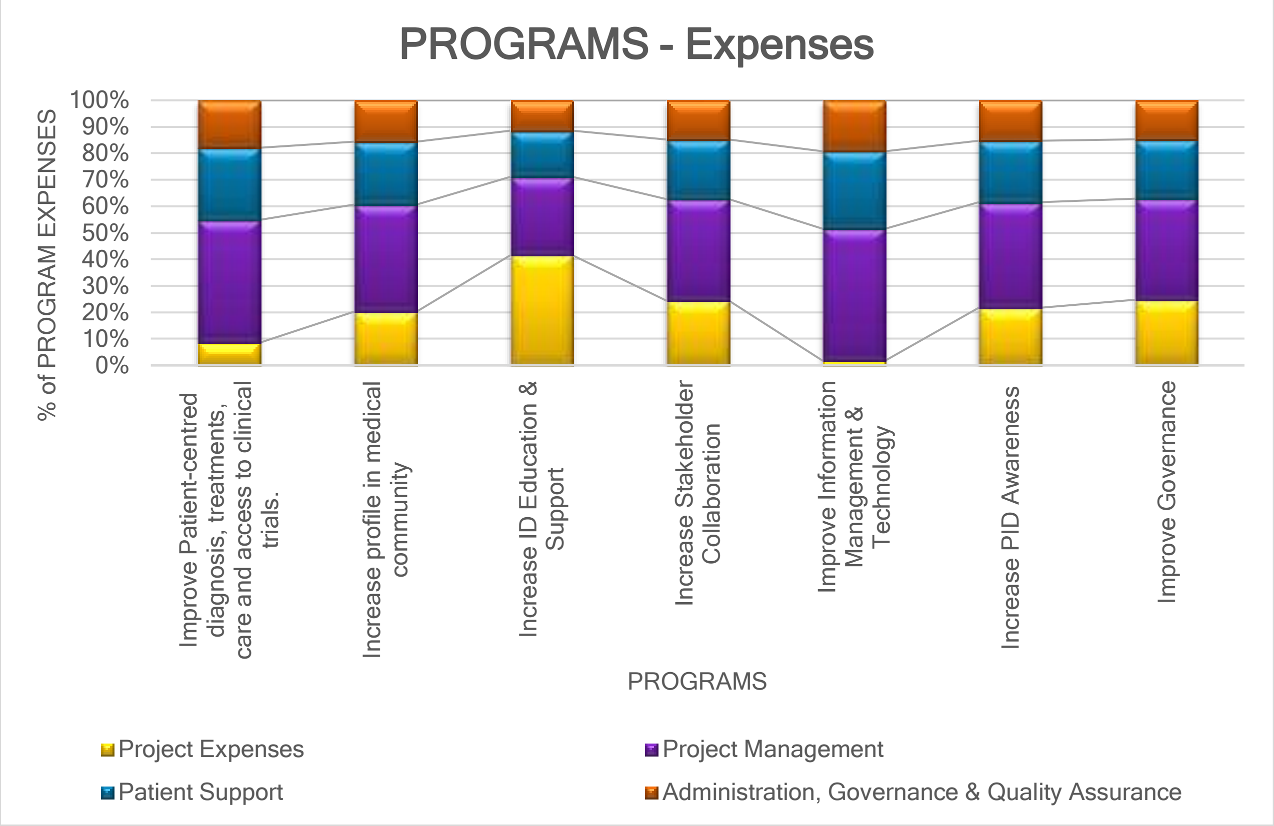
Funds raised by sales of the book will go to the Immune Deficiencies Foundation Australia (IDFA) and the Centre for Personalised Immunology at the John Curtin School of Medical Research at the ANU.



SUMMARY

All seven programs were supported by IDFA net sales and Grant and sponsorship income. Donations, Volunteer Fundraising and other income supported four Programs.





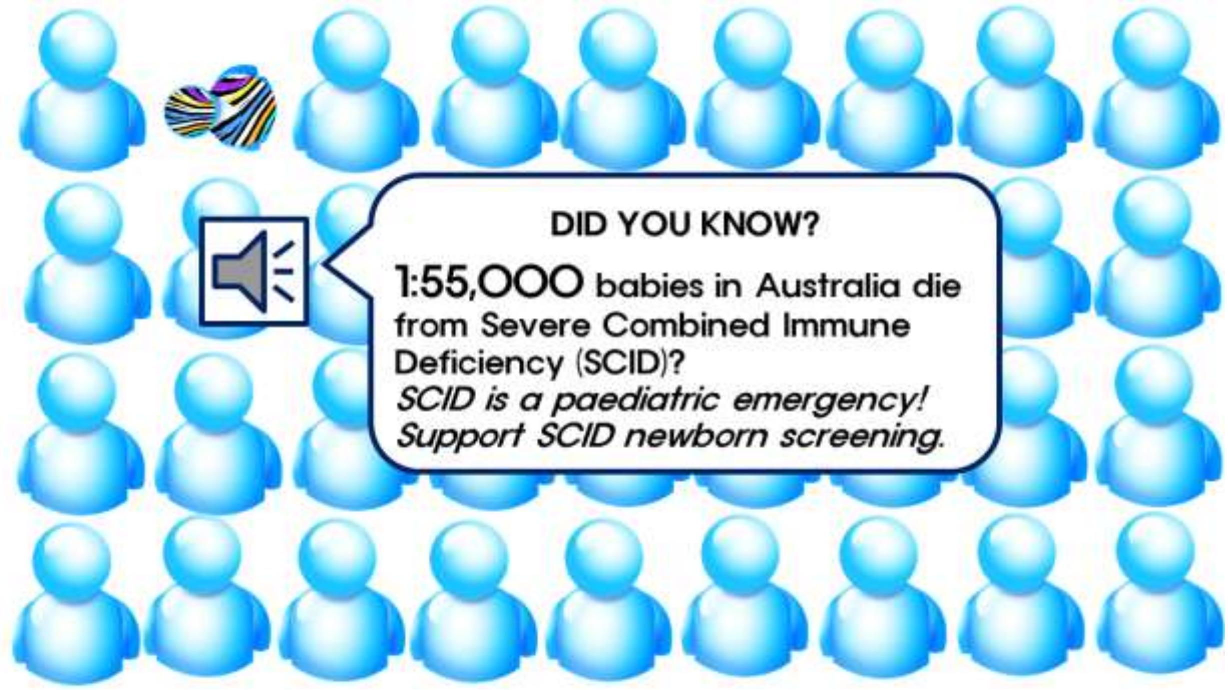
OBJECTIVES AND ACTIVITIES

Objective - Advocacy

Activities

SCID Newborn Screening petitions

To support the close of the SCID newborn screening pilot in NSW, IDFA volunteer Jenny Tyrrell has been coordinating both the physical and e-petitions for each State for SCID newborn Screening. Find links: http://www.idfa.org.au/support-newborn-screening-for-severe-combined-immune-deficiency-scid/



3 weeks was all it took to go from "he needs Panadol," to "he is fighting for life".

Australia should be newborn screening for SCID, as they are in the USA, New Zealand and many other countries of the world. This is one Primary Immune Deficiency that can be cured! If the baby is diagnosed at birth and has a Haematopoietic Stem Cell Transplant (HSCT) in the first 3 months of life, their outcomes and quality of life are greatly improved. Chances of survival decrease the longer diagnosis takes.

Patient Support

Chloe Appleton IDFA’s Member Support has been very busy helping many of you with referrals, NDIS and practical and emotional support. A booking service is available through Facebook.

ASCIA Canberra

IDFA had a booth at the Australasian Society for Clinical Immunology and Allergy (ASCIA) Conference, with all our resources.
The ASCIA Conference is a great opportunity to network with nurses, immunologists and other healthcare professionals and hand out our resource packs. The ASCIA Conference is our greatest outreach to the medical community.

National Immunology Strategy

IDFA is proud to be part of the National Immunodeficiency Strategy group. On 8th March 2019 ASCIA (Australasian Society of Clinical Immunology and Allergy) hosted a meeting in Melbourne to develop a National Immunodeficiency Strategy. The mission is to improve the health and wellbeing of people with primary immunodeficiencies (PIDs) and minimise the impact on individuals, carers, health services and the community.
Delegates from across Australia and New Zealand included clinical immunology specialists, nurses and dietitians, patient organisations, major research centres (JMF Melbourne, ANU, WEHI, Garvan) and funding bodies.

Parliamentary friends of Medicine breakfast

Christine attended a Parliamentary friends of medicine breakfast in Canberra and spoke and shared about patient views on access to immunoglobulin treatment and therapeutic plasma exchange (TPE), a common first step treatment for chronic inflammatory demyelinating polyradiculoneuropathy (CIDP).

National Blood Authority

IDFA continues to meet with the National Blood Authority (NBA) to discuss and review the global burden of immune deficiency diseases, global plasma shortage, the use of Ig for conditions other than Primary Immune Deficiencies and Kawasaki disease and the Criteria for Immunoglobulin use in Australia. IDFA recognises that plasma (human blood) is an expensive product that needs monitoring, but also seeks ways to endeavor that all diagnosed PI patients are receiving the optimum treatment to improve quality of life. Immunoglobulin products vary and dosage should be targeted according to patient needs.

Common patient concerns

Patients express concerns not only about their health but access to services such as the NDIS and Centrelink. As Immune Deficiencies are complex and require a multidisciplinary team of experts for care, Government needs to acknowledge them and make the Health Network easier to navigate and access for patients, carers and families.

Patient Concerns:

- Quality of life
- Access to services - NDIS and Centrelink hard to navigate
- Mental health
- Comorbidities
- Having children - genetics and IVF
- Ageing with ID
- Stigma
- Loneliness
- Family breakdown
- Managing fatigue and pain

Advocacy Topics discussed in International and National Forums

Diagnosis

- Saving lives - e.g. SCID newborn screening
- Access to more timely and accurate diagnosis
- Access to genetic counselling
- Comorbidities
- Mental health
- Carer and family needs

Treatments

- Immunoglobulin Criteria
- Having treatment stopped
- Immunoglobulin tender process
- Switching immunoglobulin products
- Accessing SCIg
- Cost of SCIg (mainly for adults)

Access to Care

- Access to services - NDIS and Centrelink hard to navigate
- Rare diseases rarely recognized
- Emergency department process for immune deficient patients
- National Blood Authority (NBA) Access to Igs and the Criteria
- Mental health
- Comorbidities
- Genetic studies and counselling
- Ageing with ID\ID in a rural setting
- Family breakdown
- Managing fatigue and pain

Strategies to improve patient outcomes – National and Global

- National Immunology Strategy
- National Rare Diseases Framework and Strategy
- Immune and Autoimmune Alliance
- Research in partnership with CIRCA, CPI and other Australian research institutes
- WHO - IUIS Classifications of PIs
- IPOPI - Global patient outcomes
- PPTA - Global plasma quality and supply
- EU - Rare Disease and Newborn Screening policies and frameworks

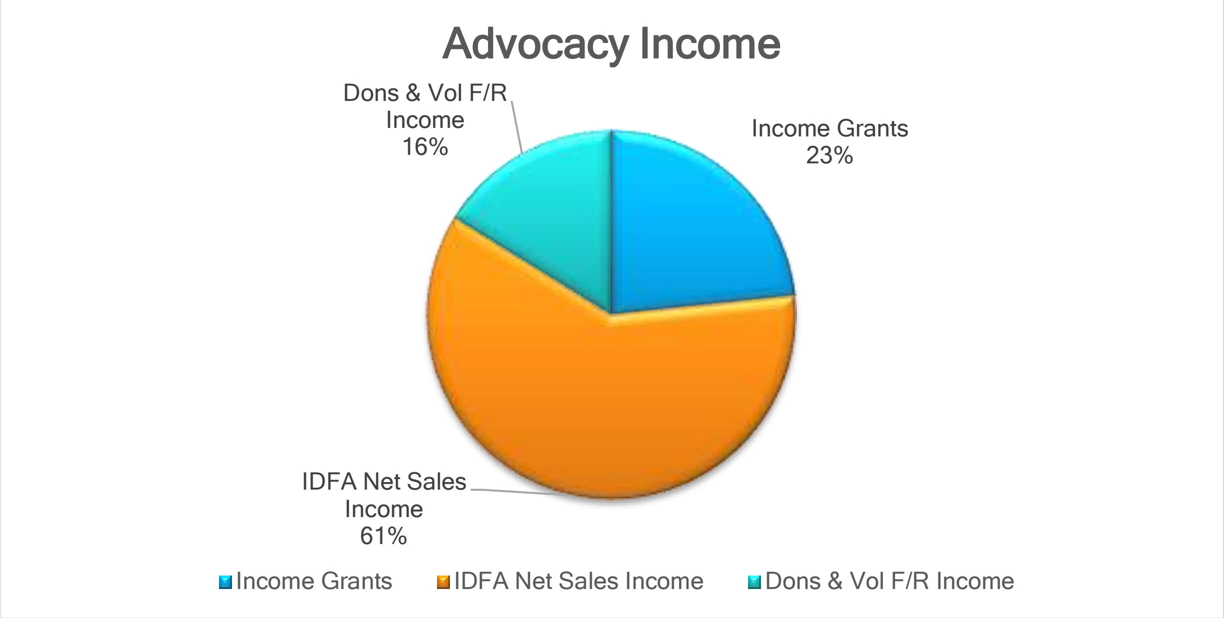
Letters for government and MPs

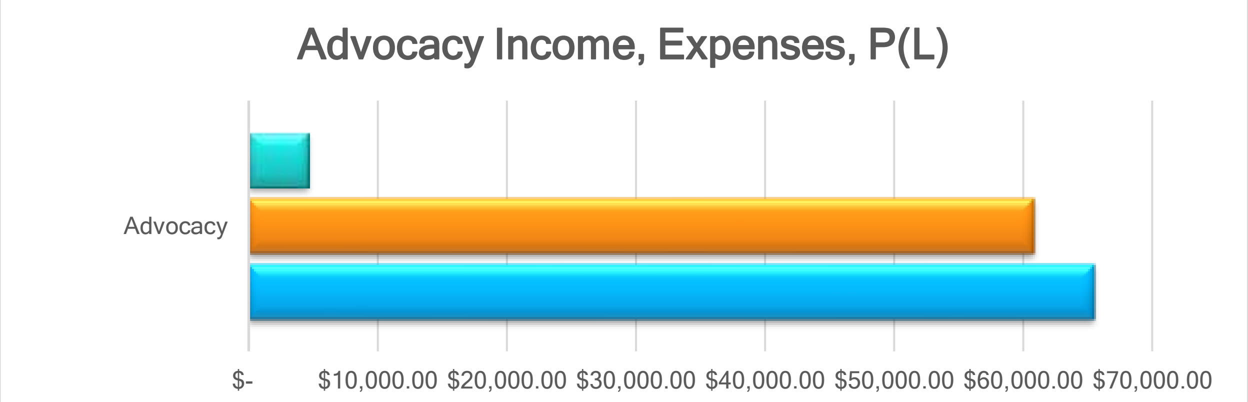
Several letters were templated for patients to send to their local MP and the National Blood Authority. These can be downloaded at: http://www.idfa.org.au/advocacy-resources/

- NBA Letter Re objection to revised criteria
- NBA Letter Re termination of immunoglobulin
- MOP letter re Immunoglobulin termination
- NBA-letter-re-access-to-SCIg
- MOP letter re access to SCIg

NDIS Assistance

Chloe has been helping members with their NDIS applications, providing a letter of support from IDFA.





	Advocacy
PROFIT (LOSS)	$4,652.63
EXPENSES	$60,869.39
INCOME	$65,522.02

Objective - Membership

Activities

National Conference

The 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. **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.

Patients and carers 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. Speakers addressed transition, bone marrow transplants, lung disease, sexual health and Australian research. Beyond this the conference provided medical and practical information about PIDs regarding manifestation, diagnosis, pathology, genetics, treatments and research.

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. There was a great masquerade dinner, offering the participants a chance to be "more than their immune deficiency".

Comments:

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

"It is very valued, making CVID sufferers feeling less isolated, also supporting carers".

Beneficiaries

108 members attended the National Conference in Brisbane.
Thank you to our sponsors of this event!

Stakeholder Collaboration

National Collaboration

IDFA Collaborates nationally with many, not for profit, research, medical, patient and governance organisations.

rare voices AUSTRALIA
NATIONAL BLOOD AUTHORITY AUSTRALIA
ascia australasian society of clinical immunology and allergy
MONASH University
genetic alliance australia
CIRCA
HAE Australasia hope • advocacy • education Australasian Patient Organisation for Hereditary Angioedema
Garvan Institute of Medical Research
CENTRE FOR PERSONALISED IMMUNOLOGY
ARRC
Walter+Eliza Hall Institute of Medical Research
CHF Consumers Health Forum OF Australia

RVA National Rare Disease Summit (Melbourne)

This summit continued stakeholder contribution to the ‘National Strategic Action Plan for Rare Diseases,’ a critical step towards a Framework and effective rare disease policy.

International Collaboration

IDFA collaborates with several International Organisations.

IPOPI Global Patients Meeting Lisbon Portugal

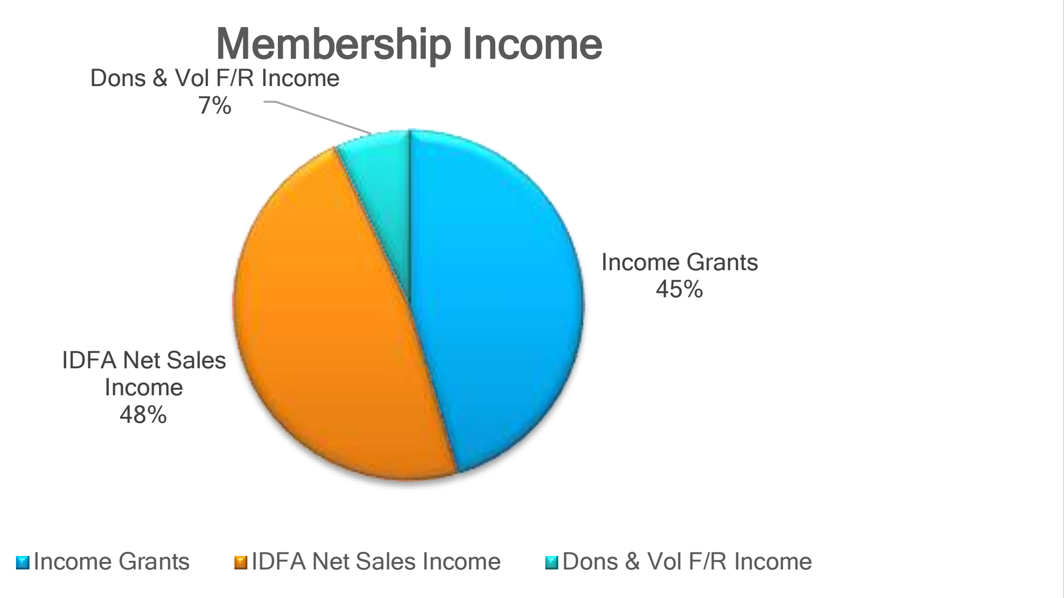
Christine, Dr Melanie Wong (IDFA Medical Advisory Chair) and Clinical Nurse Consultant (CNC) Geraldine Dunne (IDFA Medical Advisory Board) presented sessions at the combined ESID/IPOPI Meeting in Lisbon, Portugal. Cath Bampton, IDFA Board Company Secretary, also attended the IPOPI Conference on behalf of IDFA, thanks to a travel grant from IPOPI.

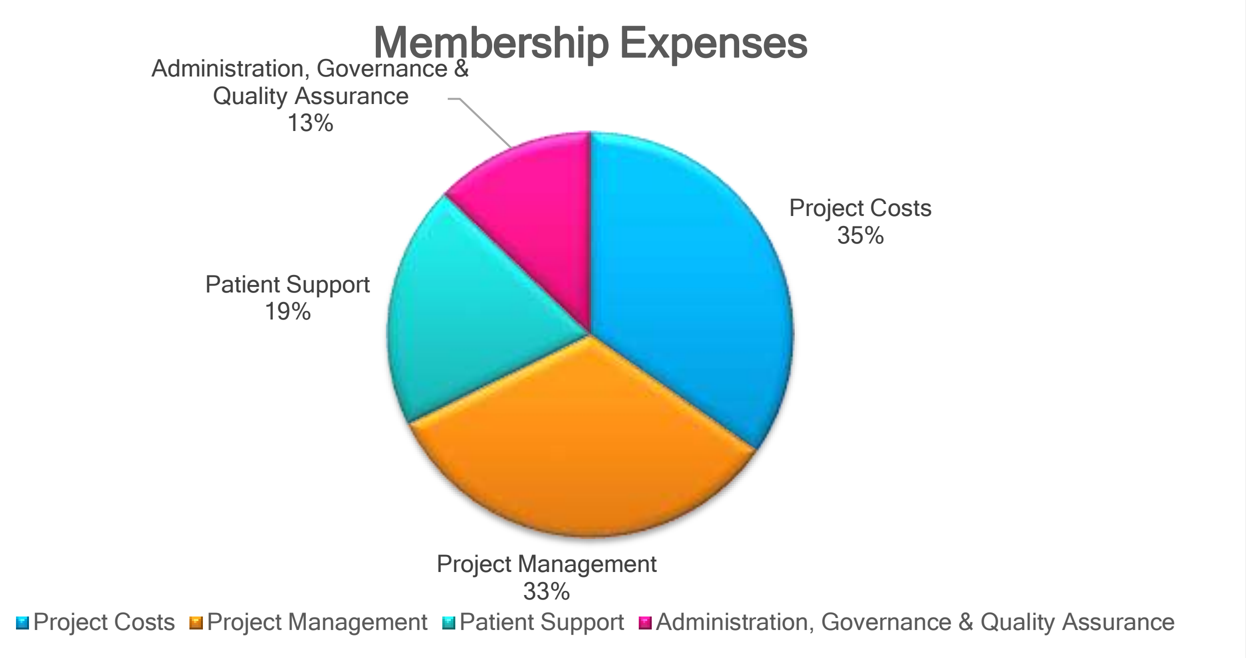
Christine Jeffery has been a member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI) Board since 2013. After serving four years as Treasurer, she was voted Vice Chair this year.

As Vice Chair of IPOPI, Christine has attended and presented at other meetings overseas:

- PPTA Amsterdam
- South East Asian Advocacy meeting Bangkok
- South East Asian Advocacy Meeting Kuala Lumpur
- APSID meeting Chongqing

Attendance to these events are funded by IPOPI.





	Membership Income, Expenses, P(L)
🟦 PROFIT (LOSS)	$2,607.61
🟧 EXPENSES	$203,284.02
🟦 INCOME	$205,891.64

Objective - Awareness

Activities

Rare Disease Day

Rare Disease Day saw the start of our Member Book of Stories.

World PI Week events

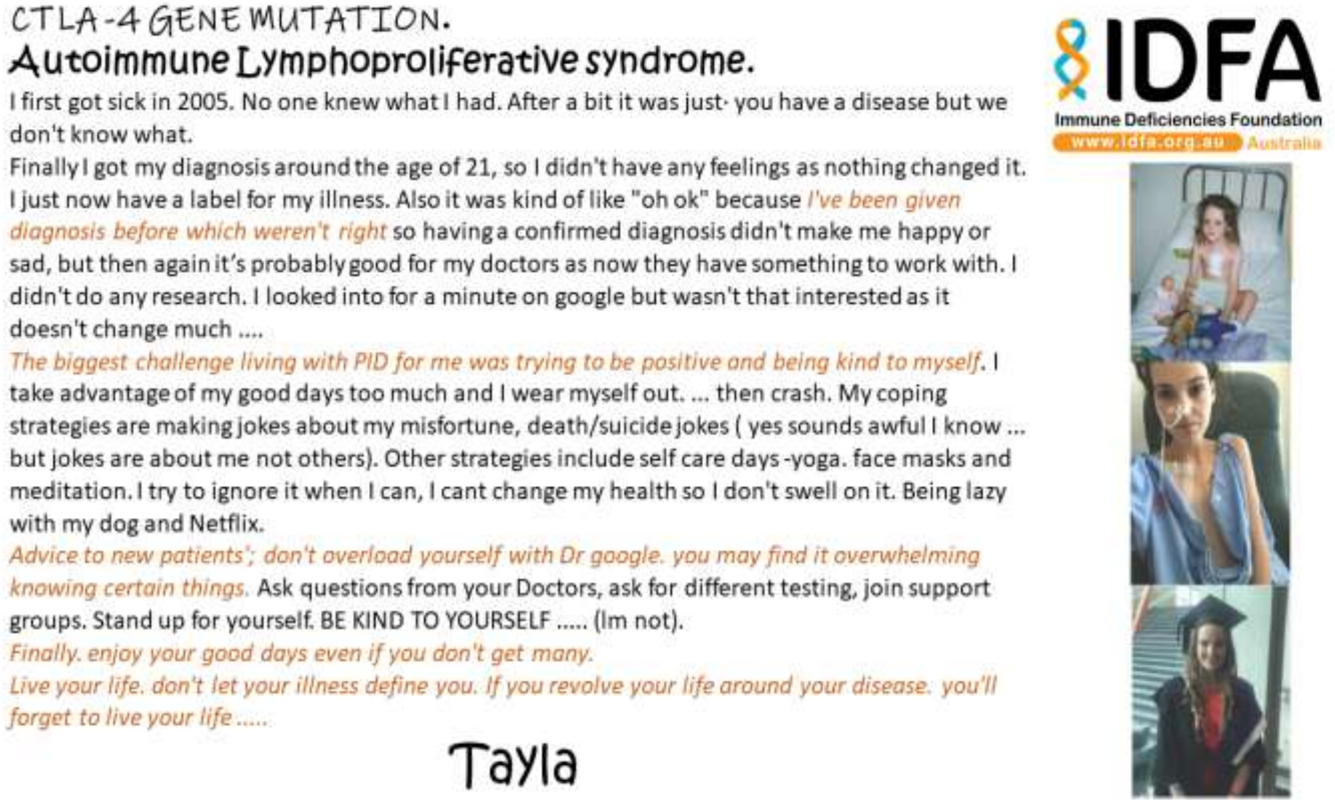
IDFA partnered with the Clinical Immunogenomics Research Consortium Australasia (CIRCA) to continue to grow our **patient storybook**.


What can you do for World PI Week?

Tell your story

Send your story and photos to info@idfa.org.au

http://www.idfa.org.au/world-pi-week-22-29-april/



CTLA-4 GENE MUTATION.

Autoimmune Lymphoproliferative syndrome.

I first got sick in 2005. No one knew what I had. After a bit it was just· you have a disease but we don't know what.

Finally I got my diagnosis around the age of 21, so I didn't have any feelings as nothing changed it. I just now have a label for my illness. Also it was kind of like "oh ok" because *I've been given diagnosis before which weren't right* so having a confirmed diagnosis didn't make me happy or sad, but then again it's probably good for my doctors as now they have something to work with. I didn't do any research. I looked into for a minute on google but wasn't that interested as it doesn't change much ....

The biggest challenge living with PID for me was trying to be positive and being kind to myself. I take advantage of my good days too much and I wear myself out. ... then crash. My coping strategies are making jokes about my misfortune, death/suicide jokes (yes sounds awful I know ... but jokes are about me not others). Other strategies include self care days -yoga. face masks and meditation. I try to ignore it when I can, I cant change my health so I don't swell on it. Being lazy with my dog and Netflix.

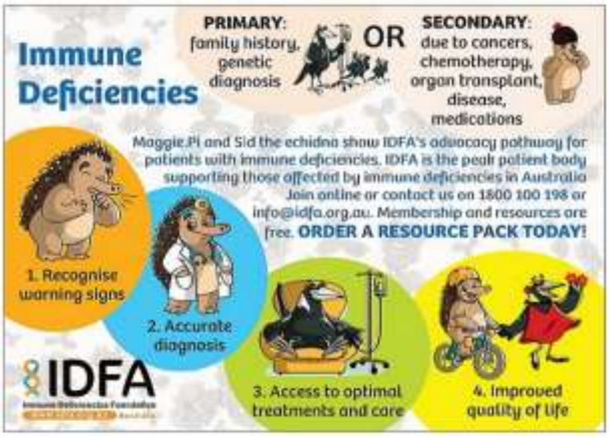
Advice to new patients'; don't overload yourself with Dr google. you may find it overwhelming knowing certain things. Ask questions from your Doctors, ask for different testing, join support groups. Stand up for yourself. BE KIND TO YOURSELF ..... (Im not).

Finally. enjoy your good days even if you don't get many.

Live your life. don't let your illness define you. If you revolve your life around your disease. you'll forget to live your life .....

Tayla

Over 1,000 **Awareness cards** were sent to GPs, Respiratory Physicians and Endocrinologists.



Maggie.Pi and Sid the echidna show IDFA's advocacy pathway for patients with immune deficiencies. IDFA is the peak patient body supporting those affected by immune deficiencies in Australia Join online or contact us on 1800 100 198 or info@idfa.org.au. Membership and resources are free. **ORDER A RESOURCE PACK TODAY!**

A: PO BOX [illegible]
Penrith NSW 2751
P: 1800 100 198
E: info@idfa.org.au

IDFA is the peak patient body providing advocacy, education and support to people affected by Primary and Secondary Immune Deficiencies in Australia

Resource Packs were posted to nurses and Immunology Units

Gail and Emily Dixon organized their **Zebra Day** at **Lindesfarne Anglican Grammar School,** promoting **plasma donation.** They also held a fundraiser at **Tweed Heads Public School.**

Your gold coin donation will help IDFA raise awareness and provide support to people affected by Primary Immune Deficiencies. What is a PID? Visit out website idfa.org.au to understand more about this genetic disorder which requires lifelong treatment and support.

Gail Dixon is 😌 feeling grateful with Chloe Appleton and Trevor Butler.

10 April

Zebra Day has begun @ Lindisfarne Anglican Grammar School!!! Great community
Donations of plasma are essential. For those that are keen to donate we have arranged a group appointment for Thursday 18 April @ Robina Blood Bank @ 2:30pm💋 or whenever you can. Please mention "Emily's Lindisfarne Legends" so we track donations 💋

Over
$1700
raised

Sharon Heathfield and her quilting group the **Warmhearts Quilt Group**, **donated 3 quilts** as prizes for a raffle drawn at the National Conference.

$1170
raised

Resources

IDFA printed five new resources this year to add to our large range of resources.

Resources can be ordered online at: http://www.idfa.org.au/advocacy-resources/

Social Media

You can find IDFA on:

- Facebook
- Twitter
- LinkedIn
- Instagram
- YouTube

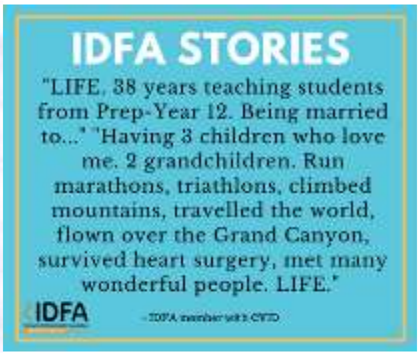
There are closed Facebook groups for Patients, Carers and Young Adult members (YAMS).

Our website is www.idfa.org.au . All our information, resources, advocacy templates and patient information is available.

PID FACT

"Most PIDs cause the body to produce too few or no functioning immunoglobulins (IGs), also known as antibodies. IGs are an important part of the immune system as they recognise and attack the micro-organisms that can cause infections."

IDFA

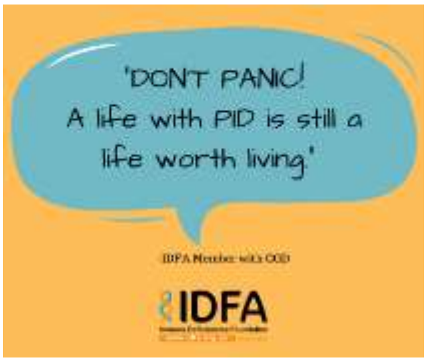


IDFA STORIES

"LIFE. 38 years teaching students from Prep-Year 12. Being married to..." "Having 3 children who love me. 2 grandchildren. Run marathons, triathlons, climbed mountains, travelled the world, flown over the Grand Canyon, survived heart surgery, met many wonderful people. LIFE."

- IDFA member with CVID

IDFA



'DON'T PANIC! A life with PID is still a life worth living'

IDFA Member with CGD

IDFA

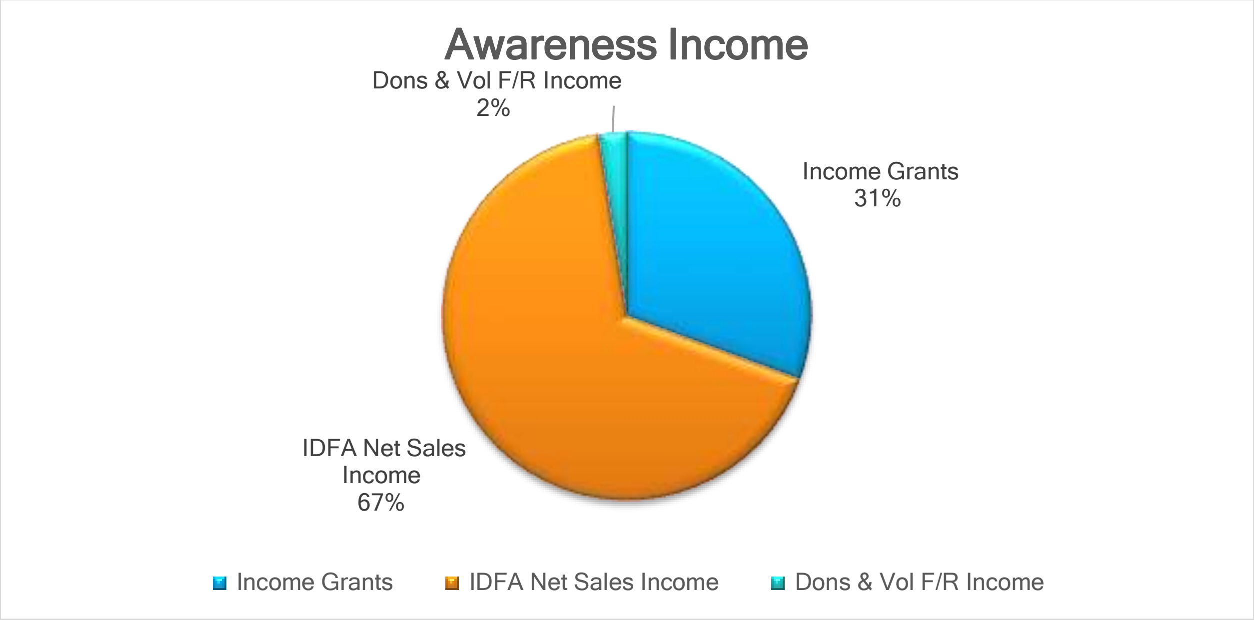
Squirtle gets his infusion! A very informative video taken by Levi...
806 views · 23 July 2019

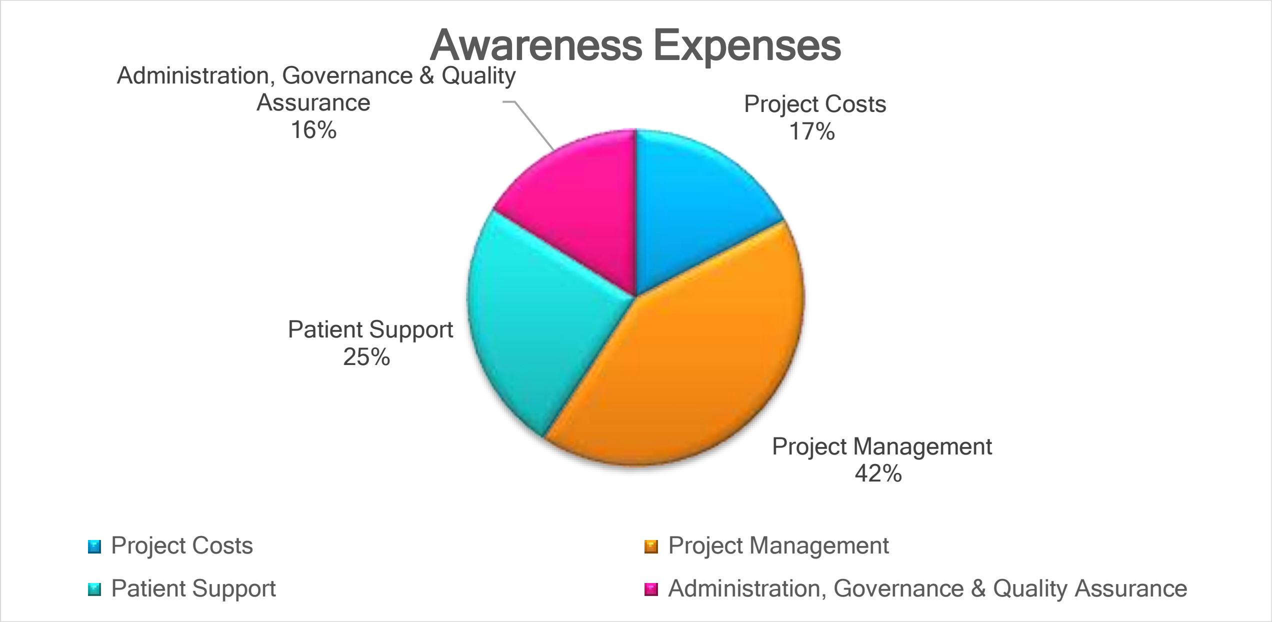
Its Rare Disease Day! This story book gives some insight into...
422 views · 28 February 2019

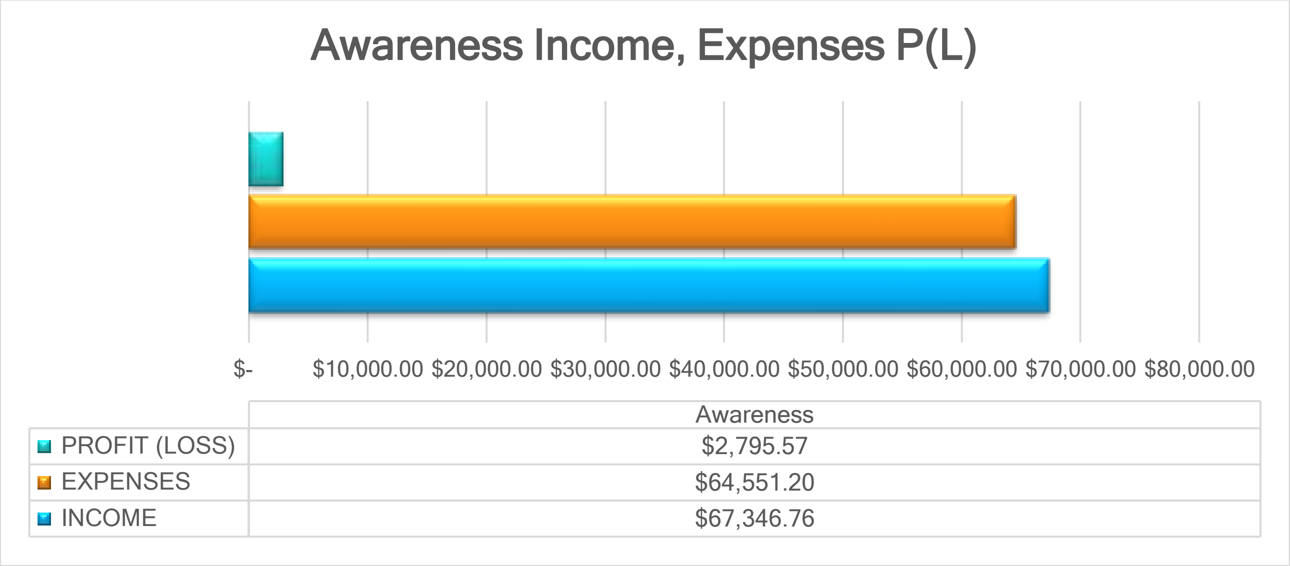
I Don't Feel Alone - IDFA YAMS
507 views · 10 February 2019

Paddling for IDFA
178 views · 9 April 2018

Find us on Facebook

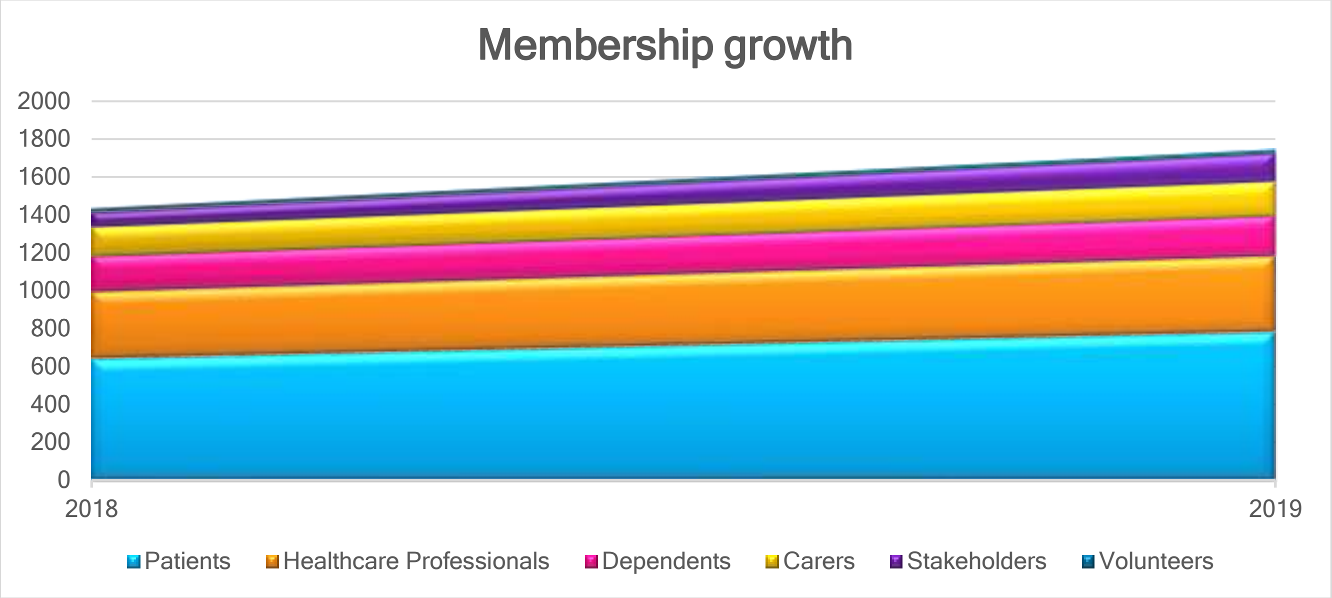

Awareness Income
Dons & Vol F/R Income 2%
Income Grants 31%
IDFA Net Sales Income 67%
Income Grants
IDFA Net Sales Income
Dons & Vol F/R Income


Awareness Expenses
Administration, Governance & Quality Assurance 16%
Project Costs 17%
Patient Support 25%
Project Management 42%
Project Costs
Project Management
Patient Support
Administration, Governance & Quality Assurance

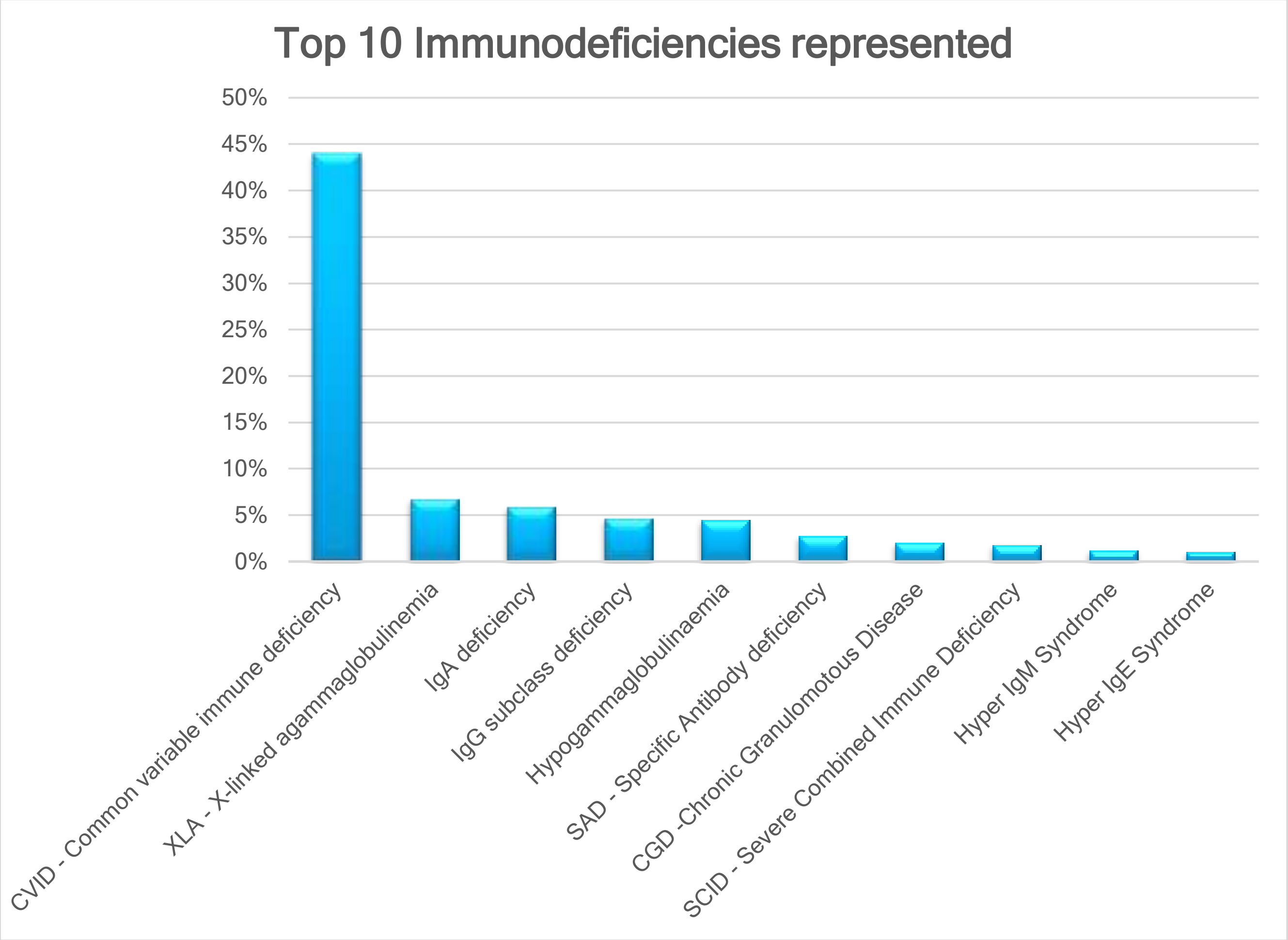

Awareness Income, Expenses P(L)
$-
$10,000.00
$20,000.00
$30,000.00
$40,000.00
$50,000.00
$60,000.00
$70,000.00
$80,000.00
Awareness
PROFIT (LOSS) $2,795.57
EXPENSES $64,551.20
INCOME $67,346.76

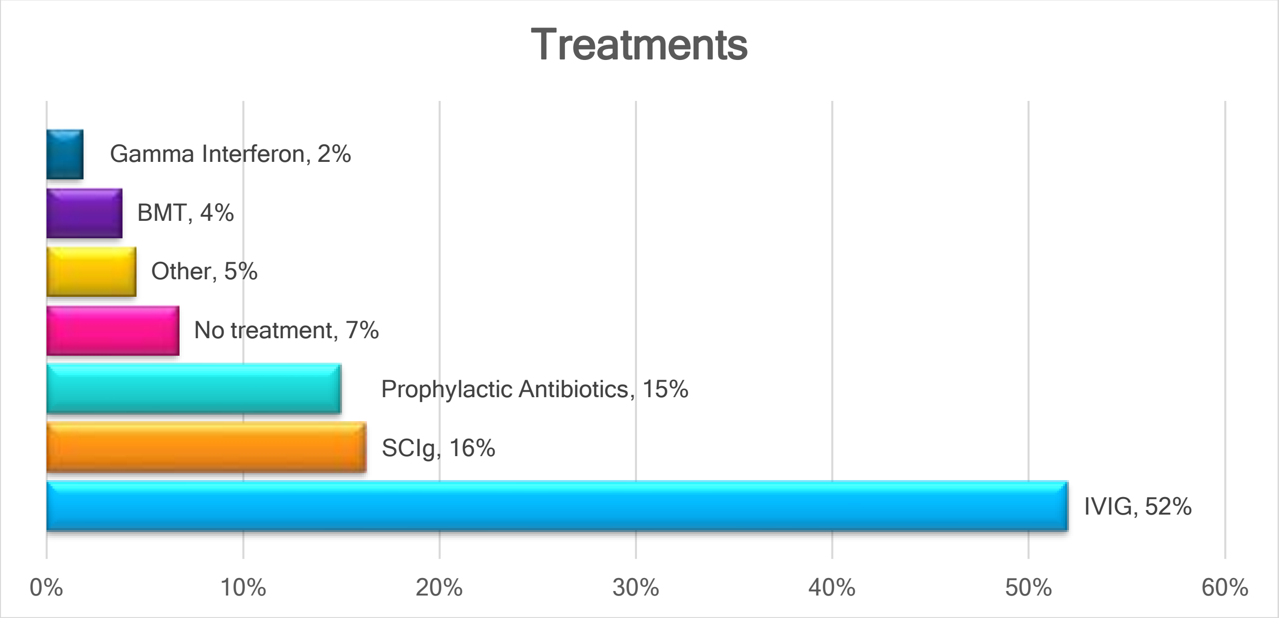
MEMBER STATISTICS

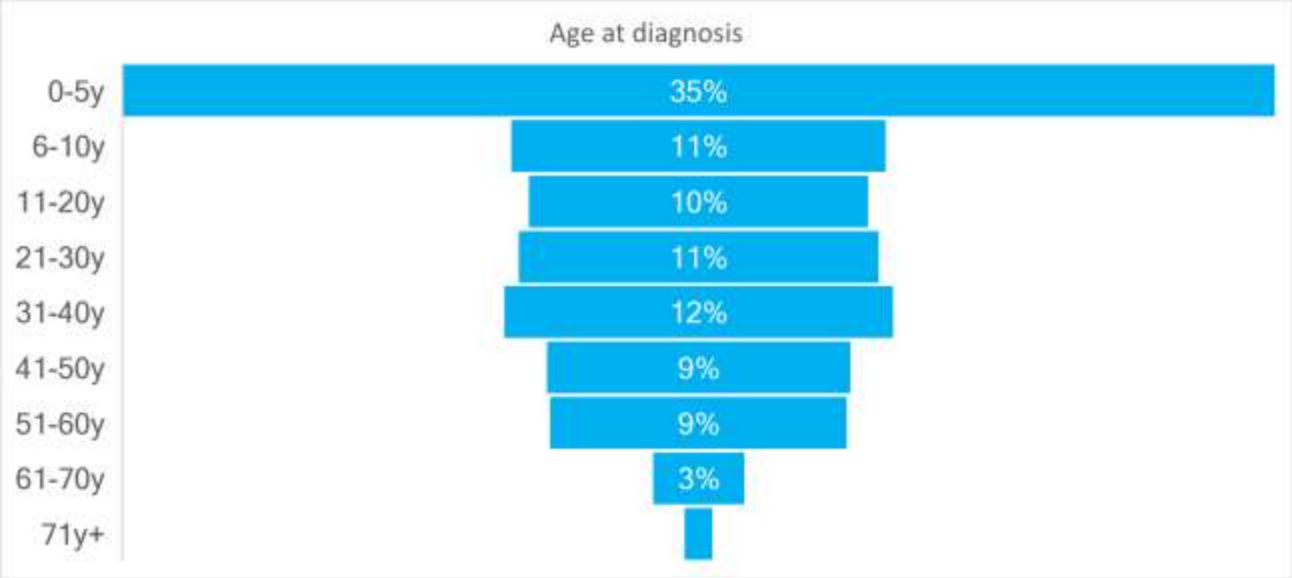
IDFA membership grew by 20% this year.

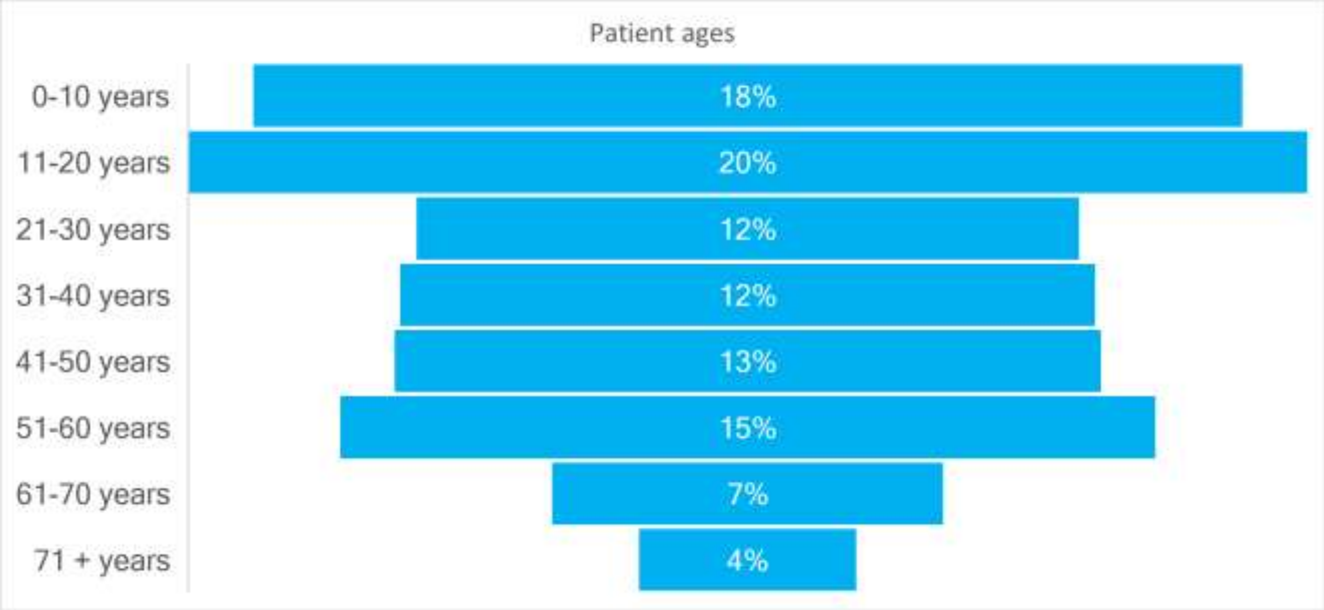


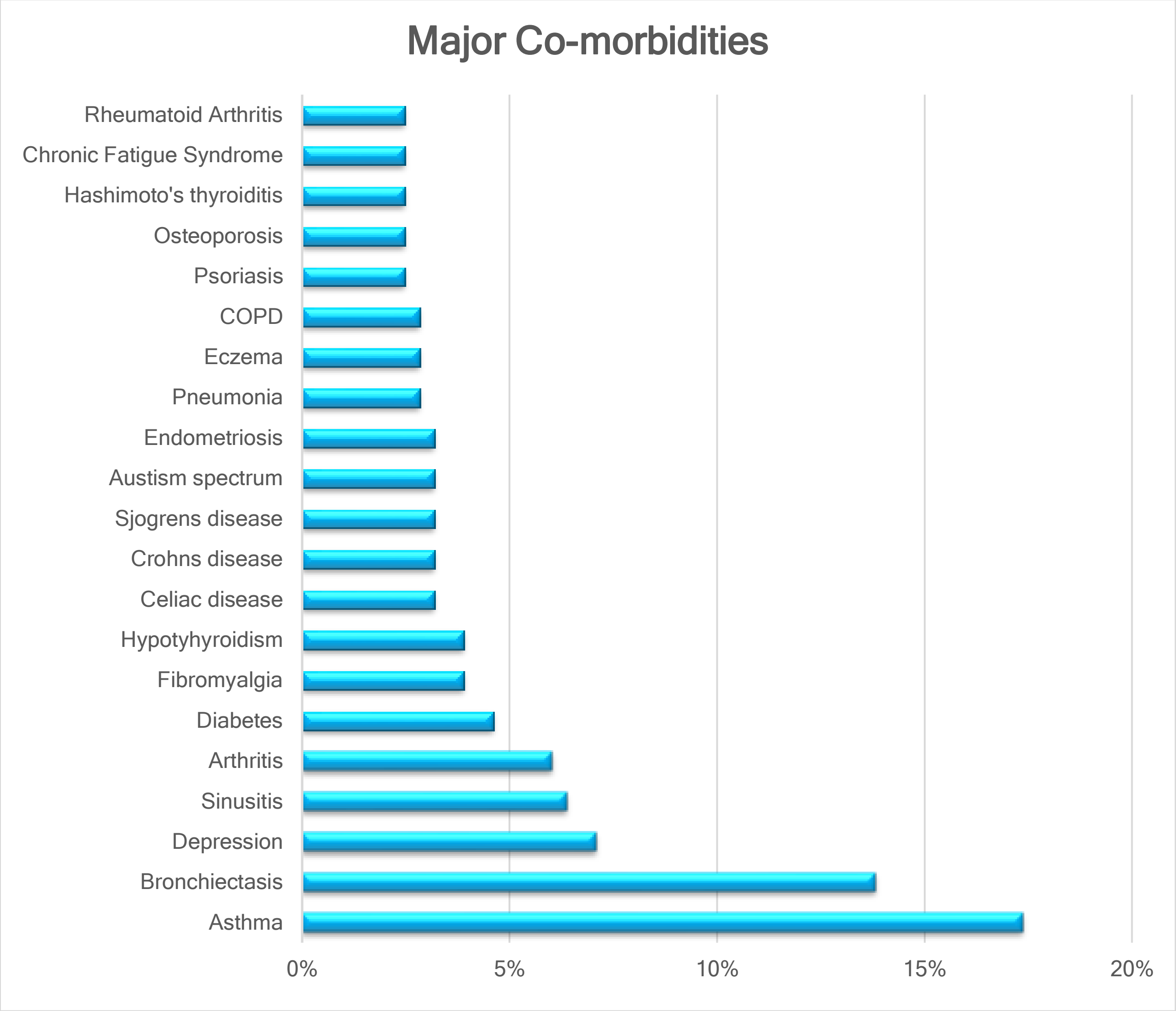
The main immune deficiency patients have is Common Variable Immune Deficiency (CVID).




Treatments
Gamma Interferon, 2%
BMT, 4%
Other, 5%
No treatment, 7%
Prophylactic Antibiotics, 15%
SCIg, 16%
IVIG, 52%
0%
10%
20%
30%
40%
50%
60%


Age at diagnosis
0-5y
35%
6-10y
11%
11-20y
10%
21-30y
11%
31-40y
12%
41-50y
9%
51-60y
9%
61-70y
3%
71y+


Patient ages
0-10 years
18%
11-20 years
20%
21-30 years
12%
31-40 years
12%
41-50 years
13%
51-60 years
15%
61-70 years
7%
71 + years
4%




Abbreviations explained...

Ig = Immunoglobulins

Another name for antibody


PID FACT

"IG replacement therapy is a life-long, life-saving treatment and, as PIDs are chronic conditions, it needs to be administered regularly."


Abbreviations explained...

SCIG infusion = Subcutaneous immunoglobulin (SCIG) infusion

Administration of immunoglobulin directly under the skin.


PID FACT

"Immunoglobulin replacement therapy (IG Therapy) is the main plasma-derived therapy used to treat PIDs." "...which help to protect against a range of infections and reduce autoimmune symptoms."


"Ask questions from your doctors, ask for different testing, join support groups. Stand up for yourself."

IDFA Member with autoimmune lymphoproliferative syndrome


PID FACT

"Immunoglobulins (or antibodies) are proteins that recognise infecting microorganisms and help immune cells to destroy them. Most PIDs cause the body to produce too few immunoglobulins, or none at all."

VALUE OF IDFA

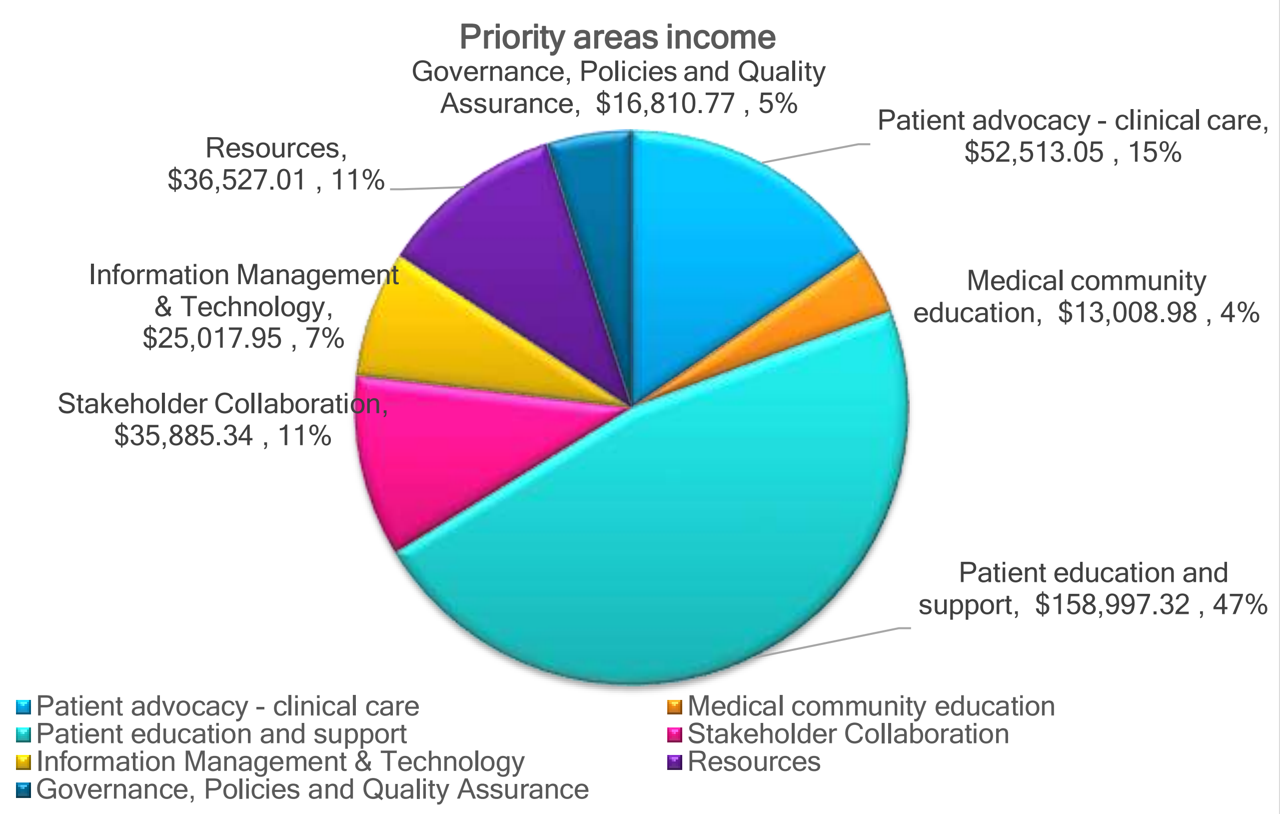
IDFA provides a valuable service to the community. IDFA raises awareness, educates, provides resources, advocates, assists, supports and links members, the medical community and the general community.

These services are provided by a handful of dedicated staff (1 full-time and 3 part-time). IDFA has continued to grow in membership (93% increase since 2015) at a rate faster than our income (12% increase in sales and 58% increase in grants, donations and volunteer fundraising). It is vitally important our financial income increases so that we can expand our member services.

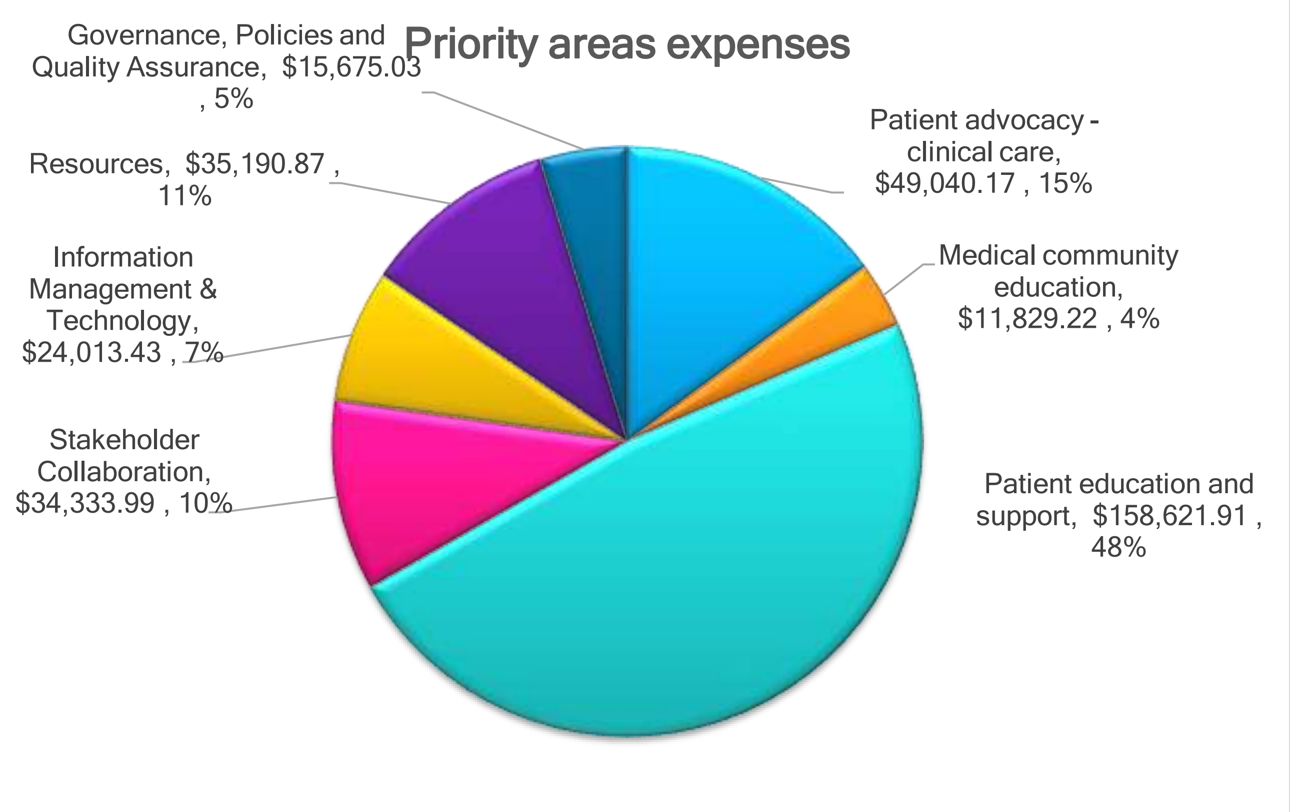
Growth comparison rates last 5 years

	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019
Income Sales (12% increase)	$983,541.00	$1,023,232.00	$991,073.00	$1,178,586.00	$1,098,129.56
Income Grants, Donations and Vol Fundraising (58% increase)	$100,275.00	$50,630.00	$203,807.00	$142,056.00	$158,580.89
Cost of Operations (33% increase)	$34,814.00	$32,207.00	$51,489.00	$46,902.00	$46,169.09
Cost of Programs and Activities (32% increase)	$213,855.00	$197,843.00	$316,293.00	$288,115.00	$282,535.52
Cost of Sales (11% increase)	$826,506.00	$842,501.00	$820,847.00	$970,913.00	$917,950.03
Staff growth (=to FT) (50% increase)	2	3	2	4	3
Membership growth (93% increase)	906	1134	1168	1433	1746

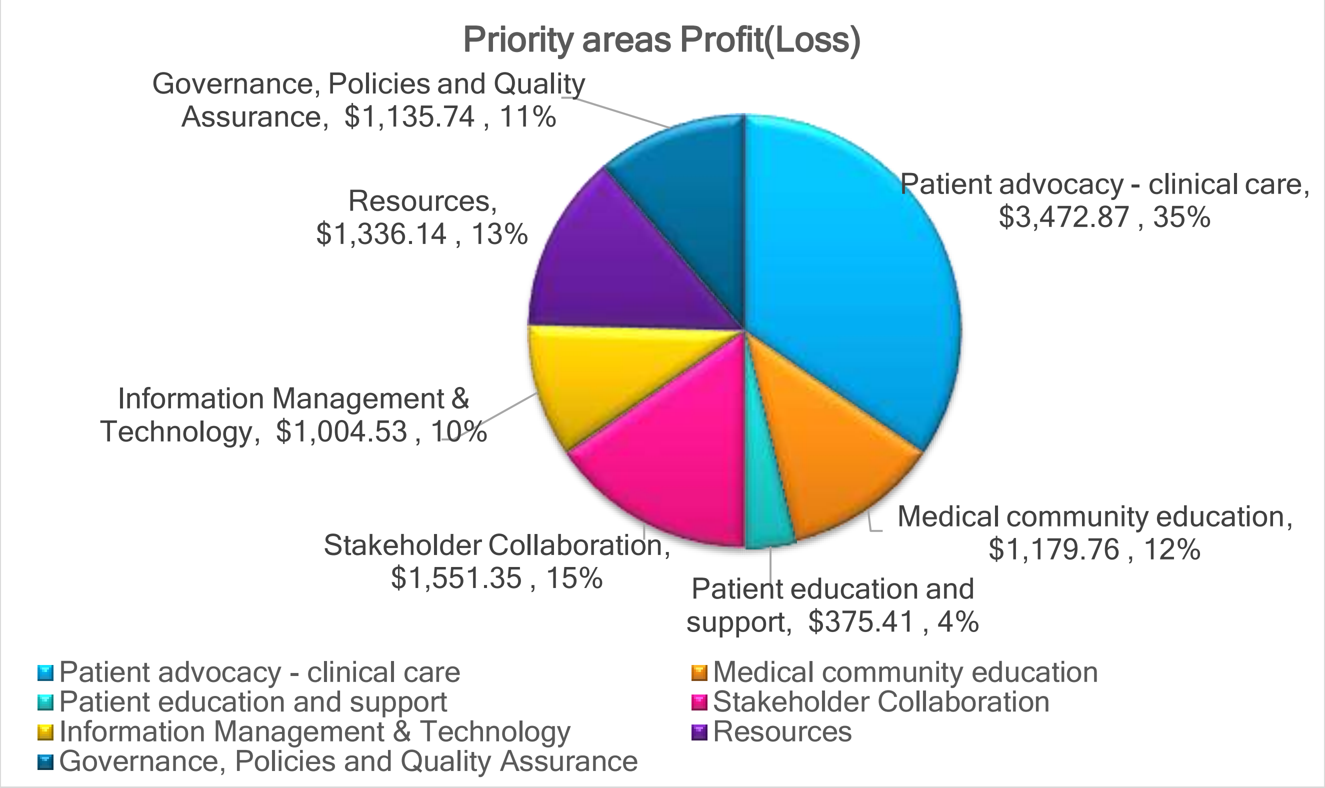
Priority areas income



Priority areas expenses



Priority area profit(loss)



Financial Impact

FINANCIAL IMPACT - value of IDFA support	% +/- on prev year	2018-2019	2017-2018
Expense per patient/carer/dependent member	-22%	$235.84	$287.16
Total Value of Support to Patients	0%	$184,662.20	$183,783.13
Total Value of support to Dependents	-8%	$49,997.94	$53,986.30
Total Value of support to Carers	-4%	$42,686.92	$44,222.82
Total Value of support to Volunteers	-11%	$5,188.47	$5,743.22

?

% decrease due to reduced income on previous year

Total financial value of support provided to members = $ 282,536

Community Impact

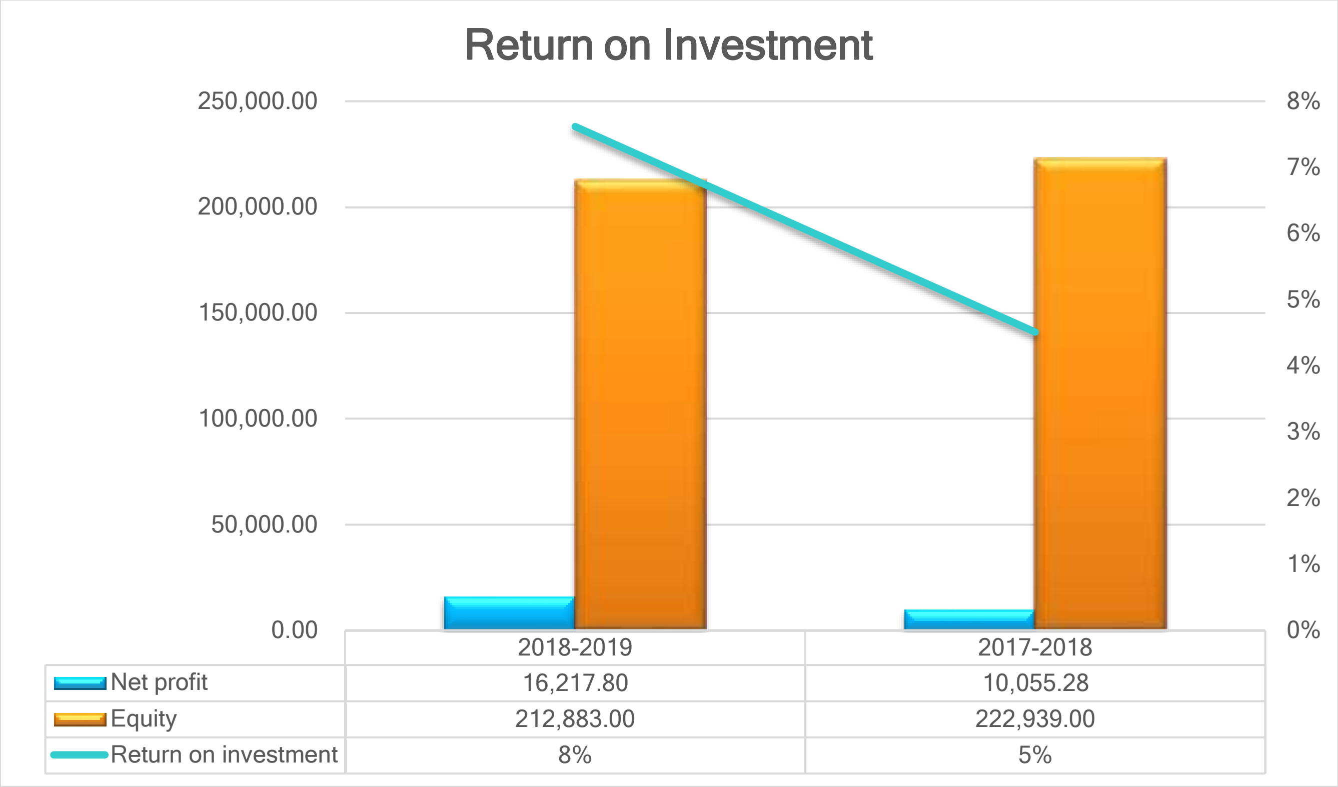
COMMUNITY IMPACT - value of IDFA support	% +/- on prev year	2018-2019	2017-2018
Number of patients supported by IDFA	18%	783	640
Number of dependents supported by IDFA	11%	212	188
Number of Carers supported by IDFA	15%	181	154
Number of Volunteers supported by IDFA	9%	22	20

% decrease due to membership increasing and income decreasing

Beneficiaries

Total patients, carers, dependents and volunteers supported = 1198

Return on Investment



	2018-2019	2017-2018
Net profit	16,217.80	10,055.28
Equity	212,883.00	222,939.00
Return on investment	8%	5%

> *…"IDFA is a fantastic support group with caring, friendly people! It's nice having the resources on hand and such a knowledgeable and empathetic team running it".*

FROM THE CEO

2018-2019 has been another busy year. Our membership has continued to grow, and IDFA have exhibited our commitment to our strategic plan by providing events, resources, advocacy and education for members and the community.

The issues for immune deficient patients, although they vary in the details, are common worldwide, and all lead to achieving optimal quality of life for patients:

1. Access to diagnosis
2. Access to optimal and effective treatments
3. Access to optimal care and services
4. Recognition of the Disease by policy makers and the community

If patient organisations, the plasma industry and policy makers collaborate, communicate and share information, we can develop frameworks, policies and guidelines to improve clinical applications for patients and ultimately give patients optimum quality of life. This should be applicable to rare diseases such as primary immune deficiencies as well as diseases that are common and recognisable.

Funding is a constant issue as we are not increasing our income or staff to match our expanding membership! IDFA receives no government funding and so we are dependent on our sponsors and donors. Thank you so much to our sponsors and partners for your support.

Thank you volunteers for your tireless work. I really appreciate it!

Thank you to the Board and Staff for your support, commitment and input into IDFA.

IDFA has demonstrated its ability to provide member services, educate and support members and advocate to improve quality of life, not just for patients, but the whole family. I am very proud of that!

C. Jeffery

Christine Jeffery
IDFA CEO

Out of clutter, find simplicity
From discord, find harmony
In the middle of difficulty lies opportunity

Albert Einstein