IDFA Immune Deficiencies Foundation Australia

2020
Annual Report

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Message from our Executive Officer

This has been a year of change at IDFA.

I commenced in this role at the end of March and was fortunate to be able to spend some time with the outgoing Executive Officer, Christine Jeffery, prior to her retirement. At that same time, we entered into lock-down due to COVID-19 and this has changed the world for all of us!

IDFA have had a very busy year supporting our members through the challenges of COVID-19 and responded by developing a range of online support programs and events to ensure that our members were able to feel supported and connected during this difficult time.

Many of the plans we had for face-to-face events, patient meetings and conference have had to be put on hold at this stage, although we remain hopeful that we can connect in this way again in 2021.

Looking forward, IDFA will be focused on delivering the key priorities identified under the Strategic Plan 2020-2023 being Education, Advocacy and Awareness. To allow us to do this we have been seeking feedback from our members about what is important to them to ensure we meet the needs of those living with an immunodeficiency.

The team are currently busy developing a range of innovative programs, events and ways of engaging with our members, partners and the broader health and medical community.

Lastly, I would like to thank the IDFA Board, staff and our key partners and sponsors for welcoming me to the team and I look forward to meeting more of our member's later this year and throughout 2021.

Carolyn Dews, Executive Officer.

Message from Lara Alexander, Board Chair

There is no doubt this financial year has been a challenging one and in many ways a year of laying down the foundations for new directions for the Immune Deficiencies Foundation Australia (IDFA).

We said 'Farewell' to Christine Jeffery who retired in April after many years of great service and dedication to IDFA. It has been an emotional event for everyone who has known Christine and appreciated her tireless work for our members, their families and IDFA.

In the midst of COVID-19, we welcomed Carolyn Dews as our new Executive Officer. Carolyn's start to the new role was a true reflection of the tumultuous and challenging times we have faced since March this year! How do you meet staff for the first time when everyone is working from home? How do you learn about your role when the office is closed and you cannot really meet people and introduce yourself the old fashion way? It has been a significant test for Carolyn and our staff, a reflection of their capacity to adapt and deliver under these unusual circumstances.

In February this year, the Board held its planning weekend with a focus on revising the Strategic Plan, re-assessing its priorities and identifying future directions. It was an opportunity to re-iterate the importance of advocacy and support for our members, finding new and better ways of ensuring our message is communicated well and wide to State and Federal Governments, increasing our collaboration with like minded peak bodies. We consolidated our future strategy to increase our advocacy for Severe Combined Immune Deficiency Newborn Screening (SCID NBS) as a significant tool for early diagnosis and treatment for infants, vital for preventing morbidity and mortality.

Overall, the revised Strategic Plan sets the wheels in motion for the Executive Officer, staff and Board to implement a number of significant key items.

The Board also acknowledged the necessity for financial improvement, developing a strategy and a clear, effective and efficient way of operating.

All of these key elements will underpin the development of services and increased collaboration with other organisations.

While IDFA is a charitable organisation it is also facing all of the same difficulties as any other business regarding finance, taxation, compliance, work health and safety, with the added responsibility of ensuring it generates enough income to enable it to continue to provide services to it's members. The Board and staff responded well during the COVID-19 shut down moving our activities to the virtual world and monitoring our revenue and expenses on a regular basis.

I would like to take this opportunity to thank our staff who has worked tirelessly throughout the year, ensuring IDFA continued servicing its members.

Also, a warm Thank You to our supporters, donors and volunteers! There is no doubt that IDFA exists because of the dedication of many people.

Strategic Plan

In February 2020 the IDFA Board and staff met to discuss the strategic direction of the organisation.

The Strategic Plan that was developed resulted in an updated Vision for the organisation and significant organisational projects based around the three priority areas of:

- Education
- Awareness
- Advocacy

Looking Forward

IDFA has ambitious plans for 2020/2021. Due to the impacts of COVID-19 we have already started to change our Business Model so that we are able to provide our education, awareness and advocacy campaigns online, continuing the development of innovative programs for our members.

The new IDFA website will go live in late 2020 and will reflect a more contemporary brand whilst ensuring that the information that is important for our members is up to date and easy to find.

We have launched a series of online member engagement events, this form of event delivery will continue throughout 2020/21. IDFA anticipates the re-commencement of face-to-face events in 2021.

Staff are reviewing the member database and developing a Membership Engagement Strategy to ensure that we continue to offer value to our members.

We are also developing a Medical Advisory Committee (MAC) and a Patient Advisory Committee (PAC) to ensure that we have broad expertise to benefit our members.

Our Vision

A future where primary and secondary immunodeficiencies are diagnosed and treated early, with affected people supported by clinicians, community and government to enable optimal quality of life.

Our Mission

Raising awareness for primary and secondary immunodeficiencies; supporting and advocating for improved health outcomes for patients, carers and families.

Our Strategic Priorities

Education
Awareness
Advocacy

Support Groups

Resources

Emotional, Social and Practical Groups

Peer Support and Mentoring Program
Online Support Groups

Education

Events and Resources
Website
Social Media inc. Facebook Groups

Education

Patients and Carers

Information Packs
Support Groups
Communications

Government

Introductions & Representations to MP's
Funded Projects

Health Professionals

Introductions & Presentations to MP's
Funded Projects

General Community

Awareness Raising Events
Website & Social Media

Awareness

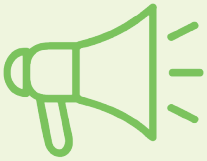
Screening and Diagnostic

SCID, NBS and Genetic Testing

Treatment and Care

SCIg Access
Access to Treatments Options

Rare Disease Action Plan



Advocacy

Governance & Staffing

The Immune Deficiencies Foundation Australia (IDFA) is the Australian peak patient body supporting those affected by immunodeficiencies (primary and secondary).

IDFA was founded in 2005, bringing together a number of separate State-based patient groups. IDFA has the support of leading immunology health professionals both in Australia and internationally. It is affiliated with the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and works closely with the Australian Society for Clinical Immunology and Allergy (ASCIA).

In 2017 the Board of IDFA resolved to also support patients with secondary immunodeficiencies caused by transplantation, disease (i.e. cancer) or treatment (chemotherapy)

IDFA is a company limited by Guarantee, a not-for profit organisation and a registered charity. A company limited by guarantee is a specialised form of public company designed for non-profit organisations. One of the key advantages of this legal form is that it allows the organisation to operate nationwide. This is important for IDFA, as a national peak body.

IDFA exists to support its ordinary members, patients, their families and medical professionals. The day-to-day management of IDFA is undertaken by a small team of paid staff, assisted by ordinary members who volunteer their time. This staff team, led by an Executive Officer, is responsible for managing IDFA in accordance with the IDFA's strategic direction.

The staff team is governed by a Board of Directors, which is responsible for setting IDFA's strategic direction. This Board reports to the voting members of the IDFA company.

The Board's composition ensures that a diversity of skills and experience are represented. Key skills for the IDFA Board include:

- Patients and/or family members with an understanding and awareness of immunodeficiencies
- Medical professionals with an understanding and awareness of adult and paediatric immunodeficiencies
- Financial management skills and/or experience
- Governance skills and/or experience
- Media, promotions, fundraising, marketing skills and/or experience
- Legal qualifications and/or experience.

While Board members do not represent specific geographic areas, the Board usually tries to ensure that its members reflect the broad geographic spread of a national peak body and come from a variety of different geographic locations.

Staff & Board

Christine Jeffery

In April 2020 Christine Jeffery retired from the role of Executive Officer after nine years in the role. We thank Christine for the enormous contribution that she has made to IDFA in significantly growing membership numbers, support services, advocacy and building the profile of IDFA both nationally and internationally.

We wish Christine all the best in her retirement and know that she will continue to be part of the IDFA community.

David Gilles

David Gilles Resigned from the IDFA Board in January 2020.

Carolyn Dews

Carolyn commenced in the role of Executive Officer in March 2020.

Our Staff

Carolyn Dews
Executive Officer

Maria Pirovic
Business Development & Strategic Member Support

Belinda Yeats
Marketing & Communications

Rachel Pearson
Administration & Membership

Our Board Members

Lara Alexander
Board Chair

Craig Mathieson
Deputy Chair

Josh Snow
Finance Chair

Catherine Bampton
Company Secretary

Dr Melanie Wong
Medical Advisory Committee Chair

Geraldine Dunne

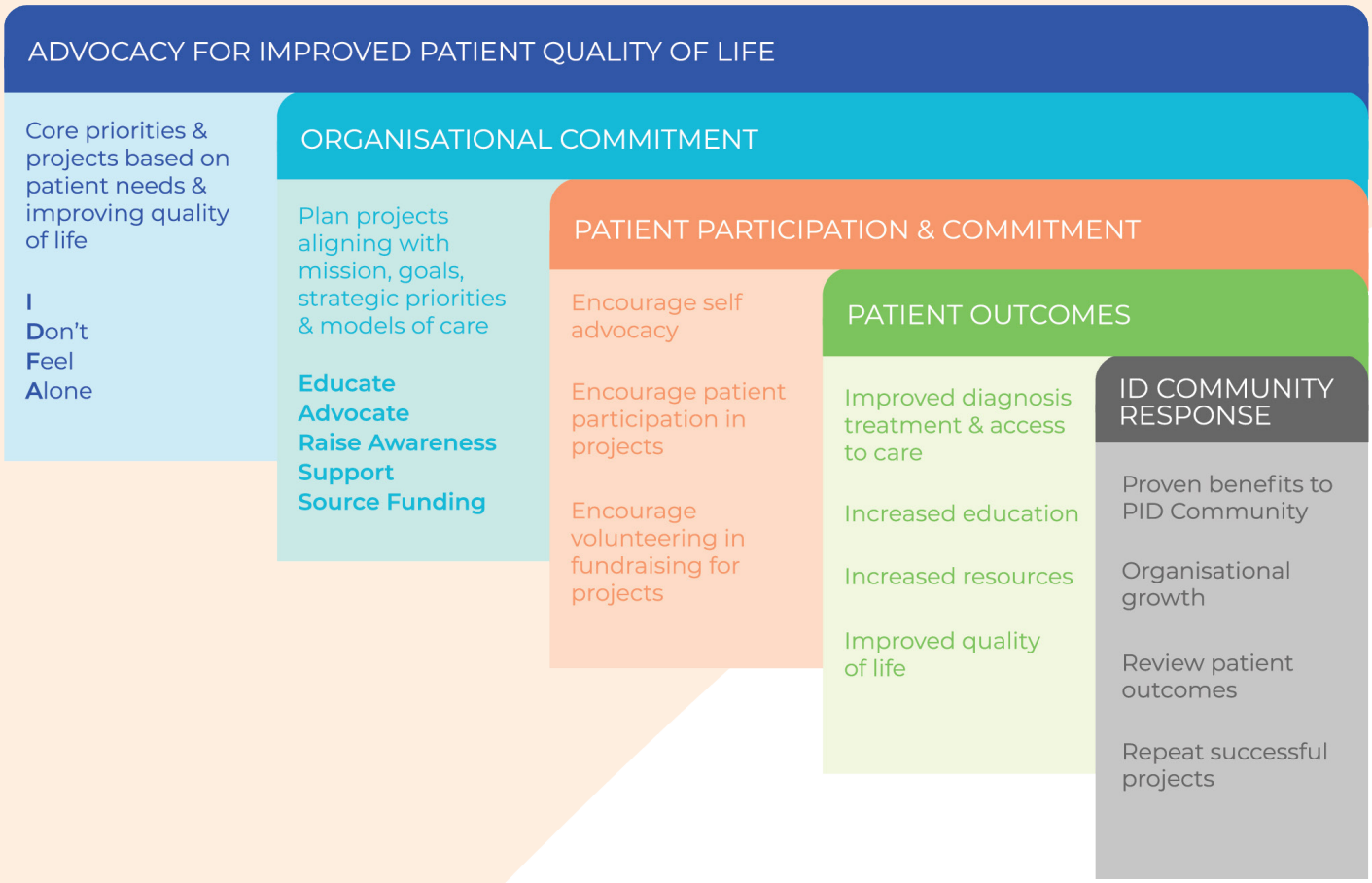
Adam Friederich

Alex James-Martin

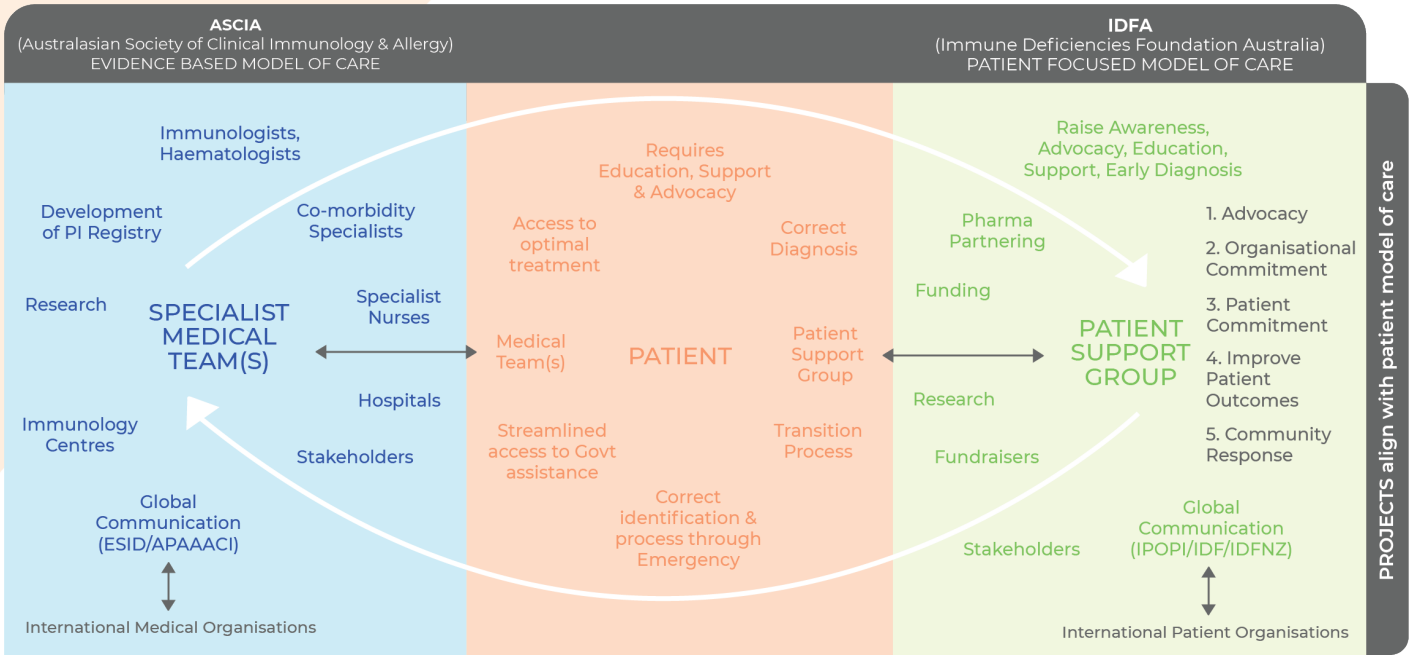
Models of Care

IDFA operate on various Models of Care:

Patient Focused Model of Care



Community Focused Model of Care



Immune Deficiencies

Primary Immunodeficiency

A primary immunodeficiency (PID) is a disorder where the immune response is weakened or absent altogether. They are often genetic in origin, i.e. inherited and result in a defect in one or more elements of the immune system. People with PID's are prone to infections which may be frequent, more severe or last longer than in individuals who have a fully functioning immune system.

A PID can be diagnosed at any stage of life, whilst some people may not show symptoms, which is a risk factor for a late or missed diagnosis. Some patients may not receive a diagnosis until reaching adulthood when they begin to present with clinical symptoms of a PID.

Other PID's are fatal without early diagnosis and treatment, such as Severe Combined Immunodeficiency (SCID).

Depending on the type of PID some people manage their condition quite well with appropriate treatment while others live with lifelong chronic illness and complex medical issues.

The International Union of Immunological Societies (IUIS) Expert Committee has classified up to 430 inborn errors of immunity/primary immunodeficiencies in their 2019 update. While this may seem like a large number, it's important to recognise that individual PID's are still considered a rare disease (the number of affected people is 5 < 10,000).

Secondary Immunodeficiency

A secondary immunodeficiency (SID) occurs when the immune system is weakened as a result of treatment for an illness (e.g. chemotherapy for treatment of cancer) or medications, or CAR-T cell therapy.

Many of the treatment options and supports offered to PID patients are similar for SID patients.

Treatment

Immunoglobulin (Ig) Replacement Therapy

Ig Therapy is one of the more common treatments among those living with a PID and helps protect patients from a range of infections. Ig's (also known as antibodies) are necessary to fight infections caused by various germs and bacteria and come from plasma donated by healthy individuals. Donated plasma undergoes a rigorous screening process to ensure it is free from infectious disease. Ig therapy is an ongoing treatment and is administered by infusion either intravenously or subcutaneously.

IVIg – Intravenous Immunoglobulin Therapy is administered intravenously (i.e. injected into the vein) in hospital by a nurse every 2-4 weeks to maintain sufficient levels of immunoglobulin.

SCig – Subcutaneous Immunoglobulin Therapy is self-administered by the patient at home, either using a pump or manually pushing after inserting a small needle under the skin. Patients using SCIg therapy generally require more frequent infusions than those using IVIg therapy.

Antibiotics

Infections are typically treated with antibiotics. In cases where infections don't respond to standard medications, hospitalisation and treatment with intravenous antibiotics may be necessary. Some PID patients may need to take antibiotics long term (prophylactic antibiotics) to prevent infections as well as permanent damage.

Gene Therapy

Gene Therapy is a relatively new treatment and not yet widely available. Gene Therapy replaces defective genes with working genes. A harmless virus is used to carry the genes into the body's cells. In turn, the newly introduced genes trigger the production of healthy immune system enzymes and proteins. Increasing numbers of genes that cause PID are being discovered, however Gene Therapy is still being refined.

Immunomodulation

Immunomodulatory drugs modify the response of the immune system and can be divided into two main groups: those that work by increasing the Immune system (immunostimulators) or those that work by suppressing the immune system (immunosuppressives). There are many different drugs within both categories and treatment depends on the specific needs caused by your PID.

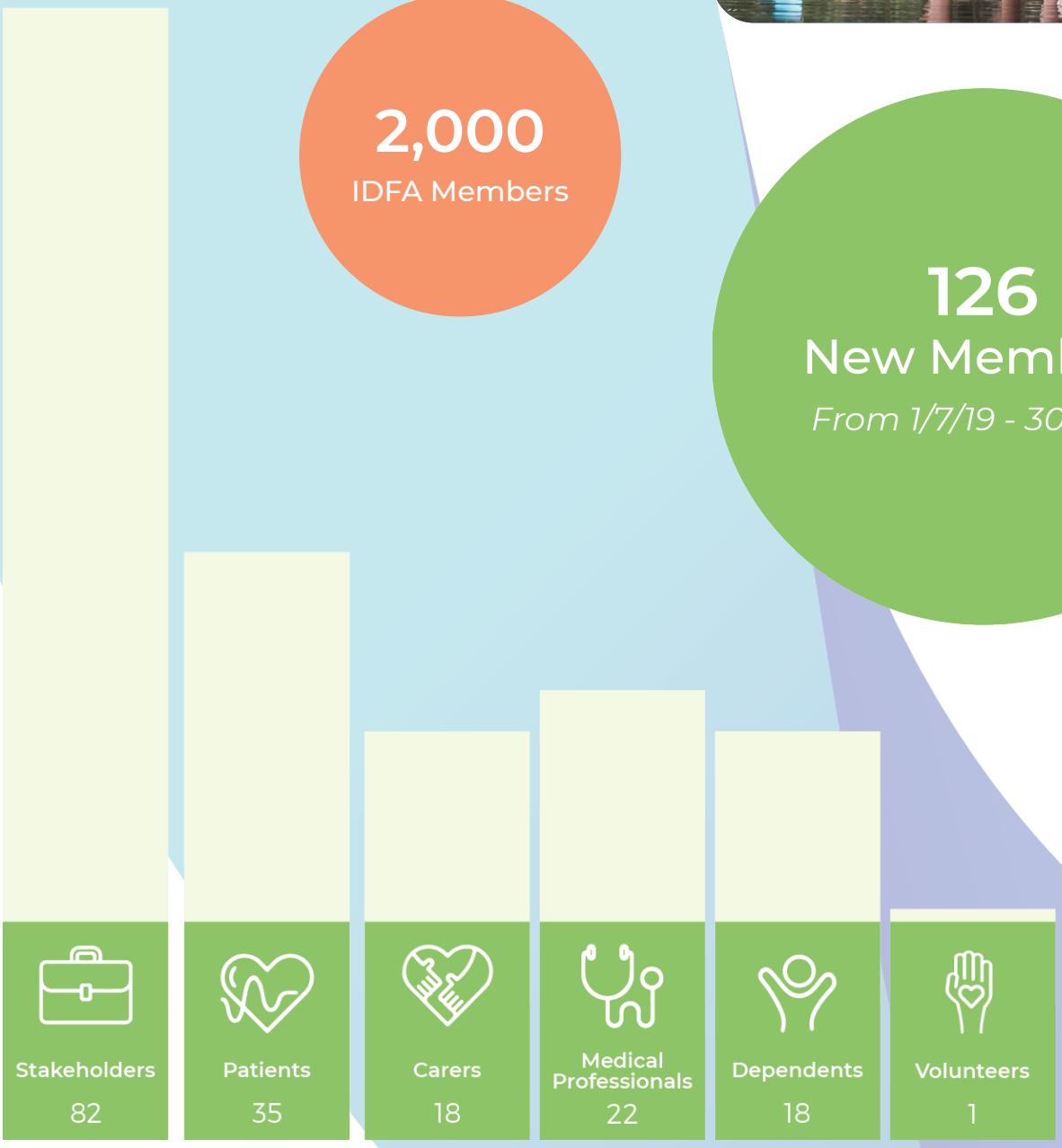
Membership

Whether you are the patient or the carer, living with a primary or secondary immunodeficiency can be a challenging journey. The physical, emotional and financial burden has an ongoing impact throughout your life. Even the most supportive friends and family might not understand how much you are affected by the diagnosis.

When you become a member of IDFA you are joining a community of people who "gets it". We like to use the motto "I Don't Feel Alone" and that's what we want for you. No matter where you live in Australia you can connect with a community of other PID/SID patients and be empowered by the extra support, information and educational opportunities.

2,000
IDFA Members

126
New Members
From 1/7/19 - 30/6/20



Member Story: Kayleigh Linnane

My name is Kayleigh and I am 27 years old. I'm originally from the UK and am now a permanent resident of Australia, living here for nearly 6 years. I met my husband while I was travelling to Australia and decided to stay, and I am a mummy to a very energetic nearly 3-year-old boy. He keeps me very busy.

I was diagnosed with CVID when I was around 10-11 years old. As a child I was sick a lot with ear infections, constant colds and chest infections, and being in primary school I picked up any bug which impacted my attendance. My GP referred me to an ears, nose and throat specialist who after various tests couldn't see a reason why I was getting recurring ear infections. I was seeing a paediatrician from birth who was looking after some other health issues and when I was around 10 years old she ran various blood tests which discovered that my IGG, IGA and IGM levels were low so I was then referred to Great Ormond St children hospital and was under the care of a children immunologist where I had to undergo a vaccine test to help diagnose that I had CVID - hypogammaglobulinemia. As a child I didn't understand what it meant apart from it was the reason I was always sick.

At the start of my diagnosis, I was put on prophylactic antibiotics to try and minimise the number of infections I was getting but unfortunately, I was still getting quite a lot of infections. When I was around 15, I started on subcutaneous immunoglobulin infusions. A nurse came to my house and trained me on how to give myself the infusions weekly. It took me about 4 sessions to be fully competent on how to do my infusions, but I felt like the treatment gave me some control over the disease and was flexible around school, so I was able to do the treatment on an evening or weekend.

As a child, my education had suffered a little with the amount of time that I had off school with viruses and infections, but I also worked hard to try and catch up on the days that I missed. The one thing that I struggled with is being told all of the things that you wouldn't be able to do due to having the disease, like working with children or nursing, which were my career choices growing up. I was also advised that I wouldn't be able to travel. I went to university and studied an event management degree all while continuing my subcutaneous infusions each week. I was under the care of an adult immunologist and the doctor was amazing.

He helped me understand that CVID doesn't define me, and we discussed me being able to make a trip to Australia to travel and see my aunt and uncle. We were able to put in place a referral to an immunologist in Australia in Sydney who would take on my care and treatment plan.

There was a hiccup in that plan. I got sick with double pneumonia and pleurisy and was admitted to hospital for a two-week stay.

This was my first admission with a severe infection and I think it was a wake-up call of how quick severe infections could hit. Previous to this, I would have a week or two oral antibiotics treatment and be okay, but this was different and I needed IV antibiotics. This was three months before I was due to leave to travel Australia on my own and now wasn't sure if I should still go but knew I would regret it if I didn't. I then changed from subcutaneous infusions to monthly intravenous immunoglobulin infusions, which would be the treatment I would receive in Australia and decided I would go ahead with the travelling as it would be a once in a lifetime trip.

I was able to travel and explore parts of Australia and I wasn't going to let my diagnosis stop me from living life to the fullest. Now living in regional NSW, I travel to Sydney every 6 months to see my immunologist and up until recently I was on intravenous immunoglobulin infusions before switching to subcutaneous infusions due to having issues with cannulation on my veins. Now I can do my infusions at home without taking time off of work or having most of the day in a hospital clinic. In the nearly 6 years I have been living in Australia I have been able to travel, seeing Melbourne and Adelaide, and backpacking along the East Coast. I've skydived above the Whitsundays and camped at Fraser Island. I got married at a zoo and my little toddler keeps me very busy, bringing so much joy to my life.

I rely on plasma donations to be able to continue receiving my immunoglobulin replacement therapy every week, which gives my immune system the antibodies it needs to fight bugs and infections, and hopefully keep my infections at a minimum. I am so grateful for everyone that donates so I am able to have this treatment, which is likely to be for life, and not only help me but help others who have an immunodeficiency.

Member Story: Tyson Gavan

Our son Tyson was born on 12th April 2013 in Sydney and was reasonably well for the first 6 months of his life. It was around October 2013 when he began to have a series of unexplained infections and fevers that would go away with IV antibiotics and return soon after they were stopped. On the third or so occasion that we ended up in a hospital, we insisted that they do further testing to find out what was happening and a few weeks later in January 2014 Tyson was diagnosed with the rare genetic disease which is X linked Chronic Granulomatous Disease.

Further testing then continued to map where the genetic fault occurred and how severe his neutrophil function was. It was some 6 weeks later that we were informed that Tyson was in the top 10% of those severely affected by this condition and a bone marrow transplant was highly recommended. Due to the mixed ethnicity of Tyson with mum being Thai and dad being Australian we were told that the tissue typing process and the chances of a solid matching donor were unlikely. This was confirmed within weeks that we only had the option of a poorly matched blood cord for transplant and, although it was an option, it was a very risky option and the statistics in this type of transplant were not good. We were told that genetic selection IVF to have a second healthy child that would be a possible match was also an option but we may not have the time to achieve so.

Immediately we got started building our case and in contact with genetic counsellors who sent us to the director of Genea who specialised in these kinds of things. After much testing and preparation, we started the process and were unlikely in the first round, although the second round we got two embryos that were unaffected by CGD and both boys and suitable. Immediately we began the process of putting the embryo back and much too our luck and amazement the embryo took and resulted in Tyson's little brother Alexander that was a 10/10 match sibling donor and happy healthy little boy.

Alexander was born 2nd August 2016 and had now put some very positive options on the table, but we now had to weigh up when was the right time to go to transplant. We had to ensure Alexander was not put in any danger, and that we could yield enough stem cells to be successful and balance how long we could wait given that Tyson's infections were getting more frequent and more serious even though he was on all the prophylaxis possible for his condition.

We ended up waiting until 16th October 2017 until Alexander was put under and Tyson was to receive a fresh transfer of his cells as well as his brother's blood cord that had been preserved and stored in case we did not have time to wait for Alex to grow.

Tyson was in isolation a few months with the chemotherapy conditioning to suppress his old immune system and then after the transplant until they were satisfied that his new immune system was strong enough to re-enter the world outside Room 1 in Camperdown Oncology Ward at Westmead Children's Hospital.

Tyson surprised everyone with minimal complications - he walked out those doors for the first time with his new immune system on-board some +35 days post BMT, the first 100 days are the riskiest with the chance of acute complications of BMT and still with a long 6 months or so ahead of him with a very immature immune system and also the risks of transplant complications still lingering. It was a long bumpy road with good days and bad days and a lot of medication to get him out of the woods, but we got there, one foot in front of the other and one day at a time.

Tyson turned 6 in April and will be 3 years post BMT on Wednesday coming of next week. We will never forget the road we walked or the help from Westmead Children's Hospital - both the immunology and oncology teams and Genea for playing their part.

It was heartbreaking to have your first child diagnosed with something so life-threatening so early and we appreciate that in Australia that we got the right help and attacked it head-on and came out with two happy healthy beautiful little boys. We are grateful for every day and what modern medicine is capable of.

Member Story: Sharon Heathfield

Hello, my name is Sharon and I am happy to say that I am 65 years old. My husband Michael and I have 3 adult children and our family is enriched by three amazing and gorgeous grandchildren (although I'm very biased!) I am so in love with them and treasure every moment I spend with them.

In 2006, life changed for me and my family. After a holiday in New Zealand, I was loving working 5 days a week in a child-care centre in the "babies' room", paddling dragon boats on the weekend and knowing our first grandchild was on the way. Life was great except for the fact that for most of the year I had chronic sinus infections. In October, after over 12 months of continuous antibiotics, I had surgery to try to put an end to the infections.

Unfortunately, the infections continued after the surgery, and on the 6th of December, a day I have no memory of, my husband took me to Ashford Emergency Department, drowsy and increasingly delirious. Doctors began blood tests and found that I had extremely low platelets. My absolute count was 16,000 so I was given 4 units of platelets overnight in the High Dependency Unit. CT scans showed I had 3 bleeds in my brain with no known cause ITP.

My family were stunned to be told that I was in a life-threatening situation and Doctors were unsure what the next 48 hours would hold. After much discussion between a team of doctors, a bone marrow biopsy, MRI, CT scan and more blood work looking for more sinister causes (because I had malignant melanoma in 2005 and suffered Rheumatoid Arthritis for over 20 years), there was nothing conclusive. On day 5 of being in a hospital, with great relief to my family, I remembered them all! The first memory I have since 6 days before was seeing the ultrasound my daughter in law had brought to show me of our first granddaughter. I had no idea of all the drama that had happened before. This experience has taught me that you do not have to be in a car accident to be in a life-threatening situation.

I was home for Christmas and over the next 3 months, I rebuilt my strength and fitness but never regained any memory of that week and frustratingly, I still had sinus infections! After seeing too many doctors, professors and specialists and having many, many tests done, in April 2007 I finally saw an immunologist. He did an allergy test which came back normal and then a vaccine response test that fortunately, I failed! This led the doctor to diagnose me with CVID, Common Variable Immune Deficiency.

Despite the name, CVID is not very common at all, only 1 in 50,000 people have it and what it means is that I have a hole in my immune system and can't fight infections.

It was also the answer to my bleed in the brain – because of the constant sinus infections my adult platelets were dying and not being replaced which meant my blood thinned and then bled in my brain.

As a result of my body not being able to fight infections, I have IVIg (Intravenous Immunoglobulin Therapy) every 3 weeks. This allows me to benefit from everyone else's antibodies through the invaluable donations of thousands blood and plasma donors. Without the incredible generosity of these amazing donors, I would not be able to hold the hands of my grandchildren and enjoy the quality of life I have today. I hold them close and cherish every smile and moment with my family as I know how close I came to not being able to be the wife, mother, grandmother, sister and friend that I am. Thank you will never be enough.

As an IDFA member you join a community.

'I Don't Feel Alone' - That's what we want for you!

Education

Support Groups

Carers Support

To celebrate National Carers week we held our first Carers Lunch in the IDFA office. The aim of hosting a Carers Lunch was to acknowledge the love and hard work of parents and carers plus provide a safe space to share their experiences.

We would like to thank those who came along for sweets and treats and shared their stories with us. IDFA hopes to host an annual Carers Lunch each year, beginning a new tradition in recognising and celebrating the hard work of those who care for patients living with PID's.

Group Support

Up until the pandemic, we continued to provide member support through one-on-one phone calls, emails, Facebook Messenger, and the occasional home/hospital visit. Since the pandemic, our support for members has involved extra focus on group chats and projects.

Group chats: We have run 18 group chats, averaging 6 attendees per week, for 1.5 hours. Topics discussed include: COVID-19 worries, isolation, family, treatments, supporting each other, chronic pain and fatigue management. As the pandemic began to worsen, we started holding the Zoom group chats more frequently. People were becoming even more isolated than before and it was a relief for many to connect.

Patient Meetings

IDFA organised a patient meeting for our WA members in September 2019. It was great to see both new and existing members in attendance. Members discussed the struggles and challenges in living with a PI over lunch. Our members introduced each other, offering strategies and tips on lifestyle choices.

IDFA members and their families enjoyed the views and amenities of Kings Parks while the kids played on the grass. Zamia Café offered a great setting for IDFA staff to meet with WA members and introduce IDFA as an organisation. The WA patient meeting was rated as a success by providing opportunities for patients to self-advocate.

Education

ASCIA Conference

IDFA attended the ASCIA Annual 2019 Conference held in Perth, Western Australia. ASCIA is the peak professional body of clinical immunology and allergy specialists in Australia and New Zealand. The Conference provided a unique opportunity to interact and collaborate with ASCIA members and health professionals working in clinical immunology and immunopathology. IDFA represented the membership by engaging with health professionals and researchers. Our staff attended the Immunodeficiency Symposium to education themselves on important and relevant topics. Our own Dr Melanie Wong and Dr Jan Sinclair presented updates on newborn screening pilot program currently in New Zealand and Australia, a key priority of IDFA's advocacy work.

A question commonly asked by people affected with a PID - is it beneficial to have vaccinations - was answered by Professor Peter Richmond in his presentation on vaccinations and immunodeficiency. Talks on immunodeficiency, genetic testing and counselling by Dr Michael O'Sullivan with the latest research supporting IDFA's goals of education and awareness. Chloe and Maria joined our front-line health staff on Nurses' Day. Engaging in stakeholder relationships is a key priority of IDFA's awareness goal signing up 30 new professional memberships. The event was a success for IDFA in terms of reaching our goals in education and awareness.

Online Webinars

IDFA partnered with the Clinical Immunogenomics Research Consortium Australasia (CIRCA) to produce a series of three free webinars on relevant and topical issues. Through our collaboration with the Garvan Institute of Medical Research we secured three experts from the CIRCA program who volunteered their time and expertise to present the following webinars:

- Webinar 1: COVID-19 and PID – A global perspective
- Webinar 2: Young people and PID – Lifestyle factors to consider
- Webinar 3: COVID-19 and our children – Impact on those living with PID's

This truly was a collaborative effort between IDFA and CIRCA. Dr Karen Enthoven from the Garvan Institute of Medical Research co-ordinated speakers and created the webinars on their software platforms while IDFA took care of event management and promotional activities. As a result, overall costs were kept to a minimum.

IDFA utilised the online platform Eventbrite to manage the webinars. This proved to be the best option to manage and track attendees as well as analyse event outcomes. The webinars were open to the public and IDFA members; they were promoted on IDFA's social media channels and via email newsletters. There were high levels of concern and anxiety amongst the PID community after COVID-19 was declared a pandemic. Professor Tangye and Dr Gray gave educational and insightful presentations, providing data and research from within the medical and scientific community specific to PID patients.

Awareness

Patient and Carers

Information Packs

This year, IDFA continued to raise awareness about immunodeficiencies through providing patients with our wide range of resources and practical advice, which they can obtain for free from our website. In response to the pandemic, we also worked to provide PID and SID patients with specific information regarding immunodeficiency and COVID-19. In particular we helped disperse information collated by the ASCIA, with links to their resources about COVID-19 on our website.

Government

Rare Disease Action Plan

As a partner with Rare Voices Australia, IDFA participated in the discussion and preparation of the Rare Disease Action Plan, which was adopted by the federal government in February 2020. IDFA staff attended workshops, meetings and contributed content to the Plan which sets priorities and will attract funding for rare disease in Australia.

SCID

IDFA continues to build positive working relationships with the government at all levels. Throughout the year IDFA have conducted a national advocacy campaign to advocate for government funding for SCID newborn screening. This campaign has involved mobilising our members to write to local MP's and to sign a petition to allow the issue to be raised in parliament. As part of the campaign we were able to meet with several government and opposition Ministers to discuss the importance of screening.

Relationships

As part of the ongoing work of IDFA, relationships with politicians at all levels will continue to be developed to allow us to raise awareness and advocate for people with immunodeficiencies on a range of issues.

Health Professionals

IDFA offers a stakeholder membership for clinicians of patients living with primary and secondary immunodeficiency. We play a key role in providing awareness for immunodeficiencies and collaborate with international and national organisations to provide health professionals with up-to-date information.

We support our health professional members in becoming better educated about their patient's diagnosis and assist them with health management. We also provide their patients with a wider network of support and keep them updated on current news, advocacy and events.

Community

Website

This year the IDFA has invested in updating our brand and completely re-designing our website. The new site will have a fresh and contemporary look, while employing more logical navigation - improving overall functionality.

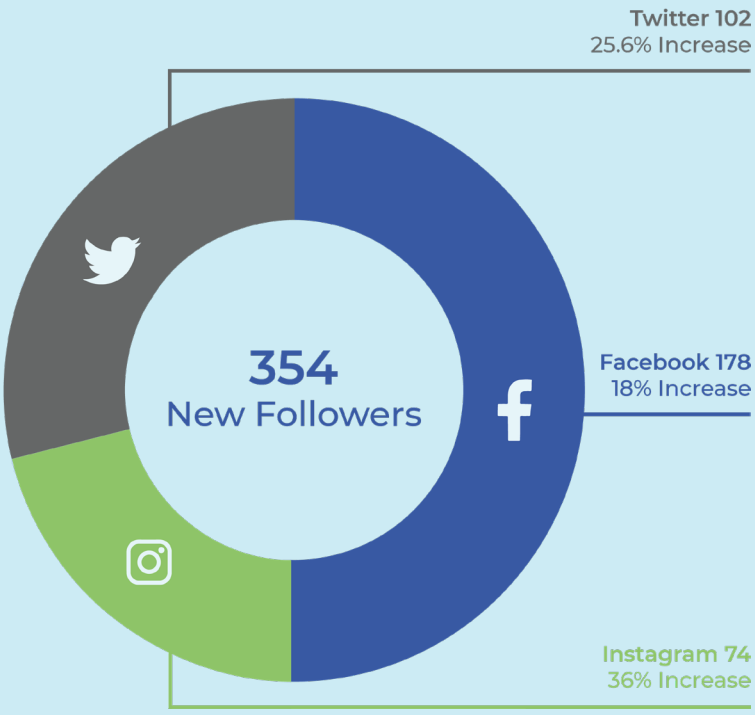
The objective is to make it easier for our members to find the information that is important to them, as well as attract new people to the website who are interested in knowing more about PID's and how the IDFA can support them. Overall, it will assist in achieving our organisational objectives of education, awareness and advocacy. The new website is expected to be launched in late 2020.

Social Media

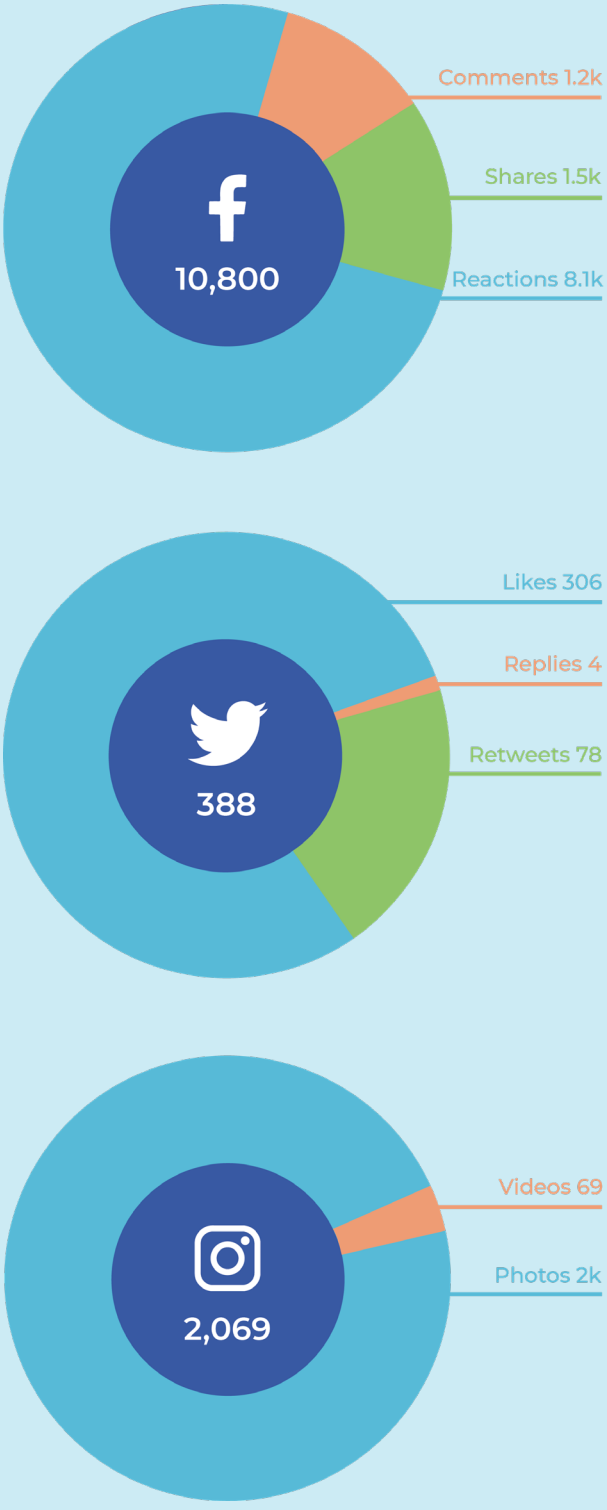
IDFA has seen a steady increase in followers across social media since employing someone to oversee these platforms, plus source and create content relevant to our audience.

We can also attribute an increased interest due to COVID-19. Some of our new followers include Garvan Institute of Medical Research as well as overseas immunodeficiency organisations including, International Nursing Group for Immunodeficiencies and Immunodeficiency Canada.

New Followers by Platform from 1/7/2019 - 30/6/2020



Engagement by Platform and Type from 1/7/2019 - 30/6/2020



Advocacy

Treatment and Care

National Blood Authority

IDFA continues to meet with the National Blood Authority (NBA) to discuss and review the global burden of immunodeficiencies, diseases, global plasma shortage, the use of Ig for conditions other than PID's 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.

Access to Treatment

One of our key advocacy activities over many years has been educating our members about the range of treatments options available, and assisting them in accessing treatment.

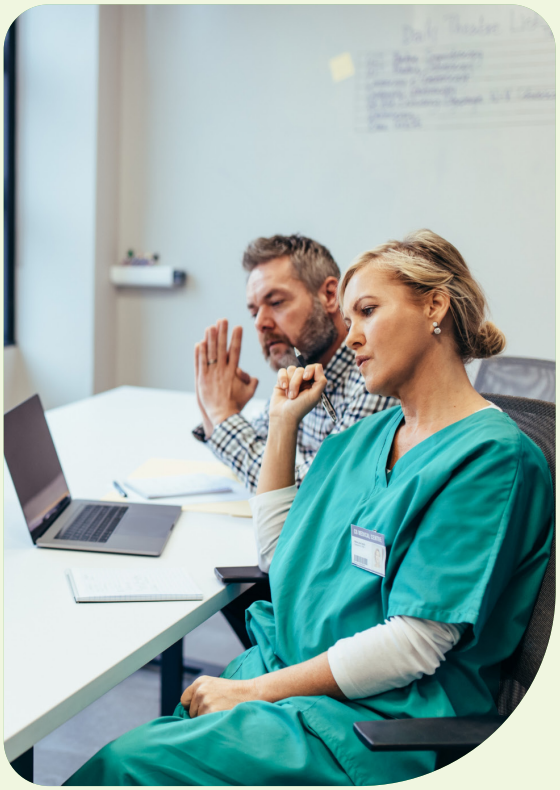
Rare Disease Action Plan

The Rare Disease Action Plan, adopted by the Federal government in February 2020, addresses issues associated with screening in two action items from the Care and Support Pillar:

2.2.1.2. Ensure all existing screening and testing programs are sustainable and evolve in line with innovation over time

2.2.2.2. Address urgent funding gaps associated with the effective implementation and sustained success of the Newborn Bloodspot Screening (NBS) National Policy Framework.

These pillars will be used as the basis for ongoing advocacy activities and to proactively seek funding.



Screening and Testing

SCID Newborn Screening

Severe Combined Immunodeficiency (SCID) is a life-threatening genetic condition in which affected babies are unable to fight even simple infections. SCID is often referred to as the 'bubble boy disease' highlighting the threat of exposure to germs and is considered an immunological emergency. Without appropriate timely treatment, most children die before the age of 2 years. If diagnosed early and then treated early, SCID can be entirely curable. Early diagnosis is possible with universal SCID newborn screening.

SCID fulfills the internationally recognised criteria for a clinical condition to be screened at birth through this process. SCID newborn screening is already standard practice in many countries including the USA, Canada, Norway, Spain and New Zealand.

Federally the Standing Committee on Screening (SCoS) has endorsed SCID to proceed to a detailed review to be considered for inclusion in the Newborn Screening Program in all states and territories.

SCID screening costs less than $10 per child and a pilot program has commenced in NSW and will conclude in late 2020. Funding should be made available for the routine inclusion of this lifesaving testing into newborn screening in all states and territories of Australia. The technology is available, and the clinical need is undeniable.

1:55,000 babies in Australia die from Severe Combined Immunodeficiency (SCID).

Lives can be saved by SCID screening, which costs less than $10/child.

Professional Networks

International Networks

National Networks

Other Networks

Immune Deficiency Foundation USA
Immune Deficiency Foundation New Zealand
National Immunoglobulin Advisory Committee
Ministry of Health NSW
Allergy and Immunology Foundation Australasia
Centre for Personalised Immunology
Allergy and Immunology Foundation Australasia
Australian Patient Organisation Network
Australian Immunological Alliance
Auto Immune Research and Resource Centre
Arthritis Australia
Leukaemia Foundation
Lymphoma Australia
Cancer Council
Clinical Immunogenomics Research Consortium Australia
Genetic and Rare Disease Network
National Disability Insurance Agency
Beyond Blue
Livewire
Australian Red Cross
Carers NSW
Centrelink
University of Western Sydney
Australian Immunological Alliance
Monash University
Thalassaemia Society of NSW
Mastocytosis Australasia
Volunteers Australia
Outer West Local Health District

Sponsors & Partners

Through the kind support of our sponsors we are able to deliver ongoing value to our members through a range of opportunities including:

- Developing and printing resources
- Creating engaging education campaigns
- Events - patient meetings, YAM Jams, Annual Conference, World PI Week, Carers Week
- Online support groups
- Projects such as maintenance of website and database
- Legal qualifications and/or experience.

The contribution of all our sponsors is important to the sustainability of IDFA and we thank you for your ongoing support.

CSL Behring
Biotherapies for Life™

GRIFOLS

Takeda

International Entertainment Shows

The generous support of International Entertainment as an external fundraiser has supported IDFA since inception.

Businesses are encouraged to sponsor tickets to our shows which in turn support children with special needs and disadvantaged families within their community. Tickets are given to these families to provide respite and an exciting and fun experience they might not be able to afford otherwise. Through the profits received from ticket sales IDFA can continue to support patients and families living with immunodeficiencies.

These shows are thoroughly entertaining and are held in locations across Australia including:

NSW
Albury
Lismore
Newcastle
Penrith
Sutherland
Wagga Wagga

VIC
Bendigo
Geelong
Melbourne

WA
Perth

QLD
Cairns
Mackay
Toowoomba
Townsville

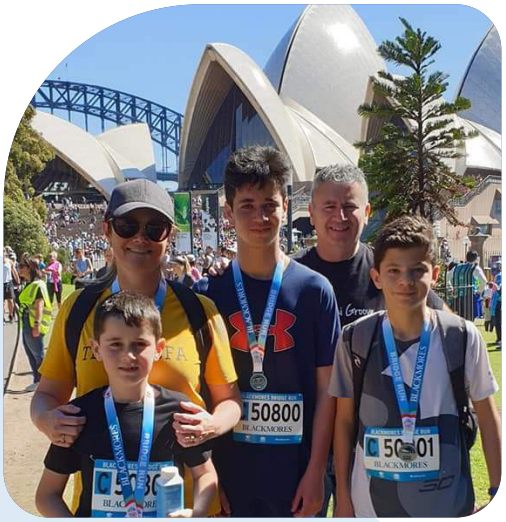
ACT
Canberra

TAS
Burnie

SA
Adelaide

Fundraising

Blackmores Sydney Running Festival



Cath Bampton

IDFA member Cath Bampton took part in the Blackmores Sydney Running Festival to raise awareness for people living with a PID. It's the fourth year Cath has walked the 10km Bridge Run, the physical effort takes its toll yet each time she is victorious in reaching the finish line. This year Cath was joined by her entire family, making the day just that little bit extra special. When Cath put out the call for donations she was supported by the Vodafone Foundation, matching donations dollar for dollar. Cath, once again you have astounded us with your efforts, your resilience and your heart. The IDFA thanks you for all that you do.

Ruth and Luke Currey

Ruth Currey and her son Luke also took part to raise funds and awareness for immune deficiencies. Ruth has been a staunch supporter of IDFA over the years, and we'd like to say a big Thank You to Ruth and Luke - you two are amazing!

Grill'd Local Matters

IDFA participated in the Local Matters campaign run by Grill'd Healthy Burgers restaurants. Each month Grill'd assists community groups to fundraise by allocating a token for every burger purchased, guests receive the token to drop into a fundraising jar for the community group of their choice. We were thrilled IDFA received the most tokens with a $300 donation coming our way.

Rare Disease Day Art Competition

To recognise Rare Disease Day and World PI Week 2020 we asked IDFA members to creatively express what it means to live with a rare disease. We were surprised with the variety of entries which included canvas and fabric artworks, digital animation and photography.

We would like to extend our thanks to Officeworks for donating this fantastic prize hamper.

Merchandise

You can support us supporting people living with an immunodeficiency by purchasing our merchandise online.

PID is a genetic disorder
Causing the immune system to be quite out of order
Coughs, colds, infections and more
Are caught easily from the tiniest spore.
Ongoing treatment, lifelong for most,
Through plasma donations by generous hosts,
Is needed to keep the nasties at bay
So, people with PID can live, work and play.
This IDFA pin
Worn with pride
Will raise awareness
Of PID worldwide.

Awareness Pin - $5

Zebra Pen - $5

World PI Week Pack - $30

Tote Bag - $20

To purchase our merchandise go to our website:
www.idfa.org.au

Donations

You can support IDFA to provide essential information and services to our members by donating through our website:
www.idfa.org.au

$10
Cost of SCID Newborn Screening Test

$20
Cost of posting a Resource Pack to one of our Members

$50
Cost to cover one of our Members attending a Patient Meeting

$100
Covers printing costs of a complete Resource Pack

$150
Helps one of our IDFA Child Members to attend a weekly activity to engage with other children with a PID

$200
Cost of registering one of our members to attend an IDFA Conference

$500
Cost of travel and accommodation for one of our members to engage with other Members at the Annual Conference

Volunteers

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 Mathieson
Julie Mathieson
Gail Dixon
Emily Dixon
Abbey Jones
Tayla West

"Thank you to our volunteer fundraisers! We thank you for your enthusiasm, commitment and support of the IDFA and our patients. You are all Champions!"

Financials

Statement of Profit or Loss and Other Comprehensive Income

	2020	2019
IE Income	$961,510	$1,096,815
Pins and Merchandise Sales	$326	$1,314
Total Sales	$961,836	$1,098,192
Cost of Sales	($766,781)	($917,895)
Gross Profit	$195,055	$180,234
Finance Income	$238	$489
Other Income	$134,030	$158,092
Marketing Expenses	($495)	-
Administrative Expenses	($263,936)	($226,061)
Functions, Awards & Presentations	($19,108)	($64,635)
Amortisation - Right-of-use Assets	($18, 659)	-
Other Expenses	($14,440)	($14,801)
Finance Expenses	($1,064)	-
Lease Expenses	-	($23,262)
Profit before Income Tax	$11,621	$10,056
Income Tax Expense	-	-
Profit from continuing operations	$11,621	$10,056
Profit for the year	$11,621	$10,056
Other comprehensive income, net of income tax	-	-
Total Comprehensive income for the year	$11,621	$10,056

Statement of Financial Position

	2020	2019
ASSETS		
Current Assets		
Cash & Cash Equivalents	$227,516	$200,691
Trade & Other Receivables	$43,057	$55,000
Inventories	$13,125	$13,125
Other Assets	$6,084	$27,950
Total Current Assets	$289,782	$296,766
Non-Current Assets		
Property, Plant & Equipment	$18,353	$10,402
Right-of-use Assets	$26,433	-
Total Non-Current Assets	$44,786	$10,402
Total Assets	$334,568	$307,168
LIABILITIES		
Current Liabilities		
Trade & Other Payables	$42,495	$31,868
Lease Liabilities	$11,796	-
Employee Benefits	$7,615	$20,861
Other Financial Liabilities	$23,048	$31,500
Total Current Liabilities	$84,954	$84,229
Non-Current Liabilities		
Lease Liabilities	$6,603	-
Employee Benefits	$4,626	-
Total Non-Current Liabilities	$11,229	-
Total Liabilities	$96,183	$84,229
NET ASSETS	$238,385	$222,939
EQUITY		
Retained Earnings	$238,385	$222,939
TOTAL EQUITY	$238,385	$222,939

IDFA Immune Deficiencies Foundation Australia

Our Vision

A future where primary and secondary immunodeficiencies are diagnosed and treated early, with affected people supported by clinicians, community and government to enable optimal quality of life.

Our Mission

Raising awareness for primary and secondary immunodeficiencies; supporting and advocating for improved health outcomes for patients, carers and families.

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