IDFA

Immune Deficiencies Foundation Australia

Annual Report 2020-2021

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Acknowledgement of Country

IDFA would like to acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First People and Traditional Custodians. We value their cultures, identities and continuing connection to country.

Supporting our members through COVID-19 has been our priority throughout the year.

Message from CEO

Like many in our community, IDFA have continued to navigate the changing environment that we are all living in.

Supporting our members through COVID-19 has been our priority throughout the year and we have more recently turned our attention to providing information about the vaccine as this is rolled out throughout Australia.

Our Strategic Plan and the three priorities of Education, Awareness and Advocacy have been top of mind in all of our activities throughout the year.

In terms of education, we have continued to offer online support to our members through regular Group Support chats and our recently developed PI Education (PIE) Program which is a twelve module education program designed to provide information and education to all our members from children to adults, carers and health professionals. This program has taken significant time to develop, and we are pleased to announce that we have sourced some well recognised experts who have partnered with us to deliver high quality content.

Our awareness raising efforts have been assisted by an IDFA re-brand including launching a new website and developing brochureware that reflects a more contemporary branding for our organisation. This information has been distributed broadly to our members, health professionals including GPs and specialists to assist in building the national profile of IDFA.

Advocacy efforts this year have been strongly focused around the Severe Combined Immunodeficiency Newborn Screening (SCID NBS) campaign, which has involved successful meetings with state and territory Ministers to advocate for funding for this important test.

As we look forward to life returning to normal with the vaccine roll-out, our plans for the coming year will build upon the work we have done through online engagement as well as getting out in the community to meet with our members and to continue to support those with primary and secondary immunodeficiencies.

Carolyn Dews, CEO

Message from Board Chair

As we navigated our way through the financial year of 2020/21, we maintained great awareness of the uncertainties still facing our world and especially the not-for-profit sector.

Having set a good course from the previous year, we have continued to focus on ensuring our financial sustainability whilst continuing to provide services and support to our members and carers as well as increasing advocacy.

The unfortunate restrictions imposed by COVID-19 on various states and territories hampered our desire for ‘face to face’ meetings but we continued to make good usage of technology and organised several webinars and patient support sessions.

Our advocacy for SCID NBS increased significantly with our CEO, IDFA Chair of the Medical Advisory Committee and IDFA members and advocates, meeting with politicians and representatives to raise this very important issue and gain support from state governments.

At our October 2020 AGM we welcomed Dr Luke Droney as our new Board Director and member of the Medical Advisory Committee. We sadly said ‘goodbye’ to Josh Snow, our Finance Chair who has provided great stewardship through the tough COVID-19 days of 2020. But we are looking forward to confirming new Board members at our next AGM in October 2021.

Behind the scenes at IDFA there is a small but very dedicated team of staff under the leadership of our CEO, Carolyn Dews and I would like to take this opportunity to acknowledge and thank them for their support and hard work.

On behalf of IDFA, I would like to express our gratitude to the donors, supporters, members and volunteers who contribute in so many ways, ensuring the meaningful work of IDFA continues into the future. Thank you very much!

Lara Alexander, Board Chair

Restrictions imposed by COVID-19 on various states and territories hampered our desire for ‘face to face’ meetings but we continued to make good use of technology.

Key Highlights

At IDFA, we work everyday to support Australians living with primary and secondary immunodeficiencies.

We are always finding new ways to raise awareness, share knowledge and advocate for our members.

Some of our key highlights from the 2020-2021 financial year are outlined below.

155
New Members

Brand Refresh

In late 2020, IDFA launched it's refreshed brand identity, which included a new, contemporary, user-friendly website.

393
New followers on social media

SCID Newborn Screening

IDFA were successful in influencing the NSW state government to extend funding for the SCID Pilot Program until August 2022.

PI Education Program

In June of this year IDFA launched it's innovative national PI Education Program: a series of online webinars aiming to increase awareness for Primary Immunodeficiencies, and provide information about PI's and associated issues to participants.

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.

Strategic Plan

Our current Strategic Plan includes an updated vision statement and is based around three strategic priorities:

- Education
- Awareness
- Advocacy

Looking Forward

The impact of COVID-19 has allowed us to develop effective online engagement tools to reach our national membership.

For the coming year we plan to continue to roll-out our PI Education Program to ensure that we address a range of topics that are of interest and relevance to our members so that they feel well informed and supported throughout their journey.

Our Member Engagement Strategy is an important tool to allow us to provide relevant members services. A key project that is underway to support this is an update to all of our IT systems including our database. This will allow us to ensure that we can communicate and engage with members in a way that is contemporary and responsive to changing needs.

With our Medical Advisory and National Patient Advisory Panels now in place, we are soon to finalise a National Health Professionals Panel that will provide a broad range of health advice from specialists across Australia and will be a useful resource for members who require information and education about their own health.

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

Strategic Priorities

Education

Support Groups
Resources

Education
Events & Resources

Website

Social Media inc. Facebook, Facebook Groups, Instagram, Twitter, LinkedIn and YouTube

Emotional, Social & Practical Groups
Peer Support & Mentoring Program

Online Support Groups

Awareness

Patients & Carers
Information Packs

Support Groups

Communications

Health Professionals
Resources

Engagement

General Community
Awareness Raising Events

Website & Social Media

Government
Introductions & Representations to MP'S

Funded Projects

Advocacy

Screening & Diagnostic
SCID, NBS and Genetic Testing

Treatment & care
SCIg Access

Access to Treatment Options

Rare Disease Action Plan

Governance and 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 a CEO, 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.
- Human resources, people and culture skills 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.

Our Staff

Carolyn Dews
CEO

Maria Pirovic
Business Development
& Strategic Member Support

Belinda Yeats
Marketing & Communications

Rachel Pearson
Administration & Membership

Chloe Appleton
Member Support Officer

Resignations

Staff

Chloe Appleton (September 2020)

After more than eight years with IDFA, our much-loved Member Support Officer, Chloe Appleton left IDFA in September 2020 to focus on her own heath and pursue other interests.

Chloe was an integral part of the growth and member engagement during her time with the organisation and had strong relationships with many of our members. We wish Chloe all the best and know that she will stay in touch.

Maria Pirovic (June 2021)

Belinda Yeats (June 2021)

We'd like to thank Maria and Belinda for their hard work at IDFA and wish them all the best for their future endeavours.

Board Members

Josh Snow (February 2021)

We thank Josh for his hard work and support as Finance Chair.

Board Members

Lara Alexander
Board Chair

Craig Mathieson
Deputy Chair

Catherine Bampton
Company Secretary

Dr Melanie Wong
Medical Advisory Panel Chair

Geraldine Dunne
Medical Advisory Panel

Dr Luke Droney
Medical Advisory Panel

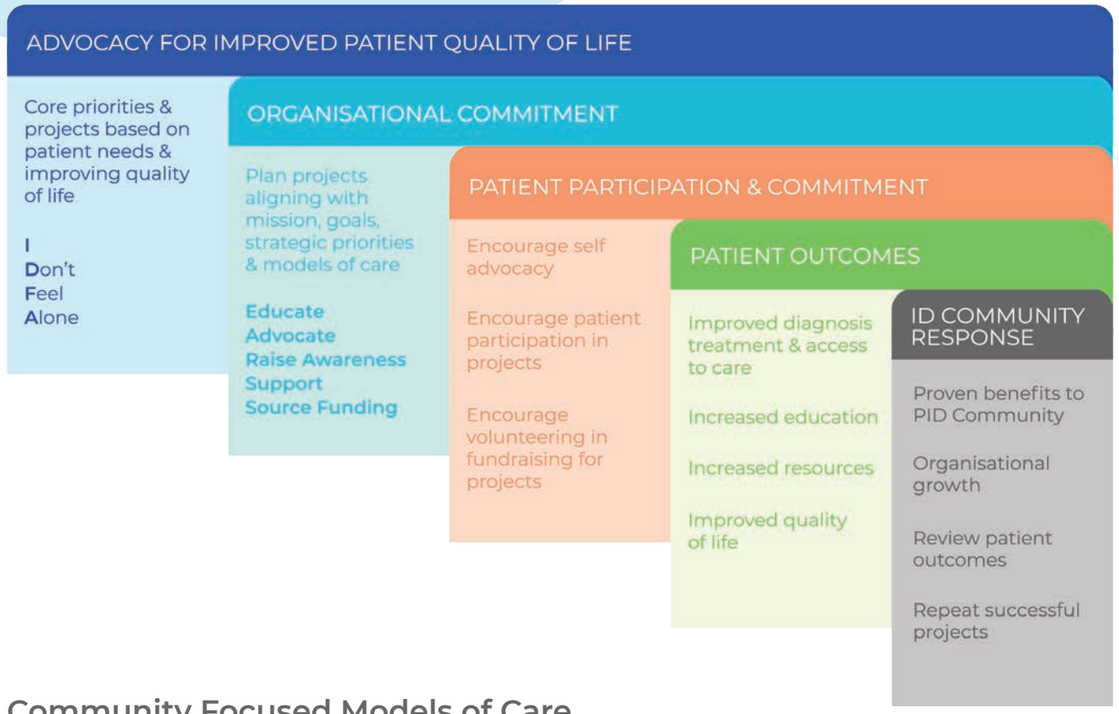
Alex James-Martin
National Patient Advisory Panel

Adam Friederich
National Patient Advisory Panel Chair

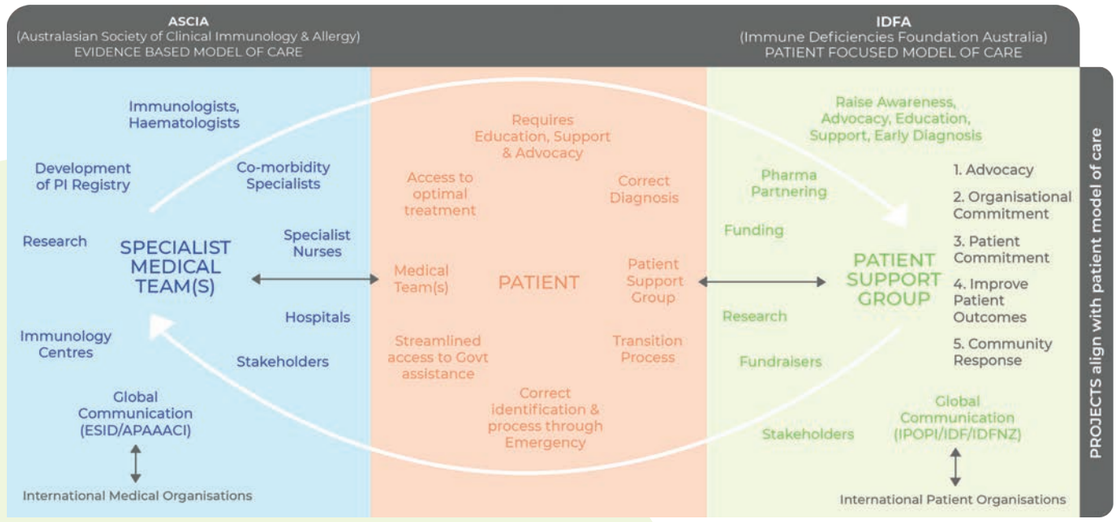
Josh Snow
Finance Chair

Models of Care

Patient Focused Models of Care



Community Focused Models of Care



Patient Advisory Panel

Medical Advisory Panel

IDFA have formed a specialist Medical Advisory Panel (MAP) lead by Immunologist and Board member Dr. Melanie Wong. The MAP is essential to allow any of our member enquiries to be answered by renowned specialists.

National Patient Advisory Panel

Earlier this year IDFA hosted the inaugural meeting of the National Patient Advisory Panel (NPAP).

The role of the IDFA National Patient Advisory Panel will be to support and reflect the status of IDFA as the peak body for those living with an immunodeficiency. The Panel will focus on outcomes aligned to the Strategic Plan and priorities set by the Board of IDFA.

NPAP is an advisory group of the IDFA Board. The composition of the IDFA National Patient Advisory Panel includes IDFA members, both adult and youth members as well as carers.

To date the NPAP has identified seven key projects which will be prioritised and delivered in the coming year.

People with PID's are prone to infections which may be frequent, more severe or last longer than individuals who have a fully functioning immune system.

Immunodeficiencies

Primary Immunodeficiencies

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 less than 5 per 10,000).

Secondary Immunodeficiencies

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 support offered to PID patients are similar for SID patients.

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 less than 5 per 10,000.

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.

One of the most effective treatments for PI's is Immunoglobulin Replacement Therapy to replace antibody levels.

2,109
Total Members

155
New Members
from 1/7/20 - 30/6/21

Membership

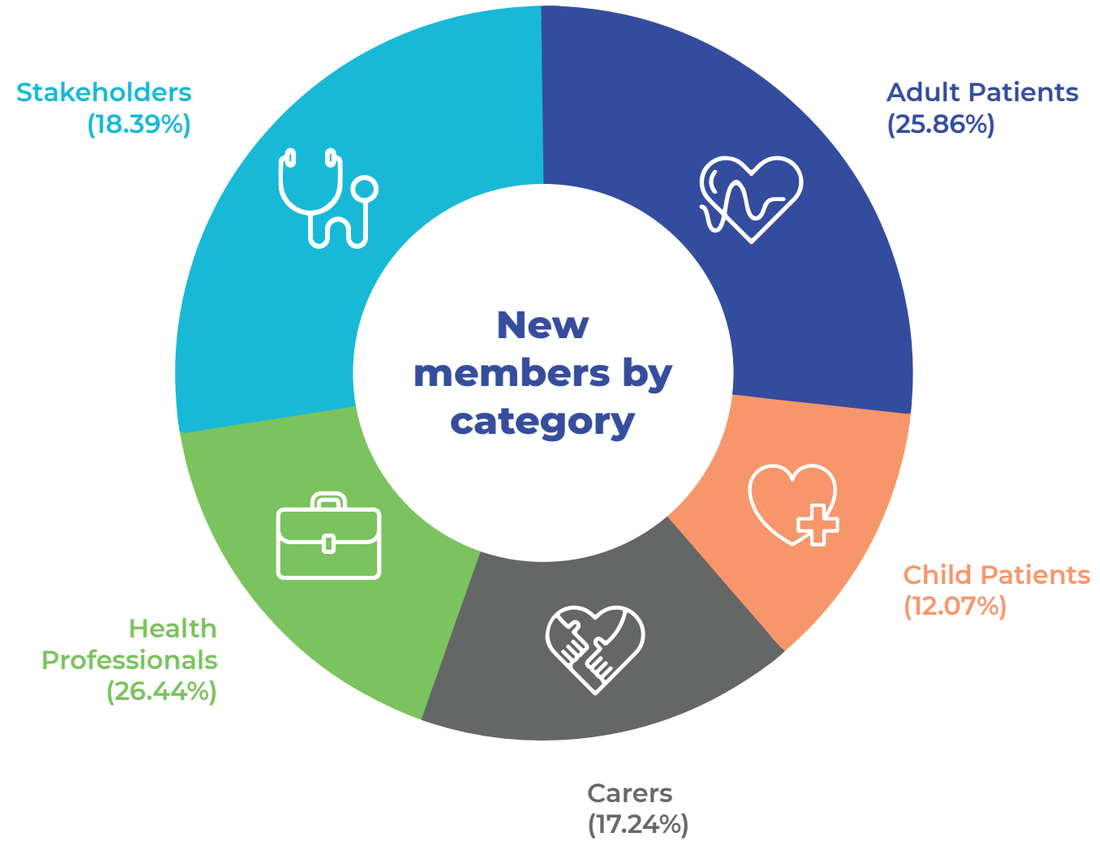
No matter where you live in Australia you can connect with a community of other PID/SID patients and be empowered by the extra support, information and educational activities.

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.

IDFA have a range of membership options including:

- Adult Member
- Child Member
- Carers
- Health Professionals
- Stakeholders



Member Stories

Bianca's family diagnosis

"Nathan and I have two inquisitive, adventurous and mischievous children, our son aged 10 and daughter aged 6. Oliver was a miserable baby, suffering from reflux and food allergies and often was unable to sleep for longer than an hour due to his severe pain. He was then a very unwell toddler, suffering regularly from viruses, recurrent ear and chest infections. Mya also suffered with reflux and food allergies however was a happier baby. She also suffered with recurrent illnesses with many ear infections. Their childhood illnesses mirrored my own. I remember regular visits to my local GP, lots of antibiotics, lots of days off from school unwell and regular doses of ghastly cod liver oil in an attempt by mum to keep me healthy!

In 2019 Oliver became very unwell with a skin infection. One school sore escalated into a large skin infection and it took seven weeks of antibiotics, antibiotic cream, steroid cream, oral steroids and antibiotic wash for his immune system to fight off this infection. This led to me demanding, for the third time in his life, a referral to the Paediatrician for investigation of his immune system.

Our next step was a Paediatric Immunologist. Armed with Oliver's medical history, which included a typed document outlining every illness that he had suffered in the last 12 months, we travelled to Brisbane. Within 30 minutes of our appointment with the Paediatric Immunologist, she queried a family history of immunodeficiency and suggested a referral for Oliver to the Children's Hospital for a case review. Genetic testing revealed that both my children and I have a NFKB2 gene variant that is associated with Common Variable Immunodeficiency (CVID) due to NFKB2 deficiency. In January 2020 we all received our diagnosis of CVID, and four months later, in the middle of the COVID-19 pandemic, we began subcutaneous immunoglobulin infusions.

We are very excited to say we have achieved an excellent level of health for the children, with both now tracking well for their height and weight. We also have been able to avoid illness and antibiotics since May 2020! This is the first time in the children's lives they have had a break from constant illness and antibiotics. We have chosen to keep the children learning from home via distance education and home schooling as we wait for the COVID-19 pandemic to resolve. I believe it is the combination of SCIg and isolation from others, that has resulted in our state of health.

2020 was definitely a stressful year. COVID-19 stress combined with confirmation we have a chronic health condition while learning to administer SCIg for myself and both children, has definitely led to more grey hairs! However, we are so very grateful for the amazing immunology and allergy team at the Children's Hospital who have provided the most excellent medical care for our children. I am also so thankful to have found IDFA and credit our regular involvement in their activities for helping me feel less isolated and alone in our medical journey."

I am so thankful to have found IDFA and credit our regular involvement in their activities for helping me feel less isolated and alone through our medical journey.

Member Stories

Lisa's journey to motherhood

"For as long as I can remember I've wanted to be a mum. As a child, when people asked me what I wanted to be, the answer was "a mum". I wanted a huge family (11 kids and a bus to be honest), but I was in for a rude awakening.

When I was 12, I did some research on my genetic condition Chronic Granulomatous Disorder (CGD). According to the literature of the day and my doctors I realised it wasn't possible which left me devastated. I genuinely believe this was the root of my subsequent depression and suicidality which lasted more than 15 years. I cannot describe the pain I carried with me.

In 2016 we moved to Tasmania and while attending a conference hosted by the Immune Deficiencies Foundation of Australia (IDFA), we met an internationally renowned specialist in CGD from France. I asked if there was any research or new treatments on the horizon that one day might mean we could be parents. He was seemingly shocked at my question and told us that in France we would already be parents. He warned that it would not be easy, that there were many risks and no guarantees... but there was hope.

This meeting changed my life. I had to get fit and healthy; quit smoking, defeat my addictions to over-the-counter pills, get off of most of my prescription pain medications, reduce my anti-depressant; change two medications that had been key to keeping me well (one of them for nearly 20 years) to less broad spectrum and effective ones, stop my immune boosting injections... and then I had to prove that after all this I could stay well. After an appointment with a genetic counsellor to consider the risks of passing on CGD, we decided to proceed. We also learned that we would be able to collect her cord blood at birth and cure her if she was affected.

It was hard. There was blood, sweat and tears aplenty. Then we still had the challenges most couples face trying to conceive, just with a whole lot more tests, supplements, doctor visits and medications.

For my 30th birthday, my husband organised my dream trip to Hobbiton in New Zealand. While we were over there, the magic happened! Until I saw that positive pregnancy test for the first time, I still couldn't even accept the possibility of success but at that moment I knew it was going to be ok! I was very well for most of my pregnancy, but my pain increased towards the end, though still manageable.

There were several complications during the birth, which were not CGD related. A few days later the autoimmune side of my condition flared up, and over the next few months this continued to be a challenge, however, with the help and support of our amazing medical team we will be fine!"

For as long as I can remember, I've always wanted to be a mum. As a child, when people asked me what I wanted to be , the answer was "a mum".

Member Stories

Jude and IRAK-4 deficiency

"Our son Jude was born in March in 2018. He was well until ten months of age. At this time, Jude was hospitalised for an infection. We believed at the time he was just unlucky. What followed was a blur of serious illnesses, an unhappy baby, sleepless hospital admissions, ambulances to the home, stressed out parents and no answers. Jude was getting worse each hospital admission and each time they were becoming more complex. This meant various illnesses at once attacking his body.

It was one particular stay when Jude was 14 months old, he was very ill, and his work of breathing was deteriorating. The support of paediatric staff at Maitland Hospital was fantastic, however the medical complexities of Jude's condition were challenging. The NETS team were called and Jude was helicoptered with them and me to the PICU ward at the John Hunter hospital. Jude was fighting for his life. He had been fighting for his life once before but the drugs he was given at our local hospital on that occasion were enough to help him. This time Jude needed more medical intervention. Jude had ten different illnesses including pneumonia and he could no longer fight. That helicopter ride is ingrained in my mind.

Amazingly though, Jude improved day by day, but the hospital staff agreed something was very wrong and further tests were needed to be carried out. This included a bone marrow biopsy, and we would wait anxiously for results. From the blood results it could be seen that Jude had almost no neutrophils in his body meaning he was neutropenic. When we were discharged, we were told Jude had neutropenia and this explained why he was getting so sick. Being neutropenic his immune system was incredibly low and unable to fight off what came his way. We were in contact with a haematologist at the hospital who would help us navigate this condition. Jude also had genetic blood testing that was sent to America. The doctors were extremely efficient in ruling out everything they could think of so decided to do these tests. The genetics in the USA are very advanced which is why they were sent there.

Three weeks after finding out Jude had neutropenia, we were called in for a meeting. We met at the haematology clinic where a number of staff including the immunology team were waiting. They explained that the tests were back from America and Jude would now be under the care of the immunology team. "We have discovered that Jude has a rare genetic autoimmune disease called IRAK-4. So rare that he is 1 in 75 people worldwide". My husband and I sat there in shock.

We had barely begun to understand that Jude had neutropenia and were trying to now understand what this meant for our son's future. It was a double-edged sword. Having answers was great but then the reality of having a complex disease that isn't that well known felt overwhelming. It felt like they were talking in another language. They were drawing diagrams and talking in medical terminology which sounded so foreign. These days for us none of it is foreign. It's common to walk down the hallways at the hospital and see familiar faces. Jude has become very popular in hospital and the staff always remember his big bright hazel eyes.

Once diagnosed, Jude started having IVIG infusions monthly at the oncology ward in hospital under anaesthesia. He also commenced daily prophylactic antibiotics. During COVID-19, Jude switched to SCIG infusions weekly from home. Jude will continue to have daily antibiotics and weekly SCIG until he is a teenager. Infusions are something you assume only a nurse or doctor is capable of doing. But when you are involved in the hospital system like we are, you do what you have to do. And we are Jude's biggest advocates.

Jude is now three. He is doing really well. He has less hospital stays and is looking really well. When he does go to hospital we have plans and strategies in place for smoother outcomes. We are also currently working on the reality of hospital trauma and other associated issues relating to having a child that spends a lot of time having procedures, tests and medical appointments. We are lucky to live in a medically advanced country with sound medical knowledge and resources. And we have nothing but praise for the paediatric hospital staff at the John Hunter Hospital and in particular the immunology team who have never given up on our son and are so wonderfully caring."

Member Stories

Alison's story as a mum and carer

"We have two daughters – gorgeous, fun, interesting, smart and each deficient in a range of antibodies.

They both have a primary immunodeficiency, meaning they and us have lived the life of sick kids since the beginning. Laurie has CVID, meaning her body doesn't make many antibodies and Beccy has an (at this stage) unconfirmable diagnosis where she is low in some and ok in others. After months of bloods and waiting, the decision is "immunodeficiency". Beccy isn't eligible for much with her "beccy-itis" diagnosis, living on prophylactic antibiotics at the moment. Laurie is on SCIG, weekly "goblin" replacement.

They both get sick, they both get fatigued, they both need days off school. Being PID kids they don't take one day to get over something, we are talking 1-2 weeks each time. Many, many times a term.

We are their parents, so we are a bit the same, juggling autoimmune conditions of our own. This is another story, for another day.

As parents who run a business and both work more than full time, the caring role takes priority. We spend the last day of school holidays working out who can work from home on what day so there is always a "plan A" for staying home when someone wakes up ill.

Our term starts with independent learning plan meetings scheduled for both girls – life is hard when you are in year seven and had up to six weeks off school sick by Term 3. We spend loads of time talking with the extra-curricular staff too (Yes, I know your kids get sick too, but this is a little different!).

We have a roster with the local pharmacy for medication delivery, and a few hours are set aside for infusions on weekends.

When this is organised we can then schedule in the specialists, the GP, therapists who help etc etc etc with school and planned absences.

Don't forget the monthly run to the local hospital to pick up the plasma.

Oh, there is also the remote learning day on Thursdays because a whole working week is a lot when your body is constantly fighting a bug that no-one else has even noticed.

There's a lot of little things that help us care for our teenage daughters: books, TV, gaming devices, cooking, gardening, cats, dogs, fluffy blankets and home delivery services for groceries.

But one of the main things that helps us get by is people understanding.

It helps when people can understand us missing events or parties, or cancelling our own at 4pm that afternoon because someone became unwell. It helps when people can look past the unfolded laundry and the craft on the floor when they come over. And it really helps when people can understand enough to be responsible around us by not coming around to our house or to work when they are sick."

They both get sick, they both get fatigued and they both need days off school. Being PID kids they don't take one day to get over something - but 1-2 weeks each time, many, many times a term.

Education that Matters

Support Groups

Carers Support

To celebrate National Carers Week, we held our first online Carers Morning Tea, to acknowledge the hard work of all our carers.

Many of our carers joined us for a virtual cup of tea and spent time sharing their stories and building relationships with other carers.

Part of our PI Education Program is to develop education modules that can provide information and support to our carers throughout the year.

Thank you for all the work that you do in caring for loved ones with an immunodeficiency.

Group Support

Since the pandemic our weekly Group Support chats have become even more important to our members, many of whom are living alone and isolated. The weekly Zoom meetings attracts a handful of regulars as well as other members who join from time to time.

Recently we have been inviting all new members to the weekly chat as a way of getting to know other members, find out more about IDFA and to have the opportunity to share challenges and success with others in a supportive environment.

Patient Meetings

Throughout the year Member Events were held in Perth, WA and Adelaide, SA.

Both events were well attended and allowed our members to come together for an outdoor picnic, make new friends and share their stories.

Thanks to Richard Price, Sharon Heathfield and Alison Copley for organising these events.

Education

Online Webinars: PI Education Program

Education is key when you live with a rare disease!
In June of this year IDFA launched an innovative national program which aimed at increasing awareness of Primary Immunodeficiency in the community and providing education to those who are affected by this rare disease.

The Program was developed in response to enquiries from our members and the community about the impact of a primary immunodeficiency on the life of an individual and those around them. The PIE Program provided education and awareness around a range of topics for those affected by PI and provided the community with greater insight into the challenges faced by our members.

Nadia, who lives with a PI, explains why education is important for her, "...being well informed with factual and medically supported information helps me to be empowered in a powerless illness... It helps me to explain my condition when I present to ER, to doctors and nurses who have never heard of it or don't know what it is. Sometimes resulting in better health care."

At 15 years old it's important to Jessica that her circle of friends understand the challenges she lives with daily. "IDFA have provided booklets that help my teachers and friends understand about my diagnosis of CVID and SAD's. About why I get sick easily or I miss school because I am in hospital, or if I can't go to a party."

"Primary immunodeficiencies are rare but significant disorders. There is often diagnostic delay and improving patient and clinician knowledge about these disorders is vital to improve patient outcomes.", says Dr Luke Droney, Clinical Immunologist and IDFA Board Member.

The program consisted of the following modules:

- Introduction to IDFA and PI Diagnosis
- PI and Treatment Options
- PI in Children
- Who supports our Carers?
- Managing Co-morbidities and PI
- Fatigue and PI
- Mental Health, Stigma, and Invisible Illness
- Self-Advocacy
- Nutrition and Healthy Lifestyle
- Families and Relationships
- Financial Burden of PI
- A Wholistic Approach: keeping on top of everything

Being well informed with factual and medically supported information helps me to be empowered in a powerless illness... It helps me to explain my condition when I present to ER, to doctors and nurses who have never heard of it or don't know what it is.

72% of particpants who rated our PI Education Webinars said that they were excellent.

Awareness that Matters

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.

IDFA continues to raise awareness about immunodeficiencies by providing patients with our wide range of resources. In the 20-21 financial year IDFA distributed 155 resource packs.

World PI Week

As part of World PI Week, IDFA were successful in obtaining a grant from IPOPI to produce a video. This featured some of our members and their inspiring stories and was well received through our social media channels.

Government

SCID

IDFA continues to build positive working relationships with the government at all levels. Throughout the year IDFA have conducted a national 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.

IDFA were also successful in influencing the NSW state government to extend funding for the SCID Pilot Program until August 2022.

Rare Disease Action Plan

Rare is many. Rare is strong. Rare is proud.

Rare disease patients need equitable access to diagnosis, treatment and care.

IDFA once again supported Rare Disease Day on 28 February 2021.

The campaign calls for action in providing equal opportunities for people living with a rare disease so they can realise their potential for participation in family, work, and social life.

The most accepted definition of a rare disease is that it affects less than five in 10,000 people and is estimated that over 300 million people globally live with a rare disease. Immunodeficiency falls within the category of rare disease and this year we asked our members to share their story of rare disease via a social media campaign.

The campaign was successful in engaging our members as well as raising awareness about rare disease in Australia.

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.

Community

IDFA updated it's branding in late 2020 to reflect a more contemporary look that is engaging to our members across all of our platforms.

Website

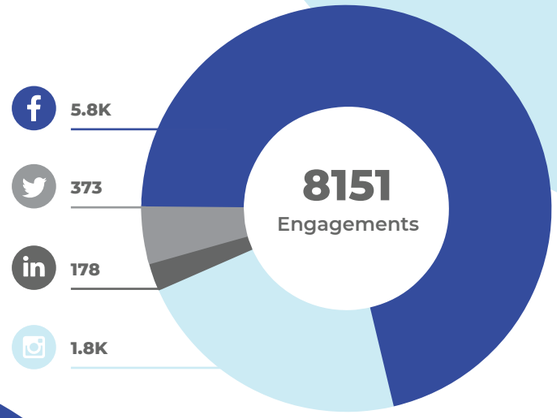
IDFA's new website was launched in November 2020. It features easy navigation and offers a seamless, user-friendly experience, allowing members and the community to find information and resources with the click of a button.

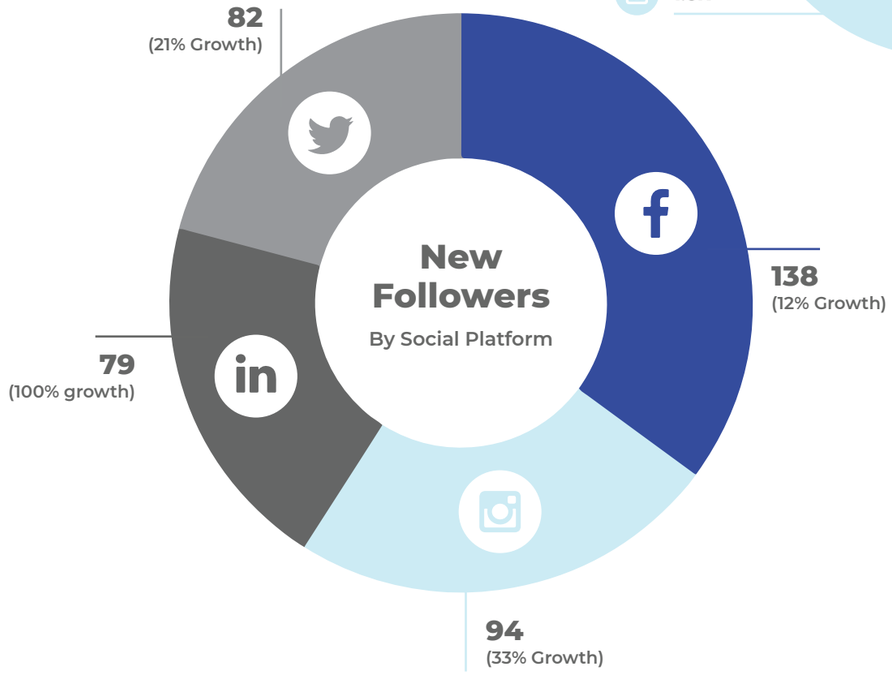
All our resources are now available in hard copy and soft copy via the website, our news section is kept up to date with interesting content and all our Webinars are uploaded on to the website so that they can be watched at your convenience.

Social Media

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

We have also seen an increase in engagement via our members Facebook Group and we have recently re-activated our YAM JAM Facebook Group as we re-engage with our younger members.





Advocacy that Matters

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.

Lifeblood

IDFA partnered with Lifeblood in a campaign where our members appealed to potential blood and plasma donors, with the message that they were recipients of these important blood products.

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.

IDFA has been approached by the Australian National University to be a partner in a research project that is funded through the Rare Disease Action Plan. The project will commence in late 2021.

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 SCID can be entirely treatable. 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 August 2022. 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.

IDFA was successful in meeting with governments from ACT, NSW and QLD to discuss the importance of screening.

1:55,000 babies in Australia die from SCID. Lives can be saved with SCID screening, which costs less than $10/child.

Newborn Screening Member Story

Henry Mills, NSW

On the 11th May, 2021 we welcomed our handsome little man, Henry Oscar Mills. We were settling into life as a family of four, discussing whose eyes he had, what colour his hair would be and if he was going to look like his big brother, Teddy.

At three weeks of age, we received a call that Henry's newborn screening results were abnormal. Within 48 hours we were seeing the Paediatric Immunologist at the John Hunter Hospital and soon realised his abnormal results were something more serious.

Henry was diagnosed with Severe Combined Immunodeficiency (SCID), the most serious kind of primary immunodeficiency. This means that Henry has no T-cells, the most important cells in the immune system, that protect against infection. This leaves Henry incredibly susceptible to illness and can be life threatening. We were also told he would require a haematopoietic stem cell transplant (aka bone marrow transplant) before three months of age to survive. A lot to reconcile when looking at your perfectly healthy three-week-old baby.

Despite a daunting diagnosis, we are optimistic about treatment and feel very fortunate to have access to this lifesaving transplant. We are also very grateful to have access to the newborn screening for primary immunodeficiencies in NSW. If Henry had been born in another state without this newborn screening, it would be a very different story for us.

Since his diagnosis, we have been isolating to minimise the risk of infection for Henry. This has meant a lot of change for our family, including dad (Jake) stopping work indefinitely. Henry's big brother and social butterfly, Teddy, was also taken out of daycare and has been isolated from his friends. And mum (Kirrilly) who has had to take it in her stride on top of all the postpartum pressures of being a new mum.

We relocated to Sydney in July for four months while Henry receives a lifesaving stem cell transplant at Sydney Children's Hospital (yes, right in the middle of a COVID lockdown). Henry's dad, Jake, was chosen as his stem cell donor while his mum, Kirrilly, continues to breastfeed Henry while in hospital.

After a week of chemotherapy, Henry received his stem cell transplant at the end of July. In some positive news, Henry was recently discharged from hospital, day 14 post-transplant because he has made such good progress.

If Henry had been born in another state, this could have been a very different story for us.

Newborn Screening Member Story

Isabelle Grant, QLD

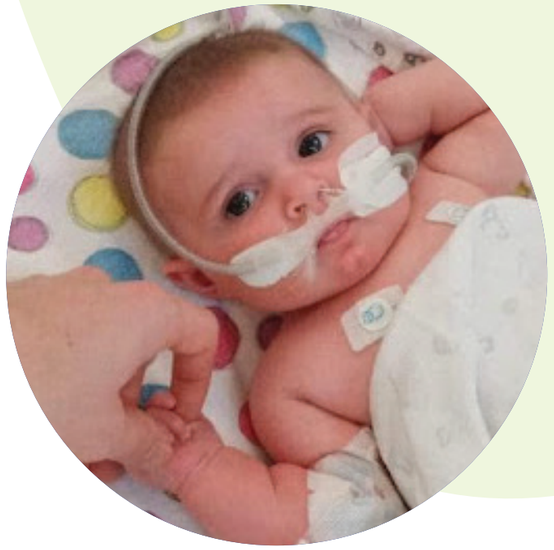
Isabelle was four months old when she suddenly stopped breathing. Fortunately, she was in the Emergency Department and was seen by her GP who delayed her vaccinations (including LIVE Rotavirus vaccine).

As a result of this, Isabelle spent 33 days in an isolated positive pressure room in Paediatric ICU battling Pneumocystis Jiroveci Pneumonia (PJP) and Rhinovirus. The PICU Nurses indicated that the cost for an ICU bed in a pressurised room was around $8,000 per day (estimated total $264,000).

Isabelle required a bronchoscopy and PICC insertion (surgery), was on 24/7 oxygen and a high-flow machine to breathe, along with NG and TPT feeding tubes. The cost for these surgeries, medicines, and X-rays, is, yet unknown. Within days of being admitted, Isabelle's Immunology team diagnosed ADA-SCID. They were astounded that after four months exposure, she had only caught PJP and Rhinovirus.

Before the Christmas shutdown period, Immunologists urgently ordered a 'bridging treatment' from Germany called "RevCovi" – a tailor made Enzyme injection for ADA-SCID.

Isabelle's SCID could not be foreseen and could only be diagnosed by screening her at birth... it's more cost-efficient to screen at birth and avoid complications before getting a SCID baby transplant.



This was the only way to stop the deoxyadenosine toxin from spreading through Isabelle's system, so she had a chance to get the transplant she needed. Each RevCovi vial cost $11,000 and Isabelle required 10 doses (estimated total $110,000 + $4,000 shipping).

Isabelle spent a further 33 days in hospital on the ward (again, in an isolated positive pressure room), fighting to get well enough to be able to survive a stem cell transplant. The chemotherapy and transplant process took a further 28 days in hospital. It also required a CVL to be inserted (surgery).

Brain wave testing revealed that the toxin had attacked both Isabelle's inner ears from birth to four months old – she was diagnosed with Permanent Severe Sensorineural Hearing Loss in both ears. She also required grommets (surgery).

She will require hearing aids and speech therapies for the rest of her life – at an unknown ongoing cost to the NDIS system and Hearing Australia. Additionally, Isabelle missed many of her 4–7 month development milestones while in hospital. She now requires ongoing NDIS funded therapies to assist with her development. Notably, genetic testing on Isabelle's parents revealed they DO NOT carry the ADA-SCID recessive genes – the mother carries a deletion. The father did not detect the gene at all – so either spontaneous mutation by Isabelle or the Mosaic Theory in the father.

Regardless, Isabelle's SCID could not be foreseen and could only be diagnosed by screening her at birth.
Don't play a defensive game – it's more cost-efficient to screen at birth and avoid complications before getting a SCID baby to transplant. Particularly, with 'live' vaccinations on Qld's Immunisation Schedule.

Professional Networks

International Networks

National Networks

Other Networks

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

Sponsors and 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 including; Patient Meetings, Carers Week Annual Conference, World PI Week and YAM JAMS
- Online support groups
- Online events including webinars and conferences

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

CSL Behring Takeda GRIFOLS

International Entertainment

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
Shepparton

QLD
Cairns
Mackay
Toowoomba
Townsville

ACT
Canberra

TAS
Burnie
Devonport
Hobart
Launceston

WA
Perth
Kalgoorlie

SA
Adelaide

Awareness Pin
$5

Zebra Pen
$5

Tote Bag
$20

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.

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

World PI Week Pack
$20

$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 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

Donations

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

Volunteers

IDFA would like to thank our very valued volunteers who continue to fundraise or work in a volunteer capacity for IDFA.

Anna Rusnov
Farnoosh Momeni
Irene Dossan
Jenny Tyrrell
Maral Setrakian
Ohene Dijma
Reanne Ghamraoui
Richard Price
Sharon Heathfield
Stephanie Liu
Vyna Keo

National Patient Advisory Panel Members

Alison Copley
Ben Johnson
Bianca Willis
Briana Cory
Charlie Gingell
Christine Jeffery
Hayley Teasdale
Javeria Ahmad
Jenny Tyrrell
Lyn Barker
Richard Price
Tricia Parry

Thank you to our volunteers! 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

	2021	2020
IE Income	$2,019,172	$961,510
Pins and Merchandise Sales	-	$326
Total Sales	$2,019,172	$961,836
Cost of Sales	($1,643,827)	($766,781)
Gross Profit	$375,345	$195,055
Finance Income	$70	$238
Other Income	$127,107	$134,030
Marketing Expenses	($1,913)	($495)
Administrative Expenses	($275,921)	($263,936)
Functions, Awards & Presentations	($2,761)	($19,108)
Lease Expenses	($964)	-
Other Expenses	($49,991)	($33,099)
Finance Expenses	($530)	($1,064)
Profit before Income Tax	$170,442	$11,621
Income Tax Expense	-	-
Profit from continuing operations	$170,442	$11,621
Profit for the year	$170,442	$11,621
Other comprehensive income, net of income tax	-	-
Total Comprehensive income for the year	$170,442	$11,621

Statement of Financial Position

ASSETS	2021	2020
Current Assets		
Cash & Cash Equivalents	$421,632	$227,516
Trade & Other Receivables	-	$43,057
Inventories	-	$13,125
Other Assets	$14,721	$6,084
Total Current Assets	$436,353	$289,782
Non-Current Assets		
Property, Plant & Equipment	$15,854	$18,353
Intangible Assets	$21,788	-
Right-of-use Assets	$2,454	$26,433
Total Non-Current Assets	$40,096	$44,786
Total Assets	$476,449	$334,568

LIABILITIES	2021	2020
Current Liabilities		
Trade & Other Payables	$57,567	$42,495
Lease Liabilities	$2,545	$11,796
Employee Benefits	$7,510	$7,615
Other Financial Liabilities	-	$23,048
Total Current Liabilities	$67,622	$84,954
Non-Current Liabilities		
Lease Liabilities	-	$6,603
Employee Benefits	-	$4,626
Total Non-Current Liabilities	-	$11,229
Total Liabilities	$67,622	$238,385
NET ASSETS	$408,827	$238,385

EQUITY	2021	2020
Retained Earnings	$408,827	$238,385
TOTAL EQUITY	$408,827	$238,385

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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IDFA

Immune Deficiencies Foundation Australia