idfa.org.au

2021 - 2022

# Annual Report

I Don't Feel Alone

IDFA

Immune Deficiencies Foundation Australia

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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.

# Message from Board Chair

These last two and a half years have been testing times. How often have we heard that statement over this period? While practicing yoga I learnt the phrase "I bend so I do not break" and I believe IDFA and its members have done very well to apply that philosophy during this time of change, uncertainty and challenge. The Board and staff of IDFA have grasped this opportunity to reflect and grow the organisation.

The addition of two advisory panels, one consisting of a broad range of health professionals and the other of people living with immunodeficiency, has strengthened and broadened the ways in which we can support our members. Webinars have reached those of you who are unable to travel and have enabled us to keep our members well informed by accessing a broader range of speakers and topics.

I was excited to work with the Australian Society of Clinical Immunology and Allergy (ASCIA) this year during the launch of their National Immunodeficiency Strategy. Its purpose, to improve the health and wellbeing of people with immunodeficiency and minimise the burden on individuals, carers, health services and community, aligns with the strategic vision of IDFA and we will continue to work closely with them.

I feel fortunate as chair of IDFA, to be working with Carolyn Dews CEO and her incredible team; Chontelle Broadwood, Charmaine Meredith, Estela Gimenez and Andriana Epistithiou, who, despite the fact that they are all employed part time, undertake an enormous amount of innovative work for IDFA, with passion.

IDFA, like many not-for-profit organisations, has experienced the effects of COVID-19 in income stream, however the Board and CEO are undertaking work to diversify income and to ensure we can continue. I would also like to thank the organisations that have and do provide financial support, to allow us to undertake the work we do.

> **"While practicing yoga I learnt the phrase "I bend so I do not break" and I believe IDFA and its members have done very well to apply that philosophy during this time of change, uncertainty and challenge."**

In my now significant nursing experience, I have observed that one of the most difficult things for humans to do, is to sit with uncertainty and that is exactly what COVID-19 has asked of us. I hope and believe that IDFA has supported its members well in this period and acknowledged that people living with immunodeficiency have challenges above and beyond the general community. Your support in ways such as volunteering or fundraising will allow us to continue and expand on this important work.

**Geraldine Dunne.**

# Message from CEO

IDFA has seen significant changes in the past year as we've continued to support our members and to navigate our way through COVID-19. The national office moved from Penrith to Wollongong in July 2021 which meant saying farewell to our wonderful staff members Rachel, Belinda and Maria, each of whom had done some outstanding work for IDFA. With the move came a new team made up of Charmaine, Chontelle, Yensina, Andriana and Estela who have settled into their roles and formed a dynamic team. The team has achieved so much in a short time, both in terms of engaging with our members and delivering education and support programs.

At the Board level we said farewell to long-standing members Alex James-Martin and Craig Mathieson. We wish to thank them for the commitment and leadership that they have shown to IDFA. We also welcomed new Board members Brendan Peek, Louise Grant, Pearl Sims, Alisa Kane, Roslyn Chataway, Sap Chatterjee, Caroline McMillen and Hayley Teasdale (Observer). Long-time Board member and Chair Lara Alexander resigned from the Board in April of this year to pursue a political career. Lara has made an enormous contribution to the leadership, governance and overall success of IDFA over a long period of time and to myself in this role. I wish to say a huge thank you to Lara and to wish her all the best for the future. I would also like to welcome incoming Chair Geraldine Dunne who has settled very quickly into the role and has been a wonderful support to myself and the team. Under Geraldine's leadership, IDFA will develop the next Strategic Plan and identify the key issues of importance to our members.

We have continued to focus on the areas of Education, Awareness and Advocacy with a number of key successes. The PI Education webinars have been vital to provide information to our members on important topics as well as a sense of connection during these challenging times. We have also held member engagement events such as state-based member meetings in-person for the first time in two years. Our awareness raising has continued through the support of key events such as Rare Disease Day and World PI Week. The biggest success from an advocacy perspective has been the federal announcement of the support of Severe Combined Immunodeficiency (SCID) as a standard newborn screening test.

The work of the National Patient Advisory Panel (NPAP) has continued with much success in delivering a range of projects as well as the day-to-day support offered by the Medical Advisory Panel (MAP). This past year saw the creation of a National Healthcare Professional Panel (HCP), guided by Alisa Kane as the Chair. This will effectively be the eyes and ears of IDFA on the ground and support us in achieving our strategic priorities and to provide health and medical expertise.

IDFA have continued to work collaboratively and in partnership with a range of organisations and had a strong involvement with the development and launch of the National Immunodeficiency Strategy, which will inform our work moving forward. As we move into the next phase of building IDFA and formulating a new strategic plan we are looking forward to continuing to provide education, support and advocacy for our members and on behalf of the broader community.

Carolyn Dews

**Carolyn Dews**

# Key Highlights

## 2021-22 FY at a glance

### Members

**168**

**new members** joined IDFA (an increase of 13% YOY).

**2,218**

Total **Members**

### Fundraising

**$10,325**

**raised** through member-initiated community fundraising campaigns.

### PI Education Webinars

**19**

**PI Education webinars** held on a range of topics including COVID-19, Self-Advocacy, Fatigue, Mental Health and Nutrition.

**20**

**expert guest speakers** presented on a range of topics as part of our PI Education Webinar program.

**854**

member **registrations received** for our PI Education Webinar program.

### Our Online Community

**2,684**

**followers** of IDFA through our online community (Facebook, Instagram, Twitter, LinkedIn, YouTube).

**66,027**

**people reached** through our online community.

**11.9%**

YOY **increase in subscribers** to our mailing list.

### Public Relations

**74**

**media articles generated** throughout the year, increasing IDFA's national profile.

**1.7M**

**people reached** through PR activity.

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**A year of new beginnings** with a new team, new Wollongong office location and a new IDFA Chair and Board members.

**Strong Rare Disease Day campaign**, featuring a partnership with WIN News TV Presenter Melissa Russell, coverage in 14 TV news bulletins, 38 PR articles generated overall and a PR reach of 1 million.

**Shortlisted as a Finalist in the IPOPI Big Award** for our SCID Advocacy Campaign. The Winner of the award will be announced in October 2022.

**Impactful World PI Week awareness raising campaign** where we launched an innovative digital member storybook 'Making a Difference to PI', supported ASCIA's National Immunodeficiency Strategy and achieved national PR coverage in 30 media outlets.

Successful **collaboration with Lifeblood** for International Plasma Awareness Week.

Positive **launch of two new Family Support Groups**, moderated by IDFA members for parents and carers.

**Partnered ASCIA** in the launch of the National Immunodeficiency Strategy.

Hugely **successful outcome for SCID Advocacy campaign** with a recommendation from the Federal Government to include SCID in state and territory newborn bloodspot screening programs.

**Development of comprehensive Member Engagement Strategy** to ensure that all of our members were welcomed in to the IDFA family and supported throughout their health journey.

# Strategic Plan

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

- Education
- Awareness
- Advocacy

## Looking Forward

It is with much anticipation that IDFA embarks on the process for developing our 2023-2025 Strategic Plan.

A review of our current Strategic Plan indicates significant progress in developing a sustainable organisation through key structures including:

- Medical Advisory Panel
- National Patient Advisory Panel
- Healthcare Professional Panel
- Finance, Risk and Audit Committee

The team, in conjunction with the Board have also developed some key documents including:

- Membership Engagement Strategy
- Marketing and Communications Strategy

This has allowed delivery on the key strategic priorities and will serve IDFA well into the future.

## 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

# 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

### Government

Introductions & Representations to MP'S

Funded Projects

### Health Professionals

Resources

Engagement

### General Community

Awareness Raising Events

Website & Social Media

## Advocacy - Driving Change

### 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 Team

**Carolyn Dews**
CEO

**Charmaine Meredith**
Membership Engagement Officer

**Chontelle Broadwood**
Marketing and Communications Officer

**Yensina Norman**
Finance and Administration Officer
*(Resigned May 2022)*

**Andriana Epistithiou**
Finance and Administration Officer
*(Commenced June 2022)*

**Estela Gimenez**
Education and Advocacy Officer
*(Commenced June 2022)*

# Our Board

**Geraldine Dunne**

Board Chair, Medical Advisory Panel

**Cath Bampton**

Deputy Chair

**Brendan Peek**

Finance, Risk and Audit Committee Chair

**Adam Friederich**

National Patient Advisory Panel Chair

**Alisa Kane**

Healthcare Professionals Panel Chair

**Dr Melanie Wong**

Medical Advisory Panel Chair

**Dr Luke Droney**

Medical Advisory Panel

**Sap Chatterjee**

Finance, Risk and Audit Committee

**Pearl Sims**

Finance, Risk and Audit Committee

**Roslyn Chataway**

General Board Member

**Louise Grant**

General Board Member

**Caroline McMillen**

General Board Member

# Personnel Changes

## Staff Resignations

**Rachel Pearson (July 2021)** With the office move from Penrith to Wollongong, we said goodbye to our Administration and Membership Officer Rachel, who had been with IDFA for over two years. We wish Rachel all the best.

**Yensina Norman (May 2022)** We thank Finance and Administration Officer Yensina for her time at IDFA, the experience she brought to the role and the work she completed in developing new financial systems and processes for our organisation.

## Board Resignations

**Craig Mathieson and Alex James-Martin (October 2021)** We wish to thank Craig and Alex for their contribution to IDFA and wish them all the best.

**Lara Alexander (April 2022)** Farewell and thank you to our long-standing Board Chair Lara Alexander, who has provided strong leadership and shown dedication and commitment to IDFA over a long period of time.

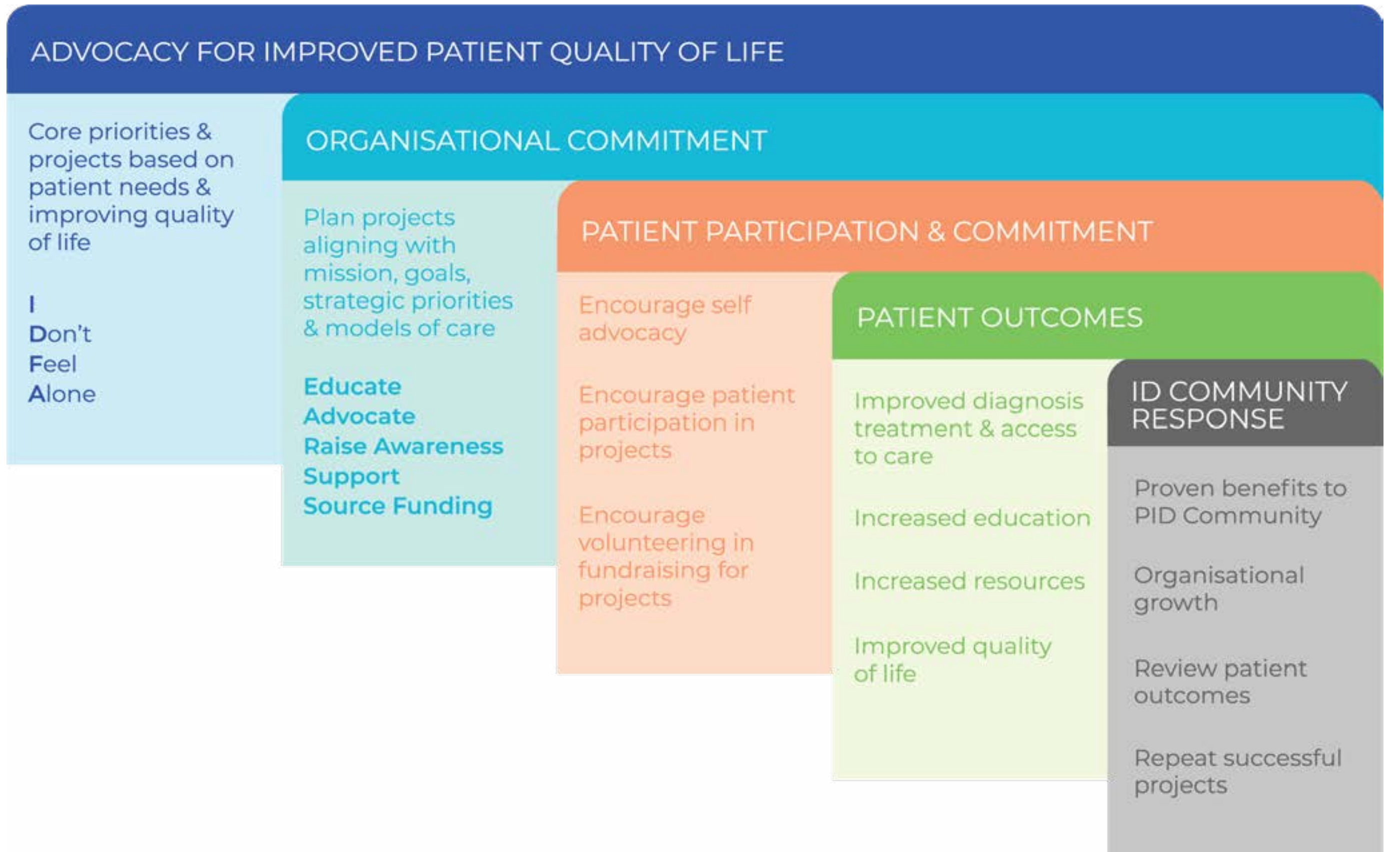
Welcome to newly appointed Chair, Geraldine Dunne.

## New Appointments

Brendan Peek
Louise Grant
Pearl Sims
Sap Chatterjee
Roslyn Chataway
Caroline McMillen
Alisa Kane
Hayley Teasdale (Observer)

# Models of Care

## Patient Focused Models of Care



ADVOCACY FOR IMPROVED PATIENT QUALITY OF LIFE

Core priorities & projects based on patient needs & improving quality of life

I Don't Feel Alone

ORGANISATIONAL COMMITMENT

Plan projects aligning with mission, goals, strategic priorities & models of care

**Educate**
**Advocate**
**Raise Awareness**
**Support**
**Source Funding**

PATIENT PARTICIPATION & COMMITMENT

Encourage self advocacy

Encourage patient participation in projects

Encourage volunteering in fundraising for projects

PATIENT OUTCOMES

Improved diagnosis treatment & access to care

Increased education

Increased resources

Improved quality of life

ID COMMUNITY RESPONSE

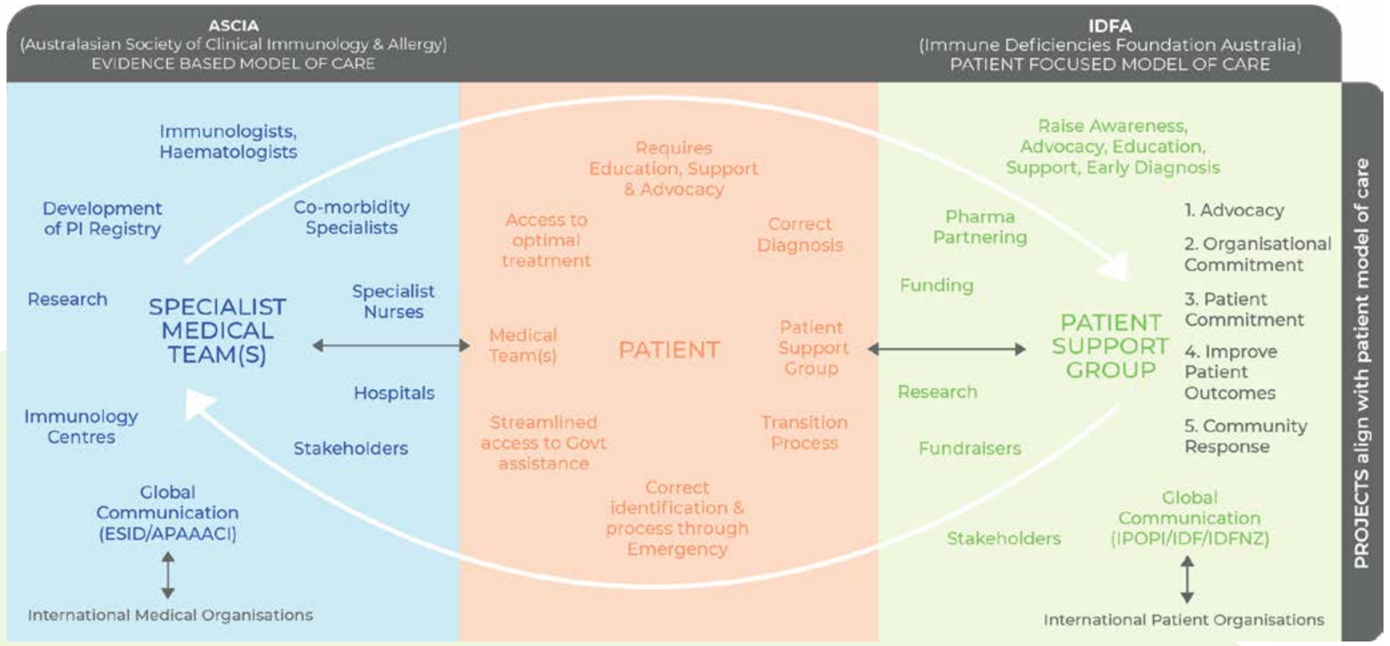
Proven benefits to PID Community

Organisational growth

Review patient outcomes

Repeat successful projects

## Community Focused Models of Care



# IDFA Advisory Panels

## Healthcare Professionals Panel

The Panel is an informal Committee whose members can be called upon to provide expert information and advice to the IDFA Board of directors on a voluntary and needs-driven basis.

The objectives of the Panel are to:

- Optimise and reflect IDFA's peak body status
- Support IDFA's Objectives and Priorities
- Support the ID community

## National Patient Advisory Panel

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.

The NPAP have identified and been working on seven key projects for the past year:

- COVID-19 Information and Updates
- SCID Advocacy Campaign
- Family Support Groups
- GP Engagement Project
- Self-Advocacy Tools
- NDIS
- Equitable access to treatment options

## Medical Advisory Panel

IDFA have formed a specialist Medical Advisory Panel (MAP) led 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.

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.

# 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).

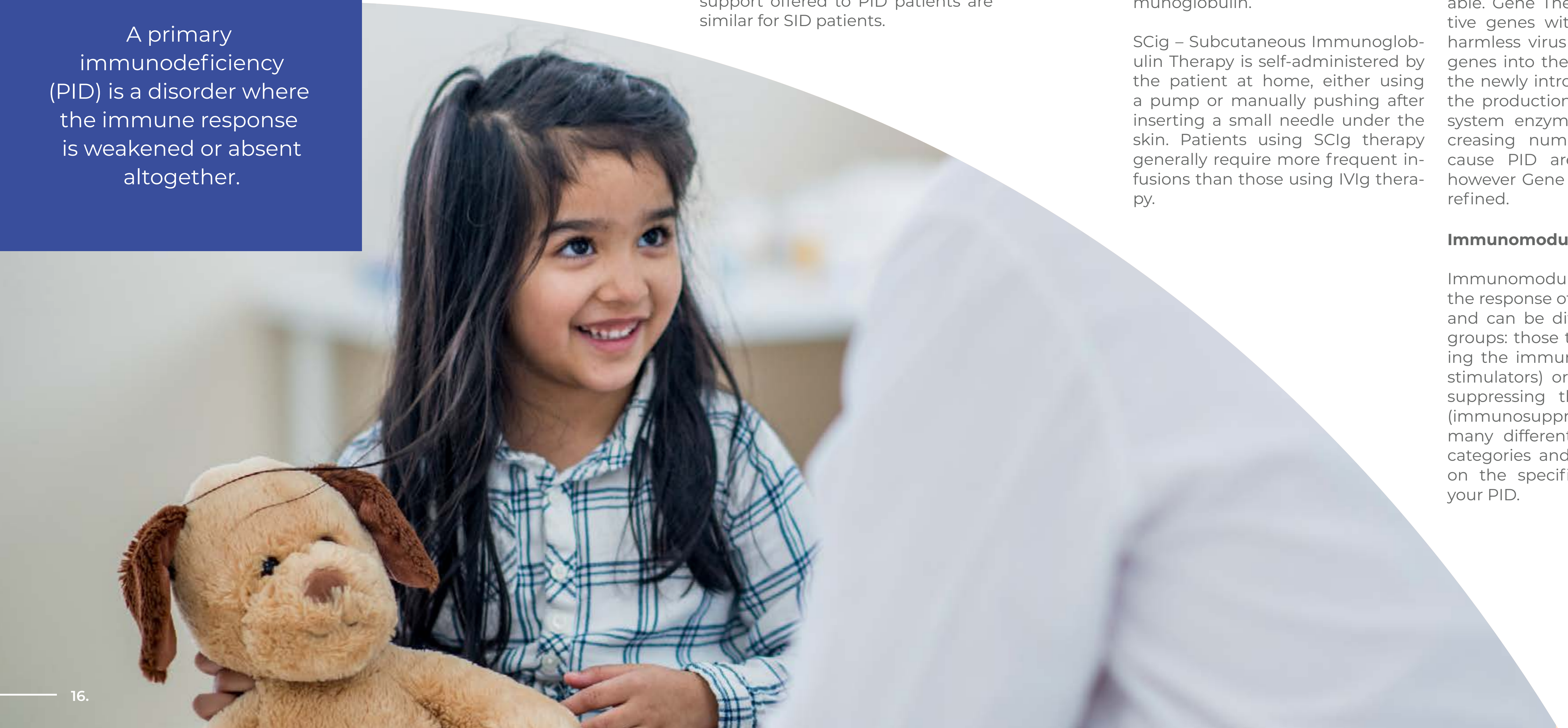
Depending on the type of PID some people manage their condition quite well with appropriate treatment while others live with lifelong chronic illness and complex medical issues.

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.

A primary immunodeficiency (PID) is a disorder where the immune response is weakened or absent altogether.



## Treatments

### 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.

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 to prevent infections as well as permanent damage.

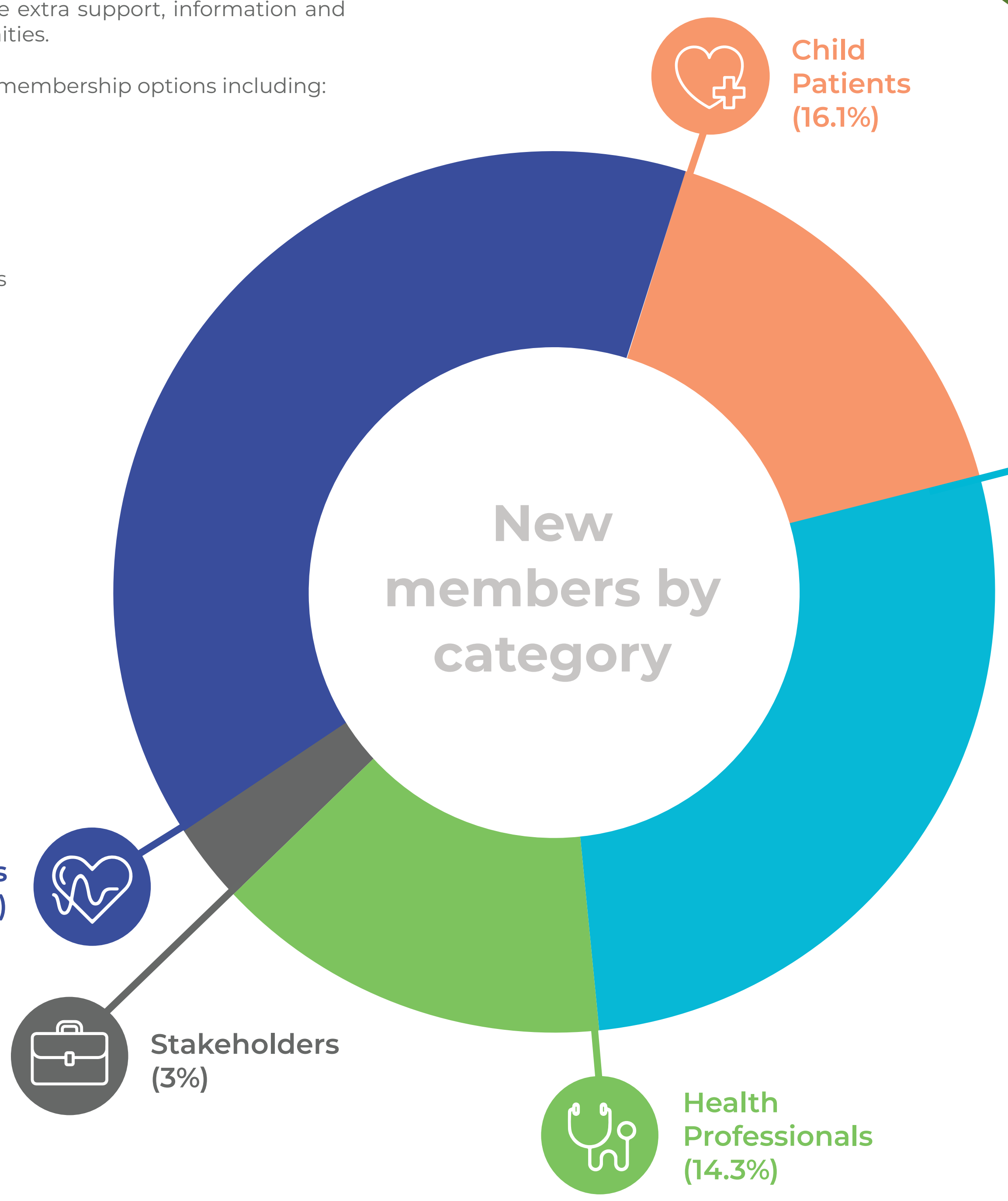
# Membership

Whether you are the patient or 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



**168**
new members from 1/7/21 to 30/6/22 (an increase of 13% YOY).

**2,218**
Total Members

> “The IDFA has been an incredible support system for my family. Here, we have found a safe place to connect with other patient families, carers and immunology professionals. The IDFA Facebook page is a great place to ask questions and advice, as well as providing access to support groups. We always look forward to IDFA events, conferences, webinars and online chats. It has helped my family so much, and I would highly recommend anyone who has been diagnosed/has a family member diagnosed with an immunodeficiency in Australia to join”
>
> **- IDFA Member.**

# Member Stories

## Lyn, VIC.

Lyn has been a member of IDFA for over 12 years and has benefited enormously from the organisation's support during this time. Lyn values IDFA for making a positive contribution to her wellbeing and the way in which she lives her life with a PID.

Lyn is happily married with two daughters and three beautiful grandchildren. Being a grandmother has become Lyn's favourite role. Lyn has been a nurse/midwife throughout her working life, commencing as a community midwife in 2001. This was a position Lyn greatly enjoyed and she struggled with the need to retire due to ill health in 2008.

Lyn was diagnosed with a primary immune deficiency in 2000 following a previously tough year with pertussis (whooping cough) but her actual diagnosis came in 2019 with combined immune deficiency. Lyn had experienced ill health for several years before her diagnosis. However, it wasn't until she was slow to recover from Pertussis that investigations commenced and eventually provided a preliminary diagnosis of hypogammaglobulinemia.

Learning to live with an immunodeficiency (which was recently compounded by a pandemic) has been a challenging time for Lyn. She spent many years as a hospital frequent flyer, requiring admission up to six times each year with severe chest infections or pneumonia. Lyn needed to stay for 10-14 days then took some time to recover at home. This was a difficult time for Lyn personally and for her family.

Lyn needed to retire from working and acquired many comorbidities due to both the impacts of infection and the treatment for those infections. Lyn now manages those comorbidities with medication and lifestyle changes and many medical reviews. Fortunately, Lyn has a good medical team of many specialists supporting her and helping her to live her best life possible.

Lyn commenced Intragam (intravenous immunoglobulins) in 2000 at three monthly interviews which was quickly increased to six weekly, then four weekly, three weekly and eventually weekly by 2015. Throughout this period, Lyn also required long term antibiotics. She then started to gradually reduce her hospital admissions and manage most infections at home. Lyn self-advocated for subcutaneous immunoglobulins (SCIG) which she happily commenced in 2021.

Since weekly Hizentra (SCIG) commenced, Lyn hasn't had any unplanned hospital admissions, she has incredible freedom to travel and she no longer requires weekly hospital day admissions. Lyn no longer requires a PICC line to assist with intravenous infusions, which she'd previously had for 12 years. This afforded her more freedoms such as swimming.

Lyn is now able to enjoy life and family, especially her grandchildren, and they are planning to travel to some of those 'bucket list' destinations soon. Lyn even managed some of the summer period last year without antibiotics which was a positive step forward for her. Lyn has also enrolled to start studying again.

"My family and I will always remain incredibly grateful to those who take the time to donate blood or plasma and to all those working to produce these life-giving immunoglobulins. You contribute to the life and wellbeing of many people with varied conditions including those of us with immune deficiencies. And we appreciate you all, remembering your gift and time, especially as we regularly infuse. Thank You!"

> **"I will always remain incredibly grateful to those who take the time to donate blood or plasma".**

## Oli, SA.

Oli is 14 years old and absolutely soccer mad. He plays for a club as well as an academy and has recently been to the National Cup in Sydney where his team came third in the Under 14's category. Oli has lightning pace backed up by a massive goal scoring ability. Last season Oli hit 25 goals in 22 games for his club, whilst also netting the most goals in the National Cup Academy side in Sydney.

Oli lives a very active lifestyle, training and playing soccer six days a week. He also makes sure he gets plenty of sleep...which he is very good at!

Oli was diagnosed with common variable immunodeficiency (CVID) around the age of eight after his GP noticed he'd had a lot of chest infections. He didn't start replacement therapy until he was 12 and commenced subcutaneous immunoglobulins (SCIG) after a routine appointment with the immunologist showed his IGG at 1.8. This had to be changed to intravenous immunoglobulin (IVIG) after a few months as he didn't have sufficient body fat to absorb subcutaneously. He also has two blood clotting disorders, meaning his infusions have to be run very slowly to lower the risk of a blood clot. With the bags of fluid before and after, he spends around seven hours at his infusions.

Since starting treatment, Oli rarely gets infections and his energy levels have improved too. It may be a coincidence, but he's grown 18cm since his first treatment 18 months ago!

As Oli is so sporty, he has struggled to accept his diagnosis and doesn't want his health to affect his sport. Oli has shared his story in the hope that there may be other young people out there who feel the same. Oli has recently received the news that he has been selected by United Kingdom (UK) Academy scouts to go for soccer trials in the UK in December.

His family is having discussions with his immunologist about how to manage his infusions whilst overseas. During this tour, Oli will play against professional UK club teams such as the Bolton Wanderers and Manchester United. At these training sessions and games Oli is hopefully looking to be selected by UK Club scouts from the North of England as he chases his dream in professional soccer overseas.

**A big congratulations to Oli on this incredible achievement from all of us at IDFA. We can't wait to follow your career and see where you end up!**

> **"Since starting treatment, Oli rarely gets infections and his energy levels have improved too. It may be a coincidence, but he's grown 18cm since his first treatment 18 months ago!"**

## Luke, WA.

Luke is based in Perth, WA and is a law graduate at DLA Piper. In his spare time Luke likes to run and also play hockey. Luke was diagnosed with primary immunodeficiency at a very early age of around two years old. It was quite clear to Luke's Mum that he had the same condition as her, common variable immunodeficiency (CVID). This has only recently been confirmed as the AICDA gene. Luke is very grateful for the support of the team at Princess Margaret Hospital under Dr Loh and the immunology team of Dr O'Sullivan at Fiona Stanley Hospital.

Luke feels very fortunate that he has managed to keep a relatively balanced lifestyle with CVID compared with many who have a number of other associated illnesses and suffer regularly from fatigue and are constantly subject to infections week in week out.

To manage his immunodeficiency, Luke ensures he has a balanced and regulated lifestyle by adopting good sleep habits, taking time to rest and relax when things get too much and by aiming to be as fit and healthy as he can be.

Luke relies on plasma treatment every four weeks. Having a great medical support team and this treatment ensures his condition is a lot easier to manage and that he feels more comfortable living with CVID.

Luke has been an active member of IDFA, sharing his story for our Young Adult Members campaign in 2021 and also at our recent Young Adult Members Conference. Last year Luke raised awareness and over $2,000 for IDFA through a fundraising campaign where he completed the Perth Marathon.

There are a number of reasons Luke wanted to run a marathon. Firstly, to see if his body could handle the rigour of training for a marathon. Having CVID he knew that there is a good chance of picking up an infection from being run down or overdoing it. Secondly, Luke recently ran a half-marathon and thought he may as well try a marathon and raise some money for a cause close to him and his family. Thirdly, to hopefully provide some inspiration to others who have primary immunodeficiencies that want to get more active, as there is definitely a correlation between having a healthier lifestyle and less infections.

"Another reason I decided to raise some money and provide exposure for IDFA was because I wish I had known about this organisation from a young age. I think the members resource pack is such a brilliant resource for people at the early teen years to understand what they are going through. I found it difficult at times to probably understand why things were the way they were and whilst I cannot complain about our treatment, this information just provides you with more knowledge and understanding. In addition the seminars and webinars on how immune deficiency affects you are brilliant, and the Facebook page provides a great community to connect with on the issues that are CVID related."

> **"I decided to raise some money and provide exposure for IDFA because I wish I had known about this organisation from a young age."**

# Hayley, ACT.

Hayley's journey as a primary immunodeficiency patient started when she became unwell with respiratory infections as a teenager. Diagnosed with common variable immunodeficiency (CVID) at 24, Hayley receives treatment for her immunodeficiency and works with IDFA, sitting on both the board and National Patient Advisory Panel and through Australian Red Cross Lifeblood to make a positive difference in relation to PI.

In her professional life, Hayley is an accomplished and energetic science and technology professional, specialising in technology development, project management and public policy. A confident and prolific communicator, Hayley has over five years of high-level local, government and international stakeholder relationship management and is currently working for the Australian Academy of Science in Canberra.

Hayley has been on IVIg treatment for over seven years. She receives treatment every four weeks, and has grown to enjoy her infusion days each month, seeing her favourite nurses and sipping cups of tea while working, watching TV shows or reading. One of the key things for Hayley in managing her immunodeficiency has been to learn about it and understand how her body is working.

> "Hayley is really passionate about blood and plasma donation because she knows what a huge difference receiving immunoglobulins from human plasma has made to her life."

Hayley is really passionate about blood and plasma donation because she knows what a huge difference receiving immunoglobulins from human plasma has made to her life. Hayley has been working with the Australian Red Cross Lifeblood for a number of years now, advocating for donations of plasma, meeting donors and sharing her story. Hayley shares her story within the community because she believes it removes some of the stigmas around chronic illness. Hayley knows how much power sharing her story publicly has in connecting with those going through similar things and empowering others who have primary immunodeficiencies.

Since starting treatment, Hayley has seen a great improvement in the number of infections she contracts each year, which has allowed her more time for the things she enjoys like study, work, travel and time with friends and family. Hayley feels physically stronger and mentally more fulfilled.

# Education

IDFA is proud to offer a wide range of resources, educational programs, webinars, patient meetings and conferences for Australians living with immunodeficiency.

# Support Groups

## Carers Support

As part of National Carers Week, IDFA focused on raising awareness about our carers and their caring roles as well as recognising, celebrating and thanking them.

IDFA partnered with Carers NSW and held a 'Carers Health and Wellbeing' webinar, offering carers a voucher to enjoy some wine and cheese during the session. IDFA also highlighted the important work that our carers do on social media, sharing two member stories and some carer self-care tips.

> "This is an amazing surprise, thank you so much! I will definitely enjoy a glass of wine with something for the webinar"
>
> **– Carers Support Webinar Attendee**

## Family Support Groups

IDFA identified the need for some small family support groups on Facebook for parents and carers moderated by IDFA members. Currently the groups include a total of 39 members. Some of the benefits in joining one of these groups include:

- To feel part of an intimate community and feel comfortable to speak, seek clarification and advice, feel validated and supported and find out about other families' coping mechanisms and strategies;
- To seek information from other members who have personal experiences with PID/SID in their family;
- To allow members to feel able to share their journey and experiences and learn from other members.

## Patient Meetings

IDFA held patient meetings in Perth, Sydney and Melbourne thanks to our sponsor Takeda. This was the first time in over two years that our members were able to gather in person.

In Perth, members enjoyed an intimate park picnic and an opportunity to connect with other members.

In Melbourne, our CEO Carolyn Dews joined and provided members with updates on our current projects and future plans. Member Lyn Barker shared her story and the work she has undertaken with our National Patient Advisory Panel. We were also joined by immunologist Dr Samar Ojaimi who answered member questions on future treatments, genetic therapies and how much caution immunodeficient patients should be taking day-to-day while living a normal life.

For our Sydney event, our Chair of the Board Geraldine joined members. Member Javeria Ahmad shared her story and the work she has been undertaking with our National Patient Advisory Panel. We were also joined by immunologist Dr Melanie Wong who answered member questions around long COVID-19 research and immunodeficient patients and safety when travelling internationally.

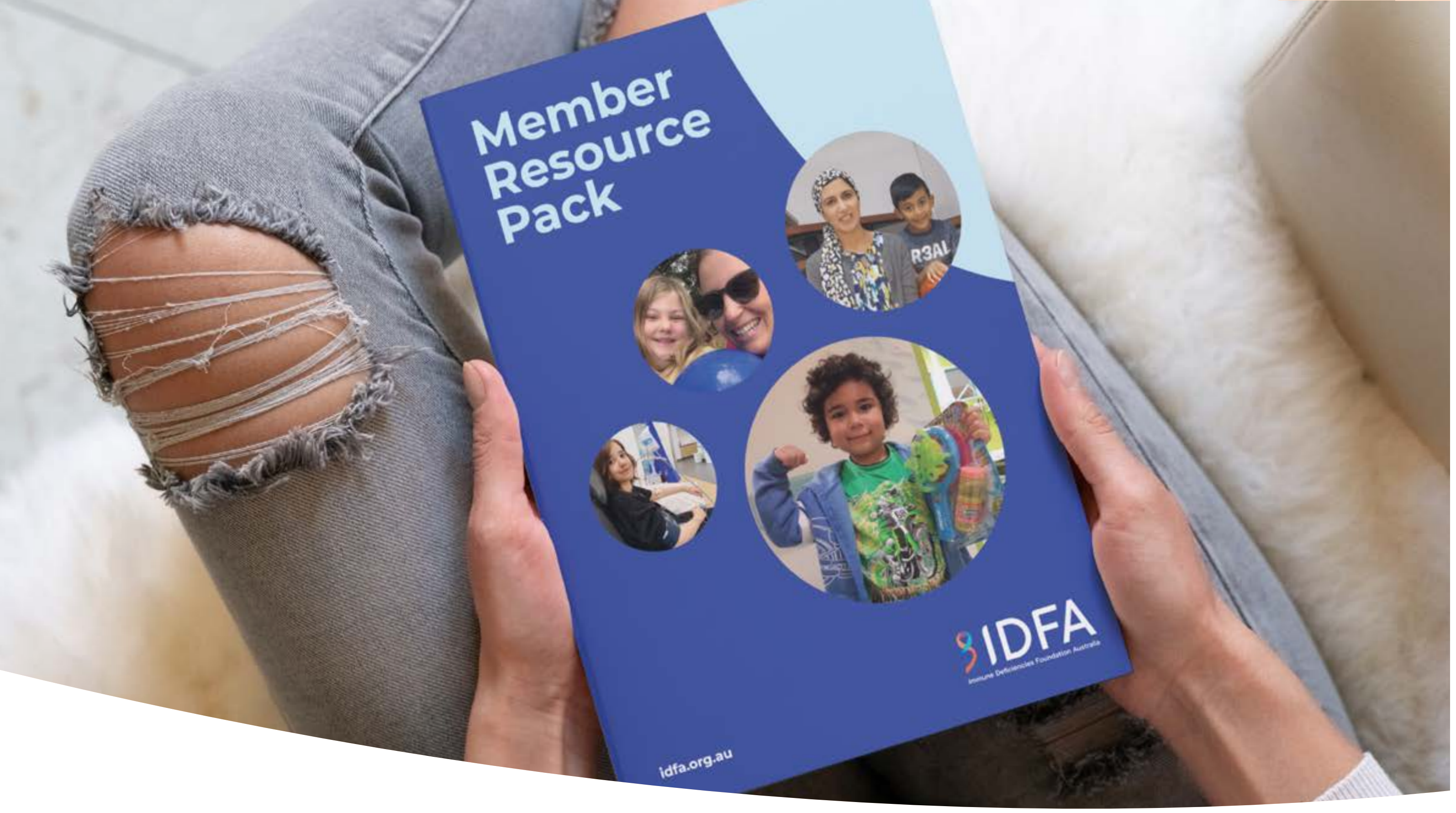
IDFA would like to thank members who attended our events and we look forward to organising in person catch-ups in other states in the future.

## Group Support

Our weekly Welcome Wednesday Support Group chats have continued to be important to our members in the face of the COVID-19 pandemic, many of whom are living alone and isolated. The weekly Zoom meetings attract a handful of regulars as well as other members who join from time to time. Recently we have been holding different themes each week to encourage more members to join and add some fun to each session. Themes have included wearing your favourite PJs, scarf or hat.

We have continued to invite 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.

> "Many thanks to IDFA for organising such a lovely catch up at a wonderful venue. It was great to be able to get together again in person, and learn some things along the way too.
>
> **– Patient Meeting Attendee**



# Educational Resources

### Member Resource Packs

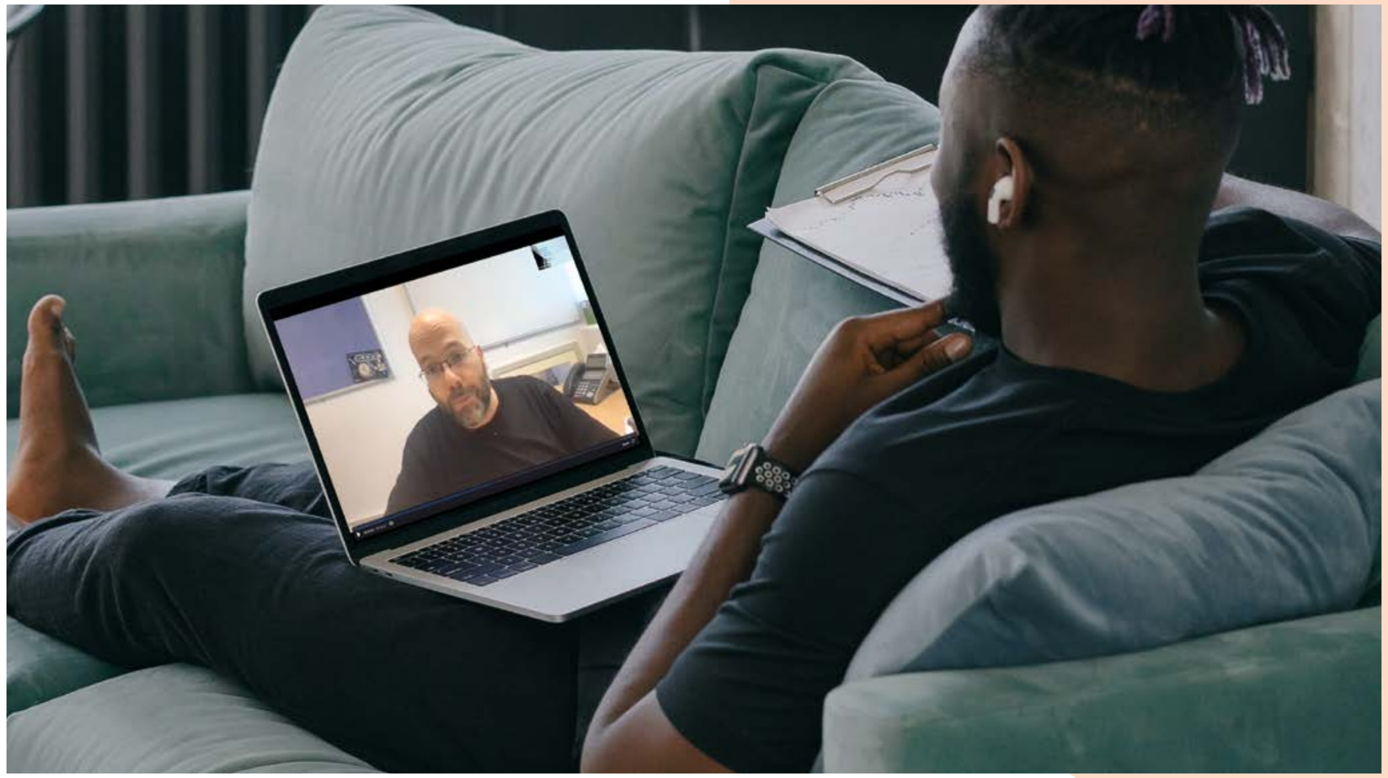
This year, IDFA refreshed the design of our member resource packs. These packs are designed to provide new members with a wide range of resources and practical advice. IDFA also provides these resources to members for free on our website.

In the 21-22 financial year IDFA distributed 168 resource packs to new members.

### Lifestyle Series

IDFA launched two new resource booklets and website landing pages as part of its new Lifestyle Series, with the first two topics focused on nutrition and fatigue. This series offers information that members can use to improve their lifestyle, overall health and well-being.

The resources were launched as part of IDFA's 'Back to School' campaign, promoting nutrition, fatigue management strategies and other practical tips for parents, carers and school-aged children to start the 2022 year.



### Online Webinars: PI Education Program

Education is key when you live with a rare disease. IDFA continued its innovative national program, our PI Education Webinar series, 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 PI Education program provides education and awareness around a range of topics for those affected by PI and provides the community with greater insight into the challenges faced by our members.

The program consisted of the following modules:

- Managing Co-morbidities and PI
- Fatigue and PI
- Mental Health, Stigma and Invisible Illness
- Self-Advocacy
- Nutrition and Healthy Lifestyle
- Families and Relationships
- Severe Combined Immunodeficiency
- COVID-19 Vaccinations and Immunodeficiencies
- Carers Health and Wellbeing
- The Changing Landscape of Pain Management
- An Understanding of Genetics and Immunodeficiency
- Primary Immunodeficiency and Family Planning
- COVID-19 Vaccines: Boosters and Third Primary Doses
- Coping Positively with COVID-19
- Understanding and Supporting Sleep
- Making a Difference to PI

**854**
**member registrations received for our PI Education webinar program.**

**20**
**expert guest speakers presented on a range of topics.**

The majority of members polled stated that all webinars presented were either **Very Good** or **Excellent.**

# Awareness

IDFA aims to increase awareness of immunodeficiency through marketing campaigns, community education and by influencing policy makers.

## Rare Disease Day

Throughout February, IDFA promoted Rare Disease Day to raise awareness amongst the general public, health professionals and decision-makers about rare diseases and their impact on people's lives.

IDFA partnered with WIN TV Newsreader Melissa Russell to film a storybook reading for social media of *A Friendship Story* which was part of the Rare Disease Day campaign toolkit. The author wrote this book inspired by her own childhood experiences living with a rare disease.

IDFA called on everyone to help the rare disease community be united by a chain of lights across the world by lighting up landmarks, buildings and their homes with the Rare Disease Day colours on 28 February. In addition to this, IDFA members were encouraged to share the Rare Disease Day colours through a unique artwork, expressing what it's like to live with a rare disease.

WIN News reported on the campaign which was syndicated to 14 news bulletins across regional QLD, VIC, NSW, ACT and TAS.

**48%**

increase in unique visitors to the IDFA website YOY during the campaign.

**14**

IDFA mentions in national TV News Bulletins.

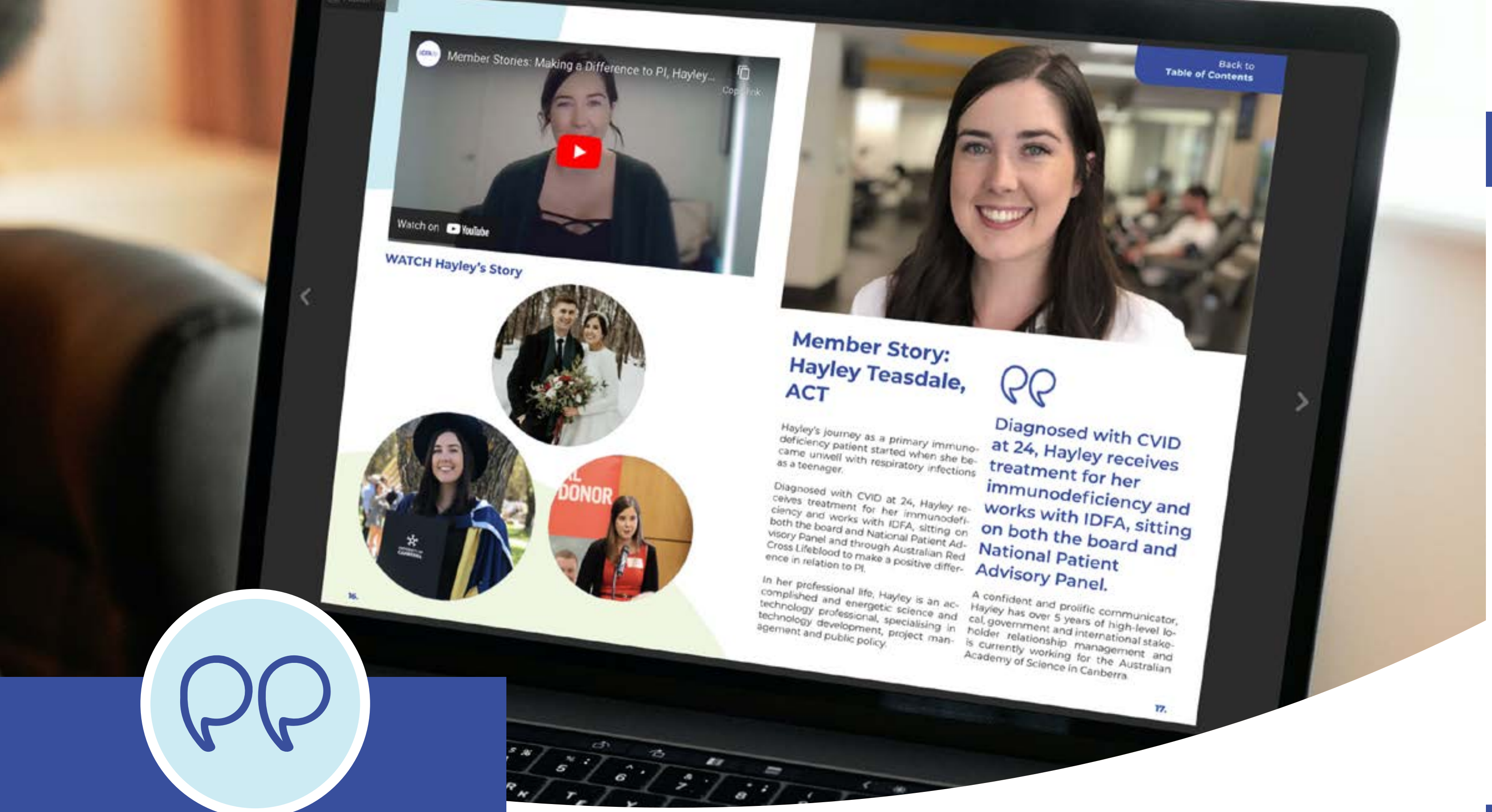
*Rare Disease Day artwork by IDFA Member, Pearl Sims.*

**38**

PR articles generated.

**1M**

people reached through PR.



Member Story: Hayley Teasdale, ACT

Hayley's journey as a primary immunodeficiency patient started when she became unwell with respiratory infections as a teenager.

Diagnosed with CVID at 24, Hayley receives treatment for her immunodeficiency and works with IDFA, sitting on both the board and National Patient Advisory Panel and through Australian Red Cross Lifeblood to make a positive difference in relation to PI.

In her professional life, Hayley is an accomplished and energetic science and technology professional, specialising in technology development, project management and public policy.

Diagnosed with CVID at 24, Hayley receives treatment for her immunodeficiency and works with IDFA, sitting on both the board and National Patient Advisory Panel.

A confident and prolific communicator, Hayley has over 5 years of high-level local, government and international stakeholder relationship management and is currently working for the Australian Academy of Science in Canberra.

17.

> “It’s really helpful to hear stories like this and there are so many things I can relate to, as the mum of an almost 13 year old who has recently been diagnosed with Primary Immunodeficiency. Thank you for sharing.”
>
> **– IDFA Member**

> “It is wonderful to listen to a story of someone little grown up. My daughters appreciate your experience.”
>
> **– IDFA Member**

# World PI Week

As part of World PI Week, IDFA launched an innovative digital member storybook *Making a Difference to PI*, sharing seven member’s stories and how they’ve made a positive difference to PI in their world. The member stories were also edited into social media video content.

IDFA also supported ASCIA’s National Immunodeficiency Strategy launch by providing member stories as part of the media activity and achieved national PR coverage in 30 media outlets.

*IDFA Staff Members participated in the ‘Strike A Y’ social media challenge as part of World PI Week.*

# Young Adult Members

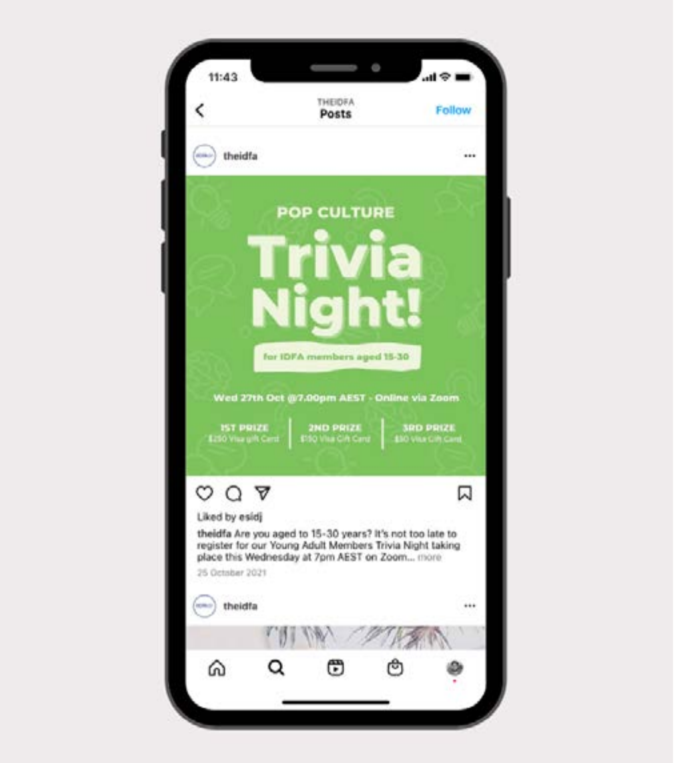
## Pop Culture Trivia Night

In light of COVID-19 restrictions and the absence of a Young Adult Members conference in 2021, there was a need to re-engage IDFA’s young adult members aged 15-30 years.

To launch the campaign, IDFA developed a new sub-brand for our Young Adult Members. Four members agreed to take part in our social media campaign where they filmed ‘a day in their life’ showing the realities of living with an immunodeficiency.

IDFA also held a Pop Culture Trivia Night which was a great success with a range of members joining from across the country and 100% of attendees stating that the event was either very good or excellent.

IDFA Young Adult Members



Liked by esidj

theidfa Are you aged to 15-30 years? It’s not too late to register for our Young Adult Members Trivia Night taking place this Wednesday at 7pm AEST on Zoom... more

25 October 2021

# Relationships

## ASCIA

IDFA was a key participant in the development of the National Immunodeficiency Strategy which was launched on 29 April 2022 as part of World PI Week. IDFA played a significant role in the launch through engaging and telling member stories through the significant national media campaign in the lead up to the strategy launch.

IDFA have had preliminary meetings with ASCIA about the implementation of the strategy and some key projects which will be jointly initiated.

## Government

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 successful in influencing the NSW state government to extend funding for the SCID Pilot Program until August 2022 and the federal government recently announced that SCID would become a standard newborn screening test across Australia.

IDFA have also advocated to federal and state health ministers on behalf of our members on issues such as Rare Disease Day and accessibility to rapid antigen testing during the COVID-19 pandemic.

# International Plasma Awareness Week

IDFA partnered with Lifeblood Australia for International Plasma Awareness Week. Activity included the sharing of Lifeblood resources, partnering in media activity and the tagging of Lifeblood in all IDFA communications.

As part of the campaign, IDFA staff visited Lifeblood Wollongong to donate plasma.

> “Many thanks to all those plasma donors. You don’t know how precious your gift is to people with PIDs.”
>
> **- IDFA Member**

# Community

## Public Relations

IDFA has been featured in 74 media articles throughout the year, increasing its national profile. Highlights have included Australia’s leading breakfast TV program Sunrise and Studio 10 as part of World PI Week and being syndicated to over 14 news bulletins as part of Rare Disease Day. Through media activity alone, IDFA has reached 1,702,608 people in the last year.

## Website

IDFA’s website has been designed to offer a simple, easy navigation and seamless user-friendly experience.

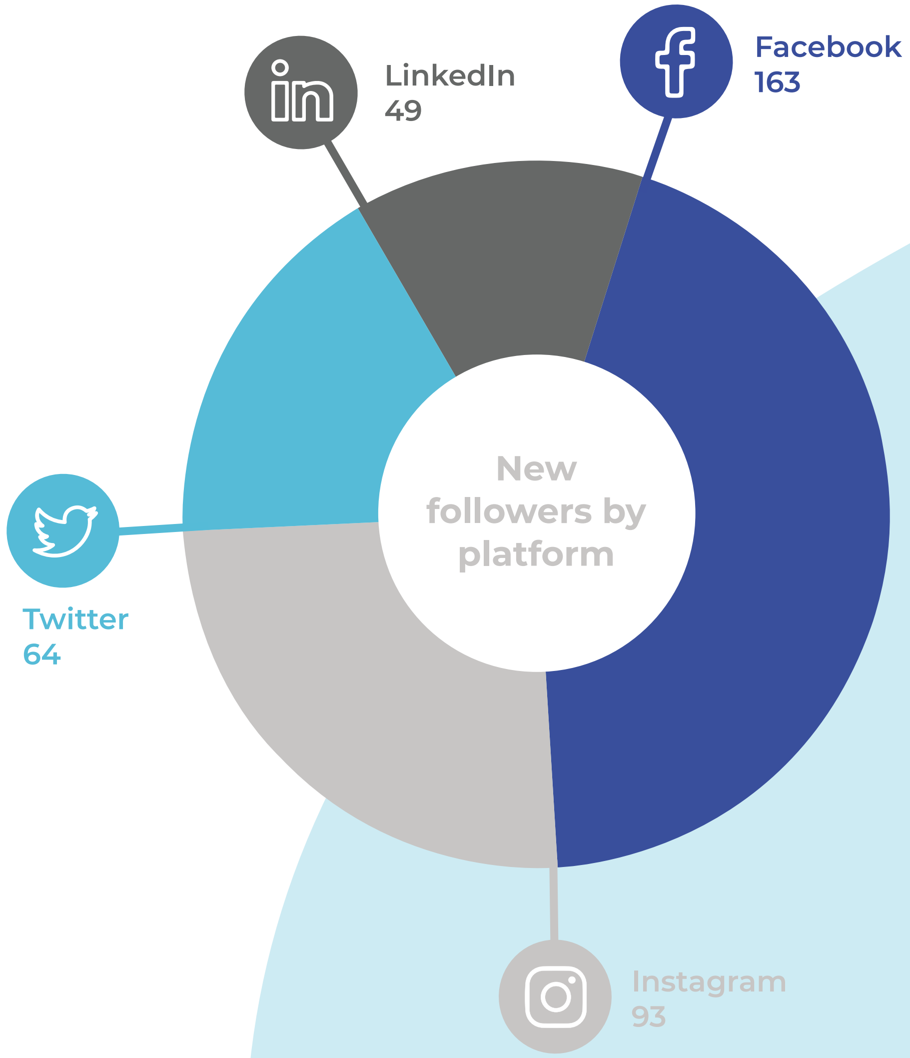
IDFA has continued to build on the content featured on its website including updates to our resources, the addition of our new Lifestyle Series landing pages, new webinars so that they can be watched at our members’ convenience and the latest news and campaign updates.

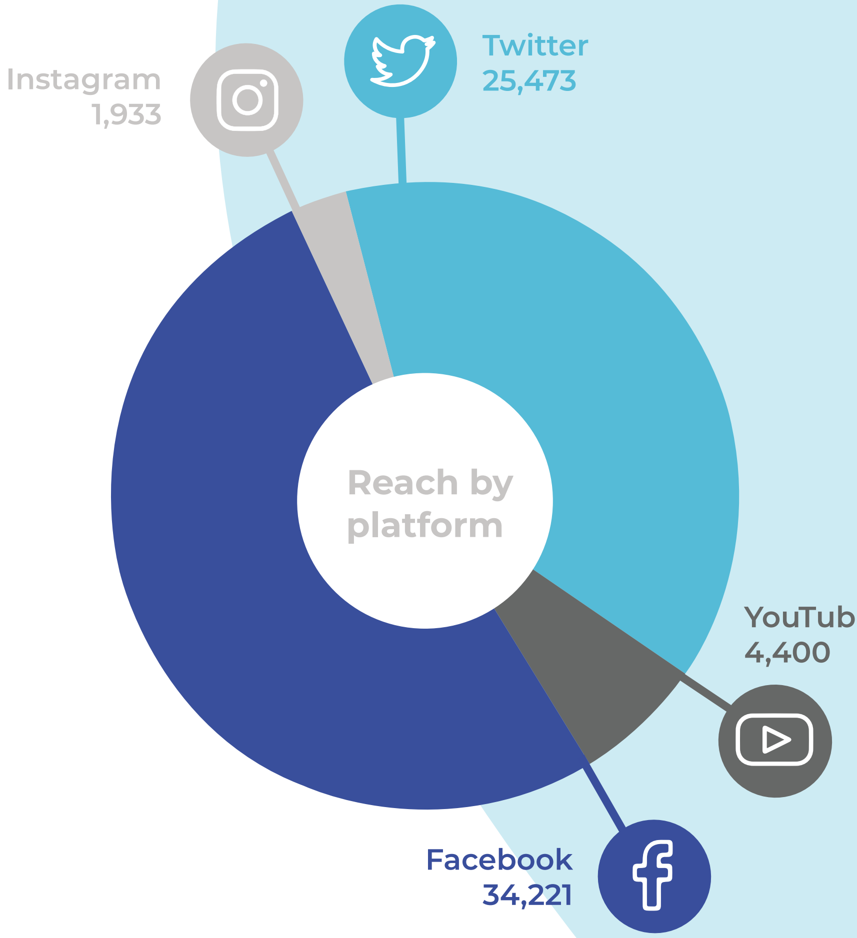
## Social Media

**2,684** followers on our online community (Facebook, Instagram, Twitter, LinkedIn, YouTube).

**7,746** engagements on our private IDFA Facebook Group (11% growth YOY).

**66,027** people reached through our online community.





# Advocacy

IDFA advocates on a range of significant issues for patients with primary and secondary immunodeficiencies.

## Treatment and Care

### 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.

In June 2022 there was an announcement by the federal government that SCID newborn screening had been adopted as a standard test.

IDFA continue to work collaboratively with Rare Voices, other rare disease organisations and as part of a number of research projects to ensure the effective implementation of the Rare Disease Action Plan.

### National Blood Authority

IDFA have continued to work with the NBA on a number of initiatives including:

- Several meetings with the NBA including representation on the NIGAC Committee as a consumer representative.
- Participation as an organisation and through engagement with members around the project looking at the optimal uptake of SCIg treatment. IDFA awaits the outcomes of this consultation to ensure that all members are able to have equitable access to treatment.

### COVID-19 Research

IDFA partnered with the University of Sydney for a research project to determine the extent of impact of the COVID-19 pandemic on individuals living with primary and secondary immunodeficiencies. The results of this study will be released in late 2022.

### 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.

> 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.

# Screening and Testing

## SCID Newborn Screening

IDFA has been advocating for the national implementation of newborn screening for Severe Combined Immune Deficiency (SCID) for several years.

SCID Newborn Screening (NBS) is NOT yet routinely available Australia-wide. In Australia, newborn screening is considered a state and federal matter. SCID NBS is currently routinely performed in New Zealand, the United States, and in some European countries, and on a trial basis in all infants born in the state of New South Wales and the Australian Capital Territory, from 2018 to 2022.

IDFA have advocated for national SCID newborn screening through awareness raising campaigns, the development of petitions (and engaging IDFA members to obtain thousands of signatures in each state of Australia) and by meeting with politicians to discuss the importance of implementing screening. As a result of IDFA and partner advocacy work, in a media statement released by the Hon Mark Butler MP, Minister for Health and Aged Care, to coincide with International Neonatal Screening Day on the 28 June, the Government stated: “In a major milestone, Severe Combined Immunodeficiency (SCID) has been recommended for inclusion in state and territory newborn bloodspot screening programs. Early diagnosis of SCID by newborn screening allows for treatment to be undertaken before infections cause complications.”

The Government has made a commitment to investing $38.4 million over four years to ensure consistency in screening across all states and territories and to expand programs in line with international best practice. This is exactly the outcome IDFA has hoped for in advocating for a national framework for SCID NBS.

Over the coming months, newborn bloodspot screening programs will be reviewed and reformed. More details on this consultation process will be available from the Federal Government soon.

In a major milestone, Severe Combined Immunodeficiency (SCID) has been recommended for inclusion in state and territory newborn bloodspot screening programs. Early diagnosis of SCID by newborn screening allows for treatment to be undertaken before infections cause complications.

# SCID Member Stories

## Sarah, WA.

Sarah gave birth to a perfect baby boy in May 2016. He was healthy, chubby and all of the best things a baby can be.

Sarah felt something wasn’t quite right with Jasper after he contracted conjunctivitis which didn’t clear quickly, followed by a virus, laboured breathing and weight loss at around 5 months old. Unfortunately this was just the start, with Jasper coughing up fluid bubbles, showing further difficulty in breathing and experiencing a number of infections.

In 2017, Jasper spent over seven months in hospital as he underwent treatment and further testing. Luckily a new doctor came onto his ward and tested Jasper for every rare disease he could, from tuberculosis to immunodeficiency. This is how Jasper received his diagnosis for SCID.

All of a sudden Jasper was seeing specialist after specialist. Sarah was asked if she had any support and if she understood how serious the situation was. While a lot of these meetings are a blur to Sarah now, one thing she will never forget is the worry on the faces of the immunology team, the haematology team and the oncology transplant team.

The next three months were full of ICU visits, surgeries and medications. Sarah and Jasper were constantly waking up to the sound of the IV kinking or finishing, beeping loudly. Sarah was far away from home and her husband and daughter. She couldn’t see them due to the risk of Jasper contracting another infection. Sarah became reclusive and paranoid about germs and anyone trying to enter their room.

When it was time for the transplant and after Jasper had spent months being treated with IV antibiotics, antifungals, antivirals and total parenteral nutrition, Sarah was told at best that Jasper had a 50% chance of survival. While Sarah was told that normally a transplant would never be considered for someone as sick as Jasper, it was his only option.

Thanks to the brilliance of Dr Shanti, Fiona and all the other medical staff, a month later Sarah and Jasper were allowed out into outpatient care at Ronald McDonald House where they spent a further three months waiting for Jasper to be healthy enough to head home.

It was a complex and terrifying time for Jasper’s family and thankfully he is a survivor. However, the physical scars are not the only ones that Jasper carries. Because he was unwell for so long, he stopped meeting his developmental milestones and is about eight months behind socially and emotionally. Jasper has trauma related issues whenever he has to have needles or go back into hospital. He becomes overwhelmed with fear, even when he is trying hard to be brave. It’s something that the family have put a great deal of work into moving forward from, but believe they still have a long way to go.

If Jasper had been diagnosed at birth, Sarah says that it would have allowed them to protect and isolate Jasper from the very beginning and he would not have gotten as sick as he did.

Sarah says that “treatment would have been much quicker and less intensive. He could have gotten through it in as little time as a month with a lot less trauma attached.”

“I wouldn’t wish what we have gone through on anyone, and we are one of the lucky ones. I got to take my son home. Not everyone with this condition gets to do that.”

# SCID Member Stories

## Emma, SA.

Emma joined the IDFA community after her son Max was diagnosed with SCID in 2017. Max was born full term and healthy. However, after experiencing several colds and viruses and multiple visits to the GP, Max had his first hospital admission at three and a half months for Bronchiolitis, Para flu 3 and Rhinovirus.

Following several short stays at hospital and home visits from nurses, Max was rushed to the resuscitation room in July 2017 where he stayed on oxygen for two weeks. The doctors tried to wean him off the oxygen but were unable to.

In August, Max's family were given the devastating news that their five month old baby "Mighty Max" had SCID. They were told that he required a bone marrow transplant to survive. Fortunately, Max's brother Blake was a perfect match.

Max was in hospital from September 2017 to January 2018 to receive his bone marrow transplant. During this time, he spent a month in intensive care because of his breathing complications and high flow oxygen requirements.

If Max had the SCID newborn screening test, Emma says that she would have been able to keep him isolated until he had his transplant. He would not have had the oxygen requirements. "Often children who have bone marrow transplants leave the hospital around day 30. Max left hospital on day 88 because of his breathing complications that he had prior to the transplant," Emma said.

Genetic testing of Max's mum and dad showed that Emma was unknowingly a carrier of SCID. Further testing on Emma's mum showed that it started with Emma as a mutation.

"Max has been diagnosed with Spastic Diplegia - Cerebral Palsy. An MRi scan showed that there was a bleed on his brain when he was very young, most likely when he was so sick and needed oxygen. Max is now five and a half years old. He can't stand independently. He requires a walker or sticks to walk. He is receiving support from the NDIS which will be lifelong," says Emma.

"I know that adding SCID to the newborn screening test costs money. However NOT having it also costs money – a lot of money. Having SCID on the newborn screening test would save so much pain and heartache for babies and their families."

"I know that adding SCID to the newborn screening test costs money. However NOT having it also costs money – a lot of money. Having SCID on the newborn screening test would save so much pain and heartache for babies and their families. It would give the baby a better chance of survival, not having complications before the tough process of a transplant. We would have done things very differently to protect our precious baby if we had known he had no immunity to protect himself."

# Professional Networks

## International Networks

ESID

INGID

IPOPI

World Health Organization

PPTA Plasma Protein Therapeutics Association

Jeffrey Modell Foundation

IDF Immune Deficiency Foundation

## National Networks

NPS

ascia

Garvan Institute

CHF

NATIONAL BLOOD AUTHORITY AUSTRALIA

Walter+Eliza Hall Institute of Medical Research

HAE Australasia hope • advocacy • education Australasian Patient Organisation for Hereditary Angioedema

circa

ARRC

genetic alliance australia

PANDIS

healthdirect

rare voices AUSTRALIA

## Networks

Allergy and Immunology Foundation Australasia
Arthritis Australia
AusPIPS
Australian Immunological Alliance
Australian Red Cross Lifeblood
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
GUARD Collective
Genetic Alliance
Genetic and Rare Disease Network
GSVN
Haemophilia Society Australia New Zealand
Immune Deficiency Foundation New Zealand
Immune Deficiency Foundation USA
Leukaemia Foundation
Livewire
Lung Foundation Australia
Lymphoma Australia
Mastocytosis Australasia
Mind Spot
Ministry of Health NSW
Monash University
National Disability Insurance Agency
National Immunoglobulin Advisory Committee
Outer West Local Health District
Sleep Health Foundation
Thalassaemia Society of NSW
University of Sydney
University of Western Sydney
University of Wollongong
Volunteers Australia

# Sponsors and Partners

## IDFA Sponsors

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 our Young Adult Members Conference engagement activity
- 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.

**Thank you to our major sponsors:**

CSL Behring

GRIFOLS

Takeda

gsk GlaxoSmithKline

## 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.

### Show locations

**NSW**
Albury
Lismore
Newcastle
Penrith
Sutherland
Wagga Wagga

**WA**
Perth
Kalgoorlie

**VIC**
Bendigo
Geelong
Melbourne
Shepparton

**ACT**
Canberra

**SA**
Adelaide

**QLD**
Cairns
Mackay
Toowoomba
Townsville

**TAS**
Burnie
Devonport
Hobart
Launceston

# Merchandise

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

To purchase our merchandise go to our website: **www.idfa.org.au/idfa-products**

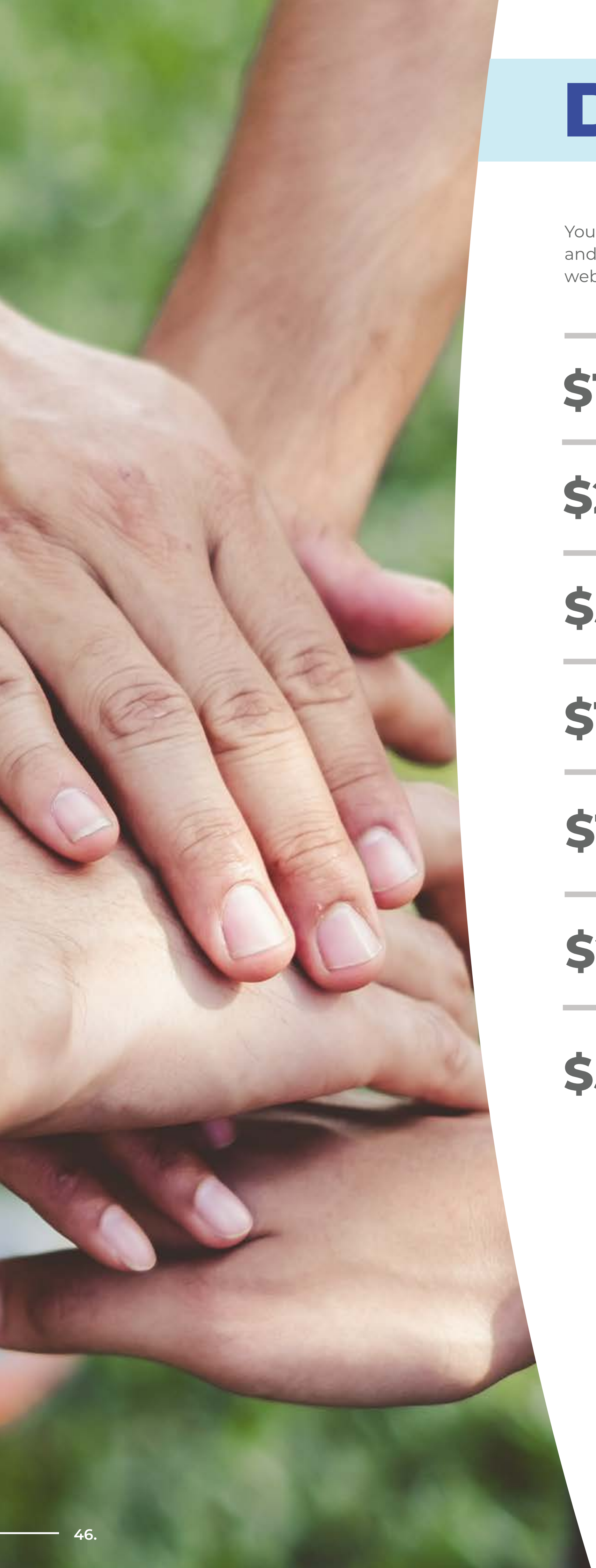
*PID is a genetic disorder*
*Causing the immune system to be quite out of order*
*Coughs, colds, infections and more*
*Are caught easily from the tiniest spore.*
*Ongoing treatment, lifelong for most,*
*Through plasma donations by generous hosts,*
*Is needed to keep the nasties at bay*
*So, people with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

**Awareness Pin**
**$5**

**Zebra Pen**
**$3**

**Tote Bag**
**$20**

**World PI Week Pack**
**$20**



# Donations

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

| | |
|---|---|
| **$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 the 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 |

> Here's to our IDFA volunteers. Those dedicated people who selflessly donate their time and talent. Thank YOU for making the world a better place.

# Volunteers

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

## IDFA Board Members

Geraldine Dunne (Chair)
Cath Bampton
Roslyn Chataway
Sap Chatterjee
Dr Luke Droney
Adam Friederich
Louise Grant
Alisa Kane
Alex James-Martin
Craig Mathieson
Caroline McMillen
Brendan Peek
Pearl Sims
Hayley Teasdale
Dr Melanie Wong
Hayley Teasdale (Observer)

## Medical Advisory Panel Members

Dr. Melanie Wong (Chair)
Dr. Luke Droney
Geraldine Dunne

## National Patient Advisory Panel Members

Adam Friedrich (Chair)
Javeria Ahmad
Lyn Barker
Alison Copley
Briana Corry
Charlotte Gingell
Sharon Heathfield
Christine Jeffery
Ben Johnson
Alex James-Martin
Tricia Parry
Richard Price
Hayley Teasdale
Jenny Tyrrell
Bianca Willis

## Students

Megan Parma
Emilia Seidel
Izzy Firmstone
Linda Lin
Ethan Italiano

## General Volunteers

Irene Dossan

## Healthcare Professional Panel Members

Alisa Kane (Chair)
Professor Leslie Burnett
Dr Paul Cameron
Dr Teresa Cole
Noelene Davies
Dr Luke Droney
Rachel Dunn
Geraldine Dunne
Di Edwards
Dr Ninna Estrella-Yuson
Dr Paul Gray
Amanda Jackson
Dr Jovanka King
Rebecca Macintosh
Dr Peter McNaughton
Dr Sam Mehr
Professor Kathryn Nicholson-Perry
Dr Phillipa Pucar
Dr Katrina Randall
Dr Luke Droney
Dr Carolina Sandler
Anna Sullivan
Professor Stuart Tangye
Dr Melanie Wong

# Financials

## Statement of Profit or Loss and other comprehensive income

| | 2022 | 2021 |
|---|---|---|
| IE Income | $1,783,413 | $2,019,172 |
| Cost of Sales | ($1,533,321) | ($1,643,827) |
| Gross Profit | $250,092 | $375,345 |
| Finance Income | $74 | $70 |
| Other Income | $132,046 | $127,107 |
| Marketing Expenses | ($14,369) | ($1,913) |
| Administrative Expenses | ($333,387) | ($275,921) |
| Functions, Awards & Presentations | ($6,406) | ($2,761) |
| Lease Expenses | ($23,041) | ($964) |
| Other Expenses | ($65,404) | ($49,991) |
| Finance Expenses | ($77) | ($530) |
| **(Deficit)Profit before income tax** | ($60,472) | $170,442 |
| Income Tax Expense | - | - |
| **(Deficit)/Profit from continuing operations** | ($60,472) | $170,442 |
| **(Deficit)/Profit for the year** | ($60,472) | $170,442 |
| **Other comprehensive income, net of income tax** | - | - |
| **Total comprehensive income for the year** | ($60,472) | $170,442 |

## Statement of Financial Position

| **ASSETS** | **2022** | **2021** |
|---|---|---|
| **Current Assets** | | |
| Cash & Cash Equivalents | $335,775 | $421,632 |
| Trade & Other Receivables | $27,500 | - |
| Other Assets | $5,281 | $14,721 |
| **Total Current Assets** | $368,556 | $436,353 |
| **Non-Current Assets** | | |
| Property, Plant & Equipment | $9,483 | $15,854 |
| Intangible Assets | $17,198 | $21,788 |
| Right-of-use Assets | - | $2,454 |
| **Total Non-Current Assets** | $26,681 | $40,096 |
| **Total Assets** | $395,237 | $476,449 |

| **LIABILITIES** | **2022** | **2021** |
|---|---|---|
| **Current Liabilities** | | |
| Trade & Other Payables | $29,749 | $57,567 |
| Lease Liabilities | - | $2,545 |
| Employee Benefits | $12,133 | $7,510 |
| Other Financial Liabilities | $5,000 | - |
| **Total Current Liabilities** | $46,882 | $67,622 |
| **Non-Current Liabilities** | | |
| **Total Non-Current Liabilities** | - | - |
| **Total Liabilities** | $46,882 | $67,622 |
| **NET ASSETS** | $348,355 | $408,827 |

| **EQUITY** | **2022** | **2021** |
|---|---|---|
| Retained Earnings | $348,355 | $408,827 |
| **TOTAL EQUITY** | $348,355 | $408,827 |

## 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.

## Head Office

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