Annual Report

2023-2024

IDFA

Immune Deficiencies Foundation Australia

Acknowledgement of Country

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

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Message from Board Chair and CEO

Geraldine Dunne, Board Chair

Carolyn Dews, CEO

IDFA are pleased to present the 2023/2024 Annual Report.

During the past twelve (12) months we have returned to pre-pandemic operations in terms of hosting a range of in-person meetings, including a national conference. Based on the feedback from our members, face to face meetings have been much appreciated in terms of reconnecting with old friends, meeting new members and having the opportunity to come together to learn about new initiatives, research and to share stories.

Throughout the year we remained focused on IDFA's key priorities.

We have delivered a range of education initiatives including continuation of our webinar series, which have been well attended by members and supported by our healthcare professional community, who have delivered diverse, interesting and informative content.

Awareness raising activities in the general community and through our government channels have included partnering with Rare Voices Australia and AusPIPS Inc. on initiatives such as Rare Disease Day, World PI Week and advocating for equitable access to treatment.

On an international level we have supported IPOPI campaigns, specifically around World PI Week and International Neonatal Screening Day and have participated in regular webinars with over 70 other countries who do similar work to IDFA.

Building community has been a key focus for us this year. We have totally revamped our member onboarding process and have built our online community to include a broader range of support groups, member mixers and opportunities for members to lead events and engage with the community.

We have built our in-person community through state-based meetups; one in every state and territory and a national conference held in Sydney. All events were well attended and received positive feedback from our members, who were pleased to be able to connect in person and have the opportunity to be part of the IDFA community.

From an advocacy perspective we have had a great outcome with the SCID campaign, with all states and territories now screening for this condition. This has been the result of many years of advocacy from a number of organisations and individuals.

Thank you to the guidance provided by our board of directors, advisory panels and the relentless commitment and work of our staff and volunteers. IDFA look forward to the year ahead and to continue to work with our members and stakeholders to build a stronger community.

Key Highlights

2023-24 FY at a glance

A year of Community Building with the development of IDFA and member-led events being hosted, including **member meetings in all IDFA member states.**

Members

159
new members joined IDFA (an increase of 7% YOY).

2,218
total members.

Fundraising

$16,885
raised through member-initiated community fundraising campaigns.

Public Relations

37
media articles generated throughout the year (including syndication), increasing IDFA's national profile.

Brought together 85 members, and professionals at the **IDFA National Conference** in Sydney.

Hosted our first ever **Plasma Party** in collaboration with **Lifeblood Australia** for International Plasma Awareness Week.

Impactful World PI Week campaign launching the NDIS and Immunodefincies handbook and achieving PR coverage in 14 news bulletins (syndicated) with IDFA Member Carrie.

Successful outcome for the SCID advocacy campaign with all states and territories now screening for SCID

Our Online Community

59,032
people reached via our online community.

2,777
followers of IDFA online community.

72
new mailing list subscribers.

Immunodeficiency Insights Webinars

12
webinars were hosted on range of topics.

36
expert guest speakers.

660
registrations received for the program.

Completed a **full refresh of how we welcome new members** to IDFA.

Strategic Plan

Our Vision

A future where all immunodeficiencies are diagnosed and treatment commenced early, enabling those impacted to lead productive and fulfilling lives.

Our Purpose

Creating awareness of all immunodeficiencies, supporting and advocating for improved outcomes for patients, carers and families.

Guiding Principals and Values

- Patient Centred Care
- Community Model of Care
- Equity of Access to Care

Our strategic priorities are reflective of the direction of IDFA.

- Creating Awareness and Education
- Building Community - Care and Support
- Driving Change - Advocacy

Looking Forward

This is an exciting time for IDFA with many new strategies being employed to support our members.

We are also working within the framework of the:

- National Immunodeficiency Strategy
- Rare Disease Action Plan

We aim to support our community of members and also to collaborate with other organisations working within the rare disease space.

Internally we are supported by the Board and a number of advisory groups including:

- Medical Advisory Panel
- National Patient Advisory Panel
- Healthcare Professionals Panel

We look forward to working with the Board, staff and our members to deliver on our strategic priorities.

Creating Awareness and Education

Patients and Carers

- Website and Social Media
- Information Packs/Digital Library
- Regular Communication and Events
- PI Education Webinars
- Health and Lifestyle Series
- Participation in Research

Government

- Engagement
- Representations to MP’s
- Funded Projects

Health Professionals

- Website and Social Media
- Information Packs/Digital Library
- Collaboration and Communication
- Webinars
- Sharing Member Stories

General Community

- Website and Social Media
- Awareness Raising Campaigns
- Fundraising

Building Community: Care and Support

Support Groups

- Emotional, Social and Practical Support
- Online Support Groups
- Peer Support and Mentoring

Engagement Events and Networking

- Member Meetings
- Medical and Healthcare Professional Network Conferences
- Engagement with other Organisations
- Celebration of Campaigns

Ask IDFA - Your Questions Answered

Driving Change: Advocacy

Screening and Diagnostic

- SCID, NBS, Genetic Testing and Counselling

Immunodeficiencies and Immune Dysregulation

- Resources

Treatment and Care

- SCIg Access
- Equitable Access to Treatment and Care Options
- Self-Advocacy Care and Toolkits

Research

- New Treatments

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, which is important for IDFA, as a national peak body.

IDFA exists to support its members, their families, carers, and medical professionals. The day-to-day management of IDFA is undertaken by a small team of paid staff, assisted by 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

Danae Pikkat

Marketing and
Communications Coordinator

Andriana Epistithiou

Finance and Administration
Coordinator

Estela Gimenez

Programs Coordinator

Maree Thomson

Community Engagement Coordinator

Alex Litchfield

Graphic Designer

Our Board

> “Since joining the board of IDFA in 2020, I have witnessed first-hand the great support that IDFA provide to patients and families affected by immunodeficiency. IDFA provides significant advocacy at many levels for this complex group of conditions that has direct impact on patient care.”
>
> **- Dr. Luke Droney**

Pearl Sims

Deputy Chair, Finance, Risk and Audit Committee

Brendan Peek

Company Secretary, Finance, Risk and Audit Committee Chair

Dr. Melanie Wong

Medical Advisory Panel Chair

Louise Grant

Finance, Risk and Audit Committee

Dr. Luke Droney

Medical Advisory Panel

Dr. Hayley Teasdale

General Board Member, National Patient Advisory Panel – Deputy Chair

Geraldine Dunne

Board Chair, Medical Advisory Panel

Dr. Alisa Kane

Healthcare Professional Panel Chair

Adam Friederich

National Patient Advisory Panel Chair

Sap Chatterjee

Finance, Risk and Audit Committee

Prof. Caroline McMillen

General Board Member

Roslyn Chataway

General Board Member

Javeria Ahmad

General Board Member, National Patient Advisory Panel

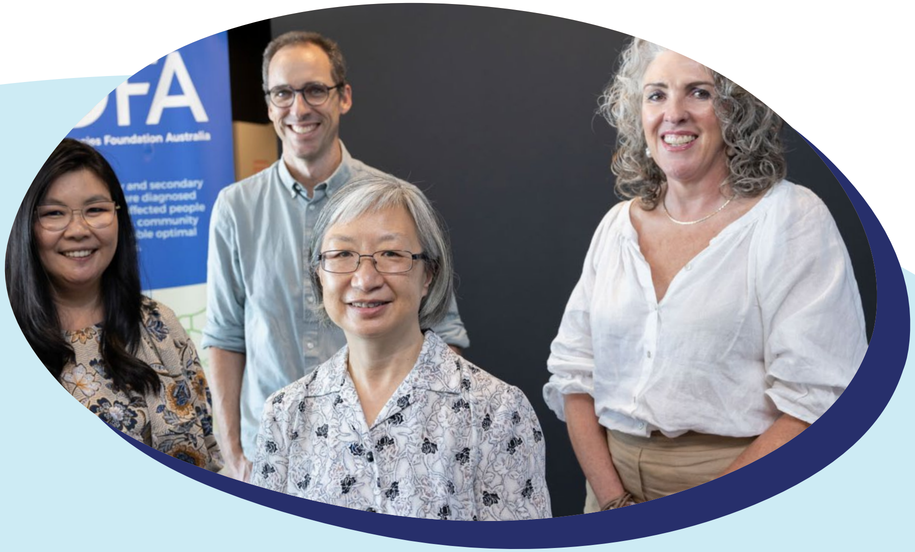
IDFA Advisory Panels

Healthcare Professional Panel

The Healthcare Professional Panel (HCP) 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 immunodeficiency community



Medical Advisory Panel

IDFA 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.

National Patient Advisory Panel

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

The IDFA NPAP has been able to identify key projects based on feedback, and are now working with members to deliver these initiatives including:

Finalisation of projects:

- COVID-19 Updates
- SCID Campaign
- Family Support Groups – SCID Connect, IDFA Parents Connect, IDFA Family Connect
- Launch of Self -Advocacy Tools

Current projects:

- Access to Treatment
- Health Professional Engagement
- Non-Qualifying Ig members
- My Aged Care
- NDIS
- Member Support Gaps
- Member Group – Immune Dys-regulation

Models of Care

Patient Focused Model of Care

ADVOCACY FOR IMPROVED PATIENT QUALITY OF LIFE

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

I
Don't
Feel
Alone

ORGANISATIONAL COMMITMENT

Plan projects alinging with mission, goals, strategic priorities and models of care

Educate
Advocate
Raise Awareness
Support
Source Funding

PATIENT PARTICIPATION AND COMMITMENT

Encourage self advocacy

Encourage patient participation in projects

Encourage volunteering in fundraising for projects

PATIENT OUTCOMES

Improved diagnosis treatment and access to care

Increased education

Increased resources

Improved quality of life

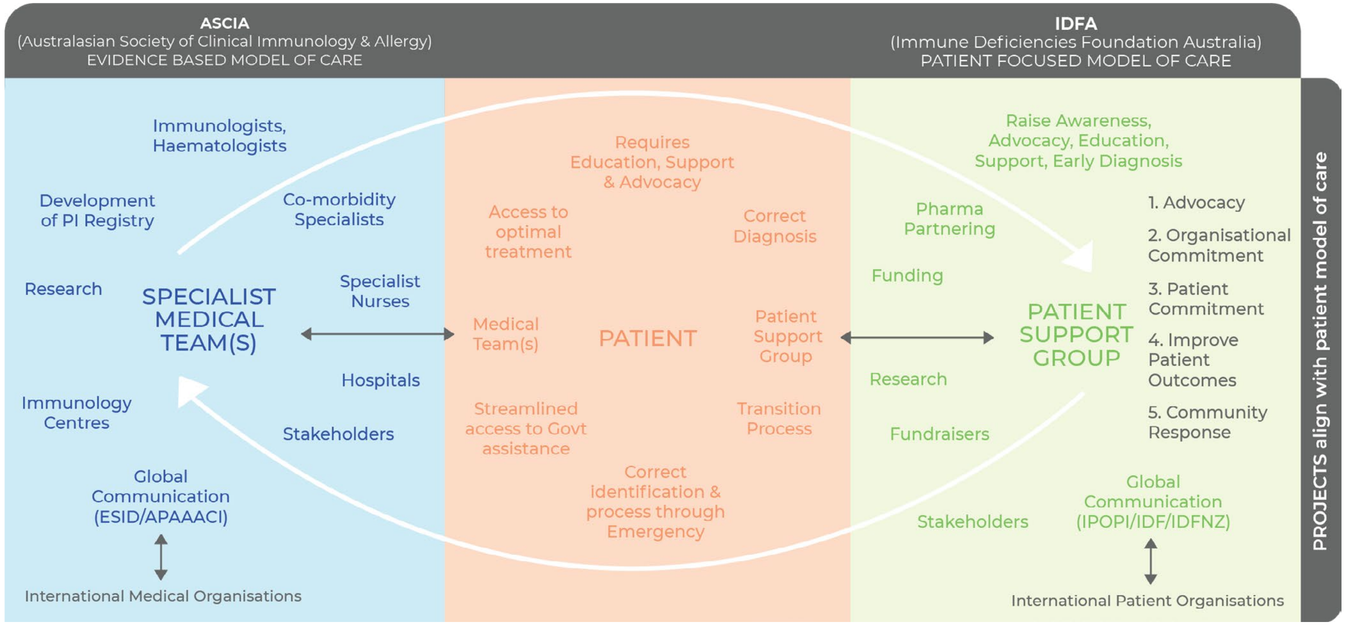
ID COMMUNITY RESPONSE

Proven benefits to PID Community

Organisational growth

Review patient outcomes

Repeat successful projects



Community Focused Model of Care

Immunodeficiencies

> 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.

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 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 485 inborn errors of immunity/primary immunodeficiencies in their 2022 update. While this may seem like a large number, it's important to recognize 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.

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.

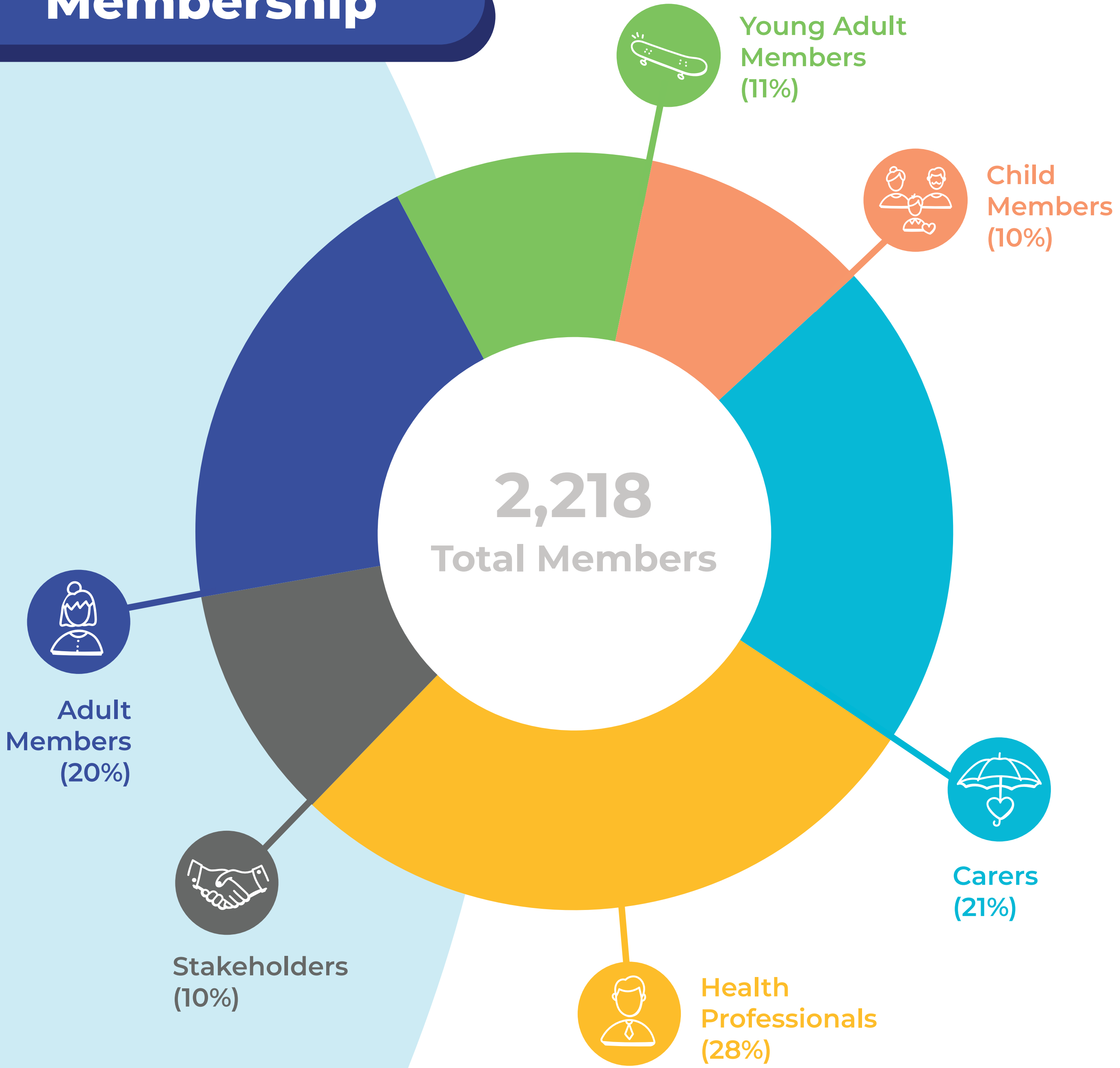
Gene Therapy

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.

Membership



This year we welcomed **159 new members** between 01/07/23 to 30/06/24 (an increase of 7% YOY).

Being diagnosed and living with an immunodeficiency is something that can greatly affect quality of life and wellbeing. At IDFA, we think there's no need to tackle that alone. We provide our members with a range of ways to connect with other members and to access up-to-date information, and educational resources.

This year IDFA completed a full refresh of how members are welcomed to the IDFA community. The onboarding process has been streamlined to provide new members with the knowledge, support, and resources to become active community members and navigate their diagnosis journey with confidence. See the next page for an overview.

IDFA membership options include:

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

New Member Onboarding

This year IDFA completed a full refresh of how new members are welcomed to IDFA. From the moment someone fills out the membership form on the website, to the welcome call at the end and everything in between.

Membership Form

- Collects personal and medical details from new members.

Welcome Email

- Automatically generated once IDFA accepts new member.
- Thanks members for joining and shares latest newsletter.

Overview Presentation

- Provides high-level overview of IDFA programs, where to access educational resources and the community spaces available to our members.

Welcome Pack

- Fresh new look to highlight diversity of members.
- A selection of hard-copy brochures and information.
- Highlights 3 ways to get involved with IDFA.

Member Toolkit

- Curated online member toolkits to provide tailored introductions into IDFA resources and conversations.

Welcome Call

- Welcome new members to the community and assesses their immediate needs and interests to connect them with relevant programs, community events and resources.

Feedback Survey

- Automatically sent eight weeks after welcome email.
- Gathers member insights and feedback regarding the onboarding process.

> **"I spent the first decade after my diagnosis pretty much alone with no information and no idea what to do when I got sick or know anyone who I could ask. When I found IDFA, I found understanding and a community. The road to diagnosis and then management is long and hard and to know you are not alone is immensely comforting."**
>
> **- Pearl**

Member Stories

Real People. Real Stories. In their own words.

Olivia

Carer Member

Although Jude's disease doesn't define him, understanding rare diseases is crucial in supporting those affected. His family is grateful for the care he received early on and the opportunity to raise awareness and advocate for others. This year, Jude starting kindergarten was a huge milestone for the family, as they once believed home schooling would be their only option if he survived those early years.

Watch Olivia's full story here:

Nic

Adult Member

Nic has faced health challenges since childhood, only receiving a diagnosis in 2012. Despite struggles, she thrives with the support of her family, her amazing GP, and the companionship of Bronson. Living with Common Variable Immunodeficiency (CVID), Nic takes daily precautions to stay healthy, from wearing masks at work to spending time in nature with her dog.

Read Nic's full story here:

Rafie

Child Member

Raife was born on his due date, a perfectly healthy baby boy, and at six hours old, he was diagnosed with SCID. Due to their history, the family had everything in place to have him tested and protected from birth. Thanks to SCID being included in the newborn screening in WA, they were able to quickly receive the results, making Raife the first baby flagged.

Read Rafie's full story here:

Kelly

Carer Member

After diagnosis, the road has had many ups and downs for the family. These days, treatment for her child is monthly IVIg (in hospital), after being on SCIg for 11 years. Both treatments have challenges, however the family did find SCIg was more effective on the child. With the current IVIg treatment, there are some side effects that impact their quality of life including myalgia, headaches and UTIs.

Read Kelly's full story here:

Carol

Adult Member

Although every day is different, Carol still enjoys gardening as much as she can. The main challenge for her is ensuring that she does her own form of mental planning so that she can tackle every day. To do this, Carol has completed the Pain Management course and find the tools and lessons learnt here to be life changing.

Read Carol's full story here:

Steve

Adult Member

In early 2021, Steve received a letter from Lifeblood, advising him to stop donating plasma due to low immunoglobulin levels and to consult a doctor. A study from the University of Queensland confirmed similar results, leading Steve to his GP, who referred him to an immunologist. In February 2021, Steve was diagnosed with Common Variable Immunodeficiency (CVID).

Read Steve's full story here:

Creating Awareness and Education

IDFA offers a range of informative resources, hosts regular webinars, and runs various campaigns to increase awareness and education for Australians living with immunodeficiency.

Educational Resources

Member Resources

IDFA, in conjunction with Taylor Made Outcomes, developed the "Immunodeficiencies and Applying for the NDIS" brochure to assist people applying to access government support from the NDIS. The resource booklet includes tools, how to access the NDIS, and advice to ensure that it meets the diverse needs of the immunodeficiency community. The launch of the resource booklet coincided with World PI Week, a global campaign dedicated to raising awareness about Primary Immunodeficiencies and advocating for better access to diagnosis and treatment.

The IDFA Overview brochure was consolidated and revamped this year, to include the 10 warning signs, IDFA strategic priorities, the IDFA story and information about immunodeficiencies.

IDFA knows that being diagnosed and living with an immunodeficiency is something that can greatly affect quality of life and wellbeing. With the IDFA Resource Pack, newly diagnosed patients can be easily connected to IDFA and resources, advocacy efforts and community-building.

Each IDFA Resource Pack contains:

- A letter from IDFA explaining resources
- 10 Warning Signs Poster x1
- Support Group Brochures x3
- IDFA Overview Brochures x3

The welcome packs for members were revamped to include a host of information for new people joining the community. The Welcome Packs for Adult, Child and Carer members included the '3 Ways to Get Involved with IDFA' as well as other key information.

The resource pack is used to onboard Healthcare Professional Members and at events that IDFA is hosting or attending. This cohesive branding provides an insight into the organisation and educates those who receive it.

IDFA has a large library of publications about immunodeficiency freely available for members to download.

Online Webinars

Immunodeficiency Insights Series

This year IDFA showcased a variety of topics highlighted by members in the 2023 Member Feedback survey. IDFA continues to focus strongly on education for members and has created three webinar categories to promote awareness. These include a ‘Practical Series’ including new tools and other resources to empower and support self-management, ‘Lifestyle Series’ focusing on living well and quality of life and a ‘Medical Series’ providing knowledge about treatment, health care and research.

The innovative Immunodeficiency Insights webinar series aims to increase awareness of primary and secondary immunodeficiencies in the community and the challenges faced by members. The program also aims to provide education to those affected and to support quality of life.

This year members submitted over 50 in depth questions during webinar registration highlighting areas needing greater awareness in the community and informing future webinars and member resources.

423
webinar views and downloads in the past 12 months.

660
member webinar registrations received nation-wide with a 25% increase from 2024.

100%
of members polled rated webinar content as either ‘Very Good’ or ‘Excellent’.

36
expert guest speakers presented on a range of topics.

94%
of webinar content was identified as ‘new’ to registrants.

During the last 12 months the Immunodeficiency Insights Program has included the following topics:

- **Medical** - GP Awareness and Primary Immunodeficiencies
- **Medical** - Young Adult Members Transitioning to Adult Care
- **Medical** - SCID Newborn Screening: A Brave New World
- **Medical** - Plasma Update and Donation Advocacy
- **Lifestyle** – Men’s Health and Primary Immunodeficiency
- **Practical** - NDIS and Primary Immunodeficiency
- IDFA End of Year Members Event
- **Medical** - Covid 19 Update: Variant and Vaccinations
- **Practical** - Voices of IDFA: Resource Launch
- **Medical** - Update: Gut Health and Immunodeficiencies
- **Practical** - Ask IDFA
- **Lifestyle** - Tips for Living Well: Anxiety

Rare Disease Day

Rare Disease Day is a globally coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse–but united in purpose.

Collectively, the number of people living with a rare disease is equivalent to the population of the third largest country (the USA) in the world - 300 million people. More than 2 million Australians have been diagnosed with a rare disease, it is a cause that is close to the hearts of many, and an important day for IDFA to educate people about Australians living with immunodeficiencies.

Each February, IDFA directs its focus towards Rare Disease Day to raise awareness and generate change for the people living worldwide with a rare disease.

This year, to raise awareness, IDFA ran a colouring competition for primary school children, with entries coming in from across Australia. A social media competition was run, calling upon the community to 'share your colours' to raise awareness for the day - this was an extension of the global campaign.

IDFA Member, Louise Grant shared her story on a podcast 'Two Peas in a Podcast' highlighting Rare Disease Day and the SCID journey she has been on with her daughter Isabelle.

For the campaign, IDFA had the opportunity to spotlight two member families, by highlighting their story to local media, and share an insight into their rare disease and how they navigate everyday life.

On Rare Disease Day, a webinar was hosted 'Voices of IDFA' a collaboration with members sharing their personal journey navigating life with an immunodeficiency. The 'Share Your Story Workshop' was also unveiled during the webinar.

2
tailored Media Releases developed.

10
entries into the colouring competition.

3
members stories shared during the campaign.

26
registrants for to the Rare Disease Day Webinar.

cury.com.au

Friday March 01, 2024

Jude's fight with rare disease

BY CHLOE COLEMAN

LOCHINVAR kindergarten student Jude Murdoch has had to be more courageous in his short five years than most adults have ever had to be.

When he was 14-months-old, Jude was diagnosed with IRAK-4 deficiency, a genetic autoimmune disease.

It's a disease so rare that Jude is one of just 75 people in the world who have been diagnosed, and one of two people in Australia.

IRAK-4 deficiency means Jude is prone to life-threatening bacterial diseases, and is kept alive by daily antibiotics and weekly immunoglobulin infusions, which come from donated plasma.

Recently, Jude completed his 200th immunoglobulin therapy, which is a huge achievement for someone so young.

Jude's mum Olivia is sharing her son's story for Rare Disease Day on Thursday, February 29, the rarest of all days, to raise awareness for all rare diseases.

"Jude started getting sick at 10-months-old, we didn't know he had a disease and it just kept getting worse and worse, and more [hospital] admissions until one night he was air-lifted from Maitland Hospital to the John Hunter Hospital into PICU, which is the ICU for paediatrics," she said.

His blood samples were sent off to America and a few weeks later the Murdochs were told about Jude's diagnosis.

Jude spent the first few years of his life in and out of hospital so much that one day, while parking at the hospital Jude asked his mum if they were home. "That was probably one of the hardest things I've ever heard," Olivia said.

While medicated, Jude is going well. "Jude relies heavily on antibiotics, so he will take two types of antibiotics twice a day, which actually keeps him alive," Olivia said.

"He also has blood plasma (immunoglobulin) from the Red Cross, so when people go and donate their blood and their blood plasma, they should know that it's helping a little boy stay alive.

"You can look at my son and think wow, he looks amazing, he doesn't look like a sick little boy, but that's because he's very heavily medicated."

This year, Jude began kindergarten, which is a huge deal for his family, who weren't sure if he would be able to attend normal school or even live to be old enough to go.

"This was huge for us, we couldn't believe it. Our son is alive and well, he's just gone to preschool and now he's going to actual school," Olivia said.

The Immune Deficiencies Foundation Australia (IDFA) is using Rare Disease Day to educate communities about Australians living with immunodeficiencies. For m information visit w org.au/rare-dise

00th intravenous
upplied

World PI Week

21%
increase in Instagram page visits (in comparison to the month before).

30
new Facebook followers throughout the month.

WIN TV
featuring World PI Week across its network.

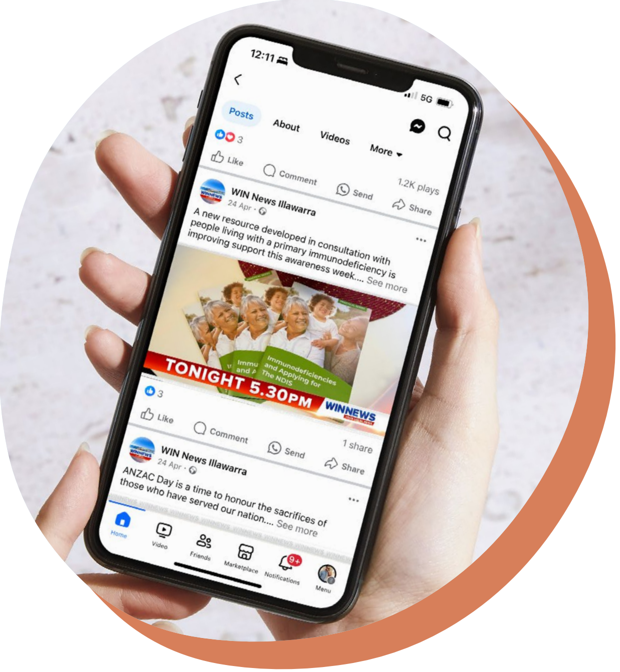
To celebrate World PI Week, IDFA employed numerous strategies to spread the message and importance of Primary Immunodeficiencies. This included a social media campaign, digital marketing (email and website), a webinar and a member engagement strategy.

The social campaign included members stories and facts and figures surrounding World PI Week. Throughout the month, 22 social media posts were shared across Facebook, Instagram, and LinkedIn, which resulted in a reach of 2.3K, and 115 interactions (likes, comments, and shares). The IDFA website and Facebook banners were updated to reflect the World PI Week Campaign materials, as well as staff email signatures. A partnership was in place with Bolster Raffles to sell raffle tickets and raise funds for immunodeficiency work.

A PR campaign was developed in collaboration with Australian Primary Immunodeficiency Patient Support (AusPIPS Inc.) to join the conversation around 'hidden disabilities.' As part of the campaign, IDFA launched a new National Disability Insurance Scheme (NDIS) booklet (Immunodeficiencies and Applying for the NDIS) to assist Australians to receive government support. This booklet was developed in conjunction with a local organisation who works in this field - Taylor Made Outcomes. From this, Carolyn Dews, IDFA CEO, spoke with Nick Rheinberger, on ABC local radio; Region Illawarra featured the story; Carolyn Dews and Carrie (an IDFA Member) were both featured on a WIN News story during World PI Week.

The campaign webinar this year was 'Ask IDFA'. This webinar covered a wide range of topical questions frequently asked by members such, as navigating treatments, products, and self-management for immunodeficiencies. It was a panel-style session, where members asked health professionals a range of questions (from members) and they were answered in real time.

The first 'Community Insights' session was hosted during World PI Week 'Your Story' to teach members how to share their story and share insights with others into how they navigate their day-to-day lives.



WIN News Illawarra
24 Apr
A new resource developed in consultation with people living with a primary immunodeficiency is improving support this awareness week.... See more

WIN News Illawarra
24 Apr
ANZAC Day is a time to honour the sacrifices of those who have served our nation.... See more

Lifeblood Australia Partnership

International Plasma Awareness Week

International Plasma Awareness Week (IPAW) is an annual initiative aimed at raising global awareness about source plasma collection, recognising the invaluable contributions of donors, and enhancing understanding of plasma protein therapies and rare diseases.

In recognition of International Plasma Awareness Week, IDFA teamed up with Australian Red Cross Lifeblood to host a ‘Plasma Party’ at the Wollongong donor centre on Tuesday, 3rd October. It was an event filled with community spirit, where donors had the chance to meet recipients and witness the positive impact their donations have on lives of others. The significance of donations and the generosity of the community was celebrated. The event was festive, with yellow splashing across the centre, with the wonderful staff donning yellow attire, and a delightful Plasma Party cake for all to enjoy. As part of the initiative, IDFA staff donated plasma.

Lifeblood Australia also welcomed Michael Klim as their new ambassador. A gold medallist and world champion, who relies on regular infusions made from donated human plasma and passionately advocates for the need for plasma donations. Carolyn Dews (IDFA CEO), Clarinda Sheeley (IDFA family member), Ismaeel and Javeria Ahmad (IDFA members) were honoured to participate in a 32-person relay (signifying how many donations are needed for one treatment for Klim), bringing attention to the growing need for plasma donations.

Every year, it takes approximately 130 plasma donations to treat one person with primary immunodeficiency, and this week, we highlighted the importance of these contributions.

National Blood Donation Week

To highlight the need for blood products, IDFA employed a sharable social media campaign. This was done to highlight the information around donations, and a call for action for people to join the #IDFALifeblood team. IDFA staff also visited the Wollongong Donation centre to give during National Blood Donation Week.

Digital Presence

Website

The IDFA website has undergone significant updates and changes over the last year to create a smooth entry pathway for new users. Content has been added, and strategically moved around to fit into the five main areas of the website:

- About Us
- Resources
- Community
- Advocacy
- Contribute

By using these new headings, it directs users to find what they need on the website. For each of the community events, a new page has been added, highlighting the importance of building community. The Pathways to Giving page now reflects the ways in which people can contribute to IDFA, either via their time or by donations.

Public Relations

IDFA has been featured in several media articles throughout the year, increasing its national profile. For International Plasma Awareness Week, IDFA Member, Ismaeel was involved in the Michael Klim campaign, and featured on Sky News.

Highlights include WIN TV featuring a story, part of World PI Week, which included commentary and videography of Carolyn Dews and an IDFA Member, Carrie, in the ACT, which was syndicated to 14 news bulletins.

Social Media

2,777

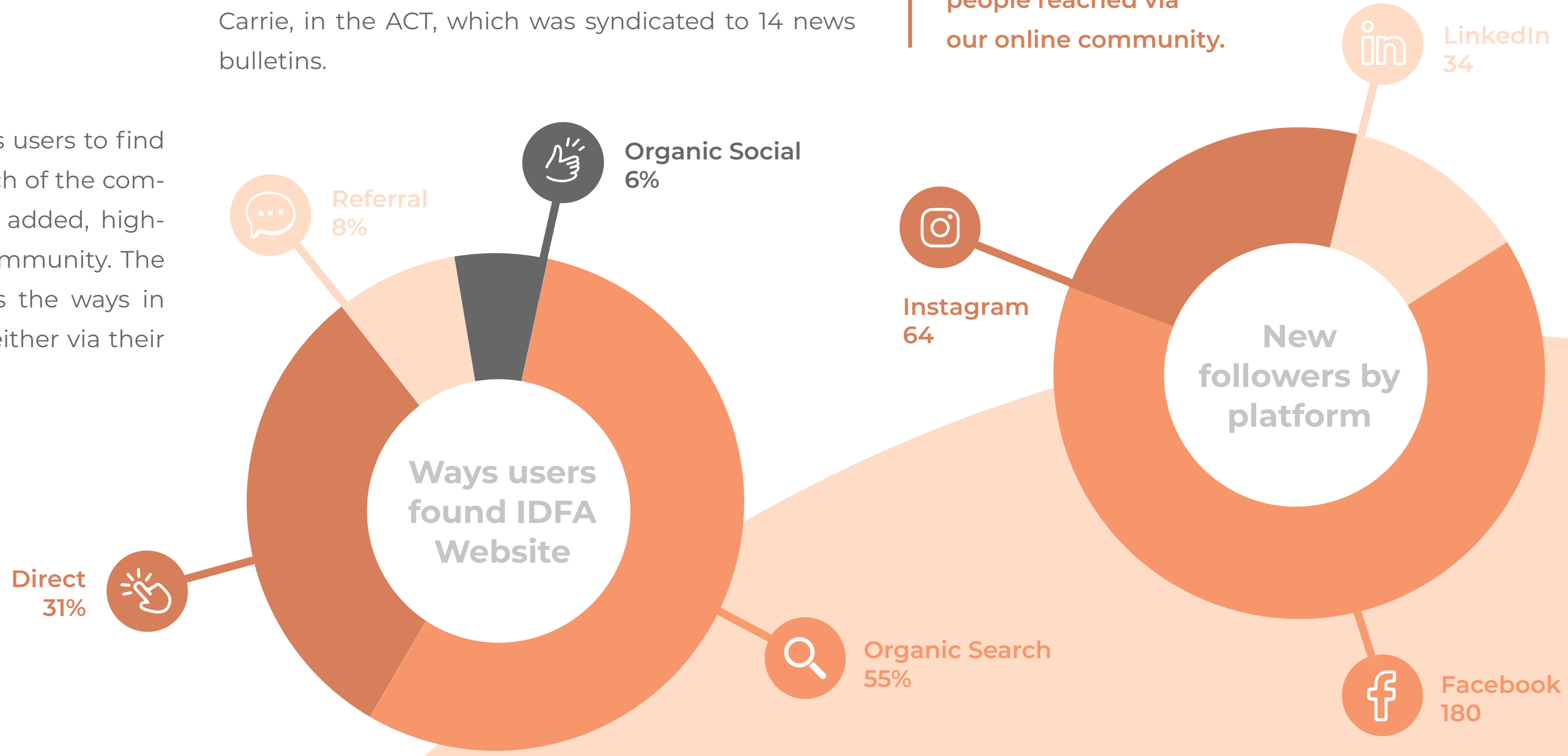
followers on our online community (Facebook, Instagram, LinkedIn, YouTube).

3,802

engagements on our private IDFA Facebook groups.

59,032

people reached via our online community.



Relationships

Member Organisations

IDFA have been working closely with both IPOPI and AusPIPS Inc. on both international and domestic programs and educational opportunities to support our members and the broader immunodeficiency community.

ASCIA

IDFA have been involved in ongoing meetings with ASCIA in relation to the National Immunodeficiency Strategy including planning for the roll-out of all initiatives within the strategy.

Government

Throughout the year IDFA has finalised a national campaign to advocate for government funding for SCID newborn screening. All state governments are now screening for SCID. This has been a significant campaign for IDFA and a range of other organisations and individuals who have been involved in advocacy over a long period of time.

IDFA have also advocated to federal and state health ministers on behalf of our members on issues with the current focus being on equitable access to treatment, specifically SCIg.

> **IDFA continues to build positive working relationships with the government at all levels.**

Building Community: Care and Support

IDFA offers a range of support initiatives including member meetups, group chats and peer mentoring for Australians living with immunodeficiency and their carers.

National Conference

In March 2024, IDFA held its National Conference in Sydney, bringing together members from across Australia. With insights from health professionals, IDFA staff and members, it was a wonderful weekend filled with smiles and connection.

A special thanks to the wonderful Andrew Cox an IDFA member and Meditation Teacher, who hosted and ran multiple sessions of Qigong throughout the conference.

IDFA also wants to acknowledge Yvonne Weldon from Metropolitan Local Aboriginal Land Council who provided our guests with a Welcome to Country.

Thank you to Geraldine and Adam for hosting the conference over the two days, and to the IDFA team who made all this possible.

IDFA is grateful it was able to hold this event at the Rydges Sydney Airport, with 85 members from most states and territories across Australia in attendance. Across the two days, guests heard from more than 15 speakers, sharing a wealth of insights within the immunodeficiency space and IDFA are thankful for the time they spent with attendees.

Scan the QR code to see the conference highlights, or the event wrap-up.

Community Events

We know that being diagnosed and living with an immunodeficiency is something that can greatly affect quality of life and wellbeing – and there's no need to tackle that alone. No matter where you live in Australia, you can connect with the IDFA community through online and in-person events.

IDFA-led Events

National Conference
This year's IDFA National Conference was held in Sydney in March.

State Member Meetups
Each year, IDFA makes its way to various states and territories to connect members with local Healthcare Professionals and each other. This year's theme was: Blossoming Together. IDFA officially completed a full tour of our members' home states and territories for the first time ever, visiting 7 different cities around the country bringing together 209 members!

First Plasma Party
At the Wollongong Donor Centre, IDFA hosted its first ever Plasma Party! It was an event filled with community spirit, where donors had the chance to meet recipients and hear about the positive impact that donations have on lives.

> **"I'm not alone and through the IDFA I have now got contacts for specialists I didn't know were available."**
>
> **- Tasmanian Member**

Member-led Events

Online Support Groups

IDFA offers a range of tailored Facebook support groups for members to connect and engage with other people who have a similar diagnosis or who are at a similar life stage. There are currently 7 different support groups with 838 members in them – the biggest is IDFA Connect with 626 members.

Online Community Catchups

Online Community Catchups are informal, member-led spaces where members can connect with others that understand what they're going through. This year IDFA supported 7 members to host 37 zoom catchups where 111 members joined in!

In-Person Coffee Club

IDFA launched its in-person event series "IDFA Coffee Club" so members can sip cuppas, chat and connect! Members can choose their favourite local café venue and a date that works for them, and IDFA promotes the event to members in surrounding areas and sends out a $5 voucher to each RSVP'd member to help cover costs. IDFA's first Coffee Club was in Caboolture, Queensland.

7

state member meetups hosted across Australia.

37

online community catchups hosted via zoom.

838

members in our online support groups.

Circle of Support

Launch Highlights 2023 – 2024

Circle of Support has now reached an exciting milestone rolling out to reach more members. Together with a pilot group of matched Peer Mentors and member Mentees, IDFA tested the Circle of Support one to one peer mentoring model tailored specifically to the needs of members living with an immunodeficiency.

Feedback from the pilot sample of Peer Mentors and Mentees was overwhelmingly positive, and together with IDFA staff over twenty recommendations were identified to roll out Circle of Support in 2024 and improve member reach and impact.

Circle of Support offers tailored one-to-one peer mentoring by a trained member who can offer connection and socio-emotional support, empowerment to develop a personal action plan, and mentoring to build confidence and skills for self-management and quality of life. Members who are newly diagnosed or facing significant challenges managing their immunodeficiency can access support for 12 weeks when they need it most, to ensure that they don't feel alone. Circle of Support Peer Mentors receive training in Mental Health First Aid, Accidental Counselling, Mental Health Support and Coaching Guidelines, Self-Management for Immunodeficiencies (SMIDs).

> Members can reach out for support by completing a registration form on the IDFA Circle of Support webpage to speak with a Peer Mentor in their state/territory to find out more.

Thank you to the pilot Peer Mentors and member Mentees and all newly trained Peer Mentors who tested this next phase of Circle of Support! IDFA looks forward to supporting more members nation-wide!

Circle of Support Core Principles:

Connect
Social support for mental wellbeing

Empower
Coaching for Self-efficacy

Support
Mentoring for self-management and self-advocacy

Peer Mentor Story: Pearl

Pearl was invited to join Circle of Support after supporting members through IDFA Connect community chat groups. As a change manager and with a special interest in alternative health support services she had a strong interest in helping members to navigate health services in her state and empower self - advocacy. After experiencing multiple inflammatory conditions related to CVID she was also very passionate about supporting member self-management and access to treatments for quality of life.

> **“Offering my support was so much more rewarding than I expected it to be. When Tina started making in-roads I felt quite proud I was able to help her with her self-advocacy.”**
>
> **- Pearl**

Mentee Story: Tina

Tina joined IDFA after feeling very disempowered and lost in the health system. She felt deflated and alone. Through Circle of Support, she has found her voice and learnt to be a ‘squeaky wheel’ using the IDFA self-advocacy tool kit to voice her health care needs and work with health professionals to provide factual information about her symptoms and progress.

She now has a much better relationship with health professionals and has received treatment for a rare fungal infection. While she still experiences setbacks with her health, she is now able to meet regularly with other members in her region and online to share her experiences and options and communicate more openly about her needs with health professionals.

> **“I was scrambling in the dark on my own but having input from my Peer Mentor and the self-advocacy forms helped me be more factual. I felt empowered to do something.**
>
> **Hearing my Peer Mentor’s path and how they managed to turn that around for themselves helped me not feel so frustrated and lost. It gave me hope. It was good to see that things can get better. The humanity of it, speaking with others, was what I needed.”**
>
> **- Tina**

Pearl, Peer Mentor and Tina, Mentee

To sign up for Peer Support or read more Mentee and Peer Mentor stories, scan the QR Code.

Driving Change: Advocacy

IDFA advocates and supports research and practical campaigns into a range of issues significant to 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 and as of May 2024, is being tested for in every state and territory.

IDFA will continue to work collaboratively with Rare Voices, other rare disease organisations and as part of several 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 several 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 are working with the NBA and other patient organisations to develop an advocacy campaign around this matter.

Research

IDFA partnered with several research organisations and universities including:

- University of Sydney
- Australian National University
- CIRCA
- Monash University
- University of Wollongong

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. IDFA is currently working with the National Blood Authority and other key stakeholders to ensure equitable access to treatment.

Screening and Testing

Nationwide SCID NBS for Australian Families

SCID is a life-threatening genetic condition in which affected babies are unable to fight even simple infections. Without appropriate timely treatment, most children have died before the age of 2 years. Since 2018 IDFA has been working with parents, carers, and families of SCID babies to share their stories and with health professionals nation-wide to advocate for universal SCID newborn screening.

Early diagnosis by newborn screening allows for SCID treatment to be undertaken before infections cause significant complications and possibly permanent disability, and even death. Prior to 2022, SCID NBS was not routinely performed unlike in New Zealand, the United States, and some European countries.

After many years of advocacy by IDFA members, health professionals and partner organisations such as Rare Voices Australia and AusPIPS Inc., universal SCID newborn screening is now a reality for all Australian families. From May 2024 IDFA carers of SCID babies and their families were greatly relieved to know all babies will be screened for SCID as part of the standard newborn screening tests, allowing for early diagnosis and access to treatment to avoid life-long impacts.

IDFA will continue to support families affected by SCID and continues to offer SCID Connect, a tailored space for parents/carers at whatever stage they are in their child's journey living with SCID.

IDFA would like to sincerely thank all our advocates, state and territory ministers and organisational partners who have supported the campaign and shared IDFA stories. IDFA SCID NBS member stories truly highlight the power of patient voices coming together to make a significant difference for future generations of people living with immunodeficiencies.

> **"My SCID Warrior, Isabelle, is about to turn 4 years old – a milestone many babies born with SCID never had the chance to reach due to their condition going undetected before they got critically sick and passed away. I'm extremely relieved SCID has finally been added to the National Newborn Bloodspot Screening tests, and proud of the efforts of every family that advocated for this change, as it means all Australian babies born with SCID now have the best chance to get an early diagnosis, protective intervention, and life-saving treatments."**
>
> **- Louise Grant**

Scan the QR code to find out more about SCID Connect.

To read more about IDFA carers advocating for SCID NBS, scan the QR code.

Self-Advocacy Toolkit

Scan the QR code for a copy of the self-advocacy toolkit.

Self-Advocate for Early Diagnosis and Treatment

Being diagnosed with an immunodeficiency can be a challenging and overwhelming journey. It can take individuals years of frustrating appointments with doctors and specialists to receive a diagnosis.

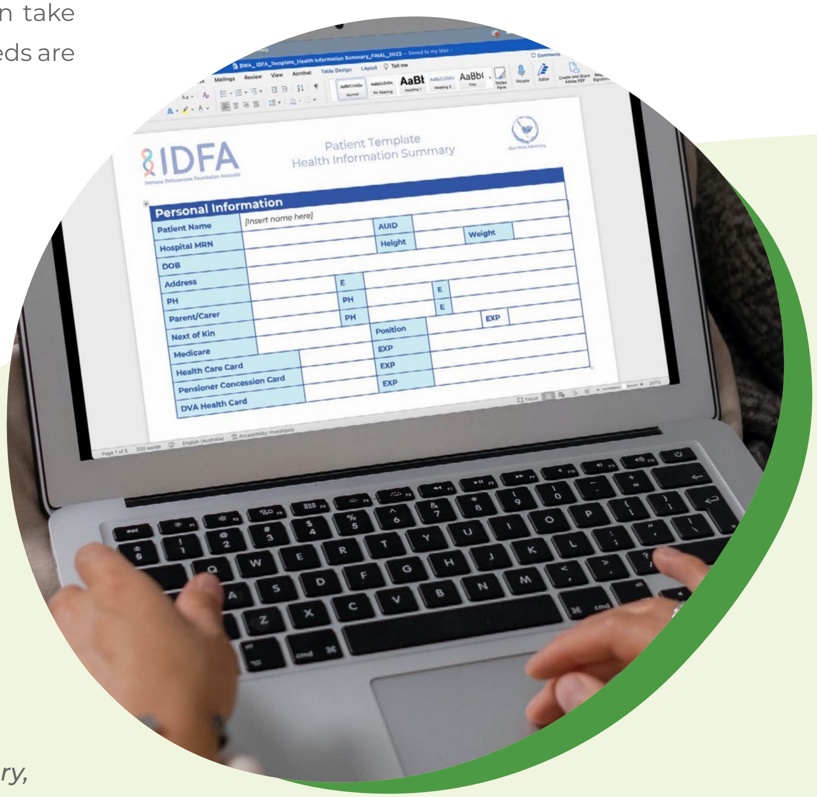
However, it is important to remember that there are steps you can take to empower yourself during the diagnosis process. That's why we teamed-up with Blue Wren Advocacy to develop self-advocacy tools specifically tailored to individuals with immunodeficiencies who are navigating the diagnosis journey and the early stages after diagnosis.

The self-advocacy tools are designed to help members communicate effectively with their healthcare providers, understand their diagnosis and treatment options, and make informed decisions about their health.

By using the self-advocacy tools, members can take an active role in their healthcare and ensure needs are being met.

> **"Self-advocacy, is a skill that patients, particularly with immunodeficiency need to learn. The toolkit helps people get faster diagnosis meaning having less long-term complications with their health, due to a delay in diagnosis. Therefore, getting treatment a lot quicker."**
>
> **- IDFA Member**

Christine Jeffery,
Blue Wren Advocacy



Patient Template
Health Information Summary

Personal Information

Patient Name	*[Insert name here]*	AUID			
Hospital MRN		Height		Weight	
DOB					
Address		E			
PH		PH		E	
Parent/Carer		PH		E	
Next of Kin		Position		EXP	
Medicare		EXP			
Health Care Card		EXP			
Pensioner Concession Card		EXP			
DVA Health Card					

Share Your Story

Every member has an important story to share!

Each person brings a unique history and outlook to their diagnosis journey, and there is so much value in sharing your lived experience and insights with others.

By sharing your story, you'll be empowering others living with a similar diagnosis and/or lifestyle and helping IDFA continue to highlight the variety, diversity, and vibrancy of the IDFA community.

In 2023/2024, IDFA developed the 'Share Your Story' workshop, a self-paced, four-part workshop, where members are sent an email each week (for four weeks), prompting them to answer a short set of questions. At the end of the workshop, participants are presented with their stories in written form.

The four-part workshop focuses on different aspects of a member's life:

- Getting to Know You
- Learning About Your Immunodeficiency
- Understanding How You Live with an immunodeficiency
- Reflecting on Your Journey

Members stories are shared in a variety of ways including social media, on the website or via public relations (media). Often for bigger campaigns such as Rare Disease Day, IDFA collaborates with members to share their story.

Scan the QR code to share your story.

> “One simple Facebook post about my husband's selfless blood donations ended up on Lifeblood's website and social media pages. It just goes to show how powerful sharing your story can be in raising awareness for Australians living with immunodeficiency.”
>
> **- Kylie**


HEBOARDRIDING C
UIKSIL

Professionals Networks

International Networks

ESID

PLASMA PROTEIN
THERAPEUTICS
ASSOCIATION

INGID

IDF Immune Deficiency Foundation

IPOPI

jm Jeffrey Modell Foundation

World Health Organization

National Networks

NPS

ascia

Garvan Institute

rare voices
AUSTRALIA

NATIONAL BLOOD AUTHORITY
AUSTRALIA

healthdirect

AusPIPS

FIAT LUX
Walter+Eliza Hall
Institute of Medical Research

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

Autoimmune Resource & Research Centre
ARRC
Quality of life through education support & research

CHF

circa

genetic alliance
australia

Other Networks

Allergy and Immunology Foundation Australasia
Arthritis Australia
Australian Immunological Alliance
Australian National University
Australian Patient Organisation Network
Australian Patient Advocacy Alliance (APAA)
Australian Red Cross Lifeblood
Australian Self Care Alliance
Auto Immune Research and Resource Centre
Better Access Australia
Beyond Blue
Business Illawarra
Cancer Council
Carers NSW
Centre for Personalised Immunology
Centrelink
Clinical Immunogenomics Research Consortium Australia
Connect Groups WA
Continuity of Care Alliance
GUARD Collective
Genetic
Genetic Alliance
Genetic and Rare Disease Network
Genetic Support Network of Victoria
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
Medicines Australia
Mind Spot
Ministry of Health NSW
Monash University
National Disability Insurance Agency
National Immunoglobulin Advisory Committee
Outer West Local Health District
Patient Voice Initiative
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

Thank you to all of our major sponsors:

CSL Behring GRIFOLS

Takeda gsk GlaxoSmithKline

Pharming®

International Entertainment

The generous support of International Entertainment as an external fundraiser has supported IDFA since inception. Businesses are encouraged to sponsor tickets to IDFA 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. With three types of Shows, Circkus Quickus (circusquirkus.com.au), World of Magic (worldfestivalofmagic.com.au) and Razzamatazz (razzamatazzshow.com.au).

Show Locations:

NSW
Albury
Lismore
Newcastle
Penrith
Sutherland
Wagga Wagga

QLD
Brisbane
Cairns
Mackay
Toowoomba
Townsville

WA
Perth
Kalgoorlie

VIC
Bendigo
Melbourne
Mildura

ACT
Canberra

SA
Adelaide

TAS
Burnie
Devonport
Hobart
Launceston

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.

IDFA Merchandise Pack
$35

Awareness Pin
$7

IDFA Pen
$5

Tote Bag
$20

To purchase our merchandise, scan the QR code.

Donations and Fundraising

IDFA operates solely on the generosity of others through sponsorships, grants, donations and fundraising activities.

Donations

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

Fundraising Partner

IDFA has also partnered with Bolsta Fundraising to raise funds, giving ticket buyers the chance to win 20k in prizes. Funds raised allow IDFA to continue our ongoing work in supporting Australians living with primary and secondary immunodeficiencies.

BOLSTA
RAFFLES

You can support IDFA by donating through our website.

$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 an immunodeficiency
$200	Cost of registering one of our members to attend an IDFA conference
$500	Cost of travel and accommodation for one of our members to engage with other members at the Annual Conference

Volunteers

IDFA are grateful for all their current and past volunteers, who have helped them get to where they are today. There are numerous areas in which people can volunteer with IDFA including by becoming a circle of support peer mentor, assisting with member events, presenting in a webinar or being on one of the panels or the board.

You can make a difference in someone's life and support IDFAs work and members by joining the pathways to giving.

IDFA Board Members

- Geraldine Dunne (Chair)
- Roslyn Chataway
- Sap Chatterjee
- Dr. Luke Droney
- Adam Friederich
- Louise Grant
- Dr. Alisa Kane
- Javeria Ahmad
- Caroline McMillen
- Brendan Peek
- Pearl Sims
- Dr. Hayley Teasdale
- Dr. Melanie Wong

Students

- Diana Rameziani
- Bailey Goodwin
- Mia Hanley

National Patient Advisory Panel Members

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

Medical Advisory Panel Members

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

Healthcare Professional Panel Members

- Dr Alisa Kane (Chair)
- Professor Leslie Burnett
- Dr Paul Cameron
- Dr Teresa Cole
- 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 Carolina Sandler
- Anna Sullivan
- Professor Stuart Tangye
- Dr Melanie Wong

Presenters/Speakers who contributed to IDFA

- Jo Cameron – National Blood Authority
- Sally Devenson – Lifeblood ACT
- Lauren Baptist – Disability Employment Service, Edge Employment Solutions
- Mandy Drain – NDIS Support Coordinator, Taylor Made Outcomes
- Mitch Durbridge – Psychologist
- Sharon Bard – Counsellor
- Dr Kahn Preece – Immunologist, John Hunter Hospital
- Dr Samar Ojiami – PhD Student, Walter and Eliza Hall Institute of Medical Research
- Dr Karuna Keat – Immunologist, Royal Price Alfred Hospital
- Dr Jason Tye-Din – Gastroenterologist, Walter and Eliza Hall Institute of Medical Research
- Chiara Migloretto – Dietitian, University of Wollongong
- Dr Emily Edwards – Vice President, AusPIPS Inc.

Financials

Statement of Profit or Loss and other comprehensive income

	2024	2023
IE Income	$1,937,349	$1,945,357
Cost of Sales	($1,602,560)	($1,593,720)
Gross Profit	$334,789	$351,637
Finance Income	$1,190	$497
Other Income	$226,390	$131,431
Marketing Expenses	($6,851)	($7,158)
Administrative Expenses	($419,745)	($339,948)
Functions, Awards and Presentations	($57,014)	($12,874)
Lease Expenses	-	($7,868)
Peer Support Program	($8,231)	($11,071)
Other Expenses	($62,151)	($90,103)
Finance Expenses	($6,636)	($3,739)
Profit before income tax	$1,741	$10,804
Income Tax Expense	-	-
Profit from continuing operations	$1,741	$10,804
Profit for the year	$1,741	$10,804
Total comprehensive income for the year	$1,741	$10,804

Statement of Financial Position

ASSETS	2024	2023
Current Assets		
Cash and Cash Equivalents	$366,679	$381,297
Other Assets	$16,871	$11,310
Total Current Assets	$383,550	$392,607
Non-Current Assets		
Property, Plant and Equipment	$11,504	$13,031
Intangible Assets	$8,018	$12,608
Right-of-use Assets	$90,473	$110,694
Total Non-Current Assets	$109,995	$136,333
Total Assets	$493,545	$528,940

LIABILITIES	2024	2023
Current Liabilities		
Trade and Other Payables	$30,661	$35,653
Lease Liabilities	$18,087	$16,288
Employee Benefits	$22,174	$9,625
Other Financial Liabilities	-	$28,621
Total Current Liabilities	$70,922	$90,187
Non-Current Liabilities		
Lease Liabilities	$78,999	$96,870
Total Non-Current Liabilities	$78,999	$96,870
Total Liabilities	$149,921	$187,057
Net Assets	$343,624	$341,883

EQUITY	2024	2023
Retained Earnings	$343,624	$341,883
Total Equity	$343,624	$341,883

Our Vision

A future where all immunodeficiencies are diagnosed and treatment commenced early, enabling those impacted to lead productive and fulfilling lives.

Our Purpose

Creating awareness of all immunodeficiencies, supporting and advocating for improved outcomes for patients, carers and families.

Head Office

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IDFA
Immune Deficiencies Foundation Australia