idfa.org.au

2024 - 2025

Annual Report

I Don’t Feel Alone

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 the country.

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Message from Board Chair

IDFA's Board of Directors are pleased to present the 2024/2025 Annual Report.

This past year, IDFA's Strategic Priorities have remained central to all the Board's activities and decisions. Our focus has been unwavering: to raise awareness of all immunodeficiencies, to advocate for improved health outcomes, and to provide meaningful support to our member patients, their carers, and families.

Education has continued to be at the heart of our work. IDFA's ongoing webinar series has delivered another year of high-quality, relevant content, made possible through the generosity of healthcare professionals and members living with immunodeficiencies. The expansion of our Peer Support Program has further strengthened our ‘Circle of Support’, enabling experienced members to mentor and guide others in their journey.

> **“Our focus has been unwavering: to raise awareness of all immunodeficiencies, to advocate for improved health outcomes, and to provide meaningful support to our member patients, their carers, and their families.”**

The Board extends its sincere gratitude to the volunteers who present in our webinars and to those who have undertaken training to become IDFA Peer Mentors, along with volunteers who run our weekly online support groups and coffee catchups. Each of you play a vital role in ensuring our motto, “IDFA: I Don't Feel Alone”, are not just words, but a lived reality for our community.

This year also marked an important step forward in IDFA's international engagement. In October 2024, our CEO represented IDFA at the Global Patient Meeting hosted by the International Patient Organisation for Primary Immunodeficiency (IPOPI) and at the European Society for Immunodeficiency (ESID) Conference. These events provided invaluable opportunities for knowledge exchange, collaboration, and enhancing IDFA's profile as an internationally recognised patient organisation.

Our advocacy and awareness efforts have continued to grow, strengthened through partnerships with Rare Voices Australia, AusPIPS Inc., Australian Red Cross Lifeblood, and other trusted organisations. Together, IDFA has participated in significant campaigns and events including Rare Disease Day 2025, World Primary Immunodeficiency Week, and national efforts promoting ‘Plasma for Life’ and equitable access to SCIg treatment.

Community connection has also been a priority. This year saw successful member meetups held in every state and territory. Looking ahead, we are excited to celebrate IDFA's 20th anniversary — a milestone that reflects two decades of commitment, advocacy, and service.

On behalf of the Board, I extend heartfelt thanks to our advisory panels, staff, and volunteers for their dedication, expertise, and tireless commitment. Together, we will continue to strengthen IDFA's role as a leader, advocate, and supportive community for all those living with, or impacted by, immunodeficiencies.

- Louise Grant.

Message from CEO

This year has been one of both consolidation and innovation for the Immune Deficiency Foundation of Australia (IDFA).

We have continued to strengthen our role as the national voice for people living with primary and secondary immunodeficiencies, ensuring that our members are informed, supported, and empowered to advocate for their health and wellbeing.

Our work this year has been guided by a clear commitment to our mission – providing education, advocacy, and awareness while fostering a community that enables better health outcomes. We have built on the foundations of previous years to deliver high-quality programs, expand our reach, and ensure that members' voices shape policy and practice.

> **“We continued to work closely with government, clinicians, and other stakeholders to ensure that the needs of our community are heard and acted upon.**

Key Achievements

- **Member Support and Programs:** Our peer support and self-advocacy initiatives have continued to grow, with more members than ever accessing tailored resources, webinars, and one-on-one assistance.
- **Advocacy:** IDFA made significant contributions to national discussions on rare diseases, immunoglobulin (Ig) governance, and equitable access to treatments. We continued to work closely with government, clinicians, and other stakeholders to ensure that the needs of our community are heard and acted upon.
- **Community Engagement:** We strengthened our online communities, expanded our regional outreach, and built stronger connections with partner organisations in Australia and internationally.
- **Capacity Building:** We invested in organisational systems, governance processes, and staff capability to better serve our growing membership and prepare for future opportunities.

The year was not without its challenges. We navigated a dynamic health policy environment, funding pressures, and the ongoing impact of chronic illness on our members' daily lives. Despite these pressures, the IDFA team demonstrated resilience, adaptability, and unwavering commitment to our purpose.

As we move forward IDFA will continue to focus on sustainability, innovation, and impact. We will explore new funding streams, strengthen partnerships, and ensure that member experiences remain at the heart of everything we do.

Our goal is to continue building a strong, connected, and informed community, and to be a leading advocate for those living with immunodeficiencies.

- Carolyn Dews.

Key Highlights

2024-25 FY at a glance

Members

114	**2,362**
new members joined IDFA.	total members.

Fundraising

$26,729.56

raised through member-initiated community fundraising campaigns.

Public Relations

35

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

Our Online Community

70,334	**3,005**	**174**
people reached via our online community.	followers of IDFA online community.	new subscribers to our mailing list.

Immunodeficiency Insights Webinars

8	**23**	**516**
Immunodeficiency Insights Webinars were held on a range of topics including NDIS, the Impact of Comorbidities on Immunodeficiencies, SCIg Treatment.	expert guest speakers presented on a range of topics.	member registrations received for the Immunodeficiency Insights Webinar program.

Partnered with Lifeblood Australia to host **8 Plasma Parties** across the country around International Plasma Awareness Week .

Impactful Rare Disease Day Campaign, with an 8K reach via social media campaign.

Established **two new committees** to strengthen IDFA's strategic focus: the Research Committee and the Philanthropic and Fundraising Committee.

$1,233 raised during the 'Stride for PI' campaign.

Launched the **IDFA Deep Dives** to deliver more in-depth and relevant content tailored to member needs.

Continued to advance the healthcare distribution strategy, aiming to ensure IDFA resources are more widely available across healthcare settings.

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 Principles 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
- Research Committee
- Philanthropic and Fundraising Committee

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
- Educationional 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

- 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.

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.

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.

Personnel Changes

IDFA Staff

- **Estela Gimenez – Program Coordinator (Resigned December 2024):** We extend our sincere thanks to Estela for her valuable contribution to the IDFA team. During her time with us, Estela played a key role in the development of our Circle of Support program and brought dedication and passion to the delivery of IDFA webinars.

- **Krystal Krizanovic – Fundraising and Events Co-ordinator (Appointed May 2025):** We are pleased to welcome Krystal to the team in the newly created role of Fundraising and Events Coordinator. Krystal's focus is on delivering engaging, high-quality events for IDFA members and fostering a strong fundraising culture that supports and gives back to our community.

Board Resignations

We wish to acknowledge and thank Dr. Luke Droney and Caroline McMillen for their dedicated service and significant contributions as members of the IDFA Board over the years.

Board Recognition and Appointments

We sincerely thank Geraldine Dunne for her outstanding leadership as Board Chair over the past three years. Her vision, dedication, and guidance have greatly strengthened our organisation and advanced our mission.

We warmly welcome Louise Grant as the newly appointed Chair of the IDFA Board.

Additionally, we are delighted to welcome Anastasia Cauchois, Dr. Natasha Mosley, and Anna Sullivan as new members of the Board. Their expertise and commitment will be invaluable as we continue to grow and strengthen our organisation.

Our Team

Carolyn Dews

CEO

Danae Pikkat

Marketing and Communications Coordinator

Krystal Krizanovic

Fundraising and Events Coordinator

Andriana Epistithiou

Finance and Administration Coordinator

Maree Thomson

Community Engagement Coordinator

Alex Litchfield

Graphic Designer

Our Board

Louise Grant

Board Chair | Philanthropic and Fundraising Committee

Pearl Sims

Deputy Chair | Philanthropic and Fundraising Committee | Finance, Risk and Audit Committee

Brendan Peek

Company Secretary | Finance, Risk and Audit Committee Chair

Dr Melanie Wong

Medical Advisory Panel Chair

Adam Friederich

National Patient Advisory Panel Chair

Dr Alisa Kane

Healthcare Professionals Panel Chair | Research Committee

Javeria Ahmad

General Member

Anastasia Cauchois

Philanthropic and Fundraising Committee

Sap Chatterjee

Finance, Risk and Audit Committee

Dr. Hayley Teasdale

National Patient Advisory Panel Deputy Chair | Research Committee

Geraldine Dunne

General Member

Dr. Natasha Moseley

Finance, Risk and Audit Committee

Roslyn Chataway

Philanthropic and Fundraising Committee

Anna Sullivan

General Member

IDFA Advisory Panels and Committees

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:

Completed projects:

- COVID 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
- Immune Dys-regulation

5
IDFA advisory panels and committees.

2
committees established in the past 12 months.

Healthcare Professional Panel

The Healthcare Professional Panel (HCP Panel) is an informal committee whose members can be called upon to provide expert information and advice to the IDFA Board and members 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 has 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.

Philanthropic and Fundraising Committee

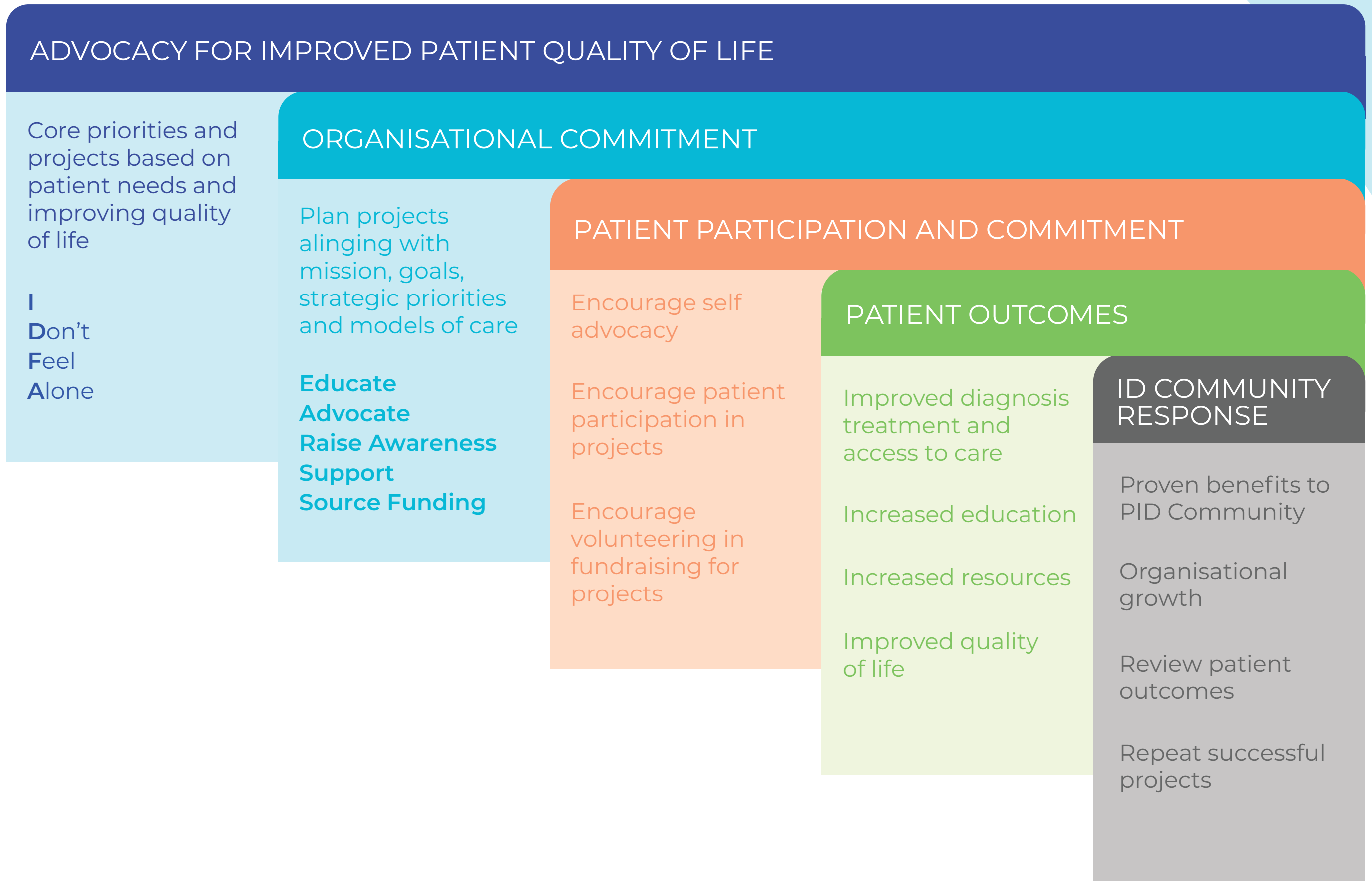
The Philanthropic and Fundraising Committee is focused on fundraising initiatives and awareness campaigns which benefit IDFA members living with primary and secondary immunodeficiencies.

Research Committee

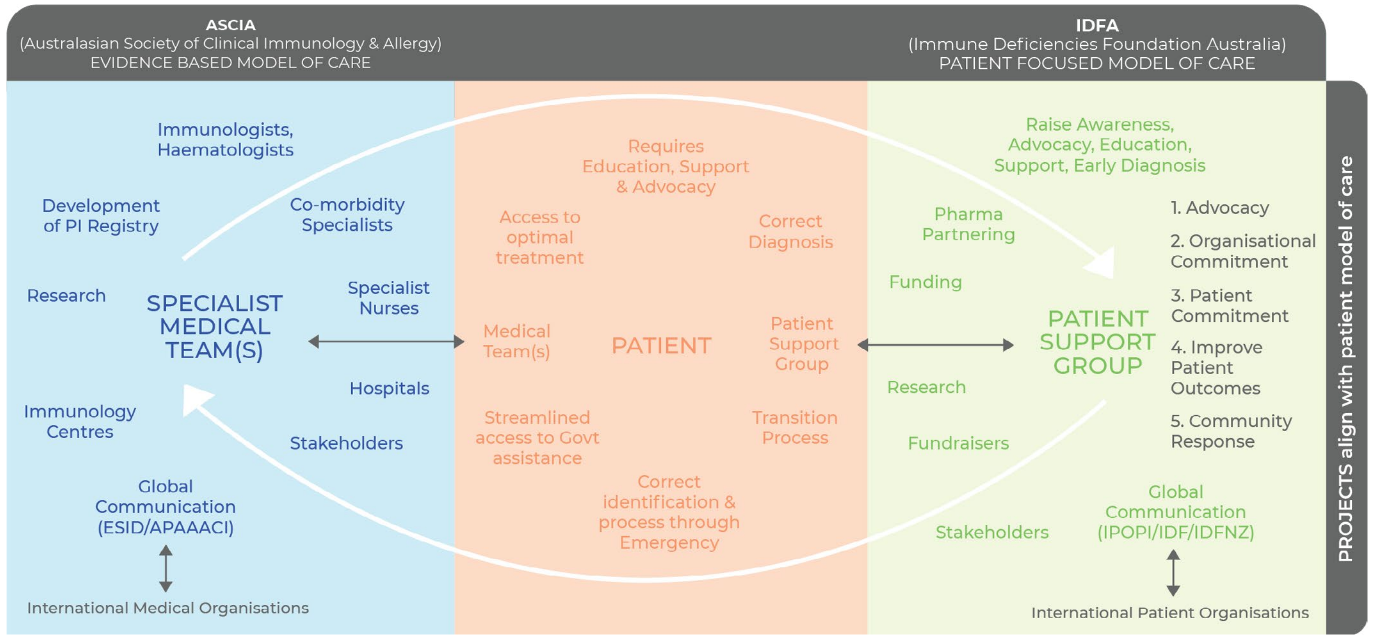
The Research Committee is focused on advancing research related to primary and secondary immunodeficiencies. The committee works collaboratively with researchers, healthcare professionals, and policymakers to support and promote research initiatives that improve patient outcomes and contribute to scientific advancements in the field.

Models of Care

Patient Focused Models of Care



Community Focused Models of Care



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 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 more than 550 inborn errors of immunity/primary immunodeficiencies in their 2024 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).

> 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.

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.

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.

Types of Ig Replacement Therapy

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.

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

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.

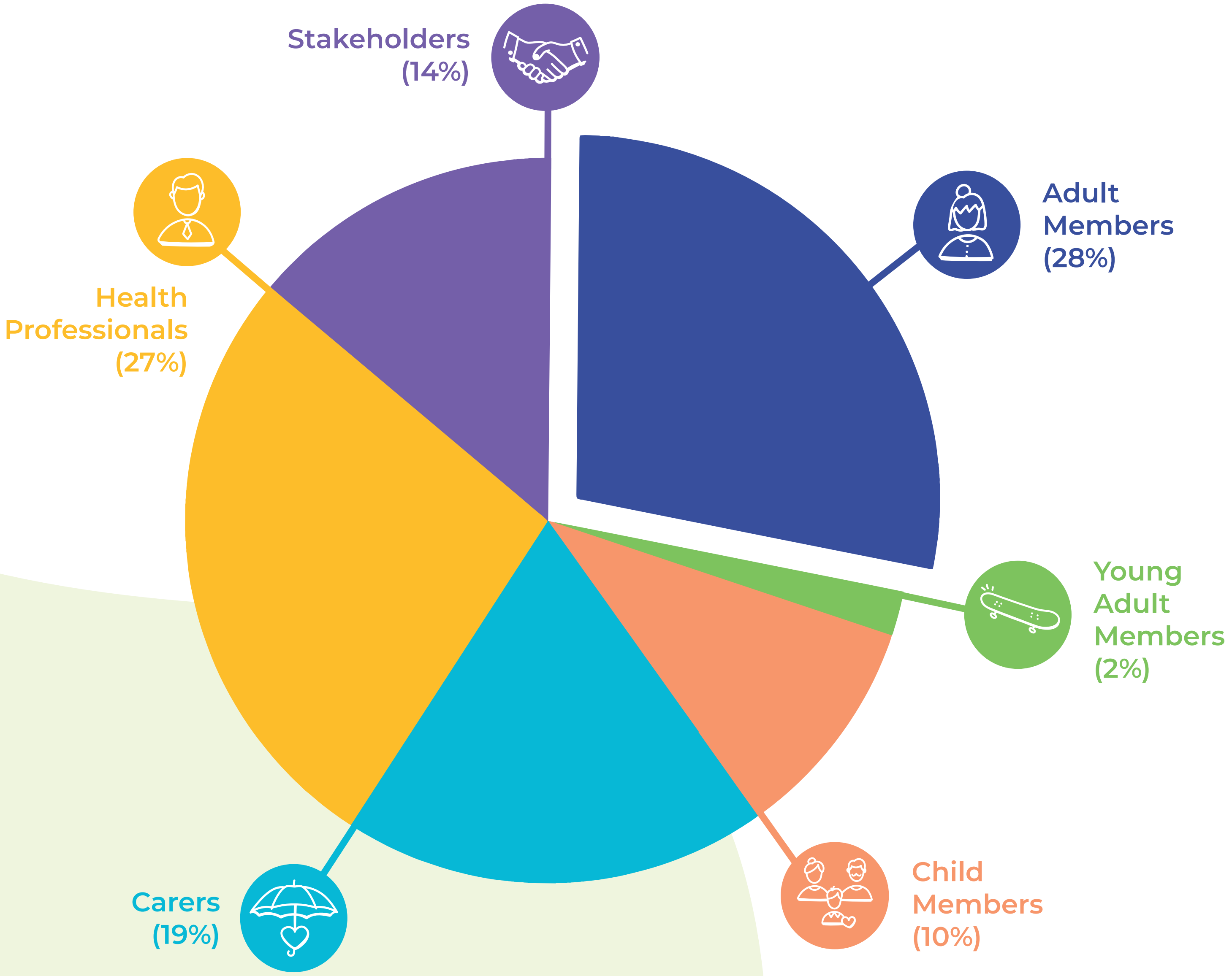
This year, we also refreshed how members are invited to get involved in the IDFA community. Alongside a streamlined onboarding process, we now highlight three flexible ways members can contribute: distributing resources, sharing their story, or connecting with others in the community. These pathways make it easy for members to participate in whatever way suits them best—whether that's raising awareness, offering support, or helping others feel seen, understood and less alone.

2,362
total members.

114
new members welcomed between 01/07/24 to 30/06/25.

IDFA have a range of membership options including:

- Adult Members
- Young Adult Members (aged 18-25)
- Child Members
- Carers
- Healthcare Professionals
- Stakeholders.



Volunteering with IDFA

At IDFA, our volunteers are at the heart of everything we do. From our Board of Directors to members hosting local coffee clubs, volunteers help us create meaningful impact for people living with immunodeficiencies across Australia.

Volunteering with IDFA is an opportunity to support education, advocacy and awareness—whether you're a patient, carer, friend or family member. It's also a way to connect with others who understand and contribute to change in the rare disease space.

The three ways to contribute that we highlight to our new members are:

- Distribute Resources
- Share Your Story
- Connect with Community.

Other volunteer opportunities at IDFA are: student placements, fundraising, facilitating member-led events, becoming a peer mentor and joining the board/advisory panels.

Distribute Resources

Getting IDFA's printed materials into clinics, hospitals and community spaces helps raise awareness of immunodeficiencies andconnects others to support. We send the packs—members help us share them in their networks.

Share Your Story

We invite members to share their lived experience to help others feel seen and heard. These stories are used in IDFA campaigns, media, and member events to raise awareness and spark connection.

Connect with Community

You can connect with the IDFA community through our conferences and meetups, online support groups and hosting member-led events like online Community Catchups, and our in-person IDFA Coffee Club.

Member Stories

Arlo

Child Member

Eight-year-old Arlo, diagnosed with the rare disorder Schimke Immuno-Osseous Dysplasia (SIOD), embodies resilience and joy. After losing his sister to the same condition, Arlo underwent a dual bone marrow and kidney transplant—both donated by his father. Supported by his devoted parents, Arlo continues to explore nature, ask questions about his health, and live each day to the fullest. His story highlights the power of advocacy, family, and finding strength in every moment.

Read Arlo's full story here:

Michelle

Adult Member

Diagnosed with Common Variable Immunodeficiency (CVID) at 57, Michelle, now 64, lives with resilience, creativity, and purpose. After a lifetime of unexplained illness and two battles with cancer, her diagnosis brought clarity and access to life-long treatment. Supported by her husband John, Michelle finds joy in photography, nature, and family. She now advocates for rare diseases, sharing her journey to raise awareness and remind others that hidden illnesses deserve recognition and understanding.

Read Michelle's full story here:

Austin

Child Member

Five-year-old Austin from Queensland lives a joyful life filled with outdoor adventures, despite his diagnosis of pan-hypogammaglobulinemia. After a delayed diagnosis, Austin now receives monthly IVIg infusions and faces medical challenges with bravery. His parents, Samantha and Trent, balance safety with a vibrant childhood. Through advocacy and support from IDFA, they've found community and strength. Austin's resilience continues to inspire, showing that even with adversity, childhood joy can thrive.

Read Austin's full story here:

Archie

Adult Member

After decades of unexplained illness, Archie was finally diagnosed at age 32 with Wiskott-Aldrich Syndrome (WAS), a rare primary immunodeficiency. The diagnosis came after a lifetime of health challenges, including ITP, lymphoma, and CVID. A successful stem cell transplant in 2021 changed his life. Now living in Sydney with his partner and children, Archie advocates for genomic testing and reminds others of the power of persistence, family, and hope.

Read Archie's full story here:

Steve

Adult Member

Steve, from Brisbane, was diagnosed with Common Variable Immunodeficiency (CVID) in 2021 after low immunoglobulin levels were detected through a plasma donation. Since then, he has embraced weekly SCIg treatment and continues to live fully—volunteering, travelling, and overcoming a needle phobia. Though cautious in crowds, Steve remains active, planning overseas trips and helping his community. His positive outlook and practical approach offer inspiration to others navigating life with primary immunodeficiency.

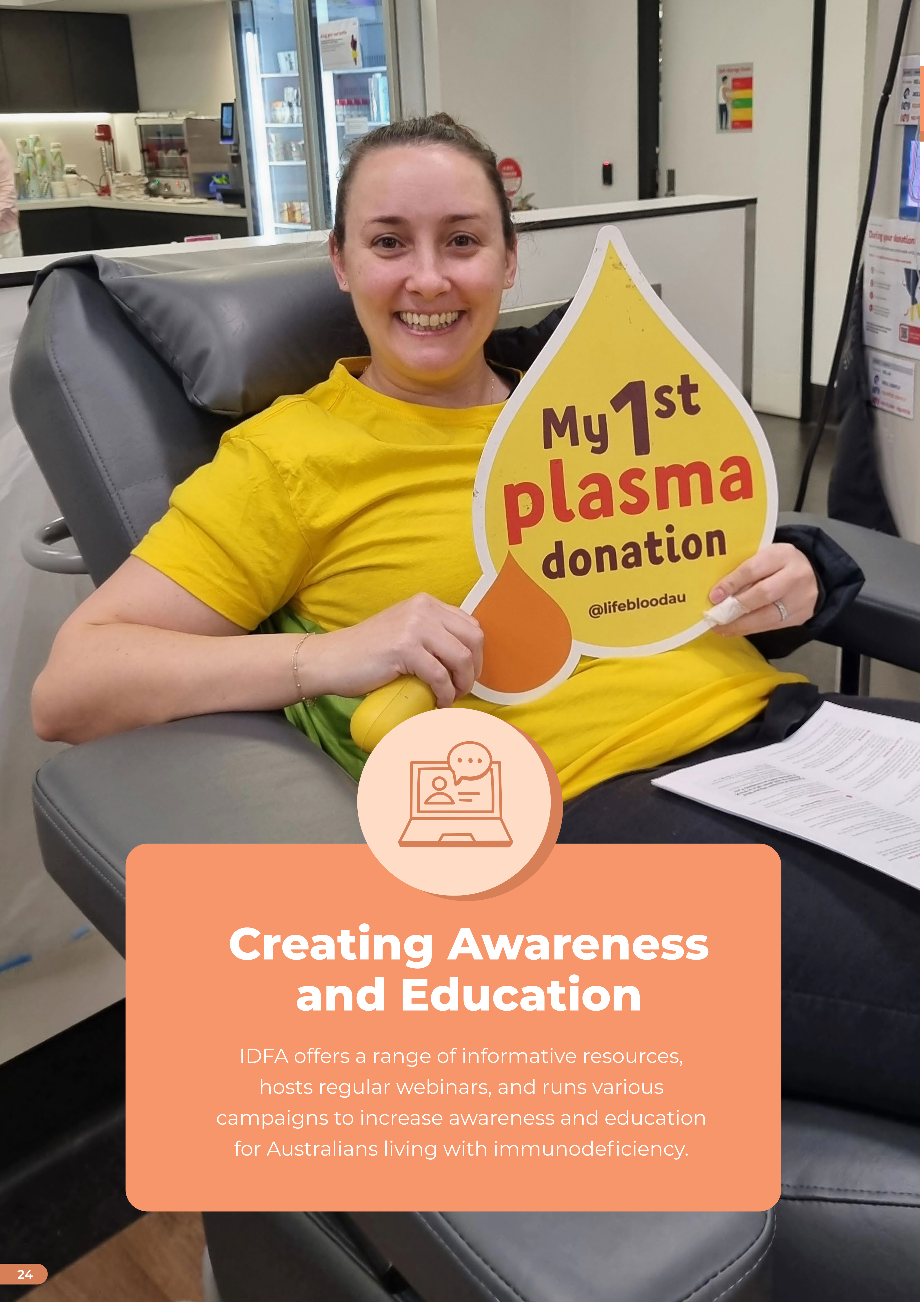
Read Steve's full story here:

Shaya

Carer Member

Shaya balances life as a paediatric intensive care nurse and carer for her young son, who lives with hypogammaglobulinemia and overlapping conditions including autism, ADHD, and EOE. Their days revolve around therapies, appointments, and managing frequent illness. Despite financial and emotional strain, Shaya finds strength in routines, family support, and the IDFA community. Her journey reflects resilience, advocacy, and the importance of connection—reminding others they don't have to walk this path alone.

Read Shaya'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

Connecting with Healthcare Settings

Ensuring that IDFA resources reach healthcare settings regularly accessed by patients with immunodeficiencies is a key part of our strategy to raise awareness and strengthen our member community.

To support this, we have developed a carefully curated IDFA Resource Pack, and a targeted outreach strategy aimed at healthcare professionals. These efforts help connect newly diagnosed individuals with the support, resources, and advocacy they need right from the start. Each IDFA Resource Pack contains:

- A welcome letter from IDFA outlining available support and resources
- 10 Warning Signs of Immunodeficiency poster (x1)
- Support group brochures (x3)
- IDFA overview brochures (x3)
- IDFA magnets

By placing these packs in clinical environments, we aim to ensure patients and their families are supported earlier in their journey and are empowered to connect with the IDFA community.

Current Projects Underway

Over the past year, IDFA has been developing three tailored resources to support individuals living with immunodeficiency. These include:

- Travelling with an Immunodeficiency
- Working with an Immunodeficiency
- A children's book designed for primary-aged children

Each resource is being developed in collaboration with IDFA members to ensure they reflect real-life experiences and needs. These important tools will be launched in the next financial year.

IPOPI Resources

IPOPI has continued to expand its library of educational resources to better support individuals living with immunodeficiencies and their healthcare providers. Newly developed materials include:

- Primary Immunodeficiencies, Fertility and Pregnancy
- Management of Primary HLH
- Management of Congenital Athymia
- Management of Hyper IgM Syndromes

These resources offer up-to-date, evidence-based information and aim to improve understanding, diagnosis, and care for people affected by rare and complex immunodeficiencies around the world.

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

Online Webinars

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

- **Lifestyle** – Tips For Living Well: Young Adults
- **Medical** – Update: Patient Perspectives on Immunodeficiencies
- **Medical** – Commemoration: SCID
- **Medical** – Update: SCIg Treatment
- **Lifestyle** – Tips For Living Well: Self Care
- **Practical** – Accessing Supports: NDIS and Non-NDIS (incl. NDIS review update)
- **Practical** – Re-Imagining Immunodeficiencies
- **Medical** – See the Unseen: The impact of Comorbidities on Immunodeficiencies

Immunodeficiency Insights Program

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 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.

516
member webinar registrations received.

330
number of webinar view/downloads in the past 12 months.

72%
of members rated the webinar content as 'Excellent'.

23
expert guest speakers presented on a range of topics.

52%
of webinar content was identified as 'new' to registrants.

IDFA Deep Dives

IDFA Deep Dives is our new digital content series designed to inform, inspire, and connect the immunodeficiency community.

Each episode takes a closer look at the issues that matter most to people living with immunodeficiencies. Featuring expert insights, timely commentary on emerging healthcare topics, and powerful personal stories from our members, Deep Dives brings education and awareness to the forefront—one meaningful conversation at a time.

Scan to explore the IDFA Deep Dives library, including Expert Series, Hot Topics, and IDFA Shorts.

Expert Series

The Expert Series features in-depth sessions led by key industry professionals, exploring complex topics like SCIg, diagnosis, and treatment options in a clear and accessible way. Each episode runs up to 30 minutes and provides valuable insights for both members and healthcare professionals.

Hot Topics

Hot Topics delivers fast, relevant commentary on emerging issues in the media that impact people living with immunodeficiencies. Designed to be timely and thought-provoking, these bite-sized episodes (up to 5 minutes) aim to position IDFA as a leading voice in the sector by responding to news and conversations as they unfold.

IDFA Shorts

IDFA Shorts are short, powerful stories from our members, offering a glimpse into real- life experiences with immunodeficiency. Each 2–4-minute video focuses on a specific theme — from IVIg treatment to "a day in the life" — giving voice to the personal challenges and triumphs that shape our community.

Rare Disease Day

Rare Disease Day 2025 was a powerful opportunity to amplify the voices of those living with immunodeficiencies and rare diseases. Through storytelling, social media engagement, and strategic outreach, IDFA successfully connected with the community, expanded its reach, and reinforced its advocacy efforts.

Key Highlights from the Campaign

"I Don't Feel Alone" Video: A Powerful Message
A key moment of the campaign was the "I Don't Feel Alone" video, featuring 10 members sharing their experiences. This in-house production resonated deeply, garnering 3.2K views, with 78% of viewers being non-followers, significantly expanding our reach. The video was shared 27 times, reinforcing the importance of connection within the rare disease community.

Campaign Heroes: Amplifying Voices
Three dedicated IDFA members became Campaign Heroes, each receiving a tailored pack containing educational resources and colouring competition entries. Their personal stories were further developed into a media release, spotlighting the realities of living with rare diseases. This initiative provided a platform for members to share their journeys and inspire others.

Creating Awareness in Schools
IDFA successfully engaged with Forbes Public School, which submitted over 100 entries into the competition. Given this strong participation, it was no surprise that the winner was from the school. As part of IDFA's ongoing awareness efforts, a school visit was organised to present the award and highlight Rare Diseases, with a specific focus on immunodeficiencies.

Scan the QR code to watch the Rare Disease Day "I Don't Feel Alone" video.

Strengthening Partnerships and Advocacy
Collaboration with partners expanded the campaign's reach:

- IDFA strengthened partnerships by joining the Sunflower Hidden Disability initiative and becoming a 'Friend' of Rare Disease Day.
- IDFA participated in Rare Voices Australia's parliamentary event, raising awareness at the national level.
- Strategic government outreach helped amplify awareness, with campaign materials shared with MPs to advocate for improved recognition and support for rare diseases.

8K
reach via social media campaign.

157
entries into the colouring competition.

15
Distribute Resource Kits sent out during campaign.

92
registrants for the Rare Disease Day Webinar: Re-Imagining Immunodeficiencies.

World PI Week

World Primary Immunodeficiency Week (World PI Week) 2025 was a powerful platform for IDFA to highlight the challenges faced by Australians living with primary immunodeficiencies (PID). Through digital engagement, media outreach, and community participation, the campaign successfully elevated awareness and encouraged national support for people living with this often-invisible condition.

Key Highlights from the Campaign

"Why PI" Video Series: Real Stories, Real Impact
A central feature of the campaign was the launch of the "Why PI" video series. Five members shared personal insights on why raising awareness of PI matters. The videos collectively achieved 4.9K views across social media, with 60% of views from non-followers, extending our reach beyond our usual audience. The videos were shared 61 times and generated nearly 200 interactions, demonstrating strong community engagement.

Stride for PI: Stepping Up for Awareness
The Stride for PI fundraiser invited members and supporters to walk in honour of those living with PI. Seven members pledged to walk in their communities, with a total of 350km walked (collectively) across Australia, and a dedicated fundraising page on GiveNow raised $1,233. A special community walk held in Wollongong attracted local media, amplifying awareness. Participants connected through a WhatsApp group to share stories and support each other throughout the campaign.

Media Coverage: National and Regional Reach
IDFA's media outreach efforts led to strong coverage across TV, radio, and online platforms, including WIN TV Illawarra, Wave FM, Pulse Illawarra, and Region Illawarra. These stories shared member experiences and promoted Stride for PI, helping increase recognition of PI as a hidden disability.

Scan the QR code to watch the World PI Week "Why PI" video.

Partnerships and Community Collaboration
Collaboration with partners expanded the campaign's reach:

- IDFA member Adam was featured in the international World PI Week campaign.
- ASCIA, RVA, and AusPIPS shared campaign content through emails and social media.
- ASCIA's newsletter led to a 1,500% increase in website traffic in one day.
- IDFA distributed branded Hidden Disability Sunflower lanyards to members as a gesture of thanks and awareness.

New Resources: Conversations Toolkit
IDFA launched a new "Conversations" resource to support members in talking about PI with healthcare providers, employers, family, and the wider community. This toolkit offered practical guidance for fostering understanding and confidence in everyday interactions.

Webinar Collaboration
In partnership with AusPIPS Inc., IDFA hosted a webinar exploring comorbidities and living with Primary Immunodeficiency. The session attracted 108 registrations and brought together both clinical perspectives and lived experiences.

5
campaign videos produced.

4.9k
video views, with 60% from non-followers.

108
webinar registrations.

61
shares and 198 interactions across social media.

$1,233
raised via Stride for PI.

7
member participants in Stride for PI.

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

IDFA teamed up with Australian Red Cross Lifeblood to host 'Plasma Parties' and 'meet and greets' across the county. IDFA appreciates and acknowledges it's members who attended and hosted events – Donna, Hayley, Nadia, Jenny, Tara, Anita, Victoria, Robyn, Dianna, Pearl, Kirsten, Domenica, Richard, Jenni and Steve.

Each event provided an opportunity to highlight immunodeficiency to the community and 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 events were festive, with yellow splashing across the centres, with the wonderful staff donning yellow attire, and a delightful treat for all to enjoy. IDFA is excited to continue this partnership and raise awareness for the need for plasma donations across the country year-round.

Members connected with donors in several locations across Australia for IPAW:

- Wollongong, NSW
- Perth, WA
- Newcastle, NSW
- Strathpine, QLD
- Mt Waverly, VIC
- Sydney CBD, NSW
- Brisbane, QLD
- Canberra, ACT

National Blood Donation Week

For National Blood Donation Week, IDFA launched its new Plasma Awareness campaign, which will continue throughout the remainder of 2025. This campaign aims to educate and empower the community about the critical need for plasma donations, particularly for those living with primary immunodeficiencies. As part of the launch, IDFA hosted a series of information sessions to inform members and encourage participation and collaboration in this important initiative. The campaign is proudly supported by Lifeblood Australia, whose partnership helps amplify the message and drive action across the country.

The Bloody Good Tour

IDFA partnered with Simmo from The Bloody Good Tour to shine a spotlight on the urgent need for plasma donations. Led by Simmo Braun — a passionate adventurer, father, and advocate for life — the tour is taking him to every Lifeblood donor centre across Australia, where he donates plasma (a vital blood component) every two weeks. His mission is to save 100,000 lives through blood donation while enhancing the well-being of recipients, their families, and donors. Along the way, Simmo has met with IDFA members in Canberra and Queensland, and IDFA looks forward to continuing this inspiring collaboration throughout his journey.

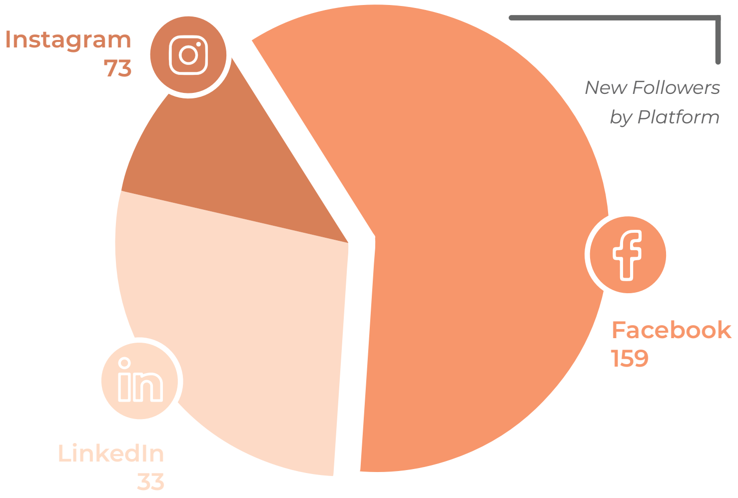
Digital Presence and Public Relations

Website

Over the past year, the website has undergone ongoing improvements to create a smoother and more accessible experience for visitors. One key update is the enhanced Publications page, which now includes additional content and improved access to resources. A new page has also been introduced to showcase the recently developed Deep Dives, along with dedicated landing pages for each of our major campaigns: Rare Disease Day, World PI Week, and Plasma Awareness.

Public Relations

Throughout the year, IDFA has received national media coverage, helping to elevate our profile and raise awareness of immunodeficiencies across Australia. For Rare Disease Day, The Forbes Advocate featured a local family's story alongside IDFA's community colouring competition. During World Primary Immunodeficiencies Week, WIN TV aired interviews with CEO Carolyn Dews and an IDFA member, spotlighting the Walk for PI held in April. International Plasma Awareness Week also attracted widespread media attention, with several outlets covering the collaborative Plasma Party hosted at the Wollongong Lifeblood Donor Centre. An IDFA member, Nicole, was also featured in a lengthy *Mamamia* article, highlighting the journey and impacts of an immunodeficiency.

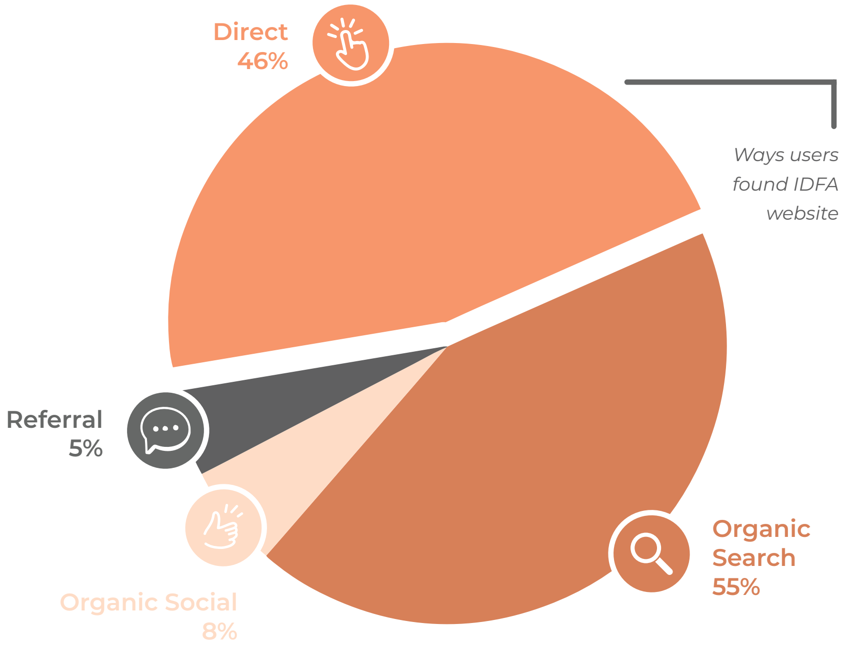


Social Media

2,020
Engagements on our private IDFA Facebook groups.

70,334
people reached via our online community.

3,005
followers on our online community (Facebook, Instagram, LinkedIn, YouTube).



Relationships

Member Organisations

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

AusPIPS Inc.

IDFA is collaborating with AusPIPS Inc. to advocate for improved access to subcutaneous immunoglobulin (SCIg) and to develop a national awareness campaign aimed at reaching and informing Australians affected by immunodeficiencies. Together, we are working to amplify patient voices, highlight treatment needs, and promote greater understanding of SCIg across the healthcare system and broader community.

Lifeblood

IDFA has been actively collaborating with Lifeblood to help increase plasma donor numbers and support research efforts through the Bloodlines project. This partnership aims to raise awareness of the critical need for plasma donations while contributing valuable insights to research that informs the future of care for people living with immunodeficiencies.

Government

IDFA continues to build positive working relationships with the government at all levels. 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 members were involved in providing input into the National Blood Authority (NBA) survey on the optimal uptake of subcutaneous immunoglobulin (SCIg) therapy. The final report contained a number of recommendations which were informed by the lived experiences of IDFA members and focused on ensuring equitable access, patient choice, and flexibility in treatment delivery. IDFA are working with NBA to ensure implementation of these recommendations.

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.

Building Community

At IDFA, our motto is "I Don't Feel Alone." We know that being diagnosed and living with an immunodeficiency can be challenging—so in 2024–2025, we focused on expanding accessible, member-led community spaces that support connection, shared experience, and emotional wellbeing. These new and evolving digital platforms give members more choice in how and where they connect—whether it's through a quick chat message, a video call, or simply being part of a group that understands.

IDFA's Online Communities

- **Online Community Catchups**
  Online Community Catchups are informal, member-led spaces where members can connect with others that understand what they're going through. Across the 2024-25 period, there were 28 online catchups.
- **IDFA Connect**
  Our largest member group, IDFA Connect, is a private and supportive space where members share experiences, ask questions, and connect with others. As of 30 June 2025, it proudly comprises 652 IDFA members and has regular online community catchups.
- **IDFA WhatsApp Community (new!)**
  To foster real-time connection, we launched the IDFA WhatsApp Community. This platform enables members to stay informed, chat casually, and discover relevant support groups in a quieter, less public setting—allowing for more private connections on their own terms.
- **IDFA Discord Servers (new!)**
  Recognising the unique needs of our younger members, we introduced two dedicated Discord servers in 2025—one tailored for Young Adult Members (16–28) and another for Adult Members (28+). These member-only, moderated spaces provide a laid-back, chat-based environment where members can hang out, share life experiences, and build connections.

IDFA's In-Person Coffee Club

There's something special about connecting face-to-face with people who just get it. That's why we introduced IDFA Coffee Club—an in-person catch-up series where members meet at a local café to sip, chat, and share life with others who understand what it's like living with an immunodeficiency or caring for someone who does.

We've made it easy: members choose the time and place, and we do the rest. IDFA promotes the event to nearby members and provides a $5 voucher to help cover the cost of a coffee or tea. This casual, low-pressure format is designed to grow, helping more members connect in their own communities, in their own way, and at a pace that works for them.

Scan the QR code to host your own Coffee Club catch-up!

28
online community catchups hosted.

652
members in our IDFA Connect community.

National Carers Week 2024

A Coffee for Our Carers and Film Night

In celebration of National Carers Week 2024, IDFA launched a heartfelt campaign to recognise and thank the carers in our community—those who provide vital, often invisible support to people living with immunodeficiencies. With a focus on gratitude, connection and inclusion, the initiative included a dual offering: a no-strings-attached coffee gift and a virtual film night designed to bring carers and families together.

As part of our "A Coffee for Our Carers" campaign, all carer members were invited to RSVP for a $5 coffee voucher as a small token of appreciation delivered to their inbox at the start of National Carers Week. This light-touch gesture aimed to connect with both engaged and previously unengaged carers in a warm, low-pressure way.

Alongside this, IDFA hosted an online Mini Film Festival on Thursday 17 October. The event featured a carefully curated line up of short films from Bus Stop Films, a pioneering inclusive production company. The evening included a segment from the powerful documentary Compromised: Life Without Immunity, along with heartfelt Bus Stop films such as Stairs, What Was It Like?, and Groundhog Night. The event was designed to be relaxed, accessible and to provide a space for carers and those they care for to unwind, connect and feel seen.

This year's campaign was made possible with the support of Carers Australia and exemplified IDFA's commitment to recognising the often-unseen work of carers and making meaningful, flexible contributions to their wellbeing and connection.

16
registrations to the film night.

20
members registered for the coffee voucher.

Circle of Support

This year marked a major milestone for the Circle of Support, IDFA's one-to-one peer mentoring program. Following a successful pilot phase, the program officially rolled out as a national offering—designed to connect members living with an immunodeficiency to trained Peer Mentors for emotional support, shared experience, and practical encouragement.

> To be able to help another member sort through what is important to them and set some simple goals and see them achieve them, is very rewarding.
>
> – Leigh VIC (Peer Mentor)

From Pilot to Program

Now in its first full year as a national program, Circle of Support continues to grow and evolve as a vital part of IDFA's commitment to holistic member wellbeing.

In 2024–2025, IDFA focused on consolidating and scaling the program to ensure consistent, high-quality support across the country. Ongoing member feedback informed continuous improvements to training, resources, and coordination processes.

Throughout the year, the program maintained its person-centred approach, offering Mentees up to 12 weeks of tailored support. With flexible connection options—such as phone, video or messaging—members can access support when and how they need it most.

As Circle of Support expands, its values remain unchanged: Connect. Empower. Support. With every new match, the program builds a stronger, more connected community—where no one has to navigate immunodeficiency alone.

Connect

Social support from someone who understands.

Empower

Coaching to build confidence and clarity.

Support

Mentoring to navigate health and life with an immunodeficiency.

Strengthening the Mentor Journey

In 2024–2025, we placed just as much focus on supporting Peer Mentors as the members they assist. To improve the onboarding experience and build mentor confidence, IDFA:

- Digitised our Self-Management of Immune Deficiencies (SMIDs) course.
- Refreshed the Peer Mentor Guide with clearer guidelines and resources.
- Refined the Mentoring Agreement to support safe, clear, and empowering relationships.

These changes give Peer Mentors the tools they need to feel supported, prepared, and confident in their role—ensuring a consistent, high-quality experience for both sides of the mentoring match.

> Often, we just need a shoulder of support if confused, a little frightened or needing reassurance. What's important is that members feel they have a safe space with someone who really understands.
>
> -Briana QLD (Peer Mentor)

Making Access Easier

This year, we simplified access to Circle of Support with a streamlined self-referral process. Members can now sign up online via a short expression of interest form.

We also provided clearer information about eligibility and what to expect, helping members feel confident and informed from the start.

These improvements are making it easier for more members to connect with the support they need, when they need it most.

Scan to the QR code to learn more or sign up for Circle of Support.

Driving Change: Advocacy

IDFA advocates and supports research 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 is now being tested for in every state and territory of Australia as of May 2024.

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
- University of Western Sydney
- IPOPI
- Lifeblood
- University of Adelaide
- University of NSW
- University of QLD
- University of Newcastle
- Garvan Institute
- Australian National University
- Murdoch Children's Research Institute
- Federation University

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.

Research Publications

IDFA were a research partner in 'Time to diagnosis for a rare disease: managing medical uncertainty', which was published in a qualitative study in *Orphanet Journal of Rare Diseases.*

Scan the QR code to read 'Time to diagnosis for a rare disease: managing medical uncertainty.'

Screening and Testing

Supporting SCID Families—Then, Now and Always

Severe Combined Immunodeficiency (SCID) is a life-threatening genetic condition where babies cannot fight even simple infections. Without timely treatment, most affected children do not survive past age two.

Since 2018, IDFA has worked alongside parents, carers, and healthcare professionals to raise awareness and advocate for universal SCID newborn screening in Australia. After years of collective effort—and support from partners including Rare Voices Australia and AusPIPS Inc.—universal SCID newborn screening became a reality in May 2024, giving all Australian babies the chance for early diagnosis and life-saving treatment.

We thank every advocate, health professional, and organisation who helped make this milestone possible. Your voices have changed lives—and will continue to do so for generations to come.

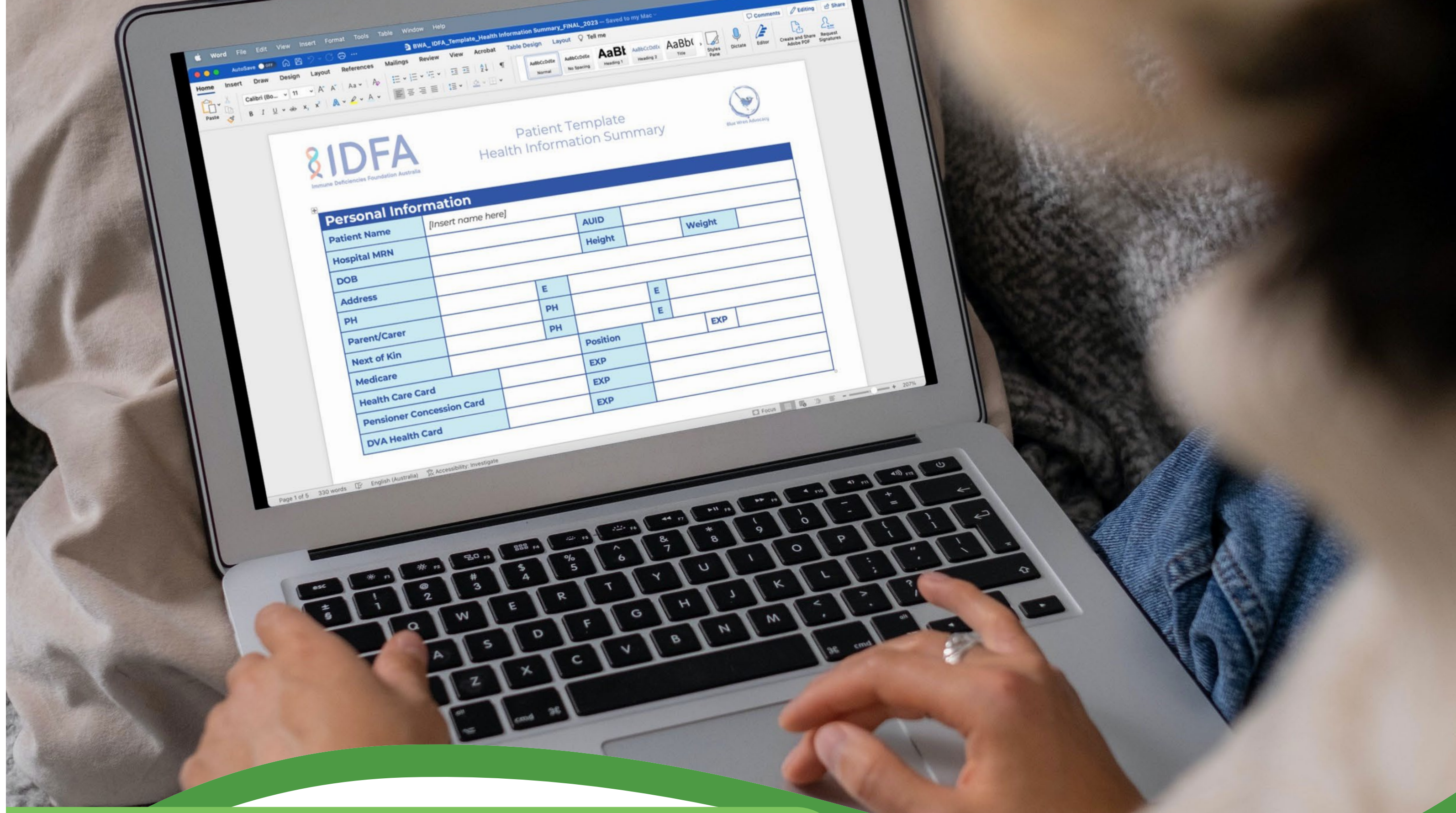
To read more about our SCID NBS advocacy, scan the QR code.

> **“For those who can’t imagine what the future looks like right now—trust me when I say, it’s a marathon. Harrison, with all of the complications of ADA-SCID and Retinitis Pigmentosa (being legally blind)… has a job at Coles as a checkout operator. As a parent of a medically unwell child… it can feel impossible to picture them as a teenager with their first job. But it’s not impossible. They grow, they become their own person… and with the right supports and employer, they can find meaningful work.”**
>
> **- Tracey, SCID Carer**

Ongoing Support with SCID Connect

IDFA continues to support families through SCID Connect, a dedicated space for parents and carers at any stage of their SCID journey—from diagnosis to treatment and beyond.

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



Self-Advocacy Toolkit

Self-Advocacy 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.

> **“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*

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.

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

Share Your Story

Every Story Matters —Including Yours

Sharing your story isn't just about raising awareness—it's also a powerful way to reflect, heal, and connect. Every IDFA member has a unique experience, and telling your story can be just as impactful for you as it is for those who hear it.

By taking the time to share your journey, you're giving voice to the real-life challenges and triumphs of living with an immunodeficiency. You're also helping others feel seen, understood, and inspired—while building a stronger, more connected IDFA community.

The process is simple and personal. All it takes is a 30-minute phone conversation with a member of the IDFA team. We'll guide you through the conversation, asking questions that help shape your experience into a meaningful story.

Once completed, your story may be featured on IDFA's website, social media, or shared through media partnerships and awareness campaigns—especially around key moments like Rare Disease Day. But most importantly, it becomes a lasting contribution to a growing community of voices.

Ready to share your story? Scan the QR Code to get Started.

Professional Networks

International Networks

ESID
IDF Immune Deficiency Foundation
INGID International Nursing Group for Immunodeficiencies
IPOPI International Patient Organisation for Primary Immunodeficiencies
jm Jeffrey Modell Foundation
PPTA Plasma Protein Therapeutics Association
World Health Organization

National Networks

ARRC Autoimmune Resource & Research Centre
ascia australasian society of clinical immunology and allergy
CHF
Garvan Institute of Medical Research
genetic alliance australia
HAE Australasia hope • advocacy • education Australasian Patient Organisation for Hereditary Angioedema
healthdirect Australia
National Blood Authority Australia
NPS
PANDIS
rare voices Australia
Walter+Eliza Hall Institute of Medical Research Discoveries for Humanity

Other Networks

- Alike WA
- Allergy and Immunology Foundation Australasia
- Arthritis Australia
- AusPIPS
- Australian Immunological Alliance
- Australian Institute of For-Purpose Leaders
- 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
- CamRARE
- CaPPRe
- Cancer Council
- Carers Australia
- Carers NSW
- Centre for Personalised Immunology
- Centrelink
- CIRCA
- Continuity of Care Alliance
- Federation University
- GUARD Collective
- Genetic
- Genetic Alliance
- Genetic and Rare Disease Network
- Genetic Support Network of Victoria
- GSVN
- Haemophilia Society Australia New Zealand
- Hidden Disability Sunflower
- The HyperIgM Foundation
- Illawarra Women in Business
- Immune Deficiency Foundation New Zealand
- Immune Deficiency Foundation USA
- Leukaemia Foundation
- Lifeblood
- Livewire
- Lung Foundation Australia
- Lymphoma Australia
- Mastocytosis Australasia
- Medicines Australia
- Mind Spot
- Ministry of Health NSW
- Monash University
- Missing Schools
- Miracle Babies Foundation
- Murdoch Children's Research Institute
- National Disability Insurance Agency
- National Immunoglobulin Advisory Committee
- National Patient Organisation Network
- Outer West Local Health District
- Patient Voice Initiative
- Safer Air
- Shoalhaven Business Chamber
- Sleep Health Foundation
- Thalassaemia Society of NSW
- University of Adelaide
- University of Newcastle
- University of NSW
- University of Sydney
- University of Western Sydney
- University of Wollongong
- University of QLD
- Volunteers Australia
- Queensland Genomics

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 and World PI Week
- Online support groups
- Online events including webinars
- Website updates
- Communications.

Thank you to all of our major sponsors:

CSL Behring
Biotherapies for Life™

Takeda

GRIFOLS

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

WA
Perth
Kalgoorlie

VIC
Bendigo
Melbourne
Mildura

TAS
Burnie
Devonport
Hobart
Launceston

QLD
Brisbane
Cairns
Mackay
Toowoomba
Townsville

ACT
Canberra

SA
Adelaide

To purchase our merchandise, scan the QR code.

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

Tote Bag
$20

Awareness Pin
$7

IDFA Pen
$5

Donations and Fundraising

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

Donations

Your contribution helps us provide meaningful support to individuals living with immunodeficiencies. Donations enable us to:

- Deliver resource packs to members across Australia
- Facilitate participation in patient education and peer support events
- Develop and distribute essential information materials
- Provide opportunities for children with immunodeficiencies to connect and engage
- Make national conferences and community events more accessible
- Support members in travelling to and attending key IDFA programs.

You can support IDFA to provide essential information and services to its members by donating through our website.

Donate today and help IDFA provide vital information and services to our members.

$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.

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

Volunteers

IDFA is grateful for all current and past volunteers who have helped them get to where they are today. Volunteers can support IDFA in many ways, including as peer mentors, event helpers, webinar presenters, or by joining panels or the board.

IDFA Board Members

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

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
- Dr. Hayley Teasdale
- Jenny Tyrrell
- Bianca Willis
- Luke Kavenagh

Healthcare Professional Panel Members

- Dr. Alisa Kane (Chair)
- Dr. Theresa Cole
- Rachel Dunn
- Geraldine Dunne
- Dianne Edwards
- Dr. Nina Estrella-Yuson
- Dr. Paul Gray
- Amanda Jackson
- Dr. Jovanka King
- Rebecca Macintosh
- Dr. Peter McNaughton
- Dr. Sam Mehr
- Kathryn Nicholson-Perry
- Dr. Phillipa Pucar
- Dr. Katrina Randall
- Dr. Carolina Sandler
- Anna Sullivan
- Professor Stuart Tangye
- Dr. Melanie Wong

Medical Advisory Panel Members

- Dr. Melanie Wong (Chair)
- Dr. Samar Ojaimi
- Geraldine Dunne
- Anna Sullivan

Students

- Kyra Jones
- Tessa Blayney
- Lucy Stiles
- Moshtaba Gheyasi
- Rahim Kamara
- Mohtashin Nahar Munni
- Nadia Moore
- Bianca Mathews
- Sasha Mason Holloway

Presenters/Speakers who contributed to IDFA

- Alex Boussioutas
- Alison Copely
- Associate Professor Elissa Deenick
- Briana Corry
- Damian Scott
- Dr. Luke Droney
- Dr. Melanie Wong
- Dr. Sara Yusef
- Dr. Alisa Kane
- Dr. Theresa Cole
- Emily Edwards
- Imogen Abba
- Janet Burke
- Javeria Ahmad
- Jenny Tyrrell
- Jess Cragg
- Kimmy Brooks
- Lauren Vanstone
- Beccy Vanstone
- Leticia Grant
- Louise Grant
- Louise Healy
- Lyn Barker
- Mandy Drain
- Michael Gavan
- Rachael Dunn
- Richard Hessian
- Sarah Pitman
- Shayne Logue
- Tanielle Stackman
- Thomas Dyne
- Wendy Hill

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

Financials

Statement of Profit or Loss and other comprehensive income

	2025	2024
IE Income	$1,839,629	$1,937,349
Cost of Sales	($1,540,976)	($1,602,560)
Gross Profit	$298,653	$334,789
Finance Income	$7,003	$1,190
Other Income	$215,190	$226,390
Marketing Expenses	($7,081)	($6,851)
Administrative Expenses	($426,998)	($419,745)
Functions, Awards and Presentations	($10,838)	($57,014)
Peer Support Program	($1,392)	($8,231)
Other Expenses	($56,249)	($62,151)
Finance Expenses	($1,402)	($6,636)
Profit before income tax	$16,886	$1,741
Income Tax Expense	-	-
Profit from continuing operations	$16,886	$1,741
Profit for the year	$16,886	$1,741
Other comprehensive income, net of income tax	$16,886	$1,741
Total comprehensive income for the year	$16,886	$1,741

Statement of Financial Position

ASSETS	**2025**	**2024**
Current Assets		
Cash and Cash Equivalents	$340,049	$366,679
Other Assets	$61,889	$16,871
Total Current Assets	$401,938	$383,550
Non-Current Assets		
Property, Plant and Equipment	$11,233	$11,504
Intangible Assets	$3,428	$8,018
Right-of-use Assets	$7,516	$90,473
Total Non-Current Assets	$22,177	$109,995
Total Assets	$424,115	$493,545
LIABILITIES	**2025**	**2024**
Current Liabilities		
Trade and Other Payables	$27,051	$30,661
Lease Liabilities	$9,909	$18,087
Employee Benefits	$13,902	$22,174
Total Current Liabilities	$50,862	$70,922
Non-Current Liabilities		
Lease Liabilities	-	$78,999
Employee Benefits	$12,743	-
Total Non-Current Liabilities	$12,743	$78,999
Total Liabilities	$63,605	$149,921
Net Assets	$360,510	$343,624
EQUITY	**2025**	**2024**
Retained Earnings	$360,510	$343,624
Total Equity	$360,510	$343,624

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.

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