



Years of Community, Support and Advocacy

2025 - 2026

Annual Report

I Don't Feel Alone

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

It is my pleasure, on behalf of the Board of Directors, to present the IDFA Annual Report for 2025/2026. This year marks a significant milestone as IDFA celebrates its 20th Anniversary. It is a time to reflect on how far we have come and to celebrate the remarkable community that has grown from a shared belief; that no one should have to face immunodeficiency alone.

What began in 2005 as a small group of determined advocates has grown into a respected national organisation dedicated to connecting, educating, advocating for and supporting Australians living with immunodeficiency. Our founders understood the isolation, uncertainty and challenges experienced by individuals and families, and they were determined to create a stronger network of support. While our programs, partnerships and reach have expanded over the past two decades, our purpose has remained constant.

Throughout the past year, the Board has remained focused on delivering IDFA's Strategic Priorities. Guided by our vision of a future where primary and secondary immunodeficiency are diagnosed and treated early, with affected people supported by clinicians, community and government to enable optimal quality of life, we have continued to strengthen our work in education, advocacy and community support.

I am pleased that IDFA remains in a strong financial position, enabling us to continue investing in education, advocacy, support services and research partnerships while building a sustainable foundation for the future. This positive result reflects the careful stewardship of the Board, CEO and staff, and ensures we are well placed to continue delivering meaningful impact for the immunodeficiency community.

When I reflect on the year, it is the people who stand out most. Our members, who generously share their experiences to help others; our carers, whose quiet strength and unwavering support are so often unseen; our clinicians and researchers, whose expertise and compassion continue to improve lives; and our dedicated staff, volunteers, partners and supporters, whose commitment transforms ideas into meaningful action.

One of the year's highlights was celebrating IDFA's 20th Anniversary in Sydney. Bringing together members, families, clinicians and supporters was a powerful reminder that connection remains at the heart of everything we do. It demonstrated the strength of our community and the lasting relationships, understanding and hope that IDFA helps foster.

“While our programs, partnerships and reach have expanded over the past two decades, our purpose has remained constant.”

On behalf of the Board, I extend my sincere thanks to everyone who has contributed to IDFA over the past twenty years. Your passion, generosity and commitment have shaped the organisation we are today. As we celebrate this important milestone, we also look ahead with confidence and determination, continuing to build a future where every person affected by immunodeficiency feels seen, supported, empowered and never alone.

- Louise Grant.



Message from CEO

This year has been one of growth, collaboration, and impact. Together with our members, healthcare professionals, researchers, volunteers, partners, and supporters, we strengthened our advocacy, expanded educational resources, and increased opportunities for people to connect with others who understand the unique challenges of living with an immunodeficiency.

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.

As we move forward, IDFA will continue to focus on consolidation, 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.

As we reflect on the past year, I am filled with gratitude for the extraordinary resilience, generosity, and commitment of our community. The Immune Deficiencies Foundation Australia exists to improve the lives of people living with primary and secondary immunodeficiencies, and throughout 2026 we continued to make meaningful progress toward that purpose.

None of this would be possible without the dedication of our volunteers, the generosity of our donors and corporate partners, and the expertise of our Board and staff. Your passion and commitment enable us to deliver programs and services that make a real difference in people's lives. On behalf of the Foundation, I extend my sincere thanks for your continued support.

Most importantly, I want to acknowledge the courage and determination of every person living with an immunodeficiency, and the families and carers who stand beside them. You are the reason we do what we do. Your experiences continue to shape our priorities and inspire us to advocate for better care, greater awareness, and stronger support.

We will continue to champion equitable care, support research, strengthen education, and ensure everyone affected by immunodeficiency feels seen, heard, and supported.

Together, we are creating a future where earlier diagnosis, better treatments, and improved quality of life are within reach for all. Thank you for being part of this journey.

- Carolyn Dews.



Key Highlights

2024-25 FY at a glance



Members

104

new members
joined IDFA.

2,483

total
members.



Fundraising

\$26,729.56

raised through member-initiated
community fundraising campaigns.



Public Relations

24

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



Resources

252

Resource Downloads from the
IDFA Website



Webinars

6

Immunodeficiency Insights Webinars
were held on a range of topics
including SClg advocacy, genetics,
and mental health.

.....

19

expert guest speakers presented on a
range of topics.

.....

378

member registrations received for
the Immunodeficiency Insights
Webinar program



Online Community

3,297

followers of the IDFA
online community
(10% increase since
last FY)

63,488

people reached
via our online
community.

1,434

Engagements on
our private IDFA
Facebook groups

11,261

users visited the
IDFA Website



Partnered with Lifeblood Australia to host **11 Plasma Parties** across the country, around International Plasma Awareness Week.



Impactful **Rare Disease Day Campaign**, with a **9K reach** via social media campaign.



\$1,077 raised during the End of Financial Year Appeal.



Celebrated **IDFA's 20th Anniversary**, bringing together 100+ members, supporters, healthcare professionals and partners on Rare Disease Day.



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

Strategic Plan

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
- Finance, Risk and Audit Committee

Our organisation is in a strong position, and we remain committed to understanding and responding to the evolving needs of our members. Through the delivery of high-quality education, meaningful support programs, and opportunities for connection, we will continue to strengthen a highly engaged and informed community of people living with immunodeficiency.

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



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



Creating Awareness and Education

Patients and Carers

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

Government

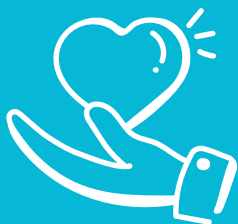
- Engagement
- Representations to MP's
- Funded Projects

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).

In 2026, IDFA commemorated 20 years of supporting individuals and families affected by immunodeficiency through advocacy, education and community.

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

Staff Appointments

Hannah McKay - Program and Events Coordinator:

We are pleased to welcome Hannah to the team in the role of Program and Events Coordinator. Hannah will focus on delivering engaging, high-quality events for IDFA members and fostering IDFA programs and fundraising that supports and gives back to our community.

Staff Resignations

We extend our sincere thanks to both Krystal Krizanovic (Fundraising and Events Coordinator) and Maree Thomson (Community Engagement Coordinator) for their valued contributions to IDFA.

Although Krystal was with the organisation for a relatively short time, her coordination of webinars and event management for IDFA's 20th Anniversary celebrations played a significant role in the event's success.

During their more than three years with IDFA, Maree made a meaningful contribution to member engagement, introducing initiatives such as the IDFA Coffee Club and leading the digitisation of the Circle of Support course and membership onboarding.

We are grateful to both Krystal and Maree for their dedication, collaboration, and commitment during their time with IDFA, and we wish them every success in their future endeavours.



Board Appointments

We are delighted to welcome Baden Marino-Hall as a new member of the Board. His expertise and commitment will be invaluable as we continue to grow and strengthen our organisation.

Board Resignations

We wish to thank Geraldine Dunne and Pearl Sims for their dedicated service and significant contributions as members of the IDFA Board over the years.





Our Team



Carolyn Dews

Chief Executive Officer



Danae Pikkat

Marketing and Communications Coordinator



Andriana Epistithiou

Finance and Administration Coordinator



Hannah McKay

Program and Events Coordinator



Maree Thomson

Community Engagement Coordinator



Alex Zappas

Graphic Designer



Our Board



Louise Grant

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



Javeria Khan

National Patient
Advisory Panel



Dr Alisa Kane

Healthcare Professional
Panel Chair | Research
Committee



Sap Chatterjee

Finance, Risk and
Audit Committee



Dr. Hayley Teasdale

National Patient
Advisory Panel Deputy
Chair | Research Committee



Anastasia Cauchois

Philanthropic and
Fundraising Committee



Dr. Natasha Moseley

Medical Advisory
Panel



Roslyn Chataway

Philanthropic and
Fundraising Committee



Anna Sullivan

Healthcare Professional
Panel



Baden Marino-Hall

Finance, Risk and Audit
Committee | Philanthropic
and Fundraising Committee



Geraldine Dunne

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.

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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
- Member Group – Immune Dysregulation

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 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.

Philanthropic and Fundraising Committee

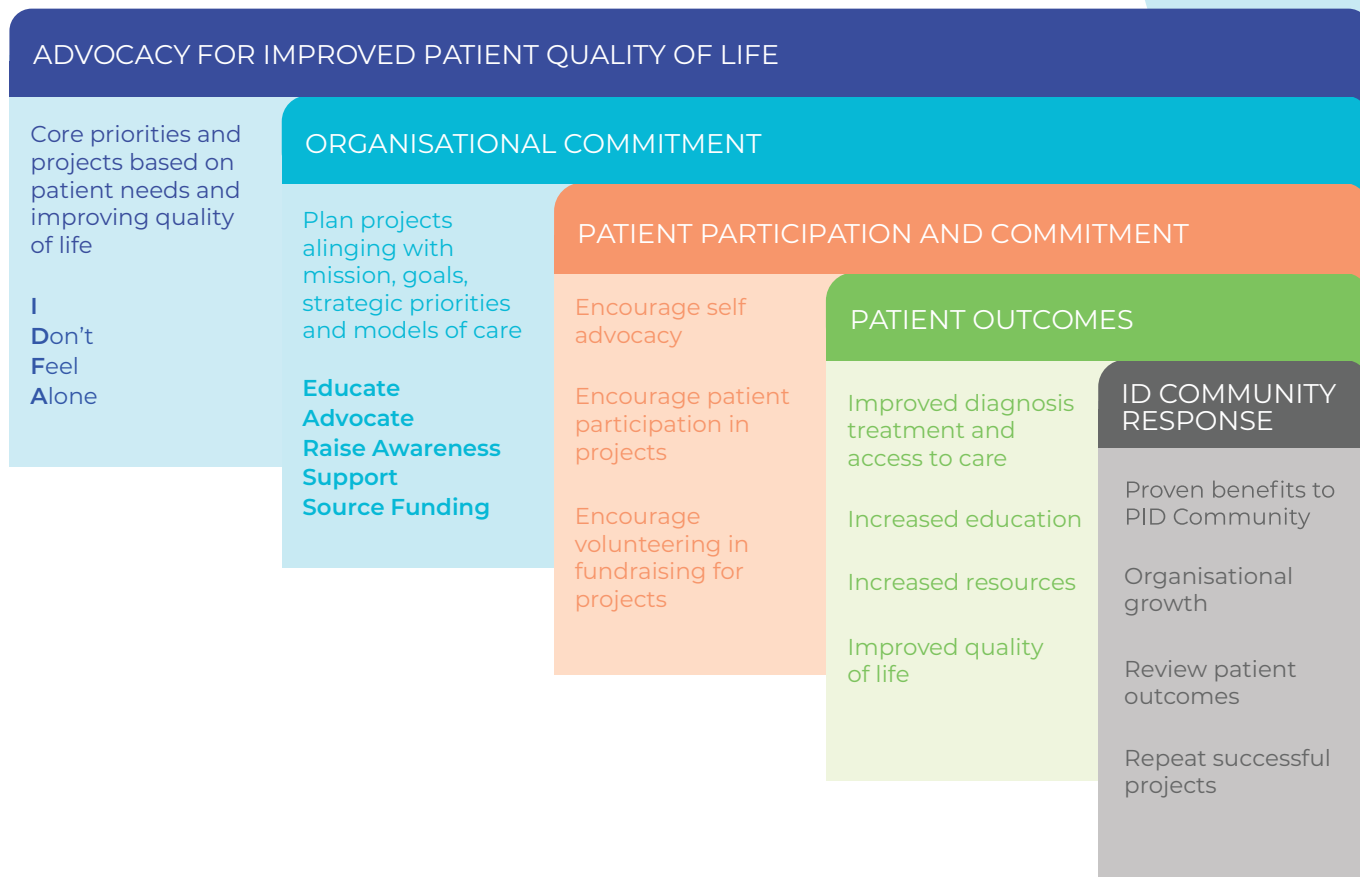
The Philanthropic and Fundraising Committee is a dedicated body within IDFA focused on fundraising initiatives and awareness campaigns which benefit IDFA members living with primary and secondary immunodeficiencies.

Research Committee

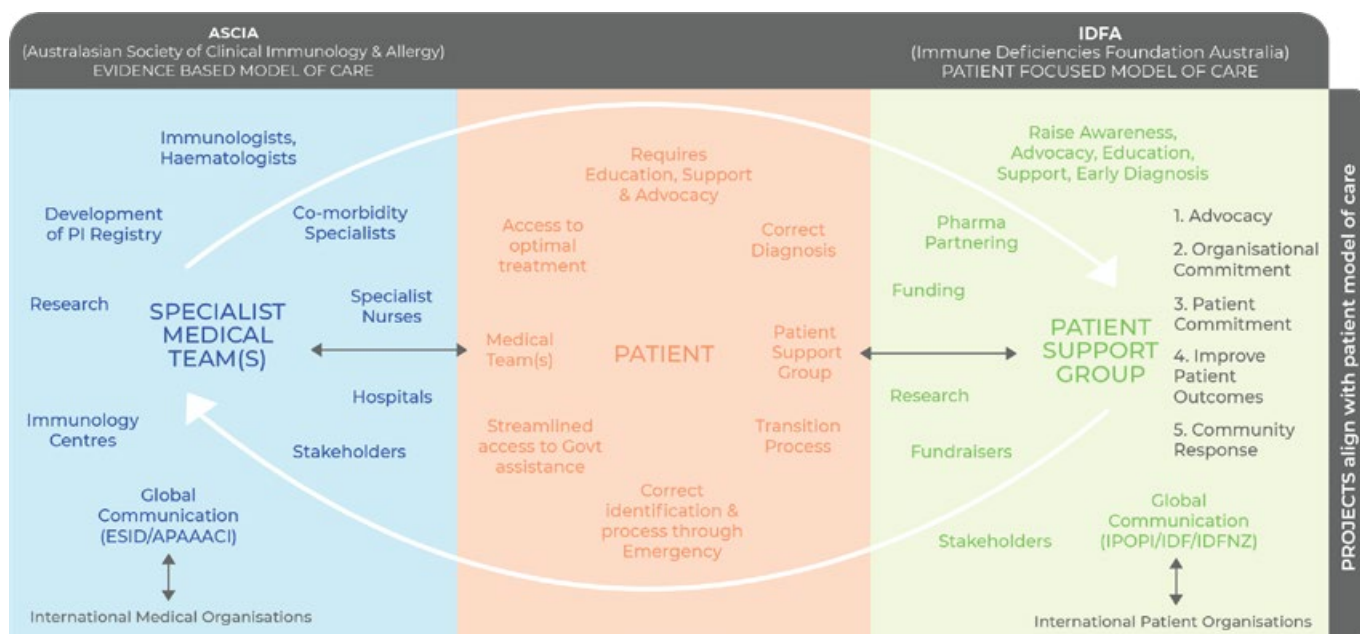
The Research Committee is a dedicated body within IDFA focused on advancing research related to primary and secondary immunodeficiencies. The committee works collaboratively with researchers, healthcare professionals, and policymakers to support and promote research initiatives that improve patient outcomes 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 recognize 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 with and living with an immunodeficiency is something that can greatly affect quality of life and well-being. At IDFA, we think there's no need to tackle that alone

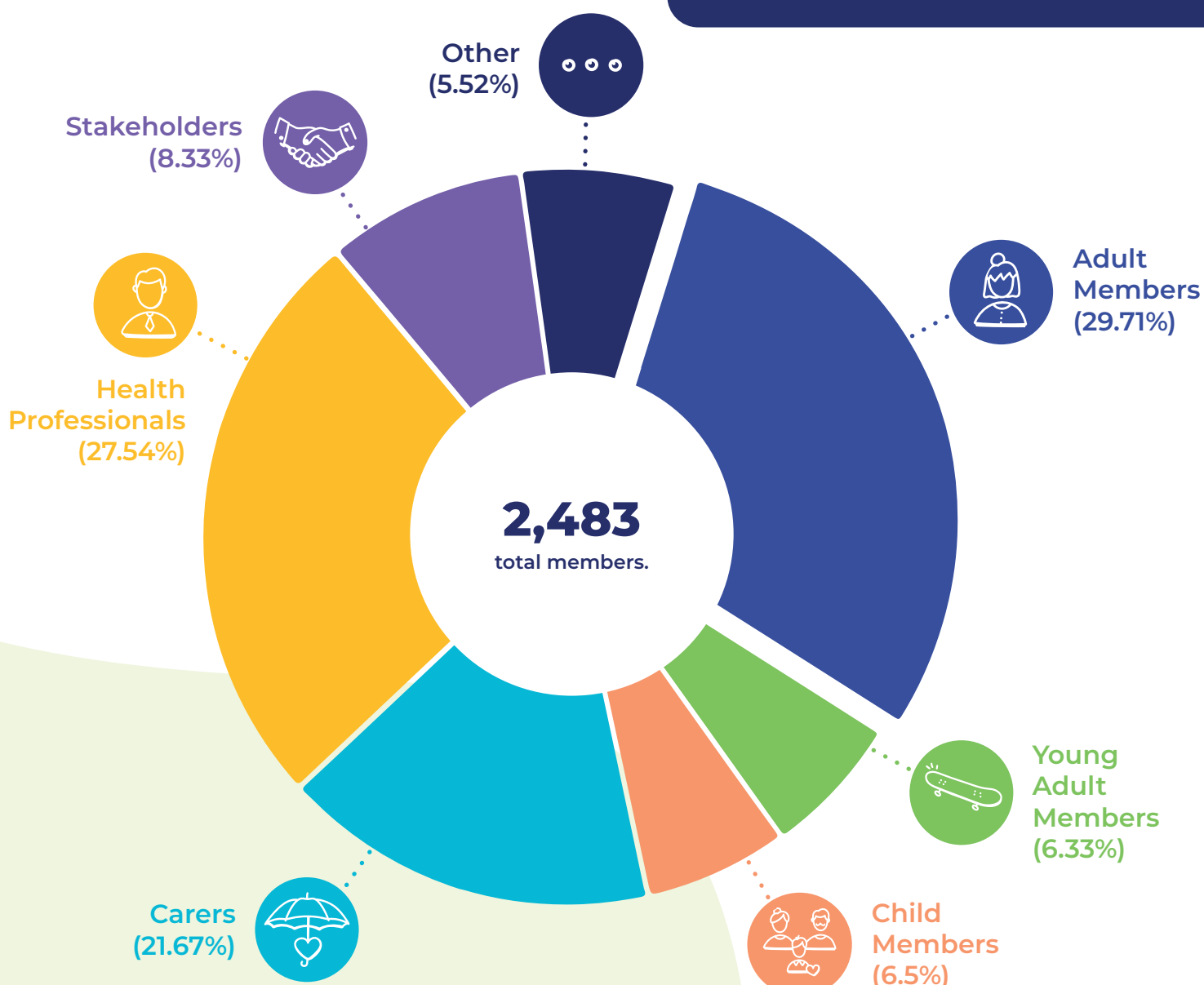
We provide our members with a range of ways to connect with other members and to access up-to-date information and educational resources.

This year, our membership applications underwent significant updates, with new information added, as well as carer forms now linked to child applications, for a more streamlined entry to becoming a member.

This year we welcomed
104 new members between
01/07/25 to 30/06/26.

IDFA have a range of membership options including:

- Adult Members
- Young Adult Members (aged 18-25)
- Child Members
- Carers
- Healthcare Professionals
- Stakeholders
- Other (volunteers, family members)





Volunteering with IDFA

At IDFA, our volunteers are at the heart of everything we do. From our Board of Directors to members hosting local catchups, 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.

This year, we streamlined how our members can contribute, by providing flexible, accessible ways for members to get involved in whatever way suits them best. The three ways to contribute that we highlight to our new members are:

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

We would like to thank all of our volunteers for their time and efforts and for the contribution that each of you make to the IDFA community.

Distribute Resources

Getting IDFA's printed materials into clinics, hospitals and community spaces helps raise awareness of immunodeficiencies and connects 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.





IDFA Celebrates 20 Years

On Rare Disease Day (28 February 2026), IDFA proudly celebrated 20 years of supporting Australians living with immunodeficiencies. More than 100 members, supporters, healthcare professionals and partners came together to reflect on two decades of advocacy, education, connection and community.

The milestone event featured a range of memorable activities, including a 20-year timeline showcasing IDFA's journey, a commemorative video highlighting our impact, the launch of *What Does Brave Feel Like?*—IDFA's children's book—and interactive breakout

sessions designed to foster learning, discussion and connection. Throughout the day, members had the opportunity to engage with healthcare professionals, hear inspiring stories, reconnect with familiar faces and meet others who truly understand the lived experience of immunodeficiency.

A key priority for IDFA was ensuring the event was as accessible as possible. Thanks to the generous support of our sponsors, IDFA was able to subsidise attendance costs for members, helping reduce financial barriers and enabling people from across Australia to take part in this significant milestone.

For many attendees, it was a rare opportunity to meet others living with immunodeficiencies in person, reinforcing the importance of creating spaces where individuals and families can connect, share experiences and realise they are not alone.

**A celebration
of two decades
of advocacy,
education,
connection and
community.**

The event not only celebrated IDFA's achievements over the past two decades but also reaffirmed the strength, resilience and generosity of our community as we look towards the future.



The celebrations continued into the evening with a special anniversary dinner overlooking the airport runway at Rydges Sydney Airport. Guests enjoyed an evening of conversation, laughter and reflection, with lucky door prizes, entertainment and a photo booth adding to the festivities. The dinner provided a relaxed and welcoming environment for members, health-care professionals and partners to strengthen existing relationships and build new ones—an important reminder that connection remains at the heart of everything IDFA does.

This milestone celebration would not have been possible without the generous support of our sponsors: Takeda, Grifols, Jeffrey Modell Foundation, McGrath Toowoomba, IPOPI and Print Media.

We also extend our sincere thanks to our event partners and suppliers, including Rydges Sydney Airport, Mark Newsham Photography, Sticky Lollies, nofilterphotobooth, Fab Fun Entertainment, Cakes2U and Guestpix, whose contributions helped make this celebration a memorable occasion for our community.



Feedback from attendees was overwhelmingly positive, with many highlighting the networking opportunities, 20-year video, timeline display and evening celebration as standout moments. The event not only celebrated IDFA's achievements over the past two decades but also reaffirmed the strength, resilience and generosity of our community as we look towards the future.

100+

**members, HCPs and partners
came together to celebrate
IDFA's 20th Anniversary.**





Member Stories



Thomas
Young Adult Member

Thomas spent much of his childhood battling infections before being diagnosed with Common Variable Immunodeficiency (CVID) after years of unanswered questions. Although delayed treatment led to bronchiectasis, weekly SCIg therapy improved his health. Despite challenges and fatigue, Thomas continues to study, volunteer with the Rural Fire Service, and support the immunodeficiency community, focusing on what he can achieve and encouraging others to stay positive.

*Read Thomas's
full story here:*



Kimmy
Adult Member

After decades of caring for others as a midwife, Kimmy's health journey led to a diagnosis of Common Variable Immunodeficiency (CVID). Following years of unexplained infections, a blood donation helped uncover her low immunoglobulin levels. Now managing her condition with SCIg treatment, Kimmy embraces life with resilience, continuing to travel, volunteer and connect with the IDFA community. Her message: knowledge, self-care and support make a difference.

*Read Kimmy's
full story here:*





Alison

Carer Member

As the mother of two teenage daughters living with Common Variable Immunodeficiency (CVID), Alison has dedicated herself to balancing caregiving, advocacy, work, and her own health challenges. By fostering independence, resilience, and confidence in her daughters, she has helped them thrive beyond their diagnosis. Alison's story highlights the strength of families living with immunodeficiency and the importance of seeing each person for who they are, not their condition.

*Read Alison's
full story here:*



Holly

Adult Member

Diagnosed with hypogammaglobulinemia in her early twenties after years of unexplained illness, Holly has learnt to balance living with primary immunodeficiency while pursuing the life she loves. Switching to home-based SCIG has given her independence, while self-advocacy has become essential in navigating healthcare. Through creativity, travel, work and sharing her story, Holly demonstrates that immunodeficiency is one part of a life filled with purpose and resilience.

*Read Holly's
full story here:*

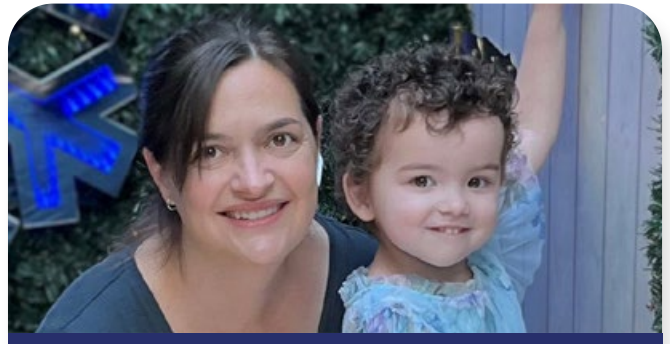


Jonno

Adult Member

Jonno's diagnosis with Common Variable Immunodeficiency (CVID) came unexpectedly after a routine health check revealed abnormal blood results. Initially fearing the worst, he felt relief when he received a diagnosis that could be treated. Today, Jonno manages his condition with weekly SCIG therapy at home, allowing him to pursue his passions. His story highlights the importance of routine health checks, early diagnosis, and not letting CVID define your life.

*Read Jonno's
full story here:*



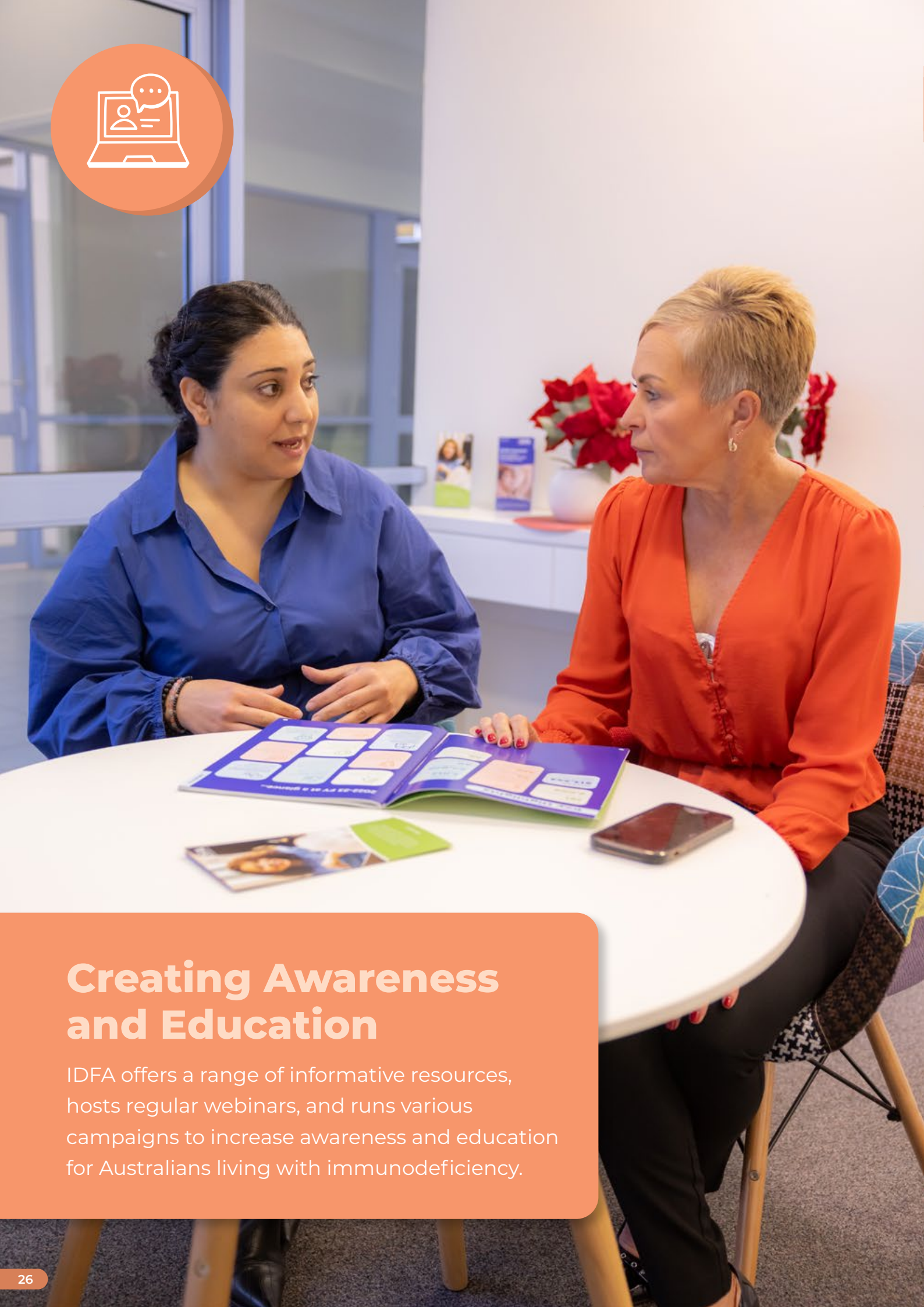
Alice and Eva

Child Member

Eva's first year was marked by severe illness, repeated hospitalisations, and months of uncertainty before genetic testing confirmed the rare immunodeficiency LRBA deficiency. In 2025, she underwent a life-saving bone marrow transplant using stem cells from her brother, Teddy. Today, Eva is thriving—off medications, full of energy, and enjoying a happy childhood. Her journey highlights the life-changing impact of early diagnosis, expert care, and family support.

*Read their
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

As part of the World Primary Immunodeficiency Week campaign, IDFA developed a new resource – *Think PI Sooner*, which is used to support healthcare professionals in recognising the signs of immunodeficiency earlier.

This is now included in the IDFA Resource Pack that is targeted at healthcare professionals.



Scan the QR Code to view or download the new 'Think PI Sooner' resource.

Online Support Brochure

IDFA's newly revamped Online Support Brochure showcases the wide range of opportunities available for members to connect, learn and support one another. From online support groups and Coffee Clubs to the Circle of Support peer mentoring program and Young Adult Members (YAM) initiatives, the brochure highlights the many ways members can engage with the community.

With a strong focus on ensuring no one feels alone, it reflects IDFA's commitment to creating welcoming, inclusive spaces where people of all ages, life stages and experiences can find connection and support.



Scan the QR Code to view the updated Online Support brochure.

IDFA Deep Dives

IDFA Deep Dives is a 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 primary and secondary 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 IDFA Deep Dives, including Expert Series, Hot Topics, and IDFA Shorts.

IPOPI Resources

Over the past year, IPOPI continued to expand its library of educational resources to better support individuals living with immunodeficiencies and their healthcare providers. This included the development of a new resource, *Secondary Immunodeficiencies (SID)*.

IPOPI 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.



Scan the QR code to browse IDFA's library of publications and resources.



IDFA Children's Book Launch

On Rare Disease Day (28 February) 2026, IDFA proudly launched its first children's book, *What Does Brave Feel Like?*, authored by IDFA members Judy Garner and Javeria Khan. Created to support children living with immunodeficiencies, the book helps families start conversations about hospital visits, treatment and what it means to be brave.

What Does Brave Feel Like? Follows Ismaeel and Ebony as they return each month for their immunoglobulin infusions, navigating waiting rooms, friendships and the challenge of facing needles. With the support of Yellow Pup, they discover that bravery isn't about never feeling scared—it can also mean feeling nervous or anxious and choosing to show up anyway. Through a warm and honest story, the book helps children feel understood, reassured and less alone while offering families, schools and healthcare professionals a valuable resource to support conversations about living with an immunodeficiency.



To order your own hard-copy of the 'What Does Brave Feel Like?' book, scan the QR code.

Online Webinars

Immunodeficiency Insights Program

Education remains one of IDFA's core strategic priorities, ensuring members, carers and healthcare professionals have access to trusted, evidence-based information about primary and secondary immunodeficiencies.

Throughout the 2025/26 financial year, the Immunodeficiency Insights webinar program delivered six live online education sessions featuring immunologists, researchers, allied health professionals and people with lived experience.

Covering medical updates, practical self-management, advocacy and wellbeing, the program empowers members with the knowledge and confidence to better manage their health and navigate available support services.

Each webinar includes opportunities for members to submit questions before and during the session, ensuring discussions address the issues that matter most to our community. All webinars are recorded and available on demand, making expert education accessible to members across Australia.

6

live webinars
delivered.

119

webinars
attended live.

19

expert guest
speakers.

45+

member questions
submitted.

378

member
registrations.

217

webinar views/
downloads.



Over the past 12 months, IDFA delivered six live Immunodeficiency Insights webinars across three education streams. The program continued to provide members with trusted education, practical tools and the latest clinical information to support informed decision-making and improve quality of life.

> Practical Series

- *Breathe Easy: Making Indoor Air Safer for Everyone*
- *SCIg Access and Advocacy: The National Picture*
- *Winter Safety for Immunodeficiency*

> Lifestyle Series

- *Mindfulness, Mental Health and Self-Compassion*
- *Think PI: Living with Immunodeficiency - Challenges, Support and Daily Strategies*

> Medical Series

- *Understanding Genetics: Carrier Screening and Targeted Support*

Rare Disease Day

IDFA's 2026 Rare Disease Day campaign focused on raising awareness of primary immunodeficiencies (PI) through community engagement, education and storytelling.

Campaign heroes Jude, Isabelle and Jack brought visibility to the experiences of children living with immunodeficiency, supporting engagement with schools and communities across Australia. IDFA also expanded its school resources, launching a new Fundraising and Communications Kit and updating its teaching resource to support awareness activities.

The annual "Win a Trip to the Zoo" colouring competition received 41 entries nationally, with the winning entry from California Gully Primary School in Victoria.

The campaign highlighted the power of personal storytelling, school engagement, and community advocacy in building greater awareness and understanding of rare diseases and immunodeficiency across Australia.



Scan the QR code to watch the 2026 Rare Disease Day "I Don't Feel Alone" video.

Digital engagement remained a strong focus throughout the campaign. A member video campaign centred on the message "I don't feel alone" reached more than 2,300 viewers, with over half of views coming from non-followers. Across February, campaign social media content reached more than 9,000 people and attracted 47 new followers across Facebook and Instagram.

The campaign was further amplified through partnerships with organisations including the Genetic Support Network of Victoria (GSNV) and RARE Revolution social media takeover, amplifying the reach of the key messages.

Media outreach also played an important role in extending campaign awareness. IDFA worked with California Gully Primary School to share the story of campaign hero Ebony Derby and her experience living with immunodeficiency. This resulted in regional media coverage, including an interview on ABC Central Victoria Breakfast with Fiona Parker and a feature story in the Bendigo Times, helping raise awareness of immunodeficiency within the wider Bendigo community.

**I DON'T
FEEL Alone**

2

media stories featuring IDFA member Ebony Derby.

9K

reach via social media campaign.

41

entries into the colouring competition.

World PI Week

World Primary Immunodeficiency Week (World PI Week) 2026 successfully delivered a multi-channel awareness campaign focused on encouraging earlier diagnosis.

Key Highlights from the Campaign

Healthcare Professional Engagement

A key achievement was the development and distribution of the new “Think PI Sooner” infographic, designed for use in GP clinics and healthcare settings. Developed in consultation with medical professionals, the resource received more than 800 views and was distributed through IDFA, healthcare stakeholders and the Australasian Society of Clinical Immunology and Allergy (ASCI). Targeted healthcare professional communications supported awareness and education efforts during the campaign, with strong engagement across the four-part email series. Paid digital advertising through AusDoc delivered approximately 25,000 impressions to healthcare audiences, resulting in requests for 57 educational resources, including GP posters and resource packs.

Partnerships and External Reach

Strategic partnerships significantly amplified campaign visibility. A collaboration with RARE Revolution Magazine delivered a dedicated World PI Week social media takeover featuring campaign content. These activities expanded the campaign's reach into both healthcare and rare disease communities and contributed to increased audience growth across IDFA channels. On Wednesday, 29 April, IDFA held a meeting in the ACT with Canberra Hospital staff and patient cohorts to raise awareness of immunodeficiencies among GPs, medical students, and the wider community. The Think PI Sooner graphic was also launched during this meeting.

3

media
stories.

61

webinar
registrants.

12K

social
reach.

63

shares of
social content.

57

Educational resources
requested by HCPs.

Community Education and Advocacy

IDFA's World PI Week webinar, Think PI: Diagnosis, Treatment and Research – Understanding Primary Immunodeficiency successfully combined clinical expertise with lived experience perspectives. Government engagement activities included targeted awareness campaigns to more than 750 parliamentary and government contacts. The campaign generated social media engagement from government representatives and helped increase awareness of primary immunodeficiencies within policy and community leadership audiences.

Media Coverage

The campaign secured three media placements featuring member advocate Lauren Hewitt, including coverage on WIN News, Canberra Daily and Pharma Dispatch. These stories highlighted the impact of delayed diagnosis and the importance of earlier recognition of immunodeficiencies.



Scan to watch the 2026
World PI Week campaign
video.

Plasma Awareness

Plasma for Life

The 2025 Plasma for Life campaign was a strong success, running from June through to International Plasma Awareness Week in October and generating outstanding visibility for IDFA members and the importance of plasma donation. The campaign video reached thousands across Facebook and Instagram, supported by storytelling posts that extended awareness beyond our existing community. Sixteen members took part in Plasma Parties across five states, connecting with donors and strengthening recipient teams including #IDFALifeblood, Team Jude, Anita's Zebras and Pain Be Gone. These moments created powerful donor-recipient connections across Australia.

Media attention further amplified the campaign, with national and regional coverage highlighting members' lived experiences and the lifesaving role of plasma donors. IDFA acknowledges the members who attended and hosted events – Olivia, Kerry, Anita, Jessica, Mary, Julie, Angela, Adaline, Rell, Richard, Tara, Kate, Kimmy, Jennifer, Jenny and Lauren.

Plasma for Life Campaign Highlights:

- **Social Media Reach:** Campaign video featuring members received over 2,000 Facebook views and 1,800 Instagram views, expanding visibility beyond followers.
- **Member Engagement:** 16 members participated in 11 Plasma Parties across NSW, TAS, WA, ACT and QLD, connecting with donors and strengthening recipient teams.
- **Media Coverage:** Stories featured in national and regional outlets, including 9Honey, ABC Sydney, ABC Newcastle, Region Illawarra, and the Maitland Mercury.
- **Lifeblood Teams:** Four lifeblood teams were created in recognition of immunodeficiencies and in collaboration with our members.



International Plasma Awareness Week (IPAW) is an initiative aimed at raising 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, highlighting just how vital plasma donors are.

National Blood Donation Week

For National Blood Donor Week, IDFA partnered with the Jeffrey Modell Foundation (JMF) to highlight the vital importance of blood and plasma donations. Together, we delivered a joint awareness campaign across multiple social media platforms, complemented by a dedicated email to the IDFA community.

This collaboration significantly extended the reach of our messaging beyond IDFA's existing audience, increasing our visibility on a global scale and helping raise awareness of the critical role plasma donations play in the lives of people living with immunodeficiencies.

We are grateful for our partnership with the Jeffrey Modell Foundation and their support in amplifying this important message.

Digital Presence and Public Relations

Website

Over the past year, IDFA has continued to enhance its website to improve the experience for members, carers, healthcare professionals and the broader community. A key development was the introduction of a new Resource Download function, allowing IDFA to track downloads for the first time and better understand the information needs of the community. During the year, 252 resources were downloaded, with these insights helping to guide future resource development and communications.

Membership application forms were also updated to provide a more streamlined experience and improved pathways for family members and carers to join and engage with IDFA.

In April 2026, IDFA launched a new donations page, making it easier for supporters to make one-off or monthly donations and providing a more accessible way to support IDFA's work and the immunodeficiency community.

Public Relations

Throughout the year, IDFA received national media coverage, helping raise our profile and awareness of primary immunodeficiencies across Australia. For Rare Disease Day, The Bendigo Times featured IDFA member Ebony Derby, while California Gully Primary School Principal and Leigh Derby were interviewed on ABC Central Victoria Breakfast. During World Primary Immunodeficiencies Week, WIN TV interviewed CEO Carolyn Dews and an IDFA member about the impacts of delayed diagnosis, with further coverage in the Canberra Daily. International Plasma Awareness Week also attracted widespread coverage, including 9Honey, ABC Sydney, ABC Newcastle, Region Illawarra and the Maitland Mercury.

Social Media

33

new members
approved to join
IDFA Connect.

1,434

engagements on
our private IDFA
Facebook group.

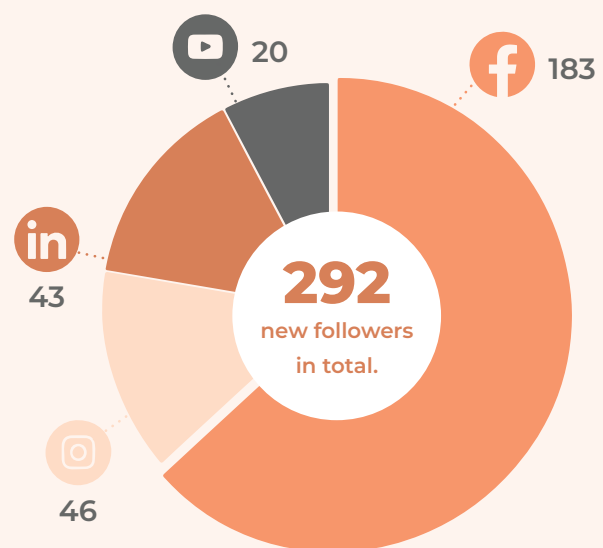
3,297

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

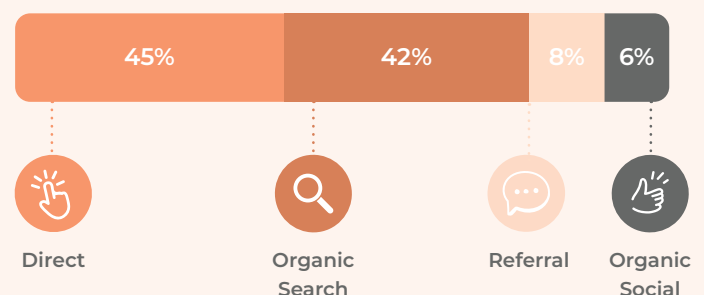
63,488

people reached
via our online
community.

New followers by platform



Ways users found IDFA website



Relationships

Rare Voices

IDFA are a partner organisation with Rare Voices, who facilitate collaboration and advocacy within the Australian Rare Disease Community.

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 continuing for the roll-out of all initiatives within the strategy.

AusPIPS Inc.

IDFA has been 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 through the Plasma for Life campaign. This aims to raise awareness of the critical need for plasma donations 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 2025–2026, we continued to work on accessible, member-led community spaces that support connection, shared experience, and emotional wellbeing.

These 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

> 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 2026, it proudly comprises 694 IDFA members.

> IDFA WhatsApp Community

To foster real-time, low-effort connection, we have made 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

Recognising the unique needs of our members, IDFA provides a dedicated Discord community — a member-only, moderated space where members can connect, chat, and share experiences in a relaxed online environment. The Discord community brings together members across different life stages, providing a place to discuss everyday experiences, ask questions, share support, and build connections with others who understand life with an immunodeficiency. With different chat channels available, members can engage in conversations that are most relevant to them, from general community discussions to specific topics and interests.

IDFA’s In-Person Coffee Club

There’s something special about sitting down face-to-face with people who truly understand. The IDFA Coffee Club brings members together in local communities for relaxed, informal catch-ups over a coffee, tea or conversation.

Living with an immunodeficiency, or supporting someone who does, can sometimes feel isolating. The Coffee Club gives members an opportunity to connect with others who share similar experiences — whether discussing diagnosis and treatment, sharing everyday wins, exchanging practical advice, or simply enjoying the company of people who “get it”.

How the Coffee Club Works:

Members choose the time and place that works best for them, and IDFA helps make it happen. Once a member registers their interest in hosting a Coffee Club catch-up, IDFA promotes the event to members in the local area and provides a \$10 café voucher to help cover the cost of a coffee or tea.

This flexible, member-led approach allows connections to happen where they are most meaningful — from small regional gatherings to catch-ups between families or members meeting for the first time.

The Coffee Club will continue to grow alongside our community, creating opportunities to build friendships, strengthen support networks and stay connected beyond the online space.



Scan to host a Coffee Club and bring local members together to connect, share and belong.



National Carers Week 2025

Recognising and Supporting Carers

For National Carers Week (12–18 October 2025), IDFA celebrated the carers who go above and beyond to support loved ones living with primary immunodeficiency. Through our Coffee for Our Carers campaign, we invited carers to take a moment for themselves and enjoy a coffee on IDFA as a small gesture of thanks for their care and dedication.

A total of 28 carers registered for the campaign (up from 18 in 2024), with half redeeming their vouchers and many reconnecting with the IDFA community through this initiative. The campaign reached 265 carers via email, with strong engagement rates — nearly 50% opened and up to 7% clicked through to participate.

To complement the campaign, IDFA launched the updated Carers Toolkit, an online resource designed to strengthen carer wellbeing and self-care, provide practical information on managing complex care, and connect carers with national supports such as Carers Australia and Carer Gateway.

We also featured Leigh's story, spotlighting his experiences as a carer and participant in our Mindfulness, Mental Health and Self-Compassion webinar. The webinar attracted 51 registrations, including 8 carers, and opened new conversations around mental health and resilience within our community.

Survey feedback highlighted that carers felt recognised and appreciated through the campaign. Many described it as “excellent” and valued that IDFA took time to celebrate carers publicly. Suggestions for future years included opportunities for in-person coffee catchups, more practical care tips, mental health resources, and ongoing advocacy and awareness campaigns.

Overall, the 2025 National Carers Week campaign strengthened IDFA's connection with its carer members, reinforced our commitment to recognising their vital role, and expanded access to practical tools and wellbeing support.

Circle of Support

Building meaningful connections through lived experience

Over the past 12 months, IDFA's Circle of Support Peer Mentoring Program continued to provide members living with primary and secondary immunodeficiencies with personalised, one-to-one support from trained volunteer Peer Mentors who understand the challenges of living with an immunodeficiency.

The program offers a safe and supportive environment where members can connect with someone who has shared lived experience, helping to reduce isolation, build confidence and empower members to better navigate their healthcare journey.

Each mentoring partnership is tailored to the individual, with members able to connect by phone, video call or online over a 12-week period, allowing support to be flexible and accessible regardless of location.

“Finding IDFA was the first time I truly felt like I was ‘one of the gang’. Through the Circle of Support, I’ve found a community that understands, connects, and reminds us that no one has to face life with immunodeficiency alone.”

- Jill Skinner,
IDFA Peer Support Volunteer



Interested in becoming a Peer Mentor or being matched with one? Scan to learn more about Circle of Support.

Growing the Program

Throughout 2025/26, IDFA continued to strengthen the Circle of Support program by improving both member access and the volunteer mentor experience. Key improvements included:

- Launching a simplified online Expression of Interest process for members seeking support.
- Continuing to expand the network of trained Peer Mentors across Australia.
- Updating mentor resources and program documentation to support consistent, high-quality mentoring.
- Continuing delivery of the digital Self-Management of Immune Deficiencies (SMIDs) training program for new mentors.
- Refining mentoring resources to support safe, respectful and empowering mentor relationships.

These improvements have helped create a more accessible, sustainable and person-centred program that continues to grow alongside the needs of the IDFA community.

Our Commitment

Circle of Support is built around three simple principles that remain at the heart of every mentoring relationship:

- **Connect**
Social support from someone who understands.
- **Empower**
Coaching to build confidence and clarity.
- **Support**
Mentoring to navigate health and life with an immunodeficiency

As the program continues to grow, these principles ensure members have access to a safe and supportive space where they never have to navigate life with an immunodeficiency alone.



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.



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

IDFA partnered with several research organisations and universities including:

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

National Immunodeficiency Strategy

The Australian National Immunodeficiency Strategy—formally the ASCIA Immunodeficiency Strategy for Australia and New Zealand—is a coordinated policy framework developed by the Australasian Society of Clinical Immunology and Allergy (ASCIA) in collaboration with patient organisations, clinicians, researchers, and other stakeholders. It was launched in 2022 after development began in 2019. It aims to improve outcomes for people with primary immunodeficiencies (PIDs), now more commonly referred to as inborn errors of immunity (IEIs). The strategy seeks to:

- Improve the health and wellbeing of people living with primary immunodeficiencies
- Enable earlier diagnosis and treatment
- Improve access to specialist care and therapies
- Reduce the burden on patients, families, healthcare services, and the wider community
- Promote coordinated research, education, and policy development.

The National Immunodeficiency Strategy identifies eight major areas for action:

1. Newborn screening for severe combined immunodeficiency (SCID).
2. Introduce universal newborn screening to identify SCID before symptoms develop.
3. Early detection enables potentially curative treatments such as stem cell transplantation before serious infections occur.
4. Earlier diagnosis of other primary immunodeficiencies.
5. Increase awareness of warning signs among healthcare professionals.
6. Improve referral pathways to clinical immunologists.
7. Reduce diagnostic delays.
8. Improved access to genomic and immune testing.

Since the strategy was launched, several important milestones have been reported:

- Nationwide newborn screening for SCID has been implemented across Australia
- An ASCIA Clinical Care Standard for Inborn Errors of Immunity/Primary Immune Deficiency has been developed to promote consistent, evidence-based care.

A key feature of the National Immunodeficiency Strategy is its collaborative, sector-wide approach to implementation. The Immunodeficiency Foundation Australia (IDFA) works alongside the Australasian Society of Clinical Immunology and Allergy (ASCIA), clinicians, researchers, government agencies, healthcare providers, and people living with immunodeficiency to help deliver the Strategy's priorities.

As the national patient advocacy organisation, IDFA brings the lived experience of patients and families into policy development, awareness initiatives, education, and advocacy.

IDFA also supports implementation by promoting earlier diagnosis, equitable access to specialist care and treatments, newborn screening, research participation, and community engagement, ensuring that the Strategy remains responsive to the needs of people affected by inborn errors of immunity.

In summary, the Australian National Immunodeficiency Strategy provides a roadmap for improving diagnosis, clinical care, treatment access, education, research, and health equity for people living with primary immunodeficiencies. Its emphasis on newborn screening, genomic medicine, coordinated specialist care, and national collaboration reflects a shift toward earlier detection and more comprehensive management of these rare but collectively significant disorders.

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 2017, 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.

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 Member Has an Important Story to Share

Every member has a unique journey, and sharing these experiences helps build awareness, understanding and connection within the immunodeficiency community.

Each person brings their own history, experiences and perspective to their diagnosis journey. By sharing your lived experience, you can help others living with immunodeficiencies feel understood, supported and connected.

Member stories help IDFA highlight the diversity, resilience and strength of our community, while raising awareness of the realities of living with primary and secondary immunodeficiencies.

A New Way to Share Your Journey

In 2026, IDFA introduced a new Share Your Story initiative, making it easier for members to share their experiences and connect with others in the immunodeficiency community.

Members are invited to book a one-on-one conversation with the IDFA team to talk about their journey, whether they are living with an immunodeficiency themselves or caring for someone who is. During these conversations, the IDFA team guides members through questions about their diagnosis, experiences, challenges, milestones and the moments that have shaped their lives.

There is no need to prepare in advance — members can simply share their story in their own words, at their own pace. Following the conversation, IDFA develops each story into a written piece, which is shared back with the member for review, feedback and approval before publication.

By sharing their stories, members help raise awareness of immunodeficiencies, support advocacy efforts and remind others in the community that they are not alone.



We'd love to hear your story.
Scan the QR code to get started.



 **Lifeblood**

Life IS THE REASON

more often?
help in 18 different ways.

 Bone marrow transplants	 Whiskered blood disorders
 Respirator B	 Smoking burns
 Heart surgery	 Kidney disease
 Diet with iron deficiency	

Professional Networks

IDFA works collaboratively across the rare disease sector as well as within the state and national healthcare system. We are also fortunate to be a part of an international community.

We are grateful to be able to work at different levels to improve the outcomes of those who live with an immunodeficiency.

We would like to thank all of our partners, networks and collaborators.



International Networks



National Networks





Collaborations and Partnerships

- > Alike WA
- > Australian Institute of For-Purpose Leaders
- > Australian National University
- > CamRARE
- > CaPPRe
- > Carers Australia
- > Federation University
- > Hidden Disability Sunflower
- > Illawarra Women in Business
- > Lifeblood
- > Miracle Babies Foundation
- > Missing Schools
- > Monash University
- > Murdoch Children's Research Institute
- > National Patient Organisation Network
- > NPS
- > Pandis
- > Queensland Genomics
- > Safer Air
- > Shoalhaven Business Chamber
- > The HyperIgM Foundation
- > University of Adelaide
- > University of Newcastle
- > University of NSW
- > University of QLD
- > University of Sydney
- > University of Western Sydney
- > University of Wollongong

Sponsors and Partners

IDFA is grateful for the ongoing support of our sponsors and partners, whose investment enables us to deliver education, advocacy, awareness campaigns and member support programs across Australia.

Rather than providing unrestricted funding, many sponsorships are directed towards specific initiatives that directly benefit our members. This targeted support allows IDFA to continue developing new resources, delivering educational programs and strengthening community connections.

IDFA Sponsors

CSL Behring
Biotherapies for Life™

Takeda

GRIFOLS

gsk GlaxoSmithKline

Pharming®

Thank you

We sincerely thank our sponsors and partners for their continued commitment to improving the lives of Australians living with primary and secondary immunodeficiencies. Their support enables IDFA to continue delivering programs and services that educate, connect and empower our community, including:

- Resource Development
- Circle of Support Program
- IDFA Children's Book
- Educational Webinars
- IDFA 20 Year Celebration
- Coffee Club
- Awareness and education campaigns.

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, helping provide children with special needs and disadvantaged families with a fun and memorable experience they may not otherwise be able to afford. Profits from ticket sales also enable IDFA to continue supporting patients and families living with immunodeficiencies.

International Entertainment hosts three shows across Australia — Cir-

cus Quirkus, World Festival of Magic and Razzamatazz. This year, the program also expanded with a new event, Children's Day Out at Fleay's Wildlife Park on the Gold Coast.

The new event welcomed children and families from more than 80 disability services, welfare organisations, youth support services, special schools/SEUs and charities. Families were able to enjoy the park's shows and animal enclosures, with drinks and snacks also included. The event provided families doing it tough with an inclusive and memorable experience that may otherwise have been out of reach.

International Entertainment Show Locations:

NSW	:	VIC
Albury	:	Bendigo
Lismore	:	Melbourne
Newcastle	:	Mildura
Penrith	:	
Sutherland	:	WA
Wagga Wagga	:	Perth
	:	Kalgoorlie
QLD	:	SA
Brisbane	:	Adelaide
Cairns	:	
Mackay	:	TAS
Toowoomba	:	Burnie
Townsville	:	Devonport
Gold Coast	:	Hobart
	:	Launceston
ACT	:	
Canberra	:	

Fundraising

Supporting Our Community Together

The generosity of our members, supporters, volunteers, corporate partners and donors enables IDFA to continue providing education, advocacy and support for Australians living with primary and secondary immunodeficiencies.

Throughout the 2025/26 financial year, fundraising activities and community support helped strengthen IDFA's programs, increase awareness of immunodeficiencies and create opportunities for members and families to connect.

Community Fundraising

One of IDFA's greatest strengths is the commitment of our members and supporters who help raise awareness and funds within their own communities.

Throughout the year, supporters organised community fundraising campaigns, raising vital funds to support IDFA's ongoing work.

These contributions help IDFA continue delivering resources, education, advocacy and support programs for people living with immunodeficiencies across Australia.

Grants and Philanthropic Support

IDFA is grateful for the support of organisations and philanthropic partners who share our commitment to improving outcomes for people living with immunodeficiencies.

Funding received through grants and philanthropic support enables IDFA to continue developing resources, delivering member programs and strengthening awareness and advocacy initiatives.

GiveNow CrowdRaiser

IDFA's GiveNow CrowdRaiser platform enables members, families and supporters to create their own fundraising pages and engage their personal networks in support of the immunodeficiency community.

Through the Stride for PI campaign, supporters created individual fundraising pages to raise awareness of primary immunodeficiencies and encourage community participation.

These community-led fundraising efforts provide an accessible way for supporters to share their stories, connect with others and contribute to IDFA's ongoing work supporting Australians living with primary and secondary immunodeficiencies.



Play for Purpose

IDFA continues its partnership with Play for Purpose, providing supporters with an opportunity to participate in prize draws while contributing to IDFA's work supporting Australians living with primary and secondary immunodeficiencies.

During 2025/26, Play for Purpose fundraising partnership contributed to supporting IDFA's ongoing education, advocacy and community programs.

End of Financial Year Giving Appeal

In 2025/26, IDFA launched its first dedicated End of Financial Year Corporate Giving Appeal, encouraging businesses and organisations to make tax-deductible contributions to support Australians living with primary and secondary immunodeficiencies.

The campaign introduced IDFA's work to new corporate audiences while creating opportunities to build future relationships with potential supporters and partners.

Donations and Merchandise

There are many ways to support IDFA and help strengthen the immunodeficiency community.

Whether through making a donation, creating a fundraiser, purchasing merchandise or sharing awareness, every contribution helps IDFA continue providing education, advocacy, resources and support for Australians living with primary and secondary immunodeficiencies.

GiveNow: Donate or Create a Fundraiser

IDFA's GiveNow platform provides a simple and accessible way for individuals, families, workplaces and supporters to support our work. Through GiveNow, supporters can:

- Make a one-off donation
- Set up regular giving
- Create their own fundraising page
- Support IDFA campaigns and community fundraising initiatives
- Engage their own networks to raise awareness and funds.

GiveNow enables our community to turn their personal connections and fundraising ideas into meaningful support for people living with immunodeficiencies.



Scan the QR code to donate or
fundraise for IDFA via GiveNow.

Making Giving Easier: IDFA Donation Landing Page

During 2025/26, IDFA launched a new centralised on-line donation page to make supporting our work easier and more accessible. The new donation system provides:

- A single entry point for all donations
- Support for both one-off and recurring giving
- A simpler donor experience
- Greater connection between campaigns and donation opportunities.

This development strengthens IDFA's ability to engage supporters and create sustainable opportunities for future giving.



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

Leave a Lasting Legacy

A gift in your Will is a meaningful way to support the future of the immunodeficiency community.

Legacy gifts help IDFA continue delivering education, advocacy and support for Australians living with primary and secondary immunodeficiencies for years to come. To learn more about leaving a gift in your Will, please contact the IDFA team.



Interested in leaving a lasting
legacy? Get in touch with us via
the QR code.



IDFA
Merchandise
Pack
\$35

IDFA Merchandise

Supporting IDFA can also be as simple as raising awareness within your own community. IDFA merchandise provides members, families and supporters with an opportunity to show their support while helping increase awareness of primary and secondary immunodeficiencies. Available items include:

- IDFA Tote Bags
- Awareness Pins
- Pens
- Merchandise Packs

This development strengthens IDFA's ability to engage supporters and create sustainable opportunities for future giving.



Scan the QR code to purchase
our merchandise online.

Tote Bag
\$20



Awareness
Pin
\$7

IDFA Pen
\$5



Volunteers



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

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.

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
- > Javeria Khan
- > Dr Natasha Mosely
- > Anastasia Cauchois
- > Baden Marino-Hall

Medical Advisory Panel Members

- > Dr. Melanie Wong (Chair)
- > Dr Samar Ojaimi
- > Geraldine Dunne
- > Dr Natasha Mosely
- > Dr Phillipa Pucar
- > Katrina Randall

National Patient Advisory Panel Members

- > Adam Friedrich (Chair)
- > Javeria Khan
- > Lyn Barker
- > Alison Copley
- > Briana Corry
- > Charlotte Gingell
- > Ben Johnson
- > Alex James-Martin
- > Richard Price
- > Dr. Hayley Teasdale
- > Jenny Tyrrell
- > Bianca Willis
- > Luke Kavenagh
- > Sharon Heathfield

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
- > Dr Phillipa Pucar
- > Dr Katrina Randall
- > Dr Carolina Sandler
- > Anna Sullivan
- > Professor Stuart Tangye
- > Dr Melanie Wong
- > Kathryn Nicholson-Perry

Students

- > Moshtaba Gheyasi
- > Mohtashin Nahar Munni
- > Nadia Moore
- > Bianca Mathews
- > Sasha Claire Mason Holloway
- > Ashley Rose Todorovski
- > Milena Teteris
- > Lizamae Gregorio
- > Ashley Todorovski
- > Abby Jackson
- > Umu Bah

Coffee Club Hosts

- > Lyn Barker (Airport West, VIC)
- > Jenny Tyrell (Canberra ACT)
- > Allison Symons (Goodwood, SA)

IDFA 20 Year Event

- > Louise Grant (Speaker)
- > Christine Jeffery (Speaker)
- > Adam Friederich (Speaker)
- > Dr Melanie Wong (Speaker)
- > Judy Garner (Book Launch)
- > Javeria Khan (Book Launch)
- > Thomas Dyne (Young Adults Program)
- > Abby Jackson (Young Adults Program and event support)
- > Lyn Barker (Circle of Support)
- > Richard Price (Balloons for Kids Corner)
- > Lizamae Gregorio
- > Mohtashin Nahar Munni



Presenters/Speakers who contributed to IDFA

- Plum Stone (The Safer Air Project, CEO and Founder)
- Amy Lewis (The Safer Air Project, Co-founder)
- Di Edwards (Nurse Practitioner)
- Jo Reynolds (IDFA Adult/Carer Member)
- Jodie Cooper (Psychology Coach and Educator)
- Elizabeth Granger (Psychologist)
- Bella Mas (IDFA Adult Member)
- Leigh Derby (IDFA Carer Member)
- Dr Emily Edwards (AusPIPS, Vice President)
- Andrew Hodder (CSL)
- Rachael Dunn (SCIg Nurse/CNS Immunology)
- Adam Friederich (IDFA Adult Member)
- Dr. Alisa Kane (Immunologist and Researcher)
- Kathleen LaMarquand (Genetic Alliance Australia)
- Rebecca MacIntosh (Genetic Alliance Australia)
- Dr Matilda Haas (Genomics Australia)
- Archie Dowell (IDFA Adult Member)
- Javeria Khan (IDFA Carer Member)
- Sara Yusuf (General Practitioner)
- Sarah-Jane Leon (Wentwest)
- Robert Willis (IDFA Adult Member)
- Katrina Randall (Immunologist)
- Dr Alberto Pinzon (Healthcare Professional)
- Lyn Barker (IDFA Adult Member)

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

Thank You

Every achievement in this report has been made possible through the generosity, dedication and collaboration of our incredible community.

To our members, families, carers, volunteers, healthcare professionals, researchers, donors, sponsors, partners and supporters - thank you.

Together, we continue to build a stronger future for Australians living with primary and secondary immunodeficiencies.

IDFA – I Don't Feel Alone.

Financials

Statement of Profit or Loss and other comprehensive income

	2026	2025
Revenue	\$1,886,962	\$1,839,629
Cost of Sales	(\$1,581,707)	(\$1,540,976)
Gross Profit	\$305,255	\$298,653
Finance Income	\$5,810	\$7,003
Other Income	\$313,657	\$215,190
Marketing Expenses	(\$10,828)	(\$7,081)
Administrative Expenses	(\$433,641)	(\$426,998)
Functions, Awards and Presentations	(\$55,095)	(\$10,838)
Peer Support Program	(\$3,000)	(\$1,392)
Other Expenses	(\$61,561)	(\$56,249)
Finance Expenses	(\$834)	(\$1,402)
Surplus before income taxes	\$59,763	\$16,886
Income Tax	-	-
Surplus for the year	\$59,763	\$16,886
Total comprehensive income for the year	\$59,763	\$16,886

Statement of Financial Position

ASSETS	2026	2025
Current Assets		
Cash and Cash Equivalents	\$454,216	\$340,049
Trade and Other Receivables	\$5,625	\$55,625
Other Assets	\$4,704	\$6,264
Total Current Assets	\$464,545	\$401,938
Non-Current Assets		
Property, Plant and Equipment	\$12,882	\$11,233
Intangible Assets	-	\$3,428
Right-of-use Assets	\$52,434	\$7,516
Total Non-Current Assets	\$65,316	\$22,177
Total Assets	\$529,861	\$424,115
LIABILITIES	2026	2025
Current Liabilities		
Trade and Other Payables	\$24,054	\$27,051
Employee Benefits	\$26,609	\$13,902
Lease Liabilities	\$21,448	\$9,909
Total Current Liabilities	\$72,111	\$50,862
Non-Current Liabilities		
Employee Benefits	\$7,071	\$12,743
Lease Liabilities	\$30,406	-
Total Non-Current Liabilities	\$37,477	\$12,743
Total Liabilities	\$109,588	\$63,605
Net Assets	\$420,273	\$360,510
EQUITY	2026	2025
Retained Earnings	\$420,273	\$360,510



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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