

Annual Report

2022 / 2023



I Don't Feel Alone
idfa.org.au

 **IDFA** Immune
Deficiencies
Foundation
Australia

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Acknowledgement of Country

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

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Message from Board Chair

We have landed at the end of another packed 12-month period where both the board and staff of IDFA have given of themselves enormously. I am genuinely grateful for the input from everyone who contributes to the work undertaken by IDFA, both remunerated and voluntary.

For many, life has returned to 'normal' now we are in our 4th year since the COVID-19 pandemic first occurred. While many of the restrictions and strategies previously implemented to prevent the spread of COVID-19 have been relaxed or removed, for those living with an immunodeficiency, aspects of life remain uncertain. While scientists and clinicians are working on the incidence and impact of Long COVID, it is too soon to know the full effect. IDFA continues to support members throughout this dynamic period, through education support and advocacy. Of note is the Circle of Support established in 2023, providing a sustainable support network for IDFA members.

The advocacy work that IDFA has been a part of has resulted in the inclusion of SCID testing in the Newborn Screening program in all states, except VIC and SA, who is expected to commence in early 2024. This achievement, although positive, means that IDFA must meet new challenges in the future, providing support education and advocacy for families experiencing an early SCID diagnosis and subsequent treatment, then

adjusting to their 'new normal' including the potential impact of the diagnosis to their wider families.

In April this year, IDFA was represented at the ASCIA National Immunodeficiency Strategy Implementation Meeting in Sydney. It was apparent and reassuring that IDFA's own strategic plan and vision aligns very well with the aims of the National Immunodeficiency Strategy will allow us to work with ASCIA in the year ahead.

Both the National Patient Advisory Panel and Healthcare Professional Panel have worked steadily and cohesively on projects that members seek information and support on. The breadth and depth of these panels have served both the IDFA board and members well.

Despite some staffing changes within the IDFA team, and a necessary move of office space, the team remains innovative, dynamic and committed. Membership of IDFA has grown again over the year. Webinars and social media remain well accessed, providing quality in-

To quote Dr Brene Brown... "connection is the energy that exists between people when they feel seen, heard and valued...when they can derive sustenance and strength from the relationship...". I believe that this ethos underpins the work that IDFA does and will continue to do in the future.



formation and support. IDFA have been proactive in providing information to members on topics such as antiviral medications, changes within the National Blood Authority, travelling with immunodeficiency, amongst others.

Many NFP organisations are currently impacted by the current fiscal climate in Australia and beyond, however Carolyn Dews, CEO, continues to strive towards income diversification. I'd like to take this opportunity to thank all the sponsors who enable the IDFA team and board to undertake the wonderful work they do. Thank you also to those members who fundraise and support the IDFA community.

Geraldine Dunne.

Message from CEO

Throughout the past year we have continued to work hard to support our members including patients, families and our healthcare professionals.

Earlier in the year we moved into a larger office that will accommodate our needs for the next couple of years. In addition to this, we welcomed two new staff members to the IDFA team: Danae Pikkat as our Marketing and Communications Coordinator and Maree Thomson as our Community Engagement Coordinator.

In February, we met with the Board and staff to develop our Strategic Plan which highlights three strategic priorities: Creating Awareness and Education; Building Community – Care and Support; Driving Change – Advocacy.

The Member Engagement and Marketing and Communications Strategy have been updated in consultation with our members to look at opportunities for member attraction, growth and retention.

In conjunction with our IT partners, we have improved our data systems so that we have a clear understanding of our membership base, including key location data, which will allow us to plan member engagement events in locations that are convenient to our members.

Guided by our National Patient Advisory Panel we have developed a range of programs to support our members including:

- A broader range of online support groups
- Peer Support and Mentoring pilot, which allows members to support each other to navigate through an immunodeficiency diagnosis
- Ongoing roll out of the innovative PI Education Program, with a total of nine webinars delivered during the period
- A World PI Week campaign where IDFA obtained a \$3,000 Grant from IPOPI to produce a series of promotional videos featuring our members
- A Rare Disease Day campaign which was our most successful campaign to date. The key activities were via social media and included: webinar in partnership with AusPips, sharing member stories, local and regional media opportunities, colouring in competition, 'wear your colours' social media challenge.

The Medical Advisory Panel has continued to respond to member questions on a weekly basis as well as reviewing IDFA resources and participating in webinars. Regular meetings and briefings with the Healthcare Professionals Panel consisting of approximately 20 HCP from across Australia. The National Patient Advisory Panel have continued to deliver on projects and guide the work of IDFA.

We wish to thank the ongoing support of our sponsors CSL, Grifols, Takeda and GSK.



We have engaged with a number of research partners including:

- ANU as part of the Rare Disease Action Plan
- Researchers at the University of Sydney completed two (2) studies on COVID-19 for IDFA. These studies involved engaging with IDFA members to obtain their experiences of COVID-19 and to determine the effects of long COVID.

The SCID Advocacy Campaign has been ongoing for several years and in June 2022, it was announced by the Federal Government that SCID would be included as part of NBS tests. Since then, all states have committed to commencement of testing and most have commenced treatment in early 2023, with all states to be testing for SCID by early 2024.

Thank you to all those who work with us to achieve our purpose and to our members and the broader community who allow us to work in this space.

Carolyn Dews.

Key Highlights

Members

191

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

2,059

Total Members.

Fundraising

\$13,243

raised through member-
initiated community
fundraising campaigns.

PI Education Webinars

9

PI Education Webinars
held on a range of topics
including Self Advocacy,
Travel Smart with
Immunodeficiencies
and Mental Health and
Immunodeficiencies.

22

expert guest speakers
presented on a range of
topics.

328

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

Our Online Community

3,013

followers of IDFA online
community.

54,878

people reached via our
online community.

46

new subscribers to our
mailing list.

Public Relations

98

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

2022-23 FY at a glance...



A year of consolidation
with the team, board and
advisory panels.



Strong Rare Disease Day
campaign, featuring a
partnership with WIN TV,
coverage in 14 TV news
bulletins, 18 PR articles
generated overall.



Revised the online
community support
network to further
build community and
engage with members.
Several new groups were
established including: SCID
Connect; Young Adult
Members Connect; Family
Connect and Carers
Connect.



Impactful World PI Week
awareness raising
campaign where we
launched the self-advocacy
toolkit and supported
ASCIA's National
Immunodeficiency Strategy
and achieved national PR
coverage. 10 original pieces
of coverage were secured
with syndications across
AAP (60) AND Fairfax
Mastheads.



Successful collaboration
with Lifeblood for
International Plasma
Awareness Week and
National Blood Donation
Week.



Supported ASCIA's
implementation of the
National Immunodeficiency
Strategy.



Successful outcome for the
SCID advocacy campaign
with all states and
territories now screening
for SCID, or agreed to
implement testing.



Development and
Implementation of a
comprehensive Community
Engagement Strategy to
ensure that all of our
members are welcomed
into the IDFA community
and supported throughout
their health journey.



Shortlisted as a Finalist
in the Illawarra Women
in Business Awards in the
'Outstanding Not for Profit
Charity' category.

Strategic Plan

We have recently reviewed and updated our Strategic Plan, vision and purpose.

Our strategic priorities have also changed to reflect 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 Committee
- National Patient Advisory Panel
- Healthcare Professionals Panel

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

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

Creating Awareness and Education



Patients and Carers

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

Government

Engagement
Representations to MP's
Funded Projects

Health Professionals

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

General Community

Website and Social Media
Awareness Raising Campaigns
Fundraising

Building Community: Care and Support



Support Groups

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

Ask IDFA - Your Questions Answered

Engagement Events and Networking

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

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

IDFA exists to support its ordinary members, patients, their families, and medical professionals. The day-to-day management of IDFA is undertaken by a small team of paid staff, assisted by ordinary members who volunteer their time. This staff team, led by a CEO, is responsible for managing IDFA in accordance with the IDFA's strategic direction.

The staff team is governed by a Board of Directors, which is responsible for setting IDFA's strategic direction.

This Board reports to the voting members of the IDFA company. The Board's composition ensures that a diversity of skills and experience are represented. Key skills for the IDFA Board include:

- Patients and/or family members with an understanding and awareness of immunodeficiencies
- Medical professionals with an understanding and awareness of adult and paediatric immunodeficiencies
- Financial management skills and/or experience
- Governance skills and/or experience
- Media, promotions, fundraising, marketing skills and/or experience
- Legal qualifications and/or experience
- Human resources, people, and culture skills and/or experience.

While Board members do not represent specific geographic areas, the Board usually tries to ensure that its members reflect the broad geographic spread of a national peak body and come from a variety of different geographic locations.

Our Team



Carolyn Dews
CEO



Danae Pikkat
Marketing and
Communications Coordinator



Estela Gimenez
Programs Coordinator



Andriana Epistithiou
Finance and Administration
Coordinator



Maree Thomson
Community Engagement Coordinator



Alex Litchfield
Graphic Designer

Our Board



Geraldine Dunne
Board Chair, Medical
Advisory Panel



Pearl Sims
Deputy Chair



Brendan Peek
Company Secretary,
Finance, Risk and Audit
Committee Chair



Caroline McMillen
General Board Member



Javeria Ahmad
National Patient
Advisory Panel



Dr. Melanie Wong
Medical Advisory Panel Chair



Adam Friederich
National Patient Advisory
Panel Chair



Dr. Alisa Kane
Healthcare Professionals
Panel Chair



Sap Chatterjee
Finance, Risk and Audit
Committee



Louise Grant
Finance, Risk and
Audit Committee



Dr. Hayley Teasdale
National Patient
Advisory Panel



Dr. Luke Droney
Medical Advisory Panel



Roslyn Chataway
General Board Member

Personnel Changes

Staff Resignations

Charmaine Meredith - Member Support (August 2022)
We thank Charmaine for the enthusiasm that she brought to the role of supporting our members and the engagement and relationships that she built during her time with IDFA.

Chontelle Broadwood – Marketing and Communications Coordinator (November 2022)
Chontelle provided a level of professionalism and skill to the role that allowed IDFA to experience enhanced engagement with our members and the media to raise the profile of IDFA and achieve strong results from our campaigns. We will miss Chontelle and wish her all the best.

Board Resignations

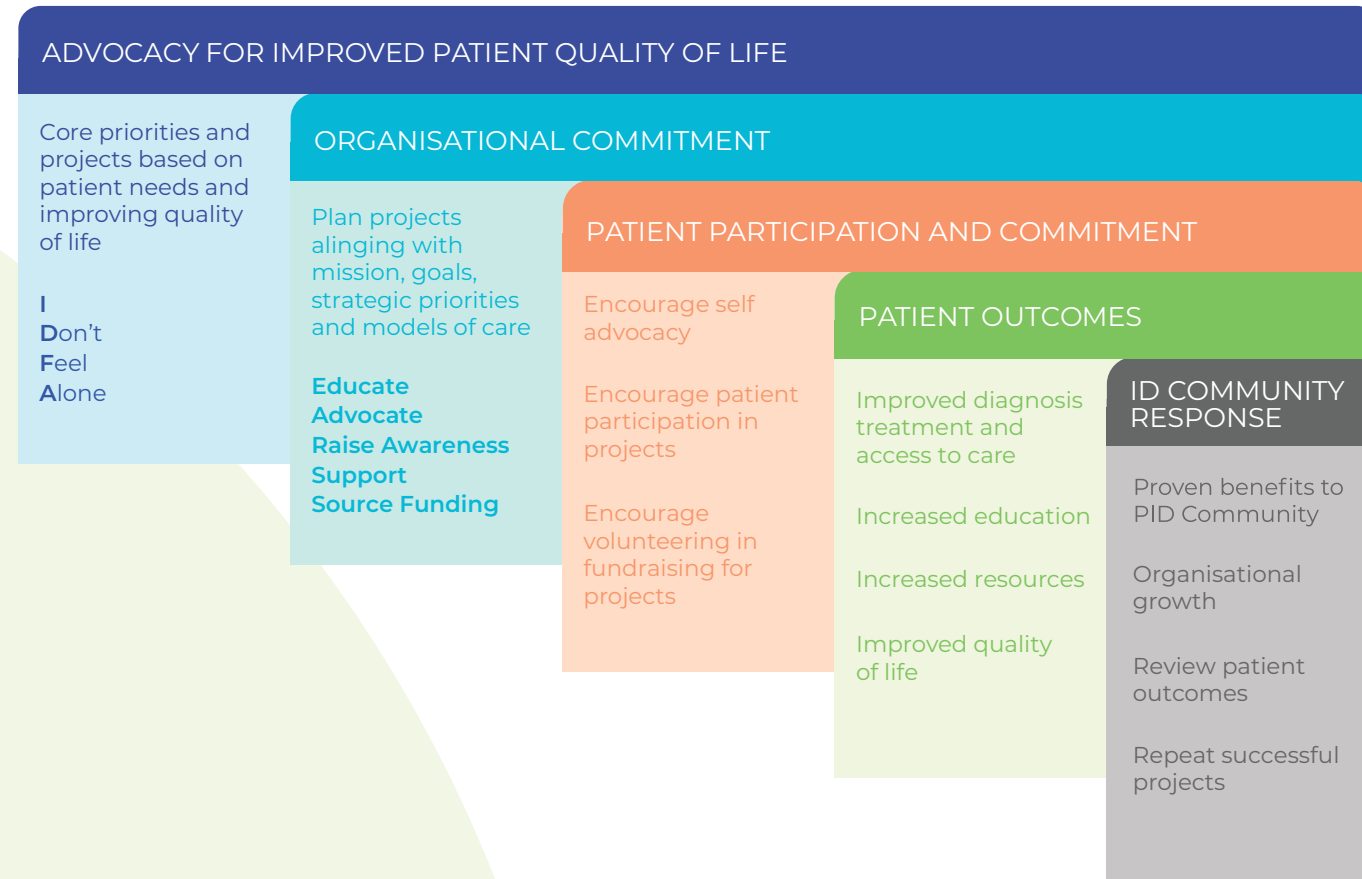
Cath Bampton
We would like to thank Cath for her strong support and contribution over many years as a Board member. Welcome to newly appointed Deputy Chair, Pearl Sims.

New Appointments

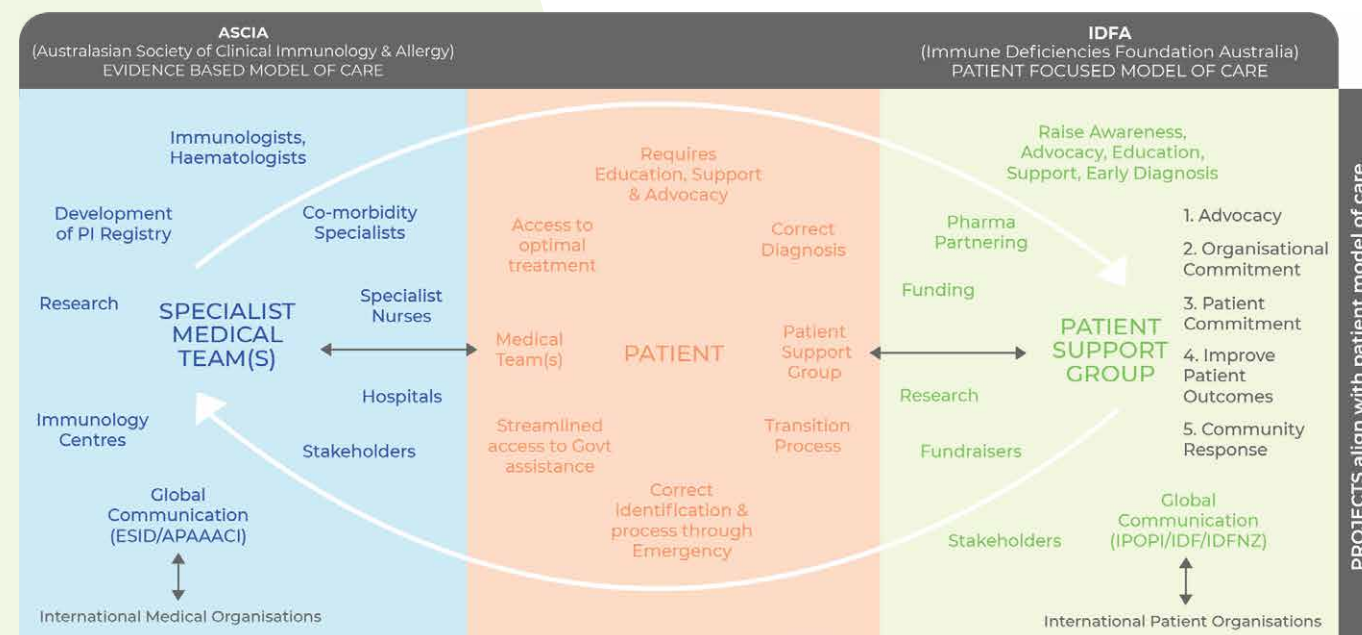
Javeria Ahmad and Hayley Teasdale

Models of Care

Patient Focused Models of Care



Community Focused Models of Care



Advisory Panels

Healthcare Professionals Panel

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

The objectives of the Panel are to:

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

Medical Advisory Panel

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

National Patient Advisory Panel

The role of the IDFA National Patient Advisory Panel 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 National Patient Advisory Panel has been able to provide strong support to our members throughout COVID-19 and are now working with members to develop new priorities and programs including:

Finalisation of projects:

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

Current projects:

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



Immunodeficiencies



A PID can be diagnosed at any stage of life, whilst some people may not show symptoms, which is a risk factor for a late or missed diagnosis.

Primary Immunodeficiencies

A primary immunodeficiency (PID) is a disorder where the immune response is weakened or absent altogether. They are often genetic in origin, i.e. inherited and result in a defect in one or more elements of the immune system. People with PID are prone to infections which may be frequent, more severe or last longer than in individuals who have a fully functioning immune system.

A PID can be diagnosed at any stage of life, whilst some people may not show symptoms, which is a risk factor for a late or missed diagnosis. Some patients may not receive a diagnosis until reaching adulthood when they begin to present with clinical symptoms of a PID.

Other PID's are fatal without early diagnosis and treatment, such as Severe Combined Immunodeficiency (SCID). Depending on the type of PID some people manage their condition quite well with appropriate treatment while others live with lifelong chronic illness and complex medical issues.

The International Union of Immunological Societies (IUIS) Expert Committee has classified up to 485 inborn errors of immunity/primary immunodeficiencies in their 2021 update. While this may seem like a large number, it's important to recognize that individual PID's are still considered a rare disease (the number of affected people is less than 5 per 10,000).

Secondary Immunodeficiencies

A secondary immunodeficiency (SID) occurs when the immune system is weakened as a result of treatment for an illness (e.g. chemotherapy for treatment of cancer) or medications, or CAR-T cell therapy. Many of the treatment options and support offered to PID patients are similar for SID patients.

Treatments

Immunoglobulin (Ig) Replacement Therapy

Ig Therapy is one of the more common treatments among those living with a PID and helps protect patients from a range of infections. Ig's (also known as antibodies) are necessary to fight infections caused by various germs and bacteria and come from plasma donated by healthy individuals. Donated plasma undergoes a rigorous screening process to ensure it is free from infectious disease. Ig therapy is an ongoing treatment and is administered by infusion either intravenously or subcutaneously.

IVIg – Intravenous Immunoglobulin Therapy is administered intravenously (i.e. injected into the vein) in hospital by a nurse every 2-4 weeks to maintain sufficient levels of immunoglobulin.

SCIg – Subcutaneous Immunoglobulin Therapy is self-administered by the patient at home, either using a pump or manually pushing after inserting a small needle under the skin. Patients using SCIg therapy generally require more frequent infusions than those using IVIg therapy.



Antibiotics

Infections are typically treated with antibiotics. In cases where infections don't respond to standard medications, hospitalisation and treatment with intravenous antibiotics may be necessary. Some PID patients may need to take antibiotics long term (prophylactic antibiotics) to prevent infections as well as permanent damage.

Gene Therapy

Gene Therapy is a relatively new treatment and not yet widely available. Gene Therapy replaces defective genes with working genes. A harmless virus is used to carry the genes into the body's cells. In turn, the newly introduced genes trigger the production of healthy immune system enzymes and proteins. Increasing numbers of genes that cause PID are being discovered, however Gene Therapy is still being refined.

Immunomodulation

Immunomodulatory drugs modify the response of the immune system and can be divided into two main groups: those that work by increasing the immune system (immunostimulators) or those that work by suppressing the immune system (immunosuppressives). There are many different drugs within both categories and treatment depends on the specific needs caused by your PID.

The International Union of Immunological Societies (IUIS) Expert Committee has classified up to 485 inborn errors of immunity/primary immunodeficiencies in their 2021 update.

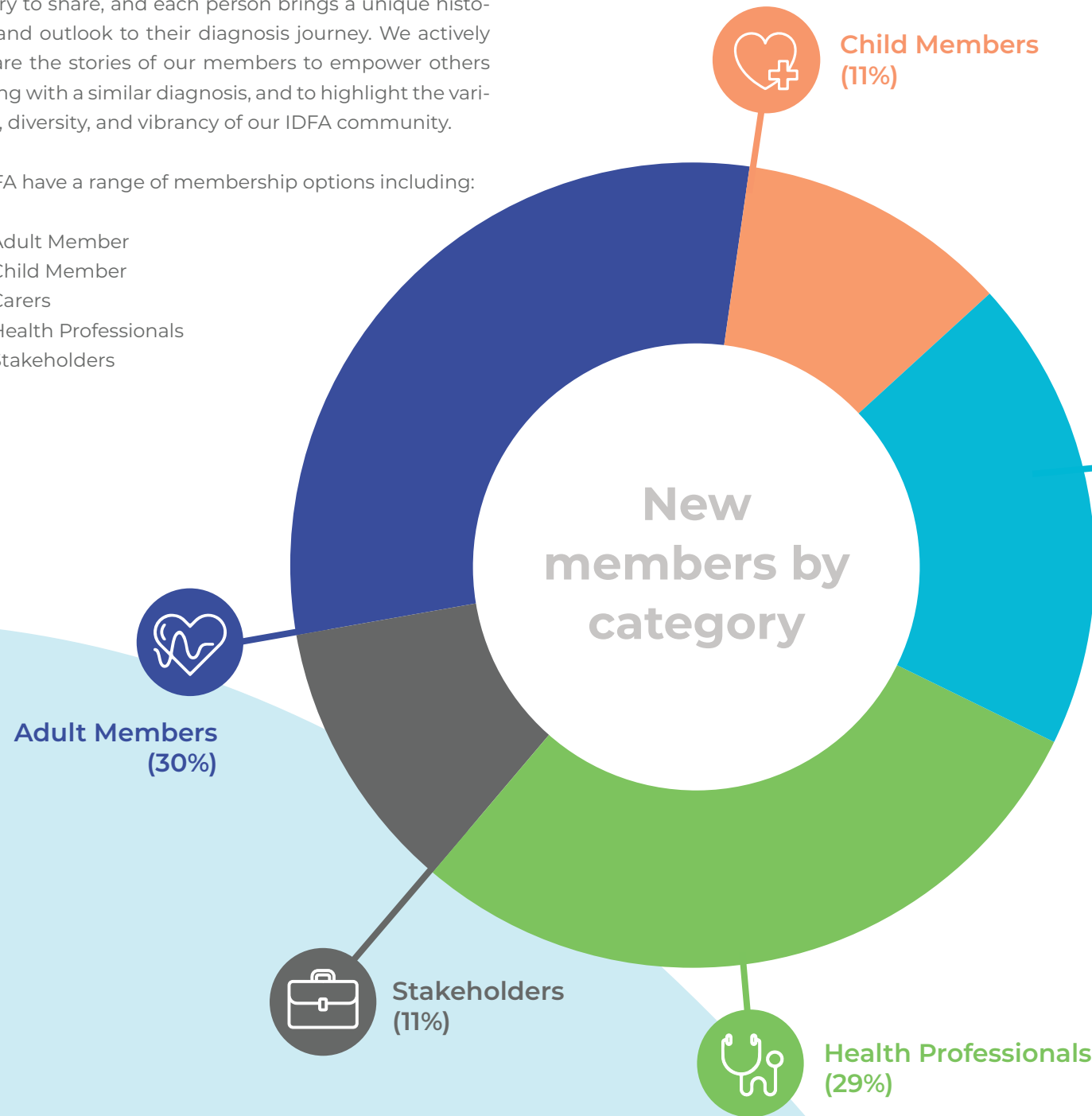
Membership

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 to be empowered by the extra support, up-to-date information, and educational opportunities we have available.

Building community is one of our key priorities as an organisation. Every member of IDFA has an important story to share, and each person brings a unique history and outlook to their diagnosis journey. We actively share the stories of our members to empower others living with a similar diagnosis, and to highlight the variety, diversity, and vibrancy of our IDFA community.

IDFA have a range of membership options including:

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



“Connecting with the IDFA community is a brave and fantastic thing to do. I’ve met such lovely supportive people and they will always be there to give you support and a virtual hug. I can’t imagine how you might be feeling but I can assure you, this community cares and supports you.”

- IDFA Member



191
new members
from 1/7/22
to 30/6/23 (an
increase of 13%
YOY)



2,059
Total Members



Member Stories

Dale Adult Member

Up until 2020, Dale was an active, fit, and healthy Australian (originating from England), who has a distinguished academic career. He is known globally for his work in disaster risk management, government policy, emergency services as well as being the Chairman of the United Nations Global Working Group on Post Disaster and Response and Recovery Assessment.

Since first displaying symptoms, Dale has been on a journey to determine the root cause of his recurring episodes of illness, which range from 2-10 days and come almost every two weeks. The immunology team at St Vincent's Hospital are continuing to work to confirm the exact kind of immunodeficiency Dale suffers from. As many of our members are already aware, this can be a lengthy process and take years to find out.

Recently, Dale was found (via a PET scan) to have evidence of some Vasculitis (a relatively rare disease that causes inflammation of blood vessels) and was treated for this. Unfortunately, the treatment for this has caused other health implications including life threatening blood clots in his lungs.

Today he is managing his symptoms with a range of medications and has regular blood tests and visits to his immunologist. Although he is grateful for some respite through medication, there are still challenges in everyday tasks. However, he tries hard to look for the joy in everyday and celebrates the small wins, for example, the ability to shower unassisted.



When he can, Dale spends as much time as possible outside gardening. He has found purpose in creating life as he is unable to currently work due to recurring sickness. Gardening has been a way for Dale to support his emotional and mental wellbeing. He often gives the plants away as presents, or sells them at markets, giving away the proceeds to charity.

Since joining IDFA, Dale has been using the self-advocacy toolkit, which he said, “has been an amazing tool to help/make sure that the medical professionals I come into contact with really understand my specific journey and all the ins and outs of what I’ve been through”.

Although a new member to IDFA, Dale has found solace in knowing that others are in similar situations to himself and is appreciative of finding this community to lean upon.

Jack

Child Member

At three months old, Jack was hospitalised in Orange with a respiratory infection and was back there again aged seven months with pneumonia. Genetic testing at nine months of age provided Jack and his family with an insight into his recurring illness.

This is an immunodeficiency that left Jack susceptible to infections and meant his platelets didn't function properly.

Although Emma (Jack's Mum) was able to get answers relatively early in Jack's life, it wasn't without uncertainty and difficult times. Since he was a newborn, he was plagued with constant bruising, eczema and respiratory infections that made Emma question what was wrong with her baby – her fourth child.



The diagnosis was challenging for the family; however, they were happy that they had a diagnosis, which meant Jack could get life-saving treatment.

Fortunately, the blood tests during his second stay in hospital revealed that Jack's platelets were abnormally low, providing an insight into what may be wrong. After a meeting with the haematologist, genetic testing was ordered, and his disease was revealed (Wiscott-Aldridge Syndrome).

Once they received a formal diagnosis, it became apparent that Jack needed to have a bone marrow transplant, if he didn't his life expectancy was low - from five to 12-years-old. All family members were genetically tested to see if they could help Jack, and it was found that nine-year-old Bethany was Jack's best match. She bravely put her hand up to be her baby brother's donor - and her mum's hero.

Bethany had to undergo an operation and the life-saving transplant took place in October 2022. Emma and Jack had to stay in Sydney - away from their family home in Forbes NSW (almost a 5-hour drive away), whilst her husband (Paul) took care of the three older children and the entire household.

Emma and her family are incredibly grateful for how well Jack is doing; however, he is still on one medication and will require life-long monitoring, but hopefully just annually. His sister's bone marrow has basically given her brother a cure, and his 100-day tests show he now has 97 per cent donor marrow.

The family has received incredible support during the entire process, staying at Ronald McDonald House on the doorstep of Westmead Children's Hospital and with Little Wings flying them to and from appointments.

Since diagnosis, the Baxter's have been connected to other families ahead of them on the journey and an on-line support group. In February 2023, children at Forbes Public School dressed in their brightest colours to acknowledge Jack and Rare Disease Day, an important day for IDFA to educate other Australians living with immunodeficiencies.

Vanessa

Young Adult Member

Before her diagnosis, Vanessa was a relatively healthy child, however in her teens and early 20s she began getting sick frequently and taking weeks or months to recover. Doctors kept prescribing antibiotics which did help to a degree but would prescribe them for months. This is when Vanessa and her family knew something wasn't right. It wasn't until she was referred to an allergy immunologist for a completely different reason when her immunodeficiency was picked up on a blood test. Due to her immune levels being so low her specialist needed to check them twice to ensure they were correct as she said "it would be expected that for someone with your immune levels being so low that they would constantly be in and out of hospital" however Vanessa had never been and looked healthy from the outside.

It was on her 23rd Birthday when Vanessa found out that she had Common Variable Immunodeficiency (CVID). Receiving a diagnosis at this age was both confronting and relieving, as she was then able to work with her healthcare team to create a treatment action plan.

Although things may have changed, Vanessa has not let her immunodeficiency stop her from doing the things she loves.



Going to hospital and getting treatment was very new for Vanessa as prior to this she had never been hospitalised. She expressed she had an incredible specialist and supportive healthcare team. Vanessa was scared to begin the treatment as it was something she needed to learn in a hospital setting so she could complete weekly SCIG independently at home. Vanessa was very lucky to have unconditional support from her family, friends, and husband and this has been the backbone to her doing so well today. Upon doing research about CVID she came across the IDFA and joined. She is grateful to be a part of a community of others with immunodeficiencies as well.

For Vanessa to stay fit and healthy, she requires SCIG therapy where once a week she administers it subcutaneously at home, which she has been doing in the year and a half since her diagnosis. SCIG treatment has also expedited recovery from infections and illnesses.

She recently got married and is enjoying her life being a wife. She enjoys being in nature and going on adventures, and loves spending quality time with her family and friends as well as travelling and being active. Vanessa is still able to work full time as an Exercise Physiologist but sometimes finds days challenging when she is tired and sick; however is learning to manage her life and ensure she is putting enough time to look after herself, her health, and her needs.

She is so grateful for people in the community who can donate plasma as it makes a huge difference in her quality of life. This new chapter has allowed her to live her life to the fullest and enjoy every second. She doesn't let anyone, or anything get in the way of her dreams and aspirations.

Ben

Carer Member

Ben was introduced to the immunodeficiency community more than 15 years ago, when he met his wife, Lisa. In their youth, they spent time partying and enjoying life, relatively oblivious to the implication immunodeficiency can have on a person's life. Although Lisa received a diagnosis at 12 years old, at this age, she was healthy. Their relationship continued and they moved in together in Queensland. Ben was working full time and Lisa was studying at university. Over the course of her study, Lisa's health was greatly impacted, and her double-degree was drawn out over eight years.

After a while, Ben realised that there were going to be times where Lisa would be dependent on him, and he needed to adopt a carer role. He decided he wanted to be there to support his partner through challenging times living with Chronic Granulomatous Disease (CGD).

The couple both had a lifelong dream of growing a family, however many doctors said they shouldn't even consider it due to Lisa's condition. This news was devastating for the couple, and greatly impacted their mental health. They struggled to see a way forward, as their dream had been shattered.

The couple pursued a fresh start and moved from Queensland to Tasmania in 2016. After moving, they attended an IDFA Conference in Melbourne, where they spoke to Dr. Nizar Mahlaoui. They shared their broken dream of having a family, Nizar simply replied "of course you can, people in France with CGD have kids all the time." From this moment on, their lives were forever changed.

They began planning a family and looked forward to the future. Ben and Lisa were fortunate enough to

"Take care of yourself as a carer. If your physical and mental health are not in a good place, you're unable to properly care for the ones you love. It's not selfish, it's smart to relax and recover" - said Ben



deliver a happy, healthy little girl, Gracie into the world three years ago. For the 11 months post birth, life was challenging, as Lisa was in and out of hospital due to open wounds and slow recovery. During this time, Ben was the backbone of the family, he took leave from his work, and supported his wife and newborn daughter.

When the decision was made to have a child, Ben researched ways to protect Gracie and they decided to store the umbilical cord blood, as this can be used for up to 20 years to cure conditions that Gracie may face, including CGD. Ben believes this is the best 'get out of jail' card he can buy for his daughter.

Each day is different for the family, depending on Lisa's health. One day Lisa could go to gym, then to work and then do the shopping, which could be followed by two days in bed. Life is unpredictable for a carer and Ben considers his adaptability to be his strongest trait, allowing him to step in when necessary, in most of the roles in the house.

Nowadays, every Friday, Ben spends the day with Gracie, which gives Lisa a chance to recuperate. As with many people in a support role, Ben says that his family comes first, which does put mental/physical strain on him as a carer.

One way in which Ben is able to switch off from being a dad and a carer is by engaging in home-based hobbies – gaming online with friends, voice acting and producing a comic. This gives him time to focus his energy on something else, but still be accessible if need be.

Creating Awareness and Education



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



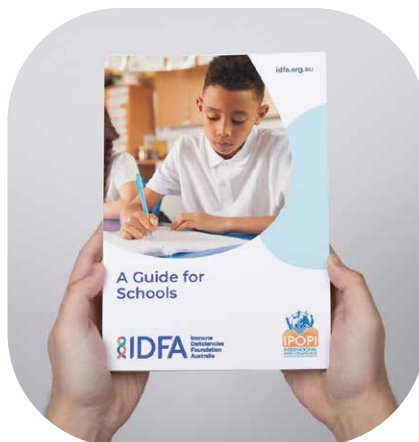
Educational Resources

Member Resources

The IPOPI Resources used by IDFA have been re-branded to reflect the IDFA brand more accurately. As the resources are reprinted, the Medical Advisory Panel are reviewing the content to ensure relevance to the Australian context.

In conjunction with its members, IDFA developed the SCID Connect brochure to support families who have received a diagnosis of Severe Combined Immunodeficiency. The Online Support Groups brochure was also developed to highlight the ways in which members can connect with each other finding online support within the community.

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



Scan the QR Code above to view our educational resources

Online Webinars: PI Education Program

Education continues to be at the forefront of our member support activities. Our innovative PI Education webinar series aims to increase awareness of primary immunodeficiency in the community and provide education to those who are affected.

The program was originally developed in response to enquiries from our members and the community about the impact of a primary immunodeficiency on the life of an individual and those around them.

The aim of PI Education Program is to provide a greater insight into the challenges faced by our members and support quality of life.

Each year a range of topics are identified from questions raised by members and areas needing greater awareness in the community.



The majority of the content was identified as new to registrants.



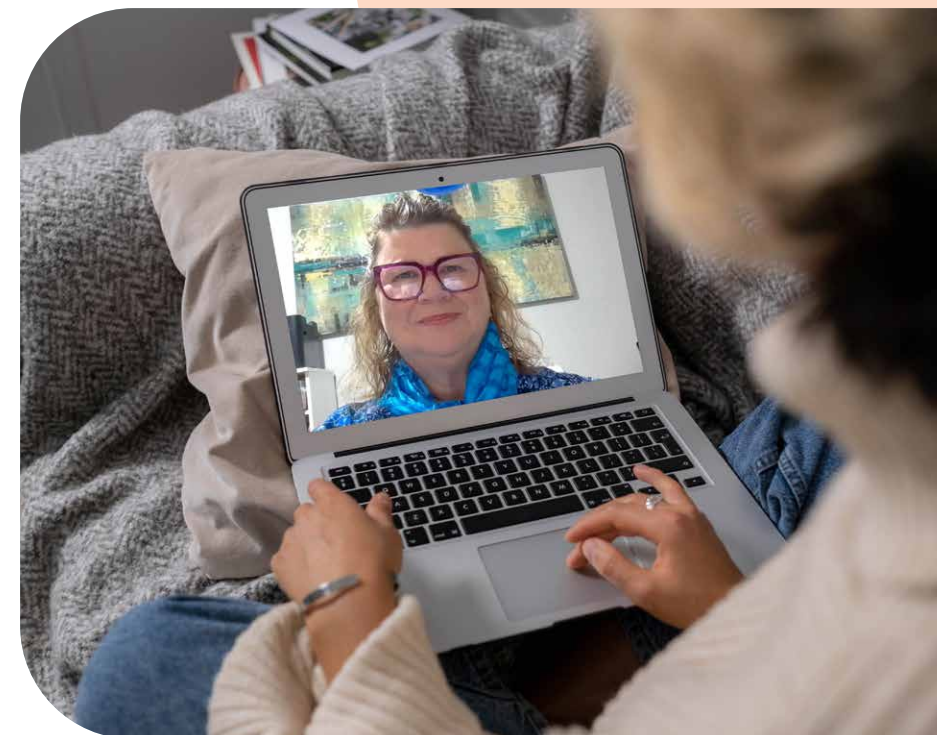
22 expert guest speakers presented on a range of topics.



328 member registrations received for the PI Education webinar program.



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



During the last 12 months our PI Education Webinar Program consisted of the following topics:

- Nutrition and Healthy Lifestyle
- SCID and Self Advocacy
- Mental Health and Immunodeficiencies (partnership with MindSpot)
- Carers Online Yoga Class (Carers Week)
- IDFA Members Update and Christmas Event
- COVID-19 and Immunodeficiencies Update - Rare Disease Day (partnership with AusPips)
- National Blood Authority Update
- Use your Voice - Self-Advocacy
- Travel Smart with Immunodeficiencies.

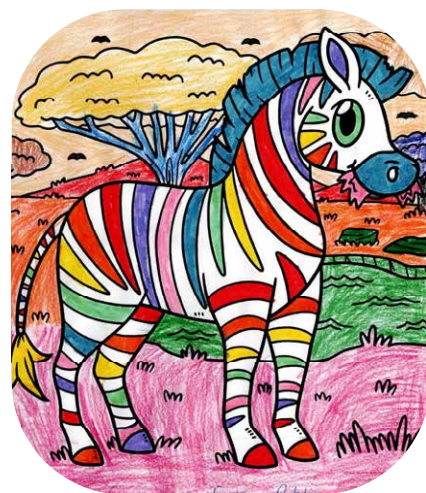
Rare Disease Day

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

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

In 2023, IDFA partnered with WIN TV Newsreader Melissa Russell to film a storybook reading for social media 'Merlin the Little Feline', by Sonia Goerger and Elodie Garcia, which is part of the rare disease day campaign toolkit. Using the analogy of a lion cub who doesn't resemble his pack, the book explores the difficulties families can have to both obtain a diagnosis for a rare disease and discover a community who can provide information and support.

To raise awareness, IDFA ran a colouring competition for primary school children. An additional social media competition was run, calling upon the community to 'share your colours' to raise awareness for the day. This was an extension of the global campaign. Students from Forbes Public School dressed up in colourful attire on the day to support a local family and IDFA member Jack Baxter.



On Rare Disease Day, a webinar was hosted 'Special Rare Disease Day Webinar: COVID-19 and Immunodeficiencies' a collaboration with AusPIPS. There were 56 members that attended the webinar, and seven panellists.



16
PR articles generated.



150
entries into the colouring competition.



56
attendees to the Rare Disease Day Webinar.



7
member stories shared during the campaign.



World PI Week

To celebrate World PI Week, IDFA employed a number of strategies to spread the message and importance of primary immunodeficiencies. These included a social media campaign, website page development, email direct marketing content series and a webinar.

The social campaign included a competition, members stories and facts and figures surrounding World PI Week.

A homepage takeover was created (on the website) and a designated landing page was developed which highlighted how people could interact with the campaign.

A designated email content series was developed which included information about ways to participate, webinar details and information and a campaign wrap-up.



A PR campaign was developed supporting the meeting for AS-CIA's National Immunology Strategy. IDFA provided a diverse range of members' stories around the need for genetic testing in Australia, resulting in approximately 10 original pieces of coverage, with syndications across AAP (60) and Fairfax.

A PI Education Webinar was held in conjunction with Christine Jeffery from Blue Wren Advocacy - where the Self-Advocacy Toolkit was launched. Attendees were provided with insights about how to self advocate as well as learn how to use the tools and hear lived experiences of those who've self advocated. A video content series was also developed for the launch with three members highlighting the need for the toolkit (with short teaser videos) and Christine Jeffery discussing how to use the tools.



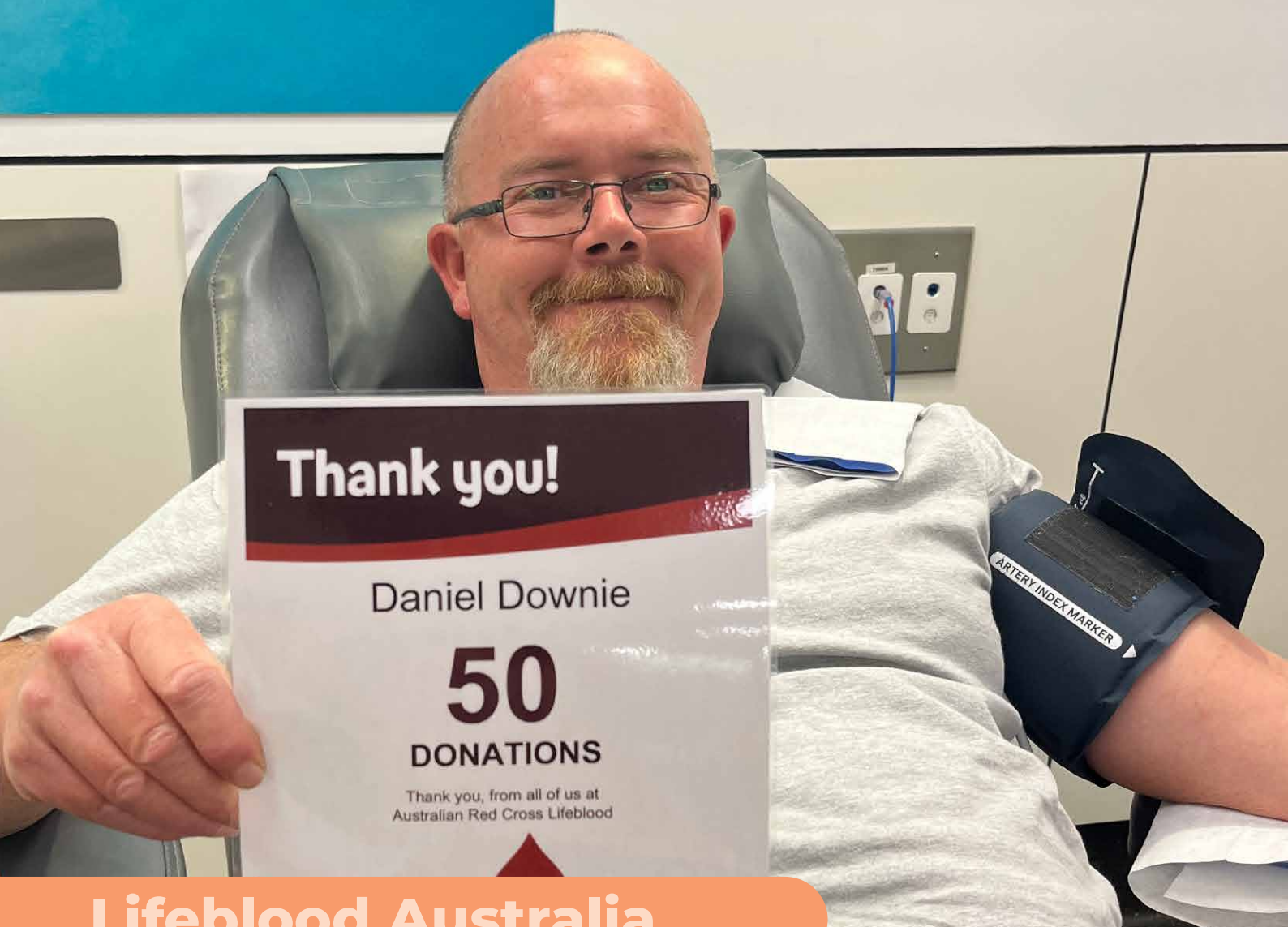
29%
increase in Facebook page visits



70%
increase in Instagram followers



Lifeblood highlighted a member story and shared the campaign



Lifeblood Australia Partnerships

International Plasma Awareness Week

IDFA collaborated with Lifeblood Australia to highlight the need for plasma donations across Australia. Activity included a joint media release distributed to local media, highlighting the team donation and raising awareness for plasma donations - with three stories secured. The campaign included the development of social media content, which included the 'plank for plasma' competition and email marketing to the membership base.

As part of the initiative, IDFA staff visited the Wollongong donor centre to donate plasma.

National Blood Donation Week

To highlight the need for blood products, IDFA collaborated with Lifeblood during the campaign period. A media release was crafted in line with the theme 'birds of a feather' that highlighted a member and her husband (who regularly donates).

A shareable social media campaign was developed to encourage members to activate their community to join the #IDFALifeblood team. To accompany this, an email campaign was developed and distributed to members.



Community

Website

IDFA's website has been updated to reflect the new strategic priorities. This has been done to create a simple user navigation and user-friendly experience. Over the last year, IDFA has continued to build on content, adding in additional member stories, event dedicated landing pages (Rare Disease Day and World PI Week); donation pages and more. To align with the updated branding of IDFA, changes have been made to several pages to ensure consistency across the entire website.

Social Media

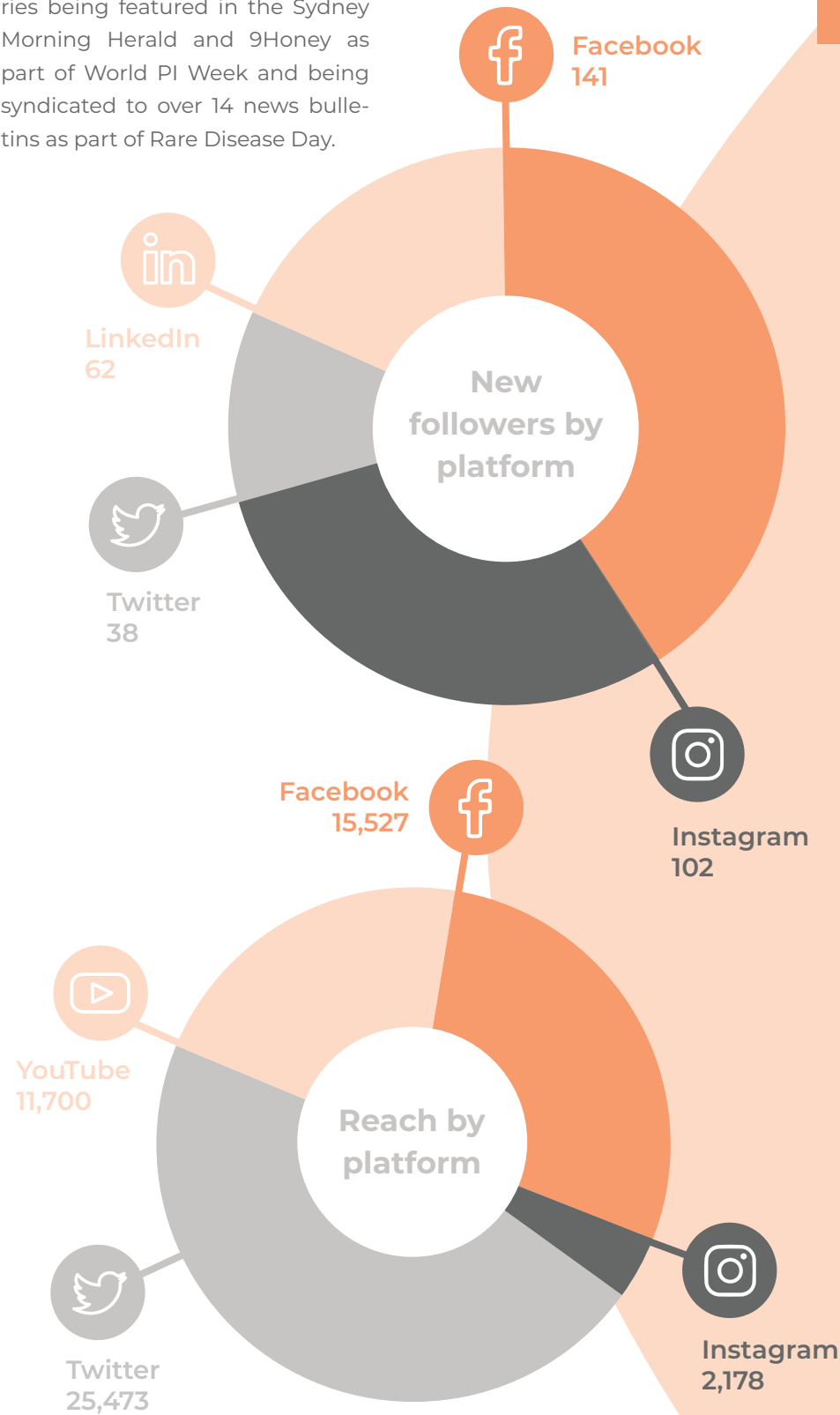
3,013
followers on our online community (Facebook, Instagram, Twitter, LinkedIn).

3,361
engagements on our private IDFA Facebook groups.

54,878
people reached via our online community.

Public Relations

IDFA has been featured in several media articles throughout the year, increasing its national profile. Highlights include member stories being featured in the Sydney Morning Herald and 9Honey as part of World PI Week and being syndicated to over 14 news bulletins as part of Rare Disease Day.





Relationships

Member Organisations

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

ASCIA

IDFA have been involved in ongoing meetings with ASCIA in relation to the National Immunodeficiency Strategy including planning for the roll-out of all initiatives within the strategy. IDFA attended the ASCIA conference in Melbourne and met with healthcare professionals interested in immunology.

Government

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

Throughout the year IDFA have conducted a national campaign to advocate for government funding for SCID newborn screening. This campaign has involved mobilising our members to write to local MP's and to sign a petition to allow the issue to be raised in parliament.

As part of the campaign we were able to meet with several government and opposition Ministers to discuss the importance of screening. IDFA were successful in influencing the NSW state government to extend funding for the SCID Pi-



lot Program until August 2022 and the federal government recently announced that SCID would become a standard newborn screening test across Australia.

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



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.

IDFA Support

Online Support Groups

Here at IDFA, our motto is I Don't Feel Alone.

When you become a member of IDFA you are joining a community of people who understand what you're moving through, because they're moving through it in their own way too. No matter where you live in Australia you can connect with the IDFA community to ask questions, share experiences, and seek feedback in safe and inclusive spaces.

This year we paid special attention to our support groups, giving them a new look and feel. Our goal, as always, is to create a suite of online spaces that cater to the diversity of our membership base. We now have a variety of opportunities for our members to connect and support each other in their journeys, including:

- IDFA Connect
- IDFA SCID Connect
- IDFA YAM Connect
- IDFA Parents Connect
- IDFA Carers Connect
- IDFA SID Connect
- IDFA Family Connect
- IDFA Youth Connect

Community Catch-ups (Online)

For this past year we have been supporting our members by having one of our staff host a 90 min catchup every week on a Wednesday evening. There was a group of six-or-so members that would regularly use this space to connect, debrief and support each other, with new members joining in sporadically over the year.

Looking forward to this coming year, we are working to set up a member-run groups platform on Zoom and upskill our members in how to facilitate a group conversation. We're aiming to allow our members to host the conversations that feel important to them, in a time slot that works for their schedule.



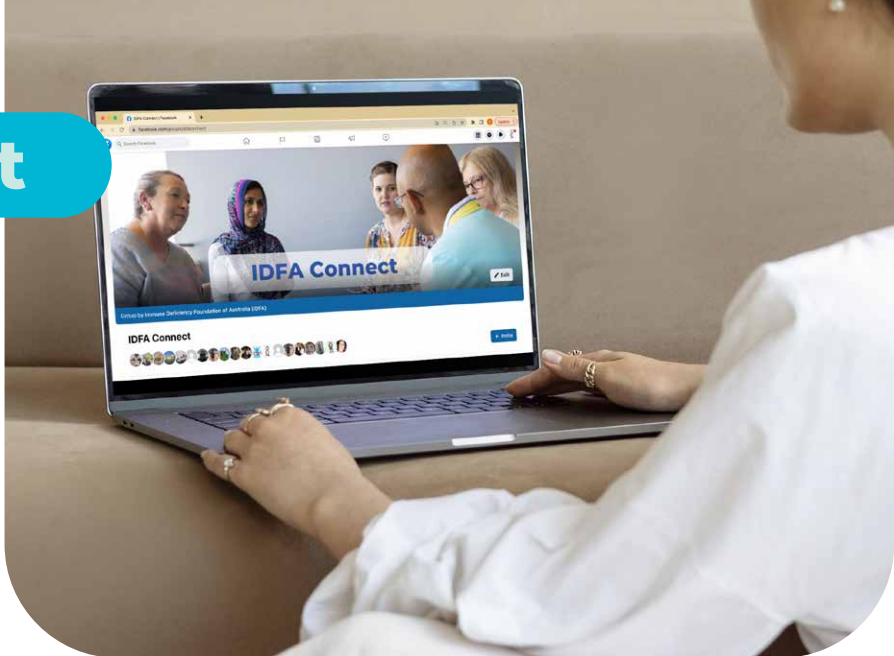
7

online support groups formed to support members.



50+

online community catch-ups hosted.



Member Meetups

Throughout the year, we continued to engage with and bring together our members for in-person meetings. Our High Tea-themed Member Meetups held in Brisbane, Canberra and Adelaide were thoroughly enjoyed by our members.

Each event offered a relaxed environment for attendees to network and receive IDFA updates and insights from Health Professionals. Presentations were made by immunologists Luke Droney, Katrina Randall and Jovanka King, and personal experiences were shared by the following members: Tricia Parry, Bianca Willis, Pearl Sims, Hayley Teasdale, Adam Friederich, Alison, Laurie and Beccy Copley.

Moving into this next year, we will continue to facilitate in-person events for our members to attend in the pursuit of information-sharing, networking and for our members to connect with other individuals who understand their journey.

National Carer's Week

We think Carers are an important part of the IDFA family. One of the ways to build community for our members is by providing social support, bringing you together with others affected by immunodeficiency. For our IDFA Carers, we connect them with a community who understands the obstacles faced by those looking after someone with complex medical needs.

During National Carers Week, IDFA takes a special focus on the Carer community to raise awareness about caring roles and recognise, celebrate and thank them for the work they do every day.

We partnered with Carers NSW to hold an online Yoga session for our Carers to relax, reflect and take some time for themselves. The aim was to help them take a break from the important work that they do every day and hopefully upskill them in how to take better breaks in the future.



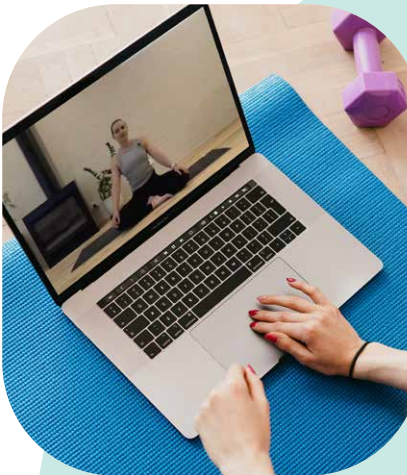
6

member meet-ups held over the year.



10

carers registered for National Carers Week event.



Circle of Support

With the help of member Peer Mentors, IDFA has created and piloted a new opportunity for members who reach out in need of support!

Circle of Support is tailored one-to-one peer mentoring by a trained member who can offer connection, socio-emotional support, empowerment to work through current challenges, build self-advocacy and achieve personal self-management and lifestyle goals for quality of life. This peer mentoring approach built upon the strengths of previous member peer support and IDFA's patient and community focused models of care.

Circle of Support aims to assist members who are newly diagnosed or who face significant challenges managing their immunodeficiency, providing support when members need it most, so they don't feel alone.

Members express interest by completing a registration form on the new IDFA Circle of Support webpage and aim to be matched with a Peer Mentor in their state/territory. Peer Mentors also work with members to develop a personal action plan to move forward and offer empowering support along the way.

Circle of Support Core Principles



Connect
Social support for mental wellbeing



Empower
Coaching for Self-efficacy



Support
Mentoring for self-management and self-advocacy



Scan the QR Code above to find out more about Circle of Support



"Thank you for putting this all together. The SMIDs topics and prompting questions are super helpful and valuable!"

"It's great to have resources at hand. You have done a fantastic job – Thank you!"

- Circle of Support
Peer Mentors

Thank you to the 10 members nationwide who tested the comprehensive Peer Mentor training. This included helping develop a series of 12 weekly immunodeficiency specific self-management sessions to support member goals. Each session explored common member issues, case studies of goals, action plans, and ways to help members build confidence to take steps forward.

The training for Circle of Support Peer Mentors included:

- Mental Health Support workshop
- Health Coaching workshop
- Mental Health First Aid workshops and self-paced online program
- Accidental Counselling self-paced online program
- 12 week Self-Management for immunodeficiencies (SMIDs) program

Trainee Peer Mentors also helped to create Circle of Support guidelines and training materials to ensure effective relationships and member safety and wellbeing.

To date, areas of support have included: mental health and wellbeing, managing treatment plans, pain management, physical activity and mobility, and support to enter the workforce managing a PI.



16

online workshop sessions completed by peer mentors



12

self-paced mental health modules completed by peer mentors

The Circle of Support pilot will be evaluated with member and Peer Mentor feedback, and materials and guidelines reviewed and finalised for ongoing member support.

We are very encouraged by emerging feedback from members and look forward to hearing more about their Circle of Support journeys!

Circle of Support: Member Stories

Mentor - Liv

When Liv was invited to join Circle of Support (CoS), she was excited for the endless opportunities that being involved with IDFA would bring. Furthermore, she was keen to be part of the process, contributing her knowledge and providing support to other members.

The initial stages of the pilot consisted of training, which Liv took to well. Learning alongside and being involved in a group of like minded individuals, passionate and professional in their own careers and life experiences was something Liv really enjoyed. Sections of the course included guest speakers sharing their experiences, all with different backgrounds in their own profession, Liv thrived from gaining knowledge from others.

The training gave Liv and the other Peer Mentors a platform to share ideas and opinions (all with different or similar PI's). That's what makes the difference in building a network together- they all achieved something from it.

Helping someone in the community is a special opportunity. Whether it be listening to their experiences or offering them guidance and support as they navigate their own world has been very rewarding for Liv. So far, she has been able to help her mentee feel more empowered on her health journey. Liv being the optimistic person she is, was able to provide a positive and encouraging way forward for her mentee during their recovery. There have been many laughs and

“Being part of a pilot program is a launchpad to learn, enhance and shape my own skills to support someone just like me living with a rare disease.”

sharing hope for their future. It's been an honour for Liv to be a part of that chapter in her mentee's life.

Liv highlights the importance of knowing there is someone you can turn to who has a rare disease and understand the challenges it brings, particularly newly diagnosed individuals. There are so many questions when being first diagnosed, so having the chance to chat with someone who has been there in their own moment and has the same or similar rare disease is a relief. Finding a connection to someone who has been in that moment of diagnosis themselves, naturally understanding and knowing what answers may be or help them find guidance is extremely important.

“Having the IDFA there in that discovery phase of my own PI was such a blessing.”



Mentee - Bella

When Bella joined the Circle of Support she didn't expect to connect so well with her Peer Mentor, Liv. Even though they live in different states, the communication between the two has been so important to Bella's journey. Having that listening ear, and someone who has been through a similar circumstance made her feel as though she was not alone.

Circle of Support is important to members such as Bella who don't have a strong support system around them. Liv was also able to share her own experiences with Bella, making her feel as though her concerns were valued and important.

Liv and Bella caught up regularly at first, growing both physically and mentally together. They also did a couple of zoom calls, which was nice to put a face to a name. Nowadays, Bella can text Liv to catch up when necessary.

Bella has gained so much from Circle of Support. Her physical and mental health journey has been very challenging, with a cancer diagnosis and treatment as well as the trauma surrounding this.

Liv has been there for Bella and supported her journey. Bella has also gained self-confidence throughout her time and been able to secure a job, something in which she never assumed possible.



“Liv has been amazing, not only as a Peer Mentor but also as a friend. Personally, I think we have learned a lot from each other.”

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.

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



National Blood Authority

IDFA have continued to work with the NBA on 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 awaits the outcomes of this consultation to ensure that all members can have equitable access to treatment.

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.



COVID-19 Research

IDFA partnered with the University of Sydney for a research project to determine the extent of impact of the COVID-19 pandemic on individuals living with primary and secondary immunodeficiencies.

The results of this study have been presented to IDFA and shared with our Board and members and were presented at the 2023 ACSIA Conference.

Screening and Testing

After several years of advocating for the national implementation of newborn screening for Severe Combined Immunodeficiency (SCID), IDFA is very pleased to see most states and territories now live.

Early diagnosis by newborn screening allows for SCID treatment to be undertaken before infections cause significant complications and possibly permanent disability, and even death. Prior to 2023, SCID NBS was not routinely performed in Australia, unlike in New Zealand, the United States, and some European countries.

Following the recommendation to include SCID in all state and territory newborn bloodspot screening programs by the Hon Mark Butler MP, Minister for Health and Aged Care on the 28th June, 2022, IDFA wrote to state and territory Health Ministers requesting a start date.

During 2022 IDFA was very pleased to hear NSW/ACT, Victoria and Queensland state health departments making successive announcements of funding commitments for ongoing SCID NBS.



This included funding for the procurement of equipment, testing of relevant technologies and systems, and development of laboratory and other infrastructure. IDFA was particularly pleased to hear the Queensland Health Department also announce the start of SCID NBS during the second quarter of 2023.

During the first half of 2023 the IDFA SCID Advocacy Working Group members remained vigilant and continued regular communication with SCID NBS member carer advocates and health professional members in each state and territory for updates on preparedness for SCID NBS.

IDFA was delighted to also receive correspondence from the WA Department of Health announcing funding for SCID NBS and advice they were working towards also starting SCID NBS in the first half of 2023. The South Australian Health Minister also communicated the state was on track to start SCID NBS in early 2024.

On 27th of May 2023 in a watershed moment, Queensland announced they were going live with SCID NBS. QLD member carer and SCID advocate Louise Grant provided a keynote address at the press conference to culminate her many years of advocacy with Pathology Queensland and the Queensland Minister for Health.

The Western Australian Department of Health have also announced the commencement of SCID NBS. The office released a media story of IDFA member carer Sarah McArthur, who was



During 2022 IDFA was very pleased to hear NSW/ACT, VIC and QLD health departments making funding commitments for ongoing SCID NBS.

expecting her second child and was incredibly relieved her new baby will be screened. Parents of SCID babies are advised they can have a 1 in 4 chance of having another child with SCID.

After extensive member petitions with thousands of signatures, regular meetings with politicians with member advocates, and ongoing IDFA communication with Health Ministers, national coverage for SCID NBS is now almost a reality.

IDFA together with advocate members, health professionals, and partner organisations like Rare Voices Australia, now stand poised ready to celebrate the monumental achievement of national SCID NBS in January 2024!

SCID: Member Stories

Antoni

On the 20th of October 2021, Ladawan gave birth to her son, Antoni at St. George Hospital. Although Antoni arrived a little earlier than expected, all went well.

A few days later, a Newborn Bloodspot Screening test was done. They received a call advising of some abnormalities in the test and to come back to hospital to do another. Following this second test, she was advised that the test was inconclusive, and if there was anything major she would be contacted (and she was not).

Antoni then attended his first immunisation appointment at 6 weeks of age. Two days later at home, he became severely unwell experiencing a seizure. This was confronting and incredibly scary for the family as they rushed their little boy to the hospital – where he was for almost a year.



Antoni's immunisations triggered an immune response that required further testing, particularly for epilepsy. During these tests, a diagnosis of SCID was provided. The family was advised that their son would need to stay in hospital and isolated to survive.

As Ladawan and her husband Miroslaw already had two children, Ladawan stayed with Antoni. Due to the need to isolate, she was the only family member that was able to be with him, creating a very lonely and mentally difficult time for her. There were no definite answers on what was going to happen next.

In March 2022, Antoni, Ladawan and a nurse travelled to London, UK to receive a Thymus Transplant. This treatment is not available in Australia, so the Government provided them the opportunity to receive this transplant. After spending one and a half months in the UK for the transplant, the family returned home to hospital in Australia.

When Antoni went home, it was short lived as after two weeks he was admitted to hospital again, after contracting COVID-19. He then stayed in hospital until November 2022. During this time, he needed a central line, which often became infected. It wasn't until Antoni turned one in October that he was allowed a few more visits from his close family members.



Once well enough to go home, he still regularly attended the hospital for check-ups. At this time, the family remained vigilant whilst also trying to continue living their life. It was and still is quite an uncertain time for the family, as Antoni is only the 56th child to receive this specific transplant in the world, there is lots of unfamiliar territory.

Ladawan has just recently embarked on a trip to Thailand to spend five weeks with her family. This kind of travel required careful planning with medication, information, and certificates from doctors to ensure a safe and healthy trip.

Antoni is almost two and the family regularly expose him to the community, as his immunity has increased and to further strengthen this. He is doing well and they are excited about the future with him.

SCID: Member Stories

Kai

In February 2022, Sumali gave birth in Blacktown Hospital, to her first child – Kai (meaning warrior). It was a relatively straightforward birth and they were so excited for the arrival of their son.

Sumali and Heshan enjoyed the newborn phase and time together as a family of three. On day three, they were discharged from hospital. The following day, a midwife from the hospital arrived at their house for a wellbeing check of Kai and mum and to do a Newborn Bloodspot Screening test.

Three days later Sumali received a call advising abnormalities in Kai's test, and to return to hospital to complete more testing. They were handed a leaflet on immunodeficiencies, which was not only daunting, but hard to understand and comprehend. As they read through the information, they struggled to digest the magnitude of the situation and the impact it would have on all their lives.

The family was then contacted by the immunology department at Westmead Children's Hospital. It was suspected that Kai has Severe Combined Immunodeficiency (SCID) and Sumali was told to stop breastfeeding immediately (due to the potential of passing CMV infection) and that they need to protect him from as many germs as possible. This situation was both challenging and overwhelming mentally and physically, however they were grateful for the support of

their immunologist Dr Melanie Wong and Westmead Children's Hospital Oncology clinic specialists who were able to guide and advise them during this time.

From this point on, it was test after test. The emotions were high for all family members, and it was a very different experience than expected with a newborn baby.

They were then advised that Kai had SCID and must live in a 'bubble' for three months until he was strong enough for a bone marrow transplant. In late May, Kai underwent 7 days of a special chemotherapy regime focused on monitoring blood cell generation. On 30 May Kai endured a lifesaving bone marrow transplant with his father as the stem cell donor. After staying nearly three months in the hospital going through different treatments, Kai was reunited with family at home in July.

Kai continued post-transplant treatments for a further 6-7 months which, whilst helpful, also caused infections. However he was able to fight these due to his strengthened immune system.

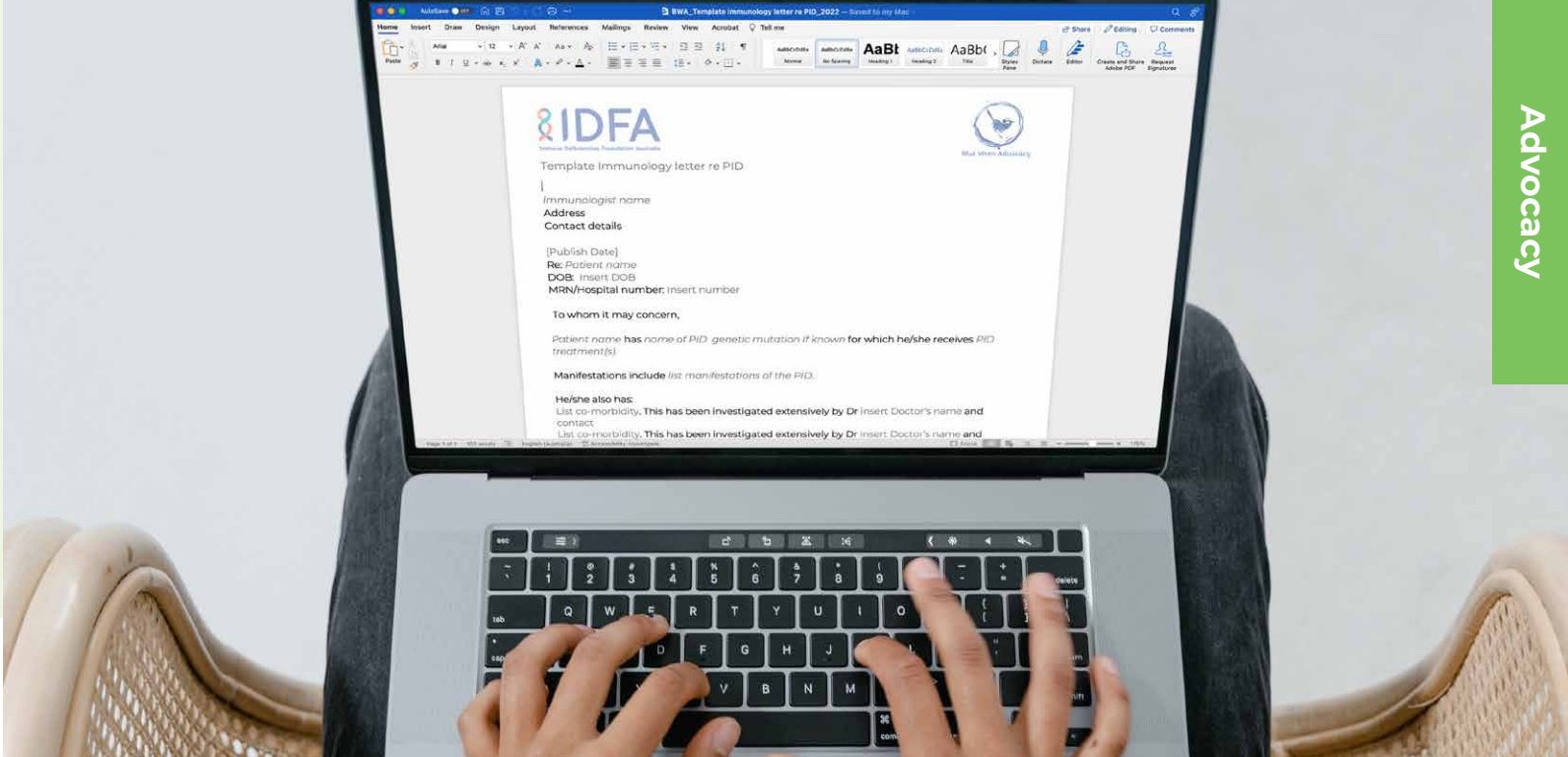
From early diagnosis, Kai did very well with the transplant and has been relatively healthy. He has been doing physiotherapy and speech therapy and the family have also received guidance to improve quality of life after a bone marrow transplant.



One year on and the testing has indicated that Kai has a good immune function and has completed his inactivated vaccines, which is a great outcome for the family. As far as they know, Kai doesn't have any significant impacts from SCID.

If they were in Sri Lanka, there is no way he would have been tested. It was also good timing for the family as there was a clinical trial for SCID to be included in the Newborn Bloodspot Screening test and they happened to be part of it. Since finding out she has a SCID baby, Sumali has joined a network of other parents in similar situations who all work together to help each other and educate the wider community of the importance of early testing.

NBS didn't only save Kai's life; it saved his family and their mental health. Kai's family is so grateful for this test and to the doctors and nurses who worked to get Kai where he is today.



Self-Advocacy Toolkit

Self-Advocate for Early Diagnosis and Treatment

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

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 Christine Jeffery at 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 above to view the self-advocacy toolkit.



Sponsors and Partners

IDFA Sponsors

Through the kind support of our sponsors we are able to deliver ongoing value to our members through a range of opportunities including:

- Developing and printing resources
- Creating engaging education campaigns
- Events including; Patient Meetings, Carers Week Annual Conference, World PI Week and our Young Adult Members Conference engagement activity
- Online support groups
- Online events including webinars and conferences

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

Thank you to all of our major sponsors:

CSL Behring

GRIFOLS



International Entertainment

The generous support of International Entertainment as an external fundraiser has supported IDFA since inception. Businesses are encouraged to sponsor tickets to our shows which in turn support children with special needs and disadvantaged families within their community. Tickets are given to these families to provide respite and an exciting and fun experience they might not be

able to afford otherwise. Through the profits received from ticket sales, IDFA can continue to support patients and families living with immunodeficiencies. These shows are thoroughly entertaining and are held in locations across Australia.

Show locations:

NSW

Albury
Lismore
Newcastle
Penrith
Sutherland
Wagga Wagga

VIC

Bendigo
Geelong
Melbourne
Mildura

ACT

Canberra

QLD

Brisbane
Cairns
Mackay
Toowoomba
Townsville

SA

Adelaide

TAS

Burnie
Devonport
Hobart
Launceston

WA

Perth
Kalgoorlie



Professional Networks

International Networks



National Networks



Networks

Allergy and Immunology Foundation Australasia

Arthritis Australia

AusPIPS

Australian Immunological Alliance

Australian National University

Australian Red Cross Lifeblood

Australian Patient Organisation Network

Australian Patient Advocacy Alliance

Auto Immune Research and Resource Centre

Beyond Blue

Cancer Council

Carers NSW

Centre for Personalised Immunology

Centrelink

Clinical Immunogenomics Research Consortium Australia

GUARD Collective

Genetic Alliance

Genetic and Rare Disease Network

GSVN

Haemophilia Society Australia New Zealand

Immune Deficiency Foundation New Zealand

Immune Deficiency Foundation USA

Leukaemia Foundation

Livewire

Lung Foundation Australia

Lymphoma Australia

Mastocytosis Australasia

Mind Spot

Ministry of Health NSW

Monash University

National Disability Insurance Agency

National Immunoglobulin Advisory Committee

Outer West Local Health District

Sleep Health Foundation

Thalassaemia Society of NSW

University of Sydney

University of Western Sydney

University of Wollongong

Volunteers Australia

Donations and Fundraising

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

Donations

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

\$10 Cost of SCID Newborn Screening Test

\$20 Cost of posting a resource pack to one of our members

\$50 Cost to cover one of our members attending a patient meeting

\$100 Covers the printing costs of a complete resource pack

\$150 Helps one of our child members to attend a weekly activity to engage with other children with a immunodeficiency

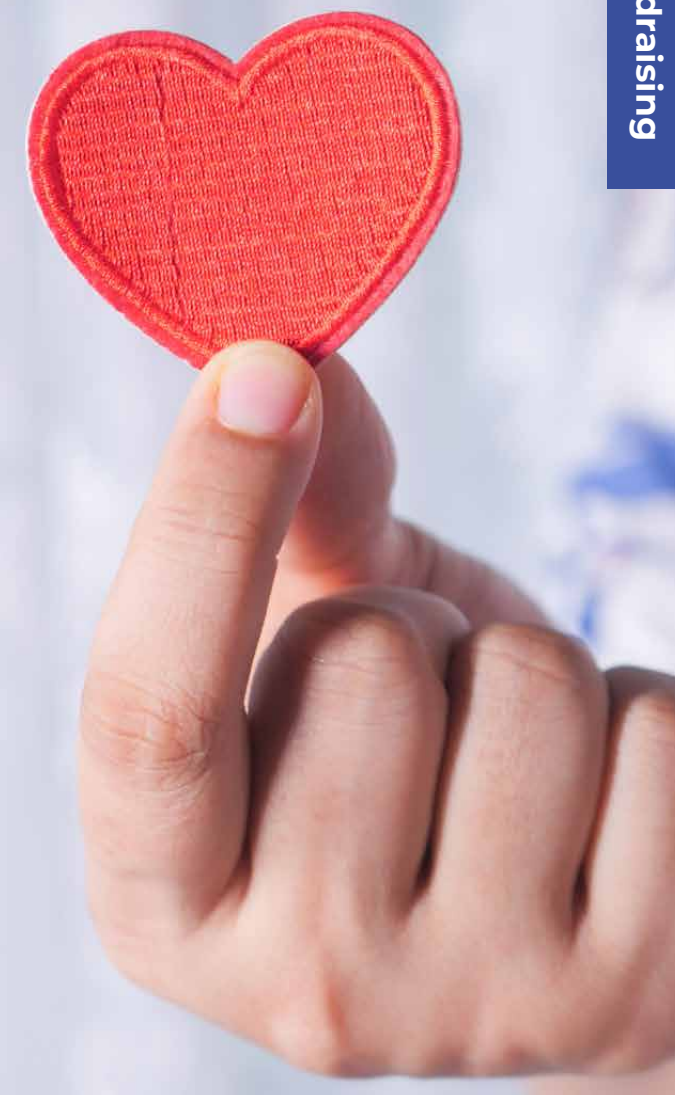
\$200 Cost of registering one of our members to attend an IDFA conference

\$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 on-going work in supporting Australians living with primary and secondary immunodeficiencies.

BOLSTA
RAFFLES



Merchandise

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

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

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

Awareness Pin
\$7

Zebra Pen
\$5

Tote Bag
\$20

IDFA Pack
\$35





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

Volunteers

IDFA Board Members

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

Medical Advisory Panel Members

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

National Patient Advisory Panel Members

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

Students

Linda Lin
Ethan Italiano
Diana Rameziani

Healthcare Professional Panel Members

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

Financials

Statement of Profit or Loss and other comprehensive income

	2023	2022
IE Income	\$1,945,357	\$1,783,413
Cost of Sales	(\$1,593,720)	(\$1,533,321)
Gross Profit	\$351,637	\$250,092
Finance Income	\$497	\$74
Other Income	\$131,431	\$114,770
Marketing Expenses	(\$7,158)	(\$14,369)
Administrative Expenses	(\$339,948)	(\$333,387)
Functions, Awards and Presentations	(\$12,874)	(\$6,406)
Lease Expenses	(\$7,868)	(\$23,041)
Peer Support Program	(\$11,071)	-
Other Expenses	(\$90,103)	(\$65,404)
Finance Expenses	(\$3,739)	(\$77)
(Deficit)/Profit before income tax	\$10,804	(\$77,748)
Income Tax Expense	-	-
(Deficit)/Profit from continuing operations	\$10,804	(\$77,748)
(Deficit)/Profit for the year	\$10,804	(\$77,748)

Statement of Financial Position

ASSETS	2023	2022
Current Assets		
Cash and Cash Equivalents	\$381,297	\$335,775
Other Assets	\$11,310	\$5,281
Total Current Assets	\$392,607	\$341,056
Non-Current Assets		
Property, Plant and Equipment	\$13,031	\$9,483
Intangible Assets	\$12,608	\$17,198
Right-of-use Assets	\$110,694	-
Total Non-Current Assets	\$136,333	\$26,681
Total Assets	\$528,940	\$367,737
LIABILITIES	2023	2022
Current Liabilities		
Trade and Other Payables	\$35,653	\$24,525
Lease Liabilities	\$16,288	-
Employee Benefits	\$9,625	\$12,133
Other Financial Liabilities	\$28,621	-
Total Current Liabilities	\$90,187	\$36,658
Non-Current Liabilities		
Lease Liabilities	\$96,870	-
Total Non-Current Liabilities	\$96,870	-
Total Liabilities	\$187,057	\$36,658
Net Assets	\$341,883	\$331,079
EQUITY	2023	2022
Retained Earnings	\$341,883	\$331,079
Total Equity	\$341,883	\$331,079



Our Vision

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

Our Purpose

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

Head Office

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