

1st April 2024-
31st March 2025

Annual report & financial statements

supporting individuals and families
affected by primary and secondary
immunodeficiency



Contents

- 03 About Immunodeficiency UK
- 06 Trustees' responsibilities and financial overview
- 07 Chairman's statement
- 08 Our achievements at a glance
- 10 Living with immunodeficiency
- 13 Supporting the immunodeficiency community
- 14 Our helpline services
- 15 Our website
- 16 Raising awareness of immunodeficiency
- 17 Booklet and information development
- 18 Providing mental health support
- 19 Providing hardship grants and pain-relief devices
- 20 Our advocacy work
- 23 Our incredible fundraisers
- 26 Financial statements

Why we are needed: Currently in the UK



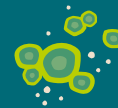
500,000+

people have an impaired immune system



5,000+

people have a diagnosed primary immunodeficiency



480+

different rare conditions are recognised as primary immunodeficiencies



6,670+

people with primary and secondary immunodeficiency rely on the life-saving therapy immunoglobulin

Primary and secondary immunodeficiencies are underdiagnosed.

Immunodeficiency UK is the only UK charity that supports and represents people affected by primary or secondary immunodeficiency.

The need for Immunodeficiency UK's patient support services has never been greater.

About Immunodeficiency UK

Immunodeficiency UK registered as an independent charity on 20 January 2021 as a continuum of the work of Primary Immunodeficiency UK (PID UK) in representing and supporting individuals and families affected by primary immunodeficiency in the UK.

Building on the work of PID UK, Immunodeficiency UK supports people affected by primary and secondary immunodeficiencies.

Immunodeficiency UK plays a vital role in supporting and representing people affected by primary and secondary immunodeficiencies

Primary immunodeficiencies (PIDs) are a group of over 480 different conditions that affect how the body's immune system works because some parts are missing or not functioning. Most people with PIDs are born with the condition. PIDs are mainly genetic disorders, meaning they are inherited and can be passed on from one generation to the next. Because PIDs are rare, some people remain undiagnosed for many years, resulting in organ damage and even disability.

Secondary immunodeficiency (SID) occurs when the immune system is weakened by a treatment or another illness. There are many potential causes of SID but the most common examples are blood or bone marrow disorders and certain drugs and treatment for cancer. Some cancers can be responsible for SID, too.

Having a PID or SID means having reduced or no natural defence against germs, such as bacteria, fungi and viruses, which surround us every day. So, people with PID and SID get severe infections more often than is normal; they can take longer to get better when they have antibiotic treatment and, even then, the infections can keep coming back.

A large proportion of people affected by a PID or SID require immunoglobulin replacement therapy, which is produced from donated plasma. This therapy, along with antibiotics and other antimicrobial medicines can help keep those with immunodeficiency free from infection. More specialised treatments and potential cures for PID include haematopoietic stem cell transplant, enzyme replacement therapy, thymic transplant and gene therapy.

Some of the challenges faced by people affected by these conditions:

- Delays in getting a diagnosis
- Frequent medical admissions and appointments
- High burden of treatment and care
- Extra financial difficulties including costs associated with travel to appointments and loss of income due to poor health and inability to work
- Lack of knowledge, understanding and awareness among healthcare staff
- Negative impact of living with a chronic condition on mental health and well-being.

About Immunodeficiency UK

Immunodeficiency UK is the voice of people affected by PID and SID

Our mission and strategy

We work with patients, healthcare professionals and other organisations to ensure that those affected by primary or secondary immunodeficiency have the knowledge needed to manage their condition effectively. We aim to ensure that their health needs are understood and addressed by those involved in policy and delivery of healthcare.

To help Immunodeficiency UK in its work, we are a member of several umbrella groups, including Genetic Alliance UK, Gene People, the Specialised Healthcare Alliance, The National Council for Voluntary Organisations and The Foundation for Social Improvement. We are the UK national member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI).

Our main strategic priorities are:

- To provide assistance, advice or guidance in relation to the diagnosis, management and treatments for primary and secondary immunodeficiencies, and to improve quality of life for those affected
- To promote awareness and understanding of primary and secondary immunodeficiency, and the impact on those affected, among the general public and within the medical profession
- To provide a helpline service, events, practical support and advice
- To encourage and support research into the causes, treatments, prevention and cures for primary and secondary immunodeficiency, and to publish the useful results of that research.

Our trustees

Dr Matthew Buckland (appointed January 2021; resigned March 2025) – Chair
Valerie Brisse-Uhlig (appointed March 2022) and appointed as Chair, March 2025
Hannah Bruce (appointed January 2021; resigned March 2024)
Tamara Moubazbaz (appointed October 2022; resigned January 2024)
Jane Shepard (appointed March 2022) – Treasurer
Diane Hammond (appointed March 2022)
Annette Toft (appointed September 2024)
Clare Brailsford (appointed September 2024)
Tom Taylor (appointed January 2025)

Our staff

Dr Susan Walsh – Chief Executive Officer (CEO; full time)
Fay Fagon – Digital Communications, Marketing and Fundraising Assistant (14 hours/week)

Our advisory panels

Immunodeficiency UK is extremely grateful for the support of our patient representative and medical advisory panels.

About Immunodeficiency UK

Patient representative panel

Our patient representatives are dedicated volunteers who act as advisers, ambassadors and spokespeople for Immunodeficiency UK. They are either directly affected or have a family member affected with an immunodeficiency.

Marian Armstrong (Cumbria and Lancashire)

Margaret Bennett (West Midlands)

Hannah Bruce (South-East)

Hannah Butler (London)

Samuel Davis

Clare Dyer (South Wales)

Patricia Hamilton

Michael Ingleston (Northern Ireland)

Rae McNairney (Scotland)

Drew Tyne (London)

Fiona Watt (Scotland)

Medical advisory panel

The Medical Advisory Panel reviews the content of our patient information to make sure that it is of high quality, clinically and scientifically. The panel provides updates to the charity on advances in immunodeficiency, scrutinises new projects and ensures that Immunodeficiency UK is engaged in activities that are medically sound and based on up-to-date science.

Dr Peter Arkwright, Consultant Immunologist, Dept of Paediatric Allergy and Immunology, Royal Manchester Children's Hospital

Dr Matthew Buckland (Chair), Consultant Immunologist, Great Ormond Street Hospital and Barts Health NHS Trust, London (resigned March 2025)

Dr Mari Campbell, Clinical Psychologist, Royal Free London NHS Foundation Trust and Honorary Associate Professor, University College London

Emily Carne, Advanced Nurse Practitioner, Dept of Immunology, University Hospital of Wales, Cardiff

Professor Helen Chapel, Professor of Clinical Immunology, John Radcliffe Hospital, Oxford

Lucy Common, Immunology and Allergy Advanced Clinical Nurse Specialist, Salford Royal Hospital

Dr Lisa Devlin, Consultant Immunologist, Regional Immunology Service, Belfast

Dr Tariq El-Shanawany, Consultant Clinical Immunologist, University Hospital of Wales, Cardiff

Dr Tomaz Garcez, Consultant Immunologist, Central Manchester University Hospitals, Manchester

Dr Aarn Huissoon, Consultant Immunologist, University Hospitals Birmingham

Dr Tasneem Rahman, Consultant Immunologist, Epsom & St Helier University Hospitals NHS Trust South London and Surrey

Statement of Trustees' responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and regulations. Under company law, the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the net incoming resources for that period.

Structure, governance and management

Governing document

Immunodeficiency UK is a registered charity and governed by its constitution dated 20 January 2021.

Trustees

The board of trustees is responsible for the overall governance, policy and strategic direction of Immunodeficiency UK. The trustees have the legal responsibility for charity operations and the use of resources in accordance with the objects of the charity. During the period 1 April 2024 to 31 March 2025, the trustees met a total of 7 times.

Public benefit

The trustees confirm that they have complied with the duty in section 17(5) of the Charities Act 2011 to have due regard to the guidance issued by the Charity Commission on public benefit.

Executive management

The executive organisation is led by the CEO, who reports to the Board of Trustees. The CEO publishes reports and performance indicators for each trustee meeting which are then used by trustees to judge progress against strategic priorities for the year.

Risk management

The trustees have overall responsibility for ensuring that Immunodeficiency UK is managing risk in a professional, responsible and constructive manner. The trustees seek to ensure that all internal controls, and in particular financial controls, comply in all respects with best practice and the guidelines issued by the Charity Commission.

Financial overview

Total income for the year was £108,694, compared with £89,709 for the financial year 2023–24. This year the expenditure was £99,242 compared with £112,809 for the financial year 2023–24.

Reserves policy

The trustees, as part of their risk management policy agree to maintain a minimum level of contingency within free reserves to provide against any unforeseen changes in income and/or expenditure. Total reserves as of 31st March 2025 were £94,349 of which £19,165 related to restricted funds leaving £75,184 of unrestricted funds. These free reserves equate to 8.7 months of operating costs and are therefore in keeping with the reserves policy of holding free reserves equal to a minimum of 5–8 months operating costs (presently £8,600 per month).

Chairman's statement

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Charities Act 2011, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).



I am honoured to have taken over from Dr Matthew Buckland as Chair of Trustees of Immunodeficiency UK, following his retirement on 31st March 2025. His commitment, also as Chair of the Medical Panel, over the past 12 years has helped shape who we are today – a stronger, more responsive, independent charity advocating for real change. We are incredibly grateful for Dr Buckland's support and guidance, and wish him all the best.

Having been a Trustee for over three years, I have gained a good understanding of the charity's work and the needs of the immunodeficiency community. I have a deep passion for supporting this community and, as the new Chair of Trustees, I look forward to helping steer the charity through its next phase of growth and impact.

We welcomed three new Trustees in the 2024–2025 period and their insights and guidance have been invaluable in helping shape our recent activities.

Importantly, the quantity and quality of projects delivered by our staff is very impressive and I am deeply grateful for their relentless efforts and commitment to Immunodeficiency UK, the individuals affected by immunodeficiency and their families, and healthcare professionals.

The extent and impact of these efforts can be seen through the fantastic tangible results achieved. They follow the many activities conducted on multiple fronts, as you will see outlined in this Annual Report: advocacy projects and events, a helpline service, mental health workshops, research support, as well as development and dissemination of information and educational materials. A key highlight included advocacy for access to a treatment for a rare primary immunodeficiency – the first-ever treatment for this condition licensed for NHS use in England and indeed in Europe.

Our increased presence through social media and our website has also gone from strength to strength. The Immunodeficiency UK website provides our community with a wealth of up-to-date information and resources on many immunodeficiency conditions, treatments and immunisations, for example, and is often a go-to for patients, carers and healthcare professionals.

Finally, a heartfelt thank you to all our volunteers and those involved in fundraising activities. I am truly grateful for your dedication and support, it means a lot to us.

Valérie Brisse-Uhlig,
Chair of Trustees

Our achievements at a glance



278

people were supported through our phone and email helpline service.

3,445+

information booklets sent to immunology centres and individuals.



Thirteen hardship grants were awarded to individuals to help with the financial strain of accessing healthcare.

We provided 27 Buzzy Shot devices to families.

These make treatment sessions using needles less traumatic for children.

We launched two new patient guides and updated three other booklets.



On average
3,274
people visited our website each month.

We had
6,615
booklet downloads

Over 1,300 people subscribed to our monthly email newsletters, keeping them updated on research, treatments, our activities and fundraising.



Our achievements at a glance

We advocated for access to specialised treatments and better care with NICE, NHS England and NHS Scotland.



We supported members with the psychological impact of immunodeficiency, holding online workshops on managing the transition from paediatric to adult care, dealing with uncertainty and an 8-week mindfulness course.



We championed early diagnosis of immunodeficiency conditions, working with Genomics England and the UK National Screening Committee overseeing the newborn screening pilot for SCID.



We helped raise public awareness of immunodeficiency and the need for plasma-derived therapy through patient stories and our involvement in global campaigns.



We had 181 new member registrations. Our Facebook reach extended to 44,808 people, and our Instagram account now has 697 followers.

Brooklyn's journey with CD40 ligand deficiency



Brooklyn was just ten months old when he was diagnosed with CD40 ligand deficiency, a rare primary immunodeficiency. Five months later, he underwent a life-saving stem cell transplant.

Choosing the transplant was not easy. "As parents, we had to decide for him, and that was incredibly difficult," they said. "But the risks of not doing it were greater – lifelong medication, frequent hospital visits, and constant fear of illness. We wanted more for Brooklyn." Brooklyn's parents were fortunate to find multiple donor matches quickly, something not all families experience.

In the lead-up to the transplant, keeping Brooklyn safe from infections was their top priority. "Even a simple cold could be dangerous. We had to isolate him – no playgroups, shops, or family visits. It was tough."

At 15 months, Brooklyn was too young to understand, but the family was determined to give him the best chance of a healthy future. They travelled to the Great North Children's Hospital in Newcastle for his transplant. After a full assessment, they relocated for the procedure. Brooklyn was admitted to a specialist ward, received chemotherapy to prepare his body, and was supported through the difficult days that followed. He became very ill, needing nutritional support and multiple transfusions. Complications kept him in hospital for nearly four months, but eventually he was strong enough to return home.

Now, Brooklyn is thriving. He continues to receive immunoglobulin therapy and medications while his immune system strengthens, but he can now enjoy things like cuddling his grandparents and going swimming. "He's always been a happy, sociable boy; it's wonderful to see him enjoy life again."

Charlie's story about SCID



Jennifer is mum to Charlie, a bright and happy little boy whose life was saved by newborn screening for severe combined immunodeficiency (SCID).

Charlie was born in October 2021, healthy and content. At five days old, he had the routine heel prick test, something Jennifer, as a second-time mum, did not think much of. Two weeks later, the phone rang — Charlie had screened positive for SCID. It was a total shock. He looked perfectly well, and there was no family history of immune disorders. But further tests confirmed the diagnosis. SCID, which severely impairs the immune system, meant Charlie was highly vulnerable to infection. The only chance of a cure was a stem cell transplant. The family immediately began isolating at home to protect him while the search for a donor began.

Thankfully, Charlie's dad was a match, and they travelled to the Great North Children's Hospital in Newcastle to begin treatment. Saying goodbye to Charlie's older brother, Alfie, who stayed in Manchester with his grandparents, was heartbreaking, but necessary. Charlie had a week of chemotherapy before receiving his transplant. The following weeks were tough — he battled sickness, weight loss and painful side effects, but slowly began to recover. By seven months old, his immune system was working well and life could return to normal.

Today, at nearly three years old, Charlie is thriving. He rarely gets ill, no longer needs medication and has enjoyed all the milestones of toddler life, including his first trip abroad. He attends nursery, plays with Alfie and lives as any healthy child would.

Jennifer says: *"Charlie is a shining example of what can be achieved when a diagnosis is given early. This, alongside the incredible knowledge, care and quick action he received means that he can walk into preschool today ready to make friends and learn, just like all the other three-year-olds in the room. We need the UK to fully adopt newborn screening for SCID as soon as possible to save children's lives."*

Living with immunodeficiency

Jess's story of living with secondary immunodeficiency



Jess was diagnosed with secondary immunodeficiency following treatment with the drug rituximab that she received to treat GPA Vasculitis (Granulomatosis with Polyangiitis).

In 2023, Jess began experiencing persistent symptoms, including a chronic cough and swollen neck lymph nodes. In August 2023, severe cervical lymphadenitis caused airway obstruction, requiring hospitalisation and marking the start of a difficult period. Her cough persisted, disrupting sleep, social life and overall wellbeing, while repeated infections led to sinus and ear complications.

After eight months of ongoing illness, an MRI scan revealed lung damage from infections, and Jess was diagnosed with secondary immunodeficiency linked to her rituximab treatment.

Her management plan includes weekly self-administered subcutaneous immunoglobulin infusions, prophylactic antibiotics, and regular monitoring.

Living with the condition has required lifestyle changes. Jess uses spoon theory to manage energy, follows strict hygiene practices in her education role, and benefits from a supportive employer offering flexible work arrangements. Her main challenges include managing infusions, medical admin, infection monitoring, and maintaining energy levels. She credits Immunodeficiency UK for providing valuable information and hope through patient stories.

She advises others with similar conditions to simplify medical routines, prepare for low-energy days, set realistic expectations, and build strong support systems.

Jess says "Immunodeficiency UK has been an invaluable resource, particularly their case studies, which provided hope and practical advice during the early stages of my diagnosis. Reading about others' experiences helped me see a positive future and gave me confidence that my symptoms could be managed effectively."

Supporting the immunodeficiency community

Over the last year, our work centred around five core areas:

- Sharing trustworthy information through a range of channels, including our website, print materials and newsletters
- Providing practical and emotional support via phone and email
- Increasing public understanding of immunodeficiency conditions
- Championing mental health as an essential part of overall wellbeing
- Advocating for individuals and families living with immunodeficiency to help shape better healthcare services and ensure access to new treatments

Our e-newsletters

We produced monthly e-newsletters that shared awareness campaigns, research findings, latest developments in treatments including a major change to how the NHS delivers immunoglobulin therapy, fundraising activities and updates on our advocacy work. The average open rate of the newsletters was 45.7% (range 42.8% to 46.9%). These figures are above the average open rate of 28.6% quoted for non-profit communications (source: [NonProfit Tech for Good: Email marketing statistics & benchmarks](#)).

45.7% open rate

6.17% click-through rate



When I tested positive for COVID, I knew that I was entitled to antiviral treatments. I also remembered that I had seen, in the Immunodeficiency UK newsletter, that the process had changed. So, my first port of call was to check the Immunodeficiency UK website and there was a dedicated page which was very helpful in pointing me in the right direction very quickly. So, I followed the guidance and process for my location and got prescribed the medication later on that day. Thank you very much, Immunodeficiency UK.

Dominique, a patient with primary immunodeficiency



Our helpline services

The demand for our online and telephone helpline services remained high. In this period, we received 278 new enquiries. We were a trusted source of information for affected families and professionals. We dealt with queries relating to accessing a diagnosis of immunodeficiency, to treatments and care, benefit entitlement and employment-related issues. Significantly, nearly 11% of queries were about access to COVID-19 vaccinations and medicines, highlighting that these remained issues for our community.

“Thanks so much for your time on the telephone this morning and your follow-up email. You have certainly helped put my mind at rest”.

A secondary immunodeficiency patient.

278

Number of new enquiries

44

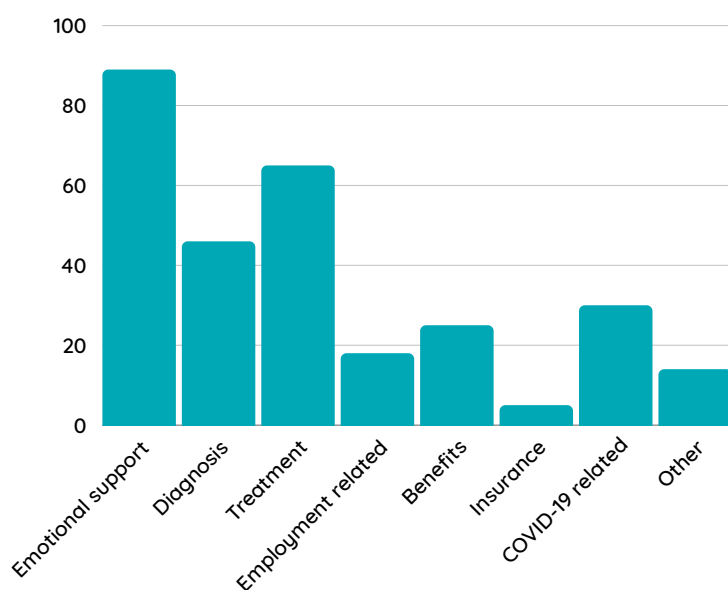
Number of re-contact enquiries

297

Emails/letters sent

Support offered

● Number of queries



Phone & Email 31

Phone only 41

How queries were answered

Email only 225

Our enquiries

Medical professional 47

Type of enquirer

Family member/patient 250

“

I found the Immunodeficiency UK helpline to be very useful. I left a message and got a call back within the hour as I was concerned about my immune system antibody levels. The lady who rang me back was great and emailed me some very helpful information sheets, including one for my GP. I was offered support and guidance and would recommend the service as the first point of contact to anyone with primary or secondary immunodeficiency.

Anthony, who was concerned about his antibody levels

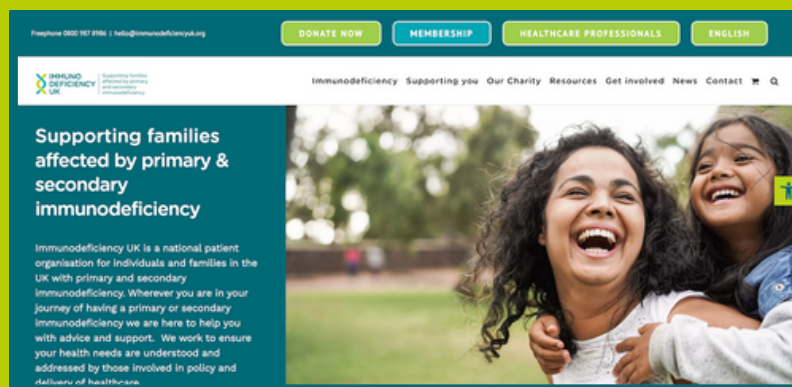
”

Our website

This year, our website continued to serve as a vital hub for people affected by primary and secondary immunodeficiencies, their families, and healthcare professionals. We've worked to ensure the site remains accessible, informative, and up to date with the latest medical guidance, patient support resources and research developments. Whether users are seeking a diagnosis guide, downloadable leaflets, or details on our helpline, our site has provided a reliable first point of contact and a trusted source of information.

Website traffic has continued to increase. Average page views increased from 7,200 monthly to 8,000, monthly unique visitors from 2,022 to 3,274 and monthly booklet downloads from 530 to 551.

The website attracted users from over 170 countries outside the UK, including the USA, Australia, Canada and India, and countries throughout Europe.



“

Three weeks ago, I was diagnosed with primary immunodeficiency. Coming to terms with this diagnosis has been incredibly challenging. It's been an overwhelming month, filled with a lot of emotion, uncertainty and anxiety. Yesterday, I began lifelong immunoglobulin replacement therapy (IVIG).

While researching the condition, I came across your charity and website. I shared it with friends and family to help them understand more about primary immunodeficiency, and it's been an incredibly valuable website in explaining such a rare condition. I'm really grateful for the clarity and support it's provided.

”

Maddison, a newly diagnosed primary immunodeficiency patient

Top downloaded booklets

- 1 Secondary immunodeficiency
- 2 Keeping well and healthy with a PID
- 3 Primary immunodeficiency – the basics
- 4 Subcutaneous immunoglobulin (SCIG) infusions – a practical guide for patients
- 5 Immunoglobulin replacement therapy – one size doesn't fit all

96,763
pageviews

39,285
unique visitors

6,615
booklet downloads

Raising awareness of immunodeficiency

World PI Week 2024

Immunodeficiency UK took part in World Primary Immunodeficiency (PI) Week, reaching over 7,800 people through social media. Our campaign focused on plasma donation and emphasised how important plasma is in the production of the life-saving medicine, immunoglobulin.

reach c.7,800 people

468 post clicks

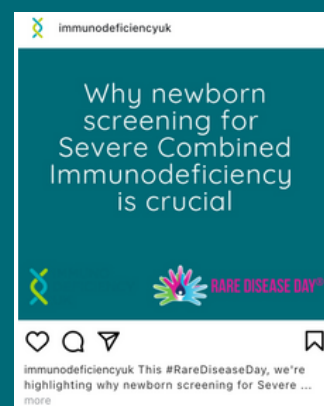


Rare Disease Day 2025

On Rare Disease Day, our social media campaign highlighted the critical importance of newborn screening in the early detection and treatment of immunodeficiency.

reach c.4,200 people

187 post clicks



Raising awareness about the importance of an early diagnosis of Severe Combined Immunodeficiency (SCID)



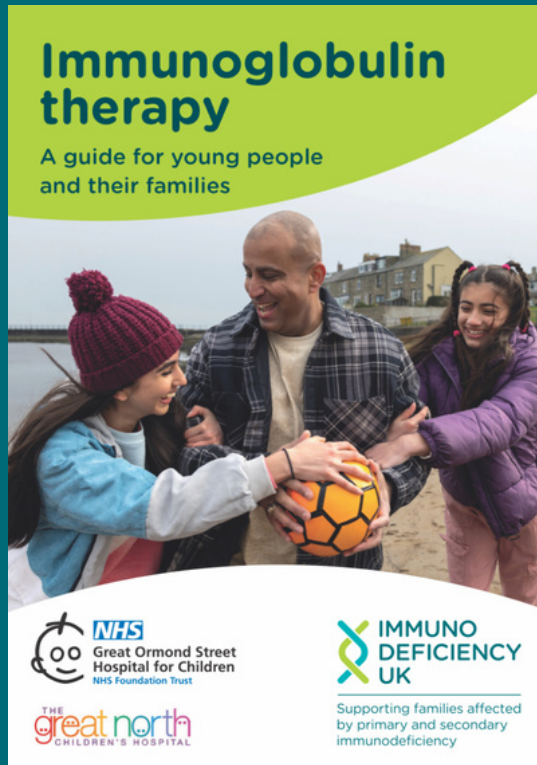
Rhys (in the orange t-shirt) with his parents and his brother Owen who was his bone marrow donor.

Rebecca's family history and experiences show how early testing and diagnosis of SCID is vital so that prompt treatment by a bone marrow transplant can be given to save a child's life. The family lost their first child, Scott, because the diagnosis was not made early enough to prevent the infections that took hold of his fragile body.

Rebecca went on to have another two children. Aware of the family history of SCID, they were offered a simple blood test for each child at birth. This simple life-saving test confirmed that their third son, Rhys, was SCID positive, and he had a bone marrow transplant to give him a healthy immune system.

Rebecca says "I can't stress how crucial early diagnosis of SCID is to improve the life outcomes of infants born with this condition. That is why adoption of a UK-wide newborn screening programme for SCID is imperative."

Booklet and information development

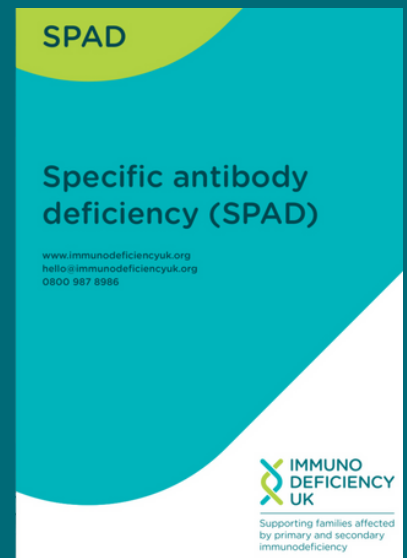


Responding to the needs expressed by the community and immunology specialists, we expanded our portfolio of educational leaflets. We collaborated with immunology consultants and clinical nurse specialists from Great Ormond Street Hospital (GOSH) and the Great North Children's Hospital (GNCH) to develop a new booklet, Immunoglobulin therapy: A guide for young people and their families.

The content was shaped with input from young people and parents who have first-hand experience of immunoglobulin treatment.

The booklet gives key information in a reassuring and accessible format and features photos of young adults receiving treatment, to give a sense of shared experience.

We also released a new patient guide: Specific antibody deficiency (SPAD). The guide explains this primary immunodeficiency in clear terms and covers symptoms, diagnosis and treatment options, such as antibiotics, and in rare cases, immunoglobulin therapy.



We updated the following booklets:

**Immunoglobulin
therapy for adults**

**Severe combined
immunodeficiency
(SCID)**

**Adenosine deaminase
deficient severe
combined
immunodeficiency
(ADA-SCID)**

Providing mental health support

Supporting people with the mental health impact of living with immunodeficiency

Immunodeficiency UK held several mental health support events, recognising the psychological challenges faced by individuals living with primary and secondary immunodeficiencies and the lack of NHS mental health provision. Working with the mental health charity RareMinds we helped to address the emotional impact of being affected by a chronic condition.

We delivered two specialised workshops

- **Managing uncertainty workshop:** This small-group online session created a safe space for members to discuss the unpredictable nature of living with immunodeficiency conditions.
- **Managing transition:** Recognising the emotional strain on families during the transition from paediatric to adult care, this workshop addressed both practical and emotional aspects of this significant change.

“

The lady who ran the session was very welcoming and considered, prompting us to consider our daughter and the challenges for transition as well as consider our own feelings. It was very helpful to reflect together.

A 'managing transition' webinar attendee

”

“

Great session, really enjoyed listening to others' experience of living with a chronic condition and how it has impacted them personally and professionally.

A 'managing uncertainty' webinar attendee

”

Our mindfulness groups

- **8-week mindfulness course:** Delivered via weekly sessions, this course was aimed at helping participants struggling with pain, fatigue and anxiety. The course provided in-depth, personalised teaching on mindfulness practices in a supportive environment. This was our second time running this course.
- **Mindfulness refresher session:** Based on positive feedback from previous participants, we offered a follow-up session to reinforce techniques and address ongoing challenges for those who took part in our first mindfulness course.

A participant told us: *"Fantastic course. Helped with many coping strategies and managing anxiety, fear of illness, fatigue and overdoing things. Meditation is a wonderful thing I have discovered and the whole learning process was made so great by a fantastic teacher."*

Providing hardship grants and pain-relief devices

Hardship grant programme

Immunodeficiency UK continued its vital hardship grant programme, offering £100 grants to individuals and families struggling to cover essential healthcare expenses. Immunology centres refer eligible patients who are facing financial barriers to accessing care. During the 2024/25 year, we awarded **13 hardship grants**, providing crucial financial relief to members of our community.

These grants make a meaningful difference in the lives of recipients, helping to alleviate the financial burden that often accompanies living with an immunodeficiency condition.

"This support is very much needed for families like us with a child who was born with SCID & it will help towards the travel cost we so regularly incur with getting access to his treatments."

Feedback from a mother of a child with Severe Combined Immunodeficiency (SCID).

Buzzy Shot pain relief programme

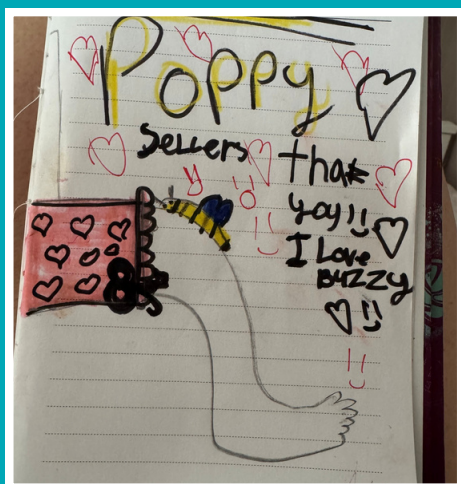
Our Buzzy Shot pain relief programme continues to provide free devices to children with immunodeficiency. These innovative devices help alleviate anxiety and discomfort associated with needle insertion, particularly for blood draws and vital immunoglobulin treatments that help prevent infections.

In this period, we supplied 27 Buzzy Shot devices to families, significantly exceeding our initial projections and demonstrating the high demand for this important support.



"Thanks for forwarding several Buzzy devices for use at our clinic. They have been fantastic for the children, who are delighted with them."

Clinical immunology specialist nurse.



Poppy's Buzzy story

This year, we received a heartwarming drawing from Poppy, a young girl living with hypogammaglobulinemia, a condition that means she has low antibody levels making her prone to infections.

Poppy uses a Buzzy provided by us to help make her regular infusions of immunoglobulin, to top up her immune system, a little less scary and a lot more comfortable. Her cheerful picture, reminds us exactly why we do what we do: to bring comfort, courage and smiles to children facing medical challenges every day.

Our advocacy work

Immunodeficiency UK continued to champion the needs of people living with primary and secondary immunodeficiencies, representing them in national policy, healthcare standards and in the development of research.

Shaping accreditation and policy

We contributed to the 5-year review of the Quality in Primary Immunodeficiency Services (QPIDS) accreditation standards led by the Royal College of Physicians. Our input ensured that the patient perspective was central to how services are assessed and delivered across the UK.



Susan, our CEO, with Mrs Sharon Hogson, MP for Washington and Gateshead South at the Parliamentary drop-in on the Generation Study

Championing early diagnosis

In January 2025, Immunodeficiency UK was one of four charities invited to a Genomics England-hosted MP drop-in event at the Houses of Parliament to promote the Generation Study — an initiative testing newborns for over 110 genes linked to primary immunodeficiencies. We highlighted the potential for early, life-saving interventions and the need for investment as the UK newborn screening programme expands.

Working with Genomics England, we reviewed 32 patient information leaflets on primary immunodeficiency conditions for the Generation Study newborn screening project.

Supporting access to genetic testing

We supported access to pre-implantation genetic testing for the monogenic condition, known as PGT-M, for autoimmune proliferative syndrome through a statement to the Human Fertilisation and Embryology Authority. The statement reflected the experiences and challenges of living with this condition. The application was successful.

Our advocacy work

Representing the voice of the community

Immunodeficiency UK provided the patient and public voice on the following committees:

**NHS Scotland's National Plasma Product
Expert Advisory Group (NPPEAG)**

**UK Primary Immunodeficiency Registry
(UKPID Registry)**

NHS England's Newborn Screening for Severe Combined Immunodeficiency (SCID)



Advocating for access to treatments and better care

In October 2024, Immunodeficiency UK's CEO, and Sophie (pictured left with her son Jasper) were patient experts at a National Institute for Health and Care Excellence (NICE) meeting assessing the clinical effectiveness and value for money of the drug leniolisib, as a treatment for the rare primary immunodeficiency called activated phosphoinositide 3-kinase delta syndrome (APDS).

Sophie, mum to Jasper who has APDS, shared her first-hand experience of the condition's impact on her child and herself as a carer. The committee considered our testimony, the results of Immunodeficiency UK's quality-of-life survey showing the impacts on other affected families, our formal consultation response, and the opinions of clinicians and other APDS experts. After further meetings and evidence presented by the pharmaceutical company, we were delighted that NICE recommended the use of leniolisib for patients with APDS, aged 12 years and over. It is the first-ever treatment for APDS licensed for NHS use in England and indeed in Europe.

We give huge thanks to Sophie for her involvement in this vital advocacy work for those affected by APDS.

We provided detailed feedback on patient care through national and international surveys, including:

**NICE's consultation on Summary of
Information for Patients (SIPs)**

**European Society for Immunodeficiencies
(ESID) survey on the need for PID-specific
guidelines**

The 2024 Rare Disease Quality Statement survey – 'What does good care look like.'

Our advocacy work

Plasma and immunoglobulin therapy advocacy

To highlight the urgent need to expand UK plasma collection to increase self-sufficiency in the availability of immunoglobulin products, we were invited to contribute to a Parliamentary roundtable discussion alongside NHS Blood and Transplant, MPs and other stakeholders. The event reinforced the critical importance of plasma for people reliant on immunoglobulin therapy and other life-saving plasma-derived medicines.

In 2024, the Medicines and Healthcare products Regulatory Agency lifted the 25-year ban on the use of UK-sourced plasma for the manufacture of immunoglobulin. To help explain this major change to our community, we collaborated with NHS Scotland to develop the patient leaflet Plasma for medicines, and with NHS England on frequently asked questions to address any queries people had about this policy change.

Following the implementation of a new commissioning framework for immunoglobulin in early 2025, we held five meetings with the Medicines Value and Access Directorate at NHS England to explore the implications for people dependent on this therapy. We raised concerns about the reduced number of immunoglobulin products available and the need to switch large numbers of patients onto different products, the anxiety this would cause and the extra workload for immunology centres. Our plan for 2025/26 is to fully explore the impacts of commissioning changes through a patient and healthcare professional survey.



Supporting research

Immunodeficiency UK was a collaborative partner with the Murdoch Children's Research Institute and the James Lind Alliance in developing the top ten research priorities for paediatric haematopoietic stem cell transplants. This work was shaped by the voices of patients and families, and we are grateful to the research team and the many families who contributed their experiences and insights.

We also partnered with researchers at Leeds Beckett University to develop and validate a patient-reported outcome measure (PROM) for people living with both primary and secondary antibody deficiency. PROMs are important tools to measure health outcomes from a patient perspective rather than from a clinical point of view, and currently, there are no validated measures for this cohort of patients.

We also:

Provided support letters for two clinical immunology research proposals

Used our newsletters and social media to promote participation in research studies

Shared research outcomes via our monthly newsletters and website updates

Our incredible fundraisers

A huge thank you to Sophie and Micky, who raised over £2,500 for Immunodeficiency UK



Sophie and Micky took on a remarkable 870-mile trek along the Welsh Coast to raise both awareness and vital funds for families affected by immunodeficiency.

Their inspiration? Sophie's young son Jasper, who was diagnosed in August 2023 with a rare form of Activated PI3K Delta Syndrome (APDS) — a complex condition that had caused years of unexplained health challenges. Jasper is currently the only known child in Wales with this specific genetic mutation.

Moved by Jasper's strength and resilience, Sophie set out to give back. Joined by her friend Micky, she completed the **135-mile Mighty Hike around Anglesey**. Their efforts ensure that other families, facing similar uncertainties, can access the crucial support, guidance and community that meant so much to them. Thanks to their incredible efforts—and the generosity of their supporters—they raised an astonishing **£2,500**. These funds will directly support families navigating the challenges of rare and complex immunodeficiencies.

£2,500 raised



Katy raised over £2,000 to support our work.

For Katy Rogers, completing the Brighton Marathon was more than a personal milestone — it was a heartfelt tribute to her sister Emma and a powerful way to raise awareness for those living with immunodeficiency.

Emma was diagnosed with Common Variable Immune Deficiency (CVID) at just 16 years old. Since then, Katy has seen the challenges Emma faces, from the difficulty of getting a diagnosis to the strength and resilience she demonstrates every day.

Motivated by her sister's journey, Katy took on the Brighton Marathon and raised over £2,000 in support of Immunodeficiency UK. We are incredibly grateful to Katy for her dedication, generosity, and for shining a light on this important cause.

Our incredible fundraisers

Shauna's skydive challenge raises £1,000 for Immunodeficiency UK



Driven by her love for her nephew, Oliver, Shauna completed an exhilarating skydive that has raised an amazing £1,000 for our charity.

Oliver has been courageously navigating the challenges of a rare genetic condition called APDS, which affects only 1 in 1 million people. This disorder significantly weakens his immune system, leading to the development of a chronic lung condition called bronchiectasis. Oliver's daily routine includes a rigorous regimen of nebulisers, chest percussion and prophylactic antibiotics. Inspired by his resilience, Shauna decided to take on the thrilling feat of skydiving as a symbolic gesture of her love and support.

The funds that Shauna's skydive has raised for Immunodeficiency UK will make a big impact. These crucial funds will go towards providing essential support to families like Oliver's who are navigating rare immunodeficiency diseases.

On behalf of the entire Immunodeficiency UK team, we extend our heartfelt gratitude to Shauna.

£1,000 raised

Our incredible fundraisers



Katie, Andy and Jackie's story

When Katie decided to take on the London Landmarks Half Marathon, it was not just about the challenge — it was personal. Living with an immunodeficiency herself, she wanted to raise awareness and support for others facing similar health issues.

She was joined by her husband, Andy, and sister, Jackie, forming a determined trio with one shared goal: to make a difference. Together, they trained hard and completed the 13.1-mile race in support of Immunodeficiency UK.

Their journey highlighted the crucial work the charity does for people affected by primary and secondary immunodeficiencies — work they have seen the importance of first-hand through Katie's experience.

£2,300 raised

Together we can make a difference

Thank you...

...to all the regular donations we receive, including those from anonymous donors; we don't know who you are, but we are so grateful for your support.

...to our corporate funders who have contributed to the work we have done this year

...to everyone who sent an in-memoriam donation or has pledged a legacy in their will to help support families with immunodeficiency in the future.

We couldn't do what we do without you.

£39,298

raised through
public donations

To make a donation, please go to
<http://www.immunodeficiencyuk.org/donate>
or scan the QR code



Charity registration number 1193166 (England and Wales)

IMMUNODEFICIENCY UK
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

IMMUNODEFICIENCY UK

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Ms D Hammond	
	Ms J E Shepard	
	Ms V D Brisse-Uhlig	
	Mr T Taylor	(Appointed 20 January 2025)
	Ms C E A Brailsford	(Appointed 16 September 2024)
	Ms A Toft	(Appointed 16 September 2024)
Charity number (England and Wales)	1193166	
Registered office	PO Box 12635 Colchester Essex United Kingdom CO7 5AN	
Independent examiner	Hazel Day Nightingale House 46-48 East Street Epsom Surrey United Kingdom KT17 1HQ	

IMMUNODEFICIENCY UK

CONTENTS

	Page
Trustees' report	1 - 6
Independent examiner's report	7
Statement of financial activities	8
Balance sheet	9
Notes to the financial statements	10 - 19

IMMUNODEFICIENCY UK

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2025

The trustees present their annual report and financial statements for the year ended 31 March 2025.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Charities Act 2011, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)".

Objectives and activities

We work on behalf of people affected by primary or secondary immunodeficiency in the UK and their families. Our mission is to work with patients, healthcare professionals and relevant organisations to ensure that those affected by primary or secondary immunodeficiency have the knowledge needed to manage their condition effectively. We aim to ensure that patients' health needs are understood and addressed by those involved in healthcare policy and delivery.

We are dedicated to helping people affected by immunodeficiency through our information, peer support and advocacy activities, and to supporting and empowering people to understand and manage their condition. We make it easy for our members to participate in research trials to further the search for treatments and a cure.

Our objectives, as set out in our Memorandum and Articles, are:

- The advancement of health and the relief of people affected by primary or secondary immunodeficiency and their families and people responsible for their welfare, including:

- by providing assistance, advice or guidance in relation to managing their condition and improving the diagnosis of these conditions, their treatment and the quality of life of those affected
- by promoting awareness and understanding of primary and secondary immunodeficiency within the general public and medical profession in order to better understand these conditions and their impact
- by providing a helpline service, events and practical help and advice.

- To encourage and support research into the causes, treatments, prevention and cures for primary and secondary immunodeficiency, and to publish the useful results of that research.

Public benefit

In setting objectives and planning activities, the trustees have given due consideration to general guidance published by the Charity Commission relating to public benefit, including the guidance 'Public benefit: running a charity (PB2)'.

Representation

To help Immunodeficiency UK in its work, we are a member of several umbrella groups, including Genetic Alliance UK, Gene People, the Specialised Healthcare Alliance and the National Council for Voluntary Organisations. Immunodeficiency UK is the UK national member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI). We are registered with the Fundraising Regulator.

Achievements and performance

Significant activities and achievements against objectives

Our helpline service and other support activities

The demand for our online and telephone helpline services remained high: we dealt with 278 new enquiries (2023/24: 261). We provided emotional support and acted as a trusted source of information for affected families and healthcare professionals. We answered queries related to accessing a diagnosis of immunodeficiency, treatments and care, benefit entitlement and employment. Nearly 11 per cent of queries were about access to COVID-19 vaccinations and antiviral medication, proving that these issues remain a concern for our community.

Through our hardship grant scheme, we awarded 13 grants (2023/24: 9). These grants help people and families with travel costs to access healthcare services.

IMMUNODEFICIENCY UK

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

We provided 27 families with free 'Buzzy Shot' pain relief devices (2023/24: 6). These devices reduce the fear and the pain associated with needle insertion for blood tests and for crucial immunoglobulin therapy that keeps children free from infection.

Mental health support

Immunodeficiency UK held several mental health support events, recognising the psychological challenges faced by individuals living with primary and secondary immunodeficiencies and the lack of NHS mental health provision. We worked with the mental health charity Rareminds to deliver two specialised workshops. The first, Managing Uncertainty, gave advice on how to deal with the unpredictable nature of living with immunodeficiency. The second, Managing Transition, recognised the emotional strain on young adults and families during the transition from paediatric to adult care.

We ran an eight-week mindfulness course, with weekly sessions aimed at helping participants struggling with pain, fatigue and anxiety. The course provided in-depth, personalised teaching on mindfulness practices in a supportive environment. This was our second time running this course. We also provided a mindfulness refresher course for those who had taken part in our first mindfulness course to reinforce techniques and address ongoing challenges. A total of 40 people took part in these events, and 85 per cent of participants recommended that the support be offered to others.

Following the success and reported benefits reported by participants, we will continue to work with Rareminds to provide tailored mental health support programmes in 2025/26.

Information development and dissemination

Over 1,300 people subscribed to our monthly e-newsletters that share community news, research findings, latest developments in treatments, fundraising activities and opportunities for clinical trial involvement. The average open rate of the newsletters was 45.7 per cent (range 43.9–50.7 per cent). These figures are above the average open rate of 28.6 per cent quoted for non-profit communications (source: Nonprofit Tech for Good: <https://www.nptechforgood.com/101-best-practices/email-marketing-statistics-for-nonprofits/>).

We promoted our charity's support services and materials to immunology medical professionals through three targeted mailings. We had a promotional stand at the annual Immunology and Allergy Nurses Group conference held in Birmingham.

Through our on-demand order service for medical professionals, we provided 3,275 booklets to support patients at immunology centres. We also distributed 137 of our booklets directly to newly diagnosed patients or those navigating their treatment pathway.

Our website – our major source of information for those affected by immunodeficiency – had high traffic, with 96,763 page views, 39,285 unique visitors and 6,615 booklet downloads. The website hosts 75 different educational booklets. The booklets most frequently downloaded in 2024/25 were Secondary immunodeficiency, Keeping well and healthy when you have a PID, Primary immunodeficiency – the basics, Subcutaneous infusions of immunoglobulin – a practical guide for patients and Immunoglobulin replacement therapy – one size doesn't fit all. During the reporting period, the website attracted users from over 170 countries outside the UK, including the USA, Australia, Canada and India, and countries throughout Europe.

Through the website and our newsletter, we kept the community updated on COVID-19 vaccination availability, access to COVID-19 antiviral medication, the introduction of UK-plasma-derived immunoglobulin products and changes in the range of immunoglobulin products available to patients due to NHS decision-making and the implications for patients' care.

Development of information leaflets and website content

Responding to the needs expressed by the community and immunology specialists, we expanded our portfolio of educational leaflets. We collaborated with immunology consultants and clinical nurse specialists from Great Ormond Street Hospital (GOSH) and the Great North Children's Hospital (GNCH) to develop a new booklet, Immunoglobulin therapy: A guide for young people and their families. The content was shaped with input from young people and parents who have first-hand experience of immunoglobulin treatment. The booklet gives key information in a reassuring and accessible format, and features photos of young adults receiving treatment, to give a sense of shared experience. With GOSH and GNCH, we also updated our information booklets on severe combined immunodeficiency (SCID) and adenosine deaminase-deficient SCID (ADA-SCID).

IMMUNODEFICIENCY UK

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

We released a new patient guide: Specific antibody deficiency (SPAD). The guide explains this primary immunodeficiency in clear terms and covers symptoms, diagnosis and treatment options, such as antibiotics, and in rare cases, immunoglobulin therapy.

Raising awareness of immunodeficiency and its impact

For those living with immunodeficiency, learning about the experiences of others who have been diagnosed with the same condition can be a valuable means of support. We added four patient stories to our library of lived experience stories, including living with secondary immunodeficiency and CD40 ligand deficiency. Two other stories highlighted the importance of early diagnosis of SCID through newborn screening and subsequent successful treatment by stem cell transplant. We thank all involved for sharing their experience.

We were involved in social media campaigns to support our mission and to highlight the experiences of our community. These included Rare Disease Day, World Primary Immunodeficiency Week, International Plasma Awareness Week and World Antimicrobial Resistance Awareness Week.

We had 181 new member registrations and increased our social media presence over the year. Our Facebook unique visitors reach was 44,808 (2023/24: 26,856). We had 9,265 visits to our Facebook page (up 224 per cent compared with 2023/24), and we had 198 new followers (up 29 per cent). We gained 68 new Instagram followers, and our reach increased by 1,100 per cent to 8,052 on this platform. We also received 1,006 visits to our Instagram page, which is an increase of 240 per cent on the previous year. Our advocacy work was our most popular content, followed by patient stories.

The average open rate of our newsletters was 45.7% (range 42.8% to 46.9%). These figures are above the average open rate of 28.6% quoted for non-profit communications (source: NonProfit Tech for Good: Email marketing statistics & benchmarks).

Supporting research and involvement in clinical trials

Immunodeficiency UK was a collaborative partner with the Murdoch Children's Research Institute and the James Lind Alliance in developing the top ten research priorities for paediatric haematopoietic stem cell transplants. This work was shaped by the voices of patients and families, and we are grateful to the research team and the many families who contributed their experiences and insights.

We also partnered with researchers at Leeds Beckett University to develop and validate a patient-reported outcome measure (PROM) for people living with both primary and secondary antibody deficiency. PROMs are important tools to measure health outcomes from a patient perspective rather than from a clinical point of view, and currently there are no validated measures for this cohort of patients.

At the request of clinical immunology research teams, Immunodeficiency UK wrote letters in support of two research proposals.

Our advocacy work to support the community

Immunodeficiency UK continued to advocate for the needs of people living with primary and secondary immunodeficiencies, representing them in national policy, healthcare standards and the development and support of research.

Our role as a patient and public voice

Immunodeficiency UK's CEO was the patient representative voice on the UK National Screening Committee overseeing newborn screening for SCID. NHS Scotland's National Plasma Product Expert Advisory Group and the UK Primary Immunodeficiency Registry Committee, and on the Haplo+4Kids clinical trial, which aims to improve stem cell transplant outcomes for children and adolescents with immunodeficiency.

Representing our community, we helped shape care standards by contributing to the five-year review of the Quality in Primary Immunodeficiency Services accreditation standards led by the Royal College of Physicians. Our input ensured that the patient perspective was central to how services are assessed and delivered across the UK.

IMMUNODEFICIENCY UK

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Championing early diagnosis

Immunodeficiency UK was one of four charities invited to an MP drop-in event at the Houses of Parliament, hosted by Genomics England and Genetic Alliance UK. The event promoted the Generation Study, a research initiative testing newborn babies for genetic conditions, including over 110 genes linked to primary immunodeficiencies. We highlighted the potential for early, life-saving interventions and the need for investment as the UK newborn screening programme expands. Furthermore, Immunodeficiency UK was approached by Genomics England to review 32 patient information leaflets on primary immunodeficiency conditions for the Generation Study newborn screening project. Our amendments and suggestions were accepted.

We supported access to pre-implantation genetic testing for the monogenic condition, known as PGT-M, for autoimmune proliferative syndrome through a statement to the Human Fertilisation and Embryology Authority. The statement reflected the experiences and challenges of living with this condition. The application was successful.

Supporting access to specialised treatment

Immunodeficiency UK advocated for access to Leniolisib, a treatment for the rare primary immunodeficiency activated phosphoinositide 3-kinase delta syndrome (APDS). In collaboration with the National Institute for Health and Care Excellence (NICE), we carried out a quality-of-life survey to understand the impact of this condition on those affected, their carers and wider family. We submitted the report findings and our formal consultation response to NICE. At the subsequent NICE health technology assessment meetings, Immunodeficiency UK's CEO and a parent of a child affected by APDS gave testimony as patient experts. We were delighted that NICE finally recommended Leniolisib as a treatment option for APDS. It is the first-ever treatment for APDS licensed for NHS use in England and indeed in Europe.

Plasma and immunoglobulin therapy advocacy

To highlight the urgent need to expand UK plasma collection to increase self-sufficiency in the availability of immunoglobulin products, we were invited to contribute to a Parliamentary roundtable discussion alongside NHS Blood and Transplant, MPs and other stakeholders. The event reinforced the critical importance of plasma for people reliant on immunoglobulin therapy and other life-saving plasma-derived medicines.

In 2024, the Medicines and Healthcare products Regulatory Agency lifted the 25-year ban on the use of UK-sourced plasma for the manufacture of immunoglobulin. To help explain this major change to our community, we collaborated with NHS Scotland to develop the patient leaflet Plasma for medicines, and with NHS England on frequently asked questions to address any queries people had about this policy change.

Following the implementation of a new commissioning framework for immunoglobulin in early 2025, we held five meetings with the Medicines Value and Access Directorate at NHS England to explore the implications for people dependent on this therapy. We raised concerns about the reduced number of immunoglobulin products available and the need to switch large numbers of patients onto different products, the anxiety this would cause and the extra workload for immunology centres. Our plan for 2025/26 is to fully explore the impacts of commissioning changes through a patient and healthcare professional survey.

We also provided detailed feedback on patient care through national and international surveys, including: NICE's consultation on the Summary of Information for Patients, the European Society for Immunodeficiencies' survey on the need for guidelines specific to primary immunodeficiencies and the 2024 Rare Disease Quality Statement survey – 'What does good care look like?'.

Financial review

Financial position

Our financial statements for the year are shown on pages 9 to 19. A summary of the financial results for the year are set out below.

Incoming resources

Total income for the year was £115,552, compared with £89,709 for the financial year 2023-24. We did not receive any income from legacies this year.

Resources expended

This year the expenditure was £114,253 compared with £112,809 for the financial year 2023-24.

IMMUNODEFICIENCY UK

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Going concern

After making appropriate enquiries, the trustees have a reasonable expectation that the Charity had adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements. Further details regarding the adoption of the going concern basis can be found in the Accounting Policies.

Reserves policy

Total reserves as of 31st March 2025 were £94,349, of which £19,165 related to restricted funds, leaving £75,184 of unrestricted funds. The trustees consider that it is both prudent and appropriate as part of their risk management policy to maintain a minimum level of contingency within free reserves to provide a level of working capital that protects the continuity of our core work, to provide a level of funding for unexpected opportunities and to provide cover for risks such as unforeseen expenditure or unanticipated loss of income. The reserves policy continues to be that holding unrestricted free reserves equal to a minimum of 5-8 months operating costs (presently £8,600 per month), as an acceptable level to hold. This reflects a balance between being prudent and allowing the charity to direct as much resource as possible into achieving its charitable activities. As of 31st March 2025, free reserves totalled £75,184, equating to 8.7 months of operating costs and is therefore in keeping with the reserves policy.

Plans for future periods

OUR AIMS FOR THE NEXT YEAR

- To raise public awareness of primary and secondary immunodeficiency and provide support services for those affected
- To advocate for access to specialised medicines and improvements in care
- To work with our community to define what needs to be done and make the case for funding
- To continue to review our information and develop new content as needed
- To broaden income streams, to include the selling of merchandise, fundraising from trusts and foundations, regular giving and donations through legacies.

Structure, governance and management

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

The trustees who served during the year and up to the date of signature of the financial statements were:

Ms H A Bruce	(Resigned 17 March 2025)
Dr M Buckland	(Resigned 17 March 2025)
Ms D Hammond	
Ms J E Shepard	
Ms T Moubazbaz	(Resigned 20 January 2025)
Ms V D Brisse-Uhlig	
Mr T Taylor	(Appointed 20 January 2025)
Ms C E A Brailsford	(Appointed 16 September 2024)
Ms A Toft	(Appointed 16 September 2024)

Recruitment and appointment of trustees

The board of trustees is responsible for the overall governance, policy and direction of Immunodeficiency UK. The trustees have the legal responsibility for charity operations and the use of resources in accordance with the objects.

During the period 1 April 2024 to 31 March 2025, the trustees met a total of 7 times.

IMMUNODEFICIENCY UK

TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Induction and training of trustees

New trustees were elected by the trustee board following an open recruitment process.

The trustees' report was approved by the Board of Trustees.

Valérie Brisse-Uhlig

.....
Ms V D Brisse-Uhlig
Chair of Trustees

Date: 22/01/2026

IMMUNODEFICIENCY UK

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF IMMUNODEFICIENCY UK

I report to the trustees on my examination of the financial statements of Immunodeficiency UK (the charity) for the year ended 31 March 2025.

Responsibilities and basis of report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011.

I report in respect of my examination of the charity's financial statements carried out under section 145 of the Charities Act 2011. In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the Charities Act 2011.

Independent examiner's statement

I report to the trustees on my examination of the financial statements of Immunodeficiency UK (the charity) for the year ended 31 March 2025.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 130 of the Charities Act 2011.
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of financial statements set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.



Hazel Day
BSc (Hons) FCA DChA
Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ
United Kingdom
Date: 23/1/2026.....

IMMUNODEFICIENCY UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Income from:							
Donations and legacies	2	106,369	6,858	113,227	81,602	7,821	89,423
Charitable activities	3	1,576	-	1,576	-	-	-
Other trading activities	4	518	-	518	30	-	30
Investments	5	231	-	231	256	-	256
Total income		108,694	6,858	115,552	81,888	7,821	89,709
Expenditure on:							
Raising funds	6	14,732	-	14,732	11,631	-	11,631
Charitable activities	7	84,510	15,011	99,521	85,294	15,884	101,178
Total expenditure		99,242	15,011	114,253	96,925	15,884	112,809
Net income/(expenditure) and movement in funds		9,452	(8,153)	1,299	(15,037)	(8,063)	(23,100)
Reconciliation of funds:							
Fund balances at 1 April 2024		65,732	27,318	93,050	80,769	35,381	116,150
Fund balances at 31 March 2025		75,184	19,165	94,349	65,732	27,318	93,050

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

IMMUNODEFICIENCY UK

BALANCE SHEET

AS AT 31 MARCH 2025

	Notes	2025 £	£	2024 £	£
Current assets					
Debtors	13	1,019		6,671	
Cash at bank and in hand		104,413		100,682	
		<u>105,432</u>		<u>107,353</u>	
Creditors: amounts falling due within one year	14	<u>(11,083)</u>		<u>(14,303)</u>	
Net current assets			<u>94,349</u>		<u>93,050</u>
The funds of the charity					
Restricted income funds	16		19,165		27,318
Unrestricted funds	17		75,184		65,732
			<u>94,349</u>		<u>93,050</u>

The financial statements were approved by the trustees on 22/01/2026.....

Valérie Brisse-Uhlig

.....
Ms V D Brisse-Uhlig
Chair of Trustees

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

Charity information

Immunodeficiency UK is a registered Charitable Incorporated Organisation (CIO) in England and Wales, established on 20 January 2021.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Charities Act 2011, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a statement of cash flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.8 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

2 Income from donations and legacies

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Donations and gifts	<u>106,369</u>	<u>6,858</u>	<u>113,227</u>	<u>81,602</u>	<u>7,821</u>	<u>89,423</u>

FUNDERS

Below is a breakdown of funding recognised in income in the financial period to 31st March 2025:

	2025 £	2024 £
Grifols	4,278	-
Biotest	2,700	-
IPOPI	2,080	4,115
Renishaw	500	500
The Hospital Saturday Fund	-	2,000
TOTAL	<u>6,858</u>	<u>7,800</u>

In addition to the above restricted funding, funds were received from:

- CSL Behring: £35,000 to support advocacy projects, awareness raising, and the provision of services for the immunodeficiency community.
- Takeda Ltd: £17,239 towards the general running costs of Immunodeficiency UK, including a contribution towards our administration and accountancy costs, and for the purchase of Immunodeficiency UK logoed T-shirts and running vests.
- Pharming: £12,324 towards the general running costs of Immunodeficiency UK, including a contribution towards our administration, website, database, IT support, and subscription costs.
- Jeans for Genes: £750 towards general running costs.

Non-monetary support was also received; this has not been included in the accounts as donations and expenditure as it is not possible to consistently value the contribution received. Details of support are given below:

Takeda - Involvement in the 'Number 17' campaign raising awareness of people living with a rare disease.

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

3 Income from charitable activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Support		
Service Level Agreement Recharge income	<u>1,576</u>	<u>-</u>

4 Income from other trading activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Merchandise income	<u>518</u>	<u>30</u>

5 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest receivable	<u>231</u>	<u>256</u>

6 Expenditure on raising funds

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising and publicity		
Event places and merchandise	2,516	-
Other fundraising costs	4,564	4,370
Support costs	<u>7,652</u>	<u>7,261</u>
	<u>14,732</u>	<u>11,631</u>

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

7 Expenditure on charitable activities

	Direct Support	Advocacy	Education and raising awareness	Total	Direct Support	Advocacy	Education and raising awareness	Research	Total
	2025 £	2025 £	2025 £	2025 £	2024 £	2024 £	2024 £	2024 £	2024 £
Direct costs									
Sundries	-	250	3,108	3,358	2	250	3,907	-	4,159
Marketing	2,170	-	10,717	12,887	2,585	-	15,272	-	17,857
Grants	5,100	-	-	5,100	2,285	-	-	1,560	3,845
	<u>7,270</u>	<u>250</u>	<u>13,825</u>	<u>21,345</u>	<u>4,872</u>	<u>250</u>	<u>19,179</u>	<u>1,560</u>	<u>25,861</u>
Share of support and governance costs (see note 8)									
Support	11,540	26,025	30,869	68,434	10,913	25,446	29,968	-	66,327
Governance	3,185	3,185	3,372	9,742	2,942	2,942	3,106	-	8,990
	<u>21,995</u>	<u>29,460</u>	<u>48,066</u>	<u>99,521</u>	<u>18,727</u>	<u>28,638</u>	<u>52,253</u>	<u>1,560</u>	<u>101,178</u>
Analysis by fund									
Unrestricted funds	6,984	29,460	48,066	84,510	16,442	27,206	41,646	-	85,294
Restricted funds	15,011	-	-	15,011	2,285	1,432	10,607	1,560	15,884
	<u>21,995</u>	<u>29,460</u>	<u>48,066</u>	<u>99,521</u>	<u>18,727</u>	<u>28,638</u>	<u>52,253</u>	<u>1,560</u>	<u>101,178</u>

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

8 Support costs allocated to activities

	2025 £	2024 £
Staff costs	72,079	69,066
Subscriptions	1,111	887
Travel and subsistence	705	1,836
IT and telephone	1,145	928
Postage and fulfilment	88	-
Storage	958	871
Governance costs	9,742	8,990
	<u>85,828</u>	<u>82,578</u>
Analysed between:		
Fundraising	7,652	7,261
Direct Support	14,725	13,855
Advocacy	29,210	28,388
Education and raising awareness	34,241	33,074
	<u>85,828</u>	<u>82,578</u>

Governance costs comprise:

	2025 £	2024 £
Audit fees	2,970	2,910
Accountancy	6,324	5,670
Legal and professional	157	157
Sundries	91	74
Bank charges	200	179
	<u>9,742</u>	<u>8,990</u>

9 Net movement in funds

	2025 £	2024 £
The net movement in funds is stated after charging/(crediting):		
Fees payable for the independent examination of the charity's financial statements	<u>2,970</u>	<u>2,910</u>

10 Trustees

No expenses (2024: £55) were reimbursed to any trustees (2024: 1) during the year.

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

11 Employees

The average monthly number of employees during the year was:

	2025 Number	2024 Number
	1	1

Employment costs

	2025 £	2024 £
Wages and salaries	64,847	62,353
Social security costs	2,693	2,349
Other pension costs	4,539	4,364
	<u>72,079</u>	<u>69,066</u>

The number of employees whose annual remuneration was more than £60,000 is as follows:

	2025 Number	2024 Number
£60,000 to £70,000	1	1

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

	2025 £	2024 £
Aggregate compensation	<u>64,847</u>	<u>62,353</u>

12 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

13 Debtors

	2025 £	2024 £
Amounts falling due within one year:		
Trade debtors	-	(1)
Prepayments and accrued income	<u>1,019</u>	<u>6,672</u>
	<u>1,019</u>	<u>6,671</u>

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

14 Creditors: amounts falling due within one year

	2025 £	2024 £
Other taxation and social security	1,748	1,694
Trade creditors	1,100	2,124
Other creditors	724	6,332
Accruals and deferred income	7,511	4,153
	<u>11,083</u>	<u>14,303</u>

15 Retirement benefit schemes

	2025 £	2024 £
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	<u>4,539</u>	<u>4,364</u>

16 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2024 £	Incoming resources £	Resources expended £	At 31 March 2025 £
Booklets	3,800	-	(1,525)	2,275
Helpline costs	1,217	500	(1,717)	-
Digital campaign & reprint of IPOPI booklets	787	2,080	(2,117)	750
Mental health webinars	16,648	-	(3,900)	12,748
Patient events and support grants	2,692	-	(1,300)	1,392
Travel costs	174	-	(174)	-
The Hospital Saturday fund	2,000	-	-	2,000
Monthly e-newsletter	-	4,278	(4,278)	-
	<u>27,318</u>	<u>6,858</u>	<u>(15,011)</u>	<u>19,165</u>

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

16 Restricted funds

Previous year:	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
Booklets	4,497	-	(697)	3,800
Helpline costs	3,717	500	(3,000)	1,217
Website	1,229	-	(1,229)	-
Digital campaign & reprint of IPOPI booklets	424	3,704	(3,341)	787
Mental health webinars	16,648	-	-	16,648
Patient events and support grants	2,692	-	-	2,692
APDS awareness project	6,000	-	(6,000)	-
Travel costs	174	432	(432)	174
The Hospital Saturday fund	-	2,000	-	2,000
Monthly e-newsletter	-	2,700	(2,700)	-
Psychology project	-	(1,515)	1,515	-
	<u>35,381</u>	<u>7,821</u>	<u>(15,884)</u>	<u>27,318</u>

The funds brought forward reflect those accumulated by the Primary Immunodeficiency (PID) UK section of Gene People (formerly Genetic Disorders UK) which were transferred into Immunodeficiency UK when it became its own entity effective from 1st April 2021. Those funds which were restricted at that date have been transferred into their own restricted funds within these accounts.

Description of funds

Booklets - Funding to cover the cost of printing copies of specific information booklets.

Psychology project - Funding support, as part of a multi-charity initiative, for a clinical psychology position at Department of Immunology, Birmingham Heartlands Hospital. This project has finished and unspent funds were returned to the funder.

Helpline Training - Funding to support the training of volunteers to man the Immunodeficiency UK helpline.

Monthly e-newsletter - Support for the publication of a monthly e-newsletter for Immunodeficiency UK members covering April 2023 - December 2023.

Website - Funds for the development of a new website for Immunodeficiency UK.

Digital campaign and reprint of IPOPI materials - Reprint and dissemination of IPOPI educational materials and support for a digital marketing campaign for World PI Week.

Mental health webinars - Support for improving the mental health of the immunodeficiency community.

Patient events and support grants - Support for patient events and patient support grants.

Activated PI3K Delta Syndrome - Development of patient stories and APDS information for the website.

Travel - funds to cover travel costs to specific events and conferences.

The Hospital Saturday fund - Provision of up to date, medically reviewed educational booklets for families affected by rare primary immune deficiencies.

IMMUNODEFICIENCY UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

17 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2024 £	Incoming resources £	Resources expended £	At 31 March 2025 £
General fund	65,732	108,694	(99,242)	75,184
Previous year:	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
General fund	80,769	81,888	(96,925)	65,732

18 Analysis of net assets between funds

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £
At 31 March 2025:			
Current assets/(liabilities)	75,184	19,165	94,349
	75,184	19,165	94,349
	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
At 31 March 2024:			
Current assets/(liabilities)	65,732	27,318	93,050
	65,732	27,318	93,050

19 Related party transactions

There were no disclosable related party transactions during the year (2024 - none).