

1st April 2023-
31st March 2024

Annual report & financial statements

supporting individuals and families
affected by immunodeficiency



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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



8,000+

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. From 2013 to the launch of Immunodeficiency UK, PID UK operated as a division of Genetic Disorders UK (company registration number 07554771 and registered charity number 1141583).

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 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 relevant organisations to ensure that those affected by primary or secondary immunodeficiency have the knowledge needed to manage their condition effectively and 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, Benefits and Work, 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 – Chair
Hannah Bruce
Valerie Brisse-Uhlig

Diane Hammond
Jane Shepard
Tamara Moubazbaz

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)

Alison Fox (London)

Stacey Garrity (Manchester)

Carolyn Grundy (North 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, Manchester

Dr Claire Bethune, Consultant Immunologist, Derriford Hospital, Plymouth (retired 12-12-22)

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

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 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 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 in 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 2022 to 31 March 2023, the trustees met a total of 6 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 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 £89,709, compared with £130,269 for the financial year 2022-23. This year the expenditure was £112,809 compared with £116,426 for the financial year 2022-23.

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 2024 were £93,050 of which £27,318 related to restricted funds leaving £65,732 of unrestricted funds. These free reserves equate to nearly to 5.4 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 £12K per month).

Chairman's statement

The trustees present their report for the period 1 April 2023 to 31 March 2024 under the Charities Act 2011, together with the financial statements for that period. The financial statements comply with the Companies Act 2006, the charity's governing document and the relevant Statement of Recommended Practice (the Charities SORP [FRS 102]).

As I reflect on the past year at Immunodeficiency UK, I am filled with both pride and gratitude for the incredible progress made in supporting individuals and their families living with primary and secondary immunodeficiency. Our mission to improve diagnosis, care, and quality of life for those affected by immunodeficiency continues to drive every aspect of our work, and this year has seen significant strides in all areas of our mission.

We have expanded our support, offering ever more resources to individuals and families. Our partnerships with healthcare professionals and other organisations, have grown stronger, enabling us to advocate for a more holistic and coordinated approach to care. The increase in public awareness and education campaigns have brought greater understanding of immunodeficiency to both the medical community and the wider public.

This year also saw a considerable increase in support for research and advocacy, with a focus on improving access to treatments and pushing for better policy changes that impact those living with immunodeficiencies. Our efforts to ensure that no one feels isolated in their journey have resulted in growing engagement from both the community and donors.

None of this would be possible without the commitment of the staff, volunteers, and supporters of Immunodeficiency UK. I am deeply grateful for their dedication and passion in advancing our mission. We look ahead to the coming year with optimism, knowing that together we can continue to make a meaningful difference to the lives of those affected by immunodeficiency.

Thank you for your ongoing support.

Dr Matthew Buckland

Chair of Trustees

A handwritten signature in black ink, appearing to read 'M. Buckland', with a large, sweeping flourish at the end.

Our achievements at a glance



people were supported through our phone and email helpline service.

4,200+

information booklets sent to immunology centres and individuals.



We launched our new website in November 2023.

We received:

36,618 pageviews;
10,113 visitors, with **2,647** information booklet downloads.

12 newsletters were sent to our members keeping them updated on research, treatments, our activities and fundraising.



Launched new booklet on immunoglobulin therapy for younger patients and expanded our website content.

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

Our members' mental health challenges were addressed through informative webinars, providing strategies and support to help maintain good mental health throughout the year.

Our achievements at a glance

We advocated for the immunodeficiency community through consultations and partnerships with other charities to emphasise the needs of immunocompromised individuals.



We raised awareness of immunodeficiency and their treatments through campaigns and people stories.

Supporting research – we awarded a grant, helping research the impact of an immunodeficiency diagnosis on psychological health.



Our Facebook page reached 26,856 people, we boosted our X followers to 1,861, and our Instagram account now has 504 followers.

Lucie's story about secondary immunodeficiency



Lucie was diagnosed with secondary immunodeficiency following a course of chemotherapy to treat lymphoma, a blood cancer.

After successful treatment of her cancer, Lucie spent the next two years constantly unwell, with extreme fatigue, repeated infections and taking numerous courses of antibiotics. She reported the symptoms at her clinic appointments, but the doctors were not concerned as there were no signs of the lymphoma returning and her blood counts appeared normal.

Left very confused as to why she was feeling so unwell all the time with no obvious explanation, she demanded answers at a haematology appointment and, finally, a doctor tested her immunoglobulin levels.

The blood tests showed that her immunoglobulin levels were extremely low. She discovered that she had hypogammaglobulinemia. She was put on a course of daily antibiotics and underwent further testing to assess her antibody responses. The tests confirmed that she needed to start immunoglobulin replacement therapy.

She chose to have subcutaneous immunoglobulin therapy because it suits her lifestyle and gives her more freedom and control over her condition.

Lucie says 'Being diagnosed with secondary immunodeficiency has been life-changing for me. Since starting treatment, I have more energy and don't feel so ill and drained all the time. The infusion treatments were a little daunting at first, but now they are something on my weekly 'to-do list' that I can fit in around my lifestyle.'

Arabella's story about APDS



Shared by her mum, Tamsin

Arabella was diagnosed aged 8 with activated PI3K δ syndrome (APDS), a rare condition which involves both immune deficiency and immune dysregulation.

APDS can cause lymphoma and they had a horrible scare of this in 2022. The family are currently trying to find a donor for a bone marrow transplant to completely cure Arabella's condition, but they are yet to find a match.

“

Arabella is a true fighter and an inspiration to our family and friends. Our aim is to raise as much awareness of APDS as we can, to support other families in the same situation.

”

When Arabella was born, she was a healthy 7lb baby with no health issues. She thrived until the age of one, when she developed what her mother Tamsin thought was a nasty chest infection. It lasted for seven long years.

They were frequent visitors to their local hospital. Then, one day, they saw a consultant at their local hospital who referred Arabella to Great Ormond Street Hospital. They then found out that Arabella has activated P13K delta syndrome, also known as APDS.

Her condition affects her lungs, mostly causing bronchiectasis and a lung collapse.

It also affects her sinuses, bowels, bladder, eyes and has caused hearing loss and dysphagia (difficulty swallowing).

Arabella is undergoing immunoglobulin replacement therapy and intravenous medications at home, which have improved her infection rates massively.

Supporting the immunodeficiency community

Over the past year, we concentrated on five key areas:

- Providing our community with reliable information through our website, printed booklets and e-newsletters
- Offering practical and emotional support via our email and telephone services
- Raising awareness about immunodeficiency
- Promoting better mental health
- Advocating for individuals and families affected by immunodeficiency to enhance healthcare delivery and access to treatments

Our e-newsletters

We produced monthly e-newsletters that shared community news, research findings, latest developments in treatments, fundraising activities and opportunities for clinical trial involvement, including the PROTECT-V and STRAVINSKY COVID-19 studies. The average open rate of the newsletters was 49.6% (range 43.9% to 54.7%). 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](#)).

49.6% open rate

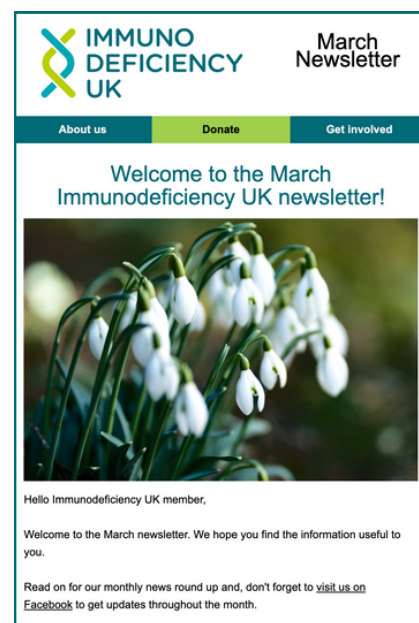
8.98% click-through rate

“

The monthly newsletter is excellent and as my sole source of information, very much appreciated, as is knowing that I can ask any questions at any time and get as comprehensive an answer as possible.

Feedback from a newsletter recipient

”



Our helpline services

The demand for our online and telephone helpline services remained high. In this period, we received 261 new enquiries. We were there as a listening ear and a provider of trusted information, signposting to services and dealing with issues relating to diagnosis, access to treatments and care, benefit entitlement and employment-related issues.

'Thank you so very much for your extremely helpful advice regarding my recent enquiry about possible immune deficiencies. I will certainly speak to my GP and try and get a referral to an Immunologist to see if this is something that finally can be diagnosed'.

Caroline, who is suffering from repeated, recurrent infections.

261

Number of new enquiries

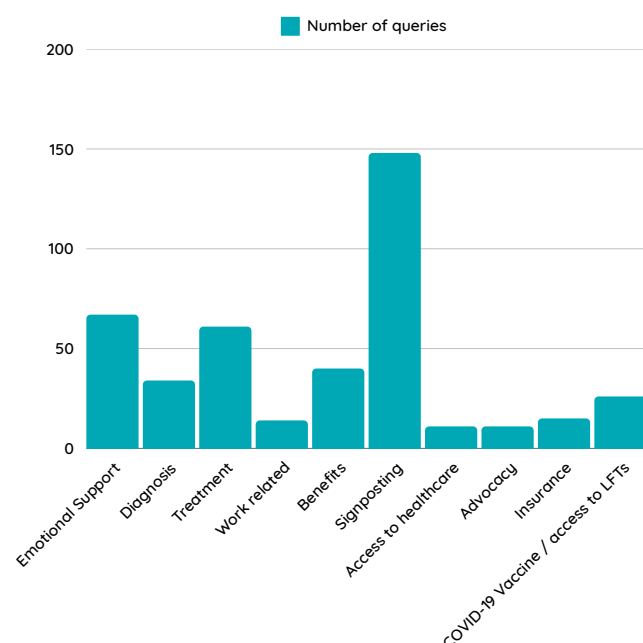
24

Number of re-contact enquiries

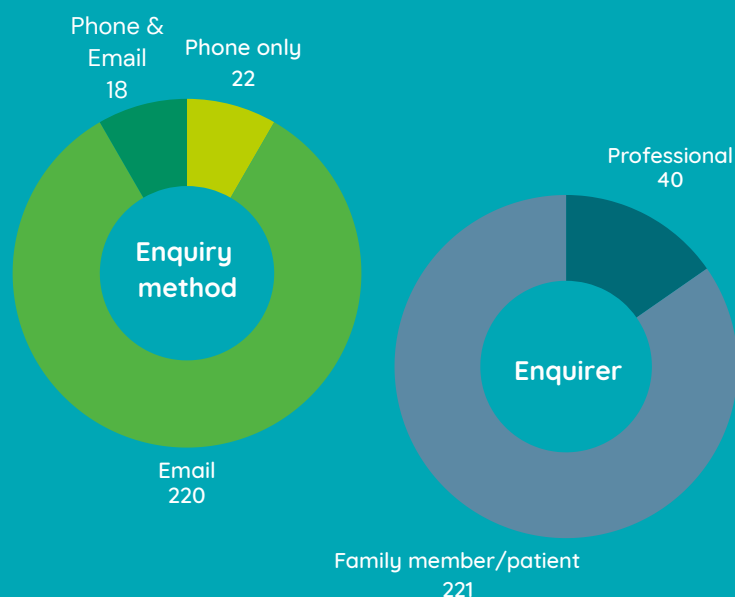
340

Emails sent

Support offered



New enquiries



Jane, mother to a child with APCED.

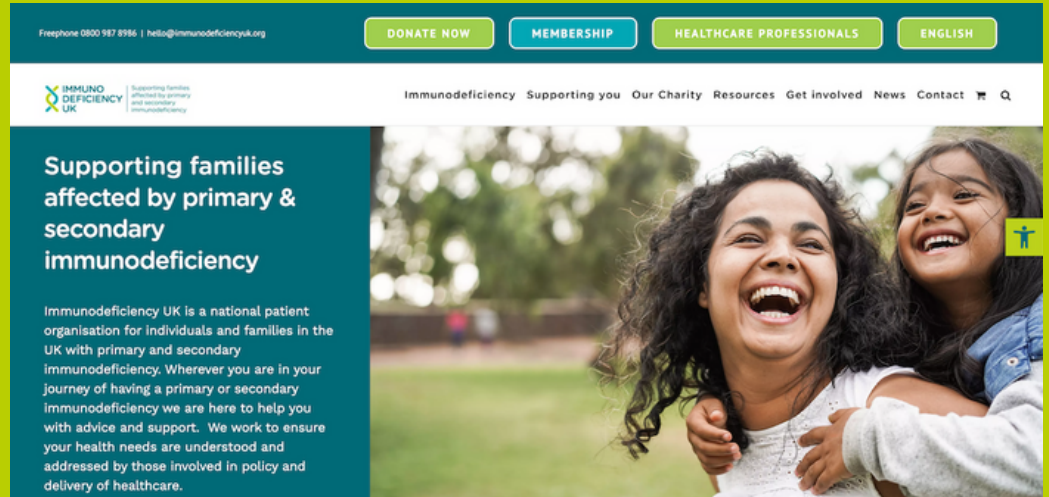
Thank you so much for your speedy response, I have used your site for my son's condition since his diagnosis last year, it is such a relief to be able to understand what is going on with his condition and you have been a great help.

Matilda, who was seeking information on her condition.

Many thanks for your response to my questions about Selective IgM deficiency. That's very helpful of you, and useful to understand what the usual approach to treatment/management is.

Launch of a new website

In November 2023, we launched a redesigned website to support patients, their families, and healthcare professionals with information about primary and secondary immunodeficiency.



The platform offers clear, accessible information covering all aspects of living with an immunodeficiency. It now incorporates a hub for medical professionals which includes in-depth guidance on diagnosing, treating and managing immunodeficiency. There are downloadable clinic posters, and portals for ordering our educational booklets for clinics and applying for hardship grants for patients in need of financial support with the costs of accessing healthcare.

The site has enhanced user experience with intuitive navigation, a mobile-friendly design, accessibility features including translation and an improved search function. The website hosts over 70 downloadable booklets, attracting users from over 130 countries, including Australia, Canada and the USA.

Top downloaded booklets

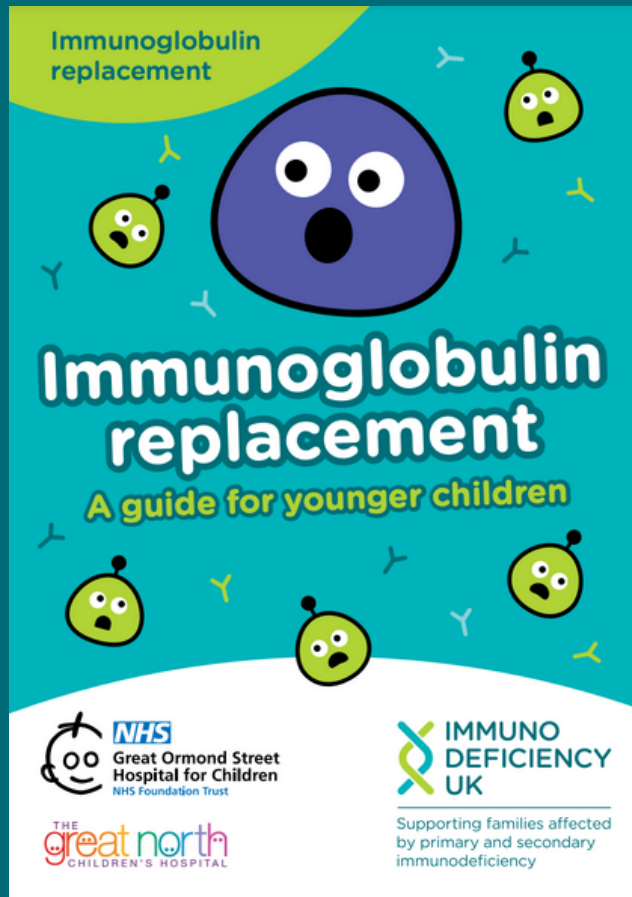
- 1 Keeping well and healthy when you have a PID
- 2 Secondary immunodeficiency
- 3 Primary immunodeficiency – the basics
- 4 Subcutaneous immunoglobulin (SCIG) infusions – a practical guide for patients
- 5 Antibiotics and PID

36,618
pageviews

10,113
unique visitors

2,647
booklet
downloads

Booklet and information development



With the help of funding support from the Hospital Saturday Fund we also expanded our educational materials in response to community and specialist needs. Collaborating with immunology experts and patient representatives from renowned hospitals, we created a new booklet: "Immunoglobulin replacement: a guide for younger children".

This colourful, reassuring publication features photos of children undergoing treatment, fostering a sense of shared experience.

We also began updating condition-specific booklets covering ten rare primary immunodeficiencies, ensuring alignment with current knowledge and treatment guidelines. These will be delivered in 24/25.

Development of new website content

To address helpline enquiries, we developed online resources on:

Living with spleen issues or post-splenectomy

The transition to Integrated Care Boards in England and its potential impact

Guidance on workplace protection under the Equality Act 2010

Raising awareness of immunodeficiency

Sharing experiences

When living with or caring for a person with an immunodeficiency, sharing experiences can be a lifeline. We know that at diagnosis, it is common for people to struggle to come to terms with living with a lifelong condition and its implications. Thanks to our wonderful contributors, we created five new people stories giving a first-person perspective of living with these conditions. These were highlighted in our newsletters and on social media.

Here Mitch shares his experience of diagnosis for the primary immunodeficiency common variable immunodeficiency (CVID):



Mitch was diagnosed with CVID aged 33.

Mitch had symptoms of primary immunodeficiency since childhood, with repeated chest and ear infections, sinus problems, and bouts of pneumonia. However, it wasn't until he developed bronchiectasis, a chronic lung condition, that his immunoglobulin levels were checked and found to be extremely low. Following further tests, he was diagnosed with CVID and immediately put on immunoglobulin therapy.

'To say I was nervous about my first immunoglobulin replacement therapy session is an understatement. The staff explained the whole procedure, which mirrored the information provided by Immunodeficiency UK. Their website explains the risks (which are minimal) but, more importantly, the benefits of this treatment.'

World PI Week 2023

Immunodeficiency UK launched a global campaign during World Primary Immunodeficiency (PI) Week, reaching over 5,800 people through social media. Our campaign shared patient stories about the challenges faced by people and treatment options for those living with primary immunodeficiency.

reach c5,800 people

501 post clicks

Rare Disease Day 2024

Rare Disease Day is a global event aimed at raising awareness about rare diseases and their impact on patients. Immunodeficiency UK participated in a social media campaign to increase public awareness, encourage decision-makers to address the needs of those living with rare diseases, and collaborate on improving rare disease care and support.

reach c1,300 people

113 post clicks

Providing mental health support

Understanding the mental health impact of living with immunodeficiency

To better understand the mental health impact of living with primary or secondary immunodeficiency on patients and their carers, we conducted a community survey. The results helped us assess the level of need and identify focus areas for future mental health support initiatives.

Key findings from our mental health survey

88% of respondents said their condition had a negative impact on their mental health

Key factors were:

- Extreme fatigue
- Anxiety
- Dealing with a diagnosis
- Concerns about the future

74% of respondents had not been offered or directed to mental health support services

80% of respondents expressed a desire for mental health support from Immunodeficiency UK

With our funding and insight, we collaborated with the mental health charity RareMinds to deliver mental health webinars and workshops tailored to our community's needs.

Given the positive outcomes and benefits, we will continue this collaboration to offer other mental health support programmes in 2024/25.

88% of participants would recommend the support given to others

“

I have completed the 8-week programme and can say it is fantastic. It has helped me with many coping strategies for pain and anxiety, fear and general pacing. I still have a very lot to learn and practice but I believe it is something to work on.

An attendee of the 8-week mindfulness course

”

“

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

A 'Dealing with Diagnosis' webinar attendee

”

Providing hardship grants and medical devices

Immunodeficiency UK continued its hardship grant programme, offering £100 grants to individuals and families struggling to cover essential healthcare expenses. Immunology centres identify and refer eligible recipients. During the 23/24 year, nine grants were awarded.

This will really help with travelling costs especially as I'll be travelling to London from Norwich quite a bit for the bone marrow transplant.

Hardship grant recipient

I have to travel to London annually for ongoing research

related to my stem cell therapy, however it's an extra expense I can't really afford especially with a newborn son. To just have some financial pressures alleviated helps reduce the stress.

Hardship grant recipient

We launched a new support programme providing free 'Buzzy Shot' pain relief devices to children with immunodeficiency, aiming to 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 'Buzzy Shot' devices to six families.

The Buzzy Shot uses cold and vibration to distract away from the pain of needles.

'The weekly subcutaneous immunoglobulin infusions for their 6-year-old boy were previously very stressful for the whole family as he got so upset and is needle phobic. The Buzzy has made a massive difference. He loves it! And says it is no longer sore getting the needle in.'

Feedback from a nurse of a family who received a Buzzy.



Our advocacy work

Promoting plasma donation

We partnered with NHS Blood and Transplant (NHSBT) to raise awareness about the critical importance of plasma donation as a source of immunoglobulin (IG) therapy, an essential treatment for over 8,000 people affected by immunodeficiency.

We used social media to share patient stories about the benefits of IG therapy and co-hosted a Plasma Awareness Parliamentary Reception at the House of Commons, attracting 50 MPs. Our CEO also spoke at the opening of a new plasma collection centre in Birmingham.



Pictured: Dr Susan Walsh, Immunodeficiency UK CEO (third from the right) with a group of immunodeficiency patients who attended the House of Commons to share their experiences.

Patient experience survey

In collaboration with Takeda UK Ltd, we conducted an online survey between July and September 2023 to better understand the experiences of patients with immunodeficiency. The results will inform a report with recommendations for NHS leaders and medical professional organisations, to be published in autumn 2024.

Supporting genetic testing

We collaborated with Genetic Alliance UK to successfully advocate for licensing pre-implantation genetic testing for the rare condition Schimke immuno-osseous dysplasia.

Advocating for access to treatments

- We represented the patient perspective at the 'UK Advanced Therapies Adoption Challenge' event, discussing barriers and solutions for access to gene therapy medicines
- We submitted a letter to the National Institute for Health and Care Excellence (NICE), co-signed by the British Society for Immunology Clinical Immunology Professional Network (BSI-CIPN), challenging the assessment route for Leniolisib as a treatment for rare primary immunodeficiency APDS.

Our advocacy work

We submitted stakeholder responses to the following consultations:

NHS commissioning policy on Abatacept for autoimmune complications of primary immunodeficiency

Welsh Health Specialised Services Committee's consultation on immunology services

Statutory pricing scheme consultation supporting the proposal to remove Voluntary Scheme for Branded Medicine Pricing and Access (VPAS) costs from plasma products

The continuing impact of COVID-19

The COVID-19 pandemic continued to have an impact on our community, with 10% still shielding and 20% having low confidence in socialising.

Immunodeficiency UK, part of the high-risk stakeholder coalition, met with NHS England and the UK Health Security Agency (UKHSA) to discuss infection rates, emerging variants, and access to medicines, vaccination programmes and free lateral flow tests.

Stakeholders co-signed letters and we provided case studies to UKHSA, raising concerns about the paused Office for National Statistics Coronavirus Infection Survey. This survey provided vulnerable people with the knowledge needed to make informed decisions regarding the risk of contracting COVID-19 through social mixing.

A letter was sent to the Secretary of State for Health and Social Care and the Prime Minister addressing the lack of timely information on COVID-19 treatment access via Integrated Care Boards and the ongoing isolation of immunocompromised individuals.



At the request of the Scottish Government, Immunodeficiency UK submitted a response to the Scottish COVID-19 Inquiry. Our response helped the Inquiry team to understand the impacts of the COVID-19 pandemic on our organisation and the members we represent.

Supporting research

Research Grant Award

We awarded £1,560 to support the study: "Impact of a diagnosis of primary or secondary immunodeficiency on psychological health in the United Kingdom". The research involves patients from seven immunology centres and will help enhance the understanding of patient needs in quality of life and mental health to help inform patient-centred care practices and supporting evidence-based decision making in immunodeficiency care.

The study is led by Dr Mari Campbell, Consultant Clinical Psychologist, Royal Free London NHS Foundation Trust (pictured top right) and Dr Philip Bright, Immunology Consultant, North Bristol Hospital Trust (pictured bottom right).



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 involvement in these research initiatives underscores our commitment to advancing scientific understanding and improving care for those affected by immunodeficiency.

Our incredible fundraisers

A huge thank you to Natassia and Matthew, who raised over £5,100 for Immunodeficiency UK



Natassia and Matthew raised a huge £5,100 to support the charity's vital work. Their motivation came from a personal place – their son Brooklyn was diagnosed at just 8 months old with X-Linked CD40 Ligand Deficiency, also known as Hyper IgM Syndrome.

Natassia and Matthew were determined to raise funds and awareness for all those living with an immunodeficiency, and the constant worries that come with chronic illness. As Natassia shared, **"The articles and support pages provided by Immunodeficiency UK were invaluable to us after Brooklyn's diagnosis, in helping us understand more about his condition."**

The couple, supported by their family and close friends, undertook a wide range of fundraising activities. These included a 5km charity walk, two charity football matches, a CrossFit challenge, the grueling Goggins challenge (running 4 miles every 4 hours for 48 hours), and a BBQ and bake sale. Immunodeficiency UK is truly thankful for the tireless efforts of Natassia, Matthew, and their loved ones. Their commitment to supporting the charity and raising awareness of immunodeficiency is remarkable.

£5,100 was raised

Our incredible fundraisers

Dedicated Fundraiser Scales New Heights for Immunodeficiency UK



Rachael Stephens (pictured on the right), a new member from Cornwall, raised an outstanding £1,225 for the charity after being diagnosed with common variable immunodeficiency (CVID) in early 2023.

Rachael, a youth worker and mental health practitioner, took on the ambitious challenge of climbing three Scottish mountains, including Ben Nevis, the highest peak in the United Kingdom. Rachael uses hiking and other activities to support the mental health of the people she works with.

After nearly a decade of developing various symptoms, Rachael became gravely ill with an infection just before Christmas 2022, leading to a period of extensive testing and medical appointments. She was eventually referred to an immunologist, who diagnosed her condition.

Undaunted, Rachael successfully completed her mountaineering challenge at the end of September 2023, surpassing her initial fundraising goal. Immunodeficiency UK is incredibly inspired by Rachael's courageous effort and for her generous support of the charity.

£1,225 was raised

Our incredible fundraisers



Katy Takes the Plunge for Immunodeficiency UK

Immunodeficiency UK couldn't be more thankful to Katy, who undertook a skydiving challenge to raise funds for the charity.

In 2017, Katy lost her uncle to CVID, a serious primary immunodeficiency that he had battled for most of his life. Katy's father also lives with CVID, and throughout her life, Katy has witnessed him struggle with recurrent infections and the need for ongoing medication.

Determined to make a difference, Katy decided to take the plunge, quite literally, by participating in a skydive to raise money for Immunodeficiency UK.

Through her ambitious fundraising challenge, Katy raised a remarkable £2,295.

£28,663

was raised through public
donations

Thank you to all our members, fundraisers, donors, volunteers, trustees, sponsors and members of our medical and patient representative panel for their continued support.

We couldn't do what we do without you.

To make a donation, please go to
<http://www.immunodeficiencyuk.org/donate>

Our aims for the next year

We will continue to:

- Raise awareness of primary and secondary immunodeficiency and provide support services for those affected
- Work with our community to define what needs to be done and to make the case for funding
- Review our educational information and respond to community needs by developing new information where needed
- Further develop our website and social media presence to ensure individuals with immunodeficiency have access to up-to-date and accurate information
- Give hardship grants to affected individuals in need
- Offer mental health support to our members
- Distribute Buzzy medical devices to children with immunodeficiency, to make needle insertion less painful and reduce stress on carers and parents
- Campaign and advocate on issues affecting our community, including access to earlier diagnosis and specialised treatments
- Secure more trusts and foundations funding to expand our staff resource and services

www.immunodeficiencyuk.org
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www.immunodeficiencyuk.org

IMMUNODEFICIENCY UK

Unaudited Financial Statements for the Year Ended 31 March 2024

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Surrey
KT17 1HQ

**Contents of the Financial Statements
for the year ended 31 March 2024**

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IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2024

The trustees present their report with the financial statements of the charity for the year ended 31 March 2024. The trustees have adopted the provisions of 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) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

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:
 - o 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
 - o 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
 - o 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, Benefits and Work, 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.

The CEO of Immunodeficiency UK is the patient representative on NHS England's newborn screening oversight committee for severe combined immunodeficiency (SCID) and NHS Scotland's National Plasma Products Expert Advisory Group (NPPEAG). She is also the patient representative on the Haplo+4kids clinical trial, which aims to improve haploidentical donor stem cell transplant outcomes for children and adolescents with immunodeficiency.

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2024

ACHIEVEMENT AND PERFORMANCE

Our helpline service and other support activities

The demand for our online and telephone helpline services remained high in this period: we received 261 new enquiries (252 in 2022/23). We were there as a listening ear and a provider of trusted information, signposting to services and dealing with issues relating to diagnosis, insurance, access to treatments and care, benefit entitlement and employment-related issues. Ten per cent of enquiries were related to COVID-19 support, down from 29% in 2022/23, with a shift from enquiries about the health risks of COVID-19 to information and problems concerning access to vaccines, antiviral medicines and free lateral flow tests.

In response to the cost-of-living crisis that has put pressure on many households' financial situation, we continued our hardship grant scheme. On referral from immunology centres, grants of £100 are given to help individuals and families who might otherwise struggle with travel costs to access healthcare for themselves or their child. We awarded nine such grants during this reporting period.

As part of our commitment to improving the healthcare experience for children with immunodeficiency, we started to provide families with free 'Buzzy Shot' pain relief devices. 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. Available by referral from a medical professional, the devices are intended to make procedures involving needles as comfortable as possible and avoid the onset of needle phobia. We provided six families with 'Buzzy Shot' devices in this reporting period.

Mental health support

Disappointingly, the much-valued clinical psychologist service for immunology patients at Heartlands Hospital and Queen Elizabeth Hospital Birmingham, which we were helping to support as part of a coalition of charities, came to an end. This was due to a unilateral decision by the Birmingham and Solihull Mental Health NHS Foundation Trust to change the existing service model, making it too expensive for our coalition to support. We remain committed to highlighting the shortage of psychology support services as an important adjunct to clinical immunology care.

We carried out a mental health survey of our community, to better understand the impact of a diagnosis and living with a primary or secondary immunodeficiency on the mental health of those directly affected and their carers. The survey also helped Immunodeficiency UK to establish the extent of need and identify topics for mental health support programmes.

We received 65 survey responses. Only 12% of respondents indicated that their condition had no impact on their mental health. Fifty-six per cent of respondents reported that a diagnosis of immunodeficiency or being a carer negatively impacted on their mental health either a lot or moderately. Excessive fatigue, anxiety, dealing with a diagnosis and uncertainty and worries about the future were reported to have a significant impact on mental health, with 74% of respondents reporting that they had not been offered or signposted to mental health support services, including counselling/psychology or peer support. Eighty per cent of respondents reported that they wanted Immunodeficiency UK to offer targeted mental health support. Responding to this unmet need, we worked with the charity RareMinds, which advocates for, and provides, specialist mental health support for the rare disease community. RareMinds delivered tailored mental health support webinars and workshops with funding from Immunodeficiency UK.

During the period, specialist facilitated webinars were delivered on dealing with diagnosis and the use of mindfulness to reduce pain, anxiety and fatigue. An eight-week immersive course enabled participants to further explore and learn mindfulness techniques. A total of 44 people took part in these events, with 88% per cent of participants recommending the support be offered to others.

Following the success and reported benefits brought to those involved, we will continue to work with RareMinds, to provide tailored mental health support programmes in 2024/25.

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2024

Information development and dissemination

We produced monthly e-newsletters that shared community news, research findings, latest developments in treatments, fundraising activities and opportunities for clinical trial involvement, including the PROTECT-V and STRAVINSKY COVID-19 studies. The average open rate of the newsletters was 49.6% (range 43.9% to 54.7%). These figures are above the average open rate of 28.6% quoted for non-profit communications (source: NonProfit Tech for Good: <https://www.nptechforgood.com/101-best-practices/email-marketing-statistics-for-nonprofits/>)

We highlighted our charity's services and materials to immunology medical professionals through two targeted mailings. We had a promotional stand at the Immunology and Allergy Nursing Group conference held in Cardiff.

Through our on-demand order service for medical professionals, we provided over 4,093 booklets to support patients at immunology centres. We also distributed 136 of our booklets directly to newly diagnosed patients or those navigating their treatment pathway.

Launch of a new website

In November 2023, we launched a redesigned website. The new platform aims to support and empower patients and families by providing clear, accessible information about primary and secondary immunodeficiency for those directly affected, their family members and carers. The website incorporates a separate hub for healthcare professionals, which contains resources that they can use to support their patients. These resources include easily downloadable clinic posters to raise awareness about immunodeficiency, an order form for patient resources, and downloadable booklets, specifically aimed at medical professionals, which provide in-depth guidance on treating patients with immunodeficiency conditions.

The redesigned website offers accessibility and language translation features to make it as inclusive as possible. It has an improved search function to allow visitors to access the information they need quickly and easily. The site hosts a library of over 70 downloadable booklets that provide in-depth understanding of immunodeficiency conditions and related topics.

Importantly, we are now able to measure the use of our website using Google Analytics. During the reporting period, the website attracted users from over 130 countries, including the UK, USA, Australia and Canada. It received 36,618 pageviews, 10,113 unique visitors and 2,647 booklets were downloaded. The booklets most frequently downloaded were 'Keeping well and healthy when you have a PID', 'Secondary immunodeficiency', 'Primary immunodeficiency - the basics', 'Subcutaneous infusions of immunoglobulin - a practical guide for patients' and 'Antibiotics and immunodeficiency'.

Development of information leaflets and website content

We continued to expand our portfolio of leaflets, responding to the needs expressed by the community and immunology specialists. We worked in collaboration with immunology consultants, clinical nurse specialists and patient representatives from Great Ormond Street and the Great North Children's Hospital to develop a new booklet, 'Immunoglobulin replacement: a guide for younger children'. This booklet presents key information in a reassuring, colourful and attractive format, and features photos of young children receiving treatment, to give a sense of shared experience.

Through this working group, we started to review the content of condition-specific booklets that cover ten extremely rare primary immunodeficiencies. We want to ensure that the information is up to date with current knowledge and management and treatment guidelines.

Responding to information requests received through our helpline, we developed online information on living with spleen problems or without a spleen and on the devolvment of healthcare in England to Integrated Care Boards (ICBs) and what it means for patients. We also provided information to empower the community about legal protection against discrimination in the workplace under the Equality Act 2010.

In the reporting period there was a significant change in England on how to access COVID treatments (antivirals) for high-risk groups of people within our community who test positive for COVID-19. Access arrangements transferred from a centralised COVID Medicines Delivery Unit (CMDU) to individual ICBs, with variations on the mechanism of access for those in need across the 42 different ICBs. This change required more bespoke signposting; therefore, we developed a new webpage devoted to information on COVID-19 medicines, incorporating the contact details for each ICB. This helped to ensure that patients had the knowledge needed to access COVID-19 treatments in a timely manner.

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2024

Raising awareness of immunodeficiency and its impact

For those living with immunodeficiency, learning about the experiences of others diagnosed with the same condition can be a valuable means of support. We added five patient stories to our library of lived experience stories. These covered the experiences of living with secondary immunodeficiency, common variable immunodeficiency (CVID) and caring for children with activated PI3K delta syndrome (APDS). We would like to thank all involved for sharing their stories.

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

We increased our social media presence over the year. Our Facebook reach was 26,856, with 6,300 visits (up 112% compared with 2022/23), and we had 154 new followers (up 6%). We gained 39 new Instagram followers, and our reach increased by 169% to 798 on this platform. On X (formerly Twitter), we had 25 new followers. Our advocacy work was our most popular content, followed by patient stories. These figures are above the average rate quoted for non-profit communications of 25.2% (source 2024 Social Media Industry Benchmark Report | Rival IQ).

Supporting research and involvement in clinical trials

At the request of clinical immunology research teams, Immunodeficiency UK wrote support letters for two research proposals. Our e-newsletters and social media channels promoted opportunities for people to take part in research studies, including the COVID-19 focused clinical trials STRAVINSKY and PROTECT-V. We published information on research outcomes in our monthly e-newsletters and on our website.

Immunodeficiency UK awarded a grant of £1,560 to support research into the 'Impact of a diagnosis of primary or secondary immunodeficiency on psychological health in the United Kingdom'. The project leaders are Dr Mari Campbell, Consultant Clinical Psychologist at the Royal Free London NHS Foundation Trust and Dr Philip Bright, Immunology Consultant at the North Bristol Hospital Trust. Involving patients from seven immunology centres, the research will focus on the quality of life and mental health of people diagnosed with immunodeficiency. It is hoped that the results of this study will give an improved understanding of patient needs in these areas, which is important for informing patient-centred care, policy development and decision making.

Our advocacy work to support the community

As a basis for advocating for improvements in care for people affected by immunodeficiency, we collaborated with Takeda UK Ltd and Interaction Marketing & Public Relations Ltd to design and conduct a voluntary online survey. Our aim was to better understand the current experiences of patients with primary or secondary immunodeficiency. The survey consisted of multiple choice and free text questions and was open between July and September 2023. The survey results were collated by an independent healthcare communications consultancy, in accordance with UK data protection laws. This work was fully funded by Takeda UK Ltd. A final report, with recommendations for NHS leaders and medical professional organisations, will be published in autumn 2024.

Immunodeficiency UK worked with NHS Blood and Transplant (NHSBT) to raise awareness of the importance of plasma donation in the UK. Plasma contains antibodies, which are vital in the fight against infections and diseases. For 7,000 people with primary or secondary immunodeficiency, immunoglobulin (IG) therapy derived from plasma donations is essential for their quality of life and survival. With a current worldwide shortage of plasma and increasing demand (the number of people requiring IG treatment has risen by 31% worldwide in the past five years), there is an urgent need to improve the UK's self-sufficiency in IG supply.

Awareness of the situation was raised through our social media channels, using people's stories about the difference that having IG therapy has made to their quality of life. We partnered with NHSBT to co-host a Plasma Awareness Parliamentary Reception at the House of Commons, which brought together MPs, healthcare professionals and our patient ambassadors to discuss the critical importance of plasma donation in the UK. The reception, which included a presentation from a primary immunodeficiency patient, served as a platform to talk about the life-changing impact of IG therapy and to seek support for policies that would better support the UK's plasma collection programme. The event attracted 50 MPs. We are extremely grateful to NHSBT and Munira Wilson MP, who sponsored the event, for the opportunity to share the experience of those affected and the needs of our community.

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2024

Our CEO was invited by NHSBT to give a talk about the importance of IG therapy for patients with immunodeficiency, at the opening of a new plasma collection centre in Birmingham.

Immunodeficiency UK collaborated with Genetic Alliance UK to support a successful application by an affected family to the Human Fertilisation and Embryology Authority to license pre-implantation genetic testing for monogenic disorders for the rare primary immunodeficiency called Schimke immuno-osseous dysplasia.

We submitted a letter to NICE, co-signed by the British Society for Immunology - Clinical Immunology Professional Immunodeficiency UK Network Steering Group (CPIN), challenging NICE's initial decision to exempt the drug Leniolisib, as a treatment for the rare immunodeficiency APDS, from assessment through their Highly Specialised Technology (HST) route. The HST programme evaluates technologies for very rare and, often, very severe, diseases that need the specific considerations and flexibilities permitted by the programme. We were delighted to learn that after consideration of stakeholder feedback, NICE decided that APDS met all the criteria for HST appraisal. Immunodeficiency UK will be advocating for access to Leniolisib through submission of a consultation response in the next reporting period.

Gene therapy is a potential cure for people with certain types of immunodeficiency but, owing to small patient numbers, it is often not commercially viable for companies to invest in and keep the therapies on the market. We were therefore delighted to be invited to represent the patient perspective at the 'UK Advanced Therapies Adoption Challenge' event at the Royal Society of Medicine in London, to discuss barriers and develop solutions.

Immunodeficiency UK also submitted stakeholder responses to the following consultations:

- NHS commissioning policy on Abatacept for autoimmune complications of primary immunodeficiency caused by CTLA-4 or LRBA mutations
- Welsh Health Specialised Services Committee's consultation on immunology services
- Statutory pricing scheme consultation supporting the proposal to remove Voluntary Scheme for Branded Medicines Pricing and Access (VPAS) costs from plasma products.

The continuing impact of COVID-19

The effects of the COVID-19 pandemic continued to have an impact on our community. Our mental health survey showed that 10% of respondents were still shielding, with a further 20% having low confidence in leaving their home and socialising.

As part of the COVID-19 high-risk stakeholder coalition, Immunodeficiency UK took part in meetings with NHS England and the UK Health Security Agency (UKHSA) concerning ongoing surveillance of COVID-19 infection rates, emerging variants, access to COVID-19 medicines, and vaccination programmes, and free lateral flow tests.

As a stakeholder in this coalition, we co-signed letters and provided case studies for the following:

- A letter to the UKHSA, raising concerns about the organisation's decision to pause the Office for National Statistics Coronavirus Infection Survey. This survey provided vulnerable people with the knowledge needed to make informed decisions regarding the risk of contracting COVID-19 through social mixing.
- A letter to the Secretary of State for Health and Social Care concerning the lack of timely information for patients on how to access post-exposure treatments for COVID-19 via integrated care boards, following the transfer of responsibility from CMDUs.
- A letter to the Prime Minister concerning the continued isolation facing immunocompromised people on the fourth anniversary of the UK COVID-19 lockdown and the need for speedy access to protective treatments.

At the request of the Scottish Government, Immunodeficiency UK submitted a response to the Scottish COVID-19 Inquiry. Our response helped the Inquiry team to understand the impacts of the COVID-19 pandemic on our organisation and the members we represent.

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2024

FINANCIAL REVIEW

Financial position

Our financial statements for the year are shown on pages 8 to 17. A summary of the financial results for the year are set out below.

Incoming resources

Total income for the year was £89,709, compared with £130,269 for the financial year 2022-23. We have not received any income from legacies this year. We offered a free will writing service this financial year and received two pledges.

Resources expended

This year the expenditure was £112,809 compared with £116,426 for the financial year 2022-23.

Reserves policy

Total reserves of the charity as of 31st March 2024 were £93,050 of which £27,318 related to restricted funds leaving £65,732 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 £12,000 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 2024, free reserves totalled £65,732 equating to 5.4 months of operating costs and is therefore in keeping with the reserves policy.

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.

OUR AIMS FOR THE NEXT YEAR

- To continue to raise awareness of primary and secondary immunodeficiency and provide support services for those affected.
- To continue to give hardship grants to affected individuals in need.
- To continue to review our information and add new information as needed.
- To launch a new website with improved accessibility and develop and increase our social media presence.
- To continue to campaign and advocate on issues affecting our community.
- To work with our community to define what needs to be done and to make the case for funding.
- To broaden income streams to include fundraising from trusts and foundations, improved promotion of regular giving and building legacy-giving.
- To establish a larger board of trustees to facilitate succession planning.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1193166

Principal address

Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ

IMMUNODEFICIENCY UK

**Report of the Trustees
for the year ended 31 March 2024**

Trustees

Ms H A Bruce
Dr M Buckland Chair
Ms D Hammond
Ms V D Brisse-Uhlig
Ms J E Shepard
Ms T Moubazbaz

Independent Examiner

Xeinadin
Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ

Approved by order of the board of trustees on ..6th January 2025. and signed on its behalf by:



.....
Dr M Buckland - Chair

**Independent Examiner's Report to the Trustees of
Immunodeficiency UK**

Independent examiner's report to the trustees of Immunodeficiency UK

I report to the charity trustees on my examination of the accounts of Immunodeficiency UK (the Trust) for the year ended 31 March 2024.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material 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 Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts 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 accounts to be reached.



Hazel Day

Xeinadin
Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ

Date: ...15th January 2025.....

IMMUNODEFICIENCY UK

Statement of Financial Activities for the year ended 31 March 2024

	Notes	Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		81,602	7,821	89,423	131,154
Other trading activities	2	30	-	30	-
Investment income	3	<u>256</u>	<u>-</u>	<u>256</u>	<u>115</u>
Total		<u>81,888</u>	<u>7,821</u>	<u>89,709</u>	<u>131,269</u>
EXPENDITURE ON					
Charitable activities					
SUPPORT		<u>96,925</u>	<u>15,884</u>	<u>112,809</u>	<u>116,426</u>
NET INCOME/(EXPENDITURE)		(15,037)	(8,063)	(23,100)	14,843
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
TOTAL FUNDS CARRIED FORWARD		<u><u>65,732</u></u>	<u><u>27,318</u></u>	<u><u>93,050</u></u>	<u><u>116,150</u></u>

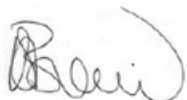
The notes form part of these financial statements

IMMUNODEFICIENCY UK

Balance Sheet 31 March 2024

	Notes	Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
CURRENT ASSETS					
Debtors	7	6,672	-	6,672	1,793
Cash at bank		<u>73,364</u>	<u>27,318</u>	<u>100,682</u>	<u>126,057</u>
		80,036	27,318	107,354	127,850
CREDITORS					
Amounts falling due within one year	8	(14,304)	-	(14,304)	(11,700)
		<u>65,732</u>	<u>27,318</u>	<u>93,050</u>	<u>116,150</u>
NET CURRENT ASSETS					
		<u>65,732</u>	<u>27,318</u>	<u>93,050</u>	<u>116,150</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>65,732</u>	<u>27,318</u>	<u>93,050</u>	<u>116,150</u>
NET ASSETS		<u>65,732</u>	<u>27,318</u>	<u>93,050</u>	<u>116,150</u>
FUNDS	9				
Unrestricted funds				65,732	80,769
Restricted funds				<u>27,318</u>	<u>35,381</u>
TOTAL FUNDS				<u>93,050</u>	<u>116,150</u>

The financial statements were approved by the Board of Trustees and authorised for issue on .6th January 2025..... and were signed on its behalf by:



.....
M Buckland - Chair

The notes form part of these financial statements

**Notes to the Financial Statements
for the year ended 31 March 2024**

1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

These financial statements contain information in relation to the Charity only.

The presentational currency of these financial statements is GBP.

The Charity is a public benefit entity.

The charity has taken advantage of the following disclosure exemption in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, 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 accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

TAXATION

The charity is exempt from tax on its charitable activities.

FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

FINANCIAL INSTRUMENTS

Financial instruments are classified and accounted for, according to the substance of the contractual arrangement, as either financial assets, financial liabilities or equity instruments -

Trade and other debtors

Trade and other debtors that are receivable within one year and do not constitute a financing transaction are recorded at the undiscounted amount expected to be received, net of any impairment.

Those that are receivable after more than one year or constitute a financing transaction are recorded initially at fair value less transaction costs and subsequently at amortised costs, net of impairment.

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2024

1. ACCOUNTING POLICIES - continued

FINANCIAL INSTRUMENTS

Cash and cash equivalents

Cash and cash equivalents comprise cash at bank and on hand, demand deposits with banks and other short-term highly liquid investments with original maturities of three months or less and bank overdrafts. In the balance sheet, bank overdrafts are shown within borrowings or current liabilities.

Trade and other creditors

Trade and other creditors are initially recognised at the transaction price and are thereafter stated at amortised cost using the effective interest method unless the effect of discounting would be immaterial, in which case they are stated at cost.

2. OTHER TRADING ACTIVITIES

	2024	2023
	£	£
Merchandise income	<u>30</u>	<u>-</u>

3. INVESTMENT INCOME

	2024	2023
	£	£
Deposit account interest	<u>256</u>	<u>115</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

TRUSTEES' EXPENSES

Expenses totalling £55 (2023 nil) were reimbursed to 1 trustee (2023 nil) during the year in respect of travel costs incurred.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	88,499	42,655	131,154
Investment income	<u>115</u>	<u>-</u>	<u>115</u>
Total	<u>88,614</u>	<u>42,655</u>	<u>131,269</u>
EXPENDITURE ON			
Charitable activities			
SUPPORT	<u>93,515</u>	<u>22,911</u>	<u>116,426</u>
NET INCOME/(EXPENDITURE)	(4,901)	19,744	14,843
RECONCILIATION OF FUNDS			
Total funds brought forward	85,670	15,637	101,307

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2024

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
TOTAL FUNDS CARRIED FORWARD	<u>80,769</u>	<u>35,381</u>	<u>116,150</u>

6. FUNDERS

Below is a breakdown of funding recognised in income in the financial period to 31st March 2024:

	2024 £	2023 £
Pharming Technologies	-	10,000
AmDel Medical	(1,515)	5,000
LFB Biopharmaceuticals	-	5,000
Octapharma	-	4,750
Biotest	2,700	3,600
Solaris Health	-	2,000
IPOPI	4,115	1,679
E Shearsby	-	1,000
CSL Behring	-	8,626
C Shearsby	-	950
Renishaw	500	500
The Hospital Saturday Fund	<u>2,000</u>	
	<u>7,800</u>	<u>42,155</u>

In addition to the above restricted funding, funds were received from CSL Behring of £35,000 (2023 £35,000) to aid Immunodeficiency UK to improve knowledge and awareness of primary and secondary immunodeficiency and support the provision of services for patients. Funds were also received from Takeda Ltd of £17,939 to help support the general running costs of Immunodeficiency UK, including administrative support, cost of storage, fulfilment, and delivery of educational booklets and costs of providing 'Buzzy' pain relief machines to families who require extra support for their child when they have immunoglobulin treatment.

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 - Collaborative project with Immunodeficiency UK involving the development and roll-out of a patient survey to explore the experience of individuals affected by primary and secondary immunodeficiencies. The contribution of Takeda was £36,000 to employ a healthcare/charity communications agency. No direct payment was made to Immunodeficiency UK.

Involvement in the 'Number 17' campaign raising awareness of people living with a rare disease and attendance at a Takeda funded online workshop on diversity, equity, and inclusion.

AmDel Medical - This project has completed and unspent funds were returned to the funder.

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2024

7. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade debtors	-	617
Prepayments and accrued income	<u>6,672</u>	<u>1,176</u>
	<u>6,672</u>	<u>1,793</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade creditors	2,124	3,569
Taxation and social security	1,694	1,594
Other creditors	<u>10,486</u>	<u>6,537</u>
	<u>14,304</u>	<u>11,700</u>

9. MOVEMENT IN FUNDS

	At 1.4.23	Net movement in funds	At 31.3.24
	£	£	£
Unrestricted funds			
General fund	80,769	(15,037)	65,732
Restricted funds			
Booklets	4,497	(697)	3,800
Website	1,229	(1,229)	-
Digital campaign and reprint of IPOPI booklets	424	363	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	-	174
Helpline costs	3,717	(2,500)	1,217
The Hospital Saturday fund	-	<u>2,000</u>	<u>2,000</u>
	<u>35,381</u>	<u>(8,063)</u>	<u>27,318</u>
TOTAL FUNDS	<u>116,150</u>	<u>(23,100)</u>	<u>93,050</u>

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued **for the year ended 31 March 2024**

9. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	81,888	(96,925)	(15,037)
Restricted funds			
Booklets	-	(697)	(697)
Psychology project	(1,515)	1,515	-
Website	-	(1,229)	(1,229)
Digital campaign and reprint of IPOPI booklets	3,704	(3,341)	363
Monthly e-newsletter	2,700	(2,700)	-
APDS awareness project	-	(6,000)	(6,000)
Travel costs	432	(432)	-
Helpline costs	500	(3,000)	(2,500)
The Hospital Saturday fund	2,000	-	2,000
	<u>7,821</u>	<u>(15,884)</u>	<u>(8,063)</u>
TOTAL FUNDS	<u>89,709</u>	<u>(112,809)</u>	<u>(23,100)</u>

Comparatives for movement in funds

	At 1.4.22 £	Net movement in funds £	At 31.3.23 £
Unrestricted funds			
General fund	85,670	(4,901)	80,769
Restricted funds			
Booklets	3,424	1,073	4,497
Helpline Training	415	3,302	3,717
Website	3,332	(2,103)	1,229
Digital campaign and reprint of IPOPI booklets	1,164	(740)	424
Mental health webinars	3,310	13,338	16,648
Patient events and support grants	3,992	(1,300)	2,692
APDS awareness project	-	6,000	6,000
Travel costs	-	174	174
	<u>15,637</u>	<u>19,744</u>	<u>35,381</u>
TOTAL FUNDS	<u>101,307</u>	<u>14,843</u>	<u>116,150</u>

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2024

9. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	88,614	(93,515)	(4,901)
Restricted funds			
Booklets	2,250	(1,177)	1,073
Psychology project	5,000	(5,000)	-
Helpline Training	6,000	(2,698)	3,302
Website	-	(2,103)	(2,103)
Digital campaign and reprint of IPOPI booklets	1,252	(1,992)	(740)
Mental health webinars	13,626	(288)	13,338
Monthly e-newsletter	3,600	(3,600)	-
Patient events and support grants	-	(1,300)	(1,300)
APDS awareness project	10,000	(4,000)	6,000
Travel costs	427	(253)	174
Helpline costs	500	(500)	-
	<u>42,655</u>	<u>(22,911)</u>	<u>19,744</u>
TOTAL FUNDS	<u>131,269</u>	<u>(116,426)</u>	<u>14,843</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.

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2024

9. MOVEMENT IN FUNDS - continued

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

10. EMPLOYEE BENEFIT OBLIGATIONS

The total amount recognised as an expense in the year for payments made to defined contribution pension schemes was £4,365.

11. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2024.

IMMUNODEFICIENCY UK

Detailed Statement of Financial Activities for the year ended 31 March 2024

	2024 £	2023 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	89,423	131,154
Other trading activities		
Merchandise income	30	-
Investment income		
Deposit account interest	<u>256</u>	<u>115</u>
Total incoming resources	89,709	131,269
EXPENDITURE		
Charitable activities		
Wages	62,353	58,823
Social security	2,349	2,225
Pensions	4,365	4,118
Sundries	4,775	4,358
Marketing	21,739	16,845
Events	<u>8,491</u>	<u>20,847</u>
	104,072	107,216
Support costs		
Governance costs		
Auditors' remuneration	8,580	8,760
Professional fees	<u>157</u>	<u>450</u>
	<u>8,737</u>	<u>9,210</u>
Total resources expended	<u>112,809</u>	<u>116,426</u>
Net (expenditure)/income	<u>(23,100)</u>	<u>14,843</u>

This page does not form part of the statutory financial statements