

1st April 2022-
31st March 2023



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



450+

different rare conditions are recognised as primary immunodeficiencies



7,000+

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

Primary and secondary immunodeficiencies are underdiagnosed

COVID-19 has made life extremely challenging for people who have an immunodeficiency

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

About Immunodeficiency UK

Immunodeficiency UK was registered as a 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).

The charity officially launched on 1 April 2021 following the transfer of all assets belonging to PID UK to Immunodeficiency UK, through a Deed of Transfer agreement approved by Board resolution from Genetic Disorders UK's trustees, taking effect at 23:59 on 31 March 2021.

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 400 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 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 have 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.

COVID-19 has made life extremely challenging for people with PID and SID

Due to their underlying health conditions, some people with PID and SID cannot make an effective immune response against COVID-19. They may have had seven or more COVID-19 vaccinations but, unlike most people, these may have given them little or no protection against infection. So, they can be at the highest risk of becoming seriously ill from COVID-19.

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, 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 (appointed 20-1-21)
Hannah Bruce (appointed 20-1-21)
Valerie Brisse-Uhlig (appointed 21-3-22)
Tamara Moubazbaz (appointed 18-10-22)

Lisa Gagliani MBE (retired 17-1-23)
Diane Hammond (appointed 21-3-22)
Jane Shepard (appointed 21-3-22)

Our staff

Dr Susan Walsh – Chief Executive Officer (CEO)
Fay Fagon - Digital Communications, Marketing and Fundraising Assistant

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 (appointed August 2022)

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 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 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 £131,269. For our first year of operation from 20/1/21 to 31/3/22 income was £100,450. This year the expenditure was £116,426. For our first year of operation from 20/1/21 to 31/3/22 expenditure was £122,240.

Reserves policy

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 against any unforeseen changes in income and/or expenditure. On the 31st March 2023 free unrestricted reserves totalled £81,296 equating to nearly seven months of operating costs and is therefore in keeping with the reserves policy of holding free reserves equal to a minimum of 6–8 months operating costs (presently £12K per month).

Trustees' report

The trustees present their report for the period 1 April 2022 to 31 March 2023 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]).

I am delighted to contribute to the second annual report for Immunodeficiency UK.

The presentation of the annual report is a fantastic opportunity to see what Immunodeficiency UK achieved in the past year. For us, 2022–23 was a busy and productive time.

As the fear of the COVID-19 pandemic receded for many, individuals living with immunodeficiency – and their families supporting them – continued to cope with the fear of infection and its complications. We provided a lot of support for our members and lobbied decision-makers to ensure that appropriate care pathways were available.

Supporting our membership was a main objective. This reporting period coincides with the cost-of-living crisis, and Immunodeficiency UK provided hardship grants to help patients and their families during this time. Distributed via clinical nurse specialists in immunology, the grants provided financial assistance to patients who otherwise would not have been able to afford to travel to a centre for ongoing care.

I am delighted that we welcomed a new trustee to the board, which further strengthens the skill set that is available to support the charity.

As our membership has continued to grow, so have the projects that we have supported: from consultations on new medicines in rare diseases, through support for new diagnostic initiatives (such as newborn screening for SCID) to developing and updating patient information and providing psychological support for patients and their families.

Immunodeficiency UK is committed to ensuring that patients and their families remain the focus of healthcare services in all four home nations, but especially following the transition of healthcare provision to integrated care boards in England.

Dr Matthew Buckland
Chair of Trustees



Our achievements at a glance



250+

people were supported through our phone and email helpline service.

4150

information booklets sent to immunology centres and individuals.



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



We gave practical and emotional support through the COVID-19 pandemic.

We raised awareness of immunodeficiency through campaigns and people stories.



We helped fund a clinical psychology service for the immunology clinics at University Hospitals, Birmingham.

Our achievements at a glance

We advocated for the immunodeficiency community through responses to consultations and alliances with other charities to highlight the needs of people who are immunocompromised.



We provided advice and practical support for living with COVID-19. We sent out 400+ COVID-19 lateral flow tests.



We awarded 13 hardship grants to help ease the burden of access to healthcare during the cost of living crisis.



We reached 30,582 people through our Facebook page; gained new followers on Twitter bringing the total to 1,836; and continued to grow our Instagram account which now has 471 followers.

Living with immunodeficiency

Jamie's story about having APDS

I am Jamie and I have the ultra-rare condition called activated phosphoinositide 3-kinase delta syndrome (APDS). I was diagnosed when I was 2 years old. I am 17 now and a student with a part-time job.

The challenges of living with APDS

My symptoms tend to affect my chest and bowels. I am prone to getting chest infections and, in the case of my bowels, and often one day in every week I will feel ill and have diarrhoea. Many of the challenges I have faced are mostly to do with trying to live a normal life – combining school, work and socialising with hospital visits, spending months at a time in hospital and being poked and prodded with needles. APDS has affected me a lot; it still does. Luckily people are very kind and will give me a pass if I miss a day owing to illness or if I have a hospital appointment.

My condition can leave me exhausted, drained, both mentally and physically

Growing up with APDS made me feel alone and it felt like I couldn't talk to anyone about it. Now I know there are other people affected, so that makes me feel less isolated.

The condition saps my energy, both mentally and physically. I think it also has an impact on my diet because when I eat something with 'bad' calories, my bowel is immediately affected. It's like my body is trying to get rid of the bad nutrients. APDS has kept me underweight for many years.



My treatment is called immunoglobulin, which means I'm given antibodies every three weeks. But I have had many tests and treatments over the years – too many to count or name. When I was young, my mum used to bribe me by saying things like, 'I will get you a hot chocolate if you're a brave boy', to help divert my attention away from the treatment towards the prize. It sounds stupid but it worked.

My condition is a thing, I think, that ruins relationships because I feel like any partner would have to watch me suffer through pain and deal with a lot of stress. This means I try to avoid relationships as much as possible. My condition means I have to use the toilet a lot, so it would hold people up when leaving a restaurant or a cafe.

Explaining APDS to other people

I explain my condition to other people as simply as I can. I tell them that I have no antibodies, so I am prone to getting a lot of infections.

My wish is to reach out to people who have APDS; to build a community where people with the condition could talk and share tips about dealing with pain or the symptoms.

Supporting the immunodeficiency community

Over the last year, our work focussed on five key areas:

- Supporting our community through authoritative information published on our website, in printer booklets and e-newsletters.
- Providing practical and emotional support through our email and telephone service.
- Raising awareness of immunodeficiency.
- Supporting better mental health.
- Campaigning and advocating on behalf of individuals and families affected by immunodeficiency to improve healthcare delivery and access to treatments.

Our e-newsletters

Our monthly e-newsletters highlighted community news and our fundraisers, and featured health information, latest developments in treatment, research findings, and opportunities for clinical trial involvement. The average open rate was 53.9% (range 47.2% to 61.6%). These figures are above the average open rates quoted for non-profit communications.

53.9% open rate

28.8% click-through rate

“

‘The information and help provided by Immunodeficiency UK is extremely professional and answers all your questions. I like to be told things in a straightforward way, and the information on their website has been invaluable in helping me and my family understand what I am living with and how my quality of life will improve in the future. It has also helped me to explain CVID to my friends, so that they understand the condition too. It’s difficult trying to summarise CVID in a short sentence or to describe it when it pops up in conversation.’

”

From Mitch, who has common variable immunodeficiency (CVID).

Supporting the community through our helpline services

The demand for our online and telephone helpline services remained high. In this period, we received 252 new enquiries. Of these 75 (29%) were related to providing COVID-19 support. 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.

‘This is just so helpful thank you. I really appreciate your swift reply. It’s good to know there is a point of contact.’ Jane, newly diagnosed with CVID.

252

Number of new enquiries

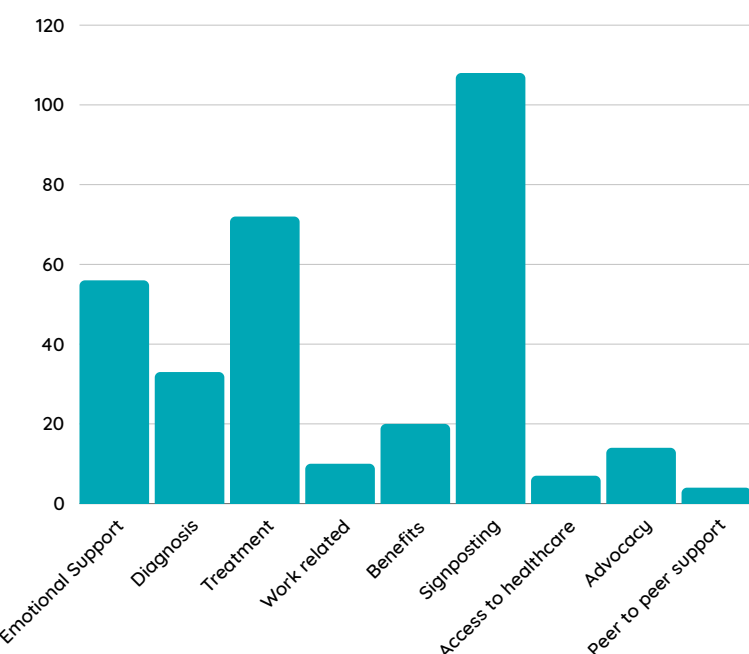
63

Number of re-contact enquiries

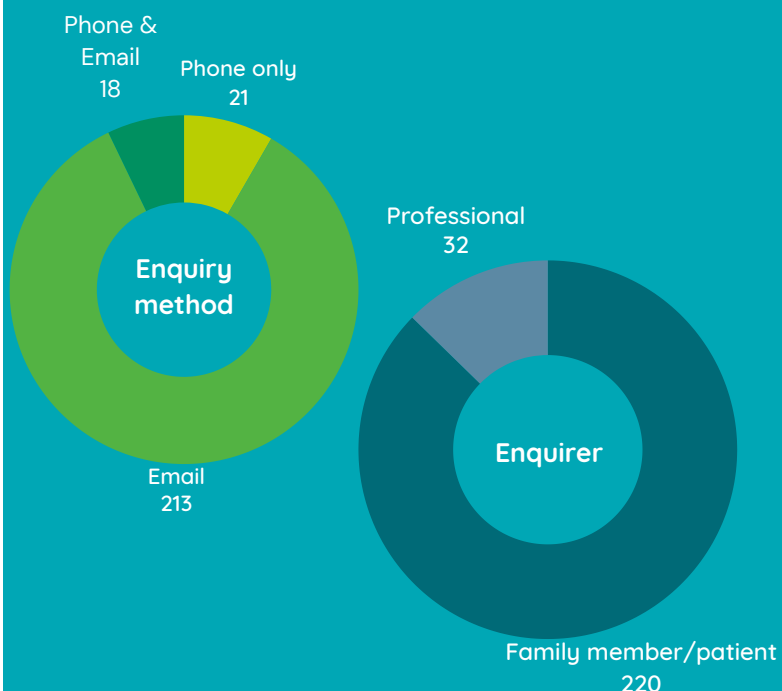
321

Emails sent

Support offered



New enquiries



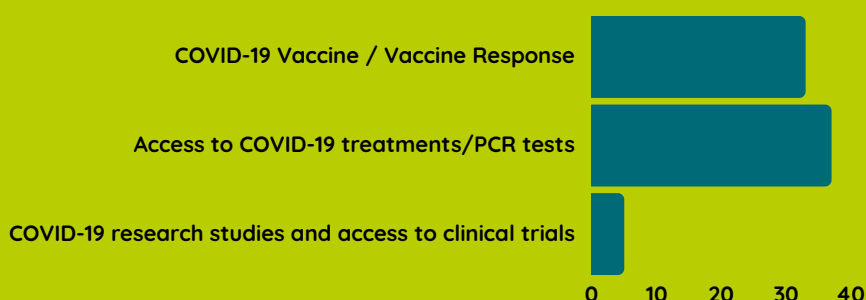
Advice on the Equality Act 2010 to Chris, affected by a

secondary immunodeficiency and who was experiencing discrimination at work.

This has been very helpful information so I would like to say thank you for this.



COVID-19 related enquiries



We also dealt with over 400 email requests for free COVID-19 LFTs.

Helping our members to have a safer time when seeing family and friends

Thanks to a donation of COVID-19 testing kits (LFTs) from 2San, Immunodeficiency UK distributed over 400 boxes of LFTs to our members. This was at the time when LFTs were no longer available free to family members of the immunocompromised or the general public.

This service demonstrated our unwavering commitment to the health and well-being of our community, ensuring easy access to essential resources during challenging times. The kits allowed people with immunodeficiency the chance to socialise by providing LFTs that they could give to friends and family so that they could test before meeting the immunocompromised.

With this initiative, we empowered our members to take proactive steps in safeguarding their health.

These tests provided a sense of security for those who are particularly vulnerable to the virus. With these testing kits, they could make informed decisions to protect themselves and their loved ones.

“As someone who doesn't respond to vaccines and relies on LFTs for myself and my family, this will make Christmas much easier.”

“Many thanks this is appreciated – it seems COVID is not going away & is a constant worry for those with compromised immunity.”

“My granddaughter has plasma every 3 weeks to treat her immunodeficiency & these tests will help us to feel safe at Easter when family are visiting.”

Providing hardship grants to people living with an immunodeficiency

Because of the increased pressure on families during the cost-of-living crisis, we wanted to do something to help families struggling with the extra costs that living with immunodeficiency can bring. So we launched a hardship grant scheme of £100 to help mitigate costs. These grants were available to people with a diagnosed immunodeficiency, with applications made by a recognised medical professional.

The grant aimed to help with the extra costs that having an immunodeficiency can bring, such as help towards the cost of prescriptions, travel to hospital and access to care. We awarded 13 hardship grants.

“It was a massive help to receive the grant as I was able to put the money towards travelling for treatment. I lose a day's pay and have to pay to travel 45 miles to my closest clinic so it's taken the pressure off a little to have some help with the costs.”

“I'm a full-time carer and live an hour away from the closest hospital that provides treatment for me, and I don't drive. Although I can claim back some money for travel I can't always have the money upfront to get to the hospital.”

“For four weeks whilst learning the infusion process, I travelled a nearly two hour round trip which with fuel prices was impacting on fuel use and one's finances. I now do treatments at home and have telephone appointments to avoid the journey. I appreciated the grant as a sole earner in the household, cost of living, elderly father at home it prevented getting into further debt.”

Supporting the immunodeficiency community

Our website and information booklets

In collaboration with clinical experts at Great Ormond Street Hospital, we developed information on the rare primary immunodeficiency Complete DiGeorge Syndrome, and its treatment using thymus transplantation. Due to the increasing use of genomics technology within the NHS we updated our information on the use of genomics for research and diagnosis of primary immunodeficiency. We continued to update our information on COVID-19 vaccination programmes and access to lateral flow tests and COVID-19 treatments.

Our work to develop a new website refreshing and improving content and accessibility continued. However, this project ran behind schedule due to the need to be reactive to emerging priorities within a small staff resource. The website remains a high priority and we are confident that this project will be delivered within the next period of reporting.

GP practice

How to work with your GP practice

www.immunodeficiencyuk.org
hello@immunodeficiencyuk.org
0800 987 8986

Ageing and the immune system

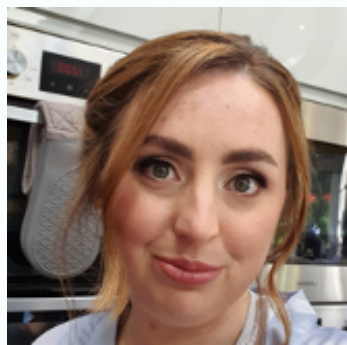
Ageing and the immune system

www.immunodeficiencyuk.org
hello@immunodeficiencyuk.org
0800 987 8986

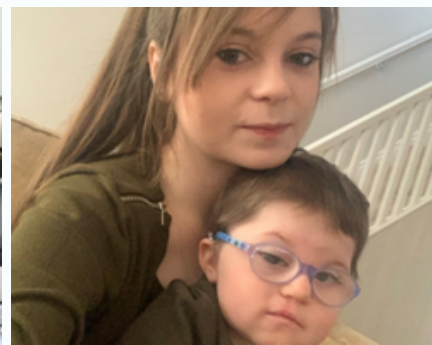
Supporting the community through shared experience

For those living with immunodeficiency, learning about the experiences of others diagnosed with the same condition can be a valuable means of support.

We would like to thank two parents who shared their experience of caring for a child with Complete DiGeorge syndrome and its treatment by thymus transplant, and two adults who shared their experience of living with activated PI3K delta syndrome (APDS).



Bethany



Bryony and Oscar

“

My wish is that all medical professionals know and understand what APDS is. The number of times I have had to explain the condition; it feels as though I am educating the medical sector. It becomes frustrating because, often, APDS is a contributory factor to my sickness at the time and impacts on my treatment plan.

Bethany, who has APDS

”

Raising awareness of immunodeficiency and its impact

We collaborated with Orchard Therapeutics to assess the impact of Wiskott–Aldrich Syndrome (WAS) on those affected and caregivers. Following the data-collection process, our CEO presented the findings at the International Primary Immunodeficiencies Congress, in Portugal. The findings underlined the direct and indirect impact of WAS on families in terms of reduced quality of life due to the burden of symptoms and care, the psychological impact and the economic cost to those affected. The results highlighted the need for continued advancement in treatment options for WAS.



RARE REVOLUTION MAGAZINE



An article on primary immunodeficiency, its diagnosis and treatment and challenges for the future was published in the Autumn 2022 edition of the RARE REVOLUTION magazine.

During this period, Immunodeficiency UK had representation on NHS Scotland's National Plasma Products Expert Advisory Group; the Prion Surveillance Study working group; the Scottish Parliament Cross-Party Group on Rare, Genetic and Undiagnosed Conditions and Public Health England's Newborn Screening for SCID Pilot Oversight Group.

Supporting the immunodeficiency community

Our advocacy work

The COVID-19 pandemic continued to impact on our community. Evidence gained through our COVID-19 patient experience survey, carried out in August 2022, indicated that 28% of 448 respondents with primary or secondary immunodeficiency in our community were continuing to shield to protect themselves from getting COVID-19, with subsequent negative effects on quality of life and mental health.

Responding to consultations

Access to anti-COVID-19 treatments, such as antivirals and monoclonal antibodies, following a positive COVID-19 test is a vital safety-net to people who are immunocompromised. Therefore, we submitted a consultation submission to the National Institute for Health and Care Excellence on the multiple technology appraisal for COVID-19 treatments: nirmatrelvir plus ritonavir (Paxlovid), sotrovimab (Xevudy), remdesivir (Veklury), molnupiravir (Lagevrio) and tixagevimab plus cilgavimab (Evusheld).

We need your help – NICE assessment of treatments for COVID-19

NICE
National Institute
for Health and
Care Excellence

Immunodeficiency UK has been asked by the National Institute for Health and Care Excellence (NICE) to take part in a multiple technology appraisal (MTA) on therapeutics for people with COVID-19. NICE has given us a very short timeline to respond to the consultation.

If are affected by a primary or secondary immunodeficiency, or a care-giver of someone affected and you haven't already taken part please give us your experience and views on living with and views on living with COVID-19 and access to COVID-19 treatments through this survey:

<https://www.surveymonkey.co.uk/r/67ML38L>

Thank you if you have already taken part!

As part of the COVID-19 high risk stakeholder group, Immunodeficiency UK took part in meetings with NHS England and the UK Health Security Agency (UKHSA) concerning the roll-out of the COVID-19 vaccination, changes in access to COVID-19 tests and COVID-19 medicines, and the ongoing surveillance of the COVID-19 pandemic. This provided an opportunity to share our community's experience and seek shared solutions to the problems encountered.



From Emma

'I had my tonsils removed when I was 16, owing to the continuous infections I had throughout my childhood that wouldn't shift with antibiotics. Then, I contracted pneumonia, which is rare at that age, but I was fortunate to be seen by an immunology specialist at the hospital. After a series of tests, I was diagnosed with common variable immune deficiency (CVID). My life had changed forever.

I'm so grateful for the support of my family and friends, and to people in a similar situation who have shared their experiences on the Immunodeficiency UK website. Talk openly to your friends and family, and visit the Immunodeficiency UK website for advice and guidance – you'll find a great online community there.'

Supporting the immunodeficiency community

Raising awareness of immunodeficiency

World Primary Immunodeficiency Week (WPIW) 2022

In the pursuit of raising awareness and fostering a sense of global community, Immunodeficiency UK took part in World Primary Immunodeficiency Week (WPIW) 2022.

This annual event serves as a cornerstone for the international primary immunodeficiency community, bringing together organisations, healthcare professionals, and individuals affected by these conditions.

Our social media platforms became vibrant hubs of information and support during WPIW 2022. Through impactful graphics, personal stories, and educational content, we reached a wider audience, sparking conversations and building a sense of community among those affected by immunodeficiencies.

reach c7,900 people

219 post clicks

International Plasma Awareness Week 2022

Immunodeficiency UK raised awareness of the critical importance of plasma donations. Through patient stories and shared experiences, we underscored the life-saving potential of plasma-derived therapies.

Participation in International Plasma Awareness Week provided Immunodeficiency UK with a platform to engage the public, encourage plasma donations, and emphasise the positive outcomes for individuals with immunodeficiency disorders.

reach c3,000 people

112 post clicks

10 warning signs of Primary Immunodeficiency

Primary immunodeficiency (PID) causes children and adults to have infections that come back frequently or are unusually hard to cure. Two or more of these warning signs could indicate the presence of an underlying PID. If you or your child have any of these symptoms, it's important to talk with your doctor. He or she might refer you to a specialist, such as an immunologist.

- Four or more new ear infections within 1 year
- Two or more new sinus infections within 1 year
- Two or more months on at least two antibiotics with little effect
- Two or more pneumonias within 3 years
- Failure of a baby or child to gain weight or grow normally (failure to thrive)*
- Need for intravenous antibiotics to clear infections.
- Persistent thrush or fungal infection (more than six months) on the skin or elsewhere
- Frequent deep skin or organ abscesses
- Two or more deep-seated infections including septicæmia (blood poisoning) within three years.
- A family history of a PID.

*There are many reasons for failing to thrive and PIDs are a rare but important cause.

People with PID rely on a range of different treatments being available. These include:

- Immunoglobulin therapy
- Antibiotics
- Anti-fungals
- Anti-virals
- Corticosteroids
- Haematopoietic Stem Cell Transplant (BMT)
- Enzyme replacement therapy
- Gene therapy
- Thymic transplant
- Immunosuppressive therapies
- Targeted therapies such as monoclonal antibodies

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IMMUNODEFICIENCY UK

www.immunodeficiencyuk.org
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0800 987 8986

Immunodeficiency UK
Published by Jen Rush · 25 April 2022 ·

A huge thank you to Rachel, who shared the one thing she wished others knew about her immunodeficiency with us.

Rachel says she is the type of person to always push herself, but this can cause her tiredness and physical pain. She trusts others in her life to remind her to stop and rest when she needs. What do you wish was more commonly known about immunodeficiency? Let us know in the comments ... See more

Play

0:00 / 0:56

IMMUNODEFICIENCY UK

Supporting the immunodeficiency community

We worked with NHS Blood and Transplant (NHSBT) in its campaign to encourage people in the UK to donate plasma. Plasma is essential to make life-saving immunoglobulin therapy which helps protect people with immunodeficiency from infection. We shared NHSBT's publicity assets, and provided case studies to emphasise the importance of plasma-derived therapies for people with immunodeficiency.

The NHS Blood and Transplant is today launching its first campaign for people to donate plasma for medicines over shortfall in donors due to lack of awareness following 20 year gap.

Dr Susan Walsh, Chief Executive Officer of Immunodeficiency UK's CEO, leads our efforts to advocate for plasma donation and ensure availability of immunoglobulin for patients affected by immunodeficiency.



“Many people affected by a primary immunodeficiency, such as XLA, cannot make the antibodies they need to protect themselves against infection. They rely on a lifesaving medicine called immunoglobulin to keep well and healthy. Immunoglobulin is made from human plasma and up to now the UK has been 100% reliant on plasma supplies from overseas.

“Removing the ban on the use of UK plasma means the UK can start to become more self-sufficient in producing immunoglobulin products. This is a tremendous step forward as it increases the security of supply of the treatment so many people rely upon to help keep life-threatening infections at bay. Please support this campaign and donate plasma, you are saving lives.

Dr. Susan Walsh
CEO, Immunodeficiency UK

The NHS needs 14,500 more plasma donors in the next three months. Plasma donation saves lives but it's new and not enough people know about.
@givebloodnhs #giveplasma #savelives

Try a
different pool
this summer

Join our pool of
plasma donors and
start saving lives.

#PlasmaPool



NHS

Plasma is needed to develop immunoglobulin replacement therapies that help so many people with immunodeficiency and other rare disorders. More donations from healthy donors means more plasma is available.

Donating plasma is safe and easy and can make a huge difference in the life of others. Will you consider donating plasma? The process is similar to blood donation and takes just over an hour.

Find out more about plasma donation and register to donate here



BLOOD.CO.UK

How to donate plasma

Giving plasma is safe and easy. Learn about what happens before, during and after.



Immunodeficiency UK

Published by Buffer · 7 October 2022 ·

Marian requires regular immunoglobulin infusions to protect her from infection as she has Common Variable Immune Deficiency (CVID). These treatments are vital in ensuring she can live a normal life.

In this video she wants to say a huge thankyou to plasma donors for their donations and the difference they make.

Would you like to help someone like Marian?

Why not sign up to donate today: <https://buff.ly/3AH4Oaf>



YOUTUBE.COM

Marian's Story

This World Blood Donor Day Marian would like to say thank you to all the bloo...

We're delighted to see Immunodeficiency UK's Patient Representative, Stacey, with her son Xander featured in the NHS Blood and Transplant campaign for people to donate plasma for medicines.

The NHS needs 14,500 more plasma donors in the next three months. Plasma donation saves lives but it's new and not enough people know about it. @givebloodnhs #giveplasma #savelives



Xander & Stacey



“Without plasma donations, in the long run, he would die. Donation will increase the security of supply for a medicine that people like Xander rely on to keep them healthy and alive.”

Xander's Mum, Stacey

Supporting the immunodeficiency community

Joining the #Forgotten500k campaign

Our COVID-19 patient experience survey highlighted the need for an alternative protection strategy as some people with immunodeficiency are unable to mount a full vaccination response due to having an impaired immune system.

To raise awareness of the immunocompromised and the need for continued support for people at high risk of becoming seriously ill from COVID-19, we joined the #Forgotten500k campaign, alongside many other charities representing immunocompromised groups.

As COVID-19 surveillance programmes were scaled back we urged the UKHSA, through jointly signed letters, to continue its monitoring programmes. These programmes are a valuable source of information to help people manage risk when living with the threat of COVID-19.



As part of the #Forgotten500k campaign there will be a vigil at Parliament Square, LONDON, on Wednesday 26th October at 12 noon. The vigil is being co-ordinated by Evusheld for the UK.

The intention of the vigil is to present an image of those stuck dealing with this silently and to invite MPs to come across to the vigil to speak to those taking part.

We know for many the prospect of travelling and taking part in something like this is beyond what you are happy to do, so... [See more](#)



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.

Our incredible fundraisers

Gateshead Rugby Club Fundraiser



In October of 2021, Steve lost his kind and fun-loving son Jezz after having two stem cell transplants to treat his immunodeficiency.

'Jezz passed away last October and left a great hole in all our lives. In his 26 years he did a lot, not just achieving for himself but in the wonderful effect he had on other people', says Steve.

To celebrate Steve's life and to help raise funds for Immunodeficiency UK the family along with Gateshead Rugby Club Beer Festival hosted a fundraiser. Jezz was a member of Gateshead Rugby Club and he was known as T Rex due to his running style.

The event raised £3,350 bringing the total raised to over £4,600 for Immunodeficiency UK and we couldn't be more grateful. This donation will go toward helping us to support more people living with primary or secondary immunodeficiencies nationwide.

£4,600 was raised in memory of Jezz

Our incredible fundraisers

Sponsored 3-hour Zumbathon



Karen Henderson is an immunology clinical nurse specialist at Addenbrookes and a long-term supporter and often signposts patients to our services.

She says 'I have over two decades experience within Immunology as a specialist nurse working with individuals and families with primary immunodeficiency and secondary antibody deficiency. I have signposted many patients to your excellent charity over the years and hope that our contribution helps with all the excellent support you provide.'

Karen organised a sponsored 3-hour Zumbathon alongside Katrina Hyland of fitness studio KFit in St Neots, Cambridgeshire.

A great bunch of amazing and charitable people got involved (pictured above). The event raised over £900 for Immunodeficiency UK.

£900 was raised

Our incredible fundraisers



Diane's Olympic Triathlon

Immunodeficiency UK trustee Diane completed an Olympic triathlon on August 28th – this consisted of swimming 1.5km, cycling 40km and running 10km – to raise funds for our helpline.

Both Diane and her daughter Rachel are affected by an immunodeficiency so this is a cause close to her heart. The pandemic has been a particularly difficult time for people who are especially vulnerable to COVID many of whom, like her daughter Rachel, don't get a full protective response from the vaccines, with some people still shielding.

Immunodeficiency UK has advocated for these patients, keeping them informed and supported in many ways, but especially through its helpline and Diane's fundraising was to further support this work. Many find it to be a lifeline for advice, guidance and emotional support.

Diane has raised over £1,500 for the helpline.

£39,359

was raised through public
donations

Thank you

Thank you to all our members, fundraisers, volunteers, staff, trustees, sponsors and members of our medical and patient representative panel for their continued support.
We couldn't do what we do without you.



www.immunodeficiencyuk.org
hello@immunodeficiencyuk.org
0800 987 8986



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

REGISTERED CHARITY NUMBER: 1193166

IMMUNODEFICIENCY UK

Unaudited Financial Statements for the Year Ended 31 March 2023

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

IMMUNODEFICIENCY UK

**Report of the Trustees
for the year ended 31 March 2023**

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1193166

Principal address
PO Box 12635
Colchester
Essex
CO7 5AN

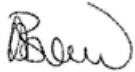
Trustees

Ms H A Bruce
Dr M Buckland Chair of Trustees
Mrs L E Gagliani MBE (resigned 17.1.23)
Ms D Hammond
Ms V Brisse-Uhlig
Ms J E Shepard
Ms T Moubazbaz (appointed 18.10.22)

Independent Examiner

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

Approved by order of the board of trustees on ..24 January 2024..... and signed on its behalf by:



.....
Dr M Buckland – Chair of Trustees

**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 Charity) for the year ended 31 March 2023.

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 Charity'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 Charity 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

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

Date: 24th January 2024

IMMUNODEFICIENCY UK

Statement of Financial Activities for the year ended 31 March 2023

				Year Ended 31.3.23 Total funds £	Period 20.1.21 to 31.3.22 Total funds £
	Notes	Unrestricted fund £	Restricted funds £		
INCOME AND ENDOWMENTS FROM					
Donations and legacies		88,499	42,655	131,154	100,450
Investment income	2	<u>115</u>	<u>-</u>	<u>115</u>	<u>1</u>
Total		<u>88,614</u>	<u>42,655</u>	<u>131,269</u>	<u>100,451</u>
EXPENDITURE ON					
Charitable activities					
SUPPORT		<u>93,515</u>	<u>22,911</u>	<u>116,426</u>	<u>122,240</u>
NET INCOME/(EXPENDITURE)		(4,901)	19,744	14,843	(21,789)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>	<u>123,096</u>
TOTAL FUNDS CARRIED FORWARD		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>

The notes form part of these financial statements

IMMUNODEFICIENCY UK

Balance Sheet 31 March 2023

	Notes	Unrestricted fund £	Restricted funds £	2023 Total funds £	2022 Total funds £
CURRENT ASSETS					
Debtors	6	1,793	-	1,793	3,962
Cash at bank		<u>90,676</u>	<u>35,381</u>	<u>126,057</u>	<u>119,041</u>
		92,469	35,381	127,850	123,003
CREDITORS					
Amounts falling due within one year	7	<u>(11,700)</u>	-	<u>(11,700)</u>	<u>(21,696)</u>
NET CURRENT ASSETS		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
NET ASSETS		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
FUNDS	8				
Unrestricted funds				80,769	85,670
Restricted funds				<u>35,381</u>	<u>15,637</u>
TOTAL FUNDS				<u>116,150</u>	<u>101,307</u>

The financial statements were approved by the Board of Trustees and authorised for issue on ...24 January 2024..... and were signed on its behalf by:



.....
M Buckland – Chair of Trustees

REGISTERED CHARITY NUMBER: 1193166

IMMUNODEFICIENCY UK

Unaudited Financial Statements for the Year Ended 31 March 2023

Tudor John Limited
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IMMUNODEFICIENCY UK

Contents of the Financial Statements for the year ended 31 March 2023

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Statement of Financial Activities	7
Balance Sheet	8
Notes to the Financial Statements	9 to 15
Detailed Statement of Financial Activities	16

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2023

The trustees present their report with the financial statements of the Charity for the year ended 31 March 2023. 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 and 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 and 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, 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).

The chief executive officer (CEO) of Immunodeficiency UK is the patient representative on NHS England's newborn screening oversight committee for severe combined immunodeficiency (SCID). She is also the patient representative on the Haplo+4kids clinical trial to improve haploidentical donor stem cell transplant outcomes for children and adolescents with immunodeficiency. Members of our patient representative panel have held patient and public involvement positions on the COVID-19 vaccination in autoimmune diseases (COVAD) study and the prion surveillance study working group.

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2023

ACHIEVEMENT AND PERFORMANCE

Our helpline service and other support activities

Through our helpline, we responded to 252 new enquiries and 63 enquiries from existing contacts. To those people who reached out, we provided reassurance, advised on diagnosis and access to treatments, helped with benefits advice and work-related issues, and signposted to other services or charities. Twenty-nine per cent of enquiries were related to COVID-19 support.

As part of our COVID-19 support, we distributed over 400 boxes of COVID-19 lateral flow tests (LFTs) to our members. The intention was to encourage friends and family to take a test ahead of meeting up with a person affected by an immunodeficiency. A negative LFT gave a degree of reassurance that any socialising among them could be safe. These testing kits were distributed when LFTs were no longer available free of charge to family members of the immunocompromised or the public. We are grateful to the company 2San for donating the LFTs to Immunodeficiency UK.

In response to the cost-of-living crisis that has put pressure on many households' financial situation, we launched a hardship grant scheme. Grants of £100 are given to help individuals and families who might otherwise struggle with travel costs to access healthcare. We awarded 13 such grants during this reporting period.

Being diagnosed and living with a lifelong chronic condition takes both a physical and mental toll. As part of a multi-charity funding initiative that recognises the need for tailored psychological support for people affected by immunodeficiency, we gave £5,000 to support the employment of a clinical psychologist for immunology patients across Heartlands Hospital and Queen Elizabeth Hospital Birmingham. The focus of therapeutic work to date has been varied, including adjustment to diagnosis; low mood and anxiety about health, the future and mortality; emotional difficulties related to the impact of health on roles and responsibilities; and fatigue.

Information development and dissemination

In collaboration with Great Ormond Street Hospital, we developed information on the rare primary immunodeficiency Complete DiGeorge syndrome and its treatment using thymus transplantation. We produced two new leaflets. The first, 'Working with your GP', promotes a positive doctor-patient relationship. The second, 'Ageing and the immune system', explains how ageing affects the working of the immune system for people affected by immunodeficiency. Recognising the increasing use of genomics technology within the NHS, we updated our information on the use of genomics for researching and diagnosing primary immunodeficiency.

We produced monthly e-newsletters, sharing community news, research findings, latest developments in treatment, opportunities for clinical trial involvement and our fundraising activities. The average open rate was 53.9% (range 47.2% to 61.6%). These figures are above the average open rate quoted for non-profit communications of 25.2% (source Mailchimp: Email marketing statistics & benchmarks).

We distributed 105 of our booklets directly to newly diagnosed patients or those navigating their treatment pathway. Through our on-demand order service, we provided over 4,000 booklets to support patients at immunology centres.

We increased our social media presence over the year. Our Facebook reach was 30,582, with 4,539 visits (up 110% compared with 2021/22), and we had 72 new 'likes' (up 38%). We gained 17 new Instagram followers and our reach increased by 83% to 604. On X (formerly Twitter), we had 181 new followers, with 27,688 impressions. Patient stories were our most popular posts, followed by news of our COVID-19 advocacy work.

We continued our work to develop a new website with improved accessibility features refreshing and improving the content of our existing website. Our progress in this area fell behind schedule, due to our small staff resource needing to react to other emerging priorities. The update of our website remains an important priority and we are confident that the launch date will be within the next reporting period.

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 would like to thank two parents who shared their experience of caring for a child with Complete DiGeorge syndrome and its treatment by thymus transplant, and two adults who shared their experience of living with activated PI3K delta syndrome (APDS).

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2023

We collaborated with Orchard Therapeutics to assess the impact of Wiskott-Aldrich Syndrome (WAS) on affected patients and their caregivers. Following the data-collection process, our CEO presented the findings at the International Primary Immunodeficiencies Congress, in Portugal. The findings underlined the direct and indirect impact of WAS on families in terms of reduced quality of life due to the burden of symptoms and care, the psychological impact and the economic cost to those affected due to lost earnings. The results highlighted the need for continued advancement in treatment options for WAS.

We were involved in many campaigns to support our mission. For World Primary Immunodeficiency Week 2022, we ran a social media campaign, with information and posters describing the signs and symptoms of immunodeficiency and the different approaches to treatment. We signposted to our library of over 30 patient experience stories, to highlight the impact and challenges faced by those affected.

We worked with NHS Blood and Transplant in its campaign to encourage people to donate plasma. The case studies we provided emphasised the importance of plasma-derived therapies for people with immunodeficiency. The overall aim is for the UK to become more self-sufficient with regards to immunoglobulin, which is made from plasma. More than 7,000 people with primary and secondary antibody deficiency rely on immunoglobulin therapy to help protect them against infection. We plan to continue with our collaborative working to encourage more donors to come forward and become plasma donors.

Supporting research

Immunodeficiency UK wrote support letters for three research proposals. Our e-newsletters promoted opportunities for people to take part in research studies. We published information on research outcomes in our monthly e-newsletters and on our website.

We collaborated with researchers from Leeds Beckett University to help develop a patient-reported outcome measure (PROM) specifically for people affected by primary and secondary antibody deficiency. With a validated PROM, we have the potential to narrow the gap between the views of medical professionals and patients concerning treatment and care. We can also help healthcare services to provide more appropriate and patient-centred care.

Our advocacy work to support the community

The COVID-19 pandemic continued to impact our community. Evidence gained through our COVID-19 patient experience survey, carried out in August 2022, indicated that 28% of 448 respondents with primary or secondary immunodeficiency in our community were continuing to shield to protect themselves from getting COVID-19, with subsequent negative effects on quality of life and mental health. Using COVID-19 survey findings, we submitted a response to the All-Party Parliamentary Group on Vulnerable Groups to Pandemics' report for the COVID-19 inquiry. It highlighted the experiences of our community during the pandemic and the ongoing challenges they face. The experiences of two of our members were featured in the Daily Mail and Daily Mirror newspapers.

We continued to keep the community in all four home nations updated on news relating to COVID-19. Our website and e-newsletters carried information on topics such as the spring and autumn vaccination programmes, access to free LFTs, COVID-19 medicines and antibody testing.

As part of the COVID-19 high risk stakeholder group, Immunodeficiency UK took part in meetings with NHS England and the UK Health Security Agency (UKHSA) concerning the roll-out of the COVID-19 vaccination, access to COVID-19 tests and COVID-19 medicines, and the ongoing surveillance of the COVID-19 pandemic. This provided an opportunity to share our community's experience and seek shared solutions to the problems encountered.

Access to anti-COVID-19 treatments, such as antivirals and monoclonal antibodies, following a positive COVID-19 test is a vital safety-net to people who are immunocompromised. Therefore, we submitted a consultation submission to NICE on the multiple technology appraisal for the following COVID-19 treatments for preventing COVID-19 in adults: nirmatrelvir plus ritonavir (Paxlovid), sotrovimab (Xevudy), remdesivir (Veklury), molnupiravir (Lagevrio) and tixagevimab plus cilgavimab (Evusheld).

IMMUNODEFICIENCY UK

Report of the Trustees for the year ended 31 March 2023

Our COVID-19 patient experience survey highlighted the need for an alternative protection strategy among the community, as some people with immunodeficiency are unable to mount a full vaccination response due to their faulty immune system. In addition, research recently published in the Lancet Rheumatology, has highlighted that: "Approximately one in five people who are immunocompromised have no serological response to COVID-19 vaccines despite receiving three or more vaccine doses."

To raise awareness of the immunocompromised and the need for continued support for people at high risk of becoming seriously ill from COVID-19, we joined the #Forgotten500k campaign, alongside the charities Blood Cancer UK, Lupus UK, Leukaemia UK, Leukaemia Care, Kidney Care UK, Kidney Research UK, Anthony Nolan, Myaware, Action for Pulmonary Fibrosis, MS Society and Crohn's & Colitis UK. As COVID-19 surveillance programmes were scaled back we urged the UKHSA, through jointly signed letters, to continue its monitoring programmes. These programmes are a valuable source of information for people to manage risk when living with the threat of COVID-19.

FINANCIAL REVIEW

Financial position

Our financial statements for the year are shown on pages 7 to 15. A summary of the financial results for the year are set out below.

Incoming resources

Total income for the year was £131,269. For our first year of operation from 20/1/21 to 31/3/22 income was £100,450.

We have not received any income from legacies this year. We will be offering a free will writing service in the next financial year.

Resources expended

This year the expenditure was £116,426. For our first year of operation from 20/1/21 to 31/3/22 expenditure was £122,240.

Reserves policy

General reserves of the Charity at 31st March 2023 were £81,296. 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 against any unforeseen changes in income and/or expenditure. The reserves policy continues to be that of holding unrestricted free reserves equal to a minimum of 6-8 months operating costs (presently £12K 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. 'Free reserves' of the Charity are calculated as total funds (£116,015) less designated restricted income (£34,719). As at 31st March 2023, free reserves totalled £81,296 equating to nearly seven 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.

IMMUNODEFICIENCY UK

**Report of the Trustees
for the year ended 31 March 2023**

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1193166

Principal address
PO Box 12635
Colchester
Essex
CO7 5AN

Trustees

Ms H A Bruce
Dr M Buckland Chair of Trustees
Mrs L E Gagliani MBE (resigned 17.1.23)
Ms D Hammond
Ms V Brisse-Uhlig
Ms J E Shepard
Ms T Moubazbaz (appointed 18.10.22)

Independent Examiner

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

Approved by order of the board of trustees on ..24 January 2024..... and signed on its behalf by:



.....
Dr M Buckland – Chair of Trustees

**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 Charity) for the year ended 31 March 2023.

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 Charity'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 Charity 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

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

Date: 24th January 2024

IMMUNODEFICIENCY UK

Statement of Financial Activities for the year ended 31 March 2023

				Year Ended 31.3.23 Total funds £	Period 20.1.21 to 31.3.22 Total funds £
	Notes	Unrestricted fund £	Restricted funds £		
INCOME AND ENDOWMENTS FROM					
Donations and legacies		88,499	42,655	131,154	100,450
Investment income	2	<u>115</u>	<u>-</u>	<u>115</u>	<u>1</u>
Total		<u>88,614</u>	<u>42,655</u>	<u>131,269</u>	<u>100,451</u>
EXPENDITURE ON					
Charitable activities					
SUPPORT		<u>93,515</u>	<u>22,911</u>	<u>116,426</u>	<u>122,240</u>
NET INCOME/(EXPENDITURE)		(4,901)	19,744	14,843	(21,789)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>	<u>123,096</u>
TOTAL FUNDS CARRIED FORWARD		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>

The notes form part of these financial statements

IMMUNODEFICIENCY UK

Balance Sheet 31 March 2023

	Notes	Unrestricted fund £	Restricted funds £	2023 Total funds £	2022 Total funds £
CURRENT ASSETS					
Debtors	6	1,793	-	1,793	3,962
Cash at bank		<u>90,676</u>	<u>35,381</u>	<u>126,057</u>	<u>119,041</u>
		92,469	35,381	127,850	123,003
CREDITORS					
Amounts falling due within one year	7	<u>(11,700)</u>	-	<u>(11,700)</u>	<u>(21,696)</u>
NET CURRENT ASSETS		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
NET ASSETS		<u>80,769</u>	<u>35,381</u>	<u>116,150</u>	<u>101,307</u>
FUNDS	8				
Unrestricted funds				80,769	85,670
Restricted funds				<u>35,381</u>	<u>15,637</u>
TOTAL FUNDS				<u>116,150</u>	<u>101,307</u>

The financial statements were approved by the Board of Trustees and authorised for issue on ...24 January 2024..... and were signed on its behalf by:



.....
M Buckland – Chair of Trustees

IMMUNODEFICIENCY UK

Notes to the Financial Statements for the year ended 31 March 2023

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 exemptions 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 2023

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. INVESTMENT INCOME

	Year Ended 31.3.23 £	Period 20.1.21 to 31.3.22 £
Deposit account interest	<u>115</u>	<u>1</u>

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2023 nor for the period ended 31 March 2022.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 March 2023 nor for the period ended 31 March 2022.

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	92,249	8,201	100,450
Investment income	<u>1</u>	<u>-</u>	<u>1</u>
Total	<u>92,250</u>	<u>8,201</u>	<u>100,451</u>
EXPENDITURE ON			
Charitable activities			
SUPPORT	<u>103,130</u>	<u>19,110</u>	<u>122,240</u>
NET INCOME/(EXPENDITURE)	(10,880)	(10,909)	(21,789)
RECONCILIATION OF FUNDS			
Total funds brought forward	96,550	26,546	123,096
TOTAL FUNDS CARRIED FORWARD	<u>85,670</u>	<u>15,637</u>	<u>101,307</u>

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2023

5. FUNDERS

Below is a breakdown of funding recognised in income in the financial period to 31st March 2023:

	2023 £	2022 £
Pharming Technologies	10,000	-
AmDel Medical	5,000	4,351
LFB Biopharmaceuticals	5,000	-
Octapharma	4,750	-
Biotest	3,600	3,600
Solaris Health	2,000	-
IPOPI	1,679	-
E Shearsby	1,000	-
CSL Behring	8,626	-
C Shearsby	-	950
Renishaw	500	-
	<u>42,155</u>	<u>8,201</u>

In addition to the above restricted funding funds were received from CSL Behring of £35,000 (2022 £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 £14,940 to help support the general running costs of Immunodeficiency UK, including IT costs, website and database hostings, bookkeeping and accountancy and administrative support.

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 is given below:

CSL Behring - Virtual training session on health technology assessments with the aims to help Immunodeficiency UK better understand the details of the process and how it can contribute and represent patients effectively. Monetary value of the training session was £488 ex VAT.

Takeda - Attendance at the Takeda/Maudsley Mental Health First Aid Skills workshop for Patient Organisations and involvement in the 'Number 17' campaign raising awareness of people living with a rare disease.

Pfizer

Immunodeficiency UK received a consultant honorarium of £200 from Pfizer. The consultation involved answering asynchronous online questions over a two-week period about how Immunodeficiency UK made provision for our high-risk patients through the COVID-19 pandemic. This amount has been included within donations within these financial statements.

6. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade debtors	617	1,250
Other debtors	-	2,712
Prepayments and accrued income	<u>1,176</u>	<u>-</u>
	<u>1,793</u>	<u>3,962</u>

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2023

7. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Trade creditors	3,569	4,457
Taxation and social security	1,594	1,598
Other creditors	<u>6,537</u>	<u>15,641</u>
	<u>11,700</u>	<u>21,696</u>

8. 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	<u>-</u>	<u>174</u>	<u>174</u>
	<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 2023**

8. 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	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>

Comparatives for movement in funds

	At 20.1.21 £	Net movement in funds £	At 31.3.22 £
Unrestricted funds			
General fund	96,550	(10,880)	85,670
Restricted funds			
Booklets	1,412	2,012	3,424
Helpline Training	-	415	415
Website	8,767	(5,435)	3,332
Digital campaign and reprint of IPOPI booklets	3,232	(2,068)	1,164
Mental health webinars	5,454	(2,144)	3,310
Monthly e-newsletter	3,600	(3,600)	-
Patient events and support grants	4,081	(89)	3,992
	<u>26,546</u>	<u>(10,909)</u>	<u>15,637</u>
TOTAL FUNDS	<u>123,096</u>	<u>(21,789)</u>	<u>101,307</u>

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the year ended 31 March 2023

8. 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	92,250	(103,130)	(10,880)
Restricted funds			
Booklets	3,851	(1,839)	2,012
Psychology project	2,500	(2,500)	-
Helpline Training	950	(535)	415
Website	-	(5,435)	(5,435)
Digital campaign and reprint of IPOPI booklets	-	(2,068)	(2,068)
Mental health webinars	-	(2,144)	(2,144)
Monthly e-newsletter	900	(4,500)	(3,600)
Patient events and support grants	-	(89)	(89)
	<u>8,201</u>	<u>(19,110)</u>	<u>(10,909)</u>
TOTAL FUNDS	<u>100,451</u>	<u>(122,240)</u>	<u>(21,789)</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 five different condition-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.

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 2022 - March 2023.

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

Digital campaign and reprint of IPOPI materials - Reprinting 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 2023

9. EMPLOYEE BENEFIT OBLIGATIONS

The total amount recognised as an expense in the year for payments made to defined contribution pension schemes was £4,118.

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2023.

IMMUNODEFICIENCY UK

Detailed Statement of Financial Activities for the year ended 31 March 2023

	Year Ended 31.3.23 £	Period 20.1.21 to 31.3.22 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	131,154	100,450
Investment income		
Deposit account interest	<u>115</u>	<u>1</u>
Total incoming resources	131,269	100,451
EXPENDITURE		
Charitable activities		
Wages	58,823	56,022
Social security	2,225	2,510
Pensions	4,118	3,922
Sundries	4,358	5,561
Marketing	16,845	24,520
Events	<u>20,847</u>	<u>19,085</u>
	107,216	111,620
Support costs		
Governance costs		
Auditors' remuneration	8,760	10,620
Professional fees	<u>450</u>	<u>-</u>
	<u>9,210</u>	<u>10,620</u>
Total resources expended	<u>116,426</u>	<u>122,240</u>
Net income/(expenditure)	<u><u>14,843</u></u>	<u><u>(21,789)</u></u>

**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 Charity) for the year ended 31 March 2023.

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 Charity'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 Charity 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

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

Date: 24th January 2024