

20th January 2021 -
31st March 2022



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



400+

different rare conditions are recognised as primary immunodeficiencies



6,800+

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

Primary and secondary immunodeficiency are underdiagnosed

COVID-19 has made life extremely challenging for people who have 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 and 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 antibodies against COVID-19. They may have had three 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. This extremely vulnerable community of patients has taken every precaution, followed the guidance, including on shielding, and at times lived away from loved ones to minimise the risk of getting COVID-19.

About Immunodeficiency UK

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

Our mission and strategy

Immunodeficiency UK's mission is to 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. Immunodeficiency UK is 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)

Lisa Gagliani MBE (appointed 20.1.21)
Diane Hammond (appointed 21-3-22)
Jane Elizabeth Shepard (appointed 21-3-22)

Our staff

Chief Executive Officer (CEO) Dr Susan Walsh
Fundraising and Marketing Jen Rush

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, patient representative for Cumbria and Lancashire

Margaret Bennett, patient representative for the West Midlands

Hannah Bruce, patient representative for the south-east region

Hannah Butler, patient representative for London

Samuel Davis, patient representative

Clare Dyer, patient representative for the south Wales area

Alison Fox, patient representative for London

Stacey Garrity, patient representative for the Manchester area

Carolyn Grundy, patient representative for the north Wales area

Michael Ingleston, patient representative for Northern Ireland

Rae McNairney, patient representative for Scotland

Drew Tyne, patient representative for London

Fiona Watt, patient representative for 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

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 and Group Head, 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, Head of Service and 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 20 January 2021 to 31 March 2022, the trustees met a total of 14 times.

The charity's work is supported by the Patient representative panel and Medical advisory panel, which advise the charity on the provision of appropriate care and information for people with primary and secondary immunodeficiency.

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 Chief Executive Officer (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.

Trustees' report

The trustees present their report for the period 20 January 2021 to 31 March 2022 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 first annual report for Immunodeficiency UK.

The transition from Primary Immunodeficiency UK, under the umbrella of Genetic Disorders UK, to an independent charity occurred during a global pandemic. Alongside the challenges of setting up a new organisation, the lives of the very patients we represent were being severely affected by COVID-19. I am proud of the way that Immunodeficiency UK led the narrative for patients and their families living with the threat of COVID-19 and helped them to understand how to live positively through the pandemic. Immunodeficiency UK advocated guidance and clarification on shielding, and made statements on vaccination and access to COVID therapies, which other organisations adopted. Immunodeficiency UK provided exceptional support during a challenging time.

The spotlight on the clinically vulnerable brought some positives. Media coverage on the reality of living with an immune deficiency was something that we were able to capitalise on. However, the pandemic meant that while Immunodeficiency UK was in its infancy, the normal activities that a charity would look to for raising funds were not possible. Nonetheless, we had amazing support from a rapidly expanding membership, and people found new and innovative ways to fundraise during lockdown. With reserves that would cover our initial costs, we planned for a negative budget in year one. But thanks to incredible support and fundraising, we improved our financial resilience. This enabled us to undertake even more activities to support our members.

This report outlines in more detail the areas in which Immunodeficiency UK has been able to fulfil its charitable aims. For a new organisation, we have made a fantastic start.



Dr Matthew Buckland
Chair of Trustees

Our achievements at a glance



400+

people were supported through our phone and email helpline service.

1964

information booklets sent to immunology centres and individuals.



12 monthly e-newsletters and 4 COVID-19 special editions 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 sent out 190 'Stand back' badges.

Please
STAND BACK
I'm still extremely
vulnerable to COVID

2

mental health webinars held attracting over

100

participants

Our achievements at a glance

We raised awareness of immunodeficiency and the impact of COVID-19 through people stories and quotes in the media with coverage in The Times, The Telegraph, Evening Standard, The Independent, Daily Mail online, BBC news, local newspapers, and radio.



We campaigned for access to anti-COVID-19 monoclonal antibody therapies, building alliances with other charities to highlight the needs of people who are immunodeficient or immunocompromised.



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



We reached 104,000 people through our Facebook page; gained new followers on Twitter bringing the total to 1,643; launched an Instagram account gaining 240 followers.

Living with immunodeficiency

Jenna's story: about having C7 complement deficiency

My name is Jenna and I have complement C7 deficiency, which makes me susceptible to some types of bacterial infections.

When I was seven, I contracted meningitis. I then became seriously ill again with different strains of meningitis at ages 12 and 15. I received fantastic care from NHS doctors and nurses and, thankfully, made a full recovery. Doctors, however, decided to investigate further after the third episode. I was diagnosed with complement deficiency when I was 17, after about a year and a half of investigation.

At the time, I was focused on catching up with my GCSEs and starting my A-levels, so the diagnosis didn't feel like it was the centre of my life. There were lots of blood tests, but one positive to come from these is that I'm not scared of needles! However, I don't think I really understood what the blood tests might lead to or what doctors were looking for because I'd never heard of primary immune deficiencies. I was a teenager at the time, and I think it was a stressful 18 months for my mum. She was a single parent and didn't have anyone to share the worry with before I was diagnosed.

I think I had a mixture of emotions following my diagnosis. I was prescribed prophylactic penicillin but, as a teenager, I didn't want to feel different.



At the same time, I didn't really understand what complement deficiency was and I still worried about whether and when I might get ill again. When I was diagnosed, I was given lots of information about meningitis but there didn't seem to be any information on complement deficiency that was accessible to patients.

I last became ill at university when I was 19, but I made a full recovery. I had to take time out of university and make special arrangements to catch up with my studies, but I was well supported by the staff. Thankfully, I have remained well since then. I became a teacher and I now work in the charity sector.

Living with immunodeficiency

I am lucky in that my complement deficiency has not impacted on my adult life or my ability to work. However, the COVID-19 pandemic has made me feel more anxious about becoming ill again. Because complement deficiency is rare, I really struggled to find information at the start of the pandemic about the level of risk and whether I needed to shield.

It has been hard to get information from my GPs because they do not always have specialist knowledge. In the past, this put me off asking them questions. I used to have annual appointments at an immunology clinic but was discharged because I have been well for over 10 years now.

I would advise someone at the start of their journey not to worry about asking questions. It's important to understand your condition properly. Although I'm really grateful for the care I received from the immunology clinic, I found that it was still difficult to get patient-friendly information from them. Now I think I would be less afraid of asking questions.

“PID UK, now Immunodeficiency UK, has helped me enormously. I came across their website when I was searching for information at the start of the pandemic. I was so excited when I saw that they had published information about complement deficiency. Finally, I understand what complement deficiency is! Having this information has given me the confidence to ask my GP questions.”

Sharing experiences

When living with or caring for a person with a primary or secondary 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 three new people stories giving a first-person perspective of living with the conditions adenosine deaminase (ADA) deficiency, hypogammaglobulinemia (low antibody levels) and secondary immunodeficiency.



Omer and parents



Paul with his grandchildren



Jo

Living with immunodeficiency

Eirini and Hector's story: about having XLA

Hi, my name is Eirini. I am Hector's mum. Hector is six years old and has X-linked agammaglobulinemia (XLA). Hector had his first ear infection at the age of six months. We spent Christmas Day in the A&E department.

From then on, Hector suffered regular ear infections. We enrolled him at a nursery when he was one, but Hector was poorly so often, after a couple of months, we decided to employ a nanny instead. When Hector was two, he was diagnosed with glue ear and had grommets inserted in his ears. We felt optimistic that this would solve it. However, soon after, Hector started coughing. He coughed, repeatedly, every night for months.

We visited the GP and the A&E department multiple times but got nowhere. Hector then got pneumonia. We felt helpless. He was prescribed mild antibiotics, which seemed to work for a while, but very soon another chest infection came. This is when we decided to go private.

We visited a paediatrician; extensive blood tests were carried out. The blood tests revealed Hector had exceptionally low immunoglobulin (antibody) levels, so we were referred to a private immunologist. He diagnosed XLA disease.

On one hand, the diagnosis was a relief. Finally, there was a reason why Hector was poorly so often. It made sense. On the other hand, we knew XLA is a serious disease with no cure. It was a lot to take in. As a mum, I felt guilty because, unbeknown to me, I was a carrier of this disease.



XLA disease has had an impact on our mental health. Prior to the diagnosis, we kept blaming ourselves every time Hector got ill. As a parent, it is a constant worry and stress. The disease has also had an impact on our social life and work. We had to take time off work for hospital visits and stays. We missed birthdays, parties and holidays.

Life is more settled now. We have a great routine. My husband and I were trained to give Hector his immunoglobulin transfusions at home. This has brought valuable independence. Hector has subcutaneous transfusions every two weeks. We use this time to relax and watch movies together. We are also more prepared. We always have antibacterial gels/wipes with us when we leave the house, and we have a great handwashing routine. As a family, we have far fewer colds now.

'The Immunodeficiency UK booklets are brilliant for passing on to teachers, nannies, and other carers. The booklets give a clear explanation of each PID condition and are a valuable resource'.

Supporting the community through our helpline services

The demand for our online and telephone helpline services remained high. In this period, we received 402 new enquiries (compared with 370 in the previous reporting year). A large proportion of queries were related to COVID-19, and we were there as a listening ear and a provider of trusted information, in addition to dealing with issues relating to diagnosis, access to treatments and care, benefit entitlement and employment.

‘The monthly newsletter is excellent and as my sole source of information, very much appreciated’

402

Number of new enquiries

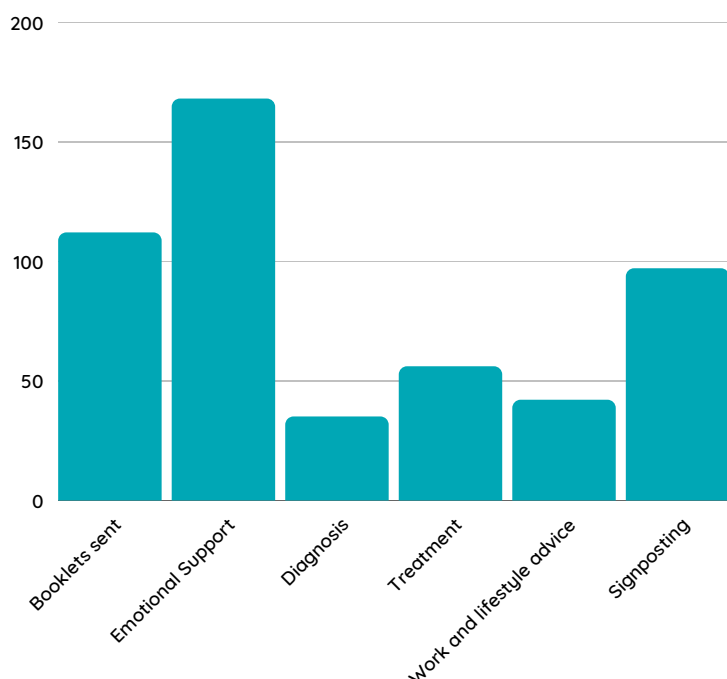
24

Number of re-contact enquiries

473

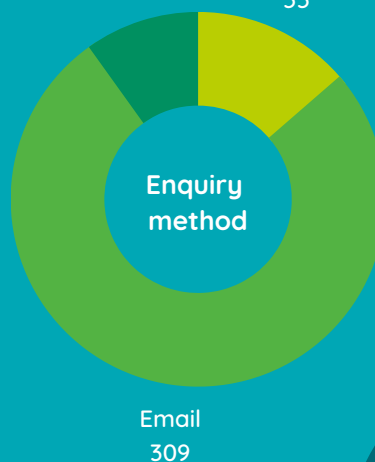
Emails sent

Support offered

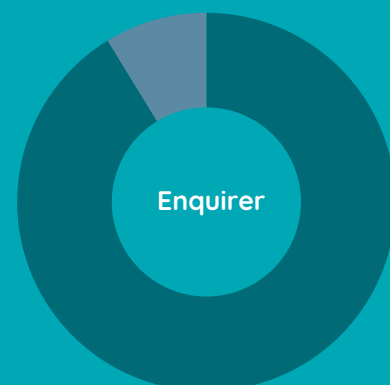


Phone and email 40

Phone only 55



Professional 35



Family member/patient 365

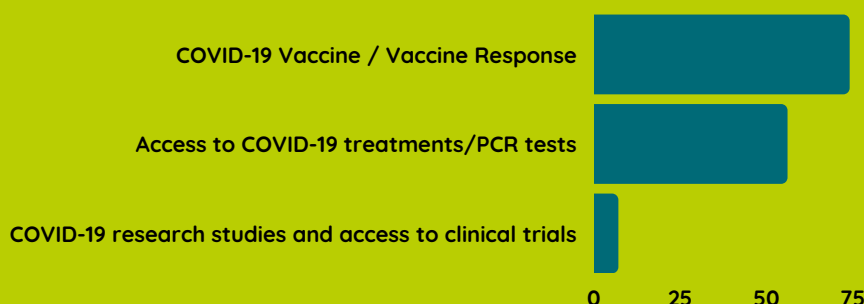


from helpline user

Thank you so, so, much for your advice and for sending the information so quickly. Just your email alone will help to indicate to my workplace that this situation is far from over. I do feel more supported already.



COVID-19 related enquiries



13

Supporting the immunodeficiency community

Over the last year, our work focused on six areas:

- supporting the community through authoritative information published on our website, in printed booklets and e-newsletters
- giving practical and emotional support through our email and telephone helpline service
- our continued response to the COVID-19 pandemic
- supporting better mental health
- raising awareness of immunodeficiency and the impact of COVID-19 through human interest stories
- campaigning and advocating on behalf of individuals and families affected by immunodeficiency.

Supporting the community through authoritative information

Our website and information booklets

During this period, our website and suite of booklets were updated and rebranded to reflect our new identity as Immunodeficiency UK. In addition to constantly updating information on COVID-19 (covered on page 17), we wrote new website content on practical tips for working with your GP, the effects of ageing on the immune system and tips for getting the most out of remote consultations. The latter was written because many people in our community were unable to have face-to-face contact with their medical team owing to COVID-19.

“

I'd just like to say a HUGE thanks for the incredibly helpful info on the site. My partner's been struggling for 5 years now (she's 25) with an on-and-off disorder that repeated hospitalisations haven't been able to identify and diagnose, and we've been left with the feeling that the myriad symptoms (repeated infections/chronic fatigue/aching limbs etc) are always being treated separately and superficially, rather than sourcing the underlying cause of it all. It's super reassuring to see similar reports and receive advice on how to help direct doctors towards PID/SIDs, as it seems a losing battle sometimes.”

”

We also started to design a new website with improved functionality. This project, unfortunately, had to take a back seat as staff concentrated on supporting and advocating for the immunodeficiency community through the worst of the COVID-19 pandemic.

Aware that people with immunodeficiency find it difficult to access life insurance, we added to our portfolio of 39 information booklets by launching a new title on this topic.

We distributed 112 of our booklets directly to patients, supporting them at diagnosis or during their treatment pathway, and we continued to make our booklets available to immunology centres via an on-demand ordering service. During the period, we provided immunology centres with 1,852 booklets.



Supporting the immunodeficiency community

Our e-newsletters

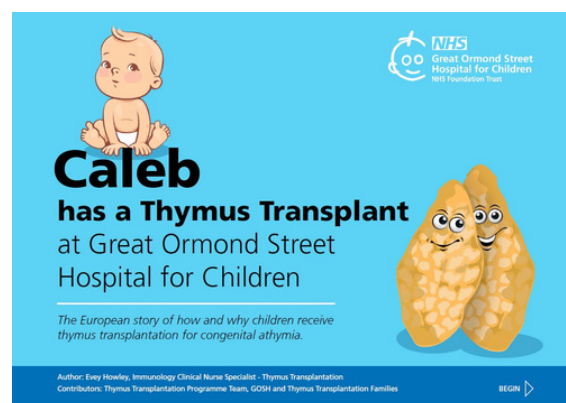
Our communications are greatly valued as a source of support and trusted information. We sent out 12 monthly e-newsletters, featuring health information, research updates, community news and fundraising. On average, 52% of subscribers who received our e-newsletters opened them (range 50–60%) and the click-through rate averaged 28.8% (range 12–40%).

52% open rate

28.8% click-through rate

Supporting the development of patient friendly information

Immunodeficiency UK contributed £500 towards the publication of a booklet on thymus transplantation as a treatment for the rare immunodeficiency Complete DiGeorge syndrome. The booklet, developed by Evey Howley, Immunology Clinical Nurse Specialist, who leads nursing care for thymus transplantation at Great Ormond Street Hospital, aims to communicate complex medical information in a meaningful way, so that families feel empowered and confident when giving informed consent for their child's thymus transplant.



“

The support from Immunodeficiency UK has been fundamental to completing the patient information project and has allowed me to reach many families, internationally spread. Our aim has been to develop a simple, consistent information resource bespoke to the thymus transplantation families, which we hope will help ease the burden when families begin this challenging treatment journey with their child.

”

Supporting the immunodeficiency community

Campaigning and advocating on behalf of individuals and families affected by immunodeficiency

Making the voice of patients heard

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; Public Health England's Newborn Screening for SCID Pilot Oversight Group and the United Kingdom Primary Immunodeficiency Network (UKPIN) 'COVID infection in patients with antibody deficiency' (COV-AD) study – part of a portfolio of national studies examining the immune responses in patients considered at high risk of COVID-19.

Responding to the shortage of immunoglobulin

The COVID-19 pandemic resulted in a shortage of immunoglobulin, an essential medicine that helps provide people who cannot make antibodies with protection against infection. We highlighted the impact of the shortage on affected patients through meetings with the NHS Commercial Medicines Unit (CMU), and encouraged the NHS to create bespoke communications to keep our community informed. In addition to meetings concerning immunoglobulin procurement, we responded to the NHS consultation on immunoglobulin commissioning and the demand management plan to be implemented in times of shortage.

We provided extensive information to Genetic Alliance UK for the Human Fertilisation and Embryology Authority (HFEA) to support an application to license PGT-M (previously known as preimplantation genetic diagnosis) for CVID8 (caused by mutations in the LRBA gene). The application was successful.

Raising awareness of immunodeficiency and the issues faced by those affected

For World Primary Immunodeficiency Week, we developed and made available on our YouTube channel a video giving patient testimony on the importance of early diagnosis of primary immunodeficiencies. **Posting the video on social media gave us:**

reach c3,300 people

395 post clicks

221 reactions

We worked with the NHS Blood and Transplant communication team to highlight the importance of plasma donation in the UK. We ran a social media campaign and supplied case studies and quotes, which appeared in press releases.

We also ran social media campaigns during International Plasma Awareness Week, World Antimicrobial Awareness Week and Mental Health Awareness Week.

Our continued response to the COVID-19 pandemic

Providing invaluable support in unprecedented times

The COVID-19 pandemic continued to dominate our work during this reporting period. Our priority was to be there for members of our community and their families. Many people with weakened immune systems were shielding and leading very limited lives. In spite of receiving two doses of the COVID-19 vaccine, some people had low or no protection against the virus.

We posted trusted information on our website and published special COVID-19 editions of our newsletter. We called for access to anti-COVID-19 therapies, supported the community through our helpline (we received 137 enquiries related to COVID-19), hosted mental health webinars and issued 'Stand Back' badges that acted as a reminder for other people to maintain social distancing.

We frequently updated our website in response to changes in government guidance brought about by the threat posed by different COVID-19 variants. For example, we provided authoritative information on:

Shielding (people with weakened immune systems were advised to continue shielding and then not on 'Freedom Day')



The successive COVID-19 booster vaccination rollouts and their clinical significance for our community

How to get free PCR tests and the process for reporting the test results



How to access COVID-19 medicines (antivirals and monoclonal antibodies (Mabs)).

In all cases, we endeavoured to filter the information coming from government, the JCVI and the NHS, to tailor it to the immunodeficiency community and present it in a more reader-friendly format.

Our special edition newsletters

We produced **four** special editions of our newsletter, to keep our members up to date with information about COVID-19.



Thank you so much for your timely and very welcome Special Edition Newsletter, giving information regarding the fourth dose of vaccine and how to access it. My fourth dose will be due shortly, and to date, I have heard nothing about it.



Our continued response to the COVID-19 pandemic

Through our helpline, we were hearing of people who were having to choose between protecting their livelihoods and protecting their lives. As restrictions eased, there was still little understanding from employers about the risk that COVID-19 posed to some members of our community. In response, we produced an online guide for employers and work colleagues to help people with immunodeficiency return to work after shielding, and provided information for those clinically vulnerable to support their transition back to the workplace. Working in collaboration with 24 other charities representing clinically extremely vulnerable people, we made available a letter that individuals could download from our website and share with their employers.

Kerry's story

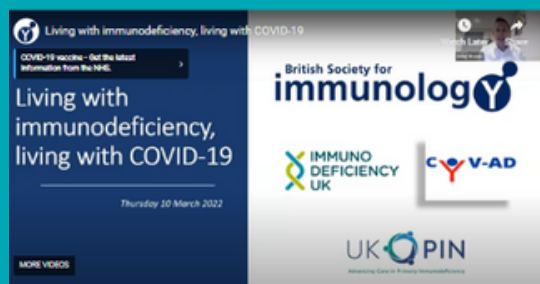


"The COVID-19 pandemic came as a real shock to me. As a person who takes immunosuppressant medication, I felt more vulnerable than I had ever felt before. I shielded at home with my daughter for 18 months and then tentatively started going out after that.

I found the Immunodeficiency UK team wonderful and supportive, and the regular COVID-19 guidance updates posted on their website were invaluable. I greatly appreciated the advice about talking to your employer about working from home and the letters they provided to support my case. This was at a time when laws and regulations were in flux owing to the impact of COVID. The webinars they organised were great and participation was so helpful.

I want to say a huge "thank you" to Immunodeficiency UK. You kept me going and sane at one of the most difficult periods in my life."

Immunodeficiency UK collaborated with the British Society for Immunology and the UK Primary Immunodeficiency Network (UKPIN; the professional body for immunologists, nurses and healthcare/academic scientists), to host a webinar to help people better understand how effective COVID-19 vaccines are in people with weakened immune systems. Based on enquiries made to our helpline, we provided a list of the most frequently asked questions that our community would value answers to. Margaret, a member of our Patient Representative Panel, talked of her experience of living with COVID-19. The webinar attracted over 460 participants.



Our continued response to the COVID-19 pandemic

Advocacy and campaigning for access to anti-COVID-19 therapies

We campaigned for access to anti-COVID-19 monoclonal antibody therapies as a vital element of providing protection against COVID-19 for people with weakened immune systems who are unable to mount a full vaccination response due to their underlying condition. A letter from Immunodeficiency UK sent to The Times was co-signed by 19 other signatories and featured in the printed edition of the newspaper dated 11 August 2021.

As another Mab therapy was developed showing greater efficacy against the emerging COVID-19 variants, such as Omicron, we continued to press the Medicines and Healthcare products Regulatory Agency (MHRA) for speedy approval, through letters and social media campaigns, such as our 'Do I not matter?' video campaign. This campaign highlighted the difference that Mab therapy would make to people's lives in enabling them to re-enter society safely, and emphasised the disparity of access in the UK compared with over 23 other countries where the therapy was already available. We provided template letters so that our community could lobby their MPs for access to this Mab therapy and for continued access to free PCR and lateral flow tests.

“

Congratulations on getting the approval for the Regeneron Mab treatment finally approved. Your letter to The Times seemed to give it the final push that it needed to get it off someone's desk and into the out-tray! It was very good news indeed! Thank you for all the work you have done in pursuing this!

”

From Mark, whose daughter has COVID

With thanks to Lord Mendelsohn, Co-Chair of the All-Party Parliamentary Group on Vulnerable Groups to Pandemics, and his parliamentary secretariat, we were able to ask questions in the House of Lords about the government's plans for high-risk groups and raise awareness of the problems faced by our community in accessing vaccinations and anti-COVID-19 Mabs.

We presented evidence of the pandemic's impact on patients at the All-Party Parliamentary Group on Vulnerable Groups to Pandemics, with coverage in the British Medical Journal.

Immunodeficiency UK was a member of the Shielding and High-Risk Coalition Group, meeting regularly with the vaccine minister and NHS representatives to highlight the needs of high-risk groups.

Our continued response to the COVID-19 pandemic

Raising awareness of the impact of COVID-19 on our community

Through our public relations work, we raised awareness of the situation of people with immunodeficiency living with the continued threat of COVID-19, using newspapers, radio and social media to make sure their voice was heard. Articles appeared in The Telegraph, the Evening Standard, the Daily Mail and the Independent newspapers, and on Upday UK, one of Europe's biggest news apps.

Margaret and Hannah, members of our Patient Representative Panel who have the primary immunodeficiency CVID, pictured below, shared their experiences on the BBC News website, in the article 'Covid-19: "For us it's not freedom day, is it?"' (6 July 2021).



'Thank you for getting the stories on to BBC News yesterday. I'm sure they would have come as a complete surprise to most folk.'
Lindsay, who has an immunodeficiency

Ben's story

Ben is 46 and has the primary immunodeficiency condition CVID. Ben says: 'The pandemic has been brutal and for the first time in the 33 years since diagnosis I felt a big distance from society, ignored by government and finding the need for a whole new set of rules to live by to stay safe.'

Immunodeficiency UK has been enormously supportive, doing all they can to provide the best available information and to campaign for really important changes to the approach from government. It's good to feel there is a group of people that's got our back, in addition to the fantastic medical staff. Thank you, Immunodeficiency UK!



Our continued response to the COVID-19 pandemic

Understanding the impact of COVID-19 on the frequency and type of patient–doctor consultations

National restrictions, resulting from the COVID-19 pandemic, caused many patient–doctor interactions to move from face-to-face to remote consultations via telephone, video or email.

We conducted a survey to understand how COVID-19 was impacting patient-doctor consultations.

Through a survey, we explored the experiences of our community, the support they were given, their opinions on this change and how it had affected their healthcare. We received 117 responses. In addition to producing a full report of the findings, which we shared with medical professionals, we used the feedback to develop top tips for patients and recommended good practice for medical teams to adopt when offering these types of consultations to patients.



Dr Claire Bethune,
Consultant
Immunologist,
Plymouth Hospital
Trust, said:



Thank you so much for sharing the results of your survey relating to remote consultations.

It was so useful for me to be able to present some of the findings from your survey at UKPIN in 2022, in an oral presentation about the changes to outpatient consultations in immunodeficiency clinics.

Presenting the views of the patients that have been affected by the move away from face-to-face clinics, alongside the data from the Quality in Primary Immunodeficiency Services (QPIDS) census highlighting the scale of the changes, helped to trigger a useful discussion at the meeting.



Supporting better mental health

The continuing threat of COVID-19

The serious health risk of COVID-19 to people with immunodeficiency or those who are immunocompromised remained throughout this reporting period. The COVID-19 vaccination programme thankfully began to reduce hospitalisation and mortality rates, but it was only in December 2021 that the safety net of access to antiviral therapies and monoclonal antibody therapies was made available to those at the highest risk who tested positive for COVID-19.

Through our helpline services, we heard first-hand that many people in our community were feeling isolated, anxious and depressed, were continuing to shield and living very restrictive lives. One day people were being told that they were classed as being extremely clinically vulnerable and the next day, not. The full lifting of restrictions with the message of 'Freedom Day' did not resonate within the community. As the guidance changed, people reported feeling 'left behind', more anxious, angry and frustrated.

What we did to provide support

Knowing that the threat of COVID-19 was having a big impact on mental health and wellbeing, we held two 'Looking after your wellbeing' webinars, covering topics to help with managing anxiety and uncertainty. These were delivered by Dr Mari Campbell, Clinical Psychologist at the Royal Free London NHS Foundation Trust. Over 50 people attended each webinar. The sessions gave tips on simple routines and techniques that could help, and these were made available on our website, alongside the presentations.

Of our survey respondents:

88%

found our webinar
useful or very useful

82%

found our webinar left
them well-equipped to
handle stress

94%

felt our webinar left
them feeling positive or
very positive

“ Thank you very much for enabling and organising the wellbeing webinar. It's such a much-needed offer to us during the pandemic, especially now, when many are tired, groups of people are stressed and angry and repercussions can be felt in the population. I was also moved by the resonance amongst the listeners last week. ”

“ It was really helpful. Lots of great tips. Also good to hear some other people's experiences. Makes you feel less alone. ”

“ One of the most useful things was hearing from other people that they are feeling what I am feeling – the anger, the frustration, the feeling of being abandoned by the Government, and the difficulties from not meeting family members and them not fully understanding why. ”

Helping fund an Immunology Psychology service at University Hospitals, Birmingham

Being diagnosed and living with a lifelong chronic condition takes both a physical and mental toll. As part of a multi-charity funding initiative recognising the need for tailored psychological support for people affected by immunodeficiency, we gave £5,000 this year to support the employment of a clinical psychologist for immunology patients across Heartlands Hospital and Queen Elizabeth Hospital Birmingham. The service began in August 2021, with the appointment of Dr Nicola Wilson, and will run for three years. The focus of therapeutic work to date has been varied, including adjustment to diagnosis, low mood and anxiety about health/future/mortality, emotional difficulties related to the impact of health on roles and responsibilities, and fatigue.



Dr Aarn Huissoon, Clinical Service Lead at Birmingham Heartlands Hospital

“

The first 10 months of the pilot Immunology Clinical Psychology Service provided by Dr Nicola Wilson has had an immediate impact on our patients and the clinical team. The nurses and doctors are more attuned to our patients' concerns and needs, and feel more confident discussing these issues with the patients and at MDT meetings. From their own feedback, individual patients are clearly benefitting from their sessions. Formal reviews of outcomes over the next 2 years will help to support the case for continuing this service beyond the pilot period.

”

Our plans for the next year

What do we plan to do next year?

We want to build on our first year of operation by:

- extending our patient support by making hardship grants available to members in need,
- continuing to campaign and advocate on issues affecting our community
- expanding our range of leaflets to cover more topics
- hosting more mental health webinars and providing more tailored mental health support
- launching a new website
- conducting surveys to learn more about the continuing impact of COVID-19 on our community, their experience of hospital services and the support needs of patients to inform our work
- recruiting more trustees who are directly or indirectly affected by an immunodeficiency; we need a larger board of trustees to facilitate succession planning
- broadening our income streams to include fundraising from trusts and foundations; we will work with our community to define what needs to be done and to make the case for funding.

Our incredible fundraisers



Yorkshire Three Peaks Challenge – in memory of Paul

In March 2021, Phil lost his friend Paul Ash, affectionately known as Pash. He was the heart and soul of every party, had an infectious laugh, and despite his struggles with his immunodeficiency he was always the guy to lift up the spirits of those around him. Paul was friend to many but also a son, brother, grandson, uncle and boyfriend.

So, In August 2021, Phil along with a large group of Paul's friends hiked the challenging 25-mile Yorkshire Three Peaks route to raise funds for Immunodeficiency UK in Paul's memory. The group raised a fantastic £6,825 for our work.

Phil said, "He left behind a large group of friends who are desperate to honour him and show what he meant to us, and it seemed only right to raise some money in the process for a charity he had worked closely with and advocated for in the past."

£6,825 was raised in memory of Paul

Our incredible fundraisers



Chelsea's story – the Great South Run

Chelsea Kellett ran the 10-mile Great South Run for Immunodeficiency UK after being introduced to the charity by her good friend Nigel.

"I met a gentleman 15 years ago who became a father figure to me, and the impact he's had on my life is incredible. I will always be in awe of his strength, patience and positivity. Suffering with immunodeficiency has sadly taken away his ability to do what he loves; teaching PE, and if it wasn't for him teaching, I'd never have met him. I couldn't be more grateful that he came in to my life, and grateful for the many life lessons he has taught me. I had signed up to do the Great South Run in October, 2021 and when I approached Nigel to see if there was a charity, I could raise money for, of his choice, he put Immunodeficiency UK forward. I'm doing this for him."

Chelsea raised a brilliant total of £1,075.

£52,468

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 Period 20 January 2021 to 31 March 2022

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

IMMUNODEFICIENCY UK

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IMMUNODEFICIENCY UK

Report of the Trustees for the period 20 January 2021 to 31 March 2022

The trustees present their report with the financial statements of the charity for the period 20 January 2021 to 31 March 2022. 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).

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

PO Box 12635
Colchester
Essex
CO7 5AN

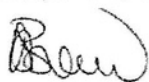
Trustees

Ms H A Bruce Trustee (appointed 20.1.21)
Dr M Buckland Trustee (appointed 20.1.21)
Mrs L E Gagliani MBE Trustee (appointed 20.1.21)
Ms D Hammond (appointed 21.3.22)
Ms V D Brisse-Uhlig (appointed 21.3.22)
Ms J E Shepard (appointed 21.3.22)

Independent Examiner

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

Approved by order of the board of trustees on23/1/23..... and signed on its behalf by:



.....
Dr M. Buckland

Trustee

**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 period 20 January 2021 to 31 March 2022.

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

Date: 24th January 2023

IMMUNODEFICIENCY UK

**Statement of Financial Activities
for the period 20 January 2021 to 31 March 2022**

	Notes	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies		92,249	8,201	100,450
Investment income	2	1	-	1
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><u>85,670</u></u>	<u><u>15,637</u></u>	<u><u>101,307</u></u>

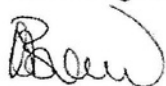
The notes form part of these financial statements

IMMUNODEFICIENCY UK

Balance Sheet 31 March 2022

	Notes	Unrestricted fund £	Restricted funds £	Total funds £
CURRENT ASSETS				
Debtors	6	3,962	-	3,962
Cash at bank		103,404	15,637	119,041
		<u>107,366</u>	<u>15,637</u>	<u>123,003</u>
CREDITORS				
Amounts falling due within one year	7	(21,696)	-	(21,696)
		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
NET CURRENT ASSETS				
		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
TOTAL ASSETS LESS CURRENT LIABILITIES				
		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
NET ASSETS				
		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
FUNDS	8			
Unrestricted funds				85,670
Restricted funds				<u>15,637</u>
TOTAL FUNDS				<u>101,307</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 23/1/23
and were signed on its behalf by:



Dr M. Buckland

Trustee

The notes form part of these financial statements

IMMUNODEFICIENCY UK

Notes to the Financial Statements for the period 20 January 2021 to 31 March 2022

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.

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the period 20 January 2021 to 31 March 2022

1. ACCOUNTING POLICIES - continued

FINANCIAL INSTRUMENTS

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.

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

Deposit account interest

£
1

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the period ended 31 March 2022.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the period ended 31 March 2022.

4. START UP COSTS

Included within Charitable activities are start up costs in relation to the formation of the Charity amounting to £1260.

5. FUNDERS

Below is a breakdown of funding recognised in income in the financial period to 31st March 2022:

	£
Biotest	2,900
AmDel Medical	4,351
C Shearsby	950
	8,201

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the period 20 January 2021 to 31 March 2022

6. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	£
Trade debtors	1,250
Other debtors	2,712
	<u>3,962</u>

7. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	£
Trade creditors	4,457
Taxation and social security	1,598
Other creditors	15,641
	<u>21,696</u>

8. 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 materials	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 period 20 January 2021 to 31 March 2022

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	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 materials	-	(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 for patients attending the clinic 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 January 2021 - March 2022. The newsletters are an essential part of communications with our membership and ensure people are kept up to date on news about Immunodeficiency.

Website - Funds for the development of a new website for Immunodeficiency UK using a Wordpress framework that is mobile and table responsive with highly secure hosting.

Digital campaign and reprint of IPOPI materials - Reproduction and reprinting of IPOPI educational materials and support for a digital marketing campaign for World PI week.

Mental health webinars - Support for the delivery of interactive webinars focussing on improving the mental health of the Immunodeficiency community during the COVID-19 pandemic.

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

IMMUNODEFICIENCY UK

**Notes to the Financial Statements - continued
for the period 20 January 2021 to 31 March 2022**

9. EMPLOYEE BENEFIT OBLIGATIONS

The total amount recognised as an expense in the year for payments made to defined contribution pension schemes was £3,922.

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the period ended 31 March 2022.

REGISTERED CHARITY NUMBER: 1193166

IMMUNODEFICIENCY UK

Unaudited Financial Statements for the Period 20 January 2021 to 31 March 2022

Tudor John Limited
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IMMUNODEFICIENCY UK

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IMMUNODEFICIENCY UK

Report of the Trustees for the period 20 January 2021 to 31 March 2022

The trustees present their report with the financial statements of the charity for the period 20 January 2021 to 31 March 2022. 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).

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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

PO Box 12635
Colchester
Essex
CO7 5AN

Trustees

Ms H A Bruce Trustee (appointed 20.1.21)
Dr M Buckland Trustee (appointed 20.1.21)
Mrs L E Gagliani MBE Trustee (appointed 20.1.21)
Ms D Hammond (appointed 21.3.22)
Ms V D Brisse-Uhlig (appointed 21.3.22)
Ms J E Shepard (appointed 21.3.22)

Independent Examiner

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

Approved by order of the board of trustees on23/1/23..... and signed on its behalf by:



Dr M. Buckland

Trustee

**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 period 20 January 2021 to 31 March 2022.

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Independent examiner's statement

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

Date: 24th January 2023

IMMUNODEFICIENCY UK

**Statement of Financial Activities
for the period 20 January 2021 to 31 March 2022**

	Notes	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM				
Donations and legacies		92,249	8,201	100,450
Investment income	2	1	-	1
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Charitable activities				
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RECONCILIATION OF FUNDS				
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TOTAL FUNDS CARRIED FORWARD		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>

The notes form part of these financial statements

IMMUNODEFICIENCY UK

Balance Sheet 31 March 2022

	Notes	Unrestricted fund £	Restricted funds £	Total funds £
CURRENT ASSETS				
Debtors	6	3,962	-	3,962
Cash at bank		103,404	15,637	119,041
		<u>107,366</u>	<u>15,637</u>	<u>123,003</u>
CREDITORS				
Amounts falling due within one year	7	(21,696)	-	(21,696)
		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
NET CURRENT ASSETS				
		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
NET ASSETS		<u>85,670</u>	<u>15,637</u>	<u>101,307</u>
FUNDS	8			
Unrestricted funds				85,670
Restricted funds				<u>15,637</u>
TOTAL FUNDS				<u>101,307</u>

The financial statements were approved by the Board of Trustees and authorised for issue on23/1/23.....
and were signed on its behalf by:



Dr M. Buckland

.....
Trustee

The notes form part of these financial statements

IMMUNODEFICIENCY UK

Notes to the Financial Statements for the period 20 January 2021 to 31 March 2022

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.

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the period 20 January 2021 to 31 March 2022

1. ACCOUNTING POLICIES - continued

FINANCIAL INSTRUMENTS

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.

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

Deposit account interest

£
1

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the period ended 31 March 2022.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the period ended 31 March 2022.

4. START UP COSTS

Included within Charitable activities are start up costs in relation to the formation of the Charity amounting to £1260.

5. FUNDERS

Below is a breakdown of funding recognised in income in the financial period to 31st March 2022:

	£
Biotest	2,900
AmDel Medical	4,351
C Shearsby	950
	8,201

IMMUNODEFICIENCY UK

Notes to the Financial Statements - continued for the period 20 January 2021 to 31 March 2022

6. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	£
Trade debtors	1,250
Other debtors	2,712
	<u>3,962</u>

7. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	£
Trade creditors	4,457
Taxation and social security	1,598
Other creditors	15,641
	<u>21,696</u>

8. 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 materials	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 period 20 January 2021 to 31 March 2022

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	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 materials	-	(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 for patients attending the clinic 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 January 2021 - March 2022. The newsletters are an essential part of communications with our membership and ensure people are kept up to date on news about Immunodeficiency.

Website - Funds for the development of a new website for Immunodeficiency UK using a Wordpress framework that is mobile and table responsive with highly secure hosting.

Digital campaign and reprint of IPOPI materials - Reproduction and reprinting of IPOPI educational materials and support for a digital marketing campaign for World PI week.

Mental health webinars - Support for the delivery of interactive webinars focussing on improving the mental health of the Immunodeficiency community during the COVID-19 pandemic.

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

IMMUNODEFICIENCY UK

**Notes to the Financial Statements - continued
for the period 20 January 2021 to 31 March 2022**

9. EMPLOYEE BENEFIT OBLIGATIONS

The total amount recognised as an expense in the year for payments made to defined contribution pension schemes was £3,922.

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the period ended 31 March 2022.

**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 period 20 January 2021 to 31 March 2022.

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

Date: 9th January 2023