WELCOME FROM THE CHAIR

It gives me great pleasure to welcome you to this, our first annual report in our new identity – “Gene People”. Many of you will have known us for years under our former name, Genetic Disorders UK. Now, as Gene People, we are reaffirming our commitment to focus on improving the lives of the people and families living with intractable and often untreatable rare genetic conditions, rather than on the syndromes and disorders that affect them.

This year has been unlike any other in our history.

We have lived with the pandemic that has dramatically impacted upon the lives of us all, but most particularly on many of those we seek to support through our work – individuals and families who found themselves uniquely vulnerable to the threat from Covid-19 and the inevitable disruption to the services and support they depend on to manage their day to day lives. I would like to pay tribute to the courage and resilience that so many families have displayed in the face of the pandemic, and to the creativity and determination that the members of our Partnership Network have displayed as they evolved new ways of supporting those affected. Many of the lessons learned will inform our, and their, future work as we face a new future where we live with Covid-19.

It is not just the external world that has been experiencing turmoil. Following a period of intense reflection we decided to refocus our efforts and concentrate on delivering services and support to those with rare genetic conditions and the groups that support them. In close partnership with the CGD Society we helped the Jeans for Genes campaign establish itself as a separate charity that can concentrate on the national fundraising campaign to raise money to support the initiatives of others. This meant we said goodbye to several members of staff who transferred to the new charity.

I would like to thank them for their commitment and wish them every success in their new role. We also helped PID UK become a new and independent charity, Immunodeficiency UK, with a focus on all immunodeficiency diseases, not just the genetic ones. Another positive move that we feel is a demonstration of our determination to be nimble in our response to changing circumstances in the best interests of those we support. We congratulate Susan Walsh on becoming CEO of the new charity and look forward to maintaining the close relationship we have with her in the future.

All this means that we can now concentrate on our key strategic goals:-

- Supporting individuals and families through our unique genetic counsellor-led helpline and with dedicated resources on our website
- Capacity building for the groups constituting our Partnership Network (currently over 130 organisations and growing)
- Contributing to national policy and service development on behalf of our partnership network and the individuals and families they support to ensure that the voice of those with rare genetic conditions is both heard and listened to.

All this means that we have diversified our funding base. We have been successful in attracting support from a wide range of funders – charitable trusts and foundations, industry, individuals (including some heroic marathon runners) and others. As we look to the future, we will continue to diversify our funding base whilst always avoiding compromising our integrity and independence.

Central to achieving the transformation of Gene People have been our two interim CEOs, Lisa Gagliani and Samantha (Sam) Barber. Both played a key role on navigating the changes we have lived through this last year and I pay public tribute to them both for their energy enthusiasm and sheer professionalism. I am delighted that Sam is now the CEO of Gene People. We are fortunate to have such a capable pair of hands at the helm.

"As we look to the future we will continue to diversify our funding base whilst always avoiding compromising our integrity and independence."

Reuben who has 1q21.1 micro deletion

I also pay tribute to my fellow trustees for their vision and commitment to ensuring the success of the charity through some very challenging and uncertain times. Without their support we would not have been able to make the changes necessary to bring us to this next phase in our development. I would like express particular thanks to my predecessor as Chair, Jill Lucas. Jill has been a tower of strength to the charity for many years, always supportive, but never flinching from difficult decisions. Thank you for all you have done. You are a hard act to follow.

This has been an extraordinary year for Gene People, for the groups in our Partnership Network and most of all for those living with rare genetic conditions and their families. I take my hat off to all of you for the determination you have shown in the face of unprecedented challenges, and I invite all of those who share our vision of a future where those living with the challenges posed by the myriad of intractable conditions receive the care and support they need to lend your shoulders to our wheel and help us move forward as we seek to address the unmet health needs that so many individuals and families struggle with every day.

Alastair Kent OBE FRSA
Chair of Trustees

IMMUNO DEFICIENCY UK

529
people supported by our free helpline and email service

6
patient films highlighting the importance of early diagnosis and access to treatment

1,632
members on our mailing list receiving monthly newsletters and Covid-19 updates

3,674
printed booklets distributing to 12 immunology centres

The strategic objectives

- To offer support to individuals and families affected by a PID
- To raise awareness and improve understanding of PIDs and the work of PID UK among affected individuals and families, the medical profession and the general public
- To be an advocate and campaigner for the needs and rights of people affected by PIDs
- To increase income from a range of sources so that PID UK can better support patients with PID

Activities

The following activities are expanded on in Appendix 1 with the following being the highlights from a challenging and productive year:

- Helpline: PID UK dealt with 549 enquiries (2020: 370) from families affected by a PID, relating to issues such as diagnosis, access to treatments and care, benefit entitlement, education and employment, insurance and the Covid-19 pandemic.

- Raising awareness of PID and the impact on those affected: Eighteen new patient stories were developed, describing the experiences of those directly affected by PID and of parents with affected children. The stories covered people's experience of living with CVID, MBL deficiency, IgA deficiency, DiGeorge syndrome, XLA and hypogammaglobulinemia. They all highlighted the challenges individuals and their families face.

- Access to medicines: After two years of lobbying as part of the UK Plasma Action Alliance (UKPA), we were delighted that the government lifted the ban on the use of UK plasma for the manufacture of immunoglobulins. This significant policy change was particularly important at a time when the Covid-19 pandemic led to plasma shortages worldwide and continues to impact on immunoglobulin supplies.

- Income: Due to the Covid-19 pandemic and the cancellation of our usual fundraising events, we launched a virtual 10K event, which raised £4,960. Revenue from regular giving rose to £2,856 (2019: £1,380), with the enrolment of 11 new regular givers.

During the course of the year, the Board of Gene People decided to demerge PID UK to become an independent charity with its own Board of Trustees. This would enable a broadening of the scope of PID UK's work. This transition took effect on 1 April 2021 when PID UK became Immunodeficiency UK.

Future Plans

The strategic goals of Immunodeficiency UK are to:

- support individuals and families affected by primary and secondary immunodeficiency through our helpline and dedicated resources on our website
- advocate for treatments and access to therapies that will help protect the community against Covid-19 in order to achieve health parity with people who have benefitted fully from the Covid-19 vaccination roll-out
- promote 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
- encouraging and supporting research into the causes, treatments, prevention and cures for primary and secondary immunodeficiency, and to publish the useful results of that research.

Financial review 2020-21

Income and expenditure

	Income		Expenditure	
	2021	2020	2021	2020
GDUK	126,375.49	79,856.33	32,011.37	26,538.04
PID UK	123,281.66	61,062.02	91,558.98	51,589.86
Jeans for Genes	421,570.89	912,105.83	388,239.38	601,658.87
Support, overhead and governance costs			376,960.27	363,274.23
	671,228.04	1,053,024.18	888,770.00	1,043,061.00

The table above shows the income and expenditure by division of Gene People for the past two financial years. The Support, Overhead and Governance costs are for all three divisions together. Since the demerger of the two divisions, the Support, Overhead and Governance costs for the current financial year are budgeted to decrease.

Reserves

On 31 March 2021, the total monies held by Gene People stood at £74,709 of which restricted funds were £15,715. Free reserves, as defined by the Charity Commission, were £58,994. This amount is just under five months of budgeted average running costs for the restructured charity based on forecast expenditure. The current reserves amount targeted is £60,000.

Structure, Governance and Management

- Governing Document

Gene People changed its name from Genetic Disorders UK (GDUK) in May 2021. The registered charity number (number 1141583) and company limited by guarantee (number 07564771) remained the same.

Gene People is governed by its memorandum and articles of association dated 15 March 2011. The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

- Trustees

The board of trustees is responsible for the overall governance, policy and strategic direction of Gene People, and have the legal responsibility for the operations of the charity and the use of resources in accordance with the objects of the charity. The trustees who have served during the year and since the year end are set out on page 23.

The charity is governed by individuals with a broad range of skills, including biotech, operations, finance and charity management expertise. A personal perspective on what it is to be part of a family affected by a genetic condition was provided by two of the six trustees during the financial year.

Trustees serve on the board for a period of three years that is renewable. New trustees are appointed by the serving trustees, considering the skills required by the board.

- 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. The charitable purpose for the charity within the meaning of the Act is enshrined within its objects, as given in the memorandum and articles of association, and the charitable objects are included in this report.

- Governance and Management

The board of trustees meets at least four times a year to review progress and policies, via video conferencing. With the ongoing changes to the charity and the impact of the pandemic, meetings were more frequent during the year. Formal reporting by the chief executive to the trustees takes place regularly at board meetings and informally as appropriate throughout the year.

The systems of control that are designed to provide reasonable assurance against material misstatement or loss include; an annual budget approved by the trustees; regular review of financial results, budget variances and non-financial performance indicators; delegation of authority and segregation of duties; and identification and management of risks.

Staff remuneration is determined according to the level of seniority and experience. New staff are offered salaries that align with the market average. As mandated by law, all staff are offered the opportunity to join the charity's pension scheme.

- Risk management

The trustees have overall responsibility for ensuring that Gene People is managing risk in a professional, responsible and constructive manner.

Trustees have considered the major risks to which the charity is exposed and have established procedures, including a risk register, to identify and manage those risks. All risks are reviewed at least twice at Board meetings during the year.

The risk register identifies the types of risks the charity may face, assessing and balancing them in terms of potential impact and likelihood of occurrence. The trustees seek to ensure that all internal controls, and in particular financial controls, comply in all respects with best practice and inter alia the guidelines issued by the Charity Commission.

The principal risks identified by trustees in the period for Gene People are:

- Competition for funds arising from new entrants seeking to support those with rare genetic diseases;
- Constraints arising as a consequence of the pandemic;
- Loss of key personnel threatening day to day operations.

Each of these key risks has a mitigation plan managed by the CEO with support from trustees.

- Covid-19 risk

It is recognised by the trustees that the financial performance of the charity has been and will continue to be impacted by the coronavirus (Covid-19), which was declared a global pandemic by the World Health Organisation in March 2020.

In 2020-21, the primary source of income for the charity was the Jeans for Genes fundraising event in September, which relies on participation from schools, nurseries and workplaces and was impacted by the pandemic. Trustees reviewed the 2020/21 budget and took some unwelcome but necessary cost reduction measures including two redundancies in order to protect the charity for the future.

Trustees decided not to put the team on furlough, rather choosing to continue providing much needed services to the genetic conditions community and to hold the Jeans for Genes fundraising event.

Reference and Administrative Details

TRUSTEES Ms R L Frankel
Mr A Kent OBE FRSA – Chair of Trustees (appointed Nov 2020)
Ms H D C Hanna (resigned Sept 2020)
Ms J E Lucas – Chair of Trustees (resigned Nov 2021)
Dr E Miller (appointed Nov 2020, resigned Nov 2021)
Ms C O'Leary (resigned Feb 2021)
Dr C Ruff (maternity leave from July 2020 until Nov 2021)
Mr S Mitra (appointed May 2020)

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

REGISTERED COMPANY NO. 07564771 (England and Wales)

REGISTERED CHARITY NO. 1141583

INDEPENDENT EXAMINERS Tudor John Limited Chartered Accountants and Statutory Auditors, Nightingale House, 46-48 East Street, Epsom, Surrey KT17 1HQ

SOLICITORS Stone King, Boundary House, 91 Charterhouse St, Barbican, London EC1M 6HR

BANKERS Barclays Corporate Level 27, 1 Churchill Place London E14 5HP

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General funds	992,865	(1,041,392)	(48,527)
Restricted funds			
PID UK	10,200	(1,699)	8,531
TOTAL FUNDS	1,003,065	(1,043,061)	(39,996)

17. EMPLOYEE BENEFIT OBLIGATIONS

The charity operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the charity in independently administered funds. The pension costs charge represents contributions payable by the group to the funds and amounted to £12,698 (2020: £22,873). Contributions totalling £870 (2020: £3,152) were payable to the funds at the year end and are included in creditors. The expense and liability have been recognised in unrestricted funds.

18. RELATED PARTY DISCLOSURES

A licence fee is paid annually to the Chronic Granulomatous Disorder Society (CGD Society), which owns the Jeans for Genes and Genetic Disorders UK (GDUK) trademarks. The fee totalled £61,138 (2020: £90,606).

In addition there is a SLA between Genetic Disorders UK and Chronic Granulomatous Disorder Society in relation to the provision of staff. The charge for the year amounted to £13,403 (2020 £42,804).

19. COMPANY STATUS

The charity is a private company limited by guarantee. The members of the company are the trustees named on page 23. In the event of the charity being wound up the liability in respect of the guarantee is limited to £1 per member of the charity.

Appendix 1

PRIMARY IMMUNODEFICIENCY UK ANNUAL REPORT 2020–21

PRIMARY IMMUNODEFICIENCY UK

Primary Immunodeficiency UK (PID UK) was launched in July 2013 as a division of Genetic Disorders UK – now known as Gene People - following consultation with medical professionals and patients. It was established to support and represent individuals and families affected by a primary immunodeficiency in the UK. Following the demerger, PID UK changed its name to Immunodeficiency UK and became an independent charity.

OUR ADVISORY PANELS

PID UK is extremely grateful for the support of our patient representative and medical advisory panel.

Patient representative panel

Our patient representatives are dedicated volunteers who act as advisers, ambassadors and spokespeople for PID UK.

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 (joined January 2020)
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

Dr Peter Arkwright, MBBS, D Phil, MRCPCH, Consultant Immunologist, Department of Paediatric Allergy and Immunology, Royal Manchester Children's Hospital, Manchester
Sister Fran Ashworth, RGN, ONC, Senior Nurse Specialist, Clinical Immunology and Allergy Unit, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield (retired February 2021)
Dr Claire Bethune, MB, BChir, FRCP, FRCPath, Consultant Immunologist, Derriford Hospital, Plymouth
Dr Matthew Buckland (chair), MBBS, BSc (Hons), MSc, PhD, FRCP, FRCPath, Consultant Immunologist, Great Ormond Street Hospital and Barts Health NHS Trust, London
Dr Mari Campbell, BSc (Hons), DClinPsy, Clinical Psychologist, Royal Free London NHS Foundation Trust and Honorary Associate Professor, University College London
Emily Carne, RN, Dip HE, MSc, Advanced Nurse Practitioner, Department of Immunology, University Hospital Wales, Cardiff
Professor Helen Chapel, MD, FRCPath, FRCP, Professor of Clinical Immunology and Group Head, John Radcliffe Hospital, Oxford
Dr Niall Conlon, PhD, FRCPath, Consultant Immunologist, Department of Immunology, St James's Hospital, Dublin
Dr Tariq El-Shanawany, MA, MBBS, MSc, MD, MRCP, FRCPath, Consultant Clinical Immunologist, University Hospital Wales, Cardiff

About Primary Immunodeficiency

Prevalence and impact

The term primary immunodeficiency (PID) covers over 40 different genetic disorders that affect how the body's immune system works. People affected by PID have a reduced or non-existent natural defence against germs, such as bacteria, fungi and viruses, because parts of their immune system are either missing or do not function correctly.

People with PID, therefore, get infections more often than is normal and PID patients can take longer to recover when they have antibiotic treatment. In addition, affected individuals often experience recurrent infections, and it is this susceptibility to infection that is one of the most common symptoms of PID. Often, PIDs are diagnosed early in a child's life, however, signs of immunodeficiency can also occur in older children, teenagers or adults.

The exact number of individuals with a PID in the UK is unknown because no national screening programme is in place. However, data held in PID patient registries around the world, indicating the prevalence of PID within populations, suggests that about 5,000 people may be affected in the UK.

The effects of having a PID on an individual can be immense. For example, a baby born with severe combined immunodeficiency (SCID) might not survive more than a couple of years without isolation in a sterile environment until a haematopoietic stem cell transplant (also referred to as bone marrow transplant (BMT)) can be carried out.

Prolonged periods of ill-health in a child can disrupt schooling and social contacts; while for an adult, frequent debilitating illnesses can make it more difficult to pursue a career or enjoy family life. Those affected can experience psychological problems.

Many people have lived with the symptoms of a PID long before they get a diagnosis, and this can often result in irreversible damage to their lungs and other body organs. People can sometimes find it difficult coming to terms with living with a chronic life-long condition. The fear of losing one's income, the sense of isolation or the anguish of caring for a sick child – they can all take their toll.

Treatment Options

A large proportion of people affected by a PID have immunoglobulin replacement therapy to help keep them free from infection and take antibiotics and other antimicrobial medicines prophylactically or as and when an infection occurs. More specialised treatments and potential cures include haematopoietic stem cell transplant, enzyme replacement therapy and gene therapy.

OUR MISSION AND STRATEGY

PID UK's mission is to work with patients, healthcare professionals and other relevant organisations to ensure that those affected by a PID 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 PID UK in its work, we are a member of several umbrella groups, including the Specialised Healthcare Alliance, Benefits and Work, the Prescription Charges Coalition and Genetic Alliance UK. PID UK is IPOPI's national member organisation for the UK.

PID UK's main strategic priorities are as follows:

i. To offer support to individuals and families affected by a PID
ii. To raise awareness and improve understanding of PIDs and the work of PID UK among affected individuals and families, the medical profession and the general public
iii. To be an advocate and campaigner for the needs and rights of people affected by PIDs
iv. To increase income from a range of sources so that PID UK can better support patients with PID

OBJECTIVES, ACTIVITIES AND ACHIEVEMENTS 2020-21

i. To offer support to individuals and families affected by a PID

Objectives

- To assist individuals and families affected by a PID through a telephone/email helpline and practical information.
- To support the community through the Covid-19 pandemic.
- To increase the sense of community and shared experience through regular communications, patient stories and by supporting patient community events.
- To empower those affected through high-quality, medically peer-reviewed information, accessible in printed and digital formats.

Activities and achievements

- Helpline: PID UK dealt with 549 enquiries (2020: 370) from families affected by a PID, relating to issues such as diagnosis, access to treatments and care, benefit entitlement, education and employment, insurance and the Covid-19 pandemic.

'Thank you so much for returning my call and responding to my plea for some support, which you gave in abundance. Your guidance today was priceless.'

'Enormous thanks for your speedy and detailed reply to my query, with all the helpful links included.
I am very grateful.'

'Thank you so much for your prompt response. Also, for clarifying our situation, which gives us a huge peace of mind.'

- Covid-19 support: In the absence of specific guidance from the government, PID UK worked with our medical advisory panel and UK PIN (the professional body representing immunology doctors and nurses) to develop consensus statements and risk profiles for shielding for those affected by PID and secondary immunodeficiency. We also developed a range of support materials, including a simple guide to shielding, ideas for coping with self-isolation, taking care of your emotional well-being and Covid-19-specific frequently asked questions. Information on Covid-19 research and studies that the community could get involved with were also highlighted. PID UK launched a 'keeping vulnerable people safe' campaign and provided facemask exemption cards and keep your distance badges to the community.

'The constant updates you give are so very helpful and very much appreciated. It isn't easy but your emails are always a solution.'

- Mental health support: PID UK held two online mental health webinars, to provide an opportunity for the community to share their experience of the Covid-19 pandemic and to discuss strategies for managing risk.

'Thank you for the updates, they are what keeps me going... I feel you are a distant hug...'

- Peer-to-peer support: PID UK facilitated help to three families, through our patient representative panel and membership.

- e-newsletters: PID UK produced and distributed monthly e-newsletters to members. These contained information about health topics relating to Covid-19, advances in research, PID UK activities and news of community fundraising.

> *I only became properly aware of PID UK in 2019 even though I was diagnosed 17 or more years ago. The newsletter has been really helpful, reassuring and informative, particularly during Covid, when GPs and hospitals were trying to make sense of the government's rules and clear communication was not available.*

In a survey to explore the value of the newsletter to the community:

- 85% of respondents said they found the newsletter informative/extremely informative;
- 92% of respondents valued updates on the latest medical treatments and advances for PID;
- 64% of respondents valued the sharing of stories and experiences from those living with PID;
- 63% of respondents indicated the newsletter made them feel part of a community; and,
- 91% of respondents were happy to receive newsletters by email rather than in printed form.

ii. To raise awareness and improve understanding of PIDs and the work of PID UK among affected individuals and families, the medical profession and the general public

Objectives

- To use patient experiences wherever possible to inform audiences about PID conditions and their impact.

- To develop new educational materials on specific conditions and topics, in both printed and electronic formats.

- To disseminate educational materials via immunology centres and at patient events.

- To monitor use of the website, and update, enhance and review online content with learning from patient experience, medical opinion and published research.

- To develop collaborative partnerships to maximise the work of PID UK for the PID community.

Activities and achievements

- Raising awareness of PID and the impact on those affected: Eighteen new patient stories were developed, describing the experiences of those directly affected by PID and of parents with affected children. The stories covered people's experience of living with CVID, MBL deficiency, IgA deficiency, DiGeorge syndrome, XLA and hypogammaglobulinemia. They all highlighted the challenges individuals and their families face.

  Six patient films were developed to highlight the importance of early diagnosis and access to appropriate treatment. These were made available through a YouTube channel and were used to support our activities during World PI Week, Rare Disease Day and International Plasma Awareness Week.

- Supporting patients through information: PID UK's educational materials were made available to PID patients through immunology centres, via an on-demand order service, and directly by post or electronically. By request, a total of 3,074 printed booklets were distributed to 12 immunology centres and 93 were sent to individual patients.

- New booklets and website content: Booklets were developed on neutrophil disorders and complement deficiencies through restricted grant awards from the Jeffrey Modell Foundation and Amdel Medical Ltd, respectively. New website content included 'How to work with your GP'; 'The ageing immune system'; 'International study reports on the impact of Covid-19 in patients with primary immunodeficiencies'; 'Study reports on the UK experience of Covid-19 in patients with primary and secondary immunodeficiencies' and 'Top tips for remote consultations'.

- PID UK saw an increase in website user engagement from the previous year. There were 58,232 unique users (2019: 40,839) across 75,245 sessions (2019: 52,756), with 173,624 page views (2019: 129,587). Facebook followers increased by 442 followers to 1,598 and there was an increase of 221 Twitter followers.

- Membership numbers increased to 1,632, with 278 new members joining PID UK over the period.

iii. To be an advocate and campaigner for the needs and rights of people affected by PIDs

Objectives

- To proactively support advocacy and awareness initiatives on behalf of patients.

- To seek opportunities for the PID patient expert view to be heard.

Activities and achievements

- PID UK responded to the following consultations: National Institute for Health and Care Excellence (NICE) consultation on SARS-CoV-2 viral detection point of care tests and serology tests; the Health Technology Appraisal 'Remdesivir for treating Covid-19' and 'The NICE methods of health technology evaluation'.

- Patient and public voice involvement: PID UK continued to have 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 | Genetic Alliance UK and Public Health England's SCID Patient Information and Training Group and Pilot Oversight Group. PID UK is the patient and public involvement lead on the NHS Genomics Immune Disorders GeCIP Domain, and member of the Royal College of Physicians' Patient and Carer Network, the Specialised Healthcare Alliance and Genetic Alliance UK.

  Our patient representative for Northern Ireland was interviewed on BBC Radio 5 Live about the ease of lockdown measures and the concerns of people who have been shielding.

- Access to medicines: After two years of lobbying as part of the UK Plasma Action Alliance (UKPA), we were delighted that the government lifted the ban on the use of UK plasma for the manufacture of immunoglobulins. This significant policy change was particularly important at a time when the Covid-19 pandemic led to plasma shortages worldwide and continues to impact on immunoglobulin supplies.

- Specific advocacy activities included: patient representation at the NHS Blood and Transplant plasma roundtable discussion, hosted by Lord Darzi; representation at meetings of the NHS Commercial Medicines Unit concerning the procurement of immunoglobulin; giving a presentation at a parliamentary roundtable, hosted by Alan Whitehead MP, on the topic of immunoglobulin supplies;

co-signing a letter to Lord Bethell asking for the introduction of specialised commissioning for plasma exchange (PLEX) in England to build resilience into the NHS following Covid-19, to help tackle the shortage of immunoglobulin.

- By invitation from Alexion, PID UK took part in roundtable discussions concerning access to medicines, resulting in the report 'Improving patient access to rare disease treatments – realising the opportunities of the NICE Processes Review'.

- PID UK became a member of the All-Party Parliamentary Group on Vulnerable Groups to Pandemics, which aims to highlight the needs of clinically vulnerable people during the COVID-19 pandemic.

iv. To increase the number of volunteers and to increase income from a range of sources so that PID UK can better support patients with PID

Objectives

- To inspire the community to fundraise through improved website content and fundraising stories.

- To increase income and support from the PID community.

- To build relationships with pharmaceutical companies to increase revenue.

Activities and achievements

- A new supporter fundraising pack was produced and content on in memoriam giving and legacy giving was uploaded to the website. Three fundraising supporter stories were posted on the website.

- Due to the Covid-19 pandemic and the cancellation of our usual fundraising events, we launched a virtual 10K event, which raised £4,960. Revenue from regular giving rose to £2,856 (2019: £1,380), with the enrolment of 11 new regular givers.

- Unrestricted grant awards were awarded from CSL Behring (£35,000); Orchard Therapeutics (£7,500); Takeda (£10,000); LFB (£5,000); Binding Site Ltd (£5,000) and Renishaw (£1,000). Restricted awards were awarded from Biotest Ltd (£3,600); IPOPI (£1,720); Grifols (£12,337) and the Jeffrey Modell Foundation (£1,810). These funds helped to support our helpline, the production of newsletters and the development and dissemination of patient information.