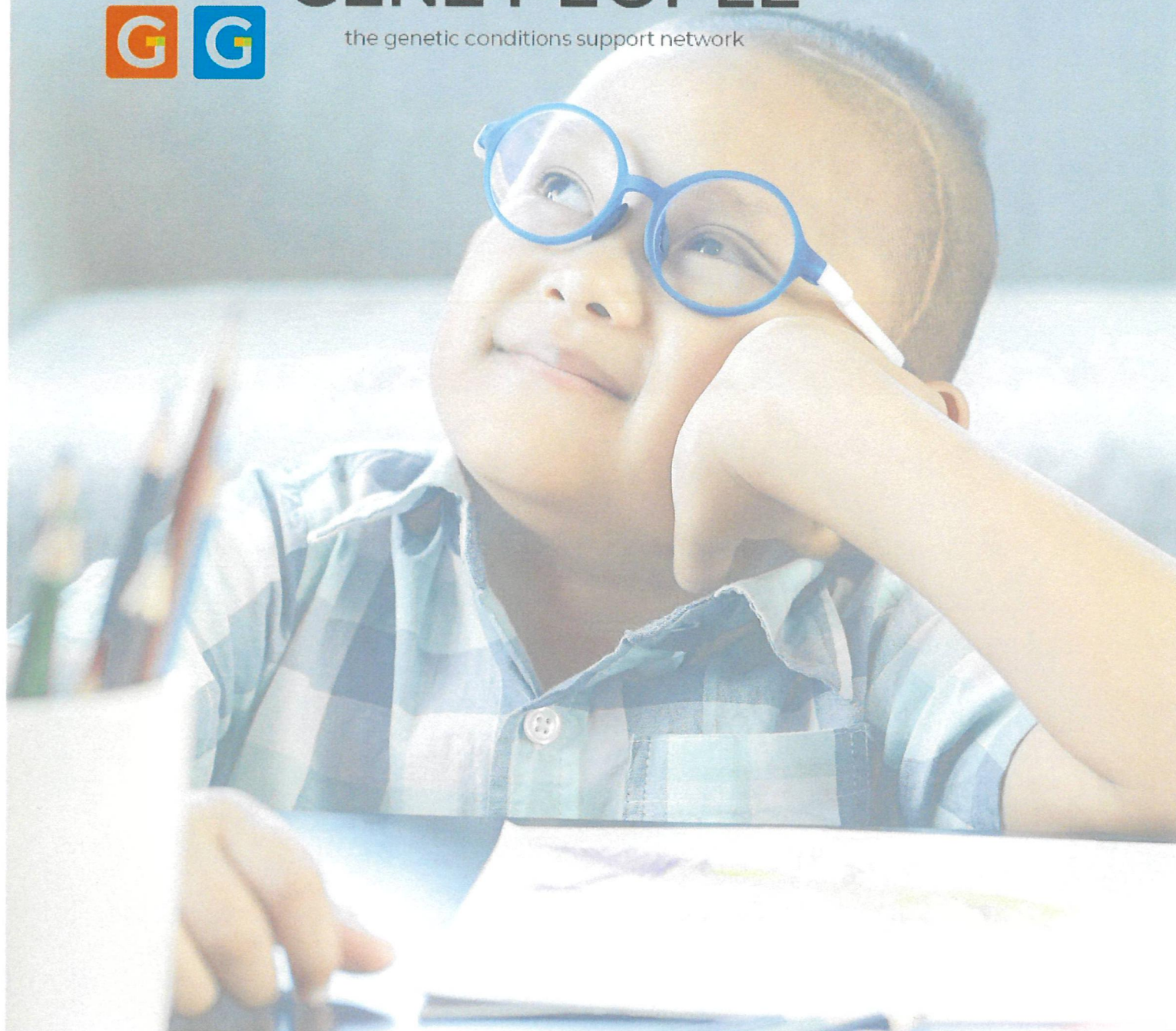




GENE PEOPLE

the genetic conditions support network



2020/2021

ANNUAL REPORT

Gene People (Formally known as Genetic Disorders UK)

Registered Charity No: 1141583

Company No: 07564771

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Note - Front cover image is a stock image. All other images included in this report have been shared by parents of the children featured to adhere to Covid-19 guidelines.

This Annual Report has been designed in house using Canva Pro for Charities.

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.

A handwritten signature in blue ink that reads "Alastair Kent". The signature is stylized, with the first name "Alastair" written in a cursive-like script and the last name "Kent" in a more blocky, capital-letter style.

Alastair Kent OBE FRSA
Chair of Trustees

Report of the Board of Trustees for the year ended 31 March 2021

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2021. 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).

Our Aims and Objectives

Gene People (formerly Genetic Disorders UK (GDUK)) was founded in 2011 with the vision of improving the lives of those affected by a genetic disorder through the provision of resources and support both to individuals and families, and to the hundreds of disorder-specific charities and patient groups that have been established in the UK.

The objectives of the charity are:

- To raise awareness and advance the education of the public on the subject of genetic disorders
- The relief of persons suffering from genetic disorders
- The advancement of medical research into the causes, cure, prevention or relief of such disorders and the publication of results of that research
- To promote the efficiency and effectiveness of other genetic disorder charities so they may achieve their charitable purposes.

We serve two distinct audiences:

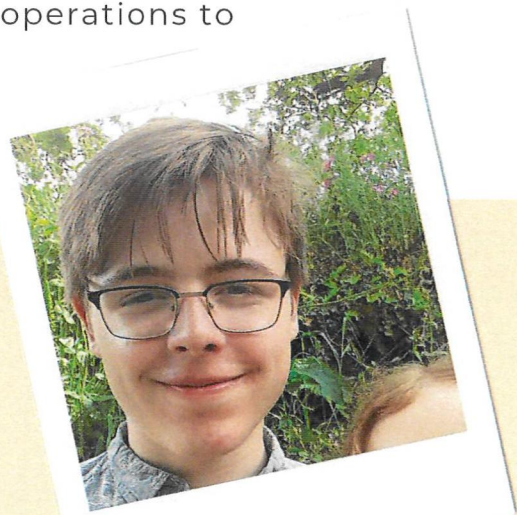
- Those affected by a genetic condition, their families and carers, and support universe
- Condition-specific support groups and charities.

*Edith who has Cystic Fibrosis
and Childhood Absence Epilepsy*



Our work over the last year has fallen in 5 main areas:

- 1.** Providing services to those affected by a genetic condition through our helpline and website: www.genepeople.org.uk
- 2.** Providing services to those affected by primary immunodeficiency through a free helpline and website within a dedicated division - Primary Immunodeficiency UK.
- 3.** Supporting genetic disorder and primary immunodeficiency charities and patient groups through a Partnership Network; providing information and advice, sharing best practice and co-ordinating an annual grant scheme (distributing funds raised through Jeans for Genes Day).
- 4.** Jeans for Genes Day – the annual fundraising campaign increasing the profile of genetic disorders with the general public and raising money for the Partnership Network members, Gene People and the Chronic Granulomatous Disorder Society (the founders and licence-holders of Jeans for Genes).
- 5.** Restructuring the charity and its operations to better equip it for the future.



Jake who has Loeys-Dietz Syndrome



GENE PEOPLE

"Thank you very much for your call today and your below email with the information that I needed. I appreciate your comments during the call and below and we will take that fully on board in deciding our next steps. Thank you once again."

- Helpline caller

429 enquirers contacted the Helpline

5,611 Twitter followers

5,557 Facebook followers

128 Partnership Network members



Aims and objectives

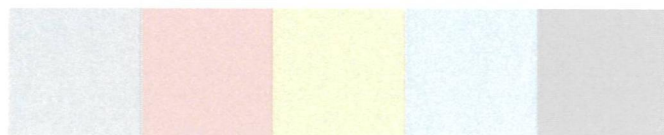
In early 2020, the trustees discussed a new strategy focused on increasing the impact for those we support and to diversify income streams for GDUK, as the charity was then known.

The agreed aims for 2020/21 were:

- To continue to provide one-to-one support and genetic counselling for individuals and families;
- To maintain GDUK's website as the leading source of information and support to those affected by genetic disorders and continue to develop the reach and impact of the charity's social media voice;
- To secure funding for core services provided by GDUK from diverse sources;
- To keep current supporters active and engaged with Jeans for Genes Day and recruit new supporters through an impact-led communications campaign, mitigating the effect of Covid-19 as much as possible through an agile, digital approach;
- To work collaboratively with the licence-holder for Jeans for Genes to further enhance the campaign's impact;
- To contribute to the funding of projects proposed by members of the UK Genetic Disorders Partnership Network through the Jeans for Genes Day grant programme;
- To manage and develop the contribution of PID UK to the PID community.

There are two sections on the specific objectives and activities of Jeans for Genes and PID UK on pages 11 and 15. The work of these divisions is being highlighted as during the course of the year, trustees decided to demerge both to become their own, separate charities.

The following sections of the report focus on Gene People during the year 2020-21.





Activities

This year was going to be one of immense challenge for Gene People (then Genetic Disorders UK) as the external pressures of Covid-19 and the previously recognised need for refocusing our work both impacted the charity. The trustees and staff are hugely proud of everything achieved for the benefit of all those affected by genetic conditions.

As well as running the Jeans for Genes campaign and hosting PID UK, the team continued a number of projects that are part of the Gene People's core work.

Our **Genetic Counsellor-led Helpline** is unique. This year the number of calls increased with the most frequent questions being about needing more information about specific conditions, and how to access genetic testing. The impact of Covid-19 on our community was shown through the number of calls about not being able to access NHS services and needing to find alternative providers for those services.

The Gene People **social media channels** provided a key means of maintaining communication with the genetic conditions' community during this challenging year, and of disseminating information from our Partnership Network. We undertook a project to benchmark our social footprint, and that for Jeans for Genes, against comparable organisations and similar fundraising appeals. As a result of these insights, our messaging was tailored, and we secured increased social media followers.

We made progress in **diversifying our income streams**, securing a significant Covid-19 Response grant from The National Lottery Community Fund to fund our core services during the difficult time of the pandemic for which the trustees are extremely grateful. We also received other grants from The D'Oyly Carte Charitable Trust and The Edward Gostling Foundation, which is testimony that the value of our work with those affected by genetic conditions is recognised outside of the community. We are enormously grateful to those who fundraised for Gene People during the year.

In addition, we continued to work with members of the Partnership Network, often providing a listening ear to those facing increasing demand during this period. Trustees decided not to hold the Leadership Symposium to focus efforts on the Jeans for Genes campaign.

The team also worked on two specific Jeans for Genes objectives: to refresh the campaign and to maximise the impact of the campaign.

As it became clear that Covid-19 restrictions would be in place for September 2020's campaign, we had to be creative to maximise participation and the funds raised. For more detail on how we did this see the section on Jeans for Genes on page 11.

Gene People's trustees held discussions with the licence-holder for the Jeans for Genes Day campaign over the course of the year to explore ways to **maximise the impact** of the Jeans for Genes Day campaign. The Gene People trustees decided that Jeans for Genes should be returned to the licence-holder for the benefit of those served by Gene People and the final few months of this year involved preparing for the demerger.

Future Plans - Embedding Change

Continuing the work to mitigate risk and to refocus on the charity's core purpose, the trustees are consolidating the changes to Gene People arising from the strategic direction set last year. They are seeking to embed the changes made in the organisation with a new team and a new fundraising strategy.

The fundraising strategy no longer rests on the success of the Jeans for Genes Day event. The strategy is to diversify income streams to include individual gifts, community fundraising, corporate support, and philanthropy. This will spread risk, develop new relationships and deepen existing ones, and reduce the cost of fundraising.

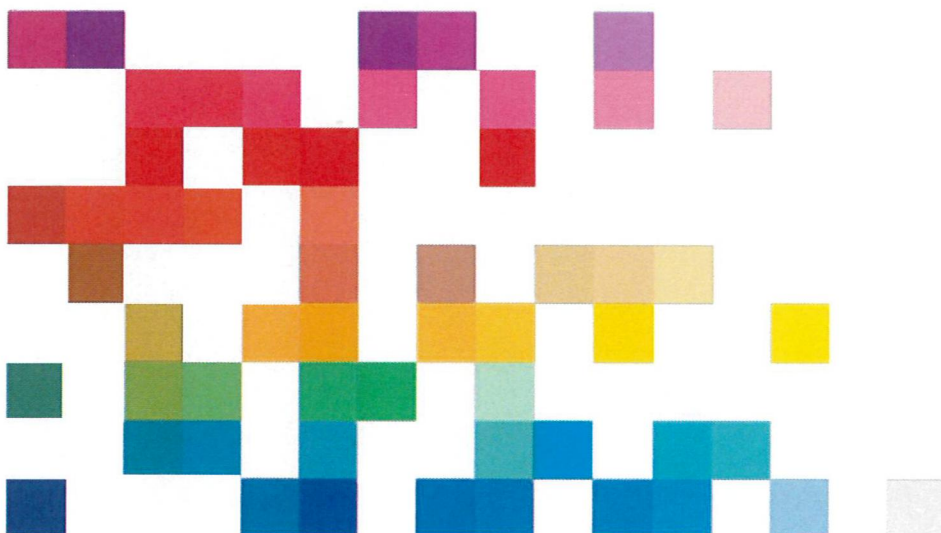


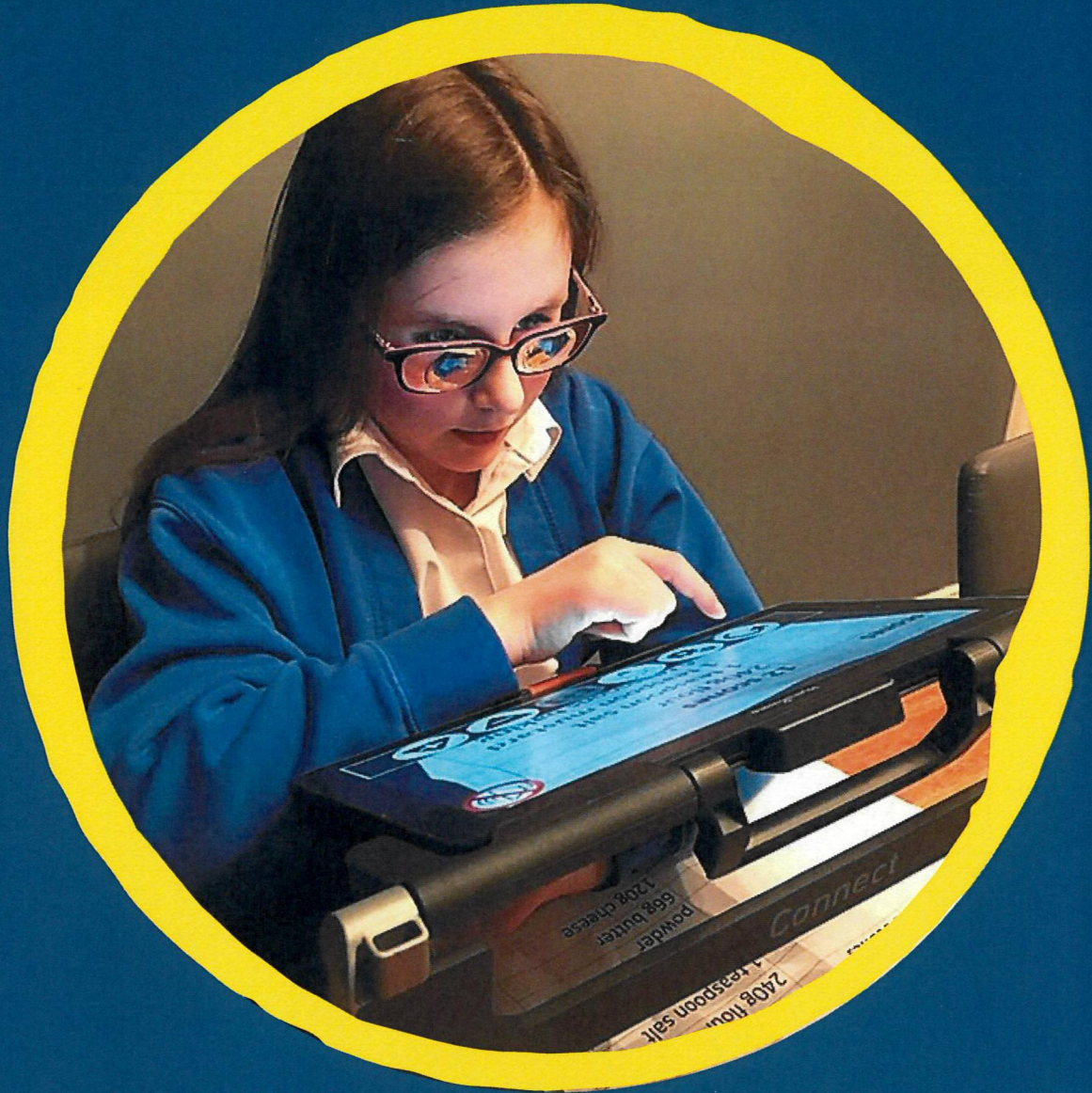
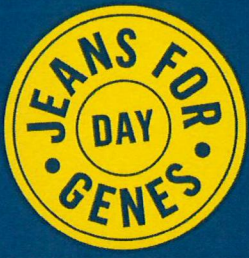
The trustees are content that the changes made, and the strategy followed will create a smaller and more resilient charity in the medium-long term.

Strategic Aims for 2021-22

The trustees agreed the following strategic aims for the coming financial year:

- Continue the change programme with a new name and rebrand, and form the new organisational structure with new team members
- Increase the accessibility of the Helpline for those with additional needs and increase the promotion of the service, particularly through social media
- Improve the resources on the website, especially developing and enhancing the Directory of Condition-Specific Groups and Charities
- Expand the Partnership Network by offering online events, online peer to peer support, and to explore other ways to support the Network
- Participate in consultations on national policy representing the experiences of the Network and those who use our services, such as the NICE Methods Review and the EU consultation on the review of the Orphan Medicinal Products Regulations
- Implement the new fundraising strategy with a focus on building long-term relationships with all those who kindly support our work.





Eleven-year-old Florence has a number of eye conditions, the result of a rare genetic condition. She has limited vision and is registered blind. Thanks to Newlife – which Gene People and Jeans for Genes has supported for the last 12 years – Florence has her own BrailleNote tablet to use at home to help with her schoolwork. It has been essential during the Coronavirus lockdown and home learning.

73,941

website
visits

1.1m

Twitter
impressions

11,810

Facebook
followers

£89,999.84 provided in grants

£60,021 raised by 1,051 workplaces

£283,424 raised by

257 nurseries

884 primary schools

231 secondary schools

35 mixed schools

Aims and objectives

To engage schools, businesses and members of the public in the Jeans for Genes Campaign to raise money to support people with genetic conditions and their families.

To grow understanding and awareness of genetic conditions and their impact on people's lives.

Activities

2020 to 2021 was a challenging year for Jeans for Genes. As with many charities the pandemic caused severe disruption to fundraising activities. For a campaign that relies largely on face-to-face activity in schools and workplaces it was a challenging year. Some aspects of the campaign were scaled down to take into account the impact of the pandemic, only 13,445 packs were sent out to remind our previous supporters to get involved, compared with 60,255 the previous year. Overall registrations were down from the previous year by 32.74%. But, the commitment and loyalty of supporters who did participate in the campaign shone through as average donations increased by 3.68% on 2019. The telemarketing campaigns saw a noticeable increase in average donation values, increasing by 10.62% on the previous year.

Primary Schools were the most successful fundraisers, generating £169,794 during the campaign, with Secondary Schools next in line, raising £92,715. Campaign activities in London and the South East continued to generate more income than other geographical areas.

Social media engagement continued to gain traction during the 2020 campaign.

So, despite the significant impact of the Covid-19 pandemic and the associated restrictions, the 2020 Jeans for Genes campaign raised £359,520 in donations from over 6,900 pre-registered supporters. The total income including merchandise was £421,571. This is a real testament to the schools, families, businesses and friends who wore their denim and raised money for people and their families living with genetic conditions.

Future Plans

In March 2021, Jeans for Genes became a separate charity. It is no longer a fundraising campaign within Gene People. Whilst Jeans for Genes and Gene People are still wholeheartedly committed to collaborating on the issue of genetic conditions, a new set of aims, objectives and plans will be unveiled for the new charity.

In its first year, as with most new charities, the focus will be on building strong foundations, a new Board of Trustees and resourcing the work. Starting with articulating the impact goals, then the strategy, the operational plans and infrastructure will follow. There will be a strong focus on engaging with the genetic conditions' community, to better understand where the new charity can add value and fill gaps in service provision and support. All charitable activities and impact will be achieved through the Jeans for Genes grant programme, funding and collaborating with organisations in communities across the UK. The Jeans for Genes fundraising campaign will continue to go from strength to strength, and income diversification will be a priority, to de-risk the current financial model which is heavily dependent on a single campaign at a single point in the year.

Meanwhile, the 2021 campaign will run very much on the basis of previous campaigns during the 2021 transition year, building back from the challenges of the pandemic, laying down a solid foundation for growth in 2022.

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

Statement of Trustee's Responsibilities

The trustees (who are also the directors of Gene People for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on 15/12/2021 and signed on the board's behalf by:

..........

Alastair Kent OBE FRSA, Chair of the Board of Trustees

Independent Examiner's Report to the Trustees of Gene People (Registered number: 07564771)

Independent examiner's report to the trustees of Gene People ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2021.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW which is one of the listed bodies.

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


1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or

2. the accounts do not accord with those records; or

3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view of the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or

4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

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 BSc (Hons) FCA DChA
ICAEW
Tudor John Limited
Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ

Date: ...17th December 2021.....

Gene People
Statement of Financial Activities
for the year ended 31 March 2021

	Notes	Unrestricted funds	Restricted funds	2021 Total funds	2020 Total funds
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	144,990	12,000	156,990	90,528
Other trading activities	3	513,430	-	513,430	912,424
Investment income	4	<u>808</u>	<u>-</u>	<u>808</u>	<u>113</u>
Total		659,228	12,000	671,228	1,003,065
EXPENDITURE ON					
Raising funds	5	377,848	-	377,848	617,464
Charitable activities	6				
Awareness and education		210,244	11,531	221,775	244,363
Relief		81,665	-	81,665	81,803
Grants awarded		<u>207,482</u>	<u>-</u>	<u>207,482</u>	<u>99,431</u>
Total		877,239	11,531	888,770	1,043,061
NET INCOME/ (EXPENDITURE)		(218,011)	469	(217,542)	(39,996)
RECONCILIATION OF FUNDS					
Total funds brought forward		277,005	15,246	292,251	332,247
TOTAL FUNDS CARRIED FORWARD		<u><u>58,994</u></u>	<u><u>15,715</u></u>	<u><u>74,709</u></u>	<u><u>292,251</u></u>

Gene People (Registered number 07564771)
Balance Sheet
for the year ended 31 March 2021

	Notes	Unrestricted funds	Restricted funds	2021 Total funds	2020 Total funds
FIXED ASSETS					
Investments	13	-	-	-	1
CURRENT ASSETS					
Debtors	14	15,819	-	15,819	93,474
Cash at bank		208,750	15,715	224,465	293,844
		<u>224,569</u>	<u>15,715</u>	<u>240,284</u>	<u>387,318</u>
CREDITORS					
Amounts falling due within one year	15	(165,575)	-	(165,575)	(95,068)
NET CURRENT ASSETS		<u>58,994</u>	<u>15,715</u>	<u>74,709</u>	<u>292,251</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		58,994	15,715	74,709	292,251
NET ASSETS		<u>58,994</u>	<u>15,715</u>	<u>74,709</u>	<u>292,251</u>
FUNDS	16			58,994	277,005
Unrestricted funds				15,715	15,246
Restricted funds					
TOTAL FUNDS CARRIED FORWARD				<u>74,709</u>	<u>292,251</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply

The notes form part of these financial statements

with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The financial statements were approved by the Board of Trustees and authorised for issue on 15/12/2021 and were signed on its behalf by:


.....

Alastair Kent OBE FRSA, Chair of the Board of Trustees

GENE PEOPLE
Cash Flow Statement
for the year ended 31 March 2021

	Notes	2021 £	2020 £
Cash flows from operating activities			
Cash generated from operations	1	<u>(70,187)</u>	<u>(11,563)</u>
Net cash used in operating activities		<u>(70,187)</u>	<u>(11,563)</u>
Cash flows from investing activities			
Sale of tangible fixed assets		(1)	(3)
Sale of fixed asset investments		1	-
Interest received		808	113
Net cash provided by investing activities		<u>808</u>	<u>110</u>
Change in cash and cash equivalents in the reporting period		<u>(69,379)</u>	<u>(11,453)</u>
Cash and cash equivalents at the beginning of the reporting period		<u>293,844</u>	<u>305,297</u>
Cash and cash equivalents at the end of the reporting period		<u>224,465</u>	<u>293,844</u>
NET ASSETS		<u>74,709</u>	<u>292,250</u>

1. RECONCILIATION OF NET EXPENDITURE TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2021 £	2020 £
Net expenditure for the reporting period (as per the Statement of Financial Activities)	(217,542)	(39,996)
Adjustments for:		
Loss on disposal of fixed assets	1	5
Interest received	(808)	(113)
Movement in subsidiary company balance	20,866	(5,219)
Decrease in debtors	56,789	117,538
Increase/ (decrease) in creditors	70,507	(83,778)
Net cash used in operations	<u>(70,187)</u>	<u>(11,563)</u>

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.4.20 £	Cash flow £	At 31.3.21 £
Net cash			
Cash at bank	<u>293,844</u>	<u>(69,379)</u>	<u>224,465</u>
	<u>293,844</u>	<u>(69,379)</u>	<u>224,465</u>
Total	<u>293,844</u>	<u>(69,379)</u>	<u>224,465</u>

The notes form part of these financial statements

GENE PEOPLE
Notes to the Financial Statements
for the year ended 31 March 2021

1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charitable company, 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 Companies Act 2006. The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value.

CRITICAL ACCOUNTING JUDGEMENTS AND KEY SOURCES OF ESTIMATION UNCERTAINTY

Estimates and judgements are continually evaluated and are based on historical experience and other factors including expectations of future events that are believed to be reasonable under the circumstances.

The items in the financial statements where these judgements and estimates have been made include:

- estimating the useful economic life of tangible fixed assets for the purposes of determining the annual depreciation charge;
- determining the basis for allocating support costs across expenditure classifications

INCOME

Income is recognised in the period in which the charity has entitlement to the income and the amount can be measured reliably and it is probable that the income will be received. Income is deferred only when the charity has to fulfil conditions before becoming entitled to it or where the donor or funder has specified that the income is to be expended in a future accounting period. Income comprises donations, legacies, grants in respect of core funding, income from the main charitable activity, Jeans for Genes, merchandise sales and interest receivable.

Donations and grants in respect of charitable activities are recognised when the charity has confirmation of both the amount and settlement date. In the event of amounts pledged but not received, the amount is accrued for where the receipt is considered probable. In the event that a donation or grant subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

Legacies are included in the statement of financial activities when the charity is entitled to the legacy, the executors have established that there are sufficient surplus assets in the estate to pay the legacy and any conditions attached to the legacy are within the control of the charity.

Entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted; the estate has been finalised and notification has been made by the executor to the charity that a distribution will be made; when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution.

Where legacies have been notified to the charity or the charity is aware of the granting of probate, but the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material. In the event that the gift is in the form of an asset other than cash or a financial asset traded on a recognised stock exchange, recognition is subject to the value of the gift being reliably measurable with a degree of reasonable accuracy and the title of the asset having been transferred to the charity.

Income from Jeans for Genes and merchandising income is recognised to the extent that it is probable that the economic benefits will flow to the charity and the revenue can be reliably measured.

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

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, exclusive of any VAT which is recoverable. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs, which contribute to more than one activity, and support costs, which are not attributable to a single activity, are apportioned between those activities on a basis consistent with the use of resources.

Governance costs include the costs incurred in the governance of the charity and are primarily associated with constitutional and statutory requirements.

Expenditure is only deferred when it relates to future years.

Grants awarded are recognised when the offer and amount of the grant is conveyed to the beneficiary. Grants are paid in furtherance of the charitable objective of the charity.

All expenditure is inclusive of irrecoverable VAT.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

TANGIBLE FIXED ASSETS

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

All assets costing more than £500 are capitalised.

Tangible assets are carried at cost, net of depreciation and any provision for impairment.

RELATED PARTY EXEMPTION

The charitable company has taken advantage of exemption, under the terms of Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', not to disclose related party transactions with wholly owned subsidiaries within the group.

TAXATION

The charity is exempt from corporation 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. The costs of raising and administering such funds are charged against the specific fund.

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

GOING CONCERN

The accounts show the anticipated further decline in income in 2020-21 due to Covid-19, therefore, the trustees have assessed whether the use of the going concern assumption is appropriate in preparing these financial statements. The trustees have made this assessment using forecasts and budgets prepared to cover the period to March 2022.

The new strategy agreed in January 2020 with a greater focus on outcomes to beneficiaries whilst further diversifying income sources and reducing back office costs was implemented during 2020-21, with immediate results in a reduced head count and new sources of income for the charity. The initial stages of the change programme concluded on 31 March when both the Jeans for Genes and PID UK divisions had been demerged.

The main Jeans for Genes fundraising event in September 2020 was impacted by the pandemic as anticipated. However, the pre-emptive action taken by trustees reduced the impact of that reduction in income.

In considering going concern at the date of signing the balance sheet the trustees have assessed the probability of successfully raising the necessary funding through the new fundraising strategy and agreed that reserves could be used in this quasi-start-up phase for the reformed charity. Given the support received from corporates, funders and individuals so far, the trustees have currently assessed that the charity should not be so effected by the changes that it should not be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

FINANCIAL INSTRUMENTS

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans, which are subsequently measured at amortised cost using the effective interest method.

2. DONATIONS AND LEGACIES

	2021	2020
	£	£
Donations	<u>156,990</u>	<u>90,528</u>

3. OTHER TRADING ACTIVITIES

	2021	2020
	£	£
Charitable activities	<u>513,430</u>	<u>912,424</u>

4. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	<u>808</u>	<u>113</u>

5. RAISING FUNDS

OTHER TRADING ACTIVITIES

	2021	2020
	£	£
Jeans for Genes Day	223,915	392,783
Staff costs	112,052	195,511
Promotional items	41,731	26,555
Corporate partnerships: Licensing and sponsorship	150	2,615
	<u>377,848</u>	<u>617,464</u>

6. CHARITABLE ACTIVITIES COSTS

	Direct costs £	Grant funding of activities (see note 7) £	Support costs (see note 8) £	Totals £
Awareness and education	102,369	-	119,406	221,775
Relief	-	-	81,665	81,665
Grants awarded	-	207,482	-	207,482
	<u>102,369</u>	<u>207,482</u>	<u>201,071</u>	<u>510,922</u>

7. GRANTS PAYABLE

	2021	2020
	£	£
Grants awarded	<u>207,482</u>	<u>99,431</u>

The total grants paid to institutions during the year was as follows:

	2021	2020
	£	£
Dingley's Promise	3,416	-
FOP Friends	3,416	-
Jessie May	3,416	-
Kleefstra Syndrome	3,416	-
Newlife (Foundation for Disabled Children)	3,416	5,000
Norie Disease Foundation	-	5,000
The Sandcastle Trust	-	5,000
Zoes Place Baby hospice	-	4,877
Nystagmus Network	-	4,850
Neuromuscular Centre	-	1,000
The 1P36 Family Trust	-	500
Kabuki UK	-	5,000
Microphthalmia Anophthalmia and Coloboma Support	-	5,000
BBS UK	-	4,900
Williams Syndrome Foundation	-	5,000
Huntingtons Disease Association	-	5,000
PWSA	-	4,957
Fanconi Hope	-	5,000
Albinism Fellowship	-	3,000
Glasgow Children's Hospital Charity	3,416	1,000
Headlines The Craniofacial Support Group	-	5,000
Annabelle's Challenge	-	3,250
The Haemophilia Society	-	5,000
PMSF UK	-	5,000
Max Appeal	-	2,560
Cure EB	-	3,000
Teddington Trust	-	5,000
Immunodeficiency UK	123,095	-
48XXYY Family Support Group UK	3,416	-
Acrodysostosis Support	3,416	-
AKU Society	3,417	-
Child Growth Foundation	3,417	-
Down Syndrome Training and Support Service Ltd	3,417	-
The Fragile X Society	3,417	-
Local families with bleeding disorders	3,417	-
My Aware	3,417	-
The Neurofibromatosis Association	3,417	-
Ring20 Research and Support UK CIO	3,417	-
Scottish Huntington's Association	3,417	-
SIBS	3,417	-
The Ataxia Telangiectasia Society	3,417	-
Muscle Help Foundation	3,417	-
Rainbow Trust Children's Charity	3,417	-
Tuberous Sclerosis Association	3,417	-
Zoe's Place Trust re Coventry	3,417	-
Zoe's Place Trust re Liverpool	3,417	-
	<u>205,095</u>	<u>93,894</u>

8. SUPPORT COSTS

	Management	Governance costs	Totals
	£	£	£
Awareness and education	105,548	13,858	119,406
Relief	81,665	-	81,665
	<u>187,213</u>	<u>13,858</u>	<u>201,071</u>

9. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2021	2020
	£	£
Auditors' remuneration	-	25,200
Deficit on disposal of fixed assets	1	5
Auditors' remuneration - audit	-	5,500
Auditors' remuneration - other services	-	3,000
Previous auditors' remuneration - audit services	<u>-</u>	<u>16,700</u>

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 March 2021 nor for the year ended 31 March 2020.

11. STAFF COSTS

	2021	2020
	£	£
Wages and salaries	270,789	327,399
Social security costs	15,778	32,738
Other pension costs	12,698	22,873
	<u>299,265</u>	<u>383,010</u>

The average monthly number of employees during the year was as follows:

	2021	2020
Fundraising	1	4
Charitable	2	3
Administration/ management	1	1
	<u>4</u>	<u>8</u>

The number of employees whose employee benefits (excluding employer pension costs) exceeded £60,000 was:

	2021	2020
£100,001 - £200,000	<u>1</u>	<u>1</u>

The aggregate employee benefits paid to key management personnel were £104,427 (2020: £199,135), the key management personnel figures include external contractors in key positions.

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	80,328	10,200	90,528
Other trading activities	912,424	-	912,424
Investment income	113	-	113
Total	<u>992,865</u>	<u>10,200</u>	<u>1,003,065</u>
EXPENDITURE ON			
Raising funds	617,464	-	617,464
Charitable activities			
Awareness and education	242,694	1,669	244,363
Relief	81,803	-	81,803
Grants awarded	99,431	-	99,431
Total	<u>1,041,392</u>	<u>1,669</u>	<u>1,043,061</u>
NET INCOME/ (EXPENDITURE)	<u>(48,527)</u>	<u>8,531</u>	<u>(39,996)</u>
Transfers between funds	<u>58,283</u>	<u>(58,283)</u>	<u>-</u>
Net movement in funds	<u>9,756</u>	<u>(49,752)</u>	<u>(39,996)</u>
RECONCILIATION OF FUNDS			
Total funds brought forward	267,249	64,998	332,247
TOTAL FUNDS CARRIED FORWARD	<u><u>277,005</u></u>	<u><u>15,246</u></u>	<u><u>292,251</u></u>

13. FIXED ASSET INVESTMENTS

There were no investment assets outside the UK.

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Trade debtors	-	15,164
Amounts owed by group undertakings	-	20,866
Other debtors	-	34
VAT	15,819	32,389
Prepayments and accrued income	-	25,021
	<u>15,819</u>	<u>93,474</u>

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021	2020
	£	£
Trade creditors	34,711	68,710
Social security and other taxes	2,168	7,645
Other creditors	125,421	2,299
Accruals and deferred income	3,275	16,414
	<u>165,575</u>	<u>95,068</u>

16. MOVEMENT IN FUNDS

	At 1.4.20 £	Net movement in funds £	At 31.3.21 £
Unrestricted funds			
General funds	277,005	(218,011)	58,994
Restricted funds			
PID UK	8,531	(8,531)	-
Roald Dahl's MCC	6,715	-	6,715
GDUK Helpline	-	9,000	9,000
	<u>15,246</u>	<u>469</u>	<u>15,715</u>
TOTAL FUNDS	<u>292,251</u>	<u>(217,542)</u>	<u>74,709</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General funds	659,228	(877,239)	(218,011)
Restricted funds			
PID UK	3,000	(11,531)	(8,531)
GDUK Helpline	9,000	-	9,000
	<u>12,000</u>	<u>(11,531)</u>	<u>469</u>
TOTAL FUNDS	<u>671,228</u>	<u>(888,770)</u>	<u>(217,542)</u>

Comparatives for movement in funds

	At 1.4.19 £	Net movement in funds £	Transfers between funds £	At 31.3.20 £
Unrestricted funds				
General funds	267,249	(48,527)	58,283	277,005
Restricted funds				
PID UK	43,843	8,531	(43,843)	8,531
Symposium	14,440	-	(14,440)	-
Roald Dahl's MCC	6,715	-	-	6,715
	<u>64,998</u>	<u>8,531</u>	<u>(58,283)</u>	<u>15,246</u>
TOTAL FUNDS	<u>332,247</u>	<u>(39,996)</u>	<u>-</u>	<u>292,251</u>

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	<u>1,003,065</u>	<u>(1,043,061)</u>	<u>(39,996)</u>

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

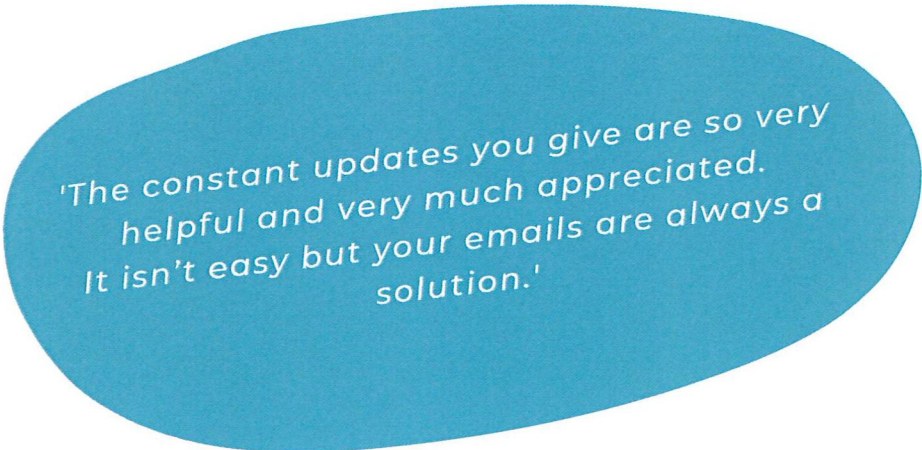
- **Helpline:** PID UK dealt with 549 enquiries (2020: 370) from families affected by a PID, relating to issues such as diagnosis, access to treatments and care, benefit entitlement, education and employment, insurance and the Covid-19 pandemic.

'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.



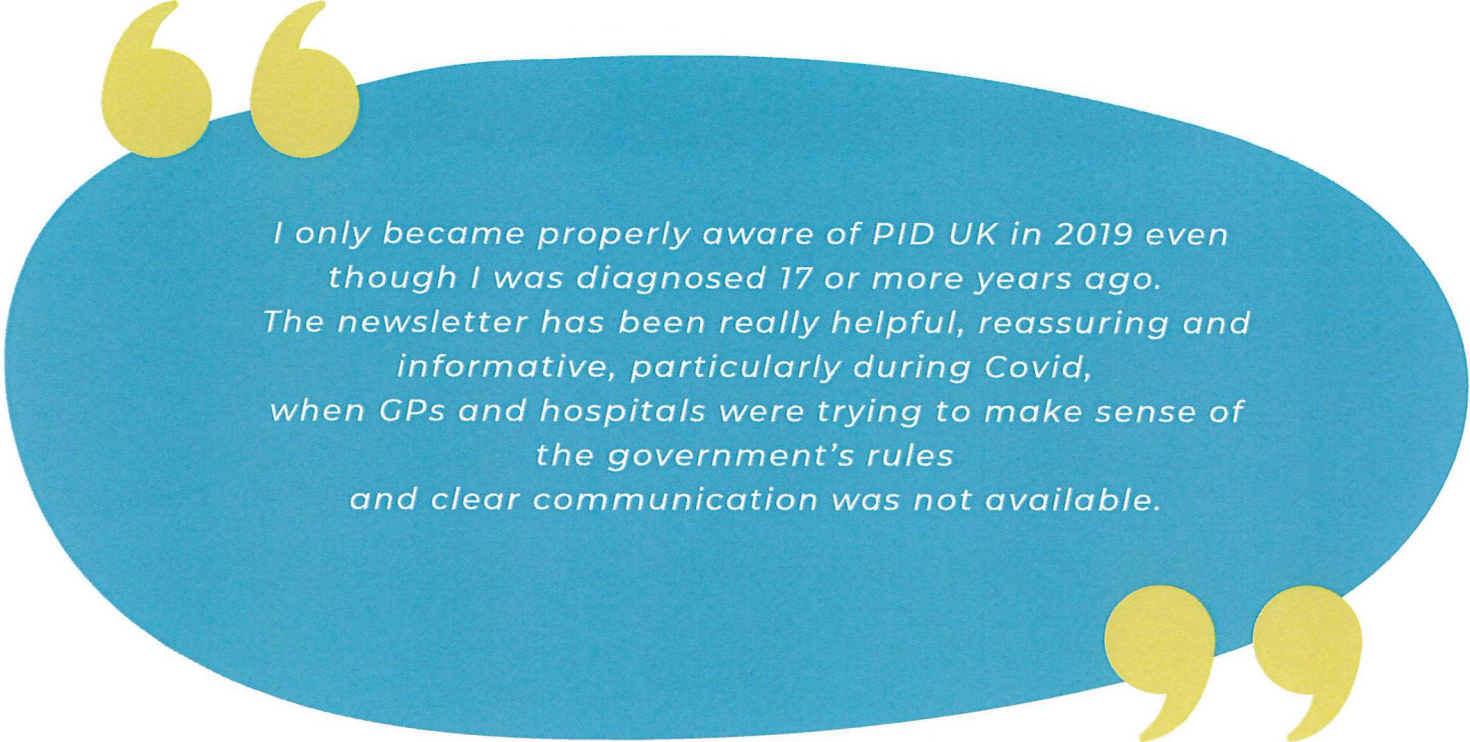
'The constant updates you give are so very helpful and very much appreciated. It isn't easy but your emails are always a solution.'

- **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.