Gene People

England & Wales · Charity number 1141583

Details

Other names	GENE PEOPLE, GENETIC DISORDERS UK, JEANS FOR GENES, GDUK, Gene People
Status	Registered
Legal form	Charitable company
Company number	07564771
Registered	2011-04-26
Register	View on the Charity Commission register

Contact

Address	c/o Tudor John Accountants Ltd Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
Phone	0800 987 8987
Email	hello@genepeople.org.uk
Website	www.genepeople.org.uk

Activities

Objects: 3.1 The Objects are:3.1.1 the relief of persons suffering from genetic disorders;3.1.2 the advancement of medical research into the causes, cure, prevention or relief of such disorders and the publication of the results of that research;3.1.3 to raise awareness and advance the education of the public on the subject of genetic disorders;3.1.4 to promote the efficiency and effectiveness of other genetic disorder charities in order to assist them to achieve their charitable purposes; and3.1.5 such other purposes as are charitable according to the laws of England and Wales for the benefit of the public.3.2 Nothing in these Articles shall authorise an application of the property of the Charity for purposes which are not charitable in accordance with any statutory provision regarding the meaning of the word charitable or the words charitable purposes in force in any part of the United Kingdom.

Activities: GENE PEOPLE (FORMERLY GENETIC DISORDERS UK) WAS CREATED IN 2011 WITH THE VISION OF IMPROVING THE LIVES OF THOSE AFFECTED BY GENETIC CONDITIONS. THE CHARITY OFFERs SUPPORT AND INFORMATION TO AFFECTED INDIVIDUALS AND FAMILIES, AND PROVIDE

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RESOURCES FOR CONDITION-SPECIFIC UK-BASED SUPPORT GROUPS AND CHARITIES.

Classification

- **How:** Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies

Geography

- **Area of benefit:** UNITED KINGDOM
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£76,635	£89,881	-	-
2024-03-31	£81,219	£68,111	-	-
2023-03-31	£108,008	£128,847	-	-
2022-03-31	£104,591	£148,200	-	-
2021-03-31	£671,228	£888,770	£74,709	4

Trustees

Name	Role	Appointed
Alastair Kent OBE	Chair	2020-11-23
Christopher John Conway		2022-03-31
Derek Ansel		2022-03-10
Dr Christine Hilcenko		2024-12-18
Dr Nicola Taverner		2022-03-19
Nigel Lorenzo Nicholls		2024-03-19
Saurav Mitra		2020-05-13

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Gene People

England & Wales - Charity number 1141583

Accounts

Charity registration number 1141583 (England and Wales)

Company registration number 07564771

GENE PEOPLE

the genetic conditions support network

GENE PEOPLE

ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

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GENE PEOPLE

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Ms A Patel Mr A J Kent OBE Mr D Ansel Mr S Mitra Mr C J Conway Dr N V Taverner Dr C Hilcenko Dr C Steward Mr N L Nicholls	(Appointed 18 December 2024)
Charity number (England and Wales)	1141583	
Company number	07564771	
Registered office	Nightingale House 46-48 East Street Epsom Surrey United Kingdom KT17 1HQ	
Independent examiner	Hazel Day Xeinadin Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ	
Solicitors	Stone King LLP Boundary House 91 Charterhouse St Barbican London EC1M 6HR	

GENE PEOPLE

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GENE PEOPLE

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2025

The trustees present their annual report and financial statements for the year ended 31 March 2025.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "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)".

Welcome from the Chair
This year has been quite tumultuous for healthcare in the UK. We have seen the new 10-year plan for the NHS with its shift in emphasis from treatment to prevention and a commitment to move healthcare out of hospital and closer to home. NHS England and the DHSC are merging. The Government and the pharmaceutical industry have been deadlocked over price negotiations – the list goes on.

For patients and families with rare genetic conditions and the groups that support them all this change has been very unsettling. Although change can often create opportunities, uncertainty about how care and support will be organized in future is stressful.

Throughout the year the team at Gene People have provided continuity, monitoring proposed changes and putting forward the needs and views of our Partnership Network and the families they support to Government, the NHS and to Industry and advocating for positive change.

We have also supported the Network through capacity building workshops and webinars, equipping them with tools that enable them to understand better the changes under way.

For individuals and families our helpline has provided invaluable support for those struggling to find a diagnosis of at a loss as to how to secure the support they need.

Our commitment is to continuity, to being a steady presence supporting our community as we navigate these turbulent times.

Alastair Kent
Chair of Trustees.

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Objectives and activities

Gene People has a vision to improve the lives of those affected by a genetic condition through the provision of resources and support both to individuals and families, and to the hundreds of condition-specific charities and patient groups that have been established in the UK. The objectives of the charity are:

- 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 the results of that research;
- to raise awareness and advance the education of the public on the subject of genetic disorders;
- to promote the efficiency and effectiveness of other genetic disorder charities in order to assist them to achieve their charitable purposes.

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

Achievements and performance

Significant activities and achievements against objectives

Everything Gene People does contributes to achieving three strategic pillars, all of which have been designed to improve the lives of those living with genetic conditions. The three pillars are:

- Support and Information
- Strengthening condition-specific support groups and organisations
- Advocacy and collaboration.

The Trustees agreed the following strategic aims for 2024-25:

- *Maintain focus on income generation through increasing visibility:* the team have improved the visibility of Gene People by a programme of speaking engagements, attending events, responding to consultations and increasing the number of partnerships we are involved in. More details can be found below. As usual, Rare Disease Day was supported by Gene People and our Network

- *Expand diversity of income to include revenues earned through contracts:* Gene People was delighted to undertake contracts with Genomics England Limited and the North West Genomics Medicine Service Alliance

- *Continue to improve and develop the Helpline:* the team have continued to consider ways in which to improve the Helpline and is a member of the Helpline Partnership

- *Hold regular webinars on a range of topics for the Partnership Network:* we held a well-received series of webinars on 'Influencing' which was kindly funded by the BioIndustry Association Rare Disease Industry Group

- *Hold the Gene People Leadership Symposium:* the Symposium took place on 23 Jan 2025 with an audience of condition-specific support groups and charities, healthcare professionals and students, and industry. We are grateful for the secretariat for this event provided by the Association of the British Pharmaceutical Industry

- *Submit responses to consultations with input from our Partnership Network where possible:* Gene People responded to several consultations from NICE, the 10 Year Health Plan and the Law Commission on Disabled Children's Social Care. Volunteer support for this area is being sought

- *Explore ways to both create efficiency in ways of working and better support our individual donors:* after a tendering process supported by Gene People's Trustee for Digital Issues, Donorfy was selected as the new customer relationship management system as it offers ways to increase efficiency and support to donors.

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

We are a member of a range of organisations including:

- Association of the British Pharmaceutical Industry Patient Advisory Council
- Association of Genetic Nurses and Counsellors Equity Diversity and Inclusion Subcommittee
- Disabled Children's Partnership
- Genetic Alliance UK
- Helplines Partnership
- NCVO
- NICE Voluntary and Community Sector Forum
- Prescription Charges Coalition
- Specialised Health Care Alliance
- Vascular Voice Network.

Speaking engagements included Advanced Therapies 2024, a conference at the Royal Society of Medicine and The King's Fund Life Sciences Conference.

In addition, the team attended a variety of events and meetings including the Cell and Gene Collective, Festival of Genomics, I am number 17 launch event, NHS Genomics Summit, Patients as Partners, Public Policy Projects Genomics conference, and the Scottish Strategic Network for Genomic Medicine Patient Involvement Advisory Group.

These activities took place alongside the core business of the Helpline, fundraising and running the charity.
To focus on the helpline briefly, this year the Gene People genetic counsellor led helpline responded to 141 enquiries from individuals, families and professionals dealing with a genetic condition. Our genetic counsellor spent 82 hours on support calls and sent 230 support emails. Enquirers most often contacted the helpline about genetic testing (30%) and for guidance on how to access clinical genetic services (27%). Emotional support was often needed, and all enquiries were managed with sensitivity and care. Enquiries were made about 70 different genetic conditions, with Cystic Fibrosis being the most common condition enquired about. Many other conditions were only enquired about on one occasion each and are extremely rare diseases. Some of the situations managed were complex and required ongoing support from the helpline genetic counsellor

Our ongoing pre and post contact impact surveys showed that 100% of those enquirers who responded found their contact with the service helpful. Some of the feedback received included:

"This is the most wonderful service for families going through the complications a rare genetic disease/s diagnosis brings. Emily was absolutely lovely and I will be back in touch in the future as this is still a very tricky time for our family. Many thanks to the work you do."

"I cannot praise this service enough. I couldn't find anyone to talk to about my fears who I felt could talk it through with me but from an educated perspective, understanding my situation and validating my feelings, until I found this service. Thank you."

"Thanks again for your help last month. It was a pretty excruciating, isolating time and you made it so easy for me to talk freely - I will never forget your kindness to me."

All of this work is not possible without the kind support of generous donors and funders. While the fundraising environment is challenging, Gene People is delighted to have been supported in 2024-25 by:

Amicus Therapeutics
GiveAsYouLive givers
London Marathon Runners
Parexel International
Regular and payroll givers

And all those who prefer to remain anonymous.

Everyone at Gene People is deeply grateful for your support. Together, we are Gene People.

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Lastly, following the adoption of an Environmental policy which includes a public statement of our carbon emissions. Oar emissions for financial year 2023-24 were 2.14 tonnes of CO2e. This is due to the number of train journeys taken in the year and one return flight to speak at a conference.

The team have actively contributed to events and meetings organised by these groups as speaker, chair or facilitator. In addition, Gene People has engaged actively with:

- Association of Genetic Nurses and Counsellors
- European Rare Disease Helpline Network
- Public Policy Projects.

We are proud of the level of work the small team has produced during the year.

Future Plans
The Trustees agreed the following strategic aims for 2025-26:

- Maintain focus on income generation
- Expand number of contracts to further diversify income
- Improve the marketing of the Helpline
- Hold the Gene People Leadership Symposium and increase participation
- Further develop efficiencies using technology, such as optimising the database and AI.

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Financial review

Reserves policy

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. Trustees recognise that the reserves policy has not been achieved and are committed to progressing towards it.

Structure, governance and management

The charity is a company limited by guarantee, as defined by the Companies Act 2006.

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 and revised 30 April 2025. 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.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Ms A Patel	
Dr C Ruff	(Resigned 18 December 2024)
Mr D G Atkins	(Resigned 1 November 2024)
Mr A J Kent OBE	
Mr D Ansel	
Mr S Mitra	
Mr C J Conway	
Dr N V Taverner	
Dr C Hilcenko	(Appointed 18 December 2024)
Dr C Steward	
Mr N L Nicholls	

Recruitment and appointment of trustees

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. New trustees are selected on the basis of their skills and experience and how these will contribute to the charity. They receive an induction that includes onboarding meetings with the Chair and chief executive, as well as access to key documents and previous board minutes.

None of the trustees has any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Organisational structure
The board of trustees meets at least four times a year to review progress and policies via video conferencing. 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.

There are two part-time employees serving as chief executive and genetic counsellor. Other roles are undertaken either as needed on an ad hoc basis or through self-employed consultants.

The trustees' report was approved by the Board of Trustees.

Mr A J Kent OBE
Trustee

Date: 12 December 2025

GENE PEOPLE

INDEPENDENT EXAMINER'S REPORT
TO THE TRUSTEES OF GENE PEOPLE

I report to the trustees on my examination of the financial statements of Gene People (the charity) for the year ended 31 March 2025.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law), you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006.

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

Independent examiner's statement

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 that in any material respect:

1 accounting records were not kept in respect of the charity as required by section 386 of the Companies Act 2006.
2 the financial statements do not accord with those records; or
3 the financial statements do not comply with the accounting requirements of section 396 of the Companies Act 2006 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination; or
4 the financial statements 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 financial statements 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 financial statements to be reached.

Hazel Day
BSc (Hons) FCA DChA
Xeinadin
Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ
Date: 12/12/2025

GENE PEOPLE

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Income from:							
Donations and legacies	2	53,927	(3,000)	50,927	43,894	9,740	53,634
Other trading activities	3	25,708	-	25,708	27,585	-	27,585
Total income		79,635	(3,000)	76,635	71,479	9,740	81,219
Expenditure on:							
Raising funds	4	29,174	100	29,274	19,736	146	19,882
Charitable activities	5	60,607	-	60,607	44,229	4,000	48,229
Total expenditure		89,781	100	89,881	63,965	4,146	68,111
Net income/(expenditure) and movement in funds		(10,146)	(3,100)	(13,246)	7,514	5,594	13,108
Reconciliation of funds:							
Fund balances at 1 April 2024		17,775	5,594	23,369	10,261	-	10,261
Fund balances at 31 March 2025		7,629	2,494	10,123	17,775	5,594	23,369

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

GENE PEOPLE

BALANCE SHEET

AS AT 31 MARCH 2025

	Notes	2025 £	£	2024 £	£
Current assets					
Debtors	**11**	10,683		17,982	
Cash at bank and in hand		4,774		24,669	
		15,457		42,651	
Creditors: amounts falling due within one year	**12**	(5,334)		(19,282)	
Net current assets			10,123		23,369
The funds of the charity					
Restricted income funds	**14**		2,494		5,594
Unrestricted funds	**15**		7,629		17,775
			10,123		23,369

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2025.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 12 December 2025.

Mr A J Kent OBE
Trustee

Company registration number 07564771 (England and Wales)

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

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1 Accounting policies

Charity information

Gene People is a private company limited by guarantee incorporated in England and Wales. The registered office is Nightingale House, 46-48 East Street, Epsom, Surrey, KT17 1HQ, United Kingdom.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "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)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a statement of cash flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

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1 Accounting policies **(Continued)**

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, 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 classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. 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. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.7 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.8 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

2 Income from donations and legacies

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Donations and gifts	53,927	(3,000)	50,927	43,894	9,740	53,634

3 Income from other trading activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Other income	25,708	27,585

4 Expenditure on raising funds

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Fundraising and publicity						
Staff costs	22,862	-	22,862	16,505	-	16,505
Trading costs						
Other trading activities	6,312	100	6,412	3,231	146	3,377
Total costs	29,174	100	29,274	19,736	146	19,882

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

5 Expenditure on charitable activities

	Awareness and education 2025 £	Relief 2025 £	Total 2025 £	Awareness and education 2024 £	Relief 2024 £	Total 2024 £
Direct costs						
IT costs	1,505	-	1,505	1,345	-	1,345
HR Services	550	-	550	660	-	660
Governance	40	-	40	140	-	140
Insurance	1,764	-	1,764	2,356	-	2,356
Bank charges	64	-	64	90	-	90
Sundry	393	-	393	499	-	499
Travel & subsistence	1,145	-	1,145	1,535	-	1,535
Training & development	113	-	113	-	-	-
	5,574	-	5,574	6,625	-	6,625
Share of support and governance costs (see note 6)						
Support	24,082	29,151	53,233	11,960	26,404	38,364
Governance	1,800	-	1,800	3,240	-	3,240
	31,456	29,151	60,607	21,825	26,404	48,229
Analysis by fund						
Unrestricted funds	31,456	29,151	60,607	17,825	26,404	44,229
Restricted funds	-	-	-	4,000	-	4,000
	31,456	29,151	60,607	21,825	26,404	48,229

6 Support costs allocated to activities

	2025 £	2024 £
Staff costs	45,614	38,364
Bookkeeping	3,360	-
Legal & professional	4,259	-
Governance costs	1,800	3,240
	55,033	41,604
Analysed between:		
Awareness and education	25,882	15,200
Relief	29,151	26,404
	55,033	41,604

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

7 Net movement in funds

	2025	2024
	£	£
The net movement in funds is stated after charging/(crediting):		
Fees payable for the independent examination of the charity's financial statements	1,800	3,240

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

9 Employees

The average monthly number of employees during the year was:

	2025	2024
	Number	Number
Fundraising	1	1
Charitable	1	1
Total	2	2

Employment costs	2025	2024
	£	£
Wages and salaries	62,847	50,973
Social security costs	909	-
Other pension costs	4,720	3,896
	68,476	54,869

There were no employees whose annual remuneration was more than £60,000.

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

	2025	2024
	£	£
Aggregate compensation	37,683	27,816

10 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

11 Debtors

Amounts falling due within one year:	2025 £	2024 £
Trade debtors	2,500	7,625
Other debtors	6,263	8,763
Prepayments and accrued income	1,920	1,594
	10,683	17,982

12 Creditors: amounts falling due within one year

	2025 £	2024 £
Other taxation and social security	3,709	2,332
Trade creditors	263	87
Other creditors	160	15,723
Accruals and deferred income	1,202	1,140
	5,334	19,282

13 Retirement benefit schemes

Defined contribution schemes	2025 £	2024 £
Charge to profit or loss in respect of defined contribution schemes	4,720	3,896

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 £4,720 (2024: £3,896). There are no contributions payable to the funds at the year end (2024: £436). The expense and liability have been recognised in unrestricted funds.

14 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2024 £	Incoming resources £	Resources expended £	At 31 March 2025 £
Symposium	5,594	(3,000)	(100)	2,494

14 Restricted funds (Continued)

Previous year:	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
Symposium	-	5,740	(146)	5,594
Helpline	-	4,000	(4,000)	-
	-	9,740	(4,146)	5,594

15 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2024 £	Incoming resources £	Resources expended £	At 31 March 2025 £
General fund	17,775	79,635	(89,781)	7,629

Previous year:	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
General fund	10,261	71,479	(63,965)	17,775

16 Analysis of net assets between funds

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £
At 31 March 2025:			
Current assets/(liabilities)	7,629	2,494	10,123
	7,629	2,494	10,123

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
At 31 March 2024:			
Current assets/(liabilities)	17,775	5,594	23,369
	17,775	5,594	23,369

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

17 Related party transactions

There were no disclosable related party transactions during the year (2024 - none).

18 Company Status

The charity is a private company limited by guarantee. The members of the company are the trustees named on page 1. 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.

Gene People

England & Wales - Charity number 1141583

Accounts

REGISTERED COMPANY NUMBER: 07564771 (England and Wales)
REGISTERED CHARITY NUMBER: 1141583

GENE PEOPLE

the genetic conditions support network

GENE PEOPLE

Unaudited Financial Statements for the Year Ended 31 March 2024

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

Our vision is that anyone affected by a genetic condition receives the support and information they need at the time they need it and in a form they can use.

Together, We are Gene People.

GENE PEOPLE

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

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GENE PEOPLE

Reference and Administrative Details
for the year ended 31 March 2024

TRUSTEES	Dr C Ruff S Mitra A J Kent D Ansel C J Conway Dr N V Taverner D G Atkins (resigned 1.11.24) Ms A Patel (appointed 24.6.23) C A Steward Director (appointed 31.1.24) N L Nicholls Director (appointed 19.3.24)
REGISTERED OFFICE	Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
REGISTERED COMPANY NUMBER	07564771 (England and Wales)
REGISTERED CHARITY NUMBER	1141583
INDEPENDENT EXAMINER	Xeinadin Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
SOLICITORS	Stone King LLP, Boundary House, 91 Charterhouse Street Barbican London EC1M 6HR
BANKERS	Barclays Corporate, Level 27, 1 Churchill Place, London, E14 5HP

Report of the Trustees
for the year ended 31 March 2024

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 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Welcome from the Chair

This year has not been an easy one for many thousands of families living with a rare genetic disease. Finding expert help from the NHS is still a struggle for many. Getting a diagnosis can often be a tortuous process involving frequent hospital visits and appointments with different doctors. Even after a diagnosis getting timely and user-friendly help and support is by no means certain.

For an increasing number of families struggling to navigate the NHS maze Gene People's unique genetic counsellor led helpline provides a lifeline, guiding families and supporting them in finding the help they need. This year we have seen an increase in the complexity of the issues families calling the helpline are facing. Often these are not just medical questions. Finding educational and social support, money worries and the impact on other family members all add to the burden families face. We do what we can to help, and the feedback we receive demonstrates how much this is appreciated, but our resources are limited. With more we could do more!

Our Partnership Network continues to expand. During the year we have run events to train and support the members of the Network increase their effectiveness in helping "their" families and argue the case for greater awareness of their specific needs. This aspect of our work links in with Gene People's policy focused advocacy. During the year we have provided expert input and commentary to an increasing number of Government and NHS consultations, putting the needs and views of our community firmly in the frame for the attention of policy makers and planners.

Our focus is not restricted to Government and the NHS. We also engage with industry through the ABPI, the BIA and with individual companies, and collaborate with charity partners where our priorities overlap. The synergy this generates boosts our impact significantly.

We have seen a growing awareness of the impact on the mental health of those with a rare genetic disorder and on their families during the year. This is a welcome development and is something we have been promoting for some time.

During the year Gene People has undertaken a number of important projects supported by, amongst others, Genomics England, LifeArc and industry sponsors. Details of these are elsewhere in this report. These are tangible proof of our growing impact as a valued partner in the development of effective help and support for all those living with unmet needs arising from a rare genetic condition.

None of this would have been possible without the tireless work of our small staff team, the guidance and support of my fellow trustees and the input from volunteers. My thanks to you all for your dedication and hard work.

I must also thank all those who have supported Gene People financially during the year. We are grateful, for without this nothing would be possible.

Looking ahead, there is much to be done, but I am confident that we will rise to the challenges we face and continue to provide a voice for our community that will be heard by those with the opportunity to bring about the changes we seek.

Alastair Kent OBE FRSA
Chair of Trustees

OBJECTIVES AND ACTIVITIES

Objectives and aims

Gene People has a vision to improve the lives of those affected by a genetic condition through the provision of resources and support both to individuals and families, and to the hundreds of condition-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.

Significant activities

This year was the second year of implementing our strategy. This is available on our website to download on this page: https://genepeople.org.uk/about-us/gene-people-strategy-2022-2025/

Everything Gene People does contributes to achieving three strategic pillars, all of which have been designed to improve the lives of those living with genetic conditions. The three pillars are:

- Support and Information
- Strengthening condition-specific support groups and organisations
- Advocacy and collaboration.

The Trustees had set some specific plans for 2023-24. These were:

- *Focus on income generation through increasing visibility:* while the fundraising environment is extremely challenging we are grateful to those who continue to support our work. We have spoken at and attended a wide range of events including the European Society of Human Genetics conference, the ABPI Conference, and Life Sciences Wales Hub and webinars such as Meddigital.
- *Focus on making the voice of lived experience informing strategic discussions about new treatments and reimbursement:* Gene People maintains a watching brief on NICE appraisals that affect our communities and advocates for lived experience to be included in decision making.
- *Continue to improve and develop the Helpline:* we have been interrogating the data we collect from callers to the helpline with support from LifeArc. A report on these findings will be published in 2025 and will help to inform our next steps in improving this vital service.
- *Hold regular webinars on a range of topics for the Partnership Network:* we began our next series of webinars on 'Influencing' which was kindly supported by the BIA Rare Diseases Industry Group. Unfortunately, the snap General Election meant a slight hiatus in delivering this series and the final webinar of this series will take place in 2025.
- *Hold the Gene People Leadership Symposium:* this took place in November 2023 and is now a firm fixture in Gene People's work.
- *Continue to seek input from the Gene People Partnership Network Advisory Panel:* this continued in 2023 and was paused in 2024 due to capacity issues. This will be reinstated in 2025-26.
- *Submit responses to consultations with input from our Partnership Network where possible:* Gene People has responded to many and varied consultations not limited to those relating to health and social care but also those of importance to charities as legal entities. Our consultation responses can be found on our website under 'National Policy'.

We represent the views of our community at events, and are a member of a range of organisations including:

- Association of the British Pharmaceutical Industry Patient Organisation Forum
- Breaking Down Barriers
- NIHR Genetics NSG Clinical Reference Network – now disbanded
- Disabled Children's Partnership
- Genetic Alliance UK
- Prescription Charges Coalition
- Specialised Health Care Alliance
- NICE Voluntary and Community Sector Forum.

The team have actively contributed to events and meetings organised by these groups as speaker, chair or facilitator. In addition, Gene People has engaged actively with:

- Association of Genetic Nurses and Counsellors
- British Society for Genetic Medicine
- European Rare Disease Helpline Network
- Public Policy Projects
- Roald Dahl Marvellous Children's Charity.

Gene People is now representing the needs of our communities on the ABPI Patient Advisory Council.

These activities took place alongside the core business of the Helpline, fundraising and running the charity.

To focus on the helpline briefly, this year the Gene People genetic counsellor led helpline responded to 156 enquiries from individuals, families and professionals dealing with a genetic condition. Our genetic counsellor spent 71 hours on support calls and sent 248 support emails. Enquirers most often contacted the helpline about genetic testing (28%) and for guidance on how to access clinical genetic services (25%). Emotional support was often needed, and all enquiries were managed with sensitivity and care. Enquiries were made about 97 different genetic conditions, with Cystic Fibrosis being the most common condition enquired about. Many other conditions were only enquired about on one occasion each and are extremely rare diseases. Some of the situations managed were complex and required ongoing support from the helpline genetic counsellor.

Our ongoing pre and post contact impact surveys showed that 100% of those enquirers who responded found their contact with the service helpful. Some of the feedback received included:

"Thank you so much for your email which provided us with lots of clarity and information! It really helped us make sense of everything and think about options moving forward. We think it's amazing the work Gene People and people like yourself do."

"It was a breath of fresh air talking to Emily who was empathic and incredibly informative. I found out more about my child's condition than I gleaned from the geneticist who gave us the diagnosis. Emily is very approachable and as such I felt able to ask questions I had been unable to ask anybody else. She sent through some brilliant links afterwards about my child's condition and said that I can contact her anytime. Invaluable! Thank you so much Gene People"

All of this work is not possible without the kind support of generous donors and funders. While the fundraising environment is challenging, Gene People is delighted to have been supported in 2023-24 by:
- Adelphi Genetics Forum
- Amicus Therapeutics
- The D'Oyly Carte Charitable Trust
- Egetis Therapeutics
- GiveAsYouLive givers
- LifeArc
- London Marathon Runners
- Parexel International
- Regular givers
- UK Bio Industry Association Rare Disease Industry Group
- And all those who prefer to remain anonymous.

Everyone at Gene People is deeply grateful for the support. Together, we are Gene People.

Lastly, following the adoption of an Environmental policy which includes a public statement of our carbon emissions. Our emissions for financial year 2023-24 were 0.83 tonnes of CO2e.

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.

FINANCIAL REVIEW

Reserves

On 31 March 2024, the total monies held by Gene People stood at £23,369 of which restricted funds were £5,594 Free reserves, as defined by the Charity Commission, were £17,775 The trustees reviewed and revised the long-standing reserves policy and are of the opinion it is prudent to target approximately £25,000 in reserve. This reflects the reduction in size of the charity and provides five months of average running costs, which trustees consider to be sufficient to respond to an unexpected emergency or cover costs of an orderly wind-up should that be necessary in the future.

Going concern

Gene People has for the first time in several years achieved a surplus.

However, given the cost of living crisis and the impact this has had on every income stream Gene People has access to, there has been an anticipated further decline in income in 2023-24, 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 2025.

In considering going concern for 2024-25, the trustees have assessed the probability of successfully raising the funding required for the reduced staffing structure. Given the continuing support received from corporates, funders and individuals and the increase in earned income in the current financial year to date, the trustees have currently assessed that the charity it should continue to be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

FUTURE PLANS

The Trustees agreed the following strategic aims for 2024-25:

- Maintain focus on income generation through increasing visibility
- Expand diversity of income to include revenues earned through contracts
- Continue to improve and develop the Helpline
- Hold regular webinars on a range of topics for the Partnership Network
- Hold the Gene People Leadership Symposium
- Submit responses to consultations with input from our Partnership Network where possible
- Explore ways to both create efficiency in ways of working and better support our individual donors.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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.

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.

Decision making

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 1.

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 trustees during the financial year with further two trustees with lived experience of a condition as parents joining during the period following the financial year.

Governance and Management

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.

The board of trustees meets at least four times a year to review progress and policies, with additional virtual meetings via video conferencing. With the 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 presented at each Board meeting and reviewed in-depth at least annually.

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:

- The charity is unable to fundraise sufficient funds and/or in a way that maintains cashflow
- Lack of investment in IT infrastructure
- Inability to meet reserves policy requirements.

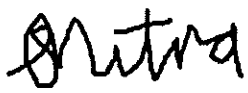
Each of these key risks has a mitigation plan managed by the CEO with support from trustees.

Report of the Trustees
for the year ended 31 March 2024

Trustees have managed expenditure and continue to seek ways to both further manage cost whilst increasing income from a diversity of sources.

The operating environment for Gene People is the same for all charities and Trustees are cognisant of the risks this creates for the charity.

Approved by order of the board of trustees on ....15th December 2024 and signed on its behalf by:



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S Mitra - Trustee

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 2024.

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
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 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.

H.M.Day

Hazel Day BSc (Hons) FCA DChA

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

Date: ....30th December 2024.

GENE PEOPLE

Statement of Financial Activities
for the year ended 31 March 2024

	Notes	Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	43,894	9,740	53,634	108,008
Other trading activities	3	27,585	-	27,585	-
Total		71,479	9,740	81,219	108,008
EXPENDITURE ON					
Raising funds	4	19,736	146	19,882	56,492
Charitable activities	5				
Awareness and education		17,825	4,000	21,825	43,653
Relief		26,404	-	26,404	28,702
Total		63,965	4,146	68,111	128,847
NET INCOME/(EXPENDITURE)		7,514	5,594	13,108	(20,839)
RECONCILIATION OF FUNDS					
Total funds brought forward		10,261	-	10,261	31,100
TOTAL FUNDS CARRIED FORWARD		17,775	5,594	23,369	10,261

The notes form part of these financial statements

Balance Sheet
31 March 2024

	Notes	Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds £
CURRENT ASSETS					
Debtors	10	17,982	-	17,982	7,741
Cash at bank		19,075	5,594	24,669	8,135
		37,057	5,594	42,651	15,876
CREDITORS					
Amounts falling due within one year	11	(19,282)	-	(19,282)	(5,615)
NET CURRENT ASSETS		17,775	5,594	23,369	10,261
TOTAL ASSETS LESS CURRENT LIABILITIES		17,775	5,594	23,369	10,261
NET ASSETS		17,775	5,594	23,369	10,261
FUNDS	12				
Unrestricted funds				17,775	10,261
Restricted funds				5,594	-
TOTAL FUNDS				23,369	10,261

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2024 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 with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 19th December 2024 and were signed on its behalf by:

S Mitra

S Mitra - Trustee

The notes form part of these financial statements

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.

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 t he 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.

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.

continued...

1. ACCOUNTING POLICIES - continued

EXPENDITURE
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.

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 shows slight increase in revenue in 2022-23, the trustees have assessed that the use of going concern is appropriate in preparing these financial statements. The trustees have made this assessment using forecasts and budgets prepared to cover period to March 2024.

In considering going concern for 2023-24, the trustees have assessed the profitability of successfully raising the necessary funding through the 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 assessed that charity should not be so affected by the changes that it should not be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

BASIS OF CONSOLIDATION
The Statement of financial activities (SoFA) and balance sheet consolidated the financial statements of the charity and its subsidiary undertaking. The results of the subsidiary are consolidated on a line by line basis. No separate SoFA has been presented for the charity alone as permitted by section 408 of the Companies Act 2006.

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.

continued...

2. DONATIONS AND LEGACIES

	2024	2023
	£	£
Donations	53,634	108,008

3. OTHER TRADING ACTIVITIES

	2024	2023
	£	£
Charitable activities	27,585	-

4. RAISING FUNDS

OTHER TRADING ACTIVITIES

	2024	2023
	£	£
Staff costs	16,505	39,236
Promotional items	3,377	17,256
	19,882	56,492

5. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 6)	Totals
	£	£	£
Awareness and education	6,625	15,200	21,825
Relief	-	26,404	26,404
	6,625	41,604	48,229

6. SUPPORT COSTS

	Management	Governance costs	Totals
	£	£	£
Awareness and education	11,960	3,240	15,200
Relief	26,404	-	26,404
	38,364	3,240	41,604

7. TRUSTEES' REMUNERATION AND BENEFITS

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

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 March 2024 nor for the year ended 31 March 2023.

continued...

8. STAFF COSTS

Staff costs were as follows:

	2024	2023
	£	£
Wages and salaries	50,973	84,567
Social security costs	-	4,367
Other pension costs	3,896	5,920
	54,869	94,854

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

	2024	2023
Fundraising	1	1
Charitable	1	1
	2	2

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

	2024	2023
£60,001 - £70,000	-	1

The aggregate employee benefits paid to key management personnel were £32,347 (2023: £69,015).

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund	Restricted funds	Total funds
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations and legacies	106,008	2,000	108,008
EXPENDITURE ON			
Raising funds	56,492	-	56,492
Charitable activities			
Awareness and education	34,938	8,715	43,653
Relief	28,702	-	28,702
Total	120,132	8,715	128,847
NET INCOME/(EXPENDITURE)	(14,124)	(6,715)	(20,839)
RECONCILIATION OF FUNDS			
Total funds brought forward	24,385	6,715	31,100
TOTAL FUNDS CARRIED FORWARD	10,261	-	10,261

continued...

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade debtors	7,625	-
Other debtors	11	11
VAT	6,252	6,252
Prepayments and accrued income	4,094	1,478
	17,982	7,741

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade creditors	87	735
Social security and other taxes	2,332	1,709
Other creditors	640	201
Accruals and deferred income	16,223	2,970
	19,282	5,615

12. MOVEMENT IN FUNDS

	At 1.4.23	Net movement in funds	At 31.3.24
	£	£	£
Unrestricted funds			
General fund	10,261	7,514	17,775
Restricted funds			
Symposium	-	5,594	5,594
TOTAL FUNDS	10,261	13,108	23,369

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	71,479	(63,965)	7,514
Restricted funds			
Symposium	5,740	(146)	5,594
GDUK Helpline	4,000	(4,000)	-
	9,740	(4,146)	5,594
TOTAL FUNDS	81,219	(68,111)	13,108

continued...

12. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.4.22 £	Net movement in funds £	At 31.3.23 £
Unrestricted funds			
General fund	24,385	(14,124)	10,261
Restricted funds			
Roald Dahl's MCC	6,715	(6,715)	-
TOTAL FUNDS	31,100	(20,839)	10,261

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	106,008	(120,132)	(14,124)
Restricted funds			
Symposium	2,000	(2,000)	-
Roald Dahl's MCC	-	(6,715)	(6,715)
	2,000	(8,715)	(6,715)
TOTAL FUNDS	108,008	(128,847)	(20,839)

13. 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 £3,986 (2023: £5,920). Contributions totalling £436 (2023: £272) were payable to the funds at the year end and are included in creditors. The expense and liability have been recognised in unrestricted funds.

14. RELATED PARTY DISCLOSURES

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

continued...

15. COMPANY STATUS

The charity is a private company limited by guarantee. The members of the company are the trustees named on page 1. 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.

Gene People

England & Wales - Charity number 1141583

Accounts

REGISTERED COMPANY NUMBER: 07564771 (England and Wales)
REGISTERED CHARITY NUMBER: 1141583

GENE PEOPLE

Unaudited Financial Statements for the Year Ended 31 March 2023

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

GENE PEOPLE

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for the year ended 31 March 2023

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GENE PEOPLE

Reference and Administrative Details
for the year ended 31 March 2023

TRUSTEES	Ms R L Frankel (resigned 21.12.22) Dr C Ruff S Mitra A J Kent Ms E Fernandez-Gonzalez (resigned 15.8.22) D Ansel C J Conway Dr N V Taverner D G Atkins Ms A Patel (appointed 24.6.23)
REGISTERED OFFICE	Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
REGISTERED COMPANY NUMBER	07564771 (England and Wales)
REGISTERED CHARITY NUMBER	1141583
INDEPENDENT EXAMINER	Tudor John Limited Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
SOLICITORS	Stone King LLP, Boundary House, 91 Charterhouse Street, Barbican, London, EC1M 6HR
BANKERS	Barclays Corporate, Level 27, 1 Churchill Place, London, E14 5HP

Report of the Trustees
for the year ended 31 March 2023

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 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Welcome from the Chair

2022-23 has been a challenging year for Gene People and the community of patients and families living with rare genetic conditions we serve and support. Emerging from the pandemic to face a cost-of-living crisis and a NHS struggling to deal with a huge backlog of patients awaiting treatment put huge pressure on the charity, but I am proud to say that our team rose to the challenge. I commend their dedication and expertise.

Our unique genetic counsellor led helpline supported over 150 families with complex needs, who were struggling to get a diagnosis, understand what it means and find the help they needed from the NHS or other statutory agencies, and the professionals supporting them. Feedback from callers shows just how valuable the help we provide is.

Our Partnership Network continues to grow and counts over 140 support groups as members. We have laid on a range of events and activities designed to enable them to build their ability and capacity to support patients and families, culminating in a hugely successful Symposium last Autumn - an event we will repeat in 2023.

Elsewhere our reach continues to extend. We are collaborating with the ABPI, the BIA, LifeArc and a range of other bodies. We have contributed thoughtful and well received inputs to consultations by Government, the NHS and other bodies, demonstrating Gene People's impact and the importance of the message we send - "speaking truth to power" - to those making policy and delivering care and support to those in need.

We receive no government funding. We rely on the generosity of donors to continue to provide vital support to patients and families, and I am grateful to everyone who has helped us. Thank you all!

Alastair Kent OBE FRSA
Chair of Trustees

OBJECTIVES AND ACTIVITIES
Objectives and aims
Gene People has a vision to improve the lives of those affected by a genetic condition through the provision of resources and support both to individuals and families, and to the hundreds of condition-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.

OBJECTIVES AND ACTIVITIES

Significant activities

A key activity for 2022-23 was creating and publishing our new Strategy. This is available on our website to download on this page: https://genepeople.org.uk/about-us/gene-people-strategy-2022-2025/

Everything Gene People does now falls into three strategic pillars, all of which have been designed to improve the lives of those living with genetic conditions. The three pillars are:

- Support and Information
- Strengthening condition-specific support groups and organisations
- Advocacy and collaboration.

The Trustees had set some specific plans for 2022-23. These were:

- *Develop and implement a UK-wide marketing strategy for the Helpline, particularly through social media:* we piloted some advertisements on social media, which, sadly, prompted a substantial amount of 'trolling' to the degree that this activity was stopped. We have yet to secure sufficient funding to undertake the UK-wide marketing we would like for the Helpline.
- *Launch the Helpline translation service to the public:* we have regularly posted messages in languages other than English to notify people that we have a translation service available. We are grateful to LanguageLine for being our translation partner.
- *Publish refreshed Directory of Condition-Specific Groups and Organisations:* due to staff capacity this is currently on pause.
- *Hold regular webinars on a range of topics for the Partnership Network:* monthly webinars on a host of topics were held for the Partnership Network. Topics included practical items like data protection, communications and fundraising. We are very grateful to the BIA RDIG for their sponsorship of this series during the year.
- *Hold the Gene People Leadership Symposium:* the first Symposium since 2018 was held online on two separate half-days. It included the first ever Gene People Awards. Feedback was overwhelmingly positive with an audience spanning each part of the genetic conditions' ecosystem from condition-specific support groups to NHS genetic counsellors to the medicines industry. This would not have been possible without the kind support from The Adelphi Genetics Forum, Ipsen, Global Blood Therapeutics and PTC Therapeutics.
- *Launch the Gene People Partnership Network Advisory Panel:* this has been created and includes small to medium sized organisations, all bringing their own perspective on the work of Gene People.
- *Submit responses to consultations with input from our Partnership Network where possible:* all the Gene People submissions can be seen on this page on our website: https://genepeople.org.uk/about-us/national-policy/ We are particularly proud of the collaboration with sister charities, industry partners and NHS colleagues in response to the Mental Health and Wellbeing Plan, which stimulated additional conversations with policy makers.
- *Continue recruitment to the Gene People Corporate Connection and develop its programme of work:* we are grateful to the first members of the Corporate Connection, Ipsen and PTC Therapeutics.

We represent the views of our community at events, and are a member of a range of organisations including:

- Association of the British Pharmaceutical Industry Patient Organisation Forum
- Breaking Down Barriers
- NIHR Genetics NSG Clinical Reference Network
- Disabled Children's Partnership
- Genetic Alliance UK
- Steering Group of Pharma Insight Group
- Prescription Charges Coalition
- Specialised Health Care Alliance.

> "Honestly you've been so helpful, more than any other doctor or optician I've spoken to" – Helpline enquirer

The team have actively contributed to events and meetings organised by these groups as speaker, chair or facilitator. In addition, Gene People has engaged actively with:

- Association of Genetic Nurses and Counsellors
- British Society for Genetic Medicine
- European Rare Disease Helpline Network
- GOSH
- Manchester University

OBJECTIVES AND ACTIVITIES

- Nuffield Council on Bioethics
- Public Policy Projects
- Rare Bone Disease Summit
- Roald Dahl Marvellous Children's Charity
- Westminster Health Forum.

These activities took place alongside the core business of the Helpline, fundraising and running the charity.
All of this work is not possible without the kind support of generous donors and funders. While the fundraising environment is challenging , Gene People is delighted to have been supported in 2022-23 by:

- Adelphi Genetics Forum
- Amicus Therapeutics
- Arnold Clark
- Edward Gostling Foundation
- GiveAsYouLive givers
- Global Blood Therapeutics
- Ipsen
- London Marathon Runners
- PTC Therapeutics
- Regular givers
- UK Bio Industry Association Rare Disease Industry Group
- And all those who prefer to remain anonymous.

> "I appreciated the speed of response and the offer of a phone call to discuss my concerns. I really didn't know what to do or who to turn to and am so grateful that this service was available. A real lifeline."
> - Helpline enquirer

Everyone at Gene People is deeply grateful for the support. Together, we are Gene People.

Lastly, following the adoption of an Environmental policy which includes a public statement of our carbon emissions. Our emissions for financial year 2022-23 were 1.04 tonnes of CO2e.

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.

FINANCIAL REVIEW

Reserves

On 31 March 2023, the total monies held by Gene People stood at £10,261 of which restricted funds were £Nil. Free reserves, as defined by the Charity Commission, were £10,261. The trustees reviewed and revised the long-standing reserves policy and are of the opinion it is prudent to target approximately £25,000 in reserve. This reflects the reduction in size of the charity and provides five months of average running costs, which trustees consider to be sufficient to respond to an unexpected emergency or cover costs of an orderly wind-up should that be necessary in the future. It is a goal to achieve the target reserves figure in the next two years.

Going concern

The accounts show the anticipated further decline in income in 2022-23 following the restructure, 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 2024.

In considering going concern for 2022-23, the trustees have assessed the probability of successfully raising the funding required for the reduced staffing structure. Given the support received from corporates, funders and individuals so far, the trustees have currently assessed that the charity it should continue to be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

FUTURE PLANS

The Trustees agreed the following strategic aims for 2023-24:

- Focus on income generation through increasing visibility
- Focus on making the voice of lived experience informing strategic discussions about new treatments and reimbursement
- Continue to improve and develop the Helpline
- Hold regular webinars on a range of topics for the Partnership Network
- Hold the Gene People Leadership Symposium
- Continue to seek input from the Gene People Partnership Network Advisory Panel
- Submit responses to consultations with input from our Partnership Network where possible.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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.

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.

Decision making

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 1.

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 one trustee during the financial year with a trustee with lived experience of a condition joining during the period following the financial year.

Governance and Management

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.

The board of trustees meets at least four times a year to review progress and policies, with additional virtual meetings via video conferencing. With the 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.

STRUCTURE, GOVERNANCE AND MANAGEMENT

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:

- The charity is unable to fundraise sufficient funds and/or in a way that maintains cashflow
- Lack of investment in IT infrastructure
- Inability to meet reserves policy requirements.

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

- Covid-19 and cost of living 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, and the cost of living crisis. Covid-19 is an especially constant and present challenge to many in our community, who face health issues impacted by Covid-19. The cost of living crisis is impacting how people and companies are able to support Gene People and our work.

Trustees have managed expenditure and continue to seek ways to both further manage cost whilst increasing income from a diversity of sources.

The operating environment for Gene People is the same for all charities and Trustees are cognisant of the risks this creates for the charity.

Approved by order of the board of trustees on .....13/12/2023..... and signed on its behalf by:

.....
A J Kent - Trustee

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 2023.

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
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 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.

H.E. Day

Hazel Day BSc (Hons) FCA DChA

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

Date: 15th December 2023

GENE PEOPLE

Statement of Financial Activities
for the year ended 31 March 2023

	Notes	Unrestricted fund £	Restricted funds £	2023 Total funds £	2022 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	106,008	2,000	108,008	104,591
EXPENDITURE ON					
Raising funds	3	56,492	-	56,492	76,537
Charitable activities	4				
Awareness and education		34,938	8,715	43,653	37,861
Relief		28,702	-	28,702	33,802
Total		120,132	8,715	128,847	148,200
NET INCOME/(EXPENDITURE)		(14,124)	(6,715)	(20,839)	(43,609)
RECONCILIATION OF FUNDS					
Total funds brought forward		24,385	6,715	31,100	74,709
TOTAL FUNDS CARRIED FORWARD		10,261	-	10,261	31,100

The notes form part of these financial statements

Balance Sheet
31 March 2023

	Notes	Unrestricted fund £	Restricted funds £	2023 Total funds £	2022 Total funds £
CURRENT ASSETS					
Debtors	9	7,741	-	7,741	18,773
Cash at bank		8,135	-	8,135	29,155
		15,876	-	15,876	47,928
CREDITORS					
Amounts falling due within one year	10	(5,615)	-	(5,615)	(16,828)
NET CURRENT ASSETS		10,261	-	10,261	31,100
TOTAL ASSETS LESS CURRENT LIABILITIES		10,261	-	10,261	31,100
NET ASSETS		10,261	-	10,261	31,100
FUNDS	11				
Unrestricted funds				10,261	24,385
Restricted funds				-	6,715
TOTAL FUNDS				10,261	31,100

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2023 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 with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on

.....13/12/2023..... and were signed on its behalf by:

.....
A J Kent - Trustee

The notes form part of these financial statements

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.

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 t he 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.

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.

continued...

1. ACCOUNTING POLICIES - continued

EXPENDITURE
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.

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 slight increase in revenue in 2022-23, the trustees have assessed that the use of going concern is appropriate in preparing these financial statements. The trustees have made this assessment using forecasts and budgets prepared to cover period to March 2024.

In considering going concern for 2023-24, the trustees have assessed the profitability of successfully raising the necessary funding through the 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 assessed that charity should not be so affected by the changes that it should not be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

BASIS OF CONSOLIDATION
The Statement of financial activities (SoFA) and balance sheet consolidated the financial statements of the charity and its subsidiary undertaking. The results of the subsidiary are consolidated on a line by line basis. No separate SoFA has been presented for the charity alone as permitted by section 408 of the Companies Act 2006.

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.

continued...

2. DONATIONS AND LEGACIES

	2023	2022
	£	£
Donations	108,008	104,591

3. RAISING FUNDS

OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Staff costs	39,236	62,072
Promotional items	17,256	14,465
	56,492	76,537

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 5)	Totals
	£	£	£
Awareness and education	8,983	34,670	43,653
Relief	-	28,702	28,702
	8,983	63,372	72,355

5. SUPPORT COSTS

	Management	Governance costs	Totals
	£	£	£
Awareness and education	26,915	7,755	34,670
Relief	28,702	-	28,702
	55,617	7,755	63,372

6. TRUSTEES' REMUNERATION AND BENEFITS

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

TRUSTEES' EXPENSES

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

continued...

7. STAFF COSTS

Staff costs were as follows:

	2023	2022
	£	£
Wages and salaries	84,567	105,056
Social security costs	4,367	5,784
Other pension costs	5,920	6,976
	94,854	117,815

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

	2023	2022
Fundraising	1	1
Charitable	1	2
	2	3

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

	2023	2022
£60,001 - £70,000	1	1

The aggregate employee benefits paid to key management personnel were £69,015 (2022: £65,890).

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund	Restricted funds	Total funds
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations and legacies	94,591	10,000	104,591
EXPENDITURE ON			
Raising funds	76,537	-	76,537
Charitable activities			
Awareness and education	18,861	19,000	37,861
Relief	33,802	-	33,802
Total	129,200	19,000	148,200
NET INCOME/(EXPENDITURE)	(34,609)	(9,000)	(43,609)
RECONCILIATION OF FUNDS			
Total funds brought forward	58,994	15,715	74,709
TOTAL FUNDS CARRIED FORWARD	24,385	6,715	31,100

continued...

9. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Trade debtors	-	10,185
Other debtors	11	11
VAT	6,252	6,252
Prepayments and accrued income	1,478	2,325
	7,741	18,773

10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Trade creditors	735	1,181
Social security and other taxes	1,709	3,057
Other creditors	201	9,530
Accruals and deferred income	2,970	3,060
	5,615	16,828

11. MOVEMENT IN FUNDS

	At 1.4.22	Net movement in funds	At 31.3.23
	£	£	£
Unrestricted funds			
General fund	24,385	(14,124)	10,261
Restricted funds			
Roald Dahl's MCC	6,715	(6,715)	-
TOTAL FUNDS	31,100	(20,839)	10,261

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	106,008	(120,132)	(14,124)
Restricted funds			
Symposium	2,000	(2,000)	-
Roald Dahl's MCC	-	(6,715)	(6,715)
	2,000	(8,715)	(6,715)
TOTAL FUNDS	108,008	(128,847)	(20,839)

continued...

11. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.4.21 £	Net movement in funds £	At 31.3.22 £
Unrestricted funds			
General fund	58,994	(34,609)	24,385
Restricted funds			
Roald Dahl's MCC	6,715	-	6,715
GDUK Helpline	9,000	(9,000)	-
	15,715	(9,000)	6,715
TOTAL FUNDS	74,709	(43,609)	31,100

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	94,591	(129,200)	(34,609)
Restricted funds			
GDUK Helpline	10,000	(19,000)	(9,000)
TOTAL FUNDS	104,591	(148,200)	(43,609)

12. 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 £5,920 (2022: £6,976). Contributions totalling £272 (2022: £835) were payable to the funds at the year end and are included in creditors. The expense and liability have been recognised in unrestricted funds.

13. RELATED PARTY DISCLOSURES

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

continued...

14. COMPANY STATUS

The charity is a private company limited by guarantee. The members of the company are the trustees named on page 1. 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.

Gene People

England & Wales - Charity number 1141583

Accounts

REGISTERED COMPANY NUMBER: 07564771 (England and Wales)
REGISTERED CHARITY NUMBER: 1141583

GENE PEOPLE

Unaudited Financial Statements for the Year Ended 31 March 2022

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

GENE PEOPLE

Contents of the Financial Statements for the year ended 31 March 2022

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GENE PEOPLE

Reference and Administrative Details
for the year ended 31 March 2022

TRUSTEES	Ms R L Frankel Ms J E Lucas (resigned 29.11.21) Dr C Ruff Mr S Mitra Dr E Miller (resigned 15.11.21) Mr A J Kent Ms E Fernandez-Gonzalez (appointed 11.3.22) (resigned 15.8.22) Mr D Ansel (appointed 10.3.22) Mr C J Conway (appointed 31.3.22) Dr N V Taverner (appointed 19.3.22) Dr D G Atkins (appointed 22.3.22)
REGISTERED OFFICE	Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
REGISTERED COMPANY NUMBER	07564771 (England and Wales)
REGISTERED CHARITY NUMBER	1141583
INDEPENDENT EXAMINER	Tudor John Limited 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

Welcome from the Chair

Re-imagining a charity in the middle of a pandemic is not an obvious course of action. Pushing ahead with the demerger of Genetic Disorders UK from Jeans for Genes and PID UK might have sensibly been put on the back burner until things quietened down. But we had a vision. We knew that the needs of people living with the daily consequences of genetic conditions would not wait until "things quietened down".

So, we decided to act. Gene People is the result.

Our focus is relentlessly on the needs of patients and families. We work with them directly through our unique genetic counsellor-led helpline, where we are in daily contact with people struggling to get or understand a diagnosis. We work closely with colleagues in the NHS and elsewhere to try and ensure that families coming to terms with a genetic condition can make plans on how to face the future and are aware of the help they can access.

Families often turn to support groups for that help. These groups are an invaluable source of expert knowledge, usually based on the experience of affected families. Many of these groups share common problems – how to organize? Where do I go to find out how to access expert help and support? How can I fundraise?

Gene People has initiated a capacity building programme for the partners in the Partnership Network. Workshops and shared learning opportunities have been initiated. This programme will grow as more resources become available.

Gene People has reached out to policy makers, politicians, the NHS and industry to make them aware of the needs and opinions of our community. We have responded to a range of consultations, working in cross-sectoral partnerships, making direct inputs where opportunities have arisen and presenting at national and international meetings – always prioritizing the needs and opinions drawn directly from our engagement with our partners and those they represent.

We are making an impact. We will continue to do so, and we welcome collaboration and support from all those who share our vision.

Finally, I must pay tribute to our fantastic staff, and thank my trustee colleagues for their hard work, their commitment and their insights, without which the decision we made a year ago would not have brought us to the position we are in today, facing a future with growing confidence and a clear vision of how we can make a difference.

Alastair Kent OBE FRSA
Chair of Trustees

GENE PEOPLE

"It is absolutely lovely that you call people back again to see how they are doing and I really appreciate it. It's a fantastic service."
- Helpline caller

174 enquirers contacted the Helpline

5,507 Twitter followers

5,573 Facebook followers

134 Partnership Network members

Report of the Board of Trustees for the year ended 31 March 2022

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 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Our Aims and Objectives

Gene People was founded in 2011 as Genetic Disorders UK 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.

Activities

Trustees were keen that the financial year 2021-22 saw the continuation of the **change programme** begun in the previous year. The name of the charity changed in June 2021 to Gene People and included a new look and feel for the charity. The charity was restructured to be leaner and more agile. There were more changes after the period of this report with the team currently consisting of the full-time chief executive and the part time genetic counsellor, with outsourced input on IT, the website, communications and accountancy.

A major part of the change programme was to create a new strategy for the coming three years. The team met with the Chair of Trustees to begin developing the strategy within the financial year. The strategy was reviewed and endorsed by the Partnership Network Advisory Panel and the Board. It is available on the website at https://genepeople.org.uk/about-us/gene-people-strategy-2022-2025/ .

Using LanguageLine
The Helpline was contacted by a non-UK patient organisation that was helping a family from Ukraine that was moving to the UK. We were able to use LanguageLine to speak with the family and suggest the best next steps so that treatment was maintained for the family member with a genetic condition.

Reaching those who need our support and information is a key priority for Gene People. To increase the **accessibility of the Helpline**, we partnered with LanguageLine, giving callers live access to translation for over 200 languages. This facility has improved the experience of enquirers to the Helpline and means that we can respond to calls even if the enquirer's first language is not English.

There were 174 enquiries during the year. The work involved in responding to those enquiries included sending 268 support emails and making 156 calls taking 72.5 hours on these calls. Enquirers asked about 89 different conditions with the majority only asked about once.

We undertook social media campaigns to highlight the availability of the Helpline on Twitter and Facebook. The learnings from these campaigns will be analysed and applied to future activity.
There is still more to be done to make the Helpline accessible to all. This will form part of our plans for the future.

The team conducted by the University of Exeter, who had conducted an external evaluation of the impact of the Helpline in 2020, presented the findings of that evaluation at the World Congress on Genetic Counselling The Gene People Genetic Counsellor also participated in this international event.

"Following all your help and guidance below (it was some time ago now) I pushed for the saliva sample and a few days ago finally got the results… my son has a microdeletion." - feedback from a Helpline enquirer

Updating and improving the resources on the website, especially the **Directory of Condition-Specific Groups and Charities** is ongoing. We secured funding from Roche to undertake this, without which we would not be able to progress this much needed work. The web build for the Directory has been completed, partner organisations have been invited to send their information for inclusion, and volunteers have been researching organisations that could be listed. It is anticipated that the Directory will launch in the final quarter of 2022-23.

A workshop was held with representatives from the Partnership Network to discuss potential new resources for the Gene People community. A list was compiled and will feed into plans for coming years. We are grateful for this positive input from our Partnership Network. This input ensures that we are responding to the needs of those we seek to support, and that the help we provide is both relevant and accessible.

The **Gene People Partnership Network** is vital to our work. It is free for condition-specific support groups to join and at the end of the financial year stood at 134.

In line with our strategic aims, we offered regular online events on a variety of topics and secured funding for the programme from the BIA Rare Disease Industry Group, for which we are grateful.

Our partnership with The National Council for Voluntary Organisations (NCVO) was launched for the Partnership Network, which gives organisations a discount on their first year of membership. This gives a host of benefits to organisations, including discounts on suppliers and draft documentation saving the partners in the Partnership Network money and time.

We wanted to involve partners in shaping Gene People's services and future. We established our Partnership Network Advisory Panel and recruited volunteers to serve on this from representatives of the support groups which comprise the network.

Work started on the first Leadership Symposium since 2018 with input from Trustees and the Network.

Gene People is in the privileged position to be able to seek the views from the Partnership Network and reflect those from Helpline enquirers when participating in consultations on **national policy**. Our responses to consultations are available on our website in alignment with our values of being transparent and collaborative: https://genepeople.org.uk/about-us/national-policy/.

We represent the views of our community at events, and are a member of a range of organisations including:

- Association of the British Pharmaceutical Industry Patient Organisation Forum
- Breaking Down Barriers
- National Institute of Health Research Clinical Reference Network: Genetics National Speciality Group
- Disabled Children's Partnership
- Genetic Alliance UK
- Steering Group of Pharma Insight Group
- Prescription Charges Coalition
- Specialised Health Care Alliance.

The team have actively contributed to events and meetings organised by these groups as speaker, chair or facilitator. In addition, Gene People has engaged actively with:

- European Rare Disease Helpline Network
- The Guide Dogs Family Team
- Liverpool Centre for Genomic Medicine
- MAP Bio HTA Conference
- Public Policy Projects: Diagnosis
- Public Policy Projects: Gene and Cell Therapies
- Rare Bone Disease Summit
- Westminster Health Forum

All of this work is not possible without the kind support of generous donors and funders. A new fundraising strategy with a focus on building long-term relationships with supporters was devised and put in place, starting with the launch of Gene People Corporate Connections for the pharmaceutical and allied industries.

Everyone at Gene People would like to take this opportunity to thank those who supported us in 2021-22:

- Alexion Pharma GmbH
- Amicus Therapeutics
- Appeal donors
- D'Oyly Carte Charitable Trust
- Great North Run and London Marathon Runners
- Hospital Saturday Fund and all the Big Give donors
- Orchard Therapeutics
- Regular givers
- Roche
- Spirit Health
- Takeda
- UK Bio Industry Association Rare Disease Industry Group
- And all those who prefer to remain anonymous.

Together, we are Gene People.

Lastly, recognising that the climate crisis will impact everyone, including the genetic conditions community Gene People serves, the Trustees agreed a new **Environmental policy** which includes a public statement in our annual report. The policy states:

Gene People acknowledges the connection between the climate and other environmental crises, as well as the major damage being caused to the world's natural eco-systems.

Gene People therefore recognises its responsibility to reduce its carbon and environmental footprints and formally commits itself to being an environmentally responsible charity.

Gene People uses a recognised online carbon footprint calculator which shows the carbon footprint for the charity was 1.53 tonnes of CO2e.

Future Plans

The Trustees agreed the following strategic aims for 2022-23:

- Develop and implement a UK-wide marketing strategy for the Helpline, particularly through social media
- Launch the Helpline translation service to the public
- Publish refreshed Directory of Condition-Specific Groups and Organisations
- Hold regular webinars on a range of topics for the Partnership Network
- Hold the Gene People Leadership Symposium
- Launch the Gene People Partnership Network Advisory Panel
- Submit responses to consultations with input from our Partnership Network where possible
- Continue recruitment to the Gene People Corporate Connection and develop its programme of work.

These strategic aims will be supported by work on the two enablers: income generation and infrastructure.

Financial review 2021-22

- Reserves

On 31 March 2022, the total monies held by Gene People stood at £31,100 of which restricted funds were £6,715. Free reserves, as defined by the Charity Commission, were £24,385. Due to the restructure, the trustees reviewed and revised the long-standing reserves policy and are of the opinion it is prudent to target approximately £70,000 in reserve. This reflects the reduction in size of the charity and provides five months of average running costs, which trustees consider to be sufficient to respond to an unexpected emergency or cover costs of an orderly wind-up should that be necessary in the future.

- Going concern

The accounts show the anticipated further decline in income in 2021-22 following the restructure, 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 2023.

In considering going concern for 2022-23, 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 affected by the changes that it should not be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

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 1.

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 three of the 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, with additional virtual meetings via video conferencing. With the 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:
- The charity is unable to fundraise sufficient funds and/or in a way that maintains cashflow
- Lack of investment in IT infrastructure
- Inability to meet reserves policy requirements.

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

- Covid-19 and cost of living 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, and the cost of living crisis.

Trustees have managed expenditure and continue to seek ways to both further manage cost whilst increasing income from a diversity of sources.

The operating environment for Gene People is the same for all charities and Trustees are cognisant of the risks this creates for the charity.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on ..16th..December..2022..... and signed on the board's behalf by:

.....

A J Kent - Trustee

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 2022.

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
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 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.

H.M Day

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

Date: 14th December 2022

GENE PEOPLE

Statement of Financial Activities
for the year ended 31 March 2022

	Notes	Unrestricted fund £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	94,591	10,000	104,591	156,990
Other trading activities	3	-	-	-	513,430
Investment income	4	-	-	-	808
Total		94,591	10,000	104,591	671,228
EXPENDITURE ON					
Raising funds	5	76,537	-	76,537	377,848
Charitable activities	6				
Awareness and education		18,861	19,000	37,861	221,775
Relief		33,802	-	33,802	81,665
Grants awarded		-	-	-	207,482
Total		129,200	19,000	148,200	888,770
NET INCOME/(EXPENDITURE)		(34,609)	(9,000)	(43,609)	(217,542)
RECONCILIATION OF FUNDS					
Total funds brought forward		58,994	15,715	74,709	292,251
TOTAL FUNDS CARRIED FORWARD		24,385	6,715	31,100	74,709

Balance Sheet
31 March 2022

	Notes	Unrestricted fund £	Restricted funds £	2022 Total funds £	2021 Total funds £
CURRENT ASSETS					
Debtors	13	18,773	-	18,773	15,819
Cash at bank		22,440	6,715	29,155	224,465
		41,213	6,715	47,928	240,284
CREDITORS					
Amounts falling due within one year	14	(16,828)	-	(16,828)	(165,575)
NET CURRENT ASSETS		24,385	6,715	31,100	74,709
TOTAL ASSETS LESS CURRENT LIABILITIES		24,385	6,715	31,100	74,709
NET ASSETS		24,385	6,715	31,100	74,709
FUNDS	15				
Unrestricted funds				24,385	58,994
Restricted funds				6,715	15,715
TOTAL FUNDS				31,100	74,709

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2022 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 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 16th December 2022. and were signed on its behalf by:

A J Kent - Trustee

The notes form part of these financial statements

GENE PEOPLE

Cash Flow Statement
for the year ended 31 March 2022

	Notes	2022 £	2021 £
Cash flows from operating activities			
Cash generated from operations	1	(195,310)	(70,187)
Net cash used in operating activities		(195,310)	(70,187)
Cash flows from investing activities			
Sale of tangible fixed assets		-	(1)
Sale of fixed asset investments		-	1
Interest received		-	808
Net cash provided by investing activities		-	808
Change in cash and cash equivalents in the reporting period		(195,310)	(69,379)
Cash and cash equivalents at the beginning of the reporting period		224,465	293,844
Cash and cash equivalents at the end of the reporting period		29,155	224,465

The notes form part of these financial statements

Notes to the Cash Flow Statement for the year ended 31 March 2022

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

	2022 £	2021 £
Net expenditure for the reporting period (as per the Statement of Financial Activities)	(43,609)	(217,542)
Adjustments for:		
Loss on disposal of fixed assets	-	1
Interest received	-	(808)
Movement in subsidiary company balance	-	20,866
(Increase)/decrease in debtors	(2,954)	56,789
(Decrease)/increase in creditors	(148,747)	70,507
Net cash used in operations	(195,310)	(70,187)

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.4.21 £	Cash flow £	At 31.3.22 £
Net cash			
Cash at bank	224,465	(195,310)	29,155
	224,465	(195,310)	29,155
Total	224,465	(195,310)	29,155

The notes form part of these financial statements

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.

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.

continued...

1. ACCOUNTING POLICIES - continued

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.

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 2021-22 following the restructure, 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 2023.

In considering going concern for 2022-23, 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 affected by the changes that it should not be regarded as a going concern and therefore the financial statements include no adjustment in this respect.

continued...

BASIS OF CONSOLIDATION

The Statement of financial activities (SoFA) and balance sheet consolidated the financial statements of the charity and its subsidiary undertaking. The results of the subsidiary are consolidated on a line by line basis. No separate SoFA has been presented for the charity alone as permitted by section 408 of the Companies Act 2006.

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

	2022	2021
	£	£
Donations	104,591	156,990

3. OTHER TRADING ACTIVITIES

	2022	2021
	£	£
Charitable activities	-	513,430

4. INVESTMENT INCOME

	2022	2021
	£	£
Deposit account interest	-	808

5. RAISING FUNDS

OTHER TRADING ACTIVITIES

	2022	2021
	£	£
Jeans for Genes Day	-	223,915
Staff costs	62,072	112,052
Promotional items	14,465	41,731
Corporate partnerships: Licensing and sponsorship	-	150
	76,537	377,848

6. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 8)	Totals
	£	£	£
Awareness and education	7,737	30,124	37,861
Relief	-	33,802	33,802
	7,737	63,926	71,663

continued...

7. GRANTS PAYABLE

	2022	2021
	£	£
Grants awarded	-	207,482

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

	2022	2021
	£	£
Dingley's Promise	-	3,416
FOP Friends	-	3,416
Jessie May	-	3,416
Kleefstra Syndrome	-	3,416
Newlife (Foundation for Disabled Children)	-	3,416
Glasgow Children's Hospital Charity	-	3,416
Immunodeficiency	-	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
	-	205,095

8. SUPPORT COSTS

	Management	Governance costs	
	Totals		
	£	£	£
Awareness and education	21,942	8,182	30,124
Relief	33,802	-	33,802
	55,744	8,182	63,926

9. NET INCOME/(EXPENDITURE)

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

	2022	2021
	£	£
Auditors' remuneration	-	2,250
Deficit on disposal of fixed assets	-	1

continued...

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2022 nor for the year ended 31 March 2021.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 March 2022 nor for the year ended 31 March 2021.

11. STAFF COSTS

Staff costs were as follows:

	2022	2021
	£	£
Wages and salaries	105,056	270,789
Social security costs	5,784	15,778
Other pension costs	6,976	12,698
	117,815	383,010

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

	2022	2021
Fundraising	1	1
Charitable	2	2
Administration/ management	-	1
	3	4

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

	2022	2021
£60,001 - £70,000	1	-
£100,001 - £200,000	-	1
	1	1

The aggregate employee benefits paid to key management personnel were £65,890 (2021: £104,427), 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	144,990	12,000	156,990
Other trading activities	513,430	-	513,430
Investment income	808	-	808
Total	659,228	12,000	671,228

continued...

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
EXPENDITURE ON			
Raising funds	377,848	-	377,848
Charitable activities			
Awareness and education	210,244	11,531	221,775
Relief	81,665	-	81,665
Grants awarded	207,482	-	207,482
Total	877,239	11,531	888,770
NET INCOME/(EXPENDITURE)	(218,011)	469	(217,542)
RECONCILIATION OF FUNDS			
Total funds brought forward	277,005	15,246	292,251
TOTAL FUNDS CARRIED FORWARD	58,994	15,715	74,709

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade debtors	10,185	-
Other debtors	11	-
VAT	6,252	15,819
Prepayments and accrued income	2,325	-
	18,773	15,819

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade creditors	1,181	34,711
Social security and other taxes	3,057	2,168
Other creditors	9,530	125,421
Accruals and deferred income	3,060	3,275
	16,828	165,575

continued...

15. MOVEMENT IN FUNDS

	At 1.4.21 £	Net movement in funds £	At 31.3.22 £
Unrestricted funds			
General fund	58,994	(34,609)	24,385
Restricted funds			
Roald Dahl's MCC	6,715	-	6,715
GDUK Helpline	9,000	(9,000)	-
	15,715	(9,000)	6,715
TOTAL FUNDS	74,709	(43,609)	31,100

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	94,591	(129,200)	(34,609)
Restricted funds			
GDUK Helpline	10,000	(19,000)	(9,000)
TOTAL FUNDS	104,591	(148,200)	(43,609)

Comparatives for movement in funds

	At 1.4.20 £	Net movement in funds £	At 31.3.21 £
Unrestricted funds			
General fund	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
	15,246	469	15,715
TOTAL FUNDS	292,251	(217,542)	74,709

continued...

15. MOVEMENT IN FUNDS - continued

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

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

16. 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 £6,976 (2021: £12,698). Contributions totalling £835 (2021: £870) were payable to the funds at the year end and are included in creditors. The expense and liability have been recognised in unrestricted funds.

17. RELATED PARTY DISCLOSURES

A licence fee was paid annually to the Chronic Granulomatous Disorder Society (CGD Society) up until the 31 March 2021, which owned the Jeans for Genes and Genetic Disorders UK (GDUK) trademarks. The fee totalled NIL (2021: £61,138).

In addition there was a SLA between Genetic Disorders UK and Chronic Granulomatous Disorder Society in relation to the provision of staff, up until the 31st March 2021. The charge for the year amounted to £NIL (2021 £13,403).

18. COMPANY STATUS

The charity is a private company limited by guarantee. The members of the company are the trustees named on page 1. 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.

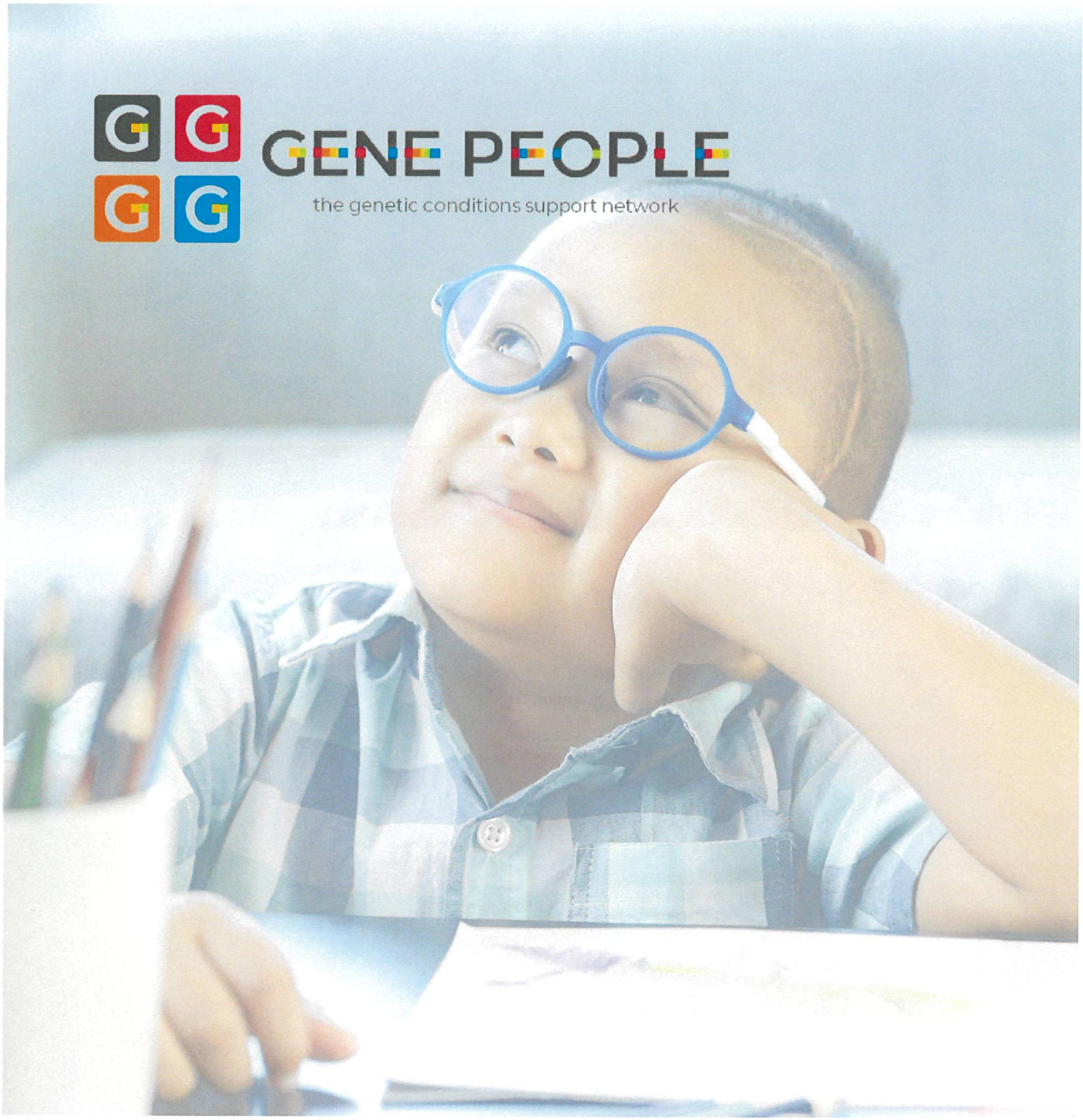
Gene People

England & Wales - Charity number 1141583

Accounts

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

Contents

- Welcome from the Chair, Page 1
- Report of the Board of Trustees for year ended 31 March 2021, Page 4 - 24
- Independent Examiner's Report, Page 25
- Statement of Financial Activities for the year ended 31 March 2021, Page 27
- Appendix 1, Primary Immunodeficiency UK Annual Report 2020-21, Page 44

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 Repot 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.

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:

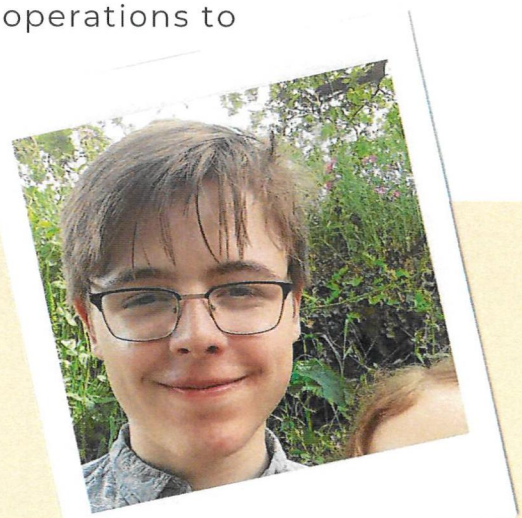
1. Providing services to those affected by a genetic condition through our helpline and website: www.genepeople.org.uk

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.

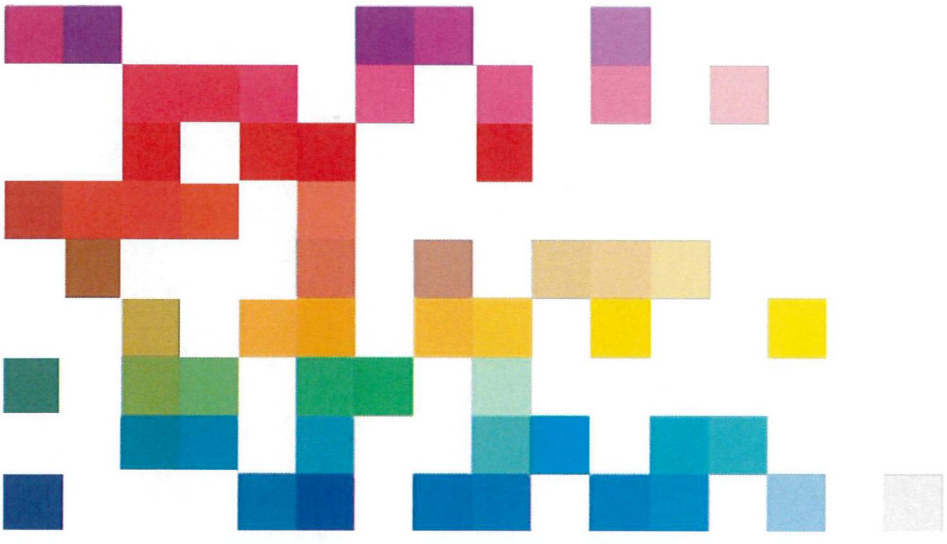
The fundraising strategy no longer rests on the success of the Jeans for Genes Day event. The strategy is to diversify income streams to include individual gifts, community fundraising, corporate support, and philanthropy. This will spread risk, develop new relationships and deepen existing ones, and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

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

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	808	-	808	113
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		207,482	-	207,482	99,431
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		58,994	15,715	74,709	292,251

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
		224,569	15,715	240,284	387,318
CREDITORS					
Amounts falling due within one year	15	(165,575)	-	(165,575)	(95,068)
NET CURRENT ASSETS		58,994	15,715	74,709	292,251
TOTAL ASSETS LESS CURRENT LIABILITIES		58,994	15,715	74,709	292,251
NET ASSETS		58,994	15,715	74,709	292,251
FUNDS	16				
Unrestricted funds				58,994	277,005
Restricted funds				15,715	15,246
TOTAL FUNDS CARRIED FORWARD				74,709	292,251

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.

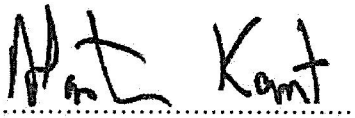
The trustees acknowledge their responsibilities for

(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	(70,187)	(11,563)
Net cash used in operating activities		(70,187)	(11,563)
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		808	110
Change in cash and cash equivalents in the reporting period		(69,379)	(11,453)
Cash and cash equivalents at the beginning of the reporting period		293,844	305,297
Cash and cash equivalents at the end of the reporting period		224,465	293,844
NET ASSETS		74,709	292,250

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	(70,187)	(11,563)

2. ANALYSIS OF CHANGES IN NET FUNDS

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

The notes form part of these financial statements

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	156,990	90,528

3. OTHER TRADING ACTIVITIES

	2021	2020
	£	£
Charitable activities	513,430	912,424

4. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	808	113

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
	377,848	617,464

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
	102,369	207,482	201,071	510,922

7. GRANTS PAYABLE

	2021	2020
	£	£
Grants awarded	207,482	99,431

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
Norrie 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 Haemosphilia 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	-
	205,095	93,894

8. SUPPORT COSTS

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

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	-	16,700

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
	299,265	383,010

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

	2021	2020
Fundraising	1	4
Charitable	2	3
Administration/ mangement	1	1
	4	8

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

	2021	2020
£100,001 - £200,000	1	1

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 ENDOWNMENTS FROM			
Donations and legacies	80,328	10,200	90,528
Other trading activities	912,424	-	912,424
Investment income	113	-	113
Total	992,865	10,200	1,003,065
EXENDITURE 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	1,041,392	1,669	1,043,061
NET INCOME/ (EXPENDITURE)	(48,527)	8,531	(39,996)
Transfers between funds	58,283	(58,283)	-
Net movement in funds	9,756	(49,752)	(39,996)
RECONCILIATION OF FUNDS			
Total funds brought forward	267,249	64,998	332,247
TOTAL FUNDS CARRIED FORWARD	277,005	15,246	292,251

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
	15,819	93,474

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
	165,575	95,068

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
	15,246	469	15,715
TOTAL FUNDS	292,251	(217,542)	74,709

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
	12,000	(11,531)	469
TOTAL FUNDS	671,228	(888,770)	(217,542)

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
	64,998	8,531	(58,283)	15,246
TOTAL FUNDS	332,247	(39,996)	-	292,251

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.

'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.'

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 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.