

CGD SOCIETY

ANNUAL REPORT & FINANCIAL STATEMENTS
2024-2025

Introduction from our Chair

It is with great pride and gratitude that I welcome you to the CGD Society's annual report for 2024/25.

This year has been one of both challenge and progress. Against a backdrop of continued global uncertainty and increasing pressures on healthcare systems, our community has once again demonstrated remarkable resilience, compassion, and determination. The CGD Society has remained steadfast in its mission to support individuals and families affected by chronic granulomatous disorder (CGD), while also supporting research, awareness, and advocacy.

Our membership has grown, and our engagement with both the clinical and research communities has deepened. This year, we have also strengthened our partnerships with international stakeholders, reinforcing our role as a global voice for those affected by CGD.

One of our proudest achievements has been the continued support to offer access to nursing provision through our partnership with Great Ormond Street Hospital (GOSH). This service has continued to provide vital access to specialist knowledge and ongoing support across the healthcare sector for those affected and living with CGD. We have supported new initiatives aimed at improving treatment pathways and access to care, while also investing in the next generation of scientific inquiry. These efforts are vital to our long-term vision of a world where CGD is better understood, better treated, and ultimately, better lived with.

The Jeans for Genes campaign has grown in strength, providing the ongoing basis for our support across the rare disease's community enabling projects and other critical work to be undertaken through the Jeans for Genes grants programme. This has provided the platform for strengthening our partnerships with other communities and charities to further our collective cause.

Of course, none of this would be possible without the unwavering support of our members, donors, volunteers, and partners. Your belief in our mission fuels everything we do. I would also like to extend my heartfelt thanks to our dedicated staff and trustees, whose commitment and expertise have guided the charity through another transformative year.

As we look ahead, we do so with cautious optimism. The road is not without its obstacles, but with your continued support, we are confident in our ability to meet the challenges ahead and to seize the opportunities that will shape a brighter future for all those affected by CGD.

Thank you for standing with us.



Wayne Kitchener
Chair of the Board

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Our charity

About Chronic Granulomatous Disorder (CGD)

CGD is a rare, potentially life-limiting, inherited condition of the immune system. It affects around eight in a million people and is caused by a faulty bone marrow gene that renders white blood cells unable to produce an enzyme needed to fight off infections caused by certain types of bacteria and fungi. As a result, those affected by CGD are susceptible to serious and debilitating illnesses, such as colitis, abscesses, and respiratory problems.

In recent years improved treatment protocols and a stem cell transplant option have improved the prospects for some patients, but nonetheless this disease remains hard to live with and can be life-limiting. In common with many rare diseases, CGD patients endure a poorer quality of life, persistent anxiety about their condition and sadly, for some, a shorter life expectancy.

There are five main types of CGD. Most cases affect boys through a single gene error in the X chromosome inherited from a carrier mother. The remaining, and much rarer four variants are 'autosomal recessive' and involved inheritance of a faulty gene from both mother and father and can affect boys and girls.

X-linked carrier mothers can be significantly affected by their genetic condition. Apart from the psychological impact, they can suffer a variety of mainly auto-immune problems that can damage their quality of life. Hence, carrier mothers have become a further important subgroup of patients affected by CGD.

Treatment of CGD

People with CGD need to take medication all the time to prevent infections. Even then, they can develop serious problems, which lead to life-threatening illnesses and long spells in hospital. As well as medication, doctors have been having increasing success in treating CGD with bone marrow transplants. Marrow has come from both relatives and unrelated donors. However, there is no one treatment or cure for all people with CGD. And a bone marrow transplant isn't possible for everyone.

Exciting gene replacement therapy trials are underway at the moment, and there's hope this may find a cure. However, more work is needed before it can become a regular treatment option. Gene therapy is a relatively new branch of medicine. Research is ongoing to improve the outcomes of gene therapy for CGD with the intention that it offers an alternative for permanent cure.

To learn more about the types of CGD, how they are inherited and about managing the disorder, please visit our website www.cgdsociety.org.

Our mission & purpose

Our *vision* is to enable families and individuals affected by CGD to live life to the full

Our *mission* is to be the leading source of information and support for families and individuals affected by CGD in the UK and around the world, by sharing the learnings and expertise from patients and medical professionals who treat them.

The Chronic Granulomatous Disorder Society (CGD Society) is a leading charity dedicated to promoting an understanding of CGD and providing support to affected individuals and their families. The charity was originally registered in the UK in 1991 under the name the Chronic Granulomatous Disorder Research Trust (CGDRT). It was incorporated and renamed the CGD Society in 2011.

This charity represents some 1,973 members of which 35% are affected individuals or family members; the remainder are supporters and medical professionals. Of those members, around 831 are in the UK and 494 in the USA. The membership is spread across 81 countries of which the UK, USA, Australia, Canada, India, Ireland, France, Spain, South Africa, and China make up the top ten. Our membership increased with 205 new members joining in the financial year 2024–2025.

Our objectives and activities

Our primary purpose is to support the patients and families of those suffering from chronic granulomatous disorder. Our methods and aims have changed over the 34 years since the charity was founded, and our current charitable objects as laid down in 2011 are:

1. The relief of persons suffering from chronic granulomatous disorder (CGD) or other primary immune deficiencies or related illnesses.
2. The advancement of medical research into the causes, cure, prevention, or relief of such disorders and/or illnesses and the publication of the useful results of that research.
3. To advance the education of the public on the subject of such disorders and/or illnesses; and
4. Such other purposes as are charitable according to the laws of England and Wales for the benefit of the public.

Our mission & purpose

How we achieve this

At the CGD Society, our work is dedicated to improving the lives of individuals affected by chronic granulomatous disorder (CGD), other primary immune deficiencies, and related conditions. We pursue this mission by delivering direct support to patients and families, advancing research, raising awareness, and advocating on behalf of the CGD community.

Our core activities reflect our commitment to the following charitable objectives:

1. The relief of persons suffering from CGD or other primary immune deficiencies or related illnesses:

We are committed to providing comprehensive support for individuals and families affected by CGD. One of our most impactful initiatives is the full funding of a dedicated **CGD Clinical Nurse Specialist** based at Great Ormond Street Hospital. This specialist serves as a vital resource, offering direct contact and expert care for patients and families dealing with CGD-related health concerns.

Their role includes supporting hospitalised children and adults, acting as a liaison for local hospitals and GPs - particularly in emergencies - and attending clinic appointments to ensure continuity of care. They also carry out home visits to administer medication and assist with social care needs, liaise directly with schools and employers to help them understand CGD and the individual needs of affected individuals, and coordinate genetic testing for patients and their families. Importantly, they also provide tailored care and support for female X-linked CGD carriers.

Our confidential email and telephone helpline is available to the CGD community worldwide and is monitored by our dedicated staff, offering guidance, information, and emotional support.



We offer a **Family Support Fund**, which provides financial assistance for essential needs such as prepayment prescription certificates, hospital travel and parking costs, equipment to help children continue their education during hospital stays, and support for families during extended hospital admissions (such as bone marrow transplants).

We also fund special days out for families to create positive memories during challenging times.

Our mission & purpose

2. The advancement of medical research into the causes, cure, prevention, or relief of such disorders and/or illnesses:

We collaborate with leading researchers and pharmaceutical companies working on innovative treatments, including gene therapy, to improve outcomes for those with CGD. Our Medical Advisory Board, composed of experts in the management of CGD, guides our approach and ensures that our activities are informed by the latest clinical knowledge. We actively participate in and support the dissemination of medical research through our partnerships and involvement in relevant medical conferences and forums.

3. To advance the education of the public on the subject of such disorders and/or illnesses:

We produce and distribute a range of high-quality medical information resources and booklets for both patients and medical professionals. Our comprehensive website serves as a hub of accessible, up-to-date information for anyone affected by CGD. We also run online events, family days, and weekend gatherings that offer educational content, peer support, and opportunities for the CGD community to connect. These initiatives help to reduce isolation and improve understanding of the condition across the public and healthcare sectors.

4. Such other purposes as are charitable according to the laws of England and Wales for the benefit of the public:

We advocate for the needs of the CGD community at national and international conferences and engage with stakeholders across the healthcare landscape to promote better access to care and treatment. We also signpost individuals to relevant external services, including mental health support, ensuring a holistic approach to care.

Through these combined efforts, we remain steadfast in our mission to support, inform, and empower those affected by CGD, while contributing to meaningful progress in treatment and awareness.

Alfie's CGD Story

My story with CGD starts from early on. I was born with a large red rash which signaled to the doctors that something was wrong. Soon after that happened, as far as I'm aware, my blood was tested for CGD. This then also meant that my brothers needed to be tested, and one of my two brothers also had CGD.

Growing up with CGD

I was sick a lot and didn't get to go on many trips with school or go out with my friends. This made it hard to make friends and socialise, but to also keep up with the rest of the kids educationally. I wasn't able to perform too well on my sats tests at the end of primary school, and when I got into secondary school it only made it harder to do well.

I had to get motivated about things I wanted to change in my life to get to where I am today. So, in year 10 I became fully committed to changing my life. I started to do more revision and soon worked harder than anyone else in my school and my GCSE predicted grades changed from 3/4s across the board to 7/8s in a year. This then enabled me to get into sixth form to do A-levels.

Moving on to A-Levels

I would say A-levels is where I decided that science was the subject for me because I wanted to help people going through a BMT (bone marrow transplant). I am now aware what science can do for people, so again I worked hard and got into university to study Biochemistry. I had my BMT the day after my 9th birthday, I'm now 19 so 10 years have now passed. As a child, I remember it as a fun trip away from school, but then as it got into more of the isolation part of the treatment where the chemotherapy started, I got angry and wanted to go home. This isolation affected me. However, I wasn't truly alone as I was with kids who were going through similar treatments and made friends with them. I just remember shouting at my poor mum and the nurses at the time when I was fed up with everything.

As a child you don't really understand what's going on or why the doctors and nurses do what they do, so having the Hickman line and the peg put in was a very odd experience for me.



You don't expect to lift your shirt and see wires and tubes coming from outside of your body, but my mum reassured me it was ok, and the doctors and nurses were ever so lovely and explained it to me as well as you can to a child.

After the Bone Marrow Transplant

The aftermath of my BMT meant I could only go to school for short periods and the rest of the time I was at home, it was hard to fit back in at school as all kids around that age are very active. Due to the treatment, I couldn't be active, so it was difficult. However, I'm still here to talk about the BMT so I'm extremely grateful for its success.

I did have a lot of mental health struggles, which stemmed from the BMT. I was isolated from all my friends, which made it hard for me to socialise and made my anxiety worse. However, I have had a lot of help with this and now make friends very easily.

I really do have to mention my mum in this story, though, as I respect and love her so much. She was with me for most of my hospital visits, took care of me when I was ill, and when I was having my BMT as I was in hospital for a long time. My Mum was with me every night and day.

I truly cannot put into words how much stuff my mum has done for me, and I probably wouldn't be here if it wasn't for her.

Delivering for the community

Beyond our patient and family support programmes and our clinical nursing service, we run a series of events throughout the year to bring families together and spread awareness. As 2024/25 was a reset year for our charity, we are proud to be able to continue this activity, despite our limited resources. Below are some of our favourites from the last 12 months.

Online get togethers

Our CGD community greatly values our online gatherings. This year, we hosted two virtual events, offering the opportunity to connect with leading experts and interact with other CGD families.

In June, we hosted a virtual gathering specifically for X-linked CGD carriers. Led by Dr Siobhan Burns, Professor of Translational Immunology at University College London, the event provided a platform for participants to share their experiences, learn about the latest advancements in treatment, and engage in an insightful discussion with Dr Burns. In February, we held a virtual gathering centred on Gene Therapies for CGD.



Attendees had the opportunity to hear from Professors Claire Booth and Emma Morris about the latest advancements in gene therapy and their potential impact on future treatment options. The session also included a chance for participants to ask questions and share their thoughts and concerns. Both events were attended by CGD families and individuals here in the UK and around the world and were a resounding success.

We extend our heartfelt thanks to Dr Siobhan Burns and Professors Claire Booth and Emma Morris for generously sharing their time and expertise to support these events.

Royal Society of Medicine

Our charity had the honour of sponsoring and attending the Royal Society of Medicine's Gene Therapy Conference on June 11th. Our CGD stand was proudly staffed by our Executive Director, Claire Liddle, and our CGD Clinical Nurse Specialist, Helen Braggins.

The conference featured insightful presentations by renowned keynote speakers, exploring topics such as the potential of cell and gene therapy and its applications in treating both acute and chronic conditions. While significant progress is still needed to develop a gene therapy treatment for CGD, we left the event feeling optimistic about the future of gene therapies.



Delivering for the community

Gene therapy

We were delighted to partnership with Ensoma this year. Ensoma are developing a new genomic medicine based on engineering hematopoietic stem cells (HSC) in vivo to develop a durable source of therapeutic blood and/or immune cells that treat chronic disease. X-linked CGD is one of three lead programmes for this new technology. In December, our Executive Director met with members of the Ensoma team to explore their vital work and discuss opportunities for collaboration to ensure that the patient's perspective is central to the process. Then in March, we hosted an online feedback session with Ensoma and our patient advisory group, comprised of individuals affected by CGD.

This group included an X-linked carrier, a parent of a child who underwent BMT, a young adult who participated in a gene therapy trial, and others living with CGD. During the session, the advisory group gained valuable insights into this promising treatment option and provided feedback on clinical trials and their potential impact on individuals and families.

The initiative was a resounding success, with committee members feeling valued and empowered, knowing their contributions made a meaningful impact. Ensoma gained invaluable feedback from the perspective of the CGD community, fostering a deeper understanding of patient needs and priorities. We would like to thank the members of our advisory board for providing their time and expertise.

Rare Disease Day at Westminster

To mark this year's Rare Disease Day, Claire, our Executive Director, and Catherine, our Fundraising and Marketing Officer, attended a Rare Disease Day reception at Westminster. Organised by Genetic Alliance UK it was a great opportunity to meet with other genetic rare disease charities, raise awareness of CGD and hear from MPs about updates on the government's Rare Disease Framework and the focus going forward.



This year's support highlights



Helen supported

274

families in the UK
and

47

patients outside
the UK

Our CGD Clinical Nurse Specialist continued providing vital support throughout the year to adults, children, X-linked carriers, and wider families affected by CGD.

Our membership
increased by

205

including individuals and families affected by CGD, medical professionals, and supporters.

We provided

11

UK families with hardship payments through our family support fund



Our email and
telephone helpline
fielded

54

requests for support
and information.

We provided

17

individuals with funded prepayment prescription certificates.

Other moments this year

Communications

We sent 14 newsletters/update emails to our members with updates on CGD, rare disease research, patient stories, and fundraising.

Our social media presence continued to grow and through this we were able to update our followers on relevant news.

- 80 new followers on Facebook.
- 48 new followers on LinkedIn.
- 84 new followers on Instagram.

Funding

We were delighted to receive grants from various trusts and foundations this year which totalled £18,000. The grants will go towards our vital support services including our CGD Clinical Nurse Specialist.

Our team

We were sad to say goodbye to Niamh, our Community Fundraising and Marketing Officer in June. Niamh did a great job in her time with the charity, and we wish Niamh well in her future endeavours.

In October, we welcomed our new Fundraising and Marketing Officer Catherine Bean. Catherine will lead our fundraising and marketing efforts.

We are deeply grateful to Geoff Creamer for his remarkable dedication and service to our charity over the past 30 years. As a longstanding trustee and Chair of Trustees for nine years, Geoff has played an instrumental role in shaping the direction and strength of our work. His wisdom, commitment, and unwavering support have made a lasting impact on the charity and the CGD community. Geoff will continue to volunteer his time this year in supporting the Jeans for Genes campaign.

Other moments this year

Governance

We welcomed Wayne Kitchener as our new Chair, with responsibility for managing our board of trustees and leading the strategic direction of the charity.

We welcomed Josh Stevens as our new Treasurer, taking over from Ning He, with responsibility for the charity's financial management.

We held a number of long-term strategy meetings to shape out the direction of the organisation for the next three years.

The board numbered 9 trustees at the start of this financial year, and we ended with a total of 5. As of the date of this report, a further 2 recruits leaves the current board with 7 trustees.

We thank all current and past trustees for the donation of their time and expertise in the pursuit of our charitable objectives.



Fundraising & Partnerships

As a small charity, we rely on donations to fund all our activities throughout the year — we receive no funding from governmental sources or from the delivery of services. Our team works phenomenally hard to raise funds from a variety of sources, and the generosity of our donors has allowed us to deliver for the CGD community for over 30 years.



Community Fundraising

We are incredibly proud — and deeply grateful — to share that, together, our amazing CGD community helped raise over **£28,000** this year! Whether you ran a marathon, hosted a fundraiser, set up a regular donation, gave a one-off gift, shared our content online, or shopped through a charity platform — you made a difference.

This incredible total is a testament to the generosity, energy, and commitment of our donors, fundraisers, and supporters. Every single action, no matter how big or small, has helped us provide vital services to families affected by CGD, fund our specialist nurse at Great Ormond Street Hospital, and continue our mission to support, inform, and empower.

Institutional Fundraising

This year, we were pleased to secure **£18,000** in grant funding to support our vital Information and Support Services, including the work of our dedicated CGD Clinical Nurse Specialist. These grants play a crucial role in helping us continue to deliver high-quality, accessible support to individuals and families affected by CGD. We would like to extend our sincere thanks to Awards for All, whose generous grant will contribute towards several core elements of our service provision. This includes funding for our helpline, the production and distribution of our newsletters, the Family Support Fund, and a much-needed refresh of our website to ensure information remains current, accessible, and user-friendly.

We are also extremely grateful to The Hospital Saturday Fund for their support through a grant specifically directed toward the ongoing cost of our CGD Clinical Nurse Specialist.



Fundraising & Partnerships



Jeans for Genes Campaign

A significant change in our fundraising activities this year was the reintroduction of the Jeans for Genes Campaign as an internal function. Previously this event has been run by partner organisations, such as Genetic Disorders UK and the Jeans for Genes Campaign charity, with the CGD Society receiving a licence fee as the founders of the event and holder of the trademark.

Following the closure of the last organisation to run this event, an offer was made by a key stakeholder to support a scaled back version of the fundraising week to maintain the momentum leading into the 30th anniversary in 2025.

This proposal turned out to be a winning formula. With low overheads and a focus on building relationships with schools, we ended the campaign year with a Grant Programme pot of nearly £150,000, the highest total allocated for nearly 10 years!

Like many charities, we faced significant challenges in the financial year 2024-2025 due to the ongoing cost of living crisis, which has affected donation levels and made fundraising increasingly difficult across the sector.

We are actively working with a comprehensive fundraising strategy focused on diversifying income streams - particularly through growing regular giving and building strong corporate partnerships - to help us meet our fundraising target moving forward.

Membership fundraising stories

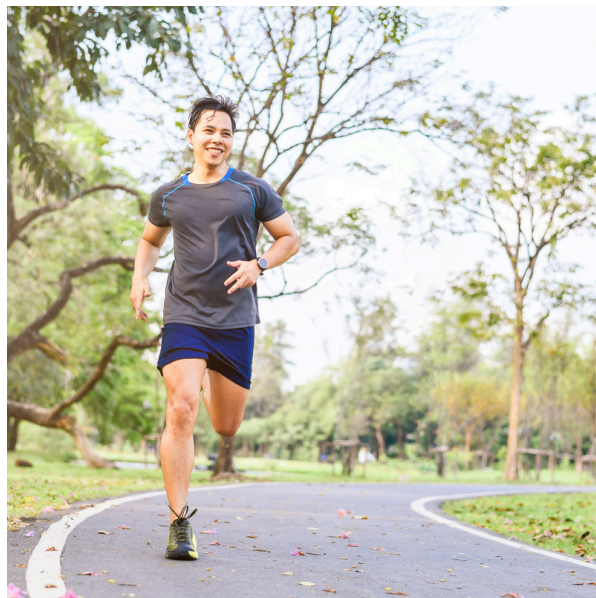
We're always encouraged by the remarkable activities of our community, who embark on an array of challenges every year to fundraise for our charity. Below are some amazing stories from our superstar supporters this year.

Craig's 100km run

Craig said: *"Two of my nephews were born with CGD. On medication since birth, neither of them has had an easy start to life.*

The oldest had a bone marrow transplant in 2015. With annual checkups and medication, he can now live life to the fullest - something he couldn't do before.

His younger brother has now also had his transplant. After months in the hospital, he was able to return home last year. While the process was more complex this time, he's gradually returning to 'normal' life and doing things he was never able to do before."



We are incredibly grateful to Craig for taking on the extraordinary challenge of running 100km in support of CGD Society. His dedication and determination have not only raised vital awareness but also much-needed funds to support individuals and families affected by CGD.

Southwest Hertfordshire's annual Vintage Sports Car Club BBQ



We're incredibly grateful to Ian Cheese and the wonderful community of car enthusiasts from the SW Hertfordshire Vintage Sports Car Club, who once again hosted their annual summer BBQ in support of CGD Society.

This year's event raised an amazing £681 and was held in honour of two brave young brothers — Bobby, who is currently undergoing treatment for CGD, and Ben, who has successfully completed his treatment.

Their parents, Bonnie and David, along with their grandfather Rod, have been steadfast supporters of this fundraiser over the years, and we're so thankful for their continued dedication to helping families affected by CGD.

Membership fundraising stories

Alex's run and cycle across Scotland

A heartfelt thank you to Alex for his phenomenal achievement — running and cycling coast-to-coast across Scotland in just one day to raise nearly £6,500 for CGD Society. On the 14th of September 2024, Alex covered an astonishing 23 miles on foot and 80 miles on and off road by bike, starting in Nairn and finishing in Glencoe. He completed the course in an incredible 11 hours and 40 minutes, placing 35th out of 400 participants. What an achievement!



Alex said: *"My nephews Ben (10) and Bobby (9) have a very rare genetic disease called CGD and have spent years under the care of specialists at Great Ormond Street Hospital.*

Ben had a successful bone marrow transplant in 2021 and has made a full recovery. Bobby had his transplant earlier this year and, although he has faced several complications, continues to show incredible strength. These two are hugely special and brave boys. Throughout their journey, The CGD Society has been by their side from day one."

Becca's 10k run

A huge thank you to our incredible supporter, Rebecca, for her determination and dedication to CGD Society. Rebecca was due to run the Great South Run on 20th October in support of our charity, but the event was sadly cancelled due to bad weather. Undeterred, she took to her local area and completed the run anyway, braving the rain, getting soaked, and still finishing with a smile. Even more inspiring, Rebecca raised over £600 to support our work with individuals and families affected by CGD.



Rebecca shared her reason for running:

"The CGD Society has been supporting my family since October 2022, when my son Elliot was diagnosed with CGD. They have been there through every hospital admission, every setback, every step of Elliot's transplant - always answering questions and providing any kind of support we need."

Our plans for the future

The new year brings a new strategy for the CGD Society – learning from what we do well and listening to the needs of our community.

In 2024/25 we have worked hard to develop our activities and operations to run in a more streamlined and resource-efficient manner. Our achievement of a budget surplus in this year has been a key deliverable of our previous three-year strategy, one which has put us on a level footing to work for the future.

Strategy

We began the work with our staff and board of trustees last year to develop a new institutional strategy to guide us for the future years. Some unexpected departures from our board delayed the launch of this new plan until a new organisational structure was in place, which was achieved in early 2025. We are now in the final stages of consultation, with our board and staff carefully considering each aspect of our programme, and we expect this to be formally put into place in Summer 2025.

Support for the CGD community

Our new strategy puts families and patients at the heart of how we work. We have developed a series of guiding principles to ensure that our mission and vision are incorporated across our operations.

We will continue to use our platform to elevate the voices of patients with CGD, their families, and the wider genetic disorder community. As a charity it is our responsibility to advocate for our community at an institutional level, which is reflected in our new working strategy. This involves working with the NHS and other medical organisations to ensure that timely and comprehensive care is provided when it's needed most. We will also work with partners to create access for holistic support services designed to meet the needs of the entire family.

We are also beginning a scope of work to redevelop our website, as we know that this source is a vital piece of information for our community and the medical professionals who support them, both at home and abroad. Our goal is to build a platform that is more user friendly with a better stock of up-to-date, high-quality information on what CGD is and how patients and families can be supported.

One of our key priorities is to further strengthen the voice of the CGD community in everything we do. We are working to establish a dedicated Community Panel — a group made up of individuals and families affected by CGD who will help shape the direction of our charity. This panel will provide valuable feedback on our work, highlight areas of unmet need, and ensure that our services, resources, and advocacy remain relevant, inclusive, and community led.

Our plans for the future

By listening closely and working collaboratively, we aim to make sure the needs and experiences of the CGD community continue to drive and inspire our mission.

We are also keen to bring the community together more often, both in person and online. In the year ahead, we hope to organise a CGD Family Day — a chance for families to connect, share experiences, and enjoy time together in a supportive environment. In addition, we plan to expand our online events, creating more opportunities for people around the world to come together, hear from experts, and find strength in community.

Knowledge and thought leadership

A core tenet of our new strategy is to make sure that what we do is both well informed and in the best interests of the community. As part of this, our board, staff, and volunteers will continue holding our mid-year review meetings to analyse our strategic plans, that will help us note which activities are behind the planned delivery schedule and crucially what our priorities should be for the year ahead.

We will continue to review our individual services and activities to ensure our work is impactful:

- We will review our nursing services to decide how to expand this if funds are available. In particular, we recognise that as patients live longer, adult nursing care needs to be reinforced. This will be a central case for support from grantors. We will also research alternative funding models for the nursing service.
- To increase the charity's effectiveness and efficiency we will develop a new business system in the form of a systems map from which we will establish our top KPIs to measure impact and progress.
- We will continue to monitor the usage of our membership support, including the email & phone helplines, the website, and the Clinical Nurse Specialist, to help identify any areas we may need to expand or develop.

Fundraising & partnerships

The new financial year also brings with it a new fundraising strategy, as we can only deliver impact as far as we can raise funds to pay for it. Our charity has gone through some difficult financial times over the past five years as a result of Covid-19, a cost-of-living crisis, and escalating global tensions. As such, we have shifted gears to focus on longer-term committed giving, both with our community as well as with corporate partners. This will ensure that we are more resilient to the peaks and troughs of charitable giving that hampers many organisations in our sector and allow us the time with our limited staff resources to reach out to new supporter communities.

Our plans for the future

We also recognise that we have a unique position amongst charities of our size with our fundraising campaign, Jeans for Genes Week. Past work, including the successes of the most recent event in 2024, have shown that the campaign has a remarkable reach and name recognition that organisations even a hundred times our size struggle to achieve. This is all due to the hard work of the many stewards of this event over the last 30 years, which we are keen to continue going forward. A key focus of our three-year strategy is to rebuild this campaign whilst maintaining the minimal cost-base that was such as success in 2024.

Organisation & governance

The last year 2024/25 was a busy time for us behind the scenes, as we had to accept the resignations of some of our long-standing trustees, due to the maximum term-limit for directors as set out in our governing articles. These changes, in addition to the warm welcoming of a host of new members to our board in the last year, gave us an opportunity to reorganise our management structure to focus on dynamic decision making.

A part of this is the redevelopment of our subcommittee structure, built around two core trustee committees, Governance & Finance and Operations, and a selection of transitional committees to suit the priorities of the year, such as Nursing and Community, which will allow us to focus our limited staff and volunteer time more effectively. We also keen to investigate how we can open our forum to our members, experts, and partners, to build a mechanism to receive, consider and implement feedback from our community.

Administrative information

The CGD Society is a charity registered with the Charity Commission of England & Wales (charity number 1143049) and a company limited by guarantee in England & Wales (company number 07607593). The charity is governed by its memorandum and articles of association dated 18 April 2011.

Our registered office is Nightengale House, 46-48 East Street, KT17 1HQ. Our primary mailing address is PO Box 454, Dartford, DA1 9PE.

Trustees and staff

Below is the list of individuals who served as trustees and directors during the year and/or up to the signing of this report:

- | | |
|---|--|
| • Wayne Kitchener | Chair of the Board |
| • Geoff Creamer (<i>stood down March 2025</i>) | Secretary |
| • Ning He (<i>stood down October 2024</i>) | Treasurer (<i>to October 2024</i>) |
| • Josh Stevens (<i>co-opted June 2024</i>) | Treasurer (<i>from October 2024</i>) |
| • Chikai Lai | |
| • Alan Keffler (<i>stood down January 2025</i>) | |
| • Kumar Perampaladas (<i>co-opted August 2024</i>) | |
| • Ceri Williams (<i>co-opted August 2024, stood down January 2025</i>) | |
| • Luke Byrne (<i>co-opted August 2024, stood down January 2025</i>) | |
| • Renee Dijeng (<i>co-opted August 2024, stood down November 2024</i>) | |
| • Sarah Robertson (<i>co-opted February 2025</i>) | |
| • Maria Loughenbury (<i>co-opted May 2025</i>) | |
| • Blessing Ikaka (<i>co-opted May 2025</i>) | |

We are also grateful to our dedicated staff for their year-round service to the organisation:

- | | |
|--|---------------------------------|
| • Claire Liddle | Executive Director |
| • Niamh Carmichael (<i>left April 2024</i>) | Fundraising & Marketing Officer |
| • Catherine Bean (<i>joined October 2024</i>) | Fundraising & Marketing Officer |
| • Helen Braggins RGN RSCN | Clinical Nurse Specialist |

Medical advisory panel

Our work is supported by the Medical Advisory Panel which advises the charity on the provision of appropriate care for people with CGD. The panel comprises of:

- **Dr Andrew Gennery**, MD, DipMedSci, DCH, FRCPCH, MRCP, Paediatric Immunology and Haematopoietic Stem Cell Transplantation, and Honorary Consultant Paediatric Immunologist, Great North Children's Hospital, England.
- **Prof. Dr. med. Janine Reichenbach**, Chair Somatic Gene Therapy, University of Zurich (UZH); Deputy Director Institute for Regenerative Medicine (IREM, UZH) Head Div. Somatic Gene Therapy, University Children's Hospital Zurich, Paediatrician, NIH Senior Investigator and Chef of the Immunology Service, DLM NIH Clinical Center, United States.
- **Prof. David Goldblatt**, MB ChB, PhD, Consultant Paediatric Immunologist at Great Ormond Street Hospital (GOSH) and Prof. of Vaccinology and Immunology .

Administrative information

- **Dr David Lowe**, MA MB BChir PhD, FRCP Consultant Clinical Immunologist, Royal Free London NHS Foundation Trust.
- **Dr Sergio Resenzweig**, MD PHD University of Buenos Aires, Paediatric and Clinical Immunologist, Director of the Primary Immunodeficiency Clinic at the National Institutes of Health in the USA.

Principal professional advisers

Independent examiner:	Xeinadin , Nightingale House, 46-48 East Street, KT17 1HQ
Bankers:	Barclays , 1 Churchill Place, London E14 5HP
Solicitors:	Hempsons LLP , 3 Dorset Rise, London EC4Y 8EN
Investment advisers:	Evelyn Partners , Portwall Place, Bristol, BS1 6NA

The board of trustees is responsible for the overall governance, policy and strategic direction of the CGD Society. The trustees, who are also directors for the purposes of company law, have the legal responsibility for the operations of the CGD Society and the use of resources in accordance with the objects of the charity. Trustees are elected to the board for a term of three years, up to a maximum of three consecutive terms.

The Executive Director is the staff lead for the organisation, reporting to the Chair of the trustees, responsible for the executive leadership and day-to-day operation of the charity in line with the trustees' instructions. They report regularly on activities and key performance indicators which the trustees use to judge progress against the priorities for the year.

Public benefit

The trustees confirm that they have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. All our activities are in line with our given charitable objects, which is reviewed regularly by the board of trustees.

Risk management

The Trustees have overall responsibility for ensuring that the CGD Society is managing risk in a professional, responsible and constructive manner. The Trustees review the risk register every year to identify significant risks and agree mitigation tactics. The Trustees seek to ensure that all internal controls, and in particular financial controls, comply in all respects with best practice and the guidelines issued by the Charity Commission.

Financial review

The UK remains a challenging landscape for charities of all sizes, with the continued impacts of inflation making it both more expensive to run a charity and more difficult for donors to give as much as they have done in the past. Like all organisations who work in the charitable health sector, we must make decisions about how to balance our intention to support our CGD community with the reality of limited resources.

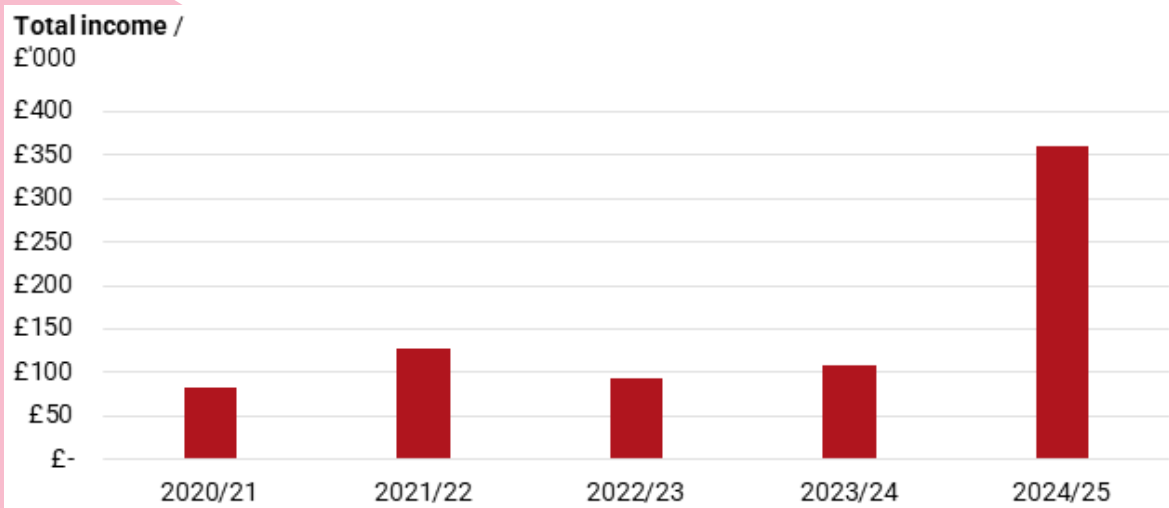
With this in mind, our trustees and leadership agreed on a deficit budget for the year, where we would use a portion of our reserves to invest in the infrastructure to better position CGD Society to deliver for our community for years to come. Therefore, we were pleased to end the financial year with a surplus position after a series of deficit years which had put pressure on our long-term reserves.

Income and expenditure



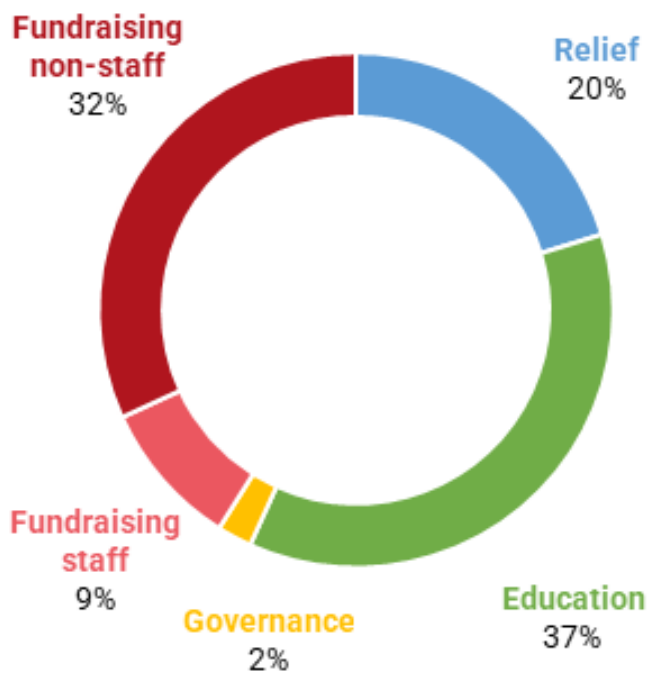
Our total income for the year increased to £360,000 (2024: £107,000), of which the largest component was donations and gifts which accounted for £348k, or 97% of total income (2024: £93,000, 86%). The significant increase in income was due to the Jeans for Genes campaign which was relaunched as an internal fundraising activity. In prior years, this campaign had been run by partner charities, with the CGD Society receiving a licence fee to use the Jeans for Genes trademarks and intellectual properties.

Included within donations is our grant funds received, which this year increased to £18k, which represented 5% of our total donations (2024: £9,000, 10%). We are grateful to our funders as their contributions, the majority of which are restricted to our projects, allow us to directly deliver our nursing and information services.



Financial review

In the year we also received other income of £7,000 (2024: less than £1,000), which represents proceeds received from the winding down of a partner charity, the Jeans for Genes Campaign, in respect of a capital loan which the CGD Society wrote off in the prior financial year.



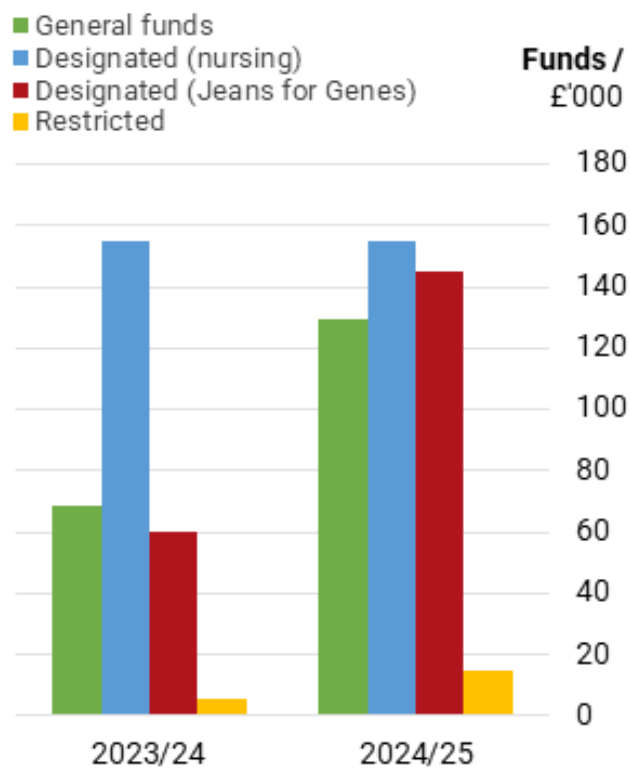
Our total spend for the year was £205,000, an increase of £4,000 from the prior year (2024: £201,000).

Our spend on charitable activities, £121,000 remains the largest proportion of our total expenditure at 57% (2024: £123, 61%). This includes spend on direct support for those living with CGD, which supported the nursing service, the family support fund, as well as the email and phone helpline. Education is another key form of support to our members, which we provide via website content development and information booklets. This year our spend on education was £75,000, or 37% of total expenditure (2024: 29,000, 14%), with the increase attributed to the relaunch of the Jeans for Genes campaign which helps promotes wider awareness of genetic disorders.

Our remaining expenditure consists of £4,000 / 2% on essential governance costs (2024: £3,000, 1%), and £84,000 / 41% on raising funds (2024: £38,000, 20%). The increase in fundraising costs is another consequence of running the Jeans for Genes campaign as an internal activity, rather than licensing this out to another charity, however we are very pleased with the overall level of funds this activity raised despite the late start in the year (see: Fundraising & partnerships – **Jeans for Genes Campaign, page 15**). We expect the percentage of fundraising costs to decrease in future years, as we have not yet recognised the expenditure of the Jeans for Genes grant programme due to the timing of the grant awards after the year end.

Financial review

We had no other expenditure in the year, whereas the balance in the previous year (2024: £40,000) represented a balance written-off from the capital loan to the Jeans for Genes Campaign, a partner charity of the CGD Society, to support the winding down of that charity.



Net movement of funds

Overall, the net movement of funds was a surplus of £154,000 (2024: deficit of £83,000). One qualifying note to this is that this does not include the Jeans for Genes grant programme costs of £145,000 which will be recognised in the next financial year 2025/26 due to the timings of the awards.

However, even with this grant programme factored in we have still achieved a net positive position for the year, which is a fantastic achievement after a series of deficit years. This is a testament to the continuing effort and dedication of our staff and our volunteers.

We hope to continue this in future years, whilst using our funds to invest in our people to continue to deliver impact and change for many years to come.

Financial review

Investment performance

Our charity has longer-term financial reserves invested in a medium risk portfolio and managed by Evelyn Partners. Over the year to March 2025, we have seen high interest rates as a result of a few years of consistently high inflation as well as some more recent volatility in global markets. Our overall goal with the investment portfolio is to achieve a gain of at least 3% per year, which we fell just shy of this year at 2.6%.

Our investment portfolio exhibited a total gain of £4,000 during the year (2024: gain of £11,000). As of 31 March 2025, the portfolio value stood at £169,000 (2024: £165,000).

Reserves

Our charity's policy is that unrestricted funds which have not been designated for a specific use should be maintained equivalent to between six- and twelve-month's expenditure. This level is reviewed annually by the trustees as part of the annual budget, last reaffirmed in April 2025. The trustees consider that this level will ensure we can continue current activities in the event of a significant drop in funding while consideration is given to ways in which additional funds may be raised.

At the year ended 31 March 2025, we maintained free reserves of £129,000, which corresponds to 6.6 months of budgeted core expenditure (2024: £69,000, 9.6 months).

We have also maintained two board designated reserves for the end of the year:

- A Jeans for Genes grant programme reserve, of £145,000, to cover grants which had not yet been issued by the end of the financial year 2024/25; and,
- A Nursing reserve, of £155,000, to cover the provision of the clinical nursing service in partnership with Great Ormond Street Hospital, as a strategic board priority.

Statement of Trustees' responsibilities

The Trustees present their annual report for the year ended 31st March 2025 in compliance with the Companies Act 2006 and the Charities Act 2011, together with the financial statements for that year. The financial statements also comply with the Companies Act 2006, the charity's governing document, and the relevant Statement of Recommended Practice (the Charities SORP [FRS 102]).

Responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable laws and regulations.

Under company law, the trustees (who are also directors of the CGD Society) must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the company and the group and of the net incoming resources for that period.


In preparing this report, the directors have taken advantage of the small companies' exemptions provided by Section 415 of the Companies Act 2006.

Disclosure of information

We, the directors of the company who held office at the date of approval of these financial statements as set out above each confirm, so far as we are aware, that:

- There is no relevant information of which the company's independent examiners are unaware; and,
- We have taken all the steps that we ought to have taken as directors in order to make ourselves aware of any relevant examination information and to establish that the company's independent examiners are aware of that information.

The trustees' annual report and financial statements included within were approved by way of a proper vote by the board of trustees on 26th July 2025 and signed on their behalf by:



.....
Wayne Kitchener
Chair of the Board

& **Josh Stevens**
Treasurer

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

I report to the trustees on my examination of the financial statements of The Chronic Granulomatous Disorder Society (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

Since the charity's gross income exceeded £250,000, the independent examiner must be a member of a body listed in section 145 of the Charities Act 2011. I confirm that I am qualified to undertake the examination because I am a member of UK, 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 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
Xeinaadin
Nightingale House
46-48 East Street
Epsom
Surrey
KT17 1HQ
Date: 31/03/25

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Statement of Financial Activities

(Including an income and expenditure account)

For the year ended 31 March 2025

		Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
		2025	2025	2025	2024	2024	2024
	Notes	£	£	£	£	£	£
Income and endowments from:							
Donations and legacies	2	330,973	17,000	347,973	87,272	5,700	92,972
Investments	3	4,516	-	4,516	13,844	-	13,844
Other income	4	7,133	-	7,133	644	-	644
Total income		342,622	17,000	359,622	101,760	5,700	107,460
Expenditure on:							
Raising funds	5	84,299	-	84,299	37,777	-	37,777
Charitable activities	6	113,115	7,856	120,971	108,041	14,951	122,992
Other expenditure	11	-	-	-	39,970	-	39,970
Total expenditure		197,414	7,856	205,270	185,788	14,951	200,739
Net gains/(losses) on investments	12	(285)	-	(285)	10,729	-	10,729
Net income/(expenditure) and net movement in funds		144,923	9,144	154,067	(73,299)	(9,251)	(82,550)
Reconciliation of funds:							
Total funds brought forward		283,817	5,799	289,616	357,116	15,050	372,166
Total funds carried forward		428,740	14,943	443,683	283,817	5,799	289,616

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

Balance Sheet

For the year ended 31 March 2025

	Notes	Total 2025 £	Total 2024 £
Fixed assets:			
Investments	13	169,080	164,850
Current assets:			
Debtors	14	4,921	60,133
Cash at bank and in hand		351,282	84,999
Total current assets		356,203	145,132
Creditors: amounts falling due within one year	15	(81,600)	(20,366)
Net current assets		274,603	124,766
Total assets less current liabilities		443,683	289,616
The funds of the charity:			
Restricted funds	17	14,943	5,799
Unrestricted funds	18	428,740	283,817
Total funds of the charity		443,683	289,616

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 **26 July 2025**.



Mr J D Stevens

Treasurer | Trustee

Company registration number 07607593 (England and Wales)

Notes to the Financial Statements

For the year ended 31 March 2025

1 Accounting policies

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, with the exception of investments which are included at market value. 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.

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) Fixed asset investments

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

1.7) 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.

1.8) 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.

(continued on next page)

Notes to the Financial Statements

For the year ended 31 March 2025

1 Accounting policies (continued)

(1.8 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.

1.9) Taxation

The charity is exempt from corporation tax on income and gains to the extent that these are applied to its charitable objects.

1.10) Retirement benefits

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

Notes to the Financial Statements

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	329,973	-	329,973	83,572	200	83,772
Grants	1,000	17,000	18,000	3,700	5,500	9,200
Total donations and legacies	330,973	17,000	347,973	87,272	5,700	92,972
Breakdown of grants:						
National Lottery Awards for All	-	10,000	10,000	-	-	-
The Hospital Saturday Fund	-	2,000	2,000	-	-	-
D'Oyly Carte Charitable Trust	-	-	-	3,500	-	3,500
Douglas Arter Foundation	-	-	-	-	500	500
Michael and Anna Wix Trust	-	-	-	200	-	200
B & P Glasser Charitable Trust	1,000	-	1,000	-	-	-
Other grantors who wished to remain anonymous	-	5,000	5,000	-	5,000	5,000
Total grants	1,000	17,000	18,000	3,700	5,500	9,200

3 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Dividends and interest	4,516	4,142
Loan interest received	-	9,702
	4,516	13,844

4 Other income

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Other income	7,133	644

Other income in 2025 includes proceeds received from the Jeans for Genes Campaign charity as part of the winding down of that charity, in respect of a capital loan written off in the prior financial year.

Notes to the Financial Statements

For the year ended 31 March 2025

5 Expenditure on raising funds

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Fundraising and publicity:		
Direct fundraising costs	65,322	16,755
Staff costs	18,977	20,718
Total fundraising and publicity	84,299	37,473
Investment management	-	304
Total expenditure on raising funds	84,299	37,777

6 Expenditure on charitable activities

	Relief 2025 £	Education 2025 £	Research 2025 £	Governance 2025 £	Total 2025 £
Charitable activities					
Direct costs	31,601	44,281	-	4,472	80,354
Share of support costs (note 7)	9,956	30,661	-	-	40,617
Total expenditure on charitable activities	41,557	74,942	-	4,472	120,971
Analysis by fund:					
Unrestricted funds	33,701	74,942	-	4,472	113,115
Restricted funds	7,856	-	-	-	7,856
	41,557	74,942	-	4,472	120,971

Previous year:

	Relief 2024 £	Education 2024 £	Research 2024 £	Governance 2024 £	Total 2024 £
Charitable activities					
Direct costs	64,705	10,326	5,000	2,500	82,531
Share of support costs (note 7)	22,265	18,196	-	-	40,461
Total expenditure on charitable activities	86,970	28,522	5,000	2,500	122,992
Analysis by fund					
Unrestricted funds	72,019	28,522	5,000	2,500	108,041
Restricted funds	14,951	-	-	-	14,951
	86,970	28,522	5,000	2,500	122,992

Notes to the Financial Statements

For the year ended 31 March 2025

7 Support costs allocated to activities

	2025 £	2024 £
Staff costs	37,617	37,461
Support consultants' fees	3,000	3,000
	40,617	40,461
Analysed between:		
Relief	9,956	22,265
Education	30,661	18,196
	40,617	40,461

8 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	2,400	1,675

9 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year, nor for the prior year.

There were trustees' expenses paid for the year ended 31 March 2025 totalling £483 (2024: £466) to 3 trustees (2024: 6).

10 Employees

	2025 Headcount	2024 Headcount
Number of employees		
The average monthly number of employees during the year was:	2	2
	2025 £	2024 £
Employment costs		
Wages and salaries	53,025	54,430
Social security costs	137	-
Other pension costs	3,432	3,749
	56,594	58,179

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

Remuneration of key management personnel

The aggregate employee benefits paid to key management personnel during the year were £46,132 (2024: £46,178).

Notes to the Financial Statements

For the year ended 31 March 2025

11 Other expenditure

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Other expenditure	-	39,970

Other expenditure in 2024 relates to a capital loan balance to the Jeans for Genes Campaign charity which was written off to facilitate the winding down of that charity.

12 Gains and losses on investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Gains/(losses) arising on:		
Revaluation of investments	(285)	10,729

13 Fixed asset investments

	Listed investments £	Unlisted investments £	Total investments £
Cost or valuation:			
At 1 April 2024	164,849	1	164,850
Additions	4,515	-	4,515
Valuation changes	(285)	-	(285)
At 31 March 2025	169,079	1	169,080
Carrying amount:			
At 31 March 2025	169,079	1	169,080
At 31 March 2024	164,849	1	164,850

14 Debtors

	2025 £	2024 £
Amounts falling due within one year		
Prepayments and accrued income	4,789	-
Other debtors	132	60,133
Total debtors	4,921	60,133

Notes to the Financial Statements

For the year ended 31 March 2025

15 Creditors

	2025 £	2024 £
Amounts falling due within one year		
Taxation and social security	949	1,392
Trade creditors	25,367	15,738
Other creditors	428	611
Accruals and deferred income	54,856	2,625
Total creditors	81,600	20,366

16 Retirement benefit schemes

	2025 £	2024 £
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	3,432	3,749

The charitable company contributes to individual personal pensions for staff; contributions are charged to the income and expenditure account as they become payable.

17 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 £
National Lottery Awards for All	5,799	10,000	(2,569)	13,230
Information and Support Fund	-	5,000	(3,287)	1,713
The Hospital Saturday Fund	-	2,000	(2,000)	-
Total restricted funds	5,799	17,000	(7,856)	14,943

Previous year:

	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
Family Support Fund	158	5,700	(5,858)	-
Orchard Therapeutics (Family Support)	3,000	-	(3,000)	-
Orchard Therapeutics (Newsletter sponsorship)	1,892	-	(1,892)	-
National Lottery Awards for All	10,000	-	(4,201)	5,799
Total restricted funds	15,050	5,700	(14,951)	5,799

(continued on next page)

Notes to the Financial Statements

For the year ended 31 March 2025

(continued: Note 17 - Restricted funds)

These funds are restricted for the following purposes:

National Lottery Awards for All - this is towards the information and support service provided by the charity.

Hospital Saturday Fund - this is funds for the clinical nursing service provided by the charity with Great Ormond Street Hospital

18 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 £	Transfers £	Gains and losses £	At 31 March 2025 £
General fund	68,865	342,622	(197,414)	(84,970)	-	129,103
Nursing fund	154,922	-	-	-	(285)	154,637
Jeans for Genes (Support)	60,030	-	-	(60,030)	-	-
Jeans for Genes (Grants)	-	-	-	145,000	-	145,000
Total unrestricted funds	283,817	342,622	(197,414)	-	(285)	428,740

Previous year:

	At 1 April 2023 £	Incoming resources £	Resources expended £	Transfers £	Gains and losses £	At 31 March 2024 £
General fund	116,774	97,605	(145,514)	-	-	68,865
Nursing fund	140,342	4,155	(304)	-	10,729	154,922
Jeans for Genes (Support)	100,000	-	(39,970)	-	-	60,030
Total unrestricted funds	357,116	101,760	(185,788)	-	10,729	283,817

The designated funds are allocated by the board of trustees for the following purposes:

Nursing fund – These are funds set aside to cover the clinical nursing service provision with Great Ormond Street Hospital for the next 3 years.

Jeans for Genes Grant Programme – These are funds allocated for the provision of core and project funding grants to other primary genetic disorder organisations, which are awarded in the following financial year.

Jeans for Genes support – These funds represented amounts set aside for the launch of the new fundraising campaign following the winding down of the separate Jeans for Genes Campaign charity

Notes to the Financial Statements

For the year ended 31 March 2025

19 Analysis of net assets between funds

At 31 March 2025

Investments
current assets/(liabilities)

Total net assets

Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £
169,080	-	169,080
259,660	14,943	274,603
428,740	14,943	443,683

At 31 March 2024

Investments
current assets/(liabilities)

Total net assets

Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
164,850	-	164,850
118,967	5,799	124,766
283,817	5,799	289,616

20 Related party transactions

Two trustees of the Chronic Granulomatous Disorder Society also serve as trustees of a related charity, the Jeans for Genes Campaign. In the prior year an amount owing as repayment of a capital loan from the Jeans for Genes Campaign charity to the Chronic Granulomatous Disorder Society of £39,970 was written off. This agreement was to facilitate the winding down of that related charity.

There were no disclosable related party transactions during the year.



Thank you!

**Thank you to all members and fundraisers,
volunteers, staff, sponsors, trustees and our
medical panel for their continued support.
We couldn't do it without you.**

