Company no 07607593
Registered charity no 1143049

CGD SOCIETY

ANNUAL REPORT & FINANCIAL STATEMENTS 2023-2024

CGDSociety
Supporting families affected by chronic granulomatous disorder

Contents

About our charity

Trustees

Executive Director: **Claire Jeffries**
Community Fundraising & Marketing Officer: **Niamh Carmichael** (appointed May 2022)
Clinical Nurse Specialist: **Helen Braggins** RGN RSCN

Registered office: c/o Tudor John, 46-48 East Street, KT17 1HQ
Principal office: PO Box 454, Dartford DA1 9PE

Independent Examiner: Tudor John, Nightingale House, 46-48 East Street, KT17 1HQ
Bankers: Barclays Corporate, 1 Churchill Place, London E14 5HP
Solicitors: Hempsons, 100 Wood Street, London, EC2V 7AN
Investment advisers: Evelyn Partners, 4th Floor, Portwall Place, Portwall Lane, Bristol, BS1 6NA

Medical Advisory Panel:

- **Dr Andrew Gennery**, MD, MBChB, DipMedSci, DCH, FRCPCH, MRCP, Clinical Reader in 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 .
- **Professor David Goldblatt**, MB ChB, FRCPCH, FRCP, PhD, Consultant Paediatric Immunologist at Great Ormond Street Hospital (GOSH) and Professor of Vaccinology and Immunology and Head of the Immunobiology Unit at the Institute of Child Health, University College London (UCL).
- Dr David Lowe, MA MB BChir PhD MRCP, Consultant Clinical Immunologist, Royal Free London NHS Foundation Trust.
- **Dr Sergio Resenzweig**, MD PHD University of Buenos Airess, Paediatric and Clinical Immunologist, Director of the Primary Immunodeficiency Clinic at the National Institutes of Health in the USA.

Our GOALS

The trustee Board is obliged to ensure that this charity meets its charitable objects as stated in the Articles of Association:

- the relief of persons suffering from CGD or other primary immune deficiencies or related illnesses
- 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
- to advance the education of the public on the subject of such disorders and/or illnesses.

Our vision, mission, and strategy

Our vision statement:
enabling families and individuals affected by CGD to live life to the full.

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

Statement of Trustees' responsibilties

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 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.

Structure, Governance, and Management

Governing document

The CGD Society is a registered charity and company limited by guarantee and governed by its memorandum and articles of association dated 18th April 2011.

Trustees

The board of trustees is responsible for the overall governance, policy and strategic direction of the CGD Society. The Trustees 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 serve on the board for a period of three years that is renewable with Board agreement three times. Geoff Creamer resigned at the Annual General Meeting (AGM) 29th October 2022 but was reappointed even though he has exceeded this nine-year limit. Authority for some activities is delegated to subcommittees who have defined terms of reference and are populated by Trustees, staff, external advisors and volunteers as appropriate. The charity’s work is supported by the Medical Advisory Panel which advises the charity on the provision of appropriate care for people with CGD.

Public benefit

The Trustees confirm that they have complied with the duty in section 17(5) of the Charities Act 2011 to have due regard to the guidance issued by the Charity Commission on public benefit.

Executive management

The executive organisation is led by our Executive Director who reports to the Chair of Trustees. She publishes a quarterly report and key performance indicators which the trustees use to judge progress against our priorities for the year.

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.

Trustees' report

The Trustees present their annual report for the year ended 31st March 2024 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]).

Our Charity

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 1,636 members of which the majority are affected individuals or family members; the remainder are supporters and medical professionals. Of those members, around 675 are in the UK and 491 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 128 new members joining in the financial year 2023–2024.

About Chronic Granulomatous Disorder

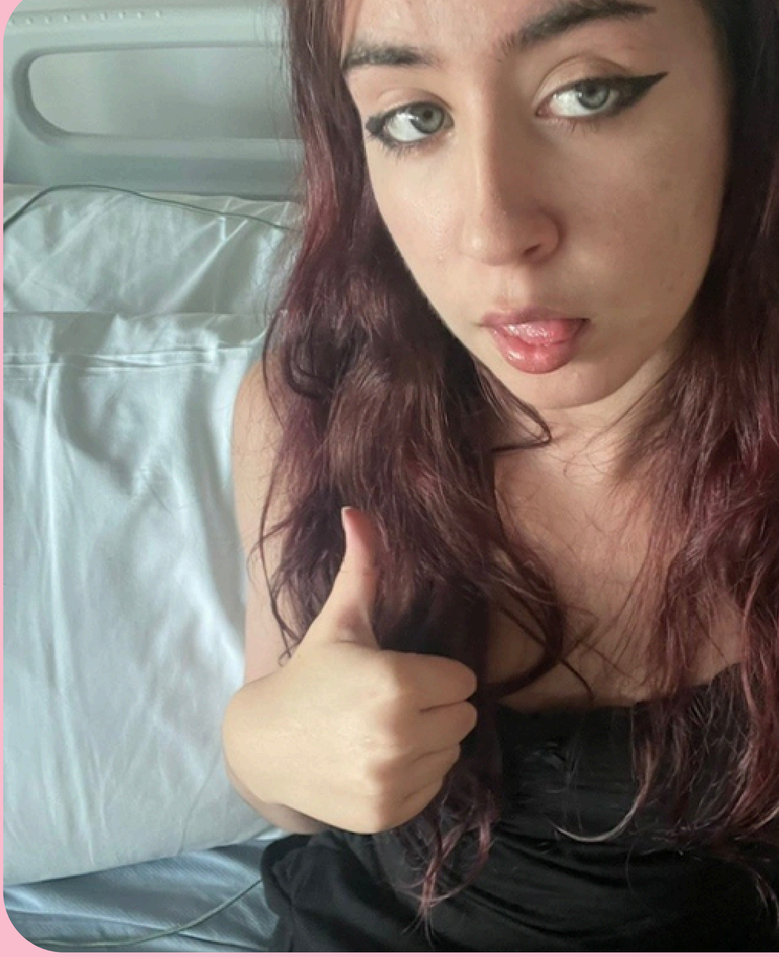
CGD is a rare, potentially life-limiting, inherited condition of the immune system. It affects around eight in a million people and is caused by a faulty bone marrow gene that renders white blood cells unable to produce an enzyme needed to fight off infections caused by certain types of bacteria and 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; the majority of 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' having inherited 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.

Shannon's Story

How to scold CGD in your late teens



Having a chronic illness during your late teens is never easy. Particularly an immunodeficiency disorder, which at times can make you look completely fine one week and then the next you're on your way to the local hospital for an overnight stay. From my understanding of CGD, many cases are with young children, so living with it during my teens has felt like a very niche experience at times, particularly as a girl. My type of CGD is a p40 deficiency which is the rarest form, so this also added on to the lack of relatability I've felt so far in my CGD journey. But I hope that by sharing a bit of my story, it will help other young people know that you're never alone and it's okay to feel overwhelmed with it all. Who could blame us?

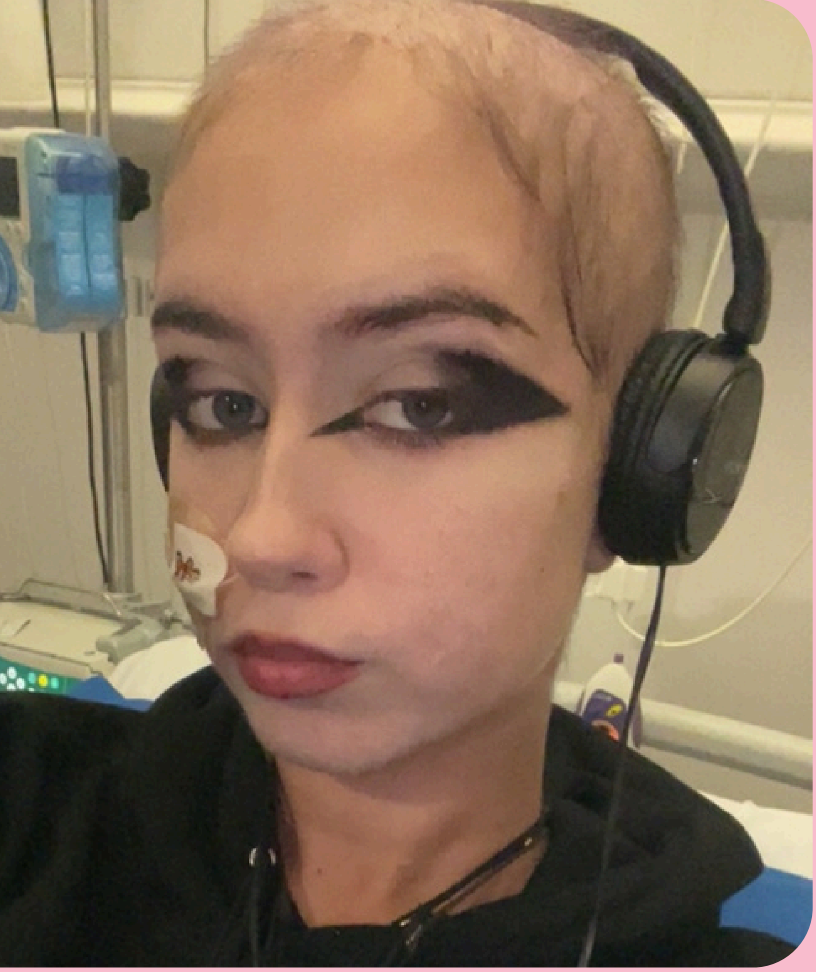
For most of my life my diagnosis was Crohn's disease, due to inflammation in my bowel and stomach (at times) and mouth ulcers picked up by my dentist as a toddler. A decade of immunosuppressants to dampen what they thought was an overactive immune system, and many trips to routine appointments. The usual. However, during March 2021, I was admitted into hospital very ill. I often reminisce back to a memory of my mum and I at the end of that long and strenuous two and a half weeks, walking back from Queen's Medical Centre's staff roof garden joking between us about whether I had Crohn's or not. As we walked onto the ward and looked down the corridor to the outside of my room, there was a group of new faces waiting for my return; one of them being who I know now as one of my main immunologists. "So, here's a diagram of your immune cells and bacteria".

I've spent the last three-ish years attempting to come to terms with a new diagnosis, which seems easy because a portion of that process is reading all the lovely, fabulous paperwork about the condition. But if you combine that part with the emotional rollercoaster one must go through when relearning their body's mechanisms and all the questioning of the past decade of their medical life, plus trying to continue living as normal of a life as you can at 15, 16, 17 and now 18, it suddenly seems like the biggest thing your life has ever thrown at you.

Now, let's not forget the big factor here. CGD is not one to wait for you to emotionally process everything and then turn up at its door saying, "Ok! I'm ready!".

Whilst writing this blog, I'm currently recovering from my bone marrow transplant (BMT), a known cure for CGD. It's been a couple months since I've been discharged and so far things are going well. I don't remember the first discussions about having a BMT as well as I do that ward corridor, but what I do remember is the feeling of anticipation and dread before.

It's something you're taught about in the conversation of cancer rather than an immunodeficiency, so it was interesting and promising to hear I could be cured. So far, they've done one cell pop test and my CGD is deemed to be gone. My BMT was eventually delayed a month and a bit because of, you guessed it, the star of the show: CGD! I ended up catching rhinovirus, COVID, and some other bacterial infections. It was almost like it was clinging on for one final time just to make a point. The chemo week went by ridiculously fast. After transplant, I was visited in hospital by the amazing CGD clinical nurse specialist, Helen, and we discussed some options about how the CGD Society can support me further in my recovery.



> ***"I hope what I've shared will help those reading, or at the very least provide entertaining ways to scold CGD to oblivion."***

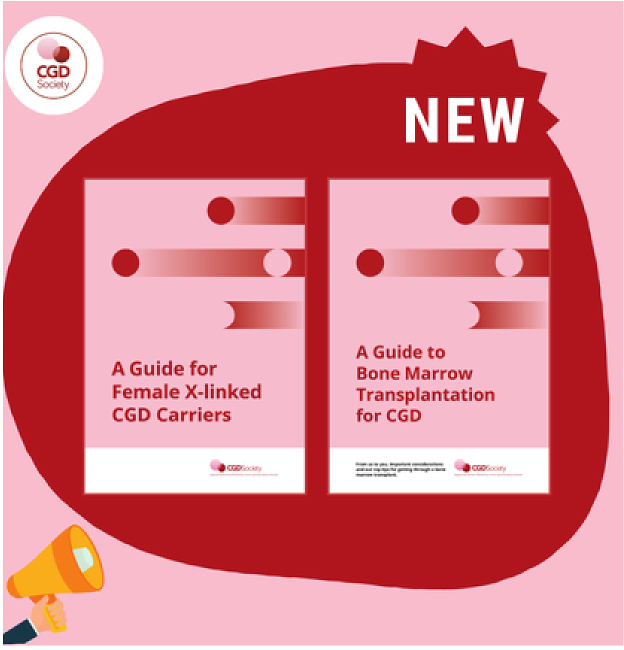
One aspect I'll remember for life is going through IVF. All women or girls who must have chemo that will affect their fertility are given this option. One reason being I started the fertility injections on my 18th birthday. I can't say that was on my list, but that's just life. But also because of the feelings surrounding the three-week process and my age. It felt daunting and invasive, which conflicted with my understanding that it was so very important to give my future self a chance at having kids if I turned out to be infertile from the treatment. A particular issue that came up was the scans being internal. I've highlighted this aspect to encourage advocacy within anyone relating to this part of my story. After expressing to the IVF clinic that I wasn't comfortable with the scans being internal, they happily opted to scanning through my abdomen instead. With my feedback, they are going to offer this option to all young patients. One thing I've learned from this is that advocating for myself was the best thing I could have done, rather than just 'dealing with it' as many of us chronic illness-havers are used to doing, and I hope this calms any worries some may have about the subject.

My experience summarised here may seem vastly negative but, to highlight an amazing thing that has come out of it, my hospital will now be testing any female paediatric gastro patients that come through their care to rule out any chance of it being mistaken for CGD. Up until this point only boys were being tested for CGD to rule it out, so this positive step will hopefully benefit many people. From what we've heard, it already has!
There's still a lot of hurdles in my journey that I've got to go through, but I'm doing well. I hope what I've shared will help those reading, or at the very least provide entertaining ways to scold CGD to oblivion.

We would like to thank Shannon for volunteering her time to write this story.

What did we do this year?

Medical Materials Update



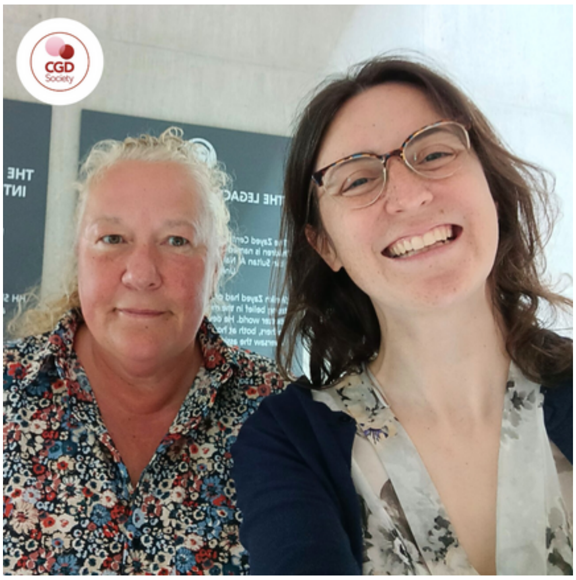
We know how valuable our CGD information booklets and leaflets are to families and medical professionals. In the summer of 2023, we worked with Costello Medical on a pro bono project to review and update some of those materials. Using data to identify our most downloaded and read materials Costello reviewed and updated 2 of our medical guides – A Guide to Bone Marrow Transplantation for CGD and a Guide for Female X-linked CGD Carriers. They also reviewed and updated 3 webpages – Lupus and carriers of X-linked CGD, FAQs on X-linked carrier issues, and Liver abscess. We would like to thank the Costello Medical team, Consultant Keval Haria, Global Health Patient Advocacy Healthcare Communications Maike Jager, and summer intern Lea Heinzer for their important work in this project.

"Working with the CGD Society throughout the past 3 months has been an unbelievably rewarding experience! Updating the medical materials has been an amazing opportunity for me to learn a lot about CGD and has also opened my eyes to the challenges as well as rewards that come with working in the field of rare diseases. It has been a pleasure working with Claire and Helen and I particularly valued that they were able to bridge the knowledge gap that exists between published research for CGD and personal experience and expertise. I am thankful to have been given this opportunity to support the CGD Society in a way that will hopefully also help the wider CGD community!" , Lea.

Immunology Study Day

Our CGD Clinical Nurse Specialist, Helen, coordinated an excellent Immunology Study Day for nurses in May 2023 at Great Ormond Street Hospital in London.

During the day, attendees heard the most incredible story from two amazing parents who are navigating severe combined immunodeficiency (SCID) journeys with their two boys. Talks were given on the latest advances in immunology care given by those working at the front line to improve lives of patients and families every day. There were also updates on newborn screening for severe combined immunodeficiency (SCID), a discussion on treatment developments and choices with immunoglobulins, thymus transplant and more. Our Chair of Trustees, Annabel, was also kindly invited to speak about quality of life in rare diseases.



What did we do this year?

Immunology and Allergy Nursing Conference

Claire, our Executive Director, represented the CGD Society at the Immunology and Allergy nurses group conference in Cardiff, Wales in May 2023. Our charity was one of the sponsors for this event which provided a great opportunity to raise awareness of CGD and the support services we provide to the CGD community and to nurses who are on the front-line of in-patient care. Claire attended the CGD Society stand, speaking to nurses about CGD, the charity and handed out our information booklets and leaflets.

CGD Study Day

In January 2024 medical professionals from around the world attended a CGD Education Day at Great Ormond Street Hospital (GOSH) London. The day provided an opportunity for key speakers to give presentations on a variety of CGD topics including gut disease and challenges of gene therapy for CGD.

Helen, GOSH's CGD Clinical Nurse Specialist whose role is fully funded by the CGD Society, led an insightful demonstration of the choices CGD patients face throughout their patient journey.

We were also moved by each of Alfie and Simon's talks about their personal experiences with bone marrow transplants and reflecting on what it is like living with CGD - thank you to both of them for coming along and speaking so candidly. Staff and trustees from the CGD Society had so many interesting discussions, making new connections and building anticipation for our new medical information booklets.

Thank you to Helen for organising such a good day; everybody learned a lot. We can now move forward with confidence that there is a brilliant community of dedicated healthcare professionals committed to working alongside us to achieve our aim of enabling families and individuals affected by CGD to live life to the full.

What did we do this year?

Online get-togethers

Our Virtual Get Together on Bone Marrow Transplant (BMT) took place in February 2024 Facilitated by Dr Robert Chiesa, Consultant in Bone Marrow Transplant and CAR-T Cell Therapy at Great Ormond Street Hospital London, this was an opportunity for families and individuals to hear the latest on BMT and have a discussion with Robert.

The event was open to families and individuals both in the UK and outside of the UK who may be considering this treatment option, who may have any questions and concerns, as well as those who have been/have a child who has been through the process and are able to offer support to others.

We were pleased to be joined by 14 families who benefited from speaking with Robert and hearing his presentation.

Rare Disease Day 2024

To mark this year's Rare Disease Day, our Executive Director Claire was invited to talk with the Rare Disease team at Costello Medical about CGD, the work of our charity, and the reality of living with a rare condition. As a patient advocate, Claire is passionate about raising awareness of CGD and the impact it has on the whole family.

The talk was well received by the team who were very engaged and were asking important questions to help with their understanding of the impact of CGD.

This year's highlights

Support

We increased our membership by 128 including individuals and families affected by CGD, medical professionals, and supporters.

Our email and telephone helpline fielded 41 requests for support and information.

Our family support fund supported 11 UK families with hardship payments and 17 individuals benefited from CGD Society-funded prepayment prescription certificates.

Helen supported

253

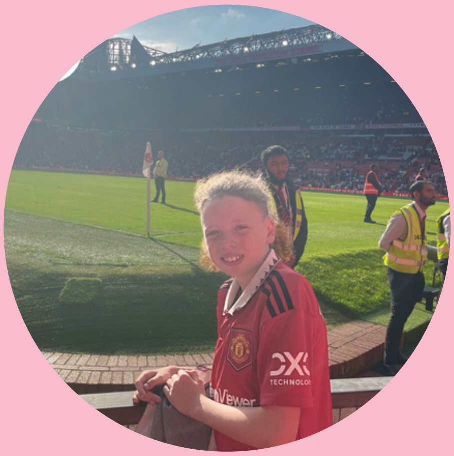
families in the UK and

36

patients outside the UK

Kian’s visit to Manchester United

We were delighted to have helped to make Kian’s dreams come true by securing tickets to a Manchester United football match. Kian’s brother, Noah, has CGD and Kian had one birthday wish this year: to watch Manchester United play a match at Old Trafford Stadium. Thanks to the generosity of the Manchester United Foundation, we were able to bring Kian’s wish to life at the end of May.



Our team

Niamh continued in her role of Community Fundraising and Marketing Officer from May 2022 forming strong relationships with our members and the wider CGD community.

Having been promoted the previous year, our Executive Director, Claire, continued to diversify her role helping to lead the delivery of this charity's annual strategy.

Andrew Orchard, who resigned as a Trustee last year, continued to support us as a volunteer particularly in the development of the Beacon CRM system. Andrew is one of our founder trustees and over the last 30 years has dedicated his time and experience to the charity and the families we support. Andrew was also instrumental in the development of our annual fundraising campaign Jeans for Genes Day which after nearly 30 years still supports the rare genetic community through grants and awareness.

Governance

Annabel continued as Chair of Trustees throughout this year but sadly had to resign in April 2024 due to a medical emergency. We will miss her and wish her a speedy recovery.

Geoff continued as Governance Secretary with responsibility for ensuring compliance with all regulatory obligations.

Ning He remained as Honorary Treasurer with responsibility for financial management

Our annual strategy meeting was held in March 2024 where we defined priorities for the next financial year.

The Board numbered 5 trustees at the start of this financial year, but with 5 new recruits added and 1 resignation, the Board ended the year 9 trustees strong. At the time of writing, a further 5 recruits offset by 4 resignations, leaves the current Board with 10 trustees. We thank all current and past trustees for the donation of their time and expertise in the pursuit of our charitable objectives.

Funding

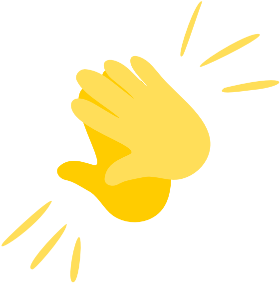
Our subsidiary charity, Jeans for Genes Campaign, had a challenging year (details below) giving us a smaller than normal license fee for the use of our trademark of £6,000.

We were delighted to receive grants from various trusts and foundations this year which totaled £9,200.

We were also really delighted to receive a one-off donation of £50,000 from a corporate sponsor.

In what was a difficult year for fundraising due to the cost-of-living crisis we still raised £29,758 from donations and fundraising activities.

THANK YOU FUNDRAISERS!



Communication

We sent 7 newsletters 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.

Where did our income come from?

Jeans for Genes

In 2021, the CGD Society founded a subsidiary charity Jeans for Genes Campaign to take responsibility for the running of the annual Jeans for Genes fundraiser. The three staff were transferred from Genetic Disorders UK (now renamed Gene People) and the first campaign was delivered in September 2021. The CGD Society loaned its subsidiary £200,000 for working capital support.

Since its inception, Jeans for Genes has faced many challenges that have significantly reduced income compared to pre-covid levels; firstly, with Covid disruptions to schools and businesses and now, during this financial year, dealing with the cost-of-living crisis in the UK and the uncertain economic landscape.

Our subsidiary team successfully increased campaign participation and registration numbers compared to the previous year but observed a concerning decline in the value of average donations across all audience segments. Despite concerted efforts to stimulate activity and elevate donation levels, this trend, and the resulting budget shortfall, forced a comprehensive review of the viability of our subsidiary.

In December 2023, both charities engaged in scenario planning to navigate these challenges into the future. Our shared commitment to the Jeans for Genes campaign and its impact remained unwavering, and we were dedicated to exploring innovative but drastic strategies to surmount these obstacles.

As of 31st March 2024, our subsidiary remained a going concern, but all future scenarios involved considerable risk to the CGD Society who as the principal creditor had an outstanding loan balance of £100,000 in jeopardy. The repayment of this loan had already been postponed by 12 months to ease cashflow problems. After due consideration, this Board decided it was no longer able to provide support to the Jeans for Genes charity, and therefore our subsidiary had no option other than to cease trading and wind up.

These events played out after the year end but for the record, the charity ceased trading on May 23rd, 2024, after three staff members had been made redundant. The CGD Society agreed to write off £40,000 of the outstanding loan so that all of the net assets could be distributed to beneficiaries including a £30,000 grant round paid to 41 applicants. For this year, the trademark license fee paid to CGDS was calculated at 20% of the grant distribution, which at £6,000 was a significant reduction from the previous year (2023; £43,000).

The closure of our subsidiary is a bitter blow to our growth plans for this iconic 30-year-old fundraiser. Several of the CGDS trustees were intimately involved in two years of work before launch and three years thereafter to nurture the new entity. The staff inherited from GDUK did an excellent job but were the victim of unfortunate timing through the challenges of COVID-19 and beyond.

We thank those staff for their tireless, professional, and passionate delivery of three campaigns and we are so sorry that their employment had to end.

This charity will now oversee the delivery of the Jeans for Genes campaign from here on and will ensure its continued success.

Community Fundraising

Our team worked hard to raise a total of £29,758 which exceeded the budget of £26,000 in what was a difficult year for fundraising for many charities as the country faced a cost-of-living crisis. Our Community Fundraising and Marketing Officer, Niamh, continued to build relationships with the CGD community and donors including representing the charity at 2 fundraising events to help improve our profile. Niamh and our Executive Director Claire worked together to produce the charity's Community Fundraising Strategy, which helped identify ways to diversify our fundraising within the constraints of the charity's limited resources. Part of the strategy was to run campaigns through our new CRM system including a successful Christmas campaign with our CGD Society Virtual Giving Christmas Tree, which raised a total of £590.

Institutional Fundraising

We continued to work with Almond Tree Strategic Consulting as part of our 'growth project' to help increase income through trusts and foundations. This year secured £9,200 in grants from various sources. Despite initial success in our first year of working with Almond Tree (2022-2023 £21,000) this year proved to be particularly difficult to secure further funding and increase our income. With factors such as the cost-of-living crisis and the after effects of COVID-19, we were not reaching our budget. This was regularly reviewed by the Board and a decision was made in January 2024 to end our contract with Almond Tree with a plan to bring this process in-house.

We would like to say a huge thank you to the following trusts and foundations for their support this year:

- Douglas Arter Foundation
- D'Oyly Carte Charitable Trust
- The Micheal and Anna Wix Charitable Trust

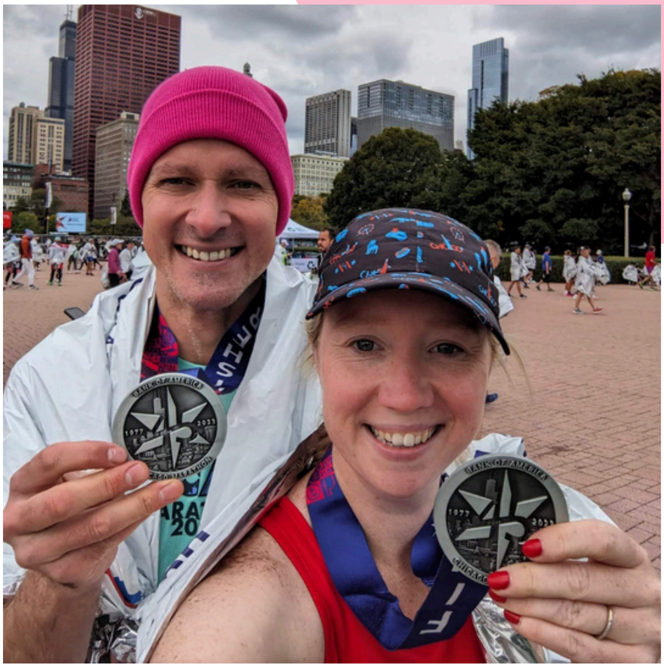
Membership fundraising stories

Our members have been busy smashing challenges and hosting events to raise funds for the CGD Society this year.

Sophie and Simon's Chicago marathon

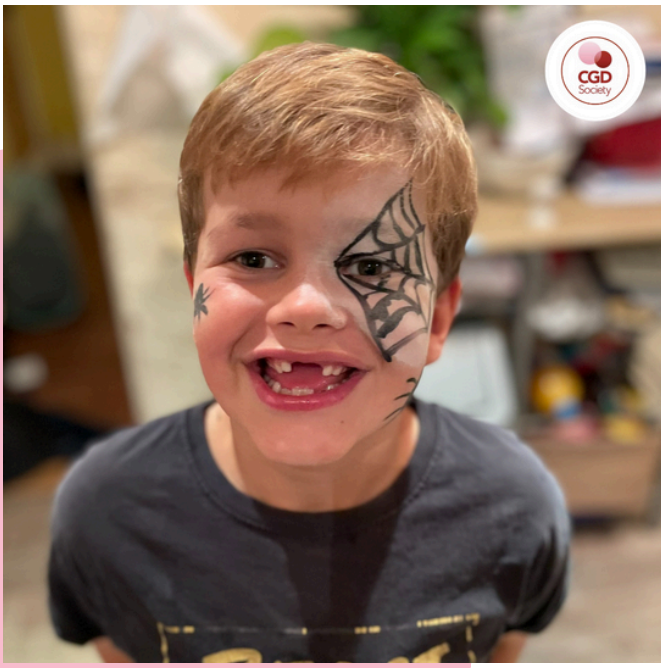
Dedicating this "once in a lifetime experience" to their nephew Ben who began his Bone Marrow Transplant (BMT) treatment for CGD the week before. They used the challenge to raise an incredible **£5,618** and even secured matched funding from Sophie's employer.

"Whatever this marathon throws at us, it will pale in comparison to the challenges being faced head-on by Ben in this week. If we can carry with us just an ounce of his resilience or a glimmer of his cheeky smile, 26.2 miles will fly by. And when times do get a little tough we'll try to listen to some advice from Ben himself and just 'stay in the moment' and enjoy it - knowing that we are supporting an amazing cause."
– Sophie



We hope they feel proud of their hard work, it will make such a difference to the CGD Society and the CGD community we support.

Bob's BMT Journey

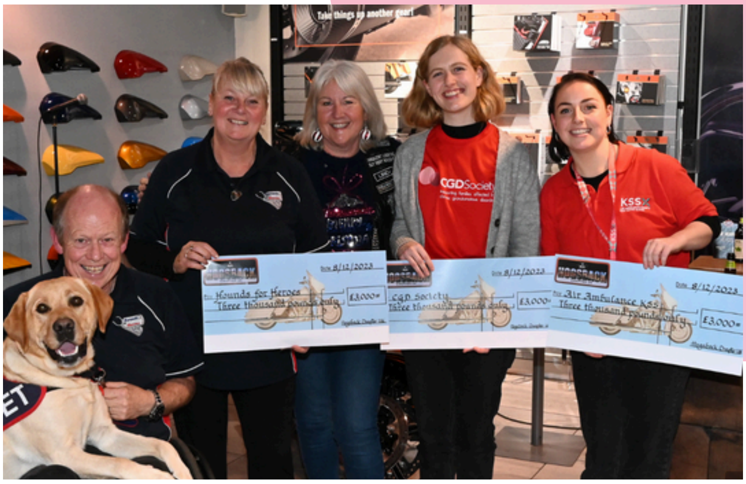


Bonnie Burgess–Biggerstaff shared her family's CGD journey as her son Bobby underwent a bone marrow transplant (BMT) for CGD in January 2024.
Bonnie also set up a JustGiving page as a way for friends and family to donate in recognition of the care and support we provided the whole family through Bobby's BMT journey. In total, the family raised **£6,000.**

Membership fundraising stories

Hogsback Chapter

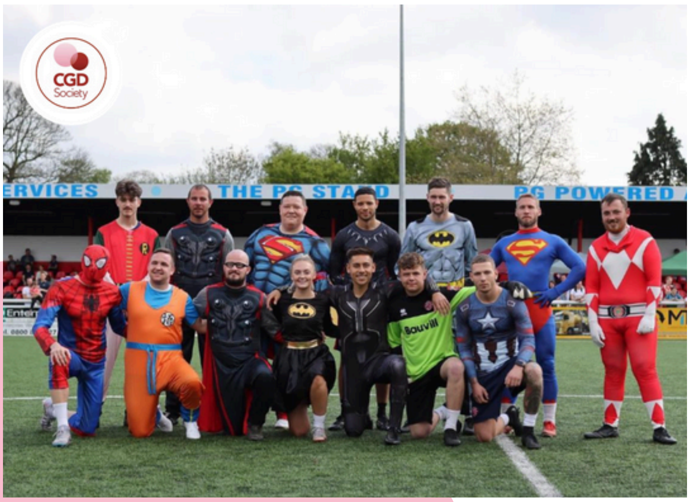
We want to give a thank you to Hogsback Chapter - HOG - Surrey UK for their dedicated support over 2023 as one of their three Charities of the Year.
By running events for their own and other Chapters' members to fundraise throughout the year, they all together raised an incredible total of **£3,000** for the CGD Society. These funds will make a real impact on our small charity's vital support for the CGD community.



Niamh was delighted to get to thank the Chapter in person in December as well as meet their two other brilliant Charities of the Year, Hounds for Heroes and KSS Air Ambulance, and even try some of their impressive Harley-Davidson motorcycles - no doubt with the engines off!

Chatham Town FC

We want to say a massive thank you to Chatham Town FC for their special day back in May 2023 to remember little Freddy Leitch who sadly passed away at 8 years old from complications of CGD. They released balloons in memory, played a special football match featuring Freddy's favourite superheroes, as well as raising an incredible **£3341** for the CGD Society.



We really appreciate the support they have enabled our charity to give to the CGD community through their fundraising, but most importantly the heartfelt send-off they gave to little Freddy.
We want to say a big thank you to each and every one of our fundraisers this year. Your support is truly appreciated and will make a difference to those affected by CGD.

“We wanted to celebrate Freddy’s life with this special day, while raising money for Demelza Hospice and the CGD Society, who have supported Freddy and his family throughout the last few years." - Chatham Town FC

Expenditure, investments and reserves

Expenditure

Our total spend for the year was £200,739, of which the largest proportion (43%) was spent on direct support for those living with CGD: £86,970 (2023: 72,673, 42%). This money 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 £28,522, or 14% of total expenditure (2023: £33,905, 20%).

We continued to partially fund the project to provide mental health support to the Birmingham Hospitals Trust, through a contribution of £5,000 for the third year. This research expenditure amounted to 2% of our total spend (2023: £5,000, 3%).

Our remaining expenditure consists of £2,500 / 1% on essential governance costs (2023: £7,086, 4%), and £37,777 / 19% on raising funds (2023: £52,494, 31%). We're pleased that fundraising and governance costs as a percentage of total costs have decreased this year, as we strive to make the most efficient and impactful use of all money donated to the Charity. As we look forward to the next year, we recognise that we will need to continue to invest in our fundraising activities, so we can continue to provide services to our members, but we aim to keep this percentage as low as we can.

In addition to this, other expenditure of £39,970 (2023: nil) represents a balance written-off from the capital loan to the Jeans for Genes Campaign, a subsidiary charity of the CGD Society, to support the winding down of that charity. This is a one-off item.

Overall, the net movement of funds was a deficit of £82,550 (2023: deficit of £84,480). The ever-present effects of the Covid pandemic and the cost-of-living crisis has put strains on the fundraising environment, particularly for smaller charities like ours. However, we are undeterred and dedicated to delivering our key services to our members, whilst looking forward to key fundraising opportunities in the coming year.

Investment policy and performance

The charity has longer-term financial reserves invested in a medium risk portfolio and managed by Evelyn Partners. Over the year to March 2024, interest rates have remained at high levels whilst the central banks attempted to control wider economic inflation caused by the cost-of-living crisis and conflicts sparking around the world. Our investments portfolio exhibited a gain of £10,729 during the year (2023: loss of £6,320).

As of 31 March 2024, the portfolio value stood at £164,850 (2023: £150,268)

Expenditure, investments and reserves

Reserves policy

The charity has a reserves policy that is used to judge the adequacy of financial assets for the coming year. The policy is reviewed annually and was updated in September 2024. It states that the charity must retain free reserves to cover 6–12 months of budgeted running costs for the year ahead, i.e. £43,000–£86,000 based on the core expenditure budget of £86,000 adopted by the Trustees.

As of 31 March 2024, the CGD Society has total reserves of £289,616, comprised of:

- £5,799 restricted reserves associated with grants that have been awarded to CGD Society
- £240,342 of designated reserves, which are not included in free reserves for the following reasons:
- Working Capital loan to CGD Society subsidiary Jeans for Genes Campaign to facilitate the 2021 campaign and beyond. (£60,030 outstanding as of 31 March 2024).
- Designated funds to cover contract commitments for the nursing service. (£154,922).

Therefore, the CGD Society has closing free reserves of £68,865 (2023: £116,774) which meets the reserves policy target and equates to approximately 10 months of planned expenditure for the year ahead.

What do we plan to do next year?

As reported above, Annabel our Chair, resigned at the end of May to focus on an urgent medical issue. Her drive and ambition for this charity, alongside her efficient management style will be sadly missed. Nonetheless our goals remain unchanged and undimmed as we describe below:

Fundraising

The fundraising climate remains difficult and uncertain so our goal to diversify income sources is arguably even more critical than in 2021 when we launched the Growth Project. Our financial statements show a substantial deficit this year and the budget for 2024-25 is similar. This is clearly unsustainable so we will attack this priority problem on 4 fronts:

Community Fundraising

Niamh has done an excellent job of fostering relationships within the community and outside that have generated income in excess of the budget expectation. Unfortunately, she resigned in June to take up a new opportunity leaving Claire in sole charge again. Hence, the first objective will be to recruit a new Fundraising and Marketing Officer as soon as possible to execute the agreed strategy. We will miss Niamh and wish her well in her new role but hope that a new recruit can be found quickly to maintain last year’s progress. The budget income for community fundraising next year is £35,000.

Grants from Charitable Trusts and Institutions

The challenge of securing grants has been emphasised by this year’s poor results whilst outsourcing and working with a fundraising consultant. This experience combined with specialist advice from colleagues generated many potential grant sources, but application success rates were disappointing. Generally, the grantors reported that their funds had been diminished by COVID-19 support grants, so less was available for new applicants.

For the year ahead, this activity will be brought in-house. Claire, using her new knowledge gleaned from working with a consultant, will seek repeat funding from known supporters, renew applications that previously failed, and seek new leads from other sources. To help her to allocate her limited time to this crucial work, the Board has agreed that she will dedicate one day per week to grant applications. The budget income from grants next year is £20,000.

Sponsorship

This new income stream will become the focus of the new Fundraising and Marketing Officer. By developing a marketing strategy to engage with corporate organisations we hope to achieve our modest target of £9,000.

Jeans for Genes

Our plans for this iconic fundraiser have obviously been disrupted by the ongoing closure of our subsidiary charity Jeans for Genes Campaign. When this Board withdrew financial support in February 2024 it accepted that a 12m hiatus would be necessary to regroup and rethink the campaign delivery. However, since the start of the new financial year, we have accepted an offer from a major supplier to run a diluted 2024 campaign using collateral from the previous year.

What do we plan to do next year? Cont.

The late start without any new creative materials will impact results but the low expected cost could result in a greater proportion of income for distribution, nonetheless. This stop-gap measure will give trustees the time to conceive a new 2025 campaign whilst keeping the brand warm and the community engaged. Nonetheless, there is no budgeted income from Jeans for Genes next year due to the uncertainties therein.

Support for the CGD Community

As always, our first priority is to provide comprehensive support to our membership. Our Clinical Nurse Specialist and our other support services will continue to be the backbone of that support.

In addition to ensuring the continued operation of these services, we will focus on improving the support we offer. Following on from the success of our online get-togethers event (see What did we do this year?), we will look to run more frequent online events on the topics of greatest importance to our membership.

We remain committed to supporting the mental health and improving the Quality of Life of our members but made limited progress in developing our support in this area in the current year. We will apply for funding to offer online mental health workshops facilitated by the charity RareMinds. These workshops will provide mental health support in such areas as ‘living with uncertainty’ and ‘coping with a diagnosis’.

We will draw on the expertise and support of our Medical Panel and use online platforms to enable a reach across our international community. We will continue to monitor feedback from our members to help determine further updates to the format and content of our patient events.

Knowledge and thought leadership

The board of trustees and the Executive Director will hold a mid-year face-to-face meeting to review the strategic plan for 2023-2024, that will help us note which activities are behind the planned delivery and crucially what our priorities should be for the year ahead.

The key deliverables are summarised below:

- Our priority is always to provide support in all forms to our membership. Our Clinical Nurse Specialist, email and phone helplines and website will continue to be the backbone of that support. We will also look to diversify this support to include mental health support.

- 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.

- We will continue to diversify our income streams . We plan to increase income from community fundraising and donations and we will focus on how we can grow income generation from corporate sponsorships and grants from trusts and foundations.

- 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.

What do we plan to do next year?

Research

We were disappointed to learn that the clinical psychology service at University Hospitals Birmingham NHS Foundations Trust that we part funded over 3 years was withdrawn unilaterally by the Mental Health Trust after 14 months of excellent service. However, it was reported that in those 14 months the service, that aside from the clinical benefit to the users, was also able to provide training to nursing and medical staff. The trusts final report has helped towards a business case being developed to provide a substantive service in the future.

It is with this news in mind that mental health support for the CGD community is one of the key priority actions for our strategy this year.

Organisation

The unexpected resignation of our Chair and three other trustees at the start of the new year will delay ongoing plans to build a more sustainable organisation. The subsequent recruitment drive to replenish the Board started immediately and has been extremely successful to date. These new volunteers bring new skills and energy that will precipitate a change in organisation structure through the sub committees and delegated authorities therein.

Also, a new Chair will be appointed who will lead this reorganisation, along with a new Treasurer and Secretary who will replace Ning He and Geoffrey Creamer respectively who have given notice to retire at the October AGM.

It is anticipated that the organisation will be back to full strength by the second half of the coming year.

2023-24 Summary

In common with many charities, the CGD Society is facing significant financial headwinds which we must address in order to secure a sustainable future for the community services that we deliver. The depletion of Institutional funds through the COVID-19 pandemic, followed by the cost of living crisis makes our Growth Project plans to diversify into grant funding even more challenging. Paradoxically, our services are more vital than ever as the reliance on 3rd sector and charitable organisations becomes ever more necessary as the NHS continues to recover post-pandemic.

Nonetheless, our community have once again beaten expectations and raised almost £30,000 through their fundraising events which is extraordinary for such a small cohort. Also, we are so grateful for a substantial sponsorship from the international employer of a member who benefitted from our advice during their CGD journey. Without this, our financial pain would have been much worse.

Our iconic national fundraiser, Jeans for Genes, has had a bumpy journey through the pandemic that sadly culminated in the closure of our subsidiary charity this year. However, this does give us the opportunity to rethink the delivery model to reduce costs but still maintain an income stream for ourselves as trade mark owner. Crucially, we will continue to award grants to other small and micro charities in the genetic disorder sector, who are facing the same financial pressures as ourselves. Exciting plans are under discussion so we are hopeful that in 2025 we can change the trajectory and restore growth to this iconic event in its 30th year.

Our community continues to grow with 128 new members this year and over 1600 in total across an extraordinary 81 countries. We continue to provide the information that our members need with updates and newsletters to maintain currency.

Our successful online meetings will continue to explore hot topics with expert advice. Our specialist nurse Helen has once again excelled as the clinical hub of this charity, backed up by the medical panel whilst Claire and Helen have raised our profile through several external events.

On behalf of the Board, I thank all of our supporters, volunteers, expert advisors, and staff for their expertise, time, and passion for our cause. We can certainly be proud of the services that we deliver and the growing cohort that we support. We offer unique advice to the world that no doubt changes lives for the better.

This report was approved by the trustees on 21/11/2024 and signed on their behalf by:

....

Dr Geoffrey Creamer
Secretary

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.

CGDSociety
Supporting families affected by
chronic granulomatous disorder

REGISTERED COMPANY NUMBER: 07607593 (England and Wales)
REGISTERED CHARITY NUMBER: 1143049

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

Unaudited Financial Statements for the Year Ended 31 March 2024

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

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

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

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY (REGISTERED NUMBER: 07607593)

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).

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a memorandum of association, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

07607593 (England and Wales)

Registered Charity number

1143049

Registered office

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

Trustees

Dr G D Creamer
Mr N He
Mr C Lai
Dr A Griffiths (resigned 23.4.24)
Mr K S Shahi (resigned 19.8.23)
Mr A G Keffler (appointed 12.9.23)
Mr W Kitchener (appointed 24.10.23)
Mr J D Stevens (appointed 7.6.24)
Mr K Perampaladas (appointed 2.8.24)
Ms R S Dijeng (appointed 2.8.24)
Ms C L Williams (appointed 2.8.24)
Mr L Byrne (appointed 2.8.24)
Dr F Drobniewski (appointed 16.9.23) (resigned 4.5.24)
Mr C Hutchings (appointed 24.10.23) (resigned 24.4.24)
Mr M Niles (appointed 24.10.23) (resigned 24.4.24)

Independent Examiner

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

Approved by order of the board of trustees on 25.10.2024 and signed on its behalf by:

N He

N He - Trustee

Independent Examiner's Report to the Trustees of
The Chronic Granulomatous Disorder
Society (Registered number: 07607593)

Independent examiner's report to the trustees of The Chronic Granulomatous Disorder Society ('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.

Hazel Day BSc DChA FCA

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

Date: ....8/11/24..........................

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

Statement of Financial Activities
for the year ended 31 March 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	87,272	5,700	92,972	43,898
Investment income	3	13,844	-	13,844	6,100
Other income		644	-	644	43,000
Total		101,760	5,700	107,460	92,998
EXPENDITURE ON					
Raising funds	4	37,777	-	37,777	52,494
Charitable activities	5				
Relief		72,019	14,951	86,970	72,673
Education		28,522	-	28,522	33,905
Medical Research		5,000	-	5,000	5,000
Governance		2,500	-	2,500	7,086
Other		39,970	-	39,970	-
Total		185,788	14,951	200,739	171,158
Net gains/(losses) on investments		10,729	-	10,729	(6,320)
NET INCOME/(EXPENDITURE)		(73,299)	(9,251)	(82,550)	(84,480)
RECONCILIATION OF FUNDS					
Total funds brought forward		357,116	15,050	372,166	456,646
TOTAL FUNDS CARRIED FORWARD		283,817	5,799	289,616	372,166

The notes form part of these financial statements

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY (REGISTERED NUMBER: 07607593)

Balance Sheet
31 March 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
FIXED ASSETS					
Investments	9	164,850	-	164,850	150,269
CURRENT ASSETS					
Debtors	10	60,133	-	60,133	126,569
Cash at bank		79,200	5,799	84,999	110,651
		139,333	5,799	145,132	237,220
CREDITORS					
Amounts falling due within one year	11	(20,366)	-	(20,366)	(15,323)
NET CURRENT ASSETS		118,967	5,799	124,766	221,897
TOTAL ASSETS LESS CURRENT LIABILITIES		283,817	5,799	289,616	372,166
NET ASSETS		283,817	5,799	289,616	372,166
FUNDS	12				
Unrestricted funds				283,817	357,116
Restricted funds				5,799	15,050
TOTAL FUNDS				289,616	372,166

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.

The notes form part of these financial statements

continued...

Balance Sheet - continued
31 March 2024

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 .25.10.2024..................... and were signed on its behalf by:

N He
....
N He - Trustee

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, as modified by the revaluation of certain assets.

INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

TAXATION

The charity is exempt from 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.

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

2. DONATIONS AND LEGACIES

	2024 £	2023 £
Donations	82,607	22,898
Gift aid	1,165	-
Grants	9,200	21,000
	92,972	43,898

continued...

2. DONATIONS AND LEGACIES - continued

Grants received, included in the above, are as follows:

	2024 £	2023 £
Douglas Arter Foundation	500	-
National Lottery Awards for All	-	10,000
Childwick Trust	-	5,000
The Hospital Saturday Fund	-	2,000
The D'Oyly Carte Charitable Trust	3,500	3,500
The Marsh Charitable Trust	-	500
The Michael and Anna Wix Charitable Trust	200	-
Louis Nicolas Residuary Charitable Trust	5,000	-
	9,200	21,000

3. INVESTMENT INCOME

	2024 £	2023 £
Other fixed asset invest - FII	4,141	-
Loan interest received	9,688	6,100
Interest	15	-
	13,844	6,100

4. RAISING FUNDS

RAISING DONATIONS AND LEGACIES

	2024 £	2023 £
Direct and support costs	37,473	50,935

INVESTMENT MANAGEMENT COSTS

	2024 £	2023 £
Portfolio management	304	1,559
Aggregate amounts	37,777	52,494

continued...

5. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 6) £	Totals £
Relief	64,705	22,265	86,970
Education	10,326	18,196	28,522
Medical Research	5,000	-	5,000
Governance	2,500	-	2,500
	82,531	40,461	122,992

6. SUPPORT COSTS

	Management £
Relief	22,265
Education	18,196
	40,461

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 trustees' expenses paid for the year ended 31 March 2024 totalling £466 (2023 £663) to 6 (2023 2) trustees.

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2022-23

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	26,898	17,000	43,898
Investment income	6,100	-	6,100
Other income	43,000	-	43,000
Total	75,998	17,000	92,998
EXPENDITURE ON			
Raising funds	52,494	-	52,494
Charitable activities			
Relief	61,472	11,201	72,673
Education	33,905	-	33,905
Medical Research	5,000	-	5,000
Governance	7,086	-	7,086
Total	159,957	11,201	171,158
Net gains/(losses) on investments	(6,320)	-	(6,320)

continued...

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2022-23 - continued

	Unrestricted funds £	Restricted funds £	Total funds £
NET INCOME/(EXPENDITURE)	(90,279)	5,799	(84,480)
RECONCILIATION OF FUNDS			
Total funds brought forward	447,395	9,251	456,646
TOTAL FUNDS CARRIED FORWARD	357,116	15,050	372,166

9. FIXED ASSET INVESTMENTS

	Listed investments £	Unlisted investments £	Totals £
MARKET VALUE			
At 1 April 2023	150,268	1	150,269
Additions	4,156	-	4,156
Disposals	(304)	-	(304)
Revaluations	10,729	-	10,729
At 31 March 2024	164,849	1	164,850
NET BOOK VALUE			
At 31 March 2024	164,849	1	164,850
At 31 March 2023	150,268	1	150,269

There were no investment assets outside the UK.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Other debtors	60,133	100,123
VAT	-	1,138
Prepayments and accrued income	-	25,308
	60,133	126,569

Please refer to Note 13 for more information regarding the Other debtor balance.

continued...

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Trade creditors	15,738	12,544
Social security and other taxes	951	(73)
VAT	441	-
Other creditors	611	1,352
Accruals and deferred income	2,625	1,500
	20,366	15,323

12. MOVEMENT IN FUNDS

	At 1.4.23 £	Net movement in funds £	At 31.3.24 £
Unrestricted funds			
General fund	116,774	(47,909)	68,865
Jeans for Genes support	100,000	(39,970)	60,030
Nursing fund	140,342	14,580	154,922
	357,116	(73,299)	283,817
Restricted funds			
Family Support	158	(158)	-
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
	15,050	(9,251)	5,799
TOTAL FUNDS	372,166	(82,550)	289,616

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

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
Unrestricted funds				
General fund	97,605	(145,514)	-	(47,909)
Jeans for Genes support	-	(39,970)	-	(39,970)
Nursing fund	4,155	(304)	10,729	14,580
	101,760	(185,788)	10,729	(73,299)
Restricted funds				
Family Support	5,700	(5,858)	-	(158)
Orchard Therapeutics (Family Support)	-	(3,000)	-	(3,000)
Orchard Therapeutics (Newsletter sponsorship)	-	(1,892)	-	(1,892)
National Lottery Awards for All	-	(4,201)	-	(4,201)
	5,700	(14,951)	-	(9,251)
TOTAL FUNDS	107,460	(200,739)	10,729	(82,550)

continued...

12. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.4.22 £	Net movement in funds £	Transfers between funds £	At 31.3.23 £
Unrestricted funds				
General fund	189,247	(82,400)	9,927	116,774
Jeans for Genes support	100,000	-	-	100,000
Nursing fund	158,148	(7,879)	(9,927)	140,342
	447,395	(90,279)	-	357,116
Restricted funds				
Family Support	4,359	(4,201)	-	158
Orchard Therapeutics (Family Support)	3,000	-	-	3,000
Orchard Therapeutics (Newsletter sponsorship)	1,892	-	-	1,892
National Lottery Awards for All	-	10,000	-	10,000
	9,251	5,799	-	15,050
TOTAL FUNDS	456,646	(84,480)	-	372,166

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

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
Unrestricted funds				
General fund	75,998	(158,398)	-	(82,400)
Nursing fund	-	(1,559)	(6,320)	(7,879)
	75,998	(159,957)	(6,320)	(90,279)
Restricted funds				
Family Support	-	(4,201)	-	(4,201)
National Lottery Awards for All	10,000	-	-	10,000
Childwick Trust	5,000	(5,000)	-	-
The Hospital Saturday Fund	2,000	(2,000)	-	-
	17,000	(11,201)	-	5,799
TOTAL FUNDS	92,998	(171,158)	(6,320)	(84,480)

A description of the purpose of the funds is as below:

Designated funds:
Jeans for Genes support - A capital loan was made in 2021 to the Jeans for Genes Campaign charity to assist with working capital in the setup stages of the charity. Subsequent to the year end an agreement was made with the charity to write off part of the balance owed (see note 13) leaving £60,000 payable in the 2024/25 financial year.
Nursing fund - Funds set aside to cover the Nursing service provision for the next 3 years.

continued...

12. MOVEMENT IN FUNDS - continued

Restricted funds:

Orchard Therapeutics - Family Support - this is funds towards the family support activity provided by the Charity.

Orchard Therapeutics - Newsletter - this is funds received towards the costs of generating the newsletter.

Hospital Saturday funds - this is funds towards the nursing service provided by the Charity

Awards for All - this is towards information and support provided by the Charity.

Childwick Trust - this is funds towards Nursing services provided by the Charity.

Family Support - The support fund is there to support eligible families and individuals in the UK affected by CGD who need financial support with any medical related costs.

13. RELATED PARTY DISCLOSURES

A licence fee is paid annually to the Chronic Granulomatous Disorder Society (CGDS), which owns the Jeans for Genes and Genetic Disorders UK (GDUK) trademarks. The fee totalled £644 (2023: £43,000). This is paid by Jeans for Genes Campaign, a charity owned by CGDS.

In a prior year CGDS made a loan to Jeans for Genes Campaign. At the year end the amount owing on this was£60,000 (2023 £100,000), after an agreement was reached with Jeans for Genes Campaign to write offf a balance of £40,000 (included in other expenditure) from the loan to facilitate the winding down of the charity. The agreement for this write off was reached after the balance sheet date but has been reflected within these accounts as an adjusting subsequent event.