CGD Society

Annual Report & Financial Statements 2022–2023

Company no 07607593
Registered charity no 1143049

CGDSociety
Supporting families affected by chronic granulomatous disorder

Contents

1. Charity information

About our Charity

Trustees:

- **Annabel Griffiths** *(appointed September 2021)* – Chair
- **Geoff Creamer** *(appointed April 2011)* – Governance Secretary
- **Ning He** *(appointed October 2015)* – Treasurer
- **Francis Drobniewski** *(appointed September 2023)*
- **Chris Hutchings** *(appointed October 2023)*
- **Alan Keffler** *(appointed September 2023)*
- **Wayne Kitchener** *(appointed October 2023)*
- **Chikai Lai** *(appointed October 2019)*
- **Michael Niles** *(appointed October 2023)*
- **Andrew Orchard** *(appointed April 2011; resigned December 2022)*
- **Kultar Shahi** *(appointed March 2022; resigned August 2023)*

- Executive Director: **Claire Jeffries**
- Community Fundraising and 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, 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

Dr David Lowe, MA MB BChir PhD, FRCP Consultant Clinical Immunologist, Royal Free London NHS Foundation Trust

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 chronic granulomatous disorder (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; and
- such other purposes as are charitable according to the laws of England and Wales for the benefit of the public.

Our vision, mission and strategy

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

Our mission statement: 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’ responsibilities

The Trustees are responsible for preparing the Trustees’ report and the financial statements in accordance with applicable law 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. We said goodbye to one Trustee, Andrew Orchard, in the year ended 31st March 2023.

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 monthly 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.

2. Trustees report

The Trustees present their annual report for the year ended 31st March 2023 under the Companies Act 2006 and the Charities Act 2011, together with the financial statements for that year. The financial statements 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 1,686 members of which the majority are affected individuals or family members; the remainder are supporters and medical professionals. Of those affected, around 250 are in the UK and 246 in the USA. The membership is spread across 50 countries of which UK, USA, Australia, Canada, India, Ireland, France, Spain, China and South Africa make up the top ten. Our membership increased with 75 new members joining in the financial year 2022–2023.

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.

Noah’s Story:
my experience as a young person with CGD

“Well, what a few years it has been for me. I honestly am not here to brag but here to finally talk about it. Let’s start at the end of 2020. Everything was going smoothly. My school grades were improving and I was on track to pass my GCSEs. I felt like I had finally started to work hard for my future dreams. Then in January 2021 I had to have my left testicle removed. This really knocked my confidence. I also said I wouldn’t play football again. I obviously wasn’t thinking straight but I finally played football again mid-February after quickly recovering. I personally didn’t think I’d be back to doing things so fast. I loved being back at school and everything was going smoothly once again until March.

I was doing so well with my football and enjoyed being back to playing the game but with only two games left out of the season I got an abscess on my bottom. Unaware at the time of this abscess, I played one last game and what a funny game it was. We lost 5–4 but it felt like a win with my Dad getting booked by the referee and me scoring a goal. A few days later I found myself in surgery, the first of many. I didn’t play for ages after that. This went on for ages and it is still going on, but we will get to know what happens soon. Anyway, I had a few more surgeries, then we got to around August and I saw my favourite doctor ever. He said he needed to talk to my mum and me, then he walked out of the room and started pacing up the corridor. That’s when I knew something was off.

> **“I then went to London to see Austin and Helen, two other people I trust like they’re family for everything they do for me.”**

He came into the room and sat me down to tell me my CGD had returned. If you don’t know what CGD is, a few bits of info: it’s bad and it makes a lot of people not work to their full potential. He then tells me I might have to have a transplant. That is still a possibility to this day, which I try not to think about.

I then went to London to see Austin and Helen, two other people I trust like they’re family for everything they do for me. They told me there’s more ways to get through this, like a blood infusion where I get a donor to pass blood to me. I am so thankful for that donor, I don’t know what they look like, their name or anything, I only know they are in America right now. I want to meet this person one day.

Then this man called Steve did a few surgeries on me. I never knew him before any of this and I was shocked at how he handled everything. He told me strength never holds back, which is good because I need that sometimes. He then told me I had to have a stoma.

This really scared me, I didn't know how to react. I just cried in my mum's arms like any boy would, because we all know us boys need our mums all the time. I love her to bits, even if she nags at me and tells me to do things, but if she didn't do the nagging then I would probably be lost in this big world already.

I got admitted to hospital where I had the stoma put in. One day in hospital I went to see my brother downstairs. I walked all the way down, that's all I could do because the stoma really made my legs not work, it took me a few tries but we got there. I saw my little brother and he was asking me what it looked like and wanted me to show him, so I did. His little face was so confused, bless him, I can't properly explain it, I wanted to laugh but even that hurt. Then my mum and I walked back to our room and the unthinkable happened – it farted for the first time! I tried not to laugh but my mum couldn't stop laughing, I was crying whilst laughing. We got back to my room and my dad came in. We were FaceTime-ing my grandma, and the doctor walks in and says "hello gorgeous", then my stoma farted at the wrong time again! We were all dying of laughter, even my grandad had a laugh.

There is always hope in everything that happens, you will get through it.

Before I got in the car to go home from the hospital, my dad handed me a Halesowen top with messages from the football team I help coach, which made me cry. When I finally got back home, they were all so happy, it was like a family reunion. The morale of the whole club, even the parents were happy I made it home.

So that's where I am now. I'm now at college doing well and making the best of bad situations. I am about to go for my second blood infusion.

A little message to anyone going through anything right now: I can promise you things get better for you. Never give in, keeping fighting your fight, you will win. There is always hope in everything that happens, you will get through it.

I want to say thank you to everyone who is helping me get through this, I really appreciate every single one of you, I love you all."

We would like to thank Noah for volunteering his time in writing his story.

What did we do this year?

As we all emerged from the Covid pandemic, the NHS started on a long road to recovery from the impact of the pandemic, aiming to restore services, meet new care demands and reduce the care backlogs.[1, 2] Shortages of healthcare professionals have led to challenges in maintaining quality of care and increased workload on staff, with pay disputes often leading to industrial action.[3] Individuals and families affected by CGD have had to navigate this complex environment when trying to secure the appropriate treatment and care from the NHS. Furthermore, the nationwide cost of living crisis is having a wide-reaching impact on individuals in the UK, with many people reporting feelings of anxiety, stress and hopeless due to their current financial situation.[4] Internationally, the Russian invasion of Ukraine prompted a wave in charitable giving across the UK as our attention turned to support the individuals and families affected by this humanitarian crisis.[5]

The support we provide to individuals and families affected by CGD has never felt more important. Our Clinical Nurse Specialist, Helen Braggins, has provided continuous support throughout the year to 162 patients in the UK. Those patients include children and adults with CGD along with their wider family and X-linked carriers. Helen also provided support to 12 patients outside of the UK. This year we have been working closely with Helen to review and improve our nursing service; we have focussed on:

- Establishing a sustainable model for collecting impact data on our nursing service, to support funding applications and direct improvements;

- Increasing the support and connectivity between Helen, Great Ormond Street Hospital and the CGD Society to facilitate the critical work that Helen does.

Based on feedback from our members, who highlighted the value of online events, we held an online coffee and chat with Helen in May 2022 on the topic of bone marrow transplant (BMT). Nine attendees joined from three different countries including the UK, who asked Helen questions about treatment options and connected with other families. We were delighted that all who attended felt they had learnt a great deal about BMT as a treatment option and it helped them to interact with others in a similar situation.

Our staff continued to run our email and telephone helpline, offering guidance and support to 62 people affected by CGD this year, with 31% of those enquiries coming from outside of the UK. Thank you to our dedicated Medical Panel for their ongoing assistance with the helpline.

CGD Society, like many other small charities, have had to face the challenges of the cost of living crisis; the voluntary sector has been plagued by falling income, climbing costs and increasing demand for services.[6] Our Executive Director, Claire Jeffries, was left as our sole member of staff in August 2021, and has continued to work tirelessly to support our membership and run the charity since that time. In May 2022, we were absolutely delighted to welcome Niamh Carmichael into Claire's team, as our new part-time Community Fundraising and Marketing Officer. Part of Niamh's role is to raise funds within our community by building lasting relationships with our fundraisers and donors and show the impact of their donations. Although a tough year for fundraising, Niamh raised £22,898 this year through various fundraising events and online donations. Niamh's role is also critical in our efforts to build a more resilient organisation, by growing our presence on social media channels and supporting those individuals and organisations who raise funds for us.

This year also saw us continue our 'Growth Project' with Almond Tree Strategic Consulting ('Almond Tree') and Robin's Trading Company. Within the 'Growth Project' the Board agreed to use external support to develop an Institutional Fundraising Strategy and process that we can build on in future years. Our Executive Director and a small team of Trustees have been working closely with Almond Tree to identify suitable funding prospects, prepare cases for support, and submit funding applications. The first year of the project was a success securing £21,000 in grants from trusts and foundations, which met the expectations detailed in our budget.

Integral to our 'Growth Project' has been the development of our first Theory of Change model, which describes how the CGD Society will make change happen in the world. It defines all the building blocks (outcomes, results, preconditions and assumptions) required to bring about our long-term goals. This model is enabling us to develop tools to better measure the impact of our activities, such as the Annual Members Survey (now in its second year), and the new Stakeholder Survey being rolled out next year. We are also now able to better collect data from our Clinical Nurse Specialist on both in-clinic support and general support provided, as well as perform social media and website analytics.

The Theory of Change formed a central part of our Annual Strategy Review meeting in February 2023; see 'What do we plan to do next year?' for more details of our goals for the upcoming year. We very much look forward to further utilising this model over the coming years as we seek to achieve our vision of enabling families and individuals affected by CGD to live life to the full.

A snapshot of our Theory of Change model is provided on the next page, with the full model presented in the Appendix. We would like to thank Robin Brady, Social Impact Consultant, for his support in guiding us through this process.

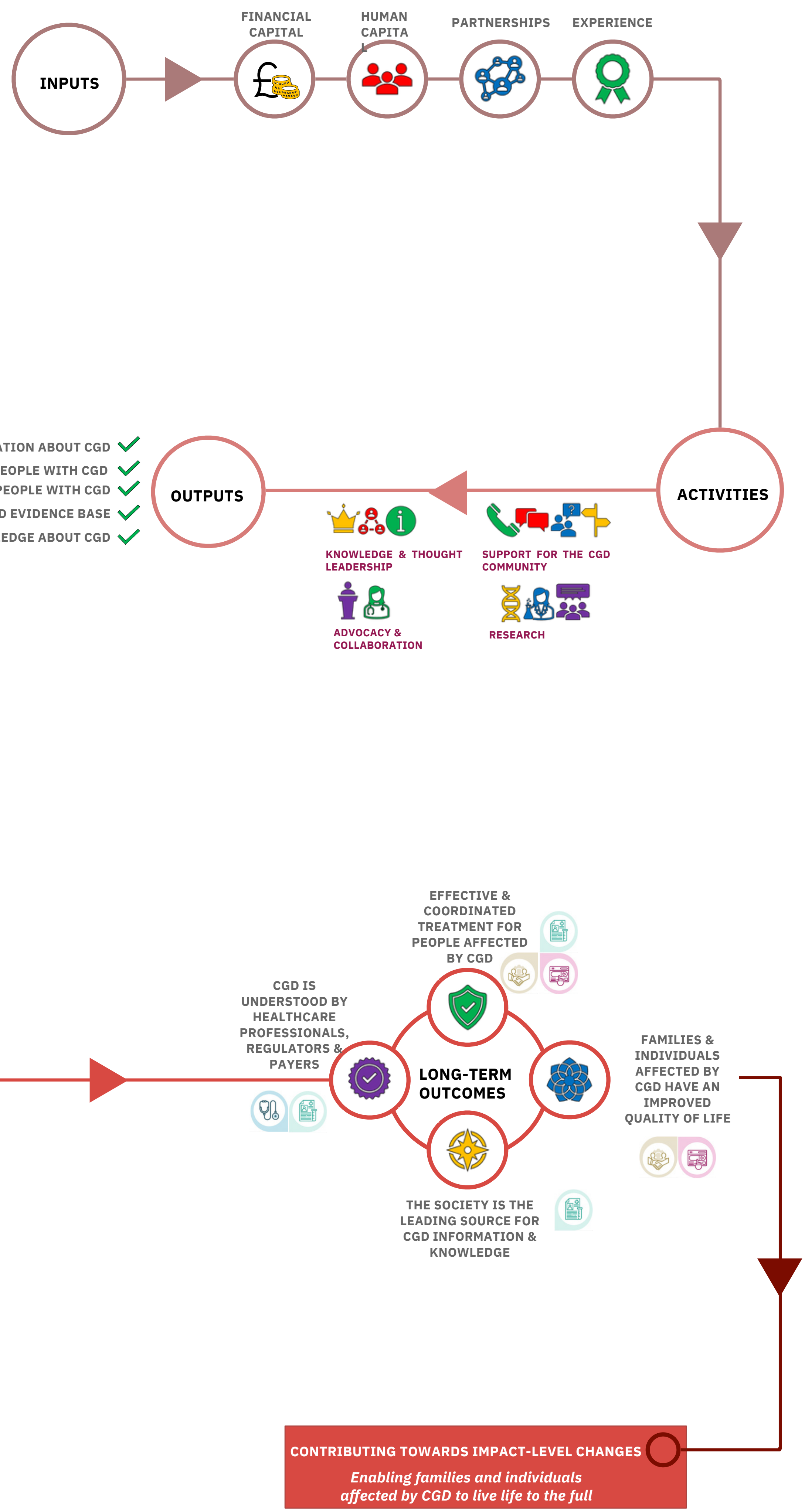
In keeping with our work to build a more resilient and robust organisation, we also invested in a new Customer Relationship Management (CRM) system via the Beacon platform. This has enabled us to better manage our data as well as monitor and improve our fundraising efforts. The platform has made a number of our operational activities more efficient, freeing up valuable time for our staff to focus on membership support. With particular thanks to Andrew Orchard for volunteering his time to support with establishing this crucial asset for the charity.

As an organisation we are committed to ensuring the voices of our CGD families are heard. Our Executive Director, Claire, and Chair of Trustees, Annabel, represented CGD Society at a Parliamentary reception at the House of Commons on Rare Diseases Day 2023 (28th February), which was hosted by Genetic Alliance UK. It was a great opportunity to discuss the experiences and challenges facing our CGD community and wider rare disease network with Parliamentarians, senior decision-makers from the civil service and representatives from other rare disease charities.

Additionally, Claire, Annabel and another of our Trustees, Geoff Creamer, were delighted to participate in the first meeting of the Access to Gene Therapies for Rare Diseases (AGORA)[6] initiative on 22nd September 2022. Claire and Geoff joined a panel focused on the patient perspective, reflecting on the importance of keeping patient groups informed as new therapies are developed. We look forward to contributing further as this innovative initiative gains momentum.

CGDSociety
Supporting families affected by chronic granulomatous disorder

THEORY OF CHANGE



INPUTS

FINANCIAL CAPITAL

HUMAN CAPITAL

PARTNERSHIPS

EXPERIENCE

ACTIVITIES

KNOWLEDGE & THOUGHT LEADERSHIP

SUPPORT FOR THE CGD COMMUNITY

ADVOCACY & COLLABORATION

RESEARCH

OUTPUTS

CLEAR AND ACCESIBLE INFORMATION ABOUT CGD ✓
EFFECTIVE SUPPORT IN CLINCAL SETTINGS FOR PEOPLE WITH CGD ✓
EFFECTIVE SOCIAL SUPPORT FOR PEOPLE WITH CGD ✓
STRONG RESEARCH-LED EVIDENCE BASE ✓
INCREASED DATA & KNOWLEDGE ABOUT CGD ✓

INTERMEDIATE OUTCOMES

GREATER AWARENESS OF CGD

PATIENTS HAVE IMPROVED CARE & CLINICAL OUTCOMES

SUPPORTIVE COMMUNITY OF PEOPLE AFFECTED BY CGD

FAMILIES & INDIVIDUALS HAVE IMPROVED WELLBEING

LONG-TERM OUTCOMES

EFFECTIVE & COORDINATED TREATMENT FOR PEOPLE AFFECTED BY CGD

CGD IS UNDERSTOOD BY HEALTHCARE PROFESSIONALS, REGULATORS & PAYERS

FAMILIES & INDIVIDUALS AFFECTED BY CGD HAVE AN IMPROVED QUALITY OF LIFE

THE SOCIETY IS THE LEADING SOURCE FOR CGD INFORMATION & KNOWLEDGE

CONTRIBUTING TOWARDS IMPACT-LEVEL CHANGES

Enabling families and individuals affected by CGD to live life to the full

For the second year in a row, Claire gave a lecture to MPhil students at Cambridge University, where she spoke about the work of our charity and her own personal CGD story. She also discussed the many challenges faced by families and individuals who are affected by a rare disease. The course organiser fed back that the students were very engaged and asked some really important questions, well done Claire!

Annabel Griffiths was appointed Chair of Trustees on 29th October, taking over the position from Geoff, who had been Chair for six years. Sincere thanks and gratitude to Geoff, who has shown tremendous commitment to and leadership of the Trustee Board during this time. We are delighted that Geoff continues to serve on the Board as Governance Secretary.

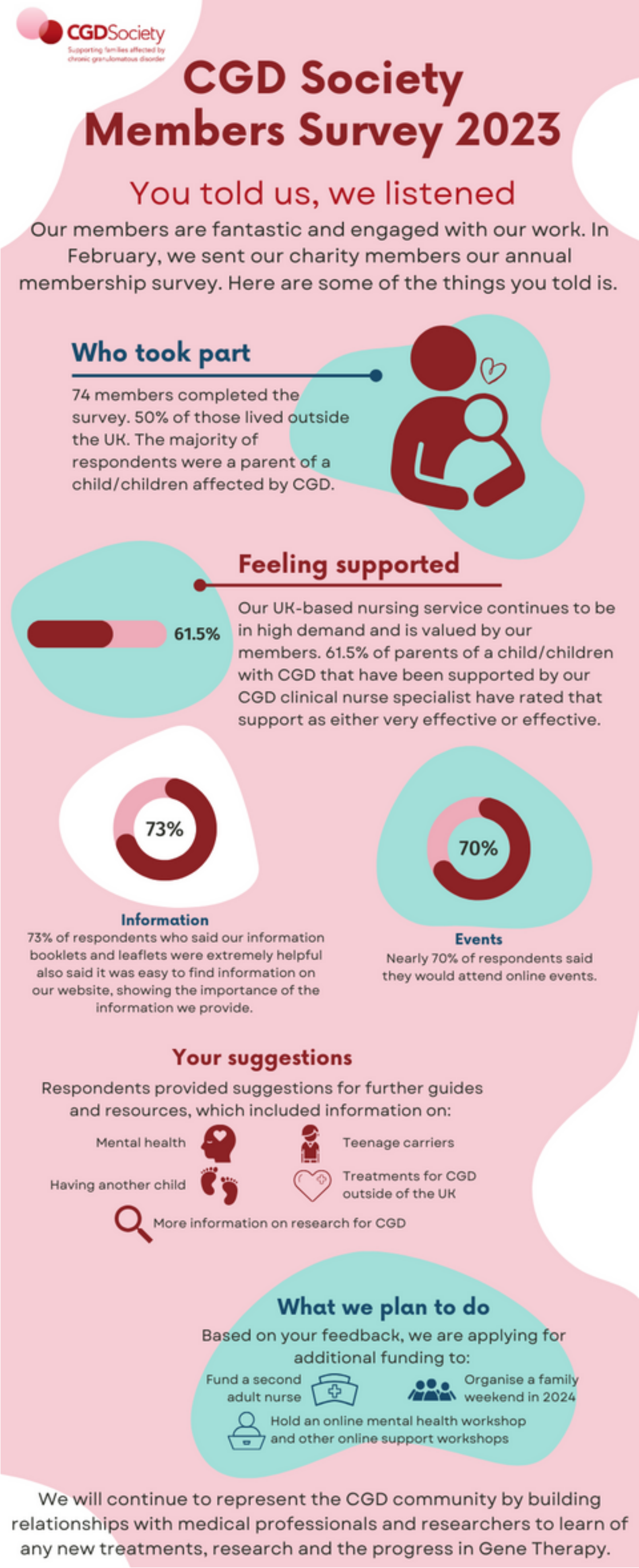
We continued to work in close collaboration with our subsidiary charity Jeans for Genes Campaign who are licensed to use our trademark for this annual fundraising event. It is widely reported that the post-pandemic fundraising landscape is extraordinarily difficult, so it was not surprising that our team faced another challenging year. The death of the Queen followed by two weeks of mourning created an unprecedented threat to their success. Nonetheless we celebrate their tenacity, passion and energy which still delivered a reduced but respectable result whilst continuing their efforts to modernise and re-energise the Jeans for Genes brand.

CGD Society
Annual Members Survey

We produced and sent out our Annual Members Survey in February 2023. These insights are invaluable in shaping our priorities and aims for the upcoming year, and we thank the 74 members who took the time to provide their thoughts. Feedback on our nursing service and information booklets has been particularly helpful in shaping our areas of focus for 2023 and 2024; see 'What do we plan to do next year?' for more details.

> **I've had multiple times where thanks to the CGD society helping me I have been able to get the most accurate care to my needs at the time. When I have tried to do the same via the GP it always goes terribly wrong or I do not receive the care I need, which ends up with me being hospitalised.**

- Feedback from a member with X-linked CGD



CGDSociety

CGD Society Members Survey 2023

You told us, we listened

Our members are fantastic and engaged with our work. In February, we sent our charity members our annual membership survey. Here are some of the things you told is.

Who took part

74 members completed the survey. 50% of those lived outside the UK. The majority of respondents were a parent of a child/children affected by CGD.

Feeling supported

61.5%

Our UK-based nursing service continues to be in high demand and is valued by our members. 61.5% of parents of a child/children with CGD that have been supported by our CGD clinical nurse specialist have rated that support as either very effective or effective.

73%

Information

73% of respondents who said our information booklets and leaflets were extremely helpful also said it was easy to find information on our website, showing the importance of the information we provide.

70%

Events

Nearly 70% of respondents said they would attend online events.

Your suggestions

Respondents provided suggestions for further guides and resources, which included information on:

- Mental health
- Teenage carriers
- Having another child
- Treatments for CGD outside of the UK
- More information on research for CGD

What we plan to do

Based on your feedback, we are applying for additional funding to:

- Fund a second adult nurse
- Organise a family weekend in 2024
- Hold an online mental health workshop and other online support workshops

We will continue to represent the CGD community by building relationships with medical professionals and researchers to learn of any new treatments, research and the progress in Gene Therapy.

This year’s highlights

Support

Our CGD Clinical Nurse Specialist continued providing vital support throughout the year to adults, children, X-linked carriers and wider families affected by CGD. In total, Helen supported 162 families in the UK and supported 12 patients outside the UK.

- The Birmingham Hospitals Trust’s mental health support programme that we are part funding entered its second year.
- We increased our membership by **75 people** including individuals and families affected by CGD, medical professionals and supporters.
- Our email and telephone helpline fielded **62 requests** for support and information.
- Our family support fund **supported 13 UK families** with hardship payments and **23 individuals** benefited from CGD Society-funded prepayment prescription certificates.

Communication

We sent **seven 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.

Funding

Sincere thank you to all of our funders!

Our subsidiary team worked hard to achieve **£434,791** gross income from the Jeans for Genes Campaign.

We were delighted to receive grants from various trusts and foundations this year which totalled **£21,000.**

In what was a difficult year for fundraising due to the cost-of-living crisis we still raised **£22,898** from donations and fundraising activities.

Our Team

Niamh
Community Fundraising and Marketing Officer
Niamh joined us in May 2022

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

Governance

Annabel was appointed Chair of Trustees on 29th October 2022 having served as Vice Chair in the previous year.

Geoff became Governance Secretary after six years of service as Chair of Trustees.

Andrew stepped down from the Board after 31 years of service. Andrew was fundamental in setting up the CGD Research Trust (as we were formally known), which started from a small group of families wanting to know more about CGD and where to turn to for support. We are delighted to say Andrew continues to support CGD Society as a volunteer.

Our annual strategy meeting was held in February 2023 where we defined priorities for the next year with a focus on the activities defined in our Theory of Change model (Appendix: CGD Society – Theory of Change).

Where did our income come from?

Jeans for Genes Campaign

Last year we reported that this campaign delivered a valuable increase in income compared to the 2020 Covid disrupted event and in spite of challenges within our new charitable company and subsidiary, Jeans for Genes Campaign. Hence, we were hopeful that in this report, we would be able to celebrate further income growth for this now stable entity with a permanent CEO and experienced team driving forwards.

Regrettably, that is not the case; the sad passing of the late Queen two weeks before the campaign and subsequent nationwide period of mourning caused a PR blackout which, combined with the cost-of-living crisis and continued Covid fall-out, all conspired to reduce income to £431,000 (2022; £482,000). CGD Society owns the Jeans for Genes trademark and benefits from a licence fee which reduced to £43,000 (2022; £59,000). In these circumstances, the team did a wonderful job to salvage even this modest result.

Nonetheless, we are pleased to report that the Jeans for Genes Board and executive team have implemented solid operational improvements within a culturally responsive organisation. They have launched their Listening Space project to hear, and adapt to, the needs of those in our community and 21 grant recipients have expressed gratitude for these unrestricted awards, which are essential to sustain their small organisations. The Jeans for Genes education materials and campaign narrative continues to improve awareness of inherited conditions and promote a greater understanding of the uniqueness of those affected. Jeans for Genes remains the only targeted fundraiser for the genetic conditions community.

It is now widely reported that the charity fundraising landscape in 2023 is extremely difficult, so it is impossible to predict what the next campaign will deliver. However, we acknowledge the passion and motivation of the Jeans for Genes team as they endeavour to build brand awareness and engagement in this challenging environment. Only by doing so will Jeans for Genes continue to support the lives of those affected by genetic disorders including our CGD membership.

Community fundraising

It was a difficult year for community fundraising as the country faced a cost-of-living crisis. Our team worked hard to raise a total of £22,898, which was 36% below budget (2022; £35,578). Our new Community Fundraising and Marketing Officer, Niamh joined the charity on a part time basis and brought a wealth of marketing and fundraising experience with her.

Niamh and our Executive Director Claire worked together to produce the charity’s community fundraising strategy, which helped identify ways to diversify our community fundraising within the constraints of the charity’s limited resources. Part of the strategy was to run campaigns using our new CRM system and we held a successful Christmas campaign with our CGD Society Virtual Giving Christmas Tree, which raised a total of £640.

Institutional fundraising

Our ‘Growth Project’ continued in earnest and we secured £21,000 in grants from various trusts and foundations, which met our expected income of £20,000. As agreed by the Board, our Executive Director and a small team of Trustees worked with Almond Tree to identify areas of our work where we could potentially seek funding. Almond Tree in turn worked to identify a database of funders and produce a case for funding a specific area of support that we provide to our community. The team also supported Robin Brady in producing our Theory of Change and MEL (monitoring, evaluation and learning) framework, which supports us in assessing the impact of our work.

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

HSF The Hospital Saturday Fund®

MARSH Charitable Trust

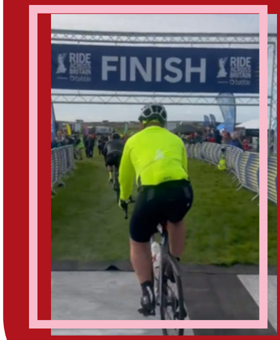
THE CHILDWICK TRUST

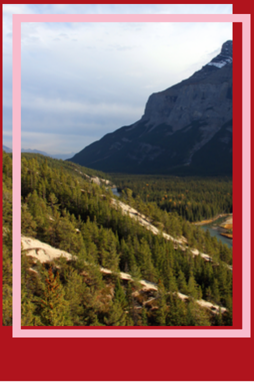
AWARDS FOR ALL

DCT The D’Oyly Carte Charitable Trust

Members fundraising stories

Super cycling





Chris spent 10 days in September cycling an impressive 980 miles, from Land's End in Cornwall to John O'Groats in Scotland, completing the Ride Across Britain challenge and raising **£4,120.**

He took on this mega challenge *"to raise funds for the charity that for many years supported my cousin, who sadly passed away last year, and his family."*

Running to the peak

Nev smashed the Peak District Challenge in July, raising **£1,328.** He ran the mighty 25km loop in the Peak District National Park *"to bring awareness to this disorder that my sister and I were born with."*

Barbeque with a cause

The South West Herts branch of the Vintage Sports-Car Club came together in July and raised **£725** as they enjoyed their barbeque and show of impressive cars. The club chose to fundraise for the CGD Society thanks to the support we gave to a family in the club affected by CGD.

Completing a marathon

Kate completed the Virtual London Marathon in October and raised **£455.** Taking the virtual option meant she could take on the 26-mile challenge with the company of supportive friends and family, even her dog Rufus joined her for part of it.
Kate says:

"I decided to fundraise for the CGD Society because of my friend Becca's son, Albie, and his amazing family's strength and courage, and because this is an incredibly rare condition. The CGD Society has helped Becca’s family to understand the complexity of CGD."

Expenditure, investments and reserves

Expenditure

Our total spend for the year was £171,158. The largest proportion (42%) was spent on direct support for those living with CGD; £72,673 (2022; £77,784) supported the nursing service, the family support fund and the email and phone helpline. Education is an equally important form of support to our members via website content development and information booklets. This year we increased our spend on education to £33,905 (2022; £20,973), which was 20% of our total spend.

We continued to part fund the project to provide mental health support to the Birmingham Hospitals Trust, through a contribution of £5,000 (2022; £5,000) for the second year. This research expenditure amounted to 3% of our total spend.

The remaining costs were 31% for fundraising at £52,494 (2022; £16,949), and 4% for governance at £7,086 (2022; £2,909). The additional spend, as compared to 2022, was used to cover continued support from Almond Tree and the hire of a dedicated Community Fundraising and Marketing Officer, Niamh. This additional expenditure includes significant one-off set up costs to support our continued efforts to diversify income and combat the challenges of the Covid pandemic and cost-of-living crisis on the fundraising environment. We expect fundraising expenditure to reduce in proportion to overall expenditure in the next reporting year.

Overall, the net movement of funds was a deficit of £78,160 (2022; surplus of £3,245) excluding revaluation of investments. This was slightly worse than the planned budget for the year, which predicted a deficit of £70,204. This was due to the reduction in income through the year exceeding our reduction in expenditure.

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 2023, stock markets have been trading in a narrow range, whilst for much of that period bond markets suffered from expectations of higher interest rates. Believing inflation was temporary, central banks had initially been slow to act on raising interest rates and then played catch over the second half of 2022 and the beginning of 2023.

Speculation on how high inflation will go and when interest rates would peak was the main driver of markets. In March 2023 the collapse of Silicon Valley Bank in the US raised concerns of another Global Financial Crisis and for a short time eased expectations of higher interests.

As of 31 March 2023, the portfolio value stood at £150,268 (2022: £158,147).

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 August 2023. It states that the charity must retain free reserves to cover 6–12 months of budgeted running costs for the year ahead, i.e. £79,000–£157,000 based on the expenditure budget of £157,000 adopted by the Trustees.

At the accounting date, the CGD Society has total reserves of £372,166, comprised of:

- £15,050 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. (£100,000 outstanding).
    - Designated funds to cover contract commitments for the nursing service. (£140,342).

Therefore, the CGD Society has closing free reserves of £116,774 (2022; £139,247) which meets the reserves policy target and equates to approximately 9 months of planned expenditure for the year ahead.

What do we plan to do next year?

With our Theory of Change model now in place, this year's strategic objectives have been designed around four categories of activities that will drive us towards our vision enabling families and individuals affected by CGD to live life to the full.

Support for the CGD community

As always, our first priority is to provide comprehensive support to our membership. Our Clinical Nurse Specialist, helpline and patient events 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, with particular attention to the feedback from our Annual Members Survey. Notably we will continue to explore opportunities through our nursing service review (see What did we do this year?) with our next focus being optimising the funding model for this critical service. We believe that achieving this objective will support our longer-term aims of ensuring sustainability of the nursing service by developing our partnerships and diversifying our income, and, when funding allows, exploring the feasibility of a future expansion of our nursing service to meet the needs of our adult members.

Following on from the success of our initial online coffee and chat event with Helen (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 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

We understand from our Annual Members Survey the critical importance of the information included in our website. The survey highlighted the fact that people with CGD supplement the clinical support they receive by making use of the information we publish on our website. We had 27 views of the top 10 advice pages of our website in 2022/23. 57% of members tell us that they use the information that we publish there, with a quarter telling us that they go to the website first and 76% saying that the information is either extremely helpful or helpful (67% specifically mention our medical leaflets and guides). Website visitors value access to a wide range of information. The newly diagnosed section is particularly valued, as are the sections on preparing for a BMT and information on children affected by CGD. We aim to be the leading source for CGD information and knowledge and are committed to ensuring the provision of the most up to date information. With this in mind, we will embark on a project to update our medical information materials with a focus on those that are used most frequently by our CGD community. We are delighted to have secured pro bono support from Costello Medical for this purpose and look forward to progressing this project in close collaboration with our Clinical Nurse Specialist and Medical Panel.

We further acknowledge the importance of continually reviewing our website for usability and accessibility. In May 2022 Costello Medical undertook a pro bono project to appraise our current website and made recommendations for its optimisation. We are currently determining the priority requirements and will then aim to secure funding to enable their implementation.

Research

Through our Clinical Nurse Specialist and correspondence between our staff and members, we have gained a greater understanding of the mental health needs of our community; a topic that has never been more important considering the strains of the pandemic and continued cost-of-living crisis. We will explore opportunities for collaboration with Rareminds, a specialist organisation that advocates for, and provides, mental health support for the rare disease community. Having defined the scope of support considered most appropriate for our community, we will begin fundraising to make these plans a reality.

Whilst it was decided, due to funding limitations, that recruitment of Medical/Technical officer was not achievable this past year, we remain extremely mindful of the limited capacity of our dedicated staff. We will continue to review our recruitment needs as an organisation and will determine this year whether future hires are needed and achievable in the intermediate term.

Advocacy and collaboration

We are delighted that our Executive Director Claire and a number of Trustees have been able to represent the CGD Society at several events this year (see What did we do this year?). We look forward to continuing to engage in national and international rare disease forums, with a keen focus on identifying potential collaborations that may offer benefits to our CGD community.

Our partnership with our subsidiary charity Jeans for Genes Campaign will be a priority area for us this coming year, as we seek to find the best ways to support and facilitate their vision and mission.

Underpinning our ability to achieve these aims is our continued focus on building a more sustainable organisation. We will continue our efforts to diversify our income with support from Almond Tree, with this next year focusing on grant applications that will help fund our support services, which include our telephone and email helpline and our regular newsletters. We will also focus on securing funding for a future family event to bring CGD individuals and families together and provide updates on the latest scientific advances from CGD medical professionals. We will also be inviting our membership to complete our Annual Members Survey to help us understand the needs of the CGD community and our impact as a charity. Following completion of these objectives, we then hope to make progress towards unlocking further opportunities in institutional and corporate fundraising.

We will action a recruitment drive for more Trustees to join our Board, with a focus on addressing gaps in our current Board's experience and expertise. This larger Board will allow longstanding Trustees to retire and to facilitate succession planning. We look forward to finding and welcoming committed individuals that will bring new perspectives and additional value to our charity and the CGD community.

2022–2023 summary

This year we have taken significant steps to increase our sustainability, with the recruitment of our Community Fundraising and Marketing Officer and the continuation of our 'Growth Project'. The development of our Theory of Change model has provided a pivotal step forward in how we design our strategy and focus our impact measures on achieving our charity's vision. We have developed our understanding and capabilities with respect to grant funding, with much valued support from Almond Tree.

The above being said, it is without doubt that we, as is the case for many charities, have faced a challenging fundraising environment. Our income has been lower than expected, despite the great efforts of our community fundraisers. The effects of the reduced income from the 2022 Jeans for Genes campaign have been felt by us and other organisations who rely on this much needed support. We must, therefore, focus our efforts on managing expenditure and updating our fundraising approaches to adapt to this new fundraising environment. We particularly hope to be able to support our subsidiary charity Jeans for Genes Campaign as they seek to increase income and rejuvenate the campaign after a challenging year.

We are delighted to have received such valuable feedback from the second year of our Annual Members Survey and have used these insights, together with our Theory of Change model, to develop our strategic objectives. With our areas of focus clear, and our committed and talented staff, we look forward to increasing the sustainability of our organisation and continually improving the support we offer individuals and families affected by CGD.

This report was approved by the Trustees on 6th December and signed on their behalf by:

....

Dr Annabel Griffiths
Chair

3. 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

With thanks to Chloe Austin, Costello Medical, for graphic design assistance.

4. Financial statements for the year ended 31 March 2023

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 2023

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

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 2023.

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

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

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

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Hazel Day BSc DChA FCA

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

Date: ....

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

Statement of Financial Activities
for the year ended 31 March 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	26,898	17,000	43,898	65,471
Investment income	3	6,100	-	6,100	2,129
Other income		43,000	-	43,000	59,260
Total		75,998	17,000	92,998	126,860
EXPENDITURE ON					
Raising funds	4	52,494	-	52,494	16,949
Charitable activities	5				
Relief		61,472	11,201	72,673	77,784
Education		33,905	-	33,905	20,973
Medical Research		5,000	-	5,000	5,000
Governance		7,086	-	7,086	2,909
Total		159,957	11,201	171,158	123,615
Net gains/(losses) on investments		(6,320)	-	(6,320)	7,260
NET INCOME/(EXPENDITURE)		(90,279)	5,799	(84,480)	10,505
RECONCILIATION OF FUNDS					
Total funds brought forward		447,395	9,251	456,646	446,141
TOTAL FUNDS CARRIED FORWARD		357,116	15,050	372,166	456,646

The notes form part of these financial statements

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY (REGISTERED NUMBER: 07607593)

Balance Sheet
31 March 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
FIXED ASSETS					
Investments	9	150,269	-	150,269	158,148
CURRENT ASSETS					
Debtors	10	126,569	-	126,569	184,399
Cash at bank		95,601	15,050	110,651	130,795
		222,170	15,050	237,220	315,194
CREDITORS					
Amounts falling due within one year	11	(15,323)	-	(15,323)	(16,696)
NET CURRENT ASSETS		206,847	15,050	221,897	298,498
TOTAL ASSETS LESS CURRENT LIABILITIES		357,116	15,050	372,166	456,646
NET ASSETS		357,116	15,050	372,166	456,646
FUNDS	12				
Unrestricted funds				357,116	447,395
Restricted funds				15,050	9,251
TOTAL FUNDS				372,166	456,646

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

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and

(b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

continued...

Balance Sheet - continued
31 March 2023

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

....
Dr A Griffiths - 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

	2023 £	2022 £
Donations	22,898	35,578
Grants	21,000	29,893
	43,898	65,471

continued...

2. DONATIONS AND LEGACIES - continued

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

	2023 £	2022 £
Bryant Fund	-	5,000
Orchard Therapeutics - Family support	-	3,000
Orchard Therapeutics - Newsletters	-	4,000
Caf resilience fund	-	17,893
National Lottery Awards for All	10,000	-
Childwick Trust	5,000	-
The Hospital Saturday Fund	2,000	-
D'Oyly Carte Charitable Trust	3,500	-
The Marsh Charitable Trust	500	-
	21,000	29,893

3. INVESTMENT INCOME

	2023 £	2022 £
Loan interest received	6,100	2,129

4. RAISING FUNDS

RAISING DONATIONS AND LEGACIES

	2023 £	2022 £
Direct and support costs	50,935	16,132

INVESTMENT MANAGEMENT COSTS

	2023 £	2022 £
Portfolio management	1,559	817
Aggregate amounts	52,494	16,949

continued...

5. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 6) £	Totals £
Relief	59,471	13,202	72,673
Education	10,762	23,143	33,905
Medical Research	5,000	-	5,000
Governance	7,086	-	7,086
	82,319	36,345	118,664

6. SUPPORT COSTS

	Management £
Relief	13,202
Education	23,143
	36,345

7. TRUSTEES' REMUNERATION AND BENEFITS

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

TRUSTEES' EXPENSES

There were trustees' expenses paid for the year ended 31 March 2023 totalling £663 (2022 £180) to 2 trustees..

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2021-22

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	35,578	29,893	65,471
Investment income	2,129	-	2,129
Other income	59,260	-	59,260
Total	96,967	29,893	126,860
EXPENDITURE ON			
Raising funds	16,949	-	16,949
Charitable activities			
Relief	53,727	24,057	77,784
Education	20,973	-	20,973
Medical Research	5,000	-	5,000
Governance	2,909	-	2,909
Total	99,558	24,057	123,615

continued...

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2021-22 - continued

	Unrestricted funds £	Restricted funds £	Total funds £
Net gains on investments	7,260	-	7,260
NET INCOME	4,669	5,836	10,505
RECONCILIATION OF FUNDS			
Total funds brought forward	442,726	3,415	446,141
TOTAL FUNDS CARRIED FORWARD	447,395	9,251	456,646

9. FIXED ASSET INVESTMENTS

	Listed investments £	Unlisted investments £	Totals £
MARKET VALUE			
At 1 April 2022	158,147	1	158,148
Disposals	(1,559)	-	(1,559)
Revaluations	(6,320)	-	(6,320)
At 31 March 2023	150,268	1	150,269
NET BOOK VALUE			
At 31 March 2023	150,268	1	150,269
At 31 March 2022	158,147	1	158,148

There were no investment assets outside the UK.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Other debtors	100,123	150,000
VAT	1,138	239
Prepayments and accrued income	25,308	34,160
	126,569	184,399

continued...

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade creditors	12,544	13,352
Social security and other taxes	(73)	229
Other creditors	1,352	1,615
Accruals and deferred income	1,500	1,500
	15,323	16,696

12. 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

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)

continued...

12. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.4.21 £	Net movement in funds £	Transfers between funds £	At 31.3.22 £
Unrestricted funds				
General fund	192,726	4,669	(58,148)	139,247
Jeans for Genes support	250,000	-	(100,000)	150,000
Nursing fund	-	-	158,148	158,148
	442,726	4,669	-	447,395
Restricted funds				
Family Support	243	4,116	-	4,359
Orchard Therapeutics (Family Support)	500	2,500	-	3,000
Orchard Therapeutics (Newsletter sponsorship)	2,422	(530)	-	1,892
Emergency Leaflet	250	(250)	-	-
	3,415	5,836	-	9,251
TOTAL FUNDS	446,141	10,505	-	456,646

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	96,967	(99,558)	7,260	4,669
Restricted funds				
Family Support	5,000	(884)	-	4,116
Orchard Therapeutics (Family Support)	3,000	(500)	-	2,500
Orchard Therapeutics (Newsletter sponsorship)	4,000	(4,530)	-	(530)
Emergency Leaflet	-	(250)	-	(250)
CAF Patient Organisations Recovery Fund	17,893	(17,893)	-	-
	29,893	(24,057)	-	5,836
TOTAL FUNDS	126,860	(123,615)	7,260	10,505

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. This is repayable over 4 years with £100,000 outstanding at 31st March 2023.

continued...

12. MOVEMENT IN FUNDS - continued

Nursing fund - During the year, the previous investment fund was redesignated for the Nursing contract. The funds have been set aside to cover the contract until it expires.

Restricted funds:
Bryant Ltd - this is funds towards the family support activity provided by the Charity.
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.
Emergency Leaflet - these were funds received towards the costs of an emergency leaflet produced by the Charity.
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.
Child Wick Trust - this is funds towards Nursing services provided by the Charity.

TRANSFERS BETWEEN FUNDS

The transfer between funds is to correct a prior year error where restricted costs where allocated against the general fund.

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 £43,000 (2022: £59,260). This is paid by Jeans for Genes Campaign, a charity owned by CGDS. As at 31st March 2023 an amount of £25,308 was unpaid and included within accrued income.

During the previous year CGDS made a loan to Jeans for Genes Campaign. At the year end the amount owing on this was £100,000 (2022 £150,000). This attracts interest at 3.25% above base rate.

5. References

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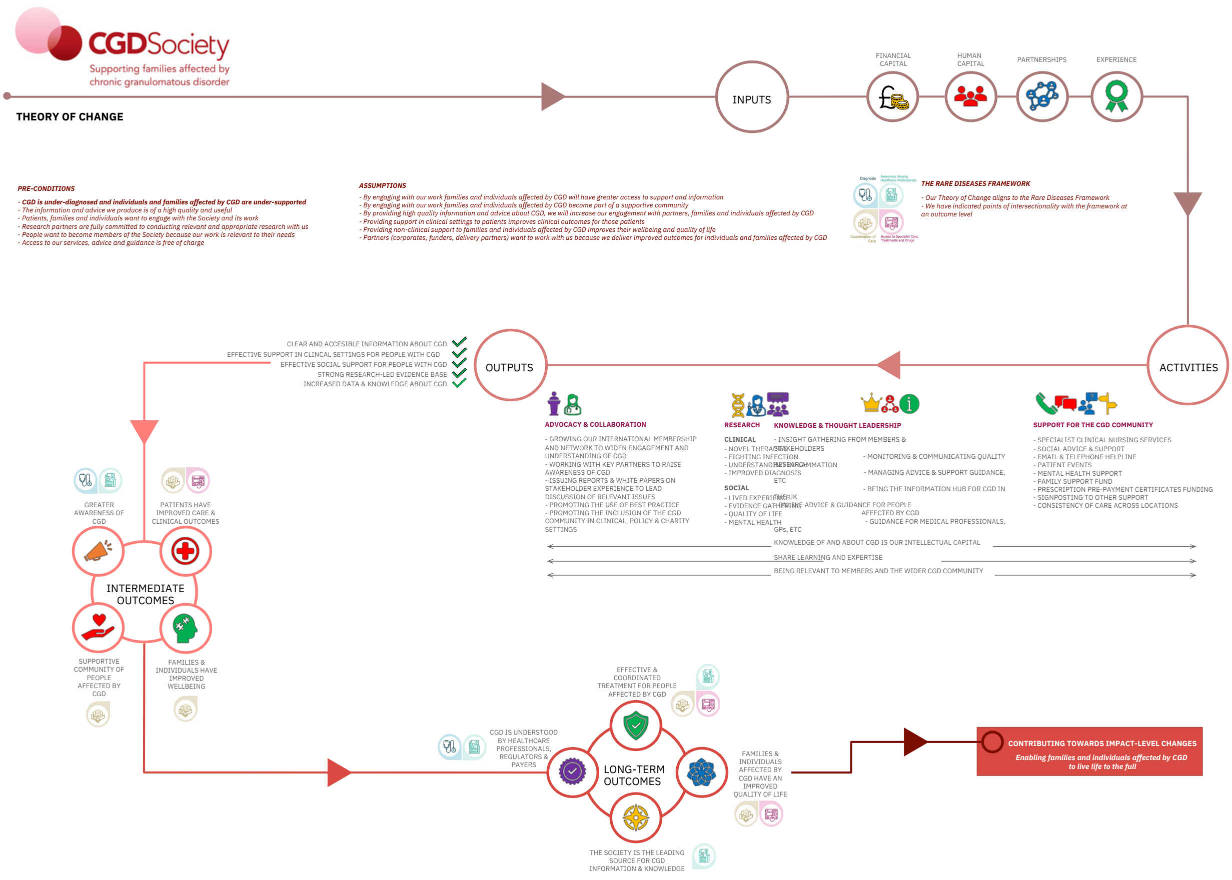
5. Charity Times. Ukraine Crisis Prompts Surge in Giving across Charity Sector. 2022. Available from: https://www.charitytimes.com/ct/Ukraine-crisis-prompts-surge-in-charitable-giving.php. Last accessed: 04.12.23.
6. National Council for Voluntary Organisations (NCVO). Meeting the Challenges of a Cost of Giving Crisis This Winter. 2023. Available from: https://www.ncvo.org.uk/news-and-insights/news-index/meeting-challenges-of-cost-of-giving-crisis/. Last accessed: 19.11.2023.
7. Fox, T; Bueren, J; Candotti, F et al. Access to Gene Therapy for Rare Diseases When Commercialization Is Not Fit for Purpose. Nat Med. 2023;29(3):518-519.

6. Appendix: CGD Society – Theory of Change

Our Theory of Change model describes how CGD Society will make change happen in the world. It defines all the building blocks (outcomes, results, preconditions, assumptions) required to bring about our long-term goals.



THEORY OF CHANGE

PRE-CONDITIONS

- ***CGD is under-diagnosed and individuals and families affected by CGD are under-supported***
- *The information and advice we produce is of a high quality and useful*
- *Patients, families and individuals want to engage with the Society and its work*
- *Research partners are fully committed to conducting relevant and appropriate research with us*
- *People want to become members of the Society because our work is relevant to their needs*
- *Access to our services, advice and guidance is free of charge*

ASSUMPTIONS

- *By engaging with our work families and individuals affected by CGD will have greater access to support and information*
- *By engaging with our work families and individuals affected by CGD become part of a supportive community*
- *By providing high quality information and advice about CGD, we will increase our engagement with partners, families and individuals affected by CGD*
- *Providing support in clinical settings to patients improves clinical outcomes for those patients*
- *Providing non-clinical support to families and individuals affected by CGD improves their wellbeing and quality of life*
- *Partners (corporates, funders, delivery partners) want to work with us because we deliver improved outcomes for individuals and families affected by CGD*

THE RARE DISEASES FRAMEWORK

- *Our Theory of Change aligns to the Rare Diseases Framework*
- *We have indicated points of intersectionality with the framework at an outcome level*

ADVOCACY & COLLABORATION

- GROWING OUR INTERNATIONAL MEMBERSHIP AND NETWORK TO WIDEN ENGAGEMENT AND UNDERSTANDING OF CGD
- WORKING WITH KEY PARTNERS TO RAISE AWARENESS OF CGD
- ISSUING REPORTS & WHITE PAPERS ON STAKEHOLDER EXPERIENCE TO LEAD DISCUSSION OF RELEVANT ISSUES
- PROMOTING THE USE OF BEST PRACTICE
- PROMOTING THE INCLUSION OF THE CGD COMMUNITY IN CLINICAL, POLICY & CHARITY SETTINGS

RESEARCH

CLINICAL

- NOVEL THERAPIES
- FIGHTING INFECTION
- UNDERSTANDING INFLAMMATION
- IMPROVED DIAGNOSIS

SOCIAL

- LIVED EXPERIENCE
- EVIDENCE GATHERING
- QUALITY OF LIFE
- MENTAL HEALTH

KNOWLEDGE & THOUGHT LEADERSHIP

- INSIGHT GATHERING FROM MEMBERS & STAKEHOLDERS
- MONITORING & COMMUNICATING QUALITY RESEARCH
- MANAGING ADVICE & SUPPORT GUIDANCE, ETC
- BEING THE INFORMATION HUB FOR CGD IN THE UK
- ONLINE ADVICE & GUIDANCE FOR PEOPLE AFFECTED BY CGD
- GUIDANCE FOR MEDICAL PROFESSIONALS, GPs, ETC

SUPPORT FOR THE CGD COMMUNITY

- SPECIALIST CLINICAL NURSING SERVICES
- SOCIAL ADVICE & SUPPORT
- EMAIL & TELEPHONE HELPLINE
- PATIENT EVENTS
- MENTAL HEALTH SUPPORT
- FAMILY SUPPORT FUND
- PRESCRIPTION PRE-PAYMENT CERTIFICATES FUNDING
- SIGNPOSTING TO OTHER SUPPORT
- CONSISTENCY OF CARE ACROSS LOCATIONS

KNOWLEDGE OF AND ABOUT CGD IS OUR INTELLECTUAL CAPITAL

SHARE LEARNING AND EXPERTISE

BEING RELEVANT TO MEMBERS AND THE WIDER CGD COMMUNITY

CLEAR AND ACCESIBLE INFORMATION ABOUT CGD ✓
EFFECTIVE SUPPORT IN CLINCAL SETTINGS FOR PEOPLE WITH CGD ✓
EFFECTIVE SOCIAL SUPPORT FOR PEOPLE WITH CGD ✓
STRONG RESEARCH-LED EVIDENCE BASE ✓
INCREASED DATA & KNOWLEDGE ABOUT CGD ✓

CONTRIBUTING TOWARDS IMPACT-LEVEL CHANGES

Enabling families and individuals affected by CGD to live life to the full