Company no 07607593
Regd charity no 1143049

CGD SOCIETY

ANNUAL REPORT & FINANCIAL STATEMENTS 2021-2022

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CGDSociety
Supporting families affected by chronic granulomatous disorder

About our charity

Trustees (* indicates a member of a family affected by CGD) :
Dr Geoff Creamer* – Chair
Ning He*
Jackie Irvine* @
Annabel Griffiths (appointed 4-9-21)
Jane Docherty*
Chikai Lai
Jayne Nicol @
Kultar Shahi (appointed 22-1-22)
Andrew Orchard*
Davina Gray* @
David Hannard* @

Note: Those marked @ resigned within the year.

Operations and Fundraising Manager (now Executive Director): Claire Jeffries
Fundraising and Marketing Officer: Adelle Scott (resigned 31st August 2021)
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: Smith & Williamson, Portwall Place, Bristol BS1 6N

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.
- Dr Janine Reichenbach, MD, Assistant Professor for Paediatric Immunology at University of Zurich, and Co-Head of the Division of Immunology at University Children's Hospital, Switzerland.
- Dr Sergio Rosenzweig, MD, PhD, Paediatrician, Director of the Primary Immunodeficiency Clinic at the National Institutes of Health (NIH), and Deputy Chief of the Immunology Service, 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.

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: Enabling families and individuals affected by CGD to thrive and live life to the full
Our Mission: To continue to inform and support the whole of the CGD community
Our Mission strategy:
To be the leading source of information and support for individuals and families affected by CGD both in the UK and around the world. By sharing the learning and expertise from UK patients and the medical professionals who treat them, the CGD Society has become the leading global authority on CGD and an organisation that is respected by affected families and medical professionals on an international scale.

Statement of Trustees' responsibilties

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 18 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. Andrew Orchard and Geoffrey Creamer resigned at the AGM 16-10-21 but were reappointed even though they have exceeded this nine year limit. Jane Docherty and Ning He were similarly reappointed for their 2nd and 3rd period respectively. We said goodbye to four trustees this year but welcomed two new recruits following a skills assessment and recruitment campaign.

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.

Trustees' report

The trustees present their annual report for the year ended 31 March 2022 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 2060 members (at year end) of which approximately half are affected individuals or family members and the remainder are supporters and medical professionals. Of those affected, around 400 are in the UK and 350 in the USA. The membership is spread across 50 countries of which UK, USA, Australia, Canada, India, Ireland, New Zealand and South Africa make up the top ten. Membership has increased by 57 (about 3%) over the year.

ABOUT CHRONIC GRANULOMATOUS DISORDER

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 curative stem cell transplant option have transformed the prospects for the modern patient but nonetheless this disease is still hard to live with. 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 sub group of patients affected by CGD.

Carly's story:

Being a carrier of X-linked CGD

It's a harsh fate, having to live with a rare, genetic and life-limiting blood disease such as CGD – most of our members will know only too well the pain and anguish it can bring to the lives of those who live with the condition.

Equally, we can easily imagine and have compassion for the emotional suffering and heartbreak of their families. Yet, there is a significant part of this story that has (until recently) been left unwritten and is therefore little understood: that is the additional *physical* burden of pain and suffering that CGD mothers also share alongside their children.

We have known for a long time that X-linked CGD (XL-CGD) is passed from mother to son in 50% of cases. We have also known for a long time that, as if the burden of guilt at passing CGD to your boys were not enough, some XL-CGD carriers suffered with unexplained and sometimes severe symptoms - without really knowing the cause. As was the case with my own mother, much was (and probably still is) attributed solely to the emotional stress or depression caused by the rollercoaster ride that is having a very sick child. Debilitating and painful conditions such as skin lesions and infections, severe mouth ulceration, chronic fatigue, increase in mood swings and even serious debilitating inflammatory conditions similar to Lupus all slipped under the radar and went medically unexplained.

Now, however, thanks to a slowly growing body of literature based on relatively recent scientific discoveries, we know that mums (and sisters) of XL-CGD boys also have impaired immune systems which can explain these symptoms. Sometimes the impairment of the XL-CGD carrier's own immune system is so great that they too could be classed as having CGD.

Carly Koncuk knows this from personal experience. She is well versed in what it means to be a part of a CGD family: her elder brother, Anthony, was born with the condition and since before she can remember, she has grown up sharing in the pain, suffering, fear and anxiety which affects everyone in a CGD family.

As a child she knew from an early age she would be a carrier but was too young to appreciate the consequences of this as she hadn't thought about having children. However, later in her life, when she did start a family with her husband Kadir it really began to sink in.

"I needed to tell my partner about it. I contacted the CGD Society and spoke to Rosemarie who sent letters to doctors in Turkey where I was living at the time to get my first baby, Murat, tested."

Murat was tested and was negative. During her next pregnancy, however, after she discovered that she would be having a second son, a maternal instinct told her that he would have CGD. "I've got one healthy son – nobody gets that lucky a second time." Aydin was born with multiple fistulas and Carly knew immediately he had CGD. And *her* Mum knew it too. Carly's mum, Debbie, has been through this journey herself with Anthony and has been a huge source of strength and support to Carly right from day one. Aydin was tested at one day old and, as Carly predicted, was positive: Carly's new family would be living with CGD.

"My hormones were all over the place and I just broke down" she said.

Two years later, Aydin's consultants were advising Carly to continue with prophylaxis as he was generally well and they were concerned about the very real risks of him having a hematopoietic stem-cell transplant, as it was known before. But Carly had already made a plan. She had previously been in contact with the CGD Society and attended our weekend conferences where families affected by the disease can get together, share their experiences, listen to experts and get advice. She learned the success rates now are close to 90% for young children. Armed with this information, plus having seen what her brother Anthony had been through as a child and an adult having not had a transplant as a baby, there was no discussion to be had. “I was steadfastly determined that Aydin should have a transplant.”

Aydin had his transplant and, in spite of some rocky, frightening moments, the graft took and he is now a bouncing, vivacious and healthy boy, cured of CGD. And of course, Carly’s brother, Anthony, took the difficult decision himself to have an HSCT as an adult and is doing well having celebrated his “first birthday” on 28th February this year.

Yet as any XL-CGD mum knows, being a carrier means this is far from being the end of the story for Carly. Carly herself has a neutrophil burst deficiency of 87% so is immuno-compromised and suffers daily from the debilitating effects of Lupus and extreme fatigue. She doesn’t let this get in the way of training to be nurse, working three days per week as a part-time health care assistant whilst at the same time, of course, raising her family.

"You’ve just got to get on with it” she says, brushing aside my astonishment at how she copes. “Life goes on – my mum dealt with it so I knew I could get through it as well.”

Debbie, also an XL-CGD carrier, experiences many of the typical symptoms but is especially plagued by mouth ulcers and severe photosensitivity and blistering (getting easily sunburnt), and has recently begun to struggle with her joints and a vitamin B deficiency – a common issue in XL-CGD carriers.

Debbie was able to support Carly before and after Aydin was born. Early on she provided the necessary urgency when he so much as developed a spot, cough or splutter, reminding Carly of the importance of early action. She would have schooled her too in the art of badgering duty doctors who know nothing about CGD to give you the right treatment in the right doses – a regular battle every one of us who copes with CGD has to fight on a regular basis when we are taken ill suddenly and can’t see our regular consultants.

Now, however, the fight has shifted focus onto the carriers. The battle is only just beginning to get doctors, even the more senior ones, to take XL-CGD carriers more seriously when it comes to their own health and getting for themselves the right treatment in the right doses. “It’s a constant battle” she told me. Carly reads me a letter she sent to her own GP after the most recent attempt to get some antibiotics for an infection went unheard. She wrote: “I would highly recommend you draw the attention of your staff to the CGD Society website – as a carrier of CGD there are serious consequences and complications if treatment is not prescribed quickly and correctly.” Their response was to suggest she seek care at another practice if she could not place her trust in them.

Trust! It is extraordinary that in this day and age, there are still doctors simply unwilling to take the time to listen and consider the possibility that there may be something they can learn from their patients. As someone whose life has been dominated by this rare and potentially fatal disease and knows the potential power of the pain and havoc it can wield over her life as a sister, a mother and now too as a patient, trust is something that needs to be earned.

As someone who also knows this disease intimately, I can attest to the fact that this lady is not for turning. She knows what she’s talking about and what’s best for herself and her family. She will never give up.

We would like to thank Simon Bostic for volunteering his time in writing Carly's story. Simon has CGD and is an advocate in raising awareness of the condition.

What did we do this year?

In this our 30th anniversary year, the Covid pandemic remained an enduring backdrop. The introduction of effective vaccines at the end of 2020 and the growth of immunity in the population did give all of us an exit to something more like normality by the end of this financial year. However, the emergence of the Omicron variant at the end of 2021 reminded us that we must live with this virus and the risk to health has not gone away, especially for our vulnerable CGD affected cohort. Thankfully, our new immunity proved sufficiently resilient, and all UK Covid restrictions were finally lifted in February 2022.

Nonetheless, in the UK we now have health services severely bruised by the impact of Covid, so true recovery will take many more years. GP appointments are scarce, there are over 6 million referrals in the NHS queue, ambulance services are under enormous strain, and waiting times in A&E departments are extraordinary. More worrying perhaps is the impact on mental health, with the Royal College of Psychiatrists reporting unprecedented demand for services in 2021. Thank goodness that we have been able to maintain our nursing service throughout, which gives our UK membership that crucial point of contact who can advocate for priority access when required.

Thankfully CGD clinics in the UK restarted in spring 2021 so our nurse Helen Braggins was able to return to something like her normal role after the disrupted lockdown period. Likewise, our helpline stayed open with the support of our Medical Panel when required. We thank these busy clinicians for their continued assistance.

In April 2021, Susan Walsh left us to become the CEO of a new charity, ImmunodeficiencyUK, which is an umbrella patient organisation advocating on behalf of Primary Immunodeficiencies. CGD is one of 350 such conditions.

Susan joined us in 2002 to set up our research funding procedures that steered almost £3.5m of grants into frontline CGD research. More recently she has been responsible for the development of our website and booklet information, as well as tracking and reporting on external research and clinical developments of relevance to our knowledge base. With her scientific research background, Susan brought rigour, accuracy and challenge to our technical portfolio. We thank her for her exemplary contribution over 19 years and wish her well in her new role.

After August 2021, when Adelle Scott also left us eventually to join the Jeans for Genes team full-time, Claire Jeffries was left as our sole employee for the rest of the year. It is due to her dedication and hard work that we were able to keep the shop open, deliver monthly e-newsletters, achieve extraordinary fundraising results, and maintain the rest of our services. To ease her workload, Jane Docherty (trustee) took over her bookkeeping role on a temporary basis. The trustees wish to thank Claire and Jane for their dedication which helped the charity to save cost and balance the budget.

Arguably, this is a time when this charity needs to do more. We would like to expand our nursing service, extend our reach into mental health support and refresh our website content, but Covid has also weakened our finances over the last two years so we do not have the funds available.

So, this year we have launched the 'Growth Project' which aims to establish a new income stream through charitable trusts and foundation grants and to build a more resilient organisation in parallel. With the help of their detailed assessment in November 2021, Almond Tree Strategic Consulting have helped us develop a plan to cautiously spend our reserves to develop the expertise necessary to sustain and build this new source of funding. This three-year project will be described in detail in next year's report, but we ended this year with the well-deserved promotion of Claire Jeffries to Executive Director as a crucial starting point.

Part of our restructuring objectives includes the Board constitution and a review of our Governance processes. We have recognised for several years that this small charity needs active trustees who can support the work of our staff. To this end, we have created a 'delegated authority' structure that has formalised four subcommittees, each of which have defined terms of reference, are led by a Trustee and report back to the main Board through quarterly trustee meetings. Their work in Finance, Membership & Fundraising, Governance & Operations and Jeans for Genes has provided oversight and steering of these crucial activities.

In September 2021, we completed a Governance Review using a standardised method from www.charitygovernancecode.org. The results confirmed that we have good governance processes in place but there are improvements to make, so the resulting action list will become the key focus of the Governance & Operations subcommittee over the next couple of years.

One important change was the addition of an Annual Strategy Review meeting held in March 2022. Our current three-year strategy was signed off prior to the pandemic so this review helped us define our objectives for next year, following a thorough examination of our priorities in this post-pandemic context. These goals are described later in this report.

Sadly, four trustees resigned this year, due to their work commitments. The Board extends grateful thanks to Jackie, Jayne, David and Davina for their contribution over recent years and we hope they will stay in touch. Two new trustees, Kultar and Annabel, were recruited leaving a Board of seven at the end of the year. Annabel, who has worked as a volunteer and mentor to Claire for the last couple of years, and also has professional experience in the rare disease sector, has further agreed to take the role of Vice Chair which has been vacant for some time. Thanks are extended to both Annabel and Kultar who have already contributed so much.

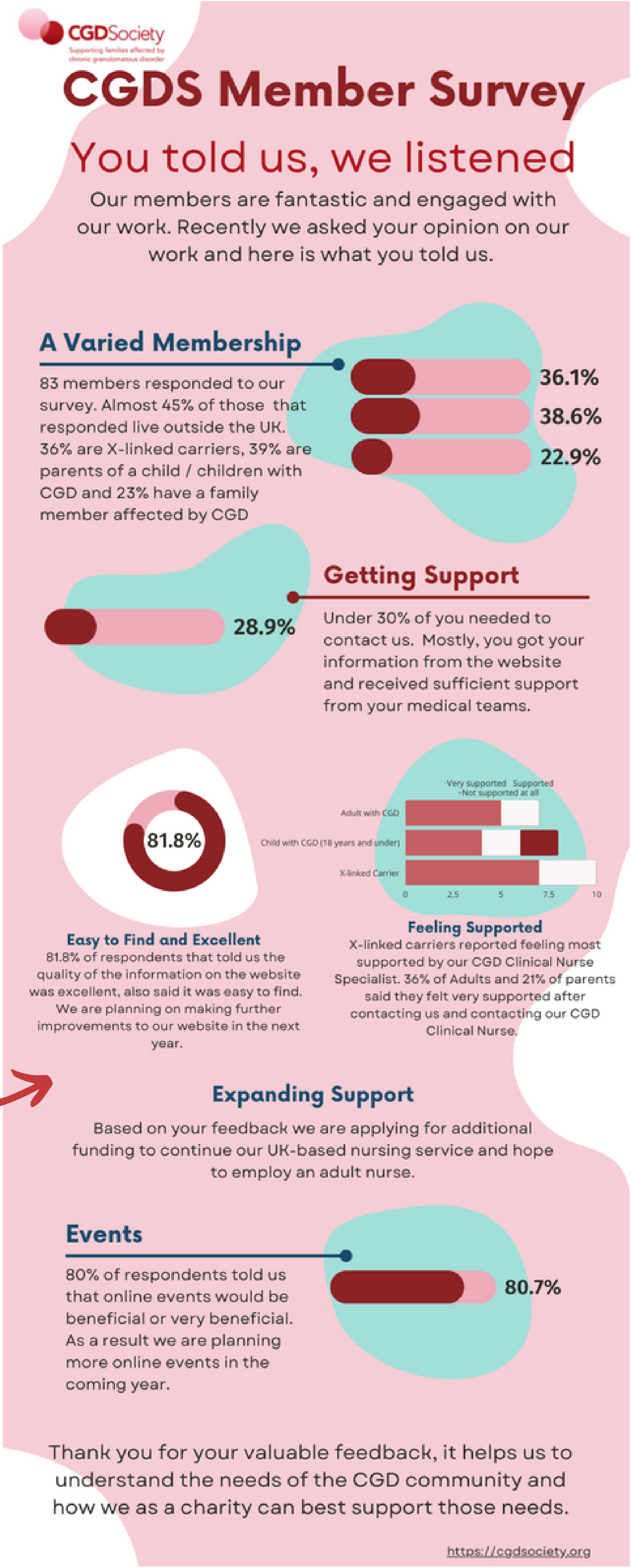
Thanks are also due to Ning He who has accepted the role of Honorary Treasurer with authority for oversight of financial matters on behalf of the Board.

Our mission to re-energise the Jeans for Genes brand and fundraising continues. Last year we established a new subsidiary, Jeans for Genes Campaign, and transferred the business from Genetic Disorders UK (now Gene People). This year, in September, the first campaign was run by the new team who delivered a 10% increase in gross income and a solid foundation from which to grow. We thank the Jeans for Genes team for their hard work but especially Leesa Harwood, as interim CEO, who built the new charity and delivered a working organisation to the newly recruited permanent CEO, Lynn Mumford, who started work in February 2022.

It is crucial that we continually measure and report the impact that our small charity delivers, so the development of tools and techniques to measure and articulate this will be an important part of the Growth Project next year.

However, our first step this year was to survey the membership to gain insights into their needs and their perspective on our performance. We had a great response with over 80 members giving feedback, nearly half from outside the UK, which will help us improve our services and define new opportunities that require external funding. The survey headlines are summarised on the right.

So, we have already restructured the Board and started to invest in new staff but under the auspices of our Growth Project we have so much more to do. Whilst this year has been a good start we have a couple more exciting years ahead as we emerge stronger from this unprecedented pandemic.



CGDSociety
Supporting families affected by chronic granulomatous disorder

CGDS Member Survey

You told us, we listened

Our members are fantastic and engaged with our work. Recently we asked your opinion on our work and here is what you told us.

A Varied Membership

83 members responded to our survey. Almost 45% of those that responded live outside the UK. 36% are X-linked carriers, 39% are parents of a child / children with CGD and 23% have a family member affected by CGD

Getting Support

Under 30% of you needed to contact us. Mostly, you got your information from the website and received sufficient support from your medical teams.

Easy to Find and Excellent

81.8% of respondents that told us the quality of the information on the website was excellent, also said it was easy to find. We are planning on making further improvements to our website in the next year.

Feeling Supported

X-linked carriers reported feeling most supported by our CGD Clinical Nurse Specialist. 36% of Adults and 21% of parents said they felt very supported after contacting us and contacting our CGD Clinical Nurse.

Expanding Support

Based on your feedback we are applying for additional funding to continue our UK-based nursing service and hope to employ an adult nurse.

Events

80% of respondents told us that online events would be beneficial or very beneficial. As a result we are planning more online events in the coming year.

Thank you for your valuable feedback, it helps us to understand the needs of the CGD community and how we as a charity can best support those needs.

https://cgdsociety.org

This year's highlights

Support

The nursing service continued throughout the year thanks to the work of Helen Braggins our Clinical Nurse Specialist

The mental health support for Immunology Clinics at Birmingham Hospitals Trust, which we are part funding, started in August with the appointment of Dr Nicola Wilson

The email and telephone helpline fielded 88 requests for support, 36% from outside the UK

The Family Support Fund supported 8 UK families with hardship payments and 15 individuals benefited from prescription contracts

334

CGD patients were seen by Helen this year

Freddy delighting in his special swimsuit, paid for using the Family Support Fund

Communication

10 monthly e-news updates and a full newsletter were published this year with updates on treatments, patient stories and fundraising

We undertook a membership survey with 84 responders, 44% from outside the UK, helping us to understand their needs, priorities and feedback on the support we deliver. This will help to guide our work and provide evidence for external funding bids

Our social media presence continued to grow with an 11% increase in Facebook, Instagram and Twitter traffic with greater reach through our new Linkedin page

Funding

- Our new subsidiary team increased Jeans for Genes gross income by 10% in their first year
- We were grateful to receive a grant of nearly £18,000 from the CAF (Charities Aid Foundation) Patient Organisations Recovery Fund
- We also thank our sponsors Orchard Therapeutics and Bryant Ltd who donated £7,000 and £5,000 respectively
- Our community fundraising exceeded budget by 40% which is extraordinary for a rare disease charity of our size

THANK YOU TO OUR FUNDERS!

Our team

- Claire Jeffries worked alone for most of the year and was promoted to Executive Director at the end of the year
- Our Technical Director, Susan Walsh, left us after 19 years
- Adelle Scott, our Fundraising and Marketing Officer left in August to focus on her Jeans for Genes role
- Jane Docherty (trustee) took over as Bookkeeper for the year

GOOD LUCK TO SUSAN & ADELLE!

Governance

- Four trustees left the Board, two new recruits joined, leaving seven in total
- Annabel Griffiths was appointed as Vice Chair and Ning He appointed as Treasurer
- A Governance Review was completed and a strategic review in March defined priorities for next year
- We launched our Growth Project to steer us to a sustainable future with greater reach and impact

Our Honorary President - Paul (Ocean) Numan

It is with great sadness that we learned of the tragic death this year of our founder and talisman Paul (Ocean) Numan. Paul, whose son Andrew had CGD, founded this charity in 1991.

The following year he launched the first Jeans for Genes campaign on a shoestring but then skillfully engineered the partnership with Great Ormond Street hospital and two other charities that lasted for 15 years and transformed this fundraiser. He also had the wisdom to register the trademark from which we still earn a licence fee today. This is a wonderful legacy for this inspirational man.

Paul returned to his native New Zealand a few years ago following Andrew's death from complications during his BMT. He lived close to the sea so it is especially sad that he drowned while swimming near his home, on September 20th 2021.

Paul was proud to be our Honorary President. We will miss his kiwi accent, his irreverent humour but above all his dedication to our cause which remained so close to his heart.

Claire's story

This year has been a productive and busy year for our charity and for me, as our Executive Director. I am responsible for the day-to-day running of the charity whilst driving the charity forward, and ensuring we are offering the best possible support and advice for those affected by CGD.

Much of this year I have been running the charity as the only member of staff, following the move of our Fundraising and Marketing Officer, Adelle Scott, to our subsidiary charity Jeans for Genes Campaign in September 2021 and the resignation of our Technical Director, Susan Walsh, to become CEO of a new charity Immunodeficiency UK. Although this has been challenging, it has also been hugely rewarding and has not affected the support we provide to so many.

With the roll-out of the Covid vaccines, some of our communities contacted us through our helpline as they were understandably nervous and unsure about receiving the vaccine. I was able to ease their concerns by keeping up to date with the latest Covid information related to CGD and updating our Covid page on the website. Our Clinical Nurse Specialist, Helen was crucial in providing individual specialist care to those in hospital and receiving treatment during the worst of the pandemic. Although Covid dramatically changed our lives, people affected by CGD were advised to have the vaccine and generally did not become severely unwell.

Raising awareness of CGD and the work we do is fundamental in the support we provide. It was an honour to give a lecture at Cambridge University in November to MPhil students about CGD, our charity and my own personal story of losing my child to CGD. I also spoke about the many challenges faced by families and individuals who are affected by a rare disease.

Helen, our CGD Clinical Nurse Specialist, and I represented the charity at the UK Primary Immunodeficiency Network conference held in Sheffield in November 2021. We secured a stand to display our information guides and spoke with medical professionals and scientists to raise awareness of CGD and the charity.

The charity also got a feature slot in Rare Revolution's Autumn 2021 edition (rarerevolutionmagazine.com). The article, written by me, focused on the importance of coordinated care for the CGD community and highlighted our nursing service.

Our support and advice continue to grow outside of the UK with people contacting us in such distant places like Brazil, Australia and India. In consultation with Helen and our medical panel we provided information on local consultants, treatment options and testing for CGD.

Then there are our amazing fundraisers and donors, without whom we would not be able to do the work we do. I had the privilege of supporting our many fundraisers this year and learning how they intend to raise awareness and funds. Their enthusiasm and the reasons they donate always inspires me to do the best I can to support such an incredible community.

I am looking forward to a new year, now as Executive Director, and putting in place our strategic plan that will build on our successes and lead our charity towards our vision - **for all families and individuals affected by CGD to thrive and live life to the full.**

Where did our income come from?

JEANS FOR GENES

The trade mark licence fee from the Jeans for Genes campaign remains our largest single income stream. This year was the first campaign run by our new subsidiary charity, Jeans for Genes Campaign (J4GC). Amid the necessary turmoil of creating a new charity, appointing staff and trustees and launching their first campaign, the team did a great job to sustain this essential event that is so crucial to many genetic disorder charities including our own. They increased the gross income by 10% and our trade mark licence fee increased to £59,260 (2021: £42,157). From the net proceeds, our subsidiary was also able to award 18 charities a substantial grant towards their core costs.

The CGD Society extended a loan of £200,000 to its subsidiary in July 2021 to provide working capital funding repayable over four years and subject to commercial rates of interest described in a formal Loan Agreement. The value of this loan outstanding at year end is £150,000.

Towards the end of this financial year, Lynn Mumford joined J4GC as their permanent CEO and, with Adelle Scott now in the role of Creative Director, we hope to see continued growth in this campaign which is now over 30 years old but provides so much support to the genetic disorder and rare disease communities. The impact of Covid is still apparent, with gross income still only just over half of pre pandemic levels. However, the restructuring of Jeans for Genes over the last two years has delivered a cost-effective organisation with a re-energised team who have exciting plans to rebuild this brand.

SPONSORSHIP

10% of our income this year came from two sponsors: Bryant Ltd (£5,000) and Orchard Therapeutics (£7,000). These funds were restricted to the Patient Support Fund and the publication of newsletters, both of which provide vital support to our membership. We give grateful thanks to both companies for their support.

COMMUNITY FUNDRAISING

For the second year running, community fundraising has exceeded budget by a substantial margin; this year by 40% to £35,578 (2021; £40,935). Clearly, the work started four years ago by Claire Jeffries to rebuild our member communication and social media presence in particular, and more recently reinforced by Adelle Scott, has reconnected this charity with its members who now want to support our work through their fundraising. For a small rare disease charity with a limited membership, this is a tremendous result. The trustees wish to thank our staff and membership for this achievement which has helped us deliver a balanced budget over the year.

INSTITUTIONAL FUNDRAISING

This year we were grateful to receive a grant from CAF totalling £17,893. Coming from their Patient Organisations Recovery Fund, the majority of this money was restricted to paying for our nursing service which provides vital support to our members especially during the Covid pandemic.

The remainder of this grant was directed towards creating a longer-term grant income stream from charitable trusts and foundations. This is a source that we have so far failed to exploit and is now more necessary than ever as we try to recover from the damage of the pandemic. So, in this financial year, we engaged Almond Tree Strategic Consulting to review our current organisation and fundraising processes and report on improvements designed to establish an institutional fundraising income stream within a sustainable staff and volunteer structure. Their report, received in November 2021, emphasised that this will be a long term project with a minimum three year delivery. Nonetheless, the trustee Board endorsed these recommendations and christened the Growth Project as our key goal in the next financial year, details of which are described later in this report.

CAF
Charities Aid Foundation

Membership fundraising stories

This year marked our 30th anniversary as a charity, which gave us the opportunity to highlight the important work we have done for the CGD community here in the UK and around the world. We created a dedicated page on our website featuring stories on 'how it all began' from the founders of our charity and promoted this special occasion on our social media platforms and in a special 30th edition of our newsletter. We were also featured in the summer edition of Rare Revolution magazine.

1,000 steps in May

Bonnie, Emily and Mary Rose took on the challenge of doing 10k steps every day in May. Bonnie's two boys, Ben and Bobby were diagnosed with CGD in 2020, with Ben subsequently receiving a BMT.

The ladies did a fantastic job achieving all those steps, raising awareness of CGD and an incredible £11,705. As Bonnie says:

"CGD is a life-limiting condition, but with the work and research done by the CGD Society children like the boys can go on to live a full life. Our Clinical Nurse Specialist based at Great Ormond Street Hospital is funded by the CGD Society. She has been a lifesaver. With relentless hospital appointments, blood tests and worries, she answers and deals with it all at the end of a phone or at the hospital."

100 little hats

After 300 hours, knitting 300,000 stitches and using 6000 metres of yarn, Rosie Wilkins managed to make 100 little hats for preschool children. Rosie's grandson Phileas was diagnosed with CGD in 2019 and has since received a BMT.

With the money raised from knitting and from the sale of the hats Rosie raised an impressive £4,119.

Swim for life

Our very own CGD Clinical Nurse Specialist, Helen Braggins, swam 30,000 metres in June at her local pool. Helen said:

"I hold a unique and privileged place in the lives of families affected by CGD. I can only do this because I'm fully funded as a Clinical Nurse Specialist by the CGD Society.

I've committed to taking on this challenge as I see every day the challenges faced by my patients and their families and want them to know how brave and amazing I think they all are."

Helen raised a brilliant £1,805 and took the challenge in her stride.

Expenditure, investments and reserves

EXPENDITURE

Our total spend for the year was £123,615, split approximately 40% on staff, 40% on nursing costs and 20% on the rest.

The largest proportion (63%) was spent on relief of those suffering from CGD. The sum of £77,784 (2021; £87,939) 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, information booklets and back office subcontracted staff resources. This year we spent a lower sum of £20,973 (2021; £29,556) because our Technical Director resigned at the start of the year and was not replaced to save cost. This was 15% of our total spend.

Finally, the project to provide mental health support to the Birmingham Hospitals Trust has got underway this year. Therefore, our part funding of £5,000 (2021; zero) for the first year was spent. This research expenditure amounted to 4% of our total spend. The remaining costs were 10% for fundraising at £16,949 (2021; £32,809) and 2% for governance at £2,909 (2021; £9735). These costs were lower than expected due to the resignation of Adelle Scott and the reduction in legal advice costs respectively.

Overall, the net movement of funds was a surplus of £3,245 (2021; deficit £76,947) excluding any revaluation of investments. This was better than the planned budget for the year which was achieved through a 14% reduction in costs compared to budget that offset the reduction in planned income.

INVESTMENT POLICY AND PERFORMANCE

The charity has longer-term financial reserves invested in a medium risk portfolio and managed by the Investment Committee which scrutinises the performance of the investment fund managers, Smith & Williamson (now Evelyn Partners). During the financial year to March 2022, a steady stock-market recovery from the previous Covid-induced slump was abruptly reversed in February by Russia’s invasion of Ukraine. The resulting volatility meant that returns over the year were virtually flat. An early review of our fund holdings showed minimal exposure to Emerging Markets and Russia.

£100,000 was transferred out of the portfolio account in April 2021 to fund the CGD Society's commitment to Jeans for Genes and to provide liquidity to support our increased expenditure and investment in the charity’s growth plan through the provision of a working capital loan. As of 31 March 2022, the portfolio value stood at £158,147 (2021: £251,705).

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 in April 2022 states that the charity must retain free reserves to cover 6-12 months of budgeted running costs for the year ahead, i.e. £100,602-£201,204 based on the expenditure budget of £201,204 for 2022/23 adopted by the Trustees.

At the accounting date, the CGD Society has total unrestricted reserves of £447,395 of which £308,148 is designated and not included in free reserves for the following reasons:

- The outstanding loan to Jeans for Genes Campaign is a debtor (i.e. not cash). (£150k)
- The investment portfolio, which is intended as a long-term investment in a medium risk portfolio under external management, is a fixed asset not available at less than 3 months’ notice. (£158k)

Therefore, the CGD Society has closing free reserves of £139,247 (2021; £192,726) which meets the reserves policy target and equates to approximately 8 months of planned expenditure for the year ahead.

What do we plan to do next year?

Through the newly christened ‘Growth Project’, we aim to establish a broader portfolio of funding which will enable us to expand services by increasing staff and other resources, within a more reliable income model. This project will be our focus for the year 2022-23.

The first goal to build a sustainable organisation less reliant on key trustees and built around an executive leader has begun with the promotion of Claire Jeffries to Executive Director. She and her new team will be responsible for delivery of our objectives in the year ahead and we are confident that she will thrive in this new position.

The second goal is to develop institutional and corporate fundraising. The Board understands that this will require us to spend some of our precious reserves to recruit the staff and gain the required expertise. We expect this to be a three-year investment with deficit budgets in the first two years until a reliable income stream is established by year three. Nonetheless, we will be financially prudent and may need to adjust our expectations if our fundraising plans falter. It is already apparent that 2023 will be a tough year for community fundraising as the cost-of-living crisis bites into family finances whilst trusts and foundations will be inundated with bids from similarly affected charities. These headwinds will increase the challenge, but we remain confident that this charity can demonstrate its impact, the needs of our membership and our good governance, all of which will persuade funders to support us.

In March 2022, our first face to face trustee meeting in two years included a review of our current three-year strategy to confirm that it is still valid, which activities are behind the planned delivery and crucially what our priority activities will be for the year ahead. This meeting was informed in part by the feedback from a survey of the membership which is described elsewhere in this report.

Based around these inputs, the key priorities for the year ahead are summarised below:

- Our first 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 recruit a Community Fundraising Officer to fill the role vacated by Adelle Scott who will lead our Community Fundraising activities through all social media and newsletter outputs which will remain a crucial communication and advocacy channel. Since the year end, Niamh Carmichael has joined the team in this role and we welcome her to our community.

- 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 recruit a Medical/Technical Officer, to replace the post vacated by Susan Walsh, who will review and update our medical information for the website and booklets on a rolling basis as well as monitor other scientific and clinical activity relevant to our knowledge base.

- Our engagement with our membership will rely on online events next year rather than a physical get together, although we will plan for a Family Weekend the following year (2023-24) subject to available funding.

- We will look for opportunities to extend the patient support fund available to members in need, subject to securing sufficient funding.

- We will recruit more trustees. We need a larger Board to allow longstanding trustees to retire and to facilitate succession planning. Our Vice Chair will take over the Chair role from the October AGM and the current Chair will become Governance Secretary.

- We remain committed to supporting the mental health and improving the Quality of Life of our members but made limited progress developing our support in this area in the current year. We will work together with our community to define what needs to be done and to make the case for funding.

- Within the Growth Project, we will use external support to develop an Institutional Fundraising process that we can build on in future years. This will involve development of a monitoring, evaluation and learning framework to support impact assessments, building cases for support based around the above priorities and developing relationships with potential funders whose priorities are aligned to ours. We will learn how to write compelling applications with the best chance of success such that towards the end of the year we can justify the recruitment of our own part-time institutional fundraiser.

- Within the same project, we will invest in a Customer Relationship Management (CRM) system so that we can track all potential funders, donors, grant applications, sponsors and other stakeholder contacts. By the end of the year this CRM system will have become the communication hub of the charity.

2021-22 Summary

Overall, this has been a year of recovery for this charity as we emerge from the Covid pandemic. Our income, especially from Jeans for Genes, remains significantly lower than pre-pandemic levels and continues to limit our scope for change. Nonetheless, following a large deficit last year the trustees are relieved and happy to report a small surplus this year as a result of stellar fundraising from our community, an unexpected CAF grant and the decision not to recruit staff to replace two leavers. Despite these resource limitations, our team have heroically managed to deliver front line services throughout.

But this can only be a temporary position. The trustees have recognised the need to plan ahead to build a more resilient organisation capable of supporting a membership arguably in greater need following the last two years of medical drama. To that end, we have launched our 'Growth Project' this year, with support from Almond Tree Strategic Consulting, that we predict will deliver a stronger financial position within a more robust organisation within two years. We will use some of our reserves to fund new staff and build the expertise to broaden our fundraising success, using the proceeds to extend our services and help our membership to thrive in spite of this challenging disorder.

We have an exciting couple of years ahead !

This report was approved by the trustees on 17th August 2022

and signed on their behalf by:

Creamer

....
Dr Geoffrey Creamer
Chair

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

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 2022.

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

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

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

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

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

H M Day

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

Date: ......17th August 2022.....

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY

Statement of Financial Activities
for the year ended 31 March 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	35,578	29,893	65,471	40,935
Investment income	3	2,129	-	2,129	-
Other income		59,260	-	59,260	42,157
Total		96,967	29,893	126,860	83,092
EXPENDITURE ON					
Raising funds	4	16,949	-	16,949	32,809
Charitable activities	5				
Relief		53,727	24,057	77,784	87,939
Education		20,973	-	20,973	29,556
Medical Research		5,000	-	5,000	-
Governance		2,909	-	2,909	9,735
Total		99,558	24,057	123,615	160,039
Net gains on investments		7,260	-	7,260	65,128
NET INCOME/(EXPENDITURE)		4,669	5,836	10,505	(11,819)
RECONCILIATION OF FUNDS					
Total funds brought forward		442,726	3,415	446,141	457,960
TOTAL FUNDS CARRIED FORWARD		447,395	9,251	456,646	446,141

The notes form part of these financial statements

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY (REGISTERED NUMBER: 07607593)

Balance Sheet
31 March 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
FIXED ASSETS					
Investments	9	158,148	-	158,148	251,706
CURRENT ASSETS					
Debtors	10	184,399	-	184,399	38,250
Cash at bank		121,544	9,251	130,795	190,330
		305,943	9,251	315,194	228,580
CREDITORS					
Amounts falling due within one year	11	(16,696)	-	(16,696)	(34,145)
NET CURRENT ASSETS		289,247	9,251	298,498	194,435
TOTAL ASSETS LESS CURRENT LIABILITIES		447,395	9,251	456,646	446,141
NET ASSETS		447,395	9,251	456,646	446,141
FUNDS	12				
Unrestricted funds				447,395	442,726
Restricted funds				9,251	3,415
TOTAL FUNDS				456,646	446,141

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

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for
(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
(b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

continued...

THE CHRONIC GRANULOMATOUS DISORDER SOCIETY (REGISTERED NUMBER: 07607593)

Balance Sheet - continued
31 March 2022

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 ....17th Aug 2022.............................. and were signed on its behalf by:

Creamer

....
G D Creamer - Chair

The notes form part of these financial statements

1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, 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

	2022	2021
	£	£
Donations	35,578	40,935
Grants	29,893	-
	65,471	40,935

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

	2022	2021
	£	£
Bryant Fund	5,000	-
Orchard Therapeutics - Family support	3,000	-
Orchard Therapeutics - Newsletters	4,000	-
Caf resilience fund	17,893	-
	29,893	-

continued...

3. INVESTMENT INCOME

	2022	2021
	£	£
Loan interest received	2,129	-

4. RAISING FUNDS

RAISING DONATIONS AND LEGACIES

	2022	2021
	£	£
Direct and support costs	16,132	30,473

INVESTMENT MANAGEMENT COSTS

	2022	2021
	£	£
Portfolio management	817	2,336

Aggregate amounts	16,949	32,809

5. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 6)	Totals
	£	£	£
Relief	52,625	25,159	77,784
Education	6,411	14,562	20,973
Medical Research	5,000	-	5,000
Governance	2,909	-	2,909
	66,945	39,721	106,666

continued...

6. SUPPORT COSTS

	Staff & Management £
Relief	25,159
Education	14,562
	39,721

7. TRUSTEES' REMUNERATION AND BENEFITS

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

TRUSTEES' EXPENSES

There were trustees' expenses paid for the year ended 31 March 2022 totalling £180 to 2 trustees (in 2021 no trustees' expenses were paid).

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2020-21

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	33,535	7,400	40,935
Other income	42,157	-	42,157
Total	75,692	7,400	83,092
EXPENDITURE ON			
Raising funds	32,809	-	32,809
Charitable activities			
Relief	81,096	6,843	87,939
Education	29,556	-	29,556
Governance	9,735	-	9,735
Total	153,196	6,843	160,039
Net gains on investments	65,128	-	65,128
NET INCOME/(EXPENDITURE)	(12,376)	557	(11,819)
RECONCILIATION OF FUNDS			
Total funds brought forward	455,102	2,858	457,960

continued...

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2020-21 - continued

	Unrestricted funds £	Restricted funds £	Total funds £
TOTAL FUNDS CARRIED FORWARD	442,726	3,415	446,141

9. FIXED ASSET INVESTMENTS

	Listed investments £	Unlisted investments £	Totals £
MARKET VALUE			
At 1 April 2021	251,705	1	251,706
Disposals	(100,818)	-	(100,818)
Revaluations	7,260	-	7,260
At 31 March 2022	158,147	1	158,148
NET BOOK VALUE			
At 31 March 2022	158,147	1	158,148
At 31 March 2021	251,705	1	251,706

There were no investment assets outside the UK.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade debtors	-	23,228
Other debtors	150,000	15,022
VAT	239	-
Prepayments and accrued income	34,160	-
	184,399	38,250

continued...

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade creditors	13,352	17,095
Social security and other taxes	229	771
VAT	-	6,430
Other creditors	1,615	6,754
Accruals and deferred income	1,500	3,095
	16,696	34,145

12. 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
Investment fund	-	-	158,148	158,148
	442,726	4,669	-	447,395
Restricted funds				
Bryant Ltd (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

continued...

12. MOVEMENT IN FUNDS - continued

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				
Bryant Ltd (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

Comparatives for movement in funds 2020-21

	At 1.4.20 £	Net movement in funds £	Transfers between funds £	At 31.3.21 £
Unrestricted funds				
General fund	83,102	(12,376)	122,000	192,726
Jeans for Genes support	372,000	-	(122,000)	250,000
	455,102	(12,376)	-	442,726
Restricted funds				
Bryant Ltd (Family Support)	2,858	(2,615)	-	243
Orchard Therapeutics (Family Support)	-	500	-	500
Orchard Therapeutics (Newsletter sponsorship)	-	2,422	-	2,422
Emergency Leaflet	-	250	-	250
	2,858	557	-	3,415
TOTAL FUNDS	457,960	(11,819)	-	446,141

continued...

12. MOVEMENT IN FUNDS - continued

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	75,692	(153,196)	65,128	(12,376)
Restricted funds				
Bryant Ltd (Family Support)	-	(2,615)	-	(2,615)
Orchard Therapeutics (Family Support)	2,000	(1,500)	-	500
Orchard Therapeutics (Newsletter sponsorship)	5,000	(2,578)	-	2,422
Emergency Leaflet	400	(150)	-	250
	7,400	(6,843)	-	557
TOTAL FUNDS	83,092	(160,039)	65,128	(11,819)

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 £150,000 outstanding at 31st March 2022.
Investment fund - This fund holds the value of the investments which are invested in medium risk, non-cash assets with a view to generating both capital and income returns for the Charity.

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.

TRANSFERS BETWEEN FUNDS

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

continued...

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 £59,260 (2021: £42,157). This is paid by Jeans for Genes Campaign, a charity owned by CGDS (in 2021 it was paid by Gene People (previously known as Genetic Disorders UK)). As at 31st March 2022 an amount of £34,160 was unpaid and included within accrued income.

In addition there was a SLA between Gene People (formerly known as Genetic Disorders UK) and Chronic Granulomatous Disorder Society (CGDS) in relation to the provision of staff. The charge for the year amounted to £Nil (2021: £13,403). In 2022 there was an SLA between Jeans for Genes Campaign and CGDS for the provision of staff with CGDS being charged £6,600.

During the year CGDS made a loan to Jeans for Genes Campaign. At the year end the amount owing on this was £150,000 (2021 £14,025). This attracts interest at 3.25% above base rate.