

Company no 07607593
Regd charity no 1143049

CGD SOCIETY

**ANNUAL REPORT & FINANCIAL STATEMENTS
2020-21**

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About our charity

Honorary president: Ocean Numan*

Trustees (* indicates a member of a family affected by CGD) :

Dr Geoff Creamer* – Chair

Jane Docherty*

Andrew Orchard*

Ning He*

Chikai Lai

Davina Gray* @

Jackie Irvine*

Jayne Nicol @

David Hannard* @

Note: The trustees marked @ above resigned after 31 March 2021 but prior to the date of this report

Operations and Fundraising Manager: Claire Jeffries

Fundraising and Marketing Officer: Adelle Scott

Clinical Nurse Specialist: Helen Braggins RGN RSCN

Registered office: 38 Glenmore, Chorley PR6 7TA

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: A cure for all with CGD

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' 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 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. Two trustees, Andrew Orchard and Geoffrey Creamer have exceeded this nine year limit but their continued service was agreed and welcomed by the Board. New trustees are appointed by the serving trustees, taking into account the skills and experience required.

Authority for some activities is delegated to sub committees who have defined terms of reference and are populated by trustees, staff and 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 Operations and Fundraising Manager 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 look for 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.

Trustee's report

The trustees present their annual report for the year ended 31 March 2021 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 2000 members of which approximately half are affected individuals or family members and the remainder are supporters and medical professionals. Of those affected, around 300 are in each of the UK and USA. The membership is spread across 58 countries of which UK and USA dominate with Australia, Canada and India making up the top five. Membership has increased by about 10% over the year which is significant for this rare disease charity.

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

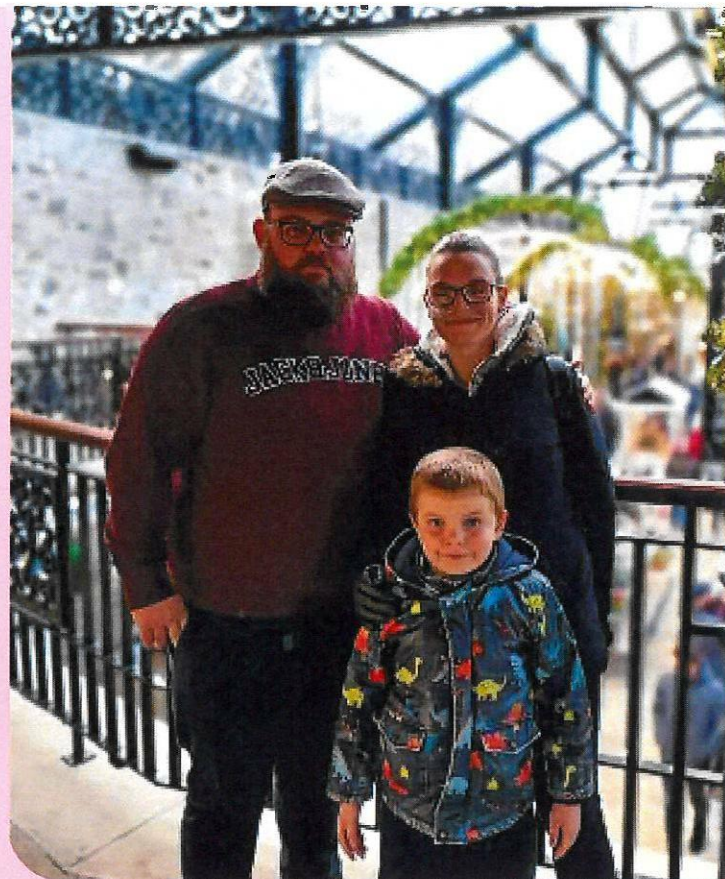
Michael's story

Tearing up rugby pitches and smashing the international water polo circuit might not be an obvious choice for a young man with a life-limiting condition, though for Michael Duddy (35) his childhood was remarkably untainted by a CGD diagnosis.

Michael who now lives in Leeds with partner Kirsty and stepson Max grew up on the sunny holiday island of Tenerife where his parents managed a restaurant for many years.

He talks fondly about his experience of living abroad and his parents' determination that he should have as normal childhood as possible. Michael remembers battles with his teacher who would try in vain to smuggle medication into chocolate bars and other kids taunting him about time he spent away from class for appointments or when unwell, but unlike others with the same condition, his symptoms could in general be controlled with medication.

Michael remained under the care of Professor Goldblatt at Great Ormond Street Hospital (where he was diagnosed at the age of two) travelling back to England for check-ups twice a year without much change. As a young adult he remained in Tenerife, eventually securing the role of airport manager for a British travel operator and playing competitive water polo. He felt healthy and fit, was hard-working and having a great time.



Unfortunately, his condition gained prominence over the past three years following his return to the UK. He was admitted to hospital with pneumonia in 2017 and was unable to return home for three months. Michael reflects that prior to this he was not taking great care of himself – working too many hours, not always taking his medication as directed and commuting long distances every day. Lung biopsies confirmed that medication would no longer keep his condition at bay and that he would need to go on the wait list for a bone marrow transplant (BMT). The search for a donor began in earnest and two years later a 10/10 match was identified.

Michael is open about times in his life when he has rebelled against or rejected his illness, refused to take the medications and when he lost faith in the NHS following the death of his mother. However, today speaking with him he appears to have a positive perspective on the forthcoming BMT and talks with great warmth and gratitude about the CGD Society.

Michael feels that in the same way the charity helped his parents come to terms with and understand his condition, they have been a rock to him also – being at the end of the phone when he has need to talk or gain some clarification as well as helping him cover loss of earnings for times he has been unable to work.

What happened this year?

This year has obviously been dominated by the Covid-19 virus pandemic. Our membership, being affected by an immune deficiency, are a priority group especially because CGD frequently damages the respiratory system which is then vulnerable to attack. Although CGD does not specifically impact a patient's viral response, the potential for bacterial or fungal complications especially of a respiratory nature, places our membership at high risk.

The good news is that clinically speaking our UK patients have coped well with the wonderful support of Helen our specialist nurse. She summarises the challenges that she has faced later in this report.

We recognize that the biggest impact this year has been on the mental health of our membership. Living with the uncertainty of a rare disease is a constant challenge but the additional burden of Isolation and Shielding, or the loneliness of hospital treatments without visits and simply the fear of further infection has been too much for some. We have seen some patients overwhelmed and needing crisis mental health support from their local services. Once again we are reminded that as the clinical management improves, mental health is exposed as the contemporary challenge for our membership.

From December 2020, Covid vaccinations have become available with most UK CGD patients following medical advice to get themselves jabbed urgently. This vaccine protection has allowed society to begin to return to normal but it will take some time before our cohort can accept that the danger has passed. After all, Covid-19 is here to stay; we are told that we must live with this virus as it ebbs and flows through the coming years. It will be critically important that our membership maintain their vaccination protection which is a new message that this charity will amplify.

What about non-UK members? We received many enquiries from overseas (especially USA) but it has been difficult to give advice without understanding the local Covid context. We hope that our guidance has been sufficiently generic to help them although we do worry that our members in countries with low vaccine availability will continue to be disadvantaged and remain at risk. We wish all members a safe and speedy exit to the new normality of our post-pandemic world.

This year has certainly demonstrated the value of this disease specific charity. With advice from our Medical Panel and in consultation with other immune deficiency charities we have regularly updated Covid guidance through our website and newsletters. Our team have fielded a record number of enquiries, often from outside the UK, as members wrestle with the reality of this dangerous virus. Our staff; Claire, Susan, Adelle and especially Helen deserve congratulations from the membership and the trustee board for keeping the service going in such difficult circumstances.

What did we deliver this year?

Support

The helpline has remained open throughout with a high number of enquiries from UK and abroad. Congratulations to Helen, our Clinical Nurse Specialist, who continued to support our community despite Covid restrictions. She helped almost the same number of patients as last year:

163 families

8 children & 2 adolescents undergoing BMT

2 patients post gene therapy treatment

3 adults post BMT

48 affected adults

81 x linked carrier females

Through the Patient Support Fund the charity has also provided 22 individual prescription contracts and 9 hardship fund payments.

The Covid pandemic has been a huge challenge for all our staff. Information and advice has been regularly posted to a dedicated website page and an increased flow of queries to our helpline have been addressed. Feedback from our nurse and other practitioners has been circulated via newsletters and the website.

The improvement of mental health support is one of our priorities for external funding. Unfortunately, the Birmingham Hospital Immunology Department mental health service has not started due to problems with recruiting the staff within the hospital. Our 3 year part funding remains in place and we hope that this will begin in 2021.

Funding

In common with many charities, the pandemic has disrupted our fundraising goals. Thanks to our new Fundraising and Marketing Officer, Adelle Scott, and her impactful social media presence, member donations have exceeded budget. On the other hand, Jeans for Genes licence fee income has reduced and grant givers have refocused on social support for those in need as a result of Covid.

We have a great plan for 30year birthday celebrations. Unfortunately, the Family Conference is cancelled due to Covid but will be replaced by an online event. We have many committed fundraisers in our membership who we hope will support this initiative.

Jeans for Genes income was badly affected by the disruption in schools and organisations so our licence fee income has more than halved contributing to an overall deficit for the year.

Resources

We have a couple of volunteers already on board and doing great work for us. Thankyou Simon and Annabel. We will recruit more in future as we learn how to use their talents and manage the additional resource

We welcomed Adelle Scott our new Fundraising and Marketing Officer onto the team in April 2020

Communication

Claire and Adelle have worked tirelessly to deliver a structured social media presence and a monthly e-newsletter. Member engagement has been transformed with donations exceeding budget by more than 30%.

More surveys are planned with content development underway.

We surveyed the membership to hear how we could improve the newsletter communication. We had 55 responses, 60% from the UK. Members spoke of the value that the newsletter brings especially because of the information provided. Few suggestions for improvement were received

Governance

No new trustee appointments were made this year and the vice chair post is still vacant. Recruitment remains an important goal which will be highlighted again in our planned governance review in 2021.

The pandemic has forced us to review priorities, so work on procedures and policies has been paused. We will restart as soon as possible

Helen's story

Navigating a safe and healthy life when living with CGD is a challenge at the best of times but COVID came and tried very hard to undo all the resilience and the safety nets people with CGD had managed to build and maintain.

Lockdown had an immediate impact on our patient's access to urgent healthcare. They were fearful of leaving home to go to hospital in case they caught the virus. Local hospitals were overwhelmed with very sick patients but travel restrictions made it difficult to travel to specialist centres for essential clinic reviews and investigations.

Patients scheduled to undergo lifesaving Bone Marrow Transplants were delayed meaning that they were more sick when they eventually had their chemotherapy and transplant. Worse still, COVID meant donor cells could not be collected from donors overseas which further compromised treatment.

If they made it into hospital, adult patients were unable to have anyone with them, often for weeks at a time. Children were only allowed one parent with them and couldn't see their siblings either. This was very tough for their mental wellbeing. If CGD patients rang the NHS services for advice concerning a high temperature, they were told to stay at home as the call centre assumed they had COVID and did not understand they might have sepsis which could kill them very quickly.



These challenges emphasised the value of a dedicated specialist nurse. My work is fully funded by the CGD Society and I was able to keep going throughout the pandemic, providing individual specialist care to those affected. I negotiated emergency admission to hospital for sick patients especially when local hospitals were overwhelmed. I could visit adults in isolation during their Bone Marrow Transplant, even doing their laundry for them! I was able to facilitate supportive local hospital care for patients who required regular treatments so they did not miss them or to arrange treatment in the home that they would normally have had in hospital. As well as medical and nursing care, I am also supporting patients' mental health which is so important in these circumstances. I provide reassurance and a friendly voice to anxious patients and their families including connecting more isolated patients with others for peer support.

I was in contact with schools for children who were Shielding as well as employers for those adults unable to work. Some children were too sick to return to school due to the COVID risk so the charity has provided them with laptops and IT support to continue their education.

It has been an extraordinary year but I am sure that through the support provided by this charity we have avoided the worst consequences of Covid infection and maintained care for our patients.

Where did our income come from?

JEANS FOR GENES

Our main source of income remains the Jeans for Genes campaign for which we own the trademark and benefit from a licence fee. Started in 1992, this event is now almost 30 years old and is about to enter a new and hopefully revitalized phase. Since 2011, Jeans for Genes has been run by Genetic Disorders UK under a licence agreement. This year the campaign benefited 24 charities who have been awarded grants totaling £82,000.

GDUK have declined to continue this arrangement which gives us the opportunity to rethink and relaunch this unique fundraiser.

The licence fee for this year was agreed at 10% of gross income, raising £42,157 (2020:£90,606)

So, for 2022 onwards, we have formed a new subsidiary charity called Jeans for Genes Campaign which will take over the campaign management. This will be an independently run charity with a new CEO, Chair and trustee Board who's aim is to maximise income for the benefit of the genetic disorder community. The CGD Society will continue to receive a licence fee via a licensing agreement. In this year the business transfer from GDUK has been completed and staff have been transferred or recruited to start work on the campaign plans for 2022. CGDS has loaned its new subsidiary the funds necessary to run the first campaign and to provide working capital going forward. This is a four-year loan facility on commercial terms and defined in a formal loan agreement.

We believe that this combination of experienced staff with new support will reinvigorate this iconic brand and shift the income graph upwards as we exploit new opportunities. However, it will take a few years to emerge from the pandemic effect and rebuild the brand so our expectations remain cautious.

SPONSORSHIP

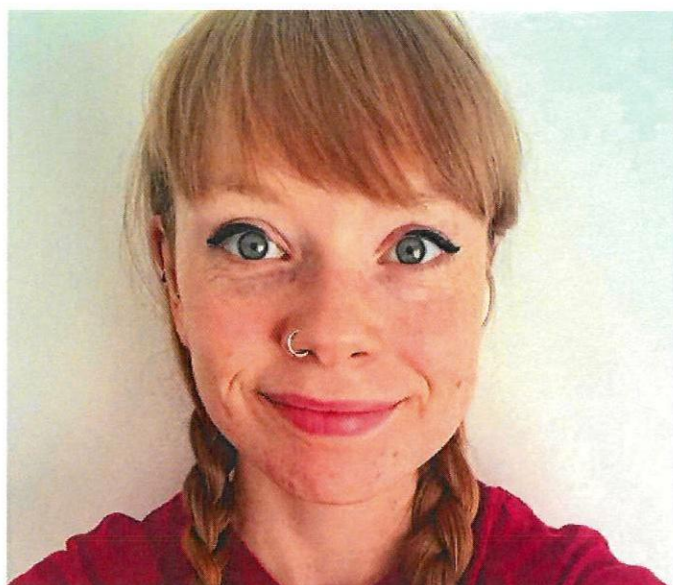
We remain indebted to our sponsors who have supported critical services again for this year. Bryant Ltd granted £5,000, restricted to the patient support fund. Orchard Therapeutics granted £7,000 to pay for newsletter costs with a top up into the patient support fund. Many thanks to both companies for their continued support.

MEMBERSHIP FUNDRAISING

We started this financial year with a new organisation and a new recruit. Adelle Scott, who is a talented creative with a long track record in the charitable sector, started in April 2020 reporting to Claire Jeffries who was promoted to Operations and Fundraising Manager in January. Thanks to them, our social media presence has been transformed with an engaging and consistent tone that has resonated well with our membership. Fundraising has flourished as a result with donation income exceeding budget by almost one third.

Supporter donations including sponsorship raised £40,935 (2020;£26,209).

Here are some of our fundraising highlights:



60 K in 31 days

Shona Munro took on the challenge of running a virtual 60k in 31 days in August. Shona is no stranger to fundraising for CGD Society having completed the Stamford Santa Run twice, in support of her partner Josh who is recovering from recently receiving a Bone Marrow Transplant (BMT) for CGD. Shona raised an impressive £170.



Alex's 2.6 Challenge

With organised fundraising events cancelled due to COVID-19, many scheduled events had to adapt and go virtual. The 2.6 Challenge was taken on by Alex Whitfield in April. Alex ran for 2 hours and 36 minutes by simply running lengths of his back garden. Alex raised over £3,000 for the CGD Society.



In loving memory

Bethany Hagues sadly lost her Mum to CGD when Bethany was very young. Bethany really wanted to do something to help others living with CGD so back in January, she decided to take on the big challenge of running 10K. As Bethany says, "I want to raise money for CGD which is a charity which helps families that are affected by this disorder. I'd love to know I've helped to make a difference and I know in my heart that my Mum would be happy to know that donations are going towards this amazing charity."

Bethany did such a great job and raised over £800. Well done Bethany, such an amazing and courageous thing to do in memory of your Mum.

Facebook Auction

In November we decided to hold an online auction to generate donations. It also gave us the opportunity to engage with the CGD community in a fun way. Adelle, our Marketing and Fundraising Officer, sourced some great items to be auctioned and we had many people taking part. In total this raised over £350.



FACEBOOK AUCTION FOR CGD

ALL MONIES RAISED FROM THESE DONATED ITEMS - FROM 6 NOV
DON'T HESITATE, PARTICIPATE!



Expenditure, investments and reserves

EXPENDITURE

56% of our expenditure (£87,939) (2020; £92,284) was spent on the relief of those suffering with CGD. This included the cost of our nurse, the family support fund and the helpline.

A further 19% of expenditure (£29,556) (2020; £23,556) was spent on education (including advocacy) which includes the website development, information booklets and sub contracted staff resources.

There was no expenditure on research although the agreed part funding of the Birmingham mental health service was held over. (£5k for 3 years) (2020; £5,400)

The remaining expenditure covered fundraising costs (£32,809) and governance (£9735)

The net movement of funds was a deficit of £76,947 excluding gains on investments. (2020; Deficit £39,759)

INVESTMENT POLICY AND PERFORMANCE

The charity has financial reserves invested in a medium risk portfolio and managed via the Investment Committee, which scrutinises the performance of the investment fund managers, Smith & Williamson.

At the end of the last financial year, the pandemic had already caused a collapse in the equity markets in the early months which wiped out over 8% of the fund value. This year, most of those losses were recovered by mid-year but, in addition, the trustees agreed to liquidate £100k of reserves to part fund the anticipated loan to Jeans for Genes Campaign.

Overall the value of the investment portfolio recovered the losses of the previous year and grew by £65,128. The value of the listed investments after withdrawing £100,000 stood at £251,705 at 31 March 2021 (2020: £288,914).

RESERVES POLICY

The charity has a reserves policy that is used to judge the adequacy of financial assets through the year. The policy is reviewed annually and this year the agreed loan of working capital to our subsidiary required a revised policy to be agreed by trustees which states that:

- The charity retains free reserves to cover running costs for 12 months of £150k min
- The loan to Jeans for Genes Campaign requires designated reserves of £200k
- A further designated contingency of £50k will be held for further working capital needs.

Based on this requirement, and taking the designated sums into account, the CGD Society has closing free reserves of £192,726 which meets and exceeds the policy targets.

What do we plan to do next year?

OBJECTIVES FOR 2021-22

Our priorities for next year reflect the new challenges that the Covid pandemic have brought us both clinical and financial. Whilst we remain committed to our 3 year strategic direction, we now recognise some new and unexpected priorities as the virus continues to disrupt our work.

- We will maintain a high level of support for members both home and abroad through our Clinical Specialist Nurse, email and phone helpline and with reference back to the Medical Panel as necessary. New advice concerning Covid will be provided as our experience informs our understanding and with clinics restarting we wish to get back to a normal UK nursing service as soon as possible. The patient support fund will continue to be a crucial support for some and we hope to continue to find sponsorship to cover and potentially extend this facility.
- We aim to better understand the impact of our services and where we can improve, we will survey our members this year to hear their feedback and begin to address any shortfall where we can.
- 2021 is the 30th anniversary of the founding of a CGD specific charity. We will take this opportunity to raise the profile of our legacy and achievements and thus encourage more membership fundraising.
- The need to diversify our income streams has never been more pressing. The income from Jeans for Genes remains uncertain so we need a pipeline of income from elsewhere to sustain this charity. Specifically, our new goal is to raise £50k from Sponsorship, Trusts and Foundation bids to pay for the nursing cost for one year.
- The pandemic has amplified the mental health impact of this disorder on our patients. We plan to survey our membership using standardized tools to measure their Quality of Life score which we will use as a basis for grant applications to support a specialist mental health support service which is yet to be defined.
- We will continue to strengthen our governance by reinforcing the Board especially with the appointment of a Vice Chair and further Trustees. We will undertake a governance review and develop processes, procedures and other tools that we identify as necessary for us to be an effective and compliant charity.

2020-21 Summary

This year has been the most challenging of our 30 year history. The impact of the Covid pandemic on our membership has been profound and will leave a clinical and mental health footprint for some time to come. The financial impact has also been severe, tipping this charity into a significant deficit and challenging us once again to look for new and diversified income sources if we are to have a sustainable long term future. However, in this difficult year our strengths have also shone through; our team have continued to provide support to CGD patients in hospital, at home, and through email and phone whilst navigating the new world of the Covid virus and learning the potential impact on our community. It has been an extraordinary year but our team have delivered a performance to match.

This report was approved by the trustees on

and signed on their behalf by:



.....
Dr Geoffrey Creamer
Chair



Thankyou!

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.



**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 2021.

Responsibilities and basis of report

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

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

Independent examiner's statement

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: 19th October 2021

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Statement of Financial Activities
for the year ended 31 March 2021**

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		33,535	7,400	40,935	26,209
Investment income	2	-	-	-	994
Other income		<u>42,157</u>	<u>-</u>	<u>42,157</u>	<u>89,594</u>
Total		75,692	7,400	83,092	116,797
EXPENDITURE ON					
Raising funds	3	32,809	-	32,809	29,658
Charitable activities	4				
Relief		81,096	6,843	87,939	92,284
Education		29,556	-	29,556	17,732
Medical Research		-	-	-	5,400
Advocacy		-	-	-	5,824
Governance		<u>9,735</u>	<u>-</u>	<u>9,735</u>	<u>5,658</u>
Total		153,196	6,843	160,039	156,556
Net gains/(losses) on investments		<u>65,128</u>	<u>-</u>	<u>65,128</u>	<u>(28,404)</u>
NET INCOME/(EXPENDITURE)		(12,376)	557	(11,819)	(68,163)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>455,102</u>	<u>2,858</u>	<u>457,960</u>	<u>526,123</u>
TOTAL FUNDS CARRIED FORWARD		<u>442,726</u>	<u>3,415</u>	<u>446,141</u>	<u>457,960</u>

The notes form part of these financial statements

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY (REGISTERED NUMBER: 07607593)**

**Balance Sheet
31 March 2021**

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
FIXED ASSETS					
Investments	8	251,706	-	251,706	288,915
CURRENT ASSETS					
Debtors	9	38,250	-	38,250	50,266
Cash at bank		<u>186,915</u>	<u>3,415</u>	<u>190,330</u>	<u>185,218</u>
		225,165	3,415	228,580	235,484
CREDITORS					
Amounts falling due within one year	10	(34,145)	-	(34,145)	(66,439)
NET CURRENT ASSETS		<u>191,020</u>	<u>3,415</u>	<u>194,435</u>	<u>169,045</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>442,726</u>	<u>3,415</u>	<u>446,141</u>	<u>457,960</u>
NET ASSETS		<u>442,726</u>	<u>3,415</u>	<u>446,141</u>	<u>457,960</u>
FUNDS	11				
Unrestricted funds				442,726	455,102
Restricted funds				<u>3,415</u>	<u>2,858</u>
TOTAL FUNDS				<u>446,141</u>	<u>457,960</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply 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

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY (REGISTERED NUMBER: 07607593)**

**Balance Sheet - continued
31 March 2021**

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 on19/10/2021..... and were signed on its behalf by:



.....
G D Creamer - Chair

The notes form part of these financial statements

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements
for the year ended 31 March 2021**

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. INVESTMENT INCOME

	2021	2020
	£	£
Loan interest from related party	<u>-</u>	<u>994</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2021**

3. RAISING FUNDS

RAISING DONATIONS AND LEGACIES

	2021 £	2020 £
Direct and support costs	<u>30,473</u>	<u>25,747</u>

INVESTMENT MANAGEMENT COSTS

	2021 £	2020 £
Portfolio management	<u>2,336</u>	<u>3,911</u>
Aggregate amounts	<u>32,809</u>	<u>29,658</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 5) £	Totals £
Relief	58,736	29,203	87,939
Education	1,012	28,544	29,556
Governance	<u>9,735</u>	<u>-</u>	<u>9,735</u>
	<u>69,483</u>	<u>57,747</u>	<u>127,230</u>

5. SUPPORT COSTS

	Staff and Management £
Relief	29,203
Education	<u>28,544</u>
	<u>57,747</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 March 2021 (in 2020 trustees' were paid expenses of £2,032).

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2021**

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2019 -2020

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	21,209	5,000	26,209
Investment income	994	-	994
Other income	<u>89,594</u>	<u>-</u>	<u>89,594</u>
Total	111,797	5,000	116,797
EXPENDITURE ON			
Raising funds	29,658	-	29,658
Charitable activities			
Relief	92,284	-	92,284
Education	15,590	2,142	17,732
Medical Research	5,400	-	5,400
Advocacy	5,824	-	5,824
Governance	<u>5,658</u>	<u>-</u>	<u>5,658</u>
Total	154,414	2,142	156,556
Net gains/(losses) on investments	<u>(28,404)</u>	<u>-</u>	<u>(28,404)</u>
NET INCOME/(EXPENDITURE)	(71,021)	2,858	(68,163)
Transfers between funds	<u>15,550</u>	<u>(15,550)</u>	<u>-</u>
Net movement in funds	(55,471)	(12,692)	(68,163)
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>510,573</u>	<u>15,550</u>	<u>526,123</u>
TOTAL FUNDS CARRIED FORWARD	<u><u>455,102</u></u>	<u><u>2,858</u></u>	<u><u>457,960</u></u>

8. FIXED ASSET INVESTMENTS

	Listed investments £	Unlisted investments £	Totals £
MARKET VALUE			
At 1 April 2020	288,914	1	288,915
Disposals	(100,000)	-	(100,000)
Revaluations	<u>62,791</u>	<u>-</u>	<u>62,791</u>
At 31 March 2021	<u>251,705</u>	<u>1</u>	<u>251,706</u>
NET BOOK VALUE			
At 31 March 2021	<u>251,705</u>	<u>1</u>	<u>251,706</u>
At 31 March 2020	<u>288,914</u>	<u>1</u>	<u>288,915</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2021**

8. FIXED ASSET INVESTMENTS - continued

There were no investment assets outside the UK.

Cost or valuation at 31 March 2021 is represented by:

	Listed investments £	Unlisted investments £	Totals £
Valuation in 2021	62,791	-	62,791
Cost	<u>188,914</u>	<u>1</u>	<u>188,915</u>
	<u>251,705</u>	<u>1</u>	<u>251,706</u>

9. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Trade debtors	23,228	50,266
Other debtors	<u>15,022</u>	<u>-</u>
	<u>38,250</u>	<u>50,266</u>

10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Trade creditors	17,095	59,852
Amounts owed to group undertakings	-	1
Social security and other taxes	771	-
VAT	6,430	4,992
Other creditors	6,754	94
Accruals and deferred income	<u>3,095</u>	<u>1,500</u>
	<u>34,145</u>	<u>66,439</u>

11. MOVEMENT IN FUNDS

	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	<u>372,000</u>	<u>-</u>	<u>(122,000)</u>	<u>250,000</u>
	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	<u>-</u>	<u>250</u>	<u>-</u>	<u>250</u>
	<u>2,858</u>	<u>557</u>	<u>-</u>	<u>3,415</u>
TOTAL FUNDS	<u>457,960</u>	<u>(11,819)</u>	<u>-</u>	<u>446,141</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2021**

11. 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	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
	<u>7,400</u>	<u>(6,843)</u>	<u>-</u>	<u>557</u>
TOTAL FUNDS	<u>83,092</u>	<u>(160,039)</u>	<u>65,128</u>	<u>(11,819)</u>

Comparatives for movement in funds

	At 1.4.19 £	Net movement in funds £	Transfers between funds £	At 31.3.20 £
Unrestricted funds				
General fund	138,573	(71,021)	15,550	83,102
Jeans for Genes support	<u>372,000</u>	<u>-</u>	<u>-</u>	<u>372,000</u>
	510,573	(71,021)	15,550	455,102
Restricted funds				
Family Conference	15,050	-	(15,050)	-
Nursing Services	500	-	(500)	-
Bryant Ltd (Family Support)	<u>-</u>	<u>2,858</u>	<u>-</u>	<u>2,858</u>
	<u>15,550</u>	<u>2,858</u>	<u>(15,550)</u>	<u>2,858</u>
TOTAL FUNDS	<u>526,123</u>	<u>(68,163)</u>	<u>-</u>	<u>457,960</u>

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	111,797	(154,414)	(28,404)	(71,021)
Restricted funds				
Bryant Ltd (Family Support)	<u>5,000</u>	<u>(2,142)</u>	<u>-</u>	<u>2,858</u>
TOTAL FUNDS	<u>116,797</u>	<u>(156,556)</u>	<u>(28,404)</u>	<u>(68,163)</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2021**

11. MOVEMENT IN FUNDS - continued

TRANSFERS BETWEEN FUNDS

The transfer between funds in the year ended 31 March 2020 is to correct a prior year error where restricted costs were allocated against the general fund.

The transfer between funds in the year ended 31 March 2021 is necessary to meet our revised Reserves Policy. Deficits over recent years have depleted Free Reserves so the Designated Reserve has been reduced and the balance transferred to the General Fund to give cover for at least one year's total expenditure.

12. RELATED PARTY DISCLOSURES

A licence fee is paid annually to the Chronic Granulomatous Disorder Society (CGD Society), which owns the Jeans for Genes and Genetic Disorders UK (GDUK) trademarks. The fee totalled £42,157 (2020: £90,606).

In addition there is a SLA between Genetic Disorders UK and Chronic Granulomatous Disorder Society in relation to the provision of staff. The charge for the year amounted to £13,403 (2020: £42,804).

At the year end Jeans For Genes Campaign owed Chronic Granulomatous Disorder Society £14,025 (2020: £Nil), Jeans For Genes Campaign was set up as a subsidiary by Chronic Granulomatous Disorder Society during the year and has common trustees.