

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

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**
(a company limited by guarantee)

Unaudited Financial Statements for the Year Ended 31 March 2020



Supporting families affected by chronic granulomatous disorder

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

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

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for the year ended 31 March 2020**

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**Report of the Trustees
for the year ended 31 March 2020**

CHARITY INFORMATION

Honorary president	Ocean Numan*
Trustees	Dr Geoff Creamer - Chair* Ning He* Jackie Irvine* Andrew Orchard* Davina Gray* Jane Docherty* Chikai Lai (appointed 05/10/2019) Jayne Nicol (appointed 02/02/2020) David Hannard* (appointed 05/10/2019) *Indicates either a CGD patient or a member of a family affected by CGD.
Operations and Fundraising Manager	Claire Jeffries (promoted January 2020)
Registered office	38 Glenmore Chorley PR6 7TA
Independent Examiner	Tudor John Limited Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ
Bankers	Barclays Corporate Level 27, 1 Churchill Place London E14 5HP
Solicitors	Blandy & Blandy LLP 1 Friar Street Reading Berkshire RG1 1DA
Investment advisers	Smith & Williamson Portwall Place Portwall Lane Bristol BS1 6NA

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PATIENT SERVICES AND ADVISORY PANELS

Patient Services

Ms Helen Braggins, RGN, RSCN, Chronic Granulomatous Disorder Clinical Nurse Specialist, Great Ormond Street Hospital for Children, London.

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.

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TRUSTEES' REPORT

The trustees present their annual report for the year ended 31 March 2020 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 the world 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.

In the 1990s, the CGDRT launched a one-day fundraising campaign to encourage pupils and employees to wear their jeans to school and work in exchange for a small donation. It called this event Jeans for Genes Day for which it owns the trade mark. In 2011, the CGD Society co-founded Genetic Disorders UK (GDUK) to manage the annual Jeans for Genes Day campaign. The CGD Society charges GDUK an annual licence fee for the use of the GDUK and Jeans for Genes trademarks, which provides the majority of the income to fund the charity's activities.

ABOUT CHRONIC GRANULOMATOUS DISORDER

Prevalence and impact

Chronic granulomatous disorder (CGD) is a rare, life-limiting, inherited condition affecting the immune system. CGD affects around six 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, life-threatening complications such as colitis, abscesses on the skin and organs, and severe respiratory problems.

Treatment options

Until the late 2000s, the majority of patients diagnosed with CGD were prescribed prophylactic medication to keep infection at bay. However, while these antibacterials and antifungals provided a level of protection, they did not prevent all types of infection, and patients with CGD often led a life of chronic ill health.

However, in recent years, the prognosis for children and adolescents diagnosed with CGD in some parts of the world has changed dramatically. Improvements in the bone marrow transplantation (BMT) process have meant that between 80 and 90 per cent of children who undergo a BMT for CGD are cured of the disorder.¹ Today, in countries such as the UK, a child diagnosed with CGD is routinely tissue-typed to identify a suitable bone marrow donor. Once a donor is found, BMT is discussed with the child and the family and, in most cases, the affected child is scheduled for transplant.

BMT is a relatively safe and increasingly successful cure for children with CGD. The younger the child and the better their infection history is, the more successful transplantation is likely to be. Furthermore, transplantation techniques are improving so rapidly that a BMT is now being considered a safe therapy for many young adults, and there is much hope that over the coming decade, it will be possible to offer a safe BMT procedure for many people affected by CGD regardless of age. Also, the donor options for a successful BMT are improving. Historically, a sibling donor or a very close unrelated match was required but today parent donors and relatively poor matches can be successful meaning that potentially all patients have a BMT donor available which is a major step forward.

¹ A BMT can cure an affected individual of CGD but it does not change the 'germline', i.e. the gene fault causing CGD still remains in the genes of the individual and can be passed on to future generations.

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Furthermore, the long standing prospect of a Gene Therapy cure for CGD is moving forward with Orchard Therapeutics who have published early clinical trial results and already claim Proof of Concept. Their work is built on over £2m of research funded by the CGD Society in the past. Registrations are now underway for further clinical trials across a broader spectrum of patients that it is hoped will demonstrate even more efficacy and safety and will ultimately result in regulatory approval in the UK and elsewhere. This is exciting but slow progress that will still take several years to reach the clinic. We will work closely with all parties to expedite these developments which we hope will provide a safer alternative to BMT for some of our patients.

It is fascinating to reflect on the history of our condition. The first reported cases were named Fatal Granulomatous Disease in the 1950's for obvious reasons. In the 1980's the identification of the faulty gene for the most common variant raised the prospect of a cure via genetic engineering whilst the new century saw Haemopoietic Stem Cell Transplant (or BMT) come of age and provide the first genuine cure for some patients. Meanwhile, management of the condition with new drugs and shared best practice has extended life expectancy and improved quality of life considerably. As we enter a new decade we are hopeful that Gene Therapy, our curative goal since the charity was started 30 years ago, will be available in the clinic before 2025.

Since the early 1990's the presence of a charity specifically focused on CGD along with the development of the internet has vastly improved the worldwide knowledge of the condition. Our contact with members across the world is extraordinary but challenges us to deliver equal support to all irrespective of the local infrastructure, medical facilities and family conditions. When this charity was started in 1991, the target was to find a cure in 5 years. 30 years later, we see great progress but still a way to go.

Inheritance

CGD can be inherited in two different ways. The first of these is via a faulty gene inherited from the mother and is known as X-linked CGD. The second is via a faulty gene from both the mother and the father and is known as autosomal recessive CGD or which there are four variants. In recent years, it has come to the attention of medical professionals that women who carry the X-linked CGD genetic fault are experiencing symptoms of CGD and therefore these female carriers are now considered an important sub-group within the CGD community.

OUR OBJECTS

The objects of the CGD Society, as stated in the Articles of Association, are:

- 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.

The principal activities of the CGD Society are the furtherance of its charitable objects as described above.

OUR VISION, MISSION AND STRATEGY

Within this year, the charity has finalised a new 3 year strategy for 2020-2023. This following content is structured around those strategic aims:

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.

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The main strategic priorities are as follows:

1. Support:

We will continue to provide support to patients and families affected by CGD by keeping abreast of new research and treatments, whilst championing fair and equal access for all. We will build on our extensive experience in promoting awareness of CGD and extend our reach internationally, providing individuals, families and medical professionals with easy access to comprehensive information and advice. We will also explore ways in which we can offer additional support for mental health and associated Quality of Life issues around living with CGD.

2. Partnerships:

We will provide strong leadership in facilitating closer working between government healthcare agencies, hospitals, clinicians and specialists in order to benefit those affected by CGD. We will facilitate closer working between national and local practitioners and achieve greater awareness of effective management of the condition and a consistent approach to care. We will support the Royal College of Physicians' QPIDS initiative to accredit primary immunodeficiency (PID) services to defined quality standards (note 1). We will build relationships with like-minded charities with similar goals to our own, and pharmaceutical companies and healthcare providers, where this is in the interest of our members and is within our strategic aims.

3. Building a sustainable community:

We will work towards achieving a robust and resilient future for the Society.

1. We will develop a clear and focused fundraising strategy aimed at diversifying our income streams. We will outline plans to increase the Society's funds year on year by maximising opportunities for grants and personal giving. We will also develop our skills in preparing bids for funding and apply to a broad spectrum of grant-givers and charitable trusts.

2. Our long-standing fundraising event, Jeans for Genes Day, will continue to be developed and promoted, potentially with new partners. However, we recognise that new sources of income are a necessity to reduce the impact of a bad year for this annual event.

3. We will aim to build our CGD community by increasing UK and international membership. We will also strengthen and diversify our board of trustees to better support our operational team in their delivery of membership-led support goals.

THE PATIENT GROUPS within the CGD community are identified as:

- The parents of children newly diagnosed with CGD who are located in countries where BMT is safe and available. In most cases, these children will be referred for BMT as soon as a donor is found
- Young adults with CGD for whom BMT is a possibility
- The parents of children newly diagnosed with CGD for whom BMT is not an option
- Adults with CGD for whom BMT is not currently an option
- X-linked CGD female carriers.

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OBJECTIVES, ACTIVITIES AND ACHIEVEMENTS 2019-20

Support

Objectives:

- The CGD Society will launch a new look website around September 2019. The website will be updated with new images, members fundraising activities, comprehensive and up to date information for both families and medical professionals. The new website will feature new and improved links for users to find information easily and will include better security and simpler tools for updating content.
- Maintain and further improve membership communication through all channels in particular promoting patient stories for the website and newsletters to encourage the sharing of experience whilst also engendering a feeling of community.
- To continue to provide direct support for families affected by CGD through the provision of nursing services, a telephone/email helpline and financial assistance where justified. Funds permitting, we will develop and plan to increase mental health support which is recognized as a dominant quality of life issue for those affected by rare diseases.
- We will establish a member volunteer panel that will support the operational team to deliver our support services as well as maximize member fundraising initiatives.

Activities and achievements:

- The CGD Society CNS attended clinics at both GOSH and the Royal Free Hospital. In addition to this the CNS provides telephone and email support to overseas families. Support was provided to:
 - 153 affected children and their families
 - 11 children and adolescents undergoing BMT and 37 follow up post BMT
 - 2 children post gene therapy
 - 52 affected adults
 - 3 adults post BMT
 - 75 X-linked CGD carrier females.
- The charity dealt with 85 (2018-19: 104) enquiries from families and medical professionals from around the world about various aspects of the diagnosis and care of patients with CGD.
- Financial assistance was provided to 27 families in the UK. This included the payment of 16 prescription pre-payment certificates and 11 family support grants.
- A new and updated website was launched this year. It included a new home page with new images and new and improved links for users to find information easier with obsolete content removed. A new dedicated page for real life stories on living with CGD was also included. New fundraising pages were added to encourage member participation and to share their fundraising stories.
- We added new content to the website including articles
 - A Promising report on Gene Therapy clinical trials
 - CGDS funding supported research on a new tool to speed up diagnosis of P47Phox CGD.
- Relatable stories from the CGD community were added to the website. The FAQ sections were expanded with new material and a dedicated page on COVID-19 was added to keep the CGD community updated on the latest developments on shielding, advice, FAQ's, emotional wellbeing and on treatments and findings.
- 17 website pages were reviewed and updated
- Updated legacy material was created and added to our website – Guidance for making a will, a CGDS legacy letter, leave a gift in your will and will legal terms explained.
- We reviewed and published second editions of the following CGD materials:
 - A guide for women carriers of X-linked CGD,
 - Making the most of appointments,
 - Going on Holiday
 - Your employment rights.
- We completed a literature review of progress on Haematopoietic Stem Cell Transplant (BMT)for CGD.

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- We have agreed to part-fund a new initiative at Birmingham Heartlands Hospital to create a mental health support unit within their immunology clinic. Initiated by Dr Aarn Huissoon, we are pleased to pledge £5,000 for each of three years, although the project has yet to start.
- Work on a member survey has started but is not released yet. We are challenged by the complexities of effective data collection and making sure that we have a robust model that will persist over several years as we try to track member's clinical and personal progress.
- A Volunteer Panel has yet to be created so this will be carried forward to next year

ii. Partnerships

Objectives:

- To develop a plan for a significant presence at the ESID conference in Birmingham in October 2020 such that we take this opportunity to promote ourselves among the international medical professionals who will attend this biennial event.

Activities and achievements:

- We have maintained our affiliations with AMRC, Genetic Alliance and IPOPI.
- We continue to work closely with GDUK to improve our fundraising through Jeans for Genes. We have agreed that GDUK will run this event for a further year in 2020 but we anticipate a new arrangement for 2021 and beyond for which plans are being developed.
- We have maintained close contact with Orchard Therapeutics who are a commercial organization developing Gene Therapy techniques for X linked CGD. We undertook two projects with them:
 - To mark Rare Disease Day, Claire, our Operations and Fundraising Manager, and a CGD patient spoke at their London office on what life is like living with CGD and to promote the charity within their team.
 - We have started a project to provide photographs of four members to give Orchard a more personal connection with their commercial activity in their offices. Two photos were delivered before COVID intervened and the project was paused for a period.
- CGDS agreed to sponsor and attend this years' Immunology and Allergy Nurses Group conference due to take place (11 – 12 May 2020 in Oxford). The event was cancelled due to COVID-19 with our sponsorship carried over to the 2021 conference.
- CGDS secured a stand at the ESID conference in Birmingham (14 – 17 October 2020). This event is now scheduled to run online due to COVID- 19 so our stand has been cancelled.

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iii. Building a sustainable community

Objectives:

- Our aim is to maintain membership fundraising at a high level whilst in parallel making resources available for high quality applications to Charitable Trusts and other grant givers. We aim to at least match the membership donation total from 3rd party sources
- Recruitment of a further two new Trustees to expand the Board and improve our skills.

Activities and achievements:

- Claire Jeffries, who has achieved so much in her role as Charity Coordinator has been promoted to the full time post of Operations and Fundraising Manager, starting January 1st 2020 .
- A second employee in the role of Fundraising Officer, has been recruited and will start on April 1st 2020.
- Both of these appointments are designed to increase our fundraising activity and bolster our management processes to improve the resilience of this charity
- 18,291 users visited the charity's website www.cgdsociety.org and undertook 23,893 sessions.
- The CGDS Facebook page attracted 98 new followers and 76 new Twitter followers
- Ten eNews updates and two Full Newsletters were sent to members of our database. These contained information about CGD health issues, CGD community news, CGDS activities and community fundraising.
- Membership of the charity rose from 1821 to 1962 during the year. 60 members came from the UK while the rest came from 22 different countries. In total, 69 countries are represented in our membership.
- Personal donations of £45k (2018; £14k) showed a significant reduction from last year (2018-19 £45k) but this was an exceptional total, sadly as a result of two young adults losing their lives and the fundraising that followed. Nonetheless, this year's sum is a steady increase on historical totals and should be increased further when our new employee joins in April.
- Overall, the charity has seen a significant and welcome re-engagement of the membership in all aspects of our work. The monthly ENews bulletins and positive social media content have rebuilt the trust and commitment to our cause from a low ebb a couple of years ago. Our appointment of Claire two years ago has been a resounding success and we hope for more next year with our new organization and second employee Adelle Scott.
- Three new Trustees were appointed during the year:
 - David Hannard, a father of a CGD child who has successfully gone through a BMT
 - Chikai Lai, who has no CGD family connection and works in the pharmaceutical industry
 - Jayne Nicol, who also has no CGD connection and trained as a nurse before retraining as a lawyer specializing in medical negligence cases.

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In particular the appointment of two trustees without a CGD family connection should help us to broaden the perspective of the Board as well as our skill set. Sadly, no Deputy Chair was appointed so this is still an open position.

Coronavirus COVID 19 impact

As this financial year came to a close, the emerging threat of the Covid19 virus had crystallized into a UK wide lockdown on March 23rd. For our members affected by this immune deficiency, Covid has proved to be their biggest challenge probably for a lifetime. For those already compromised by their condition, more severe Shielding was recommended but for all members, Isolation became the norm. This posed huge challenges on our team who urgently needed to provide support and advice for a very concerned cohort on an international scale.

Working alongside our Medical Panel and with PIDUK, our sister charity advocating for all immunodeficiencies, Claire, Helen and Susan were able to generate specific advice on our website and social media in record time. They also fielded a high number of specific enquiries from members some of whom were clearly in distress. Although strictly only covering one week within this report, this is a good opportunity to pay tribute to our team, who have worked under great stress to support our membership. This continues to be the perfect demonstration of a committed charity supporting a clinically challenged group who could have been severely compromised without such specialised care and advice.

As I write this, Covid is still here so we continue to wrestle with it but especially with the clinical and mental health impact of extended Shielding for those who need it. This will dominate our plans for next year.

But for now, well done to Trustees and employees for the wonderful support that you have delivered in this unprecedented situation.

FINANCIAL PERFORMANCE 2019-20

The main source of income for the CGD Society is the licence fee paid by GDUK for the use of the Jeans for Genes and GDUK trademarks. This licence fee is agreed annually by the CGD Society trustees in consultation with the trustees of GDUK. For the financial year 2019-20, the licence fee decreased, raising £89,594. (In 2018-19, the licence fee raised £113,231) Supporter donations totalled £26,209 (2019: £60,378).

£92,284 (2019: £74,542) was spent under the Society's charitable object of the relief of persons suffering from CGD. These costs comprised the salary of the CGD CNS at Great Ormond Street Hospital for Children, grants awarded from the family support fund and the management fee paid to GDUK to oversee the helpline and member support services.

£15,590 (2019: £62,165) was spent under the charitable object of education. These costs included the continued development of the website and the creation of new content, including booklets.

The net movement in funds was a reduction of £68,163 (2019: surplus £29,080)

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INVESTMENT POLICY AND PERFORMANCE 2019-20

The articles allow the trustees to hold investments using the general funds of the charity. The investment policy is determined by the trustees and managed via the Investment Committee, which scrutinises the performance of the investment fund managers, Smith & Williamson.

With continuing uncertainty due to Brexit and the coronavirus pandemic causing further volatility in the markets, the portfolio has been retained with a medium risk profile. £44,000 was liquidated from the equity investments during the year and withdrawn from the cash fund held within the portfolio to give funding support for the Jeans for Genes campaign.

The investment portfolio had a return over the year of -8.3%. The value of the listed investments after withdrawing £44,000 stood at £288,914 at 31 March 2020 (2019: £365,229).

RESERVES

The Trustees reserves policy is reviewed annually and requires that free reserves should cover core costs for 12 months, including those related to the nursing service and the outsourced costs to GDUK. A further restricted sum is allocated to the continuity of the Jeans for Genes campaign, firstly in the form of loan capital to support the annual event and secondly a working capital sum that would allow CGDS to run the campaign should the current arrangements break down, for example in the event of poor income in a difficult year. The CGD Society currently has closing free reserves of £83,084. It is recognised that this falls short of our reserves policy requirement so in the current year the policy and the available funds will be reviewed and adjusted to meet ongoing requirements.

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OBJECTIVES FOR 2020-21

- The Society will maintain a high level of support to our members both home and abroad. This will be via the provision of nurse services, a helpline which ultimately can access advice from our Medical Panel if required, and access to a hardship fund where financial support is needed.
- The continuing presence of the Covid 19 virus will require specific advice for those in Isolation or Shielding. We will work hard to keep our members free from this disease and continue to provide the CGD community with the latest information and advice on COVID-19 through our website and newsletters.
- The improvement of mental health support is one of our priorities for external funding. We hope to see the Birmingham Heartlands Hospital initiative for a mental health facility within the Immunology clinic functioning within this year. The Society is part funding this for 3 years.
- Our aim is to diversify and increase our funding from all sources such as 3rd party grant givers, pharmaceutical companies and healthcare providers as well as membership donations especially regular givers. The budget aims to raise over £50k from non Jeans for Genes sources.
- We hope for a successful 2020 Jeans for Genes campaign although the impact of Covid makes the result very uncertain. This will be the last campaign run by Genetic Disorders UK. We plan to have a new J4G arrangement in place by the end of 2020, ready to run the 2021 campaign which we hope will deliver a more robust future for this event which is unique among the genetic disorder community.
- By the end of the next financial year, we will have decided on a plan for our 30th year celebrations including the prospect of a 2021 Family Conference although this may be impossible if the Covid restrictions are still in place. We hope that our anniversary year will provide a new impetus to our membership fundraising in 2021-22.
- We aim to further improve our member communications via Adelle Scott our new Fundraising Officer using all channels but specifically social media and newsletters. We are aiming for a modest increase in member donations for the year.
- We will review the potential for a Volunteer Panel to support the work of our staff. We can see advantage in the engagement and promotion of our fundraising by a small volunteer team, but we need to measure this value balanced by the effort and workload that this brings.
- We aim to launch a survey of members to measure their current condition both clinically and mentally. We will use this evidence to inform our charitable activities as well as provide a baseline for external developments such as Gene Therapy where regulatory and financial approval will rely on good quality data.
- The Trustee Board recognizes the need for a Safeguarding Policy and associated procedures which are currently under development and will be completed in the next financial year. Our aim is to describe a process for supporting staff, volunteers, beneficiaries, donors and members of the public when they are interacting with our charity.
- The Trustee Board will be strengthened by further appointments where skills gaps are identified. We hope to encourage an existing Trustee to take on the role of Deputy Chair once the ongoing reorganisation has sufficiently reduced the workload for this volunteer position.

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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. The CGD Society has a wholly owned trading subsidiary, Chronic Granulomatous Disorder Society Trading Limited (registered number 07731513), which is currently dormant.

TRUSTEES

The board of trustees is responsible for the overall governance, policy and strategic direction of the CGD Society. The members of the board of 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. The trustees who have served during the year and since the year end are set out on page 1.

The charity is governed by individuals with a broad range of skills, including general management, legal, financial, pharmaceutical and IT expertise. A personal perspective on CGD is provided by a majority of trustees, who either have CGD themselves or have an affected family member.

The board of trustees meets at least four times a year to review progress and policies. Trustees serve on the board for a period of three years that is renewable. New trustees are appointed by the serving trustees, taking into account the skills and experience required by the board.

Trustees are advised by the Finance Committee that meets twice a year and monitors and reviews progress and policies relating to cash flow, operational and investment matters. The committee reviews the end of year financial statements of the charity and recommends them to the board of trustees. It also monitors the independent examination process and any management actions recommended by the independent examiner. The committee monitors the performance of the charity's investment portfolio, and is responsible for the appointment of the investment adviser.

The charity's work is supported by the **Medical Advisory Panel** which advises the charity on medical matters and on the provision of appropriate care for people with CGD. It is also responsible for reviewing the medical content of the CGD Society website and publications to ensure that the information provided is accurate and up to date. Its members are distinguished clinicians and healthcare professionals in the fields of immunology, stem cell transplantation and general practice.

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.

The charitable purpose for the charity within the meaning of the Act is enshrined within its objects, as given in the Memorandum and Articles of Association, and the charitable objects are included in this report.

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EXECUTIVE MANAGEMENT

This year the Society has started a reorganisation with Claire promoted to a more senior role and a second part time employee soon to start work. The Trustee Chair has been acting in a CEO capacity for the last couple of years but will now start to hand over some governance tasks to the new organization. This will improve our resilience and flexibility for the future. The essential elements of good governance will remain being:

- An annual budget approved by and with payments authorised by Trustees.
- At least a quarterly review of financial reports with feedback to the Board concerning variance to budget.
- A monthly KPI report to track non financial performance.
- An annual risk register to update and manage our risk profile.
- Strategic planning and objective setting to deliver our planned goals.

RISK MANAGEMENT

The trustees have overall responsibility for ensuring that the CGD Society is managing risk in a professional, responsible and constructive manner. This has involved identifying the types of risks the charity may face and assessing and balancing them in terms of potential impact and likelihood of occurrence. The trustees seek to ensure that all internal controls, and in particular financial controls, comply in all respects with best practice and inter alia the guidelines issued by the Charity Commission.

The trustees will continue to assess risk to safeguard the future of the CGD Society. The board is conscious of the challenges that the Society faces in light of its reliance on the income generated by Jeans for Genes Day each year to fund its activities and is now making a concerted effort to diversify its income to other sources.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (UK Accounting Standards) and applicable law.

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 these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently
- make judgements and accounting estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

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

**Report of the Trustees
for the year ended 31 March 2020**

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the company's and group's transactions and disclose with reasonable accuracy at any time the financial position of the company and group and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

Finally, we would like to thank all patients, carers and donors for their continuing support.

This report was approved by the trustees on 09/11/2020

and signed on their behalf by:



.....
Geoff Creamer
Chair

**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 2020.

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').

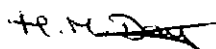
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). 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 IHQ

Date: 9th November 2020

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Statement of Financial Activities
for the year ended 31 March 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		21,209	5,000	26,209	60,378
Investment income	2	994	-	994	-
Other income		<u>89,594</u>	<u>-</u>	<u>89,594</u>	<u>113,231</u>
Total		111,797	5,000	116,797	173,609
EXPENDITURE ON					
Raising funds	3	29,658			20,743
Charitable activities	4				
Relief		90,142	2,142	92,284	74,542
Education		17,732	-	17,732	62,165
Medical Research		5,400	-	5,400	-
Advocacy		5,824	-	5,824	3,283
Governance		5,658	-	5,658	4,356
Total		<u>154,414</u>	<u>2,142</u>	<u>156,556</u>	<u>165,089</u>
Net gains/(losses) on investments		<u>(28,404)</u>	<u>-</u>	<u>(28,404)</u>	<u>20,560</u>
NET INCOME/(EXPENDITURE)		(71,021)	2,858	(68,163)	29,080
Transfers between funds	11	<u>15,550</u>	<u>(15,550)</u>	<u>-</u>	<u>-</u>
Net movement in funds		(55,471)	(12,692)	(68,163)	29,080
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>510,573</u>	<u>15,550</u>	<u>526,123</u>	<u>497,043</u>
TOTAL FUNDS CARRIED FORWARD		<u>455,102</u>	<u>2,858</u>	<u>457,960</u>	<u>526,123</u>

The notes form part of these financial statements

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

**Balance Sheet
31 March 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
FIXED ASSETS					
Investments	8	288,915	-	288,915	365,230
CURRENT ASSETS					
Debtors	9	50,266	-	50,266	79,831
Cash at bank		<u>182,360</u>	<u>2,858</u>	<u>185,218</u>	<u>158,996</u>
		232,626	2,858	235,484	238,827
CREDITORS					
Amounts falling due within one year	10	(66,439)	-	(66,439)	(77,934)
NET CURRENT ASSETS		<u>166,187</u>	<u>2,858</u>	<u>169,045</u>	<u>160,893</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>455,102</u>	<u>2,858</u>	<u>457,960</u>	<u>526,123</u>
NET ASSETS		<u>455,102</u>	<u>2,858</u>	<u>457,960</u>	<u>526,123</u>
FUNDS	11				
Unrestricted funds				455,102	510,573
Restricted funds				<u>2,858</u>	<u>15,550</u>
TOTAL FUNDS				<u>457,960</u>	<u>526,123</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2020.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2020 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 2020**

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 09/11/2020
and were signed on its behalf by:



.....
Geoff 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 2020**

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

	2020	2019
	£	£
Loan interest from related party	<u>994</u>	<u>-</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

Notes to the Financial Statements - continued
for the year ended 31 March 2020

3. RAISING FUNDS

RAISING DONATIONS AND LEGACIES

	2020 £	2019 £
Direct and support costs	<u>25,747</u>	<u>16,894</u>

INVESTMENT MANAGEMENT COSTS

	2020 £	2019 £
Portfolio management	<u>3,911</u>	<u>3,849</u>
Aggregate amounts	<u>29,658</u>	<u>20,743</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 5) £	Totals £
Relief	62,807	29,477	92,284
Education	2,747	14,985	17,732
Medical Research	4,162	1,238	5,400
Advocacy	1,908	3,916	5,824
Governance	<u>-</u>	<u>5,658</u>	<u>5,658</u>
	<u>71,624</u>	<u>55,274</u>	<u>126,898</u>

5. SUPPORT COSTS

	Staff and Management £	Governance costs £	Totals £
Relief	29,477	-	29,477
Education	14,985	-	14,985
Medical Research	1,238	-	1,238
Advocacy	3,916	-	3,916
Governance	<u>-</u>	<u>5,658</u>	<u>5,658</u>
	<u>49,617</u>	<u>5,658</u>	<u>55,274</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

Notes to the Financial Statements - continued
for the year ended 31 March 2020

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2020 nor for the year ended 31 March 2019.

TRUSTEES' EXPENSES

Trustees expenses of £2,032 (2019 £3,637) were paid during the year.

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES 2018 - 2019

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	45,328	15,050	60,378
Other income	<u>113,231</u>	<u>-</u>	<u>113,231</u>
Total	158,559	15,050	173,609
 EXPENDITURE ON			
Raising funds	20,743	-	20,743
Charitable activities			
Relief	74,542	-	74,542
Education	62,165	-	62,165
Advocacy	3,283	-	3,283
Governance	4,356	-	4,356
	<u> </u>	<u> </u>	<u> </u>
Total	165,089	-	165,089
Net gains on investments	<u>20,560</u>	<u>-</u>	<u>20,560</u>
NET INCOME	14,030	15,050	29,080
 RECONCILIATION OF FUNDS			
Total funds brought forward	496,543	500	497,043
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS CARRIED FORWARD	<u>510,573</u>	<u>15,550</u>	<u>526,123</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

Notes to the Financial Statements - continued
for the year ended 31 March 2020

8. FIXED ASSET INVESTMENTS

	Listed investments £	Unlisted investments £	Totals £
MARKET VALUE			
At 1 April 2019	365,229	1	365,230
Disposals	(44,000)	-	(44,000)
Revaluations	<u>(32,315)</u>	<u>-</u>	<u>(32,315)</u>
At 31 March 2020	<u>288,914</u>	<u>1</u>	<u>288,915</u>
NET BOOK VALUE			
At 31 March 2020	<u>288,914</u>	<u>1</u>	<u>288,915</u>
At 31 March 2019	<u>365,229</u>	<u>1</u>	<u>365,230</u>

There were no investment assets outside the UK.

9. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Trade debtors	50,266	79,120
Prepayments and accrued income	<u>-</u>	<u>711</u>
	<u>50,266</u>	<u>79,831</u>

10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Trade creditors	59,852	61,146
Amounts owed to group undertakings	1	1
VAT	4,992	8,648
Other creditors	94	4,639
Accruals and deferred income	<u>1,500</u>	<u>3,500</u>
	<u>66,439</u>	<u>77,934</u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2020**

11. 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)	-
Patient 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><u>526,123</u></u>	<u><u>(68,163)</u></u>	<u><u>-</u></u>	<u><u>457,960</u></u>

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				
Patient Support	<u>5,000</u>	<u>(2,142)</u>	<u>-</u>	<u>2,858</u>
TOTAL FUNDS	<u><u>116,797</u></u>	<u><u>(156,556)</u></u>	<u><u>(28,404)</u></u>	<u><u>(68,163)</u></u>

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2020**

11. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.4.18 £	Net movement in funds £	Transfers between funds £	At 31.3.19 £
Unrestricted funds				
General fund	496,543	14,030	(372,000)	138,573
Jeans for Genes support	<u>-</u>	<u>-</u>	<u>372,000</u>	<u>372,000</u>
	496,543	14,030	-	510,573
Restricted funds				
Family Conference	-	15,050	-	15,050
Nursing Services	<u>500</u>	<u>-</u>	<u>-</u>	<u>500</u>
	<u>500</u>	<u>15,050</u>	<u>-</u>	<u>15,550</u>
TOTAL FUNDS	<u>497,043</u>	<u>29,080</u>	<u>-</u>	<u>526,123</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	158,559	(165,089)	20,560	14,030
Restricted funds				
Family Conference	<u>15,050</u>	<u>-</u>	<u>-</u>	<u>15,050</u>
TOTAL FUNDS	<u>173,609</u>	<u>(165,089)</u>	<u>20,560</u>	<u>29,080</u>

TRANSFERS BETWEEN FUNDS

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

**THE CHRONIC GRANULOMATOUS DISORDER
SOCIETY**

**Notes to the Financial Statements - continued
for the year ended 31 March 2020**

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 £89,594 (2019: £113,231).

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 £44,210 (2019 £46,345).

