CGDSociety
Supporting families affected by
chronic granulomatous disorder

JOIN THIS FRIENDLY BOARD AND HELP US MAKE A DIFFERENCE

<u>Message from Dr Geoff Creamer, Chair of Trustees</u>

Hello,

Thank you for responding to our trustee recruitment drive. I have been active in this charity for 30 years but I remain passionate about what we do and what a difference we make for our membership.

There are more than 6000 inherited conditions most of which are rare diseases like CGD so we cannot expect the NHS to provide expert care to our members especially in Primary Care and regional hospitals. So, our specialist nurse and our information sources are critical to educate our membership and the medical professionals that support them.

I believe that we have the best CGD resources anywhere in the world. Access to our website is open to all without cost so our reach is extraordinary. When we are able to hold the next Family Conference Weekend, we will welcome members from all over the globe who value our support so much. This is the motivation for me and our Board to continue pushing this charity forward.

Perhaps you would expect that after 30 years there would be nothing left to do but this could not be further from the truth. For example, genetic engineering will transform the landscape for inherited conditions, so we want to be at the top of the list for a curative option for all our members through Gene Therapy. We are proud that our investment in research over 3 decades has helped to get us to stage 1 clinical trials but there is a long way to go before this technology will arrive in the clinic.

So, we are already a successful charity, but we have so much more to do. I hope that you, having read the information below and having looked through our website, will feel compelled to apply to join us. However, if you still have questions unanswered, please drop me a line on hello@cgdsociety.org

With best wishes,
Geoff

Trustee recruitment pack

Who are we & what do we do?

The Chronic Granulomatous Disorder Society (CGD Society) is a small, friendly, family led organisation with international reach. We are dedicated to promoting an understanding of CGD and providing support to affected individuals and their families. We are a registered charitable company limited by guarantee. (reg no 1143049). We have been supporting our members for 30 years firstly as the CGD Research Trust and since 2011 as the CGD Society.

CGD is a rare, potentially life-limiting, inherited condition of the immune system. It affects around six in a million people and is caused by a faulty bone marrow gene that renders white blood cells unable to fight off infections. As a result, those affected by CGD are susceptible to serious and debilitating illnesses, such as colitis, abscesses, and respiratory problems. 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.

We now also understand that carrier mothers can often face significant health challenges, similar to those seen in patients directly affected by CGD so this is another cohort in need of our support.

We represent some 2000 members of which approximately half are affected individuals or family members and the remainder are supporters and medical professionals. The membership is spread across 58 countries with significant numbers in the UK, USA, Australia, Canada and India.

We have a small staff who maintain our helpline, our website and our information resources. We also pay for a Clinical Nurse Specialist who works out of a London hospital and provides frontline care for members in hospital but also at home, in school or in the workplace. Through a Medical Panel of expert clinicians, we ensure that the information we provide is appropriate and best practice.

In 1992, we launched a one-day fundraising event called Jeans for Genes Day, which still takes place annually. We own the trade mark for this campaign from which we earn a licence fee. Our subsidiary charity Jeans for Genes Campaign runs this event for the benefit of all genetic disorder charities.

Our vision statement:
A cure for all with CGD

Our mission statement:
To continue to inform and improve our support to 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. To continue to be the leading global authority on CGD and an organisation that is respected by affected families and medical professionals on an international scale.

Our three-year strategy (2020-22):
Our future plans are described under three headings and summarised below:

Support:
We will continue to provide support to patients and families affected by CGD by keeping abreast of new research and treatments, and championing fair and equal access to best practice. 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 quality of life issues associated with living with CGD.

Partnerships:
We will provide strong leadership to facilitate 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.

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.

Sustainability:
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 implement 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 our reliance on this campaign.
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.

Our Trustee Board and our culture

The charity is led by a Trustee Board of six volunteers the majority of whom are members of families affected by the condition. We have a three-year strategy to deliver and value the friendliness, openness and diversity of thought that our Board brings to this work.

We plan for 5 Board meetings per year but we also have several sub committees who meet regularly and take on certain tasks from the board. Trustees would normally engage in at least one subcommittee as well as prepare for and attend Board meetings.

Our subsidiary charity Jeans for Genes Campaign organises this unique UK wide annual fundraising event for the benefit of the genetic disorder community. As trade mark owner, the CGDS Board maintain oversight and close contact with this independently run event.

Our trustees are UK based and unpaid, but expenses will be reimbursed.

Why are we recruiting?

It is healthy to refresh the Board from time to time by bringing new trustees with new ideas into the picture. We have had three resignations this year due to changed personal circumstances, so this has provided an opportunity to reconsider the skills that we require and recruit new talent to help us deliver our goals.

We are looking to recruit up to five volunteer trustees. You don't necessarily need any prior experience of charities or any specific qualifications; we are looking for hands on people ready to roll their sleeves up and engage with and oversee our work. We will be there alongside you with training and coaching provided as required.

We have some specific skills gaps we would like to fill which are listed below but in doing so we are also particularly keen to diversify our Board in terms of age, race, gender and religion.

Legal (ideally with some charity context) as an essential point of reference
Improving our **bid writing** skills to maximise grant funding
fundraising strategy to help us diversify our income streams
Governance secretary (Company secretary) to ensure compliance
Information Technology to ensure we remain efficient and up to date
Brand development to get the most out of our assets
Digital Marketing to help our fundraising and communication
Healthcare professional to help our understanding of healthcare delivery in the UK

Experience or knowledge of a rare genetic condition would be advantageous but is not a requirement.

What's in it for the trustee?

Living with this rare disease can be tough.

Those affected can be chronically ill, perhaps unable to go to school or work, parents may become full time carers and abandon their career aspirations and in total, quality of life can be damaged for those families blighted by this inherited condition.

So this charity is a ray of hope for many but we have so much more to do even after 30 years. A trustee will help steer this work and see the impact that we make.

Our small, intimate charity is a great place for new and experienced trustees. You will join our community and feel their warmth and gratitude for everything that we do. You will quickly make a difference by being part of strategic decision making, influencing and shaping projects to improve the health and wellbeing of our members. You will also join our network of friendly, like-minded volunteers and you will learn new skills to benefit your professional role as well.

Above all, you can make a difference.

Refer to www.cgdsociety.org for more insights.

Trustee Role Description

What is a trustee?

Trustees have overall control of a charity and are responsible for making sure it's doing what it was set up to do. For CGDS, trustees are also known as Directors because it is a company that is also registered as a charity.

Trustees are the people who lead the charity and decide how it is run. Trustees use their skills and experience to support a charity, helping it achieve its aims. Trustees are jointly responsible for any decisions made and where necessary can use the charity funds to seek advice from external partners.

For more information refer to the Charity Commission document CC3 "The Essential Trustee" https://www.gov.uk/government/publications/the-essential-trustee-what-you-need-to-know-cc3

Eligibility criteria

You must be at least 16 years old to be a trustee of the CGD Society.

You must not act as a trustee if you are disqualified unless authorised to do so by a waiver from the Commission. The reasons for disqualification include:

- being bankrupt or having an individual voluntary arrangement (IVA)
- having an unspent conviction for certain offences (including any that involve dishonesty or deception)
- being on the sex offenders' register

Full details are available from the Charity Commission. https://www.gov.uk/guidance/automatic-disqualification-rules-for-charity-trustees-and-charity-senior-positions

If appointed to the Board, the trustee will sign a Declaration of Willingness to confirm their eligibility. This also includes their acceptance of a Code of Conduct which can be viewed here.

A trustee would normally be expected to commit to a term of 3 years after which they may be invited to stay for up to a further 2 terms by mutual agreement.

What are the key duties of a trustee?

- Trustees have a responsibility for the governance (i.e. management) of the charity.
- Our governing document is the Articles of Association within which are described our charitable objects. The trustees ensure that the work of the charity remains within this scope. The charity conducts an annual strategic review to help ensure that our activities are suitably focussed.
- Other duties are described in Charity Commission standing instructions such as the need to review certain processes annually. Full training will be given to explain these governance obligations but if in doubt, advice is always available from experienced trustees and the Chair.
- The Trustee Board is responsible for scrutiny of the charity's processes to confirm that the staff are working to the agreed strategy. The Trustee Board are responsible for overseeing

the strategy while the staff are responsible for delivering it. Monthly reports with performance indicators will be available to track progress in key areas.

- Trustees will work closely with the staff to ensure the organisation operates effectively, efficiently and economically, with a culture that is positive, and focused on the needs of those it serves and other customers and stakeholders.
- As well as attending board meetings, trustees are encouraged to join a subcommittee and use their skills to support our staff and maximise effort in a specialist area.
- Trustees will provide oversight, direction and constructive challenge to the organisation's chair and senior staff.
- Trustees must satisfy themselves as to the integrity of financial information, whilst approving each year's budget, business plan and annual accounts prior to publication.
- Trustees will oversee control and risk management frameworks in order to safeguard the assets, compliance and reputation of the organisation.

What time commitment comes with the role?

We are a small charity with big ambitions but we can only afford a few paid staff so our trustees tend to be quite active in support of our strategic goals. Typically they would:

- Attend 5 Saturday morning Board meetings per year. 4 are virtual of max 3 hours each and one hybrid strategy review meeting of longer duration where trustees can decide to physically attend or not. (This pattern is dictated by the ongoing Covid risk and may change).
- For each Board meeting, papers will be issued a few days beforehand and need to be read ready for discussion.
- Each trustee will be encouraged to join a sub committee and take away actions in support of improvement projects, governance obligations, fundraising and so on. The meeting frequency is variable, and probably on weekdays, but at most is likely to be monthly.
- In order to understand the current issues it may be appropriate that a trustee initiates meetings with staff on an ad hoc basis.
- One of our strategic goals is to forge partnerships with other charities, umbrella groups, pharmaceutical companies and healthcare providers. Trustees will lead this initiative and therefore will need to research and make contact with potential partners from time to time.

This is a daunting list, but we judge that a trustee would typically donate around 2 hours per week on top of the time to attend Board meetings. However, we can be flexible and adjust the commitment to fit the individual.

Summary

Hopefully this recruitment pack has answered many questions for potential applicants. A trustee position on the CGDS Board is a legally defined role so applicants need to appreciate what is expected of them both by the charity and by the Charity Commission. However, whilst the list of duties looks daunting, this position is a great way to help others and feel the gratitude from our members. With only a few hours of your time you can add more skills to your CV and share in our future successes. We need your help and hope to hear from you.

If you are interested to apply, please describe your reasons and motivation in an email along with a copy of your CV to recruitment@cgdsociety.org .

Thankyou.