

Trustee Recruitment Pack

Join this **friendly** and **ambitious** board and **make a difference** to those affected by chronic granulomatous disorder.

Message from Annabel Griffiths, Chair of Trustees:

Chronic Granulomatous Disorder (CGD) is a rare, life-limiting immune disorder, where children and adults get frequent bacterial and fungal infections, which can be serious and life-threatening.

The CGD Society (CGDS) is the first port of call for those who find themselves facing a diagnosis of CGD and provides invaluable information and support to families throughout their CGD journey. Our charity is led by our inspiring and dedicated Executive Director, Claire Jeffries, who works tirelessly alongside our specialist nurse, Helen Braggins at Great Ormond Street Hospital and Niamh Carmichael, our Community Fundraising and Marketing Officer. Although based in the UK, we support some 1,500 members across 77 countries, and are immensely proud to represent this global community.



I became a Trustee having previously [volunteered for CGDS](#) and haven't looked back since! This small but ambitious charity is driven by some of the most dedicated and inspiring people I've had the pleasure to work with in my career so far. As a Trustee I continue to learn so much about CGD and the charity sector and am able to use my professional skills to make a positive and sustainable difference for the rare diseases community.

Join us as we continue to strive for better outcomes for our CGD families and find out just how rewarding it can be to fulfil a Trustee position!

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Who are we & what do we do?

The CGDS is a friendly, ambitious and family-orientated organisation dedicated to promoting an understanding of CGD and improving outcomes for individuals and families affected by this disease.

Our vision statement:

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

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.

See Appendix A for our newly developed Theory of Change model!

Why join our Trustee Board?

The impact of a rare inherited disorder can be profound, with quality of life damaged through illness, caring commitments and strains on mental health. The aim of this charity is to be a ray of hope for those individuals and families affected by CGD. You will quickly find yourself making a difference by being part of strategic decision making, influencing and shaping projects to improve the health and wellbeing of our members, and supporting our Executive Director and her team.

“When I joined the CGD Society (originally the CGD Research Trust) as a trustee, I was driven by the emotion of having a son with CGD and the need to make a difference to his life, that of our family and of others presented with this terrifying, poorly documented medical condition. I could see the concerns of those affected by CGD and wanted to help them all. Whatever your reason for becoming a trustee, there is much to do as our services see increasing demand whilst inflation and rising energy costs put pressure on our income. The role is interesting, challenging and rewarding and you will be fully supported by a team of like-minded people striving to support those affected by this rare, life-threatening condition.”

- Andrew Orchard, Trustee 1991 to Present



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You will be motivated by hearing the voices of our CGD community, who are keen to show thanks for the support they receive but honest about the areas where we can do more to support them. You will help steer our critical work, monitor the impact we make, and above all, see us making a positive and long-term difference to the CGD affected community.

"It means the world to me to have people to reach out to."
- CGDS email helpline user



Our small, collaborative charity is a great place for either new Trustees looking to take their first steps into the sector, or experienced Trustees seeking a new challenge with a brave and agile organisation. You will also join our network of friendly, like-minded volunteers and learn new skills to benefit your professional role as well.

How it works

You will join a Trustee Board made up of volunteers who are dedicated to improving the lives of individuals and families affected by CGD. We plan to host five Board meetings per year, but we also have several subcommittees who meet regularly and steer aspects of the charity on behalf of the Board. All meetings are virtual except for our annual strategic review, which is normally in London, where physical attendance is encouraged. Our Trustees are UK based and unpaid, but expenses will be reimbursed.

"It was a pleasure to be able to meet (nearly) all trustees in person in my first official board meeting as part of CGD Society. The meeting was very productive as it enabled us to review the issues affecting the charity and CGD patients, and then decide the best way to start addressing these over the coming year."

- Kultar Shahi, Trustee January 2022 to Present



Our subsidiary charity, [Jeans for Genes Campaign](#), organises a unique UK-wide annual fundraising event for the benefit of the genetic disorder community. Two of our Trustees are co-opted onto their Board to maintain oversight and support their goals.

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Why are we recruiting?

We are always open to new volunteers joining our Board, to bring fresh ideas and perspectives to what we do and make us as effective as possible as a team.

To become a Trustee, you don't need any prior experience from the charity sector; we are looking for committed people who are ready to roll their sleeves up, engage with and oversee the work of our charity staff. Other Board members will be there alongside you to provide training as required.

Whilst we welcome applications from anyone, regardless of past experience, we have identified some specific skills gaps that would be beneficial for the charity to fill. These are listed below. Given the nature of our work, we also encourage applications from individuals affected by CGD or another rare disease, however, this is not a requirement. We remain committed to providing equal opportunities and are keen to diversify our Board in terms of age, race, gender and religion. These are listed below:



- **Legal** (ideally with some experience within the charity setting) as an essential point of reference



- **IT** to support our use of technology, to run our charity and to keep our membership informed



- **Digital marketing** to help our fundraising and communication efforts



- **Healthcare professional** to help our understanding of healthcare delivery in the UK

Trustee Role Description

What is a trustee?

Trustees have legal 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 also registered as a charity.

Trustees use their skills and experience to support a charity, helping it achieve its aims. They are jointly responsible for any decisions made and, where necessary, can use the charity funds to seek advice and training 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 and 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, please see Appendix B for this.

A Trustee would normally commit to a term of three years after which they may be invited to stay for up to a further two terms by mutual agreement.

What are the key duties of a trustee?

- Trustees have a responsibility for the governance of the charity.
- Our governing document is the Articles of Association within which are described our charitable objects which (abbreviated) are:
 - The relief of persons suffering from CGD
 - The advancement of medical research into the causes, cure, prevention or relief of such disorders
 - To advance the education of the public on the subject of such disorders
 - Such other purposes that are charitable... for the benefit of the public.
- 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.
- The Trustees are responsible for defining and overseeing our strategy while the staff are responsible for delivering it. Regular reports with performance indicators are available to track progress and an annual impact assessment is planned to start in 2023.

Trustee Role Description

- 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 specific area. Our current subcommittees cover Governance, Finance, Community and Medical, Fundraising and Partnerships, and Jeans for Genes Oversight.
- Trustees will provide oversight and constructive challenge to the organisation's Chair of Trustees and Executive Director.
- Trustees must satisfy themselves as to the integrity of financial information, whilst approving annual budgets, business plans and accounts.
- Trustees will oversee other activities required by the Charity Commission such as control and risk management frameworks to safeguard the assets, compliance, and reputation of the organisation.

What time commitment comes with the role?

We estimate that a Trustee would typically donate around **two hours per week** on top of the time for Board meetings. However, we can be flexible and adjust the level of commitment to suit the individual.

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

- Prepare for and attend five Saturday morning Board meetings per year. Four are virtual and last approximately three hours each. One strategy review meeting is a longer duration and physical attendance is encouraged. For each Board meeting, papers will be issued a few days beforehand and need to be read in advance of discussions.
- Participation in at least one subcommittee, including preparation for and participation in meetings, which are a maximum of one hour monthly and typically held on weekdays.
- Provide support in executing agreed actions from either Board or subcommittee meetings in a timely fashion, working proactively and collaboratively with other Board members and staff as required.
- To understand the current issues, we encourage Trustees to engage with staff on an ad hoc basis.

Summary

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. This position is a great way to help those affected by CGD and feel rewarded by the contributions you make to our community. With only a few hours of your time you can make lasting improvements that will benefit CGD families both now and in the future. We need your help and hope to hear from you soon.

If you are keen to apply, please describe your reasons and motivation for applying in an email along with a copy of your CV to recruitment@cgdsociety.org. Thank you for considering this position and if you have any further questions, please do not hesitate to contact Annabel Griffiths, Chair of Trustees, at annabel.griffiths@cgdsociety.org.

Appendix A: CGD Society - Theory of Change

Our Theory of Change model describes how CGDS will make change happen in the world. It defines all the building blocks (outcomes, results, preconditions, assumptions) required to bring about our long-term goals. The document is continuously evolving, and any feedback is welcome.



THEORY OF CHANGE



PRE-CONDITIONS

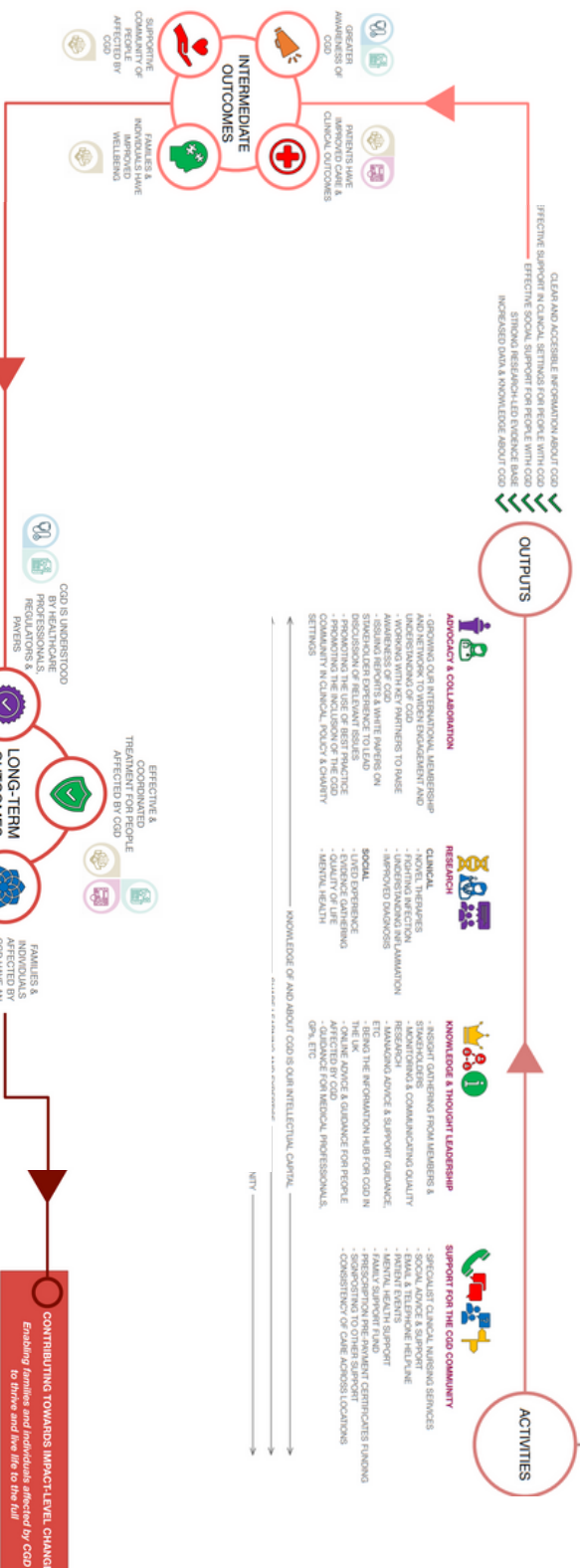
- CGD is under-diagnosed and individuals and families affected by CGD are under-supported
- Patients, families and individuals want to engage with the Society and its work
- Research partners are fully committed to conducting relevant and appropriate research with us
- Support to become members of the Society becomes our work as relevant to their needs
- Access to our services, which are products of the 4 change

ASSUMPTIONS

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

THE BLUE DISEASES FRAMEWORK

- Our Theory of Change aligns to the Blue Diseases Framework
- We have recognised points of interconnectivity with the framework at an individual level



Appendix B: CGD Society – Trustee Code of Conduct

This Trustee Code of Conduct version 1.0 has been approved by Geoff Creamer on 27th November 2022, to be reviewed in November 2023.

Responsibilities

In order to maintain the culture and team spirit of the Board as well as to ensure compliance with legal guidelines, it is appropriate to ask Trustees to accept the code of conduct below in everything that they do for the charity. Confirmation of this acceptance will be requested when signing the Declaration of Willingness.

It is the responsibility of Board Members to:

- Act within the governing document and the law – being aware of the contents of the Charity’s governing document and the law as it applies to CGD Society. Training will be given to explain this.
- Act in an open and transparent way with relevant persons in relation to the provision of our services.
- Act in the best interest of CGD Society as a whole – considering what is best for the charity and its beneficiaries and avoiding bringing CGD Society into disrepute.
- Manage conflicts of interest effectively – registering, declaring and resolving conflicts of interest and loyalty. Not gaining materially or financially unless specifically authorised to do so.
- Respect confidentiality – understanding what confidentiality means in practice for CGD Society, its Board and the individuals involved with it.
- Have a basic knowledge of CGD and its impact – engage with our membership and staff to appreciate the current environment for CGD and rare diseases in general.
- Attend Board meetings or give apologies – 3 consecutive absences without good reason could result in dismissal from the Board.
- Prepare fully for meetings and all work for CGDS – reading papers, querying anything you don’t understand and thinking through issues in good time before meetings.
- Actively engage in discussion, debate and voting in meetings – contributing positively, listening carefully, challenging sensitively and avoiding conflict.
- Act jointly and accept a majority decision – making decisions collectively, standing by them and not acting individually unless specifically authorised to do so.
- Work considerately and respectfully with all – respecting diversity, different roles and boundaries, and avoiding giving offence.
- Acknowledge the challenges of charity management and ensure that success is celebrated within a constructive culture of change that can adapt to deal with new obstacles as they arise.

Conclusion

These obligations are hopefully common sense and normal practice for business and charity leaders. This policy deliberately avoids authoritarian language preferring to rely on the individual to appreciate that the success of their trusteeship in this collaborative organisation relies on engendering a positive culture within a strong and mutually supportive team.

This charity welcomes feedback on this policy. The Chair also expects Trustees to make him/her aware of any sustained interaction with colleagues that does not meet these standards.