



Trustee Recruitment Pack

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

Who are we & what do we do?

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.

CGD Society 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, who works tirelessly alongside our CGD specialist nurse, at Great Ormond Street Hospital and our 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.

The CGD Society is a friendly, ambitious and family-orientated charity dedicated to raising awareness of CGD and improving outcomes for individuals and families.

Our vision statement:

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

Our mission statement:

To be the leading source of information and support for families and individuals affected by CGD in the UK and around the world, by sharing the learnings and expertise from patients and medical professionals who treat them.

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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.

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 community.

"We have no one locally to see regarding CGD only in London and my GP which can prove difficult, so having this opportunity for someone to help has been a godsend." - A CGD affected adult who contacted our email helpline.



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

Information about our trustees can be found [here](#).

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 a minimum of four Board meetings per year, but we also have several subcommittees who meet regularly and steer aspects of the charity on behalf of the Board. These subcommittees provide an opportunity for you to get directly involved in delivery of key priorities. 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.

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Why are we recruiting?

We welcome new volunteers to join our Board, as their fresh ideas and perspectives contribute to maximizing our effectiveness as a team.

To become a Trustee, you don't need any prior experience in 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 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:



- **Lived** experience of CGD or a rare disease.



- **Finance, Governance and Legal expertise**, preferably within a charitable context, to provide essential guidance.



- **Fundraising proficiency**, including grant writing abilities and corporate to enhance income diversification.



- **Information Technology**, digital platforms, and digital marketing



- **Representation from the healthcare sector** ideally in rare disease to enrich our understanding of healthcare delivery in the UK.



- **Marketing, Digital and IT** to maximize the utilization of our assets.

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 CGD Society, 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 key performance indicators are available to track progress alongside an annual operational strategy plan.

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, and Fundraising and Partnerships.
- 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:

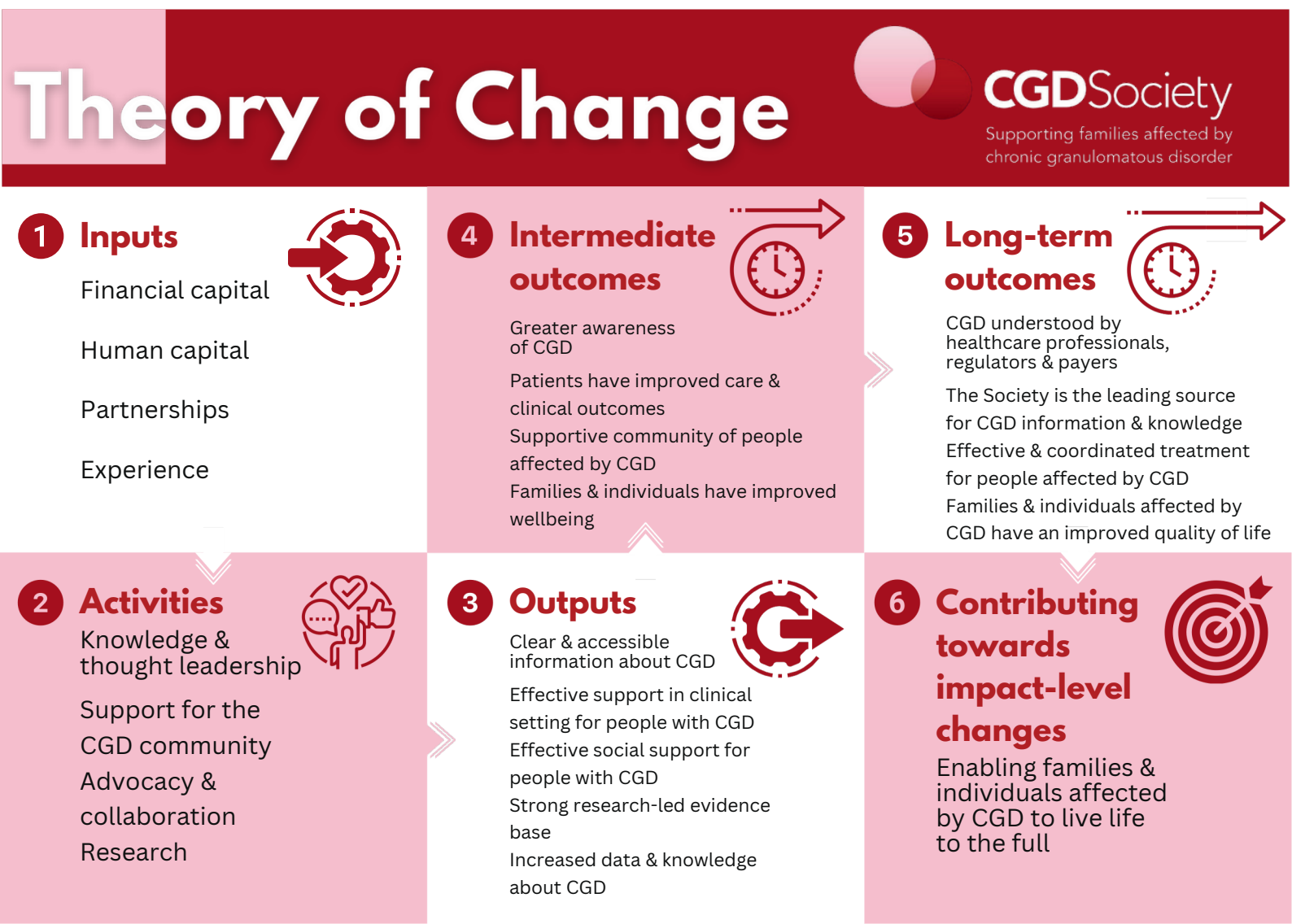
- Prepare for and attend a minimum of four Saturday morning Board meetings per year. They are virtual and last approximately three hours each. One strategy review meeting is a longer duration and physical attendance is encouraged. For each Board meeting, papers will be issued a few days beforehand and 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/every two months 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 CGD Society 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.

Appendix A: CGD Society - Theory of Change

Our Theory of Change model describes how CGD Society 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.



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 2024

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.