

*Your voice  
matters*



# Volunteer as a Trustee

Help us advocate for those affected by CGD and ensure that we will be able to support our community for many years to come.

## About our Society

The CGD Society is the first port of call for those who find themselves facing a diagnosis of chronic granulomatous disorder. We know how hard it can be facing a rare, life-limiting immune disorder, at risk of frequent and potentially life-threatening bacterial and fungal infections, and so our aim is to make that process **easier** and **provide comfort** to those experiencing this.

Our team, alongside our clinical nursing specialist at Great Ormond Street Hospital, work tirelessly to support the community of individuals and families affected by CGD. We provide holistic support and financial assistance, curate plain language documents about care and symptoms, and advocate for our beneficiary's needs as part of the wider genetic condition community.

**1,500**

Members that we support across the world, representing a truly global community.

**£200k+**

Spent on charitable activities in the last year, supporting those with CGD and other genetic conditions.

**£45 million over 30 years**

Raised through our [Jeans for Genes campaign](#) which raises awareness of all genetic health conditions in the UK.

## What is a trustee?

Our trustees are volunteers who sit on our *Board*, and are the top level of decision-makers for our Society. It's their job to guide the direction of the organisation, help us spend our money wisely, and **ensure that the needs of those affected by CGD are at the forefront of everything that we do.**

The trustees meet once every two months to receive updates from our staff and provide instructions on key priorities going forward. Some examples of the work they do include:

- Monitoring our funds and deciding where to spend them.
- Setting the Society's annual and three-year strategies.
- Agreeing policies, such as how we safeguard vulnerable people.

## A word from our Chair

“Our main focus is to take a step back and make sure that everything we do as a charity aligns with our mission and **puts our beneficiaries first.**”

It can be a challenge to look at the big picture sometimes, but we support one another and make all our decisions as a team. It really is a rewarding role, especially if you want to have an impact.”



**Josh Stevens**  
Chair of the Board  
Trustee since 2024

## A range of backgrounds

It is great if you have skills or experience which you think would be useful to support our board, but this is by no means a requirement. We're looking for people who are **enthusiastic** about us doing good work for the community and **committed** to helping us see this mission through.

## Lived experience with CGD

A fantastic bonus is if you have some experience of CGD, whether you yourself or someone in your family has CGD or is a carrier of the disorder (such as X-linked carriers). This **lived experience** is really important for our Society, as this helps focus our discussions around what our **community actually needs**.

As of April 2026, 33% of our management and governance team has lived experience with CGD, and a further 33% has professional experience in a health or medical field.

*I can't be a trustee because I don't know anything about how to manage a business or run a charity.*

*Myth!*

We provide a full induction and training to everyone who joins as a trustee, and we also encourage interested parties to attend a board meeting *before joining* so you can see how we work.

## Commitment from you

Being a trustee is an official duty as they have joint legal control of the charity and are ultimately responsibly for making sure it's doing what it was set up to do. The CGD Society is also a registered company in England & Wales, so our trustees are *also* directors for the purposes of company law.

We expect the following of **all of our trustees**, committing around one hour of time per week:

1. To attend our board meetings, which occur via video conference every two months.
2. To keep in touch via email, through an official email address that we will provide for you, at a minimum of once per week.

Our board meetings occur 6 times a year, usually on a weekday evening, and we provide an agenda with reading material two weeks in advance. We ask all participants to read this material and come prepared with comments and questions. **Every input is welcomed, debates are encouraged, and all views matter.**

We try to host one meeting per year - our Annual General Meeting or AGM - in-person at a central location, to provide an opportunity for our team to meet face-to-face. We cover all travel expenses for trustees to attend these in-person if they are able to.

We also encourage our trustees to engage with one of our **subcommittees**, which are smaller groups overseeing specific areas of our work, such as our nursing service or financial governance. This is optional, as we recognise that not all of our trustees can spare the time to participate.

# Interested? We hope so!

To find out more, we encourage you to get in touch with our team for an informal discussion first. As this role comes with a legal and fiduciary duty, we will offer you a chat with an existing member of our board to make sure that you understand the responsibilities.

## To express your interest:

Please send us an email at [hello@cgdsociety.org](mailto:hello@cgdsociety.org) with a subject line including "Trustee interest".

If you have lived experience of CGD, please include in your email a brief explainer for why you are interested in the trustee role, and if you have any professional experience that you think would be useful.

Otherwise, please include a brief explainer of how you came across the CGD Society and why you are interested in becoming a trustee of our organisation. Including a copy of your CV is useful, but not required.



The Chronic Granulomatous Disorder Society is a charitable company limited by guarantee and registered in England & Wales (registered charity number 1143049 and registered company number 07607593). Our registered address is Nightingale House, 46-48 East Street, Epsom, KT17 1HQ