



Secretary to the Board of Trustees

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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About the role.

The Secretary is one of the officer roles on the Board of Trustees, and in the CGD Society (CGDS) the Secretary is also a volunteer Trustee themselves.

The Secretary role has two components: they are the Company Secretary, maintaining registrar records, organising board meetings, and filing returns, as well as the Governance Lead, ensuring that the Society is up to date on wider regulations and expectations. As trustees of the CGD Society are limited in tenure by our Articles of Association, this role will work closely with the Executive Director for day-to-day support and to ensure continuity is maintained.

For charities in England & Wales, governance is a responsibility which is shared amongst all the trustees of the board, so the Secretary position is one which leads our governance work, rather than doing it all themselves. They will have close support from our other officers, the Chair and the Treasurer, as well as the wider Board and staff. Additionally, they will be a core part of the Governance & Finance Subcommittee of the board, which meets throughout the year.

A key focus for us is making sure that we are doing things according to best practice rather than minimum requirements. As such, we hope for the Secretary to gradually develop a good understanding of The Charity Commission - the primary regulator for charities in England & Wales - as well as their rules, regulations, and guidance. As we are a charitable company, we are also beholden to Companies House as a secondary regulator. This is a great opportunity for this who want to gain experience in the compliance environment that charities operate in.

The position comes with a good platform of knowledge to help the Secretary get a running start. We maintain a Governance Calendar which is used to guide the Board to ensure that appropriate governance requirements are met. Some of these are dictated by the regulator, whereas others are good practice targets that we have put in place as a committee. This document must be renewed annually and will probably be adjusted through the year as priorities change, and resources are assigned.

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Role description

Regular responsibilities

- **Maintain Governance Calendar**
 - Review and update calendar to ensure all governance requirements are met.
 - Report on progress and upcoming actions to the Board at meetings.
- **Maintain Company House records**
 - Maintain register of Directors, recording changes such as resignations and appointments online within 14 days.
 - Ensure all trustees comply with ID verification requirements upon appointment.
- **Maintain Charity Commission records**
 - Maintain register of Trustees, recording changes such as resignations and appointments online within 14 days.
 - Complete any Special Incident Reporting.
- **Act as lead on Governance protocol**
 - Be the main point of knowledge for interpreting the Articles of Association, which dictate how we are run and what activities we can undertake.
 - Maintain oversight of the Charity Commission and Companies House for new guidance and where appropriate bring to the attention of the Board.
 - Maintain active Policies & Procedures with the Executive Director and flag to the board when policies are being ignored or overlooked.
 - Maintain list of external advisors (e.g. solicitors, NVCO, Chartered Governance Institute) and seek external consultation when required.
- **Take charge of Governance administration**
 - Schedule full board meetings, ensuring agendas are appropriately distributed and pre-reading materials are provided.
 - Ensure meetings are quorate and that board rules are followed (such as who can or cannot vote).
 - Prepare and distribute minutes for full board meetings, to be signed at the beginning of the following meeting.
 - Onboard new trustees alongside the Chair, including sharing of key documents/policies and ensuring necessary training is organised.
 - Maintain intellectual property register (trademarks & domain names), and ensure renewals are completed.

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Annual responsibilities

- Lead on the production of the Trustees' Annual Report as part of the year-end process, to be signed at the Annual General Meeting.
- Organise Annual General Meeting (AGM) and ensure that the necessary actions and voting takes place.
- Ensure annual returns are submitted to the relevant authorities:
- Annual Confirmation Statements for CGDS and the CGDS Trading Company to Companies House.
- Annual accounts for CGDS and the CGDS Trading Company to Companies House (*usually completed by our accountants and Treasurer respectively*).
- Annual Return questionnaire and Annual Report & Accounts to the Charity Commission.