



THE ROLE

Job Title:	CEO
Reporting to:	Chair of Trustees
Location:	Remote with occasional travel as and when required
Hours of Work:	Full time, 35 hours per week

KEY RESPONSIBILITIES

- 1.To lead on the strategic direction and vision for the future of the charity.
- 2.To represent the charity and its interests in a positive light internationally.
- 3.To advocate on behalf of the charity, raising the profile of the conditions we support.
- 4.To lead the research strategy of the charity by managing the process of funding of scientific research.
- 5.To ensure patients, their families and the public are made aware of the rare conditions we provide advocacy for.
- 6.To inform and educate different audiences on the medical and genetic basis of rare conditions, the scientific research undertaken in the field and prospects.
- 7.To form collaborations, partnerships and lead the charity in new directions for the benefit of rare condition patients.
- 8.To establish funding paths and create new opportunities for financial support.
- 9.To be responsible for the day-to-day management of the charity including finances and governance as the company secretary.
- 10.To be responsible for the accuracy and integrity of all published materials on the website and elsewhere.
- 11.To manage the trusts staff team by distributing work to the relevant team members.



SKILLS AND EXPERIENCE

ESSENTIAL

- Postgraduate degree in a relevant biological science with research experience.
- A strong commitment to open scientific communication.
- Capable of working independently and using own initiative.
- Excellent interpersonal and communication (written and oral) skills.
- Understanding and sensitivity dealing with people affected by, and professionals concerned with, rare genetic conditions.
- Flexibility to attend meetings outside of normal UK office hours.
- Able to travel globally for conferences and networking.
- Experience of leading a staff team.

DESIRABLE

- Familiarity with publication level scientific style.
- Knowledge of fundraising.
- Knowledge of genetics and rare conditions.
- Knowledge of charity regulations and financial responsibilities.
- Knowledge of finances including budget management.

CONTACT

☎ 020 8050 2091

✉ recruitment@myrovlytistrust.org

🌐 www.myrovlytistrust.org