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

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