



Summary

Sturge Weber UK charity is run by volunteers who strive to support the members of the charity and improve the care and quality of life of people living with Sturge Weber Syndrome. Living with Sturge Weber Syndrome is a lifelong journey, not only for the person affected with it but their caregivers also. We are motivated to support our members in advocating for themselves and supporting parents in advocating for their children.

The statutory duties of a trustee

The board of trustees are both jointly and individually responsible for the overall governance and strategic direction of the charity, its financial health, the probity of its activities and developing the organisation's aims, objectives and goals in accordance with the governing document, legal and regulatory guidelines.

In addition to the responsibilities of a trustee, duties of the Engagement Trustee include the following:

- Lead in the development of local support groups
- Working alongside the trustees in engaging with members and family liaison
- Providing families with advice on benefits
- Assisting with organising and attending the Family Weekend
- Working with professionals
- Lead families transition to adult services
- Interaction on social media platforms
- Administration duties
- Safeguarding duties
- Assisting alongside the trustees with fundraising
- Any other related duties the charity may require you to do

Accountability

The post-holder will be accountable to the Chair and Board of Trustees.

Person Specification

In deciding who to shortlist and appoint to this post, we will be looking for evidence of the following skills, knowledge, experience, and personal qualities.

Essential:

Availability to volunteer 2+ hours weekly.

Ability to work effectively as a member of a team.

Experience and good knowledge of social care.

Effective administrative and organisational skills.

Ability to communicate clearly and effectively with different audiences.

Ability to motivate, empower and successfully engage with people.

Ability to manage own work performance effectively.

Availability to attend face to face meetings and meetings over Zoom

Willingness to travel in accordance with the requirements of this post.

Desirable:

Knowledge of Sturge Weber Syndrome