



SEDSCoconnective is an expert-by-experience-led, voluntary Charity that improves and actively supports the lives of people with Symptomatic Hypermobility, EDS (Ehlers-Danlos Syndromes), Hypermobility Spectrum Disorders (HSD), Joint Hypermobility conditions and Neurodivergence (primarily Autism, ADHD, Dyspraxia, Tourette's syndrome, and associated conditions).

Our mission is to empower individuals and their families by providing education, advocacy, and community-building opportunities. Over the past 5 years, SEDSCoconnective has made significant progress in establishing itself as a leading charity in the field, attracting a dedicated community of supporters and volunteers.

Trustees have overall legal responsibility for how a Charity is run and they work closely to ensure that the Charity operates to the best of its abilities and complies with its constitution and all legislation. Our Trustees meet quarterly, and it is helpful if Trustees can support and attend other meetings and events throughout the year. We ask that Trustees also use their skills and expertise in subgroups and use their networks and connections to further our important work.

The Trustee role includes ensuring the charity pursues its objective of making all things possible regardless of ability, giving firm strategic direction, ensuring financial stability and legal compliance, and working with the Chair and her team of volunteers.

Skills

As the charity is peer led, 60% of the Trustees should ideally identify as being neurodivergent or be the carer of someone with neurodivergence or symptomatic hypermobility disabled. This lived experience is invaluable as is awareness of the protected characteristics and chronic illness/disability issues that affect neurodivergent people. We are also keen to strengthen the board with professional skills drawn from Finance, HR, Law, Healthcare, Education, Business Development or Project Management, although people with a passion for equity from a variety of employment backgrounds are encouraged to apply.

In addition to the statutory duties, each trustee should use any specific skills, knowledge or experience they have to help the board of trustees reach sound decisions. This may involve:

- Leading discussions with members
- Feeding back views of the membership
- Focusing on key issues
- Providing guidance on new initiatives
- Business planning and strategy
- Other issues in which the trustee has special expertise such as knowledge of diversity, representation, and inclusion.

Those wishing to become a Trustee should be able to provide a commitment to the organisation and a willingness to speak their mind. Leadership skills and experience of committee work would be a bonus together with good communication and interpersonal skills, tact, and diplomacy.

Benefits

A SEDSConnective Trustee has strategic input to the direction of a growing charity and will be making a difference to the lives of neurodivergent people and those with physical health conditions in Sussex and beyond.

Practical Considerations

The Charity operates across Sussex and beyond, mainly by Microsoft Teams. IT skills are needed.

Travel expenses paid.

When do I need to be available?

Monday to Sunday – approximately 2.5 days a month but opportunity to do more. This is a hands-on Trustee role. We do not have an executive CEO or paid staff.

Details

Trustee meetings held quarterly, during the day AGM held. Trustees are also encouraged to attend and support other events and meetings throughout the year.

To apply please email general@sedsconnective.org