

We Need You! Opportunity for a Volunteer Grants Officer

We are looking for an individual who can use their experience in grant writing to further the work of our passionate, small, national charity. With your help we can continue and grow our support for people with an under-recognised group of genetic conditions.

Who we are

Fragile X is a family of inherited genetic conditions, which may affect multiple members of families in different ways. These conditions include Fragile X Syndrome: the most common inherited cause of learning disability. Up to 175,000 people in the UK have or are at risk of a Fragile X-associated condition. However, individuals and families still struggle to access understanding and support for their conditions, and many remain undiagnosed.

We are the only UK charity dedicated to those living with Fragile X. We provide information and practical guidance to support and empower individuals and families living with Fragile X, and the professionals who support them.

Established by parents almost 30 years ago, we remain led primarily by people with personal experience of Fragile X on our board of Directors. Our work is supported by a small staff team (2.5 full time-equivalent). Our community continues to grow, with almost 2000 member families and a broader network of many more individuals, families and professionals to whom we provide direct support, or who access our resources.

Why we need you

We are passionate about our work and the services that we are able to provide to the Fragile X Community, such as our National Helpline, run by our Families and Professionals Advisors.

We are aware that grant funding is an area for potential growth in our income. We are looking for a volunteer who can share their expertise to help is to make the most of opportunities to seek funding from Trusts and Foundations. This includes ensuring that our work is being presented in a clear way that is attractive to funders.

What you will be doing

- Researching grant opportunities
- Writing grant applications, assisting with presenting a clear case for support. Initially the focus will be on seeking support to maintain our much-needed services.
- This work will be conducted with support from the Board's Fundraising Sub-Committee.

Skills and experience

- Experience with grant writing (preferred)
- Experience of working with small charities (preferred)
- Understanding of Fragile X and our charity (preferred, but not essential)

When and where

- Home-based, will need access to a computer (you will be given access to an account to use Microsoft Teams, to facilitate joint, remote working).

- Approximately equivalent of 2-3 hours per week

How to apply or find out more

Please send a copy of your CV and a cover letter to Alex Case (Head of Fundraising Subcommittee): alex@fragilex.org.uk

If you would like to find out more or have preliminary discussion, please don't hesitate to get in touch.