

# Trustee

Are you driven by work that **makes a difference**? Are you seeking an opportunity to **broaden your skills**, whilst also boosting the efforts of a **small charity within the rare diseases space**? If so, our board are looking for new Trustees to help us in our pursuit to support families affected by [CACNA1C-related disorders](#).



## About the Role

As a result of increased awareness and signposting for individuals receiving a positive CACNA1C diagnosis, our community is increasing in size. Therefore, we are seeking new Trustees who will take an active role in the board, bringing new skills and ideas for how to support our community, advocating for improvement to CACNA1C diagnosis, outcomes and quality of life and to support CACNA1C research initiatives.

Our new Trustees will be responsible for setting the overall strategy and direction for TSA, as well as monitoring the charity's activity to evaluate progress towards our objectives and goals.

This can include making sure the charity complies with regulations, overseeing financial management and monitoring financial performance, creating and implementing policies and procedures to mitigate risk, and supporting the charity's operations. Additionally, you will also have the chance to help develop fundraising strategies, including applying for funding and grants to support TSA's work. Whilst representing the charity externally, there will also be plenty of opportunities to advocate for TSA's mission of supporting individuals and families affected by CACNA1C-related disorders and raising awareness for this rare disease.

## FAQs

How big is the current Board and what opportunities might there be in the future?

- The board currently consists of 7 Trustees. As the charity's turnover continues to grow, they are currently going through an evolution in their structure and the operations of the charity. This means the new Trustees will be presented with enormous opportunities to shape the future of the charity and to play a leading role on the board moving forward. As a result, it is expected that there will be an opportunity for a new Trustee to develop into the Chair of Trustees role soon.

What are you looking for in candidates?

- As a small team, we are ideally seeking those who have prior experience of being a Trustee at a UK based charity or working within the UK charity sector, who can bring demonstratable experience of navigating the challenges that face small charities.

However, we also welcome applications from candidates with an interest in or prior knowledge of charity law and compliance; the change management process; volunteer management; financial planning, processing and auditing; regulatory or policy issues; data management or fundraising.

UK based candidates are preferred, however this is not essential.

What time commitment do you expect from Trustees?

- As well as our Board of Trustees meetings, which currently take place 4 times a year, we ask Trustees to dedicate around 2 hours per week to the work of the charity. However, this may fluctuate during busy or quiet periods.

I haven't heard of TSA or CACNA1C-related disorders before. Can I still be a Trustee?

- Absolutely! We are working in the rare diseases space and raising awareness is one of our key goals. Therefore, we have plenty of resources that can help you to learn more about this disorder and how it affects our community. We just ask that people have a passion for helping people and improving patient outcomes.

## Benefits

As well as supporting the charity and members of the TSA community, we will provide you with opportunities to grow and develop. For example, in this role you will be able to:

Develop new professional and personal skills: Our current Board of Trustees have expertise in leadership, safeguarding, chairing meetings, strategic planning, learning and development, stakeholder engagement, marketing and branding. This is an opportunity to work with, and learn from, a new group of people and build skills in different areas.

Take on a new challenge: The role of a Trustee is unlike many other professional positions, giving you the chance to take on a brand-new challenge which many of our Trustees find hugely motivating. Additionally, there are many challenges facing small charities as well as the wider rare diseases community, for example fundraising during a cost-of-living crisis as well as connecting with our members after the pandemic. Considering new and innovative approaches to tackle these issues is essential, pushing you to think creatively.

- Delve into a selfless and rewarding role: Given the under-represented nature of rare diseases, as well as the challenges surrounding research, diagnosis and treatment, the work of charities like TSA is crucial. We can sometimes be a family's only support network, so you will be deeply motivated by seeing firsthand the difference the charity makes to families. Real-life impact is at the heart of everything we do for our growing community.

## How to Apply

Please send your CV and cover letter to [joinus@timothysyndrome.org](mailto:joinus@timothysyndrome.org). We anticipate that the recruitment process will involve an initial telephone call, followed by an interview with members of the Board. Your application should be submitted by Monday 30<sup>th</sup> September 2024. Once applications have closed, we will be in touch in the week commencing Monday 14<sup>th</sup> October regarding next steps.

If you have any further questions, please contact us via [joinus@timothysyndrome.org](mailto:joinus@timothysyndrome.org) and we will aim to respond to your email within 7 days.

By submitting your application, you are confirming you have read and understood the privacy policy (<https://timothysyndrome.org/privacy-policy/>).

## About the Charity

The Timothy Syndrome Alliance (TSA) is a charity set up to improve diagnosis, treatment and care of individuals with CACNA1C-related disorders, including Timothy Syndrome and LongQT8, and to support the families and carers of those diagnosed worldwide. The charity is run entirely by families and volunteers, who work with scientists, researchers and medical professionals.

To learn more about us and our work, please visit our [website](#) or our social media pages on [LinkedIn](#), [Facebook](#), [Twitter](#) or [Instagram](#). You can also read the Annual Report here: <https://timothysyndrome.org/about-us/#report>.