

# TIMOTHY SYNDROME ALLIANCE (TSA)

---



## ANNUAL REPORT

FOR FINANCIAL PERIOD

1 DECEMBER 2022 TO 30 NOVEMBER 2023



# CONTENTS

---

01	<a href="#"><u>Who we are</u></a>
02	<a href="#"><u>What is CACNA1C?</u></a>
03	<a href="#"><u>What is TSA's impact to date?</u></a>
04	<a href="#"><u>How has TSA been raising awareness?</u></a>
07	<a href="#"><u>How is TSA improving treatment, diagnosis &amp; care?</u></a>
11	<a href="#"><u>How does TSA help support the global community?</u></a>
13	<a href="#"><u>How does TSA provide trusted informaton?</u></a>
14	<a href="#"><u>What has TSA done to drive research &amp; clinical care?</u></a>
17	<a href="#"><u>What is the impact of CACNA1C real-world data?</u></a>
19	<a href="#"><u>Why is it clinically important to screen individuals?</u></a>
20	<a href="#"><u>How does TSA raise funds?</u></a>
21	<a href="#"><u>How does TSA spend funds?</u></a>
22	<a href="#"><u>Thank You for your support</u></a>
23	<a href="#"><u>Ways you can help</u></a>
24	<a href="#"><u>Structure, governance and management</u></a>
26	<a href="#"><u>Our accounts</u></a>

# WELCOME



Timothy Syndrome Alliance (TSA) is a Registered Charity in England (Charity number: 1185523) run entirely by parents and volunteers.

## Our Vision:

Our vision is a world where shared knowledge and understanding lead to a cure for everyone with a CACNA1C genetic variant.

## Our Mission:

Our mission is to improve the diagnosis, treatment and care of individuals worldwide with CACNA1C-related disorders including Timothy Syndrome and LongQT8, and to support the families and carers of those diagnosed.

## How we work

In order to achieve our mission our focus is on five interdependent areas of activity – raising awareness, improving diagnosis treatment and care, supporting the global community, providing information and advice, and driving research and clinical development.

By working together and collaborating globally, we can harness greater strength. Using a method of sustainable growth, our goal is to build and support our global community.

Our core values and beliefs combine to form a solid foundation for the way we approach everything we do. We are determined, supportive, empowering and we are a community.





# CACNA1C

## What is CACNA1C?

CACNA1C is a gene that provides instructions for making a protein that forms part of a calcium channel in cells throughout the body. This protein manages the movement of calcium in and out of the cell (crucial for many cells' functions). Changes to the gene can cause changes to the protein and its ability to manage calcium movement, making it work more, less, or not at all.

## What is a CACNA1C-related disorder (CRD)?

CACNA1C variants have been identified in a broad spectrum of both cardiac and neurodevelopmental disorders including typical and atypical syndromic Timothy Syndrome (TS), structural heart disease with Long QT Syndrome (LQTS), isolated long or short QTS, and isolated neurologic symptoms. This is now referred to as the CACNA1C-related disorder (CRD) spectrum that encompasses a range of clinical features caused by variants predicted to both increase and decrease channel function.

The most common symptoms include abnormal heart function, irregular heartbeat, abnormal heart structure, developmental delay, incoordination, hypotonia, autism spectrum disorder (autistic features), seizures, and attention-deficit/hyperactivity disorder.

Other symptoms include low blood sugar levels (hypoglycaemia), immunodeficiencies, endocrinological dysfunction, gastrointestinal concerns, an unusually low body temperature (hypothermia), facial anomalies, syndactyly (joined fingers or toes), mild dental, skin, eye, and hair anomalies.

## What is Timothy Syndrome?

Timothy Syndrome (TS) is a sub-diagnosis of just 1 genetic CACNA1C variant with mixed neurologic and cardiac symptoms. There are two types of TS: TS1 (exon 8A) and TS2 (exon 8).

## What is LongQT Syndrome (LQTS) and Short QT Syndrome (SQTS)?

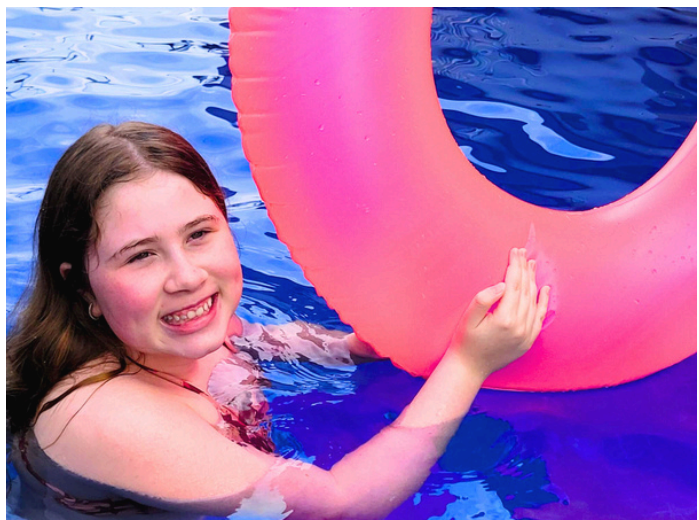
Long QT and Short QT are heart conditions that affect the electrical activity of the heart, causing it to take longer or shorter than normal to recharge between beats. This can lead to irregular heartbeats, which in some cases may cause fainting, seizures, or sudden death. LQTS associated with CACNA1C is known as LQTS 8 or LongQT8.

## How common are CRDs?

CRDs are rare and their prevalence is unknown.

There are <100 cases of TS diagnosed worldwide.

Prevalence is unknown due to the rarity and recent identification of CRDs.

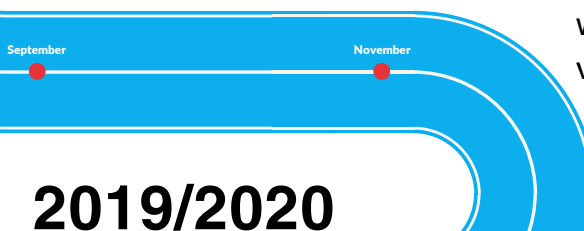




# IMPACT ROADMAP

43 known (living)  
individuals  
with CACNA1C  
variants in the world.

Award winning awareness film  
'Timothy Syndrome Alliance'.  
Website built and up and running.  
Family Day.  
Preimplantation Genetic Testing  
approved for Timothy Syndrome.



**2019/2020**

Award winning awareness film  
'Rare Strikes Back'.  
First annual Awareness Day.  
Brain Research Conference.  
First international study  
investigating the effects of  
CACNA1C on brain  
development & mental health  
Cardiff University & Stanford  
University.

November December

**2020/2021**

Film production 'Rare Disease  
Research Journey' underway.  
Interactive Guide for Healthcare  
Professionals underway.  
Genetic testing approval for Genetic  
Epilepsy.

Mind the Gap Mental Health &  
Wellbeing counselling.

Best Research Partnership Award.  
CACNA1C Community Registry launch.

A Cross-Sectional Study of the  
Neuropsychiatric Phenotype of CACNA1C-  
Related Disorder,  
Levy et al published.

December November

**2021/2022**

'The Diagnosis Challenge' film.  
Wikipedia page approved.  
Scientific Advisory Board formed.  
Connect CACNA1C Global  
Network Conference.  
Genetic testing approval for  
Congenital Hyperinsulinism.  
CACNA1C diagnosis in the UK  
project.  
Mind the Gap Mental Health &  
Wellbeing counselling.

November December

**2022/2023**

Approx 160 known  
families/individuals with  
CACNA1C variants in  
the global CACNA1C  
Support Group

A black and white photograph of a young child, likely a boy, wearing a dark-colored hoodie with a large white Reebok logo on the front. The child is smiling and looking towards the camera. The background is slightly out of focus, showing what appears to be a grassy area.

# ACHIEVEMENTS AND PERFORMANCE

## Raising Awareness

---

Out of more than 780 entries received, our film [Rare Strikes Back](#) earned its place among the 93 films selected for the World Health Organization (WHO) 4th Health for All Film Festival 2023. WHO staff from all over the world participated in this preselection.

Further broadening our reach, Rare Strikes Back made an appearance at the Health in Focus Film Festival, hosted by the School of Public Health at Boston University. This event featured our film and included a virtual Q&A session, providing an opportunity for meaningful dialogue on the issues addressed in the film.

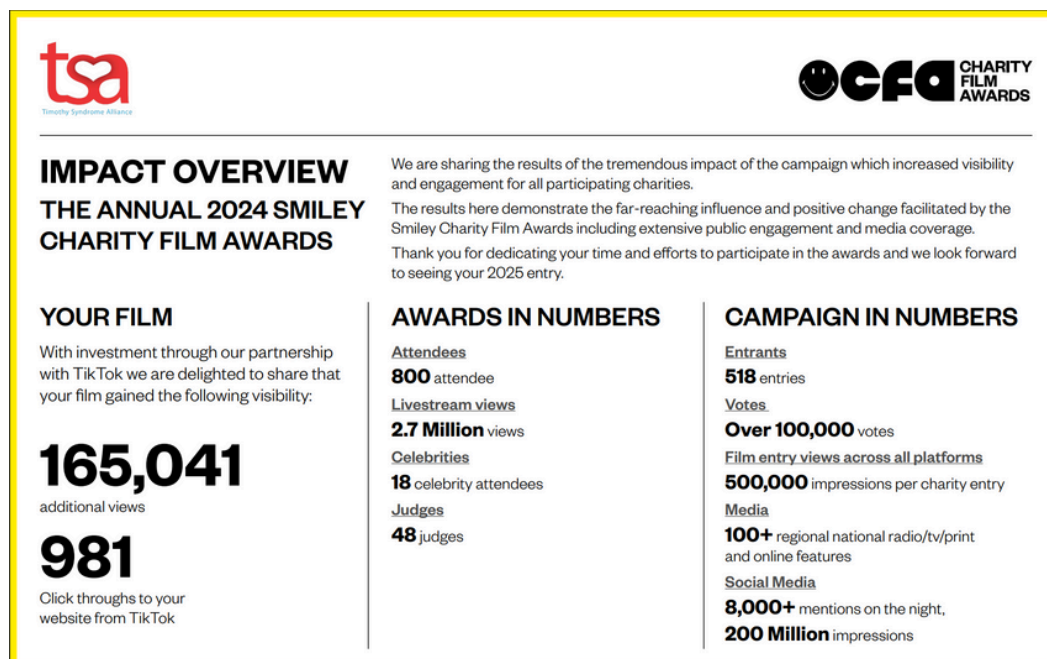
The collaborative effort behind [The Rare Disease Research Journey](#) highlights our commitment to advancing understanding and awareness. This film continues to evolve, a product of the ongoing partnership between the Neuroscience and Mental Health Innovation Institute (NMHII) University of Cardiff and TSA. Significant strides have been made with the interviews conducted with families and researchers such that we have been able to share film shorts on our social media platforms to reach diverse audiences, particularly on CACNA1C Awareness Day.

Simultaneously, considerable efforts have been devoted to our pathway-focused [Educational CACNA1C Interactive Guide for Healthcare Professionals](#). We extend our heartfelt appreciation to OPEN Health, a leading global healthcare communications agency with extensive scientific expertise, for their invaluable contribution of 200 hours of support. As filming for case studies nears completion, we remain steadfast in our commitment to accuracy, delaying the guide's launch to ensure alignment with ongoing high-level discussions regarding CACNA1C nomenclature.

For Rare Disease Day on the 28th of February (29th in a leap year), we created a short film titled '[The Diagnosis Challenge](#)'. Using a montage of interview snippets, the film conveys families' frustrating journeys, through the naming of healthcare professionals they've seen from first noticing that something isn't right and going to the doctor to actually receiving a diagnosis.

It is a process that can take many years, with seemingly endless tests along the way, a journey known as the 'Diagnostic Odyssey'. Tackling this challenge is crucial to provide families with the necessary knowledge and resources. It is equally as important to empower primary healthcare professionals to be able to identify and consider rare diseases

# ACHIEVEMENTS AND PERFORMANCE



when making a diagnosis. The film was entered in the Smiley Charity Film Awards 2024 and widely shared.

In addition to our internal productions, we have participated in two external film projects, further expanding our reach and impact.

Firstly, we had the privilege of collaborating on "CEOs in Unusual Places", a short film produced at the Neuroscience and Mental Health Innovation Institute (NMHII) at Cardiff University by the Smiley Movement team, the same team behind The Charity Film Awards, an accolade we were honoured to receive last year, winning the Gold award. Through this partnership, we continue to leverage the power of storytelling.

Our friends at Media Trust organised a film project to highlight the invaluable contributions of volunteers. Our website volunteer with whom we were matched through Media Trust and who has been with us on this journey since 2020, was featured in the film to accentuate the profound impact of their efforts on micro charities like ours.

Continuing to use our social media platforms to raise awareness, build lasting relationships and inspire support for our mission we joined the TikTok platform as well running some focused campaigns. Notably during the month of February leading up to Rare Disease Day our social media channels underwent an informative and engaging takeover thanks to biology student Gavriella who is based in Atlanta, Georgia, who aims to become a Genetic Counsellor.

Our **Awareness Day** on 1st October focused on support in its many forms complete with a takeover of Rare Revolution Magazine social media channels in the lead-up to the big day.



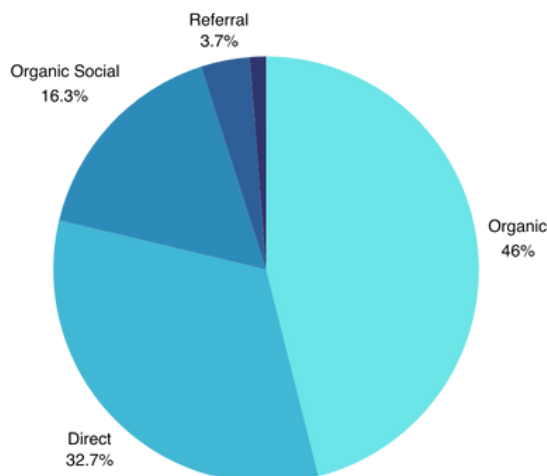
# ACHIEVEMENTS AND PERFORMANCE

The best way to raise awareness and gather interest is to spread the word so we are delighted to see that our **social media platforms and website** are doing just that. Compared to our previous year we can evidence growth in all areas.

Organic traffic (from search engine results) to our website is more likely to be from users who are new to the diagnosis, looking for community or looking to find out more information about CACNA1C. For direct traffic (typing our website's URL directly) these users typically have a specific purpose and prior knowledge of our charity, driving them to access the website directly for support, information, and community resources. Additional signposting to our website has been successful through our collaborations, press and blog articles, plus partnerships with ERN-GUARD Heart, Neurological Alliance, EURORDIS, Rare Diseases International, and Global Genes to name a few.

It is heartening to see that people are leaving their social networks and social media platforms (16.3%) to directly visit our informative website and learn more about CACNA1C. Everything we post uses the same signposts #CACNA1C #TimothySyndrome #LongQT8.

**Traffic to our website**



## Organic growth of our social media platforms and website



↑ **32.4%**

Page reach

↑ **31.3%**

Profile visits

↑ **43.1%**

New followers



↑ **155.4%**

Page reach

↑ **87.7%**

Profile visits

↑ **28%**

New followers



↑ **65.9%**

New followers



↑ **115.2%**

Users

↑ **96.8%**

Views

↑ **114.3%**

New users

## #CACNA1C

### Awareness Day



↑ **2.2K%**

Page reach



↑ **2.2K%**

Page reach

DATA BASED ON TSA SOCIAL MEDIA POSTS  
MADE ON 1ST OCTOBER 2023

Reach visits continue to increase post event

ALL DATA REPRESENTS DATE RANGE 1ST DECEMBER 2022 TO 30 NOVEMBER 2023



# ACHIEVEMENTS AND PERFORMANCE

The Student Voice Prize was again on our radar this year. It is an annual international essay competition raising the profile of rare diseases within the medical field, particularly with medical students, nurses and scientists who may not come across rare diseases in their training. Both Beacon for Rare Diseases and Medics4RareDiseases host the competition together and the winner gets published in The Orphanet Journal of Rare Diseases. Our students didn't win but we are thankful to both Hussain and Diana for submitting their essays and for their increased awareness of rare diseases in particular CACNA1C.

Finally, there have also been plenty of in-person and online opportunities to raise awareness and network including the Beacon London Rare Disease Showcase, RAREsummit23, Advanced Therapies Conference, EJPRD Networking Symposium, Gene People Leadership Symposium, Rare Disease Research Network and EURORDIS Alumni training.

## Improving diagnosis, treatment and care

---

In January 2023 our application was approved for both Timothy Syndrome and CACNA1C-related disorders to be included as a green (diagnostic evidence level) gene on the Congenital hyperinsulinism panel R144 within the NHS National Genomic Test Directory (PanelApp). This sits alongside the Epilepsy syndromes panel we advocated for last year. These additions widen the symptom net for CACNA1C to be identified on an individual's diagnostic pathway.

As PanelApp is an open platform and knowledge base of evidence for gene-disease associations used by the wider global scientific community it is hoped these gene panel additions may influence panels used in other countries.

We continue to be members of ePAG ERN GUARD-Heart, EURORDIS, Neurological Alliance, British Heart Rhythm Society, Rare Diseases International, Genetic Alliance and Gene People, offering us invaluable access to expertise, resources, and networking opportunities, whilst empowering us to advocate effectively at both national and European levels.



# ACHIEVEMENTS AND PERFORMANCE

This year we have worked with two global genetic testing companies, GeneDx and Invitae, to make the post-diagnostic journey easier for individuals who receive a positive CACNA1C result. Collaborating with these companies ensures patients receive trustworthy information and support resources including signposting to TSA, our community and the CACNA1C Community Registry.

## Advocacy Project

As a patient advocacy organisation, we have observed a notable lack of growth in the number of individuals identified with a CACNA1C variant in the UK, compared to rapid growth globally. This year we began to question the assumption that it is because we are ultra-rare. We launched a project to investigate if there were any barriers to reporting rare diseases in the UK. Barriers hinder global diagnosis, research, development of treatments and therapeutics, recognition and support mechanisms, particularly concerning ongoing healthcare. Obtaining more information about the prevalence and incidence of CACNA1C in the UK could also help identify gaps in diagnosis and signposting where we need to focus, which in turn would aid our global advocacy efforts.

We know that CACNA1C is currently included in several gene panels used to test various clinical indications. Some are delivered by the centralised Whole Genome Sequencing (WGS) service and others are testing with alternative technologies within the Genomic Laboratory Hubs (GLHs). The data generated from both testing pathways is analysed within the GLHs but the way pathogenic variants detected through that analysis are recorded is slightly different. GLHs will hold locally derived reported variant database but in addition for WGS there is a centralised variant database called the clinical variant ark.

At present, most of this data is not shared outside of the NHS Genomic Medical Service (GMS) nor is anonymous data on variants detected shared with an international open source database called ClinVar which helps support the diagnosis of other individuals with the same genomic variants. We therefore made a significant number of Freedom of Information (FOI) requests to understand the diagnostic pathways of CACNA1C in the UK and to see how this compared with the numbers on ClinVar for the rest of the world alongside those in our global CACNA1C Support Group. Our initial requests were made in England for the years 2021 and 2022, under the Freedom of Information Act 2000, which allows the public to access information held by public authorities.



# ACHIEVEMENTS AND PERFORMANCE

The infographic below summarises our FOI findings. In 2021 and 2022 there were 7 + < 5 individuals in England confirmed to have pathogenic or likely pathogenic (disease causing) CACNA1C variants.

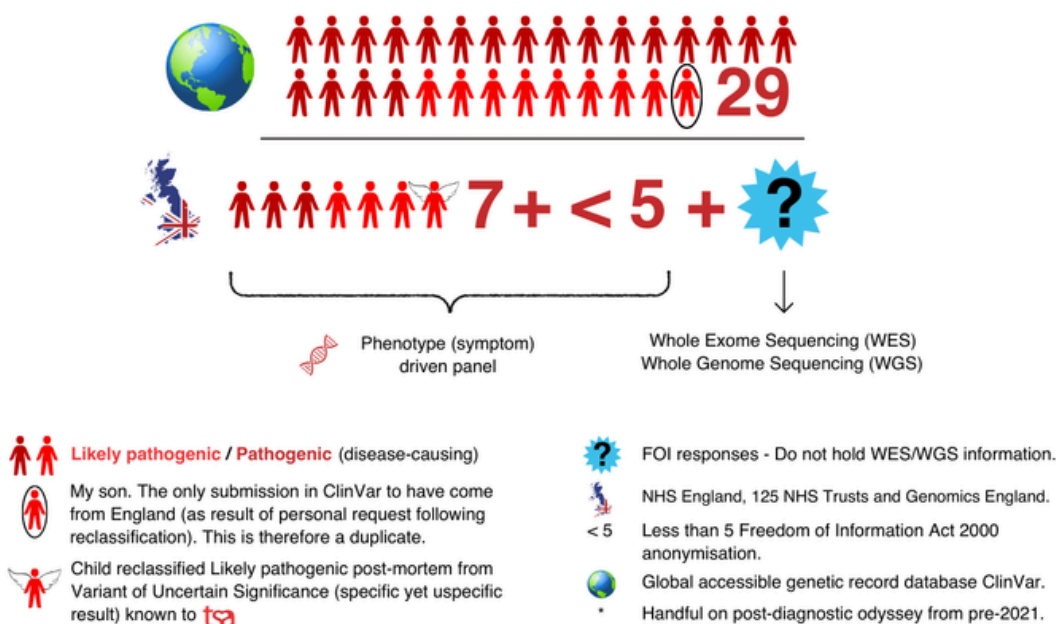
TSA is only aware of two of these individuals; the individual represented with wings and the individual circled with the ring. The individual circled is the son of TSA Chair Sophie. He is the only CACNA1C individual to have been submitted by a GLH in England on ClinVar in 2021 and 2022 following a specific request from the family. The UK did not submit any of the remaining 28 individuals.

In 2023 we were unable to obtain the anonymised data from Genomics England. However, in April 2024 they confirmed there were no patients with pathogenic or likely pathogenic CACNA1C variants identified as a result of whole-genome sequencing across the three years (2021-2023).

## Are barriers to reporting hiding cases of Rare Diseases?

Knowing how many people are currently affected by a rare genetic disease (prevalence) can help us understand how often new cases are emerging (incidence). It also helps in allocating resources for research and developing treatments. Where the number of existing cases is small every new case can significantly impact the overall picture.

**How it works:** Illustrated are the number of people with a rare disease-causing CACNA1C change in their DNA sequence detected by genetic testing in 2021 and 2022. During this time period the global CACNA1C Support Group grew by 42 individuals.\*





# ACHIEVEMENTS AND PERFORMANCE

As part of this project, we are looking at CACNA1C Variants of Uncertain Significance (VUS). Variants of Uncertain Significance are variants detected during genetic sequencing, for which there is no or insufficient evidence either for or against pathogenicity - a VUS is both a specific yet also an unspecific result. Often this is because they have only been identified in a limited number of people (sometimes only one). This is a very common situation for ultra-rare diseases such as ours.

Due to low awareness, phenotypic variability, a lack of genotype-phenotype correlations for atypical variants, and no extant multicentric CACNA1C cohorts, clinical genetic testing results are not influencing clinical management, with many classified as VUS. Our project confirms this.

FOI findings so far confirm more than 96 individuals in England were found to have a CACNA1C variant classified as VUS between 2021 and 2023. It is standard practice in the UK and in many other countries not to inform individuals of VUS findings. These individuals are therefore also unlikely to have received cardiac or neuropsychiatric screening.

According to the ACMG (American College of Medical Genetics and Genomics) Guidelines - who produce internationally accepted guidelines for the interpretation of variants, adopted for UK laboratories by the ACGS (Association for Clinical Genomic Science) - a VUS should not be used in clinical decision-making. If a patient is identified to have a VUS, all clinical decisions should be based on personal and family history and not on the presence of the VUS. Re-analysis in the future may establish that the VUS either is or is not Pathogenic.

TSA advocates that all individuals found to have a CACNA1C gene change, even if classified as VUS, should receive cardiac and neuropsychiatric screening due to the multisystemic effects of CACNA1C. CACNA1C-related disorder is a syndromic cause of cardiac arrhythmia that also impacts neurodevelopment.<sup>1</sup>

It is clear there is much more work to be done to inform clinical and medical treatment. We will continue this project in 2024, incorporating CACNA1C diagnostic findings from Wales and Scotland.

1. Levy, Rebecca J.; Timothy, Katherine W.; Underwood, Jack F.G.; Hall, Jeremy; Bernstein, Jonathan A.; Paşca, Sergiu P. (January 2023). "A Cross-Sectional Study of the Neuropsychiatric Phenotype of CACNA1C-Related Disorder". *Pediatric Neurology*. 138: 101–106.  
doi:10.1016/j.pediatrneurol.2022.10.013. PMID 36436328





# ACHIEVEMENTS AND PERFORMANCE

## Supporting our global community

---

The diagnosis of a rare disease emotionally impacts all areas of life. Living with a rare disease is psychologically and emotionally demanding. Lengthy diagnostic odysseys, uncertain prognoses and treatment pathways, and fears about the future can impact physical and mental health.

The focus of care however is often just managing the physical symptoms. With Rareminds we are helping build the emotional resilience and wellbeing of our CACNA1C community through our 'Mind the Gap' workshops and individual /couples counselling delivered by qualified, specialist therapists and designed to address the key challenges in our rare journey.



**“Connecting with families in the same journey has given us hope; we realise we're not alone.”**

TSA also administrates an online private Facebook Support Group for individuals and families of CACNA1C-related disorders including Timothy Syndrome and LongQT8, offering 24/7 access to emotional and practical support and information via our community.

The benefits of this are huge. It enables:

- meeting and befriending other people with the same rare disorder and similar experiences from across the world
- learning about CACNA1C
- giving and receiving emotional support
- having a place to speak openly about the impact of CACNA1C and one's thoughts and feelings
- learning coping skills
- feeling empowered and hopeful
- advocating to improve healthcare

**“Parent and support groups like the TSA are incredible because they give us support. The exchange of experiences between families is very important because even today, 8 years after the diagnosis, almost no doctor in Brazil has been able to help us because they have never heard of the CACNA1C mutation.”**

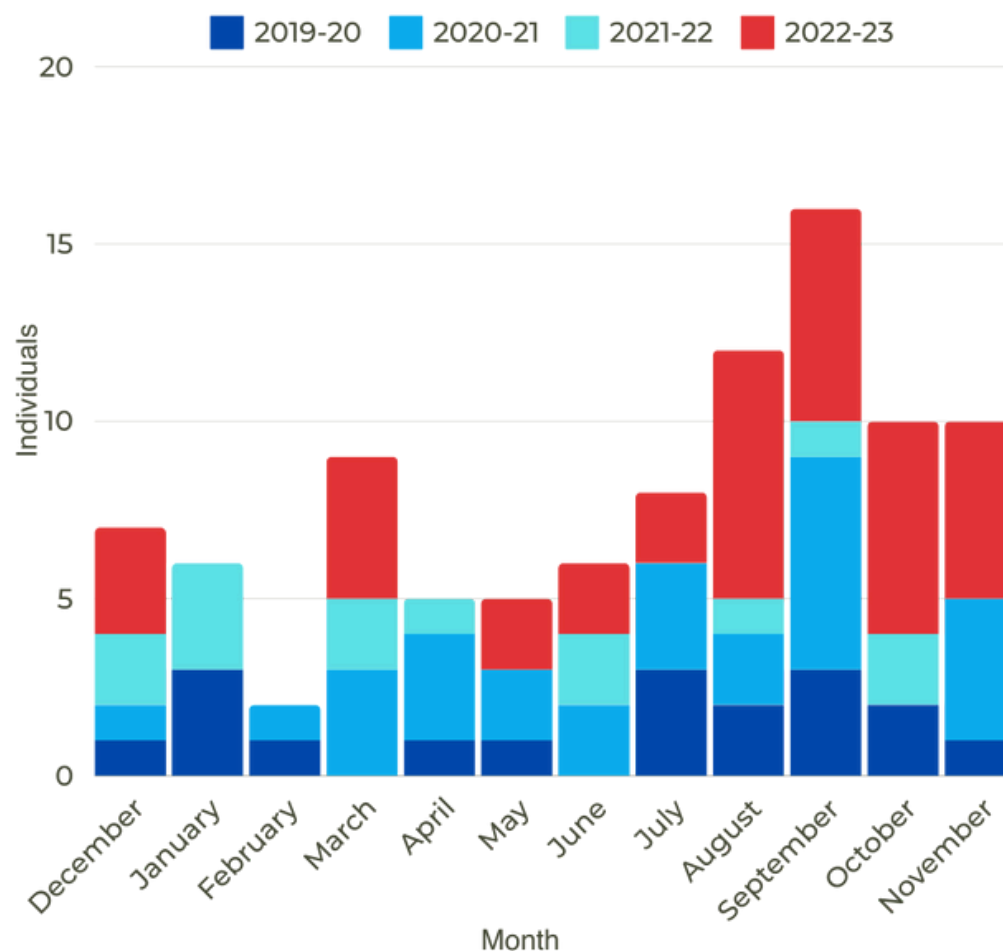


# ACHIEVEMENTS AND PERFORMANCE

Many people find it comforting and helpful to talk to someone who has experienced the same things they are facing when they or their child have a health problem. Having a rare condition can often be extremely isolating due to the lack of people with the same condition. It can be just as challenging to be a parent to someone with a rare disease. Rare disease support groups are an important source of emotional and practical support. 'The use of such advocacy-based coping may help patients to foster a sense of empowerment, efficacy, and hope' (Ayme et al., 2008)

**“I think anyone new to the diagnosis should know there are people who understand a lot as well have their own experiences which gives you comfort and support even if you’re not quite ready yet.”**

**Growth of CACNA1C Support Group**  
**within TSA accounting years (1 Dec to 30 Nov)**



Note, this represents the net number of families/individuals with different CACNA1C variants joining the Support Group and NOT the number of individuals in which CACNA1C gene changes were identified.

# ACHIEVEMENTS AND PERFORMANCE

## Providing information and advice

At the beginning of the year, thanks to support from Healx the first [Wikipedia page for CACNA1C-related disorders](#) was approved creating:

- **Visibility and Awareness:** a dedicated page on Wikipedia increases visibility for our rare disease. It provides a platform where people can learn about CACNA1C, symptoms, research and available resources serving as a central hub where experts, patients, and advocates can contribute accurate and up-to-date details including research, and clinical trials.
- **Educational Resource:** Medical professionals, students, and caregivers can use the Wikipedia page as a quick reference as it provides concise information, reducing the need to search multiple sources.



## ≡ CACNA1C-related disorders

Article [Talk](#)

Pageviews since approval:874

Monthly average:73

In addition to the information available on our website and social media channels, TSA administers an online private [Patient Advisory Board](#) with 190 members of our global CACNA1C community. It is here TSA updates and works with our community on advocacy, ongoing research, collaborations and campaigns - in fact, anything of interest to our community relating to CACNA1C and our mission. Together we aim to build upon the progress made in previous years and work towards new actions to address the priorities of our community.

# ACHIEVEMENTS AND PERFORMANCE

## Driving research & clinical development

On 23 June 2023, we were thrilled to gather our global CACNA1C individuals, families, caregivers, researchers, scientists, healthcare professionals, advocates, and supporters, for our virtual language-accessible conference. By embracing this digital platform, we ensured that everyone, regardless of their geographic location, had the opportunity to join us.



Neuroscience and Mental Health  
Innovation Institute  
Sefydliad Arloesedd  
Niwrowyddoniaeth ac Iechyd Meddwl



## CONNECT CACNA1C GLOBAL NETWORK CONFERENCE

23 JUNE 2023 3PM-7:30PM BST

We collectively shared current knowledge and ongoing studies, exchanged ideas, and fostered collaborations to help shape the future of CACNA1C research, and improve diagnosis and care.

Our programme featured presentations by members of our Scientific Advisory Board and guest speakers, all experts in their respective fields. In addition, we had two breakout discussion rooms and a dedicated Q&A session where speakers were available to address questions. Using the inclusive Translation app, participants engaged in real-time listening or reading along in their preferred language.

With 75 registrants and 48 attendees at any one time we were aware that not everyone could join us for the entire 4.5 hours. In anticipation of time constraints and varying time zones, we recorded the presentations to be available post-event.

All six presentations from the day are available via our website with language transcripts (Arabic, Brazilian Portuguese, Chinese, English, Finnish, French, German, Hindi, Italian, Norwegian, Polish, Russian, Spanish, Turkish and Ukrainian). While we cannot guarantee perfect translation, as that is not possible with AI, our approach in preparing these



# ACHIEVEMENTS AND PERFORMANCE

presentations has eliminated transcription errors that by definition contribute to ultimate translation errors.

We hope the conference for those attending left you feeling inspired and well-informed about the latest advancements in the field of CACNA1C, and will do the same for those yet to see the recordings. This conference was a product of collaboration and passion to understand CACNA1C.

A sincere thank you to all speakers and members of the Scientific Advisory Board who generously shared their latest knowledge and understanding of CACNA1C and to Cardiff University for hosting through their conference Zoom subscription.

To the CACNA1C families and individuals – you are not alone on this journey!

## TSA Scientific Advisory Board



**Dr. Jack Underwood**  
Wellcome Trust GW4-CAT Clinical Research Fellow, NMHII, Cardiff University



**Dr. Rebecca Levy**  
Clinical Scholar, Neurology & Neurological Sciences. Postdoctoral Scholar, Neurology & Neurological Sciences, Stanford Medicine



**Dr. Gemma Wilkinson**  
Research Associate, NMHII, Cardiff University



**Dr. Nicola Hall**  
Postdoctoral Researcher, University of Oxford



**Dr. Anwar Baban**  
Bambino Gesù Children Hospital and Research Institute, IRCCS, Rome



**Dr. Wilfried Haerty**  
Group Leader of Evolutionary Genomics, Earlham Institute



**Prof Liz Tunbridge**  
Director of Translational Neuroscience, Boehringer Ingelheim

The [CACNA1C Community Registry](#) (CCR), accessible worldwide, continues to increase in participants and at the end of this year had 59 individuals enrolled. This is a vitally important research tool in which all families and individuals with an identified CACNA1C gene change are encouraged to participate. The CACNA1C Community Registry has been designed with the input of clinical researchers to identify information and issues relevant to families and pertinent to developing translational research. People are unique genetically and even though everyone in our community has the same gene in common, not everyone has the same genetic variant. Genetic variants are not the same - they don't necessarily act in the same way and they might have different mechanisms in terms of how they are treated. As variants in CACNA1C are so rare clinicians may only see one or two individuals in their lifetime, and therefore gathering global data is vital to understanding the natural history and



# ACHIEVEMENTS AND PERFORMANCE

features of the condition. We are working with our SAB to analyse the Registry data and see how this can be published as research and used to inform clinical and medical treatment.

Preliminary findings from those who consented to participate in the CACNA1C Community Registry between June 10, 2022, and May 5, 2023 were presented at the Connect CACNA1C Global Network Conference and have been summarised on the poster (next page).

In November and April, we were successful in being selected, together with members of our SAB, to attend 'Collaborating for Change' Rare Neurology/CNS Partnering Events held at The Royal Society of Medicine, London. The "speed-date" style networking events build collaborations between patient groups, and pharmaceutical and biotech companies interested in finding treatments for rare diseases that affect the brain and nervous system.

As our community grows epilepsy and seizures are seemingly becoming a more common symptom. To understand more we are now part of the GW4 Epilepsy Community, which links researchers and clinicians aiming to improve research models, diagnosis and treatment of epilepsy. They are studying ion channel mutations, like CACNA1C that cause epilepsy using brain tissue from epileptic patients, genomics, electrophysiology, fly and computational modelling. PhD student Sophie, funded by Bristol University, will study the role of CACNA1C voltage-gated calcium channel signalling in epilepsy and Alzheimer's disease using fruit fly models in Dr James Hodge's lab. Epilepsy is the most common primary neurological disorder worldwide and is a co-morbidity of Alzheimer's but what is the connection? They wish to test genes like CACNA1C that might contribute to both.

TSA is now a patient and public involvement and engagement (PPIE) member of [Bristol Neuroscience Research Hub in Neurodevelopment \(ND\)](#). The Network supports strategic planning and networking across the University of Bristol, two Bristol NHS Trusts, GW4 and Industry partners through collaborative research, planning funding bids and events.

Continuing with epilepsy TSA are now part of [UK Rare Epilepsies Together \(UKRET\)](#) a network of patient support groups and charities representing all those impacted by rare and complex epilepsies across the UK.

# The impact of *CACNA1C* real-world data: *CACNA1C* Community Registry (CCR) design

Sophie Muir (1), Joshua Henderson (2)

(1) Timothy Syndrome Alliance (TSA), UK (2) Pulse Inframe, London, Ontario, Canada

The *CACNA1C* Community Registry is a patient registry for all *CACNA1C* gene related conditions, managed by Timothy Syndrome Alliance (TSA) and powered by Pulse Inframe. The purpose of the *CACNA1C* Community Registry is to obtain insights to better characterise *CACNA1C*-related disorders, including Timothy Syndrome and LongQT8, and their presentation, management and treatment. The registry was launched in June 2022 and is available for worldwide participation. This decentralised registry is not tied to a site and enables anyone, anywhere in the world with a *CACNA1C*-related disorder to sign up for the registry and participate from their home.

## REGISTRY AIMS

- Allow researchers to study common aspects among the different conditions caused by variations in *CACNA1C*.
- Increase the visibility of *CACNA1C* so those navigating the many health concerns may be improved through research and clinical trials.
- Document how different variants present with different symptoms and outcomes.
- Assist researchers anywhere in the world interested in studying variations in this gene.

## ESTABLISHING *CACNA1C* COMMUNITY REGISTRY

TSA set out to create a patient registry to help increase the visibility of *CACNA1C*-related disorders and gain insights that will help facilitate research into this group of rare genetic disorders. The Pulse Inframe platform follows a governance framework that allows data to be collected and housed from multiple different rare disease communities. As a result, researchers are enabled to study multiple conditions. These capabilities made Pulse Inframe the ideal candidate to build the *CACNA1C* Community Registry. With this partnership, Pulse Inframe and Timothy Syndrome Alliance hope to facilitate better research for the *CACNA1C* community. Different variants on this same gene present a variety of outcomes. By collecting data on one platform, TSA and researchers can work with patients anywhere in the world which has proven to be critical when studying diseases with patient populations this small.

## PRELIMINARY FINDINGS

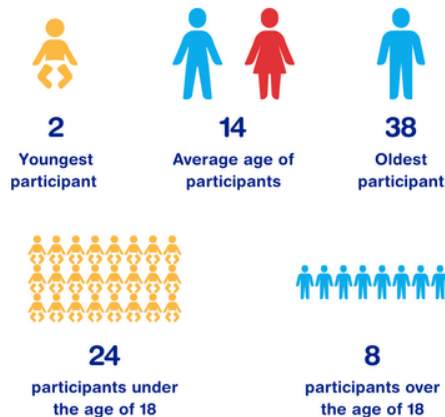
Results are based upon individuals with *CACNA1C*-related disorders (CRD) who consented to participate in the *CACNA1C* Community Registry between June 10, 2022, and May 5, 2023. Through May 5, 2023, 43 individuals with CRD consented to participate in the registry, of which 32 completed forms that provided information on demographics, clinical characteristics, and symptoms. Data presented here are based on these 32 participants. As of June 2024 there are 73 participants in the *CACNA1C* Community Registry.

## CONCLUSION

Families living with a *CACNA1C* variation face many difficulties, including having to educate many healthcare professionals about the condition. They also have limited treatment options. Continued enrollment and participation in the *CACNA1C* registry will help those affected by a variation and researchers in this gene in many ways:

- Increase understanding of all *CACNA1C*-related disorders
- Encourage efficient and timely diagnosis
- Enable progress in research and clinical trials
- Facilitate the development of treatments for *CACNA1C*-related disorders

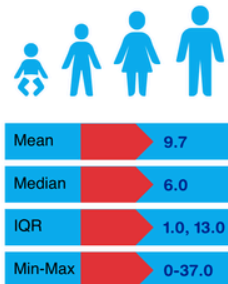
### Demographics



### Gender



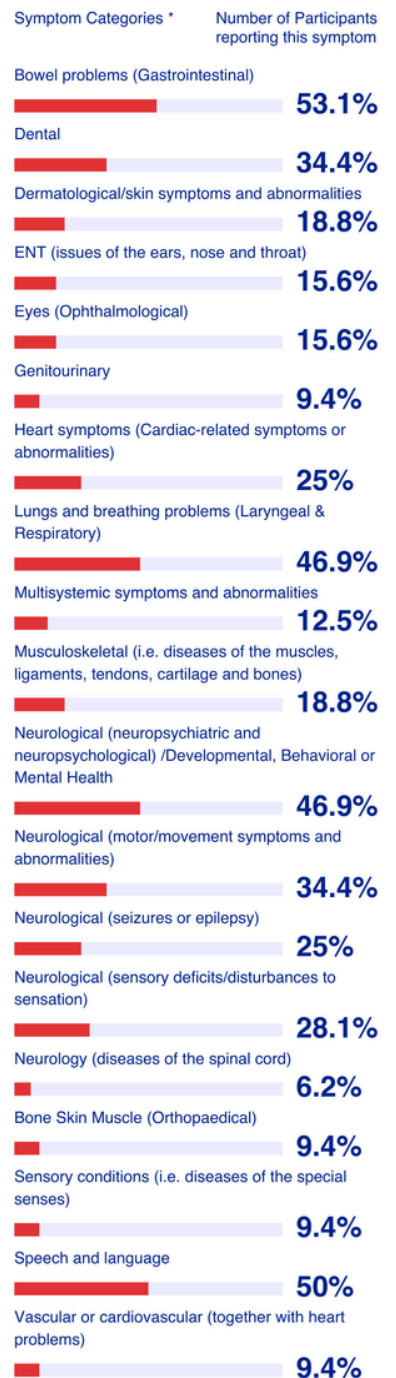
### Age at Diagnosis



### Age at First Symptom



### Overview of current symptoms.



\*Participants can present with multiple symptoms

sophie@timothyalliance.org





# ACHIEVEMENTS AND PERFORMANCE

We joined UKRET rare epilepsy members with our respective scientific advisors for a first-of-its-kind Patient Advisory Group Roundtable meeting with Genomics England (GEL) to discuss the GEL service offering and potential for data access for research to address the unmet needs of our patient communities.

In January our scientific poster (next page) was accepted at the London's Festival of Genomics & Biodata, the UK's largest annual life sciences event. In October it was part of RAREsummit23, an event that brings all stakeholders in rare diseases together as equals to drive patient group, researcher and industry partnering opportunities and our abstract has been accepted for the British Paediatric Neurology Association (BPNA) Conference in January.

In May we were honoured guests at the University of Cardiff launch of the innovation institute where we presented on our collaboration with the NMHII to date.

Supporting the mission of TSA Sophie (Chair of TSA) is a Working Group Member of the Rare Diseases Research Network (RDRN), a partnership project between CamRARE and Patient Led Research Hub, funded by the National Institute for Health and Social Care Research (NIHR) and sponsored by Cambridge University Hospitals NHS Foundation Trust. The project aims to support the rare disease community in building an online network of partnerships and resources to facilitate new patient-centred research opportunities.

Finally, the Voltage-Gated Calcium Channel Collective (VGCCC) has formed, a collaboration of the ten CACNA1 channel patient advocacy groups dedicated to raising awareness and promoting collaboration across the voltage-gated calcium ion channelopathies.

# "Clinical importance of screening and therapeutically addressing neuropsychiatric symptoms in all individuals with CRD."<sup>1</sup>

## CACNA1C-related disorders (CRD) & Timothy Syndrome Alliance (TSA)

### INTRODUCTION TO TSA

Timothy Syndrome Alliance (TSA) registered as a UK charity in 2019:

- Raises awareness of CACNA1C-related disorders including Timothy Syndrome and LongQT8 to improve the diagnosis, treatment and co-ordination of care
- Shares expertise and best practice - Scientific Advisory Board established January 2023
- Maintains a global CACNA1C Community Registry to improve the understanding of the epidemiology of CACNA1C to accelerate and support clinical and basic research
- Promotes research on treatment options and diagnostics
- Facilitates a global support network for individuals, families and carers of those diagnosed

### INTRODUCTION TO CACNA1C

CACNA1C is a gene that provides the code for a protein found in the walls of cells throughout the body. This protein manages the movement of calcium in and out of the cell, which is critical for many cells' function. Changes to the gene can affect the protein's structure and its ability to manage calcium movement, making it work more, less, or not at all. Variants in the gene are associated with CACNA1C-related disorders including Timothy Syndrome (pathogenic p.G406R protein change)<sup>2</sup> and LongQT8 (non-syndromic cardiac-only)<sup>3</sup>. As we identify more individuals with CACNA1C variants there is considerable variability in the phenotype (ranging from severely affected with serious cardiac events to apparently mildly affected with only a few features). These phenotypes are multi-system, but typically individuals present with autism spectrum disorder, developmental delay, prolonged cardiac QT interval, syndactyl/hip dysplasia, hypotonia, epilepsy and hypoglycaemia.

Due to low awareness, phenotypic variability, a lack of genotype-phenotype correlations for atypical variants, and no extant multicentric CACNA1C cohorts, clinical genetic testing results are not influencing clinical management, with many classified as **Variants of Uncertain Significance (VUS)**.

It is now recognised that CACNA1C variants result in a spectrum of phenotypes<sup>4</sup>, from neurodevelopmental through cardiac and musculoskeletal. CACNA1C studies have highlighted substantial advances in our understanding of CACNA1C. TSA and the CACNA1C community have been collaborating on research with NIMH, Cardiff University, University of Oxford and Stanford University for the past 3 years.

### CACNA1C COMMUNITY REGISTRY

This registry went live June 2022 and collects information from CACNA1C individuals and caregivers worldwide to serve as a research platform of real-world data.

Comprehensive multisystemic characteristics and symptomology data including variant, age at diagnosis plus full demographics data are collected upon enrollment and yearly thereafter.



### Phenotypes include Epilepsy<sup>5</sup>/ Seizures...

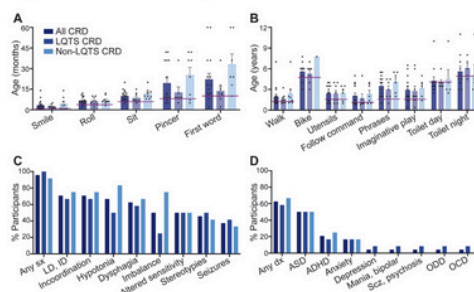
Caregiver-reported survey-based data (TSA Nov 2022) representing n=18; 17 CRD, 1 TS and 1 LQT8 individuals from our CACNA1C community (global support network comprising ~120 individuals with identified CRD in which n=19 are known to have presented with seizures/epilepsy - in some cases this may be just one occasion). Final survey awaiting translation.

- Typical absence (very brief lapse in awareness, sometimes with staring)
- Tonic (body, arms, or legs suddenly stiff or tense)
- Automatisms (such as lip smacking, finger rubbing, chewing)
- Clonic (sustained, rhythmic jerking of part or the whole body)
- Myoclonic (brief, shock-like jerks)
- Infantile spasms
- Atypical absence (some/no lapse in awareness, sometimes with staring. Individual may be able to respond a bit)
- Behaviour arrest (movement stops, sometimes called a freeze or pause)
- Eyelid myoclonia (rapid blinking or jerks of one or both eyelids, sometimes with eyeball movements)
- Cognitive (such as impaired language, confusion, feeling of déjà vu, illusions, or hallucinations)
- Autonomic (such as increased heart rate or blood pressure, sweating, facial flushing)
- Emotional (such as sudden fear or joy)
- Atonic also known as drop (sudden loss of muscle tone causing body to go limp and fall down)
- Restless leg syndrome (RLS) or the urge to move the legs
- Hyperkinetic (such as thrashing legs, pedaling, or rocking back and forth)
- Sensory (such as tingling or numbness, visual symptoms, smells, sounds)

## ...developmental delay, incoordination, hypotonia, autism spectrum disorder (autistic features) and attention deficit hyperactivity disorder with and without prolonged QT.

### PHENOTYPE

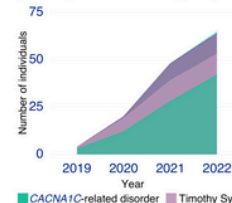
Developmental, neurologic, and psychiatric symptoms are highly prevalent in CRD but do not differ by history of LQTS. Figure and data from Levy et al 2022.



(A) Mean age in months or (B) years at which participants achieved developmental milestones. All participants are depicted next to participants with and without LQTS. There were no significant differences between subgroups. Age at achievement in 50% of typical population denoted by purple lines derived from the Denver II Developmental Scale. (C) Percent of participants who reported the most common neurologic symptoms. There were no significant differences between subgroups. (D) Percent of participants who reported the most common psychiatric symptoms. There were no significant differences between subgroups. Abbreviations: ADHD: attention deficit hyperactivity disorder; ASD: autism spectrum disorder; CRD: CACNA1C-related disorder; dx: diagnosis; ID: intellectual disability; LD: learning disability; LQTS: long QT syndrome; OCD: obsessive compulsive disorder; ODD: oppositional defiant disorder; Scz: schizophrenia; sx: symptoms.

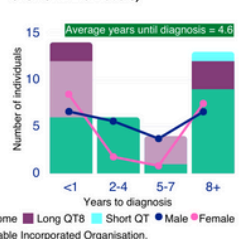
### COMMUNITY

Cumulative yearly increase of individuals joining our CACNA1C Community (global support network) since registration of TSA as CIO on 27 September 2019 (CRDs represented not caregivers)



### DIAGNOSIS

CACNA1C Community survey based data (TSA Aug 2022) indicating time to accurate diagnosis (survey completed by 34 individuals representing a total of 37 CRD individuals)



### Common misdiagnoses reported by CACNA1C Community (TSA March 2022)

- Fragile X syndrome
- Angelman syndrome
- DiGeorge syndrome
- Cystic Fibrosis
- Celiac disease
- Failure to thrive (FTT)
- Prader-Willi syndrome
- Ehlers-Danlos syndrome
- Glycogen storage disease
- Wolff-Parkinson-White syndrome
- Muscular dystrophy
- Down syndrome
- Myotonic dystrophy
- Cardiomyopathy

### CACNA1C Clinical significance on ClinVar submitted records (SCV)<sup>6</sup>

- Conflicting interpretations (138)
- Benign (358)
- Likely benign (885)
- Uncertain significance (885)
- Likely pathogenic (25)
- Pathogenic (82)

### REFERENCES

1. Levy RJ, Timothy KW, Underwood JFG, Hall J, Bernstein JA, Pasca SP. A cross-sectional study of the neuropsychiatric phenotype of CACNA1C-related disorder. *Pediatr Neurol* [Internet]. 2022;102542. Available from: <https://doi.org/10.1016/j.pediatrneurol.2022.1013>
2. Bauer R, Timothy KW, Golden A. Update on the Molecular Genetics of Timothy Syndrome. *Front Pediatr*. 2021;9(May).
3. Szlavovsk I, Timothy KW, Sharpe LM, Decher H, Kumar P, Bloise R, et al. CaV1.2 calcium channel dysfunction causes a multisystem disorder including arrhythmia and autism. *Cell Cell Press*; Oct 1, 2004.
4. Rodan LH, Spillmann RC, Kurata HT, et al. Phenotypic expansion of CACNA1C-associated disorders to include isolated neurological manifestations. *Genet Med* 2021
5. Bozarth X, Dines JN, Cong O, et al. Expanding clinical phenotype in CACNA1C related disorders: From neonatal onset severe epileptic encephalopathy to late-onset epilepsy. *Am J Med Genet A* 2018;176(12):2733-9.
6. <https://www.ncbi.nlm.nih.gov/clinvar/?term=CACNA1C%5Bgene%5D&redir=gene> (Accessed 3 January 2023)



Author: Sophie Muir, Chair  
Timothy Syndrome Alliance (TSA)  
[sophie@timothysyndrome.org](mailto:sophie@timothysyndrome.org)

Registered Charity no: 118552319



SCAN ME

# ACHIEVEMENTS AND PERFORMANCE

## Funding/Fundraising

Our total income for the year was £21,405, compared to £10,005 in the previous year (2021/22). This represents an overall increase of 114%, however, this was not experienced evenly across all sources of income. Support through voluntary donations continues to be a challenge due to low awareness of ultra-rare diseases compared to more well-known rare diseases hence low audience numbers, and because many of our supporters are families caring for children while also managing the cost of living crisis.

That said, a wonderful selection of Facebook birthday and activity-based fundraisers, one-off and regular gifts raised £3,483 of income to support our community and projects. Unrestricted income such as this allows us to direct funds to those aspects of our work which will have the greatest impact on achieving our global goals. We have been deeply touched by your support. We couldn't do what we do without you. Thank you.

We have the tools to raise funds from an international audience as well as those in the UK. GlobalGiving allows tax-deductible giving for donors who are US taxpayers, and JustGiving accepts donations in five default currencies, which eliminates bank currency conversion fees and makes the donation process more cost-effective. Moving forward, we will increase communication of these options.

Restricted income from grants, as well as a restricted donation, was £17,922 (2021/22: £4,706). We would like to extend a special thank you to the following trusts and foundations who have given grants during this financial year:



The Waterloo Foundation for their committed three year support of the CACNA1C Community Registry enabling meaningful change for our existing and future CACNA1C community.



The Stanley Grundy Foundation for funding the translation service. Their generous support enabled our conference to be inclusive, accessible and global.



'Mind the Gap' Mental Health & Wellbeing Support. This work has been made possible by an award from Postcode Local Trust, a grant-giving charity funded entirely by players of People's Postcode Lottery.



# ACHIEVEMENTS AND PERFORMANCE



The Renishaw Charities Committee for supporting the Educational CACNA1C Interactive Guide for Healthcare Professionals.

Our total expenditure for the year was £12,305 an increase of 161% on the previous year. The mix of spending included: CACNA1C Community Registry (66.3%), community Mental Health and Wellbeing support (9%), Connect CACNA1C Global Network Conference (9.8%), Interactive Guide/Rare Disease Day film (7.5%) and other charitable activities eg. alliance memberships, website (7.1%).

Restricted funds remaining in the account (£10,982) are for the upcoming annual CACNA1C Community Registry and further 'Mind the Gap' Mental Health & Wellbeing Support with our partners Rareminds.

In the next financial year the current unrestricted funds (£8,114) will assist with the remainder of the annual registry payment alongside an anticipated Speech and Language Research project we are finalising and for which we will need to source additional funding support.

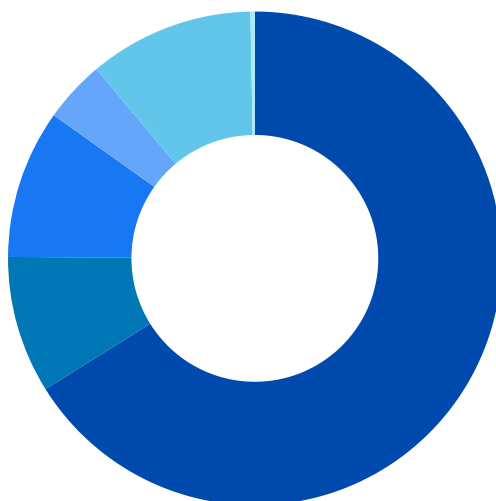
## Income £21,405

- Voluntary Receipts
- Restricted Income - grants



## Expenditure £12,305

- CACNA1C Community Registry
- Mind the Gap Support
- ConCACNA1C Conference
- Interactive Guide/RDD Film
- Charitable activities
- Governance costs



# THANK YOU



We would like to express our gratitude to our anonymous donor for supplying this specialised and adjustable classroom seat designed to promote strength and independence for one of our families. We also want to thank Gardiner Bros & Co (Leathers) Ltd for covering the shipment costs from the UK to the USA.

We sincerely thank our anonymous donor for their generous gift towards our registry payment. Your support is vital to our mission's success. Thank you.



TSA is a small charity punching above its weight and making a significant impact despite limited resources. This is made possible thanks to the people and organisations who help fund our work and provide pro bono support through internal resources and dedication of time and energy. Thank you to all of you, as well as to those we have mentioned throughout this report and our Scientific Advisory Board members, for their dedication to understanding CACNA1C.

Our voice wouldn't be as strong without the support and engagement of our CACNA1C community. Besides sharing stories and photos which greatly helps signpost new families, encouraging and supporting each other, attending our conferences, supporting our social media channels, joining the registry, and contributing to research, they make the impossible possible. Thank you. We are Stronger Together.

As we enter 2024, we are thrilled to announce that we have been selected as the Healx Charity of the Year. We look forward to making an even greater impact together.

Our growth is through strength, our strength is through growth.



## WAYS YOU CAN HELP



Like and share our social media



[@timothysyndromealliance](https://www.facebook.com/timothysyndromealliance)



[@timothysyndromealliance](https://www.instagram.com/timothysyndromealliance)



[@tsa\\_charity](https://twitter.com/tsa_charity)



[@timothysyndromealliance](https://www.tiktok.com/@timothysyndromealliance)



[Timothy-Syndrome-Alliance](https://www.linkedin.com/company/Timothy-Syndrome-Alliance)



Donate to support our work



[JustGiving](https://www.justgiving.com/JustGiving)



[GlobalGiving](https://www.globalgiving.com/GlobalGiving)



[Charities Aid Foundation](https://www.charitiesaidfoundation.org/CharitiesAidFoundation)



[Join the registry](#)



Start a fundraiser



Volunteer



Feedback on how we can help you



## TIMOTHY SYNDROME ALLIANCE (TSA) TRUSTEES' REPORT General Information



REGISTERED CHARITY NUMBER: 1185523

TRUSTEES:

Sophie Muir – Chair

Nick Muir

Katherine W Timothy

Galina Gardiner

Meg McLoughlin

REGISTERED OFFICE:

8 Butt Street, Minchinhampton, Gloucestershire GL6 9JP

For the year ended  
30 November 2023.

**Objectives:** To relieve the needs of those affected by deleterious CACNA1C gene changes resulting in CACNA1C-related disorders including Timothy Syndrome and Long QT8, their families and carers worldwide in particular but not exclusively by:- (1) Promoting greater understanding of the causes, symptoms and treatment of CACNA1C-related disorders including Timothy Syndrome and Long QT8, by the promotion of research and sharing and disseminating of the results of such research for the benefit of the general public; (2) Raising public awareness of the symptoms, needs and related medical conditions of those living with CACNA1C-related disorders including Timothy Syndrome and Long QT8.

**Structure, governance, and management:** Timothy Syndrome Alliance (TSA) is a registered charity number 1185523, governed by the Charities Act 2006. The charity is a Charitable Incorporated Organisation registered on 27 September 2019 under the Foundation Governing Document. The Trustees delegate the charity's day-to-day management to Sophie Muir. Trustees met four times during the year and corresponded regularly via email and other digital means, particularly to keep financial performance under review. New trustees are appointed by the serving trustees, considering the skills required by the board. Trustee induction includes online training (NCVO) to give an overview and understanding of charity governance, regulation and best practice alongside Essential Information for Trustees from the Charities Commission.

**Public Benefit:** The Trustees confirm that they referred to the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives for the year. Public benefit has been achieved through the activities outlined in the Achievements and Performance section of this report.

**Reserves Policy and Going Concern:** The charity receives funding for specific purposes which are restricted funds – these are not available for expenditure on other purposes. The general reserves are the unspent unrestricted funds of the charity. The charity currently owns no fixed assets, so the general reserve is held in cash. The general reserve is therefore the free reserves of the charity plus any designated funds, also termed 'unrestricted funds' in the charity's balance sheet.

The purpose of the general reserve is:

- a) fund shortfalls when income does not reach expected levels.
- b) fund unexpected expenditures, for example when projects overrun or unplanned events

occur.

c) ensure that the Charity is not unnecessarily holding back on spending in favour of using the resources it has to meet its charitable objectives.

We assess the level of general reserve needed by looking forward and considering the risks to our funding balanced against our expenditure commitments. Future plans show levels of committed expenditure for which we are seeking funding, but to ensure we can continue to operate in accordance with our plans, we hold a general reserve in the range £1,500 - £2,000 to cover unfunded committed costs for the next 6 months.

Our general reserves on 30 November 2023 were £8,114 (of which £2,000 will go towards the registry fees and £4,000 towards a Speech and Language Research project), leaving £2,114 of Free Reserves which is slightly over policy. Our reserves policy is reviewed annually and updated as necessary.

The trustees have reviewed the circumstances of the Charity and consider that adequate resources continue to be available to fund its activities for the foreseeable future. The trustees are of the view that the Charity is a going concern.

#### Trustees' responsibilities statement

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The trustees are required to prepare accounts for each financial year, which reflect the receipts and payments of the charity and the surplus or deficit of income against payments for the year.

The trustees are responsible for:

- keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the Trust deed; and
- safeguarding the assets of the charity and hence taking reasonable steps for prevention and detection of fraud and other irregularities.

Approved by the trustees on **8 July 2024** and signed on their behalf by

Sophie Muir - Trustee (Chair)



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
**Timothy Syndrome Alliance (TSA)**

No (if any)  
**1185523**

**CC16a**

## Receipts and payments accounts

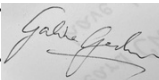
For the period from	01/12/2022	To	30/11/2023
------------------------	------------	----	------------

### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Voluntary Receipts	3,483	17,922	-	21,405	10,005
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>3,483</b>	<b>17,922</b>	<b>-</b>	<b>21,405</b>	<b>10,005</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>3,483</b>	<b>17,922</b>	<b>-</b>	<b>21,405</b>	<b>10,005</b>
<b>A3 Payments</b>					
Cost of Charitable Activities	1,330	10,940	-	12,270	4,706
Governance Costs	35	-	-	35	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,365</b>	<b>10,940</b>	<b>-</b>	<b>12,305</b>	<b>4,706</b>
<b>A4 Asset and investment purchases. (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>1,365</b>	<b>10,940</b>	<b>-</b>	<b>12,305</b>	<b>4,706</b>
<b>Net of receipts/(payments)</b>	<b>2,118</b>	<b>6,982</b>	<b>-</b>	<b>9,100</b>	<b>5,299</b>
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	5,996	4,000	-	9,996	4,697
<b>Cash funds this year end</b>	<b>8,114</b>	<b>10,982</b>	<b>-</b>	<b>19,096</b>	<b>9,996</b>



## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>		8,114	10,982	-
		-	-	-
		-	-	-
	<b>Total cash funds</b> (agree balances with receipts and payments account(s))	8,114	10,982	-
		OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>	Details			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Galina Gardiner	8 July 2024	