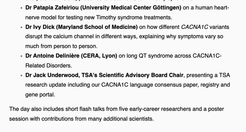
Timothy Syndrome Alliance

CACNA1C

Connect CACNA1C Global Network Conference Cardiff 2026

Bringing together the global CACNA1C community of families, researchers and clinicians.

Something we have worked towards for years is finally happening this month! Our CACNA1C community are travelling to Cardiff from Italy, Germany, Spain, Norway, the Netherlands, Romania, Brazil, the United States, Australia and across the UK. Ten countries. Four continents. One room. Two days. Families and researchers, together shaping the future of CACNA1C-Related Disorders!



This month in Cardiff:
21 families · 10 countries · 4 continents · 10+ researcher and clinician speakers · 150 attendees · 2 days

22-23 July

We will be in the Hadyn Ellis Building, Cardiff University - home of Neuroscience and Mental Health Innovation Institute (NMHI), our research partner since 2019. Seven years ago, eight families met in the same building to launch the charity!

Here's what is happening:

Day 1: Research Talks
Over ten researchers are presenting, and the range tells you how far this field has come! Research talks cover antisense oligonucleotide (ASO) therapies, human heart-nerve models, variant classification, and the genetic mechanisms linking CACNA1C to specific symptoms. Highlights include:

- **Dr Rebecca Levy (Stanford Medicine)** on genetic testing, translational research and potential ASO approaches to treatments for Timothy syndrome.
- **Dr Pelagia Zafeiriou (University Medical Center Göttingen)** on a human heart-nerve model for testing new Timothy syndrome treatments.
- **Dr Ivy Dick (Maryland School of Medicine)** on how different *CACNA1C* variants disrupt the calcium channel in different ways, explaining why symptoms vary so much from person to person.
- **Dr Antoine Delinière (CERA, Lyon)** on long QT syndrome across CACNA1C-Related Disorders.
- **Dr Jack Underwood, TSA's Scientific Advisory Board Chair**, presenting a TSA research update including our CACNA1C language consensus paper, registry and gene portal.

The day also includes short flash talks from five early-career researchers and a poster session with contributions from many additional scientists.

Day 2: Family and Research Priorities
This is the day we are prioritised. It is built around one goal: families and researchers shaping a patient-prioritised research agenda together. They run parallel sessions (families chaired by Lauren Roberts, CEO of RareMinds; researchers chaired by Dr Jack Underwood), then a 'speed dating' round with healthcare and research professionals including genetic educators from Wales Gene Park and the Cardiff University Biobank. It closes with 'Pitch a Priority', a Dragon's Den-style session where researchers put their questions to families, and the families decide what matters most. Excitement is building, and as one family in our community put it:

"We are genuinely so appreciative of all people engaging in and working on improving and increasing knowledge about CACNA1C around the world."

Staying part of it

If you are not in the room, you have not missed your chance to shape this. Recordings of every talk on Day 1 will be added to our website and YouTube channel with language transcripts after the Conference.

And what starts in Cardiff will not stay in Cardiff: the research agenda shaped here will be opened up to the wider community after the Conference and then published. We have much more to announce on this in the months ahead.

For families
More RareMinds support webinars are on their way, building on the themes families will be raising in Cardiff.

For researchers and clinicians
Off the back of this conference, we are preparing for a Scientific Round Table next year, and the author of the winning poster in Cardiff will be invited to join us. With the Scientific Round Table in mind, if you know colleagues working on CACNA1C or related channelopathies who would want to be part of what comes next, please ask them to sign up to our newsletter so they hear about it first.

For our supporters
We do not say this lightly: this momentum does no happen on hope alone. Flying families in from four continents, bringing leading minds in the field to the same table, building an agenda that will steer years of research - all of it rests on the support behind us. From 43 people in 2019 to a community now setting the direction of a whole field, this is what backing TSA makes real. There is a great deal more to come.

This conference is supported by a grant from the **Chan Zuckerberg Initiative's Rare As One Network**, which named TSA a Cycle 3 grantee. Their funding is a direct part of what makes it possible to bring this community into one room.

Questions about the conference? Please contact admin@timothysyndrome.org

And the winners are...

We were so impressed by three contributions to our Conference T-shirt Design Challenge and couldn't choose between them - so we combined them to create our exclusive Cardiff Conference 2026 T-shirt. And not only that but we love this brilliant design so much, we have created it as a sticker (available in our official TSA shop).

So huge congratulations to our 3 winning designers:

- **Serena from Italy**
- **Ava from the United States**
- **Nikola from Poland**

who will all receive a limited edition conference T-shirt as their prize. Thank you for your inspiration and creativity - you are all 🌟🌟🌟

Thank you to all who participated and showed their support.

What's New?

All Things CACNA1C....

Our shop is open for business to everyone!

From T-shirts to baseball caps, water bottles to stickers...every item starts a conversation about CACNA1C-Related Disorders with someone who has never heard of them, and every purchase, that's 100% of the profits, funds our work.

Our new shop runs on Teemill, who produce made-to-order clothing (from organic cotton) and accessories, and printed using renewable energy.

Visit the shop here:

https://cacna1c.teemill.com/

and please pass the link on to family and friends.

Plans are already in progress to add more new and exclusive designs in the coming months.

Spread the word and wear the message!

Shop Now

Why support TSA?

- Because we're not filling a gap. We're building the system.
- Because families and scientists deserve to work side-by-side.
- Because what's rare to the world is everything to us.
- Because with you, the impossible becomes possible.

Donate Today!

UK Donors (GBP)

US Donors (USD)

International Donors (EUR, CAD, AUD)

Spread the Word...

We know not everyone can give financially, but sharing our work on social media helps more than you might think. It spreads awareness, reaching those who can support our impact and those living with CACNA1C-Related Disorders who face an immense burden, managing crisis-level symptoms within systems that still don't understand their needs. Every post, like, and share truly makes a difference, so please hit that button! 📩

Thank you for reading this edition of our TSA newsletter and giving your continued support. TSA is run by parents and volunteers and we thank every one of you.

Team TSA 💗

Join the conversation

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