Connect CACNA1C Global Network Conference 2026

Conference feedback report

Postcards, families and professionals

22–23 July 2026 · Hadyn Ellis Building, Cardiff University

Timothy Syndrome Alliance
CACNA1C

Cardiff University
Prifysgol Caerdydd

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

About this report

Three feedback datasets were gathered at the July 2026 conference: free-text postcards from feedback trees, questionnaires completed by attending families across the two days, and a questionnaire completed by attending professionals. Each result is shown with the verbatim survey question that produced it.

Around 140 people attended each day: 20 families (39 adults, 27 children), 41 professionals and researchers, and other delegates. Volunteers, staff, and the childcare and translation teams supported the event and did not complete questionnaires.

140
attended each day (approx.)

20
families (39 adults, 27 kids)

31
professionals responded

82%
adult response rate
32 of 39

10
family countries

41
postcards

Datasets and coverage

Feedback-tree postcards. 41 free-text postcards, hand-coded by theme and author type.

Family questionnaires. 32 of 39 attending adults responded, several from the same families. 28 Day 1 and 30 Day 2 forms.

Professionals questionnaire. 31 respondents from seven countries. Several were Day 1 speakers, so the sample skews toward already-engaged researchers.

Reading the figures. Family percentages are of individual respondents, on bases of roughly 20 to 29, with smaller bases where only some families used a service. In several families more than one adult chose to complete the questionnaire, so these figures reflect the views of most attending adults, not a single nominated respondent per family. The data is self-selected among those who responded, so it shows the depth of impact on an engaged community rather than a representative rate. Bases (n) are on every chart.

Summary of findings

One coherent story across three datasets: belonging for families, collaboration for researchers, and genuine two-way alignment between them.

100%

felt less alone after Day 1

27 of 27 respondents

96%

greater hope about the future

27 of 28 respondents

97%

would recommend TSA events

28 of 29 respondents

97%

of professionals said the event exceeded expectations

30 of 31

73%

of professionals left with new or potential collaborations

22 of 30

77%

of professionals changed how they understand the lived experience

23 of 30

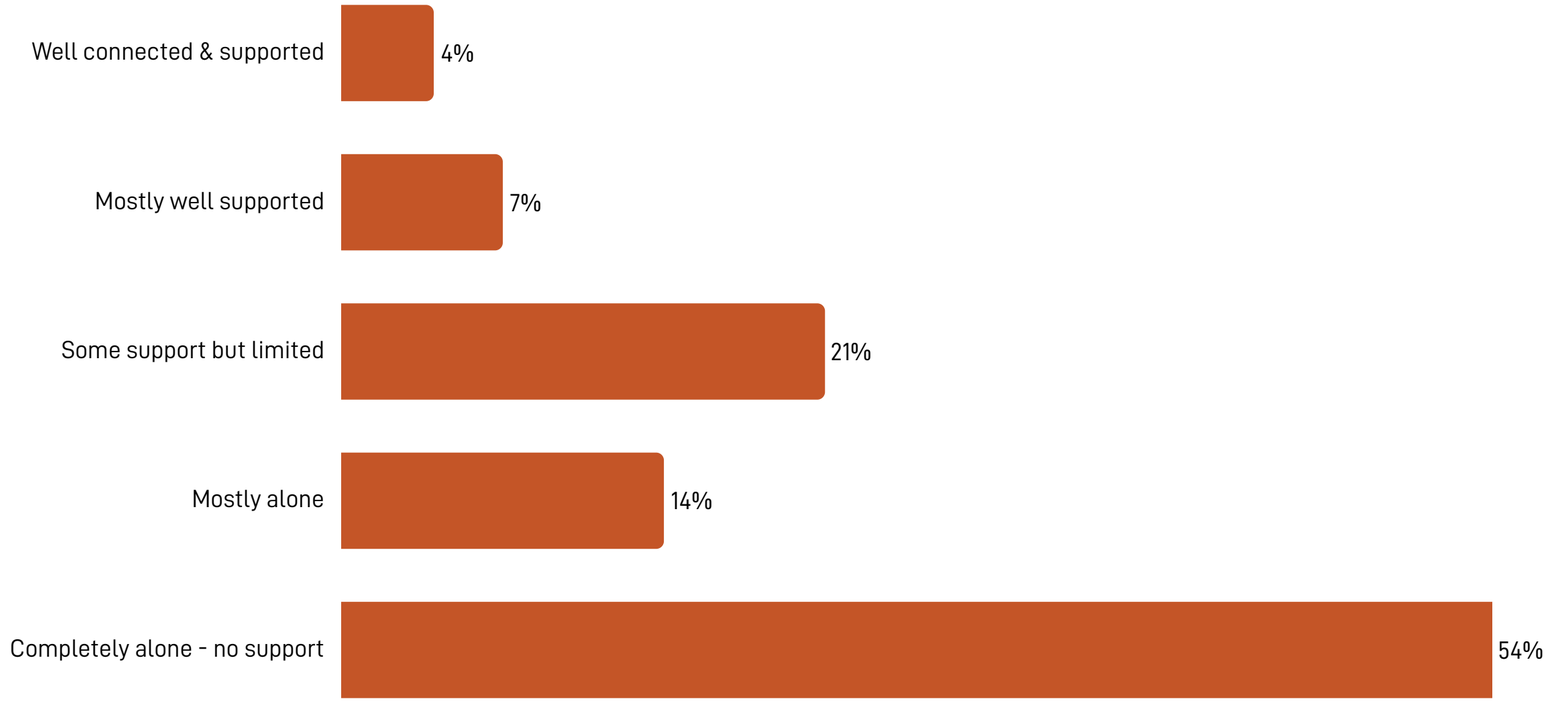
SECTION ONE

Family feedback

01

Before connecting with TSA, families were isolated

Most respondents were parents or guardians (24 of 28). Half describe themselves as completely alone before TSA.



54%

felt completely alone, no support at all

15 of 28

61%

waited 6+ years for diagnosis

17 of 28

"It's good to know there are other families facing the same problems. At the same time, it's sad we're all fighting the same battle and often not heard or seen."
— Parent

D1 Q6. *Before connecting with TSA, how isolated did you feel in managing the diagnosis? (n=28)*

The conference broke the isolation

100%

felt less alone (74% significantly)

27 of 27

96%

made new connections on Day 1

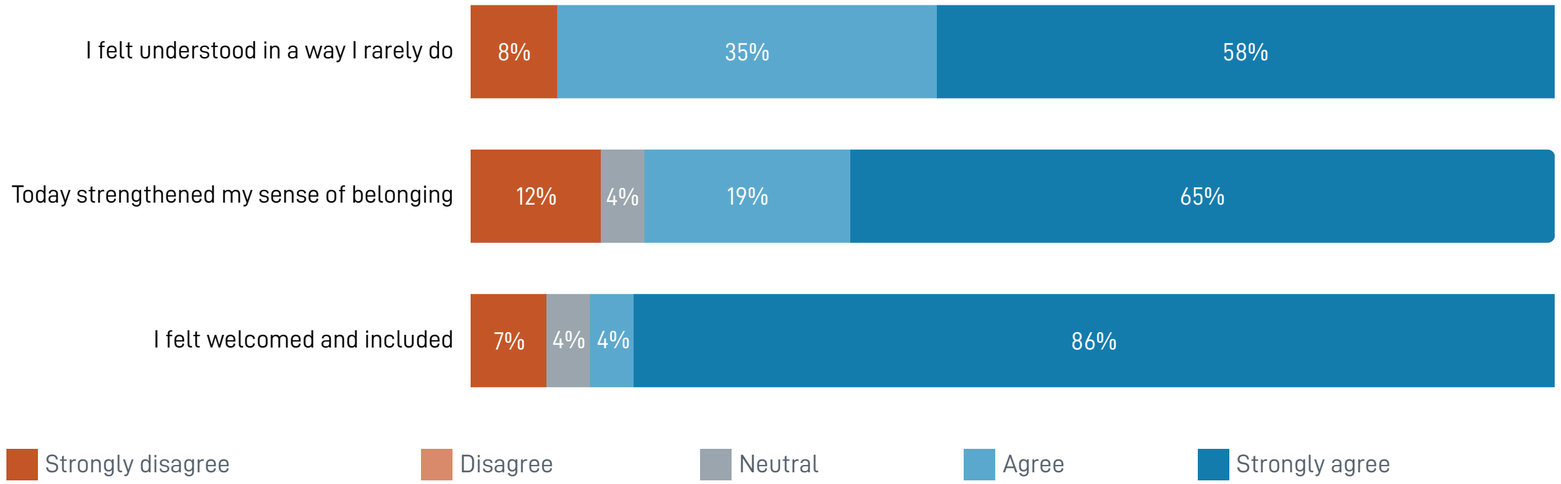
27 of 28

39%

met another affected family in person for the first time

11 of 28

How strongly respondents agreed (Day 1)



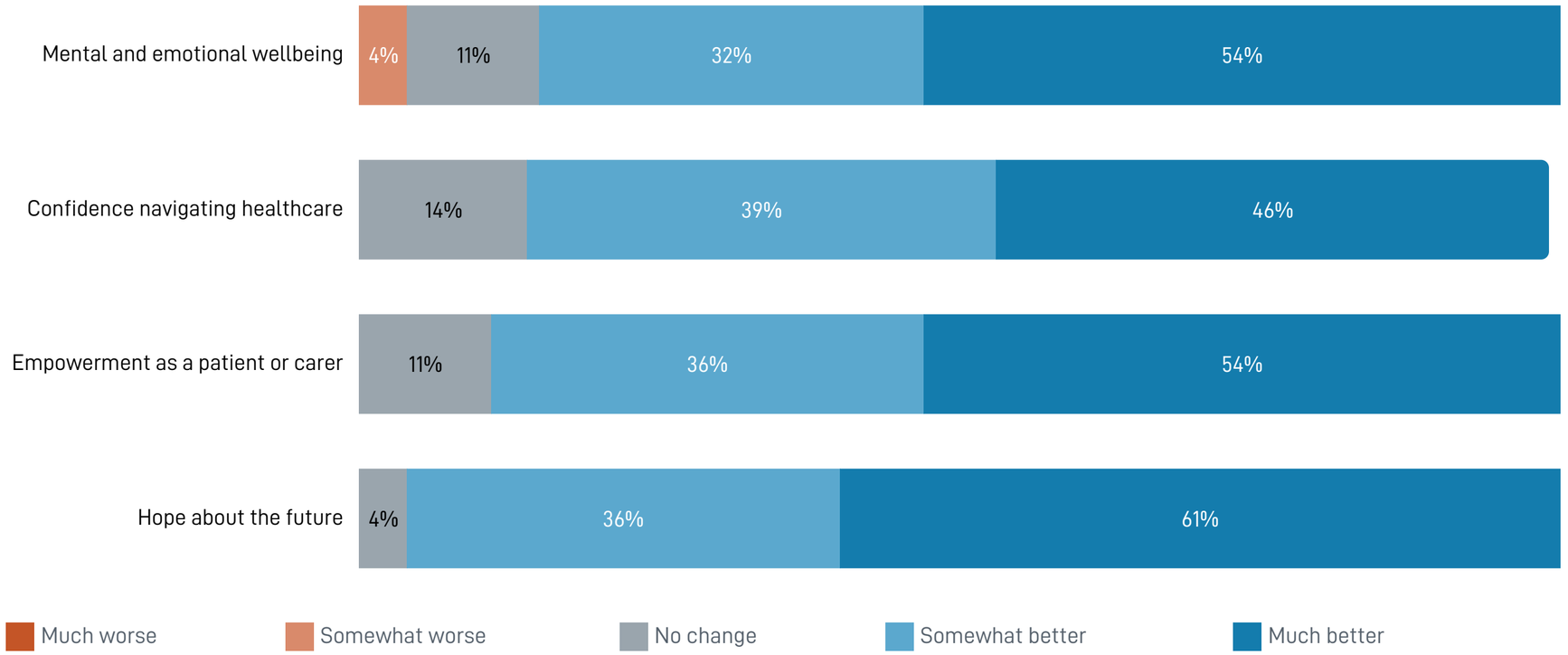
Note: two respondents entered "strongly disagree" to all three statements while reporting significant positive impact on every other question, consistent with a reversed-scale entry. Responses are shown unchanged.

Connection you could see. Most people wore the conference t-shirts through both days: families, clinicians and researchers alike, each made to their own size. One of the two designs was created from the community's own entries. A room with no visible line between patients and scientists. Organisers' context, not survey data.

D1 Q9 / Q10 / Q8 / Q11. *Did today help you feel less alone? Did you make new connections today? Had you met an affected family in person before? Agreement statements. (n=26–28)*

Reported shifts in wellbeing across the two days

Share of family respondents rating each area better after the conference than before. Ratings are self-reported and retrospective, given after the event.



96%

greater hope (61% much better)

27 of 28

89%

greater empowerment

25 of 28

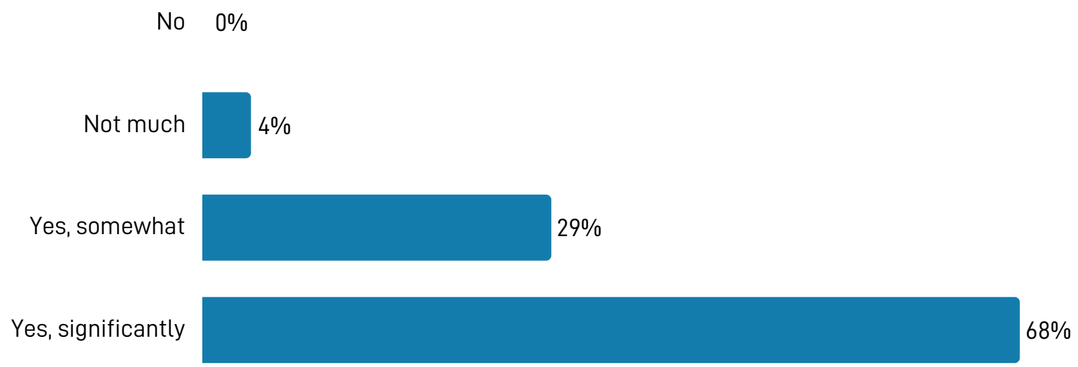
"There is hope for these children. The most valuable thing was learning things I had been unaware of until now."
— Parent

Note: Figures may not sum to 100 due to rounding.

D2 Q10. *Before/after this conference – my sense of hope / empowerment / confidence navigating healthcare / mental and emotional wellbeing. Rated retrospectively in the post-event form. (n=28)*

Families left more informed and more confident

Did the presentations increase your understanding?



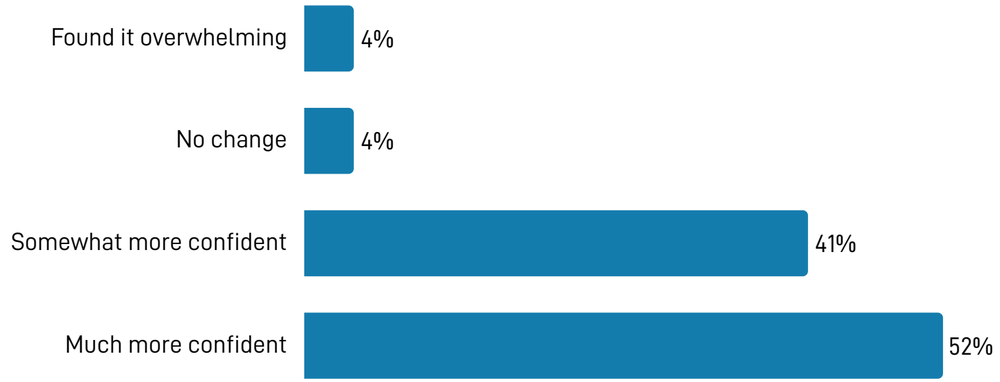
96%

gained understanding of CRDs and research

27 of 28

93% also left more confident discussing care with their medical team (25 of 27).

More confident discussing care with the medical team?

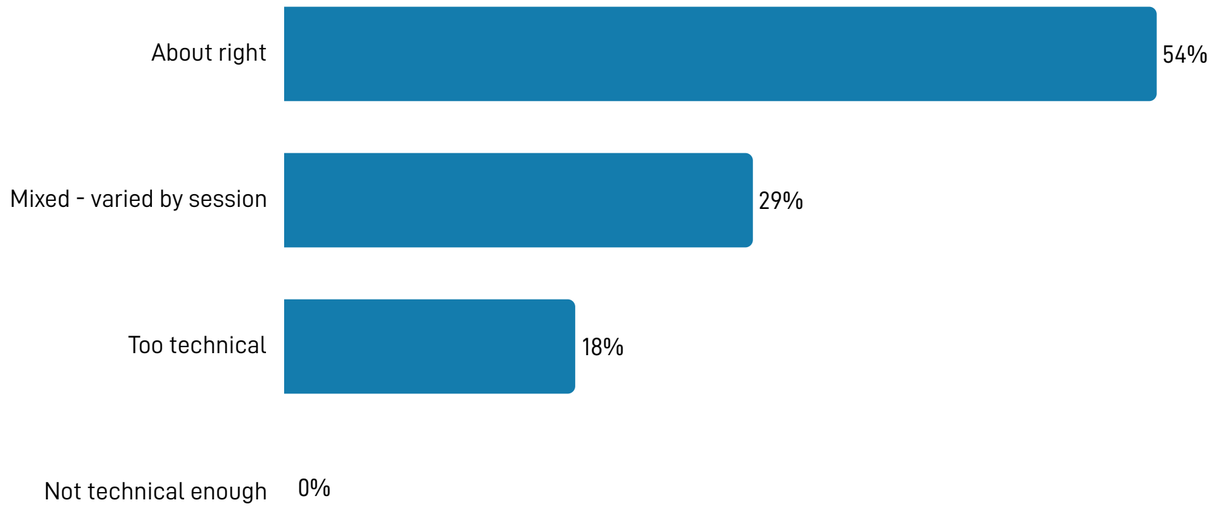


"I had no idea of the extent of CACNA1C disorders and the research programmes at universities around the world. The conference has been a real eye-opener."
— Parent

D1 Q12 / Q13. *Did the presentations increase your understanding? After today, do you feel more confident discussing care with the medical team? (n=27–28)*

Simplify the science even further

The talks were tiered and speakers briefed. Some content still landed as too technical, which reflects how complex CACNA1C is.



46%

found the level too technical or uneven

13 of 28

"I felt the afternoon talks were in-between scientific and lay. It may help to give speakers feedback beforehand."
— Professional respondent

The talks were grouped with stepped technical level, speakers pre-emptively advised, and plain-language summaries for every poster are going out after the event. Some content still landed as too technical, which reflects how complex CACNA1C is rather than a gap in delivery. The step for future events is more granular lay tiering, for example a basic-lay and a medium-lay strand, so both newly diagnosed and long-immersed families are served.

D1 Q17. *Were the presentations pitched at the right level for you? Single select of four options. (n=28)*

Families felt their voice will shape the research agenda

96%

of Pitch a Priority attendees felt it was genuinely empowering

23 of 24

79%

found the parallel priorities session genuinely meaningful

23 of 29

Will your family priorities influence future CACNA1C research?

"My connection with other mothers going through the same thing, and the teacher who made us feel so important through our testimonies."
— Parent

D2 Q4 / Q1 / Q5. *Did Pitch a Priority make you feel your lived experience has value in shaping research? Was the parallel priorities session meaningful? Will your priorities influence future CACNA1C research? (n=24–29)*

Translation made the conference accessible

Two thirds of responding families were not first-language English speakers. Translation is what let them take part.

62%

not first-language English

18 of 29

Everyone who used translation support took part in the conference

12 of 13 fully, the last one mostly

100%

of non-English-speaking families were given written materials in their own language

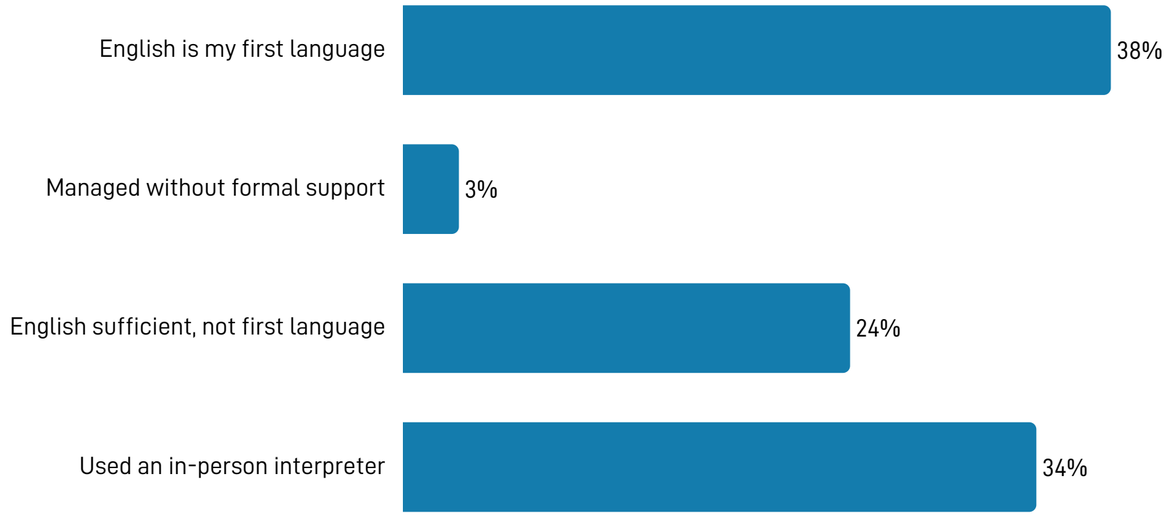
18 of 18

75%

rated interpreters excellent

9 of 12

How families engaged with language



"Your provision of translators was excellent. I got to talk to international families, which wouldn't have been possible otherwise."
— Professional respondent

D2 Q13–Q17. *Language engagement, full participation, written materials and interpreter rating. (n=12–29; interpreter-rating and participation bases are those who used translation)*

Childcare made it possible for parents to take part

Every family that used the childcare said it let them focus on the programme.

100%

of families who used childcare said it let them focus

20 of 20

86%

of children enjoyed the provision

18 of 21

"I dreaded that my 18-year-old granddaughter would fuss about the children's activities. But she loved them, and her mother and I could enjoy the talks in peace. Long live TSA."
— Grandparent, feedback tree

"The childcare made it 100% easier to attend the sessions. Otherwise it would have been impossible to concentrate."
— Parent

D2 Q7 / Q8 / Q9. *Did the children enjoy the provision? Did it let you focus on the programme? Any changes you would suggest? (n=20–21; focus figure among the 20 families who used it)*

The conference dinner drove connection

Nearly everyone came, most felt relaxed enough to connect, and translators kept it inclusive.

93%

attended the conference dinner

26 of 28

92%

felt relaxed enough to connect

23 of 25

91%

said children's entertainment worked well

20 of 22

"Everything was perfect. I've found a new family."
— Parent

Every family who needed language support could take part in the evening

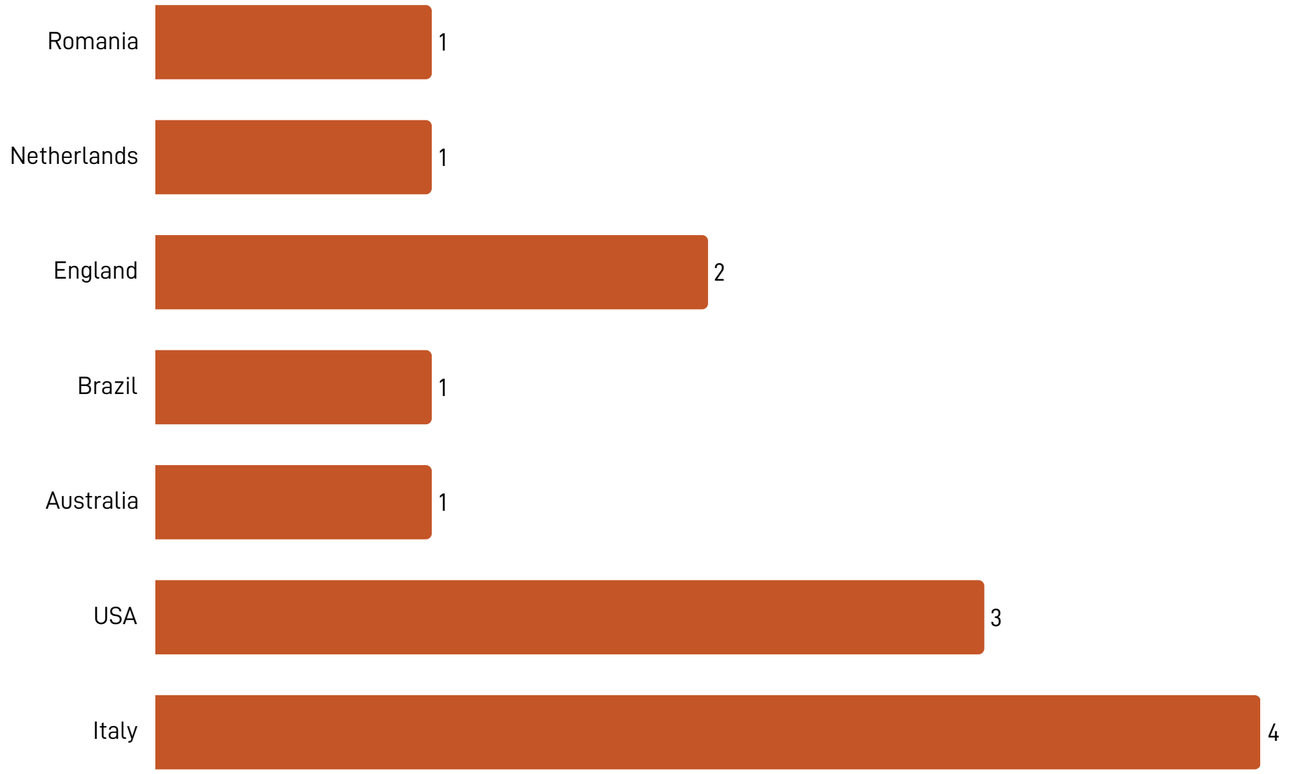
9 helped by translators, 4 managing informally, of 13

Beyond the dinner. Families were welcomed on arrival with drinks, goodie bags and programmes, so connection began before the sessions. On the final evening, most families gathered at the hotel to socialise together. Organisers' context, not survey data.

D1 Q23–Q27. *Did you attend the conference dinner? Did it feel relaxed enough to connect? Did the children's entertainment work? Were translators available when needed? (n=13–26). The dinner was on the first conference day; families had arrived the day before.*

The cost of attending with a rare disease

Before booking travel, 13 families from 7 countries applied for travel support, setting out what attending would cost them.



13/20

families applied for travel support

3

countries, requiring long-haul travel

Why this matters. These are application-stage words, written before families had even booked. On top of the everyday costs of a rare disease, out-of-pocket therapies, continuous medical bills, savings already spent, the cost of travel is often the difference between attending and not. Cost, not interest, is what keeps international families away. It is direct evidence for a distance-based travel bursary model at future conferences.

Travel bursary applications. *Families' own words on why support was needed to attend, given before booking travel. (13 applications, 7 countries)*

In their words: why families needed support

Written at application stage, before booking. The cost of a rare disease, set against the drive to seek answers.

We pay out of pocket for much needed therapy for our daughter, and hospital and doctor bills are continuous. We looked into flights and immediately knew it wouldn't be an option for us.
— Parent in USA

I have a resident doctor's salary, very low in my country, and we have used all our savings for our child's therapies. We are still trying to keep what we can for his future needs.
— Parent in Romania

The estimated cost for all of us to go is between six and seven thousand dollars. Even with extra help, we may not be able to attend. It's a lot to save in a short time.
— Parent in USA

We can't leave our other two children behind, so the five of us have to go, with the flights costing nearly €1,000.
— Parent in Italy

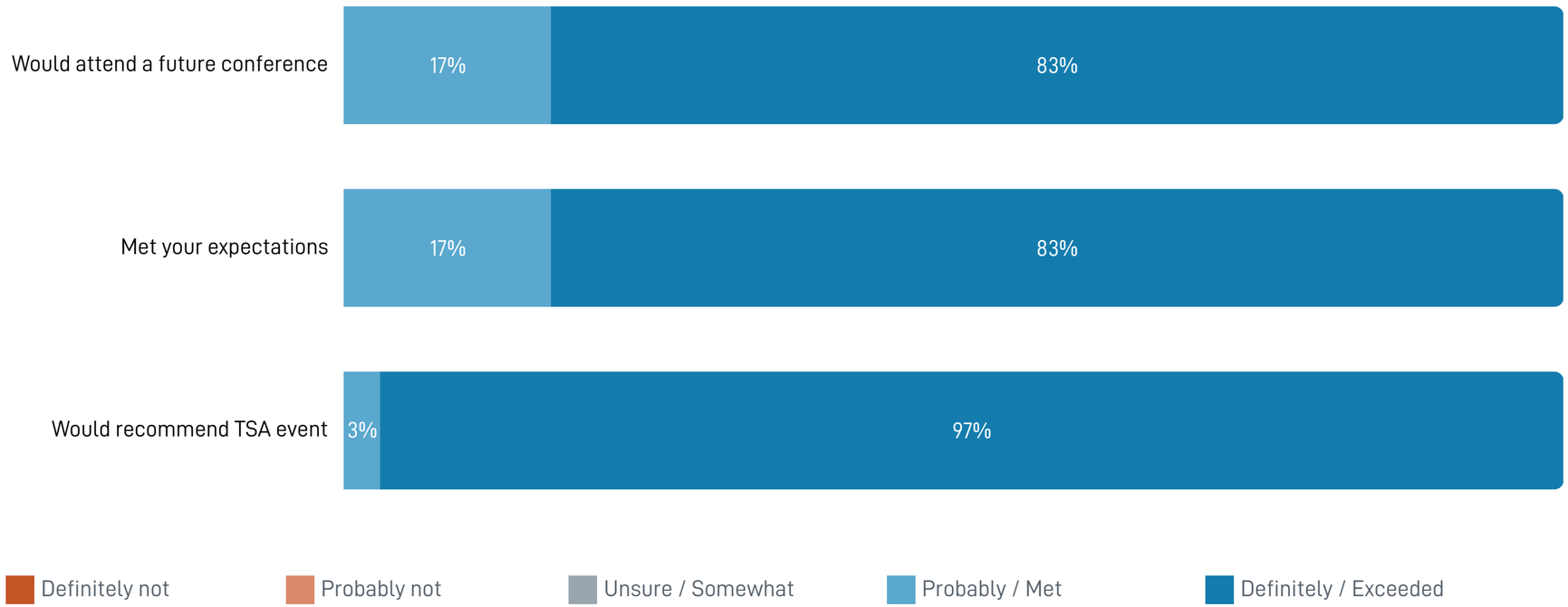
Crossing three continents to seek answers makes us good candidates. I provide support and information for other parents. I have much to offer the group.
— Parent in Australia

It would help, as bills are so high at the moment.
— Parent in England

Travel bursary applications. *Families' own words on why support was needed, given at application stage before booking travel. Shown with country of residence.*

Overall verdict from families

Overall impact



79%

rated it extremely useful

23 of 29

97%

would recommend

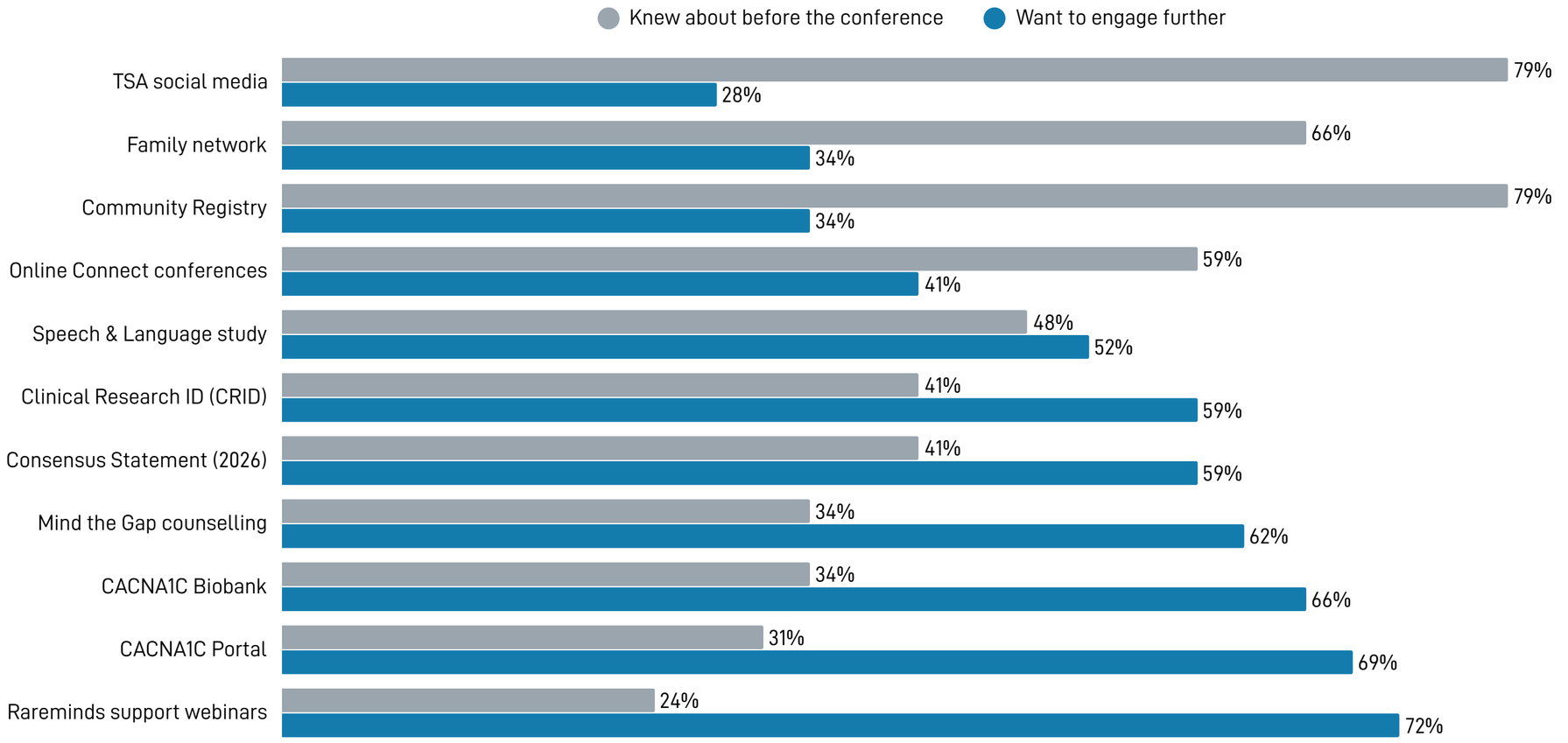
28 of 29

"A network of hope for my son, that I can give him the best future possible."
— Parent

D2 Q20 / Q21 / Q22 / Q23. *How useful was the conference? Did it meet expectations? Would you attend a future conference? Would you recommend TSA events? (n=29)*

Families left wanting more of TSA's services

For most services, more families left wanting to engage than knew about it beforehand.



D2 Q11. *Which TSA services did you know about before the conference, and which would you like to find out more about or engage with? (n=29)*

Why families came

Connection and research updates drew families in equal measure.

D1 Q7. *What were your main reasons for coming to this conference? (tick all that apply, n=28)*

In their words

Families on the single most valuable thing about attending, and what gave them hope.

Someone is doing research on my variant!
— Parent

What gave me hope was seeing children and young adults with the same diagnosis as my daughter.
— Parent

Wonderful to meet like-minded families with the same journey. Thank you.
— Parent

It was very emotional to share our story with people who actually understand what I feel.
— Parent

Usually it is the mums speaking, especially in the support group. At this conference you could hear the dads. Really empowering.
— Parent

Hearing other families' histories made us emotional. We know exactly how they feel and the challenges they went through.
— Parent

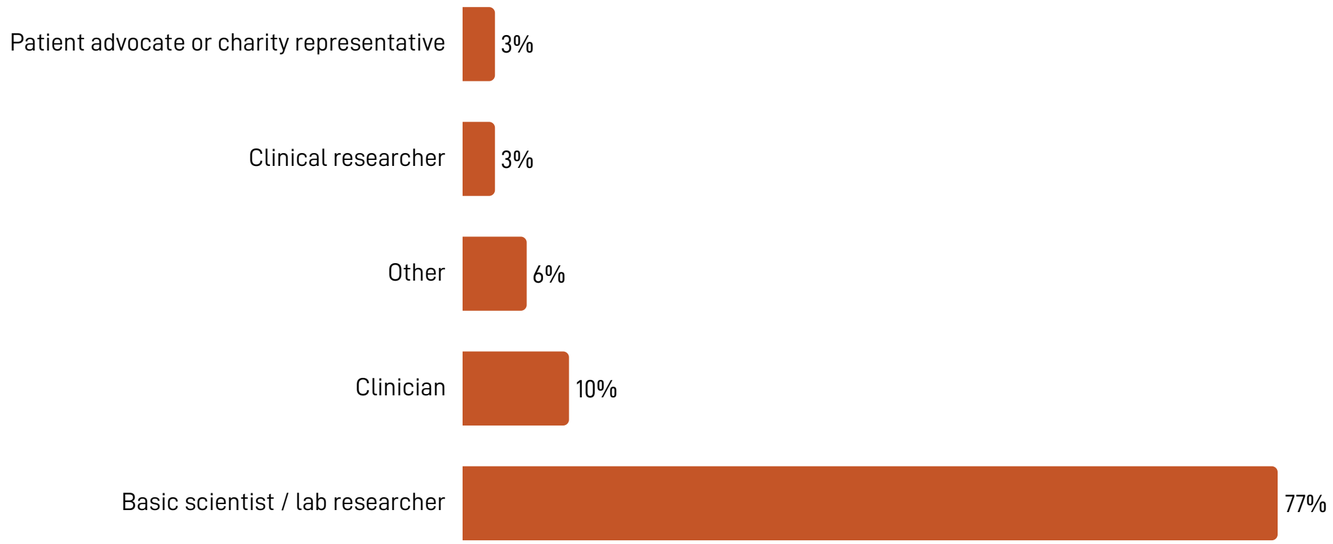
D2 Q24 / Q25. *What was the single most valuable thing about attending? Did anything particularly affect you emotionally or give you a sense of hope? Anonymised quotes used with permission.*

SECTION TWO

Professional feedback

A research-focused professional audience

31 respondents from seven countries. Three quarters were basic scientists or laboratory researchers.



This research-heavy mix matters directly for TSA's objective of assembling a collaborative research network, including basic researchers.

Q1. *What is your primary role? (n=31)*

77%

basic scientists or lab researchers

24 of 31

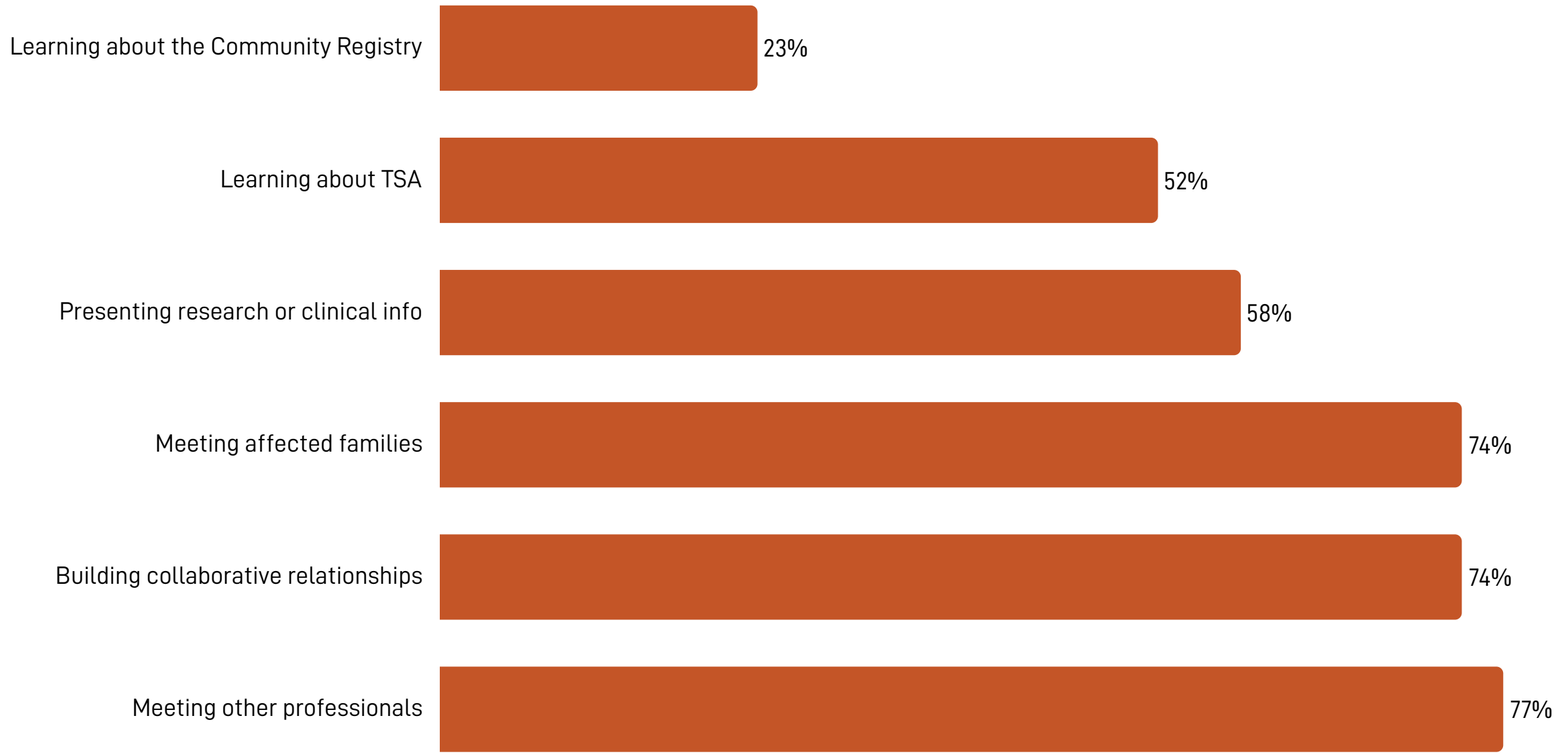
7

countries represented

"I can see the difference to my own CACNA1D research. We don't have a 'TSA' and are decades behind. You are a role model."
— Researcher

Why professionals came

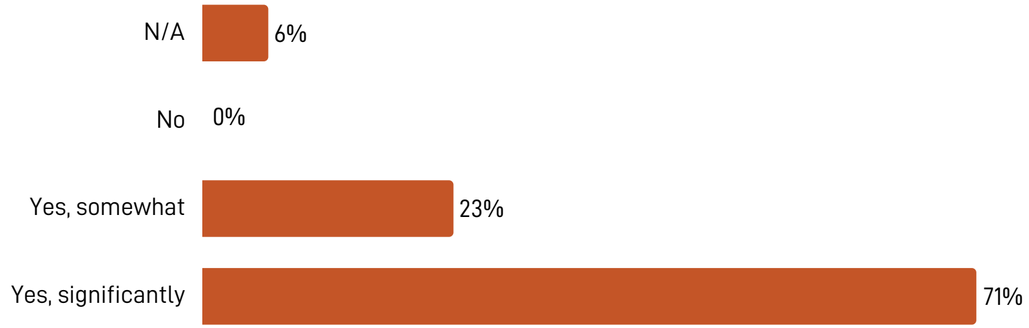
Collaboration and connection, not just presenting.



Q3. *What were your reasons for attending? (tick all that apply, n=31)*

The convening built new research collaborations

Valuable networking with other professionals?



73%

left with new or potential collaborations

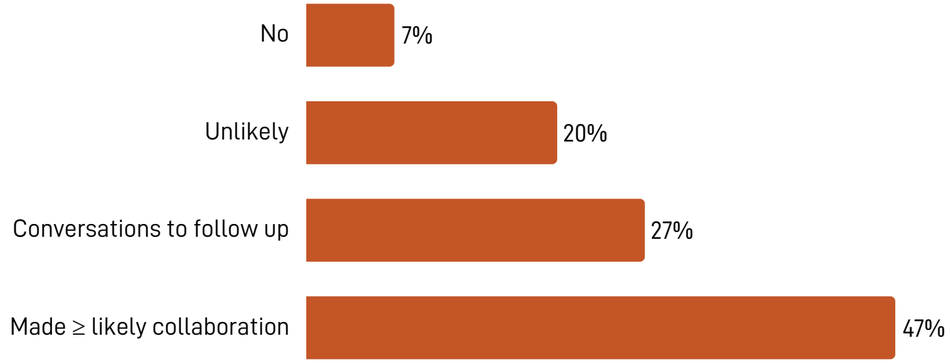
22 of 30

100%

opted in to the 2027 Scientific Roundtable

25 of 25

Likely to lead to new collaborations or partnerships?



"My student presented her sleep data on a CACNA1C variant that another group is studying, so we are following up this week."
— Researcher

Q6 / Q7 / Roundtable. *Did the conference provide valuable networking? Are interactions likely to lead to new collaborations? Would you like to be kept informed about the 2027 Scientific Roundtable? (n=25–31 answering each)*

Meeting families changed how researchers see the work

Two-way alignment, not a one-directional patient voice.

77%

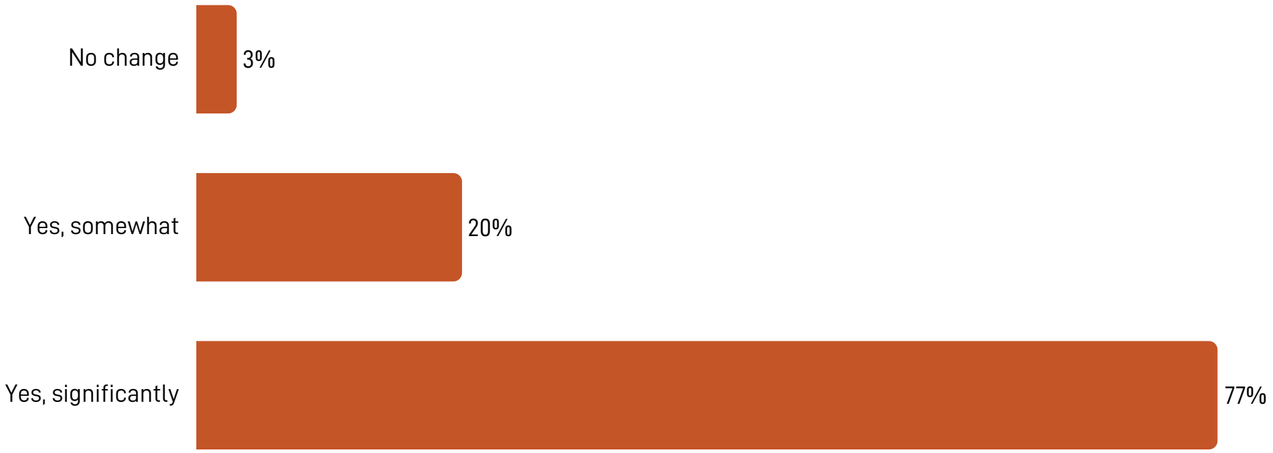
significantly changed their understanding

23 of 30

97%

reported at least some change

29 of 30



"As a technician working on CACNA1C research, it has been impactful to create new research networks and focus on what patient and family needs as a priority."
— Research technician

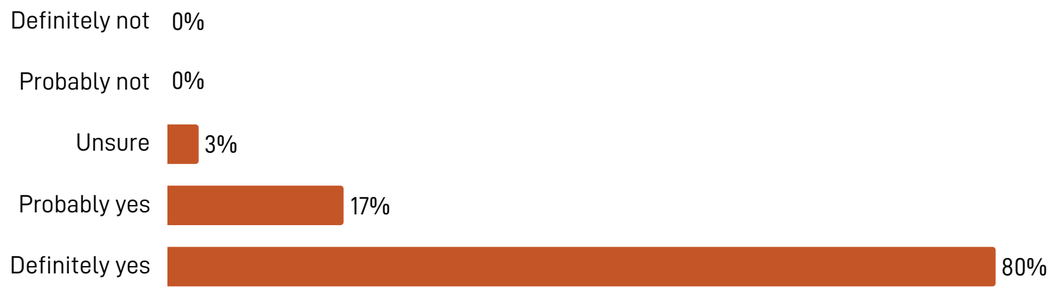
Professionals asked TSA to sustain this between conferences: standing researcher and clinical meetings by topic, a researcher 'meet and match' database, centralised data and patient cell lines, and continued portal development.

Q8. *Did meeting families affect your understanding of the patient and carer experience? (n=30)*

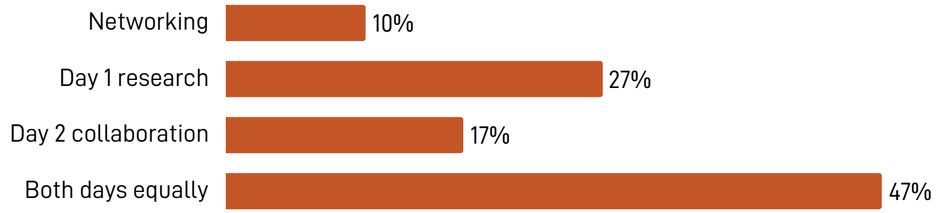
Overall verdict from professionals

Did the event meet your expectations?

Would you attend a future TSA conference?



Most valuable part professionally



97%

exceeded expectations

30 of 31

80%

would definitely attend again

24 of 30

"Up to now, a pillar and binder of the community. Based on what I have seen in this meeting, TSA will be much, much more – an active force shaping the research."
— Researcher

Q4 / Q9 / Q5. *Did the event meet your expectations? Would you attend a future TSA conference? Which day or session was most valuable professionally? (n=30-31)*

In their words: professionals

Professionals on the role TSA plays for the CACNA1C community.

Bringing patients, families, researchers and clinicians together.
— Clinician

Two fold: connect scientists to each other, and ensure they ask the questions that matter to families.
— Clinician

Connecting researchers with the families affected improves understanding and appreciation on both sides, and gives a sense that we are one step closer to better diagnosis and treatment.
— Researcher

Gathering researchers and families together helps set the priorities for research and care, and works to reduce the burden on families.
— Researcher

The conference felt like a warm familial environment: a focus for the community where families and clinical researchers meet and share.
— Researcher

Connection, advocacy and feedback: a hub that connects the community, understands its needs, and feeds this back to researchers and into support for clinicians.
— Professional respondent

Q11 / Q13. *What is the most important role TSA plays for the CACNA1C community? Any further comments? Roles are each respondent's own Q1 answer. Anonymised quotes used with permission.*

03

SECTION THREE

Feedback tree postcards

What attendees chose to write

41 free-text postcards. Connection and belonging was the dominant, unprompted message, across every author group.

“There may be very few diagnosed with CACNA1C, but knowing there are people who care to research and find treatments for one child is the greatest gift.”
— Attendee

“What I loved most was seeing my brother fit in with people similar to him. At home I try my hardest to spend time with him; here I don't have to try as hard.”
— Sibling

Who wrote them

Parents	**12**
Unattributed	**12**
Scientists / researchers	**8**
Family members	**7**
People with a CRD	**2**

“There is nothing more rewarding for a scientist than connecting with the families that inspire our research.”
— Scientist

Feedback trees. *Attendees wrote a free-text reflection on a postcard and hung it on the trees. Every author group is represented. (41 postcards)*

In their words: the feedback tree

A selection of the 41 messages attendees hung on the trees, unprompted.

> *It is cool to see people like me.*
> — Child

> *Sometimes hope is what gives you the strength to keep going. Thank you.*
> — Attendee

> *Fantastic to meet both researchers and other families living with CRD. I hope this can be arranged more often.*
> — Attendee

> *A huge thanks for bringing together this community of brilliant minds and beautiful hearts. Incredible. Inspiring.*
> — Attendee

> *Speakers could be slightly less technical, to fully include any newcomers.*
> — Attendee

> *After meeting people living with CACNA1C-related disorders, I work harder as a scientist to help patients and their families.*
> — Scientist

> *Childcare gave more people the chance to listen to the lectures and focus on the information.*
> — Parent

> *Translator headphones were such a good idea, and made the lectures very inclusive.*
> — Attendee

> *I'd expand this format to all ten CACNA1 isoforms, and help us other genes achieve what you already have.*
> — Scientist

Feedback trees. *Free-text messages written on postcards and hung on the trees, shown as written. A representative selection across themes and author types. (41 postcards)*

In their words: the feedback tree

More of the messages attendees hung on the trees, unprompted.

> *An exceptional experience. Thank you for making me feel part of this wonderful family, in the hope our journey will bring so much hope to so many children.*
> — Parent

> *I had an amazing two days with scientists and parents, and I'm looking forward to future discussions on how to bring the field forward. Thank you.*
> — Scientist

> *I found it really helpful and fun to meet other children.*
> — Child

> *It was a huge help for us with a newly diagnosed baby. We are really grateful to everyone involved.*
> — Parent

> *Great to finally meet people in person instead of through a screen.*
> — Attendee

> *Investing in science is investing in health. Every breakthrough leads to more accurate diagnoses and more effective treatments.*
> — Family member

> *I'd recommend spreading and simplifying the talks over two days. Otherwise you are fantastic.*
> — Attendee

> *Such an amazing safe place for families to come together and belong.*
> — Researcher

> *Every detail was thought of. We learnt so much, and it was amazing to meet and connect with families like us. Thank you.*
> — Parent

Feedback trees. *Free-text messages written on postcards and hung on the trees, shown as written. (41 postcards)*

Learning and improvement

Feedback was strongly positive, so these refine a well-received event rather than rescue a weak one.

1 Simplify a complex subject further

Despite structuring the talks and briefing the speakers, some content still landed as too technical, which reflects how complex CACNA1C is. Next time: more granular lay tiering, a basic-lay and a medium-lay strand.

2 Give the collaborative sessions more time

The Day 2 small-group, priority-setting and brainstorming formats were the most valued elements and the main ask was for more of them. These are exactly what serves TSA's network-building and priority-setting aims.

3 Families named where the evidence runs out

Gastrointestinal effects, other organ systems, and behavioural features came up repeatedly from families and researchers alike, alongside the practical question of what to do after a diagnosis. A multisystem condition cannot be covered in two days, and it does not need to be. The value is that the priority-setting captured these gaps, which now feed the research agenda and a future care-pathway resource.

4 Childcare that spanned every age, across both days

Provision ran across both days and was built around age and need, with separate focused support for younger children and the 11 to 18s, a quiet area to step back to, and a balloonist and mindfulness colouring at the dinner. Parents said it is what let them focus fully throughout. An evening strand for older teenagers would be a lovely future addition, with the safeguarding and cost it carries putting it on the wishlist rather than marking a gap here.

These shape the 2027 programme and the between-conference plan.

In one line

The convening delivered belonging for families, new collaborations for researchers, and genuine two-way alignment between the two.

The clearest improvement is to tier scientific content for mixed audiences. The clearest opportunity is to give the collaborative Day 2 formats more time and to sustain them between conferences.

With thanks

The people

To everyone who made the two days possible: the families who travelled so far and shared so openly, the researchers and clinicians who came to listen as much as to present, our volunteers and staff, the childcare and interpretation teams, our speakers, and our Scientific Advisory Board. Thank you.

Our host

To Cardiff University, for hosting us in the Hadyn Ellis Building.

CARDIFF UNIVERSITY
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Neuroscience and Mental Health Innovation Institute

Sefydliad Arloesedd Niwrowyddoniaeth ac Iechyd Meddwl

Our funder

To the Chan Zuckerberg Initiative. Through the Rare As One programme, CZI made this conference possible. In a demanding funding climate, that support lifted a real burden from a small team and let us bring our global community together in person, with the interpretation and childcare that allowed everyone to take part. It shows what a rare-disease community can achieve when its mission is properly resourced.

RARE AS ONE