DOLTONE HOUSE
Darling Island Wharf
48 Pirrama Rd,
Pyrmont, Sydney

2025 Angelman Syndrome Collaborative Conference

First Conference Attendee Guide

Shaping the future, supporting today

19-20 September 2025

angelmancollaborativeconference.au

WHO ORGANISES THE ANGELMAN SYNDROME COLLABORATIVE CONFERENCE

Shaping the future, supporting today

WHO IS FAST AUSTRALIA?

FAST Australia launched in September 2010. Inspired by the mission and energy of FAST in the United States, we are driven to address the lack of research and understanding of Angelman syndrome in Australia. Our combined energies create a powerful force in the search for therapeutic interventions and a cure to treat Angelman syndrome. In an age where Angelman syndrome therapeutics are being developed globally, FAST is working to ensure communities worldwide are organised and prepared to participate in studies for potential therapeutics. FAST has affiliates in Canada, France, Germany, Italy, Latin America (Argentina, Chile, Colombia), Poland, Spain and the UK. FAST has a vision of a world where lives are no longer limited by a diagnosis of Angelman syndrome. The mission of the Foundation for Angelman Syndrome Therapeutics Australia is to improve the quality of life for individuals with Angelman syndrome through timely diagnosis, access to best practices in care and treatments, and advancing research for a cure.


Meagan
CEO


Shane
Chairperson


Sarah
Exec Assistant


Chloe
Chief Science Officer

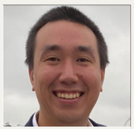

Jeromie
Vice Chairpesrson


Kristy
Treasurer


Emma
Fundraising Coordinator


Christoff
Director


Anna
Board Member

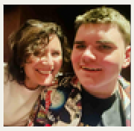

Tom
Board Member

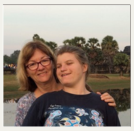
WHO IS ANGELMAN SYNDROME ASSOCIATION AUSTRALIA?

Angelman Syndrome Association Australia (ASAA) is the key advocacy and peer support organisation for people living with Angelman syndrome and their families in Australia. We are an all-volunteer committee consisting of family members of people living with Angelman syndrome (AS).

The committee dedicate their time and expertise to supporting families, working with other rare disease, disability and Angelman organisations, raising awareness of the needs of people and families living with AS, and advocating at all levels of government, to create a better world for people living with AS and their families.

ASAA is a registered not-for-profit incorporated association and is registered under the Associations Incorporation Act 1981. Proudly providing Advocacy, Support and Awareness for over 30 years.


Fiona
President


Sue
Vice President


Lysandra
Treasurer


Annie
Secretary


Chrissy
VIC State Rep


Joelene
NSW State Rep


Jasmine
QLD State Rep


Rachael
TAS State Rep


Kevin
Committee Member


Vange
SA/NT State Rep


David
Committee Member


Michelle
Committee Member

WELCOME TO THE ANGELMAN SYNDROME COLLABORATIVE CONFERENCE, 2025

Shaping the future, supporting today

We're so glad you're here. Whether this is your first conference or your fifth, we know how much courage and care it takes to show up. This space is for you, to connect, learn, reflect, and recharge. Here are some tips to help you make the most of your time with us:

This conference is built with families in mind. Your voice, your story, and your presence matter. Thank you for being part of this community.

FRIDAY 19 SEPTEMBER 2025 - DAY 1 - FAST AUSTRALIA

RESEARCH AND CLINICAL TRIALS

This day has been designed to answer your questions, not overwhelm you with science.

Whether it is your first conference or your fifth, you will walk away feeling more informed, more connected and more hopeful.

SATURDAY 20 SEPTEMBER 2025 - DAY 2 - ASAA

ADVOCACY AND SUPPORT

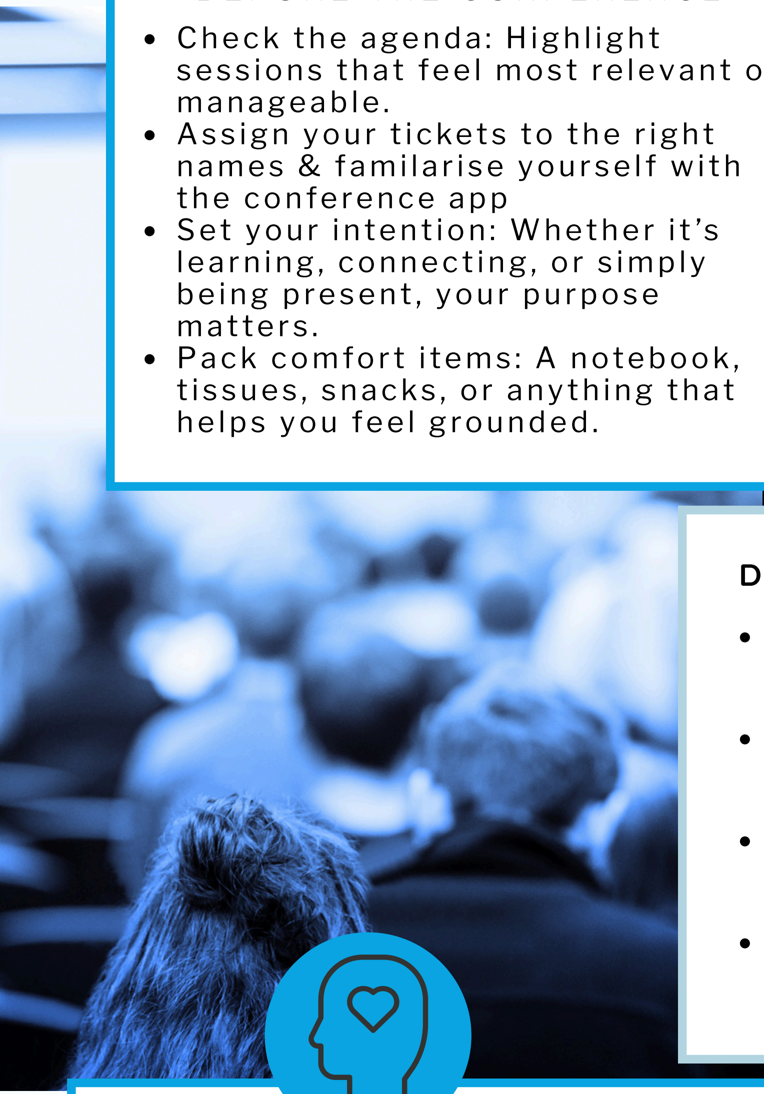
From systemic advocacy and NDIS navigation to gut-health hacks and caregiving across every life stage, we've got practical know-how on tap.

Hear from families, advocates and experts sharing real-world strategies you can use today.

PREPARATION & INSIGHTS

BEFORE THE CONFERENCE

- Check the agenda: Highlight sessions that feel most relevant or manageable.
- Assign your tickets to the right names & familarise yourself with the conference app
- Set your intention: Whether it's learning, connecting, or simply being present, your purpose matters.
- Pack comfort items: A notebook, tissues, snacks, or anything that helps you feel grounded.



DURING THE CONFERENCE

- Take breaks: It's okay to step away. Emotional fatigue is real, and your wellbeing comes first.
- Connect with others: Many families are walking similar paths. A simple hello can lead to lasting support.
- Use the app: Engage with polls, Q&As, and interactive features, it's a great way to stay involved.
- Ask questions: Your lived experience is valuable. You don't need to be an expert to contribute.

LOOKING AFTER YOURSELF

- Everyone was a first-time attendee once: We understand how you might be feeling. You're not alone.
- Be gentle with yourself: You are already doing enough. Just being here is a brave and generous act.
- You may hear a lot of new information: You don't need to act on it, become an expert, or take it all in at once.
- Give yourself time: Let things settle. You might find clarity days or weeks after the conference.
- Not everything will be relevant: And that's okay. Take what serves you, and let the rest go.
- Let it out: You may feel a range of emotions, we all do. Tears, laughter, silence… it's all welcome here.
- Find quiet spaces: Step away when needed.
- Lean on your support: If you're attending with someone, check in with each other throughout the day.
- Talk to an FAST/ ASAA board member/ committee member: We're here to support you. If you need help, guidance, or just a listening ear, please reach out.

SOCIAL EVENTS

Angelman syndrome family social night

ASA AUSTRALIA

Join us for a free social gathering on Friday evening. Pizza and finger food will be provided, and drinks are available for purchase at bar prices. The venue is within walking distance of Doltone House. Children welcome.

The Laneway Hotel & Sports Bar
84 Union Street, Pyrmont
https://www.thelanewaypyrmont.com.au

Friday 19th September from 6pm

- ☑ Family friendly
- ☑ Drinks at bar prices
- ☑ Finger food and pizza served
- ☑ GF and vegan/vegetarian options included.

Join us for a relaxed evening of connection and camaraderie, a chance to wind down from the day and share space with fellow AS families from across Australia.

Whether you're reconnecting with familiar faces or meeting someone new, this low-key social night is all about meaningful moments. Expect heartfelt stories, laughter, and maybe even a few tears as friendships old and new come to life.

This gathering is for you, a time to simply enjoy each other's company and celebrate the strength of our community.

fast AUSTRALIA

2025 Unstoppable

Gala Dinner with proceeds going to

Foundation for Angelman Syndrome Therapeutics

Get Ready to Be Moved

This is FAST's biggest fundraiser of the year, and it's more than just an event. It's a celebration of strength, hope, and the incredible Angelman Syndrome community.

Be sure to have tissues nearby as we premiere the Gala Video, a powerful tribute to every individual living with AS. It's a moment that will stay with you.

Most importantly, take time to soak it all in. Whether you're dancing like no one's watching, sharing stories, or simply enjoying the company of those who understand, this night is yours.

Let's celebrate together, united by one cause and one extraordinary community.

THE CONFERENCE HAS FINISHED - WHAT DO I DO NOW?

You’ve just spent time in a space filled with stories, knowledge, and emotion. Whether you’re feeling inspired, overwhelmed, or somewhere in between, here are some ways to process and carry the experience forward:

TAKE TIME TO DECOMPRESS

Rest is essential: Conferences can be emotionally intense. Give yourself permission to slow down.

Journal or reflect: Write down what moved you—moments, quotes, people. It helps make sense of it all. Can become a resource to reflect on later on.

Talk it out: Share your experience with someone you trust. Sometimes, just being heard is healing.

STAY CONNECTED

Reach out: If you have any questions please contact either FAST Australia or ASAA.

Join the community: Follow social media pages, newsletters, make sure you are apart of the facebook family pages and know your ASAA state representative.

Share your feedback: Your voice helps shape future events. Let us know what worked and what could improve.

HONOUR YOUR JOURNEY

Celebrate your courage: Showing up, listening, and sharing takes strength. You did that.

Acknowledge your emotions: It’s okay to feel grief, hope, anger, or joy. All of it belongs.

Remember, you’re not alone: The AS community exists because of people like you. You’re part of something powerful.