



DOLTONE HOUSE Darling Island Wharf

48 Pirrama Rd,
Pyrmont, Sydney



2025 Angelman Syndrome Collaborative Conference Guide

Shaping the future, supporting today



19-20 September 2025



CONFERENCE OVERVIEW

Shaping the future, supporting today

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.



FRIDAY 19 SEPTEMBER 2025 - ASAA FAMILY SOCIAL NIGHT

FREE ASAA SOCIAL GATHERING

Come and meet new and old friends and enjoy the beautiful evening on Sydney Harbour. The Laneway Hotel and Sports Bar is within walking distance of Doltone House.

Pizza and finger food will be provided, and drinks are available for purchase at the bar.



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.



REGISTER



SATURDAY 20 SEPTEMBER 2025 - DAY 2 - FAST GALA

UNSTOPPABLE GALA - HOSTED BY FAST AUSTRALIA

Join the community for an unforgettable evening of purpose, progress, and powerful stories as we unite to fast-track a cure for Angelman syndrome.

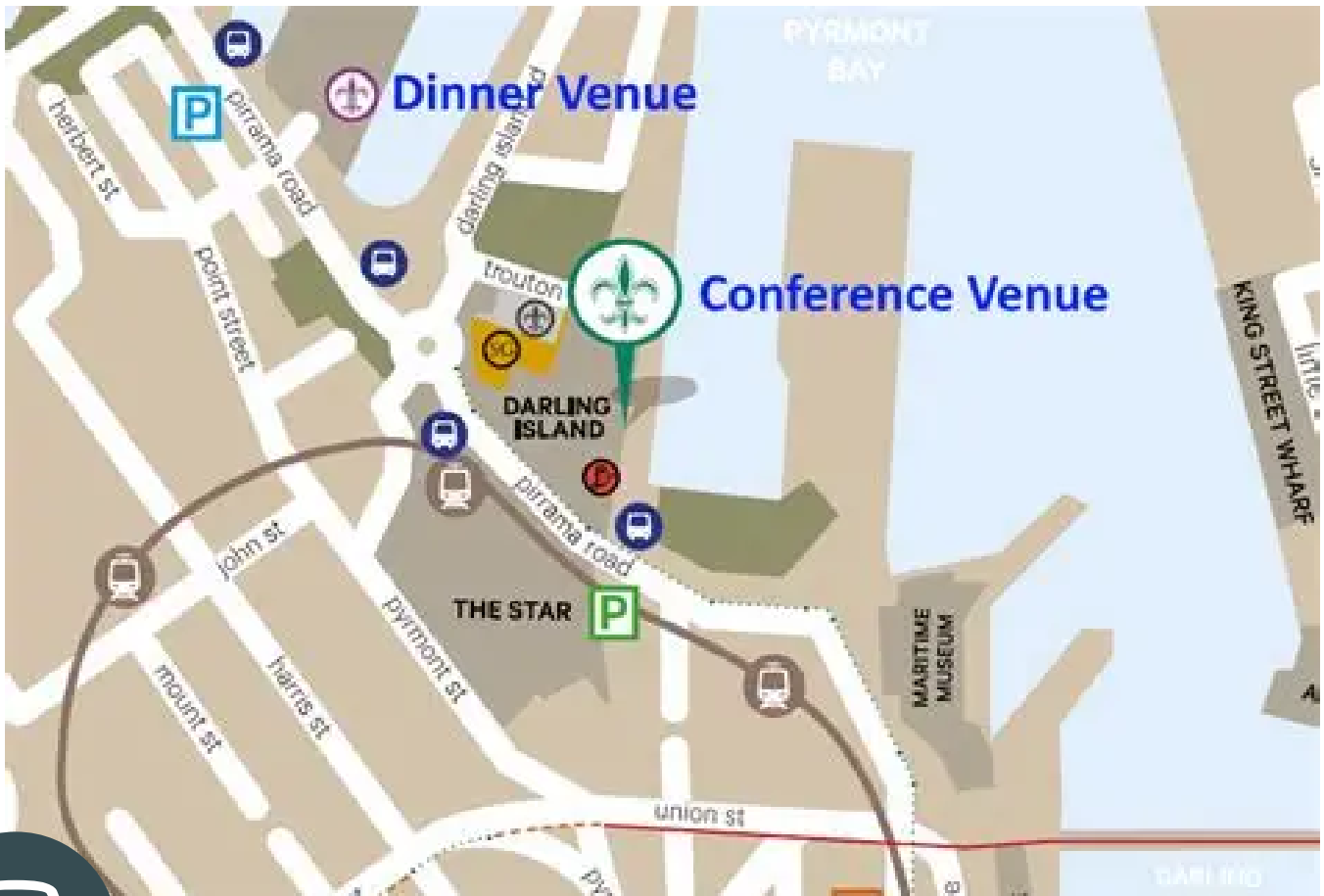
Special Guest: The Honourable Chris Minns, Premier of New South Wales



BUY NOW



CONFERENCE LOCATION



PARKING

Car parking facilities are located on 17-23 Pirrama Road, Pyrmont - Opposite Doltone House Jones Bay Wharf.

Pre-book your parking through bookabay.wilsonparking.com.au with the promo code: Doltone- \$23 per day.

Alternative Parking: The Star Parking Station, a 5min walk from Doltone House. Located at 2 Edward Street, Pyrmont - approx. \$30 per day

PUBLIC TRANSPORT

Train

Departs from Central Station to Town Hall Station regularly - 1.5km walk from Town Hall Station

Light Rail

Departs from Central Station to The Star every 10-15 mins, operates 24/7.

Bus

Route 389 regularly departs from City - Town Hall Park St to Pirrama Rd.

Ferry

Wharf No. 5 at Circular Quay stops at Pyrmont Bay

CONFERENCE DETAILS



CONFERENCE TICKETS

[REGISTER HERE](#)

Parent/Caregiver

Full Pass (2 Days) = \$180 + \$4.93 (fee)

One Day Pass = \$125 + \$3.98 (fee)

Professional

Full Pass (2 Days) = \$280 + \$6.66 (fee)

One Day Pass = \$150 + \$4.42 (fee)



CONFERENCE TIMES

Registration and tea/coffee - 8.00am

Friday 19 September - 8.30am - 5.30pm

Saturday 20 September - 8.30am - 3.30pm

Lunch is 12.30pm daily (approximately)



DIETARY REQUIREMENTS

Please notify the conference organisers of your dietary requirements and any food allergies at time of purchase of tickets and confirm again at time of Registration.

This includes for the conference, Angelman Activities, ASAA Family Dinner, and FAST AU Gala.

Note: We are not able to guarantee any last-minute requests for special dietary requirements as the catering has been finalised.



INCLUSIONS

Conference registration includes arrival tea and coffee, morning tea, lunch, and afternoon tea.

Satchel contains promotional material



CONFERENCE WIFI

Free conference wifi available on the day. Check your tables for the code.

DRESS CODE

Dress code for the conference is comfortable smart casual.

Please be aware that the venue air conditioning can fluctuate so layers are recommended.

Dress code for the FAST Gala is Cocktail (not Black Tie).



CONFERENCE AGENDA - DAY 1



Session 1: What's taking so long?

Professor Ed Weeber (FAST United States) and Dr Barbara Bailus (The Keck Graduate Institute)

If you've ever wondered why treatments still feel out of reach or found yourself thinking you've heard it all before, this is where we begin the day. We'll explore how research transitions from the lab to real-life applications and why this process can take time. It's okay to feel impatient, and it can be especially hard when clinical trials seem to be happening in the background, and you aren't hearing much. Often, that silence is not about keeping you in the dark but about protecting sensitive work as it moves through critical stages. Even if it hasn't always felt visible, progress is happening. The future remains incredibly bright. Angelman syndrome is at a turning point, and FAST is helping to make sure that no promising path is left unexplored.

Session 2: Why we keep talking about genetics...

Drs Allyson Berent (FAST United States, AS2Bio and ABOM), Elizabeth (Emma) Palmer, (Sydney Childrens Hospital Network) and Niki Armstrong (FAST United States)

We revisit genetics every conference because it's foundational and, let's be honest, not easy to absorb all at once. Each time we explain it, we hope it becomes a little clearer. This session will help you understand the different genotypes, why deletions introduce added complexity, and how mosaicism is helping shape new perspectives. Even if you've heard some of this before, it's worth revisiting - because understanding it can help make sense of the treatments being developed.

Session 3: What about all the things we don't know yet?

Drs Allyson Berent (FAST United States, AS2Bio and ABOM)

You may have heard of ABOM, INSYNC-AS or AS2Bio and wondered what they actually do? In this session, we'll explore the behind-the-scenes work that makes clinical trials possible, from collecting critical data to building global research tools that help us track progress across genotypes and geographies. We'll also talk about the importance of identifying gaps early, anticipating challenges, and figuring out what we don't know yet, so we're ready for all shots on goal. This is where planning meets possibility. You'll hear how FAST is supporting a range of approaches to make sure no opportunity is missed, and every child has a chance.

Session 4: Replacing what's missing

Christoph Tautpaeus (FAST Australia Board), Drs Allyson Berent (FAST United States, AS2Bio and ABOM) & Dr Barbara Bailus (The Keck Graduate Institute)

One approach to therapeutics, known as Pillar 1, focuses on replacing the missing or non-functional UBE3A gene or protein in the brain. In this session, we'll explore what that actually means, who's leading the charge, how the treatment might be delivered, how far we might be from seeing these therapies in the clinic, and what it could mean for your loved one, no matter their genotype. Whether this is your first introduction to gene replacement or you've been following closely, this session brings you up to speed on one of the most promising areas of progress.

Session 5: Unlocking the silent gene

Drs Alexandra (Alex) Johnson (Sydney Children's Hospital Network), Allyson Berent (FAST United States, AS2Bio, and ABOM) & Dr Barbara Bailus (The Keck Graduate Institute), Rob Komorowski (Ionis Therapeutics), Oak Hill Bio

Another area of therapeutic development focuses on "turning on dad's gene" - activating the paternal copy of UBE3A. This is known as Pillar 2 of the FAST Roadmap, and it's an area that has progressed from research to real-world clinical trials. In this session, we'll hear directly from the teams behind three programs that are already being tested in children and adults, all now heading into phase 3, and new single treatment therapies that could accomplish a similar thing. We'll explore how these treatments work, how they're delivered, and what families involved in the trials are experiencing. If you've ever wondered how close we are to having approved therapies, this session offers one of the clearest glimpses yet.

Session 6: Treating the effects, not the gene

Shane Jez (FAST Australia Chairperson) & Neuren pharmaceuticals, Dr Alvin Huang (Brown University)

Not every treatment in development is designed to alter DNA. Pillar 3 focuses on therapies that aim to improve the symptoms of Angelman syndrome by restoring balance in the brain, where things are out of sync. These approaches may help alleviate sleep disturbances, seizures, motor coordination issues, or other challenges associated with missing the UBE3A protein. In this session, we'll explore what is in development, how these therapies work without altering genes, and whether they could offer meaningful improvements for children and adults across all genotypes. If you're wondering what might help now or alongside other treatments, this session will be especially relevant.

Session 7: The work that gets us ready for treatments

Meagan Cross (FAST Australia), Ellen Koekoeckx (FAST Global), Niki Armstrong (FAST US), Stef Cola (Ligantic), Prof Richard De Abreu Lourenco (University of Technology Sydney).

It might not feel like the most exciting part of the roadmap, but it's essential to turning research into real outcomes. Pillar 4 is about making sure we are ready when therapies arrive, with the systems, data, and clinical networks needed to deliver them. Access to treatment is not automatic, and every country must pave its own path. FAST Australia is focused on this work both globally and locally; the Global Angelman Syndrome Registry, aligning clinical champions, launching programs such as asNavigators, preparing for health technology assessments, and progressing newborn screening. While a great deal of this work is also being led in the US, this session will focus on the contributions being made here in Australia, and the work you are helping drive forward, and the impact it is already having.

Session 8: Behind the scenes of clinical trials in Australia

Dr Michael Duhig (Centre for Clinical Trials in Rare Neurodevelopmental Disorders, Queensland), Kaitlyn Griffin (Kids Neuro Trials team, Sydney Children's Hospital Network) & Prof Richard De Abreu Lourenco (University of Technology Sydney)

Clinical trials for Angelman Syndrome have been running in Australia since 2020. Originally focusing on symptom management with offerings from Ovid and Neuren to more recent and complex, advanced therapies from Ultragenyx, Ionis and Oak Hill Bio. Despite increasing recognition, many families have yet to hear or experience participating in a clinical trial. In this session, you'll meet the teams running these trials, who will hopefully "myth bust" some of the things you may have heard, including the nutritional value of ECG dots. They'll walk through the different stages of clinical trials, why some assessments can feel overly cumbersome, what's involved in getting a therapy approved, and how cost and reimbursement play a part in access. They will explain why some trials stay quiet, what makes a child eligible, and what participation actually involves, from screening to site visits and beyond. If you've ever wondered where things are or how to get involved, this is the place to start.

CONFERENCE AGENDA - DAY 2



Session 1: Systemic Advocacy

This session explores how systemic advocacy serves as a vital tool in driving change for the Angelman syndrome community. By uniting our voices and efforts and working collaboratively with State and Federal Government and other peak disability organisations, we can address structural barriers, influence policy, and champion the rights of individuals and families living with Angelman syndrome to improve overall quality of life.

8.45am: Consortium Advocacy - Disability Representative Organisations (DROs)- Intellectual Disability & Chromosomal Variations

Erin Papps (Advocacy and Policy Manager at Down Syndrome Australia)

The ASAA is a member of the DRO Consortium, which represents and advocates for individuals with intellectual disabilities and chromosomal variations. Erin from Down Syndrome Australia – the lead organisation of the Consortium—will provide an overview of how the Consortium has been engaging with the Federal Government to ensure our voices are at the table. DRO advocacy work addresses the key issues of: prenatal screening, health, NDIS, education, employment and migration.

9.15am: Potentially preventable, practically treatable - the Neuropsychiatry of Neurodevelopmental Disorders

Associate Professor Rebecca Koncz (Chair of Intellectual Disability Mental Health, National Centre of Excellence in Intellectual Disability Health)

Families often report that physical or mental health and behavioural concerns for relatives with Angelman syndrome are dismissed as 'just part of Angelman Syndrome', even when some issues could be prevented or even treated. Rebecca will discuss strategies for managing symptoms of neurodevelopmental disorders like Angelman syndrome and how to effectively advocate for necessary care to improve quality of life.

9.45am: Navigating the NDIS reform, your essential guide

Victoria White (The Growing Space, Specialist Support Coordinator), Fiona Lawton (President of ASAA, CEO at Neu Pathways Australia), Mirella Manna (NSW/ACT Community Engagement Manager, My Plan Manager)

This panel session is not one you are going to want to miss! In a time of significant change and disruption to NDIS, we have brought together frontline service providers and policy experts to help you navigate what you need to know, what you need to do and how you need to do it. The discussion will offer guidance to ensure the NDIS accommodates the complex needs of people with Angelman Syndrome, including funding and high-level support.

Session 2: Support

This session will explore innovative strategies and resources to support carers of people with Angelman syndrome to help improve both their quality of life and that of those being cared for.

11.00am: Caring throughout the Ages

Kelly Reid (Program Manager at Belongside Families), Sylvana Mahmic (CEO at Plumtree Children's Services), Jasmine Young (ASAA Qld State Representative), Sue Hones (ASAA Vice President)

This panel will focus on caregiving across all ages. These caregivers, siblings and expert speakers will address challenges at each stage of life, sharing support strategies, and discuss the value of community and family in supporting caregivers and the people they care for.

11.45am: Holistic Gut Health and Wellbeing in Angelman Syndrome

Dr Vinita Prasad (Developmental Paediatrician and Child Development, QLD Children's Hospital), Lysandra Callahan (ASAA Treasurer and asNavigator Nurse, QLD Children's Hospital), Sara Horsey (Continence Nurse and Director, Engage Care Services (Video))

Gut-related concerns are common among people with Angelman syndrome, and topics such as reflux, constipation, and cyclic vomiting etc. frequently appear on AS social media pages. Dr Vinita Prasad will address the importance of gut health and its effects on the overall well-being of people with Angelman syndrome. It will discuss multiple aspects of holistic gut health, including the function of the gut biome in symptom management, and cover dietary interventions, probiotics, and other approaches to promote a healthy gut environment.

Session 3: Workshop intensives

1.15pm: Breakout Sessions - Age Group Awareness Intensive Q&A (Various leads):

Afternoon sessions are divided into Early years, School years, and Independent years. Join the session group that fits your or your loved one's stage for focused discussion and advice.

Breakout 1 - Early Years

Sylvana Mahmic (CEO at Plumtree Children's Services), Anna Bech (Speech Therapist, Skyward Speech Therapy), Rachael Parry and Chrissy Cimino (ASAA State Representatives and Angelman Mums)

ASAA NSW Representative Joelene Wand will facilitate this panel session for families of pre-school children with Angelman syndrome. Join in the conversation with our panel members for in-depth discussions and reflections around topics including: models of therapy and how to choose the right fit for your family, positive psychology and the importance of play, life after diagnosis, what we wish we'd known, and the importance of communication.

Breakout 2 - School Years

Eliza Hoare (Senior Peer Facilitator at Belongside Families), Diana Backhouse (Angelman Mum and award-winning educator) and Dr Vinita Prasad (Developmental Paediatrician and Child Development, QLD Children's Hospital).

ASAA Committee Member Michelle Chong will facilitate this panel session exploring important aspects of the school years, including: navigating puberty with intellectual disability, optimising the school relationship, immersive communication, and how to get it working with school and home, as well as sibling relationships through the growing years.

Breakout 3 - Independent Years (16+)

Professor Kylie Valentine (Director of the Social Policy Research Centre and Centre for Social Research in Health), Christina Creech (Clinical Lead, Positive Behaviour support at CoSupport (pre-recorded video), Victoria White (Social Worker and Specialist Support Coordinator, The Growing Space), and Anne Funke (Angelman Mum)

ASAA SA/NT State Representative Vange Ignatiou will facilitate this panel session for families considering independent living options. Topics include positive behaviour support in independent living, purchasing your own SDA, innovative housing for people with complex needs, Microbusiness Enterprises and managing transitions with NDIS.

3.15 – 3.30 pm: Closing remarks and reflections from ASAA President Fiona Lawton

SOCIAL EVENTS

Angelman syndrome family social night



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>



- ✓ Family friendly
- ✓ Drinks at bar prices

- ✓ Finger food and pizza served
- ✓ GF and vegan/vegetarian options included.

Friday 19th September from 6pm





2025

Unstoppable

Gala Dinner with proceeds going to
Foundation for Angelman Syndrome Therapeutics

Unstoppable Gala

 Sat, September 20, 2025 7:00 PM - 11:00 PM

 Doltone House Darling Island
48 Pirrama Rd, Pyrmont NSW 2009, Australia

Dress: Cocktail

Register:

\$250 per person

\$2,500 per table of 10

www.galabid.com/unstoppablegala

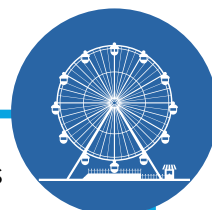


Angelman Activities

19TH & 20TH SEPTEMBER 2025

What Ability
FOUNDATION

REGISTRATION IS ESSENTIAL



Angelman Syndrome Association Australia, with support from What Ability Foundation, is delighted to provide tickets for some fun, family activities throughout the conference. Join the group or head along at your own steam - everyone is welcome.

WHO IS THIS FOR?

People with Angelman syndrome and their carer/support.
Companion Cards are accepted.
Siblings/family members are welcome.

WHAT IS PROVIDED?

Individual or family/group tickets to your nominated event.
Snack bags with water and treats.
BYO food and drinks.

HOW DO I REGISTER?

Email ASAA to register for tickets - info@angelmansyndrome.org

FRIDAY ITINERARY - LUNA PARK

Luna Park is among Sydney's top family-friendly amusement parks. This iconic destination is tucked away at Milsons Point towards the northern end of the iconic Sydney Harbour

SATURDAY ITINERARY - SEA LIFE AQUARIUM

No trip to Sydney is complete without visiting SEA LIFE Sydney Aquarium. Situated on the city side of Darling Harbour, SEA LIFE Sydney Aquarium houses over 13,000 animals from 700 species, including sharks, dugongs, turtles, stingrays, penguins, and more.



Family-friendly Activities in Sydney

Harbour Sightseeing Cruise or Manly Ferry

Jump onto the ferry from Circular Quay and cruise through Sydney Harbour.

Taronga Zoo

Experience the animal world at Taronga Zoo, and see native and exotic animals.

Sydney Big Bus Hop-On Hop-Off tour

Ride around Sydney on a double-decker bus, hop on and hop off at your leisure.

Sydney Opera House

Catch a performance or snap a photo outside our most renowned and iconic landmark.

Royal Botanical Gardens

Australia's natural masterpiece and oldest botanical garden, overlooking Sydney Harbour.

Sydney Tower Eye:

Visit the observation deck, 250 meters high, and 360-degree panoramic views 80km into the distance.

Bondi Beach

Visit the world-famous Bondi Beach, see the iconic icebergs, and maybe catch sight of the Bondi lifeguards.

Blue Mountains Adventure

Visit Scenic World, waterfalls, and the Three Sisters.

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Thank you 



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EXHIBITORS



CONFERENCE SWAG BAG SUPPORTERS

