

CONFERENCE AGENDA

2026 Noonan Syndrome Family Conference



★ **DATE:** July 29th - July 31st

★ **LOCATION:** Austin, Texas / Kalahari



All event times and locations are subject to change.



This schedule applies to attendees only. Please wear your lanyard or event wristband at all times, as it serves as your admission ticket to conference sessions and events.



* Events require additional registration and cost.

DATE	SESSION/EVENT	ROOM	TIME
WEDNESDAY JULY 29th ★	Family Advisory Sessions Individual families meet with a pair of clinicians to give informal suggestions to bring back to their care teams. NOTE: Must have a confirmed appointment.	Registration D	8:00am – 5:00pm
	Registration Note: Registration will still be available at the Social Event.	Registration D	2:00pm – 6:00pm
	Life with Noonan Syndrome Calling all parents, siblings, caretakers and most of all people with Noonan syndrome! Come make your voices heard and talk to our Social Outreach team about how Noonan syndrome has touched or impacted your lives and find out how you can help us spread the word about Noonan syndrome!	Nile	3:30pm – 6:00pm
	Yeehaw Social: Opening Reception Enjoy a light dinner, games, and entertainment—the perfect opportunity to connect or reconnect with your Noonan Syndrome family! Casual attire. Cash bar available.	Kalahari Ballroom	6:00pm – 8:00pm
	Teen Night (ages 12–18)* Get ready for a night of strikes, spares, and sweet treats! Join us for a special teen-only bowling and dessert night. Challenge your friends, show off your skills, and finish the night with some amazing desserts! Limited supervision.	B Lux Bowling	8:00pm – 10:00pm
	Guys Night (21+)* Live your game show fantasy! We're heading toGameOn! ATK for a night of live-host, TV-style competition, and, in the final, hit the buzzers, and fight for your place on the Winners Wall!	Meet in Nile	8:15pm – 11:30pm

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DATE	SESSIONS/EVENTS	ROOM	TIME
THURSDAY JULY 30 TH — ★ —	Sunrise Strength, Stretch & Serenity Join us for an invigorating morning workout, following by a rejuvenating stretch and relaxation session.	Salon H	6:30 am – 7:30 am
	Registration	Registration D	7:30 am – 4:00 pm
	Breakfast	Kalahari Ballroom	8:00 am – 9:00 am
	General Sessions Hear from experts as they discuss key medical and developmental considerations in Noonan syndrome and Noonan-like syndromes.	Salons ABCD	9:00 am – 12:15 pm
	Camp Noonan* Attend your sessions worry-free while your kids have fun! We offer childcare for potty-trained children ages 5–12. Included is an Activity Wristband, good for the whole stay (note: waterpark activities are not included).	Salon I	9:00 am – 12:15 pm
	Family Viewing Room We've created a space this year for families who want to attend sessions but have little ones too young for childcare or simply need a break from sitting in the conference room. Select sessions will be livestreamed into this space so you won't miss a thing.	Nile	9:00 am – 12:15 pm
	Lunch	Kalahari Ballroom	12:15 pm – 1:15 pm
	Pathway Sessions Expert sessions continue, but with two concurrent tracks: one for ages 0–5 and another for ages 6 through adulthood. Attend what interests you!	Salons AB / Salons CD	1:15 pm – 4:30 pm
	Family Viewing Room (continued)	Nile	1:15 pm – 4:30 pm
	Camp Noonan* (continued)	Salon I	1:15 pm – 4:30 pm
	Let's Talk: Adults with Noonan Syndrome This session is designed exclusively for adults with Noonan syndrome. Join several presenters and NSF board members for an open discussion where you can ask questions, share your experiences and connect with others.	Zambezi	3:00 pm – 3:45 pm
	Young Adult Night (Ages 18–25)* Head out for a night of bowling, pizza, and sweet treats! It's the perfect, chill, alcohol-free environment to connect, hang out, and make new friends. Come ready to mingle and have fun!	B Lux Bowling	5:00 pm – 7:00 pm
	Ladies Night (21+)* Enjoy an evening of axe throwing, snacks, and decadent desserts at a local brewery. If axe throwing isn't your thing, there's plenty of space for sitting and catching up!	Meet in Nile	7:15 pm – 10:30 pm

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DATE	SESSION/EVENT	ROOM	TIME
FRIDAY JULY 31 ST — ★ —	Sunrise Strength, Stretch & Serenity Start your day with an invigorating morning workout, following by a rejuvenating stretch and relaxation session.	Salon H	6:30 am – 7:30 am
	Registration	Registration D	8:00 am – 10:00 am
	Breakfast	Kalahari Ballroom	8:00 am – 9:00 am
	General Sessions Hear from experts as they discuss key medical and developmental considerations in Noonan syndrome and Noonan-like syndromes.	Salons ABCD	9:00 am – 12:45 pm
	Family Viewing Room We've created a space this year for families who want to attend sessions but have little ones too young for childcare or simply need a break from sitting in the conference room. Select sessions will be livestreamed into this space so you won't miss a thing.	Nile	9:00 am – 12:45 pm
	Camp Noonan* Attend your sessions worry-free while your kids have fun! Full-day childcare for potty-trained children ages 5–12. Included is an Activity Wristband, good for the whole stay (note: waterpark activities are not included).	Salon I	9:00 am – 12:45 pm
	Lunch	Kalahari Ballroom	12:45 pm – 1:45 pm
	Pathway Sessions The expert sessions continue, but with two concurrent expert tracks: one targeting ages 0–5 and one ages for 6 through adulthood. Attend what interests you!	Salons AB / Salons CD	1:45 pm – 4:00 pm
	Family Viewing Room (continued)	Nile	1:45 pm – 4:00 pm
	Camp Noonan* (continued)	Salon I	1:45 pm – 4:00 pm
	Life with Noonan Syndrome Calling all parents, siblings, caretakers and most of all people with Noonan syndrome! Come make your voices heard and talk to our Social Outreach team about how Noonan syndrome has touched or impacted your lives and find out how you can help us spread the word about Noonan syndrome!	Nile	4:15 pm – 5:45 pm
	Wild West Soiree: Banquet & Silent Auction Close out the event with a bang! Join us for an unforgettable grand finale featuring a live DJ, a professional photographer to catch your best angles, and an exciting silent auction. Kick things off with cocktail hour from 6–7 PM, followed by dinner at 7 PM. Dress code? "Western Chic"—but honestly, just wear whatever makes you feel best in.	Kalahari Ballroom	6:00 pm – 10:00 pm

SESSION OVERVIEW

Thursday, July 30, 2026



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GENERAL SESSIONS

Salons ABCD

9:00 am – 9:45 am	A Heart-to-Heart Chat: Cardiac Involvement in Noonan Syndrome and What Are We Going to Do About It <i>Dr. Gelb</i>
9:45 am – 10:30 am	Musculoskeletal Findings in Noonan Syndrome <i>Dr. Stevenson</i>
10:30 am – 10:45 am	Break
10:45 am – 11:30 am	Chronic Pain in Noonan Syndrome <i>Dr. Roberts</i>
11:30 am – 12:15 pm	When Sleep Isn't Simple: Recognizing and Managing Sleep Difficulties in Noonan Syndrome <i>Dr. Weaver</i>

PATHWAY A

Salons AB

1:15 pm – 2:00 pm	Feeding Difficulties in Noonan Syndrome <i>Dr. Shields</i>
2:00 pm – 2:45 pm	Caregiver Burnout: Tangible & Realistic Steps Towards Improving Family Quality of Life <i>Dr. Ellison</i>
2:45 pm – 3:00 pm	Break
3:00 pm – 3:45 pm	Disordered Bleeding in Noonan Syndrome <i>Dr. Briggs</i>
3:45 pm – 4:30 pm	Behind the Letters: A Guide to Understanding Your Genetic Test Results <i>Pilar Magoulas</i>

PATHWAY B

Salons CD

1:15 pm – 2:00 pm	Neurodevelopment & Mental Health in Youth with Noonan Syndrome <i>Dr. Pierpont</i>
2:00 pm – 2:45 pm	From Genes to Behavior: Autism Related Traits in Noonan Syndrome and NSML <i>Chloe Deakin</i>
2:45 pm – 3:00 pm	Break
3:00 pm – 3:30 pm	To Test or Not to Test? Utility of Pediatric Neuropsychological Evaluation, and How to Make the Most of One <i>Dr. Ellison</i>
3:30 pm – 4:00 pm	IEPs, 504 Plans and Noonan Syndrome: Building Effective Educational Pathways <i>Ruth Sherred</i>
4:00 pm – 4:30 pm	Q&A of Afternoon Speakers

ZAMBEZI

3:00 pm – 3:45 pm	Let's Talk: Adults with Noonan Syndrome <i>Exclusively for Adults with Noonan Syndrome</i> <i>Select NSF Board and Presenters</i>
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SESSION OVERVIEW

Friday, July 31, 2026



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GENERAL SESSIONS

Salons ABCD

9:00 am – 9:45 am	GI Considerations in Noonan Syndrome <i>Dr. El-Chammas</i>
9:45 am – 10:30 am	Why Doesn't My Doctor Know Anything About Noonan Syndrome? <i>Dr. Shiels</i>
10:30 am – 10:45 am	Break
10:45 am – 11:30 am	Growth Hormones and Beyond: Endocrine Considerations in Noonan Syndrome <i>Dr. Dolak</i>
11:30 am – 12:45 pm	The Future is Bright <i>Representatives from the RASopathies Network, Mayo Clinic, NSF Board, and Medical Advisory Panel</i>

PATHWAY A

Salons AB

1:45 pm – 2:30 pm	Understanding the Connection: Noonan Syndrome, Chiari Malformation and Tethered Cord <i>Dr. Klinge</i>
2:30 pm – 3:15 pm	The Milky Way: Lymphatic Involvement in Noonan Syndrome <i>Dr. Gelb</i>
3:15 pm – 4:00 pm	Occupational Therapy for the Young Child <i>Lisa Otto</i>

PATHWAY B

Salons CD

1:45 pm – 2:30 pm	Dental Manifestations in Noonan Syndrome <i>Dr. Browning</i>
2:30 pm – 3:15 pm	Growing Up With Noonan Syndrome: Puberty & Future Family Choices <i>Dr. Weaver</i>
3:15 pm – 4:00 pm	Transitioning to Adulthood <i>Michelle Gray</i>

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Registration	Registration D	2:00 pm – 6:00 pm
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Yeehaw Social: Opening Reception	Kalahari Ballroom	6:00 pm – 8:00 pm
Teen Night (12–18)	B Lux Bowling	8:00 pm – 10:00 pm
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★ JULY 31ST ★

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CONFERENCE MAP

Kalahari Resort & Convention Center

Use this map to help you find your way around the conference.

