



The NASCARR Annual Meeting brings together research teams, clinicians, trainees, NIH partners, advocacy partners, self-advocates, and community members to advance shared research priorities for sex chromosome aneuploidy (SCA) conditions, including XXY/Klinefelter syndrome, Turner syndrome, Trisomy X, XYY, XXYY, and all related X&Y chromosome variations.

What researchers, clinicians, and research teams should expect: The NASCARR Annual Meeting is an opportunity for investigators, clinicians, trainees, research teams, advocacy partners, and community members to share progress, strengthen collaborations, and help shape research that is meaningful to the Turner syndrome and extra X&Y chromosome variation communities. The meeting will include updates on NASCARR projects, resources, pilot grants, trainee activities, and clinical trial readiness efforts, while centering community voices and shared input to guide future priorities, programs, and consortium directions.

What individuals, families, and community partners should expect: The NASCARR Annual Meeting is a research consortium meeting focused on collaboration, progress, and future research planning. Family members, self-advocates, and advocacy group partners are warmly invited to participate as research partners by providing input on the priorities, outcomes, and resources that matter most to the SCA community. This meeting is different from a traditional family conference and is not intended to provide individualized care recommendations. Community participants can expect to learn how NASCARR is strengthening SCA research infrastructure, supporting early-career investigators, and expanding knowledge, while contributing their perspectives to ensure that the work is guided by lived experience.

Monday Sept 28 Preconference Session – Fulginiti Pavilion

9:00a **ROADMAP: Orientation for Advocates and Community Members**

Monday Sept 28 Conference Sessions – Fulginiti Pavilion

11:30a **Conference Check-In Opens, Social Lunch (until 1pm)**

1:00p **1** **SESSION 1**
The Starting Line: NASCARR Vision and Advocacy

6:00p **Happy Hour (6p) and Dinner (7p) at Hyatt House Hotel**

Tuesday Sept 29 Conference Sessions – Krugman Auditorium

8:30a **2** **SESSION 2**
The Fast Lane: Scientific Updates & Resources

12:00p **NASCARR Awards, Lunch, and Posters**

1:30p **3** **SESSION 3**
The Next Lap: Working Together Toward Research Readiness

6:00p **CLOSING CEREMONY: Dinner at Denver Museum of Nature & Science**

LOCATIONS:

Day 1: Monday 9/28/26

Fulginiti Pavilion

CU Anschutz Center for Bioethics and Humanities Building
13080 E 19th Ave, Aurora, CO 80045

Day 2: Tuesday 9/29/26:

Krugman Auditorium

Research 2 (RC2) Building
2nd floor
12700 E 19th Ave, Aurora, CO 80045

Google Maps

DAY 1



DAY 2



Monday, September 28, 2026
PRE-MEETING SESSIONS (Fulginiti Pavilion)

9:00–12:00 PM



ROADMAP: Orientation for Advocates and Community Members

What to expect: ROADMAP is a dedicated orientation for advocacy representatives, self-advocates, and family/community members joining the NASCARR Annual Meeting. The session will introduce NASCARR's structure, meeting format, and key opportunities for community input so participants feel prepared to engage throughout the conference. It will emphasize how community partners can contribute meaningfully through lived experience and practical insight.

9:00–9:20 AM: Welcome & Opening Remarks

Leaders: Kelly Ranallo & Sharron Close, PhD, CPNP-PC

Welcome attendees to the Advocacy Leadership Pre-Conference Meeting, framing the day's goals and the community's vital role within the NASCARR network.

9:20–9:35 AM: Participant Introductions

In-person and virtual attendees are invited to briefly introduce themselves, their organization or community, and their connection to NASCARR and SCA advocacy.

9:30–10:20: NASCARR Overview: Network Mission, Structure & NIH Partnership

Leaders: Shanlee Davis, MD, PhD & Nicole Tartaglia, MD

A comprehensive orientation to NASCARR, including its role within the NIH Rare Diseases Clinical Research Network (RDCRN), its funded research projects, clinical sites, patient registries, and goals for advancing clinical trial readiness. Presenters will highlight opportunities for community engagement and share scientific priorities.

10:20–10:35 AM: Networking Break

10:35–11:30: The Importance of Community Engagement in Rare Disease Research

Leader: John Strang, PsyD

People with Y and X variations represent a remarkably diverse community, spanning a wide range of life experiences and priorities. Community-based participatory research (CBPR) offers a framework to ensure that lived experience, rather than simply the intellectual curiosities of those who study these communities, drives the research agenda. This session explores how building genuine partnerships can ensure that research best serves the people for whom it is being done.

11:30 – 11:50 AM: Open Discussion & Q&A

Facilitated discussion open to all attendees. Community members are encouraged to raise questions, share perspectives, and identify priorities for the meeting ahead.

11:50 AM – 12:00 PM: Closing Remarks & Transition to Scientific Meeting

Summary of key themes, preview of the 2026 NASCARR Scientific Meeting program, and logistical notes for in-person and virtual participants. Brief overview of how advocacy voices will continue to shape the proceedings.

Monday, September 28, 2026
ANNUAL MEETING SESSIONS (Fulginiti Pavilion)

11:30–1:00 PM: Conference Check-In Opens & Social Lunch

What to expect: Attendees check in, receive meeting materials, and have informal lunch to connect and become nourished before meeting begins.

1:00 PM–5:30 PM

1

SESSION 1

The Starting Line: NASCARR Vision and Advocacy



1:00–1:20 PM: Welcome Session

Leader: Nicole Tartaglia, MD

What to expect: NASCARR Overview & Vision; Conference Goals & Logistics

1:20–1:30 PM: NIH Welcome

Leader: Tiina Urv, PhD, Program Director of RDCRN

What to expect: An introduction to the NIH Rare Diseases Clinical Research Network and how NASCARR contributes to this national framework for collaborative, patient-centered rare disease research.

1:30–3:15 PM: The SCA Lived Experience and Advocacy Group Partners

Leaders: Kelly Ranallo and Susan Howell, MS, CGC

What to expect: A panel of self-advocates and parent leaders from Patient Advocacy Groups will share their stories and the history and priorities of their organizations. This session is intentionally centered on lived experience and uniting all of the X&Y chromosome variations under the shared SCA umbrella. Panelists will also share hopes and recommendations related to NASCARR's research goals, and engage researchers to lead research that is responsive to real-world needs. Questions and discussion encouraged.

3:15–3:30 PM: Coffee & Candy Break

3:30–4:30 PM: NASCARR Project Summaries & Progress

Leaders: Shanlee Davis, John Strang, Siddharth Prakash, Armin Raznahan

What to expect: Each NASCARR project team will provide an overview of the project, and a brief update on its goals, current progress, planned activities, and anticipated impact. These updates will help participants understand how each project contributes to the broader NASCARR mission including clinical trial readiness and community-informed priorities. Questions and discussion encouraged.

4:30–5:30 PM: Group Photo & Optional Tours of Children's Hospital Colorado eXtraOrdinary Kids Multidisciplinary Clinic

6:00 PM: Happy Hour at Hyatt House Hotel, Dinner at 7pm

Tuesday, September 29, 2026
ANNUAL MEETING SESSIONS (Krugman Auditorium)

8:30 AM–12:00 PM



8:30-9:40AM: Pilot Core Presentations

Leader: David Hong, MD

Presentations by:

Adrianna San Roman, PhD, Duke University: "Modeling Respiratory Infection Susceptibility to Advance Hearing Loss Prevention Strategies in Turner Syndrome"

Sarayu Ratnam, PhD, Lurie Children's Hospital: "Biological, Developmental, and Psychosocial Determinants of Fatigue in Youth with SCAs to Advance Clinical Care and Support Clinical Trial Readiness"

Conor Gruber, MD, PhD, Children's Hospital of Philadelphia: "Mapping Inflammatory Immune Profiles in Turner Syndrome for Biomarker Discovery"

What to expect: Pilot projects test new ideas, generate preliminary data, and shape future research. Pilot awardees will present background and progress of their current pilot projects, including how they advance clinical trial readiness and potential future impact. Dr. Hong will also present lessons learned from the first pilot grant cycle, opportunities for the next pilot funding cycle, and expectations of awardees. We encourage questions and feedback.

9:45-10:55 AM: Career Enhancement Core (CEC)

Leaders: Judith Ross, MD and Chijioke Ikomi, MD

Presentations by:

Karli Swenson, PhD, University of Colorado "From Early Detection to Translational Discovery in Sex Chromosome Aneuploidy"

Antionette Farrell, MD, University of California San Diego "A Study of Continuous Progesterone in Adolescents and Young Adults with TS Compared to Traditional Cyclical Hormone Replacement"

What to expect: Past and current CEC fellows will present their projects and training experiences to demonstrate how NASCARR is helping build the next generation of investigators. CEC leaders will present broad goals and planned implementation of new tracks for the CEC, with solicitation of input and feedback from attendees.

11:00–11:30 AM: NASCARR Resources to Support Investigators

Leaders: Nicole Tartaglia, Aston King, Samantha Bothwell, Talia Thompson

What to expect: The NASCARR Research Support Team (NRST) will introduce the resources available to help sites and investigators with grant writing, study design, data analysis, qualitative research, and dissemination of SCA research.

11:30-11:45 AM: RDCRN Data Management & Coordinating Center (DMCC)

Leader: Erin Fontaine, MS, CCRP, Cincinnati Children's Hospital

What to expect: Our DMCC leader will highlight the tools used to manage NASCARR data, including how data quality, harmonization, and security are achieved, and also present DMCC strategies that help raise NASCARR's visibility, support recruitment and disseminate accomplishments through the website, newsletters, and social media.

11:45-12:00PM: NASCARR Summer Intern Research Spotlights

Leader: Shanlee Davis, MD, PhD

What to expect: Interns from the eXtraOrdinary Research summer internship will share short project summaries and personal impact of the internship experience.

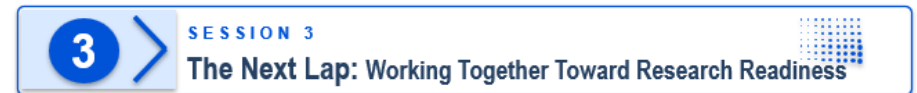
12:00–1:30 PM

Awards Lunch and Poster Session

This session will recognize contributions across the NASCARR community, including inspiration awards, top enrolling sites, new clinics and investigators, and other achievements reflecting progress, collaboration, and commitment to the SCA field.

Investigators are invited to bring posters highlighting SCA research, SCA clinics and/or rare disease or translational research to provide an interactive forum for trainees, community members, and investigators to share updates and learn from one another.

1:30–5:00 PM



1:30–3:00 PM: Breakout Working Groups

Group 1: GalaXY/InsighTS PIs and Research Teams

Group 2: Project 2 XY Voices

Group 3: Advocacy Groups and Community Members

Group 4: Early Career Investigators, Mentors, & NASCARR/NIH leadership

What to expect: Participants will divide into focused groups to work on projects, troubleshoot challenges, strengthen relationships, support emerging investigators and leaders, and provide input to strengthen NASCARR's future.

3:10-3:40 PM: Working Group Debrief

What to expect: Working groups will share summary of their working group activities with the whole group, followed by discussion from all attendees.

3:45–4:30 PM - KEYNOTE

Clinical Care Guidelines for Turner Syndrome and Klinefelter Syndrome: A Foundation for Clinical Trial Readiness

Keynote Speaker: *Claus Gravholt, MD, PhD, Professor, Aarhus University Hospital, Denmark*

Commentary: *Shanlee Davis, MD, PhD, Associate Professor, University of Colorado School of Medicine*

What to expect:

This keynote will use Turner syndrome as a powerful example of how clinical practice guidelines can move a field forward. Dr. Claus Gravholt will discuss the development of the Turner syndrome guidelines, provide an overview of key recommendations, and highlight how the guidelines have advanced clinical care. He will also address strategies for disseminating guidelines both scientifically and directly to advocacy groups and families.

Building on this model, Dr. Davis will highlight the Klinefelter syndrome clinical practice guideline meeting taking place in Denver immediately after the NASCARR meeting—an international effort involving many NASCARR team members. She will connect this work to broader clinical trial readiness efforts by emphasizing how guidelines can standardize care, identify evidence gaps, strengthen research infrastructure, and create a clearer path toward future therapeutic trials across SCA conditions.

4:30–4:50 PM

Inspirational Discussion and Wrap-Up

What to expect: The final session will synthesize key meeting themes—including scientific progress, research resources, community priorities, and career development—and incorporate attendee feedback to help shape NASCARR's next steps. Together, these reflections will help align coordinated scientific and community efforts to advance clinical trial readiness for all X&Y variations over the coming years.

5:30PM BUS LEAVES FOR DINNER

