



ALPORT CONNECT DENVER

July 27-28 • 2024

Adult Program

Please note all times are listed in Mountain Daylight Time (local event time) and are subject to change.

All sessions will be held on the second level of the Convention Center and rooms are subject to change.

Note: Simultaneous Teen Program agendas are separate and will be directly emailed to those participants and their caregivers.

Saturday, July 27th

8:00 AM – 9:00 AM (60 minutes)

Check-in

Location: Pre-Function A Hallway near Aurora Ballroom D

Check in with ASF Staff and volunteers to receive your materials and agendas for the weekend. Coffee and light breakfast items will be served.

9:00 AM – 9:10 AM (10 minutes)

Welcome & Opening Remarks

Location: Aurora Ballroom D

Speakers: Andrew Kronenberg, ASF Board Chair and Lisa Bonebrake, ASF Executive Director

9:10 AM – 9:30 AM (20 minutes)

Life Beyond Diagnosis: Young Patient Accomplishments

Location: Aurora Ballroom D

Moderator: Afton DeLucca, ASF Associate Director

Speakers: Rachel Denham, Alex Jones, Max Lagas, Maddison Martin

Young adult patients share their diagnosis and success stories.

9:30 AM – 10:20 AM (50 minutes)

Patient & Caregivers Panel: Alport Journeys in Your Words

Location: Aurora Ballroom D

Moderator: Dusty Atchinson, ASF Emerging Leadership Council

Speakers: Becca Cheung, Zachary Malo, TJ Mayfield, Amy Rhodes, Philip Seymour

A diverse group of individuals impacted by Alport syndrome share their experiences navigating treatment, parenting, post-transplant life, hearing loss, and more.

- 10 minute break -

10:30 AM – 11:15 AM (45 minutes)

Treatment Strategies to Preserve Native Kidney Function (For All Ages) and Moderated Q&A

Location: Aurora Ballroom D

Moderator: Lisa Bonebrake, ASF Executive Director

Speakers: Dr. Caitlin Carter and Dr. James Simon

Members of ASF's Medical Advisory Committee will discuss the current standard of care for patients of all ages.

11:15 AM – 11:35 AM (20 minutes)

Clinical Trial Considerations

Location: Aurora Ballroom D

Introduction: Lisa Bonebrake, ASF Executive Director

Speaker: Dr. Bradley Warady

Dr. Bradley Warady of ASF's Medical Advisory Committee will discuss clinical trial considerations and current opportunities.

- 5 minute break -

11:40 AM – 12:15 PM (35 minutes)

Alport-Related Hearing Loss and Moderated Q&A

Location: Aurora Ballroom D

Introduction and Moderator: Maddison Martin, ASF Patient Engagement Coordinator

Speaker: Dr. Brittany Slaff

Brittany Slaff, AuD, will discuss Alport-related hearing loss and answer questions.

12:15 PM – 12:30 PM (15 minutes)

Ways to Get Involved with ASF

Location: Aurora Ballroom D

Speakers: ASF Board and Staff

ASF Board Members and Staff will discuss volunteer opportunities and ways to get further connected to the Foundation and larger Alport Community.

12:30 PM – 1:30 PM (60 minutes)

Lunch and Learn

Location: Aurora Ballroom D

Opportunities to learn about Alport Syndrome Foundation resources/research and connect with researchers and industry partners. Buffet-style lunch will be provided.

1:30 PM – 2:15 PM (45 minutes)

Breakout #1: 2 simultaneous sessions

Locations: Summit 6 and Summit 7

Summit 6: Renal Diet + Nutrition Q&A

Moderator: Kevin Schnurr, ASF Managing Director

Speaker: Megan Pitts, MA, RD, CCTD

Summit 7: “All Things Pediatrics” Discussion

Moderators: Afton DeLucca, ASF Associate Director, and Amy Rhodes, ASF Board of Directors

Speakers: Dr. Caitlin Carter, Dr. Bradley Warady, Dr. Brittany Slaff, and Mary-Beth Roberts, CGC

- 5 minute break -

2:20 PM – 3:00 PM (40 minutes)

Late-Stage Kidney Disease: Preparation and Management

Location: Aurora Ballroom D

Introduction: Kevin Schnurr, ASF Managing Director

Speakers: Dr. Geoffrey Block and Dr. Alexander Wiseman

Nephrologists will cover preparation for renal failure and discuss current treatment modalities for those in stage 5 CKD (kidney failure).

3:00 PM – 3:40 PM (40 minutes)

Extrarenal Conditions: Current Understanding of Alport syndrome in the Eyes and Aorta

Location: Aurora Ballroom D

Introduction: Dr. André Weinstock, ASF Research Director

Speakers: Dr. Paul Bernstein and Dr. Carmen Halabi

Paul Bernstein, MD, PhD, and Carmen Halabi, MD, PhD, discuss non-renal Alport issues and ongoing research in these areas.

3:40 PM – 4:00 PM (20 minutes)

Caring for Caregivers: Supporting Yourself and Patients You Love

Location: Aurora Ballroom D

Moderator: Afton DeLucca, ASF Associate Director

ASF Board and Staff Speakers: Lisa Bonebrake, Dr. Stephen Malach, Amy Rhodes

4:00 PM – 4:10 PM (10 minutes)

Event Evaluations – Day 1

Location: Aurora Ballroom D

4:10 PM – 4:30 PM (20 minutes)

Group Photography

Location: Aurora Ballroom D

4:30 PM – 5:00 PM (30 minutes)

Social Reception

Location: Aurora Ballroom D

Snacks and beverages will be provided during this 30-minute opportunity to interact with event speakers, fellow patients, and ASF Staff/Board and event volunteers.

5:00 PM

Conclusion of Saturday Programming

Sunday, July 28th

8:30 AM – 9:00 AM (30 minutes)

Pre-Admission Photos and Coffee

Location: Outside Aurora Ballroom D

Have your photo taken by a professional, participate in swag giveaways, and enjoy coffee before the day begins.

9:00 AM – 9:45 AM (45 minutes)

Alport Inheritance Findings and the Importance of Genetic Counseling for All Patients

Location: Aurora Ballroom D

Introduction: Dr. André Weinstock, ASF Research Director

Speakers: Mary-Beth Roberts, CGC and Libby Valenti, MS, CGC, Natera representative

Renal genetics counselor Mary-Beth Roberts reviews important information for all patients. A Natera representative will share genetic findings from the Renasight genetic testing program.

- 5 minute break -

9:50 AM – 10:35 AM (45 minutes)

Breakout #2: 2 simultaneous sessions

Locations: Summit 6 and Summit 7

Summit 6: Coping with Hearing Loss: Patient & Caregiver Experiences

Moderators: Maddison Martin, ASF Patient Engagement Coordinator and Kevin Schnurr, ASF Managing Director

Speakers: Alport patients and Brittany Slaff, AuD

Summit 7: How to Become a Strong Self-Advocate

Moderator: Lisa Bonebrake, ASF Executive Director

Speakers: Dr. James Simon, Maxwell Lagas, ASF Emerging Leadership Council, and Sharon Lagas, ASF Board of Directors

- 10 minute break -

10:45 AM – 11:30 AM (45 minutes)

Breakout #3: 2 sessions sessions

Locations: Summit 6 and Summit 7

Summit 6: Emotional Health for All Ages and Stages of Kidney Disease

Moderators and Speakers: Afton DeLucca, ASF Associate Director and Dr. Stephen Malach, ASF Board of Directors

Summit 7: Clinical Trials: Questions and Patient Experiences

Moderator: Lisa Bonebrake, ASF Executive Director

Speakers: Dr. Bradley Warady; Dr. André Weinstock, ASF Research Director; and patients with experience participating in clinical trials.

11:30 AM – 11:40 AM (10 minutes)

Event Evaluations – Day 2

Locations: Summit 6 and Summit 7

11:40 AM – 12:30 PM (50 minutes)

Boxed Lunch and Outdoor Picnic

Location: The Front Range Lawn outside Gaylord Convention Center

12:30 PM

Conclusion of Sunday Programming
