



10th International Conference and Scientific Symposium

October 4-9, 2023

Sheraton North Baltimore Hotel

WEDNESDAY, OCTOBER 4 PRECONFERENCE ARRIVALS

09:00 – 20:00	ARRIVALS
13:30 – 15:00	PRE-CON MEETING W/ Sheraton
18:00 – 20:00	DINNER - At your leisure

THURSDAY, OCTOBER 5 PRECONFERENCE / REGISTRATION / ORIENTATION

06:30 – 09:30	Breakfast –
07:30 – 08:30	ASI Department Head Meeting – Cole Boardroom
09:00 – 22:00	Conference Registration
15:00 – 16:00	Conference Overview – <i>What to expect?</i> – Gina Denbow, ASI Chair
17:30 – 19:00	Welcome Reception – Warfield Room
19:00 – 21:00	Dinner - At Your Leisure
21:00 – 23:00	A-Teams, Parents, and Professional Networking

SCIENTIFIC SESSIONS: SYMPOSIUM FOR PHYSICIANS AND RESEARCHERS

08:30 – 08:45	Welcome – Clair Francomano, MD, Chair of ASI SAB
08:45 – 09:15	<i>Mild Phenotypes in Alström Syndrome</i> – Pietro Maffei, MD, PhD
09:15 – 09:45	<i>Of Alstrom and Lipids, or the Complex Lipid Metabolism Traits of a Monogenic Disease</i> Vincent Marion, PhD
09:45 – 10:00	COFFEE BREAK
10:00 – 10:30	<i>Ophthalmic Findings in Alström Syndrome</i> – Alex Levin, MD
10:30 – 11:00	<i>An Update on the Natural History of Alström Syndrome</i> – Tonie Kline, MD
11:00 – 11:30	<i>The lungs in Alstrom syndrome: What do we know so far?</i> – Shyam Madathil, MD
11:30 – 13:15	LUNCH
13:15 – 14:00	<i>Overview of Setmelanotide in patients with Alstrom syndrome</i> – Sonali Malhotra, MD

14:00 – 14:30	<i>Ears, Nose, and Throat in Alström Syndrome – Lucy Dalton, MD</i>
14:30 – 15:00	<i>Metabolic syndrome in Alström and role of GLP-1 analogues – Tarek Hiwot, MD, PhD</i>
15:00 – 15:15	COFFEE BREAK
15:15 – 15:45	<i>Cardiomyopathy in Alström syndrome is not yet curable but is a treatable condition - Alfonso Ortigado, MD, PhD</i>
15:45 – 16:15	<i>Models of cardiomyopathy in Alström Syndrome - Leena Roy, MD</i>
16:15 – 16:45	<i>Investigating the molecular basis of Alström Syndrome through disease models Diana Valverde, PhD</i>
16:45 – 17:00	WRAP UP
18:00 – 20:00	PRESENTER OFF-SITE DINNER

FRIDAY, OCTOBER 6

DAY - 1

FAMILY SESSIONS

The following spaces will be available pretty much full-time throughout the conference!

- **AS Memorial**
- **Meditation Room**
- **A-Team Getaway Room**
- **Siblings Hangout**
- **Tot Room (1-5 yrs)**

06:30 – 08:00	BREAKFAST BUFFET
06:30 – 10:00	REGISTRATION FOR LATE COMERS
08:00 – 08:30	DEPART for Washington, DC – Museums A-Teamers and Ages 13-17 DEPART Hyper Kidz (ages 6-12) 9-12 AM / Monster Mini Golf 1-4 PM
08:30 – 08:45	WELCOME AND INTRODUCTIONS – Eric Beresford, PharmD, ASI Executive Director and Chase Palmer, PharmD, ASI President
08:45 – 09:30	<i>Introduction to Alström Genetics - Clair Francomano, MD</i>
09:30 – 10:00	<i>Common Drug Classes in Alström Syndrome – Chase Palmer, PharmD</i>
10:00 – 10:15	COFFEE BREAK
10:15 – 10:45	<i>Clinical Overview of Alström Syndrome - Tonie Kline, MD</i>
10:45 – 11:15	<i>Drug Development in Rare Diseases – Eric Beresford, PharmD</i>
11:15 – 12:00	<i>Why and when do patients with Alström syndrome develop diabetes and fatty liver disease? What can be done about it? - Tarek Hiwot, MD, PhD</i>
12:00 – 13:00	LUNCH and ANNOUNCEMENTS
13:00 – 21:00	Silent Auction, winners announced at 9PM – Second Floor Hallway/Grason Room
13:00 – 13:45	<i>Endocrine Issues in Alström Syndrome - Pietro Maffei, MD, PhD</i>
13:45 – 14:30	<i>Ears, Nose, and Throat in Alström Syndrome – Lucy Dalton, MD</i>

14:30 – 15:15

Transitioning to Adulthood: Independent Living - Kerry Leeson

FRIDAY, OCTOBER 6

DAY - 1

15:15 – 15:30

BREAK

15:30 – 16:15

*Impactful discussions: Helping families understand progression of Alstrom symptoms related to hearing and communication and creating pathways to success – **Bridget Garrison, Au.D., Mary Kane, M.A.***

16:15 – 17:00

Against All Odds: Advocating for your Child
Panel Discussion - Gina Denbow / Janet Fee / Kim Wedel

18:30 – 20:30

DINNER and Keynote Speaker – Do we all look the same? Rick Steeds, MD

20:30 – 23:00

NETWORKING and RELAXING

SATURDAY, OCTOBER 7

DAY - 2

06:30 – 08:00

BREAKFAST BUFFET

07:00 – 08:00

ASI: Department Head Meeting

09:00 – 12:00

DEPART to Baltimore Aquarium (Everyone)

12:00 – 16:00

Boxed Lunch 12-1 PM, Port Discovery Museum 1-4 PM (Ages 6-12)

13:00 – 16:00

DEPART Bowling and Arcade (Ages 13-17)

08:30 – 09:15

*Eye Findings in Alström and Hope for a Seeing Future - **Alex Levin, MD***

09:15 – 10:00

The use of cell and animal models to understand the biology of Alström's disease
Diana Valverde, PhD

10:00 – 10:45

Milestones in the cardiomyopathy in Alström Syndrome: Lights and Shadows
Alfonso Ortigado, MD, PhD

10:45 – 11:00

COFFEE BREAK

11:00 – 12:00

*Alström and the heart in the adult – **Ashwin Roy, MD***

12:00 – 13:00

LUNCH and ANNOUNCEMENTS

13:00 – 14:30

The ASI Saga: From Kitchen Table to National Prominence and the World Stage
Robin Marshall, SASF, and the ASI Originals

14:30 – 15:00

COFFEE BREAK

15:00 – 16:00

Of Alstrom and Lipids, or the Complex Lipid Metabolism Traits of a Monogenic Disease
Vincent Marion, PhD

16:00 – 18:15

CASH BAR COCKTAILS

18:30 – 20:30

DINNER – Fitzgerald Ball Room

20:30 – 23:00

DANCE PARTY!! Fitzgerald Ball Room

SUNDAY, OCTOBER 8

DAY - 3

07:00 – 09:00

BREAKFAST BUFFET

09:00 – 11:30	<i>CHELSEY'S OLYMPICS</i> – Shelly Marshall/Jennifer Potter
09:00 – 11:30	<i>JUST FOR SIBLINGS</i> – Katie Marshall
09:00 – 11:30	<i>ASK THE A-TEAM</i> – Panel Discussion <i>The Determined Working Woman</i> – Jamie Seeger <i>Securing Guide Dogs</i> – Chelsey Kostick <i>Enrolling in and Attending College</i> – Hannah Wedel / Callie Marshall
12:00 – 17:00	LUNCH - At your leisure
14:00 – 16:00	Tech Display – Sharon Herman Paynes
18:00 – 20:00	CLOSING DINNER – Fitzgerald Ballroom
20:00 – 23:00	RELAX, NETWORK, ENJOY THE POOL

MONDAY, OCTOBER 9

DAY - 4

06:30 – 09:30 **BREAKFAST**

09:00 – 11:00 GENERAL MEETING WITH FAMILIES: Meeting your needs

11:00 – 12:00 **CHECK-OUT and FAREWELLS**

Conference Room Assignments

Amphitheatre (2 nd)	-	Movie Night, Family Sessions
Burke Room (2 nd)	-	Sibs Room
Cole Room (2 nd)	-	ASI Board Room
Duncan Room (2 nd)	-	A-Team Room
Fitzgerald Ballroom (1 st)	-	Scientific Symposium, Dinner presentations
Grason Room (2 nd)	-	Auction storage
Lindsay-A Room (2 nd)	-	Tot / Play Room
Lindsay-B Room (2 nd)	-	ASI Storage Room
Lindsay-C Room (2 nd)	-	Memorial Room
McIntosh Room (2 nd)	-	Meditation Room
Warfields Room (1 st)	-	Check-in, Family Presentation, Chelsey's Olympics