



Alström Syndrome International Newsletter

TO THE ASI COMMUNITY



MORE INFO COMING SOON!



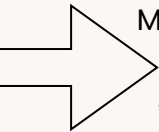
The whole group from the ASI Family Conference in Baltimore in 2023

11th Family Conference & Scientific Symposium Announcement



If you have seen our Facebook posts then you might already know the news! The Alström Syndrome International 11th Family Conference & Scientific Symposium will be in... Fort Worth, Texas, USA on May 22-25, 2026! More information to come soon. Yeehaw!

CHECK OUT OUR SOCIAL MEDIA POSTS



March Clinic in Baltimore



Group photo from the pediatric clinic in March

June Clinic in Indianapolis



Group photo from the adult clinic in June

More on the Clinics on Page 2



March & June Clinics

Alström Syndrome International recently organized two clinics for both adult and pediatric patients with Alström Syndrome.

In March, the Alström Syndrome Pediatric Clinic at The Jan D. Marshall Center of Excellence for the Treatment of Alström Syndrome at Greater Baltimore Medical Center hosted six families. This pivotal gathering provided specialized care and support, offering tailored medical guidance from experts in ophthalmology, ENT, audiology, cardiology, genetics, genetic counseling, psychology, endocrinology, and gastroenterology.

In June, the adult clinic took place in Indianapolis at the Indiana University School of Medicine, where five adults with Alström Syndrome received care from specialists in ophthalmology, genetics, genetic counseling, cardiology, endocrinology, ENT, and pharmacology.

Both clinics not only delivered crucial medical evaluations and personalized care strategies but also fostered a supportive community. Attendees shared experiences and built connections, finding solace in mutual understanding and enhancing their daily lives.

A key goal of these clinics is to improve the quality of life for individuals with Alström Syndrome, emphasizing empowerment and ongoing support throughout their unique health journeys. The success of these gatherings promises continued progress and hope for the future.



The whole group of Alström attendees for the Clinic in June



Chelsea Kostick with her guide dog, Essex at the Clinic in June



Lucky Kilari, Samarth Saxena and Blaire Usher at the Clinic in March,

Living with Alstrom Syndrome

We're thrilled to launch our new Facebook page dedicated to Alström Syndrome. We'll feature stories of individuals navigating this rare genetic disorder, showcasing their daily lives, passions, and resilience. Join us to celebrate their achievements and learn how they thrive despite the challenges they face.

GET A PEEK INTO THE LIFE OF THOSE LIVING WITH ALSTROM

WANT TO BE FEATURED? EMAIL US!

1st Annual Gala ✨ & Silent Auction ✨

Our 1st Annual Gala & Silent Auction was Saturday, March 23rd in Good Will-Hinckley, ME. Thanks to everyone's generosity we were able to raise over \$14,000 for Alström Syndrome! The day of the Gala it snowed about 22 inches. We still had a great turnout at our Gala even with the weather. We greatly appreciate everyone who braved the snowstorm and attended and everyone who donated towards our Gala! Our sponsors and attendees made it possible for us to reach our fundraising goals and we cannot thank them enough.



Chase & Barbara Gourley with flowers at the Gala

THANK YOU
TO OUR
SPONSORS



Silent Auction tables at the Gala



Attendees standing and clapping at the Gala

We had so many great donated Silent Auction items at our Gala by various individuals and companies. Thank you to everyone who donated towards our Gala and towards our Silent Auction!

The Voice of the Patient - The Alström Syndrome Journey

ASI held an externally led Patient Focused Drug Development (eI-PFDD) in 2022 where ASI presented to the FDA with the patient perspective in mind. From this 8 hour patient testimony, The Voice of the Patient - The Alström Syndrome Journey was created.

You can read the full report, or watch the PFDD recording on our website.
<https://www.alstrom.org/pfdd/>



We recently changed donor software so we have a new QR code! Scan this with your phone to donate! You can even create your own Fundraiser using our link and then share with your friends and family.



NEXT CLINIC MARCH
2024

*** New ***

MORE INFO ON PAGE 5

Update from the Executive Director



Eric and Ryan Fielder at the conference in Baltimore

Dear Alström Family and Friends,

My name is Eric Beresford, and I am the Executive Director of Alström Syndrome International. I've had the great pleasure of meeting many of you during our Baltimore, Indianapolis clinics, and the ASI Conferences in Baltimore and Galveston, TX. There are still many more families to meet and even more seeking to join this amazing family, which is Alström Syndrome International. Under the guidance and supportive wisdom of Robert (Robin) Marshall, who you all know and love, ASI introduced changes to the Executive Leadership Team early last year. Chase Palmer became ASI President, Jennifer Potter became ASI Treasurer, and Gina Denbow became Chair of the ASI Board of Directors.

Additionally, Mike Kirby remains our secretary and Dr. Clair Francomano remains our Chair of the scientific advisory board. We are all blessed to serve ASI in a capacity to the best of our abilities. Working together as one Team, with one common goal, to support the health and wellbeing of individuals affected with Alström Syndrome.

Once you have joined ASI you will find yourself surrounded by a number of Alström parents and family members who selflessly dedicate their time and efforts in supporting ASI's clinics, conferences and gatherings. You will also be surrounded by high quality science presentations and clinical updates from the world's leading clinicians and researchers regarding the treatment of all aspects of Alström Syndrome. Currently, we hold both a pediatric clinic in March and an adult clinic in June of each year in Baltimore and Indianapolis, respectively. ASI also holds an International Conference every three years, with the most recent held 2023 in Baltimore, Maryland. For additional insight into Alström Syndrome, a great resource is our Patient-Focused Drug Development (PFDD) presentation provided to the Food & Drug Administration.

Alström Syndrome International is extremely fortunate to have a talented and supportive Board of Directors, a superb Scientific Advisory Board of dedicated doctors and researchers, the A-Team, made up of talented and accomplished Alström adults, Family Support Coordinators, who provide initial and ongoing contact, information, support, and guidance through the often-difficult maze of dealing with Alström Syndrome.

Continued on Page 5



Update from the Executive Director continued

You will find that everything about Alström Syndrome is challenging! The ALMS-1 gene responsible for causing Alström Syndrome is a very large gene by comparison to other genes, and therefore contains over 250 different disease-causing variants. So, the actual variation in everyone is very challenging to locate. Additionally, no two individuals, even siblings, having the exact same genotype results in the development of differing medical conditions, phenotypes, and severity for each condition.

Our social media campaign strongly supports and shares among other Alström afflicted individuals, families, and caretakers. We support (2) Facebook platforms, a private page for more personal discussions <https://www.facebook.com/groups/33208859609> and a public page as well at the links listed here.

The Mission Statement of Alström Syndrome International is "To provide support, information, and coordination world-wide to families and professionals effectively treating Alstrom Syndrome as we work toward a cure."

Whether you are a person with Alström, a parent of an individual with Alström Syndrome, or purely engaged to support the Alström community, you are welcomed at Alström Syndrome International, where we encourage uniqueness and embrace our diversity!

Respectfully,
Eric J Beresford, PharmD, BCMAS
Executive Director, Alström Syndrome International

Save the Date! Next Clinic- March 2025

If you are interested in attending our next pediatric or adult clinic next year please reach out. The next clinic will be a pediatric clinic in March at the Jan D. Marshall Center of Excellence for the Treatment of Alström Syndrome at Greater Baltimore Medical Center.



Lionel Craddock smiling at the camera

REACH OUT
FOR A CHAT

Let's connect!

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FACEBOOK PAGE

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www.alstrom.org