



Circle of Care | Vision for a Cure™

# N THE BEAM

## LSA SPOTLIGHT



*l. to r. - Robert Nussbaum, Hunter Haugen, Claude Aguilar*

## Global Lowe Syndrome Research Initiatives

The LSA co-hosted two international research symposiums (Naples, Italy in 2023 and Purdue, Indiana in 2024) and the outcomes from both gatherings illustrate a clear call to action: support multiple tracks of complementary research approaches to serve a broad population of LS boys and men with various genetic mutation nuances. This approach gives our community the best chance of finding effective treatments. Every LS family has the oppor-

tunity to contribute towards our research efforts by sharing their son's genetic data through our collaboration with Citizen Health. When data is combined globally, we will finally have accurate information to better understand Lowe syndrome and why certain symptoms emerge in some patients, while not in others. This information is key to helping researchers shape their studies and answer many unknown questions across our community. If you have not already done so, please take

*LS families can contribute by sharing their son's genetic data through Citizen Health.*

5 minutes to sign-up with Citizen Health! <https://www.citizen.health/partners/lsa>

*Below is an overview of the key research initiatives underway.*

### Can-Fite Pharmaceuticals to Initiate Phase II Study in the Rare Genetic Disease Lowe Syndrome with Piclidenoson

(Full article here:

<https://firstwopharma.com/story/5943355>)

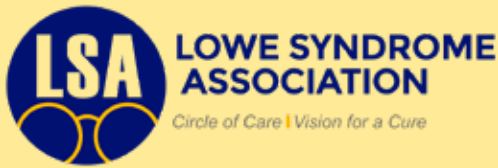
Here are a few highlights shared by Dr. DeMatteis regarding this research:

**1.** If Piclidenoson proves to be active in this pilot study, a larger study including a broader population of LS patients from different countries could be considered in the future. The study is fully supported by Can-Fite.

*Research, continued on page 7*

## In this issue

- 1 Research Update
- 2 President's Message
- 3 Family Stories
- 5 Memorials
- 8 LSA Conference Agenda
- 10 LSA News
- 11 LSA Supporters
- 12 LSA Financial Overview



**The Lowe Syndrome Association, Inc.** is a non-profit corporation dedicated to the following purposes:

Improve the lives of persons with Lowe syndrome and their families through fostering communication, providing education and supporting research so that individuals can attain their highest potential.

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# PRESIDENT'S MESSAGE



Dear Friends,

We are less than three months away from our 18th International Lowe Syndrome Association Conference, taking place June 27 - 29, 2025 at The Summit Hotel in Cincinnati, Ohio. This edition of our digital newsletter includes the most up to date agenda for our event, which is packed full of support, resources and fun for our families!

I'm hopeful this year's attendance surpasses all previous conferences! It's super heartwarming to see so many extended family members that have a grandchild or nephew with Lowe syndrome (LS) register for this event. If you are curious about LS, please come to our conference to learn! Registration and hotel booking information is available through our conference link here: <https://www.lsa2025.com/>.

As our conference is around the corner, I am asking for support in any way you feel inclined. We are seeking corporate and individual sponsorship(s), stipend support for family travel, items to raffle or include in gift bags for our families (traveling from as far as Belgium), matching gifts if offered through your employer, dessert (ice cream vendor for Friday or Saturday), and a volunteer photographer who might pop in and out throughout event to take photos.

Cincinnati is a tight knit community that supports many nonprofits. That said, as a virtual and international nonprofit without a brick and mortar building, it is tough to attract the philanthropic support many other organizations receive. If you can help in any way, please contact me directly at [president@lowesyndrome.org](mailto:president@lowesyndrome.org).

I encourage you to read through our entire newsletter as we share updates on research, community engagement, and honor the boys and men who fought their best fight against Lowe syndrome. You are forever in our hearts.

Thank you all for supporting our association and keeping us focused on our mission to foster communication among families, provide education, and support research so that individuals can attain their highest potential.

Warm regards,

Jeri

Jeri Kubicki

President, Lowe Syndrome Association

# FAMILY STORIES



*l. to r. - Ewan, Laura Kim, Judah, Nathan, Lily, and Stacey Vrtiska, and Shane and Jennifer Hartmann*

## LSA Families Meet Up

On a warm February afternoon, three families from the Lowe syndrome community met at Proud Bird, an aviation-themed restaurant near Los Angeles International Airport, providing families an opportunity to connect and children an outdoor space to play on a jungle gym and with model airplanes.

Attendees included Shane (23) and his parents, Jennifer and Steven Hartmann, from Torrance; Ewan (6) and his parents, Laura Kim and Fitz Carlile, from West Los Angeles; and Judah (7), his sister Lily (6), his mother, Stacey Vrtiska, and his father, Nathan, who traveled from Hawaii along with his aunt. This gathering was particularly special as it marked the first time Shane and Ewan met Judah, who was in Los Angeles for glaucoma surgery.

Ewan has already successfully undergone glaucoma surgery as an infant, making this connection even more meaningful to the families involved, offering support to Judah and his family through lived experiences. Since Ewan's procedure, his eye pressures have remained

stable. Judah was preparing to have stents implanted to help regulate eye pressure, a procedure that typically provides stable, long-term results in managing glaucoma in children with Lowe syndrome. Throughout the afternoon, commercial jets roared overhead, providing an exciting backdrop to the gathering. Families sat together for a nice lunch, enjoying the opportunity to connect and share their experiences. The children stayed engaged with a

variety of activities - Ewan and Judah played with Ewan's electric train and track set, while all three boys raced Matchbox cars on model airplanes, climbed the jungle gym, and ran through the open space.

During lunch, the group also discussed plans for a future outing with Shane, considering a Dodgers, Lakers, or Clippers game, or a football game at SoFi Stadium.

Bringing families together in person is invaluable in strengthening the sense of community among parents while also creating meaningful experiences for the boys. These gatherings allow families to share their journeys, provide support, and build lasting friendships. Just as importantly, the boys benefit from the time spent together, forming connections with others who understand and share their experiences.

*Laura Kim*

# FAMILY STORIES

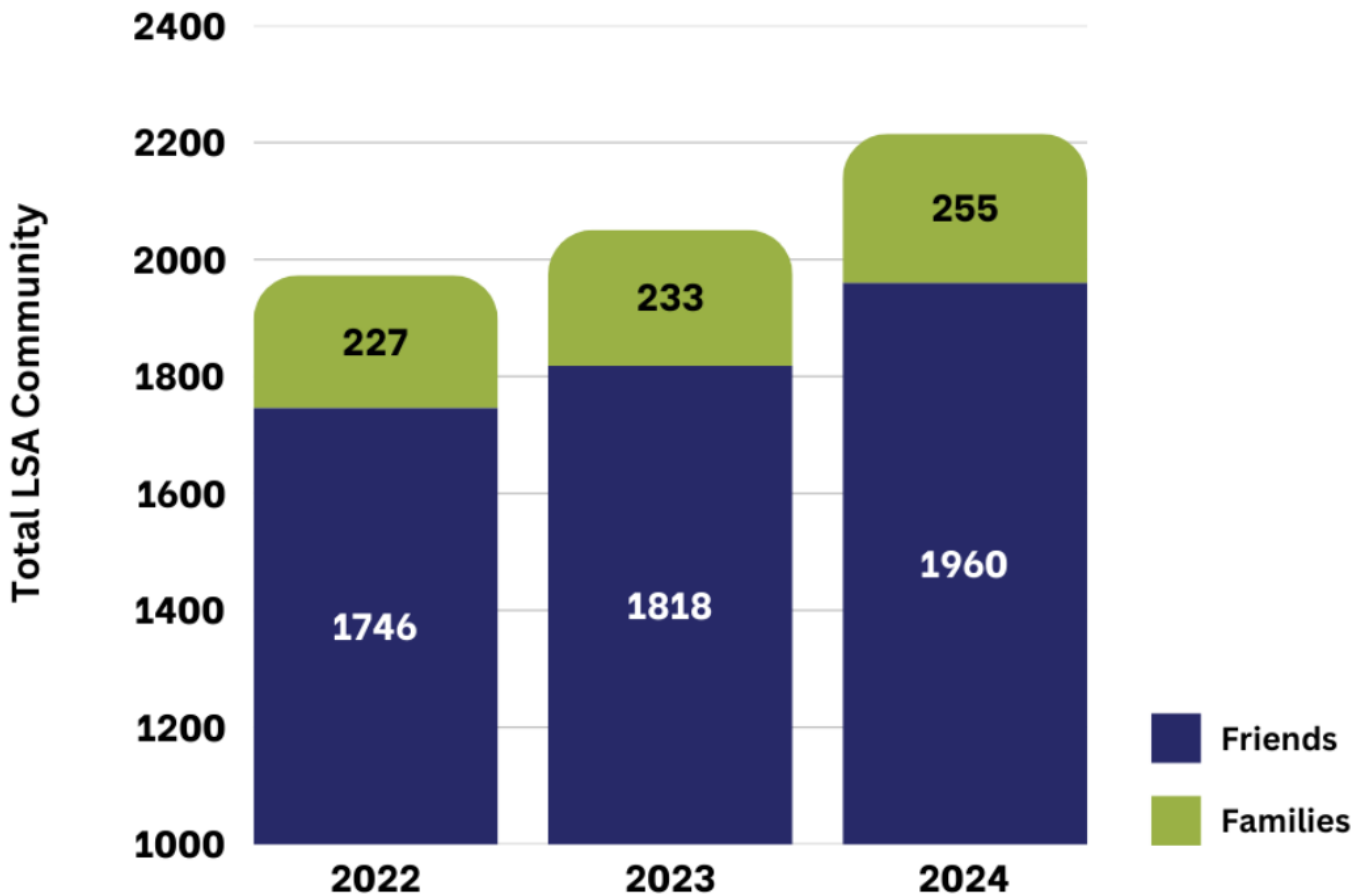
## New Friends or Families

We are growing and wish for all LS families - globally - to join us! Families can easily join the LSA community through our website (<https://lowesyndrome.org/join>) and by answering a few questions on our LSA Community Facebook page (<https://www.facebook.com/groups/808357192619974>).

It's important that we have an accurate number of individuals living with Lowe syndrome and other data. If you are not in our database, then our data regarding all things LS is not fully accurate. Help us help all those living with LS by joining the LSA Community!



## LSA COMMUNITY



# MEMORIALS

## Julius Nikolasi Afeaki

September 28, 2024 - February 11, 2025



*Julius Akeala*

Our little love was born on the 28th of September 2024. When we took him home, we were smitten over him, fighting over who would get to hold him or who would get to change his nappy. At 8 weeks, our lives changed when we found out Julius had cataracts and was experiencing liver issues. At 11 weeks, we were told our baby had 2 rare genetic disorders (Alagille Syndrome and Lowe Syndrome). After the initial shock wore off, we vowed to give him the best life we could. Julius got to spend Christmas and New Year's with our family and friends who showered him with so much love and cuddles. Unfortunately after 3 weeks of being at home we were admitted back into Sydney Children's Hospital as he was vomiting. For 5 hard weeks Julius underwent daily blood tests, countless cannulas inserted into his arms and legs, 2 tubes inserted in his nose, a mixture of medications, supplements and a central line put in. He fought so hard to stay with us every day even though he was in so much discomfort. Julius was the sweetest baby and would be comforted by our cuddles. Unfortunately, the liver and kidney conditions associated with his genetic syndromes were too much for his body. He left this earth as we cradled him in our arms on the 11th of February 2025. Even though his life was short, he has made a huge impact on many people's lives.



We love you forever and always, our beautiful Angel Julius.

## Tim Gray

October 9, 1967 - March 22, 2025

Tim Gray, always vibrant with laughter and a smile, loved life and lived it to its fullest, died on March 22, 2025. Tim faced numerous physical and developmental challenges head on and instead of complaining, he always had time to ask you "How's it goin'." Second only to his love and care for family (especially his nieces, nephews and great nephews), music was everything to Tim. He was happiest playing his guitar at church, the VFW, the family cabin, or any stage he was allowed. Tim's indistinguishable laugh and wide smile will be missed by anyone he has ever met.

We love you Tim.  
Tim's brothers,  
*Mike and Paul Gray*



*Tim Gray*

# MEMORIALS

## Daniel Martin

December 17, 1992 - December 15, 2023



*Daniel Martin*

Hello LS family,

Friday, December 15th, 2023 at 1:22pm, was one of the most difficult days in our families lives for Andy & I and our daughter Kayla and her fiancé' Chris. Daniel passed away peacefully on this day in the hospital's Palliative care ward. Son was admitted the day before and was diagnosed as having pneumonia. We were told it would be an uphill battle. We were never told there was no hope. When son passed away, it was a huge shock. He passed away two days before his 31st birthday.

Son lived a life of ups and downs, laughs, cries and so many other emotions that come with battling LS. One of the last conversations he had, was with two of his aunts at his hospital at his bed side, talking about what he wanted for his birthday, Anyone who truly knew our son does not need to guess as to what was on his wishlist, Hotwheels of course. He had approx 3,500 Hotwheels/ Matchbox cars.

Son had many things that brought him joy in his life: Hotwheels, drawing roads, pylons, N64 games, especially Mario Kart, Tom & Jerry and Zelda, bus rides, seabus rides,



walks, the Vancouver Canucks, movies (he loved to laugh and repeatedly watch the same movie and his favourite parts of the movie), traveling by vehicle, Kayla's cat Khalua who loved to snuggle with him, holidays and much more.

Son faced cataracts, glaucoma, fibromas, arthritis, seizures, low muscle tone, to name a few things. Lowe syndrome is so hard on our sons bodies and spirits.

We miss our Warrior and Superhero very much, everything that made him who he was in our lives, the laughs, the love and the meltdowns. What I would give to hear his voice and receive one more hug.

He is LS-free, now. No more walker, wheelchair, or pain in the Ever After Life. He is happy, full of love and joy. Spread your wings Warrior, Son and fly, be free. Until we meet again. We will always love you bunches.

*Andy & Liana, Kayla & Chris, Khalua and Harley*



# RESEARCH UPDATE

*Research, continued from page 1*

## **Can-Fite Pharmaceuticals to Initiate Phase II Study in the Rare Genetic Disease Lowe Syndrome with Piclidenoson** *continued*

**2.** Piclidenoson has not yet been tested in patients under 18 years of age. Therefore, this initial pilot study had to include patients aged 18 and above – though, of course, the sooner, the better. The primary endpoint of the study is the kidney's protein re-absorption capacity. From the article, Dr. De Matteis stated, "We chose to investigate Piclidenoson based on the availability of extensive scientific data showing its excellent safety, coupled with efficacy in this disease in pre-clinical studies which involves renal, cerebral, and ocular manifestations."

**3.** If next steps, including regulatory approvals, proceed swiftly, the study might begin by the end of the year.

## **Cure Lowe - Gene Therapy for Lowe Syndrome**

Led by co-founder parents Cecilie Bech Hammer and Sebastian Honore after their son, Walther was diagnosed with Lowe syndrome (LS), Cure Lowe is singularly focused on finding a gene therapy cure for LS. With a team that includes expertise in medical and biotherapeutics and regulatory/market advisors, Cure Lowe is primed to proceed with a multi-year approach targeting the proximal tubule cells affected in LS. Next steps will involve engaging the broader medical community to share knowledge and harness broad expertise.

## **The ALPEDENT Study Testing FDA-Approved Drug Alpelisib in Dent Disease 2 is Officially Open**

Find the details of this LSA, LST, and Dent disease foundation supported trial at <https://euclinicaltrials.eu/search-for-clinical-trials/?lang=en&EUCT=2024-514196-17-00>

Dent disease 2 is caused by mutations in the OCRL gene that causes the same reduced kidney reabsorption capacity as Lowe syndrome.

Typically without severe effects on other organs, Dent disease 2 offers a safer way to test whether alpelisib will help Lowe patients in the future.

This follows earlier preclinical work from Dr. Gallop and Dr. Devuyt. Dr. Emma informs us that on March 14, the Site Initiation Visit (SIV) was held at the Bambino Gesù Hospital clinical trial center in Rome, so the first Italian patients can be enrolled. The SIV is a formal event where everyone involved in the trial must attend and read the entire protocol as part of Good Clinical Practice standards, designed to protect the rights, safety, and well-being of participants and ensure the reliability of clinical trial data.

## **Repurposing FDA-Approved Drugs**

Drug repurposing has increasingly become a popular approach to treating various illnesses because it expedites the drug development process. Several selected FDA-approved drugs can directly restore the shape and function of mutated enzymes in patients with Lowe syndrome and Parkinson's disease. Some of these FDA-approved compounds showed greater efficacy than the original experimental compounds discovered initially. The Aguilar lab, at Purdue University is seeking funding to execute further research to identify the best

therapeutic FDA-approved agents and create patient-derived organoids (for kidney, brain, etc) using Lowe syndrome patient skin cells obtained from biopsies and standard genetic techniques to reprogram them into organoids. This technology offers the possibility of personalizing treatments, eliminates the need for invasive organ biopsies, and reduces or replaces reliance on experimental animals. Once established, this collection of organoids will be available to researchers in the field.



# CONFERENCE LSA AGENDA



The Lowe Syndrome Association is excited to share our most up-to-date agenda and featured speakers for our LSA 2025 Conference, taking place June 27 - 29, 2025 in Cincinnati, Ohio.

Conference registration and hotel booking information is available through our conference website here: <https://www.lsa2025.com/>.

Please note, this is our current agenda; however, it is subject to change. For a printable version, click here: <https://drive.google.com/file/d/19o4pa0GJVv6Zr4pCBVNI7hY2w7pax7aZ/view>

## FRIDAY June 27, 2025

### 7:45 am - 9 am

LSA Board of Directors Breakfast

### 9 am - 10 am

New Family Coffee Meet & Greet  
With LSA Board of Directors

### 10 am - 12:15 pm

Registration, Citizen Health  
Sign-Up

### 11:30 am - 12:30 pm

Box Lunches Available!

### 12:15 pm - 12:30 pm

Conference Opens: Welcome Video  
by Barry Ross Rinehart

### 12:30 pm - 1:30 pm

Keynote Speaker: Ruchi Koval

### 1:30 pm - 3:30 pm

Charting the Lifecourse Workshop  
Presented by Celia F. Schloemer,  
Family Support Coordinator,  
UCCEDD/CCHMC

*A short break will be included.*

### 3:30 pm - 3:45 pm

Donor Recognition

### 3:45 pm - 5 pm

Reception (Cash Bar)

### 5 pm - 6 pm

Family Talks - Mom Session

### 6 pm - 7:30 pm

Dinner (Buffet)

### 7:30 pm - 8:30 pm

Family Talks - Dad Session

## SATURDAY June 28, 2025

### 7 am - 8 am

Breakfast

### 8 am - 5 pm

Skidaddles Childcare  
Fun Room for LS Boys & Men

### 8:15 am - 9:15 am

Panel Discussion: Lowe Syndrome  
& the Kidneys  
Understand kidney labs, treat  
Fanconi syndrome and learn more  
about kidney transplants.  
Presented by Dr. Eileen Brewer and  
the Albertson family

### 9:30 am - 10:45 am

Seizure Training & Certification/  
Family Panel  
Presented by Dr. Crystal Hall,  
DrPH - Epilepsy Foundation

LS 101 - New Parent Session with  
MSAB  
LSA's Medical & Scientific  
Advisory Board

### 10:45 am - 11 am

Break

### 11 am - 11:45 am

Self-Care for the Caregiver  
Presented by Dr. Naila Goldenberg,  
MD

### 11:45 am - 1:30 pm

Lunch

MSAB Lunch with Board of  
Directors  
Guest Speaker: Dr. Nina Gross -  
Cincinnati Children's Medical  
Center

### 1:30 pm - 2:30 pm

Experienced Parent Panel /  
Navigating Resources Discussion  
Cori DeGori, Theresa Haugen, and  
Leeah Broms

Sibling Social  
Cristin Alberts

### 2:30 pm - 3:45 pm

Grief / Emotional Support for the  
LS Family / Family Panel  
Presented by Donna McCartney,  
LISW, MHA

### 3:45 pm - 4 pm

Break

### 4 pm - 4:45 pm

Onboarding A New Dentist with  
Dr. Tesini and Dr. Gennantonio  
Led by Dr. Tesini and Dr.  
Gennantonio

### 5:30 pm - 6:30 pm

Dinner

### 6:45 pm - 7:45 pm

Wump Mucket Puppets Show  
presents, The Adventures of  
Oh Really O'Reilly,  
Cryptozoologist

### 8 pm - 10 pm

School of Rock Band

# CONFERENCE LSA AGENDA



## SUNDAY June 29, 2025

**7 am - 8:30 am**

Breakfast

**8 am - 12:00 pm**

Skidaddles Childcare  
Fun Room for LS Boys & Men

**9 am - 9:15 am**

Opening Comments  
*Presented by Dr. Robert Nussbaum, Medical and Scientific Advisory Board*

**9:15 am - 10:15 am**

Transforming Possibility into Reality: The Power of Research and Hope  
*Presented by Dr. Jenny Gallop, Medical & Scientific Advisory Board*

**10:15 am - 10:30 am**

Break, Hotel Check Out

**10:30 am - 11:15 am**

LSA Fundraising & GiveLively Platform

**11:15 am - 11:45 am**

Closing Comments / Wrap Conference

## Additional Resources & Activities

### Sprinter Van

The Summit will provide complimentary sprinter van usage (5 mile radius) for LSA participants during the following times:

- Thursday, June 26, 2025  
from 5 - 9 pm
- Saturday, June 28, 2025  
from 5 - 7 pm

\* Travel up to 11 miles (downtown Cincinnati) for \$35 per person round trip

### Element Eatery

(<https://www.element-eatery.com/>)

Located right next to The Summit Hotel (3 minute walk), Element Eatery is home to 10 food vendors, a 48-tap beer garden and bar, an outdoor patio, a lawn game space, and a live event venue.

## Saturday Evening Entertainment

**Wump Mucket Muppet Show by Terrence Burke:** The Adventures of Oh Really O'Reilly, Cryptozoologist Terrence Burke combines his interests in theatre, music, and puppet design to share laughter and joy with our world. Burke and his puppets performed their first show in 2010 and have since performed original stories, songs, and silliness for thousands of children at libraries, schools, museums, and festivals. Over the years, Wump Mucket Puppets have appeared on numerous guest segments on the radio and television, even being featured on PBS!

Join 19th-century gentleman explorer, William O'Reilly, in The Adventures of "Oh Really" O'Reilly Cryptozoologist. Search Ohio for mysterious creatures including the Lake Erie Monster, Sasquatch, and the Lov land Frog. Will he find them before not-so-good guy gazillionaire G. Nefarious Meens does? Adventure awaits!



### School of Rock Band

School of Rock is a growing, passionate community dedicated to enriching lives through performance-based music education with both youth and adult students learning to play an instrument - guitar, bass, drums, keys or vocals - and how to work as a team in a band.



### Art with Intention

We are excited to have Patti McDonald, CEO of Art with Intention, join the LSA conference to help with our sibling social and lead the development of an art piece that we will raffle off!

Art with Intention has a mission to bring calm to the mind, joy to the heart, quality to life, and connection to community for those facing neurological and developmental challenges with a program of simple midline crossing movements and creative expression through guided painting.

Learn more about this amazing organization here:

<https://www.artwithintention.org>

# LSA NEWS



*Celanie Christensen, M.D.*

## Meet Dr. Celanie Christensen

We are thrilled to share the newest addition to our Medical & Science Advisory Board representing neurology- Dr. Celanie Christensen! Dr. Christensen is a passionate advocate for children with neurodevelopmental conditions.

Dr. Christensen is an Assistant Professor of Clinical Pediatrics and Neurology. Born and raised in north-east Iowa, she completed her undergraduate training at The University of Iowa. She moved to Indianapolis for graduate training and obtained a MS in Medical and Molecular Genetics at Indiana University. Prior to starting medical school, she practiced as a genetic counselor in adult and child neurology, biochemical genetics, and medical genetics. She returned to

medical training at Indiana University in 2007. She completed her Neurodevelopmental Disabilities residency at Indiana University School of Medicine. She is the Co-Division Chief of Developmental Medicine and Neurodevelopmental Disabilities Residency Program Director. Current clinical activities include neurodevelopmental pediatrics, Down syndrome, and neurogenetics. Primary interests are the diagnosis and management of genetic neurodevelopmental disorders and feeding.

Look for more information soon about an upcoming zoom conversation with Dr. Christensen!



## Meet Anna

At LSA, Anna is in charge of updating, streamlining, and maintaining our community database as well as onboarding new members and supporting LSA's incredible donors. Anna is passionate about advocating for those who too often go unheard. She loves working with donors who have a similar passion, writing, organizing databases, and a good ol' spreadsheet.

Anna also works with Activities Beyond the Classroom (ABC), writing grants to support accessible, enriching afterschool programs for low-income Cincinnati Public School students.

Originally from Amarillo, Texas, Anna moved to Cincinnati to pursue ballet at the University of Cincinnati's conservatory. About a year in, she realized this was no longer where her passion lied, but had grown to love the city. She began to take



*Anna Farris*

classes exploring the nonprofit sector, graduating with a bachelors in Organizational Leadership with a focus in nonprofit management.

Late 2019, Anna moved back to her hometown in Texas where she and her fiancé, Ian, met and now live with

their two dogs and one cat.

Anna will be attending and working our conference in June and is so looking forward to meeting the amazing LS boys, men, and families that she has been able to work with so far behind the screen.

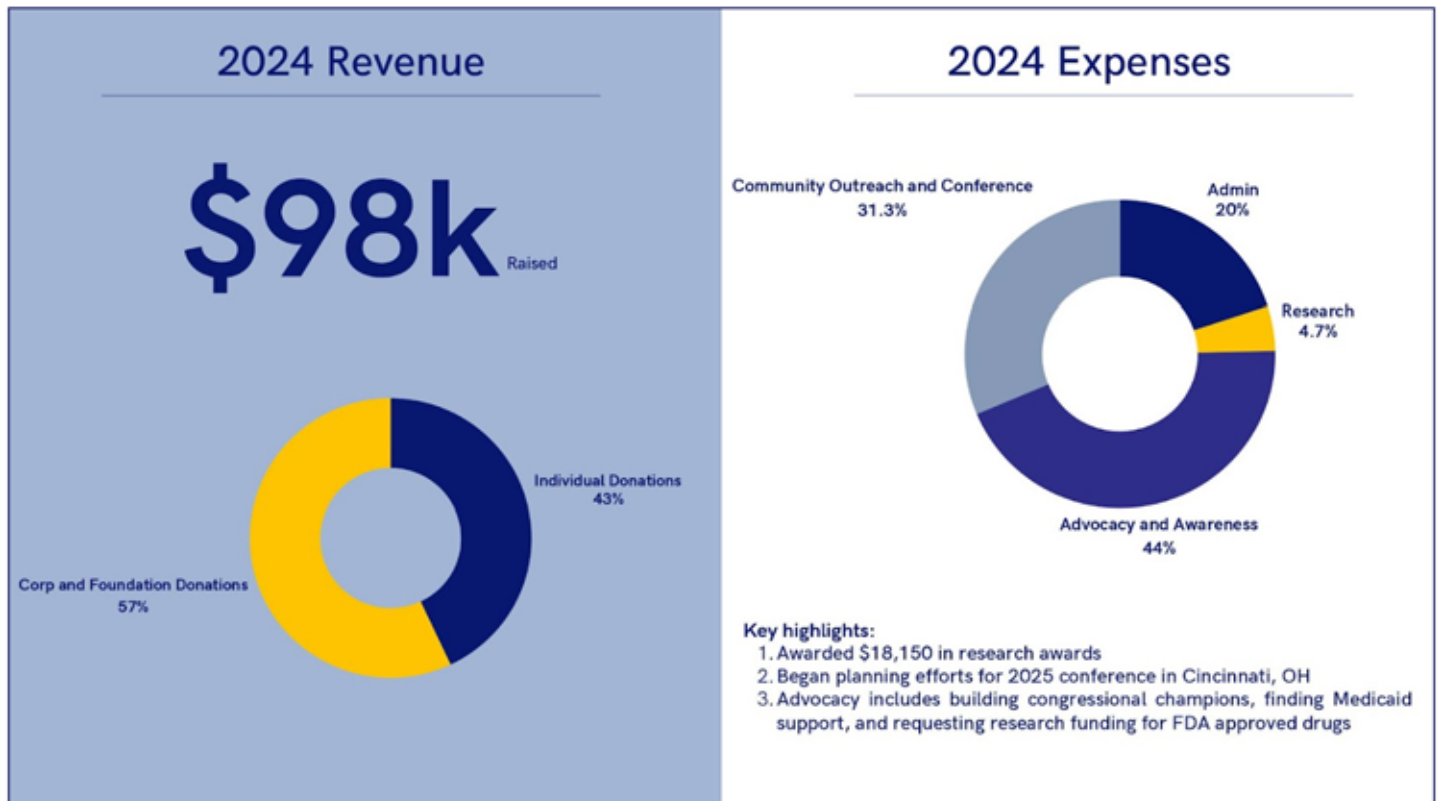
Please do not hesitate to reach out to Anna at

[lsa-admin@lowesyndrome.org](mailto:lsa-admin@lowesyndrome.org) if you have any questions regarding joining the LSA community, fundraising, making a donation, or just looking for general support.



# THANK YOU LSA SUPPORTERS

## 2024 Financial Highlights



## Fundraising Donations

The Lowe Syndrome Association (LSA) extends our deepest gratitude to our many generous donors. Your investment allows LSA to foster communication, provide education, and support research to improve the lives of persons with Lowe syndrome and their families, empowering individuals to attain their highest potential.

Thank you to everyone who financially supported the Lowe Syndrome Association. We are sincerely grateful for your compassion and continuous support.

Anne Lebherz Berry  
*Birthday Facebook*  
Lebherz, William & Diane household  
Staley, Susan household  
Staley, Tracey household

Kelsey Carman's Fundraiser  
*Facebook*  
Lewin household  
Stefanelli household  
Tharp household  
Varanyak household

Clare Gromoll's Fundraiser  
*GiveLively*  
Hanson household  
Nielson household  
Richey household

Robert-Irene Hare's Fundraiser  
*Facebook*  
Hare household  
Medellin household

Patricia Horan's Birthday Fundraiser  
*Facebook*  
Bramwell Siconolfi household  
Caminiti household  
Horan household  
Maas household  
Michael household

Jeri Kubicki's Fundraiser  
*GiveLively*  
Becker household  
Hartung household  
Pohlman household  
Vantine household  
Walker household



# LSA SUPPORTERS

**Thank you**

**to everyone**

**who financially supported**

**the Lowe Syndrome**

**Association.**

**We are sincerely**

**grateful for your**

**compassion and**

**continuous support.**

## Amy Nichols' Fundraiser

*Facebook & Instagram*

Arons household  
Beni household  
Carrier household  
Diaz household  
Gann household  
Gwdbis household  
Hamner household  
Karrh household  
Kim household  
Kirner household  
Levy household  
Liljegren household  
McCue Lee household  
Nicoll household  
Osman household  
Ricciardi household  
Richards, Amy & Mark household  
Saltzman household  
Sullivan, Michele household  
Vascellaro household  
Williams household

## Lisa Katz Waldbaum's Fundraiser

*Facebook*

Cohen household  
FX household  
Golubitsky household  
Goodman household  
Harrison household  
Henderson household  
Holz household  
Kerzhner household  
Newman, Donell household  
Newman, Zoe household  
Ochiai household  
Olgin household  
Rosen household  
Setton Bianchi household  
Sher household  
Smith household  
Sullivan, Brian household  
Villa household  
Waldbaum, Naomi & Basil household  
Waldbaum, Sadie household  
Waldbaum, Simon household  
Wildfeuer household  
Wolfson household  
Zhitenev household

We would like to thank the following individuals who created fundraisers on the LSA's behalf

★ Special thanks to those who raised more than \$500.

Cricket Alberts  
★ Naomi Alvarado  
Anne Lebherz Berry  
★ Fitz Carlile  
★ Kelsey Carmen  
Cecelia Confer  
★ Lisa Cookson  
Fernanda Dal Pozza  
★ Rachel Elizabeth  
★ Clare Gromoll  
Robert-Irene Hare  
Kimberly Haubert  
Theresa Haugen  
Cole Higgins  
Beka J. Kleinpeter  
★ Jeri Kubicki  
Isi Lopez  
Kayla Guss Martin  
Kendell Payne  
Heidi Gioia Payot  
January Pepper  
★ Amy Richards  
Katie Carlile Stanton  
★ Lisa Waldbaum

We would like to thank the following corporations and foundations who provided generous donations.

Dayton Foundation  
El Fish and Wildlife Foundation  
Friedman Townsend Foundation  
The Gates Foundation  
Greater Cincinnati Foundation  
JAM Service Company  
Playstation Cares  
Service Roofing  
Top Jewish Foundation  
Trust Mark Foundation

**Note:** Fundraising donations listed in this section include all donations received in 2024 (January 1, 2024 to December 31, 2024).

# THANK YOU LSA SUPPORTERS

## Direct Donations

### \$1,000

DeGori household  
 Kubicki, Jeri & Josh household  
*in honor of Blake Kubicki*  
 Lee, Michael household  
*in memory of Kang-Suk Andrew Lee*  
 Myatt Household  
*in honor of Dylan Myatt and Family*  
 Taverna household  
 Wright household  
*in honor of Blake Kubicki*

### \$500 - \$999

Brunelle household  
*in honor of Joseph Andrew Felkl*

### \$250 - \$499

Bopp household  
*in honor of Gregory Clark*  
 Gill household  
*in honor of Robert Erlandson*  
 Gromoll household  
*in honor of Sam Gromoll*  
 Hartung household  
 McCue Lee household  
 Newton household  
*in honor of Carson Newton*  
 Richey household  
 Sietz household  
*in honor of Blake Kubicki*  
 VanderGoot household  
 Waldbaum, Naomi & Basil household  
*in honor of Alex Waldbaum*

### \$100 - \$249

Alberts, Michael & Cathy household  
 Arons household  
 Bass household  
*in honor of Aiden Bass*  
 Beni household  
 Bramwell Siconolfi household  
 Buchs-Hammonds household  
*in honor of Sam Gromoll*  
 Byles household  
*in honor of Blake Kubicki*

Clausen household  
*in honor of Ethan Clausen*  
 Cohen household  
 Colwell household  
*in memory of Michael Tyler Richardson*  
 Craig household  
*in honor of Blake Kubicki*  
 Daringer household  
*in honor of Clayton and Levi Arnold*  
 Dubrovsky household  
*in memory of Lenny Benjamin Dubrovsky*  
 Eysmans Denion household  
 Fletcher-Gill household  
*in memory of Nicholas Fletcher*  
 FX household  
 Gann household  
 Getty household  
*in honor of Noah Wood*  
 Gillespie, Ben household  
*in honor of Blake Kubicki*  
 Gillespie, Debbie household  
*in honor of Blake Kubicki*  
 Hamner household  
 Hardin household  
*in honor of Liam Lotz*  
 Higgins household  
 Holz household  
 Kubicki, Laura household  
*in honor of Blake Kubicki*  
 Lebherz, William & Diane household  
*in honor of Corbin Berry*  
 Lee, Jay & Young household  
*in memory of Kang-Suk Andrew Lee*  
 Lee, Jean Ah household  
*in memory of Kang-Suk Andrew Lee*  
 Levy household  
 Lewis household  
 Nicoll household  
 O'Boyle household  
*in honor of James Jerman*  
 Olgin household  
 Orlando household  
*in honor of Cristopher Orlando*  
 Orr household  
*in honor of Scott Richards*  
 Pohlman household  
 Rader household  
*in honor of Scott Richards*  
 Richards, Amy & Mark household

Richards, Lynn & John household  
*in honor of Scott Richards*  
 Saltzman household  
 Sher household  
 Springer household  
 Stein household  
*in honor of Alec Everitt*  
 Strauss household  
*in honor of Scott Richards*  
 Sullivan, Brian household  
 Sullivan, Michele household  
 Top Jewish Foundation  
 Vantine household  
 Varanyak household  
 Vascellaro household  
 Waldbaum, Adam & Lisa household  
 Waldbaum, Simon household  
 Wenglikowski household  
*in honor of Scott Richards*

### \$50 - \$99

Becker household  
 Benos household  
 Carrier household  
 Hanson household  
 Haugen household  
 Henderson household  
 Horan household  
 Karrh household  
 Lewin household  
 Liljegren household  
 Maas household  
 Mancuso household  
*in honor of Ethan Clausen*  
 Michael household  
 Nielson household  
 Osman household  
 Ricciardi household  
 Setton Bianchi household  
 Smith household  
 Staley, Susan household  
 Staley, Tracey household  
 Stamm household  
*in honor of Kyle Alberts*  
 Tharp household  
 Tietz household  
 Villa household  
 Wildfeuer household  
 Wolfson household

# THANK YOU LSA SUPPORTERS

## \$1 - \$50

Alberts, Cristen household  
Caminiti household  
Diaz household  
Evenson household  
*in honor of Sam Gromoll*  
Golubitsky household  
Goodman household  
Gwdbis household  
Hare household  
Harrison household  
Johnson household  
*dedicated to the Johnson Boys*  
Kerzhner household  
Kim household  
Kirner household  
Kroger household  
Maren Bjork household  
*in honor of Sam Gromoll*  
Medellin household  
Newman, Donell household  
Newman, Zoe household

O'Brien household  
*in memory of Samir O'Brien*  
Ochiai household  
Payot household  
Rosen household  
Siconolfi household  
*in honor of nephew with LS*  
Stefanelli household  
Waldbaum, Sadie household  
Walker household  
Williams household  
Zhitenev household

**Note:** Direct donations listed in this issue were those received from November 1, 2024 to December 31, 2024. Donations received after that date will be included in the next *On the Beam*.



## LSA Merchandise Available

LSA merchandise is now available at [www.zazzle.com/lowe\\_syndrome\\_assoc](http://www.zazzle.com/lowe_syndrome_assoc). Options include apparel, mugs and phone cases. A portion of all sales are given to the Lowe Syndrome Association. Help us spread awareness of the good work of the Lowe Syndrome Association and support our boys.