Newsletter of the Lowe Syndrome Association • Spring 2025 • Vol. 43, No. 1

Circle of Care | Vision for a Cure"

IN THE BEAM

LSA SPOTLIGHT



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

Global Lowe Syndrome Research Initatives

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 opportunity 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 5 minutes to sign-up with Citizen Health! h ttps://www.citizen.health/partners/lsa)

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

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

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LOWE SYNDROME ASSOCIATION

Circle of Care | Vision for a Cure

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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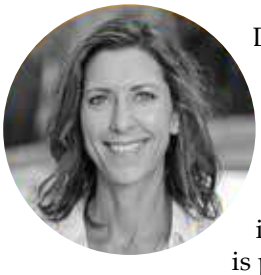
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PRESIDENT'S MESSAGE



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.

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.

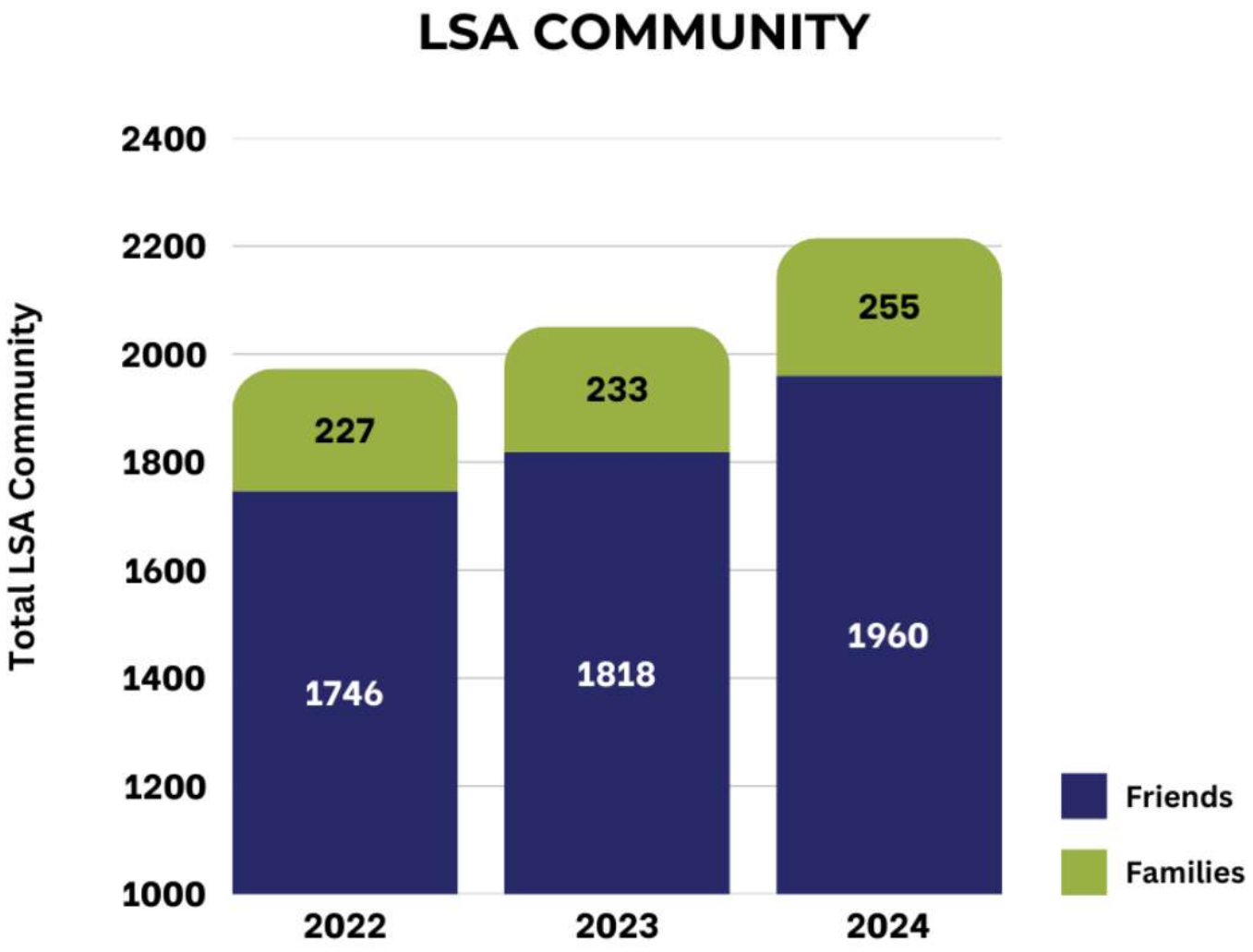
Laura Kim

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!



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 fiance' 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 aunties 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, 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. Devuyst. 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 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'Reilley, 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 northeast 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 classes exploring the nonprofit sector, graduating with a bachelors in Organizational Leadership with a focus in nonprofit management.



Anna Farris

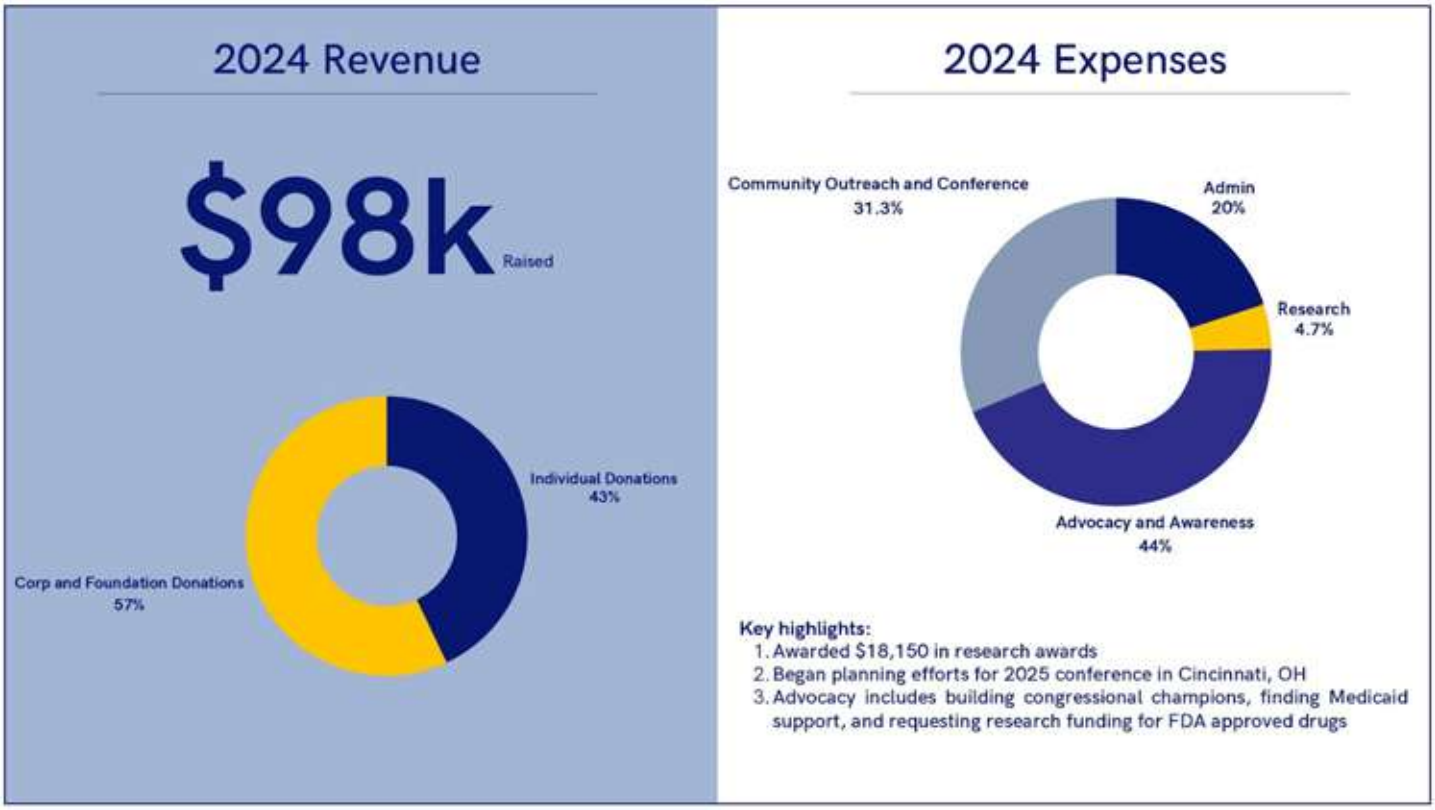
Late 2019, Anna moved back to her hometown in Texas where she and her fiance, Ian, met and now live with their two dogs and one cat.

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 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 thnks 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 follwoing corporations and foundations who provided generous donations.

Dayton Foundation
Fl 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. 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.