Newsletter of the Lowe Syndrome Association ▪ Spring 2026 ▪ Vol. 45, No. 1

LSA

Circle of Care | Vision for a Cure

ON THE BEAM

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RARE DISEASE DAY: SHINING A LIGHT ON LOWE SYNDROME TO BUILD AWARENESS

After this year's Rare Disease Day, we are feeling incredibly inspired by the power of our community. Rare Disease week is all about coming together to raise awareness, share stories, and celebrate the strength of those impacted by Lowe syndrome.

Throughout the week, families and individuals showed up in such a meaningful way by sharing photos, stories, and moments that truly capture what this journey looks like.

Continued on Page 3.

LOWE SYNDROME ASSOCIATION

Circle of Care | Vision for a Cure

The Lowe Syndrome Association, Inc. (LSA) is a non-profit corporation dedicated to 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 LSA Community,

Over the past few months, I've had the opportunity to spend time in person with several Lowe syndrome families. I cannot overstate how meaningful those moments are. There is something uniquely powerful about being together – sharing experiences, laughter, and understanding in a way that simply can't be replicated from a distance.

That sense of connection is top of mind as we begin planning for our 2027 conference. By our next newsletter, we expect to have finalized the venue and will be shaping an agenda that supports individuals with Lowe syndrome at every stage of life – from newly diagnosed children through adulthood – while also honoring and including families who have lost a child, whose perspectives continue to guide our community.

We are also incorporating much of the insights attendees shared following our 2025 conference. Your feedback is invaluable as we shape an experience that reflects what matters most and continues to bring people together in meaningful ways.

As the seasons shift, so does the rhythm of our work at LSA. We are focused on strengthening the infrastructure that supports everything we do so that we can better serve our families today while building for the future. This includes updates to our CRM, a new website, preparations to launch the LSA Research Endowment Fund, and the addition of new talent to our Board. We are also strengthening our fundraising and development efforts to sustain both research and family programs over the long term.

Our focus remains clear: advancing research, expanding awareness, and strengthening the connections that make this community so resilient. Emerging efforts – like those led by the Cure Lowe Foundation and research into Alpelisib's potential to impact multiple systems of the body – reflect the progress that sustained commitment and collaboration can make possible.

At the same time, we recognize the realities of today's research environment, where even promising work often faces significant funding challenges. This is why building long-term research support, expanding advocacy at the congressional level, and fostering the next generation of researchers are so critical.

Thank you for being part of this community and for the many ways you help move this work forward. Together, we are building momentum for our sons.

Warm Regards,

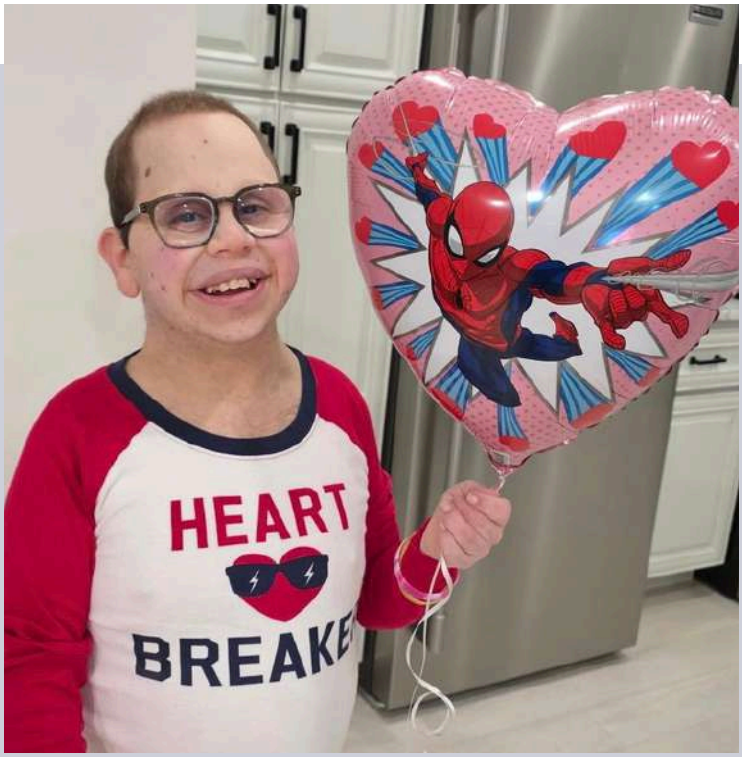
Jeri Kubicki, President
Lowe Syndrome Association

SHINING THE LIGHT ON LS TO BUILD AWARENESS

Continued from Page 1.

Throughout the week of Rare Disease Day, families and individuals showed up in such a meaningful way by sharing photos, stories, and moments that truly capture what this journey looks like. Each image reflects love, resilience, and the everyday victories that deserve to be seen and celebrated.

These moments remind us that awareness starts with connection. When we share our stories, we help others understand, we build community, and we continue moving forward together towards better support, more research, and one day, a cure.



Alec

Liam

Jonny

"When we share our stories, we help others understand, we build community, and we continue moving forward together..."

SHINING THE LIGHT ON LS TO BUILD AWARENESS

Blake

Thomas

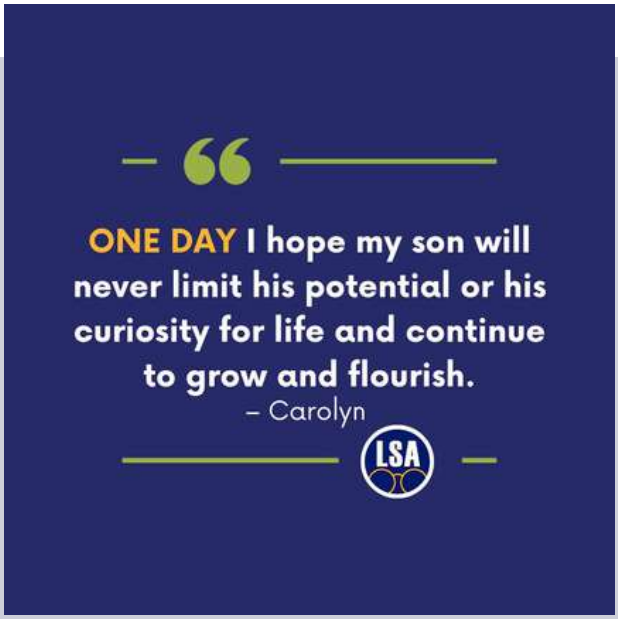
"Each image reflects love, resilience, and the everyday victories that deserve to be seen and celebrated."

Aiden

Theo

SHINING THE LIGHT ON LS TO BUILD AWARENESS

The “One Day” graphics highlight the hopes, dreams, and lived experiences of families in the Lowe syndrome community. Through personal quotes from parents and caregivers, the campaign raises awareness, builds connection, and shares the meaningful aspirations they hold for their loved ones. These messages invite others to better understand the impact of Lowe syndrome while fostering support, compassion, and community.



Click the link to share your community moments and/or “One Day” quotes with our LS community. Join us in building community, helping others better understand, and continuing to move forward together towards better support and resources.

Share Your Moments Here!

Inspiring the Next Generation of Philanthropists

Cincinnati's Guardian Angels 8th Grade Class Nominates the Lowe Syndrome Association for a Magnified Giving Award

Lowe Syndrome Association President, Jeri Kubicki, sits with the 8th grade class at Guardian Angels (GA) School in Cincinnati, Ohio.

On March 2, 2026, the Lowe Syndrome Association (LSA) had the opportunity to visit the 8th grade class at Guardian Angels (GA) School after being nominated by the students for a Magnified Giving Award – an initiative designed to introduce students to the power and responsibility of philanthropy.

Through Magnified Giving, students learn how charitable organizations address real-world challenges. They research nonprofits, invite representatives to speak with their class, and ultimately decide together which organization will receive a grant. The experience gives students a meaningful opportunity to explore community needs while learning how thoughtful giving can make a difference.

SHINING THE LIGHT ON LS TO BUILD AWARENESS

The GA students approached the process with impressive curiosity and care – asking thoughtful questions about Lowe syndrome and the realities faced by families navigating this condition. Their questions reflected both empathy and a genuine desire to understand topics such as how rare diseases occur, why some conditions affect boys more often than girls, and how children with medical challenges grow and develop over time.

The discussion also gave students a glimpse into running a rare disease nonprofit. They learned how the Lowe syndrome community spans many countries and cultures, and how organizations like LSA work virtually to connect families, fund research, and advocate for greater awareness and support.

Programs like Magnified Giving help young people see that philanthropy is not only about donating money – it is about learning, asking questions, and understanding how compassion and action can improve lives. We are deeply honored to be considered by the GA students for this meaningful award.

"Programs like Magnified Giving help young people see that philanthropy is not only about donating money – it is about learning, asking questions, and understanding how compassion and action can improve lives."

OUR COMMUNITY IN PHOTOS

LSA Community Moments

We love celebrating the everyday moments that make our community so special. Thank you to the families who shared these snapshots of joy, growth, and connection with us!

Matt

Matt is hard at work at Winter Bros, and we love seeing him in his element. Moments like these highlight the independence and dedication within our community.

Matisse and Evie

Nothing beats a snowy day spent with siblings. Matisse and Evie are enjoying time together, making memories and embracing the simple joys of winter.

OUR COMMUNITY IN PHOTOS

Brooks

Brooks is all smiles as he continues to thrive and explore the world around him. His joyful spirit shines through as he happily gets around in his walker, bringing so much light to those around him.

OUR COMMUNITY IN PHOTOS

Raymond

Raymond is fully in the holiday spirit. From participating in a festive Christmas run in his community to meeting Santa, his joy is contagious. One of his favorite traditions includes stopping by Starbucks for his milk, and sharing that moment with Santa made it even more special.

Sebastian

Sebastian is soaking up joyful moments during his time in Australia, embracing new experiences and making memories along the way.
His adventures are full of fun and discovery.

OUR COMMUNITY IN PHOTOS

Ewan

Ewan is staying cool this winter! One of Ewan's favorite things is to play with his electric cars, trains, and train tracks. Ewan is quick to show others how to play along.

OUR COMMUNITY IN PHOTOS

Dylan

Dylan turned 20 years old this year and is living at home with the daily support of carers. Dylan recently stayed with his favorite carer for two weeks while his mom took a well-deserved, solo ski trip in Japan! Dylan is very happy at “Emma’s House,” playing with his favorite toys and carers.

Thank you for sharing your photos with us!
You can submit or email photos and/or stories of your son, your family – whatever you want to share with our LS community.

Submit photos here!

LSA MEMORIALS

As a community, we come together in celebration of life and in remembrance of those we have lost. We mourn the passing of cherished individuals whose lives were a testament to courage, resilience, and love. Their memory will forever remain in our hearts and continue to inspire our mission to support one another and advance progress for those affected by Lowe syndrome. With deepest respect and affection, we honor:

Matthew Bradney

04/22/1986 - 01/12/2026

LSA MEMORIALS

Hunter Haugen

02/06/1995 - 01/21/2026

Our beloved son and brother, Hunter John Haugen, passed away on January 21, 2026 at the age of 30. Born in Saint Paul, Minnesota, Hunter graduated from Centennial High School where he participated in adaptive softball, choir, and was a manager for the varsity football team. He attended many school activities including the homecoming dance, Prom and the senior all-night party.

In 2018 Hunter asked to move out like his brother who was away at college and in 2019 Hunter lived with two roommates at his group home. He took pride in gaining the confidence to move out on his own terms to a new group home, where he enjoyed group outings, playing games and helping with meals with his staff. He worked with a group of his peers at Pentair through the RISE community work program assembling parts for hydration systems. With his profound passion for good food, Hunter met Paula Deen in 2010 through the Make-A-Wish Foundation, and in 2020 he participated in a filming of Diners, Drive-ins and Dives.

The Haugen Family

LSA MEMORIALS

In 2021, he received the honor of throwing out the first pitch at his brother's final collegiate home baseball game.

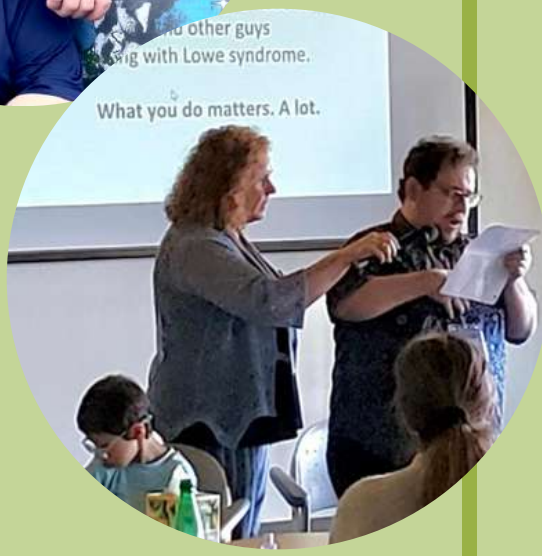
In 2023, Hunter and his friend Brooke were hired to do a video interview for a graduate course on art education for special needs students.

Hunter attended a multitude of International Lowe Syndrome conferences and in October 2024, he traveled to the International Lowe Syndrome Research Symposium at Purdue University where he publicly thanked the medical researchers for their work.

He enjoyed socializing with the college students, especially the women.

Hunter had a magnetic charm that brought light and laughter into every room and made people feel welcome and valued.

Hunter and his brother, Blake Haugen.



Hunter speaking at the International Lowe Syndrome Research Symposium at Purdue University.

He loved dogs, music and summer concerts, bowling, errands with Grandpa, solving math equations, farm animals especially highland cows, pigs and goats, cooking, puppy visits and dog training, trips to the coffee shop bookstore, sharing a meal, reading to horses, drawing birthday cards, movies or dancing with his friend Brooke, and all of his favorite snacks, especially pickles.

He will be deeply missed.

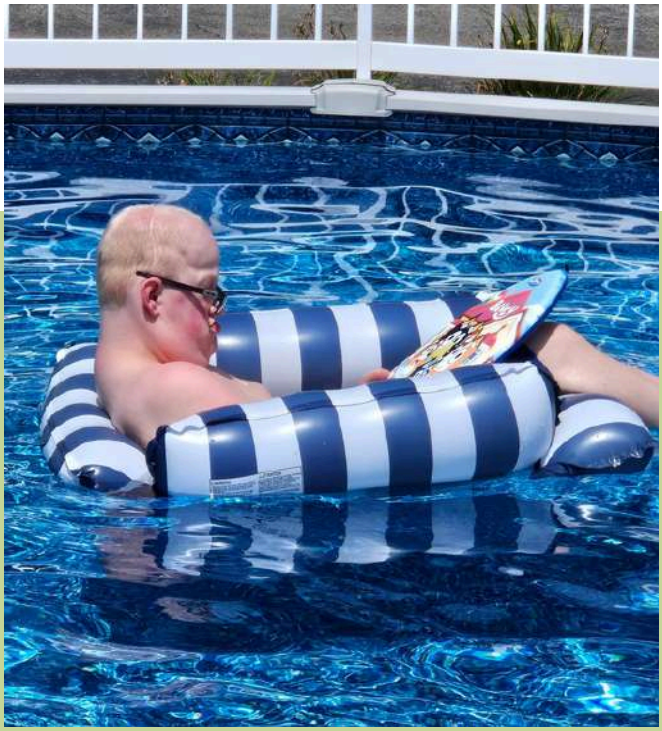
Dave, Theresa and Blake Haugen

LSA MEMORIALS

Thomas Allen Hays Jr.

10/22/1998 - 01/27/2026

LSA MEMORIALS



Thomas Allen Hays Jr.

LSA MEMORIALS

Barrett Scott

6/30/2025 - 01/18/2026

Barrett Matthew Scott was our miracle baby. He came into this world through an emergency C-section and faced multiple medical complications, including Lowe syndrome and liver disease. During his six months of life, he spent over four of them in the hospital and underwent numerous surgeries.

Even though our time with him was short, we treasured every single moment. From weekends spent together in the NICU as a family to celebrating his older brother's Ninja Turtle birthday party right in his hospital room, those memories will forever be close to our hearts.

His sister showed her love in the purest way — always checking on him and laying beside him whenever she could, making sure he knew he was never alone.

He learned about Power Rangers from his brother and even earned his own set of Power Stars. He was our little snuggle bug, happiest when he was being held and cuddled by his Momma and Dadda.

We are incredibly blessed to have had the time we did with him. He will forever be our baby Barrett, living on in our memories and in the stories we share with the kids. His strength and his fight continue to inspire us and keep us moving forward.

We will always love you, baby Barrett.

Beyond the Kidney: How Alpelisib is Opening New Doors for Lowe Syndrome

By Dr. Jenny Gallop
Department of Biochemistry, University of Cambridge and Gurdon Institute

A DOUBLE-WIN FOR DISCOVERY

Our recent experiments have taken us beyond the kidney. We've discovered that alpelisib (al-pel-i-sib) shows effectiveness in both eye and brain cells - a massive win for looking at Lowe syndrome holistically. We also dug into how it works. Does it help via actin filaments, or through the pathways it uses for other diseases? The answer is both! By working in two ways at once, alpelisib outperformed other related medicines, which only worked in one way and only in kidney cells. This confirms that alpelisib is our strongest candidate for further study.

Following work by Claudio Aguilar (Purdue, Indiana) and Antonella de Matteis (TIGEM Italy), we looked at six different cellular processes affected by the loss of the OCRL protein. We are thrilled to report that alpelisib improved three out of those six processes. While three remained unchanged, these were in areas that are historically harder to study with more variable results. Overall, seeing improvement across several complex functions is as good as we could have realistically hoped for!

PERSONALIZING THE FUTURE OF TRIALS

One of our most exciting breakthroughs happened right in the lab: we successfully grew kidney cells from a volunteer with Lowe syndrome.

This "opens the door" to a future where boys and men with Lowe syndrome could have their own cells tested against alpelisib before deciding to join a clinical trial. It takes the guesswork out of participation and puts the power back in the hands of the patients and their families.

"One of our most exciting breakthroughs happened right in the lab: ***we successfully grew kidney cells from a volunteer with Lowe syndrome."***

PERSISTENCE IN THE FACE OF HURDLES

To take this to the next level, we applied for funding to test alpelisib on cells from ten UK volunteers and biobanked samples from Francesco Emma's team in Italy. Unfortunately, the current funding climate is incredibly competitive, with success rates below 10%.

RESEARCH & ADVOCACY UPDATES

Despite receiving positive feedback on the high potential of our work, we weren't selected this round. However, because we've proven we can do the work technically, we aren't giving up. We are already preparing to try again.

Additionally, since research does not happen in a vacuum, we continue to strengthen our global links, including our partnership with Raghu Padinjat's lab.

Our team member, Thomas Blake, recently visited them in Bangalore, India, to share knowledge and advance our collective mission.

Raghu Padinjat, Thomas Blake, and Yojet Sharma

REACHING THE DESTINATION TOGETHER

Just like these two Indian Peafowl (peacocks!) captured during Thomas Blake's visit to Bengaluru (previously called Bangalore) in India, research is a shared journey. We are moving forward side-by-side with global partners to find answers for Lowe syndrome.

Two Indian Peafowl (peacocks) captured by Thomas Blake's visit to Bengaluru, India,

SCIENCE DOESN'T STOP AND NEITHER DO WE

We want to extend our heartfelt thanks to the Lowe Syndrome Association (LSA) and the community that supports it. Your hard work and tireless fundraising allows us to complete these studies and keeps progress coming. We are in this together!

RESEARCH & ADVOCACY UPDATES

Federal Engagement Update

By Alex Perez
Director of Federal Affairs, The Normandy Group

"Personal perspectives play a critical role in shaping how offices prioritize research funding and consider requests..."

As we continue building support for Lowe Syndrome research on Capitol Hill, our efforts remain focused on increasing awareness and creating new opportunities for federal investment that can help move research forward and bring meaningful progress to families.

A key part of this work is a congressional letter led by Rep. Greg Landsman that would include Lowe Syndrome as an eligible condition under the Peer Reviewed Medical Research Program within the FY27 Defense Appropriations bill. This program is one of the most important federal pathways for advancing medical research through the Department of Defense. Inclusion would open the door to critical funding for studies that are already showing promise.

To support this effort, we are engaging a targeted and bipartisan group of congressional offices, focusing on those involved in defense appropriations and Members of the Rare Disease Caucus. These conversations focus on helping offices understand both the urgency of the need and the broader impact that Lowe syndrome research can have across related conditions.

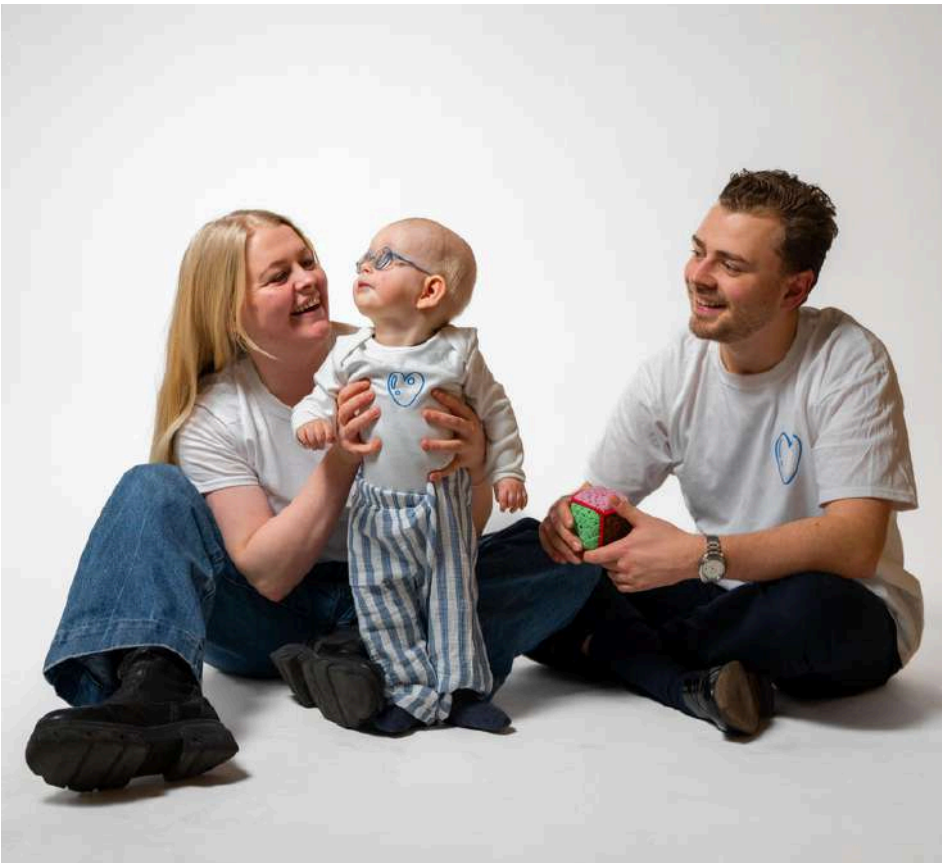
In the coming weeks, we will begin reaching out to congressional offices to schedule a series of short virtual meetings between LSA families and their Members of Congress and staff. These meetings are designed to complement the congressional letter and provide offices with the opportunity to hear directly from families. Personal perspectives play a critical role in shaping how offices prioritize research funding and consider requests like this.

Our team will handle scheduling and preparation to make participation as simple as possible. We will work closely with families to ensure they feel comfortable and supported throughout the process.

If you are interested in participating in one of these virtual meetings, please reach out to Alex Perez at aperez@thenormandygrp.com.

Cure Lowe Foundation: A Father's Mission to Develop a Gene Therapy

By Sebastian Honoré
Founder & CEO, Cure Lowe Foundation & Walther Therapeutics



Three years ago, I was an economist at the Danish Ministry of Finance, expecting my first child with my partner Cecilie. When our son Walther was born, the first thing I noticed were his eyes - completely black. He had been born with cataracts in both eyes. Over the following weeks, as his condition worsened and we were admitted to the hospital, a genetic test confirmed what we had not known to fear: Lowe syndrome.

The doctor told us what many of you reading this already know too well. Walther would depend on medical care for the rest of his life. The disease would affect his brain, his eyes, and his kidneys. Life expectancy shortened. And, critically, no treatment that would change the course of the disease.

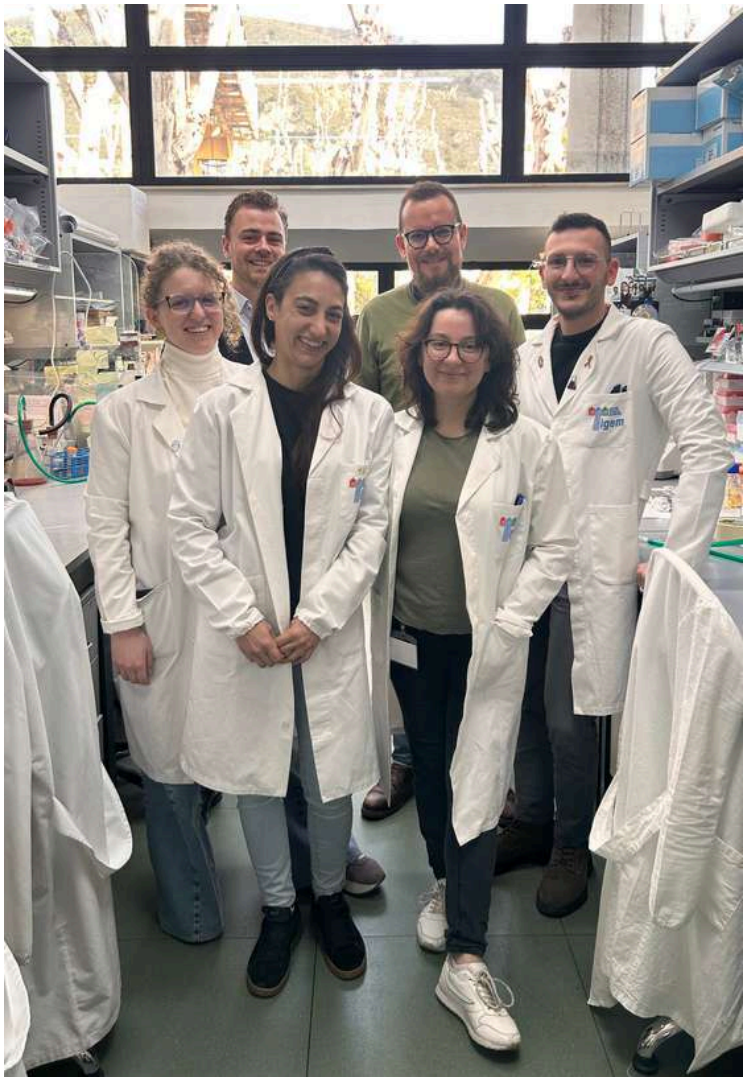
The same day we received the diagnosis, I told Cecilie we would find a way. I am not a scientist - my background is in economics - but the more I looked into it, the clearer it became that the reason so few rare diseases have treatments is not purely scientific.

Of more than 7,000 known rare diseases affecting 300 million people worldwide, only about five percent have any therapy at all. The obstacles are, to a large extent, economic: the cost of development, the difficulty of assembling a team, the struggle to fund work that serves very small patient populations. That is a problem I understood how to attack.

I left my job in the Ministry and founded the Cure Lowe Foundation, and from it our gene therapy company, Walther Therapeutics - named after our son. We have one goal: to develop a gene therapy for Lowe syndrome before it is too late for Walther and the children like him.

WHAT IS THE CURE LOWE FOUNDATION

The Cure Lowe Foundation is a nonprofit research organization, registered in Copenhagen. Our purpose is narrow and specific: to fund and drive forward the science needed to bring WTX-001, our AAV gene therapy candidate, from the laboratory into clinical trials for Lowe syndrome patients. That is the problem we exist to solve. We are a research engine, and we cannot do this work without the trust of the community.



THE TEAM

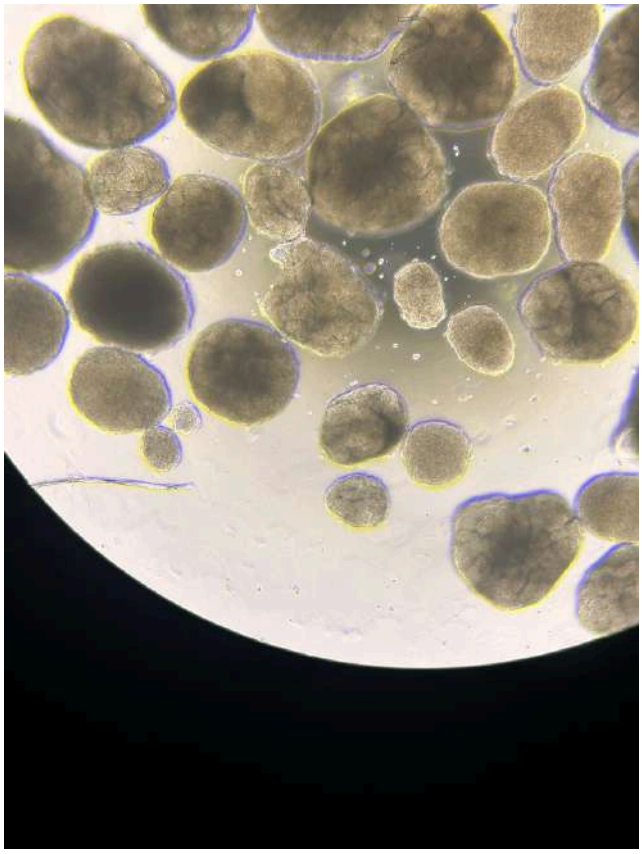
We have built a team with the exact experience this program needs. Dr. Leopoldo Staiano, our Chief Scientific Officer, has been working on Lowe syndrome specifically since 2012 - he knows this disease as well as anyone in the world. Dr. Nadina Grosios brings over two decades of drug development experience across preclinical, clinical, and regulatory work, including at uniQure and Novartis. Dr. Erich Ehlert, our Head of CMC, spent a decade at uniQure overseeing AAV manufacturing.

Our scientific advisory board is composed of four researchers who have each personally taken AAV gene therapies through clinical trials to patients: Dr. Xavier Anguela (VP Gene Therapy at Lilly, formerly AskBio and Spark Therapeutics), Dr. Federico Mingozzi (former CSO at Spark Therapeutics), Dr. Virginia Haurigot (ex-Spark Therapeutics) and Katie Wachtel (VP of Regulatory, Eli Lilly).

RESEARCH & ADVOCACY UPDATES

WHERE WE ARE

The science has come a long way. Our gene therapy delivers a working copy of the OCRL gene directly to kidney cells. Working with Dr. Staiano's laboratory in Naples, we have shown that the therapy corrects the cellular defects in cells taken from Lowe syndrome patients, and, in human kidney organoids grown from those cells, restores function to healthy levels. In non-human primate studies, we have confirmed that our delivery approach reaches the right cells in the kidney.



Across every model and every measurement, the answer has been the same: it looks like it works. We are now preparing Orphan Drug Designation applications with both the European and U.S. regulatory agencies - a significant milestone on the road to clinical trials.

None of the work described here would have been possible without community support. The LSA and the Lowe Syndrome Trust have both contributed to moving this program forward, and this is exactly the kind of international collaboration that gives us the best chance of reaching children in time. We share the same ultimate goal, and pooling our efforts - whether through funding, data sharing, or patient networks – is how we get there faster.

One example: establishing the OCRL mouse colony needed for our preclinical work. Only a handful of animals carrying the right genetic profile existed anywhere in the world. To secure the colony, our team organized a large-scale breeding procedure with a specialist facility in New York, and studies are now underway. This simply would not have been possible without your support.

WHAT COMES NEXT

We are still far from starting clinical trials. We need to complete safety studies, finalizing manufacturing with a specialist partner, and prepare the regulatory submissions needed to open a trial. All of this requires funding and specialized knowledge to pull together, but we are getting there.

RESEARCH & ADVOCACY UPDATES

We are planning to organize an international clinical workshop that will bring together nephrologists, patient representatives, and regulatory experts from across Europe and the U.S. to define the trial design together. More information on this later.

We are currently fundraising to support these final steps, drawing on a combination of grants, foundation support, and philanthropic capital. Every introduction, every shared voice, and every dollar raised moves us closer to a therapy for our children.

Walther taught me that nothing is impossible. The odds of a child being born with Lowe syndrome are so small they barely register - and yet here he is. If that can happen, so can the opposite: a therapy, against the odds.

Thank you for standing with us on the way there.

"We share the same ultimate goal, and pooling our efforts - whether through funding, data sharing, or patient networks – is how we get there faster."

LSA Board of Directors Welcomes Terry Johnson

The Lowe Syndrome Association is pleased to welcome Terry Johnson to our Board of Directors.

Terry joins the Board with a strong commitment to our mission and a clear vision for strengthening the LSA's financial future. A dedicated member of our community, Terry is the father of Matthew and Andrew (Andy), who has Lowe syndrome. Together, their family has attended nine LSA Conferences, reflecting a deep and long standing connection to our community.

The Johnson Family at the LSA 2025 Conference in Cincinnati, Ohio.

Since the 2025 conference, Terry has generously volunteered his time and expertise to support the LSA's financial strategy and long-term planning. His professional background includes service in the U.S. Army, executive leadership roles in retail and emergency medical transportation, and his current position as Executive Director of the McEachern Endowment Fund. He also brings valuable public service experience, having served on Planning & Zoning Commissions for multiple municipalities, along with advanced degrees in Leadership, Business Administration, and Public Administration.

As Terry transitions into Board service and prepares to step into the role of Treasurer, he will help lead the LSA into an important new chapter of financial stewardship. Under his leadership, the organization is advancing the development of both the LSA Research Endowment Fund and a Director Endowment Fund- key initiatives designed to preserve, sustain, and grow our financial resources for long-term impact. These efforts, in partnership with external financial institutions, represent a significant step forward in ensuring the LSA's stability and ability to invest in research and community support for years to come.

We are grateful for Terry's willingness to serve and for the experience, leadership, and heart he brings to this role. We look forward to the impact he will have as we continue working toward a future where the challenges of Lowe syndrome are met with meaningful solutions.

Thank You to Cricket Alberts for Six Years of Dedicated Service

The Lowe Syndrome Association extends our deepest gratitude to Cristen ("Cricket") Alberts for her exceptional service as Treasurer and Board member since 2020.

Cricket has been instrumental in building a strong financial foundation for the LSA. Her leadership brought structure, clarity, and sustainability to our financial operations- most notably through organizing our financial systems into a streamlined, cloud-based environment and establishing consistent, reliable processes that continue to serve the organization today.

One of Cricket's most significant contributions was guiding the LSA through its first-ever external financial audit - a voluntary step taken by the Board to strengthen transparency and accountability. The successful outcome of that audit affirmed the LSA's strong and compliant fiduciary position and marked an important milestone in our organizational maturity.

Beyond her technical expertise, Cricket's commitment to the LSA is deeply personal. As the sister of Kyle, who has Lowe syndrome, she has been a long standing part of this community - attending conferences alongside her family and growing into a leader within the organization. She has balanced her Treasurer responsibilities alongside her professional career as a Certified Public Accountant, all while remaining actively involved in her brother's care and close to her family in North Carolina.

We are incredibly fortunate to have benefited from Cricket's time, talent, and dedication, and we thank her for all she has given to the LSA and our community. Her impact will be felt for years to come through the systems she built and the integrity she brought to every aspect of her role.

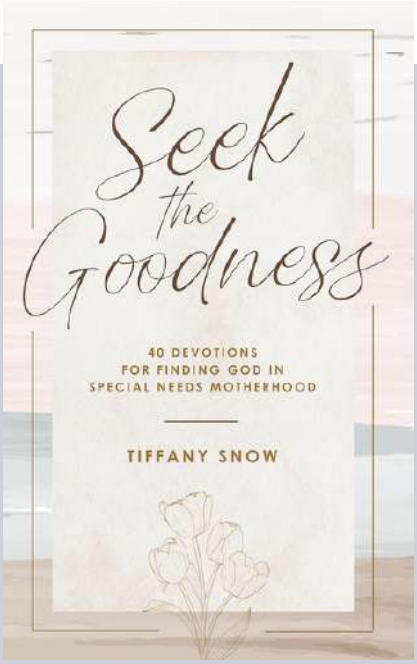
Cricket and Tyrese at the LSA 2025 Conference in Cincinnati, Ohio.

LSA NEWS

A Lowe Mom's Journey to Support Others

One of the many beautiful parts of our Lowe community is the way our moms continue to use their stories, faith, and experiences to encourage others.

Tiffany Snow, one of our Lowe moms, reached a special milestone by creating a devotional inspired by her personal journey in special needs motherhood. Her hope is to encourage and walk alongside other moms, demonstrating the strength and compassion within this community.



If you would like to connect with the author, you can reach her online at tiffanysnowwrites.com, send an email to tsnowwrites@gmail.com, and find Tiffany's devotional here.

Help Advance Dental Research for Lowe Syndrome

Dr. Tesini and Dr. Gennantonio are seeking copies of lateral head films (see example below) of your child with Lowe syndrome to help develop orthodontic growth norms for LS.

Once we have sufficient community wide information, we will share this with you, which in turn might be very useful for your local dentist and/or orthodontist.

We've crafted an email for you to cut, paste, and send to your dentist or orthodontist before any upcoming appointment!

LSA NEWS

Lowe Syndrome Mom's Retreat

Hosted by: Kristina Gill Erlandson
(Robert's Mom)

LoweSyndrome.MomsRetreat2026@gmail.com
(805) 234-6399

520 Drake Street
Cambria, CA 93428

View more trip details here!

Did You Know?

Founded in 1983 by Kaye McSpadden, the Lowe Syndrome Association operates under a set of bylaws incorporated in the state of Indiana. These bylaws are the foundation for how the LSA Board governs the organization, ensuring responsible stewardship, consistency, and accountability.

Check out our bylaws anytime on our website.

LSA Bylaws

How will you Walk & Roll for 2026?

2026 Walk & Roll for Lowe Syndrome Awareness starts Tuesday, November 24 through Wednesday, December 2, 2026!

As we begin looking ahead to our second Walk & Roll season, we're excited to start imagining all the creative, meaningful, and community-driven ways our families and communities will take part. Walk & Roll is more than a single event. It is a collection of individual stories, local gatherings, and personal efforts that come together to move our mission forward. For 2026, we're inviting you to start thinking about your own plans: How will you Walk & Roll?

Last year, we saw incredible examples of what's possible when families bring their own ideas and passions to Walk & Roll.

The Carbonneau Family and their community in Connecticut (US) led an incredibly strong local effort that brought people together in a powerful way.

The Carbonneau Family and their community gather for their local 2025 Walk & Roll event.

The Brehm Family in Indiana (US) hosted an indoor event to come together as a community to connect, better understand, and raise awareness of our LS community.

The Brehm Family and their local community gather to raise awareness of Lowe syndrome.

These efforts remind us that creativity and connection are at the heart of this event.

There is no single “right” way to participate. The goal is to find something that feels authentic to you and your community. We know that each family’s experience is different, and that’s what makes Walk & Roll so special. Whether your plan is big or small, public or personal, your participation matters. You are building a stronger, more connected, more understanding Lowe syndrome community.

We’d love to hear your plans for 2026. What are you thinking about organizing? What worked well for you last year? What new ideas are you excited to try? Share your Walk & Roll plans with us, and we’ll highlight selected stories and events in our upcoming summer newsletter as we build momentum together.

Let’s continue to support one another, share our ideas, and create another meaningful Walk & Roll season together!

2025 INCOME & EXPENSES

LOWE SYNDROME ASSOCIATION

The following is a summary of our 2025 financials. Our mission is to foster communication, provide education, and support research so that individuals with Lowe syndrome can attain their highest potential. In support of this mission, our funding model balances community support with continued progress in research.

Revenue is driven primarily by individual donors (~60%), alongside valued foundation and corporate partners. Approximately 80% of expenses were invested in our 18th International Conference and in advocacy and awareness efforts—supporting families, expanding access to resources, and elevating Lowe syndrome nationally to accelerate research and care.

Conference years (2022 and 2025) reflect significant investments in families, while non-conference years allow a greater share of funding to be directed toward research.

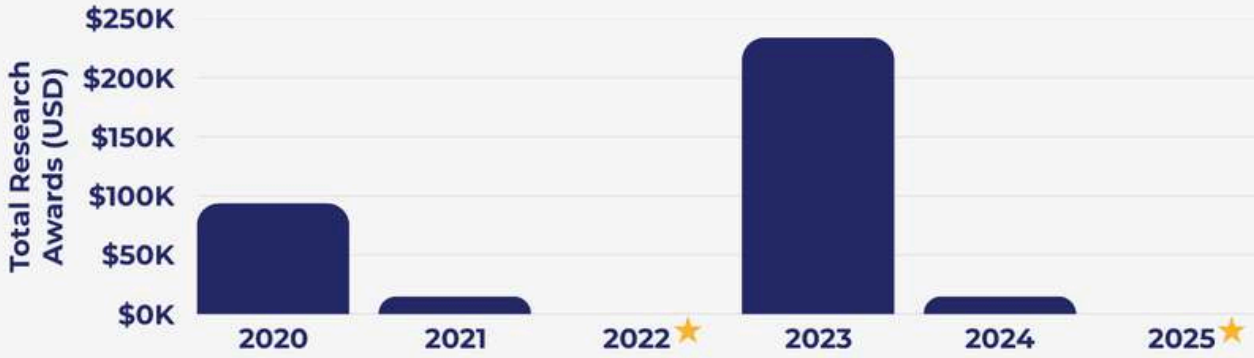
INCOME

- Individual Donors — 59.8%
- Foundation Donors — 25.8%
- Corporate Donors — 13.3%
- In-Kind Conference Donations — 1.1%

EXPENSES

- Community Outreach & Support — 57.9%
- Advocacy & Awareness — 21.8%
- Administrative — 14.5%
- Fundraising — 4.7%
- Research — 1%

Research Grants & Awards 2020-2025



★ 2022 and 2025 are LSA conference years — funding is prioritized for community programming, resulting in lower research grant totals in those years.

THANK YOU LSA SUPPORTERS

LSA Establishes Formal Research Endowment Fund

Research has always been a cornerstone of the Lowe Syndrome Association's mission to improve the lives of individuals and families affected by Lowe syndrome. For years, LSA has maintained a dedicated research fund to support promising scientific efforts and collaborations.

Today, we are proud to share an important step forward.

LSA has officially established a **formal Research Endowment Fund in partnership with Fidelity Investments**, marking a new chapter in how we invest in the future of Lowe syndrome research.

This evolution allows us to move beyond annual funding cycles and into a more strategic, sustainable model - one that strengthens our ability to grow resources over time, expand fundraising opportunities, and provide greater transparency to our community.

WHY AN ENDOWMENT FUND?

For small, mission-driven nonprofits like LSA, establishing an endowment fund is a powerful way to:

- Build long-term financial stability for research initiatives
- Reinvest earnings to grow impact year over year
- Provide confidence and clarity to donors about how funds are managed
- Align with best practices recommended by nonprofit and philanthropic leaders

This direction has also been encouraged by several of our dedicated community members and supporters who actively fundraise on behalf of LSA and believe deeply in creating a lasting research legacy.

"This evolution allows us to move beyond annual funding cycles and into a more strategic, sustainable model..."

HOW IT WILL WORK

The LSA Board will establish an **Investment Committee** to oversee the endowment, ensuring thoughtful stewardship, responsible investment decisions, and alignment with our mission.

LSA is proud to seed the fund with an initial **$25,000 investment**, demonstrating our commitment to long-term research growth.

THANK YOU LSA SUPPORTERS

HONORING HUNTER HAUGEN

We are especially honored to share that the **Haugen family**, in celebration of **Hunter Haugen's life**, has chosen to direct all funds raised in his memory to the Research Endowment Fund – contributing nearly $2,000 to this effort.

Their generosity and vision beautifully reflect what this endowment represents: a lasting legacy of hope, progress, and impact for future generations.

As we look ahead, the LSA Research Endowment Fund will serve as a foundation for sustained scientific advancement - helping us move closer to better treatments, deeper understanding, and ultimately, a cure. We are deeply grateful to our community for helping us take this meaningful step forward.

"Their generosity and vision beautifully reflect what this endowment represents: a lasting legacy of hope, progress, and impact for future generations."

THANK YOU LSA SUPPORTERS

The Lowe Syndrome Association (LSA) extends our deepest gratitude to the many generous donors that support us throughout the year. Your investment allows the 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 LSA **between December 22, 2025, and April 26, 2026.** We are sincerely grateful for your compassion and continuous support.

$25,000

Anonymous
In honor of William Bass

$10,000

Athene Charitable Foundation
In memory of Reece Christopher Hicks, "This gift is made to honor Reece's life, and to support the compassionate life changing work that the LSA provides to individuals and families living with the challenges of Lowe syndrome."

$2,500

Myatt Household, Dean and Diane
In honor of Dylan Myatt and his family

$1,000

Anonymous
In support of Alex Everitt
McSpadden Household
In memory of Leland McSpadden
NZ Waldbaum Living Trust
In honor of Alex Waldbaum's 18th Birthday
Ott Household
In memory of Hunter Haugen
Theordore Eckert Foundation
In honor of Scott Richards

$500 – $999

Anonymous (multiple donors)
In memory of Hunter Haugen
Gillespie Household, Ben
In honor of Blake Kubicki
Haugen Household, Theresa and Dave
In memory of Hunter Haugen
Nussbaum Household
Otani Household
In memory of Nicholas Avila; in honor Theresa Haugen, "for all her hard work for LSA;" in honor of Andrew Otani; in memory of Hunter Haugen
Smith Household
In honor of Blake and the Kubicki Family

$250 – $499

Anonymous
Dearth Household
In honor of "our son Austin born in 1991. He is an incredibly busy guy and teaches us constantly about the strength of human life."
Guy and Paul Dowden, friends of Eric Dowden
In honor of Eric Dowden
Mueller Furniture
In honor of employee, Collin Morgan
Risman Household
In honor of Raymond Hiett

Note: Donations listed in this issue were those received as of ***December 22, 2025, to April 26, 2026****. Donations received after that date will be included in the next* On the Beam *issue.*

THANK YOU LSA SUPPORTERS

$250 – $499 (cont.)

Falck Household
In memory of Hunter Haugen, "With heartfelt sympathy and love to the Haugen family. Your Bunco Babes are holding you close and honoring Hunter's light with this gift."
Gillespie Household, Brad
In honor of Blake Kubicki
Byles Household
In honor of Blake Kubicki and family

$100 – $249

Abell Household
In memory of Hunter Haugen
Bardwell Household
Bass Household
Clancy Household
In memory of Hunter Haugen
DeGori Household
In memory of Hunter Haugen
DeMars Lucey Household
In honor of Jackson Carbonneau
Demers Household
In memory of Nicole Carbonneau Jones
Diallo-Young Household
In memory of Hunter Haugen
Dubrovsky Household
In memory of Lenny Benjamin Dubrovsky
Gillespie Household, Debbie
In honor of Blake Kubicki
Goldstone Household
In honor of Blake Kubicki
Greensweig Household
In memory of Hunter Haugen
Haugen Household, Kathleen
In memory of Hunter Haugen
Le Household
In memory of Hunter Haugen

$100 – $249 (cont.)

Lebherz Household
Lee Household
In memory of Andrew Lee
Morgan Household
In support of Matthew Wondra, "my brother [who is] such a bright light in a dim world. He brings joy to anyone he comes into contact with."
Nallen Household
In memory of Nicole Carbonneau Jones
O'Meara Household
In honor of "my pal Ian MacInnes. Love you buddy!"
Orlando Household
In honor of Christopher Orlando
Robinson Household
In memory of Craig Robinson
Rush Moore LLP
In honor of Andrew Otani
Schroerlucke Household
In honor of the McSpadden Family
Shelstad Household
In memory of Hunter Haugen
Siconolfi Household
In honor of Casey Risola
Stoll Household
Tietz Household
In memory of Hunter Haugen
Zalewski Household
In support of Adam Snow's FB Birthday Fundraiser

Up to $100

Beal Household
In support of Mitchell Beal's FB Birthday Fundraiser
Beane Household
In honor of "my great, great grandson Kaison"

THANK YOU LSA SUPPORTERS

Up to $100 (cont.)

Bomar Household
In support of Annette Galloway Wright's FB Birthday Fundraiser

Brown Household
In support of Heather Knapik's FB Fundraiser

Cannon Household
In memory of Hunter Haugen

Clausen Household
In honor of Ethan Clausen

Cougar Football Manager, Mike Diggins, from Centennial High School Varsity Football Program
In memory of Hunter Haugen

Czaja Household
In memory of Leland McSpadden

Dentino Household
In support of Laura Kim's FB Fundraiser

DuBreull Household
In support of Heather Knapik's FB Fundraiser

Fellows Household
In memory of Hunter Haugen, "May his memories forever be a blessing!"

Garduno Household
In support of Heather Knapik's FB Fundraiser

Goodwin Household
In support of Laura Kim's FB Fundraiser

Hale-Rathbun Household
In memory of Hunter Haugen, "Your smile will be missed."

Haugen Household, Annette
In memory of Hunter Haugen

Hults Household
In memory of Hunter Haugen

Jarnagan Household
In memory of Nicole Carbonneau Jones

Johnson Household
In dedication to the Johnson Boys (Georgie, Billy, Eric and Brian) and their Daddy.

Jones Household
In support of Yvonne Owen's FB Birthday Fundraiser

Kubicki Household, Laura and Jason
In honor of "our beloved nephew, Blake Kubicki"

Lansing Household
In memory of Hunter Haugen

Lindgren Household
In memory of Hunter Haugen, "Rest in Peace"

Marois Household
In memory of Nicole Carbonneau Jones

Marson Household
In support of Adam Snow's FB Birthday Fundraiser

Owen Household
In support of Yvonne Owen's FB Birthday Fundraiser

Parrish Household
In support of Anna Baldwin's FB Birthday Fundraiser

Payne Household
In support of Mitchell Beal's FB Birthday Fundraiser

Richards Household
In support of Adam Snow's FB Birthday Fundraiser

Shorago Household
In support of Laura Kim's FB Fundraiser

Spenceley Household
In support of Yvonne Owen's FB Birthday Fundraiser

Steiner Household
In memory of Hunter Haugen, "He will be remembered for his zest for life and love of pickles"

Stole Household
In support of Heather Knapik's FB Fundraiser

Thomas G. O'Brien III and Allison R. O'Brien Fund
In memory of Samir O'Brien

Trucks Smith Household
In support of Annette Galloway Wright's FB Birthday Fundraiser

Williams Household
In support of Mitchell Beal's FB Birthday Fundraiser