Newsletter of the Lowe Syndrome Association ▪ Winter 2025 ▪ Vol. 44, No. 3

Circle of Care | Vision for a Cure

ON THE BEAM

Team Jackson

In This Issue

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

A Campaign Powered by Community

What happens when a handful of families say yes – and an entire community follows?

The idea for **Walk and Roll for Lowe Syndrome Awareness** was first floated at our **June 2025 conference**. By **September**, families had a toolkit in hand. By **October**, fundraisers were already being built. And by the time the campaign officially launched, our community had **already raised over $10,000**.

That momentum tells a powerful story.

> *"By the time the campaign officially launched, our community had already raised over $10,000."*

A small group of families stepped forward – not for themselves alone, but on behalf of hundreds of families around the world raising children with Lowe syndrome. Their leadership turned an idea into action, and action into impact.

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.

On the Beam, ISSN #0740-218X, All contributions are tax-deductible under Section 501(c)(3) of the Internal Revenue Code. Reproduction of this newsletter or any parts thereof are not allowed without the prior written consent of the Lowe Syndrome Association.

8190 Beechmont Avenue, Suite 111
Cincinnati, OH 45255
(216) 630-7723
info@lowesyndrome.org
www.lowesyndrome.org

PRESIDENT'S MESSAGE

Dear LSA Community,

As we close out 2025, I find myself reflecting less on any single accomplishment and more on the collective momentum our community created together this year.

It began with our biennial conference – a powerful moment of connection that brought families, clinicians, and researchers together, welcomed many newly diagnosed families, and reaffirmed why community matters so deeply in rare disease.

It continued with meaningful scientific progress, including newly published research by Dr. Ragu Pajinet, whose work is advancing our understanding of how Lowe syndrome affects the brain. And it expanded in new ways through our first international virtual fundraiser, where families across the globe stepped far outside their comfort zones – leading teams, sharing their stories, and helping raise awareness in ways that were both courageous and deeply personal.

We wrapped up the year watching that momentum carry all the way to Washington, D.C. With the help of committed parents – and a few especially charming young advocates – we began building champions on Capitol Hill, laying the groundwork for the federal support that research like ours urgently needs.

2025 was a busy and productive year, but more importantly, it was a year that set the stage for sustained growth — in research, advocacy, and community engagement. None of this happens without people willing to give their time, talent, and hearts.

As we turn the page, I want to offer special appreciation to Theresa Haugen, whose selfless service to the Lowe Syndrome Association over the many years has shaped so much of who we are – from our visual identity to the way our families' stories are told. We will miss her deeply and are forever grateful for the legacy she leaves behind.

I hope you enjoy this final newsletter as we close out 2025. On behalf of the Board, thank you for being part of this community and for helping carry this work forward.

Wishing you and yours good health, and many blessings in 2026.

Warmly,
Jeri

Jeri Kubicki

Jeri Kubicki
President, Lowe Syndrome Association

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

A Campaign Powered by Community

Continued from Page 1.

Together, **more than 500 donors** came alongside these family-led teams. And together, we **raised over $62,500** through our inaugural Walk & Roll campaign.

But the impact goes far beyond dollars.

This campaign helped raise awareness of our children – their brilliance, their challenges, and the realities of living with a rare disease. It fuels the work that must happen together: funding the search for meaningful treatments, funding global researchers, recruiting experienced clinicians to advance clinical guidelines and other critical resources, continuing to educate and engage our families.

None of this happens in isolation.
It takes a community.

Thank you to the families that led this effort and the donors who stood beside them. Your support set a powerful example and established a high bar for what this community can achieve together. **Every contribution matters, and every action counts.**

Team Scotty
Amy Nichols Richards and Mark Richards
$9,798

Team Jonah
Amanda and Jeremy Brehm
$9,014

Team Jackson
Stephanie and James Carbonneau
$8,983

Team Robert
Kristina Gill Erlandson and Jon Erlandson
$6,169

Team Alex
Lisa and Adam Waldbaum
$6,119

Team Krew
Brian and Julie Samaniego
$4,875

Team Elliot
Caroline and Edward Tsai
$4,451

Team Blake
Jeri and Josh Kubicki
$2,550

Team Raymond
Sheila Dentino
$1,170

Team Sam
Clare Gromoll
$1,015

Team Judah
Stacey and Nathan Vrtiska
$720

Gallop Lab
Dr. Jenny Gallop and Team
$634

Team Aiden
Patricia and John Bass
$370

Team Shaun
Johanna Yee
$295

Team Bryant
Lyndse Pepper
$25

Thank you to everyone who supported the LSA during our very first, annual Walk & Roll fundraiser.

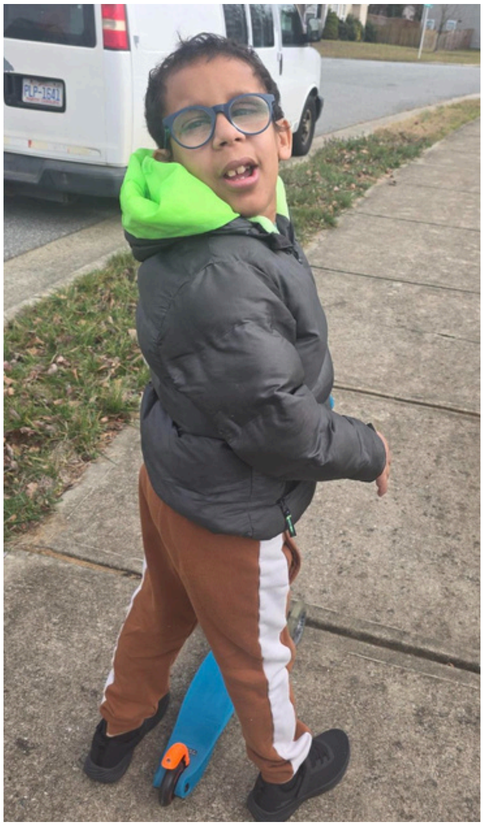
All Walk & Roll fundraisers and donors are listed on Page 25.

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Thank you for sharing your photos with us!

Team Aiden

Patricia and John Bass



Team Elliot

Caroline and Edward Tsai

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Sunshine, History, and Wellbeing: Walk and Roll at the Gurdon Institute

Team Gallop Lab

Dr. Jenny Gallop and Team

By Dr. Jenny Gallop

November 26, 2025

The sun shone brightly on a crisp Cambridge day for the special Walk and Roll edition of the Gurdon Institute's Wellbeing Walk! Twelve members of our Professional, Technical, and Research staff and students, came together for a one-mile stroll through some of Cambridge's most iconic sights.

We began at the Fitzwilliam Museum, founded in 1816, before heading down Silver Street to admire the Mathematical Bridge at Queens' College, originally built in 1749. Conversations flowed as we walked along 'The Backs' by the River Cam, with the Gothic splendour of King's College Chapel glowing in the sunlight.

Continued on Page 6.

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Continued from Page 5.

Crossing Garret Hostel Bridge gave us a stunning view of Clare College Bridge, the oldest surviving bridge in Cambridge, dating to 1639. From there, we wound through medieval streets to King's Parade, passing the Senate House, the ceremonial heart of the University since the 1720s.

Our final highlights included the imposing King's College Chapel from the opposite side and the Corpus Clock, complete with its time-devouring Chronophage sculpture, a modern masterpiece unveiled in 2008.

We returned refreshed and energised, with sunlight on our faces and new connections made, ready to continue advancing research with renewed enthusiasm!

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Team Jackson

Stephanie and James Carbonneau

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

SAVE THE DATE

NOV. 24
THROUGH
DEC. 2
2026

Mark your calendars for the Lowe Syndrome Association's second annual event!

LSA

WALK & ROLL
FOR LOWE SYNDROME AWARENESS

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Team Jonah

Amanda and Jeremy Brehm

MN Families with Lowe

Team Hunter: Theresa and Dave Haugen
Team Sam: Clare Gromoll

FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Team Raymond

Sheila Dentino

Team Robert

Kristina Gill Erlandson and Jon Erlandson

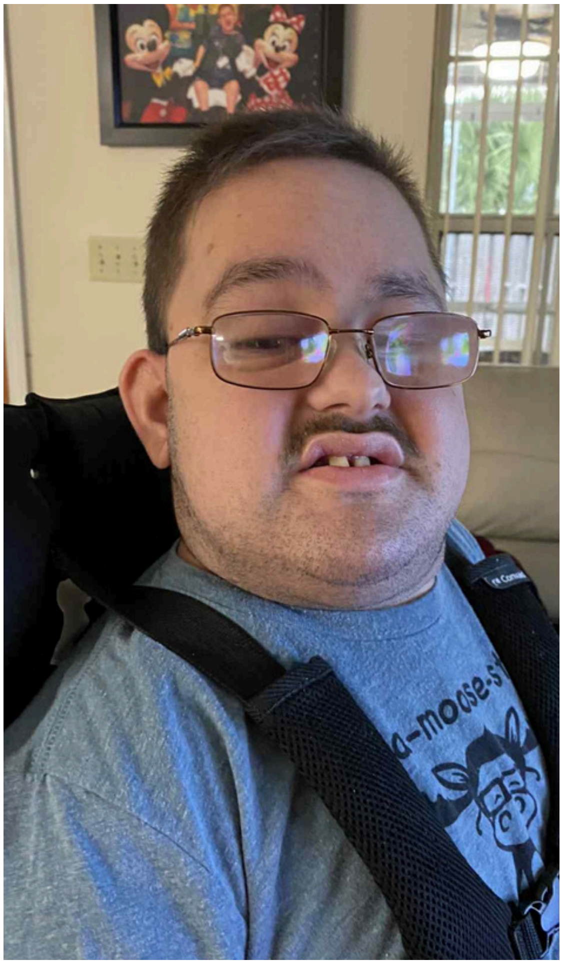
FIRST ANNUAL WALK & ROLL FOR LOWE SYNDROME AWARENESS

Team Scotty

Amy Nichols Richards and
Mark Richards

LSA MEMORIALS

As a community, we come together in celebration of life and in remembrance of those we have lost. This year, 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:



Nicholas Avila

06/11/1993 - 07/01/2025

Mark Beattie

08/29/1987 - 12/21/2025

Continued on Page 13.

LSA MEMORIALS

Clyde Doggett

05/16/1963 - 06/20/2025

In Loving Memory of Clyde Doggett
Clyde Doggett passed away in June of this year after 62 years of living an extraordinary life.

My parents and I often wondered why Clyde held on for so long, given the many physical challenges that caused him pain and discomfort throughout his life. After his passing, I heard from countless people who shared that Clyde was their inspiration – that if he could endure, so could they. Only then did we fully understand the depth of his impact. Clyde truly was a blessing to all who had the privilege of knowing him.

Isn't that often how life goes? We rarely realize whose lives we are touching, because many people don't express their appreciation while we are still here.

Clyde was totally blind at birth and later legally blind after undergoing seven eye surgeries. For several years after he was born, he had no muscle tone and was described as being like a "rubber hose left in the sun." His early school years were difficult, and he experienced bullying in public school. Eventually, he was able to attend the Washington State School for the Blind, where he thrived and loved every minute of his time there.

Throughout his life, Clyde spent countless hours in doctors' offices and hospitals. He participated in extensive medical research related to tumors that developed in his feet – tumors that caused painful skin stretching and made walking increasingly difficult. Despite all of this, he never complained. As the tumors progressed, his feet were amputated, followed later by amputations at the knee.

Continued on Page 14.

LSA MEMORIALS

Continued from Page 13.

Near the end of his life, another tumor developed on his hip, leading to a fracture and significant pain.

Clyde's kidney function gradually declined, even though our parents were meticulous in following every medical recommendation. He was on dialysis for nearly six years, again without complaint. When his doctor eventually suggested that stopping dialysis was an option, Clyde asked if that choice would mean he would die. When told yes, he reflected deeply. Although emotionally he was like a young teenager, his intellect and spirituality were remarkable. He said that choosing to stop dialysis would feel, to him, like choosing death – something he could not do.
He endured surgery to repair his dialysis fistula without complaint and lived with significant bowel complications that were painful and difficult to manage, yet he remained quiet, patient, and dignified through it all.

Clyde lived with such grace and humility that many people never realized how much he was carrying.

Lessons Clyde Taught Us:

- Be humble.
- Be grateful for what we have and for what we can do, even if it is limited compared to others.
- Do the best you can in all things.
- If you appreciate someone for who they are or for the example they set, tell them while you can.

I may be the luckiest person alive to have known Clyde and to have learned from him. Despite his limitations, he was a spiritual giant.

To all those living alongside someone who is differently abled: there is a reason you were brought together. Be strong.

- Ralph Doggett (Brother)

Continued on Page 15.

LSA MEMORIALS

John Erwin Jr.

02/27/2007 - 08/31/2025

Alexandre Riou

10/20/1993 - 03/29/2025

RESEARCH & ADVOCACY UPDATES

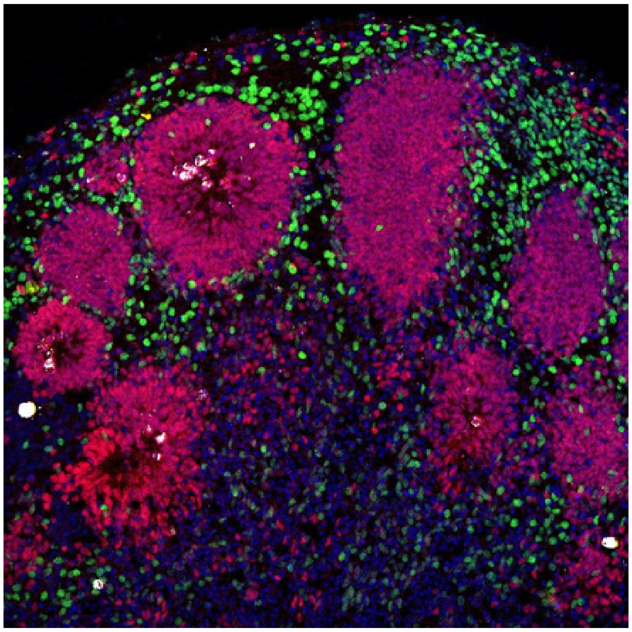
Enhanced Notch dependent gliogenesis and delayed physiological maturation underlie neurodevelopmental defects in Lowe syndrome by Yojet Sharma; Priyanka Bhatia; Gagana Rangappa, Sankhanil Saha, and Padinjat Raghu.

Read the full article here.

While we shared this article and press release via email, here is the value this research has on our community.

WHAT THIS NEW LOWE SYNDROME RESEARCH MEANS FOR OUR FAMILIES

A new study has given us some of the clearest answers yet about what goes wrong in the brain in Lowe syndrome - and, most importantly, it shows a possible path toward future treatment. Lowe syndrome happens because of a change in a gene called OCRL. This new research helps us understand what that change actually does inside developing brain cells.



WHAT THE RESEARCHERS FOUND

Using powerful new tools that allow them to study single cells one at a time, the team led by Yojet Sharma from Raghu Padinjat's lab (National Centre for Biological Sciences (NCBS-TIFR), Bangalore, India), discovered two main problems:

1. Brain cells get "misdirected." The human brain needs a precise balance of different types of cells to send messages (neurons) and provide support (glial cells). In models of LS development, this balance is disrupted early on:

- Early brain cells (precursors) are mistakenly steered toward becoming support cells (glial cells) instead of communicator cells (neurons). A greater number of precursor cells than normal are "misdirected" to the support path.
- The neurons that do form don't work as well. Even the neurons that grow are less active and don't fire signals normally, which could affect how the brain processes information.

WHY DOES THIS HAPPEN?

The team found that LS cells build up too much of a natural molecule called PI(4,5)P_2. This excess molecule turns on the Notch pathway, a system that tells cells how to grow and what type of cell to become. When it's overly active, cells end up on the wrong path.

> *"The hopeful part: these problems can be fixed in the lab."*

Continued on Page 17.

RESEARCH & ADVOCACY UPDATES

Continued from Page 16.

THE HOPEFUL PART: THESE PROBLEMS CAN BE FIXED IN THE LAB

This is the most exciting finding for our community:
When researchers lowered the levels of that PI(4,5)P_2 molecule, BOTH major problems improved.

- Cells developed into neurons the way they should
- The neurons became more active and worked more normally

They achieved this using a compound that blocks the enzyme that makes PI(4,5)P_2.

WHAT THIS MEANS FOR THE FUTURE

While this is early-stage research, it gives us something powerful: A clear target for future treatments.

For the first time, scientists can see a way to possibly correct the underlying cell problems caused by Lowe syndrome – not just managing symptoms. This brings real hope and momentum as the research community continues pushing toward meaningful therapies for our boys and men.

> ***"For the first time, scientists can see a way to possibly correct the underlying cell problems caused by Lowe syndrome – not just managing symptoms."***

Congressional Engagement

By Alex Perez, The Normandy Group

This year, the Lowe Syndrome Association (LSA) continued to strengthen its presence in Washington D.C. by meeting directly with members of Congress who influence national health and research policy. Early in the year, our meetings focused on protecting Medicaid with Lowe Syndrome (LS) family participation. We engaged lawmakers from across the country, including leaders involved in the Rare Disease Caucus and others who oversee key federal scientific priorities. These conversations helped raise awareness of Lowe Syndrome and positioned LSA as a steady and informed voice on Capitol Hill.

Congressman Greg Landsman (OH-1) with Group

During these discussions, we highlighted the ongoing research led by Dr Aguilar and the team at Purdue University and the promise of leveraging already approved FDA drugs as treatments for rare disease. This work served as a helpful reference point when explaining why continued federal attention and investment matter for small, rare disease communities like ours. Offices appreciated hearing that meaningful research is underway, in addition to our conversations around families and their daily and long-term needs- from social inclusion, funding for schools, programs and caregiver support to transitioning from school into the broader community.

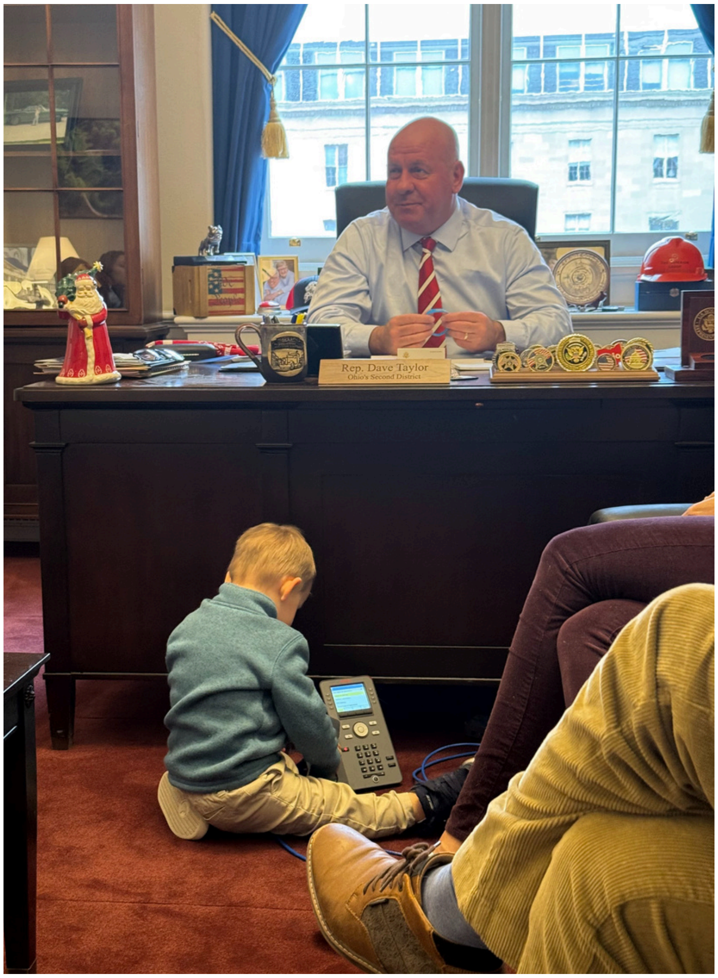
Continued on Page 19.

Continued from Page 18.

A major bright spot this year was the strong relationship we built with Representative Greg Landsman of Ohio. Representative Landsman has become a genuine supporter of LSA, and our meeting with him and his team was productive and forward looking. We continue to work with his and other offices on several federal approaches that support LSA priorities.

ENGAGEMENT WITH FEDERAL AGENCIES & NATIONAL PARTNERS

LSA also expanded its engagement with federal agencies this year, including important conversations with leadership at the new FDA Rare Disease Innovation Hub. The FDA team walked us through how they are improving rare disease pathways, including drug reporting systems, early-stage regulatory review, and how the agency evaluates scientific progress for small patient populations.



Matisse in Taylors Office

They were especially encouraged to hear about the work led by Dr Aguilar, noting that having active research underway gives FDA more to follow as they look at future therapeutic possibilities for rare conditions. Staying connected to this effort helps ensure that Lowe Syndrome is part of the larger federal conversation around research, reporting, and emerging treatment models.

Congressman David Taylor (OH-2) with group

We also stayed in touch with the EveryLife Foundation on broad advocacy issues while continuing to strengthen LSA's own independent presence in Washington.

Continued on Page 20.

Continued from Page 19.

LSA'S FIRST CAPITOL HILL FLY IN

December 10 was LSA's first Capitol Hill fly in, bringing local families to Washington for a full day of targeted congressional meetings.

A special thank you to the Tresca, Clausen, and Kubicki families for your generous time and focused engagement with lawmakers and staff in both the House and the Senate, including offices involved in the Rare Disease Caucus and other committees that oversee federal research and health policy.

During these meetings, families shared their stories and experiences directly with the offices, which had a clear impact on the members and staff we met with. The discussions focused on specific family challenges- from managing with a single income to ensuring programs are intact for young adults after high school and ultimately securing resources to fund clinical trials for improving kidney function in Lowe syndrome. Offices asked detailed questions, engaged seriously with the material, and several expressed interest in continued follow up in 2026.

LOOKING AHEAD TO 2026

Our work this year created significant momentum. Through congressional outreach, engagement with senior federal leaders, and the success of our first fly-in, LSA enters 2026 with stronger relationships, greater visibility, and a solid foundation for supporting scientific progress and long-term goals for the Lowe Syndrome community.

As we grow our champions in multiple states, we will reach out to in-district families who may want to participate in discussions.

Matisse and Blake

Theresa Haugen Tribute

In Gratitude to Theresa:

For capturing the heart of our community - through your art, your lens, and your love for every family.

Artful & Creative Leadership From:

2008 - 2025

Tribute continued on Page 22.

Theresa Haugen Tribute

Theresa Haugen has served on the LSA Board of Directors since 2008, with her term concluding this December. For seventeen years, she has shaped the visual heart of our organization- developing artwork across countless workstreams, including campaigns, newsletters, website imagery, conference themes, annual mailers, and even birthday cards.

Theresa also spent years capturing our community through her lens, photographing conferences and attending nearly every LSA event- often alongside her beloved family, including her husband Dave and sons Hunter and Blake. In everything she did, Theresa put families and individuals with Lowe syndrome first, ensuring their stories were seen, honored, and shared through art. Projects like The Big Picture exemplify her unique ability to elevate the voices, needs, and ideas of our community.

It is difficult to single out her finest contribution, but the Lowe Syndrome & Me video series- developed in partnership with Dr. Jenny Gallop and her team- may best capture the essence of our community: its challenges, resilience, and hopes for the future. This work has already driven global awareness of Lowe syndrome, and its impact will endure for years to come.

As Theresa steps away from the Board to take on a new project that will demand her full attention, we are grateful that she will continue to engage with LSA in a volunteer capacity. In true Theresa fashion, she will no doubt continue to love and support our community just as she has for the past seventeen years.

Thank you, dear friend. You are truly remarkable, and we will deeply miss your daily camaraderie.

Jeri Kubicki
On behalf of the LSA Board of Directors

Lowe Syndrome Mom's Retreat - 2026

CAMBRIA, CALIFORNIA
NOVEMBER 13 – 16, 2026

By Kristina Gill Erlandson, Retreat Host

Hosted by: Kristina Gill Erlandson (Robert's Mom)
520 Drake Street
Cambria, CA 93428
(805) 234 - 6399
LoweSyndrome.MomsRetreat2026@gmail.com

Location: I am hosting this retreat near our home in Cambria, California. Cambria is a small town located on the beautiful Central Coast just south of Big Sur, mid-way between San Francisco and Los Angeles. Known locally as "Pines by the Sea," Cambria is nestled in a native Monterey Pine forest overlooking the Pacific, and our dark skies make for excellent star gazing (when it's not foggy). We have abundant wildlife viewing, including deer, sea otters, elephant seals and migrating grey and humpback whales!

Save the Date!
Lowe Syndrome Mom's Retreat
Nov 13-16, 2026

Camp Ocean Pines
Cambria, California
www.campoceanpines.org

San Luis Obispo County
Regional Airport (SBP)

Send email to sign up!
$100 deposit due June 15th, remaining amount due August 15th, 2026
LoweSyndrome.MomsRetreat2026@gmail.com

Getting Here: San Luis Obispo County boasts a convenient airport ~40 minutes away from Cambria in San Luis Obispo (airport code SBP) that connects to major cities throughout the west (www.sloairport.com). We do not have regular taxi/uber services from the airport to Cambria, but I will try and arrange local transportation options once I get confirmation of your travel plans. We check-in to the Camp on the afternoon of Friday Nov 13th, and check out Monday Nov 16th mid-morning. Please try to arrange your travel on those days for group transportation logistics. You are also welcome to rent a car or arrange an Uber ahead of time. If you are in California already, we are about a 4-hour drive from San Francisco and Los Angeles, and Amtrak stops in both Paso Robles and San Luis Obispo.

Accommodations: In an effort to keep costs down, we will be staying at Camp Ocean Pines (www.campoceanpines.org). The camp is rustic, with bunkrooms that sleep up to 8 people in each, a main lodge/dining area, separate workshop areas and craft cabins, and an outdoor firepit to sip wine (or tea) at sunset and under the stars. Each bunkroom has a flush toilet, sink, and shower, and we would have refrigerator space in the main lodge. Meals are included, and the kitchen prides itself on serving delicious food and is happy to accommodate dietary preferences and allergies. Please indicate dietary restrictions in your email.

Continued on Page 24.

Lowe Syndrome Mom's Retreat - 2026

Continued from Page 23.

Sign Up: Sign up via email to indicate your interest in coming, and I will be in touch with details as we move forward with planning! Looking forward to spending time with you!

LoweSyndrome.MomsRetreat2026@gmail.com

Cost: The total base cost for accommodations and included meals at Camp Ocean Pines will be ~$500/per person. Additional expenses include getting here and the cost of certain activities you choose to do. All group excursions will have a no-cost option, and you will have the option to remain at Camp as well. To secure your spot, please send me an email to sign up. A deposit of $100 is due June 15th, and the remaining amount will be due August 15th. Total remaining amount will depend on activities you choose to reserve.

Activities: This part of the Central Coast is known for beautiful beaches, lots of outdoor activities, and more than 200 wineries in the Paso Robles region alone. We are located just south of the Big Sur coastline, and the fall is the perfect time to visit. November temps average around 55 to 60 degrees F.

The coastline is stunning, has great hiking, fishing, and places to kayak/stand up paddleboard. Whale watching is available out of Morro Bay, ~25 minutes south of us, and we can drive up towards San Simeon (~10 minutes) to view elephant seals and sometimes zebras (from the historic Hearst Ranch Zoo). Hearst Castle in San Simeon is a popular place to visit, a one-of-a-kind museum now run by State Parks (www.hearstcastle.org). The charming town of Cayucos ~15 minutes south of us has shopping, a pier, and a beautiful sandy beach with gentle surf if you want to swim or surf. Moonstone beach in Cambria is locally known for small jade and moonstone pebbles on the beach, with a walking path along the coastline. We have several local wineries, a glass blowing shop, and a historical downtown area. For the yoga-minded, we can bring in a local certified yoga/pilates instructor for a private group class at the Camp overlooking the ocean. Ultimately, we can do as many or as few activities as you'd like!

Activities that will incur some additional cost are whale watching ($65), kayak/SUP rental ($20), Hearst Castle ($35), and some wine tasting (varies from free-for-members to $20).

Explore:
https://visitcambriaca.com
https://visitsansimeonca.com
https://www.morrobay.org

THANK YOU LSA SUPPORTERS

2025 Walk & Roll Donations

The Lowe Syndrome Association (LSA) extends our gratitude towards the many donors that contributed to our first, annual Walk & Roll for Lowe Syndrome Awareness fundraisers. Your support raises awareness of the Lowe syndrome community and allows us to foster communication and support research to improve the lives of persons with Lowe syndrome and their families.

TEAM AIDEN

Patricia and John Bass

$370 Raised

8 Donations

Anonymous (2)
Crowell Household
Erlandson Household
Griffin Household
Hairston Household
McEneaney Household
Parker Household

TEAM ALEX

Lisa and Adam Waldbaum

$6,119 Raised

39 Donations

Anonymous (3)
Benjamin Household
In honor of the Waldbaum's and all their efforts so special.
Bianchi Household
Blackman Household
Cohn Household
Fierro Household
Herman Household
Holz Household
Hude Family, Silvana Hude GYM
Israel Household
Kowal Household
Kretch Household
Lee Hyder & Associates
Levinson Household, Fred
Levinson Household, Jon and Diane

Team Alex (cont.)

Levitan Household
Marsha Sher Family Charitable Fund
McKey Household
McPhillips Household
Mirman Household
Novak Household
Oconnell Household
Providente Household
Reichek Household
Rosen Household
Schlessel Household
Schneider Household
Shapiro Household
Shomer Household
Smith Household
Sulliavn Household
Tavens Household
Waldbaum Household, Lisa
Waldbaum Household, Naomi
Waldbaum Household, Simon
Wortzman Household
Yechiel Woodbridge Household

TEAM BLAKE

Jeri and Josh Kubicki

$2,550 Raised

17 Donations

Anonymous (4)
Byles Household
Coe Household
Collins Household

Team Blake (cont.)

Diehl Household
Gennantonio Household
Hodgson Household
Instone Household
Klette Household
Stahl Household
Randy and JoAnne Suer Fund
Wright Household

TEAM BRYANT

Lyndse Pepper

$25 Raised

1 Donations

Owens Household

TEAM ELLIOT

Caroline and Edward Tsai

Additional Fundraisers: Ted Bland, Ella Twork

$4,451 Raised

43 Donations

Anonymous (4)
Amani Household
Armstrong Household
Bland, Ted (Fundraiser)
Carmody Household
DeLuccia Household
Doan Household
Eschenfeldt Household
Flint Household
Foltz Household

THANK YOU LSA SUPPORTERS

2025 Walk & Roll Donations (cont.)

Team Elliot (cont.)

Frisbee, Sherri Mankofsky
Graham Household
Ignite Construction, Krystal Coppola
Ives Household
Joy Cleaver Household
Kieper Household
Kwa Household
Lin Household
Maltzan Household
Mangini Household
Marks Household
Maycock Household
Park Household
Pursley, James
Pursley, Jenna
Rachel Schneider, Anne
Richards Household, Liziah
Rose Household
Rubinstein Household
Salkowski Household
Schneider Household
Schreiber, Jessica
Schreiber, Laura
Steele Household
The Young Family
Tsai Household
Twork, Ella (Fundraiser)
Walker Household
Wexler Household
Woodruff Household

GALLOP LAB

Dr. Jenny Gallop and Team

$634 Raised

17 Donations

Anonymous (7)
Blake, Thomas

Gallop Lab (cont.)

Broadwith, Phillip Alexander
Debney, Sarah
Fayers, Matthew
Gadsby, Jonathan
Gallop Lab
Gurdon Institute, Emma Rawlins
Jeyarajasingham, Miss M P
Lestari, Sri A.
Plowden Roberts, Melissa

TEAM HUNTER (MN FAMILIES WITH LOWE)

Theresa and Hunter Haugen

$800 Raised

10 Donations

Anonymous (2)
Anonymous
In honor of Hunter "aka My ButterCup"
Haugen Household, Annette
Haugen Household, Kathleen
Haugen Household, Theresa
Larsen Household
Nordenstrom Household
Schuett Household
Tester Hastings Household

TEAM JACKSON

Stephanie and James Carbonneau

$8,983 Raised

79 Donations

Anonymous (12)
Anonymous
In memory of Sue Sherman
Amber and Tyler
Bachmair Household

Team Jackson (cont.)

Barina Household
Bonnayer, Jeannine
Bonnayer, Lynn
C. Rouquie Memorial Fund
Chili Brothers Food Co.
Carbonneau, James and Stephanie
Carbonneau, Jonathan
Carbonneau, Meme and Pepe
Coppolo, Al and Dreana
Coppolo, John
Cote, Elizabeth
Cote, Irene
Crough Household
Doreen Castor Household
Duquette Household
Durante Household
Fenneuff Household
Forsyth Esq, Duncan J.
Fournier Household
Grandma Z
Girard Household
Hall Household, Donny
Hall Household, Vaughn
In memory of Sue Sherman
Iozzo Household, Nicholas
Iozzo Household, Vincent
Jones Household
Lamphere Household
Leaman Household
Lekarczyk Household
Lestorti Household
Longo Household
Loos Household
Lorenzo Household, Ben
Lorenzo Household, Joe
Lucey Household
Malone Household
Marcello Household

THANK YOU LSA SUPPORTERS

2025 Walk & Roll Donations (cont.)

Team Jackson (cont.)

Maury and Yvonne
Messier Household
Miller Household
Misiaszek Household
Mlyniec Household
Morissette Household
Murphy Household
Pankraz Household
Patel Household
Pelow Household
Peters Household
Platner Household
Pokorny Household
Pray Household
Reipold Household
Ryann and Jarrett
Smith Household
Spanswick Household
The Kearney Family
TRUMPF, Inc.
Van Hee Household
Vigeant Household
Watterson Household
Wray Household
Yost Household
Zalewski Household

TEAM JONAH

Amanda and Jeremy Brehm

$9,014 Raised
60 Donations

Anonymous (11)
Alder Household
BAYADA Home Health Care
Brammer Quiocho, Abbie
Brehm Family Charitable Fund
Brehm Household, John and Deborah (Fundraiser)

Team Jonah (cont.)

Brehm Household, Amanda
Brehm Household, Meredith (Fundraiser)
Brehm Household, Shelby
Calles Household
Collier Household
Dury, John and Nancy
Farris Household, Trevor
Gaughan Household, Maggie
Gaughan Household, Martina and Nicholas
Gilbert Household
Greuel Household, Brian and Jane
Greuel Household, Craig
Greuel Household, Jane (Fundraiser)
Greuel Household, Nate and Kim
Greuel Household, Scott and Debra
Huber Household
Huffer Household
Kadar Household
Kime Household
Klein Household
Leverton Household
Litzkow Household
Mahalingam Household
McKenney Household
Muren Household
Murphy Household
Nagel Household
Narayan Household
Patel Household
Plopper Household, Allison
Plopper Household, Hendrika
Robinson Household
Sananikone Household
Smith Household
Snyder Household
Solomon Household

Team Jonah (cont.)

Symanowitz Household
Van Deursen, Faythe M.
Webb Household
Wilkins Household
Williams Household
Winkle Household
Winter Household
Woolf Household

TEAM JUDAH

Stacey and Nathan Vrtiska

$720 Raised
7 Donations

Anonymous (2)
Dentino Household
Figueira Household
Johnson Household
Ray Household
Vrtiska Household
In honor of Judah, "Love Nana"

TEAM KREW

Brian and Julie Samaniego

$4,875 Raised
37 Donations

Abner Household
Boermana Household
Carlile Household
handler Household
Clements Household
Culwell Household
Donahue Household
Eagan Household
Frederick Household, Ashley
Frederick Household, Jean
Hawley Household
Hernandez Household
Hitchcock Household

THANK YOU LSA SUPPORTERS

2025 Walk & Roll Donations (cont.)

Team Krew (cont.)

Hoefler Household
Janes Household
Kelm Household
King Household
Lagafuaina Household
Lawrence Household
London Household
LOOP, Fred Simon
Marie Petruzzelli Household
Mathiesen Household
Murphy Household
Pearson Household
Pellauer Household
Richardson Household
Rimehart, Chris and Larry
Sakoda Household
Samaniego Household
In honor of Duane Grubbs & Alfred and Sandra Castillo
Travis Household
Tunberg Household
Vasquez Household
Walter Household
Wise Household

TEAM RAYMOND

Sheila Dentino

$1,170 Raised
13 Donations

Anonymous
Baize Household
Barajas Household
Burrus Household
Dentino Household
Henry Household
Jones Household
Lee Household

Team Raymond (cont.)

Marjorie Boag Household
Ortiz Household
Palmer Household
Retzer Household
Zamora Household

TEAM ROBERT

Kristina Gill Erlandson and Jon Erlandson

$6,169 Raised
44 Donations

Anonymous (8)
Avera Household
Ayres Household
Benoit Household
Biasotti Household
Connolly Household
Erlandson Household
Farris Gall Household
Gallant Household
Gettmann Household
Gill Household
Gomes Household
Gossen Household
Hinkle Household
In memory of Jared Rodney Fong
Johnson Household
Kennedy Household
King Household
Krier Household
Lewis, Anna and Lindon
Martin Household
McNeill, Harriet and William
Meinke-Smith Household
Nicchitta Household
Price Household

Team Robert (cont.)

Putnam Household
In memory of Robert's Grandfather, "Elwood"
Sacramento Capitol A's Model A Ford Club, Carolyn Bertoni
Sacramento Capitol A's Model A Ford Club, Paul Keller
Schmidt Household
Scholes-Corey Household
Spanne Household
Thomas, Kathy Jo
Webb Household
Wieters Household
Wilcox Household, Michelle
Wilcox Household, Sharon
Zevenbergen Household

TEAM SAM (MN FAMILIES WITH LOWE)

Clare Gromoll

$1,015 Raised
14 Donations

Anonymous
Buchs-Hammonds Household
Elfstrom Household
Gander Household
Gromoll Household
Hanson Household
Keely, Barbara Anne
In honor of Sam's Mom, Clare
Litfin, Mary Ann
Morris Trumbauer Household
Nelson Household, Marley
Nelson Household, Susan
Purfeerst Household
Richey Household
Rollberg Household

THANK YOU LSA SUPPORTERS

2025 Walk & Roll Donations (cont.)

TEAM SCOTTY

Amy Nichols Richards and Mark Richards

$9,798 Raised

80 Donations

Anonymous (8)
Arons Household
Avansino and La Vigne Household
Beach Household
Beni Household
Boucher Household
Buchanan Household
Burke Household, Brian
Burke Household, Molly
Centofante Household
Cichoski Household
Davis Household
Derchak Household
DiGuido Household
Dishnica Family Trust
Donovan Household
Doyle Household
Dudeck Household
Erlandson Household
Falango Household
Fisher Household
Flannery Household
Fried Household
Green Household
Ha Household
Hamner Household
Hanson Household
Hart Household
    In honor of Scotty's Birthday
Herlihy Household
Hinojosa Household
Huff Household, Christen
Huff Household, Nancy
Ireland Household
Jossey Household

Team Scotty (cont.)

Karp Household
Karrh Household
Klein Household
Knapp Household
Kreuzberger Household
Kuo Household
Lee Household
Lessin Household
Letier Household
Levy Household
Macdonald, Alicia
McCann Household
McCreary Household
Miller Household
Millikin Household
Montondon Household
Nichols Household
OBrien Household
Phillipps Household
Purdy Household
Purdy Berg Household
Richards Household, Amy
Richards Household, Terese
Ruby, Dianne
Ruby, Stephanie
Sluter Household
Smith Household
Strauss Household
Thompson Household
Tokar Household
Troitino Household
Vanderhoff Household
Wenglikowski Household
Weston Household
White Household
Wigert Household
Wilkoff Household
Wolf Household
Yale Household

TEAM SHAUN

Johanna Yee

$295 Raised

8 Donations

Anonymous
Anonymous
    In memory of Susy Graham
Barylskiy Household
Choweller Household
Ferlet Household
Vernon Household, Kim, Grayson, and Family
Whittaker Household
Yee Household

GENERAL WALK & ROLL DONATIONS

$5,525 Raised

Anonymous (3)
Antley Household
Benos Household
Blom Household
Brewer Household
Colwell Household
    In memory of Tyler Richardson
Daniels Household
    In honor of Grayson Alexander
The Normandy Group, LLC, Ron Eritano
The Kim Family
    In memory of Mary Kim
Lewis Household
Macdonald Household, John
    In honor of Dickson Macdonald
Menz Household
Mistretta Household, Michael
    In honor of Grayson
Monneret Household

THANK YOU LSA SUPPORTERS

2025 Walk & Roll Donations (cont.)

General Walk & Roll Donations (cont.)

Newton Household
In honor of Carson Newton
Riou Household
Snyder Household
Tenenbaum Household
In honor of Laura and Ewan
Tesini Household
Theis Household
In memory of Theis Jean-Pierre
Tietz Household
In honor of "My Great Nephew, Colin Tietz"
Torres Household

Additional Fundraisers

The Lowe Syndrome Association (LSA) thanks the following individuals for creating a fundraiser on behalf of the LSA – as well as the many generous donors that supported us – **between August 1, 2025, and December 21, 2025.** Your investment allows us to continue our mission to foster communication, provide education, and support research to improve the lives of persons with Lowe syndrome and their families.

We are sincerely thankful for your generosity and support.

Amanda's Birthday

Amanda Weiss

Facebook

Wildt, Meg

Betty's Birthday

Betty Joanne Johnston

Facebook

Matthews, Tiffany

Charles's GivingTuesday Fundraiser

Charles Buchs-Hammonds

Facebook

Buchs-Hammonds Household

Thank you for creating a birthday fundraiser as well in honor of the LSA!

Kakie's Facebook

Kakie Walters Franz

Facebook

Johnsen, Nancy
Richards, Amy

Kelsey's Facebook Fundraiser

Kelsey Carman

Facebook

Ann, Donna
Apai, Michele
Byrne, Elaine
Carman, Kelsey
Carman, Maureen
Chainer, Michele
Coulston, Eileen
Crivelli, Julie
Dabronzo, Mark
Galbraith, Georgette
Hanson, Meg

Kelsey's Facebook Fundraiser (cont.)

Hayman, Jeanne
Leslie-Post, Cindy
Lynn, Kristi
Marozzi, David
Mycols, Denise
Reed Apoldite, Ellen
Ross, Lorry
Smith, Colleen
Stefanelli, Erica
Stefanelli, Aggie
Tharp, Jeanne
Tharp, Sherl
Tonti, Iris
Varanyak, Kate
Varanyak, Alexis
Whalen, Nancy
Zazzarino, Anita

THANK YOU LSA SUPPORTERS

Additional Fundraisers (cont.)

Melissa's Birthday Fundraiser

Melissa Mayne Nadeau (Facebook)

Carbonneau, Stephanie

Phyllis's Birthday Fundraiser

Phyllis Redfield-Sears (Facebook)

Hiatt, Jackie
Palma, Margaret

Rosana's Birthday Fundraiser

Rosana Granillo (Facebook)

Campbell, Melissa
Contreras, Cecilia
Gee, Urs
Hare, Robert-Irene
Medellin, Rosi
Meyers, Bobby
Nelson, Kathy
Rivas, Joe

Kubicki Health Ventures LLC. Fundraiser

(Facebook)

Wilkins, John

Thank you to the following individuals for creating a fundraiser on behalf of the LSA!

Angus's Birthday Fundraiser

Angus Lee Noder (Facebook)

Charlene's Birthday Fundraiser

Charlene Martin (Facebook)

Charles's Birthday Fundraiser

Charles Buchs-Hammonds (Facebook)

Donna's Birthday Fundraiser

Donna Carden Eaves (Facebook)

January's Birthday Fundraiser

January Pepper (Facebook)

Lyndse FB Fundraiser

Lyndse Pepper (Facebook)

Jonathan Ankrom's Pizza Ranch Fundraiser

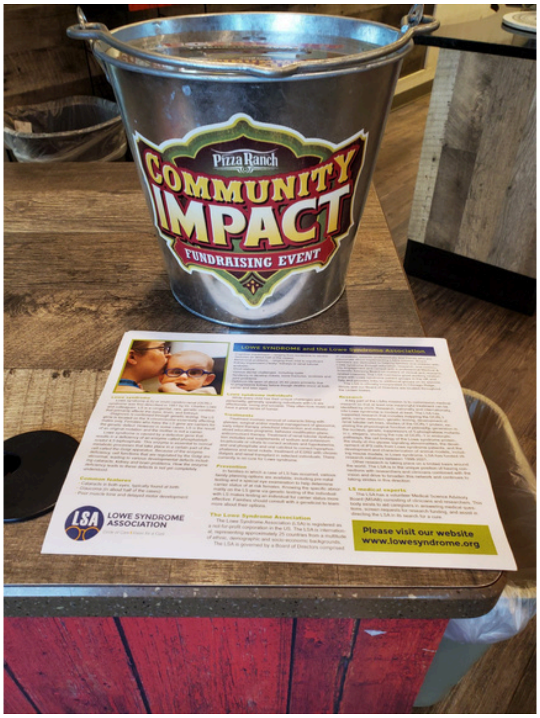
$1,345 Raised

Hansen Household
PR Rhinelander Inc. DBA Pizza Ranch Rhinelander

Thank you to Jonathan, Michelle, and Rod Ankrom for hosting a fundraiser at their local Pizza Ranch in Rhineland, WI!

The Ankrom's had a team of seven people helping bus and wash tables as well as taking dishes to the kitchen to be washed.

The Ankrom Family and team raised a total of $1,345 that will directly support LS research. Thank you for raising awareness and funds on behalf of the LSA!



THANK YOU LSA SUPPORTERS

Additional Fundraisers – Ankrom Family Fundraiser (cont.)

Pizza Ranch

DATE 08/18/25

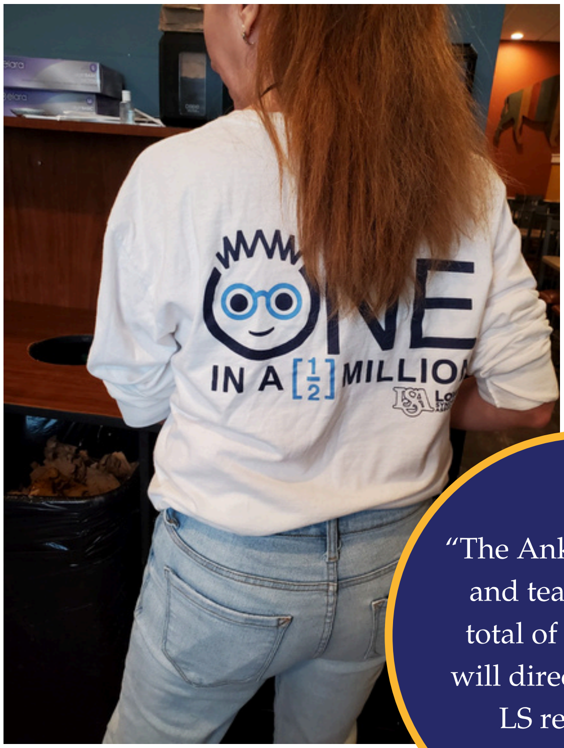
PAY TO Lowe Syndrome Association $ 1244.48

one thousand two hundred forty four 48/100 DOLLARS

MEMO Fundraiser

Rhinelander pizza ranch

⑆0000000000⑆ ⑆0000000000⑆ 1025



> "The Ankrom Family and team raised a total of $1,345 that will directly support LS research."

THANK YOU LSA SUPPORTERS

General Donations

The Lowe Syndrome Association (LSA) extends our deepest gratitude to our many generous donors that support us throughout the year. 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 LSA **between August 1, 2025, and December 21, 2025.** We are sincerely grateful for your compassion and continuous support.

Up to $9,000

DeGori Household
In honor of Matthew DeGori

$1,000 – $4,999

Anonymous
In support of Matisse Tresca and in memory of his Grandmother, Lindsey Edwards
Anonymous
In memory of Andrew Lee
Day and Pascoe Household
In honor of Blake Kubicki
Peach Pit Foundation
In memory of Reece Christopher Hicks
Taverna Household
In honor of James Montenero aka (Jimmy Hollywood)
Trustmark Foundation

$500 – $999

Anonymous
In honor of Ethan Clausen, "Happy birthday belated birthday Ethan!"
Brunelle Household
In honor of Joseph Andrew Felkl and in remembrance of Robert Valadez, Joseph, and Aurora Valadez
Denion Household
In memory of William "Billy" Denion
Gillespie Household, Ben
In honor of Blake Kubicki
Gillespie Household, Brad
In honor of Blake Kubicki
Nieberding Household
In honor of Blake Kubicki

Note: Donations listed in this issue were those received as of ***August 1, 2025 - December 21, 2025.*** *Donations received after that date will be included in the next* On the Beam *issue.*

$250 – $499

Bower Household
In memory of Reece Christopher Hicks
Duffe Household
Galbato Household
In honor of Blake Kubicki and "his wonderful mom, Jeri, for always helping others"
Marks Household
In support of, "Our good friend Mason Snow! We love you Mason!"
Mueller Furniture Co.
On behalf of employee, Collin Morgan
Schroerlucke Household
In memory of Gilbert and Bettye Schroerlucke and Leland McSpadden

$100 – $249

Dubrovsky Household
In memory of Lenny Benjamin Dubrovsky
Macdonald Household, John
O'Boyle, Judy and John
In honor of James Jerman
Risman, Iwan and Christina

Up to $100

Anonymous
Kroger Community Rewards
Morgan Household
O'Neill Household
In memory of Michael Rochvarg
Pledgeling Foundation
Siconolfi, Daniel
In honor of Casey Risola