



Circle of Care | Vision for a Cure™

ON THE BEAM

LSA SPOTLIGHT



Sam beams as he proudly displays the artwork he created for The BIG Picture project.

The BIG Picture project: A visual voice for those with Lowe syndrome

While the first LSA Spotlight of the first LSA On The Beam digital newsletter highlights an art project, the real spotlight shines on the visual voice of those creating the art— the charming and resilient boys and men living with Lowe syndrome (LS).

The LSA logo, radiating rays of sunlight in the On The Beam masthead, features eye-

glasses, a common everyday object that parents of children with Lowe syndrome know all too well.

It is often the first thing others see when meeting a baby or young child with LS. But did you know the glasses also represent the world, communities and family through the lens of those boys and men living with LS? Their perspective, their voice also matters.

The real spotlight shines on the visual voices of the charming and resilient boys and men living with LS.

The BIG Picture is an art project organized by Theresa Haugen, LSA board member, to showcase art created directly from the lens and perspective of those living with LS. This art project began with a simple request: create something that shows who you are, what you like. Isabella and Jillian, two teen siblings who graciously volunteered to help, sat with the artists offering different colored oil pastel sticks and encouraging each artist to create a masterpiece but all artwork is solely the creation of the artist. Each artist chose what they wanted to draw, which colors were used, how they wanted to start and more importantly, when each masterpiece was finished. The BIG Picture project was exhibited at the 2022 Lowe Syndrome conference in Fort Worth, Texas on June 25.

The full exhibit can also be viewed in this newsletter on pages 10-12.

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

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

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PRESIDENT'S MESSAGE



Welcome LSA friends to a new year, and to the very first edition of the Lowe Syndrome Association's digital newsletter!

The new year brings changes to the LSA. I'd like to share a special thank you to Lisa Waldbaum and her family for their exemplary service to the LSA for seven years. Lisa led the association through COVID and all the things a virtual world dictated for us. Lisa will continue to serve on our Board of Directors but she has earned her desire to step away as President. Lisa and her family- Adam, Josh, Sam, Laura, Naomi and Basil Waldbaum worked several conferences and illustrated the importance of family and community.

Having collaborated with Lisa since 2015, I am both grateful and energized to serve as the incoming LSA President. I also bring an amazing family with me on this journey- husband Josh, daughter Jillian and our son Blake.

In this first newsletter, I'd like to take a moment to re-introduce our newsletter title: "On the Beam"- created by our founders in 1983. "On the Beam" is portrayed as a sunbeam- a ray of light and it means "spot on", "this is it", "this is where we should be". This sentiment still applies today and this newsletter is intended to shine the light on your life, to provide helpful information and share ways we can achieve our BIG goals. I had the privilege to talk with our founder, Kaye McSpadden about the newsletter and her journey. Kaye inspired me to contemplate how to best accomplish the goals of the LSA today recognizing things have evolved so much since its founding. To focus on who we support, why and how.

The Big Picture project - defines our who and why. The boys and men with Lowe syndrome inspire, motivate and challenge us every day to find ways to improve their lives and our journey with them. They keep us connected as we share in the blessings, milestones and sorrow that comes with this disease. Support is such a big aspect of the role we play as parents, caretakers, friends, and family. Today families seek support online, both medical and social. And location is no longer a barrier to face to face engagement and learning. Technology- zoom, social media will never replace our conferences, and the warmth only face to face communication brings. But we can use it to fill in the gaps and to engage, educate and grow our community.

In closing, as we compete for money, time and winning over hearts in a world full of worthwhile causes, I am confident we will deliver the things our community has asked for- opportunities to learn, fundraise and to lead cutting edge research on Lowe syndrome. If I can make one request it's to get involved in some way- give your time, ideas, expertise or support our fundraising efforts. Here's to a new year, the start of many new accomplishments and blessings for this organization.

Kind Regards,
Jeri

FAMILY STORIES



The Samaniego family

The pandemic impacted everyone's life in one way or another whether it was an inconvenience to wear a mask all the way to the loss of loved ones. The pandemic brought a different experience for us. The months leading to Krew's birth had moments of stress and lots of unknown, not because we expected a child with Lowe syndrome since we had a perfectly normal healthy pregnancy and weren't expecting any complications, but because just prior to his birth the guidelines were such that a patient admitted to the hospital had to be alone. The doctors started preparing us for this scenario but thankfully, by the time Krew was born, they lifted that restriction so spouses could be present.

I can't tell you enough how grateful I was to have Brian with me at his delivery. That moment started a spiral

of emotions and unknowns. Krew went into distress during delivery and came out with his cord tightly wound twice around his neck. The doctor could hardly get it cut mid delivery and the NICU team came rushing in to whisk him away the second he came out. Despite all this, he bounded back

and we were able to take him home two days later. Largely because of his breathing difficulties at birth, no one ever checked his eyes at the hospital. We were discharged with the belief that everything was fine.

At five days old it was clear there was something going on with Krew's eyes. Thanks to COVID the pediatricians were only doing telehealth appointments and chalked his watery irritated looking eyes up to clogged tear ducts. At his one-month checkup one parent was finally allowed to bring him into the doctor's office where they, once again, insisted his watery eyes with red eye rims were simply the result of ongoing clogged tear ducts. His lack of movement and floppiness was simply because all babies are different and he would firm up with time.

**Krew has come
such long way from the
little guy who couldn't see
and didn't really move.**

This same routine was repeated at his two-month checkup and two weeks later I brought him back and told the doctor I wasn't leaving until they figured out what was wrong with his eye stating he was either blind or autistic or perhaps both because he can't see, doesn't look at anything and doesn't do anything. The doctor FINALLY checked his eyes and immediately saw the cataracts. By 5pm that evening we were at the local pediatric eye specialist who then sent us to Children's Hospital Los Angeles, as she believed he had glaucoma in addition to the cataracts. The following day we had a new pediatrician!

Krew had the cataract surgery at three months old and we finally received a formal diagnosis from the genetics doctor at 4 months old. By 7 months old he had his first glaucoma surgery in the left eye and, thank the good Lord, both eyes have been stable ever since. At the time of his surgeries, once again, only one parent was allowed in the hospital so I worried and stressed by myself in the patient waiting room while my husband worried alone in the car waiting for us. Thankfully these restrictions have gotten much looser and a bigger thanks that we haven't had anything major come up.



Krew Samaniego

FAMILY STORIES



Krew Samaniego

Krew has come such long way from the little guy who couldn't see and didn't really move. He started crawling shortly after his first birthday.

Not a lot, mind you, but he had the desire to move and began pulling himself across the floor with his arms. A year later, and he's one of the fastest little crawlers I've ever seen and also started taking steps towards walking. He's

very unsteady on two feet but he's getting there! Krew has also become somewhat of an adrenaline junky, much to my dismay, but it keeps him

moving and always trying something new. For that reason alone, I could not be more grateful. Whether it's riding the car down the backyard roller coaster, crawling after the chickens, bear crawling up the slide to turn around and ride back down it head first with his hands up, he lives every moment with joy.

Needless to say, Krew has changed our lives in so many ways, and I am so very grateful for the love and joy he has brought into them. He truly is a blessing and continues to teach us every day about patience, love and grace.

June 24 to 26, 2022. Three days filled with learning, laughing, hugging, crying, dancing, and love. That sums up this year's Lowe Syndrome Association (LSA) conference in Dallas, Texas.

It was great to see so many of you this summer. This was our eighth LSA conference. While we missed seeing many families from past conferences, it was wonderful to reconnect with old friends who did attend and to meet new friends, many of whom were attending their first conference. Our son Andrew (27 years old) was one of the older men affected by Lowe Syndrome in attendance. It warmed our hearts to see the younger boys, many of whom were just learning new life skills. We remember hearing "he may never walk, he may never talk, he may never read" when Andrew was younger. But in time, at his own pace, he walked, he talked, and he

Tony, Andrew and Caroline Otani



FAMILY STORIES

read. We hope that seeing Andrew gave the parents of the younger boys some hope for the future. Even if your son does not achieve certain milestones, know that he is a valuable member of your family and of our LSA family.

As always, the conference sessions were educational and inspirational. The session presenters and the medical professionals provided valuable information for all who attended. The social events allowed us to bond in non-judgmental settings as we all “get it” where our boys/men are concerned. We particularly like the “Fathers Only” and “Mothers Only” sessions because they give us the opportunity to share, in an intimate setting, what we have learned over the last 27 years and to see what others have gone or are going through.

We remember our initial conference in San Diego in 2006. We did not know what to expect and were somewhat nervous about being there. Immediately, we were embraced by the participants at that conference. The Alberts family was the first family that we met then, and they approached us before the conference began, having recognized Andrew as a boy affected by Lowe Syndrome. It is heartening that Cricket Alberts continues her family’s involvement with LSA as its treasurer. Because of how warmly we were welcomed and as conference veterans, we now make an effort to reach out to new families who are attending their first conference. Social media has expanded our abilities to communicate with one another, but it can still be overwhelming to meet others affected by Lowe syndrome in person.

Texas in the summer is something to experience. We come from a place that is warm year-round, but



Andrew, Tony and Kaitlyn Otani

we were unprepared for how hot it was in Texas. Of course, spending a whole day at Six Flags over Texas in Arlington was probably not the smartest thing to do in 100+ degree weather. Thank goodness for air conditioning at the hotel and in our car. We loved most of the food we ate, were impressed with AT&T Stadium (home of the Dallas Cowboys) and had a grand time exploring Bucce’s. We have tried to tie our family vacations to conference locations and appreciate the family-friendly venues the conferences have been held at. We are looking forward to our future family vacation at the next conference location.

We would like to thank the LSA Board members and the conference committee for putting together another wonderful conference. In Hawaii, after a get together, we often say “A Hui Hou” or “until we meet again” to say goodbye. Although we physically said goodbye to one another at the end of June, we did not really say goodbye. Lowe syndrome gives us a connection to one another that is not lost through geographical distance, and we hope to see one another again in the future. Until we meet again, take care and stay safe.

Tony and Caroline Otani

RESEARCH UPDATE

Clinical Trial of Alpelisib

Where are We and What are the Next Steps?

As the LSA strives to achieve therapeutic options to help Lowe syndrome patients, we are staying very close to the network of European researchers who are aligned with this goal.

Dr Francesco Emma and Dr Jenny Gallop submitted their plan for an innovative, small-scale trial to the European Medicines Agency for scientific advice and received positive and constructive feedback to incorporate into the study. They are continuing to liaise with stakeholders and ethical review bodies and apply for funding.

Meet Dr. Francesco Emma

Based in Rome, Italy, Dr Emma is the Head of the Department of Pediatric Subspecialties at the Bambino Gesù Children's Hospital. Prior to this role Dr Emma was the Head of the Pediatric Nephrology Division. Dr.

Emma received his medical degree from the Catholic University of Louvain,

Brussels, Belgium, where he specialized in Pediatrics. He subsequently completed his training in Pediatric Nephrology at Boston Children's Hospital, Harvard Medical School. Dr Emma's

primary research interests lie in rare kidney diseases, such as Fanconi

Syndrome, Cystinosis, or Nephrotic Syndrome.

Dr Emma has authored more than

200 research articles and several textbook chapters, and is a senior editor of the IPNA textbook "Pediatric Nephrology". He has served in several editorial boards and scientific society committees in the fields of Nephrology and Pediatric Nephrology. His clinical research consists of co-authoring 161 peer reviewed articles and participating in several clinical trial in the past years.

Dr Emma participated in the LSA's 2020 Research Symposium where he graciously shared his research efforts with other experts in the U.S. Canada, and Europe. He collaborates with Dr Gallop (presented at the 2022 LSA Conference) and others across ERKNet – the European Rare Kidney Disease Reference Network - to advance clinical trials around rare kidney disease.

Reminder

Please complete your Patient Registry <https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL>



The group picture at the 2022 LSA conference in the Dallas/Fort Wroth area of Texas June 24-26.

CONFERENCE HIGHLIGHTS



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CONFERENCE HIGHLIGHTS



VISUAL VOICE

The BIG Picture Artist Statement
A complex medical journey doesn't diminish the bright spirits of boys and young men living with Lowe syndrome. The BIG Picture project offered this group a visual voice. A chance to express themselves without limitations or others speaking for them.

These boys and young men were given paper and oil pastels and told to create something that reflected who they are

And, they did
Brilliantly.



THE BIG PICTURE



THE BIG PICTURE

While the boys and young men with LS created art, their siblings had the opportunity to make masks and connect with each other.



FUNDRAISING CORNER



Creating a Fundraising Circle

We are a community united to achieve our mission- to support and engage our families through education and collaboration and lead research efforts that will yield treatments to improve the lives of those living with Lowe syndrome. This page is dedicated to supporting and highlighting those efforts!

Fundraising Tips

Thanks to the overwhelming feedback from our LSA 2022 post conference survey- we have pulled together a few key things to make fundraising as simple as possible.

- [LSA Fact Sheet](#)
- [Key Tips/Ideas and Important 2023 Dates](#)

Please let us know if these tools are helpful for you!



LSA Merchandise Available

LSA merchandise is now available at www.zazzle.com/lowe_syndrome_assoc. 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.

LSA Merchandise- We Are Seeking a Volunteer!

Are you interested in helping us add new merchandise while also raising funds for the LSA? We are seeking a volunteer to work with us on just this! Please contact Jeri at jgkubicki@gmail.com

Shop & earn dollars for the LSA

There are several ways to support the LSA throughout the year. Raise funds for the LSA for free by linking your shopping rewards to our organization. Shop as you normally would, and the retailers do the rest. This really adds up! Please keep an eye out here and our website for updates. A few current ways to shop and give back:

- [Amazon Smile](#)
- [IGive](#)
- **New!** [Mabel's Labels](#)
Custom labels to help you organize! After going to the main page: Simply select "Support a Fundraiser" at the top right of the page and insert Lowe Syndrome Association
- [Gift Matching Programs](#)
Many employers will match gifts and the LSA benefits greatly from these contributions. A few top employer's that match donations are here: <https://doublethedonation.com/list-matching-gifts-companies>
- **LSA As a Beneficiary/Legacy Giving**
Have you considered adding the LSA as a beneficiary in your will? Please contact the LSA if you are interested in becoming a legacy giving member!

Hoxie Family Fundraiser

The Hoxie family held a fundraiser that raised more than \$3000 for Lowe syndrome.



GET THE LOWE DOWN

Save the Date and Join These LSA Information Sessions

Save The Date for the following Zoom sessions (links to be provided a minimum of one week prior to the sessions via LSA FB page):

January 25, 2023 (12-1 ET.)

California Social Security Administration (SSA)

Did you know that a Lowe syndrome diagnosis may qualify you for additional benefits through your states social security administration (SSA) account? This SSA Workshop will cover an overview of the Social Security Disability and Supplemental Security Income programs for California residents. The content will include eligibility requirements, how to file, and information regarding claims processing. Additional information will include: reporting responsibilities once an individual receives benefits, access to services with SSA, ways to contact SSA and how to get more information. Please note- additional SSA zoom calls for other states will be conducted throughout 2023. Look for updates on the LSA Facebook page.

February 23, 2023 (12- 1 p.m. ET)

May We Help

We hope all LSA families can join us to learn about "May We Help" – a Cincinnati, Ohio based company that leverages a team of 75 volunteer engineers, industrial designers, inventors, welders, woodworkers, seamstresses, doctors, occupational and physical therapists who design, build and deliver custom devices at no cost to hundreds of recipients every year. Yes you heard that right! We are thrilled to bring our community this free resource. Learn more at www.maywehelp.org and join the call on January 19!

February 16, 2023 (12-1 p.m. ET)

LSA Patient Registry with Coordination of Rare Disease Sanford (CoRDS)

Did you know that patient registry's provide critical information for researchers about our son's experience with Lowe syndrome? This data is also needed before clinical trials can be conducted. Our goal is to have all Lowe Syndrome patients in the LS specific patient registry. This call with CoRDS will allow you to learn more about the importance of our registry and answer any questions you have. To enroll in the LSA registry or update an existing registry- please go here: <https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL>

March 16, 2023 (12 -1 pm ET)

Understanding Your Kidney Results with Dr. Eileen Brewer

Are you curious or confused about what your child's kidney results actually mean? Join our Medical & Science Advisory Board expert, Dr. Eileen Brewer, who will walk us through what we need to know.

March 22, (11:30 a.m.- 12:15 p.m. EST)

Ohio Social Security Administration (SSA)

Join us for a presentation from the Ohio SSA to learn about eligibility and the services they provide.

The OCRL-1 Gene of Lowe syndrome

- Common physical characteristics of boys and men with Lowe syndrome include hindrance of cognitive ability, reduction of proper kidney function, and bilateral congenital cataracts. Physiologically will include a mutation to the Oculocereborenal syndrome of Lowe gene, OCRL1.
- Lowe syndrome is correlated with the mutated OCRL1 gene. This gene is located along the long arm of the X-chromosome, and is a recessive disorder. However random mutations can occur, and have the same effects as the mutations that were obtained via hereditary.
- OCRL1 is involved in the trans-golgi transportation system, aiding in the transportation of small, broken down substances to move throughout cells. This could include substances that are needed for energy or building block needs.

THANK YOU LSA SUPPORTERS

Giving Tuesday

With the collaboration of many LS members, family and friends, the LSA raised \$12,874.10 on Giving Tuesday!

Thank you to all of our members and donors for supporting our circle of care and our vision for a cure.

Anonymous
Pete B
Trisha Bass
Jocelyn Beni – *In Honor of Scotty Richards*
Teresa Bernstein
Dorrie Burke
Robert Byles – *In Honor of Blake Kubicki*
Stacy Cohen
Christine Crowell
Genevieve Custer Weeks
Myron and Kim Daringer – *In Honor of Clayton and Levi Arnold*
Dee Dee
Laura Deutsch – *In Honor of Matthew DeGori*
Jackie Fletcher-Gill – *In Memory of Nicholas Fletcher*
Lauren Floyd
Jennifer Gann
Susan and David Getty
Trisha Gibbs
Dave and Peggy Gill – *In Honor of our Grandson, Robert, and all the LS boys who bring a special kind of joy to our lives.*
Carol Goldstone – *In Honor of Blake Kubicki*
Amy Hatsushi
Kathleen Haugen - *In Honor of Hunter Haugen*
Rickey Hernaez
Manny and Maria Hondroulis – *In Honor of the Everitt Family*
Cheryl Jones
Mary Karth
Laura Kim
Kan Kinhong - matched by Rakuten Americas
Marla Kowalski
Josh and Jeri Kubicki
Don La Vigne
Samuel Lessin

Jessica Lessin
Courtney Loeb
Noelle Marie
Geoff McDonald
Amy Nichols
Kristin Nimsger
Jim O'Meara - *matched by MFS Gives in honor of Ian MacInnes*
Mujde Ozenoglu-Pidduck
Susan Patturelli – *In Honor of Ian MacInnes*
Sue Perichon
Jane Phillips
Linda Phillips – *In Honor of Scott Richards*
Jane Pidduck – *In Honor of Scott Richards*
Marguerite Platt
Marla Prince
Elizabeth Quadrino
Amy Richards
John Richards
Mark Richards
Barry Ross Rinehart and Claire Vande Polder – *This is a tribute to all the families and friends who have volunteered to make the LSA a vital, meaningful, and valued beacon of light. Thank You!*
David Robinson
Miguel Rodriguez - *matched by Gates Foundation in honor of Blake Kubicki*
Jodie Ruby
Amy Saltzman
Richard and Cathy Samaniego – *In Honor of our Grandson, Krew Smaniego*
Michelle Schrantz – *In Honor of Hunter Haugen*
Megan Seidler
Kenneth Socha
Holly Soroca
Jessica Stark
Rosario Stracuzzi
Kristina Taheri
Suzanne Taverna – *In Honor of James "Jimmy Hollywood" Montenero*
Crystal Taylor
Elizabeth Thomas
Bruce and Patricia Townsend
Mary Vascellaro

Adam and Lisa Waldbaum – *In Honor of Alex Waldbaum*
Naomi and Basil Waldbaum – *In Honor of Alex Walbaum*
Robin Weintge – *In Honor of Olver Reynolds*
Linda Wenglikowski
Joe Wigert
Cami Williams
Rebecca Yale

Donations

Anonymous
Stratos Benos, GREECE
Tom Eysmans and Sheila Denion, Bloomfield, CT
Gregory Friedland
Julie Griggs
Rickey Hernaez, New Orleans, LA
Susan Hinger, San Antonio, TX
Debbie and Greg Jacobs, Lucas, TX
Joyce and Robert McCann, Crown Point, IN
Bonnie Miller, CANADA
Thomas and Anette Muench, GERMANY
Vicky and Gary Nichols, Santa Paula, CA
Thomas G and Alison R O'Brien, Palm Beach Gardens, FL
Carley Quinn
Jason Redlus, New York, NY
Patricia and Gregory Rice, Baytown, TX
Keith and Sandra Schroerlucke, Madison, WI
Service Roofing & Sheet Metal Company, Mike Richardson, Greenville, SC
Daniel Siconolfi, Clark, NJ
Janet and Michael Swain, Walpole, NH
Shirley and Peter Unmack, AUSTRALIA

Memorials

In Memory of the boys we lost in 2022
Barbara and Mike Heinz, Broomfield, CO

*In Memory of Lynn Balek, cousin of
Tyler Abundis*
Brenda and Eric Abundis,
Plymouth, IA

In Memory of Daniel Basel
Kelly and Ken Basel, Harpursville, NY

In Memory of Pat Martin
Mickey Martin, Boise, ID

In Memory of Dona Martinez,
Steve and Peggy Kirkpatrick, Corsi-
cana, TX

In Memory of Leland McSpadden
Carol Czaja, Kingston, RI

*In Memory of Roger J. Mondello and
in honor of Mark and Ethan Mondello*
Melissa Agnew, Kansas City, MO
Karen Hannon, Billerica, MA
Marie Herb, Hyde Park, MA
Janet Jones, South Freeport, ME
Mark Matteson, Ashland, MA
William Moran, Duxbury, MA
John Pelose, Braintree, MA
Angie Wollmar, Georgetown, ME

In Memory of Tyler Richardson
Beverly Colwell, Raleigh, NC

In Memory of Michael Rochvarg
Carol O'Neill, Swarthmore, PA

*In Memory of Timothy Ralph Trapper,
Godfather of Luke Myers*
Columbia Valley Sportsmanship
Association, Budd Lake, NJ
Ken and Laura Gresham,
Acworth, GA
Milan and Cecilia Hibbard,
Springville, PA
Sarina Myers, Coopersburg, PA
Robert and Susan Oristaglio,
Lake Worth, FL
Armond and Rosemary Palazzari,
Olyphant, PA
Julieanne Prex, Canonsburg, PA
Debbie and John Rogalo,
Stanhope, NJ
Jeri Shepherd, Greeley, CO

*In Memory of Robert Varanyak,
grandfather of member Kelsey Car-
man*
John Lewin, Churchville, MD
Jacqueline Mullineaux, Brooklyn, NY
Kristi Ruffini, Hamilton, NJ

*In Memory of Stanley Zalewski,
grandfather of member Stephanie
Carbonneau*
Barbara Champagne,
Longmeadow, MA
Duncan Forsyth, Kiawah Island, SC
Tony and Marie Gazda,
South Dennis, MA
Barbara and Carl LeGrand,
South Hadley, MA
Nancy and Martin Pirnie,
Longmeadow, MA
Robert Veilleux, Chicopee, MA
Pat and Stefan Vokbus, Amherst, MA

Special Occasions

*In Honor of all the LSA Boys and their
moms*
Yury Samoylenko, RUSSIA

*In Honor of Harrison Adams and his
first Birthday*
Adrienne Deters, Spokane, WA
Heidi Garrod, Spokane, WA

In Honor of Harrison Adams
Samuel and Sarah Adams,
Spokane, WA
Anonymous
Ronald and Permsuk Ketchum,
Colbert, WA
Matt Porter, Spokane, WA
Jessica Slind, Clayton, WA
Leigh Anne Weller, Bothell, WA

*In Honor of Jonathan Ankrom and his
31st birthday*
Carol Ann Ankrom, Mansonville, IA

In Honor of Nicholas Avila
Wanda Goggans

In Honor of William Bass
Mr. and Mrs. Nelson Rusche
Foundation, Willis, TX

In Honor of Corbin Berry
William Lebherz, Frederick, MD

In Honor of Jonah Brehm
Deborah Brehm, Carmel, IN
Brian and Jane Greuel, Fishers, IN

In Honor of Gregory Clark
Garry Bopp, Covington, GA

In Honor of Ethan Clausen
Jeffrey and Terri Clausen,
Kensington, MD

*In Honor of Myron and Kim Daringer
and their 2 grandsons*
Marilyn Dahlof, Harlan, IA

In Honor of Matthew DeGori
Cori and Vinny DeGori,
Kings Park, NY

In Honor of Robert Erlandson
Robert and Dolores Webb,
Mesquite, NV

In Honor of Alec Everitt
Felice Breidner, Little River, SC
Carolyn and Irwin Everitt,
East Meadow, NY
Michele and David Shouel,
East Brunswick, NJ
Gail Stein, Port Washington, NY

*In Honor of Alec Everitt's 23rd Birth-
day*
Carolyn and Irwin Everitt,
East Meadow, NY
Gail Stein, Port Washington, NY

In Honor of Sam Gromoll
Linda and Chuck Buchs-Hammonds,
Mounds View, MN
Clare Gromoll, Shareview, MN

In Honor of James Jerman
Michael Byrnes, Locust Valley, NY
Kathleen and Thomas Duffe,
Commack, NY
The Durst Organization,
New York, NY
Eric Engelhardt, Rockville Centre, NY
Michael Gallagher from JSCS,
College Park, NY
Vincent Jerman, New Haven, CT
Isabelle Laurier, Brooklyn, NY
Judy and John O'Boyle,
New York, NY

Lynda Soldo, West Islip, NY
Mary and Eugene Walsh,
Crestwood, NY

In Honor of Nicholas Johnston, age 30, who battles each day to be the best he can.
Kathleen Johnston, CANADA

In Honor of Joshua Kim
Joon Kim, Ridgefield, NJ

In Honor of Laura Kim
Courtney Martin, Los Angeles, CA

In Honor of Brooks Kirkpatrick
Chris Calandro, Dallas, TX
Yale Fairchild, Dallas, TX
Caroline Kirkpatrick, Fort Worth, TX
Henry Kirkpatrick, Dallas, TX
Renee Price, Austin, TX
Madison Wickham, The Hills, TX

In Honor of Blake Kubicki and his birthday
Laura Kubicki, Winston Salem, NC
Greg Smith, Cincinnati, OH

In Honor of Andrew Lee
Jay and Young Hee Lee,
Syracuse, NY

In Honor of Ian MacInnes
Esterlina and Michael MacInnes,
Medford, MA

In Honor of Nathan Meester
Larry and Mary Meester,
Mesquite, NV

In Honor of Douglas Mitchell
Douglas Mitchell, Beach Park, IL

In Honor of James Montenero
Joseph and Jane Peluso,
Saugus, MA

In Honor of Dylan Myatt
Sheryyn Avendano, AUSTRALIA
Betty and Ewan McRobert,
AUSTRALIA
Dean Myatt, Moraga, CA

In Honor of Carson Newton
Elizabeth Newton

In Honor of Andrew Otani
Doris Quon, Pearl City, HI
Jo Ann Woodring, Honolulu, HI

In Honor of Angad Padebettu and all his LSA Bros
Rohit Padebettu, Jersey City, NJ
S & P Global, employer match

John and Stephanie Orr, Ventura,
CA
Giving Tuesday Facebook fundraiser

In Honor of Scott Richards
Katherine Eckert Grunder, Theodore
Eckert Foundation, NY, NY
John and Dianne Ruby, Camarillo, CA

In Honor of LSA founding member, Kathy Schroerlucke, for her milestone birthday. Donations were made to the Leland McSpadden Memorial Medical Research Fund.

Bruce and Kaye McSpadden,
Indianapolis, IN
Nadine McSpadden and Family,
Indianapolis, IN
Sally and Jim McSpadden,
Indianapolis, IN
Jennifer Schroeder, Golden Valley,
MN
Keith and Sandra Schroerlucke,
Fitchburg, WI
Kelly Schroerlucke, Louisville, KY
Sarah Schroerlucke, Richfield, MN
Jeanne Thompson and Kim
Schroerlucke, Louisville, KY
Jonathan, Solveig, and Eowyn
Schroerlucke, Stoughton, WI

In Honor of Santosh Srinivasan
Aparna Arunachalam, CANADA

In Honor of Mason Snow
Canyon Haley, Scottsdale, AZ
Stephanie and Pete Laugen,
Bluffton, SC
The Marks Family, Chandler, AZ
Denise Ramirez, Scottsdale, AZ
Louise Snow, Beaverton, MI

In Honor of Cody Stegman
Alva and Darla Stegman, Hooker, OK

In Honor of Colin Tietz
Martha Tietz, Kewanee, IL

In Honor of Alex Waldbaum
Andrea Gottlieb
Laura and Jonathan Waldbaum,
Lake Mary, FL

Donations in Support of the LSA Conference
Paul Richard
Gene and Carol Robinson, Hope, AL
Waylon Sullivan Foundation,
Hamilton, AL

Member and Community Fundraising

Longtime Member Brenda Abundis held her annual Pampered Chef and Thirty One fundraiser along with friend, Merel Wharam. Together they raised \$1369.49 for the LSA! Thank you for the continuous support!

Naomi and Chris Alvarado held a Lowe Syndrome Benefit in honor of Hayden Alvarado. Together, with the community, over \$2100 was raised!

Anonymous
Carissa Creek, Santa Rosa Beach,
FL

David and Dayle Fligel, Hartdale,
NY

Victoria Hughes, Santa Rosa
Beach, FL

William Potter, Santa Rosa Beach,
FL

Laura Sullivan, Santa Rosa Beach,
FL

Nicholas Turner, Blues Musicians
Society, Miramar, FL

With your continued support by shopping with Amazon Smile, the LSA received \$744.86. Please keep telling your friends and family to keep on shopping!

Ann Brennan asked friends and family to donate to the LSA for her birthday this year. The LSA is a charity that means a lot to her. Thank you for raising \$681!

Linda Adams
Charlotte Alice
Catherine Austin
Brona Brady
Bridie Brennan
Gerry Brennan
Grainne Brennan
Gill Broaders
Sheila Coll
Marion Curran
Lorraine Docherty
Katrina Douglas
Sandra Duggan
Tracy Duggan
Maureen Duggan Boyle
Anna Ferry
Una Ferry
Ava Fletcher
Ronni Hale
Kelly Jones
Alison Lowry
Vikky Manning
Deirdre Mcbreathy
Paraic McCarrick
Máire McCole
Anna Murray
Bernadette O'Donnell
Sarah Parnell
Evelyn Parsons
Hughie Shields
Anna Sullivan

For the 5th year in a row, Kelsey Carman, asked friends and family to support the LSA in honor of her birthday. Your annual fundraiser raised \$1200 and helped raise awareness!

Neil Campeas
Sally Comiski
Julie Crivelli
Barbara DeStefano
Lindsay DeStefano
Ed Foma
Georgette Galbraith
Susan Golden
Meg Hanson
Sharon Hayman
Peggy Howell
Krista Inotayev
Patti Lewin

John Lewin
Donna Lynn
Katie Lynn
Mary Marshall
Aggie Stefanelli
Erica Stefanelli
Denise Stremlo
Tom Tharp
Jeanne Tharp
Kate Varanyak
Nancy Whalen
Anita Zazzarino

Thank you Cecilia Confer for raising money for the LSA for your birthday this year! Together with your friends and family you raised \$280! Happy Birthday!

Deborah Aydlott
Kimberly Boyer
Cecilia Confer
Jim Connolly
Sheila Dentino
Ashley Gauvin
Chris Sawyer

DoGood Donations has dispersed \$3675 in 2022. Thank you for the support!

Thank you, Jeff Forrest, for creating a birthday fundraiser for the LSA. Your friends and family raised \$260 our boys!

David Arkenberg
Rick Asbury Sr.
Andrea Brown
Rosemary Forrest
Ronald Houston
Michael Likens
Barbara Russell
Karen Timmel-Hatzell

Rosana Granillo created a birthday fundraiser in honor of her 45th birthday! Thank you for raising \$415 for the LSA! Happy Birthday!

Joshua Contreras
Robert and Irene Hare
Rosie Medellin
Ruben Medellin
Bobby Myers

For her 40th birthday, Clare Gromoll, asked friends and family to donate to the LSA in honor of her son, Sam. With all the support, over \$1000 was raised! Thank you, Clare, and Happy Birthday!

Paula Achenbach
Sam Bardwell
Dorothy Bass
Mike Bjork
Michelle Boesch
Jennifer Broadbent
Joya Colon-Berezin
Bob Dickie
Rachel Frieders
Clare Gromoll
M. Aidan Gromoll
Jane Hanson
Marian Heinrichs
Bill Horger
Clare Lachance
Leonard Larsen
Adam Lasker
Sharon Neuenfeldt
Vonda Pearson
Chris Pica
Cynthia Bronson Sweigert
Joann Vaughan

United Way, Riverside County Campaign: Thank you Kecia Harper-Ihem for continuing to invest in the LSA!

Kimberly Haubert, a member since 2003, asked friends and family to make donations to the LSA in honor of her birthday. Thank you for your continued support and raising \$140 for the organization

Steven Camacho
Sheila Dentino
Stephanie Green
Kathy Nelson

Denise Kleefisch raised \$55 with her birthday Facebook Fundraiser! Thank you and Happy Birthday! Mary Roberts

Thank you, Joan Langgaard, for raising \$30 in support of the LSA. #FamilyMatters Morag Donald Joan Langgaard

Happy Birthday Elissa Martin! Thank you for raising \$35 with your birthday fundraiser.

Elissa Martin
Jay Martin

Thank you, Kayla Martin for raising \$119 for the LSA with your birthday fundraiser.

Rosie George-Dapp
Dorothy Hood
Ann Paquette

Angus Lee Noder held a Facebook Fundraiser and raised \$170 from his family and friends. Thank you!

Laura Bjorkman
Conner Bogar
Marty Matney
Angus Noder
Patrick Noder
Aly Sanders

I honor of her birthday, Jennifer Quinn raised \$85 for the LSA. Thank you for your support and Happy Birthday!

Mimi Gilbert-Quinn
Jennifer Quinn
John Villa

Kay Tansey raised \$26 with her birthday fundraiser this year. Thank you for supporting the LSA!

Leanne Hall
Hilary Tennant

Wendy Tilden asked friends and family to support the LSA with her birthday fundraiser. We appreciate your support in raising \$55!

Heather Armstrong Bruchet
Amanda McChesney
Bonnie Miller
Jo Rayburn

United Way, Riverside County Campaign: Thank you Kecia Harper-Ihem for continuing to invest in the LSA!

Thank you, Pamela Vandale, for setting up a Facebook fundraiser in honor of your birthday! You and your donor raised \$58 in support of the LSA

Pam Cassidy
Sharon Desrosiers
Randi Scansen
Pamela Vandale

Thank you, Alexandre Vigneault, for your support in raising \$40 for the LSA!

Guy Ruel

Johanne Jojo Vigneault raised \$30 for the LSA this year! Thank you for your support!

Marido Caronlap
Rejeanne Larrivee

Thank you, Stacey Vrtiska, for creating a birthday fundraiser in honor of the LSA. Through the donations of your friends and family, you raised \$410 for the LSA!

Sheila Dentino
Carol Gospodnetich
Kathy Kent
Ryan Knox
Steve Payne
Ree Ree
Laurie Reed
Amy Richards
LaShante Smith
Stacey Vrtiska

Happy Birthday Mary Williams! Thank you for asking your friends and family to invest in the future of the LSA

Alexandra Almeida
Mark Doyle
Jose Monarrez
Enid Weiser
Mary Williams

Monthly Recurring Donations

Ben Gillespie, Mason, OH
Christina and Iwan Risman,
San Diego, CA
Daniel Siconolfi, Clark, NJ
Mary and Mike Tietz,
Eden Prairie, MN

Note: *Donations listed in this issue were those received as of August 31, 2022. Donations received after that date will be included in the next On the Beam.*