

ANNUAL REPORT 2025

HELPING INDIVIDUALS AND FAMILIES IMPACTED BY HLH



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About Us

HLH stands for hemophagocytic lymphohistiocytosis and is a rare disease that typically occurs in young children, but may also occur in adults. The HLH Heroes Foundation is a 501(c)3 non-profit organization formed in 2021 by a group of HLH caregivers who wanted to honor their warriors by building a community of support.

Our Mission & Vision

Our Mission:

The HLH Heroes Foundation is dedicated to providing support to individuals and families impacted by HLH.

Our Vision:

No One Fights Alone



Our Team

We have a small but mighty team that works hard everyday to pay it forward to the HLH Community. This is a passion project for everyone on the team and this small organization has accomplished so much in the last few years in order to fill a much needed gap in the HLH Community.

Our dream of creating a place of hope and support for the HLH Community has come to life and continues to evolve and grow.

Thank you all for helping this organization to thrive!



Jessica Streit-Hrevus
President



Courtney Grant
Vice President



Jake Hrevus
Treasurer



Carrie Vice
Secretary



Molly Bley
Fundraising
Chair



Dan Vice
Growth & Development
Coorindator

Message from the President

Dear HLH Community,

As we look back on this past year, I am filled with immense gratitude and pride for all that we have accomplished together. The HLH Heroes Foundation was born from a shared purpose — to bring hope, awareness, and connection to those affected by Hemophagocytic Lymphohistiocytosis (HLH). This year reminded us that even in a rare community, there is incredible strength in unity. When families, advocates, and supporters come together, something remarkable happens. We feel less alone, we feel understood, our voices are amplified, hope is restored, and our passion for raising awareness about HLH ignites. A parent, caregiver, or warrior sharing their story, the community supporting a warrior's family, or a volunteer lending their time — contributes to a chorus that cannot be ignored.

Our progress this year reflects that collective power. From expanding outreach and patient support to deepening partnerships and raising awareness nationwide, these milestones belong to all of us. Every connection made, every life touched, and every step forward underscores the impact of working hand in hand.

As we move into the coming year, let us continue to build on this spirit of togetherness. Let us amplify each other's voices and ensure that no one facing HLH ever feels alone. Together, we are not only raising awareness — we are creating a legacy of strength, compassion, and hope.

Thank you for being part of this extraordinary community. Thank you for believing in our mission and for standing with the HLH Heroes Foundation as we fight for every life, every family, and every future touched by HLH.

With heartfelt gratitude,



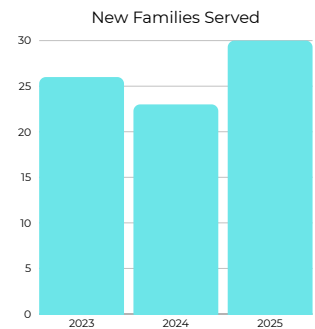
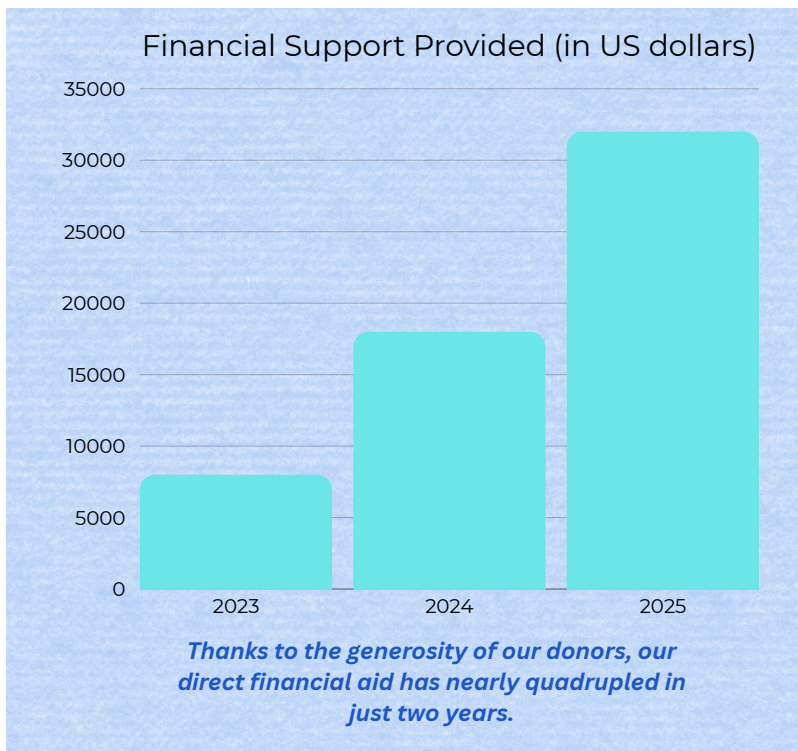
Jessica Streit-Hrevus, MSW, LCSW
President
HLH Heroes Foundation



Supporting Warriors

Scaling our Impact: A Year of Growth and Support

HLH Heroes Foundation is committed to providing emotional, educational, and financial support to individuals and families impacted by an HLH diagnosis. This year, our efforts focused on expanding our reach to more and more families while building a stronger system for connecting HLH families with valuable resources and other HLH families within our community.



After a stabilization period, we have expanded our reach to a record high in 2025.



We have seen consistent, linear growth in our sibling support initiative.

Family Spotlight



The Challenge: After a diagnosis of primary HLH, the Montanez family faced a "double burden": the medical necessity of a bone marrow transplant, and the logistical nightmare of relocating hours away from home for treatment. Recently, declining chimerism levels required a second move to a more specialized facility even farther away.

Our Support

Mentorship: We connected the parents with foundation members who have survived the BMT process, providing answers that doctors sometimes can't give.

Financial Safety Net: We helped to alleviate the financial burden associated with ongoing medical treatment by providing financial assistance that the family could use for housing and other necessities.

The Outcome: While the medical journey is ongoing and complex, the Montanez family has the freedom to pursue the best possible care for their daughter, regardless of geography, backed by a community that understands their fight.

What's Next?

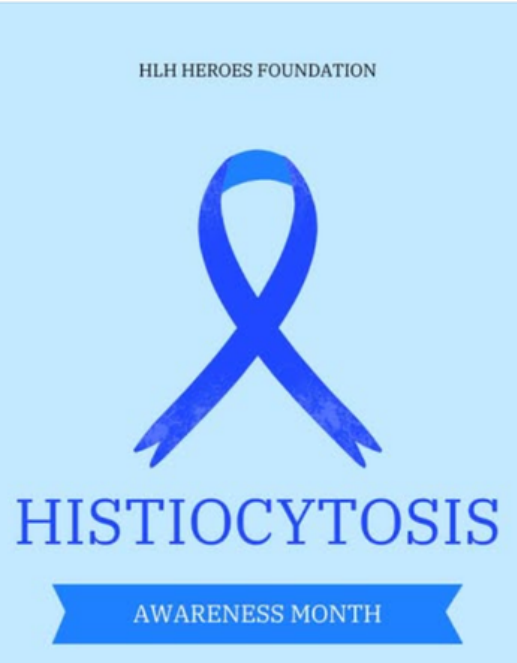
In 2026, HLH Heroes Foundation hopes to continue its outreach within the HLH community in order to reach more families. We also plan to recruit volunteers to help us launch our Caring Companions Program - a system of support that works to create an even stronger community for newly diagnosed families.

SOCIAL MEDIA ANALYSIS REPORT

Period: January 1-December 31, 2025

2.8K Followers	665 New followers	93.8% Followers in US	613,062 Views during the year
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TOP PERFORMING CONTENT



INSIGHTS AND RECOMMENDATIONS

- Our Warrior Stories and posts about Histiocytosis Awareness month were our top content of 2025
- This insight helps drive us to spread awareness about this rare disease and continue to be there to let families and individuals know they are not alone on this journey with HLH.

Events

As we reflect on 2025, we are filled with gratitude for our incredible community of supporters, families, volunteers, and partners. Because of you, HLH Heroes Foundation continued its mission to raise awareness, support families, and fund efforts related to HLH. Every step taken, every question answered, and every dollar raised made a meaningful difference this year.



Virtual 5K – May 2025

Our Virtual 5K brought supporters together from near and far, united by a shared purpose. Participants walked, ran, and rolled in honor of HLH warriors everywhere. Beyond the miles logged, this event raised critical funds and increased awareness about HLH, while reminding families affected by rare disease that they are not alone. We were able to raise over \$45,000!

Trivia Night – November 2025

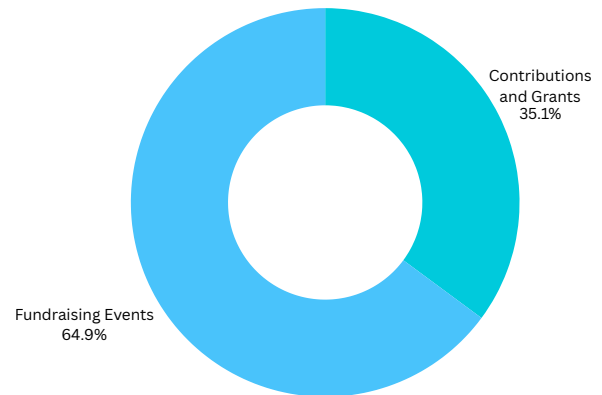
Our Trivia Night was a huge success and a highlight of the year! Friends and families gathered for an evening of fun, friendly competition, and community spirit. Thanks to the enthusiasm of our attendees and the generosity of our sponsors, this event helped fuel our programs while strengthening the bonds that make our foundation so special. We were able to raise over \$22,000!

One Year Review

STATEMENT OF ACTIVITIES

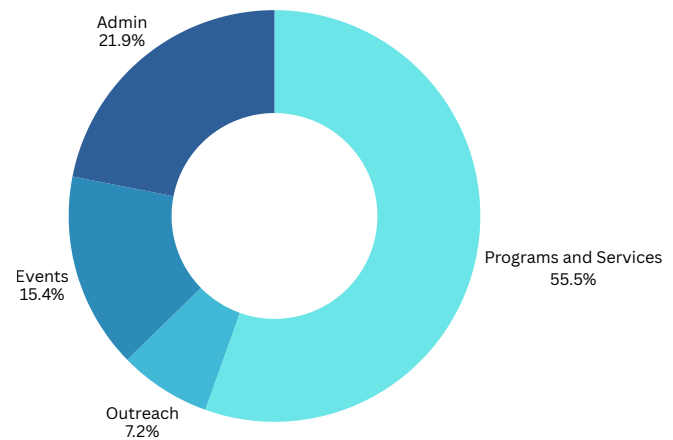
SUPPORT AND REVENUES

Contributions and Grants	\$34,338
Fundraising Events	\$63,408
Total Support and Revenues	\$97,746



EXPENSES

Programs	\$37,173
Events	\$10,316
Outreach	\$4,841
Administrative	\$14,695
Total Expenses	\$67,025



When individuals and families get some of the worst news, HLH Heroes Foundation hopes to be there to walk alongside them as they make their way through their HLH journey. Trying to connect with families as soon as they are diagnosed is a goal of ours, so we continue to increase our outreach efforts to connect with more families and individuals impacted by HLH, and sooner. We appreciate all of the support from our community and our donors to help make our vision a reality.

DONORS

Your support means the world to us and allows us to work towards our vision of: No One Fights Alone

*From the bottom of our hearts,
Thank You!*

A Williams	Basilica of St. Mary	Claudia Gutierrez	Gina Dinardo	Jonathan Fiumara	Lauren McReynolds	Mike Stohler	Scott Passet
Aaron Shavorinsky	Becky Schroeder	Claudia Marquez	Gina Scott	Jonathan Rawlins	Lauren Wilson	Mitzi Pfendt	Sean Crowley
Adam Adkins	Ben Burkett	Colette Dunham	Glori Sparrow	Jonathan Spacek	Laurie Pull	Mo Malakoutian	Shanda Faris
Adam Quirk	Ben Lutterbach	Connie Dlugosch	Grace Dingess	Jordan Hamons	LeAsha Printup	Molly Bley	Shan Karren
Adriane Domareckyj	Bernd Schoel	Connie Rubner	Hamacher	Joseph Radcliff	Leah Heinz	Molly Boatman	Shanon Gibson
Aileen Ortiz	Blade Rouse	Constance	Resource Group, Inc	Josephine and Walter Vice	Leah Kohler	Mona Dunn	Shannon Hayes
Alana Steinmetz	Bradley Armour	Konopinski	Hannah Sherrard	Josh Meyer	Lenore Gregg	Nancy Buening	Shannon Pfitzer
Alisha Hacker	Brandon Taylor	Construction Unlimited	Heather Nettles	Judy Kottschade	Leslie Dingess	Nancy Pull	Shannon Sweeney
Alicia Herd	Brenda Hauge	Corey Dixon	Heather Simmons	Judy Lange	Leslye Madden	Natalie Brown	Sheryl Large
Alina Wells	Brenda Lindeman	Corinne Lott	Heidi Schriefer	Julia Grayson	Liams Lighthouse	Nathan Niese	Shiela Beers
Alison Levin Bishop	Brenda McWhorter	Cortney McGuire	Henry George	Justin Steensma	Linda Davies	Nick Stumpo	Shonda Bedel
Alyse Seibert	Brendan Holroyd	Courtney Grant	Hensley Schr	Kaitlin Sobocinski	Linda Dunshee	Nicole Fiumara	Simon Jonas Alfano
Alysha Olinger	Brett Crowthers	Courtney Jones	Holly Kohler	Kaleigh Howe	Lindsey Franzi	Nicole Goetter	Sobi
Alyssa Sanchez	Brian Conner	Craig Waggy	Holly Victor	Kari Moore	Linzi Scheidler	Nicole Willse	St Mary Church
Alyssa Spacek	Brian Leonard	Crystal Jones	Jack Ryan	Karina Crouch	Lisa Marie Montanez	Nicole Zombotti	Staci Schutte
Amanda Boss	Brian Williams	Cynthia Lewis	Jackie Hejduk	Kassandra Kruger	Lisa Sweeney	Nop Lam	Stan Lane
Amanda Ginley	Brianna Edsall	Cynthia Sellers	Jacob Guy	Katarina Meier	Liz Nover	Pam Carey	Stephanie
Amanda Guerrero	Bridget Peters	Damian DeLeone	Jacob Hundley	Kate Poort	Liz Virtue	Pat Sumen	Stephanie
Amanda Helge	Brittany Comparato	Dan and Carrie Vice	Jake and Jess Hrevus	Katharine McCamment	Lori Brandt	Patrick Ginley IV	Borgmann
Amanda Rader	Brittney Franklin	Dana Keisker	Jame Blaisdell	Katharine Rawlins	Lori Karasti	Paul and Linda Streit	Stephanie
Amelia Powers	Brittney Massey	Darin McClure	Jami Mirka	Katherine Quirke	Lori McClure	Paul Klingberg	Willenborg
Amy Basel	Bryan Herbst	David Schwartz	Jane Kennelly	Kathleen Angello	Lynne Dukes	Paula Tardibone	Stephen Kostel
Amy Martinez	Cabrini Jablon	Deanna Zakis	Jared Eck	Kathleen Bonar	Mallorie Barnes	Pete Burkett	Stephen McGill
Amy O'Mara	Caitlin Drew	Deborah Carter	Jayme Croff	Kathryn Lockett	Marc Longo	Polly McNeill	Stephen Sobocinski
Amy Salinas	Caitlin Erb	Deck Farms	Jaymie Sullivan	Kathryn Mendoza	Marcilyn Quirk	Rahsaan Roberson	Steve Burnside
Amy Shaffer	Cameron Smith	Diane and Phil Williams	Jean Wollaston	Kathy Stephens	Marcia Stumpo	Ralph Jacobson	Sue Endsley
Ana Hernandez	Cameron Warner	Diane Mayer	Jeff Albert	Katie Chillemi	Maria Ryan	Rami Abbass	Susan Burkett
Andrea Janssen	Candice Dunn	Dominique Leclerc	Jeff Johnson	Katie McCrary	Marissa Wong	Rebecca Bjerke	Susan Hudson
Andrea Kerns	Candice Guanci	Donna Egeland	Jennifer Blankman	Katie Ricklefs	Marta Britton	Rebecca Pfendt	Suzanne Flynn
Andrea Schilstra	Carin Sevigny	Donovan Lovelace	Jennifer Draper	Kayla Bartlett	Mary Beth Young	Rena Everett	Suzanne Guy
Andrea Weide	Carlene Stumpo	Douglas Watson	Jennifer Miller	Kayla Gidel	Mary Chirillo	Rhonda Stanfill	Tara Brehm
Andrea Williams	Carol Poletti	Elizabeth Bates	Jennifer McConville	Kayla Kohlman	Mary Hamilton	Richard Deluge	Teagan Thompson
Andreas Janssen	Caroline Sanchez	Elizabeth Brackett	Jennifer Sawyer	Kayla Thompson	Mary Howe	Riley Green	Terry Hrevus
Andrew Schilstra	Carolyn Watson	Elizabeth Despina	Jennifer Vanderver	Keely VandenBerge	Mary Shoalmire	Robin Egeland	Tiffany Reiser
Angela Schneider	Carrie Burkett	Elizabeth Marigold	Jennifer Vogler	Keith Sexton	Matthew Gauck	Robin Guy	Tim Sobocinski
Ann Lobo	Cassandra Colin	Emma Guy	Jennifer West	Kelli Merritt	Meaghan Boland	Robyn Eck	Tina Liesen
Anne Clark	Cassandra Martinez	Erica Stick	Jennie Streit	Kelley Johnson	Megan Abraham	Robyn Shoalmire	Tracey Erb
Annamarie Santa	Catherine Borgmann	Erik Forgione	Jeremy Ryan	Kenneth Luckstead	Megan Blaisdell	Ronald Shands	Trisha Alunday
Maria	Catherine Rawlins	Erika Hernandez	Jessica Barbeau	Kevin Nichols	Megan Hayslett	Rosa Neely	Troy Booker
Anthony Lorimer	Catherine Waggy	Erin Jennings	Jessica Benhardt	Kimberly Allen	Megan Hrdlicka	Rosemary Bernato	Tyler Deaton
Antonio Aguilar-Lingo	Chad Culpepper	Erin Korsmo-Leonatti	Jessica Hitchell	Kimberly Neal	Megan Starr	Ryan Gullett	Valencia Gaston
Ashton Abbe-Seieroe	Charisma Rodriguez	Erin Weible	Jessica Landrud	Kirstin White	Megan Waggy	Samuel Brasses	Vanessa Warner
Ashley Bradley	Chelsea Arduser	Fred and Linda Banks	Jessica Nilsen	Kristen Hrabak	Melanie Gibson	Samantha Simpson	Vatche and Maral
Ashley Densmore	Chelsi Young	Gabrielle Montiel	Jessie Smith	Kristina Kersting	Meleney Albert	Sarah Brown	Keuffedjian
Barbara Kennedy	Cheryl Francisco	Gabriella Scacchetti	Jim Russell	Kristy Iaccino	Meredith Rielly	Sarah Rampulla	Wes Golladay
Barbara McGill	Cheryle Horjes	Galena Staroselsky	Jo Anne Englebert	Lacey Mallory	Michelle Koesterer	Sarah Soriano	William Brzeski
	Chris Shaffer	Gary and Beth Matters	Jocelyn Love	Lara Madden	Michelle Wilson	Savannah Sefton	Yannine Abundis
	Christopher Albert	Geoffrey Ebeling	Joe Federer	Larry Eekhoff	Mikala Glass	Scott Nelson	Yvonne Beuschel
	Ciara Boatner	Gig Harbor Wine	John Kilbourne	Laura Saltonstall	Mike Scott		
	Cindy Cramer		Jon Angello	Lauren Bellante			
			Jon Conrad				

Work with Us

This foundation was created for the HLH Community. If you would like to be part of the foundation, you are always welcome to join. Please reach out to info@hlh-heroes.org or click [here](#) to complete a volunteer form.

We want to take a minute to THANK our committee members and volunteers for making this year so successful!

Committee Members:

Caitlin Erb, Amy Salinas, Liz Despina, Cathy Rawlins, Kirsten Martinez, Donna Baines, Charlene Hurst, Heidi Blair, Kim Ryan

Volunteers:

Charisma Rodriguez, Erika Hernandez, Carrie Schmitt, Katie McCrary, Christine Bereitschaft

On behalf of our Board, Committee Members, and individuals and families that we serve, thank you from the bottom of our hearts for helping to make our year a success!

Contact Us



HLH Heroes Foundation
5051 Peyton Place Court
St. Louis, MO 63128

