



ANNUAL REPORT

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# HLH Heroes Foundation



# 2023

# SHINE WITH CONFIDENCE

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FROM THE FRONTLINE



## HLH HEROES FOUNDATION

-NO ONE FIGHTS ALONE-

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.

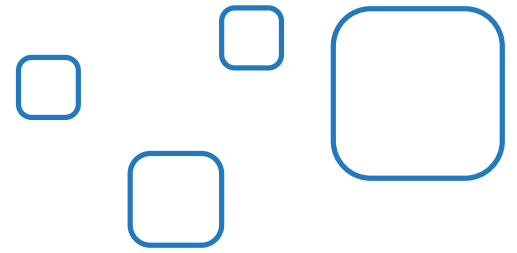
## Mission:

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

## Vision:

No One Fights Alone!

# MESSAGE FROM OUR PRESIDENT



RARE... a word that HLH individuals and families know all too well. From the first day of diagnosis an individual and family often steps into uncharted territory. Our foundation hopes to ease the waters that they are navigating.

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HLH Heroes Foundation continues to grow and evolve to help meet the needs for individuals and families facing an HLH diagnosis and help steady the waters. Even though this is a rare community, people continue to find our foundation and reach out for help and support. This is one of the biggest compliments a small, newer, foundation could receive. We are small, but we are mighty, and we are continuing to get the word out about our foundation and the support that we can provide to the HLH Community.

HLH Heroes Foundation would like to thank our community of families, supporters, and donors for an incredible year.



We are small,  
but we are  
mighty...

#NoOneFightsAlone

# SUPPORT PROGRAMS

HLH Heroes Foundation understands that an HLH diagnosis impacts not only the individual, but the entire family. This year, we updated our assistance application in order to gather more specific information about particular needs within our community, so we are better able to support families. We were able to make great strides in all aspects of support for HLH individuals and families.

## Emotional Support



We have continued to provide a variety of emotional support gifts (No One Fights Alone gift, Hospital care packages, 100 Days milestone gift, memorial gift). We connected more individuals/families with others who have previously undergone treatment for HLH to share experiences and provide emotional support. This year, we launched our sibling support program with sibling sidekick backpacks, a gift of activities for the siblings of HLH patients, who often spend hours, days, or months attending doctor's appointments alongside their loved one or separated from family while they undergo treatment.

## Educational Support



We continue to raise awareness about the importance of blood donation and bone marrow registration in our communities. We helped to send information or swab kits to over 50 new people to the Be the Match Registry at this year's virtual 5k event. We partnered with other organizations to promote and inform the HLH community about the into-HLH registry, a new registry started to gain greater knowledge about the outcomes of HLH treatment in order to advance treatment for patients. We also created a compilation of valuable resources to share with patients/families to help them navigate a new diagnosis and treatment journey.

## Financial Support



There is a gap in financial resources available to HLH patients, despite the fact that, like cancer, the treatment journey often requires a patient or caregiver to leave work, therefore sacrificing income. We are proud to be able to contribute toward filling this gap by offering gift cards to offset the cost of everyday expenses, assisting in bill pay or rent/mortgage requirements, and/or travel or lodging expenses. This year, we were able to increase the amount of financial support provided per family by 67% over last year.

### This Year's Highlights:

- Assisted 26 new families.
- Sent 12 sibling sidekick backpacks.
- Sent information and/or swab kits to over 50 new people for Be the Match registry.
- Increased financial support by 67%

# REACH

This year we have expanded our reach making it easy for our followers to stay connected to all the work our foundation is doing and to help show the support for the HLH families that we are helping everyday.



## Followers

Facebook: 2,005

Instagram: 356

We reach over  
40,000 people  
on Facebook



## Followers per Countries

1,800 USA

38 United Kingdom

27 Australia

15 Canada

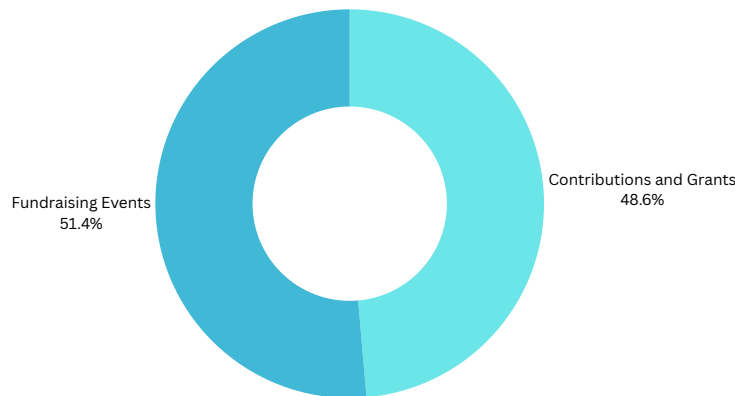
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# FINANCIAL REPORT

## STATEMENT OF ACTIVITIES

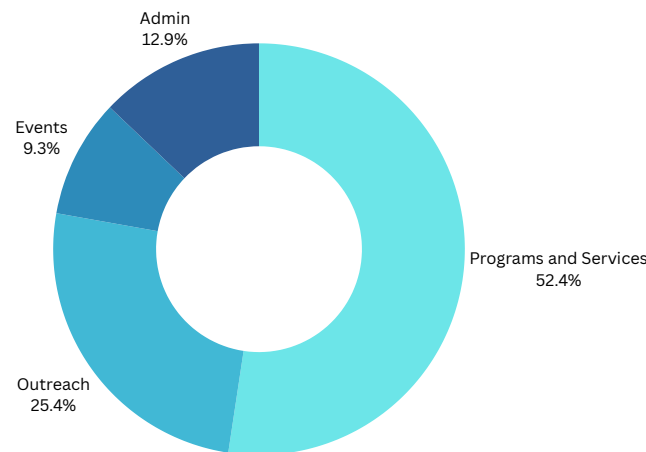
### SUPPORT AND REVENUES

<span style="color: #00A0C0;">■</span> Contributions and Grants	\$43,366
<hr/>	
<span style="color: #0070C0;">■</span> Fundraising Events	\$45,792
<hr/>	
<b>Total Support and Revenues</b>	<b>\$89,158</b>



### EXPENSES

<span style="color: #00A0C0;">■</span> Programs	\$16,757
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<span style="color: #0070C0;">■</span> Events	\$2,975
<hr/>	
<span style="color: #00A0C0;">■</span> Outreach	\$8,127
<hr/>	
<span style="color: #004A80;">■</span> Administrative	\$4,126
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<b>Total Expenses</b>	<b>\$31,985</b>



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.

# YEAR IN REVIEW

**Keep Fighting.** It reminds us of our journey when we had to advocate because we knew something was wrong, it reminds us of when we were diagnosed with something we had never heard of before, it reminds us of the time spent learning and researching everything imaginable about HLH, it reminds us of those hospital nights spent with machines beeping, it reminds us of the family/friends/strangers who came to our side to help us fight on, it reminds us of the nurses that became family it reminds us of the hope/courage/strength/perseverance/determination/tenacity we had, it reminds us of those we lost that we hope to honor, it reminds us of the survivors that inspire so many, it reminds us of the families - as their lives are forever changed, and it reminds us to push on to **pay it forward**.



## 2nd Annual Virtual 5k

Raised over \$35,000 to help support families and individuals impacted by HLH

- Participants from 22 states and 3 countries
- Over 15 teams represented

## Histiocytosis Awareness Month

### Keep Fighting

- Foundation sent out awareness stickers and ribbons to individuals and families impacted by HLH to recognize and honor their warriors.



## Trivia Night

A crazy, fun night that raised over \$14,000 for families and individuals impacted by HLH.

- Lots of food, laughter, and tickets!

Thank you to all our generous donors, supporters, and community for helping us to fulfill our mission of “No One Fights Alone.” We are beyond grateful for the support you all have provided to help us ease the waters for families and individuals entering an HLH diagnosis. What a year!



# 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!*

## **Sponsorships:**

ADG  
Sobi  
Michael Scott  
World Wide Technology  
Stratum Structural Systems  
Liam's Lighthouse  
All Star

Marcia Stumpo  
Teresa Anderson  
Brittany Gigliotti  
Diana Reyna  
Katelyn Everett  
Jessie Leak  
Allie Buehne  
Sydney Menefee  
Jennifer Angello  
Danielle Schomber  
Ashton Abbe-Seieroe  
Terry Hrevus  
Carol Poletti  
Katie Chillemi  
Heather Simmons  
Tara Brehm  
Shanda Faris  
Cassandra Colin  
Kimberly Grassley  
Brooke Callaghan  
Caitlin Drew  
Alisa Rosillo  
Elizabeth Burns  
Janet Streit  
Jessica Barbeau  
Jessica Benhardt  
Corrine Hellwig  
Jennie Streit  
Stephanie Mastropietro  
Corey Wollaston  
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Rena Everett  
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Michele Watson  
Sheryl Grossman  
Julissa Carbonell  
Rosemarie Correia  
Aubrey Grassley  
Kate Lockett  
Ryan Roberts  
Ryan Gullett  
Natalie Cavanaugh  
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Elyse Callaway  
Shannon Rice  
Veeda Dorri  
Paige Burnett  
Travis Williams  
April Weitzl  
Chloe Hall  
Sara Mohr  
Sandra Sanchez  
Kate Guerrero  
Linda Davies  
Dillon Simmons  
Paulette Sow

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Stuart Croff  
Theresa Ripley  
Tia Osborne  
Lara Duy  
Mary Chirillo  
Brian Chirillo  
Barbara McGill  
Tiffany Reiser  
Judy streit  
Paula Tardibone  
Kyle Kubat  
Osi Juergens  
Ann Lobo  
Tammie Waggy  
Jennifer Vogler  
Shan Rogers  
Molly Bayless  
Jonny Angell  
Kevin Bagwill  
Melissa Jenkins  
Tabi Adkins  
Lindsey Franzi  
Laurie Brace  
Courtney Grant  
Kara Davis  
Jon Fiumara

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Michelle Costa  
Susan Estes  
Marilyn Weindel  
Megan White  
David Stumpo  
Andee Williams  
Laura Fudge  
Tyshiauna Link  
Courtney Cucchiara  
Rebecca Dunn  
Cody Erb  
Jennifer Sawyer  
Jessica Landrud

# DONORS

*Honoring and remembering all of our HLH Warriors.*

## Memorial Donations

### **Emmett Linn**

Lynn Schreiner  
Jacob Melchert  
Sarah Amundson  
Amber Lindeman  
Kimberly Shillingstad  
JoAnn Schreiner  
Ruth Rosseau  
Anthony Schumacher  
Amy Kuntz  
Cheryl Earhart  
Susan Lick  
Laura Linn  
Ann Marie Woelfel  
Tia Newcomer  
Brenda Gustafson  
Angela Sinner  
Darla Nemas  
Gregory Schneider  
Carol Anderson  
Jeanne Engelking

### **Finn**

Natalie Cavanaugh  
Jessica Landrud

### **Isabella Stoehr**

Karl Stoehr

### **Kathleen Koelsch**

Margaret Walsh  
Kenyon Kilber  
Patricia Kemerer

### **Meagan**

Sandra Hall

### **Michael Henderson**

Fidelity Charitable: Long and Allen Families

## Memorial Donations

### **Joe Chirillo**

Carl Schneider  
David Stumpo  
Claudia Vice  
Vincent and Joanne Cascino  
Michael Kamnikar  
Bethanne Wyatt  
James Stumpo  
Ann Van Zelst  
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Jeff Angello  
Pamela Nicholson  
Roselee Maddalon  
Ed Perkins  
Joanne Prieto  
Megan Maas  
SFE Sunshine  
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Rick Adamsky  
Danielle Lockett  
Michelle Eberts  
Cynthia Kuhn  
Barbara Hefley  
Nancy Chirillo  
Kathleen Davis  
Richard Pavlik  
Josephine and Walter Vice  
David Vice  
Stephen McGill  
Maurine Halpern  
Eileen Singel  
Margaret Tracy

## Memorial Donations

### **Joe Chirillo (continued)**

Patrica Johnson  
Terri Conlon  
Laura Bansemmer  
Natalie DEWeese  
Brian Mullholland  
Marie Miller  
Frank Stumpo  
Marlene Bauer  
The Crothers Family  
Dan and Carrie Vice  
Joe Spinelli  
Deborah Stumpo

### **Ruby Honey-Brooks**

### **TJ Burgin**

Dana Keisker

### **Wayne F Wellman**

Sandi Green  
Susanne Reimer  
Elizabeth Lueg  
Kristin Reaves  
Paul Fey  
Doug Bohl

## Honorary Donations

### **Ayden Hower**

Frances A Duggan

### **Lucie Romero**

Steven Hill

### **Vaeda**

Ashtyn C Webb  
Ann Meyer  
Leslie Dingess  
Pamela Ewalt  
Patricia Sidner

# ACKNOWLEDGEMENTS

We want to take a minute to thank our entire crew of volunteers for making this year a success.

**Board:**

Jessica Streit-Hrevus (President), Courtney Grant (Vice President), Carrie Vice (Secretary), Jake Hrevus (Treasurer), Molly Pull Bley (Fundraising Coordinator), and Cassandra Colin (Support Coordinator)

**Committee Members:**

Dan Vice, Courtney Mares, Jessie Giglotti, Liz Despina, Gina Scott, Charisma Rodriguez

**Volunteers:**

Michelle Costa

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*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!*

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## CONTACT

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