



## primary HLH support groups

### **HELPFUL RESOURCES FOR PATIENTS AND FAMILIES**

Finding out that you or your loved one have primary HLH can be overwhelming. The good news is that you are not alone. The organizations in this brochure can provide you with helpful information, emotional support, and financial assistance.

HLH=hemophagocytic lymphohistiocytosis.

These groups were all founded by families affected by HLH. They offer information about the condition, and they fundraise for awareness, research, and treatment-related expenses. Use their contact information to get in touch and explore all they have to offer.



## LIAM'S LIGHTHOUSE FOUNDATION

Liam's Lighthouse Foundation (LLF) was founded in memory of a 1-year-old boy who lost his life to HLH. His mother launched the foundation to increase awareness of HLH and other similar conditions.

LLF hosts charity events to raise funds for research and education at medical centers. The LLF website provides an overview of HLH. It also links to information about stem cell donations, fundraising, and more.

 [info@liamslighthousefoundation.org](mailto:info@liamslighthousefoundation.org)

 [liamslighthousefoundation.org](http://liamslighthousefoundation.org)

 [@liamslighthousefoundation](https://www.facebook.com/liamslighthousefoundation)



## ERIC'S JOURNEY FOUNDATION

Eric's Journey Foundation was created by Amanda and her husband Eric, who was diagnosed with HLH and Still's disease shortly after their marriage. Their organization is dedicated to raising awareness about HLH and other histiocytic disorders, and providing support for patients, families, and friends dealing with these diseases.

You can visit their website or Facebook page to learn more about the charity events they host, and to read about Eric's journey on his blog.

 [eric@ericshourney.org](mailto:eric@ericshourney.org)

 [ericshourney.org](http://ericshourney.org)

 [@EricksJourneyFoundation](https://www.facebook.com/EricksJourneyFoundation)



## HLH HEROES FOUNDATION

HLH Heroes Foundation is a new foundation created to provide support to individuals and families impacted by HLH. This organization was created by family members and caregivers of HLH warriors and angels to build a strong support network for those in need. You can learn more about HLH Heroes Foundation by visiting their Facebook page.



These groups offer information and support for a broader range of conditions, including HLH.

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## HISTIOCYTOSIS ASSOCIATION

The Histiocytosis Association provides helpful information to patients and families dealing with primary HLH. It offers podcasts, webinars, videos, and more to help explain the condition. The association can also help connect patients with doctors who have experience treating primary HLH.

 [856-589-6606](tel:856-589-6606)

 [info@histio.org](mailto:info@histio.org)

 [histio.org](http://histio.org)

 [@histio](https://www.facebook.com/histio)



## IMMUNE DEFICIENCY FOUNDATION

The Immune Deficiency Foundation (IDF) works to inform and connect families facing conditions like primary HLH. IDF hosts virtual meetings for people to share their experiences in a casual setting. The IDF website offers lots of resources, including educational materials and newsletters. It also includes information about starting your own fundraiser or joining a fundraising event.

 [800-296-4433](tel:800-296-4433)

 [primaryimmune.org](http://primaryimmune.org)

 [@ImmuneDeficiencyFoundation](https://www.facebook.com/ImmuneDeficiencyFoundation)

Patients with primary HLH may need a bone marrow transplant. Below are 2 groups that can help you through the process.

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## BLOOD & MARROW TRANSPLANT INFORMATION NETWORK

This organization's website provides basic information about stem cell transplants. It includes a Video Learning Library, books for patients, and more. BMT InfoNet also provides a one-on-one peer support program.

 888-597-7674

 [help@bmtinfo.org](mailto:help@bmtinfo.org)

 [bmtinfonet.org](http://bmtinfonet.org)

 [@bmtinfonet](https://www.facebook.com/bmtinfonet)



## BE THE MATCH

This is the largest and most diverse bone marrow registry in the world.

 888-999-6743

 [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

 [bethematch.org/one-on-one](http://bethematch.org/one-on-one)

 [@bethematch](https://www.facebook.com/bethematch)





you don't have to face  
primary HLH alone

**WE HOPE THE ORGANIZATIONS  
IN THIS BROCHURE CAN HELP  
YOU DURING THE PRIMARY  
HLH JOURNEY**

**Talk to your healthcare team for questions  
about additional resources and support.**