## HEMOPHAGOCYTIC LYMPHOHISTIOCYTOSIS

Hemophagocytic lymphohisticocytosis (HLH) is a disorder of the immune system primarily affecting young infants and children. The prevalence of HLH is 1.2 in every 1,000,000 children under the age of 15.

We currently know that HLH occurs either on the basis of genetic defect or as a secondary form with underlying diseases such as infections, cancer, or rheumatic disease.

The onset of HLH is usually early in life and a persistent cure can only be achieved with aggressive chemotherapy treatments and successful Bone Marrow Transplant.

There are several histiocytic disorders: LCH, HLH, JXG, Erdheim-Chester, and Rosai-Dorfman.

To learn more about HLH and other histiocytic disorders, please visit the Histiocytosis Association website at:

www.histio.org/diseaseinformation

## **ABOUT THE ASSOCIATION**

The Histiocytosis Association is an international partnership of parents, patients, physicians and friends bound together by their mutual interest in histiocytic disorders. The Association provides educational and emotional support programs, and promotes scientific and medical investigation into histiocytic disorders through its research program with the aim of establishing better treatments, prevention, and a cure for these diseases.



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# **SATURDAY, MAY 22, 2021**



## **Jeffrey White**

The Goal: To raise \$5,000 for family support, awareness, and research for a cure.

http://histio.org/HistioRunJeffreyWhite

## **RUN DETAILS**

The Histio Run in memory of Jeffrey White is a 5K USATF certified course that will start and end at the Mannford High School.

For young and novice runners, please join us for the Mile Fun Run taking place just prior to the 5K event.

## **SATURDAY, MAY 18**

7:00 - 8:00 AM CHECK-IN/REGISTRATION

8:00 - 9:00 AM MILE FUN RUN

9:00 AM 5K START

## **REGISTRATION**

	EARLY BIRD REGISTRATION (ends April 30)
\$35	Includes: 5K run access and t-shirt
\$25	Includes: Fun Run access and t-shirt
	REGULAR REGISTRATION (ends May 21)
\$45	5K run access and t-shirt
\$35	Fun Run access and t-shirt
	ON-SITE REGISTRATION (May 22)
\$55	5k run access and t-shirt while supplies last
\$45	Fun Run access and t-shirt while supplies last
	TEAM OF 10 REGISTRTION

5k run access and t-shirts for 10 runners

## **FUNDRAISING GOAL**

\$250

The funds raised for the Histio Run In Memory of Jeffrey White will benefit the Association's family support, awareness, and research programs. These support programs include educational brochures, regional education meetings and awareness campaigns. The objectives of the Research Program are to fund worthy scientific research projects, educate physicians and scientists, encourage and support symposia into histiocytic disorders, directly participate in research projects, and encourage publication of scientific information. Please help us reach our goal of \$5,000 with your donation today!

## **JEFFREY'S STORY**

Our second son, Jeffrey, was born after a long eight and a half years after our first son. Our miracle baby! At birth his platelet count was low but after a couple of days corrected itself and was written off as jaundice. We took him home thinking we had a healthy baby boy. At four months more symptoms began.

He had a strange unresponsive diaper rash, what looked to be cradle cap, and a white "cottage cheese" substance in his mouth. It was initially written off as common baby issues, but I insisted that it wasn't. After four months of being camped out in doctors' offices, the diagnosis finally came: Langerhans cell histiocytosis (LCH). I couldn't even pronounce it let alone grasp what was happening. We were told it was only skin and bone involvement and six to twelve months of chemo should do the trick. But once we started chemo, it just seemed to make the disease angry. He just got sicker and sicker. It moved to his spinal fluid then his liver, spleen, kidneys and brain. Then the diagnosis change from LCH to hemophagocytic lymphohistiocytosis (HLH).

Jeffrey was transferred to Texas for a bone marrow transplant. After three months the doctors decided he was well enough to do the transplant. It seemed to be working—his bone marrow was making his own blood and his count was coming up to normal. At fifteen days out the doctors were hopeful. The next morning, Thanksgiving Day 2001, Jeffrey crashed. The doctors worked on him until noon to no avail - our miracle baby went to heaven at 2:30 PM.



## WHY WE RUN

We are running to raise money for this "orphan disease" so that no child has to go through what Jeffrey had to go through. This is a rare disease and there isn't a lot of research money. It is up to the families of the children stricken with it. Please donate and help find a cure.

## **MAKE A DIFFERENCE**

Name of Person Sponsored:

Thank you for being a part of this special event by sponsoring a Histio Run in Memory of Jeffrey White participant. Your donation directly supports awareness and research programs into improved treatments for children and adults affected by the histiocytic disorders. Thanks for making a difference! Your donation may be tax deductible under IRS code 501(c)(3).

Tribute Name: Jeffrey White		
Donate Online:		
Go to: www.histio.org/HistioRunJeffreyWhite		
Click the link "Donate to This Event" button		
• Enter in the runner's first or last name and click "Search"		
Click the "Donate Now" button next to the walker's name		
Donate In Person Enter the data below and give this form with your donation directly your favorite runner. The runner will give it to the Histiocytos Association.		
Donate by Mail Send your donation along with this completed panel to: Histiocytosis Association Attn: Histio Hike Shenandoah 332 North Broadway Pitman, NJ 08071		
Name:		
Address:		
City: State: Zip:		
Phone:		
Email:		
□ Cash		
☐ Personal Check or Money Order		
Payable to the Histiocytosis Association • Include runner's name on check		
☐ Credit Card: Visa/Master Card/American Express/Discover		
ACCOUNT NO.		
AUTHORIZED SIGNATURE		
CVV/SECURITY CODE EXP. DATE STOTAL DONATION AMOUNT		

□ I prefer to make this donation anonymously.