

Histiocytosis Association Newsletter December 2021 Edition

The Histiocytosis Association strives to keep you informed of news and updates in the Histo Community as we continue to fight for better treatments and a cure.



We want to thank each and every one of you for your continued support, your ideas, your feedback, your generosity, and your commitment to us.

With 2021 coming to a close, we reflect back on the milestones of this year... launching a new website; the publication of the NCCN Clinical Guidelines for LCH, RDD, and ECD; holding several regional meet-ups with the community; over five educational webinars; launching the Beyond the Diagnosis Podcast; reopening our research program to fund research into all histiocytic disorders; joining the PCORI Rare Disease Advisory Panel; participating in several events; and there are certainly milestones not mentioned.

As we look into 2022, we are encouraged by the opportunities that lie ahead, and are eager to continue to find ways to meet the needs of this amazing community.

We thank you for standing by us, with us, and know that together, we will find a cure!

*Anna Jacobs Vester
Kristen Abner
Erica Melnick Kathy*

Share a Smile!



Bring a smile to your Histo Warrior with a Monkey Grins care package.

The Aaron Family, members of our Histo Community started Monkey Grins in honor of their beloved son, Jenson. At just 9 months old, Jenson was diagnosed with histiocytosis – his battle lasted 2 ½ years and included chemo and bone marrow transplant.

While recovering from the transplant, Jenson saw a picture of another little boy fighting histio. He said to his mother, "I need send him a monkey!" Jenson's big sister Sydney also wanted to help histio families by adding monkeys for brothers and sisters and lollipops for the family.

Jenson got to see the first five "Monkey Grins" care packages sent to Warriors like him before he sadly passed away at just 3 years old in May 2012. Through each Monkey Grin care package, Jenson's compassionate heart lives on.

Every Monkey Grin care package contains a stuffed monkey for your Histo Warrior and one for their sibling(s), plus lollipops for everyone in the family.



Request a Monkey Grin for your Warrior today at <https://histio.org/monkey-grins/> or histio.org/monkeygrins/donate.

Monkey Grin care packages are available once per patient/siblings - kindly, no duplicate requests. Due to COVID-19, Monkey Grins are currently only available to ship to recipients in the USA.

Calling All Hockey Fans!

Join us on Saturday, January 8, 2022 at 7:00pm ET for our first-ever Histo Night at The Philadelphia Flyers! Tickets are discounted by nearly 40% off retail for most seats. Plus, \$10 from every ticket purchased will be donated to the Histiocytosis Association in support of research, educational resources, and emotional support for patients and families.

Tickets must be purchased here: <https://fevo.me/histio> (<https://fevo.me/histio>).

**The Wells Fargo Center invested millions of dollars and implemented dozens of new safety protocols to keep everyone as safe as possible - read more about the safety protocols that the Wells Fargo Center is taking to protect fans, players, and employees, [here](https://www.wellsfargocenterphilly.com/back-to-broad) (<https://www.wellsfargocenterphilly.com/back-to-broad>).*



Have You Heard?

Beyond the Diagnosis Podcast

There are two new episodes of the Beyond the Diagnosis Podcast, now available! In episode 10, Kathy welcomes back Deanna Fournier, Executive Director of the Histiocytosis Association, to give a year end update on what the Association has been working on this year, as well as a glimpse into what is to come in 2022. In episode 11, Sara Clyburn, Project Coordinator for NACHO, the North American Consortium for Histiocytosis discusses what consortia are, why they are important and what NACHO is doing to drive research for histiocytosis toward better treatments and ultimately a cure.

Check it out at www.histio.org/beyondthediagnosis (<http://www.histio.org/beyondthediagnosis>) or wherever you listen to podcasts!

Histio Community Yoga

We are thrilled to bring the histio community together, for a very special wellness event, Histio Community Yoga. This class is Open Level, therefore will incorporate postures that are accessible to all skill levels and will offer recommendations for accommodations for certain postures. The class will be led by Becca Florczyk, a registered yoga teacher & certified holistic nutritionist. Becca received her training through the Awakening Yoga Academy and is also registered with the Yoga Alliance. As a community based class, there is a \$5 suggested donation, not required to join us on the mat.

Register here: www.histio.org/histioyoga (<http://www.histio.org/histioyoga>)



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Excutive Director Blog

Thinking about participating in a clinical trial, but are not certain what it entails or how to locate an opportunity near you? In the most recent blog post, Deanna seeks to learn more about navigating the decision to participate in a clinical trial for treatment. Our partners at Be The Match – Jason Carter Clinical Trials Search & Support Program (JCCTSS), walk us through the facts and explain how their Patient Support Center and Clinical Trial Navigators can help!

Read more here, on the blog! <https://histio.org/clinical-trials-a-deeper-dive/> (<https://histio.org/clinical-trials-a-deeper-dive/>)

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