



March eNewsletter

HISTIOCYTOSIS ASSOCIATION

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

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.

The Road To A Cure

Established in 1990, the Histiocytosis Association **Research Program** (<https://histio.org/research/>) continues to award seed grants for research into histiocytic disorders.

Over the lifetime of the program, the Association has funded over \$7million in research, totaling over 190 grants. In 2021, the Association funded an additional four projects, through the support of the Histio Community! We are humbled and grateful for all that you make possible and for your continued support of our vision **to see a world free of histiocytic disorders.**

You can find out more about our **Research Program** (<https://histio.org/research/>) on our website, and even explore all of the **grants we have funded by year** (<https://histio.org/research/grants-awarded/>), since 1992!

We will share more about the research funded in 2021 in an upcoming, dedicated message.



International Rare Disease Day

International Rare Disease Day is coming up on February 28th - although, every day is Rare Disease Day

when you are living with or you are caring for someone who has a histiocytic disorder.

The experience is often isolating and lonely, but on this special day, we are all urged to come together as one to

call attention to the special challenges faced by 'rare' patients and those that care for them.

Sponsored in the United States by the **National Organization for Rare Disorders (NORD)** (<https://rarediseases.org/>), and internationally

by **Eurordis** (<https://www.eurordis.org/>), Rare Disease Day is observed on the last day of February (the rarest date on the calendar)

to underscore the nature of rare diseases and what patients face. On and around this day, thousands of patients,

families, and patient organizations from countries and regions around the world participate in awareness-raising activities to elevate public understanding of rare diseases.

Be a part of the change happening this Rare Disease Day!

Check out these **EASY WAYS TO PARTICIPATE** (http://give.histio.org/site/DocServer/Get_Involved_Rare_Disease_Day.pdf?docID=122) in the **Rare Disease Day** (<http://www.rarediseaseday.org/>) movement!

Together, let's raise awareness for histiocytic disorders and the rare disease community!



New Program Alert!

Through the support of a grant from Investors Bank and Roma Bank Community Foundation, we are nearing the official launch of the new **Histo Ambassador Program**, guided by our dedicated Outreach Program Coordinator, Melinda Atnip!

Melinda brings a background in education and nonprofit work, along with her personal experience as the wife and advocate of an ECD Warrior. Her passion and talents led to the creation of an engaging program.

Histo Ambassadors are passionate leaders who seek opportunities to share their valuable experience with others, to promote community outreach, and to share histiocytosis information as an advocate for the histio community and the Association.

If you are interested in learning more about the program, email Melinda at matnip@histio.org (<mailto:matnip@histio.org>)!



New Episode: Beyond the Diagnosis!

In the latest podcast episode, Kathy speaks with Debbie Drell, the Director of Membership for the National Organization for Rare Disorders (NORD). In the conversation, we learn more about how NORD

supports the rare disease community, and explore Rare Disease Day 2022 - how it has impacted the rare disease world over the years, and how you can get involved in Rare Disease Day this year.

Tune in through **our website** (<https://histio.org/beyond-the-diagnosis-podcast/>), on Spotify, or wherever you listen to podcasts.

New episodes released monthly! Subscribe to the Podcast to stay up to date!



Histio Hike Shenandoah... IS BACK!

After two years of virtual hikes, Histio Hike Shenandoah we will be back in person in beautiful Shenandoah National Park for the 13th annual hike, on April 29-30, 2022. The Histio Hike Shenandoah honors those affected by histiocytosis, helps fund Association research grants and services, and is a way to connect with other histio warriors and families.

In the last thirteen years, the Histio Hike Shenandoah, hosted by the Brown Family, has brought together 1,555 participants and has raised over \$784,600, with thanks to the generosity of the community.

Meet Tracy, Ryan, and their son and Histio Warrior, Ian and find out why they hike, [here](https://histio.donordrive.com/index.cfm?fuseaction=cms.page&id=1102&eventID=644) (<https://histio.donordrive.com/index.cfm?fuseaction=cms.page&id=1102&eventID=644>).

Registering is easy - visit the [Histio Hike Shenandoah](http://give.histio.org/site/R?i=mizq_5E9XhxeZdQE4BIUqGJodePGPIDR9cjEuUhQ3f9oxmxbyO2DA) (http://give.histio.org/site/R?i=mizq_5E9XhxeZdQE4BIUqGJodePGPIDR9cjEuUhQ3f9oxmxbyO2DA) page to learn more.


**OPEN LEVEL
YOGA FOR
HISTIO**
With BeckaFloYoga



Now Live: Yoga for Histio - Online

Emotional and physical wellness are important for everyone. When we are faced with an obstacle, such as receiving a diagnosis of a rare disease or knowing that a loved one is ill, it is more difficult to focus on our emotional and physical wellbeing. Yoga is just one way to take a moment for yourself; at its core, yoga is meant to encourage relaxation of the mind and the body.

With the histiocytosis community in mind, yoga instructor Rebecca Florczyk has developed a series of online yoga classes that take into consideration all levels of experience with yoga, in addition to the possible modifications for mobility, flexibility, and balance. The classes are considered Open Level and are available online via our website.

Visit the **[Yoga for Histio Online Studio \(https://histio.org/resource-overview/yoga-for-histio/\)](https://histio.org/resource-overview/yoga-for-histio/)** to discover the Lower Body Chair Yoga and Deep Breathing Exercises classes.

**New classes will be launching monthly, so be sure to check back!
Have an idea for a class? Email us at info@histio.org!**



Bring a smile to your Histio Warrior with a Monkey Grins Care Package!

The Aaron Family, members of the Histio Community, started Monkey Grins in honor of their beloved son, Jenson.

At 9-months old, Jenson was diagnosed with histiocytosis - his journey lasted 2 1/2 years, and included chemo and bone marrow transplant.

While recovering from the transplant, Jenson saw a picture of another little boy fighting histio. "I need to send him a monkey!" Jenson told his mother. His 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 himself, before he sadly passed away at just 3-years old, in May 2012. Through each Monkey Grins care package, Jenson's compassionate heart lives on!



YOU can send a Monkey Grins care package, today! Every Monkey Grins package contains a stuffed monkey for your Histio Warrior and one for their sibling(s), plus lollipops for everyone in the family.

Request a Monkey Grins Package at histio.org/monkeygrins (<https://histio.org/monkey-grins/>), or support the program at histio.org/monkeygrins/donate (<https://histio.org/monkeygrins/donate>).

*Monkey Grins 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.*

FOLLOW US

<http://www.facebook.com/histio>

<http://www.twitter.com/histiocytosis>

http://www.instagram.com/histiocytosis_association

<http://www.youtube.com/histiocytosisassoc>

332 North Broadway, Pitman, New Jersey 08071 USA

Tel: +1 856-589-6606

Histiocytosis Association ©2026 All rights reserved.

Unsubscribe (<http://give.histio.org/site/CO>) | View this email in your browser (http://give.histio.org/site/MessageViewer?em_id=10610.0&pgwrap=n)

POWERED BY  <http://www.convio.com/poweredby>

Histiocytosis Association, Inc.

332 North Broadway, Pitman, New Jersey 08071 USA

Phone: +1 856-589-6606 | Fax: +1 856-589-6614

Email: info@histio.org

(<mailto:association@histio.org>)

US & Canada Toll-Free: 1-800-548-2758

Tax ID: 22-2827069

[Make a Donation today \(Donation2?mfc_pref=T&df_id=2240&2240.donation=form1\)](#)

Stay Connected to the Histo Community

[Sign Up for Our Newsletter \(SSurvey?ACTION_REQUIRED=URI_ACTION_USER_REQUESTS&SURVEY_ID=1900\)](#)

- **f** (<http://www.facebook.com/histio>)
- **X** (<http://www.twitter.com/histiocytosis>)
- **@**
(http://www.instagram.com/histiocytosis_association)
- **▶**
(<http://www.youtube.com/histiocytosisassoc>)