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eNewsletter

HISTIOCYTOSIS ASSOCIATION

— AUGUST NEWSLETTER

Awareness Frames

Social Media Frames Available

Social media is a great way to spread histio awareness all year long! Even though Facebook profile frames have gone away, we found an alternative! Select one of our custom frames, send us your photo and we will take care of the rest. Check out the custom designs below.



And
more...

Submit your profile photo

(https://docs.google.com/forms/d/e/1FAIpQLSfTJcitRUHVk8UxNtXok8sHsMXpyu7HNMLdZkHTM5W3bOHtJQ/viewform?usp=sf_link).

Results of the DImond Survey

The DImond Survey assessed the characteristics of patients with central diabetes insipidus (DI) from diagnosis to management of the condition.

Here are some key findings:

85%

Of patients say they would be in favor of a name change as 80% say health care professionals have gotten their condition confused with Diabetes Mellitus

36%

of patients recognized psychological changes subjectively associated with their diabetes insipidus and 64% reported lower quality of life.

26%

of patients had at least one hyponatremic episode leading to hospitalization

See more info on the results below

DImond Survey Results

[https://www.sciencedirect.com/science/article/pii/S2213858722002194?](https://www.sciencedirect.com/science/article/pii/S2213858722002194?dgcid=coauthor&fbclid=IwAR1fu8PEZRv-ODWWS949t4K8TeQlZgva_ppxRTIVj-jpvOoJUG-diU1LkCc)

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Events

Together for the Cure

HISTIOCYTOSIS
5K & FAMILY FUN DAY
WALK/RUN SAT SEPT 10



Chula Vista, CA



WHO WILL YOU RUN FOR....

The Histo Blue Ribbon Run unites the Histo Community everywhere, to run/walk together in spirit and in recognition of Histo Awareness Month and our commitment to the patients and families impacted by histiocytic disorders.



Order your Histo Blue Ribbon Run bib today!

Together for the Cure

[https://histio.donordrive.com/index.cfm?](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=657)

[fuseaction=donorDrive.event&eventID=657\)](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=657)

A WARRIOR'S VISION

[https://histio.donordrive.com/index.cfm?fuseaction=cms.page&id=1212&eventID=659\)](https://histio.donordrive.com/index.cfm?fuseaction=cms.page&id=1212&eventID=659)

Events

Registration is NOW OPEN!

CAMP OUT FOR HISTIO
SEPTEMBER 30

Pillow Forts
Camp Fires
Friends
S'mores

The first 10 registered campsites will be entered for a chance to win two (2) YETI tumblers.

More Info for Camp Out

<https://histio.donordrive.com/event/campout>

Education Corner

Do you kNOW Histio?



?? Have a histio question?
our histio doctors may have the
answer this September!

Submit a question in the form
linked below



Histio Question Form

https://docs.google.com/forms/d/e/1FAIpQLSfz8HH0EvKz2fxlh5D_IJF0dBKwjXS-HtHBjWYrJERNI-QXw/viewform?usp=sf_link

Two New Blog Posts!

Our Executive Director, Deanna Fournier, has written two new blog posts this month. Both on different aspects of Advocacy.

The first post focuses on general advocacy for patients around the world, highlighting us and other international non-profits dedicated to histiocytic disorders.

The second post focuses on advocacy through activism and legislation, featuring Leisa Greathouse, a long-time community member who is passionate about advocacy.



Executive Letters Blog

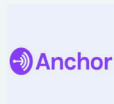
(<https://histio.org/blog/>)

Beyond the Diagnosis

New Episode Available!

The latest episode of the Beyond the Diagnosis Podcast is now available! In this episode Kathy talks with 3 of the Association's new Ambassadors about the events they are planning for Awareness Month. Come roll and run into September with us!

Check it out at <https://histio.org/beyond-the-diagnosis-podcast/> or wherever you listen to podcasts!



Check out the show notes for each episode, where you'll find additional resources, links, and information to expand upon the episode's conversation - and, subscribe to be the first to know when a new episode becomes available. You can say you heard it first!



UNITE
LEARN
SHARE

Resource of the Month

Pituitary World News Podcast on DI



Recently, Jorge Faccinetti graciously hosted the Histiocytosis Association, Histiocytosis Association of Canada, and Erdheim Chester Disease Global Alliance to discuss the relationship between histio and diabetes insipidus. We look forward to hosting a webinar soon, to talk about diabetes insipidus with Jorge's "partner in good", Dr. Lewis Blevins, renown neuroendocrinologist and co-founder of PWN.



ERDHEIM-CHESTER DISEASE
GLOBAL ALLIANCE



HISTIOCYTOSIS™
ASSOCIATION
A Rare Community



Histiocytosis
Association of
Canada

Hosted by :

Pituitary World News

(http://give.histio.org/site/R?i=-JUb25UZ1S8SgIRIZnqEqk4h88ney_ugVwbe6yDVzgH9b1bf1LIUgA)

PWN Podcast

(http://give.histio.org/site/R?i=-JUb25UZ1S8SgIRIZnqEqk4h88ney_ugVwbe6yDVzgH9b1bf1LIUgA)

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332 North Broadway, Pitman, New Jersey 08071 USA

Tel: +1 856-589-6606

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[. \(http://www.convio.com/poweredby\)](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

[. \(mailto:association@histio.org\)](mailto:association@histio.org)

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

Tax ID: 22-2827069

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