



HAEA in Action February Newsletter!



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Start the new year healthy and happy!

It's not always easy to keep our New Year's resolutions. This year, the HAEA wants to help you reach these two goals - to be healthier and happier! Thanks to all of your responses to the HAEA's Interest Survey, we have a full calendar

of events and activities planned just for you and your family. From our exciting multi-city HAE IN-MOTION® 5K's, additional support groups to fit your schedule, monthly educational Café webinars, a new phone APP to help manage your HAE, to our patient-hosted awareness events throughout the country, together we can all find ways to enjoy a healthier and happier year. This month's HAEA in Action newsletter includes a preview of some of these upcoming events and activities, so don't forget to SAVE THE DATE, and keep a look-out for more exciting announcements all year-round!



Get ready for the 2018 HAE IN-MOTION® 5K EVENTS!

Members of the HAEA patient community, families, friends and our company partners will come together to RUN, WALK or CHEER, but most importantly, HAVE FUN, all for the cause near and dear to our hearts - raising awareness and funding for programs that benefit patients who suffer from Hereditary Angioedema (HAE).

The **HAE IN-MOTION® 5K** events are the largest fundraising effort of the US HAEA. Proceeds raised from these 5k events go to support the following three programs:

- **HAEA Scholarship Program** - provides financial support for HAE patients who are entering or attending college and seeking to improve their lives through academic achievement
- **HAEA Compassion Fund** - offers financial assistance through PSI for patients in need who must travel to see an HAE medical specialist at the US HAEA Angioedema Center at UCSD
- **HAE Research** - supports expert researchers in their efforts to solve the remaining scientific mysteries of HAE through the US HAEA Angioedema Center at UCSD

These events offer a good opportunity for you to meet patients and doctors in your area, while enjoying a fun outing. Register today at <http://events.haea.org/> and make a difference in the lives of HAE patients! For more information, to set up a virtual team, or if you would like to help us fundraise within your local community, contact Sherry Swanson at sherryswanson@haea.org.

Saturday, March 24, 2018 Pecos Legacy Park Henderson, NV	Saturday, June 2, 2018 Holmes Lake Park Lincoln, NE	Saturday, September 22, 2018 Nomahegan Park Cranford, NJ
Sunday, April 22, 2018 Hopkins Park & Shelter DeKalb, IL	Saturday, August 4, 2018 Danada Forest Preserve Wheaton, IL	Saturday, October 6, 2018 Roger Williams Park - Carousel Village Providence, RI
Saturday, April 28, 2018 Winding Trails, Inc. Farmington, CT	Saturday, September 8, 2018 Blue Lake Park Fairview, OR	Saturday, November 17, 2018 Brushy Creek Lake Park Cedar Park, TX

CLICK HERE to REGISTER for an HAE IN-MOTION® 5K event!



Let's Support Each Other!

Living with a rare disease, such as HAE, can present many challenges. You can often feel alone, thinking no one around you understands your health journey. At the US HAEA, we understand first-hand the difficulties you have to face each day. Whether you are a patient, caregiver, or parent of a child with HAE, you are not alone.

We would like to invite you to join one of our support groups where you can listen to others who are going through similar experiences, and share your own stories. Starting in February, new groups will be forming and will be available for your convenience during both daytime and evening hours. For more information, contact Troyce Venturella at troyce@haea.org.

To join a support group, [CLICK HERE!](#)



ACTION ALERT



Action Alert - Defend Charitable Premium & Co-pay Assistance Programs

The HAEA is deeply troubled by recent legislative efforts to restrict patient access to charitable premium and co-pay assistance for individuals with rare, chronic, and life-threatening illness. It is our hope that policymakers will take meaningful action to protect the lives and livelihoods of their constituents. We first became aware of emerging challenges in 2015 when HAE patients in one particular state were notified that their charitable premium assistance was being rejected, and their coverage would be subsequently canceled as a result of the interpretation of the HHS interim final rule entitled, *Third Party Payment of Qualified Health Plan Premiums*. Since then, this scenario of cancellation, threatened cancellation, and threatened legal action has been repeated in nearly every state. As the HAE advocacy organization for the entire US, we will be working hard to defend the preservation of these Charitable Assistance Programs, so that our entire patient community continues to receive the support and access to life-saving therapies without jeopardizing their quality of life.

To learn how you can take action, contact John Williamson [HERE!](#)



Check out our NEW Events Page!

We've added a brand NEW page to our website! The haea.org events page is a tool to keep the HAEA community updated on events and activities taking place year-round. It's also designed to help you host and promote your own HAE awareness event, with fun ideas on building new relationships locally and educating your own community on HAE. Visit our events page TODAY and start planning your local event!

If you are interested in hosting an event, please contact Jenny Barnes at jennybarnes@haea.org

Or click [HERE](#) to Host an Event!



Scholarship Applications for Fall 2018 are NOW Open!

Attention students! Don't forget to fill out your application for the 2018 US HAEA College Scholarship Program! The US HAEA is dedicated to helping the younger members of our patient community achieve their lifelong educational goals and aspirations. The HAEA Scholarship Program is available to US citizens with a confirmed HAE diagnosis. This Program will provide financial support for HAE patients seeking to improve their lives through academic achievement!

The application DEADLINE is March 23, 2018.

To learn more about the Scholarship Program, [CLICK HERE!](#)



February

HAEA Café Webinar: A plasma-free medication to treat your HAE with Dr. Marc Riedl! JOIN us on February 15th, 2018 at 7:30 PM EST to hear Dr. Riedl's expert presentation on HAE treatment options.

And tune in to this FREE WEBINAR at the HAEA

CAFE: <https://haea.zoom.us/j/729686346> or join by phone: +1 (415) 762-9988 (Meeting ID: 729 686 346)

ADD the WEBINAR to your CALENDAR here!

Coming Soon!

STAY TUNED for our next **Café Webinar: Women and Pregnancy – From the Patients' Perspective**. Listen to these personal stories of HAE patients and their experiences during their pregnancy.

March

HAE IN-MOTION 5K of 2018 on March 24th, at Pecos Legacy Park in Henderson, Nevada.

HAEA Scholarship Application Deadline is March 23rd

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