



*Research, Advocacy, Compassion, Empowerment*

Spring 2015

## Letter From the President

Dear HAEA Friends,

Those of us who live in the northern climates are just beginning to experience the warmth and energy that comes as spring begins to appear. This year, the anticipation of flowers beginning to bloom and foliage reappearing led me to realize that right now, in March 2015, we are experiencing a springtime for HAE. That is because as noted in this newsletter, 5 pharmaceutical companies are making significant investments in exciting next generation medicines that hold the promise of considerable improvement in our quality of life. This is a remarkably large number for such a rare disease. Clearly, the companies sponsoring this vitally important research are confident that members of the HAEA we will once again meet the call and volunteer to participate in clinical trials.

My dear friends, clinical trials pave the path to a better future for our community and nothing can happen until a sufficient number of HAEA friends enroll in one of the exciting research programs that are currently available. Please take advantage of the opportunity to help create a better quality of life for yourself, your children, your grandchildren, and future generations.

I encourage you to discuss trials available in your area with John Williamson, the HAEAs Patient Services Team Member who coordinates clinical trial participation. John can be reached at (972) 984-0621 or [john@haea.org](mailto:john@haea.org).

Finally, we are excited about the events being planned to celebrate hae day :- ) which takes place on May 16. It is not too late to plan an event in your community. Please contact HAEA Patient Services Team member Jenny Barnes (252-585-0763 or [jennybarnes@haea.org](mailto:jennybarnes@haea.org)) for information on how you can be part of hae day :- ) .

Warm regards,  
Tony



## New HAEA Informational Facebook Page



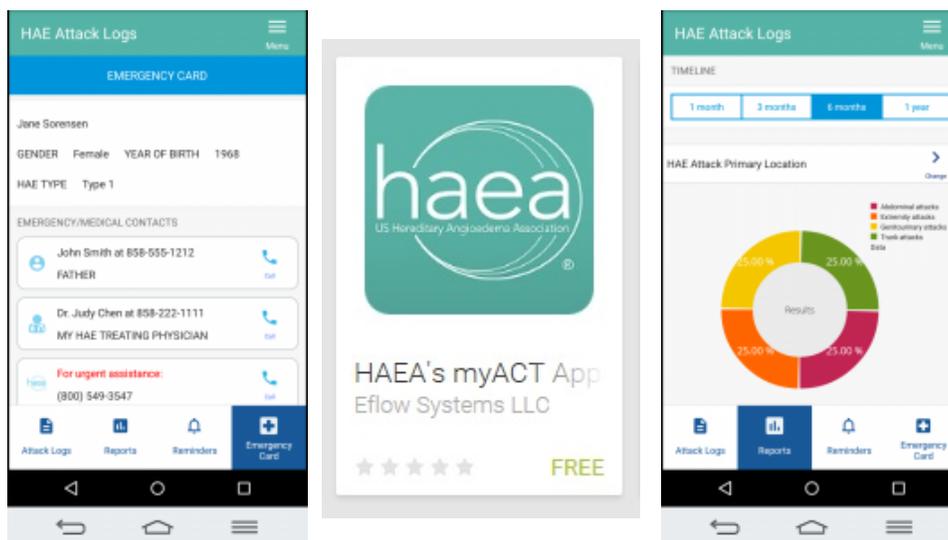
As part of our ongoing commitment to empowering patients by providing real-time information and updates related to HAE, the US HAEA has launched an official Facebook page for our Association. This page is for our community to enjoy and make use of as a resource for on-going communication and outreach. Within just a few days of launching the official page, it had amassed nearly 400 "Likes" and it had a reach to over 2,000 people in under a week.

This new FB page will contain posts of all of the HAEA's advocacy efforts, including hae day news and events, public policy initiatives, industry news, research updates, etc. Take a moment to "Like" the page so that you can stay informed and feel free to SHARE! [www.facebook.com/hereditaryangioedema](http://www.facebook.com/hereditaryangioedema)

## Announcing the new HAEA myACT App

This App is a free tool for you to use as your personal HAE patient information diary. There are many apps out there for HAE, but only the myACT app allows you to keep information on multiple HAE medicines in one place along with an easy emailing feature

The myACT app also keeps your information private what you record is yours and yours alone. Its an easy to use electronic resource to address any insurance challenges you might face as a patient and to help your physician develop the HAE management plan that helps you achieve lifelong health.



### What can I do with the myACT app?

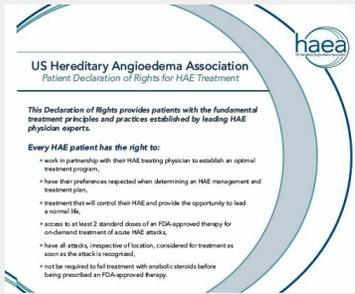
- View your attack reports over time in easy-to-read graphs and charts
- Set up treatment reminders
- Set up medicine refill reminders
- Email your attack information directly to your doctor
- Email your attack information to the US HAEA Scientific Registry, if you are a member
- Keep your emergency contact information readily accessible for any emergent situation

All of these options are customized on the app to your personal needs with just the click of a button! This simple record keeping resource can be a powerful tool in advocating for your access to HAE therapies.

The myACT app is currently available for Android devices Samsung phones, Kindles, some tablets, etc. and will soon be available for iOS (Apple products)!

You can download your myACT app by going to the Google Play Store and searching for the HAEA's myACT App!

# US HAEA Patient Declaration of Rights for HAE Treatment



HAE patients have the right to treatment that alleviates suffering and improves quality of life. This Declaration which is based on HAE physician treatment recommendations published in a medical journal outlines the basic concepts of a sound approach to HAE treatment. It can be shown to emergency room physicians, the doctor who is responsible for your day-to-day care, family members, and anyone else who plays a role in your HAE treatment. Print your own copy at <http://www.haea.org/resources/patient-toolbox/patient-bill-of-rights/>

## HAEA Scholarship Fund

The US HAEA has declared 2015 the Year of the HAEA Youth. In support of our HAEA younger generations, the HAEA is proud to announce the HAEA Scholarship Fund.



The HAEA is dedicated to helping our young community achieve their lifelong goals and aspirations. The Scholarship Program provides financial support for young HAE patients seeking to improve their lives through academic achievement.

The HAEA Scholarship Program is available to US citizens with a confirmed HAE diagnosis (letter from a licensed physician) who will be enrolled in an undergraduate educational institution. All applications will be reviewed by the Scholarship Committee, an independent adjudicatory board with no HAEA affiliation. Scholarships will be awarded based on a combination of financial need, academic effort, and individual educational goals.

You can learn more at <http://www.haeascholarship.org/>

## Grand Opening US HAEA Angioedema Center at UCSD



The US HAEA Angioedema Center at the University of California San Diego celebrated its Grand Opening on January 31, 2015. But the doors have been open since September 2014 for this specialty care and research clinic with a primary focus on patients with HAE and chronic swelling disorders. The Center is staffed by caring expert Angioedema physicians dedicated to improving the lives of patients.

### Who Should Consider Setting an Appointment with an Expert Physician at the Angioedema Center?

#### HAE patients who are:

- interested in having their care managed or overseen by internationally recognized expert physicians
- in need of an expert consultation to set up a comprehensive treatment plan to be implemented by their local physician
- looking for another opinion on their current treatment regimen

#### Anyone who is:

- suffering from an undiagnosed swelling disorder
- seeking another opinion on their current diagnosis

#### Book your appointment today!

*Travel and other financial assistance available based on need.* Please call your Patient Services Team member at 866-798-5598 to learn more. And be sure to visit [www.angioedemacenter.com](http://www.angioedemacenter.com).

## Clinical Trials

Clinical trial participation may seem like a small thing, but consider that everyone who has given their time, travel and an arm or two to a needle has not only advanced our understanding of HAE, but made it possible for everyone with HAE to have access to not one, but FIVE FDA-approved HAE medicines.

Clinical trials not only have helped bring HAE therapies to market in the past, but continue to do so today! There are MORE medicines being developed ones to try to help us all achieve lifelong health!

Many of you have probably participated in the past not just for your own benefit, but for the future of your children and grandchildren. HAE is an inherited disease, so you recognized that future generations depend on clinical trials to help them live normal childhoods and young adulthoods.

This is the HAEA Year of the HAE Youth, so as you consider participating in a Clinical Trials going on today, please remember our younger generations.

***When you volunteer, you not only gain access to medicine yourself (clinical trial participation is free!) and help to refine the treatment options available now, but you also secure a brighter future for all of your fellow HAE community members.***



## hae day :-) 2015

As we look to May 16, 2015, it is never too early to start planning your own hae day :-) educational event or fundraiser!

Check out <http://www.haea.org/hae-news/hae-day/about-hae-day-2/> where you can find:

- guidelines and a tool kit to help you with your awareness event or fundraiser
- an event form to fill out and return once you create your event
- an array of fundraiser products for you to purchase for your event or just for your own use



And be sure to check out all of the past years events held by HAEA patients and families!

MANY FACES  
ONE FAMILY

We are here to help with your event, your event web site - with ALL of your hae day :- ) event needs!  
For more information and for assistance, please contact your HAEA Patient Services Team member,  
Jenny Barnes - jennybarnes@haea.org

**Join in an event already listed or create your own event today!**

## US HAEA Scientific Registry

The Registry is celebrating its 5th year anniversary - starting in January 2015 and continuing throughout the year!



Scientific Registry members were treated to 5 Year Anniversary celebration items including glass paperweight prizes for excellence in reporting, award mugs for 5 year members, and Anniversary cards for all Registry members.

The invitation has gone out again via HAEA social media channels to join the US HAEA Scientific Registry if you have not done so already, please go to <http://www.haea.org/get-involved/us-haea-scientific-registry/> today to join! ***It's easy to sign up online and it's free!***

For those members who just don't think they can handle the computer questionnaires, the Registry can

help you overcome any online reporting hurdles! *Just ask!*

The Scientific Registry Administrators are here to help you with encouragement, reminders, and caring phone calls to make sure your Registry participation is easy and enjoyable.

## Opportunities for the HAEA Community to Connect!

Did you know your HAEA has an Instagram accounts!? Do you follow the HAEA President on Twitter? Many of you may have been founding members of the original HAEA Listserv chat group! Or maybe you are a member of the HAEA Facebook group or a teen member of the HAEA Teen Facebook page!

These are the many innovative ways the HAEA provides for you to connect with other HAE patients and families. We are pleased to let you know of a new social media resource - an HAEA Facebook page where you can learn about new HAE research, publications and the latest therapies. You will also find the latest HAE publications, news and events. There will be Frequently Asked Questions and real time reports of what your HAEA is accomplishing as a united community.

***LIKE the page!***  
***SHARE the page!***  
***Stay INFORMED!***  
***GET CONNECTED!***

And be sure to check out all of the resources available for our community to connect:



Facebook: <https://www.facebook.com/hereditaryangioedema>

HAEA Twitter: [https://twitter.com/US\\_HAEA](https://twitter.com/US_HAEA)

Tony Castaldo's Twitter: <https://twitter.com/TonyJCastaldo>

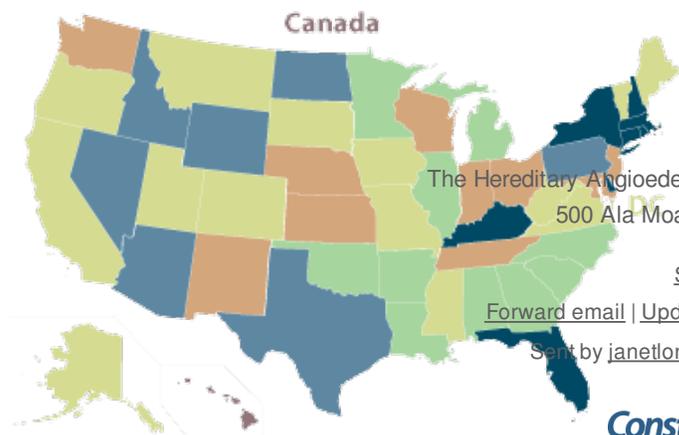
Instagram: [https://instagram.com/us\\_haea/](https://instagram.com/us_haea/)

Contact a [Patient Services team member](#)

Toll Free: (866) 798-5598

For urgent assistance (866) 841-HAEA OR (866) 841-4232

Fax: (508) 437-0303



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