Throughout 2018, the US HAEA worked to nurture the sense of community among HAE patients and families through the kind and compassionate services offered by our HAEA Advocates and a wide range of programs designed to raise awareness and foster ground-breaking research. During the year, our HAEA team had almost 20,000 interactions with members of our community that involved providing answers to HAE-related questions or problems, making referrals to knowledgeable physicians, or helping to solve issues regarding access and reimbursement to HAE medicines.

The HAEA’s 2018 body of work reflects our commitment to offering an array of activities that unite our HAE community. Highlights from the year include our:

**HAE IN-MOTION® 5K** run/walk events that attracted over 1,000 participants;

**Educational Webinar Series** which provided authoritative information on a broad range of topics relevant to living a better life with HAE,

**HAEA Annual Capitol Hill Day** during which 90 HAEA friends (including a motivated group of HAE Youth) visited more than 80 congressional offices to ask for continued full access to HAE medicines,

**Youth Leadership Council** webinars and group chats to provide peer to peer support and information sharing.

**Pam King HAEA Scholarship Fund** which awarded 42 scholarships to help HAE patients afford higher education, and

**Brady Club**, a safe online space where children, ages 4-12, engaged in fun, yet educational HAE-related activities.

Research remained a high priority during 2018. The HAEA completed a study to educate health insurers on the economic value brought by the extraordinary increases in quality of life experienced by patients on the new subcutaneous prophylaxis therapies. In addition, researchers at the US HAEA Angioedema Center published an important article on their discovery of an assay (blood test) that would allow physicians to determine the cause of swelling in cases where the diagnosis is not clear. This test will be of particular help for HAE patients with normal C1-Inhibitor to get access to the medicines they need to improve their quality of life.

We wake up every day excited about every opportunity to serve you, our fellow patients and caregivers. I encourage you to contact one of our HAEA Advocates and get involved!

Warm regards,

Tony
ABOUT THE US HAEA

Founded in 2000 and staffed by HAE patients and HAE patient caregivers, the US Hereditary Angioedema Association (HAEA) is a 501 (c)(3) non-profit patient advocacy organization dedicated to serving individuals with Hereditary Angioedema. The US HAEA has grown to a vibrant, goal-advancing organization with a membership of over 5,600.

OUR MISSION

To lead a nationwide advocacy movement to increase HAE awareness and education, empowering patient access to a suitable therapy, and fostering groundbreaking research that includes searching for a cure.

OUR VALUES

Providing the HAE community with authoritative and unbiased information.
Offering highly personalized services with kindness and compassion.

OUR PILLARS

HAE Health
Advocacy
Engagement
Advances in Research
The HAEA Health team is dedicated to working closely with everyone in our community by offering personalized support to anyone with a chronic, hereditary swelling symptom who needs help in getting a diagnosis and finding a treatment. While HAE is most commonly caused by a deficiency in the C1-Inhibitor protein, the HAEA Health team puts significant time, attention, and investment into helping people who suffer from chronic swelling, but have normal levels of C1-Inhibitor. Every day, we aim to create long-lasting connections that unite us in the quest to help everyone with HAE attain wellness and happiness.

Obtaining a correct diagnosis and having an optimal HAE treatment plan are the cornerstones of a better life. We have built a nationwide network of knowledgeable physicians who know how to diagnose and treat HAE. Our Health team provides referrals to these physicians and can also arrange appointments with the highly skilled angioedema specialists at the US HAEA Angioedema Center at the University of California at San Diego.

Many in our HAE family wish to connect with others to share life situations and challenges being faced when dealing with HAE. To meet this need, we offer a virtual support group that provides a warm and caring environment conducive to supportive, compassionate discussions, and problem solving.

We will not rest until all medical professionals have at least a basic understanding of HAE. We have therefore dedicated significant time and resources to our Physician Outreach program, which provides high quality Continuing Medical Education courses to health care professionals through our special portal at www.haeedu.com:

- HAEA Continuing Medical Education Courses
- HAE Body Interact
- Consensus Guidelines on Improving the Management of HAE
- Angioedema in the Emergency Medicine Setting: Optimizing Management for Every Patient
HAEA BY THE NUMBERS IN 2018

- 5,600 HAEA Members
- 535 New HAEA Members
- 480 Reimbursement & Benefits Assessment Support
- 809 Physician Referrals & follow-ups
- 4,557 Patient outreach
- 4,278 Patient/Caregivers Survey Responses
- 1,472 Physician outreach
- 753 Support group participants
- 1,037 Responses to Inquiries from Patients & Caregivers
- 212 Referrals to HAEA Angioedema Center at UCSD
The HAEA leads a nationwide advocacy movement to protect the rights of HAE patients. Our HAE Advocacy program strives to unite HAE patients and families in the fight for full and continued access to HAE therapies, financial support for treatment, and funding for research.

CAPITOL HILL DAY

On July 18, 2018 over 90 HAEA friends joined our HAE Advocacy team on Capitol Hill, marking the highest HAEA Hill Day participation in the HAEA’s history. Our delegation of HAE patients, caregivers, and family members visited more than 80 congressional offices to ask for continued full access to HAE medicines and a commitment to fund HAE research.

This Capitol Hill Day was particularly meaningful because it included 20 highly motivated members of our HAE youth group. Our youth members participated in a specially designed youth advocacy training program, and had the opportunity to use these skills during visits to congressional offices.

We are all grateful that so many HAEA friends traveled to Washington, DC and spoke to our elected representatives with a strong and united voice.

Thanks to the our HAEA membership, our advocacy accomplishments for 2018 include:

- Persuading additional congressmen to co-sponsor H.R. 3976, the Access to Marketplace Insurance Act, which protects people’s ability to use charitable premium and co-pay assistance to pay for HAE medicines.
- Securing another year as one of only a few rare diseases that can submit research proposals under the Department of Defense Peer-Reviewed Medical Research Program, and
- Expanding the National Institutes of Health HAE research portfolio.
Members of the YLC participate in a specialized advocacy youth training during Capitol Hill Day in Washington D.C.

HAE patient, Doug Selsor, helps present Congressman David Young a recognition plaque on behalf of the US HAEA patient community.

Tracy Conaway-Richards, Avi Gupta, Jake Conaway and Bobbi Peters meet with Congressman Dan Newhouse during Capitol Hill Day to advocate on behalf of patient rights and to request the advancement of HAE/rare disease legislative policies.
The HAEA Engagement team works to unite and empower the HAE patient community to “Imagine the Possibilities” through engagement and education.

**HAEA YOUTH PROGRAMS**

**Youth Leadership Council**

The Youth Leadership Council (YLC) fosters youth engagement through peer to peer initiatives led by HAE youth and family members. In its second year, the YLC successfully engaged teens, ages 12-18, in diverse events during Youth Advocacy Month, and provided advocacy opportunities and training to 22 Youth Advocates during Capitol Hill Day.

In 2018, the YLC held five youth edition webinars to provide support among HAE youth patients. The YLC also held three group chats during which youth speakers gave presentations on: listening to your body, the importance of participating in awareness events, how 504 plans can improve life at school, life before HAE therapy, and how treatment has improved quality of life.

**Brady Club**

The Brady Club is an online, fun space just for children, ages 4-12, who have been diagnosed with HAE or are a sibling of a child with HAE. In 2018, there were 40 kids participating in Brady Club activities.
The interactive space encourages the HAEA’s youngest members to better understand, cope with, and manage their HAE so they can thrive as healthy and happy children. In addition to the online accessibility, in 2018 the HAEA unveiled a Brady Club mobile app to improve the interactive experience. Through the Brady Club App, kids can share their personal stories about living with HAE and ask an HAE medical expert their questions through the Ask Dr. C feature. Brady Club members also get quarterly activity books with additional fun activities mailed to them at home.

We invite HAE families to explore our Brady Club website and app, and invite your children to join Brady in learning about HAE.

PAM KING HAEA SCHOLARSHIP PROGRAM

In 2018, the HAEA family suffered a great loss in the passing of Pam King, our Chief Operating Officer, who valiantly battled cancer. We renamed our HAEA Scholarship Program to honor Pam’s passionate dedication to HAE patients and families. The Pam King HAEA Scholarship Program provides financial support to college bound HAE patients who display the desire for academic achievement.

In 2018, forty-two students across the United States received awards that will help them achieve their dreams

42 | # of scholarships awarded in 2018

30% | Increase in applicant submissions over 2017

$2,000 | Annual Award per recipient

We congratulate our scholarship recipients and wish them much success in their academic endeavors.

“The Pam King HAEA scholarship has lightened the financial burden of college and allowed me to attend the school of my dreams. It has also provided opportunities for me to get more involved in HAEA and meet other college students and children with Hereditary Angioedema. I am so thankful for their generosity and interest in getting more people involved and giving back to our special community.”

- Sidney, Texas Christian University
“With this disease, many challenges follow you daily. This scholarship will help me to strive past those challenges and be able to achieve my dream of graduating from Auburn University. I will forever be grateful for this scholarship and what it will help me achieve!”

- Katie M.

HAE DAY :-) 

May 16th is hae day :-) in the United States and around the world. Since 2012, the HAEA has dedicated this special day to raise HAE awareness among the public and the medical community through special events, fundraisers, and dissemination of HAE information. In 2018, we distributed over 3,000 ER Tool Kits and 1,700 other HAE awareness products, resources, and literature to hospitals, schools, and work places all across the country.

HAEA CAFÉ

The HAEA Café is an online community where HAE patients can learn about the FDA-approved therapies, research advances, and follow the latest news over a cup of coffee in the comfort of their own homes. Membership in the Café offers access to exclusive events, news, and informative webinars. It is also an excellent way to connect with HAEA Advocates, share HAE journeys, and participate in virtual support groups. Last year, members of our community logged in for well over 2,000 HAE Café sessions to personally contact our Patient Advocates and keep up to date on the latest HAE developments.
HAE IN-MOTION® 5K

The HAE IN-MOTION® 5K run/walk events are an excellent opportunity to raise HAE awareness in your community. The 5Ks also help HAE patients and families raise funds for HAE research. In 2018, ten (10) HAE IN-MOTION® 5K events were held in the states of Connecticut, Florida, Illinois, Nevada, New Jersey, Oklahoma, Oregon, Rhode Island, and Texas. Over 2,000 people participated in our 2018 events!
**EDUCATIONAL WEBINARS**

In 2018, the HAEA launched and expanded its program of webinars designed to provide information on broad range of topics relevant to living a better life with HAE. A total of fifteen (15) webinars reaching over 750 people were offered throughout the year, including three specifically geared to youth patients.

**2018 HAEA WEBINAR SERIES**

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<td>Learn About a Subcutaneous Therapy Option for HAE – CSL Behring</td>
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<td>HAE Community Members Tell Their Experience with C1-INH Subcutaneous Therapy - CSL Behring</td>
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<tr>
<td>How to Tell People About HAE - Youth Edition – HAEA</td>
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SOCIAL MEDIA OUTREACH

The US HAEA enjoys frequent communications with HAE patients, families, and physicians. Our members can avail themselves of readily accessible information on our events, support tools, therapies, and research. In 2018, we greatly increased our communications and interaction through popular social media outlets.

Follow us on Instagram, Facebook and Twitter and connect with your HAEA family!

- **45.9%**
  Increase in Total Number of Engagements in Twitter, Facebook and Instagram

- **36.4%**
  Increase in Total Facebook Impressions

- **3,296**
  Followers of HAEA Fan Page
To further improve engagement with our members, in 2018 we introduced the HAE in Action Newsletter. This monthly, electronic resource provides regular and updated information on HAEA activities, actions, and specialized projects. The HAE in Action Newsletter reached 18,000 recipients last year. Subscribe to HAE in Action via email to get the latest news on the US HAEA!

The HAEA also launched Action Alerts to keep our advocates involved and active in legislative affairs. These Action Alerts reached 2,868 people in 2018.

1,640 Followers on Twitter

19.77% Increase in followers on Facebook

675 Followers on Instagram

106.5% Increase in followers on Twitter

@hereditaryangioedema
HAEA INITIATED RESEARCH TO BENEFIT THOSE WITH HAE WITH NORMAL C1-INHIBITOR

We continue to make substantial investments in groundbreaking clinical and scientific research aimed at understanding the genetic and biochemical causes of swelling experienced by a very important segment of our community that is diagnosed with HAE Normal C1-INH.

Researchers at the US HAEA Angioedema Center at the University of California at San Diego recently announced a HAEA funded and potentially ground-breaking assay (blood test) that determines the cause of swelling in cases where the diagnosis is not clear. The medical journal article providing details on this discovery is entitled - “Threshold-stimulated kallikrein activity distinguishes bradykinin from histamine-mediated angioedema.”

This test will be of particular help for HAE patients with Normal C1-INH. The HAEA plans to lead “validation research” (to be conducted at the Angioedema Center) to expedite availability of this important blood test.

HAEA INITIATED STUDY ON THE VALUE OF NEW HAE THERAPIES

Recent clinical trials evaluating two new, subcutaneous prophylactic treatments reveal significant reductions in the number of HAE attacks and improvement in Quality of Life (QoL). Despite the clear advantages these medicines offer to patients, questions have been raised about their value when compared to an “on-demand only” treatment model in which medicines are administered only when the patient is experiencing an attack. A full and fair analysis of the value brought by these medicines will help insurers understand why prescriptions for these new medicines should be filled and reimbursed.
Working in partnership with HAE International and physicians at the US HAEA Angioedema Center at UCSD, the HAEA initiated a comprehensive study to illustrate the economic value and quality of life impact of these medicines. The health economists who assisted us in this effort recommended that we collect data by asking the patient and caregiver community to fill out a detailed questionnaire. The response we received was overwhelming with a record setting 737 HAE friends completing the survey. This treasure trove of real patient data forms the basis for a medical journal article that the HAEA will submit in 2019.

**US HAEA ANGIOEDEMA CENTER AT UCSD**

Established in 2015 by the US HAEA, the US HAEA Angioedema Center at University of California San Diego (UCSD) delivers comprehensive care for HAE patients, participates in clinical trials, and conducts groundbreaking HAE-related biochemical and genetic research. The Center offers medical consultations and expert patient care for all angioedema cases. In 2018, 404 people with angioedema visited the Center—many were referred by the HAEA Health team.

The US HAEA Angioedema Center at UCSD also provides educational opportunities for physicians, nurses, and other healthcare professionals who seek greater knowledge regarding HAE diagnosis and treatment.
ADVANCE HAE SCIENTIFIC REGISTRY

The HAEA Advance HAE Scientific Registry is a confidential database launched over 10 years ago to obtain uniform, long-term, and accurate information on HAE. Clinical data is collected online from patients while biological samples are stored in a secure biorepository. Advance HAE is the only registry in the US that collects its data directly from patients and family members to support HAE research. Registrants can input their HAE attack data with ease through the Advance HAE mobile app. In-depth research to solve the remaining mysteries of HAE is made possible by each and every submission made to the Advance HAE Scientific Registry.

1,300
Registrants

872
Active Members

855
Bio Bank Sample Contributors

HAE CLINICAL TRIALS

Since our inception as an organization, the HAEA has played a major role in recruiting for studies (called clinical trials) that are required to validate the safety and effectiveness of a new medicine before it can be made available in the US. In 2018, the HAEA contacted over 450 people regarding the existence of a clinical trial close to where they live.
OUR 2018 CORPORATE SPONSORS

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HAEA LEADERS

CSL Behring
Biotherapies for Life®

Pharming

HAEA CONTRIBUTOR

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The US HAEA Medical Advisory Board is composed of HAE experts from across the country who advise the Association on everything from medical research to peer-reviewed publications.

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Ianice Viel, Social Media Manager, Digital Platforms & Engagement
John Williamson, Patient Advocate, Advocacy & Clinical Trials
INFORMATION TECHNOLOGY

Frank Palaia, Information Technology Analyst
Joyce Wilmot, Information Technology Analyst
Cube Whidden, Information Technology Analyst

HAEA ADMINISTRATIVE SUPPORT

Michele Agostinho, Accounting Assistant
Nicole Jewell, Administrative Support
FINANCIAL INFORMATION

The distribution of expenditures shown in the chart below reflects the US HAEA’s commitment to focusing on high impact programs, activities, and research aimed at improving the lives of HAE patients.

100 percent of every dollar donated by an individual and/or non-corporate source goes to the following three patient support programs: the Pam King HAEA Scholarship Fund, the HAEA Compassion Fund that provides travel assistance for patients seeking care from an expert HAE physician, and/or groundbreaking research including our HAEA Scientific Registry.

Corporate donations are earmarked to fund our many wide-ranging programmatic activities as well as administrative expenses.

The HAEA maintains rigorous and disciplined internal financial controls. Every HAEA expenditure is reviewed meticulously to ensure compliance with the Association’s policies and procedures.

SUMMARY

- Administration (8%)
- Research (28%)
- Patient Services (31%)
- Education and Advocacy (33%)