program called HAE IN-MOTION®. This program launched a new advocacy and awareness campaign in their own communities with the HAEA’s full support.

Each 5k event is a fantastic opportunity for family, friends, students, co-workers, and colleagues to come together to increase HAE awareness and raise funds to support research, scholarship program and public policy initiatives for people with HAE.

In 2016, more than 100 patients and family members gathered to formally establish HAEA Puerto Rico. Más Salud, Mejor Vida! Troyce Venturella, the newly established HAEA Patient Advocate and Puerto Rico resident, organized this gathering. The Café included open enrollment for our Patient Advocate Program for all angioedema patients, family members to better understand, manage and cope with their disease while inspiring and empowering others to foster groundbreaking research to find a cure.

Our youngest HAE patients are of special interest to the HAEA and many parents want their children to be able to participate in educational tools in line with the ACCP guidelines.

The HAEA takes a comprehensive approach to providing information to health care professionals. For more than a decade, the HAEA has hosted an annual educational symposium. This year, two one-day modules focused on the treatment of HAE in the Emergency Department. This training reflects the HAEA’s commitment to continuing education.

The session for emergency physicians focused on the signs and symptoms of angioedema, treatment options, and both pharmacologic and non-pharmacologic options. The session for other medical professionals focused on the treatment of HAE in the Emergency Department. This training was designed to provide timely information on advanced therapeutic approaches to managing HAE. We appreciate all of participating ER physicians on Hereditary Angioedema in the Emergency Medicine Setting: Optimizing Management for Every Patient, in partnership with the American College of Emergency Physicians.

The HAEA leads a nationwide advocacy movement to foster groundbreaking research to find a cure. All of our events and services aim to support this goal is to boost timely and accurate angioedema diagnosis, to amplify patient access to therapy, and to support patients, families and the healthcare professionals who treat them. To achieve this goal the HAEA has been dedicated to three core endeavors: Research, Advocacy and Compassion and a menu of valuable resources for patients and families.

In June 2016, the HAEA sponsored a highly successful Capitol Hill Day in Washington, DC. A group of 21 advocates met with their Senators and House representatives, advocating for greater understanding of Hereditary Angioedema and the need for continued funding for research.

The HAEA also partnered with the National Organization for Rare Disorders (NORD) to convene an international meeting in Geneva, Switzerland. 130 patients, family members and advocates from 22 countries attended the meeting. Seven expert panels with more than 200 participants focused on best practices for treatment and care of HAE patients and highlighted the value of sharing best practices around the world.

The Mines four-day conference was designed to provide patients, families and medical professionals an opportunity to network and receive the most current information on the diagnosis, treatment and care of HAE. More than 120 medical professionals and 100 patients and family members attended.

Some of the topics include: Access to HAE therapies; Access to care and treatments; Access to investigational drugs; Access to HAE research; Access to comprehensive information and support; Access to quality patient care; Access to new therapies and new treatments; Access to education and support; Access to appropriate help and support; Access to patient support and education; Access to comprehensive care.

The HAEA has a deep commitment to providing patient education and support. More than 3,000 physicians are educated on HAE through the annual symposium each year.

As part of our continued support for HAE medical professionals, the HAEA partnered with the American College of Emergency Physicians (ACEP) to sponsor an educational session at the ACEP national conference. The session, “Emergency Department Management of Hereditary Angioedema: Optimizing Management for Every Patient,” focused on the signs and symptoms of angioedema, treatment options, and both pharmacologic and non-pharmacologic options.

The HAEA Patient Advocates and the HAEA are very excited to be able to offer membership at no cost to all angioedema patients, family members and medical professionals. Through all of this have missed our online webinars, the HAEA is dedicated to continuing to educate healthcare professionals and patients on the signs and symptoms of angioedema. We look forward to continuing our efforts to improve the care and treatment of angioedema.

Michelle Cuevas organized this gathering which our youngest HAE patients are of special interest to the HAEA and many parents want their children to be able to participate in educational tools in line with the ACCP guidelines.
ABOUT THE U.S. HAEA
Founded in 2000 and staffed by HAE patients and HAE patient caregivers, the US Hereditary Angioedema Association (HAEA) is a non-profit patient advocacy organization dedicated to serving individuals with hereditary angioedema. The U.S. HAEA has grown into a forceful and effective, 501 (C)(3) non-profit organization with a membership of over 5,600 people.

HAEA MISSION
To lead a nationwide advocacy movement that focuses on increasing HAE awareness and education, empowering patient access to a suitable therapy, protecting the rights of patients in the legislative and regulatory environments, and fostering groundbreaking research that includes searching for a cure.

HAEA VISION
Lifelong health for HAE patients

HAEA VALUES
Fellow patients providing the HAE community with authoritative and unbiased information and highly personalized services with kindness and compassion.
PRESIDENT’S MESSAGE

Dear HAEA Friends,

Throughout 2016, the US HAEA maintained a laser-like focus on improving the lives of our community by delivering a wide variety of programs, activities, and services. Our highest priority is to provide kind and compassionate assistance to fellow patients with HAE-related challenges. During the year, we fulfilled this fundamental commitment through almost 45,000 interactions with members of our HAEA community who had a HAE-related question, were seeking a physician referral, or needed assistance with access to, or reimbursement for, HAE medicines.

The HAEA’s 2016 body of work reflects our longstanding commitment to nurturing a sense of community among HAE patients and families. Our HAE IN-MOTION® 5k run/walk races attracted over 1,000 participants, and HAEA members sponsored a record number of hae day :-) events. We provided support to our younger members through our HAEA Scholarship Program and the Brady Club—a secure online interactive space that helps children better understand their condition through games and other fun activities.

Capitol Hill Day 2016 was an unqualified success with patient visits to congressional offices resulting in HAE once again being eligible for research grants under the Defense Department Peer Reviewed Medical Research Program. In addition, uncertainties over the direction of health care policy prompted us to aggressively expand our grassroots network of patients interested in contacting and educating elected officials about the need for continued access to life-saving HAE medicines. We encourage all HAEA friends to get involved in this effort to make our U.S. Representatives and Senators aware of our concerns.

Research remained a high priority during 2016. The US HAEA Angioedema Center at the University of California at San Diego and members of the HAEA Medical Advisory Board are heavily involved in research to: Better understand the biological mechanisms that trigger swelling symptoms, and develop the next generation of HAE therapies. We strongly encourage all HAEA friends to be under the care of a HAE expert. Please remember to contact a member of the HAEA Patient Advocacy Team for assistance and support.

As we move forward together, we are strengthening the HAEA’s mission by realigning our teams and developing a more focused approach centered on four pillars: HAE Health, Advocacy, Engagement and Advances in Research. Through these four areas of focus, we will offer specialized programs and customized, personal attention to meet the challenges of an ever-changing HAE world.

Warm regards to all,

Anthony Castaldo
President, US HAEA
AREAS OF STRATEGIC FOCUS
As part of our 2016 strategic goals, the US HAEA focused its resources on providing high impact programs and activities in three areas of focus—HAE Health, Advocacy, and Research.

HAE HEALTH –
Driving continuous improvement in HAE CARE
Patient Identification and Diagnosis
Physician Referrals
Access and Reimbursement
CME Programs

ADVOCACY –
Empowerment, education & engagement
Capitol Hill Day
Scholarship Program
HAE IN-MOTION® 5k
hae day :-)
Puerto Rico Patient Group
Brady Club
HAEA Café
Special Blood Screenings
Public Service Announcement (PSA)
Social Media Outreach

RESEARCH –
Pioneering innovations in HAE science
US HAEA Angioedema Center
HAEA Medical Advisory Board
HAEA Scientific Registry
Clinical Trials
Scientific Publications
HAEA-authored “Survey at a Glance”
HAE HEALTH – DRIVING CONTINUOUS IMPROVEMENT IN HAE CARE

Passion for helping HAEA Patients

44,547
Interactions with Patients Requesting Assistance

Patient identification and diagnosis

Our HAE Health team works to identify new patients, provide much-needed guidance for obtaining an accurate diagnosis, as well as on-going support for successfully managing HAE symptoms.

362
Newly diagnosed patients

708
New HAEA members

Physician referrals

Physicians with experience treating HAE are key to an accurate diagnosis and obtaining access to HAE therapy. The HAEA provides referrals to its robust network of HAE knowledgeable physicians. Evaluation criteria for our HAE knowledgeable physicians include:

- Number of HAE patients treated
- Knowledge of HAE therapies and the process for prescribing the medicines, and
- Updated contact with physician’s office

Our referral service assists in identifying a physician in close proximity to the patient. For interested patients, we can also provide a referral for an appointment with experts at our US HAEA Angioedema Center at UCSD.

Access and Reimbursement

The HAE Health team assists patients in obtaining access to the HAE therapy they have been prescribed.

Services provided include:

- Assistance with health insurance selection
- Assistance with insurance denials, quantity limit overrides, and billing matters

559
Reimbursement & benefits assessment support

2,646
Physician Referral Requests
CME Programs
Our newest Continuing Medical Education (CME) module focuses on the treatment of HAE in the Emergency Department. This training reflects the HAEA’s leadership in providing health care professionals with timely information on advanced therapeutic approaches to managing HAE. We partnered with the American College of Emergency Physicians in designing this new and groundbreaking educational tool.

Angioedema in the Emergency Medicine Setting: Optimizing Management for Every Patient
Experts discuss the challenges that angioedema can present in the Emergency Room. Pathophysiology and differential diagnosis for all angioedema types are included.

In addition, we offer a comprehensive CME program to continue to educate healthcare professionals.

Consensus Guidelines on Improving Management of HAE
Experts discuss all aspects of Hereditary Angioedema (HAE) from diagnosis to treatment, and comprehensive continued care plans.

*Accreditation
Both programs have been designed in line with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME).

As part of our continued support for HAE medical education and awareness, the US HAEA also attended the ACEP national conference in Las Vegas, NV this past October to educate thousands of participating ER physicians on Hereditary Angioedema.

For more than a decade, the HAEA has hosted an information booth at the American College of Allergy, Asthma and Immunology (ACAAI) and American Academy of Allergy, Asthma and Immunology (AAAAI) annual international conferences. More than 3,000 physicians are educated on HAE annually through the HAEA’s exhibit and materials provided at these meetings.
The HAEA leads a nationwide advocacy movement focused on disease awareness and education. Our goal is to boost timely and accurate angioedema diagnosis, to amplify patient access to therapy, and to foster groundbreaking research to find a cure. All of our events and services aim to support this important advocacy movement.

Capitol Hill Day

In June 2016, the HAEA sponsored a highly successful Capitol Hill Day in Washington, DC. A group of 21 HAEA advocates, who are patients, caregivers and family members, made their voices heard in over 53 Senate and House offices, advocating for:

- the continued need for accurate and timely diagnosis;
- access to treatment;
- reimbursement issues/hurdles;
- continued development and refinement of HAE therapies; and,
- Federal funding for new scientific research.

Pictured with HAEA President Tony Castaldo and Senator Schatz is HAEA Director of Patient Advocacy and Engagement Lois Perry. During this event, Tony Castaldo presented the Senator with an award for his outstanding support of legislation that benefits HAE patients and families.
US HAEA Scholarship Program

The US Hereditary Angioedema Association Scholarship Program provides financial support for HAE patients seeking academic success and a brighter future! Twenty-eight (28) scholarships were awarded in 2016 – a 56% increase over the year before.

28
# of scholarships awarded in 2016

56%
Increase in scholarships awarded

Inspiring testimonials from past scholarship recipients:

“I am very honored and appreciative to be one of the recipients of the 2015 HAEA Scholarship. I have been accepted to the University of Illinois at Chicago as a biological sciences/pre-med major and will begin my studies in August 2015. By awarding me this scholarship, you have lightened my financial burden, which will allow me to focus more on the importance of course work and research. Your generosity and continued support for our HAE family inspires me. I know with the support of my immediate and HAE family that the sky is the limit.”

Kelsie Neahrung, University of Illinois at Chicago

“I am thrilled to receive this scholarship to help my family with my college expenses. Through all of this I have loved school and found helping others helped me. I look forward to continuing serving and learning in higher education.”

Sydney Peel, Texas Christian University

“The HAE Scholarship that I was awarded will help me buy the books that I need for my classes. I’m taking classes for my major that are very new, and therefore have new textbooks that will be expensive. Without this scholarship, I wouldn’t be able to do what I wanted with my college career.”

Noah Harrington, Alma College
**HAE IN-MOTION® 5K**

In 2016, the US Hereditary Angioedema Association launched a new advocacy and awareness program called HAE IN-MOTION®. This program helps patients to create 5k walk/run race events in their own communities with the HAEA's full support.

Each 5k event is a fantastic opportunity for family, friends, students, co-workers, and colleagues to come together to increase HAE awareness and raise funds to support research, scholarship program and patient benevolence fund.

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**In 2016: Over 1,000 participants in 9 HAE IN MOTION® 5K Events**

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**2016 HAE IN-MOTION® EVENTS**

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Over 300 runners participated in Puerto Rico’s first HAE IN-MOTION® 5k in July 2016
2016 HAEA EVENTS

Hae day :-) May 16, 2016.

2016 marked the fifth successful year of HAE awareness events and fundraisers celebrated in the US on May 16 and all throughout the year. Established in 2012 to raise disease awareness, hae day :-) features HAE patients, patient caregivers, family and friends participating in events throughout the USA.

The #myMove4HAE campaign sparked the creativity and humor of patients, friends and family, who celebrated hae day :-) by raising awareness in multiple social media outlets.

HAEA Puerto Rico

On August 7, 2016 more than 100 patients and family members gathered to formally establish HAEA Puerto Rico.

HAEA Patient Advocate and Puerto Rico resident, Michelle Cuevas organized this gathering which included local expert HAE physicians Dr. Rafael Zaragoza and Dr. Anardi Agosto along with HAEA representatives Tony Castaldo, Janet Long, and Troyce Venturella. The newly established HAEA Puerto Rico is actively planning activities to center around awareness, improved access to therapy, diagnosis, and family testing.

Smaller patient meetings were held in November and December to close out this year of growth for HAEA Puerto Rico. Más Salud, Mejor Vida!
HAEA Director of Patient Advocacy, Lois Perry represented HAE and other rare disease patients at the Lifecycle Massachusetts meeting.

**Brady Club**

Our youngest HAE patients are of special interest to the HAEA and many parents want their children to begin learning about HAE at an early age. The Brady Club is an online, secure space just for children diagnosed with HAE and their siblings. The interactive space encourages HAEA’s youngest members to better understand, manage and cope with their disease while inspiring and empowering these boys and girls through fun activities. It is also a great place for kids to connect with others in similar situations.

HAEA volunteer advocate John Harrington and his son Michael and HAEA President Tony Castaldo are pictured presenting the HAEA Distinguished Public Service Award to Congressman Leonard Lance. Rep. Lance signed a letter to the NIH asking for more HAE research funding and is a member of the Rare Disease Caucus.

**The US HAEA Café**

A unique virtual community

The Café is an online platform for direct communication between HAEA Patient Advocates and our HAEA members. In 2016, we introduced new features developed to improve and increase our community’s online participation. The Café included a new virtual table for our Spanish-speaking members in Puerto Rico!

As an online community open exclusively to HAE patients and families, members are able to:

- Chat live with a HAEA Patient Advocate
- Participate in webinars on issues like product access and reimbursement
- Check out the latest HAEA news
- Access past webinars through the Café Archive
- Participate in virtual support groups

Scoreboard at Yankee Stadium welcoming HAEA friends to the ballpark.
For those who have missed our online webinars, the Café allows the HAEA to archive them so that patients can pull up a virtual chair at any time to view one of the many programs produced in 2016. Some of the topics include:

- HAE and Children
- US HAEA Angioedema Center
- Public Policy Patient Advocacy
- HAE in the Emergency Room
- Treatment, Clinical Trials and the Future
- Managing your HAE
- Stress Management and your Health
- Open Enrollment
- Advocating for Care in the ER

Members are welcomed with a warm cup of compassion and a menu of valuable resources for lifelong health!
**Special Blood HAE Documentary Screenings**

In 2016, a feature length documentary was the culmination of more than a year’s work for HAE patient and Film Director, Natalie Metzger and her crew. Special Blood chronicles the lives of four patients with HAE, who speak honestly about the hurdles they have faced. Natalie artistically tells a heartfelt story about these brave individuals and their emotional journeys that spread HAE awareness and changed not only their own path in life, but the outlook for a more hopeful future among others who suffer from HAE.

HAEA members were encouraged to take the initiative and schedule a screening of the documentary in their own town. Dozens of screenings took place across the US over the year and will continue into 2017, spreading HAE awareness at the grassroots level.

29 Screenings
Over 3,000 Viewers

**U.S. LOCATIONS**

- Cullman, AL
- Fresno, CA
- Los Angeles, CA
- Riverside, CA
- San Diego, CA
- Avon, CT
- Boca Raton, FL
- Atlanta, GA
- Rockford, IL
- New Albany, IN
- Sikeston, MO
- Winston-Salem, NC
- Mountainside, NJ
- Albany, NY
- Cleveland, OH
- Philadelphia, PA
- San Antonio, TX
- Tyler, TX
- Colonial Heights, VA
- Fairfax, VA
- Spokane Valley, WA

**INTERNATIONAL LOCATIONS**

- Graz, Austria
- Bristol, England
- Skopje, Macedonia
- Alesund, Norway
- Fredrikstad, Norway
- Perth, Scotland
- Madrid, Spain

**Public Service Announcement (PSA) on HAE**

The HAEA is proud to be a recipient of one of very few awards (for writing, producing, and directing a Public Service Announcement) given by the prestigious Women in Film, a non-profit organization, based in Los Angeles, California. The award resulted in a moving Public Service Announcement depicting a severely affected female HAE patient who is able to enjoy her wedding day, after finally learning how to successfully manage her disease.

The PSA describes HAE and directs viewers to the HAEA.ORG web site.

HAEA PSA - HAEA/ Women in Film
Social Media Outreach

US HAEA is maximizing the ever-expanding reach of social media to maintain effective and reliable channels of communication with its patients, family and physicians.

HAEA on Facebook

1,500+
Members in Patients Only Page

2,500+
Followers of HAEA Business Page

HAEA on Twitter

2,500+
Followers on Twitter
PUBLIC POLICY ADVOCACY

Our primary public policy event of the year is Capitol Hill Day. We organize a large group of HAE patients who visit at least 60 strategically selected House and Senate offices to discuss the public policy strategic goals listed below:

• Ensure HAE is recognized as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program.

• Lead community efforts to improve patient access to quality, affordable healthcare, and innovative treatments.

• Expand the HAEA, and related conditions research portfolio at the National Institutes of Health (NIH) through growth in FY 2018 appropriations and demonstrated congressional interest in this area.

• Cultivate a national network of grassroots advocates capable of effectively engaging their elected officials to advance a legislative and public policy agenda.

• Stay current and engaged on relevant legislative and public policy issues by monitoring media outlets, participating in coalition advocacy activities, and attending events on Capitol Hill.

PATIENT ENGAGEMENT

US HAEA National Patient Summit 2017 – Stand Up Strong!

The 2017 US HAEA National Patient Summit will be held on September 15-17 in Bloomington, MN! This year’s theme, “Stand Up Strong”, is a unifying call to action for the HAE community and a celebration of work being done by HAE heroes who make a difference every day by raising HAE awareness within their communities.

The 2017 meeting is open to the entire US HAEA patient community and will feature programs for the entire family! Don’t miss the opportunity to: learn about breakthrough therapies on the horizon, get your questions answered by our world-class HAE expert physician/researchers, hear first-hand from Washington insiders the latest on healthcare legislative issues; and be the first to gain insights into never previously disclosed data from the HAEA’s Scientific Registry. You’ll end the day with an incredibly fun evening that includes dinner and entertainment with the entire HAEA community. On Sunday morning, we’ll close out the 2017 Patient Summit with another exciting HAE IN-Motion® 5K walk/run!

Also, this year’s Youth Programs offer special events organized just for children and teens attending the conference. There will be a variety of engaging activities as well as plenty of time to get to know other kids and teens in the HAEA community. A super fun off-site TEEN trip for ages 12-17 is planned for Saturday, September 16, while KIDS 5-12 will enjoy their time together on-site at the SUMMIT venue.

We look forward to seeing you in Bloomington, Minnesota!
The US HAEA Angioedema Center at UCSD

The US HAEA Angioedema Center at UC San Diego offers comprehensive care for patients with angioedema, state-of-the-art diagnostic tests and techniques, the latest available treatments, a full range of patient support programs, and cutting-edge angioedema research. The Angioedema Center, in partnership with the US HAEA, aspires to improve the lives of angioedema patients throughout the world.

The US HAEA Angioedema Center at UC San Diego offers a unique “bench-to-bedside” approach to patient care and angioedema research. Our multi-disciplinary team works together to determine the best treatment options available for each patient. Patients, along with their physician, decide on the best course of treatment. From research in genetics to the most advanced treatments, the Angioedema Center is at the forefront of angioedema research to benefit the patient community.

If you are interested in getting more information or setting up an appointment at the Center, contact a HAEA patient advocate.

US HAEA Scientific Registry

2016 was a landmark year in progress for the US HAEA Scientific Registry!

Broad-based and consistent participation in the Scientific Registry is crucial to advancing the science of HAE and finding a cure. The US HAEA Scientific Registry is a combination of a clinical data registry and a bio-repository. Clinical data is collected through online patient questionnaires while DNA blood samples are also collected from participants. We will provide patients with links to publications stemming from the Registry data they have supplied.

Our Registry membership has grown to over 1200 participants in total and the HAEA has worked to create new and innovative ways to connect with all of our Registry members this past year.

- We successfully disseminated our first user survey, which gave us valuable feedback.
- The Scientific Registry Online system underwent several updates to make data reporting even quicker and easier.
- We created new avenues to connect with the Scientific Registry staff by opening our Scientific Registry “table” in the HAEA Café.

One of the biggest changes to the Registry in 2016 was the transfer of its collection of DNA samples from a private biobank to the US HAEA Angioedema Center at UCSD. The close proximity of our Center HAEA experts to the DNA samples will allow for more expedited and advanced HAE research.

With dedicated Scientific Registry participants, we can:

- Accelerate the development of new HAE treatments
- Help physicians increase knowledge about the day-to-day lives of HAE patients
- Assist researchers in efforts to improve current HAE therapies

We look forward to adding new Registry members at the HAEA Summit in 2017, as we continue to provide scientist with the data needed to find a CURE!
Clinical Trials
Clinical trials are studies in which people volunteer to test new drugs or devices. Clinical trials are crucial to learning whether a new treatment works and is safe for people. These kinds of studies are necessary to develop new treatments for serious diseases like HAE.

In 2016, the HAEA contacted more than 2000 patient members regarding participation in a number of clinical trials. As new treatments are being developed, HAEA patients will again be offered the opportunity to take part in these important studies. The future is bright when we all support future research through clinical trial participation.

Scientific Publications
The US HAEA is constantly working towards improving HAE management and advancing scientific knowledge. Physician/scientists at the US HAEA Angioedema Center and on our Medical Advisory Board, along with HAEA executives, recently published a variety of important medical journal articles.


2016 Facts Regarding HAE Care in the US
The HAEA is committed to helping patients successfully manage their HAE and overcome any impediments to leading a normal life. Every day, our team works diligently to HAE patients to lead a normal life. We frequently gather information to identify our members’ health needs and areas of improvement.

With this in mind, the HAEA conducted a survey entitled “Current state of HAE management in the US”.

Following are some highlights of the survey:
- Highlights – 980 respondents
- 74% - more than one attack per month
- 30% - more than one ER visit in the preceding 6 months
- 50% - somewhat to not at all satisfied with therapy
- 50% - moderate to no knowledge of available therapies
- 15% - are using or have used an indwelling port

Based on the results of this survey, and mindful of the ever changing HAE landscape, in 2017 the HAEA will restructure its programs, activities, and staff resources as we advance our data and automation capabilities to pinpoint our patient communities’ evolving needs.
LOOKING FORWARD – 2017 MAJOR INITIATIVES

In 2017 we will reorganize our work teams and refocus our programs and activities to align with 4 pillars that represent areas vital to achieving the goal of life long health for HAE patients’ Health, Advocacy, Engagement and Advances in Research (HAEA).

OUR PILLARS

<table>
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<tr>
<th><strong>hae health</strong></th>
<th><strong>advocacy</strong></th>
<th><strong>engagement</strong></th>
<th><strong>advances in research</strong></th>
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| -Patient Identification and Diagnosis  
- Patient Education  
- Physician Education  
- Physician Referrals  
- Access and Reimbursement  
- Assistance with health insurance selection  
- Assistance with insurance denials, quantity limit overrides, and billing matters  
- CME programs  
- Topical Health Webinars  
- Coordinate Support Groups  | - Capitol Hill Day  
- Grassroots Network  
- Action Alerts  
- Legislative Webinars  
- FDA Patient Focused Drug Development Meeting  
- Monitor and comment upon legislative and regulatory proposals affecting HAE and rare disease patients  
- Active role in rare disease coalitions protecting access to and reimbursement for treatments  
- Testifying before state utilization review boards advocating for HAE medicine insurance coverage  | - HAE IN-MOTION® 5k  
- hae day :-)  
- Puerto Rico Patient Group  
- Youth Leadership Council and other Youth Programs  
- Brady Club  
- Scholarship Program  
- HAEA Café  
- Special Blood Screenings  
- HAE ER Tool Kit  
- Social Media Outreach  
- HAEA in Action Newsletter  | - US HAEA Angioedema Center  
- HAEA Medical Advisory Board  
- HAEA Scientific Registry  
- Clinical Trials  
- Scientific Publications  
- HAEA Research Network |
HAE Health
The US HAEA is committed to helping patients overcome barriers to successfully managing their HAE and leading a normal life. Our HAE Health team works diligently to provide patients with comprehensive and highly personalized services.

Advocacy
The HAEA leads a nationwide advocacy movement focused on maintaining a strong political advocacy presence in health related legislative and regulatory policy. The HAEA vigorously fights on behalf of patients when any health policy or “access to therapy” challenge arises. We also play a prominent role in important national rare disease patient coalitions.

Engagement
The HAEA unifies and empowers the HAE patient community to Stand Up Strong for HAE. As shown below, we continuously develop a broad range of activities and programs that encourage our HAEA members to educate, engage, and raise HAE awareness within their own local communities.

Advances in Research
HAEA is committed to advancing scientific research on HAE management, therapies and ultimately, finding a cure.
FINANCIAL INFORMATION

HAEA Focuses its Resources on Improving the Lives of Patients

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

100 percent of every dollar donated by individual and non-corporate sources goes to:

Groundbreaking research, the HAEA Scholarship Fund and/or the HAEA Benevolence Fund that provides travel assistance for patients seeking care from an expert HAE physician. Corporate donations are earmarked to fund administrative expenses as well as many of our programmatic activities.

The HAEA maintains rigorous and disciplined internal financial controls that are overseen by our Financial Director who, among other duties, reviews every HAEA expenditure to ensure reasonableness and compliance with the Association’s policies and procedures.
The future is bright when we all offer the opportunity to number of clinical trials. As new treatments are successfully managed their HAE and overcome any diseases like HAE. These kinds of studies are to test new drugs or devices. Clinical trials are recently published a variety of important medical advisory board, along with HAEA executives, the US HAEA is constantly working towards improvement. We frequently gather information to normal life. The HAEA is committed to helping patients successfully manage their HAE and overcome any diseases like HAE.

Clinical Trials

The continued generosity of our donors enables the HAEA to provide an expansive array of programs and activities detailed in this Annual Report. The US HAEA would like to acknowledge our corporate donors.

2016 Core Donors

The US Hereditary Angioedema Association (HAEA) is a non-profit 501(c)(3) patient advocacy and research organization with nearly two decades of experience serving the HAE patient community. The continued generosity of our donors enables the HAEA to provide an expansive array of programs and activities detailed in this Annual Report. The US HAEA would like to acknowledge our corporate donors.

US HAEA Board of Directors

Karen Baird
Henrik Balle Boysen
Anthony J. Castaldo
Dr. Eric Phillips
Larry Salus
Christopher Whalen

Your HAEA Team

Executive Team
Anthony Castaldo, President
Pamela King, Acting Chief Operating Officer
Larry Salus, Financial Director

HAEA Directors
Janet Long, Senior Director of Research
Lois Perry, Director of Patient Advocacy and Engagement
Michelle Cuevas, Acting Director of Communications
Leigh Farrar, Director of Data and Automation
Christine Selva, HAEA Project Manager

US HAEA Health Advocate Team
Sally Urbaniak, Health Advocate
Troyce Venturella, RN, Health Advocate
Heidi Polek, Health Advocate

Patient Advocates
John Williamson, Sr. Patient Advocate
Jenny Barnes, Sr. Patient Advocate
Sherry Swanson, Patient Advocate
Lisa Facciolla, Patient Advocate

Scientific Registries
Saira Shaikh, Project Manager – HAEA Scientific Registries
Anna Chenoweth, Administrator - Scientific Registries

HAEA Support Staff
Michele Agostinho, Accounting Assistant
Joyce Wilmot, Information Technology Analyst
Brenda Minnick, Patient Advocacy and Engagement Administrative Support
Ianice Viel, Social Media Manager

HAE IN-MOTION®

These 5K events are held nationwide and open to the public. Each event promises to be a fantastic
In 2016, the HAEA contacted more than 2000 people necessary to develop new treatments for serious HAE and is safe for people. These kinds of studies are called clinical trials. In these trials, people volunteer to participate in studies to help doctors learn more about diseases and treatments. These clinical trials are studies in which people volunteer to participate. Clinical trials are important for improving HAE management and advancing scientific and medical capabilities to pinpoint our patient communities’ needs. These trials are the first step in the development of new therapies.

The US Hereditary Angioedema Association (HAEA) is a worldwide organization with nearly two decades of experience improving HAE management and advancing scientific and medical capabilities to pinpoint our patient communities’ needs. Based on the results of this survey, and mindful of the importance of increasing access to current HAE therapies for those in need, we have developed the following priorities for 2017.

1. Science, Education, and Advocacy to Drive Access to Current HAE Therapies
2. HAE Health with Patient Support and Engagement
3. Patient Participation in a National Patient Registry

The continued generosity of our donors enables the HAEA to prioritize and support these initiatives. The US HAEA is committed to helping patients better manage their disease, to stand up strong for a CURE, and to lead a normal life. Our HAE Health Center offers comprehensive care for patients with HAE and related conditions. Patients, along with their physician, and disciplinary team works together to determine patient care and angioedema research. Our multi-disciplinary team includes world-class HAE expert physician/researchers, genetic counselors, nurse practitioners, social workers, and support staff. The patient demographic includes patients who visit at least 60 strategically selected centers around the world. We also play a prominent role in health-related legislative and regulatory matters. The HAEA leads a nationwide advocacy movement and engages every day by raising HAE awareness within the entire family! Don’t miss the opportunity to: action for the HAE community and a celebration of the year’s theme, “Stand Up Strong”, is a unifying call to raise for a CURE! The 2017 US HAEA National Patient Summit will be held in Minneapolis, Minnesota! We look forward to seeing you in Bloomington, Minnesota! Your charitable contribution to the US HAEA helps the US HAEA maintain rigorous and disciplined fiscal operations and support the continued growth of patient support programs, and public policy advocacy. The HAEA maintains rigorous and disciplined fiscal operations and supports the continued growth of patient support programs, and public policy advocacy. The HAEA leads a nationwide advocacy movement and engages every day by raising HAE awareness within the entire family. Don’t miss the opportunity to: action for the HAE community and a celebration of the year’s theme, “Stand Up Strong”, is a unifying call to raise for a CURE! The 2017 US HAEA National Patient Summit will be held in Minneapolis, Minnesota! We look forward to seeing you in Bloomington, Minnesota!

The HAEA unifies and empowers the HAE patient community to Stand Up Strong for HAE. As shown, we play a prominent role in health-related legislative and regulatory matters. The HAEA leads a nationwide advocacy movement and engages every day by raising HAE awareness within the entire family! Don’t miss the opportunity to: action for the HAE community and a celebration of the year’s theme, “Stand Up Strong”, is a unifying call to raise for a CURE! The 2017 US HAEA National Patient Summit will be held in Minneapolis, Minnesota! We look forward to seeing you in Bloomington, Minnesota!

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opportunity to increase HAE awareness and fundraise for a CURE!
Read more on page 9 or at: http://Sk.haea.org

**hae day :-)***

hae day :-) is a global celebration and the US HAEA is the largest HAE patient group in the world. If you are interested in organizing an hae day :-) event – no event is too small … or too large! – we have ideas and tools for you. Read more on page 10 or at http://www.haea.org/resources/hae-day/

**Donate**

Your charitable contribution to the US HAEA helps to provide a wide range of services to patients and their families. Contributions are tax deductible. One hundred percent (100%) of each private donation received supports three of the main services of the HAEA –

* **The HAEA College Scholarship Fund**
  Students with angioedema will be eligible for college tuition grants

* **The Patient Benevolence Fund**
  Patients with a financial need can apply for travel assistance to see an HAE expert physician

* **HAE Research for A Cure**
  Funding to Support the HAEA Scientific Registry and research for a cure

To make a donation go to: www.haea.org or write us at:

The US Hereditary Angioedema Association
10560 Main Street, suite PS40
Fairfax City, VA 22030
Clinical trials are studies in which people volunteer to participate. It is crucial to learning whether a new treatment works or not. The future is bright when we all work together to find a cure.

The US HAEA is constantly working towards improving HAE management and advancing scientific research. The HAEA leads a nationwide advocacy movement that brings together HAE organizations from across the globe and coalitions. It exists to ensure HAE patients have access to quality, affordable healthcare, and to focus on the importance of early diagnosis and treatment. One of the biggest changes to the Registry in 2016 was the launch of the HAEA Scientific Registry. The disclosed data from the HAEA's Scientific Registry is crucial to advancing the field of angioedema research to benefit the patient community.

The United States Hereditary Angioedema Association (US HAEA) is a patient organization with nearly two decades of experience in engaging the patient community to Stand Up Strong for HAE. As shown below, we continuously develop a broad range of programmatic activities. One of the biggest changes to the Registry in 2016 was the launch of the HAEA Scientific Registry. The disclosed data from the HAEA's Scientific Registry is crucial to advancing the field of angioedema research to benefit the patient community.

In 2017 we will reorganize our work teams and refocus our programs and activities to align with 4 pillars that represent areas vital to achieving the goal of lifelong health for HAE patients. Health, Advocacy, Engagement, and Research.

- Health:
  - Accelerate the development of new HAE therapies.
  - Support the development of patient educational resources and training materials.
  - Fund and support the development of patient advocacy leaders.

- Advocacy:
  - Continue advocacy initiatives for patients and families to increase public awareness and understanding of HAE.
  - Create opportunities to improve HAE management and outcomes through legislation.
  - Advocate for the development of patient supports and services.

- Engagement:
  - Improve HAE management and outcomes through education and community empowerment.
  - Provide information to patients, families, and healthcare professionals about the impact of HAE on the patient community.

- Research:
  - Expand the HAEA's research portfolio at the National Institutes of Health (NIH).
  - Support research on patient needs that will improve HAE management.
  - Support research on patient needs that will improve HAE management.

HAEA is committed to advancing scientific research and creating opportunities for all. In 2016 we will continue to focus on high-impact programs and activities. One hundred percent (100%) of each private donation supports programmatic activities.

Scientific Publications


Advisory Board, along with HAEA executives, recently published a variety of important medical studies. The future is bright when we all work together to find a cure.