

## **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 to a vibrant, goal-advancing, 501 (C)(3) non-profit organization with a membership of over 5,600 people.

## **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.  
Providing highly personalized services with kindness and compassion.



## PRESIDENT'S MESSAGE



2017 was a year of transformation and engagement at the HAEA. To better support our mission, we focused on four patient-oriented strategic areas: HAE Health, Advocacy, Engagement and Advances in Research. These strategic areas narrow our team's focus on addressing critical patient needs and helping our members achieve lifelong health and happiness. I am pleased that these adjustments have already produced positive outcomes, particularly with respect to the engagement and active participation of HAE patients and caregivers.

The HAEA was one of a small group of organizations selected to participate in the FDA's Patient Focused Drug Development Program. In late September, a large group of HAE patients visited the FDA's Maryland campus to offer FDA officials a comprehensive overview of how HAE affects quality of life. During the meeting, our patient community stressed the importance of swift regulatory approval for new HAE medicines, consistent, of course, with safety standards.

Throughout 2017, we asked our members to Stand Up Strong 4 HAE and they delivered! On Capitol Hill Day, over 50 patients and caregivers (a new record) visited 55 congressional offices in support of patients' rights. In addition, one of our members represented the entire HAE community at the State of the Union Address after being invited to Washington by her Congressional representative. To commemorate HAE day :-), our community raised awareness by distributing over 2,000 ER Kits to emergency rooms, schools and workplaces.

In mid September, we celebrated our best patient summit ever in Bloomington, Minnesota, with over 800 patients and caregivers in attendance. In addition, our efforts to engage younger patients took root during the year. Our Youth Leadership Council has become a vibrant and active community led by impressive and brave young kids who wish to live happy lives while managing their HAE.

In late June, the FDA approved the first subcutaneous HAE therapy for HAE prophylaxis and multiple pharmaceutical companies unveiled successful studies on new therapies. We are well on our way to getting better therapies that will greatly improve quality of life!

As we move forward to 2018, I want to thank the HAE community and our HAE Heroes who selflessly participated in events and activities held throughout the year. We count on everyone's continued support as we collectively work to improve patient quality of life!

Warm regards to all,

A handwritten signature in blue ink that reads "Anthony Castaldo".

Tony Castaldo

## US HAEA FOUR PILLARS: STRATEGIC FOCUS

2017 was a year of transformation at the US HAEA as we assessed our operations to determine what is most impactful to our patient community. As a result, we refined and reorganized our operations to focus on four major pillars; Health, Advocacy, Engagement and Advances in Research (HAEA).

By organizing around these four pillars in 2017, the HAEA designed new specialized programs, and focused existing activities that offered greater personalized attention to our members. The impact has been remarkable as evidenced by record setting levels of patient participation throughout 2017.

As we move forward, the HAEA is committed to delivering the highest quality of services with kindness and compassion.



## HAE HEALTH

### Helping New Patients

Our HAE Health team not only identifies new patients, but also provides them and their families with much-needed support and education geared towards sustaining a happier and healthier life. Additionally, we provide physician referrals, introduce new patients to educational programs, offer support groups, and answer non-medical questions on living with HAE. The HAE Health Team also encourages patients and families to join the HAEA Scientific Registry and help expert physician/researchers in the quest for improving HAE patient quality of life.

### Assist with Access

At US HAEA, securing access to an effective therapy is one of our most important objectives. The HAE Health team helps patients get answers to questions regarding health insurance selection, insurance denials, limits on the amount of medicine dispensed, and billing issues. Finally, we assist patients in the coordination of travel arrangements for appointments at the US HAEA Angioedema Center at UCSD.

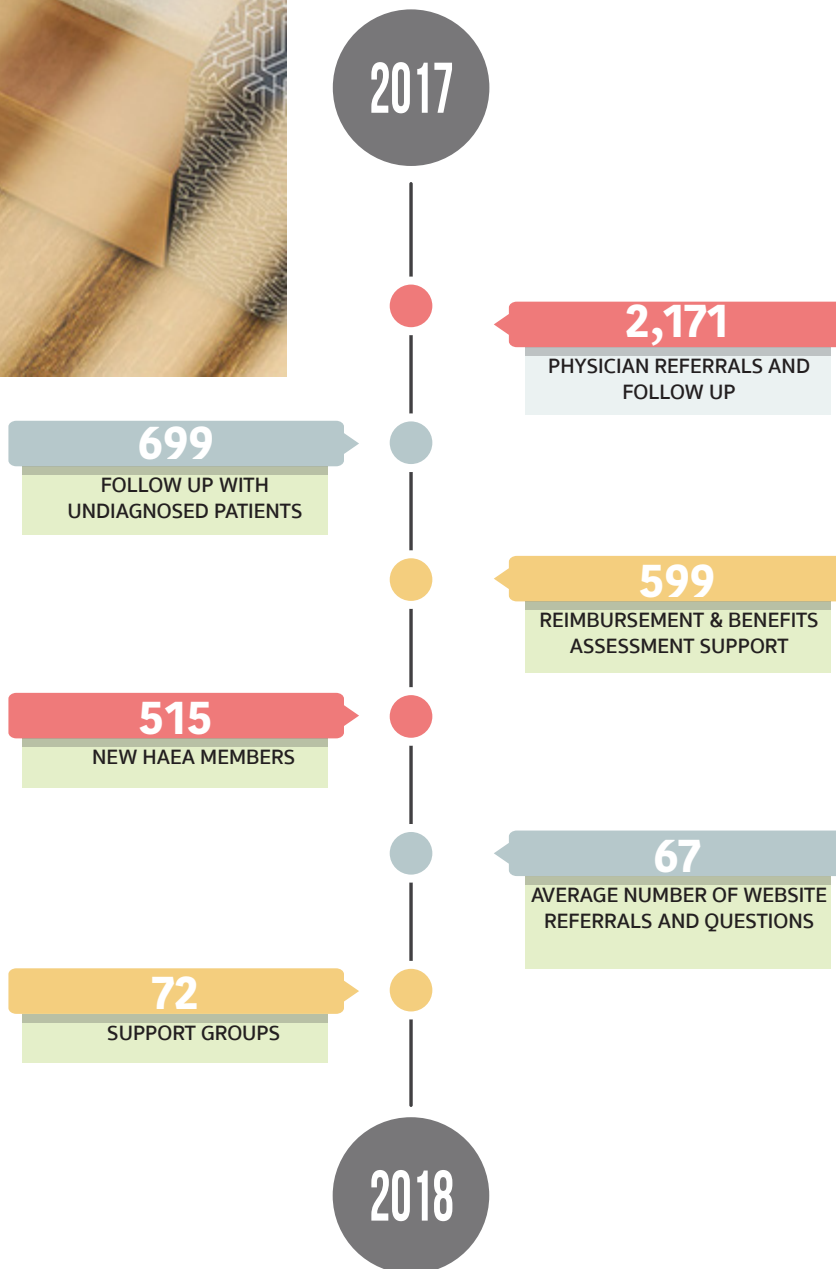




## Education and Empowerment

Our HAEA Health Team seeks to educate and empower HAE patients by providing support and information to help them manage their disease. We offer webinar presentations and support groups throughout the year. In addition, we also collaborate with physicians on educational programs covering breakthroughs and new treatment options available to HAE patients.

2017 was a busy year for our HAE Health Team. Take a look at our advances to reach and support HAE patients and their families:



### Continuing Medical Education Programs for Healthcare Professionals Programs

The HAEA offers outstanding educational programs to help physicians identify, diagnose, and offer suitable treatment options for HAE patients through its Continuing Medical Education Programs for Healthcare Professionals (CME). The HAEA keeps physicians up to date with the latest medical and scientific information available in the continuously evolving field of Hereditary Angioedema.

CME credits are granted upon completion for in-depth reviews of the following courses:

- Consensus Guidelines on Improving the Management of HAE as published by US HAEA's Medical Advisory Board;
- Angioedema in the Emergency Medicine Setting: Optimizing Management for Every Patient is a course designed to provide clinical insight on HAE diagnosis and treatment in the ER setting; and
- Improving HAE Patient Care through an Interactive Patient Simulation Platform. The course offers physicians the opportunity to increase their understanding and awareness of hereditary angioedema by virtually managing a patient with undiagnosed HAE presenting acute facial swelling in the emergency room as well as follow up once the patient's symptoms have subsided and can be discharged.

interested in taking advantage of these CME programs can access them via [www.haeedu.com](http://www.haeedu.com)

## ADVOCACY – EMPOWERMENT, EDUCATION AND ENGAGEMENT

### Food and drug Administration's Patient-Focused Drug Development

As part of our advocacy activities, on September 25th our group of HAE advocates attended the Food and Drug Administration's (FDA) Patient-Focused Drug Development meeting. The purpose of the meeting was to provide the FDA with the HAE patient and caregiver perspective. Members of the HAEA community stressed the need for continuous improvement in the efficacy and dosing convenience of HAE therapies. Despite impressive advances over the past few years, a patient survey conducted by the HAEA underlined that 75% of patients still suffer an HAE attack on a monthly basis and 60% remain unsatisfied with current treatment options. Patients also called attention to challenges presented by access to therapies, as insurance coverage often controls treatment options available to patients.



# CAPITOL HILL DAY



“Patient advocacy is important to all of us with Hereditary Angioedema because with patient advocacy we have treatment options, modern medications and access to them, we can obtain health insurance, we can keep our means of employment, we have government funded research to bring new treatments to us, we have support from each other, without being afraid of repercussions. Only with advocacy can we live satisfying and fulfilling lives and procure the future for our children to do the same.

- Carol Edwards

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In July 2017, over 50 HAE patients and families joined the HAEA on Capitol Hill to meet with congressional members and staff in Washington, DC. Participants were asked to tell their personal stories and ask Congress for help in; advancing research and improving patient care. Together, we visited over 55 congressional offices and successfully advocated for congressional action on policy issues that impact HAE patients in the US including:

- 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.

We thank our HAEA heroes who made this our most successful Capitol Hill Day to date. You definitely Stand Up Strong for HAE and it shows!

## Our advocacy accomplishments for 2017 include:

- o One of our patients was an invited guest at President Trump's first State of the Union Address, and spoke with the reporters' circle about healthcare issues.
- o Five patients joined HAEA President Tony Castaldo, and the HAEA staff in a June "Senate Fly-In Day" which took place on the original vote day for the repeal and replacement of the Affordable Care Act (ACA).
- o Three letters from HAE patients were read by Members of Congress on the Floor and included in the Congressional Record.

- o Supported additional funding for the National Institutes of Health (NIH) for Year (FY) 2017. NIH has recently included a research portfolio in HAE. Meaningful funding increases are needed moving forward to ensure this portfolio can expand and advance.
- o Affirmed Hereditary Angioedema as a condition eligible for research grants through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2017.
- o Rallied initial congressional support for modifying the Centers for Medicare and Medicaid Services (CMS) Rule on Third Party Payment for Qualified Health Plans to ensure qualified charities can continue to provide payment assistance for individuals with rare, chronic, and costly medical conditions.
- o Advocated that the following “four pillars” of patient protection are included in any serious proposal moving through Congress:
  - Maintain the prohibition against pre-existing condition discrimination
  - Allow dependents to stay on family insurance until age 26
  - Continue to prohibit lifetime and annual caps on insurance coverage
  - Limit out-of-pocket costs for patients in a meaningful way



Patients and their family members traveled from 23 states to deliver a vitally important message – protect our patient community's access to life saving HAE medicines.



## ENGAGEMENT

### US HAEA National Patient Summit 2017 – Stand Up Strong!

The 2017 US HAEA National Patient Summit held on September 15-17 in Bloomington, MN was a tremendous success! We had our best turnout yet, with over 800 patients and family members attending the conference.

The Summit's theme, "Stand Up Strong", was 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 conference featured multiple sessions and panels framed under the Association's four pillars: Health, Advocacy, Engagement and Advances in Research (HAEA). It also provided one-on-one learning opportunities with HAE physicians and researchers to educate members on practical ways to manage the disease, and the latest research developments.

The 2017 conference also featured a Teen Summit, led by the Youth Leadership





Hundreds of attendees helped make the 2017 HAEA Patient Summit event an unforgettable one. Families, medical/scientific experts, HAEA staff, and industry partners came together in Bloomington, Minnesota to learn the latest HAE news, updates, and therapy details.



Council (YLC), which attracted over 50 youth.

#### **HAE IN-MOTION® 5K Events**

The HAE IN-MOTION® program supports patients and caregivers interested in holding a fundraising event to raise HAE awareness. Each event presents a unique opportunity for family, friends, co-workers, physicians, hospitals, industry partners, and others in the local community to come together and advance the work of our national patient advocacy organization. The HAE IN-MOTION® 5K events support three of our main 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 for patients in need who must travel to see an HAE medical specialist.

**HAE Research** – supports expert researchers in their efforts to solve the remaining scientific mysteries of HAE through the US HAEA Angioedema Center at UCSD.





Since its creation just over two years ago, 19 HAE IN-MOTION® 5K events have been celebrated across the Nation, attracting close to 3,000 participants. In 2017, ten HAE IN-MOTION® 5K events were held and we were able to increase our participation from 1,000 in 2016 to almost 2,000 in 2017!

**2,000**

PARTICIPANTS IN 2017  
HAE IN MOTION® 5K EVENTS

INCREASE IN PARTICIPANTS FROM  
2016 TO 2017

**50%**

Ten HAE IN-MOTION® events are currently scheduled for 2018, providing a full calendar for the year. If you are interested in sponsoring a 5K event in your community, please contact us via email at [5k.haea.org](mailto:5k.haea.org), and we can consider it for the 2019 schedule. Our goal is to reach as many communities as possible so we can raise HAE awareness and improve the lives of HAE patients.





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“My name is Luci Toman and I am 9 years old. I have HAE. I stand up for HAE by raising awareness in my community. I have organized a slot car race to raise awareness and I enjoy taking ER kits to my school, doctors' offices and local hospital so they can learn more about HAE. This makes me feel like I'm in charge of my disease.”

-Luci Toman

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### hae day :-) May 16, 2017

May 16th is hae day :-) in the United States! Established in 2012, hae day :-) aims to raise HAE awareness among the public and the medical community through special events, fundraisers, and dissemination of information. Each year, more and more HAE patients host events, and promote them using social media. These patient-driven hae day events raised close to \$30,000. In addition, hundreds of patients held individual activities to educate others by wearing their t-shirts or handing out infographics. In addition, some of our members have been featured in newspaper articles and TV interviews.

Over 2,000 ER Tool Kits were handed out by HAEA members and families during our biggest awareness campaign for 2017's hae day :-). This campaign provided our patients with a powerful advocacy tool that engaged doctors, nurses, and first responders. The HAE ER Tool Kit is a handy, practical guide to help physicians understand HAE symptoms and provide patients with appropriate care and treatment. The Tool Kits were distributed to local hospitals and emergency rooms, schools and work places.





### THE HAEA Café

The Café is an online platform for direct communication between HAEA Patient Advocates and our HAEA members. This virtual community enables live chats with HAEA Patient Advocates, access to educational webinars, the latest HAEA news, and participation in virtual support groups. The Café also features an events calendar page and webinar archives.

### Youth Leadership Council

Recognizing that our younger HAEA community offers a special perspective of the future, in 2017 HAEA launched the Youth Leadership Council (YLC). YLC is a group created to help develop a strategy that meets the needs of the young HAE patient, siblings, and other family members. The Council encourages engagement through peer to peer communications and is open to any and all young patients and family members who want to take on leadership roles with our HAEA community.

The YLC made great strides in advancing our goal to reach and support our young patients and their families. Thanks to their effective leadership, the Teen and Kids Programs at the 2017 Summit were a resounding success, with over 75 youngsters attending both programs. A Parent Survey conducted after the Summit pointed to a 100% approval for the Summit's Teen Program, among respondents.

For next year, YLC has an aggressive and exciting agenda that includes regional gatherings, developing targeted HAE Café webinars for youth, and participating in the HEA International HAEi conference in Vienna, Austria.



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I am involved in the HAEA YLC because I have always been interested in standing up for what I believe in, and the YLC offers an incredible opportunity to do just that. It allows all participants to be involved in the bigger picture that affects kids with HAE, while simultaneously connecting us to other youth that share similar experiences to our own.

-Kobe Mukes

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### Brady Club

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 so they can enjoy a happy and healthy childhood.

In an effort to better engage with our HAEA kids and families, this year we re-launched Brady Club with even more entertaining and exciting games that capture their attention while educating them on ways to manage their HAE. We also asked families and children to submit and share their personal HAE stories to find friendship and empathy in shared experiences. To extend our reach, we made the Brady Club available to families in Australasia and the United Kingdom.

The new Brady Club format has been a success as shown by a 25% increase in family sign ups. We encourage families to explore Brady Club and share their personal stories. We are certain that these shared experiences will foster positive bonds to guide our youngest members as they learn to manage HAE. The Brady Club will continue to grow as a safe place where HAEA kids can have fun and find comfort.



### US HAEA Scholarship Program

The US Hereditary Angioedema Association celebrates the drive and aspirations of HAE patients who strive to expand opportunities through education. The HAEA Scholarship Program provides financial support for HAE patients seeking a brighter future by pursuing academic studies in colleges and universities. In 2017, the HAEA awarded thirty (30) scholarships to HAE patients – an increase of 7% over 2016.

35

SCHOLARSHIPS AWARDED IN 2017

7%

INCREASE IN SCHOLARSHIPS AWARDED

#### Morgan Douglas: Southeast Missouri State University

This scholarship is a great help in reaching my goals. It is a hard and scary time for HAE patients to go to college and leave the families that have always been there to support them. Knowing that the HAE Association is also there to support them is a huge honor. I am very thankful for all the Association has done for me in helping me find my doctor and now helping to send me to college. I am truly grateful.  
Thank You.



PASSION LED US HERE

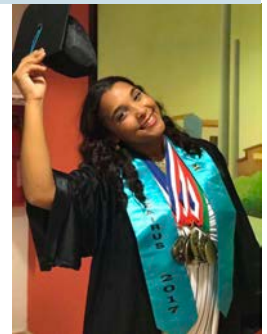


**Sydney Peel: Texas Christian University**

Thank you so much for providing this scholarship. This scholarship has allowed me to attend an amazing school that supports my health as well as my education. Having HAE is a daily challenge that has pushed me to be the best version of myself and to go for my dreams without hesitation. Thank you for providing the support I need to be able to attend school and pursue my degree in Art Education. I want to give back by becoming an Art Therapist and helping other persons with disabilities through my passion for art!

**Sarimar Mateo: Universidad del Sagrado Corazón**

This Scholarship granted to me by the US HAEA will help me greatly in funding my studies, books and university needs. I am extremely grateful to the HAEA for this privilege and for having confidence in me and my abilities. I will responsibly rise to the HAEA's expectations.

**Laura Shotola-Schiewe: University of Oregon**

I am grateful to be one of the recipients of the 2017 HAEA Scholarship. This award will lighten the burden of my university tuition, allowing me to continue to pursue my passion as an Interior Architecture major at the University of Oregon. I am appreciative of this scholarship program for supporting students like myself with the continuation of their education. The program has provided me with confidence in my academic endeavors and has further encouraged me to continue on with my personal aspirations to be an interior architect.

**Jack Gray: Southern Illinois University Edwardsville**

Thank you from the deepest part of my heart, for this opportunity. It has been difficult getting through nursing school with HAE, yet here I am with only one year to go. It is my dream to one day work with fellow HAE patients in the clinical setting, and this scholarship has helped me get one step closer. Again, thank you so very much.



**Shannon Pflomm: University of Connecticut**

Thank you so very much for awarding me this scholarship for the second year in a row. It will be used towards funding my education abroad in the Fall of 2017 as I travel to Cape Town, South Africa to pursue my role as a student nurse in clinics and hospitals throughout the city. As I finish up my last year of nursing school, I think back to when I was diagnosed with HAE as a high schooler, a pivotal point in my life that sparked my passion for the art of nursing. This foundation and this scholarship has helped me to defray the cost of my education at the University of Connecticut and I can't wait for the opportunities that are to come in my near future.

**Abigail Sickles: SUNY Geneseo**

Thank you so much for considering my application, and awarding me this scholarship. It is truly appreciated and it will go a long way in funding my college tuition.

**Morgan Ellen, University of Texas at Austin**

My name is Morgan, and I am going to be a sophomore at the University of Texas at Austin in the fall. I am so truly grateful for receiving this scholarship from the Hereditary Angioedema Association. This scholarship helps me to continue my college education and pursue my academic interests. I am majoring in Biology and am very passionate about science in general. My ultimate goal in life is to continue my education in medical school. I want to become a doctor so that I can use my strengths and talents to help other people. Thank you so much for awarding me this scholarship. This will be extremely helpful as I further my studies.





# HAEA PUERTO RICO

## FACEBOOK

**1,669**  
Members in Patients  
Only Page

**2,852**  
Followers of HAEA  
Business Page

**65.7%**  
Increase in Followers of  
HAEA Business Page

**209.8%**  
Increase in Total  
Engagements  
since 2016



## TWITTER

**824**  
Followers

**100%**  
Increase in Followers

**5.7%**  
Increase in Engagements



## HAEA PUERTO RICO

The hurricane did not stop our HAEA community from Standing Up Strong for HAE. Two years after establishing a chapter on the island, our community continues to grow its membership and expand its activities. In April, our HAE IN MOTION® 5K race in San Juan drew over 500 participants, making it our most attended event by patients and the general public for two years in a row!

Our 2017 agenda in Puerto Rico also featured a screening of the documentary, Special Blood, and health and wellness presentations, including:

- o “Improving HAE Care: Changes on the Horizon”, by Dr. Marc Riedl, Clinical Director for HAEA’s Angioedema Center at UCSD, which focused on the future of therapies for HAE
- o “Managing HAE”, by Dr. Ileana Fumero, psychiatrist, focusing on anxiety & depression in patients with chronic conditions

## Social Media Outreach

The HAEA maintains frequent, open and reliable channels of communication with patients, families and physicians. We strive to establish meaningful and long-standing relationships with our HAE community, and popular social media outlets are one of the many channels we use.

Join us on Facebook and Twitter and stay up to date with your HAEA family!

## RESEARCH – PIONEERING INNOVATIONS IN HAE SCIENCE

### The US HAEA Angioedema Center at UCSD

The US HAEA Angioedema Center at UC San Diego offers comprehensive care for patients with all types of angioedema, state-of-the-art diagnostic tests and techniques, an expert understanding of all of the latest FDA-approved HAE treatments, and cutting-edge scientific research. The Angioedema Center, in partnership with the HAEA, aspires to improve the lives of angioedema patients in the US and around the world. The US HAEA Angioedema Center's multidisciplinary team works together to determine the best treatment options available for each patient. As outlined in the HAEA Medical Advisory Board's HAE Management Recommendations, patients decide on the best course of treatment to meet their unique needs in partnership with their physician.

In 2017, the Center welcomed its first scholarship recipient for a 2-week educational training session. Dr. Erick Njenga from Kenya reported that he learned a great deal about HAE, about patient treatments, and disease management at the Center. Also in 2017, the first Center Fellow completed preliminary research on new aspects of understanding HAE with Normal C1 Inhibitor. The Center welcomes the opportunity to work with new Fellows each year to prepare them to be future HAE experts.

From research in genetics to expert guidance on today's modern, FDA approved HAE treatments, the Angioedema Center is at the forefront of angioedema patient care and research, to benefit the entire HAE patient community.



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“For my Eagle Scout Project, I created a Garden of Remembrance at the Washington City Cemetery in Washington, Utah. The garden consists of a landscaped walkway with three columbarium towers. I created this garden for my mother who is an inspiration to me. My mom has hereditary angioedema and her example of strength, hope, and courage have helped me to become a better person. I dedicated the Garden of Remembrance to Hereditary Angioedema patients worldwide.”

Gaven Michael Wright

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### ADVANCE HAE SCIENTIFIC REGISTRY

Advance HAE Scientific Registry is an invaluable patient-driven movement for advancing basic HAE research and therapy development. Patients submit confidential clinical data using an online portal, as well as blood samples. Advance HAE provides the research community with de-identified, uniform, long-term, accurate information on HAE. In 2017, we made significant updates making it easier for patients to contribute their individual registry reports. We also added features that enable patients to review their HAE symptoms and overall sense of well-being on a weekly, monthly and annual basis.

We successfully transferred the collection of DNA samples from a commercial 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.

We are taking advantage of advances in healthcare technologies by introducing a HAE Scientific Registry Mobile App in 2018! The new mobile app will make it easier for patients to keep track of HAE symptoms, leading to more precise monitoring of their HAE.

1,200

REGISTRY MEMBERS

4,655

BIOLOGICAL SAMPLES

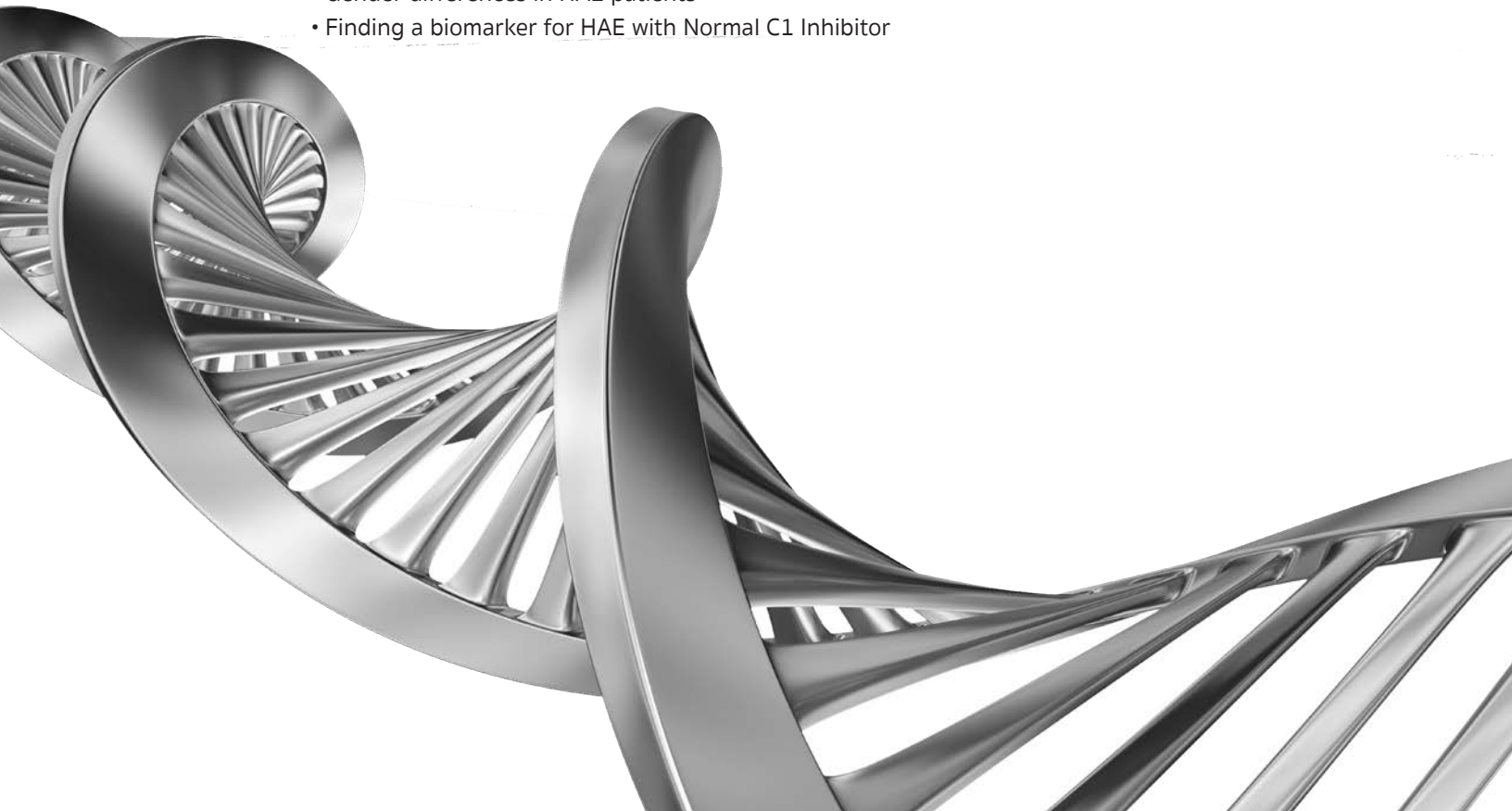
2,714

COMPLETED REPORTS

#### Advances in Research

HAEA is committed to advancing scientific research on HAE management, therapies and ultimately, finding a cure. Our research agenda for 2018 includes the following topics:

- NEW HAEA Medical Advisory Board Treatment Guidelines
- Psychological factors and HAE
- Gender differences in HAE patients
- Finding a biomarker for HAE with Normal C1 Inhibitor



## FINANCIAL INFORMATION

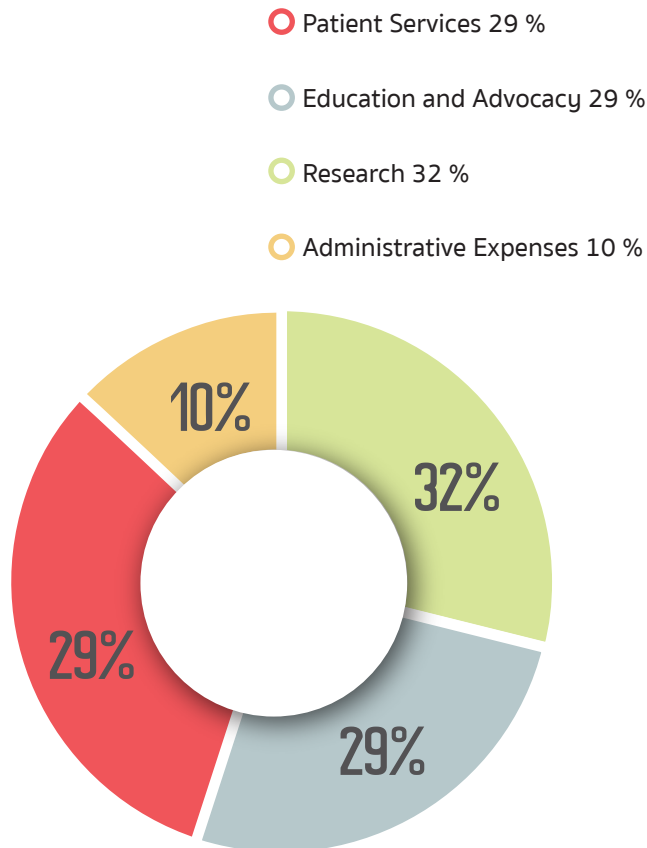
### HAEA Focuses its Resources on Improving the Lives of Patients

The distribution of expenditures shown in the chart below reflects the US HAEA's commitment to focusing on high impact programs, 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: Groundbreaking research including our HAEA Scientific Registry, the HAEA Scholarship Fund and/or the HAEA Compassion 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 wide-ranging 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 compliance with the Association's policies and procedures.



## HAEA SERVICES PROVIDED IN 2017

Patient Identification and Diagnosis

Collaboration and Communication with Patients and Health Care Professionals

Reimbursement Assistance and Enrollment Support

Access to Therapy

Physician Outreach

Education & Advocacy Services

Educational Programs (Patients & Physicians)

Virtual Support Groups

Educational Webinars

Education of Healthcare professionals

Emergency Room CME

Scholarship Program

Capitol Hill Day

Brady Club Online Kids Zone

Research & Clinical Support

US Angioedema Center at USCD

Medical Advisory Board

Scientific Registry

Scientific Publications

Clinical Trials Recruitment & Support

Engagement & Awareness

hae day :-)

HAE IN-MOTION® 5K

HAE ER Tool Kit

Special Blood Documentary Screenings

Youth Leadership Council



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“My little sister has experienced more pain than any 7 year-old should know because of HAE. It is watching her suffer and feeling helpless in those moments that make me strive to raise awareness and find a cure. So much has been accomplished in her short life in terms of developing better medication and research. It gives me hope and motivation to keep pushing until a cure is found.”

-Michael Ardito

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## OUR CORPORATE PARTNERS

The continued generosity of our donors enables the HAEA to focus our efforts on an expansive array of individualized health services, educational programs, advocacy and engagement activities, and groundbreaking research.

### HAEA President's Circle



### HAEA Leader



### HAEA Supporter



### US HAEA Board of Directors

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

### Christopher Whalen – IN MEMORIAM

The HAEA family lost a beloved friend and supporter with the passing of Christopher Whalen. Chris was a founding member of the HAEA Board of Directors and served the HAE patient community for over 17 years. Most importantly, Chris was a beloved husband, father, and friend. He will be missed.

## US HAEA MEDICAL ADVISORY BOARD

The US HAEA Medical Advisory Board (MAB) is composed of HAE experts from across the country. The MAB serves as the HAEA's principal advisers on all medical and scientific matters. The HAEA community greatly appreciates the contributions made by these dedicated professionals.

## YOUR HAEA TEAM

### EXECUTIVE TEAM

Anthony J. Castaldo, President  
Pamela King, Chief Operating Officer  
Larry Salus, Financial Director and Treasurer

### HAEA DIRECTORS

Janet Long, Sr. Director of Research  
Lois Perry, Director of HAE Health  
Michelle Cuevas, Director of Communications  
Leigh Farrar, Director of Data and Automation  
Christine Selva, Project Manager

### HEALTH TEAM

Lois Perry, Director of HAE Health  
Sally Urbaniak, Health Advocate  
Troyce Venturella, Health Advocate

### PATIENT ADVOCATES

Jenny Barnes, Sr. Patient Advocate  
John Williamson, Sr. Patient Advocate  
Sherry Swanson, Patient Advocate  
Lisa Facciolla, Patient Advocate  
Ianice Viel, Social Media Manager & Patient Advocate  
Mike Mallory, Patient Advocate

### SCIENTIFIC REGISTRY

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

### INFORMATION TECHNOLOGY

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

### HAEA ADMINISTRATIVE SUPPORT

Michele Agostinho, Accounting Assistant  
Brenda Minnick, Patient Advocacy and Engagement Administrative Support

## HOW CAN I SUPPORT THE HAEA?

Consider hosting or participating in one of the opportunities listed here:

### HAE IN-MOTION®

These 5K events are held nationwide and open to the public. Each event promises to be a fantastic opportunity to increase HAE awareness and fundraise for a CURE!

Read more on page 12 or at: <http://5k.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 14 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 the HAEA's overall commitment to improving the lives of HAE patients through the following three areas:

**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 for patients in need who must travel to see an HAE medical specialist.

**HAE RESEARCH** – supports expert researchers in their efforts to solve the remaining scientific mysteries of HAE through the US HAEA Angioedema Center at UCSD.

The US HAEA is a not-for-profit 501(c)(3) patient advocacy and research organization. We are proud of our more nearly twenty (20) year long history of providing our patient community with a variety of services that include Health Education, Advocacy, Engagement, and Advances in Research. Your donation helps us to continue these programs as well as create new services for HAE patients and families.

## MEDICAL ADVISORY BOARD



**Bruce Zuraw, MD**

MAB Chairman

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