

SCALING NEW HEIGHTS

US HAEA 2025 ANNUAL REPORT



**“Thank you for all you do for those
with HAE and their loved ones, friends
and family. This organization is the
most awesome support for a rare
disease community. Together we can
do anything.”**

Sheena S

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Leadership Message



Anthony J. Castaldo

CEO & Chairman of the Board



Henrik Balle Boysen

President & Board Member

Dear HAEA Friends,

Our community has always been defined by its unity and deep commitment to improving the lives of people with HAE. As we look back on 2025, that commitment has produced something remarkable. The HAEA now stands nearly 11,500 strong, and as you will read in the pages that follow, the impact of what we continue to build together is reaching further than ever before.

In 2025 alone, three new HAE therapies received FDA approval, bringing the total to 11. That record is unmatched in the rare disease world, and more therapies are on the way.

Our longstanding goal is to make sure that everyone diagnosed with HAE benefits from these advances. Achieving it has been challenging because until now there has never been a reliable estimate of the US HAE population. To change that, the HAEA conceived and led a study unprecedented for a patient advocacy organization. Working with expert physicians, demographers, and statisticians, we produced the first reliable estimate of how many people in the United States have been diagnosed with HAE across all known types. Published in a top-tier peer-reviewed journal, the study puts that number at almost 10,000, giving us a clearer picture of the community we serve.

This work is part of a broader effort to publish scientific evidence that demonstrates the value of appropriate care and access to HAE therapies. Toward that end, the HAEA partnered with HAEi to convene a distinguished international group of HAE experts who developed a consensus viewpoint on the genetics, biological mechanisms, diagnosis, and treatments for HAE with normal C1 inhibitor. Their conclusion was clear and important: anyone diagnosed with this condition by an expert physician should be provided access to their prescribed treatment. Published in a leading peer-reviewed journal, this statement gives people with HAE and their physicians solid grounds to stand on when facing coverage denials.

New medicines can only reach their full promise if people with HAE can actually access them. Insurance denials have become an almost routine obstacle, and the HAEA Health Team has been highly successful in overturning them, helping more than 500 community members in 2025 alone.

The 2025 National Summit in Baltimore brought more than 1,400 HAEA friends together in our largest gathering ever, four days of learning, connecting, sharing stories, and celebrating the progress we have made.

Our advocacy reach continues to expand. The Grassroots Advocacy Network grew to 1,285 members across all 50 states and Puerto Rico, and our Capitol Hill Day brought 93 advocates into more than 60 Congressional offices. The Give the Kids a Chance Act, a priority for our community, passed both chambers of Congress. The voices of our grassroots advocates are being heard.

Our youth programs continue to thrive, giving young people with HAE the tools, connections, and confidence to step into leadership roles that will shape the future of our community.

A recent survey found that 92% of respondents felt more hopeful because of HAEA's advocacy efforts. This statistic confirms something vitally important; we are moving forward together as one.

In every sense, the HAEA community is scaling new heights. Through all that lies ahead, our vision remains unchanged:

Unrestricted access to therapy so people affected by HAE are unburdened by symptoms and able to experience life to the fullest.

We wish all HAEA friends health and happiness.

Warmest regards,



Anthony J. Castaldo

CEO & Chairman of the Board



Henrik Balle Boysen

President & Board Member

The US HAEA

Everything we do is guided by our longstanding mission, vision, and values:

Mission

To lead a nationwide advocacy movement that focuses on increasing HAE awareness and education, empowering access to suitable treatment, and fostering ground-breaking research that includes searching for a cure.

Vision

Unrestricted access to therapy so people affected by HAE are unburdened by symptoms and able to experience life to the fullest.

Values

To fulfill our community's highest priority needs with innovative programs, services, and activities that are delivered with an extraordinary level of empathy, kindness, and compassion.

Our Roadmap to Success

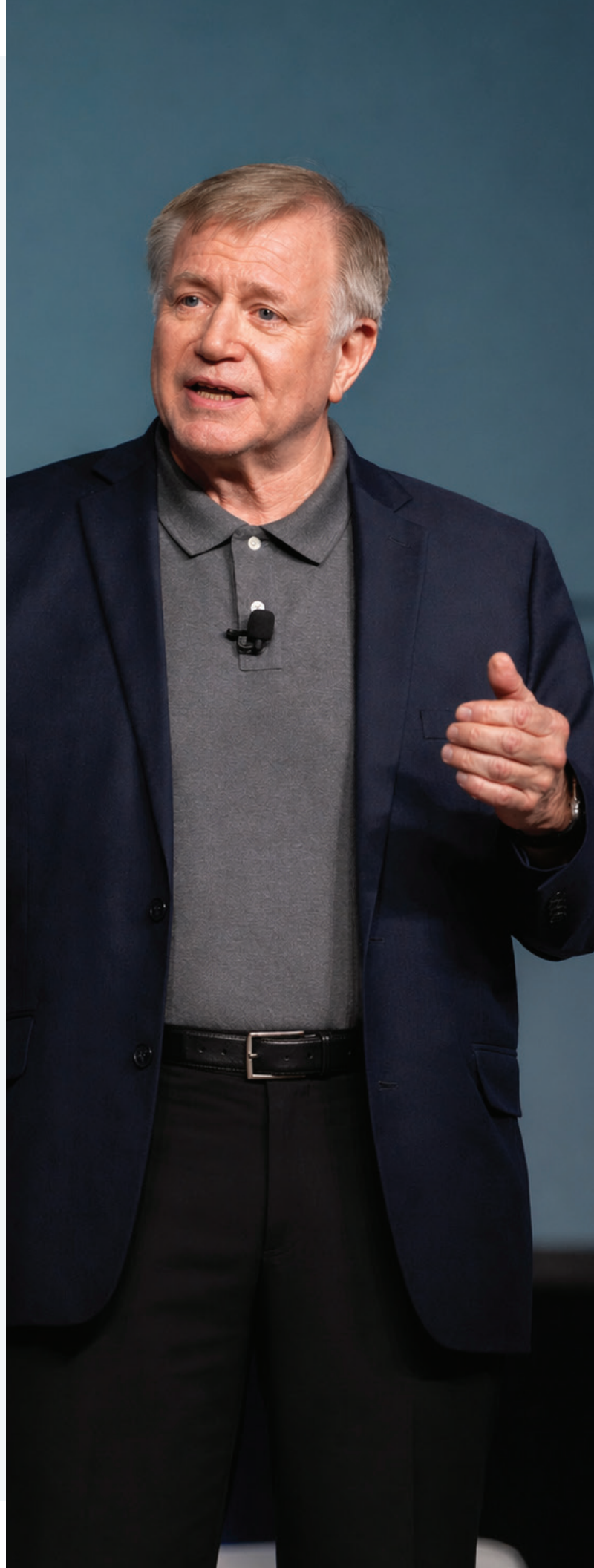
The US HAEA is a membership-based advocacy and research organization dedicated to serving people with HAE by offering programs, services, and activities across four key pillars. These are:

HHealth

Advocacy

Engagement

Advances in research



HAEA Impact at a Glance in 2025

To provide a snapshot of the HAEA's performance in 2025, we present three statistics that illustrate the impact on the three key objectives that are at the heart of our mission:

Increase HAE awareness and education

Our 2025 National Summit in Baltimore, MD was our largest ever, with over 1,400 members of the HAEA community attending

Empower access to suitable treatment

Successful in overturning nine out of ten cases of medication denials

Foster ground-breaking research

Published a landmark HAEA-initiated study that provided the first-ever estimate of the number of people in the US with an HAE diagnosis

Thanks to the efforts of everyone on team HAEA, we welcomed 531 new HAE friends into our community.

In 2025, 283 new members added their voices to the HAEA Grassroots Network, swelling the membership to **1,285.**



A Community United by Hope

We conducted an HAEA Community Survey with members who had used our tools, programs, or services. Survey results appear throughout this report.



Baltimore, MD 2025 National

500+ HAEA members helped to access medications.

AT THE END OF 2025, HAEA M





Summit drew **1,400+** attendees.

Almost **4 million** views on social media posts and content

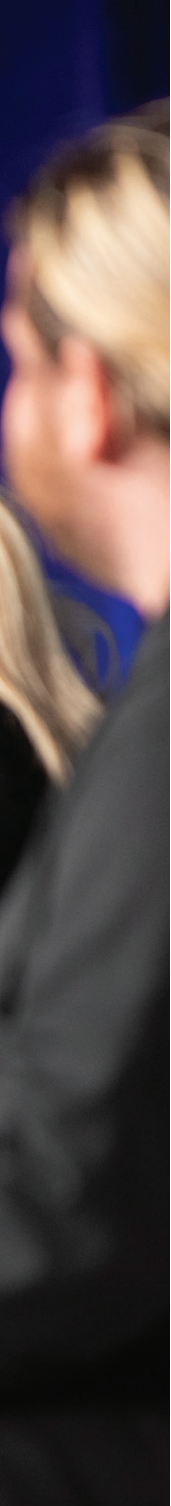
MEMBERSHIP REACHED 11,515



HAEA Health Team

Supporting the health and well-being of people affected by HAE





The kind and compassionate advocates who comprise our HAEA Health team are on the front lines helping our community overcome the obstacles that stand in the way of living a healthy and happy life with HAE. This group of experienced and dedicated advocates are problem-solvers who are always ready to meet the unique and seemingly constant challenges posed by this rare condition.

The Health Team is active at every stage of the HAE journey:

Supporting Diagnosis

The first and most important step for anyone with HAE is to secure a definitive diagnosis. The Health Team is ready to step in whenever people with HAE struggle to find an HAE-knowledgeable physician who can help with diagnosis. In 2025, the Health Team oversaw 2,596 physician referrals. This is 2.5 times more referrals than in 2024.

Nine out of ten respondents to our community survey (90%) said that their understanding of treatments and how to access care was improved thanks to HAEA’s activities

Additionally, the Health Team secured financial support through the HAEA Compassion Fund that enabled 24 people, who could not otherwise travel, to see an HAE specialist.

Helping to Secure Access to Prescribed HAE Medications

Sustained access to HAE therapies is critical to the well-being of people with HAE. In 2025, Health Team Advocates helped 509 members of our community deal with issues associated with access to their prescribed therapy. Much of this work involved helping HAEA friends with delays and denials, copay and insurance premium assistance, and shipping problems. The Health Team remains tuned into issues on the horizon and is always ready to act on matters that affect the lives of our HAE friends.

The Power of Community to Reverse Denials

Despite the increase, the US HAEA team successfully overturned 91% of denial cases, which is a testament to the power of our community and fierce advocacy.

2,596

In 2025, the Health Team oversaw 2,596 physician referrals.

216

On average, our Health Team managed 216 referrals for diagnosis every month in 2025.



“Many thanks for this amazing blessing of the travel grant. It’s a HUGE help for us.”

Eryn D.



66%

of cases managed by the HAEA Health team involved insurance denials, almost double from what was seen in 2024.

92%

HAEA gave almost everyone who took our community survey more hope.

77%

Three-quarters+ said that their hope was moderately or substantially increased.



The US HAEA Health Team has got your back, every step of the way. In nine out of ten cases of medication denial by an insurer, the initial decision was reversed after we got involved.

Supporting Efforts to Recruit for Clinical Trials.

The discovery and testing of new and innovative HAE therapies are vital to improving our community's health and well-being. That is why the HAEA devotes considerable effort to clinical trial recruitment. In 2025, our Health and Research teams pitched in with a colossal effort to reach potential trial participants by:

- **Making 7,658 outgoing calls**
- **Sending 11,168 emails**
- **From all these contacts, almost 100 HAEA friends went forward to a clinical trial.**

Supporting the Emotional and Mental Health of our Community

Recognizing that the mental health and well-being of our community is a vitally important part of maintaining quality of life, that is why the HAEA Health Team also provides our community with virtual support groups. These sessions are called CARE, because they offer: Community, Acceptance, Respect, and Empathy. HAEA organizes three group sessions per week to accommodate

time zones across the US. In 2025, 162 HAEA friends came together to discuss shared issues and find solutions. These sessions saw participation increase by 55% compared to 2024.

The HAEA's work positively impacted the quality of life for more than eight out of ten patients who responded to our community survey (88%).

In an additional gesture of positivity, the US HAEA sends birthday greetings to members who wish to receive communications. In 2025, 4,631 Happy Birthday emails were sent.

Educating the Community to Build Long-term Community Resilience

HAEA Academy

Since launching in 2024, the HAEA Academy has continued to grow, offering on-demand online courses focused on topics that are important to HAEA friends. In 2025, four new modules were added:

- **Travel and emergency preparedness**
- **Stress management / self-care strategies**
- **Back to school medication management**
- **Medicare basics**
- **Advocacy 101**

“

“Thank you so much for offering this time to meet with others. I like that I can talk to others ‘who get it’ when my family and friends don’t understand why I am always sick.”

C Farley

”





Advocacy

Paving the way for a better future for HAEA friends

The rights of people with HAE and their families is one of the HAEA's highest priorities. The HAEA's advocacy efforts focus on legislative and regulatory matters affecting our community, activities to maintain our access to modern therapies, and programming to educate our community.

Advocacy is an investment in the future. Every individual who makes a call, writes a letter, or meets their representative is making life better for tomorrow.

Grassroots Advocacy Network

The HAEA Grassroots Advocacy Network offers strength in numbers, amplifying our community's messages to great effect. At both Federal and State levels, it is vital to have grassroots advocates who persuasively communicate our community's needs to policymakers. In 2025, 283 new members added their voices to the Network, swelling the membership to 1,285.

HAEA grassroots advocates are present in all 50 States and Puerto Rico.

Capitol Hill Day 2025

Each year, the HAEA hosts a Capitol Hill Day during which grassroots advocates visit strategically chosen House and Senate offices. This event offers a tremendous opportunity to interact with legislative decision-makers and advocate for key public policy initiatives that will benefit the HAEA community.

The 2025 Capitol Hill Day was conducted virtually with 93 HAEA advocates from 33 states who visited and spoke to policymakers in over 60 Congressional offices.

93

HAEA advocates from 33 states met virtually with policymakers across 60+ Congressional offices during 2025 Capitol Hill Day.

In 2025, the HAEA

Grassroots Advocacy

Network sent **275**

letters to

legislators across

42 states.



HEREDITARY ANGIOEDEMA ADVOCATE



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Update on Legislative Progress

The HAEA Advocacy Team has been closely monitoring and commenting on a range of bills in recent years. It was positive to see that all four were reintroduced in the 119th Congress:

PROPOSED BILL	HOUSE STATUS	SENATE STATUS
Safe Step Act	47	32
HELP Copays Act	15	14
Accelerating Kids' Access to Care Act	Passed in the House in 2026	Passed in the Senate in 2026
Give the Kids A Chance Act	Passed unanimously in the House in 2025	Passed in the Senate in 2026

Other HAEA Advocacy Team highlights included:

The HAEA Advocacy Team was present at the following events:

- Chronic Disease Day
- Ohio Rare Disease Summit
- Northwest Rare Disease Payers Conference
- Rare Disease Diversity Coalition Capital Briefing
- National Minority Quality Forum Summit
- InformaConnect Rare Disease Summit
- Rare Across America
- National Organization of Rare Disorders Breakthrough Summit
- 2025 Rare Disease Legislative Advocates Conference





Engagement

Reaching our HAEA friends and beyond

The HAEA Engagement Team's goal is to educate, unify, and empower our community. In 2025, this meant taking on the biannual challenge of bringing together one of the largest gatherings of HAEA friends on Earth: the US HAEA National Summit.

Over 1,400 of our best HAEA friends came together near the historic Baltimore waterfront. Here are some Summit highlights:

US HAEA National Summit 2025 – Embracing a Brighter Future

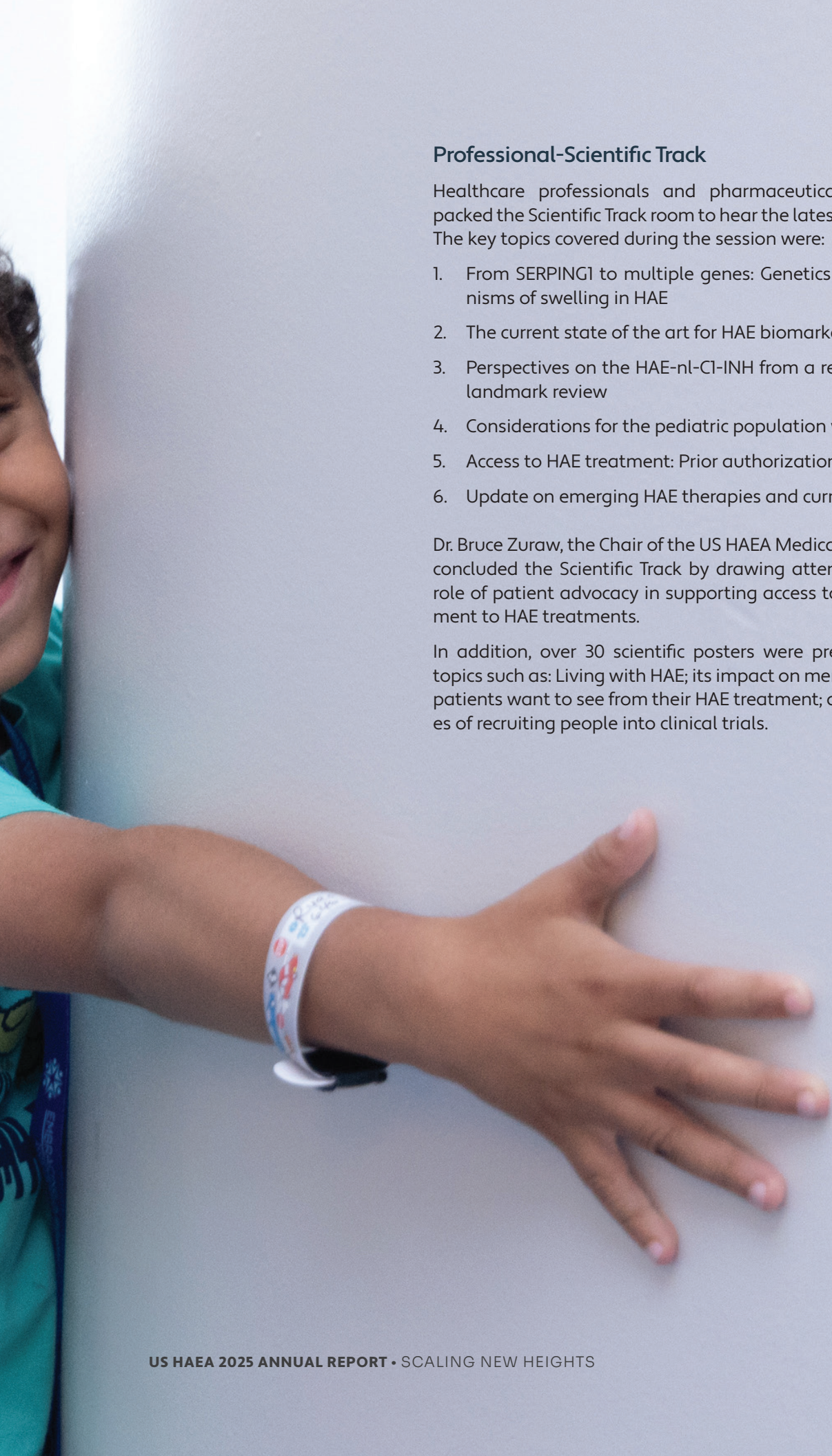
The 2025 HAEA National Summit, held in Baltimore, Maryland, was an incredible success! From July 10–13, more than 1,400 HAEA community members, including people with HAE, their caregivers, medical professionals, researchers, and industry sponsors, came together for an unforgettable weekend of education, empowerment, and connection.

This year's Summit theme, "Embracing a Brighter Future," came to life as HAEA friends:

- Met and connected with others in the community,
- Shared their stories and learned from one another,
- Heard about the latest advances in HAE therapies and the underlying science,
- Joined the movement to protect access to HAE medicines, and
- Had a lot of fun!

The Summit also featured youth programs designed to provide the youngest HAEA members opportunities to learn advocacy skills, foster friendships, and meet other young people with HAE, their siblings, and children of parents with HAE.





Professional-Scientific Track

Healthcare professionals and pharmaceutical industry staff packed the Scientific Track room to hear the latest in HAE research. The key topics covered during the session were:

1. From SERPING1 to multiple genes: Genetics and the mechanisms of swelling in HAE
2. The current state of the art for HAE biomarkers
3. Perspectives on the HAE-nl-CI-INH from a recently published landmark review
4. Considerations for the pediatric population with HAE
5. Access to HAE treatment: Prior authorizations and eligibility
6. Update on emerging HAE therapies and current clinical trials

Dr. Bruce Zuraw, the Chair of the US HAEA Medical Advisory Board, concluded the Scientific Track by drawing attention to the vital role of patient advocacy in supporting access to and reimbursement to HAE treatments.

In addition, over 30 scientific posters were presented covering topics such as: Living with HAE; its impact on mental health; what patients want to see from their HAE treatment; and the challenges of recruiting people into clinical trials.

98%

Almost everyone who took our community survey said they would recommend the HAEA to others in the HAE community.

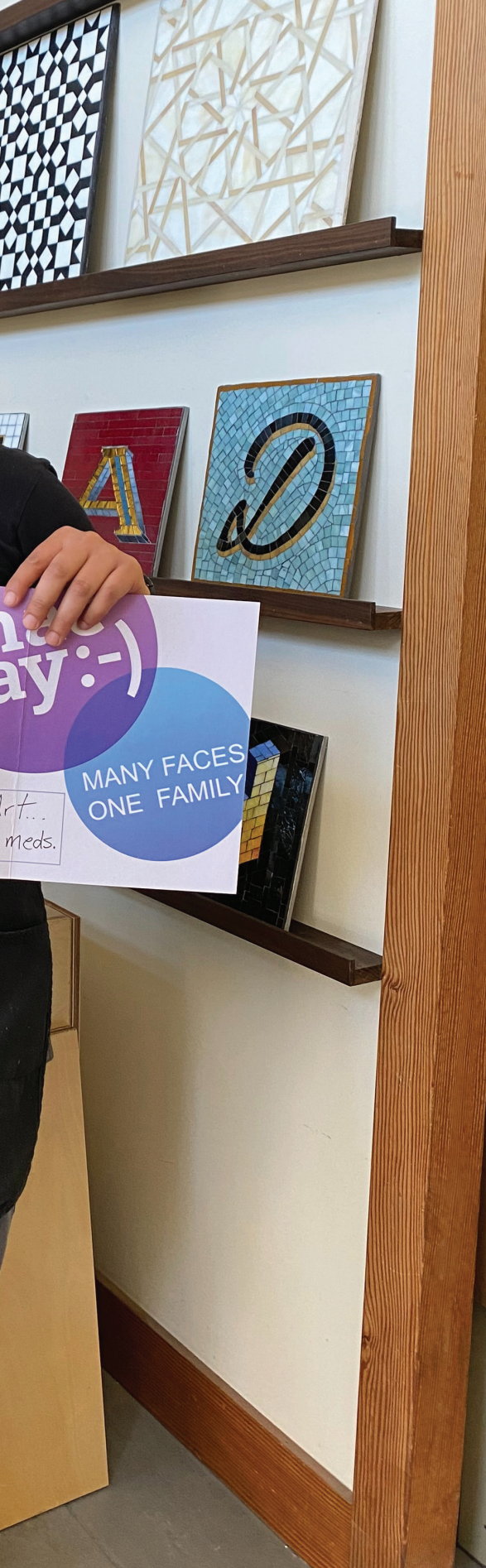
**118
million**

The US HAEA
community got
#Active4HAE
to the tune
of 117,975,983
steps in 2025.

17,587

followers across
social media
channels,
marking a 10%
year-on-year
increase.





hae day :-)

hae day :-), recognized every May 16th, is a powerful reminder of what we can achieve when we come together as a community. In 2025, we asked our members to: join the Global #Active4HAE campaign, log activities, and share photos using an awareness poster that was sent to 6,500 HAEA friends.

The community stepped up to the plate this year. US participants in the Global #Active4HAE campaign more than doubled to 1,972. In addition, the number of activities logged also increased to 802.

Social and Digital Media Performance

The HAEA remains highly active on social and digital media in 2025:

- In total, HAEA educational content (webinars, roundtables, and podcasts) had over 1 million views, doubling last year's total.
- Social media posts and content have been viewed 3,923,252 times
- Engagement with social media posts grew by 39%, producing content our community wants to see and hear.
- There were more than 35,000 direct mailings and 100,000 text messages sent to keep our community informed.

The HAEA remains active on the following key social channels:



We have now amassed 17,587 followers across all of these channels. A 10% increase year-on-year.

HAEA Round Table Series

The HAEA Round Table series, hosted on Facebook Live, provides people living with HAE and their caregivers with an opportunity to discuss the challenges of living with HAE.

In 2025, we conducted two round tables addressing (1) a genetic cause of HAE with Normal CI Inhibitor, and (2) HAE and travel. These episodes were viewed 92,976 times, an increase of approximately 30% compared to the previous year.



516,313

views were recorded for the HAEA Treatment Education Series webinars

8

The HAEA hosted 8 Community Connections Events in 2025.

HAE IN-MOTION®

HAE IN-MOTION® continues to be a popular program for raising awareness and fundraising for research on HAE. In 2025, a virtual-only event drew more than 650 participants who stepped it up for HAE. HAE IN-MOTION® logged 10,500 miles in 2025.

HAEA Community Blog

For 2025, the HAEA Community Blog covered seven topics and personal stories of relevance to people living with HAE and caregivers. These were:

- From Tennessee to DC: Raising HAE Awareness on Capitol Hill
- My Experience at the HAEi Leap Program
- 6 Tips to Prepare for Traveling With Hereditary Angioedema (HAE)
- Gen Z Advocacy in 2025
- Breaking the Cycle: Finding Relief From Hereditary Angioedema (Sponsored)
- A Future Written in Hope: Reflections from the HAEA National Summit (Sponsored)

There were 6,612 blog visits in 2025, and it remains one of the most popular pages on the HAEA website.

Educational Webinars

There were 13 webinars in 2025, with content covering new treatment options, legislative updates and caregiving. Unlike previous years, all content is now available entirely on-demand. This switch has dramatically increased viewership of this content, with 516,313 views in 2025, a 2,000% increase compared to 2024.



HAE Speaks Podcast

The HAE Speaks podcast gives everyone in our community the chance to share their views and insights about the latest stories in HAE. We produced ten episodes in 2025, covering topics such as:

- What's next for HAE
- Must-ask questions for HAE
- Understanding Medicare enrollment
- Mindfulness and meditation
- Understanding the full spectrum of an HAE attack
- Insights from two grassroots leaders

Every episode is available on Spotify and Apple podcasts

Community Connection Events

Our Community Connection events bring local HAEA members together to meet, share their stories, and learn about HAEA programs and resources. We hosted eight Community Connection events in 2025. Our HAEA family met in the following cities in 2025:

San Francisco • Orlando • Virginia • Chicago • Birmingham • Detroit • Connecticut • Puerto Rico

Native American Community Outreach

The HAEA team is active in offering friendship and support across the US. For example, HAEA team members have attended events in two Native American communities:

- The Cherokee Nation Rare Disease Summit took place in 2025. There are currently 12 HAE patients in the community. HAEA was present to provide support and advocacy.
- The Red Lake Nation Annual Health Fair took place in July 2025, and the HAEA was on hand to raise awareness amongst the 650 attendees.

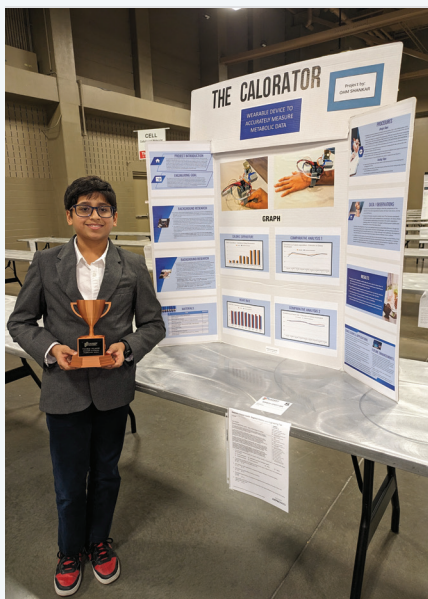
6,612

blog visits in
2025, making
the HAEA
Community
Blog one of the
website's most
popular pages.



“As a proud member of HAEA and a newly appointed member of the Youth Leader Council, I am honored to be part of such a dedicated and inspiring organization. Our collective efforts contribute to meaningful advancements and a stronger community. For my entire family it is a privilege to work alongside so many passionate individuals who share a common vision. I deeply value the opportunities for growth and collaboration that HAEA provides. Being a part of this esteemed group fills me with immense pride and a sense of purpose.”

– Ohm S.



Youth Program

Young members of the HAEA family are the future of our community. That is why the HAEA Engagement Team offers a wide range of programs and services committed to organizing, educating, and empowering young people of all ages.

Youth Leadership Council

The HAEA Youth Leadership Council (YLC) is a group of young advocates who provide valuable insight, perspectives, and support to ensure that the HAEA’s programs effectively address their unique needs and challenges. The YLC offers an opportunity for youth to actively participate in decision-making processes and contribute to the mission of the HAEA. In 2025, the total number of YLC members grew to 24.

Youth Advocacy Achievement League

The Youth Advocacy Achievement League (YAAL) recognizes young people who have achieved success advocating for and raising awareness about HAE.

Following the 2025 HAEA National Summit, 34 young advocates received a special YAAL award and a personalized notecard. We highlighted each person’s accomplishments along with a photo on our HAEA Youth social media channels during Youth Advocacy Month (October).

Ohm makes a fast start to his advocacy journey

Ohm first connected with the HAEA just over 12 months ago. Since then he has brought passion, maturity, and professionalism to every interaction, which has inspired lasting change in the HAEA community. At 14 years old, Ohm is an enthusiastic member of HAEA Youth who has written a blog article sharing his family’s diagnostic journey, hosted an episode of the #Beyond-HAE podcast, has been nominated to be a recipient of the 2025 YAAL award, and accepted a position as one of the newest members of the HAEA YLC.



1,200+

In 2025, we
sent over 1,200
Activity Books.

Social Media Internship

The HAEA Youth Internship program provides young people between the ages of 17-25 with an opportunity to learn professional skills while connecting with their peers. This highly successful program continues to turbocharge our online presence by driving higher engagement rates and positive community feedback. Every one of the five interns who participated in 2025 learned about communications, social media, advocacy, and working in a professional setting.

Brady Club

The Brady Club is a program designed solely for children with HAE and their siblings aged 4-12. All Brady Club members receive quarterly activity books that address living with HAE through games, jokes, and stories from other members. In 2025, we sent over 1,200 Activity Books. In addition, Brady the Bear sent club members over 300 personalized birthday cards.

HAEA Cares Kits Program

The HAEA Cares Program helps young people with HAE understand their condition and overcome the obstacles presented by HAE. The program remains a vital source of support for many new participants, such as those recently diagnosed. The contents of the kits were revised and updated in 2025, to ensure they remain relevant to the needs of this audience. We distributed 75 kits in 2025.



12

episodes of
#BeyondHAE

27K+

“listens”, a five-fold
increase over the
previous year

Youth Podcast - #BeyondHAE

#BeyondHAE is a podcast designed for and created by HAEA youth. The podcast is dedicated to amplifying the voices of young people affected by HAE and raising awareness about the disease. #BeyondHAE continues to grow in scope and popularity. In 2025, the number of episodes expanded to 12 with 27,089 “listens”, a five-fold increase over the previous year.

HAEA Scholarship Programs

Our scholarship for those seeking academic advancement is named after our beloved former Chief Operating Officer, Pam King. The program provides financial support for people with HAE seeking higher education. We awarded 100 scholarships in 2025. In addition, in 2025 we awarded four HAEA scholarships for Aspiring Healthcare Professionals.

Families4HAE

The Families4HAE campaign continues to support the HAEA’s programs and services for children and young adults. Thanks to the generosity of so many within the HAEA community, the 2025 campaign raised well-over \$50,000. Every dollar goes directly to funding the HAEA’s life changing youth programs that continue to provide education and critical support to young people coping with HAE.

Youth-Led Initiatives from HAE International’s Learn, Experience, Advocate, Pave the Way (LEAP) Program

A Guide to Navigating Insurance & Healthcare as a Young Adult: Developed by Isabel B., the guide addresses issues faced when transitioning off a parent’s insurance plan including common questions and coverage options.

A Guide to Making the Transition to College: Developed by Ally B., the guide offers practical steps, like building a personalized treatment plan, managing prescriptions, connecting with campus resources, and educating others about HAE.



I love someone

with a



We now estimate that nearly **10,000** people in the U.S. have received a diagnosis of HAE.

Advances in Research

Our research activities focus on generating rigorous, evidenced-based data that supports improving the HAEA community's quality of life, best practices in HAE care, and medical journal publications.

Over the years, our HAEA-initiated research has demonstrated the efficacy of modern HAE therapies and the importance of uninterrupted access to treatment.

2025 Research Projects

Establishing a Hereditary Angioedema Prevalence for the United States Using a Large Administrative Claims Database

In September of 2025, a top rated peer-reviewed medical journal published our landmark study that determined, for the first time, how many people in the U.S. are living with HAE—across all known types. The often-quoted figure of 1 in 50,000 comes from older European studies and only reflects HAE caused by C1 inhibitor deficiency.

We now estimate that nearly 10,000 people in the U.S. have received a diagnosis of HAE. As noted earlier, this number includes all forms of the condition—not just those caused by C1-INH deficiency—and provides the clearest picture yet of the HAE population in the U.S.

Getting this study published in a respected medical journal is a major milestone for the HAEA community. It gives us real numbers to back up what we've long known. The new, much larger HAE population statistic puts us in a much stronger position to protect what matters most to people with HAE and their families.



Expert Consensus on HAE With Normal C1 Inhibitor

Researchers State that Treatment is Warranted When an Expert Physician Diagnoses the Condition

In a joint initiative with HAEi, the HAEA Research Team convened a distinguished international group of HAE experts to deliberate and reach a consensus on the latest science regarding genetic mutations, physiological markers, diagnosis, and treatment for HAE with normal C1 inhibitor. The research teams at HAEA and HAEi worked with the authors to finalize this landmark study, which was recently published in the prestigious medical journal – Clinical Reviews in Allergy & Immunology.

The HAEA and HAEi are pleased that this important expert-consensus medical journal publication includes a vital point that members of our community with Normal C1 Inhibitor should cite if they run into insurance coverage hurdles when getting a prescription filled for an HAE treatment:

In essence, this statement by the world’s leading angioedema researchers concludes that anyone who receives the HAE with Normal C1 Inhibitor diagnosis by an expert physician should be given access to their prescribed HAE treatment.

The US HAE-C1INH-QoL Short Form and Establishing the Minimal Clinically Important Difference (MCID)

Following publication of the US HAE-C1INH-QoL (quality of life) instrument, we launched a follow-on project to develop a condensed short form and to establish a numeric threshold that represents meaningful change when the tool is administered over time. We completed additional statistical analyses over the past year and prepared a manuscript for submission to a peer-reviewed medical journal. We anticipate publication by mid-2026.



“Many if not most patients with possible HAE-nC1INH do not have a demonstrated pathologic mutation. Even without an identified mutation, a presumptive diagnosis of HAE-nC1INH made by an expert physician is sufficient. Since these patients are at risk of serious morbidity and mortality, treatment needs to be available even for a presumptive diagnosis of HAE-nC1INH.”

- HAEA Initiated Expert Consensus





Registry at 2025 US HAEA National Summit

The ADVANCE HAE Scientific Registry is a nationwide research project driven by the HAEA community. The registry collects biological samples that are matched to participants who submit quarterly reports regarding their HAE attacks, symptoms, and therapies. The ADVANCE HAE Scientific Registry is an important tool helping researchers resolve the remaining mysteries of HAE and accelerate the advancement of future therapies.

At the 2025 National Summit, we delivered the organization's most advanced registry operation to date, collecting 198 biological samples and launching first-time DNA collection that significantly expands the Scientific Registry's research impact. HAEA Medical Advisory Board member, Dr Henry Li and his team processed the biological samples that resulted in nearly 600 DNA extractions.

Ongoing Projects

The nature of scientific publication requires a multi-year outlook. There are several highly significant ongoing research projects outlined below:

HAEA's Impact on Young People, Illustrated Through Personalized Body Mapping Artwork

This HAEA-initiated research project, conducted in collaboration with researchers at Henry Ford Health System in Michigan, features artwork created by 19 adolescents living with HAE. Each participant produced a deeply personalized body map illustrating how the condition affects their daily life. The study also includes findings from a focus group of 20 caregivers. Fieldwork was completed in 2025, and the research team is preparing a manuscript for submission to a medical journal in 2026.

198 samples collected, generating
nearly **600 DNA extractions** –the most
advanced registry effort to date.



Year-Long Longitudinal Study of HAE Will Help Us Plot the Future of HAE Care

Years of consistent advocacy by the HAEA Community has brought new therapies and improvements in our quality of life. We initiated this study, in collaboration with a trusted partner, Adelphi Real World, to help the next chapter in HAE treatments and standards of care. The project has two main goals:

- Provide data that supports reimbursement submissions for HAE treatments, and
- Contribute timely real-world evidence to support future HAEA-authored scientific publications and presentations aimed at demonstrating how HAE treatments dramatically improve quality of life.

Study of HAE's Impact on Caregivers

There is little if any real-world evidence regarding the perspectives and burdens associated with caregiving for someone affected by HAE. We worked with health economists and HAE expert physicians to gather data through a comprehensive caregiver survey. We are in the process of preparing a manuscript that will be submitted for publication in the second quarter of 2026.



886

HAEA friends

participated in 22 community research projects that offered invaluable information to support development of the next generation of HAE therapies.

”

“This endowed chair will fuel research and better treatments for angioedema, as well as train future immunologists and allergists who will treat generations of patients to come.”

Professor Marc Riedl, HAE Community Endowed Chair in Angioedema Clinical Excellence

“

Hereditary Angioedema (HAE) Community Endowed Chair in Angioedema Clinical Excellence

In March 2025, the University of California, San Diego established the HAE Community Endowed Chair in Angioedema Clinical Excellence. The endowed chair was made possible through the collaborative efforts of the US HAEA and pharmaceutical companies BioCryst and Pharming Group. The inaugural holder is Marc A. Riedl, MD, MS, who also serves as the clinical director of the US HAE Angioedema Center and is a member of the HAEA Medical Advisory Board. The endowment provides Dr. Riedl with the ability to champion research, education, and training focused on improving care for people with HAE.

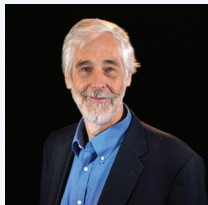
Community Research

One of the reasons why the HAEA community has 11 approved HAE treatments – something that is unprecedented in the rare disease landscape – is our ability to continuously attract investment in new therapies. Our Community Research program leverages the willingness of HAEA friends to anonymously share their opinions on the remaining unmet needs and challenges HAE poses for everyday life. In 2025, 886 HAEA friends participated in 22 community research projects that offered invaluable information to support development of the next generation of HAE therapies.



US HAEA Medical Advisory Board

The US HAEA Medical Advisory Board (MAB) includes many of the foremost experts in diagnosing and managing HAE. These world-class professionals collaborate with us on research projects and treatment guidelines while ensuring the information we disseminate is accurate and reflects the latest and best science.



Bruce Zuraw, MD
MAB Chairman
Professor of Medicine
Director and US HAEA Endowed Chair
US HAEA Angioedema Center at UCSD
San Diego, CA



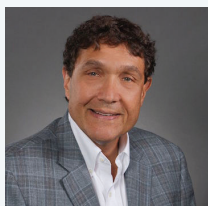
Timothy Craig, DO
Professor of Medicine and
Pediatrics
Penn State University
Hershey, PA



Aleena Banerji, MD
Assistant Professor
Harvard Medical School
Boston, MA



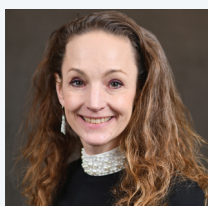
Mark Davis-Lorton, MD
Director
Clinical Immunology
Winthrop-University Hospital
Mineola, NY



Jonathan Bernstein, MD
Professor
Clinical Medicine
University of Cincinnati
College of Medicine
Cincinnati, OH



Henry Li, MD, PhD
President
Institute for Asthma and Allergy
Chevy Chase, MD



Paula Busse, MD
Associate Professor
Clinical Immunology
Mount Sinai Hospital
New York, NY



William Lumry, MD
Clinical Professor
Internal Medicine
University of Texas
Southwestern Medical School
Dallas, TX



Sandra Christiansen, MD
Professor of Medicine
Director of Translational Research
US HAEA Angioedema
Center at UCSD
San Diego, CA



Marc Riedl, MD
Professor of Medicine
Clinical Director and HAE
Community Endowed Chair in
Angioedema Clinical Excellence
US HAEA Angioedema Center
at UCSD, San Diego, CA

US HAEA Corporate Sponsors

We thank the following corporate sponsors for their generous support of the HAEA Community in 2025:

HAEA CHAMPION



HAEA LEADER



HAEA CONTRIBUTOR



HAEA SUPPORTER



HAEA FRIEND



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 to improve the lives of people with HAE. 100 percent of every dollar donated by an individual and/or non-corporate source is allocated (with no deductions for administrative or any other expenses) to our five programs that directly support people with HAE:

HAEA Scholarship Fund

The Pam King Scholarship and the Scholarship for Aspiring Healthcare Professionals provide financial support for people with HAE who are entering or attending higher education and seeking to improve their lives through academic achievement.

HAEA Compassion Fund

The Chris Whalen Compassion Fund offers financial assistance for those in need who must travel to see an HAE medical specialist.

HAEA Research Fund

Supports a variety of HAEA-led research initiatives, including the HAEA Scientific Registry.

HAEA Youth Programming Fund

Supports HAEA youth programs to transform the lives of young people living with HAE.

HAEA Endowment Fund

Financial support that ensures the HAEA can continue to provide our community with personalized and impactful services now and in the future.



100%

of individual and noncorporate donations go directly to our five HAE support programs.

Rigorous Internal Controls

The HAEA's Audit Committee, independent external auditor, and Chief Financial Officer, oversee the HAEA's financial operations and maintain rigorous and disciplined internal controls, including ongoing, detailed reviews to ensure strict compliance with policies, procedures, and non-profit accounting standards.

Ongoing Improvement to Better Serve Our Community

The US HAEA Operations Team continuously identifies ways to streamline processes, reduce costs, and maximize impact, ensuring that our resources go further for the communities we serve.

EXPENDITURES

General and Administrative:

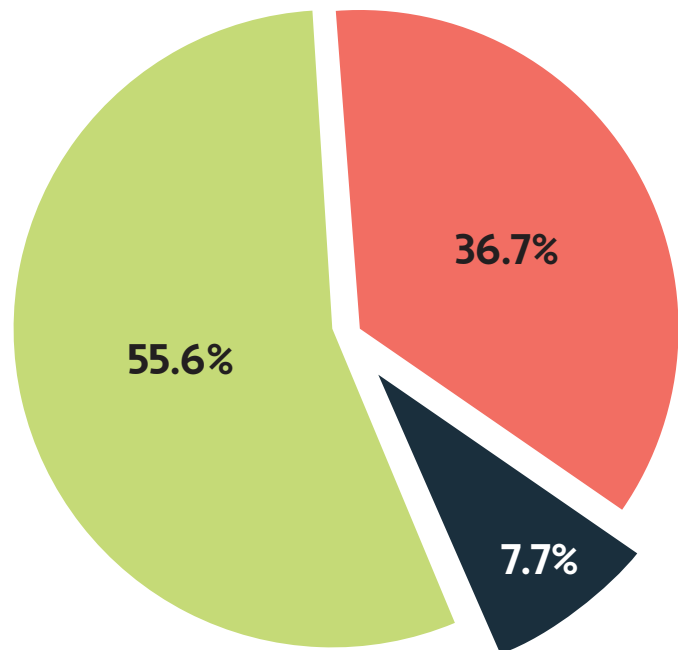
7.7%

Health and Research:

55.6%

Advocacy, Engagement, and Education:

36.7%



The US HAEA Team

The HAEA Team shares an unwavering commitment to improving the lives of people affected by HAE. Here we recognize all the people who played a part in the work of HAEA in 2025:

US HAEA Board of Directors

Anthony J. Castaldo
(Chairman of the Board)

Karen Baird

Henrik Balle Boysen

Lois Perry

Eric Phillips, MD

Larry Salus

US HAEA Executive Team

Anthony J. Castaldo
CEO & Chairman of the Board

Henrik Balle Boysen
President & Board Member

Leigh Farrar
Senior Executive VP & CFO

Christine Selva
Executive VP of Health & Research

Ianice Viel, MA
Executive VP of Advocacy, Communications & Engagement

Larry Salus
Compliance Officer

Managers

Lisa Facciolla
Youth Programs Manager

Nicole Jewell
Operations & Administrative Manager

Jessica Myers, MA
Communications & Advocacy Manager

Troyce Venturella, MPH, RN, CCM, BCPA
Health Services Manager

Administrative Team

Jen Curran

Executive Administrative Specialist

Suse Glass

Administrative Specialist

Engagement & Communications

Hannah Carroll

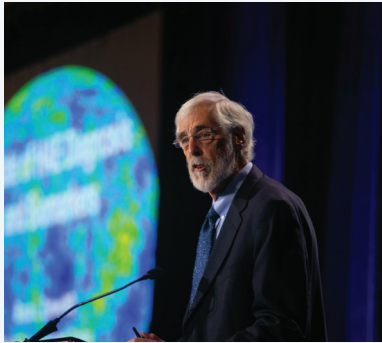
Senior Communications & Research Specialist

Sandy González, MA

Senior Graphic Designer

Carlie Dalgo, MA

Communications & Engagement Associate



Health Team

Amanda Granat, MJ, RN, PACS, CCM
HAE Health Advocate / Nurse Case Manager

Adina Mauk
HAE Health Advocate

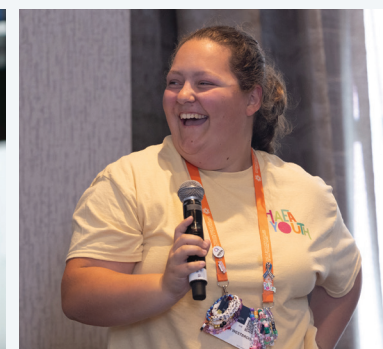
LucyAnn Ramos, MA
Health & Research Specialist

Sherry Swanson
Research & Advocacy Specialist

Sally Urbaniak
Research & Advocacy Specialist

Research Team

Karissa Ewing
Research & Advocacy Specialist



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