In 2009, the US Hereditary Angioedema Association (HAEA) celebrated 10 years of serving the HAE community. The Association was founded and is staffed by HAE patients and HAE patient caregivers. This sets us apart from most rare disease organizations and allows us to serve you from a deep personal understanding of everything you experience as an HAE patient.

The US HAEA’s growth has been exponential, but our core principles remain the same – caring, compassion and kindness. As we look ahead to the future, the US HAEA is proud to make its mark as a cutting edge patient services and research organization.

We are always working to improve the health and lives of HAE patients. We have been there for you through the last decade and will continue to be there for you for many decades to come.

MISSION STATEMENT
Helping HAE patients and their families to achieve lifelong health.

VISION STATEMENT
All HAE patients will have access to an individualized treatment plan that empowers them to lead a full and healthy life.
It seemed like just yesterday when HAE friends had to rely on clinical trials or foreign importation for access to a non-steroidal HAE treatment. Remarkably, a committed and united HAE community persevered in a decade-long quest for better treatments, and we now have access to three new FDA-approved therapies. More good news is on the horizon as two more promising HAE medicines wind their way toward FDA approval. Always keep in mind that the HAEA is run by fellow patients who have a deep understanding of how HAE can affect lives. Our patient services group stands ready to provide every HAE friend with knowledgeable and highly compassionate assistance.

As you will see in the pages that follow, 2010 was a busy year for the HAEA! Here are some highlights of what is included in this yearbook:

• The HAEA website continues to evolve and serve as your only unbiased source for HAE-related information.
• Our Scientific Registry is growing and will serve as the central platform for research directed at finding a cure for HAE.
• Six regional patient meetings provided great opportunities for HAE friends to meet and learn from world class physicians.
• HAEA staff actively participated in national physician conferences to ensure HAE receives maximum visibility within the medical community.

• Capitol Hill Day was a major success as HAE friends visited with their congressional delegations to advocate Federal support for HAE research.
• Video educational initiatives for physicians and patients designed to improve HAE diagnosis and ensure patients receive treatment tailored to individual needs.
• Information on how to go about discussing HAE with your physician, and
• Linda’s story—that describes one brave woman’s quest to obtain a diagnosis and treatment.

As we close the books on 2010, we are committed to achieving even more in 2011! Mark your calendar for the 2011 HAEA National Patient Conference that will take place in Las Vegas in September.

Remember to visit www.haea.org for the latest information on all things HAE!

Warm regards to all,
Anthony J. Castaldo
President, HAEA
Expectations have been greatly exceeded! More than 720 patients and family members joined the US HAEA Scientific Registry by the end of 2010. There is still room for you and your family! Every patient who participates in the Scientific Registry brings us closer to better HAE treatments and, ultimately, a cure!

Join today!

The US HAEA Scientific Registry was launched in August 2009. Nearly 100 HAE patients signed up for the registry in the first 48 hours after it was launched.

The goals of the Registry are to:
• Create a resource to promote Hereditary Angioedema research
• Study HAE genetics
• Increase understanding of the disease

Who can participate?
• individuals who have HAE
• individuals (with or without HAE) who are a blood relative of an HAE patient
In 2010, the US HAEA provided an opportunity that Association members could personally support – the new HAE Image Repository.

When you donate your photographic or medical images (x-rays, etc.) to the HAE Image Repository, you are helping the US HAEA fulfill our mission to educate both medical professionals and the general public about HAE.

Very few actual images exist of the symptoms of HAE that physicians may encounter in their office or emergency room. The Repository is an on-line database of photos of patients in various stages of an HAE attack that can be purchased.

They say a picture is worth a thousand words and we are sure the Image Repository will help to increase HAE education and awareness not only in the US, but around the world.

We hope to see more photos added to the Repository in 2011 - please see www.haea.org for more information. Your contribution will build a better future for all HAE patients.
2009’s hugely successful National Patient Conference in Orlando, FL was followed in 2010 by a series of smaller regional meetings, allowing HAEA members and their families to meet others in their geographical area.

Meetings were held in Bethesda, MD, Cincinnati, OH, Portland, OR, Dallas, TX, New York City Area and Anaheim, CA.

HAE physician experts included Dr. Bruce Zuraw, Dr. William Lumry, Dr. Marc Riedl, Dr. Paula Busse, Dr. Henry Li, Dr. Jonathan Bernstein, Dr. James Baker and Dr. Mark Davis-Lorton. These physicians presented keynote addresses as well as answered patients’ questions specific to their own HAE health.

Information was provided on how to navigate the complex insurance and reimbursement issues regarding access to new FDA-approved therapies. Pharmaceutical sponsors supplied information on their own products at sponsor display tables.

Breakfast, lunch and snack breaks offered lots of time to meet new HAE friends and family members. US HAEA President, Anthony Castaldo opened and closed each meeting urging all HAE patients to pursue access to an HAE therapy, to treat each attack early and have an emergency plan in place.
The US HAEA is an innovative patient services and research organization. Our Patient Services team continues to offer a wealth of HAE informational resources, individualized patient support and advocacy work. HAE research will move us forward toward new treatment options and, eventually, a cure.

We look forward to the 2011 US HAEA National Conference – we hope to see YOU there!

Tony told the crowds at each meeting how much the HAE Association has achieved over the past decade as a patient services and research organization, expressing gratitude to our members and their families for being invaluable in making the Association the formidable force it is today in the world of HAE. He closed each meeting emphasizing, “It is through our day to day interactions with all of you, our HAE friends, that the HAEA demonstrates its culture of caring and kindness.”
The new HAEA web site features updated content, easier navigation and new features – including stories provided by HAE patients, a discussion group just for our teen and college age HAEA members, and even a chance to build your own medical family tree.

Old favorites remain – Scientific Registry sign up, Wallet ID cards, a list of your Patient Services Representatives and the US HAEA Newsletter. www.haea.org remains your authoritative source for detailed, unbiased HAE information. Visit often and check out all the ways you can Get Involved!

Read the web site’s first patient story on the next page…
LINDA'S STORY

For most teens in modern societies, adolescence is a critical period of social and psychological development. It is a time that marks the beginning of movement away from the parents, and toward the formation of life-long bonds with others. It is also a period of intense need to be accepted by friends, and to that end (especially for the girls), to look like, sound like, think like, and be exactly like the rest of the group.

Throughout my adolescence, I never had the freedom to do that. I was too preoccupied with keeping my occasional, grotesque deformities, which had started when I was 13, hidden. When I had a swelling episode in my hand, it would get so big, it looked like an inflated surgical glove! Then the swelling would travel all the way up to my shoulder. A foot swelling would become so painful, I couldn’t walk, or even wear a shoe. I had excruciating stomach episodes and frightening throat swellings as well. The smallest pressure or slightest muscle-pull could set me off. I lived in a world of complete uncertainty. When all the girls would sit on the floor and gab, as teenagers tended to do, I would sit in a chair or on a bed because I knew sitting on the floor might trigger a swelling. (It was like “The Princess and the Pea!”) To others, I must have seemed odd. Over time I came to be known as undependable because I often didn’t show up for get-togethers, even though I said I would. Eventually, the invitations stopped coming.

I remained undiagnosed/misdiagnosed (“allergies”) until the mid-seventies when my internist read an article in a medical journal about people with weird swelling symptoms…something called Hereditary Angioedema. He contacted Dr. Michael Frank, one of the authors, and shortly thereafter, a blood test showed I did indeed have HAE. Finally, my “weirdness” had a name! By then I was married with four children, three of whom share this condition.

But my nightmare continued, as there was no treatment for my swelling episodes. Moreover, frequent trips to the emergency room—especially when out of town—had become fraught with tension between the doctors and me. I had to tiptoe around egos. When I tried to explain anything about what to expect during my swelling attack, their attitude was: Who is she to tell us, how to approach treatment? The answer? Probably the only one among them who actually knew.

Unfortunately, for years there continued to be no treatment options for HAE patients—only pain control and hydration for abdominal swellings, and observation/intubation for throat swellings. Finally, that changed when David decided to take on Goliath. Because of the unrelenting, unyielding efforts of one Anthony Castaldo, later joined by a selfless, tireless, dedicated group of determined HAEA go-getters, not only do I now have a choice of outstanding, effective treatments, but my children, and my children’s children don’t have to deal with emergency room egos, pain, shame, or the fear of seeming “odd.”

Life is good.
Representing US HAEA Members at National Physician Conferences

Your US HAEA staff actively participated in three national physician conferences in 2010 to ensure that HAE receives maximum visibility within the medical community. Pictured to your left is the display table where HAEA staff provided information on HAE, on the Association and on the new FDA-approved HAE therapies. Attention to HAE within the medical community has greatly increased over just the past few years and the HAEA will continue to capitalize on this new interest, raising awareness and serving as a point of contact for HAE treating physicians.
The past year has been exceptionally exciting for the HAE community. There are now a number of new HAE therapies and exciting plans for additional drugs on the horizon. In 2010, the US HAEA celebrated an unprecedented level of interest and awareness in HAE for among healthcare providers.

The renewed level of activity in the field of HAE presented an opportunity to fulfill an important objective of the US HAEA - to create an HAEA Educational Initiative.

The US HAEA wanted to create an educational program that not only encompassed the most current scientific data and clinical understanding in the areas of recognition, diagnosis and therapeutic management of HAE for educating physicians, but also a program that could also be used as a resource for HAE patients.

The Educational Initiative was divided, then, into two distinct sections. The healthcare providers section is offered as a CME program (it can be used for educational credits) for physicians, nurses, pharmacists, and many others. The patient section is intended to empower HAE patients to advocate for themselves for the HAE treatment of their choice, which includes educating themselves on their own disease and on the new therapeutic options available.

See the next page for more on this online resource…
The panel for the Patient Empowerment program is comprised of thought leaders from the HAE medical community and HAE patients. This program offers patients, their families and medical professionals involved in their care, important insights into HAE from the patient perspective. It also offers a more effective and empowered approach for patients and patient caregivers to become more active in the management of their HAE medical care.

Our educational program was created and produced by the US HAEA, based on direct, first-hand experience of our patient population. As time goes by, we will continue to review and add the most recent and relevant information on HAE to the Educational Initiative. This program is carefully constructed to be an authoritative, unbiased source of HAE information in a still changing HAE landscape. With this program, the US HAEA reinforces its commitment to HAE research and education with a focus on patient services.

The US HAEA Educational Initiative will have on-going value for healthcare practitioners and patients alike. We hope you will go to www.haeedu.com to take advantage of this ground-breaking program.
DISCUSSING HAE WITH YOUR PHYSICIAN – DO’S AND DON’TS
PROVIDED BY DR. MARC RIEDL, MD, MS - DAVID GEFFEN SCHOOL OF MEDICINE, UCLA

**DO**
- have your medical records readily accessible
- be clear about your goals/expectations for treatment
  - take a list of your questions to make sure they are all discussed to your satisfaction – and take notes of the answers in case you wish to look them over again later
  - tactfully and politely, but confidently, assert your feelings about which therapy is best for you
  - understand that your doctor may need some time to gather information or pursue the treatment you request
  - be sure to do your part of the “legwork” to arrange your treatment plan
  - talk to your local treatment location (doctor’s office, ER) about your condition and treatment needs ahead of time

**DON’T**
- expect the health care system to automatically be prepared for your treatment needs – not every treatment center will have your treatment waiting for you on the shelf
  - expect your doctor to “fix” all of your past difficulties – leave the past behind and move forward with the advances now available
  - bring a large stack of printouts from Internet searches – bring just a couple pages, if you need, to present information relevant to you
  - underestimate the complexity of treating HAE (acquiring medication, arranging treatment details, monitoring side effects, etc.)
  - be alarmed if your physician wishes to get input from other specialists – more information is always of benefit to you

**You** are your own best advocate, but your physician is an essential partner in managing your HAE – find a good match
**You** know your situation/needs better than anyone – your physician values clear, concise information and communication
**Your** treatment plan requires teamwork – planning and effort by both you and your physician
The US HAEA, in collaboration with the Health and Medicine Counsel of Washington, visited Capitol Hill Day on Dec. 14, 2010 in Washington, DC to meet together with key members of Congress, especially those who sit on the various House and Senate appropriations committees and subcommittees.

Capitol Hill Day was a major success as HAEA friends spoke with Congressional leaders to advocate for Federal support for HAE research at the National Institutes of Health (NIH).

NIH remains the gold standard for biomedical research, developing standards and programs that serve as a model worldwide. The Cures Acceleration Network, the Therapeutics for Rare and Neglected Diseases program, and the Rare Disease Clinical Research Network are all examples of opportunities to reengage in HAE research.

Follow-up visits with key members of the new Congress are planned in 2011. Watch for more advocacy news in coming US HAEA quarterly newsletters.
In response to many patient requests, a new private email support group for teen and college age HAE patients (ages 13-22) was launched in 2010. This online community provides an open forum for information sharing, emotional support, and frank discussions on issues facing the younger members of our HAE patient community. The US HAE Association values the privacy of our Teen/College Listserv members - we take great efforts to ensure that any personally identifiable information will never be disclosed to an outside party.

If you are interested in joining this online discussion group, please go to [www.haea.org](http://www.haea.org) and click on the Get Involved tab!
There have been a number of ID cards that have been made available by a variety of sources, but the US HAEA was the first to provide this valuable resource for HAEA friends.

The US HAEA wallet-sized, tri-fold ID card contains a brief description of HAE and the risk associated with laryngeal swelling. There is a box provided for your physician to include additional information as he/she sees fit.

These ID cards are a vital piece of your emergency treatment plan. Carry your card with you and be sure to get one for each of your HAE-affected family members, too.

More than 3175 US HAEA wallet cards have already been mailed to HAEA friends. To order yours, please go to www.haea.org and click on Resources or contact your Patient Services Representative.

Important Patient Information on HAE

For urgent assistance, please contact Donna Davis (800) 216-1029, donna-davis@haea.org or Michelle Williamson (330) 814-2929, michellewilliamson@haea.org

Hereditary Angioedema (HAE):
• is a life-threatening genetic disorder caused by a deficiency and/or functional inactivity of C1 Inhibitor
• requires airway support in cases of facial/laryngeal swelling episodes which may lead to complete airway obstruction, asphyxiation and death
• may also involve the gastrointestinal tract causing dehydration and severe pain; abdominal symptoms can be misdiagnosed, leading to unnecessary surgical procedures
• Note: Antihistamines, corticosteroids & epinephrine have shown to have only a transient effect on acute HAE attacks

For more information please visit our website http://www.haea.org

Important information on Hereditary Angioedema (HAE)
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<thead>
<tr>
<th>Name</th>
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<th>Region</th>
<th>States</th>
<th>Email</th>
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ANNOUNCING THE US HAEA NATIONAL PATIENT CONFERENCE FOR 2011

We hope you will join us!

The South Point Hotel, Casino & Spa
9777 Las Vegas Blvd. South
Las Vegas, NV 89183
Phone: 702-796-7111

The multi-day 2011 Conference will feature renown HAE keynote speakers, a variety of HAE informational workshops, a full day's schedule for children and another just for young adults. We will also continue with our celebrated HAE physician expert Question & Answer panel, provide guidance regarding access to FDA-approved medications and much, much more. And, of course, there will be lots of opportunities to meet and chat with fellow HAE patients and families as well.

Attendees will also be able to sign up for the US HAEA's Scientific Registry while at the 2011 National Patient Conference. Watch www.haea.org for more details as they become available.

Save the date and make your plans now to attend - see YOU there!

September 16-18, 2011
See YOU in Las Vegas!
US HAEA
Seven Waterfront Plaza
500 Ala Moana Blvd.
Honolulu, HI 96813

866-798-5598
For urgent assistance, please call:
Donna Davis 808-216-1029 or
Michelle Williamson 972-814-5205

www.haea.org