



Issue 2 · April 2016

# HAEi Newsletter



**Meet the newly appointed  
HAEi Regional Patient Advocates**

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## A Message from the President

**Dear HAEi Friends,**

Here in the northeast United States, flowers and trees are shedding their winter dormancy and we are anxiously anticipating the optimism and energy that accompanies new spring growth. It is with a similar positive expectation and enthusiasm that I look forward to HAEi friends gathering in mid May at our biannual HAE Global Conference.

This year's gathering will be special in many ways, not to mention having a bit of a royal touch. We are honored that our host member organization – Asociación Española de Angioedema Familiar (AEDAF) –received confirmation that Her Majesty the Queen of Spain has accepted the Presidency of Honor for the Global Conference.

Also, please join me in extending warm well wishes and buena suerte ("good luck" in Spanish) to the 80 brave souls from 14 countries who will celebrate hae day :- ) and the spirit of overcoming the burden of HAE by walking around 50 kilometers along the El Camino de Santiago – a pilgrimage route with a rich and fascinating history.

The Global Conference provides HAEi friends with a unique opportunity to interact with peers from throughout the globe and share strategies, experiences, successes, and failures. I strongly encourage all conference attendees – patients, caregivers, physician/scientists, and industry representatives –to bring their most creative ideas regarding improving diagnosis and broadening access to live saving HAE medicines. This meeting is a perfect laboratory for innovative thinking to spark systematic action aimed at improving the lives of the patients throughout the world.

Finally, there will be a HAEi General Assembly meeting at the Global Conference that will include an election for five Executive Committee positions. Please join me in thanking all Committee members for their dedicated and effective service to the world's HAE community. This talented and experienced group of advocates has presided over the extraordinary growth in HAEi's member organizations (now at 52) and the expansion of programs and activities aimed at improving patient quality of life throughout the globe.

It is with great excitement that I look forward to personally greeting you in Madrid!

Warmest regards,

Anthony J. Castaldo  
 President, HAEi



**HAEi** HAEi is a global non-profit umbrella organization dedicated to working with its network of national HAE member organizations to raise awareness of HAE

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Cover photo: HAEi Regional Patient Advocates – meet them on page 8

Layout and design: Rikke Sørensen, Plus R

Newsletter staff:

Mr. Steen Bjerre, Communications Manager, E-mail: [s.bjerre@haei.org](mailto:s.bjerre@haei.org), Phone: +45 22 20 46 01  
 Mr. Henrik Balle Boysen, Executive Director, E-mail: [h.boysen@haei.org](mailto:h.boysen@haei.org), Phone: +45 31 591 591

Subscription:

If you would like to subscribe to our Newsletter please send an email to [info@haei.org](mailto:info@haei.org) or register directly on our website [www.haei.org](http://www.haei.org)

HAEi is registered as a non-profit/charitable organization in Switzerland

## Queen Letizia Accepts Presidency of Honor for HAE Global Conference

It is with the greatest of pleasure that HAEi and the Spanish HAE organization AEDAF have received confirmation from the Royal Household of His Majesty the King of Spain that Her Majesty the Queen has agreed to accept the Presidency of Honor for the HAE Global Conference in Madrid 19-22 May 2016.



In the area of health, the Queen of Spain has devoted herself to encouraging and giving visibility to those suffering from infrequent conditions, known as “rare diseases”, and their families, and to the fight against cancer.

For her commitment to infrequent diseases, in 2010 the Queen was invited to attend a research awards ceremony in Berlin, Germany; this was the first of her activities abroad.

At that occasion Queen Letizia said: “Three million people in our country, many of them children and teens, are suffering from rare diseases. And it is a priority for our society to give greater visibility to and raise awareness of them, and achieve the commitment of us all to their daily struggle.”

The other members of the Honorary Committee are:

**Juan Carrión Tudela**, President, Federación Española de Enfermedades Raras (FEDER)

[www.enfermedades-raras.org](http://www.enfermedades-raras.org)

**Alfonso Alonso Aranegui**, Minister of Health, Social Services and Equality

[www.msssi.gob.es](http://www.msssi.gob.es)

**Joaquín Sastre Domínguez**, President, Sociedad Española de Alergología e Inmunología Clínica (SEAIC)

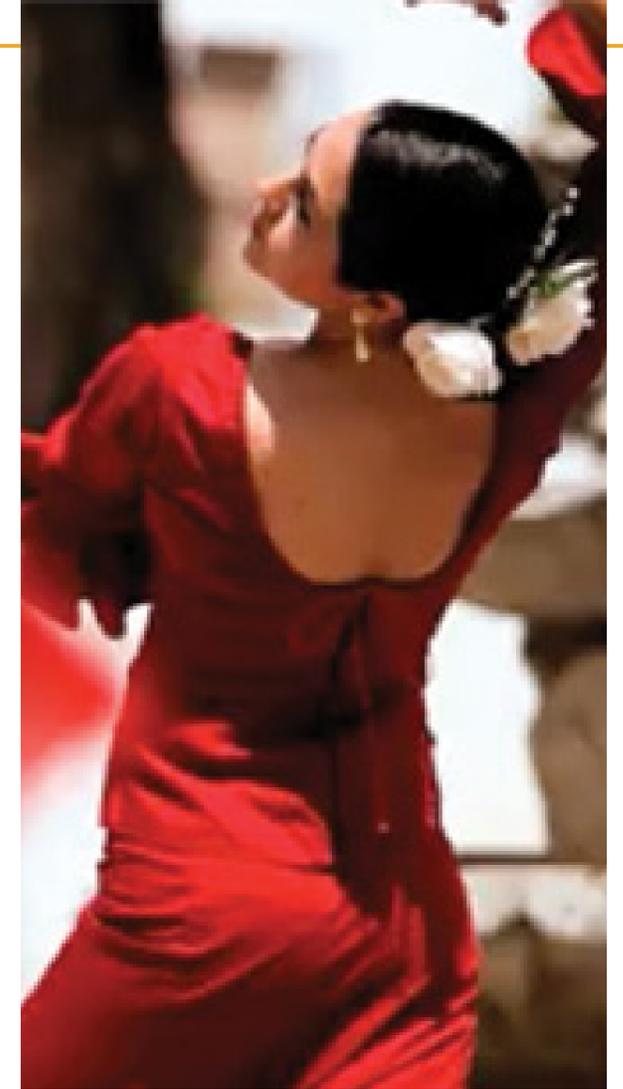
[www.seaic.org](http://www.seaic.org)

**Cristina Cifuentes Cuencas**, President, Comunidad de Madrid

[www.madrid.org](http://www.madrid.org)

**Anthony J. Castaldo**, President of HAEi

[www.haei.org](http://www.haei.org)



## HAE Global Conference

HAEi cordially invites you to attend the 2016 HAE Global Conference, which will take place in Madrid, Spain 19-22 May 2016.

We are now well over 500 delegates registered for the third HAE Global Conference. Patients, care givers, health care professionals, and industry representatives will join to learn more about HAE, share experiences and knowledge in a friendly atmosphere conducted and driven by the patient community through HAEi.

It is still possible to register for the conference in all categories. But please do so before 1 May 2016 – from that date all registration will be on request, based on hotel availability.

### REGISTRATION

Go to the registration website at

<http://www.trippus.net/hae2016-website>



## Raising awareness step by step on the Camino

**80 people – most of them suffering from HAE – will meet mid-May in northern Spain to walk part of the legendary Camino de Santiago together.**

It is far from an everyday occurrence to walk the kind of mileage these patients enter into on the Camino. However, on 14 May 2016 they will join forces and take part in the “HAE Camino Walk” together with caregivers, doctors, and industry representatives from Canada, USA, Mexico, Venezuela, Brazil, Argentina, Sweden, Denmark, Hungary, Italy, Spain, Australia, New Zealand, and Japan.

There is a dual purpose of the ‘HAE Camino Walk’. Firstly, for each and every patient to prove that the disease does not limit the ability to live life to the fullest. And secondly to raise the global awareness of the disease through every step they take on the Camino.

The ‘HAE Camino Walk’ takes place on and around 16 May, the global awareness day for HAE. Also, the walk is quite appropriately leading up to the HAE Global Conference.

The aim is continuously to find ways to improve time to diagnosis, secure life saving therapies, and get funding for these – allowing HAE patients around the world to lead a safer life and fulfill their life’s potential.



## Join the global Camino Walk

Would you like to do the ‘HAE Camino Walk’ but are unable to come to northern Spain? Well, the good news is that you can participate wherever you are.

All you need to do is

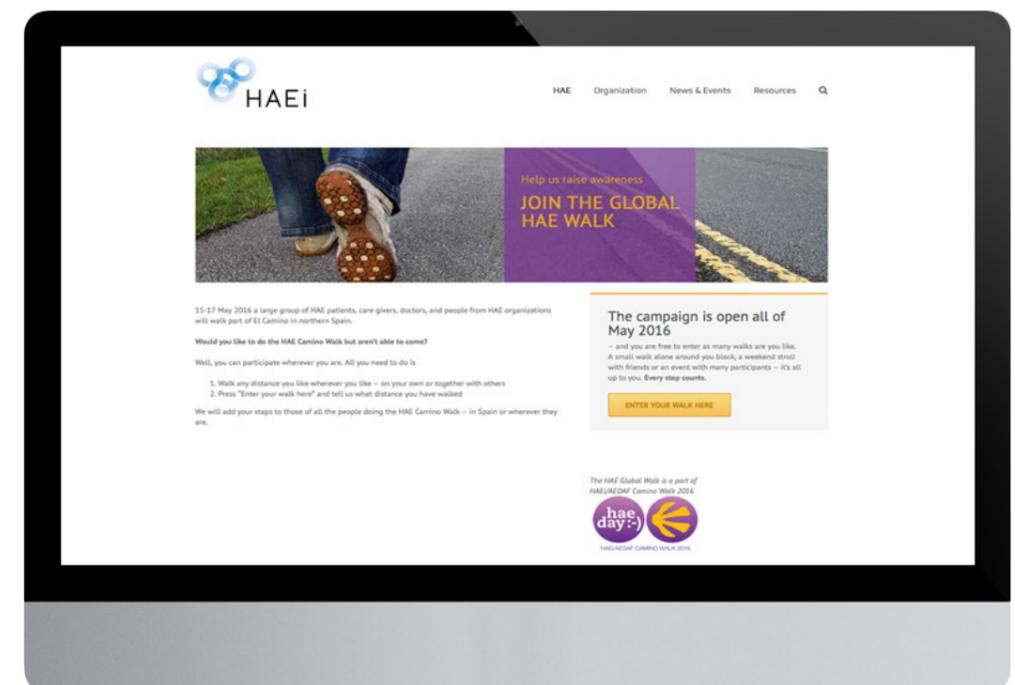
1. Walk any distance you like wherever you like – on your own or together with others,
2. Go to the campaign website at [www.haei.org/steps](http://www.haei.org/steps),
3. Press “Enter your walk here” and tell us what distance you have walked

We will then add your steps to those of all the people doing the HAE Camino Walk – in Spain or wherever they are.

The campaign is open all of May 2016 – and you are free to enter as many walks as you like.

A small walk alone around your block, a weekend stroll with friends or an event with many participants – it’s all up to you. Every step counts.

At [www.haei.org/steps](http://www.haei.org/steps) you can see how many steps have been taken, who has entered their walks, and where the walkers are located. Please visit – and please come back to enter your steps.





Michal Rutkowski

Rashad Matraji

Natasa Angjeleska

Alejandra Menéndez

Maria Ferron Smith

## HAEi Regional Patient Advocates

## Meet the Regional Patient Advocates

Earlier this year HAEi appointed the first five Regional Patient Advocates, dividing a large portion of the world between them.

The role of the Regional Patient Advocates for the next six months is primarily to support the member organizations already in place – and after that to try and help set up more or less formal groups in countries where no organization exists at this point.

**Alejandra Menéndez** (Argentina) is co-founder and Secretary of HAEi. She is a founding member and President of the Argentinian HAE organization. She also works at raising HAE awareness in all of Latin America and is now serving as HAEi Regional Patient Advocate for that region. A patient herself, Alejandra has two daughters with HAE. She lives in Buenos Aires.

**Michal Rutkowski** (Poland) is co-founder and President of the Polish HAE organization. Michal has been involved in HAE advocacy in his home country since 2005 and he became Vice President of HAEi in 2011. Michal was diagnosed with HAE at the age of 17. He is an architect and project manager, living with his wife and daughter in Krakow.

**Rashad Matraji** (United Arab Emirates) was born and raised in Tripoli, Lebanon where he studied engineering. In 2007 he moved to work in Dubai, United Arab Emirates, and is currently working as Regional HSE Manager within Al Futtaim Group. Rashad has been involved in HAE advocacy since 2011. Rashad – was diagnosed in 2009 but has experienced symptoms since he infancy – lives with his wife and daughter in Dubai.

**Natasa Angjeleska** (Macedonia) is the dedicated mother of a boy with HAE. Her professional background is in educational sciences so she believes that if you educate people you can achieve a lot. Natasa works on raising public awareness for HAE and educating patients and medical staff for HAE in Macedonia – and in number of other countries in her region. Natasa lives in Skopje.

**Maria Ferron Smith** (Malta) has recently joined HAEi as HAEi Regional Patient Advocate. She is a HAE patient herself as are her father and both her sisters. Maria is Spanish but she lives in Marsaskala since 2013 and works for Mediterranean Bank Plc.

Read more about the countries covered by the Regional Patient Advocates at

[www.haei.org/organization/meet-the-team](http://www.haei.org/organization/meet-the-team)



## Ask the Doctors

Last year the US HAE Association implemented a process for answering patient’s questions about HAE. Physician/Scientists at the US HAEA Angioedema Center at the University of California San Diego field questions and the answers are posted on Facebook pages for Angioedema Center Facebook Page and the US HAEA. Below, Dr. Sandra Christiansen, Dr. Marc Riedl, and Dr. Bruce Zuraw answer a recently asked question.

*“Is there a recommended protocol patients should work with their primary physicians to set up in case of an emergency?”*

**Dr. Christiansen:** This is a topic that is critical to consider for all patients with HAE. As in all things we need to “hope for the best, plan for the worst”. As all patients can experience unpredictable attacks of swelling it is recommended that everyone have two doses of effective therapy for on demand treatment. All patients are also at risk of a life threatening laryngeal attack and need to have a plan of action. We recommend that a written emergency plan be constructed in consultation between the patient and their doctor. The basic outline should include what and how medication is to be taken, who will administer, who to contact in the event of an emergency and where to go. We give all of our patients an emergency card to have with them and take to the ED which includes information on HAE, what are and are not effective therapies for HAE and what the on demand treatment is, and if relevant the prophylactic program for the individual patient. The US HAEA is also a valuable resource here with 24-hour call in to speak with someone to assist with coordination of emergency care.

**Dr. Zuraw:** I’d like to reinforce the point that every HAE patient is at risk of having a severe attack. It’s human nature to become complacent when things are going well; however, HAE is an unpredictable disease. Being prepared can make the difference between an attack being a nuisance versus it becoming a catastrophe. It’s also worth reiterating that it is a good idea to have a physician who is knowledgeable and experienced in managing HAE be involved in your care. Our philosophy at the US HAEA Angioedema Center at UC San Diego is that medical care can be layered, allowing expert HAE physicians to work with primary physicians to deliver the best possible care for patients.

**Dr. Riedl:** Establishing an effective acute treatment plan for managing HAE attacks is the “first rule” of overall HAE treatment. However, there’s no specific protocol that can be recommended as each person’s situation has unique factors to consider. HAE treatment is best individualized so sitting down with your HAE specialist to discuss these details is important. The basic steps to cover include:

1. Selecting an acute medication to treat attacks.
2. Ensuring you have reliable access to that medication – usually this means having the medication in your possession, though occasionally medication will be stored at a treatment site such as a hospital or clinic.
3. Knowing how to administer the medication – this may be self-administration in many cases, but might also involve receiving treatment assistance from your physician, a nurse, or a family member/friend.
4. Knowing exactly where to go in case of any emergency such as an airway attack, difficulty giving the medication, or lack of an adequate response to the medication. This “back-up” plan is important to develop ahead of time.
5. Knowing who to contact if you have questions or need advice about your treatment plan.
6. Knowing how to refill your medications efficiently once they are used to treat an attack. It’s also a good idea to have a letter or wallet card from your HAE physician that can be shared with other physicians (such as Emergency staff) outlining the basics of your condition and recommended treatment plan as well as HAE specialist contact info. This can sometimes facilitate better communication and avoid misdiagnoses and ineffective treatments in the event of an emergency.

## Let HAEi host your website

A growing number of national HAE organizations have their own websites with their own individual hosting solution. However, some of them would like to change hosting or altogether change the look and content of their websites. And others would like to just have a website at all.

“In order to accommodate any such national HAE organization we have established a system under the HAEi website allowing us to host national websites as well as provide them with templates for an individualized website – naturally all in their native language,” says HAEi Executive Director, Henrik Balle Boysen.

The first national HAE organization to introduce a website under the HAEi umbrella was HAE Spain. Have a look at the new Spanish website at

[www.angioedema-aedaf.org](http://www.angioedema-aedaf.org)

The next ones will most likely be Iceland and Turkey – with Serbia and Kenya coming up later this year.



## HAE News from Around the Globe



Kenya [www.facebook.com/100009028142543](http://www.facebook.com/100009028142543)



Patricia Karani of HAE Kenya writes about the Rare Disease Day 2016 in Kenya:

"We had our very first Rare Disease Day on 27 February 2016 at Getrude's Hospital in Nairobi. It was a successful day where HAE Kenya was represented and we got to share what our conditions are all about and how they affect our lives. It involved both old and young patients as well as caregivers and a physician. The other rare diseases represented where MD (Muscular Dystrophy), MS (Multiple Sclerosis), hemihypertrophy, hydrocephalus and albinism among others. The rare disease organizations that were represented included Muscular Dystrophy Society Kenya and Stepping Stones Kenya in partnership with Eurordis. It was a successful day as we got to learn a lot about other conditions. HAE Kenya was able to give a presentation and highlight what HAE is all about, how it affects our lives and the current state of medical intervention in the country, which possess a great challenge on prompt and proper HAE diagnosis. It was concluded from this meeting that it would be good to be meeting regularly so as to become more heard in Kenya and come up with a good advocacy plan for our rare conditions."

Hear Patricia Karani tell about her life with HAE at

[www.youtube.com/watch?v=WgMQ9Vj0GQ4&feature=player\\_embedded](http://www.youtube.com/watch?v=WgMQ9Vj0GQ4&feature=player_embedded)



Austria [www.hae-austria.at](http://www.hae-austria.at)

HAE Austria will be celebrating the 10th anniversary of the national organization 3-4 September 2016.



United Kingdom [www.haeuk.org](http://www.haeuk.org)

Laura Szutowicz, CEO of HAE UK writes:

"Winter at last seems to be loosening its soggy grip and the days are lengthening which is always heartening. Sadly, several of our members have had attacks over the winter with most often viral infections being the trigger, but hopefully the fine weather will help us all to put a "Spring" in our step!

Our fundraisers have been very active, in the last bulletin from the UK we told you about Rick Talbot, who did his Boxing Day Swim and raised a staggering amount of money for HAE UK. We are also lucky to have Dana Shapiro climbing Mount Kilimanjaro, following in the footsteps of Ed Price who did it a few years ago. Clever Izzie Sealey raised money at her local school by selling items in conjunction with a maths project. And Furkhanda Haxton is raising money by adopting healthy eating for March.

Also, amazing Samantha Jones ran the Cardiff Half Marathon on Easter Sunday, in aid of HAE UK. Despite the run taking place in the middle of "Storm Katy" with gale force winds and relentless rain, she achieved a "Personal Best" time. She had had some training and health issues in the lead up to the run, which makes her achievement even more extraordinary. And 14-15 May Danny Owen will be taking part in the London Revolution, a cycling event of 185 miles around the capital. I cannot tell you how grateful we are to all these people and the many others who support HAE UK. Finances are always a difficult area for small charities and we rely heavily on individuals.

Rachel Annals has designed HAE UK T-shirts, which we are giving to people who are fundraising at events, and she and I will be wearing them for the HAE Global Conference in Madrid.

The Trustees have agreed to allow us to sponsor a person under 18 (and a parent or guardian) to go to the HAE Global Conference in Madrid in May. The conference has a specific "Youth Track" and we want our delegate to go and meet other young people with HAE and join in

all the lectures and discussions so that they can come back to the UK and be our "Youth Ambassador". This role will then work in conjunction with myself and Rachel Annals to set up the Young HAE "wing" and help design services specially to meet the needs of younger HAE patients.

HAE UK Trustees Board; Ann Price, the founder and early driving force of HAE UK has now stood down as a Trustee. HAE UK owe her immense thanks for all her work and wish her a very happy retirement. We are delighted to announce that Dr. Tim Crouch, a member of the Medical Advisory Panel, has agreed to take up the role of Trustee as has Tom Pickering who is a lawyer with City firm Travers Smith and has considerable experience with charities.

Finally, we have set dates and venues for the Patient Day meetings; a Scottish meeting in Perth on 1 October 2016 for all those Scottish patients who tend to be unable to come to the patient day because of distance. The annual Patient Day is 19 November 2016 in Bristol.

The upcoming HAE Global Conference will be my first one; I am very excited about attending and meeting you all. I will be wearing my T-shirt, so come up and say 'hello.'"



Serbia [www.haei.org/location/hae-in-serbia](http://www.haei.org/location/hae-in-serbia)



**HAE organization founded:** The last days of February 2016, 21 out of 33 known Serbian HAE families attended the founding assembly of HAE Serbia. Ivana Golubović was appointed president, Jovana Cvetković vice-president, and Dušan Dašić board member – and following the meeting the organization has been formally registered in Serbia. During the meeting Dr. Sladjana Andrejevic and Dr. Radovan Mijanovic gave a lecture on HAE and PID in general, HAE Serbia distributed HAE leaflets, and the participants discussed the organization's strategy and long-term goals.

**Meeting with officials:** HAE Serbia also has held an hour-long meeting with government officials at the Ministry of Health, discussing therapy for HAE and changes of certain law clauses.

**Medical Advisory Board established:** HAE Serbia has established a Medical Advisory Board consisting of four immunologists from Belgrade, Southwest Serbia, and North Serbia, and a pediatrician immunologist from Belgrade. The coordinator of the board is Dr. Sladjana Andrejevic.



Chile [www.facebook.com/angioedema.hereditariochile?fref=ts](http://www.facebook.com/angioedema.hereditariochile?fref=ts)



**Rick Astley:** It is always good if you can get someone famous to market your cause. That is just what HAE Chile did earlier this year when the organization got English singer, songwriter, musician, and radio personality Rick Astley to take part in a photo shoot.

**HAE Symposium:** Primer Simposio Regional de Angioedema Hereditario will take place 6 May 2016 in Santiago de Chile. The speakers are Dr. Anete Grumach (Brazil), Dr. Alejandro Malbrán (Argentina), Dr. Konrad Bork (Germany), and Alejandra Ginaca (Argentina).



**Ana Tijoux:** HAE Chile also got the French-Chilean musician Ana Tijoux to pose for the cause. Ana Tijoux became famous in Latin America as the female MC of the hip-hop group Makiza during the late 1990s and during the last decade she crossed over to the mainstream of Latin pop.


**Canada** [www.haecanada.org](http://www.haecanada.org)

Patient meetings will be held during 2016 in Winnipeg and Victoria. Information on dates and venues will be posted on the HAE Canada website.


**Macedonia** [www.haemacedonia.mk](http://www.haemacedonia.mk)

РЕТКИ СМЕ И НИ ТРЕБА  
ВАША ПОДДРШКА!  
Дојдете „За ХАЕ, на точак“  
во сабота, 20.02.2016 во 12:00 во Жена парк.



**Let's Cycle for HAE:** HAE Macedonia organized a humanitarian event "Let's Cycle for HAE" on 20 February 2016. This initiative was planned to attract public attention to patients with HAE in order to inform about the challenges they face in everyday life, including work, school and sports. The initiative was co-organized with a non-formal group of enthusiasts called "On bicycle" that strive for healthy lifestyles mainly through securing clear and safe environment and at the same time promoting healthy lifestyle by riding bicycle to work, school and for recreation. The event was accompanied by volunteers from the "On bicycle" initiative, students from a primary school that one of the patients attends, as well as friends, humanists and random walkers that joined on their bikes. The ride was organized cycling on the main streets in the capital city, accompanied by police vehicles so that a lot of attention was gathered on a busy, rainy Saturday noon. The end of the ride was in the main City Park where cyclists got refreshments and healthy snacks prepared by a friend blog cooker. HAE Macedonia managed to raise small donations during the event, serving as a base for a fundraising campaign for organizing the First Balkan HAEi meeting in Skopje, planned for 17-19 June 2016. The event was covered by television, radio and online media and it was a start-up of a rare disease week in February, where HAE Macedonia participated in many additional events for marking and celebrating the Rare Disease Day in Macedonia.

**Rare Disease meeting:** HAE Macedonia representatives held a meeting with the president of the Rare Disease

Committee, Aspazija Sofijanova, MD on 1 April 2016. The goal of the meeting was to discuss the benefits and the challenges with regard to the available therapy for HAE patients in the country. The start-up of the HAE medicines supply in Macedonia was good (Behrinert has been available to children, and both Behrinert and Ruconest have been available to adult patients) since September 2015, but after a 6-month period HAE Macedonia was able to assess the gaps in regard to availability, sufficiency and way of distribution of the medicines. The Macedonian organization has submitted the remarks for the future period for HAE therapy:

1. Increase of the available medicines, especially for adult patients;
2. Continuous supply of the medicines throughout the year without deficits;
3. Treatment accessibility for patients living outside the capital and far from the University Clinic Hospital;
4. Setting a procedure for registering new patients and their entry into Rare Disease Register and access to treatment.

The president of the Rare Disease Committee expressed her conviction in the positive outcome concerning the increase of the needed therapy for adult patients, as well as the general support for the HAE Macedonia activities for better quality of life for HAE patients in the country.


**United Arab Emirates** [www.facebook.com/groups/111656808988882/?fref=ts](https://www.facebook.com/groups/111656808988882/?fref=ts)


The 2nd Gulf States HAE Meeting took place in Qatar 18-19 March 2016 and gathered 44 patients and doctors from all countries in the region. In addition to providing attendees with important HAE-related information, the meeting served as a forum for ideas on broadening access to treatment in the Gulf region.


**Turkey** [www.facebook.com/groups/hereditoranjiyodem](https://www.facebook.com/groups/hereditoranjiyodem)


With the help of Prof. Dr. Okan Gülbahar and Prof. Dr. Nihal Mete Gökmen, the first HAE Clinic has just opened in Ege University Faculty of Medicine at Izmir, Turkey. HAE Turkey is delighted to share that information with all HAE patients around Turkey as they can now visit and make their regular check-ups and prescribe their medicines at the clinic.

"With these developments, the fight with HAE can be pursued with more ease as more and more patients have access to a more extensive care. Thus, negative physical and psychological effects of HAE can be maintained, or even lowered in a significant rate. Hence, we hope to see an increase in number of HAE clinics in Turkey as soon as possible", says Ersan Sevinç of HAE Turkey.


**Spain** ([www.angioedema-aedaf.org](http://www.angioedema-aedaf.org))

The Spanish HAE organization held its annual general assembly 16 April 2016 at Hospital Universitario La Paz.

US HAEA Angioedema Center Clinical Director, Prof. Marc Riedl was the invited expert guest lecturer and he gave informative talks on the pathophysiology of HAE as well as optimal HAE treatment approaches. Among the other speakers were Dr. Hassan Mobayed ("Delay in diagnosis of HAE"), Dr. Fadel Al Sabbag ("Laboratory Diagnosis of HAE and Pitfalls in Lab Diagnosis"), and Dr. Maryam Al-Nesf ("Establishing GCC-HAE Guidelines"). The attendees worked together to achieve a very positive outcome – a consensus advocacy approach for eliminating roadblocks impeding access to modern HAE therapies in the region.


**USA** [www.haea.org](http://www.haea.org)

The American HAE association hosted its first ever 5K run/walk to benefit HAE patients immediately following the 2015 National Patient Summit in Denver, Colorado. Since then US HAEA has established HAE In-Motion® 5K as a national fundraising event. Patients and members of the HAEA community are encouraged to host their own 5K events to raise awareness and help HAE patients achieve lifelong health. At this point 5K runs/walks have been scheduled for:

- Cullman, Alabama – 30 April 2016 (register at <https://runsignup.com/Race/AL/Cullman/HAEinMotion5kTeamLyndon>)
- Omaha, Nebraska – 5 June 2016 (register at <https://runsignup.com/Race/NE/Omaha/HAEinMotion5kOmaha>)
- Philadelphia – 18 June 2016
- Puerto Rico – 10 July 2016
- Seattle – 23 July 2016
- Chicago – 13 August 2016
- Cincinnati – 10 September 2016
- Atlanta – 22 October 2016
- Boston – October 2016
- Florida – November 2016

You can read much more about HAE In-Motion® 5K at

<http://5k.haea.org>.



Japan 🇯🇵 [www.haej.org](http://www.haej.org)

Beverley Yamamoto, President of HAE Japan, writes:

**Registration of HAE Day in Japan:** Thanks to the tenacity of Yukie Imamura, Executive Director of HAE Japan, we have registered hae day :- ) as an official day to be remembered with the Japan Anniversary Association. There will be an official ceremony in Tokyo this month when we will receive a certificate to mark the registration. The Japanese hae day :- ) will be registered on the Association's webpage. One small step!

**APARDO meeting in Singapore:** In November 2014 an agreement was reached to form the Asian Pacific Alliance of Rare Disease Organizations (APARDO) in Singapore. On 22 March 2016, APARDO held its second Annual General Meeting and Executive Board Meeting as well as two workshops as pre-conference and conference events at the BioPharma Asia Convention in Singapore. The Japan Patient Association (JPA), the main patient advocacy umbrella organization in the country, had been a key driver behind the creation of APARDO on the Japan side. As their international relations spokesperson, Dr. Yukiko Nishimura, was unable to attend, I had been asked to attend. As an organization HAE Japan has joined APARDO and I was very honored to be invited to speak.

On 23 March 2016 APARDO had organized an afternoon session in the conference entitled "Improving access to care and treatment for rare diseases in APAC". I spoke as part of a panel entitled "How Patient Organizations are influencing national policies for rare diseases and orphan drugs: APARDO and Rare Disease International". I was joined by Durhane Wong-Rieger, President of APARDO and the Canadian Organization for Rare Disorders, Rachel Yang, in charge of International Relations, Chinese Organization of Rare Disorders, and Richard West, who is President of Bachets International. It was fascinating to hear how other rare disease organizations in the region are moving policy and practice along.



**Visit by Professor Konrad Bork:** In the final week of March 2016, HAE stakeholders in Japan had the great pleasure of welcoming Professor, Dr. Konrad Bork to give several lectures on HAE. As strict compliance regulations forbid patients attending a meeting sponsored by industry, I was very sad to have missed the main event in Professor Bork's visit, a lecture meeting on 27 March 2016 attended by 30+ Japanese physicians. However, three of us from HAE Japan, Dr. Daisuke Honda, Yukishi Yamamoto and I, were able to spend a delightful time showing Dr. Bork the sites and restaurants of Tokyo over two days before this meeting. The main topic of conversation was of course HAE, but we also had more cultured conversations about art, history and music. Sitting in the National Museum café, with a backdrop of cherry blossoms, which had just come into bloom, talking about patient care and treatment will be an enduring memory. We are looking forward to seeing Professor Bork again.



## Global Advocacy Work

### Recent events

**23-26 February:** HAEi met with rare disease experts (representing the hemophilia, immune deficiency and rare disease groups) in **Bangkok, Thailand** to plan expansion in South East Asia. HAEi identified and met with a pediatric immunologist from Chulalongkorn University Hospital in Bangkok, who will be the main contact person for the HAE reference network in Thailand. The university hospital is currently planning a workshop in October 2016, in which HAE will be the main focus. HAEi has been asked to help plan and speak at the event. Allergists from all over Thailand will participate in this meeting.

**1-4 March:** HAEi participated in the Healthcare Information and Management Systems Society (HiMSS) in **Las Vegas, USA**.

**4-7 March:** HAEi took part in the 2016 American Academy of Allergy, Asthma and Clinical Immunology (AAAAI) in **Los Angeles, USA**.

**9 March:** HAEi spoke at the Foro Internacional Angioedema Hereditario, which took place in the Legislative Chamber of the Mexican House of Deputies in **Mexico City, Mexico**. HAEi's presentation was entitled 'Reimbursing HAE medicines is a cost effective policy that saves lives'.

**16-20 March:** HAEi participated in and together with the regional representative coordinated the 2nd Gulf Region workshop in **Doha, Qatar**.

**8-10 April:** HAEi will hold its first Regional Patient Advocates' workshop in **Frankfurt, Germany**.

**22-25 April:** HAEi met with the Philippine Society of Rare Disorders. Discussions centered on finalizing the objectives, scope, and milestones for a HAEi Development grant to raise HAE awareness among the medical community and identify patients and physicians interested in forming a HAE group. The meeting took place in **Manila, The Philippines**.

**27-28 April:** HAEi participated in the 6th Nordic Bradykinin meeting (organized by Shire) in **Stockholm, Sweden**.

### Upcoming events

**23-25 May:** HAEi will participate in the PLUS meeting in **Lisbon, Portugal**.

**11-14 June:** HAEi will participate in EAACI 2016 in **Vienna, Austria**. During the conference HAEi will also be part of the task force working on an updated version of the WAO Guidelines for treating HAE.

**16-20 June:** HAEi will participate in the HAEi Balkan Regional Workshop, which will take place in **Skopje, Macedonia**.

## News from the Industry



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Feb, 2016

**BioCryst Pharmaceuticals, Inc.** has announced financial results for the fourth quarter and full year ended December 31, 2015.

“In 2015, we gained clarity on both of our HAE drug candidates. Our efforts are now focused on completing the bioavailability study of a solid dosage form of avoralstat and completing the APeX-1 clinical trial of BCX7353,” said Jon P. Stonehouse, President & CEO. “We ended 2015 with a balance sheet that enables us to achieve these two near-term data events without the need to raise capital. These two programs give us two shots at achieving our goal of developing a highly effective, conveniently dosed, oral drug candidate for the prophylactic treatment of HAE patients.”

On February 8, 2016, we announced results from OPuS-2 (Oral P rophylaxiS-2), a clinical trial of avoralstat administered three times daily in a liquid-filled soft gel formulation for the prophylactic treatment of HAE attacks. The primary efficacy endpoint was angioedema attack frequency. Treatment with 500 mg and 300 mg of avoralstat three times daily failed to demonstrate a statistically significantly lower mean attack rate versus placebo. Statistically significant improvements in duration of attacks and in the Angioedema Quality of Life total score were observed comparing the 500 mg three times a day avoralstat arm to placebo. Following the analysis of OPuS-2 results, the decision was made to discontinue further development of softgel avoralstat formulation in order to focus development efforts on a novel solid dosage form of avoralstat.

BioCryst expects to report results from a relative bioavailability study testing the novel solid dosage form of avoralstat by mid-year 2016. The primary goal of this study is to achieve meaningfully better drug exposure in a twice daily dosing regimen.

BioCryst expects to report results from the BCX7353 APeX-1 dose ranging study in HAE patients by year end. The design of APeX-1 trial will be described once it is initiated.

(Source: BioCryst)

## PHARMING

27

Feb, 2016

Following evaluation of a dossier submitted by **Pharming Group N.V.** last year, the Committee for Medicinal Products for Human Use (CHMP) has

issued a positive opinion to the European Commission on the company's request to include the treatment of HAE attacks in adolescents with HAE and to remove the requirements for rabbit IgE testing that forms part of the EU label for Ruconest.

Following adoption of the CHMP opinion by the European Commission, this will mean that adolescents with HAE now also have access to (non-blood derived) recombinant C1- inhibitor therapy for the treatment of their angioedema attacks. In addition, the requirement to test HAE patients for pre-existing antibodies against rabbit dander, prior to treatment with Ruconest and following each tenth treatment with Ruconest, will be removed from the label. The requirement for IgE testing was a specific EU request based on a single adverse drug reaction in a study subject, who did not disclose the pre-existing rabbit allergy prior to rhC1Inh treatment. The need for testing was not required in the US as more safety data were available at the time of the Biologics License Application (BLA) and subsequent FDA-approved label in 2014.

Prof. Bruno Giannetti, MD, PhD, Pharming's COO commented: “This EU label change will now also give adolescent in the EU the long awaited access to treat their HAE attacks with a non-blood derived C1-inhibitor and in addition, the positive CHMP opinion confirms the well-established safety profile of Ruconest, based on a database of a dozen controlled clinical trials as well as more than 12,000 post-marketing doses of Ruconest provided to HAE patients. After adoption of the CHMP opinion by the European Commission, this will remove the burden on patients and doctors to perform testing prior to and after treatments with Ruconest and enable emergency treatment with Ruconest for HAE attacks in previously untreated HAE patients. HAE patients previously dependent on plasma derived C1INH therapies, including adolescents, will be able to receive Ruconest with the benefit of eliminating risks of exposure to known blood borne pathogens, such as Hepatitis A, B, C, E, HIV, and CJD, as well as continuously (re)-emerging pathogens, such as the recent ZIKA virus.”

(Source: Pharming)

## PHARMING

29

Feb, 2016

**Pharming Group N.V.** reiterates its commitment to the treatment of rare diseases on Rare Disease Day 2016, an annual global initiative committed to

improving public understanding of rare diseases and highlighting the exceptional challenges facing patients and their carers.

Nearly 7,000 different rare diseases have been identified to date, directly affecting the daily life of more than 60 million people in Europe and the US alone. Today, people living with or affected by a rare disease, patient organizations, politicians, carers, medical professionals, researchers and industry will come together in solidarity to raise awareness of rare diseases.

Pharming developed Ruconest, currently marketed in the US and EU, for the treatment of HAE attacks. Ruconest is also in development for paediatric use and for prophylaxis of HAE.

Sijmen de Vries, Pharming's CEO, commented: “Pharming supports Rare Disease Day to recognize the many patients around the world living with the burden of such diseases. As an R&D company, we are working diligently, through our technology platform, to find new solutions. Through Ruconest, we are providing a safe and efficacious non-blood derived (recombinant) enzyme replacement therapy for HAE patients in countries where the treatment is approved and available and through the HAEi Global Access Plan in the rest of the world.”

Rare Disease Day was launched by EURORDIS (The European Organization for Rare Disorders) and it's Council of National Alliances in 2008. Held on the last day of February each year, it seeks to raise awareness of the impact that rare diseases have on the lives of patients and those who care for them. The campaign began as a European event but has quickly become international in scope, with the US joining in 2009, and participation in over 80 countries around the world in 2015.

For more information, please visit [www.rarediseaseday.org](http://www.rarediseaseday.org).

(Source: Pharming)



4

Mar, 2016

**Avalanche Biotechnologies, Inc.**, a gene therapy company committed to discovering and developing novel medicines for patients suffering from

chronic or debilitating disease, has reported financial results for the fourth quarter and year ended December 31, 2015.

“We were looking for opportunities to leverage our expertise and resources by identifying additional assets to bring into the company,” said Paul B. Cleveland, president and CEO. “On February 1 we announced a proposed combination with Annapurna Therapeutics, a gene therapy company with four product candidates in development, including a candidate for the potential treatment of HAE which is expected to be in the clinic in 2017. We believe that this transaction will transform Avalanche into a leading gene therapy company with an extensive pipeline.”



8

Mar, 2016

**Alnylam Pharmaceuticals, Inc.** is announcing the addition of a new program to the company's genetic medicines pipeline, ALN-F12, an

investigational RNAi therapeutic targeting F12 for the treatment of HAE. Pre-clinical data for ALN-F12 were presented at the American Academy of Allergy, Asthma & Immunology (AAAAI) Annual meeting, held March 4-7, 2016.

Pre-clinical data showed that administration of ALN-F12 resulted in dose-dependent reduction of vascular permeability in two different mouse models of bradykinin-driven vascular leakage, demonstrating that suppression of F12 mRNA has the potential to mitigate excess bradykinin stimulation. Further, in non-human primates, a single subcutaneous dose of ALN-F12 at 3 mg/kg resulted in potent and durable knockdown of serum FXII of greater than 85 percent, with knockdown of over 50 percent sustained out to three months following administration.

Alnylam believes these pre-clinical data demonstrate the potential of ALN-F12 as a promising approach for prophylaxis of HAE attacks.

(Source: Alnylam)



8  
Mar, 2016

**Arrowhead Research Corporation**, a biopharmaceutical company developing targeted RNAi therapeutics, has presented additional preclinical data suggesting that ARC-F12, an RNAi therapeutic that inhibits the production of Factor XII (F12), has the potential to treat HAE and to prevent thrombosis. Data presented in a poster at the 2016 American Academy of Allergy, Asthma & Immunology Annual Meeting (AAAAI), show that ARC-F12 had the desired effects of significantly reduced swelling in a rat model of edema and inhibition of blood clot formation in a mouse model of thrombosis, without the undesired effect of increased bleeding risk.

In a carrageenan-induced paw edema model in rats, treatment with ARC-F12 seven days prior to carrageenan challenge led to a significant reduction in edema ( $p < 0.001$ ). The reduction in swelling in ARC-F12 treated rats is similar to that seen in rats treated with a kallikrein-targeted antibody. This supports Arrowhead's position that F12 inhibition could be an attractive target for HAE.

In a mouse model of thrombosis, a dramatic increase in occlusion times was observed in mice receiving ARC-F12. The time to blood flow occlusion is measured as a clinically relevant indicator of physiological response to F12 knockdown and is a measure of the inhibition of thrombus formation. Further, in multiple relevant models of bleeding risk, ARC-F12 did not cause an increase in bleeding times or bleeding risk. Anticoagulants can be used to reduce thrombus formation and thromboembolism occurrence, but also can cause an increase in serious bleeding risk. ARC-F12 may be able to reduce the risk of blood clot formation, without the undesirable bleeding risk caused by anticoagulants.

In vivo studies in wild type mice showed that a single 2 mg/kg dose of ARC-F12 achieved greater than 95% knockdown of F12 levels. In multi-dose primate studies, a 4 mg/kg dose resulted in greater than 90% knockdown with even greater knockdown following subsequent doses. Knockdown was also highly durable with greater than 80% reduction maintained between monthly doses. ARC-F12 appeared to be generally well-tolerated and no drug-related changes in toxicity markers were observed as measured by clinical chemistry and hematologic parameters.

F12 is a key component of the contact activation pathway involved in thrombosis and the kinin-kallekrein system involved in angioedema. It is predominantly produced in the liver and circulates in plasma, so Arrowhead believes that it is a uniquely suited target for an RNAi-therapeutic delivered with the proprietary Dynamic Polyconjugate™ (DPCTM) delivery system.

Consistent with its process for all of its RNAi-therapeutic candidates, Arrowhead's discovery of ARC-F12 followed a screening funnel process that includes: bioinformatic selection of RNAi trigger sequences; trigger synthesis and in vitro screening; synthesis of cholesterol-RNAi triggers and in vivo screening; multiple iterations of structure-activity relationship (SAR) studies and in vivo screening to assess various chemical modifications to improve RNAi trigger activity; in vivo screening in non-human primates; efficacy testing in disease relevant models; non-GLP toxicology studies; and lastly, the selection of a lead candidate.

(Source: Arrowhead)

## PHARMING

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Mar, 2016

In the financial report for the full year that ended 31 December 2015 Sijmen de Vries, CEO and Chairman of the Board of **Pharming Group N.V.** writes (in extracts):

2015 was the year that Pharming started to move forward again, after years of consolidation and transition. Sales of Ruconest grew well in 2015. This was most strongly seen in the US, where initially Salix Pharmaceuticals Ltd. and thereafter Valeant have continued to roll out Ruconest to patients. The changes in sales organizations caused by this acquisition have impacted the speed of growth, but the overall result was still positive for Pharming.

We are proud that more than 12,000 attacks of HAE have now been successfully treated with Ruconest and that the very low rate of adverse events observed and documented in clinical trials continues to be confirmed. It is already the most effective treatment (based on comparison of published data) for resolution of acute HAE attacks, with no significant side effects and very fast resolution of these painful and frightening episodes for patients. As the only pure recombinant product, it also avoids many of the concerns, complications and costs, such as the formation of potentially life-threatening blood clots and mandatory pre-testing and regular testing for blood-borne infections like Hepatitis B and C and HIV, which are associated with products fractionated from blood plasma, for which the risk of new blood-borne infections (such as Zika virus) also remains significant. As a further testament to Ruconest's safety profile, the CHMP recently issued a positive opinion to cancel the requirement for rabbit allergy testing in Europe prior to first use and for the label to be extended further to allow it to be used to treat adolescent patients.

Starting in January with the initiation of a randomized double-blind placebo-controlled Phase II clinical trial for Ruconest in prophylaxis of HAE, we have relaunched Pharming as a company engaged in developing new products and markets. Since the year-end, we announced that this trial was fully recruited and we now expect the preliminary outcome from the study in the end of the second quarter of 2016. We have also extended our agreement with Cytobiotek S.A.S to an additional four Latin American countries, reflecting the good start that they have made in bringing Ruconest to patients in Colombia and Venezuela.

In 2015 we also entered into an international global access collaboration for HAEi together with Clinigen Group plc. The "HAEi GAP" program will provide access to Ruconest for eligible patients with HAE who currently do not have access to effective medication to treat acute attacks of the disease, and the first patients are now coming through this program.

We intend to increase our own commercial activities, with additional territories and products as opportunities arise, and to continue to develop our pipeline to produce the next generation of therapies. We expect to announce the full pipeline development program, including the anticipated timings of the clinical trial steps, in the second quarter of 2016 once our program leads have been optimized.

Later in the year, the US Food and Drug Administration granted an extension for Ruconest data exclusivity until 2026. This should enable us to add new revenue-generating products to our arsenal and identify opportunities in 2016 and beyond. It should also enable us to bring these products to market and develop sales under the "extended umbrella" of revenues from Ruconest.

With a solid base built in 2015 and strong opportunities becoming available already, we look forward to an even more positive year in 2016, with strong inflection points from the Phase II prophylaxis study and from increasing sales of Ruconest.

(Source: Pharming)



24  
Mar, 2016

Cinryze is now available in Canada to patients with HAE who may benefit from routine prevention. It is the first and only treatment in Canada with an approved indication for routine prevention against angioedema attacks in adolescent and adult patients with HAE.

The Canadian Blood Services (CBS) will distribute Cinryze throughout the country, except for Québec. **Shire Pharma Canada ULC** is actively working to provide HAE patients in Québec with timely access to Cinryze, like all other Canadians.

“The launch of Cinryze in Canada marks yet another important milestone that further strengthens our commitment to Canadians living with HAE,” said Eric Tse, Shire Canada General Manager. “Shire is now able to provide Canadians with a portfolio of two complementary treatments for HAE: Cinryze and Firazyr.”

Canadians prescribed Cinryze by their physician for the prevention of their HAE attacks are eligible to enroll in the Shire OnePath Patient Support Program to access services designed to train patients to prepare and self-infuse Cinryze, among other services.

“HAE often takes a physical and emotional toll on patients and their families, which is why it is essential that people living with the condition have access to treatment options that best meet their individual needs,” mentioned Jackie Badiou, HAE Canada President. “The fact that Canadians with HAE have access to yet another Health Canada approved treatment option marks an important step forward in providing more choices for the Canadian HAE community to improve their quality of life.”

(Source: Shire)



29  
Mar, 2016

**Global Blood Therapeutics, Inc.**, a biopharmaceutical company developing novel therapeutics for the treatment of grievous blood-based disorders with significant unmet needs, has reported business progress and financial results for the fourth quarter and year ended December 31, 2015.

Among the “2016 Anticipated Milestones” you will find:

- Hereditary Angioedema: Complete IND-enabling toxicology studies, submit an IND, and initiate a Phase 1 study for GBT18713, an orally bioavailable kallikrein inhibitor.

(Source: Global Blood Therapeutics)



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Mar, 2016

HAE related information from the **Shire plc** 2015 Annual Report:

- The \$6 billion acquisition of Dyax expands and extends our industry-leading portfolio in HAE. With Dyax we bring into our portfolio DX-2930 (now SHP643). If approved, this therapy has the potential to expand HAE-treated patients and achieve worldwide sales of up to \$2 billion with exclusivity beyond 2030.
- Our HAE portfolio, Cinryze and Firazyr, grew 23% and 22%, respectively.
- We also worked to strengthen our manufacturing position through renegotiation of our agreement with Sanquin. We are now in a position to seek a second source of supply to boost production of Cinryze.

(Source: Shire)

## PHARMING

7  
Apr, 2016

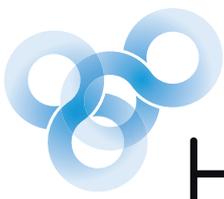
The European Commission has adopted the CHMP recommendation to include the treatment of HAE attacks in adolescents with HAE and to remove the requirements for rabbit IgE testing that formed part of the EU label for Ruconest. The CHMP also noted that the importance of favorable effects of Ruconest is further supported by the continued availability of supply of Ruconest (produced by recombinant technology) in comparison to supply from blood donor plasma that may vary and not being a blood derived product thereby removing the potential risk of exposure to blood borne pathogens.

This will mean that, effective now, adolescents also have access to (non-blood derived) recombinant C1- inhibitor therapy for the treatment of their angioedema attacks. In addition, the requirement to test HAE patients for pre-existing antibodies against rabbit dander, prior to treatment with Ruconest and following each tenth treatment with Ruconest, has been removed from the label. The requirement for IgE testing was a specific EU request based on a single adverse drug reaction in a study subject. The need for testing was not required in the US as more safety data were available at the time of the Biologics License Application (BLA) and subsequent FDA-approved label in 2014. The EU patient information leaflet will be updated to reflect these changes over the coming months.

Prof. Bruno Giannetti, MD, PhD, COO of **Pharming Group N.V.**, commented: “This EU label change now also gives adolescents in the EU the long awaited access to treat their HAE attacks with a non- blood derived C1-inhibitor and in addition, the adoption by the European commission of the CHMP recommendation again confirms the well-established safety profile of Ruconest , based on a database of a dozen controlled clinical trials as well as now some 13,000 post-marketing doses of Ruconest provided to HAE patients. We are pleased that the burden on patients and doctors to perform testing prior to and after treatments with Ruconest has been removed and that emergency treatments of HAE attacks in previously untreated HAE patients, that were until now dependent on plasma derived C1INH therapies can now be made with Ruconest, with, as per the CHMP opinion, the added benefit of eliminating risks of exposure to known blood borne pathogens, such as Hepatitis A, B, C, E, HIV, and CJD, as well as continuously (re)-emerging other pathogens.”

(Source: Pharming)





# HAEi

HAEi is a global non-profit umbrella organization dedicated to working with its network of national HAE member organizations to raise awareness of HAE.



## You are not alone

## HAEi Worldwide

Currently you will find HAE member organizations in 52 countries:

**North America (2):** Canada, United States of America

**Central America and Caribbean (3):** Costa Rica, Mexico, Puerto Rico

**South America (8):** Argentina, Brazil, Chile, Colombia, Ecuador, Peru, Uruguay, Venezuela

**Europe (28):** Austria, Belarus, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Macedonia, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, Switzerland, The Netherlands, Ukraine, United Kingdom

**Middle East (3):** Israel, Turkey, United Arab Emirates Africa (1): Kenya

**Central Asia (1):** Russia

**South Asia (1):** India

**East & Southeast Asia (3):** China, Japan, Malaysia

**Australia/Oceania (2):** Australia, New Zealand

You will find much more information on the HAE representations around the globe at [www.haei.org](http://www.haei.org). On our World Map you will find contact information for our member organizations as well as care centers, hospitals, physicians, available medication, and clinical trials.

The information on [www.haei.org](http://www.haei.org) is being updated as soon as we receive fresh data from the national member organization.

### Your feedback is very welcome

Please let us know what you believe should be included in future newsletters. You can do that by providing feedback to Executive Director Henrik Balle Boysen or Communications Manager Steen Bjerre. In addition, we invite you to submit articles on any topics that you believe would be of interest to other readers. We look forward to your comments and working with you on future newsletters.

### Corporate Information

HAEi is officially registered as a non-profit/charity organization in the Canton of Vaud in Switzerland. The registered address is:

HAEi  
Avenue de Montchoisi 33  
1006 Lausanne  
Switzerland

Corporate Registration Number:  
CHE-160.474.141

Bank Connection:  
UBS Nyon, Switzerland

EUR Account:  
IBAN: CH06 0022 8228 1117 3360 T  
SWIFT/BIC: UBSWCHZH80A

USD Account:  
IBAN: CH54 0022 8228 1117 3361 Z  
SWIFT/BIC: UBSWCHZH80A

### Operations

HAEi  
Kirstinelundsvej 7  
8660 Skanderborg  
Denmark  
E-mail: [info@haei.org](mailto:info@haei.org)

Executive Director  
Henrik Balle Boysen  
Phone: +45 31 591 591  
E-mail: [h.boysen@haei.org](mailto:h.boysen@haei.org)

Communications Manager  
Steen Bjerre  
Phone: +45 22 20 46 01  
E-mail: [s.bjerre@haei.org](mailto:s.bjerre@haei.org)

Project Manager  
Deborah Corcoran  
Phone: +44 77 8060 8797  
E-mail: [d.corcoran@haei.org](mailto:d.corcoran@haei.org)