



2016

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HAEi Annual Report



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## Overview of HAEi

### HAEi Vision

HAEi's global vision is to improve time to diagnosis and facilitate access to and reimbursement for treatment that enables lifelong health.

As a global umbrella organization, our objective is to develop a network of national member organizations that advocate for HAE awareness and access to modern therapy. Currently, HAEi is represented in 55 countries worldwide.

In some countries, we have fairly large member organizations while in others there are a few enthusiastic advocates. The prospect for expanding global access to HAE treatments motivates us to inspire the formation of new HAE advocacy groups, and to help existing member organizations expand their activities.

### HAEi Mission

1. Helping to find, organize, and empower patients with an interest in forming new HAEi member organizations.
2. Supporting our existing member organizations in their ongoing efforts to grow their organizations and raise HAE awareness, increase diagnosis, and advocate for patient access to and reimbursement for modern life saving therapies.

## Executive Director's Message



On behalf of the Executive Committee, this annual report sets out the progress that HAEi has made on many fronts this year and introduces the initiatives we want to take forward into 2017.

As a global umbrella organization, our objective is to develop a network of member organizations that advocate for HAE awareness and access to modern therapy.

This year, we continued our efforts to develop member organizations in new countries, raise global awareness, and drive improvements in diagnosis and patient access to HAE treatments.

Some of our key achievements in 2016 included:

- Incoming four new HAEi member organizations,
- Reaching thousands of new HAE patients, clinicians and nurses with our meetings and workshops,
- Our fifth global awareness day **hae day :-)** supported by a revamped online platform at [www.haeday.org](http://www.haeday.org),
- Planning and executing the third HAE Global Conference, and
- Refreshing our website at [www.haei.org](http://www.haei.org), with additional information and functionality.

The HAEi Team is proud to be part of the HAE family. We constantly strive to improve the situation for HAE friends all over the world. Thank you to everyone who works with us and supports us to make this possible.

Warm regards,

Henrik Balle Boysen  
Executive Director

## President's Message



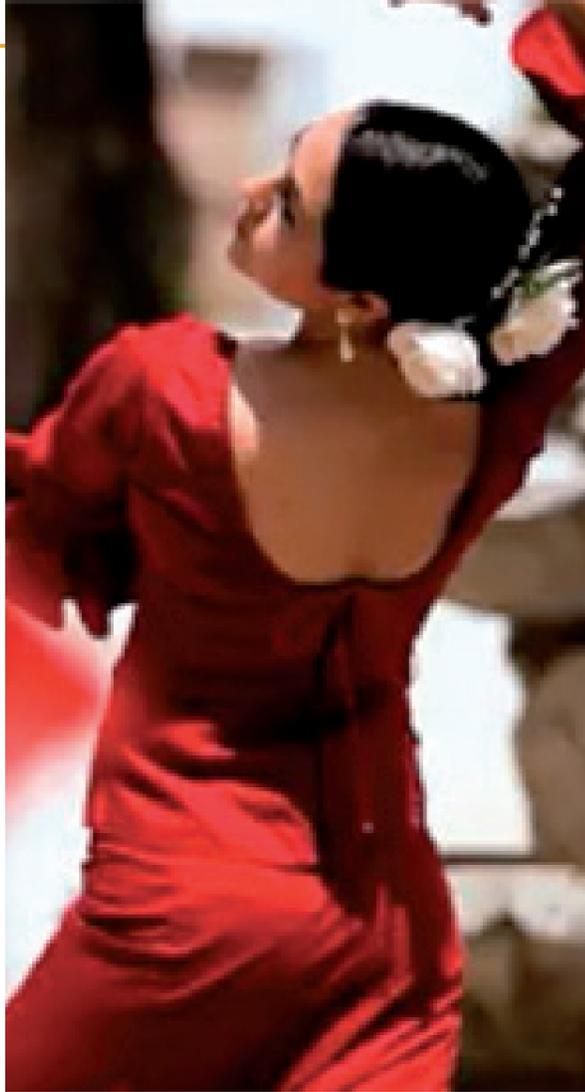
Thanks to the leadership of HAEi's Executive Committee and the hard work put in by the HAEi staff and patient advocates in our member organizations, 2016 was yet another busy and successful year. Our continued focus on helping new patient groups get started met with great success as four new national organizations joined HAEi creating a global patient advocacy community that is now 55 nations strong.

As you will read in the following pages, during 2016 HAEi continued to vigorously fulfill its core mission of supporting member organizations through a wide variety of important activities including: Sponsoring Regional workshops attended by patients and health care professionals; publishing 'first of its kind' reports for Europe and Latin America; and rolling out a comprehensive initiative to convince patients to get all family members tested for HAE.

While we continue to make good progress, we are motivated to take on the many challenges that face us. We are more committed than ever to leading aggressive advocacy efforts aimed at broadening access to life saving medicines in areas where limitations have a negative impact on patient quality of life. We look forward with enthusiasm to continue working with all of our stakeholders – member organizations, physicians, and pharmaceutical companies – to eliminate barriers that prevent access to life saving modern therapy.

Warm regards,

Anthony J. Castaldo  
President



## Record-breaking third global conference

The third HAE Global Conference in Madrid, Spain was record-breaking in a number of ways: The largest Scientific Program Committee, the largest number of participants (528) and countries represented (52), the largest number of keynotes, presentations and posters, the first HAE Global Conference with royal patronage – and an international gathering with a very successful youngsters' track.

Once again, there was a tremendous interest for travel grants and all grants were allocated. In total more than 320 people received travel grants from HAEi, enabling them to take part in the conference.

The theme for the conference was 'Creative Advocacy for Expanding Access to Therapy', where the aim

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

Besides the general sessions the 2016 HAE Global Conference had four tracks: A patient and caregiver track, a healthcare professional track (developed together with our three Scientific Program Committee Co-Chairs, Professors Marco Cicardi, Konrad Bork and Bruce Zuraw), a nurses educational and networking track, and a HAE youngsters track.

Additionally, we introduced the US film director Natalie Metzger's film 'Special Blood' focusing on a number of patients with HAE.

It was with the greatest of pleasure that HAEi and the Spanish HAE organization (AEDAF) received confirmation from the Royal Household of His Majesty the King of Spain that Her Majesty the Queen agreed to accept the Presidency of Honor for the conference.

In the area of health, the Queen of Spain has devoted herself to encouraging and giving visibility to those suffering from 'rare diseases' and their families, and to the fight against cancer. For her commitment to rare 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."

There is thorough coverage of the HAE Global Conference in the June 2016 newsletter – see [http://haei.org/wp-content/uploads/2016/06/HAEi\\_Newsletter\\_June2016\\_MV.pdf](http://haei.org/wp-content/uploads/2016/06/HAEi_Newsletter_June2016_MV.pdf)

Furthermore, we have collected some of the highlights of the conference at <http://haei.org/gc2016>. Here, among many other things, you will find an overview of the delegates country by country, the conference program in highlights, and the results of a survey conducted amongst the participants. Also, the website includes short videos with some of the delegates, the official trailer for the 'Special Blood' film, and a lot of pictures from the conference days in Madrid.

Here are just two extracts from the survey on the 2016 HAE Global Conference:

- 97 percent of the respondents rated the conference as either 'extremely useful' or 'useful'
- 97 percent of the respondents would attend the HAE Global Conference in the future.



Also, the 2016 HAE Global Conference website is where you will find short videos with HAE patients from Australia, Belarus, Brazil, Colombia, Denmark, Ecuador, Kenya, Serbia, Turkey, United Arab Emirates, United Kingdom, and USA, letting you in on their lives with an extremely rare disease. Some videos are in English while others are in Arabic, Portuguese, Spanish, Swahili, or Turkish.

Once again we were delighted to have the support from a number of leading pharmaceutical companies in the field of HAE: Shire (Diamond sponsor), BioCryst Pharmaceuticals and CSL Behring (Gold sponsors), Pharming Group NV/Sobi (Silver sponsor), and KalVista Pharmaceuticals (Basic sponsor).

## Reaching new countries around the world

Supporting the development of new member organizations is one of HAEi's core activities. We actively seek out interested patients or physicians who wish to make a difference and establish a member organization in their country.

In 2016 HAEi welcomed four new member organizations, which brings the total number to 55.

Initiating a new HAE group in any country takes time, dedication and partnership amongst many stakeholders. One country where HAEi sees great potential in terms of HAE patient identification is the Philippines. The country has a strong medical infrastructure and an experienced organization that represents rare disease patients, the Philippine Society for Orphan Disorders (PSOD) – and a potential of some 3,000 HAE patients. Throughout 2016 we worked with PSOD officials to come up with a plan for patient identification, physician education, and formation of a HAE group under the PSOD umbrella. In August we met with a Filipino family afflicted by HAE that is now in the process of forming a national organization.

2016 also brought a meeting with the newly established patient association in Turkey – among other things on the planning of a patient/physician workshop – as well as discussions with rare disease experts in Thailand to plan expansion in South East Asia.

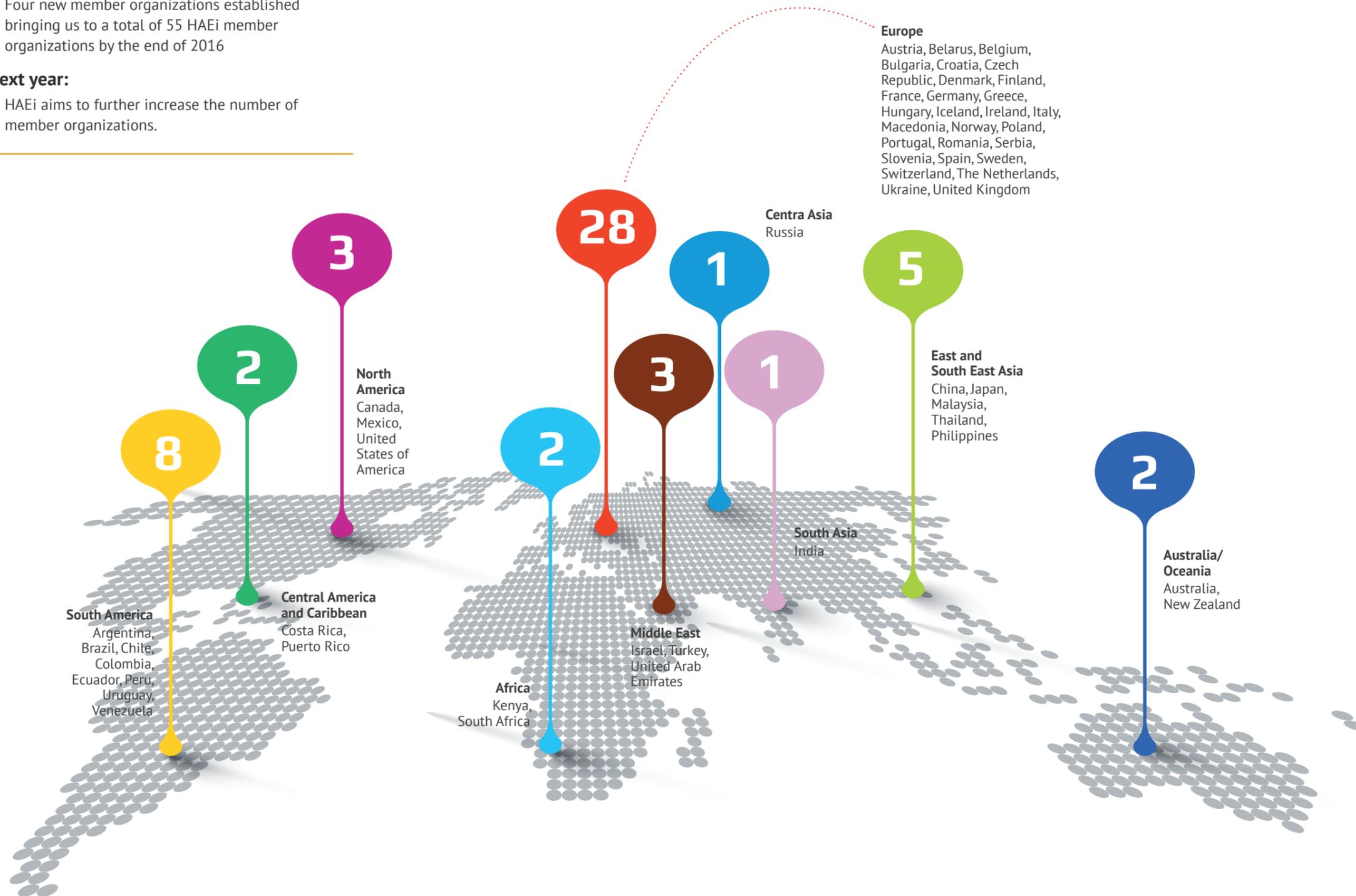
Current information on HAEi's global presence can be found at [www.haei.org](http://www.haei.org). The website includes an updated list of organizations by country as well as a searchable map with a listing for each country including contact data for the member organizations. The website also provides you with information on care centers, hospitals, and physicians as well as available medications.

### This year:

- Four new member organizations established bringing us to a total of 55 HAEi member organizations by the end of 2016

### Next year:

- HAEi aims to further increase the number of member organizations.





Michal Rutkowski

Rashad Matraji

Natasa Angjeleska

Maria Ferron Smith

Alejandra Menéndez

#### This year:

- HAEi created the role of Regional Patient Advocates to act as the bridge between HAEi and individual countries
- HAEi participated in four member organization national meetings
- HAEi helped organize and/or participated in four regional workshops

#### Next year:

- Continue to participate in member organization national meetings
- Organize three to five regional workshops
- Expand the network of Regional Patient Advocates, firstly to Sub-Saharan Africa

## Supporting member organizations around the world

In January 2016 HAEi appointed the first five Regional Patient Advocates (RPAs), dividing a large portion of the world between them. For the first six months the role of the RPAs were 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.

These are the first five RPAs:

- **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. 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 – who was diagnosed in 2009 but has experienced symptoms since his 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 a number of other countries in her region. Natasa lives in Skopje.
- **Maria Ferron Smith** (Malta) 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 <http://haei.org/organization/meet-the-rpas>.

Throughout the year HAEi has continued a strong support of the member organizations. For example, we participated in national meetings and conferences in Brazil, Austria, and the United Kingdom helping to educate and empower HAE patients.

In Sao Paulo, Brazil we met with the national member organization in order to evaluate and enhance the access to medication process in the country, while in Vienna, Austria we took part in the 10th anniversary celebration for the national organization – and in Bristol, United Kingdom we participated in the HAE UK Patient Day. It was a very successful meeting with great speakers and highly motivated patients, and we were especially pleased by the active involvement of youngsters with HAE.

In addition, we helped organize and/or took part in four regional workshops, which brought together HAE patient advocates, nurses and physicians to meet and exchange information and ideas about HAE management and advocacy:

- In Doha, Qatar we participated in and helped the HAEi Regional Patient Advocate coordinate the 2nd Gulf Region workshop with a good representation from all the Gulf Region countries
- In Skopje, Macedonia we participated in and helped the HAEi Regional Patient Advocate coordinate the HAEi Balkan regional workshop
- In Warsaw, Poland we attended the successful 2016 HAEi Central & Eastern Europe Countries conference
- In Dubai, United Arab Emirates we conducted a workshop/board meeting with the HAEi Regional Patient Advocate and physicians from the region, focusing on devising strategies to find more patients and enhance the patient/physician partnership in order to gain better access to HAE medicines.

## Supporting the HAE family globally

A key part of the HAEi support for patients as well as member organizations throughout the world involves sharing experiences and information. This is done via a number of channels – from the HAEi websites and social media presence to the HAEi magazine and other publications. Naturally, the annual HAE Awareness Day is also a vital part of the way we support the HAE family around the globe.

### HAEi websites

This year, HAEi has further developed the website [www.haei.org](http://www.haei.org), among other things with a presentation of the Regional Patient Advocates, highlights from the 2016 HAE Global Conference, and a few more patient stories.

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 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 and free of charge.

At the end of the year national websites had been launched for Iceland, Greece, Kenya, Macedonia, Serbia, Spain, and Turkey – and a few more were in the making.

Also, we have redesigned the campaign website at [haeday.org](http://haeday.org) in order to better match **hae day** :-) 2016.

### Social media

HAEi uses a number of social media channels to communicate with the HAE family:

-  **Facebook** (1,900+ members):  
<http://facebook.com/groups/172320032283>
-  **LinkedIn** (200+ followers):  
<https://goo.gl/QfMTHL>
-  **Twitter** (175+ followers):  
<http://twitter.com/HAEDAY>
-  **YouTube channel** (45+ subscribers):  
<http://youtube.com/user/haedaychannel>

### HAEi magazine

First introduced in November 2012, the HAEi newsletter has developed quite a lot. Thanks not least to the enthusiasm of the national member organizations the content grew from issue to issue and since a newsletter is normally expected to be pretty short we had to realize that it wasn't really a newsletter any longer.

As a consequence we decided to introduce 'Global Perspectives', a magazine that continues HAEi's commitment to bringing the readers timely information on the issues, activities, and events that are relevant to the global HAE community.

We aim at distributing 'Global Perspectives' to the now more than 1,000 recipients four times during 2017.



### Publications

During the first months of 2016 HAEi announced the publication of the first report titled 'State of Management of HAE in Latin America'.

The report – including the results of the first survey conducted among representatives of HAE patient associations and groups from 9 Latin American countries – revealed that the situation throughout the region is far from acceptable. In only two of the surveyed countries the support for HAE patients was gradually approaching the optimal treatment and management model for this disease. The survey also revealed that the quality of diagnosis, patient care and treatment availability varies significantly between the region's countries but that, in all cases, it is clearly deficient and calls for immediate, radical change.

This report is available in Spanish at <http://goo.gl/08jAsD> and English at <http://goo.gl/2VgN5l>.

### hae day :-)

We launched the first **hae day :-)** in 2012. This was done with the aim to establish a global and national awareness day for HAE and to give our member organizations an annual focal point for awareness and fundraising efforts.

Previously we have kept to supplying the national organizations with a toolkit of documents and information to guide them through key stages of organizing an event, raising awareness through the media and holding meetings with key physicians. However, for 2016 we decided also to organize a truly global HAE awareness event and from 15 to 17 May 80 people – the majority of them suffering from HAE – walked part of the legendary Camino de Santiago in northern Spain together.

Over three days they took close to 4,000,000 steps for HAE awareness. These brave souls – coming from Argentina, Australia, Brazil, Canada, Denmark, Hungary, Italy, Japan, Mexico, New Zealand, Spain, Sweden, USA, and Venezuela – joined forces and proved to themselves and others that obstacles are only there to be overcome. Indeed, if you want to – you can.

A lot of pictures from the event – organized with the invaluable help of the Spanish national organization AEDAF – as well as comments from the participants can be found on [www.facebook.com/groups/172320032283](https://www.facebook.com/groups/172320032283).

Before **hae day :-)** 2016 quite a number of people told us that they would really have liked to take part in the Camino Walk but were for one reason or the other unable to go. Therefore we set up a website for a 'HAE Global Walk' and encouraged everyone interested to participate. All they needed to do was to walk any distance they would like wherever they would like – on their own or together with others – and report the distance walked to the website. We would then add these steps to those taken by the people doing the Camino Walk.

It was a delight to see how well the idea caught on, literally all over the world. The campaign opened late April and ran all through May 2016, allowing people to enter as many walks as they would like. And there really was a tremendous amount of HAE walking going on. Including the almost 4,000,000 steps taken during the Camino Walk we registered more than 12,000,000 steps taken by individuals as well as by groups wanting to be part of the HAE awareness movement. With almost 1,200 people walking in Argentina, Australia, Austria, Belgium, Brazil, Canada, Cyprus, Czech Republic, Denmark, France, Germany, Greece, Honduras, Ireland, Italy, Kenya, Luxembourg, Macedonia, Malta, Mexico, New Zealand, Peru, Russia, Serbia, Spain, Sweden, Switzerland, The Netherlands, Turkey, United Arab Emirates, United Kingdom, Uruguay, USA, and Venezuela there is no doubt that this became a truly international event – just like the HAE Global Conference.

### HAE Global Conference

As for the 2016 HAE Global Conference held in Madrid, Spain you will find detailed information on page 6.

The venue for the 2018 HAE Global Conference will be disclosed on **hae day :-)** 2017. Once again we will be looking for the cheapest and best option, not least when it comes to flight connections throughout the world. The conference will take place 17-20 May 2018 – and the planning has already begun. For the upcoming HAE Global Conference we will let the member organizations take care of marketing the conference – and decide who will participate in the conference.

#### This year:

- Further developed [www.haei.org](http://www.haei.org) and hosted more national websites through this platform
- Redesigned [www.haeday.org](http://www.haeday.org)
- Introduced one more patient story on the website
- Published the first report titled 'State of Management of HAE in Latin America'
- Produced and distributed three editions of the HAEi newsletter – and then the first issue of the magazine 'Global Perspectives'
- Planned and delivered the HAE Global Walk as well as the HAEi/AEDAF Camino Walk
- Planned and delivered the 2016 HAE Global Conference

#### Next year:

- Increase the number of languages supported on [www.haei.org](http://www.haei.org)
- Increase the number of member organizations with web presence hosted via [www.haei.org](http://www.haei.org)
- Update the toolkit to support national awareness events around **hae day :-)**
- Plan and deliver the 2017 HAE Global Walk
- Plan and deliver the 2017 HAEi/AEDAF Camino Walk
- Plan the 2018 HAE Global Conference

## Advocating for and supporting access to medicine



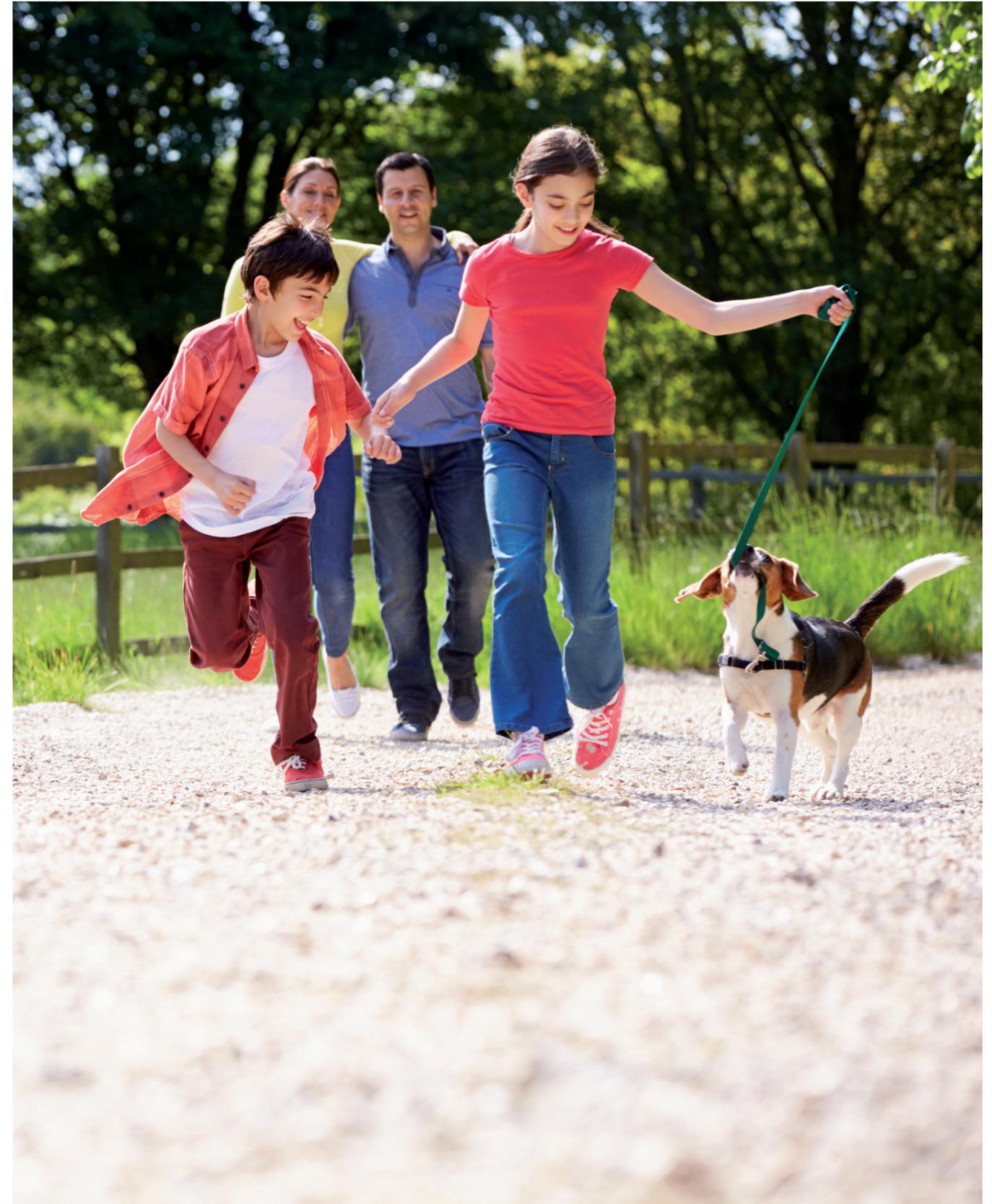
In 2015 HAEi launched a unique Global Access Program (HAEi GAP). It is the first time that a patient group has initiated this type of medication distribution program.

The HAEi GAP model initially includes a 'Named Patient Program' where a doctor orders the medication and the government, hospital or the patient's medical insurance, pays for the cost of the medication. Later it is planned to include a 'Compassionate Use Program' that offers donated medication to patients in parts of the world where this type of program is allowed, and an 'Early Access Program' where access to medication will be given in conjunction with a phase III clinical trial.

The first pharmaceutical company to join HAEi GAP was Pharming Group. As a result, HAEi GAP enables patients in all countries where Ruconest® is not commercially available to gain access to the drug through an ethical and regulatory compliant 'Named Patient Program' mechanism.

During 2016 we looked at ways for speeding up the awareness and get more traction to the program. As part of improving the GAP we invited four service providers to give us an overview of their capabilities to administer the GAP. We expect to have the service provider in place over the first months of 2017, allowing us to relaunch the GAP later on during the year.

Find more information about the HAEi GAP at [http://haei.org/hae/global\\_access\\_program](http://haei.org/hae/global_access_program).



## Advocating on behalf of patients and engaging healthcare professionals

As passionate patient advocates, HAEi constantly seeks input and collaboration with leading HAE experts. Attending medical conferences provides an efficient and cost effective way to interact with HAE key opinion leaders and other healthcare professionals. During 2016 we attended these meetings:

### January

- The Plasma User Group (PLUS) Consensus Meeting in Estoril, Portugal, discussing topics such as plasma donation from MSM donors

### March

- HiMSS 2016 (The Healthcare Information and Management Systems Society), in Las Vegas, USA
- AAAAI 2016 (The American Academy of Allergy, Asthma and Clinical Immunology), in Los Angeles, USA
- Foro Internacional Angioedema Hereditario in the Legislative Chamber of the House of Deputies in Mexico City, Mexico – we presented on the topic 'Reimbursing HAE medicines is a cost effective policy that saves lives'

### April

- The 6th Nordic Bradykinin meeting (organized by Shire) in Stockholm, Sweden

### May

- The Plasma Users Group (PLUS) meeting in Lisbon, Portugal discussing topics such as plasma supply and safety

### June

- EAACI 2016 in Vienna, Austria – HAEi was a part of the task force working on an updated version of the WAO Guidelines for treating HAE

### September

- The annual meeting of ASCIA (The Australasian Society of Clinical Immunology and Allergy) at Goldcoast, Australia
- The 3rd HAWK Consensus Conference in Gargnano, Italy with HAEi chairing a session on pharmacoeconomics and the cost of HAE medicines
- The Bradykinin Symposium in Berlin, Germany
- A conference including allergist/ dermatologist specialists from all over the country taking place in Bangkok, Thailand and prominently featuring HAE including a session with patients

### November

- The 2nd Rare Disease Asia Conference 2016 in Kuala Lumpur, Malaysia
- The Early Access Program's Conference in London, United Kingdom

### This year:

- Attended 13 HAE related medical conferences or major meetings
- Held one-to-one meetings with several global HAE experts

### Next year:

- Maintain attendance at HAE related medical conferences (global or regional)

## Updates and looking to the future

The following are some of the areas where HAEi expects to expand its activities during the coming year.

### Regional Patient Advocate training

Five Regional Patient Advocates (RPA's) were selected early 2016 and we expect to strengthen the network with at least one more RPA during 2017. We will conduct a Regional Patient Advocate workshop designed to support core skills required to fulfill the role and responsibilities in the regions.

### Youngsters' summer camp

Based on feedback from the youngsters, who gathered for the 2016 HAE Global Conference in Madrid, Spain there is a huge interest to bring young HAE patients together for a summer camp.

After analyzing several potential locations, we are planning for a first summer camp in Frankfurt, Germany in early August 2017. The primary reason is that the German national organization already has significant experience working with the youngsters.

### HAEi Connect

HAEi Connect is a cloud-based solution that will bring a wealth of possibilities to our member organizations. Initially, the functionality offered will be

- Member organization patient/member database with link to MailChimp for easy communication with members
- Webinar facility on the HAEi Connect portal/ dashboard – as well as a download area for presentations and other documents

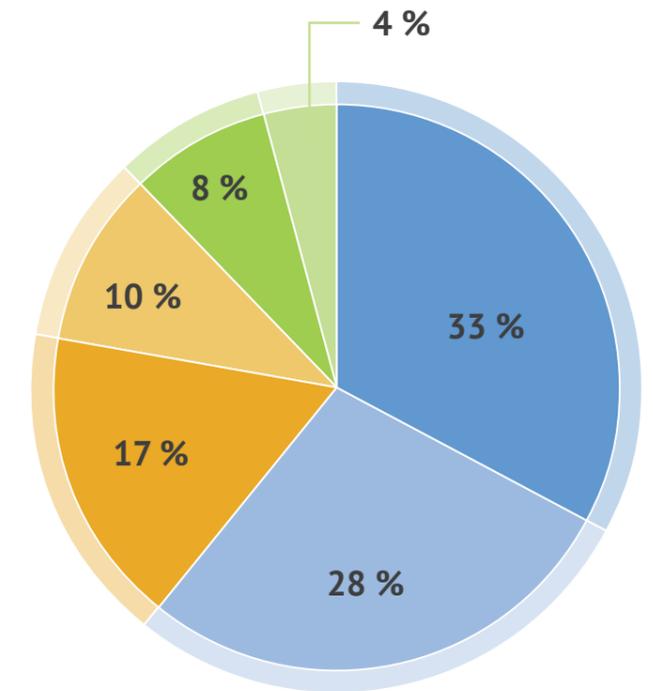
We expect to start beta testing in early 2017 in Scandinavia, Australia, and New Zealand with launch sometime during the year.





## Fiscal Year 2016

HAEi Expenses by Key Activity Category



## HAEi Executive Committee

We are delighted to introduce you to the HAEi Executive Committee:



**Anthony J. Castaldo, President**

Tony is a co-founder of HAEi and has been President since the organization's inception. He also serves as the President of the US HAE Association and on the Board of Directors of the National Organization for Rare Diseases. He dedicated much of his life to driving improvement in HAE care and remains highly motivated by the challenge of global HAE advocacy.



**Michal Rutkowski  
Vice President**

Co-founder and President of the Polish HAE organization Michal has been involved in HAE advocacy in his home country since 2005. 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 in Krakow, Poland with his wife and two children.



**Alejandra Menendez, Secretary**

Alejandra 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. A patient herself, Alejandra has two daughters with HAE. She lives in Buenos Aires, Argentina.



**Fiona Wardman, Treasurer**

Fiona is the President of the Australasian HAE organization which she co-founded in 2011. She is also the Treasurer for HAEi. Fiona is passionate about making a difference to HAE patients in her own region as well as globally. A patient herself Fiona lives in Glossodia, NSW, Australia.



**Sarah L. Smith Foltz**

Sarah is a co-founder of HAEi and served as treasurer until 2014. She is a founding member and president of the Spanish HAE association. Apart from Spain, she has supported efforts in Latin America through involvement in the Patient Advocacy Forum initiative. Sarah's husband and 3 daughters are HAE patients. She lives in Madrid, Spain.



**Jørn Schultz-Boysen**

Jørn holds the position as Treasurer of HAE Scandinavia. He has worked for a number of large Danish corporations including Bang & Olufsen and currently holds a management position with Grundfos. Jørn is a patient himself as is one of his two children. He lives in Struer, Denmark.



**Rachel Annals**

Rachel is Executive Officer of the UK HAE organization. She is focused on patient advocacy and one-to-one support as well as organizing patient events. Rachel is a HAE patient herself. She lives with her husband and daughter in Bridgwater, United Kingdom.



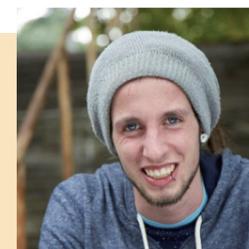
**Beverley Yamamoto**

Beverley serve as the President of the Japanese HAE organization, enjoying greatly being able to contribute to both the national and the global patient organizations. Beverley is a HAE patient herself as is her son. In her day job she is a university professor, living in Osaka, Japan.



**Natasha Jovanovska Popovska**

Natasha is the President of the Macedonian HAE organization. She is very active towards raising awareness on HAE among medical staff and the general public, dedicated to bringing closer the entire Balkan region to tackle HAE. Natasha is a HAE patient herself. She lives in Skopje, Macedonia.



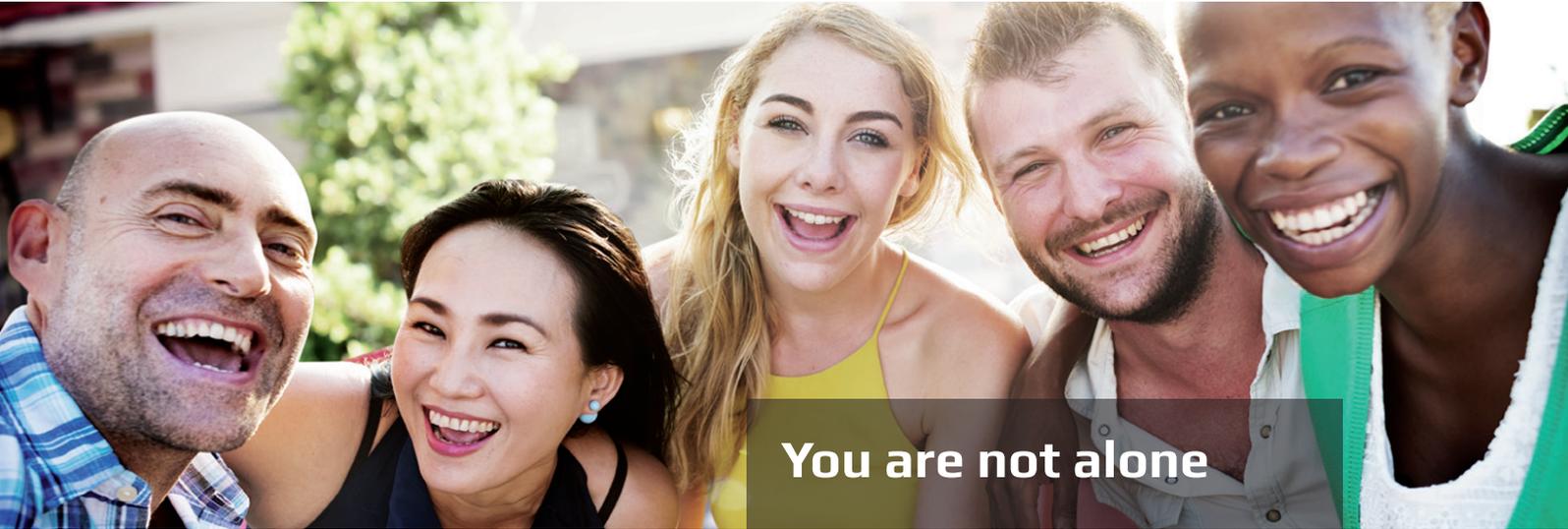
**Nils Berretz**

Nils is working with public relations within HAE Germany and just like his father and younger brother he is a HAE patient, diagnosed when he was born. In 2013, Nils was part of the first HAE-Youngster meeting in Berlin and most recently he has taken part in the HAE film "Escaping the Labyrinth". Nils, who wants to study for social worker, lives in Eschweiler, Germany.



**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**

### **Corporate Information**

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

The registered address is:

HAEi  
Av. Parc-de-la-Rouvraie 3  
Case postale 87  
1000 Lausanne 8  
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**

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