

Dear HAEi Member,

Over the years, we have communicated with you, our HAEi member organizations, through our website, [www.haei.org](http://www.haei.org). This inaugural HAEi newsletter is part of our strategy for expanding our ability to keep in touch and inform you about HAEi activities. We plan to send the HAEi newsletter on a quarterly basis. We would like to know what you believe should be included in future newsletters, so please provide feedback to either Henrik Boysen at [h.boysen@haei.org](mailto:h.boysen@haei.org) or Steen Bjerre at [s.bjerre@haei.org](mailto:s.bjerre@haei.org). In addition, we invite you to submit articles on any topics that you believe would be of interest to other member organizations.

We look forward to your comments and working with you on future newsletters.

***HAEi Executive Committee***

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### **HAEi Newsletter – November 2012**

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### **HAEi 2012 global conference – the largest international HAE event ever held**

Some 350 delegates from all over the world including distinguished scientists and health care professionals gathered in Copenhagen, Denmark 17-20 May 2012 to share ideas and strategies to advance HAE “Advocacy and Access”.

Judging from the overwhelmingly positive emails, phone calls, and comments on Facebook, this first ever global conference for HAE patients, caregivers, health care professionals, and industry representatives was an amazing success.

Following meetings of the HAEi Executive Committee and the HAEi Scientific Program Committee on Thursday 17 May, the conference opened Friday 18 May with a scientific track that addressed “Pathophysiology of HAE, what do we still need to know?” and “HAE in women and children, specific unresolved problems.” Although primarily aimed at the international doctors and health care

professionals (representing Argentina, Australia, Brazil, Chile, China, Denmark, France, Germany, Italy, Hungary, Poland, Romania, Spain, Switzerland, and USA) many patients and other non-health care professionals chose to sit in on the sessions and absorb the important information being presented.

All of the conference delegates gathered for the Friday afternoon general assembly session. HAEi Executive Director Henrik Boysen started the meeting by asking the assembled delegates to explore innovative strategies to fulfill the conference theme – “Advocacy and Access”. Henrik noted that the lessons learned during the conference will serve as a call to action to guide advocacy efforts when delegates return to their respective countries:

“It is our hope that this meeting will encourage greater interaction between patients, the scientific and medical community, and the pharmaceutical manufacturers, leading to innovative and aggressive strategies for more timely diagnosis and wider access to life saving HAE therapies.”

Marco Cicardi, Professor of Internal Medicine at Milan University, delivered the conference’s keynote address. Professor Cicardi is a pioneering HAE physician/scientist who has authored over 150 scientific papers on the disease and sees more than 600 patients. Prof. Cicardi provided the audience with a very enlightening talk that gave the delegates an insight into the history of HAE science and patient care. Next, HAEi President Tony Castaldo discussed the importance of all stakeholders—patients, physicians, and pharmaceutical companies—working together to advocate for access to HAE medicines.

The third speaker – Mrs. Birthe Byskov Holm, the co-founder and current President of the Danish rare disease alliance and a patient representative on the Committee of Orphan Medical Products of the European Medicines – provided an overview of (1) best practices for obtaining rare disease medicine reimbursement, and (2) the role of regulatory authorities on orphan drug approval. Marc Riedl, Associate Professor of Medicine and Section Head of Clinical Immunology and Allergy in the Department of Medicine at the University of California at Los Angeles delivered the final address of the afternoon session. Dr. Riedl provided invaluable insights into how HAE patients can approach their physicians to obtain optimal care.

The Saturday morning 19 May conference proceedings offered scientific and patient sessions. The scientific track covered topics such as (1) the state of HAE diagnosis in the world, (2) how to improve timely recognition of the disease, and (3) what can be done to assure a minimum standard of care. During the patient session, delegates from 25 countries provided fellow patients with a status report on HAE diagnosis and treatment in their countries.

In the afternoon delegates gathered for the final general session where the Scientific Committee and the HAEi Executive Committee shared insights gained from the unique design of this conference which blended science with patient advocacy. During this session, health care providers and patients discussed

a variety of strategies for putting into practice what conference attendees had learned about HAE “Advocacy and Access”. HAEi President Tony Castaldo closed the meeting by summarizing the significance of this groundbreaking meeting:

“This inaugural event is the largest worldwide gathering of HAE patients that has ever been organized and it has been extremely informative. The unique blending of science with patient and physician interaction demonstrated that we are not alone in facing the many challenges of HAE. Delegates from throughout the world now have some basic strategies and tools to advocate for HAE patients in their home countries. This conference has proven beyond any doubt that we stay stronger if we stay connected and that is just what we will do until the next global conference that will take place in May 2014.”

While the conference involved a very full agenda, there were also ample time for the HAEi community to socialize and exchange views and information on HAE treatment in their respective countries during the welcome reception, lunches and coffee breaks, the gala dinner that was held on Saturday evening, and the Sunday morning sight-seeing tour of Copenhagen.

The HAEi community is grateful for the generous support provided by Diamond sponsors ViroPharma and Shire, Gold sponsors CSL Behring and Dyax/Sigma-Tau, and Silver sponsor SOBI Swedish Orphan Biovitrum – enabling us to host this first global HAEi conference.

## **A new member of the HAEi Operations Team**

Mr. Steen Bjerre has come on board to serve as HAEi’s Communications Manager.

Steen graduated from the Danish School of Journalism in 1984. He was with the first wave of independent television and radio stations in Denmark and later on worked at the national radio station. After some years as a copywriter, PR employee and Public Relations Manager with advertising agencies, he established his own communications company in 1992. He has worked with a very broad spectrum of companies, both within the private and the public sector.

In addition to running his own company Steen was co-owner of a Danish fundraising company (2004-05), Chairman of the private foundation Tall Ship Aalborg Fonden (2004-09), and Chief Communications Officer for a major Danish advertising agency (2008-11).

Steen has considerable experience working in the HAE field. In 2011, he was hired by the Danish HAE patient organization to write a book about living with HAE. The book was published for the Danish organization’s 10th anniversary and carried the title “Livet er ikke det værste man har” (“Life is not the worst thing you have”).

Steen's contact details are:

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### **Website soon to be launched in Russian as well**

As you might recall the HAEi website at [www.haei.org](http://www.haei.org) has always been available in five languages – English, German, Italian, Spanish, and French. Our translators are busily working to ensure that the website will soon be available in Russian as well.

### **Countdown to hae day :-) 2013**

On 16 May 2013 we will once again celebrate global **hae day :-)** HAEi will once again serve as the international hub for HAE activities sponsored by our member organizations and expect to launch the updated website early January 2013.

The goal of **hae day :-)** is to (1) raise awareness of HAE among the general public as well as the medical community, (2) create an environment for earlier and more accurate diagnosis, and (3) spread knowledge that HAE patients can use to advocate for better care that will lead a healthier life.

Please make sure to follow the planning of national and international events for the 2013 version of the **hae day :-)** at [www.haeday.org](http://www.haeday.org), and—most importantly—to load your own events “live” on the website.

We made a lot of noise with our 2012 **hae day :-)** campaign – and, in 2013, are aiming at being even more visible and securing additional awareness of the global need for early and accurate HAE diagnosis and access to suitable therapies.

### **HAEi's global advocacy work**

HAEi is invited to participate in a variety of international meetings. Below is a brief overview of recent activities:

August 2012: **Bradykinin workshop** at the **Charité University Hospital in Berlin**. Organized by Berlin-based Professors Maurer and Magerl, this meeting included discussions on a variety of topics including (1) regarding the role of bradykinin in angioedema, and (2) the possibility of a European emergency card/pass for patients to present at emergency rooms. HAEi recognizes that the emergency card/pass is

a very important project and will work with leading European HAE physicians to get this program implemented.

September 2012: HAEi participated in a workshop (arranged by Dr. Dumitru Moldovan in **Romania**) aimed at establishing guidelines for the treatment of Romanian HAE patients. We met and provided guidance to three patients who are in the process of registering a patient association in Romania. HAEi will continue to support these patients and, hopefully, we will soon be welcoming Romania into the growing family of HAEi National Member Organizations.

In September HAEi took part in the conference **ASCIA 2012 (Australasia Society for Clinical Immunology and Allergy)** in **Wellington, New Zealand**. HAEi together with HAE Australia set up a booth so we could greet and chat with attending physicians. During the conference, HAEi worked with physicians who are interested in helping patients establishing a patient group in New Zealand.

Also in September, HAEi traveled to **the Philippines** to meet with officials from the **Department of Health** and **the Philippine Society for Rare Diseases (PSOD)**. These meetings provided a first step towards organizing an advocacy group that includes patients and physicians. PSOD—which has been successful in organizing and obtaining treatment for patients with lysosomal storage diseases – is excited about working with HAEi to facilitate the establishment of an HAE patient advocacy group. PSOD is also in the process of putting HAEi in contact with other rare disease advocacy groups in the Western Pacific.

In November HAEi will be present at the 2012 **ACAAI (American College of Allergy, Asthma and Immunology)** in **Anaheim, California, USA**. The ACAAI meeting is attended by many of the world's leading HAE doctors and in 2012 will feature a variety of HAE lectures and events. It is typically a big focus event for HAE and thus a great opportunity to network with both physicians and industry.