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A Message from the President

Dear HAEi Friends,

These are exciting times as HAE friends in more countries become active and join the global HAE advocacy movement.

We congratulate our member organizations for yet another successful global awareness day. The growth in both the number and scope of **hae day :-)** events has been nothing short of extraordinary. There is no doubt that the 2014 version of the **hae day :-)** will be even bigger and continue to highlight the energy, optimism, passion, and creativity that is characteristic of HAEi friends throughout the world.

The forthcoming Global HAE Conference (see announcement below) that will take place in the Washington, DC metropolitan area 15 - 18 May 2014 will provide HAE advocates from around

the world with the opportunity to share experiences and strategies regarding

- forming an HAE organization,
- finding more patients,
- raising patient and physician awareness and education,
- improving the timing and accuracy of the HAE diagnosis, and
- gaining access to and adequate reimbursement for HAE medicines.

In addition, we will have the opportunity to learn from and interact with the world's leading HAE physician researchers. Of course, let's not forget that the conference will also be a lot of fun and there will be plenty of time for interacting with fellow patients and physician participants.

Warm regards to all,

Tony

Anthony J. Castaldo
President, HAEi

Global Conference 2014

At the first HAEi global conference in Copenhagen, Denmark in May 2012 we decided that the next conference of its kind should take place in 2014.

We have now started the preparations for this big event that will take place in Washington D.C. Metro Area, USA from 15 until 18 May 2014.

Please keep an eye out for more information about the global conference 2014 and for where to register on www.haei.org, www.haeday.org, www.facebook.com/haeday, and www.twitter.com/haeday.

We expect to be ready for registrations in late October 2013.





“Running for Better Life” was the marathon theme for hae day :-) 2013 in Macedonia

Successful hae day :-) 2013

The global **hae day :-) 2013** was quite successful with a number of activities in many countries around the world – below are examples of a few events.

The HAEi National Member Organization in Macedonia organized a series of exciting **hae day :-)** events that spanned almost the entire week from Sunday 12 to Saturday 18 May 2013. HAE Macedonia and the rare disease association *Life with Challenges* participated in an annual marathon that took place in the Macedonian capital Skopje on 12 May. Rare disease patients and supporters ran under the motto **“Running for Better Life.”** The runners wore pink T-shirts to stand out from the crowd and emphasize the plight of rare disease patients. We are happy to report that the HAE Macedonia women won first place honors! The event had media coverage and HAE patients had a chance to speak out.

In addition, on 16 May HAE Macedonia members made numerous

appearances on the country’s TV and radio programs in order to raise awareness and highlight the fact that funding for HAE medicines has not yet been addressed by the Macedonian government.

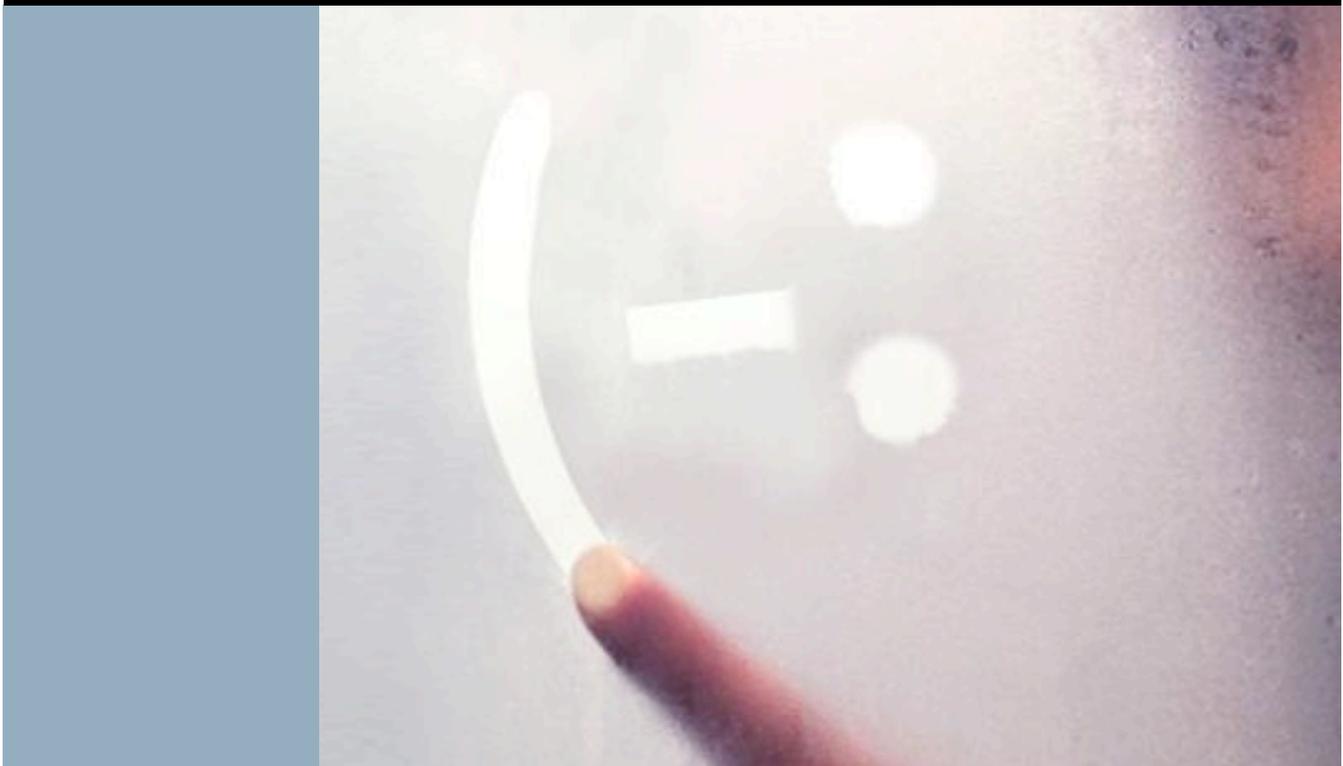


In Turkey more than 40 patients attended an **hae day :-)** meeting held in Ankara. Officials from SGK (the main health foundation organization in Turkey) attended the meeting, providing patients a chance to discuss the lack of HAE therapeutic options in Turkey. The HAE patients’ organization in Turkey also provided information about the plight of patients to journalists who work at various Turkish newspapers.



The US HAE Association was on hand to raise HAE awareness in the Commonwealth of Puerto Rico, following the Puerto Rican government’s vote to declare 16 May as **hae day :-)**. Puerto Ricans are US citizens and an estimated 130 HAE patients live on this island.





HAE Canada Continues to Grow

After securing the first significant funding from sponsors, the Board of Directors of the National Member Organization in Canada retained the services of Association Management International to provide administrative support for the operations of HAE Canada. Peter Waite, who is the President of the company, became the first Executive Director of the Canadian organization and he and his team have seen HAE Canada through a year of tremendous activity and growth. Part of Peter Waite's responsibilities was to support the work of the affiliated physician network, the Canadian Hereditary Angioedema Network (CHAEN).

Over the past year CHAEN became a fully incorporated non-profit organization and secured funding for projects which will include a conference in November to establish Canadian HAE Guidelines. HAEi has been invited to attend this meeting.

HAE Canada and CHAEN are pleased to announce that Paulette Vinette will be taking over primary responsibility for HAE Canada as the Executive Director. Peter will be concentrating on his expanding role as Executive Director of CHAEN.

Paulette, who has been helping Peter since October 2012, has many years of experience working in non-profit management and has now had a chance to meet patients at meetings HAE Canada has been holding from coast to coast.

HAE Canada has grown from 12 to 150 members in just one year. The primary focus of the organization is on publishing comprehensive care standards for patients across Canada, as well

as offering Home Infusion Guidelines and online HAE educational tools.

The second Annual General Meeting of HAE Canada will be held in Toronto on 4 October, followed by a HAE update event. Dr. Stephen Betschel will give the keynote presentation that will focus on HAE treatments and will also preside over a questions and answers session. A French-language HAE update was held on 21 September in Montreal, featuring a keynote presentation by HAE specialist Dr. Jacques Hébert.

Presence on Facebook

In addition to participating in the patient community on the HAEi website, National Member Organizations also post information on Facebook. One of the most recent we have seen is HAE Austria which has an open group at www.facebook.com/home.php#!/home.php. HAE Austria has posted information on activities such as the HAE telephone hotline open daily from 9 to 18 and the family weekend held 31 August to 1 September 2013.

While the National Member Organization in Portugal is still working on getting the website up and running our Portuguese friends are now also present on Facebook. Check out what is happening in the westernmost corner of the European mainland at www.facebook.com/adah.portugal?fref=ts.





From the HAE Australasia meeting in Brisbane.

The EAACI-WAO Congress was opened by Andrea Bocelli - and followed by an intensive scientific program - also covering a lot around HAE.

Fruitful HAE Australasia patient meeting

The National Member Organization covering Australia and New Zealand held its second patient meeting in spring 2013.

Fiona Wardman, President of HAE Australasia, spoke of the progress of the group over the two years, the greatest achievements being the listing of Icatibant for reimbursement and the inclusion of New Zealand patients in the organization. Professor Connie Katelaris, who is the HAE Australasia medical advisor, delivered an overview of HAE, the cause, the symptoms and the treatment. She also spoke about the usage and experiences of Icatibant since its listing on the Pharmaceutical Benefits Scheme of Australia in August 2012 as well as on the benefits of forming a Patient Registry, and the contribution this could make to treatments. Among the other speakers were Maureen Hutchinson, who shared her personal HAE story, Associate Professor Richard Loh, who informed the participants of his experiences of thirty years of treating HAE patients, and Pam Burton of Campbelltown Hospital, who demonstrated the technique required for the self-administration of Icatibant subcutaneously.

Just around the time of the patient meeting HAE Australasia launched its website – please see www.haeaustralasia.org.au.

HAE Presentations at EAACI-WAO in Milan

Representatives of HAEi were among the close to 7,700 attendees taking part in the EAACI-WAO Congress in Milan 22-26 June 2013. The scientific program had over 340 sessions, some of them that specifically focused on HAE. The HAE-related sessions included:

“Pathogenesis of hereditary angioedema” – chaired by Marco Cicardi (Italy) and Henriette Farkas (Hungary)

“Early treatment outcomes in HAE types I and II: bradykinin receptor blockade using Icatibant in the real-world

setting”, chaired by Hilary Longhurst (United Kingdom) and Bruce Zuraw (USA),

“An interactive case based approach to the diagnosis and management of HAE”, chaired by Marco Cicardi (Italy).

There were a number of poster presentations and poster discussion sessions on HAE.

EAACI-WAO: Examples of lectures by physician/scientist groups

- Burden of illness (*T. Caballero, Hospital de la Paz, Spain*)
- HAE due to C1 inhibitor deficiency: clinical descriptive study in an international cohort (*M Caminoa, Hospital La Paz, Madrid*)
- HAE due to C1 inhibitor deficiency: clinical descriptive study in an international cohort (*M Caminoa, Hospital La Paz, Madrid*)
- Does treatment choice affect the duration of an HAE attack? Results from a Milan patient cohort (*M. Cicardi, Milan University, Italy*)
- Is there anything new to learn about the pathogenesis of HAE? (*M. Cicardi, Milan University, Italy*)
- Idiopathic non-histaminergic angio edema: a clinical odyssey (*M. Mansi, Università degli Studi di Milano, Italy*)
- Assessment in the delay in diagnosis in patients with HAE with C1 inhibitor deficiency: findings from an international registry (*A. Zanichelli, University of Milan, Italy*)
- Efficacy of the demand treatments in reducing duration of symptoms in patients with angioedema due to hereditary C1 inhibitor deficiency: a prospective observational study (*G. Pereti, Università degli Studi di Milano, Italy*)
- Kinin catabolism and disease severity in HAE with F12 mutation: (*D. Charignon, University Joseph Fourier Grenoble, Switzerland*)
- Icatibant for the treatment of laryngeal attacks in HAE: an update of the FAST-3 study and its open-label extension (*D. Moldovan, Mures County Hospital, Romania*)

The US HAEA Angioedema Center at the University of California in San Diego is soon a reality. It is a long standing dream come through for the US HAE Association.

Anthony J. Castaldo
President US HAE Association
President HAEi



EAACI-WAO: Examples of poster presentations

- HAE in the emergency department – time to drug administration (*M. Branco Ferreira, Hospital Santa Maria, Portugal*)
- HAE type III or without deficiency of C1 INH – clinical characteristics of six families (*A. Garcia-Moral, Hospital Vall d'Hebron, Spain*)
- HAE with normal C1 inhibitor and factor XII mutation: a French cohort (*I. Boccon-Gibod, Grenoble University Hospital, France*)
- Hydatidosis as cause of anaphylaxis and recurrent urticaria and angioedema (*I. Raducan, Hospital Clinico Valencia, Spain*)
- Type I and II HAE: clinical characteristics and treatment response with human C1-inhibitor in a French cohort (*L. Bouillet, Grenoble University Hospital, France*)
- Oestrogen-independent type III HAE in a 10-year-old boy (*M.M. Bergmann, University of Geneva, Switzerland*)
- Acute oesophageal necrosis and sudden death in a man with C1 inhibitor deficiency HAE (*M. Piñero-Saavedra, University Hospital V del Rocio, Spain*)
- Children with HAE due to C1 inhibitor deficiency respond better to tranexamic acid than adults (*K. Djenouhat, Institute Pasteur d'Algerie, Algeria*)
- The first case diagnosed as both type III HAE and familial Mediterranean fever (*S. Buyukozturk, Istanbul University, Turkey*)

US HAEA Angioedema Center Slated for December 2013 Opening

The dream of the US National Member Organization of having a comprehensive care and research center dedicated to patients with swelling problems is about to become a reality. The US HAEA Angioedema Center at the University of California at San Diego will be open and begin seeing patients later this year.

The fundamental mission of the center is to provide the HAE patient community with access to internationally respected expert angioedema clinicians and researchers in a warm and

caring environment. The center will be available for any patient who experiences problems with swelling. It will offer a full range of diagnostic services, the opportunity to work with an expert physician to prepare a comprehensive care/management plan, and post-visit coordination and consultation with the local physician to help implement that plan.

The center will also serve as a leader in setting the USA standard for angioedema diagnosis and care and conducting important angioedema research. In addition, the US HAEA will be fully integrated into the center's operations and will be responsible for working closely with patients to set up appointments, coordinate insurance determination and travel arrangements, and stay in touch during and after their trip to San Diego. The US HAEA believes that the center will have a major impact on angioedema diagnosis and care and will bring patients closer towards meeting the US HAEA's strategic vision of helping patients achieve life-long health.

The center marks the first time that a rare disease patient organization has been responsible for establishing and helping to fund such an all-encompassing care center.



UC San Diego
HEALTH SCIENCES

General Meeting in the Netherlands

The National Member Organization in the Netherlands will hold its General Meeting on 5 October 2013. The meeting will take place in Amsterdam and the main topic on the agenda is the latest information on developments in the field of medicines. More information on www.hae-qe.nl.

HAE specialist in Germany opens private practice

After many years with the hospital of the Johann Wolfgang Goethe University in Frankfurt am Main, Germany Dr. med. Carmen Escuriola-Ettingshausen, Dr. med. Inmaculada Martinez-Saguer and Dr. med. Wolfhart Kreuz have opened a private practice under the name Hämophilie-Zentrum Rhein Main. The center is focused on diagnosis, therapy and research into rare disorders, not least haemophilia and HAE.

The clinic is treating patients with congenital and acquired coagulation disorders, immune defects and HAE. In addition, the clinic offers expert diagnosis and treatment of hemophilia A and B as well as other bleeding disorders, venous and arterial thrombosis. Other valuable services offered include psychosocial and nutrition counseling, orthopaedic advice and physiotherapy by experts.



Dr. med. Wolfhart Kreuz

US HAEA patient summit in Orlando

HAEA – the National Member Organization of the USA – will be holding its next patient summit on 27-28 September 2013. The summit will take place in Orlando, Florida and the US HAEA has reservations for well over 800 participants. The US HAEA is structuring this conference to make patients a part of exciting and unique opportunities to contribute to medical science and the understanding of HAE as HAE scientists conduct interactive data research.

Conference participants are also going to

- Learn how to make their voices heard in Washington, DC,
- Learn about the impact of US Healthcare Reform on insurance reimbursement for HAE medicines,
- Have the opportunity to talk one-on-one with physician/researchers, experts in all areas of angioedema.

More information is available at: www.haea.org



UK patient day in November 2013

The National Member Organization in the United Kingdom is planning a patient day in London on 16 November 2013. HAEi President Tony Castaldo and Executive Director Henrik Boysen have been invited to speak at the conference. Further information on the event is available on www.haeuk.org.

Jump for HAE

According to HAE Australasia, there is no better way to raise money for HAE than challenging yourself to the extreme.

Imagine the reaction when our Australasia HAE colleagues told family and friends that they were going to jump out of a perfectly good airplane from 8,000 ft to raise money for HAE!

We are sure this unique event will raise a nice sum of money to support activities sponsored by the Australasia HAE group.

This unique HAE event will take place in Perth, Australia on 12 October 2013.

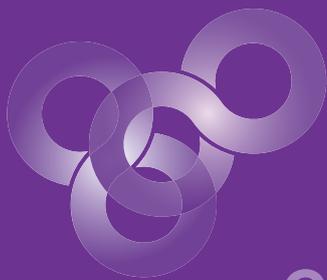


The US HAEA has set sail

On 11 July the yacht Bodacious IV participated in a Transpacific sailboat race from California to Hawaii.

Bodacious IV used a sail with the US HAEA logo on it throughout the 2,225 nautical mile journey. The race was used as a platform to reach as many people as possible in an awareness and fund raising campaign to support the HAEA Research and a newly created US HAEA patient support fund.



HAE GLOBAL CONFERENCE WASHINGTON DC 15-18 MAY 2014

Remember to reserve space in your calendar for the upcoming 2014 HAE Global Conference, which will take place from 15 until 18 May 2014 in Washington DC Metro Area.

HAEi Patient Advocacy Forums

In June 2013, HAEi conducted it's 3rd Patient Advocacy Forum (PAF) in Frankfurt, Germany. We are currently preparing a publication that will be entitled, *The Burden of Illness of HAE in Europe*. It will be based on scientific data developed by the European Burden of Illness Study (with participants from Germany, Spain and Denmark) and will provide European HAE patients with a strong, evidence-based tool to advocate for better HAE treatments and more rapid/accurate diagnosis.

HAEi Executive Committee member Alejandra Menendez is leading efforts to organize a Latin American Patient Advocacy Forum in December this year. The Latin American PAF will take place in Buenos Aires, Argentina



and will be conducted in Spanish (with translation to the Portuguese speaking delegates).

HAEi Global Advocacy Work

Early October HAEi is invited to speak at a youth conference for HAE patients and their caregivers in Berlin, Germany.

In November HAEi is invited to speak at a patient/physician seminar in Stockholm, Sweden about the topic: "Burden of Illness for HAE".

Also in November HAEi will speak at the HAE UK patient day in London, United Kingdom.

Late November HAEi is conducting the second DACH-Meeting in Munich, Germany. Based on existing guidelines and consensus documents, the focus will be on securing better treatment guidelines for the German speaking countries. Also HAEi will be conducting a physician awareness workshop in Dubai, United Arab Emirates for physicians from all over the Gulf Region.

The latter will be planned in coordination with our local representative in Dubai, Mr. Rashad Matraji.

Early December - as previously mentioned - HAEi will conduct it's first Latin American Patient Advocacy Forum in Buenos Aires, Argentina. The aim is to publish a report "The State of Management of HAE in Latin America".

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 at h.boysen@haei.org or Communications Manager Steen Bjerre at s.bjerre@haei.org.

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.

News from the industry

To mark **hae day :-)** 2013 **Dyax Corp.** launched HAE Allies, a program recognizing the physicians, nurses, family members and friends who support HAE patients in their efforts to live life to the fullest. Thus, HAE Allies asked HAE patients across the USA to nominate the people in their lives who provide the support which enables them to better manage their condition, to achieve their personal and professional goals, or cope with the unpredictability of HAE. For each submission, Dyax will donate 25 USD to the US Hereditary Angioedema Association (HAEA).

Five honorees will be recognized at the HAEA Patient Summit in Orlando, Florida 27 September 2013 and a donation of 250 USD will be made in the honoree's name to the HAE advocacy organization of their choice.

Santarus, Inc. and Pharming Group NV has announced that the U.S. Food and Drug Administration (FDA) has accepted for filing the Biologics License Application (BLA) for the investigational drug Ruconest® (recombinant human C1 esterase inhibitor) 50 IU/kg. Santarus and Pharming are seeking U.S. marketing approval of Ruconest for the treatment of acute angioedema attacks in patients with HAE.

The FDA indicated that as part of its review it plans to present the BLA to the Blood Products Advisory Committee. Pursuant to the Prescription Drug User Fee Act (PDUFA) guidelines, Santarus and Pharming expect the FDA will complete its review or otherwise respond to the RUCONEST BLA by April 16, 2014.

As part of its ongoing commitment to support the rare disease community, **Shire** held an educational symposium at the EAACI-WAO congress in June 2013 where a distinguished panel of HAE specialists from across the globe talked on key topics and themes. The 90-minute event was co-chaired by Dr. Hilary Longhurst (London, UK) and Professor

Bruce Zuraw (San Diego, USA) and also featured Professor Bork (Mainz, Germany) and Professor Cicardi (Milan, Italy). The panel presented to 350 delegates and discussed results of their clinical experiences of treating HAE attacks.

Pharming Group NV has announced that recombinant human C1 esterase inhibitor (rhC1INH; Ruconest®), an investigational drug in the U.S., has been shown to have a beneficial effect as a donor pre-treatment therapy in an animal model of kidney transplantation. The results of the study were presented at the American Transplant Congress in Seattle, Washington. In the study, Dr. Luis Fernandez of the University of Wisconsin used a non-human primate model to evaluate the outcomes of kidney transplantation from brain dead donors. Kidneys that were treated with rhC1INH prior to transplantation had a significantly lower incidence of delayed graft function (DGF) when transplanted to the recipient animals.

Dyax Corp. has announced dosing of the first subject in a Phase 1 clinical study evaluating the safety and tolerability of single subcutaneous administration of DX-2930, its fully human monoclonal antibody inhibitor of plasma kallikrein. Dyax is developing DX-2930 as a subcutaneous injection for prevention of HAE attacks. DX-2930 was discovered using Dyax's proprietary phage display technology platform.

This Phase 1, single-center, randomized, double-blind, placebo-controlled study is designed to assess the safety and tolerability and to characterize the pharmacokinetics (PK) of single, subcutaneous administrations of DX-2930 in healthy subjects. Approximately 32 subjects will be enrolled into four ascending dose cohorts (n=8 per cohort) of DX-2930 or placebo. The study will be conducted at the clinical trials unit of Vince & Associates Clinical Research, a recognized "Center of Research Excellence", located in Overland Park, Kansas.

ViroPharma Incorporated has presented the results of new data analyses from the randomized, placebo-controlled and open label clinical trials of Cinryze® (C1 esterase inhibitor [human]). While clinical trials have demonstrated the efficacy and safety of Cinryze for the long-term prevention of HAE, these data demonstrate that Cinryze is an important option, even in patients who have been managed on anabolic androgens and continue to experience multiple attacks of HAE. It reinforces current evidence based guidelines for the management of HAE, especially given the long-term risk/benefit of anabolic androgens.

The BRAVE Awards is an international awards initiative that recognizes the courage and dedication of non-professional caregivers. Developed and implemented by **Shire** the BRAVE Awards honor unpaid, non-professional caregivers who give of themselves in a meaningful, dedicated and selfless manner. The program is eligible in 19 countries, and up to 20 recipients each will be awarded 10,000 USD or the equivalent in local currency.

There are no restrictions on the type of care being provided, no correlation with any health condition or therapeutic area, and the care recipient need not be prescribed a Shire medicine or treatment. The recipients of the BRAVE Awards will be chosen by a Selection Committee made up of Shire employees and non-Shire caregiving experts, and will be announced in November 2013. To learn more please visit www.shireBRAVEawards.com

BioCryst Pharmaceuticals, Inc. has announced that the randomized, placebo-controlled, Phase 1 clinical trial of orally-administered BCX4161 in healthy volunteers successfully met all of its objectives. The safety, tolerability, drug exposure and on-target kallikrein inhibition results of this Phase 1 trial strongly support advancing the development program into a Phase 2a study in HAE patients.

The Phase 2a clinical trial in patients with HAE is expected to begin in the fourth quarter of 2013.



Approximately 25 patients who have a high frequency of attacks (≥ 1 per week) will be enrolled. The main goals for this clinical trial are to evaluate the safety and tolerability of BCX4161 and to estimate the degree of efficacy in reducing the frequency of attacks. This study is designed to provide proof of concept for oral kallikrein inhibition as a treatment strategy for HAE.

Pharming Group NV and Shanghai Institute of Pharmaceutical Industry (SIPI), a Sinopharm Company, have entered into a strategic collaboration for the development, manufacture and commercialization of new products based on the Pharming technology platform. In addition, Pharming has granted SIPI an exclusive license to commercialize Ruconest (conestat alfa) in China.

Under the terms of the agreement, Pharming will transfer the Pharming technology platform and manufacturing know-how to SIPI, such that joint global development for new products will take place at SIPI's facilities in Shanghai and benefit from both the cost advantages of the Pharming platform and the competitive development and manufacturing costs structures at SIPI. The first projects to be jointly developed at SIPI will be C1-inhibitor (conestat alfa) and Factor VIII.

Laureate Biopharma has announced its successful collaboration with **Dyax Corp.** for process development and cGMP production of a new treatment candidate for HAE. The drug candidate, known as DX-2930, is a fully human IgG antibody designed to prevent HAE attacks by inhibition of plasma kallikrein.

In working with the cell line producing DX-2930, Laureate's scientists were able to successfully scale-up and manufacture a high-titer antibody process.

This process was amendable to cGMP production in both stainless-steel and single-use bioreactors. Application of Laureate's platform downstream process for IgG antibodies led to high protein recovery and purity. Aseptic filling, a routine operation at Laureate, produced the clinical drug product in 98% yield. Finally, careful project management of the program by both companies resulted in the successful release of bulk drug substance.

Following discussion with the Center for Biologics Evaluation and Research (CBER) division of the U.S. Food and Drug Administration, **ViroPharma Incorporated** is going to discontinue the Phase 2 study of subcutaneous Cinryze® (C1 Esterase Inhibitor [Human]) with recombinant human hyaluronidase (rHuPH20).

The discontinuation of the study is a precaution related to the emergence of an unexpected incidence and titer of non-neutralizing anti-rHuPH20 antibodies in a number of patients with the formulation being used in this study. These antibodies have not been associated with any adverse clinical effects and are of unknown clinical significance. The study was fully enrolled and 41 patients completed at least one dosing arm of study drug with a total of 20 patients having completed both dosing arms. These data will be informative for design of future subcutaneous administration studies.

In parallel with the conduct of this Phase 2 study, ViroPharma has developed an optimized, low-volume subcutaneous formulation of Cinryze. As a result, ViroPharma expects to conduct a Phase 3 subcutaneous registration study with this alternative formulation in the same time frame that had been anticipated previously for the combination product.

HAEi is a global umbrella organization dedicated to raising awareness of C1 inhibitor deficiencies around the world. It is a non-profit network of national HAE patient organizations.

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HAEi - International Patient Organization for C1 Inhibitor Deficiencies



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