

## A global awareness day for a rare life-threatening condition: World HAEday, 16<sup>th</sup> May 2018

*Leiden, The Netherlands, 16 May 2018:* On May 16<sup>th</sup> Hereditary Angioedema (HAE) patient organizations from around the world, led by HAEi (The international HAE patient organisation), come together to support the global awareness day for Hereditary Angioedema; a rare life-threatening condition. “[haeday:](#)” aims to raise global awareness to ensure each and every patient receives faster diagnosis and the care they need to lead a healthy life.

Various events are taking place across the globe in aid of the global awareness day. HAEi arranges the HAE Global Walk 2018 from 1 April – 31 May 2018, allowing everyone to participate to walk for HAE awareness, no matter where they are on [www.haeday.org](http://www.haeday.org).

The fourth HAE Global Conference will be held in Vienna, Austria on 18-20 May 2018. Around 700 HAE patients, their families, caregivers, healthcare professionals and industry representatives will be attending. Pharming is also supporting this event, which is the largest international gathering of its kind solely with a focus on HAE.

### Dr Sijmen de Vries, Pharming’s CEO commented:

*"Pharming has been collaborating with the HAE community since 2000. We are delighted to support this year's [haeday:](#) and are dedicated to continue making a difference in patients' and their families' lives, working in close partnership with HAEi and its local affiliates. As provider of the first and only recombinant (C1-esterase inhibitor) protein replacement therapy for the treatment of acute angioedema attacks in adults and adolescents with HAE, we provide the HAE community with a reliable source of blood-plasma free medicine and are dedicating significant research efforts to improve convenience and quality of life further, including investigations into the potential application of needle-free technologies. On this day we wish everybody living with HAE and those caring for them the very best outcome for the future."*

“HAE is a rare genetic disorder that causes attacks involving swelling to various parts of the body, and can be fatal when the swelling affects the throat due to the risk of suffocation”, explains Mr. Henrik Balle Boysen, Executive Director of HAEi, the international patient organization, leading the day. “Global awareness initiatives such as the [haeday:](#) are necessary in order to help patients receive faster diagnosis and care to manage the disease.”

HAEi is the international umbrella organization for the world’s Hereditary Angioedema (HAE) patient groups. HAEi is dedicated to raising awareness of C1 inhibitor deficiencies, as HAE patients have a defect in the gene that controls C1INH, and so the disorder is also commonly referred to as C1-inhibitor deficiency. HAEi is a non-profit international network of 63 national HAE patient organizations at present, spread across the globe.

“HAEi has been established to promote co-operation, co-ordination and information-sharing between HAE specialists and national HAE patient associations to help facilitate the availability of effective diagnosis and management of C1 inhibitor deficiencies throughout the world. Our purpose is to join the efforts and experience of the global HAE community to achieve optimal standards of care and treatment for all those patients affected by C1 inhibitor deficiencies”, says Mr. Balle Boysen.

The main symptom of HAE is swelling of the body tissues, which doctors call “edema”, occurring mainly in the face (e.g. lips, eyelids), although the extremities and genitals are often affected. Swelling of the internal organs, specifically the mucous membranes of the larynx, nose or tongue, is potentially life threatening as it can cause death by suffocation. More than 50 per cent of HAE patients will experience at least one attack of this type in their lifetime.

“Patients are frequently misdiagnosed because HAE symptoms often resemble those of more common conditions. Through 2018 [haeday:](#)) we hope to spread the word about HAE, so patients can receive an accurate diagnosis and appropriate medical care,” Mr. Balle Boysen explains: “We are very excited by the level of participation from the HAE national organizations across the globe and hope that the awareness day will make a real difference to lives of HAE patients in the future.”

HAE places extraordinary strain on patients, often restricting their ability to lead normal lives. Untreated HAE patients can lose 100 to 150 workdays per year or more. Currently there is no permanent cure for HAE, but treatment options are available to try and prevent attacks from occurring or to treat attacks when they do occur.

- Join the official [haeday:](#))
  - Website at [www.haeday.org](http://www.haeday.org)
  - Facebook page at [www.facebook.com/haeday](https://www.facebook.com/haeday)
  - Twitter account at [www.twitter.com/haeday](https://www.twitter.com/haeday)
  - YouTube channel at [www.youtube.com/haedaychannel](https://www.youtube.com/haedaychannel)
- Other sources
  - HAEi website: [www.haei.org](http://www.haei.org)
  - [www.angiooedeemvereniging.nl](http://www.angiooedeemvereniging.nl)

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### About Pharming Group N.V.

Pharming is a specialty pharmaceutical company developing innovative products for the safe, effective treatment of rare diseases and unmet medical needs. Pharming's lead product, RUCONEST® (conestat alfa) is a recombinant human C1 esterase inhibitor approved for the treatment of acute Hereditary Angioedema ("HAE") attacks in patients in Europe, the US, Israel and South Korea. The product is available on a named-patient basis in other territories where it has not yet obtained marketing authorization.

RUCONEST® is distributed by Pharming in Austria, France, Germany, Luxembourg, the Netherlands, the United Kingdom and the United States of America. Pharming holds commercialisation rights in Algeria, Andorra, Bahrain, Belgium, Ireland, Jordan, Kuwait, Lebanon, Morocco, Oman, Portugal, Qatar, Syria, Spain, Switzerland, Tunisia, United Arab Emirates and Yemen. In some of these countries this is done in association with the HAEi Global Access Program (GAP).

RUCONEST® is distributed by Swedish Orphan Biovitrum AB (publ) (SS: SOBI) in the other EU countries, and in Azerbaijan, Belarus, Georgia, Iceland, Kazakhstan, Liechtenstein, Norway, Russia, Serbia and Ukraine.

RUCONEST® is distributed in Argentina, Colombia, Costa Rica, the Dominican Republic, Panama, and Venezuela by Cytobiotech, in South Korea by HyupJin Corporation and in Israel by Megapharm.

RUCONEST® is also being examined for approval for the treatment of HAE in young children (2-13 years of age) and evaluated for various additional follow-on indications.

Pharming's technology platform includes a unique, GMP-compliant, validated process for the production of pure recombinant human proteins that has proven capable of producing industrial quantities of high quality recombinant human proteins in a more economical and less immunogenetic way compared with current cell-line based methods. Leads for enzyme replacement therapy ("ERT") for Pompe and Fabry's diseases are being optimized at present, with additional programs not involving ERT also being explored at an early stage at present.

Pharming has a long term partnership with the China State Institute of Pharmaceutical Industry ("CSIPI"), a Sinopharm company, for joint global development of new products, starting with recombinant human Factor VIII for the treatment of Haemophilia A. Pre-clinical development and manufacturing will take place to global standards at CSIPI and are funded by CSIPI. Clinical development will be shared between the partners with each partner taking the costs for their territories under the partnership.

Pharming has declared that the Netherlands is its "Home Member State" pursuant to the amended article 5:25a paragraph 2 of the Dutch Financial Supervision Act.

Additional information is available on the Pharming website: [www.pharming.com](http://www.pharming.com)

### Forward-looking Statements

*This press release of Pharming Group N.V. and its subsidiaries ("Pharming", the "Company" or the "Group") may contain forward-looking statements including without limitation those regarding Pharming's financial projections, market expectations, developments, partnerships, plans, strategies and capital expenditures.*

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*As a result, the Company's actual performance, position and financial results and statements may differ materially from the plans, goals and expectations set forth in such forward-looking statements. The Company assumes no obligation to update any forward-looking statements or information, which should be taken as of their respective dates of issue, unless required by laws or regulations.*

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