

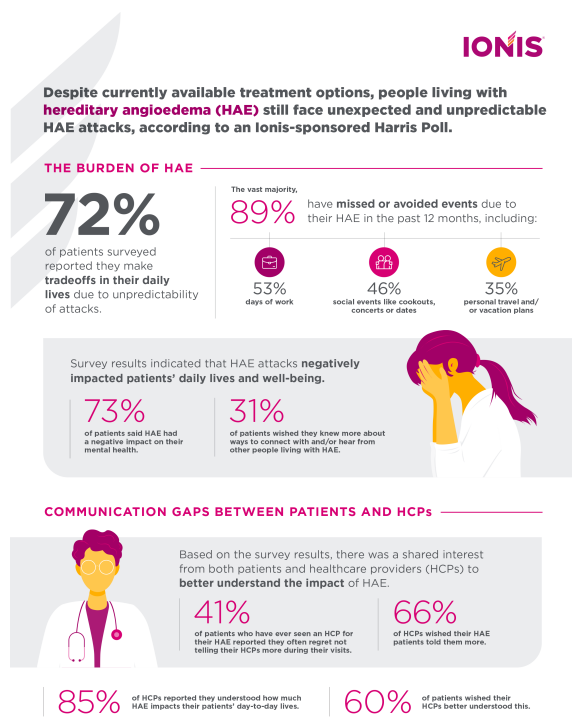


## New Harris Poll findings reveal HAE patients are unsatisfied with current prophylactic treatment options, with over 90% interested in trying new therapies

April 29, 2025

– Despite currently available treatment options, the majority of surveyed adults with HAE reported making tradeoffs in their daily lives due to the unexpected and unpredictable nature of HAE attacks –

– Opportunity exists for more consistent use of tools to support transparent communications between patients and their doctors, as HCPs may underestimate the full burden of HAE –



CARLSBAD, Calif., April 29, 2025 – [Ionis Pharmaceuticals, Inc.](#) (Nasdaq: IONS) today announced results from a new survey showing that 91% of surveyed adults living with hereditary angioedema (HAE) were interested in trying a new prophylactic therapy, with nearly two-thirds (65%) reporting they haven't yet found the best treatment option for them. The Ionis-sponsored survey was conducted online by The Harris Poll among 150 adults living with HAE and 228 allergists/immunologists who see HAE patients in the U.S.

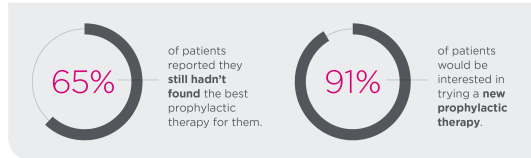
HAE is a rare and potentially life-threatening genetic condition that involves recurrent attacks of severe swelling (angioedema) in various parts of the body, including the hands, feet, genitals, stomach, face and/or throat. A majority (72%) of patients in the survey said they made tradeoffs in their daily lives because they were not able to predict when they might have an attack. Despite most (85%) HCPs reporting that they understood how much HAE impacts their patients' day-to-day lives, 60% of patients who have seen an HCP for their HAE wished their HCPs better understood this impact.

"These survey findings shed light on the holistic experience of living with HAE, as patients continue to experience painful and unpredictable attacks with a significant impact on their day-to-day lives, despite available treatments. We see that patients may be hesitant to share the full extent of their disease burden with their doctor, and as a result HCPs may be overestimating patients' level of disease control," said Dr. William Lumry, M.D., clinical professor of Internal Medicine, University of Texas Southwestern Medical School. "In my practice, I've found that using a standardized questionnaire can help aid in these discussions, providing a simple way for patients to objectively evaluate and communicate their disease burden and thus supporting more informed

conversations about treatment considerations.”

The use of standardized disease control tools, such as the Angioedema Control Test (AECT), can be an effective way to evaluate disease control and understand the full impact of HAE on people living with this serious disease. Only about a third (36%) of patients surveyed reported using a standardized tool with their HCP to regularly assess their level of HAE control, suggesting these resources may be underutilized.

#### TREATMENT CONSIDERATIONS



**Despite advances in HAE treatment, survey results suggested that patients are still looking for options that are effective, convenient and safe.**

#### ABOUT THE STUDY

The research was sponsored by Ionis Pharmaceuticals and conducted online in the U.S. by The Harris Poll among two groups: 150 U.S. adults aged 18 and older who have been diagnosed with HAE by a HCP, and 228 licensed and board-certified allergists or immunologists aged 18 or older, practicing in the U.S., who have been in practice between 3 and 35 years, spend at least 60% of their professional time treating patients, have treated at least 3 patients living with HAE in the past 12 months and have at least 1 HAE patient on prophylactic therapy. The patient survey was conducted from November 13–December 5, 2024, using a 70-question questionnaire, and the HCP survey was conducted from November 12–December 20, 2024, using a 56-question questionnaire; both surveys consisted primarily of closed-ended pick-list and scale questions. Full research methodology for both surveys is available upon request.

<b>For more information on HAE, visit the following resources:</b>	<b>People living with HAE:</b>  <a href="https://haevnhub.com">HAEVNhub.com</a> or <a href="https://haea.org">haea.org</a> <small>U.S. Hereditary Angioedema Association (HAEA)</small>	<b>Healthcare providers:</b> <b>HAE UNCOVERED</b> <a href="https://HAUncovered.com">HAUncovered.com</a>
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## The Burden of HAE

The full extent of the burden of HAE is often underrecognized, as patient respondents reported a significant impact on their daily lives and well-being.

- More than two-thirds (67%) reported living in fear of experiencing an HAE attack at any time.
- 89% reported missing or avoiding desired activities in the last 12 months, including work, socialization and travel due to their HAE.

## Communication Gap between Patients and HCPs

Fewer than half (47%) of patients surveyed told their HCP about every time they experience symptoms or an attack, regardless of severity. As a result, HCPs may underestimate the prevalence of HAE attacks.

- A majority (93%) of patients surveyed said they experienced their most recent HAE attack in the last year; however HCPs reported that, on average, only about two-thirds (64%) of their patients experienced an attack in the past year. Yet, 77% of HCPs believed their patients accurately communicate the total number of attacks they've experienced since their last appointment.
- Two thirds (66%) of HCPs reported wishing their HAE patients told them more during visits, indicating an opportunity for clearer communication between patients and HCPs.

## Treatment Considerations

Additional survey results indicate a need for more frequent and transparent conversations around treatment options, with 65% of patients surveyed feeling like they still haven't found the best prophylactic therapy for them.

- Nearly two-thirds (65%) of patients reported that they wished their HCP shared more information about new treatment options, even if they don't directly ask to change their treatment plan. However, the majority (90%) of HCPs believe they often do this.
- Patients (68%) and HCPs (70%) agreed that patients typically felt like they must make tradeoffs between a treatment's effectiveness, convenience and safety when making treatment decisions about their HAE.
- When considering an ideal prophylactic therapy for HAE, patients felt it was very important that the treatment works to control HAE symptoms and/or attacks (79%), provides greater peace of mind (73%) and is affordable and/or easy to access (71%).

## **About the Survey**

The research was conducted online in the U.S. by The Harris Poll on behalf of Ionis Pharmaceuticals among two groups: 150 U.S. adults aged 18 and older who have been diagnosed with HAE by a HCP, and 228 allergists or immunologists practicing in the U.S. who are duly licensed, have been in practice between 3 and 35 years, are board-certified, spend at least 60% of their professional time treating patients, have treated at least 3 patients living with HAE in the past 12 months and have at least 1 HAE patient on prophylactic therapy. The patient survey was conducted from November 13–December 5, 2024, using a 70-question questionnaire, and the HCP survey was conducted from November 12–December 20, 2024, using a 56-question questionnaire; both surveys consisted primarily of closed-ended pick-list and scale questions.

Complete research methodology is available upon request.

## **About Hereditary Angioedema (HAE)**

HAE is a rare and potentially life-threatening genetic condition that involves recurrent attacks of severe swelling (angioedema) in various parts of the body, including the hands, feet, genitals, stomach, face and/or throat. HAE is estimated to affect more than 20,000 patients in the U.S. and Europe. In the U.S., doctors frequently use prophylactic treatment approaches to prevent and reduce the severity of HAE attacks in patients.

## **About Ionis Pharmaceuticals, Inc.**

For three decades, Ionis has invented medicines that bring better futures to people with serious diseases. Ionis currently has six marketed medicines and a leading pipeline in neurology, cardiology, and select areas of high patient need. As the pioneer in RNA-targeted medicines, Ionis continues to drive innovation in RNA therapies in addition to advancing new approaches in gene editing. A deep understanding of disease biology and industry-leading technology propels our work, coupled with a passion and urgency to deliver life-changing advances for patients. To learn more about Ionis, visit [ionis.com](https://ionis.com) and follow us on X (Twitter), LinkedIn and Instagram.

**Ionis Investor Contact:** D. Wade Walke, Ph.D.  
IR@ionis.com  
760-603-2331

**Ionis Media Contact:** Hayley Soffer  
media@ionis.com  
760-603-4679