

# MIND THE HAE ATTACK

**Unmet needs** of people  
living with hereditary  
angioedema (HAE)

**Results of the HAE Attack Journey Survey  
and Burden of Treatment Survey**

# KalVista partnered with the HAE community on 2 surveys to clarify unmet needs in HAE

## HAE Attack Journey (HAJ) Survey

**Objective:** To understand how people living with HAE prepare for an attack, make decisions about on-demand treatment, and how their lives are impacted by attacks.<sup>1</sup>

**Methodology:** People living with HAE type I or II were recruited by the US HAEA to complete a 20-minute, self-reported, online survey between September and October 2022.<sup>1,2</sup>

**Demographics:** 107 participants, 80% female, 98% adults (age ≥18 years). 50% of participants were being treated with both long-term prophylaxis (LTP) and on-demand treatment. 50% of participants were using on-demand treatment only.<sup>1</sup>

## Burden of Treatment (BOT) Survey

**Objective:** To better understand the burden of existing injectable on-demand treatments.<sup>3</sup>

**Methodology:** People living with HAE type I or II were recruited by the US HAEA to complete a 20-minute, self-reported, online survey between April and June 2023.<sup>3</sup>

**Demographics:** 94 participants (80 adults and 14 adolescents) who treated 1 or more HAE attacks within the prior 3 months with an on-demand treatment. 54% were taking LTP at time of last attack, and 46% were using on-demand treatment only.<sup>3</sup>

Despite having clear and established HAE treatment guidelines from the WAO and EAACI, treating HAE attacks still comes with significant challenges<sup>1,2,4-6</sup>

**1** Despite prophylaxis, on-demand HAE treatment still impacts many aspects of patients' lives<sup>4</sup>

**2** Most people living with HAE do not always carry their current on-demand treatments with them<sup>1</sup>

**3** Most people living with HAE do not treat all attacks<sup>2</sup>

**4** Most people living with HAE delay on-demand treatment<sup>5</sup>

EAACI=European Academy of Allergy and Clinical Immunology; US HAEA=United States Hereditary Angioedema Association; WAO=World Allergy Organization.

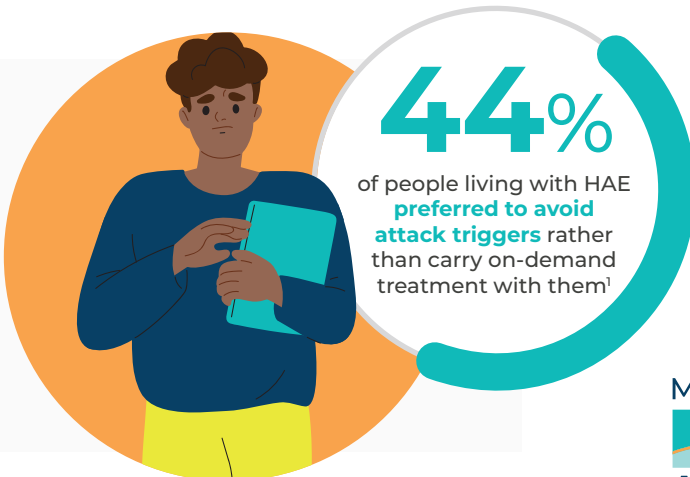
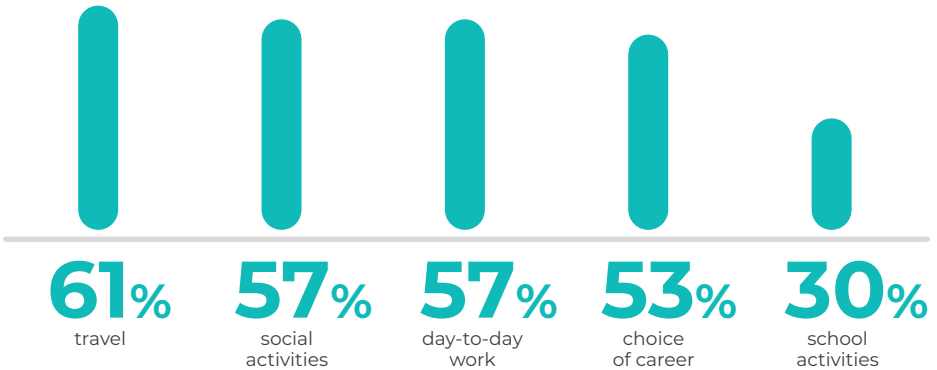
# People living with HAE continue to make compromises in their lives<sup>4,6</sup>

The international WAO/EAACI guideline for HAE management recommends:

The goals of treatment are to **achieve total control of the disease** and to **normalize patients' lives**.<sup>6</sup>

Most people (96%) living with HAE who were treated with prophylaxis and on-demand treatment reported that they **didn't feel like they were 100% themselves** all the time.<sup>4</sup>

The need for on-demand treatment impacted<sup>4</sup>:



# Most people living with HAE do not always carry on-demand treatments with them<sup>1</sup>

The international WAO/EAACI guideline for HAE management recommends:

All patients have sufficient medication for on-demand treatment of at least 2 attacks **and carry on-demand medication at all times.**<sup>6</sup>

**2 out of 3** people living with HAE said they **don't always carry their on-demand treatment with them**<sup>1</sup>



- Only 36% always carried on-demand treatment<sup>1</sup>
- 0% of people ≤24 years old always carried on-demand treatment<sup>7</sup>



People living with HAE traveled an average of

**3.5 hours** away from home

without their on-demand treatment<sup>1</sup>



## There are many reasons why people living with HAE do not carry on-demand treatments<sup>1</sup>

Current on-demand treatments are administered either intravenously or subcutaneously, which may lead to a **complex decision-making process.**<sup>8</sup>

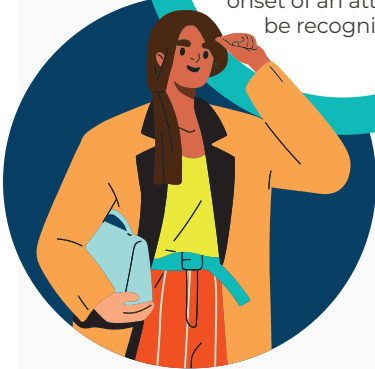
# People living with HAE do not treat all attacks<sup>2</sup>

The international WAO/EAACI guideline for HAE management recommends:

**All attacks** are considered for on-demand treatment.<sup>6</sup>

94%

of people living with HAE agreed that the initial onset of an attack can be recognized<sup>9</sup>



69%

of people living with HAE reported that they **do not** treat all attacks<sup>2</sup>

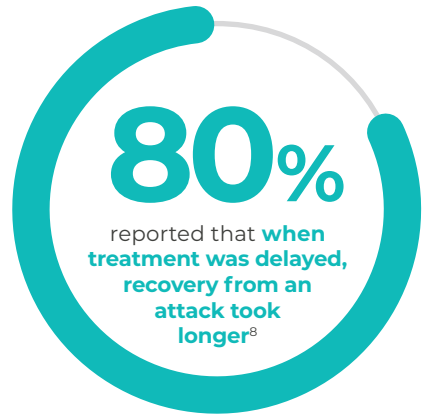
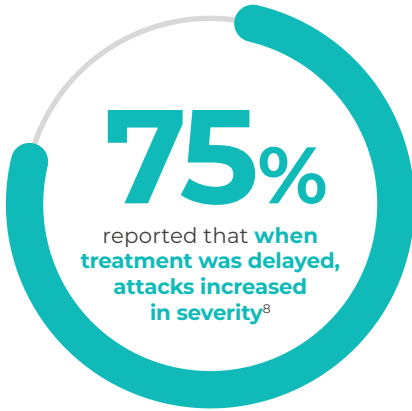


# People living with HAE delay treatment for hours<sup>5</sup>

The international WAO/EAACI guideline for HAE management recommends:

Attacks are treated **as early as possible**.<sup>6</sup>

People living with HAE are aware of the consequences of **delayed treatment**.<sup>8</sup>



People waited an average of

**3.8 hours**

**before treating** attacks with on-demand treatment<sup>5</sup>



of prophylaxis patients **experienced moderate to high levels of anxiety** when anticipating on-demand treatment administration<sup>10</sup>

# Conclusions

To better control their HAE, patients should be encouraged to:

**1** Carry on-demand medication at all times<sup>6</sup>

**2** Consider all attacks for on-demand treatment<sup>6</sup>

**3** Treat attacks at the onset<sup>6</sup>

# MIND THE HAE ATTACK

Visit [MindtheHAEattack.international](https://MindtheHAEattack.international)



- Share with the HAE community
- Download the HAE Attack Shared Decision-Making Guide
- And so much more!

**References:** **1.** Betschel S, van Kooten S, Heckmann M, Danese S, Goga L, Guilarte M. HAE patients decision to carry on-demand treatment when away from home. Abstract presented at: 13th C1-inhibitor Deficiency & Angioedema Workshop; May 4-7, 2023; Budapest, Hungary. **2.** Soteres DF, Grumach AS, van Kooten S, et al. Anxiety associated with refilling on-demand therapy for HAE attacks contributes to treatment delay and non-treatment. Abstract presented at: AAAAI Annual Meeting; February 23-26, 2024; Washington, DC. **3.** Wedner HJ, Radojicic C, Ulloa J, et al. Anxiety associated with on-demand treatment for hereditary angioedema (HAE) attacks. Abstract presented at: AAAAI Annual Meeting; February 23-26, 2024; Washington, DC. **4.** Betschel S, van Kooten S, Heckmann M, Danese S, Goga L, Caballero T. Remaining burden of hereditary angioedema (HAE) attacks despite modern long-term prophylaxis. Abstract presented at: EAACI 2023 Hybrid Congress; June 9-11, 2023; Hamburg, Germany. **5.** Christiansen S, O'Connor M, Ulloa J, et al. Delayed on-demand treatment of hereditary angioedema attacks: patient perceptions and associated barriers. Abstract presented at: AAAAI Annual Meeting; February 23-26, 2024; Washington, DC. **6.** Maurer M, Magerl M, Betschel S, et al. The international WAO/EAACI guideline for the management of hereditary angioedema—the 2021 revision and update. *Allergy*. 2022;77(7):1961-1990. doi:10.1111/all.15214 **7.** Geng B, van Kooten S, Heckmann M, Danese S, Goga L, Radojicic C. Understanding why hereditary angioedema patients often do not carry their on-demand treatment with them. *Ann Allergy Asthma Immunol*. 2023;131(5)(suppl 1):S37. doi:10.1016/j.anai.2023.08.119 **8.** Grumach A, van Kooten S, Heckmann M, Danese S, Goga L, Garcez T. Understanding the complex decision-making associated with on-demand treatment of hereditary angioedema (HAE) attacks. Abstract presented at: EAACI 2023 Hybrid Congress; June 9-11, 2023; Hamburg, Germany. **9.** Manning M, Burnette A, van Kooten S, et al. In their own words - patient descriptions of the earliest recognition of HAE attack onset. Abstract presented at: 2023 US HAEA National Summit; July 20-23, 2023; Orlando, FL. **10.** Betschel S, Radojicic C, van Kooten S, et al. Characterizing the HAE patient perspective on first-line prophylactic treatment. Abstract presented at: AAAAI Annual Meeting; February 23-26, 2024; Washington, DC.