

In the management of hereditary angioedema (HAE)

WHAT IF YOU COULD

**deflate HAE**

WITHOUT DEFLATING  
EXPECTATIONS?

Life with HAE can be a burden.  
Its management shouldn't be.<sup>1,2</sup>

**BALANCING THE BURDEN**

Real person  
living with HAE.

**What people with HAE  
want you to know**

**See inside to learn about this disruptive, rare disease.**

FOUR REAL PEOPLE WITH HAE. FOUR UNIQUE STORIES.

# deflate HAE TOGETHER

SEE HOW HAE AND ITS MANAGEMENT BURDENS THEIR LIVES



Real person  
living with HAE.

## MEET ANDJELA

Married with two sons, trauma nurse,  
diagnosed with HAE at age 27

“ ”

Some people didn't believe I had a  
disease; they thought I was exaggerating  
my pain or that it was all in my head.<sup>5</sup>



WATCH  
ANDJELA'S STORY



Real person  
living with HAE.

## MEET EMMA

Medical school student,  
diagnosed with HAE at age 24

“ ”

If I am starting to have a swell, I  
tend to stay home. I just don't like  
to be seen in public because it's  
not something I can hide.<sup>5</sup>



WATCH  
EMMA'S STORY



Real person  
living with HAE.

## MEET GABBY

Recently engaged,  
diagnosed with HAE at age eight

“ ”

But when I do get upset is when I can't get an  
IV started. I will stick myself over and over and  
I just try to stay calm, but sometimes, if my  
hand is swelling, I just can't do it.<sup>5</sup>



WATCH  
GABBY'S STORY



Real person  
living with HAE.

## MEET JAMIE

Married with three sons, two have HAE,  
language arts teacher, diagnosed at age 20

“ ”

HAE has disrupted my job, my  
friendships, and my everyday life.<sup>5</sup>



WATCH  
JAMIE'S STORY

**HAE is a rare and potentially life-threatening condition**

HAE causes recurrent attacks of angioedema ranging from  
disabling peripheral swelling and painful abdominal swelling  
to potentially life-threatening laryngeal edema.<sup>1-4</sup>

#deflateHAE

Keep reading to investigate the burden of HAE.

FOR PEOPLE WITH HAE

# LIFE CAN BE FILLED WITH BURDEN

HAE attacks are often disfiguring and debilitating, resulting in lost time from school, work, and family/social activities<sup>1,6</sup>

In addition, people with HAE reported feeling anxious and fearful, anticipating the next attack.<sup>1,4,7,8</sup>



Real person living with HAE.

## EMOTIONAL BURDEN

CONSEQUENCES INCLUDE:

- Some people with HAE may potentially have ongoing anxiety about their next attack, causing them to cancel plans<sup>1,4,7,8</sup>
- Possible embarrassment and feelings of shame in front of friends, co-workers, and strangers<sup>7,8</sup>

**“So if I’m swelling, emotions are heightened, absolutely. There is a sense of panic that occurs during a swell.<sup>5”</sup>**

— Gabby, real person living with HAE



Real person living with HAE.

## SOCIAL BURDEN

CONSEQUENCES INCLUDE:

- Avoiding social events out of fear of having an attack in public<sup>7,8,10</sup>
- The stigmatization of living with a rare, isolating disease<sup>11</sup>
- Navigating the negative attention of onlookers during an attack<sup>1,7,8,11</sup>

**“HAE also made me lose friends, because we would make plans and then I would end up canceling because I was sick.<sup>5”</sup>**

— Andjela, real person living with HAE



Real person living with HAE.

## OCCUPATIONAL BURDEN

CONSEQUENCES INCLUDE:

- Perceived limitations of available jobs and lack of career advancement<sup>1</sup>
- Potential fear of being seen as undependable and unproductive by co-workers<sup>1,9</sup>

**“Medical school is very competitive, and I do not want to be considered a weak link by my colleagues.<sup>5”</sup>**

— Emma, real person living with HAE



Real person living with HAE.

## FAMILY BURDEN

CONSEQUENCES INCLUDE:

- Concerns over children missing classes, practices, or events, resulting in repeatedly being held back from important childhood milestones<sup>1,12</sup>
- An inability to participate in contact sports, such as American football, rugby, or the martial arts<sup>2,9</sup>

**“For me, the biggest burden with these medicines is traveling with them. Two of my sons have HAE, so between all three of us, our medications and supplies take up a whole carry-on!<sup>5”</sup>**

— Jamie, real person living with HAE

Up next: Understand the trade-offs people with HAE are forced to make.

#deflateHAE

## IS CURRENT HAE MANAGEMENT

# FORCING PEOPLE TO MAKE TRADE-OFFS?



### TRADE-OFFS WITH HAE INJECTIONS

#### FEAR OF NEEDLES

Needle phobia is common and may lead to delayed or avoided treatment<sup>13,17,18</sup>

#### SIDE EFFECTS

May cause pain and/or a reaction at the injection site<sup>9,13,18</sup>

#### FAMILY PLANNING

Treatment options should consider impact on personal choices in family planning<sup>19</sup>

#### REQUIRES TRAINING

Self-injection requires patient education and proper technique to ensure efficacy<sup>20-23</sup>

#### CUMBERSOME

May not be easily transportable<sup>13,18,24</sup>

#### NEEDLE FATIGUE

Long-term injectable regimens may be associated with diminished treatment adherence<sup>9,13</sup>

While today's HAE management has reduced the disease burden, people still may be making trade-offs among efficacy, tolerability, and convenience.<sup>1,2,13-16</sup>



### TRADE-OFFS WITH HAE ORALS

#### EFFICACY

On average, oral treatments may not provide injection-like efficacy<sup>TM2,16</sup>

#### MULTIPLE DOSES

On-demand treatment may require multiple doses to fully resolve an HAE attack<sup>25</sup>

#### SIDE EFFECTS

For prevention of attacks, currently available orals may have side effects that could lead people to discontinue therapy<sup>16,26-28</sup>



### TRADE-OFFS WITH HAE INFUSIONS

#### TIME CONSUMING

Often require administration in a healthcare setting, delaying time to treatment<sup>10,29</sup>

#### HARD TO SELF-ADMINISTER

People may have poor venous access and difficulty with administration<sup>29</sup>

#### MAY NEED OTHERS TO HELP

May require caregiver or professional support, limiting independence<sup>29</sup>

#### TRAVEL ISSUES

Equipment and storage needs can complicate treatment outside the home<sup>29</sup>

#### SIDE EFFECTS

May cause headaches, nausea, rash, and fever<sup>30</sup>



# BRADYKININ AND ITS CRITICAL ROLE IN HAE

Most people with HAE often have an underlying deficiency of functional C1 inhibitor (C1INH) that leads to dysregulated plasma kallikrein activity<sup>1</sup>



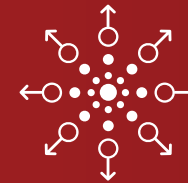
Low  
C1INH

In most people with HAE, there is either a quantitative or a functional deficiency of C1INH (as seen in HAE types 1 and 2, respectively).<sup>31,32</sup>



Uncontrolled  
kallikrein activity

The loss of C1INH control allows **dysregulated activation of plasma kallikrein**, resulting in an overproduction of bradykinin.<sup>31</sup>



Overproduction  
of bradykinin

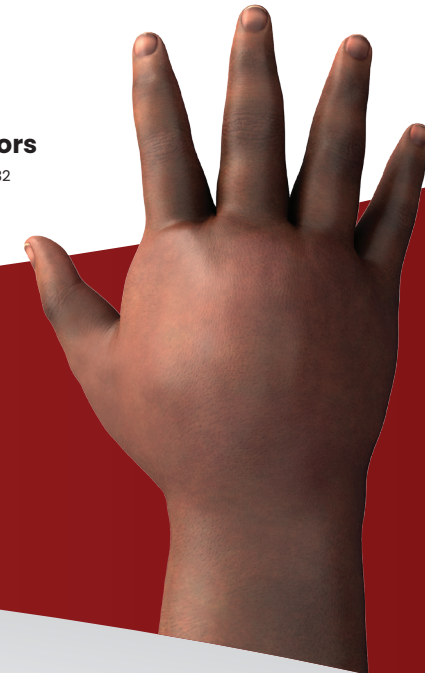
Activation of bradykinin B2 receptor leads to opening of endothelial junctions, causing vasodilation and increased vascular permeability, **with the resultant fluid extravasation into surrounding tissues** being the clinical hallmark of HAE.<sup>33,34</sup>

Unlike histaminergic angioedema, **HAE does not respond to antihistamines, corticosteroids, or epinephrine.**<sup>4,31</sup>

**Swelling in HAE is generally a result of excess bradykinin production.**

Bradykinin is a peptide mediator that plays a central role in increasing vascular permeability. In the most common types of HAE, it is produced through the kallikrein-kinin system when plasma kallikrein cleaves high-molecular-weight kininogen (HMWK).<sup>4,31</sup>

Bradykinin acts primarily by **binding to bradykinin B2 receptors** on vascular endothelial cells.<sup>4,32</sup>



**EXCESS  
BRADYKININ  
PRODUCTION**

=

**ANGIOEDEMA<sup>4,32</sup>**

# DISCOVER A WORLD OF RESOURCES

For you and people with HAE



## ANGIOEDEMA CENTERS OF REFERENCE AND EXCELLENCE (ACARE)

[acare-network.com](http://acare-network.com)

The ACARE program is a joint initiative by GA<sup>2</sup>LEN (Global Allergy and Asthma Excellence Network) and HAEi (Hereditary Angioedema International) with the aim of developing and accrediting an interactive network of centers of excellence in angioedema management.



## HEREDITARY ANGIOEDEMA ASSOCIATION (HAEA)

[HAEA.org](http://HAEA.org)

A non-profit advocacy organization serving people with HAE and their caregivers. Through a passionate commitment to the HAE community, they offer a wide variety of services and resources that further HAE education, clinical research, community engagement, access to medications, personalized support networks, and a wide range of services to help people living with HAE lead a normal life.

### HAE FACTS

**HAE attacks may be triggered by injury, stress, or even excitement, but may also appear for unknown reasons.<sup>4,35</sup>**

**Managing HAE is different from managing angioedema associated with histamine since antihistamines, corticosteroids, and epinephrine have little effect on HAE swelling.<sup>31</sup>**

**Options that either inhibit production of bradykinin or prevent binding of bradykinin to the bradykinin B2 receptor are currently utilized.<sup>14</sup>**



## HAE INTERNATIONAL (HAEi)

[HAEi.org](http://HAEi.org)

A global non-profit network of patient associations dedicated to improving the lives of people with HAE. They are a group of compassionate HAE patients and caregivers who make it their life's work to raise awareness of HAE, improve time to diagnosis, and fiercely advocate for approval and reimbursement of lifesaving therapies to everyone suffering from HAE.



## HAEi LEAP

[youngsters.haei.org/leap-welcome-program/](http://youngsters.haei.org/leap-welcome-program/)

An educational program, developed by HAEi, that allows young people to learn new skills and develop as individuals and advocates.



## NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

[rarediseases.org](http://rarediseases.org)

A comprehensive resource for people with a rare disease and their caregivers, including rare disease facts and statistics, information on living with a rare disease, mentoring organizations, improving clinical care, and community support.

NORD and the NORD logo are registered trademarks of the National Organization for Rare Disorders. NORD is a registered 501(c)(3) charity.



## PEOPLE WITH HAE

# MAY NOT BE LIVING THEIR LIFE TO THE FULLEST

## IF TRADE-OFFS GET IN THE WAY

Today's HAE management may be forcing people to choose among efficacy, tolerability, and convenience<sup>1,2,13</sup>

Until people with HAE can get efficacy, tolerability, and convenience, they may be hidden in compromise.

Real person  
living with HAE.

DISCOVER MORE ABOUT HAE, INCLUDING VIDEOS OF REAL PEOPLE LIVING WITH THE BURDEN

[deflateHAE.com](https://deflateHAE.com)



**References:** 1. Lumry WR, et al. *Allergy Asthma Proc.* 2020;41(Suppl 1):S08-S13. 2. Betschel SD, et al. *J Allergy Clin Immunol Pract.* 2023;11(8):2315-2325. 3. Christiansen SC, et al. *Ann Allergy Asthma Immunol.* 2023;131(6):766-774. 4. Maurer M, et al. *Allergy.* 2022;77(7):1961-1990. 5. Data on file, Pharvaris. 6. Longhurst HJ, et al. *Br J Hosp Med (Lond).* 2019;80(7):391-398. 7. Lo SH, et al. *Pharmacoecon Open.* 2022;6(2):231-239. 8. Anderson J, et al. *Allergy Asthma Clin Immunol.* 2021;17(1):60. 9. Food and Drug Administration. The voice of the patient - Hereditary angioedema. Published May 2018. Accessed June 3, 2025. <https://www.fda.gov/files/about%20fda/published/The-Voice-of-the-Patient-Hereditary-Angioedema.pdf> 10. Savarese L, et al. *Allergy Asthma Proc.* 2021;42(1):e1-e7. 11. Chong-Neto HJ. *World Allergy Organ J.* 2023;16(3):100758. 12. Johnston DT, et al. *Allergy Asthma Proc.* 2020;41(Suppl 1):S43-S46. 13. Radojicic C, et al. *Allergy Asthma Proc.* 2021;42(3):S4-S10. 14. Busse PJ, et al. *J Allergy Clin Immunol Pract.* 2021;9(1):132-150. 15. Geba D, et al. *J Drug Assess.* 2021;10(1):51-56. 16. Covella B, et al. *Future Pharmacol.* 2024;4(1):41-53. 17. Riedl MA, et al. *Allergy Asthma Proc.* 2021;42:S17-S25. 18. Betschel SD, et al. *Allergy Asthma Clin Immunol.* 2024;20(43):1-8. 19. Hsu FI, et al. *Allergy Asthma Clin Immunol.* 2022;18(64):1-9. 20. Haegarda [prescribing information]. CSL Behring GmbH. Accessed June 10, 2025. <https://www.fda.gov/media/105611/download> 21. Takhzyro [prescribing information]. Dyax Corp. Accessed June 10, 2025. [https://www.accessdata.fda.gov/drugsatfda\\_docs/label/2022/761090s003lbl.pdf](https://www.accessdata.fda.gov/drugsatfda_docs/label/2022/761090s003lbl.pdf) 22. Firazyr [prescribing information]. Shire Human Genetic Therapies, Inc. Accessed June 6, 2025. [https://www.accessdata.fda.gov/drugsatfda\\_docs/label/2024/022150s016lbl.pdf](https://www.accessdata.fda.gov/drugsatfda_docs/label/2024/022150s016lbl.pdf) 23. Tuong LAC, et al. *Allergy Asthma Proc.* 2014;35:250-254. 24. Soteres DF, et al. *Clin Case Rep.* 2021;9(11):e050886. 25. Riedl MA, et al. *N Engl J Med.* 2024;391:32-43. 26. Farkas H, et al. *Clin Transl Allergy.* 2021;11(4):e12035. 27. Wedner HJ, et al. *J Allergy Clin Immunol Pract.* 2021;9(6):2305-2314.e4. 28. Zuraw B, et al. *J Allergy Clin Immunol.* 2021;148:164-172. 29. Riedl MA, et al. *Ann Allergy Asthma Immunol.* 2017;119(1):59-64. 30. Cinryze [prescribing information]. Takeda Pharmaceuticals U.S.A., Inc. Accessed June 6, 2025. <https://www.fda.gov/media/75907/download> 31. Lima H, et al. *Front Allergy.* 2023;10(4):1-5. 32. Zuraw BL. *World Allergy Organ J.* 2010;3(9 Suppl):S25-S28. 33. Busse PJ, et al. *N Engl J Med.* 2020;382:1136-1148. 34. Smith TD, et al. *Ann Allergy Asthma Immunol.* 2024;133:380-390. 35. Aygören-Pürsün E, et al. *Allergy.* 2013;68(8):1034-1039.