

# Your guide to being a Family Champion

**Tips and suggestions on starting the  
HAE conversation with your relatives**



*Embracing the Hereditary of HAE*

# Welcome to Family Champion

You've taken an important first step in becoming an advocate for yourself, your family, and those with hereditary angioedema (HAE). Being a Family Champion means that you are taking your health and the health of your family members seriously.

We understand that discussing health matters can often be an uncomfortable topic of conversation. Whether you have other relatives with HAE, or you're the only one who has been currently diagnosed, sharing knowledge is an important step in the Family Champion process. This guide includes information, tips, and suggestions that are designed to help start and facilitate conversations with your family.

***Let's get started.***

# HAE runs in the family

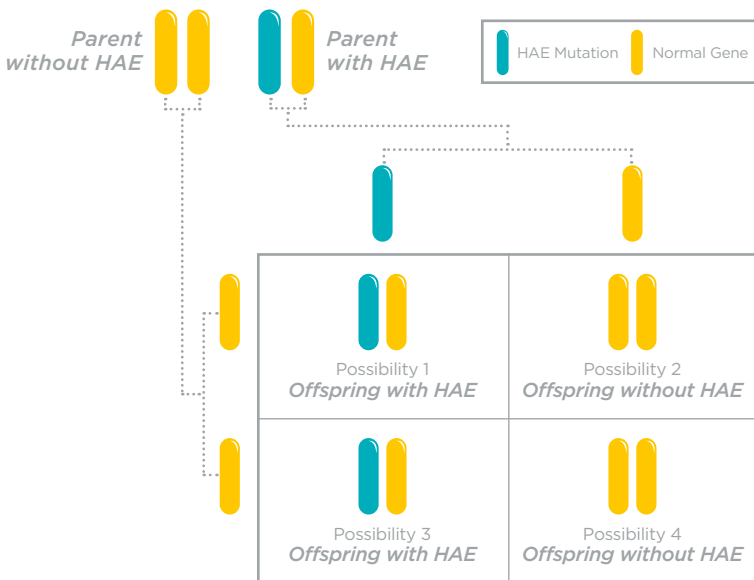
In a survey, HAE patients had an average of 2 immediate and 2 extended family members who had been diagnosed with HAE<sup>a</sup>



*This means that **as a diagnosed patient** you may have undiagnosed family members who **also have HAE**.*

About 75% of people with HAE inherit the disease and about 25% of people with HAE have a spontaneous genetic mutation that causes it.

If one parent has HAE, each child will have a 50% risk of inheriting the condition. If a child **does not inherit the disease** from his or her parents, he or she will not pass it on to future generations.



<sup>a</sup>In a global survey of 313 patients.

# Empowered by knowledge

Because HAE is a rare disease, some doctors may not be as familiar with the condition as you are. In fact, the symptoms of HAE can be mistaken for those of other conditions, including allergic reactions or appendicitis.<sup>a</sup> Sometimes, misdiagnosis can lead to unnecessary surgery, medical procedures, or the prescribing of medications, such as antihistamines, corticosteroids, or epinephrine, that don't treat the swelling associated with HAE.

## Screening for HAE

Empower your family to get answers by encouraging them to get tested for HAE. Doctors use blood tests to determine whether a person has HAE. They measure the levels of specific proteins in the body (C4 and C1 esterase inhibitor) that may be lower than normal or dysfunctional in patients with HAE.

Even if your family members have never experienced an HAE attack, they could still have HAE. Getting tested can confirm a diagnosis and help them be better prepared for the possibility of a future attack, which can happen at any time.

If a family member is interested in finding a doctor who knows about HAE, the US Hereditary Angioedema Association (HAEA) can help. Visit their website at [www.haea.org](http://www.haea.org).



**Tip:** Write down the questions you asked when first diagnosed with HAE—this may give your family members some ideas on questions to ask their own doctors.

<sup>a</sup>In a global survey of 313 patients.

# Every family needs a voice

Approaching family, especially those you aren't very close to, to tell them about a disease they may have can be an uncomfortable topic of conversation. Here are some suggestions on when and where you can have the HAE conversation with them:

## **Speak with family members one-on-one**

If you prefer to keep conversations more intimate, you can speak with each of your family members individually. Ask each person to meet you for coffee or lunch, or schedule visits to their homes.

## **Make a phone call**

For family members who may live far away, a phone call can go a long way in helping you share your experiences and encouraging HAE testing.

## **Host a gathering at your house**

If you have relatives who live close by, ask them to come over for a small get-together to discuss your family's health history. Encourage everyone to fill out the Health History Tree on [www.discoverhae.com](http://www.discoverhae.com) to help put them in the right frame of mind for the conversation.

## **Take advantage of holidays**

If your family always gets together for certain holidays, plan to use part of the day to have the conversation about HAE. Thanksgiving is a great example as it has been designated Family Health History Day by the Surgeon General.

## **Have a group video chat**

If you are having trouble getting everyone in the same room at the same time, consider using online services to video chat with family members near and far to discuss HAE.

Once you decide when and where to start your conversations, use the guide on the following page to help facilitate an open and positive dialogue.

# The conversation starts with you



## Talk about your journey to diagnosis

You can set the tone of the discussion by first talking about how HAE has affected your life and how your diagnosis came to be, including how long you've experienced symptoms and any misdiagnoses you may have had. It can be reassuring to know that answers and treatments are out there, especially if family members have been experiencing symptoms themselves.



## Explain that HAE is hereditary

Talk about how HAE is a rare disease that can be passed down through parents. You can use the graphic on page 3 to help guide this part of the conversation.



## Encourage HAE testing

Confirming a diagnosis is the first step in managing HAE. Even if your family members who have HAE aren't currently experiencing symptoms, they can experience attacks at any time and can potentially pass HAE down to their children. Being aware of whether you have HAE or not can prepare you for these possibilities.



## ***Tip: Plan your conversations***

Create an outline of the conversation you'd like to have with your family members, including your personal experiences. Have the outline on hand to make sure you have a positive and productive conversation.



### **Share how you manage your life with HAE**

Getting tested for a disease like HAE can be scary. You can help to ease the anxiety of getting tested for your family members by sharing how you manage your life with HAE. Let them know that both support and treatment are available.



### **Help them find a doctor**

Talk to your family members about finding a specialty doctor, such as an allergist or immunologist, to help manage their HAE should they be diagnosed. You can speak with your own doctor, or use the HAEA, to help your family find a doctor who treats HAE.



### **Be your family's advocate**

Make sure they know that you will be there for them throughout their own HAE journey—from testing and diagnosis to treatment. You can also let them know about additional resources available from Shire and other organizations, as listed on the back cover.

# Resources for you and your family

## DiscoverHAE

Family Champion is part of DiscoverHAE. Visit [www.discoverhae.com](http://www.discoverhae.com) to learn more about HAE and visit [www.facebook.com/DiscoverHAE](https://www.facebook.com/DiscoverHAE) to join the community.

## US Hereditary Angioedema Association (HAEA)

The HAEA is a non-profit organization that serves and supports patients with HAE, their families, and their caregivers. Visit [www.haea.org](http://www.haea.org) to learn more.

## Additional resources

National Organization for Rare Disorders  
[www.raredisease.org](http://www.raredisease.org)

American Academy of Allergy, Asthma & Immunology  
[www.aaaai.org](http://www.aaaai.org)

World Allergy Association  
[www.worldallergy.org](http://www.worldallergy.org)



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