



HAE in the Family

The impact beyond attacks
for children and caregivers

HAE=hereditary angioedema.

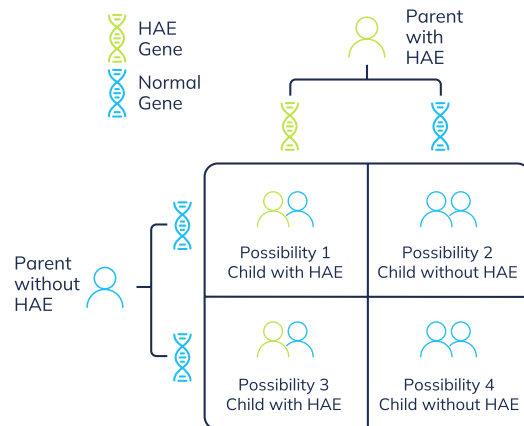
DISCOVER HAE

HAE often runs in the family

Genetics can play a big part in HAE

Hereditary angioedema (HAE) is typically found in the family tree, which is why the word “hereditary” is used in the disease name.

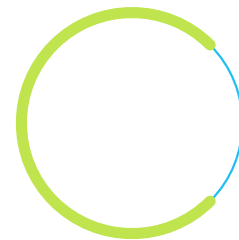
If one parent has HAE, each child has a 50% risk of inheriting the condition. If a child does not inherit the disease, they will not pass it on to future generations.



HAE isn't always inherited

HAE is often passed down from a parent, but that's not always the case. Some people develop HAE because of a spontaneous change in their genetic code, so it can't be traced to their family tree.

75%
Inherited
gene



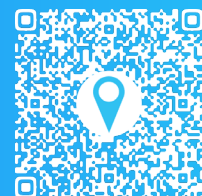
25%
No family
history

Getting an accurate HAE diagnosis for your child

Family health history is important for identifying and diagnosing HAE. To be certain your child has the disease, your doctor will evaluate them and ask for a detailed history of their symptoms. The doctor will also perform a blood test and, if needed, a genetic test to get a diagnosis.

Encourage family members to test for HAE

If a family member is interested in finding a doctor who understands HAE, let them know there are specialists who can help diagnose and treat it. **Click the button or scan the QR code to connect with an experienced HAE physician.**



FIND AN HAE SPECIALIST

The impact of HAE on children and families

The real impact of HAE goes beyond the attacks. The emotional pressure that people living with HAE experience can extend to other family members as well. Caring for a child with a lifelong condition like HAE can take a toll on parents, especially those who are managing their own HAE.

Challenges for children with HAE

At times, the unpredictability of attacks can be more stressful to children than the attacks themselves. Fear of future HAE attacks that may happen can cause children to avoid:



School



Social activities
with friends



Sports and other
physical activities

As children get older, their HAE attacks may become more frequent and/or severe. Caregivers should be on the lookout for attacks becoming more severe during or after puberty.



One family's experience with HAE



Meet Beth and Andrew

Beth has HAE, but her story goes beyond her own experience with the condition. She also cares for her son Andrew, who had his first attack when he was just 6 years old.



I have HAE myself. I experienced everything my son Andrew would go on to fight through, but it was just so much harder watching him. I overlooked so many things about what it would be like to care for a child with HAE.

There were months when my son would have not 1, not 2, but 4 abdominal attacks. He'd miss so much school, and then we'd encounter a teacher who just couldn't understand what he was going through.



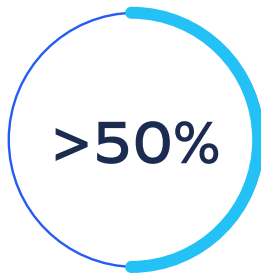
While my husband and I knew treating Andrew with preventive medication wouldn't stop him from having attacks completely, it might very well prevent some of his attacks. That's all I could ask for.

I hope in hearing my story today, you know that your experiences are real. They're hard. But you're not alone.

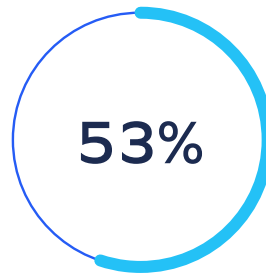
—Beth

Statistics show the real impact of HAE on the family

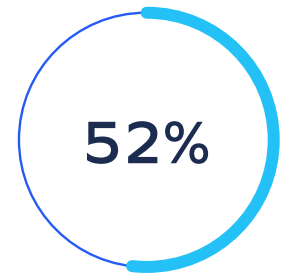
People with HAE and caregivers have reported that the symptoms of HAE can interfere with many aspects of life.



In a study of 450 adults with HAE, **more than half** felt that missing school due to HAE attacks impacted their educational choices later in life.



In a survey of 30 caregivers of adults and children with HAE, **53%** agreed that HAE impaired patients' everyday activities to some extent.



In the same survey, **52%** of caregivers agreed that patients avoided social activities because of HAE.

Consider HAE management options for your child

You're probably aware that there are 2 treatment types available to people with HAE. When your doctor understands how HAE is impacting your child's life, they will get a clearer picture of your child's individual treatment needs.



On-demand treatment

Taken when an HAE attack happens, to help reduce the effects of the attack



Preventive treatment

Taken to help reduce the frequency and severity of attacks before they happen

A comprehensive HAE management plan for your child may include both on-demand and preventive therapy.

How is HAE *really* affecting your child?

It's important to maintain regular communication with your doctor so they can stay informed about the impact HAE is having on your child and family. Below are a few questions designed to help your doctor better understand that impact.

1. What activities in your child's life are impacted by HAE? Select all that apply:

- Travel
- Time spent with family and/or friends
- School
- Exercise
- Sports
- Special events

2. Has this impact changed for them in the last 6 months?

- It's gotten better
- It's stayed the same
- It's gotten worse

3. How often do you cancel or change plans for your child due to an HAE attack or fear of an attack?

- Never
- Occasionally
- Frequently
- All the time

4. HAE can be unpredictable. How do you and your child try to deal with that unpredictability?

Select all that apply:

- Keeping on-demand medication with us at all times
- Taking a preventive treatment as prescribed
- Avoiding HAE triggers (events, physical activities, foods, stress, etc.)
- Other

[Download](#) or print a copy of this brochure to review your answers with your doctor at your next appointment—so together you can create the right HAE management plan for your child.

