



## **Creating equitable care for people living with hereditary angioedema (HAE)**

Putting patients first —  
that's the Takeda way

# Supporting people with HAE through every step of their journey

Everyone experiences their own unique set of challenges; however, a debilitating and challenging rare disease like HAE is something that **no person should ever fight alone.**



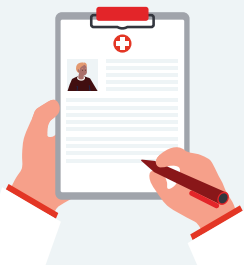
Approximately **1/5** of the US population lives in a rural location, where barriers to optimal health care exist, particularly for those with rare medical conditions.<sup>1</sup>



Individuals affected by **HAE in rural areas** may face increased diagnostic and treatment challenges owing to a lack of access to specialists, medication, and other health care services.<sup>1</sup>



**20+ years** partnering, researching and advancing innovative treatments for the HAE community.



Meeting unmet needs **across generations of people with HAE** by investing in four key areas:

- ✓ Delivering Disease Education and Awareness
- ✓ Reducing Time to Diagnosis
- ✓ Creating Equitable Access to Treatment
- ✓ Advancing our Portfolio of Acute and Prophylaxis Medicines

# We are helping advance health equity for the HAE community

## Addressing unmet needs for people with HAE:

Providing access to care and treatment options to those affected across generations, including in under-resourced communities.



of what influences our health comes from outside of the doctor's office, also known as social determinants of health.<sup>2</sup>

## Serving as a trusted partner:

Meeting people with HAE where they are with assistance and support programs throughout their treatment journey.

## Expanding educational opportunities:

Collaborating with HAE advocacy organizations to provide educational, culturally-relevant materials for people with HAE and their caregivers.

## Caring for all communities:

Identifying and tackling community level barriers to improve care in HAE, especially in rural areas.

## Driving progress in HAE:

Publishing research to raise awareness of disease management focused in underserved communities.

**References:**  
<sup>2</sup> Going Beyond Clinical Walls: Solving Complex Problems. Institute for Clinical Systems Improvement. [Internet cited June 2024] [https://www.icsi.org/wp-content/uploads/2019/08/1.SolvingComplexProblems\\_BeyondClinicalWalls.pdf](https://www.icsi.org/wp-content/uploads/2019/08/1.SolvingComplexProblems_BeyondClinicalWalls.pdf)

# Advancing health equity in rare disease with patients at the center

Starting with a timely and accurate diagnosis, **we strive to improve the standard of care and address health care disparities** faced by all people living with rare diseases, including HAE, to create a more equitable health ecosystem.

Part of our commitment includes working with patients, advocacy organizations, community partners and industry partners to explore new opportunities to **accelerate the diagnostic journey for the HAE community**



## 6 years

the average time from symptom onset to receive an accurate rare disease diagnosis.<sup>3,4</sup>



There are more than

## 500,000 patients

in the U.S. with a rare disease  
Takeda treats.<sup>5-18</sup>

**References:** **3** About us. EveryLife Foundation for Rare Diseases. [Internet; cited June 2024]. <https://everylifefoundation.org/about-us/> **4** Rare Diseases. Barriers to rare disease diagnosis, care and treatment in the U.S.: A 30-Year Comparative Analysis [Internet; cited June 2024]. [https://rarediseases.org/wp-content/uploads/2022/10/NRD-2088-Barriers-30-Yr-Survey-Report\\_FNL-2.pdf](https://rarediseases.org/wp-content/uploads/2022/10/NRD-2088-Barriers-30-Yr-Survey-Report_FNL-2.pdf) **5** Busse PJ, et al. (2020). U.S. HAEA Medical Advisory Board 2020 Guidelines for the Management of Hereditary Angioedema, The Journal of Allergy and Clinical Immunology: In Practice. [https://www.haea.org/assets/img/Treatment\\_Guidelines040321.pdf](https://www.haea.org/assets/img/Treatment_Guidelines040321.pdf) **6** Bleeding Disorders Awareness Month. National Bleeding Disorders Foundation (Formerly NHF). [Internet; cited February 2024]. <https://www.hemophilia.org/give/join-us/bleeding-disorders-awareness-month> **7** von Willebrand Disease data from the HTC Population Profile. Centers for Disease Control and Prevention (CDC) Community Counts. [Internet; cited February 2024]. <https://www.cdc.gov/ncbddd/hemophilia/communitycounts/data-reports/2023-9/table-3-vwd.html> **8** Gaucher Disease. National Organization for Rare Disease. [Internet; cited February 2024]. <https://rarediseases.org/rare-diseases/gaucher-disease/#disease-overview-main> **9** Celik, B., et al. (2021). Epidemiology of Mucopolysaccharidoses Update, Multidisciplinary Digital Publishing Institute (MDPI). <https://www.mdpi.com/2075-4418/11/2/273> **10** Hunter Syndrome. Project Alive. [Internet; cited February 2024]. <https://projectalive.org/hunter-syndrome/> **11** Stoller, J. K., & Brantly, M. (2013). The Challenge of Detecting Alpha-1 Antitrypsin Deficiency. Journal of Chronic Obstructive Pulmonary Disease, 10(1). <https://doi.org/10.3109/15412555.2013.763782> **12** Boyle, J. M., & Buckley, R. H., (2007). Population Prevalence of Diagnosed Primary Immunodeficiency Diseases in the United States. Journal of Clinical Immunology, 27 (6). <https://doi.org/10.1007/s10875-007-9103-1> **13** U.S. and World Population Clock. Census.Gov [Internet; cited 2022]. <https://www.census.gov/popclock/embed.php?component=popondate&date=20220522> **14** Voice of the Patient, Chronic Inflammatory Demyelinating Polyneuropathy. GBS CIDP Foundation. [https://www.gbs-cidp.org/wp-content/uploads/2022/08/GBSCIDP-Voice-of-the-Patient-Report\\_Final.pdf](https://www.gbs-cidp.org/wp-content/uploads/2022/08/GBSCIDP-Voice-of-the-Patient-Report_Final.pdf) **15** Vlam, L. et al. (2011). Multifocal motor neuropathy: diagnosis, pathogenesis and treatment strategies. Natural Reviews Neurology 8(10). <https://www.nature.com/articles/nrneuro.2011.175> **16** Meuth, S., & Kleinschmitt, C. (2010). Multifocal Motor Neuropathy: Update on Clinical Characteristics, Pathophysiological Concepts and Therapeutic Options. European Neurology 63(11). <https://karger.com/ene/article-pdf/63/4/193/2721167/000282734.pdf> **17** Short Bowel Syndrome and Crohn's Disease. Crohn's & Colitis Foundation. <https://www.crohnscolitisfoundation.org/sites/default/files/legacy/assets/pdfs/short-bowel-disease-crohns.pdf> **18** O'Shea, K., et al. (2017). Pathophysiology of Eosinophilic Esophagitis. Gastroenterology. <https://www.gastrojournal.org/action/showPdf?pii=S0016-5085%2817%2935952-8>



“Every patient’s experience is different, so it’s important to work with your doctor. When I think about the first time I went hiking (with HAE) and where I am today, I have a whole new perspective now through my journey with HAE.”

— Kelly, patient living with HAE

**Find out more about HAE.**

**GET STARTED**

**Discover Takeda’s commitment to health equity in rare disease.**

**LEARN MORE**

