Redefining expectations for life with **hereditary angioedema**

About hereditary angioedema (HAE):

HAE is very rare, occurring in
1 in 10,000 to
1 in 50,000 people[1]

HAE can affect
various parts
of the body,
including the hands, feet,
face and airway[1]

HAE can be life-threatening, as attacks that affect the throat can close the airway and lead to
suffocation[1]

HAE can be very hard to diagnose, with the average time between the onset of symptoms and diagnosis ranging from
13-21 years[1]

Diagnosis is vital, as the risk of death is up to
nine times
higher with undiagnosed HAE compared to those who have a diagnosis[1]

HAE can be very painful, with
two thirds
of patients rating the pain of their most recent swelling attack as 'moderate' or 'severe'[1]

HAE can be life-limiting, with one in three patients experiencing more than one attack per month and the average attack lasting
2 – 5 days[1]

HAE can have wider socioeconomic impacts on both patients and caregivers, with
82% of patients
with severe HAE reporting work or school absenteeism during their last attack, for an average of 5.1 days[1]

Takeda's vision

Takeda believes that all countries should take action to **redefine the expectations of people living with HAE from focusing on the challenges created by the condition to being able to live a life unlimited by the disease**. We look forward to working with a wide range of stakeholders, including clinicians, patients, patient organisations and policymakers to make this vision a reality.

Takeda's recommendations for improving the quality of HAE care

Speeding up diagnosis

- Increase awareness among clinicians of the signs and symptoms of HAE
- Ensure that established best practice in referral and testing is followed
- Offer cascade testing to the family of all patients who are newly diagnosed

Delivering holistic care for patients

- Provide patients with access to high quality services that facilitate individualised management and treatment
- Establish international consensus on the standards that these services should meet based on expert clinical and patient consensus

Providing access to the right treatments at the right time

- Involve patients in decision-taking about their treatment
- Adhere to international best practice guidelines
- Provide rapid interim access to new treatments from the point of regulatory approval for appropriate patients

Collaborating internationally to share best practice and data

- Identify barriers to the adoption of international consensus guidelines on HAE at national level
- Forge partnerships between national expert groups, governments and healthcare systems to encourage greater collaboration in best practice sharing and data collection mechanisms

1. HEAi, The Current State of HAE management in Europe, 2015. Last accessed: January 2020

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