

## Abstract from HAEi Global Leadership Workshop, Frankfurt 6–9 Oct 2022

### An international physician real-world practice patterns survey evaluating the burden of illness in hereditary angioedema type I/II

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**Rationale:** The ultimate goal of treating hereditary angioedema (HAE) is to achieve no HAE attacks. There is a need to understand the real-world healthcare provider (HCP) practice patterns and assess the burden of this disease to identify the necessity for novel therapies in achieving treatment goals.

**Methods:** A physician survey was performed (2020/21) to understand the disease landscape and identify current HAE type I/II standard of care practices. Specialized HAE HCPs completed the survey and information was collected on HAE patient population and patient management.

**Results:** Sixty-six HCPs from 22 countries in Europe, Israel and Canada were initially contacted. Of the 43 HCPs who accepted to participate and who were sent surveys, 40 responded. Thirty-nine HCPs were included in the analysis and mainly working in a hospital/clinic (95%). HCPs reported seeing HAE patients every 2-6 months (41%) or 6-12 months (33%). 36% of HCPs reported patient diaries are routinely used by the patient/caregiver to document HAE attacks. HCPs not collecting diaries (64%) confirmed that at least one important HAE attack characteristic is commonly collected and documented in the medical records (e.g., attack date, location, severity, duration). All HCPs indicated that they have at least one adult patient  $\geq 18$  years at their practice with inadequately controlled HAE; 77% of HCPs treat at least one adolescent (12-17 years) with inadequately controlled HAE. The most common reasons HCPs consider a patient with inadequately controlled HAE included: frequent attacks (57%), impact on quality of life (30%), low/no compliance to treatment (24%), and severity of attacks (19%).

**Conclusions:** HAE attack data is likely to be found in patient medical chart. There is still a need to better record attacks with diaries in daily practice. Further research is warranted to better understand the burden of disease with the current treatments to achieve better goals of therapy.