

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

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### Understanding the HAE Patient Journey in Brazil

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**Rationale:** Hereditary angioedema (HAE) is a primary immunodeficiency (PID) and not an allergy. The support and guidance provided to patients and family members by the Brazilian Association of HAE Carriers (ABRANGHE), contribute to minimizing the burden and disseminating knowledge about the disease. There are few data published in Brazil related to sociodemographic, quality of life, self awareness in this disease. and access to treatments were addressed.

**Methods:** ABRANGHE together with Medical Affairs Team from CSL Behring Brasil created a survey containing 30 questions in multiple-choice and in open format; data were anonymized and the responding patients in the survey data couldn't be identified.

**Results:** The data was obtained from 178 responders (1500 people in the list). Demographic profile was characterized by 93% of caregivers, 81% female, 62% with University level and in 74% older than 30 years. Regarding the time to get HAE diagnosed, 47% it took more than 10 years. The patients considered the disease highly impacts in their quality of life, in 78%.

Most of this group received oral drugs in 49%, and IV in 20%. During the attacks the areas mainly affected are face, upper and lower limbs in 82% and it was considered important to have a drug at home during an attack in 100%.

Regarding self-infusion, they considered as feasible a home administration of an IV drug in 59%. However, if it changes to SQ it was considered as possible in 88%.

**Conclusions:** This research was important to listen to patients voice. The authors could identify unmet needs in HAE treatment to structure a PSP (patient support program) that could really make a difference in patients journey.