

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

### Surveys on Access to Modern Medicines for Hereditary Angioedema (HAE)

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**Rationale:** Analyze hereditary angioedema (HAE) patient access to innovative therapies, treatment goals and quality of life, and determine if there are differences with respect to clinical guideline recommendations.

**Methods:** AEDAF conducted an anonymous online survey for AEDAF members and other HAE patients residing in Spain. On the other hand, through the Spanish Society of Allergology and Clinical Immunology (SEAIC) and the Spanish Pediatric Society of Clinical Immunology, Allergology and Asthma (SEICAP), another anonymous online survey of physicians from different hospitals and autonomous regions who manage HAE patients was conducted.

**Results:** The patient survey was completed by 168 respondents, 22% of whom have not received self-administration training and only 33% of whom have received training for intravenous (IV) self-administration. 20% have been disabled in their daily activities (domestic, workplace, school or leisure) for more than 10 days during the last 6 months as a result of their attacks.

The physician survey was completed by 82 healthcare professionals from 58 hospitals. The data indicate a lack of availability of specific innovative drugs for long-term prophylaxis (intravenous/subcutaneous C1 inhibitor plasma concentrate and lanadelumab) in the majority of hospitals, which is even more apparent in the smaller hospitals (Figure 1). Approximately 40% of the hospitals do not have a self-administration training program.

**Conclusions:** The surveys on access to HAE therapies have highlighted the actual availability of HAE therapies, as well as aspects related to home self-administration and patient quality of life. The data will help to determine future courses of action aimed at improving HAE patient healthcare.

Figure 1. Percentage of hospitals with availability of HAE LTP therapies according to number of hospital beds.

