

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

## The project of free diagnosis of hereditary angioedema in Ukraine

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**Rationale:** Hereditary angioedema (HAE) incidence is about 1 per 50 000. The estimated number of cases in Ukraine is about 800 cases. Instead, by the beginning of 2021, only 50 cases were registered. And effective steps are needed to improve diagnosis so that people suffering from HAE have a better quality of life. The goal, to improve the diagnosis of HAE in Ukraine.

**Methods:** A project on free diagnosis of HAE was developed by Ukrainian Association of Pediatric Immunology and patient's organization "Ukrainian Association of Patients at the HAE." Examination of patients within the scope of the grant. The inclusion criteria were the presence of clinical symptoms of HAE or asymptomatic patients with a family history of HAE. Laboratory examination included the C4, C1-inhibitor concentration and activity complex. The special referrals were distributed among allergists and immunologists in different regions of Ukraine.

**Results:** During the 4 months, 41 women and 26 men aged from 2 to 66 y.o. (average age is 31 y.o.) were examined. Among the examined, 42 patients had consistent to HAE symptoms and 25 were asymptomatic relatives.

New 17 HAE patients were diagnosed: 16 HAEI cases and 1 HAEII case. The average age of those diagnosed is 26.8 y.o. (range 7-52 y.o.), 10 adults and 6 children. 5 new asymptomatic HAE cases were diagnosed in children aged 3 to 14 years, 4 boys and 1 girl. Interestingly, patients were primarily diagnosed in those regions of Ukraine where the HAE incidence was higher.

**Conclusions:** Availability of laboratory diagnostics is essential to improve the detection of new patients. Diagnosis in the preclinical phase allows planning the state treatment programs and patient education, preventing unpredictable consequences. Patients are better diagnosed by those doctors who have a high level of awareness, which determines the wider awareness of the medical public concerning HAE.