

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

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### HAE patients in Ukraine under war conditions

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**Rationale:** On February 24, 2022, the Russian Federation attacked Ukraine, causing a mass migration of Ukrainian citizens fleeing the war. Patients with HAE were no exception. The situation is complicated by special needs, considering sensitivity to triggers, orphan drugs, access to medical facilities. Understanding the routes of migration of patients is important both from a humanitarian point of view and understanding the need for treatment, because in Ukraine, the state provision of treatment is tied to the place of residence. The purpose: to study the impact of war on the fate of patients with HAE.

**Methods:** A Google form with questions was created and distributed on social media among patients with PID and HAE and the doctors who care for them. Answers were received from 106 people, among them 40 patients with HAE.

**Results:** Almost half of the respondents (18/40; 45%) had to change their place of residence due to the start of the war, 11 of them moved to another region of Ukraine, 7 went abroad. Three patients were in the occupied territory. 40% could not answer the question about their future plans, reflecting instability and frustration. Countries patients from Ukraine moved: Poland, Germany, Switzerland, Italy, Bulgaria. Everyone wants to come back home either as soon as possible, or after the end of the war. About 30% of patients had problems with access to treatment due to the war, 73% continue to receive medicine due to the state of Ukraine, only 1 patient receives medicine at the expense of another state, 23% do not receive medicine at all.

**Conclusions:** The war had a significant impact on the migration of patients with HAE and their access to treatment. Nevertheless, in Ukraine, the state provision of medicines is available for the majority of patients. It is necessary to develop effective programs to support patients in need of orphan drugs.