

# “Ukrainian SMA registry: assessing the impact of the war on a rare disease community”

**Keywords:** spinal muscular atrophy, rare disease registries, CSMA, SMA Europe, war, russian invasion, Ukraine

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Before the war, people living with rare diseases in Ukraine faced many challenges, and access to specialized medicines and treatment was generally difficult and not prioritized by the government.

However, the current war has impacted the lives of people living with rare diseases immensely and their situation has become critical. Many rare disease families are forced to decide whether they stay in Ukraine or risk the dangerous journey to reach safer grounds.

In this study, we investigate how (families of) individuals living with SMA are deciding on this difficult question. To investigate the extent to which SMA families have evacuated, a survey was conducted.

The survey was emailed to the SMA families through the Ukrainian SMA registry’s mailing list, it was posted on the website of the CSMA Foundation, and on social media. The survey was completed by 150 Ukrainian SMA families, which makes up approximately 45% of the total Ukrainian SMA population known to the Ukrainian SMA registry. The results show that half of the respondents are in Ukraine, and 30% of the respondents have moved away since the start of the war. Of the families who moved out of Ukraine after the start of the war, 72% crossed the border to Poland; and 68% of all those who left Ukraine are staying in Poland.

The russian invasion of Ukraine has led to many challenges and life-threatening situations for individuals living with rare diseases such as SMA. Half of the Ukrainian SMA patient community is currently living outside of Ukraine. Through the SMA disease-specific registry and a European network it was possible to contact individuals and to assess their locations, and subsequently to coordinate support based on their individual needs. In addition, the registry is a tool to keep together the Ukrainian SMA Community who will be scattered all over Europe.