

Ukrainian SMA registry: assessing the impact of the war on a rare disease community.

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ABOUT US

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 prioritised by the government.

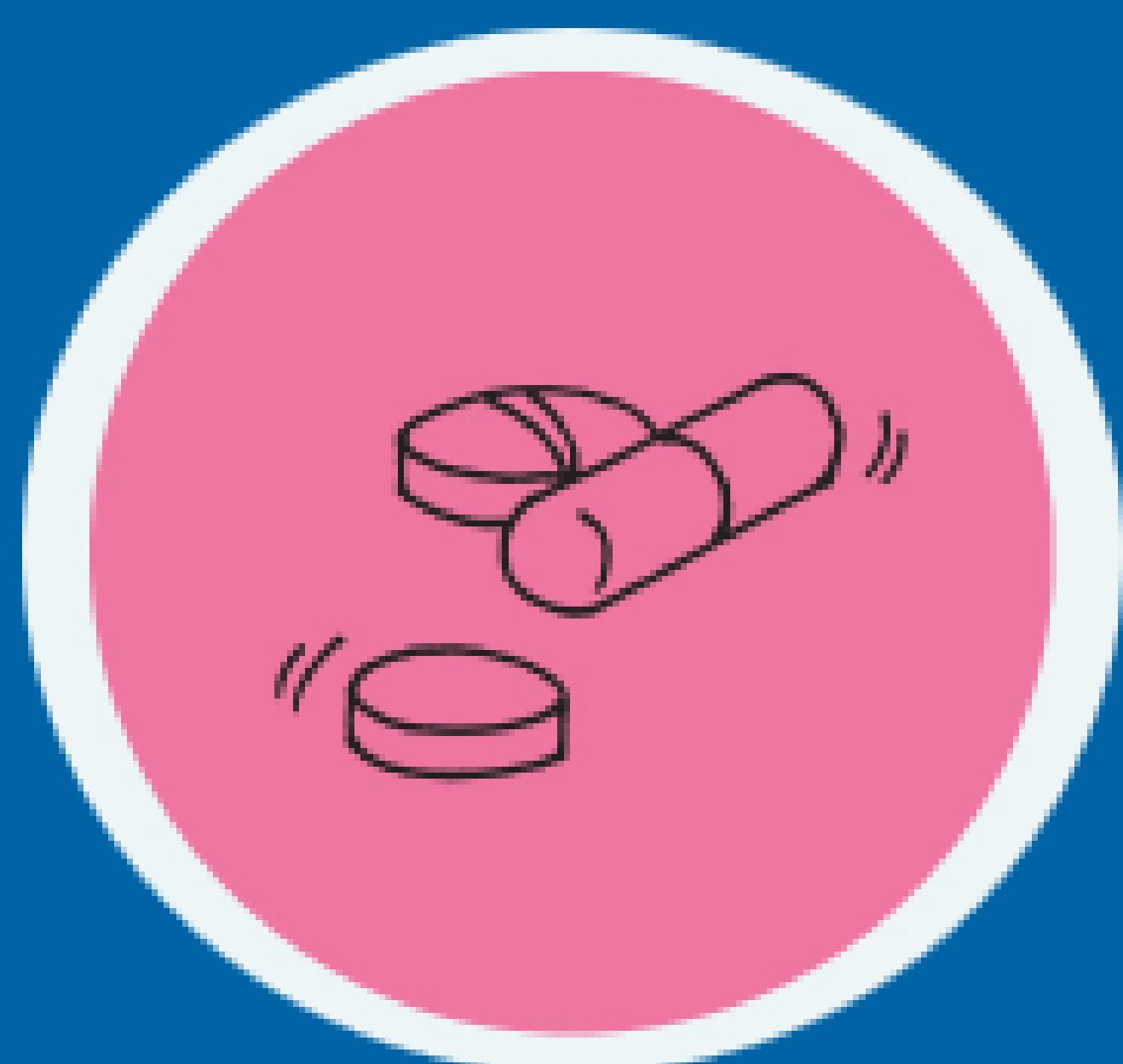
However, the current war has impacted the lives of people living with rare diseases immensely and their situation has become critical. Many rare disease families are forced to decide whether they stay in Ukraine or risk the dangerous journey to reach safer grounds.

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.

METHOD

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.



RESULTS

Among people who had access to the internet and emails, 50% reported staying at home, in Ukraine, while another 50% reported being abroad. Also, 30% of respondents indicated having moved after the war had started. Most families, who were abroad at the moment of survey completion, left Ukraine on February 28th, March 1st, and March 7th-8th. Those waves may be explained by the overloaded roads and infrastructure. It shows that from a third to a half of the Ukrainian SMA patient community left their country immediately after the hostilities started.

As for the first country of entry, people tended to choose Poland. The Ukrainian-Polish border was the most frequently crossed. The reasons could be that Poland offered the best conditions as well as much help after relocation. Furthermore, 68% of all those who left Ukraine are staying in Poland. While some respondents indicated that they would plan to move to a different European country, this was a very small part.

Together, these findings show that a large portion of the SMA families is currently either living in Poland and is planning to stay there, or they are aiming to relocate there from Ukraine in the future. This indicates that Poland is not only the most often crossed border, but also that the conditions of living and the help available after relocation is very suitable for Ukrainian SMA families.



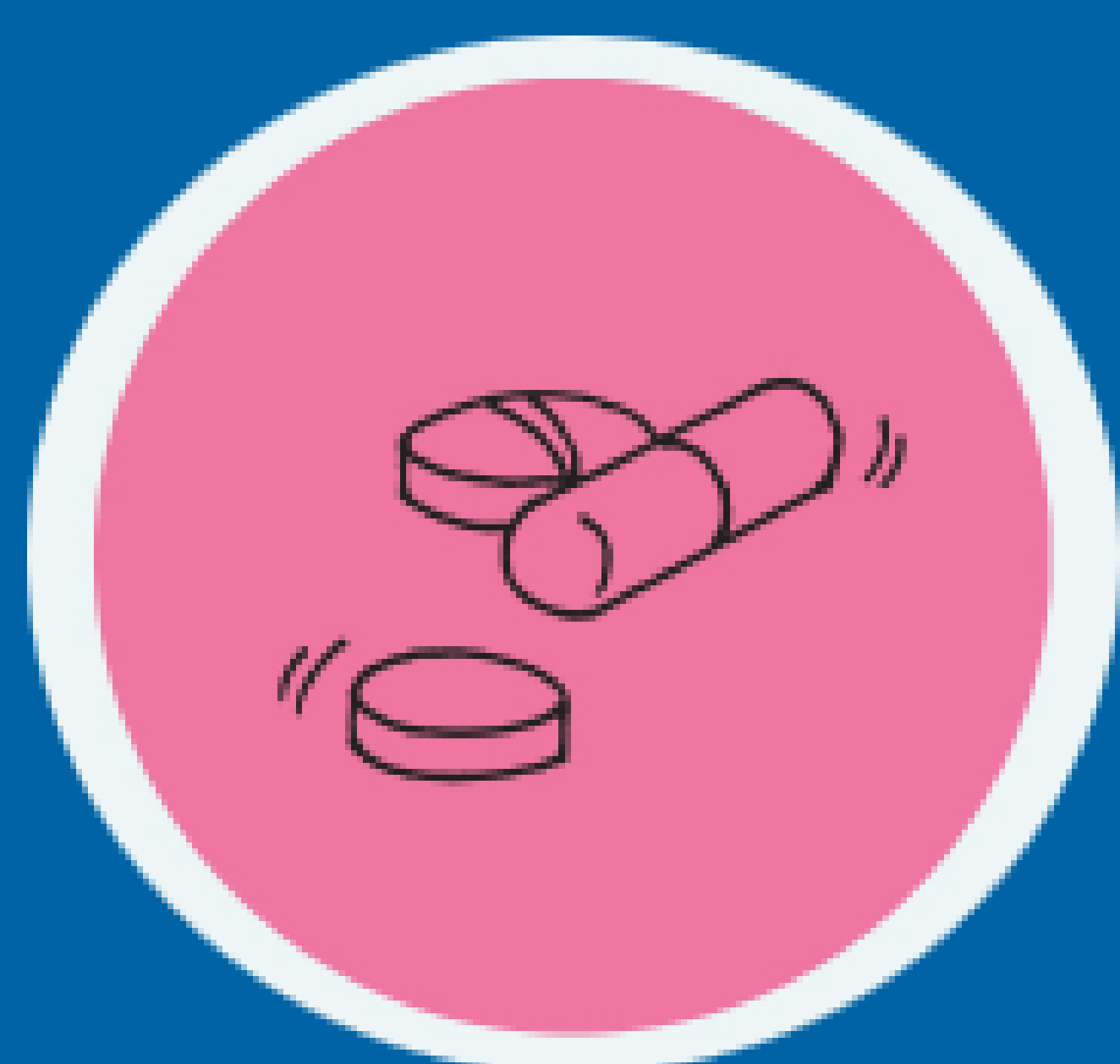
CONCLUSIONS

No country in today's world, especially in Europe, could have foreseen a full-scale war. The Russian invasion to Ukraine has led, among other things, to huge obstacles and life-threatening situations for people living with rare diseases, such as SMA, in Ukraine. Our study shows that a third to a half of the Ukrainian SMA patient community left their home country immediately after the hostilities started.

As this survey also showed that families have had difficulties accessing the Internet, it is unclear how many patients who did not respond immediately to the survey are trapped without access to the outer world and without proper treatment and care. Importantly, this is not specific to the SMA only, the situation is about the same for the whole Ukrainian rare disease community.

Many families responded to the survey asking for help, and thanks to this they were able to get first aid through the global SMA network. This adds value to the existing disease-specific registries and opens up a new global role for patient driven registries. CSMA is grateful to the parents who take part in the Ukrainian Register.

On behalf of all Ukrainian families with SMA, we are also grateful to the countries that are currently hosting our families. Special thanks to SMA Europe and Polish SMA Foundation for their support since the beginning of the war.





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Thank you.

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