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Family's Harrowing Journey to Save Their Son Milwaukee Woman Helps Ukrainian Children With Rare Diseases

Lesia Kutarenko would do just about anything to save her son's life. Fortunately, so would a stranger across the world. Today, the women's lives are intertwined in ways neither could ever have imagined.

In September 2021, five months before Russia began its full-scale invasion of Ukraine, Lesia's son Oleksandr, who is called Sasha, was born. He was crawling and pulling himself up like a normal child his age but his development regressed as his muscles seemed to become increasingly weaker. Lesia knew something was seriously wrong and that her son needed to be seen by a doctor in a major city like Kyiv but due to the war, the country's healthcare system was strained, hospitals were being bombed and medical treatments were increasingly unavailable and unaffordable.

"It was layer upon layer of fear," Lesia said in Ukrainian with Anya Verkhovskaya translating. "We lived in a small village that was less likely to be targeted by missiles, so it was very scary to travel to the hospitals in Kyiv. The Russian forces were close to Kyiv and there was lots of shelling, including the hospitals. Due to martial law we had to be home by 10 p.m. and it was very difficult to make it home in time. It was very stressful."

Power outages meant trips were often made in complete darkness. Signs warned of roadside mines. Making it through the checkpoints was tense. Lesia and her husband Ruslan were constantly worried that if they were stopped, he would be drafted and their car would be confiscated for the army. The terror and uncertainty of war amplified their fear about the health and survival of their son.

"Jobs were no longer available. You might get called to a job and you didn't know if you would get paid or not. A lot of people left Ukraine. A lot of people were drafted. Psychologically, it was very scary and difficult," said Lesia.

In the midst of it all, Sasha's test results came back and the news was devastating. He was diagnosed with Spinal Muscular Atrophy (SMA), a genetic disorder that starts in the central nervous system and affects all muscles in the body. The degenerative disease causes a decline in muscle strength and without treatment, it is almost always fatal.

"It was like a bolt of lightning hitting us on the head. We didn't know what to do. We were lost, depressed and scared. No one could advise us what to do and we had nowhere to turn."



Finding Solutions Through Virtual Support

Novartis, the company that developed the gene-therapy medicine for SMA, periodically conducts a lottery to provide free treatment to children in participating countries, including Ukraine. However, because all flights to Ukraine were halted after the Russian invasion, the country's participation in the Novartis lottery was halted.

The turning point for the Kutarenkos was connecting with a WhatsApp group of families whose children had received the SMA gene-therapy treatment. Lesia and Ruslan felt some relief simply by connecting with other parents who had encouraging stories to share. Lesia immersed herself in learning everything she could about SMA.

In their search for help, the Kutarenkos were connected with Anya, of Mequon, Wisconsin, and her team at the Milwaukee-based nonprofit Friends of Be an Angel. Linking up with Anya would change their lives forever.

A businessperson and global human rights activist, Anya, who has Jewish Russian and Ukrainian heritage, fled the Soviet Union in the 1980s as a 19-year-old political refugee. Since the Russian invasion, she has led significant disaster, humanitarian aid and trauma relief efforts for Ukraine. When she learned of the children suffering from SMA, she turned to her team, who jumped into action to research the disease, reach out to hospitals and doctors, plow through seemingly endless paperwork and plan medical evacuations to Germany and the United States.

"One of the community leaders told me there is a very sick child with a mother who is very young and grief stricken and she needs help. I couldn't walk away even though I had no idea how to help. I knew I couldn't do this by myself and that I needed to bring it to the team, a collection of individuals from different walks of life with a passion for humanitarian support of those in need," Anya said.

Arrangements were made for Sasha to be treated at Children's Wisconsin in Milwaukee. A key factor was Ruslan being granted permission to leave the country rather than being recalled to active duty like most Ukrainian men his age. The couple, who had only five weeks to prepare to leave Ukraine, had to make the devastating decision to leave their two daughters behind with their parents. Anya knew bringing a family of five to the U.S. was too complicated, expensive and risky for the couple to get to Milwaukee for treatment. Having to advise the family of this, she said, will haunt her forever.

"We had so little time and I had to make a decision about whether we could bring the other two kids to the U.S. To leave them to be raised by someone else—in a war zone...who am I to tell her that? I feel extremely guilty and heartbroken about it every single day."

The arduous journey to the U.S. began with an all-night train ride to Lviv in western Ukraine and a 10-hour bus ride from there to Warsaw during which Lesia and Ruslan watched in shock and fear as a Ukrainian man and his five-year-old child were removed from the bus. After an

overnight stay in Warsaw to allow Sasha to get some much-needed rest, they finally arrived at the Warsaw airport only to be informed that their stack of official paperwork lacked a single, but crucial, document. Lesia was seconds away from cancelling the tickets when the document came through—a last-minute administrative miracle pulled off by Anya’s team.

The couple, exhausted and unable to speak English, arrived in Chicago with two suitcases, a seriously ill child and an apprehensive yet resolute trust in the strangers who were helping them. They were settled into an apartment near Children’s, which a local Ukrainian group completely furnished, outfitted and stocked—all while the family spent a few hours at a museum.

Within a week, Sasha was examined by a neurologist at Children’s and all the same blood tests that took such a long time in Ukraine were repeated with results back in a week. Three weeks later, Sasha received the gene-therapy treatment and within a month, he began to regain his ability to crawl.

The family has been in Milwaukee for nine months while Sasha undergoes physical therapy to build his strength and endurance so he will be able to stand and walk. At 2½, he lags behind children his age in many ways, but his progress—his mere survival—gives his parents hope and fills them with gratitude.

“Now I feel hopeful because I can see Sasha trying to walk. He is getting stronger and is able to do so many things he couldn’t do before,” said Lesia, overcome with emotion. As she speaks, Sasha zips around Anya’s house on all fours, bedeviling her cat and pulling toys out of the cupboard she stocked for him. Lesia watches him and says, “We are so grateful to everyone who has helped us get to this point.”

Anya, who has formed a close bond with this family, frequently wipes away tears as Lesia and Ruslan share their story.

“We are so eternally grateful to everyone who participated in the entire process, the 50-60 people who worked together to make it all possible for Sasha to be here. These are all volunteers, people who couldn’t stand by and watch this happen and not do something about it.”

But the real hero in this story, according to Anya, is Lesia.

“She is my heroine. What she has been through is unfathomable and she has been so strong; so brave. The lesson here is that it’s really important to help and support each other and try to understand what others are going through. It is not possible for Ukrainian families to even think about getting treatment and paying for it. There are many children suffering immensely without any support,” Anya said. “They desperately need help.”

'It Takes a Community'

So far, Friends of Be an Angel has arranged the medical evacuation and treatment for 41 Ukrainian children with rare diseases at hospitals in Germany and the U.S. The drug and long-term physical and occupational therapy and rehabilitation along with living expenses costs millions of dollars (a single dose of the gene-therapy drug alone costs about \$2.1 million). The government program Uniting for Ukraine, Medicaid and hospital foundations cover a large portion of the expenses while the remainder relies on sponsors, donations and grassroots fundraising.

“In Ukraine—in a war zone—we raise more money than here in the United States. There are thousands of organizations here that would love to help, but they don’t hear about it,” Anya said. “My team needs help making those connections, sharing the stories, raising awareness and raising funds. Introductions and opening doors are so important. They say it takes a village to raise a child. It take a community to save one.”

To learn more and to sponsor the medical evacuation of a child through Be an Angel or to donate to Ukrainian humanitarian aid or mental health education programs, visit friendsofbeanangel.org or contact Anya at anya.verkhovskaya@yahoo.com. Anya notes that 100 percent of donations for humanitarian aid and mental health education programs goes directly to those causes.

Note: Since this article was written, three additional Ukrainian families have been brought to Milwaukee for their children to be treated for rare diseases at Children’s.