

Supporting Ukrainian Pompe Patients To Continue Treatment

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On February 24, 2022, at 5 am in the very early morning, I woke up to a WhatsApp message that vibrated. One of the mothers of a Pompe child messaged: 'We woke up to explosions and the sound of planes'. I think it was one of the most unrealistic messages I ever received.

Despite their fear, and totally unknown, the family who 'woke me up' packed to go to hospital as their little babygirl, Masha, should receive her infusion that day. While they were driving I received another message: '*Maryze, we are driving towards Kyiv, but there are many many cars leaving Kyiv*'. The dedication to get treatment for their daughter is so strong that the family continued driving to the hospital. That day the hospital advised them not to return home, but to stay in hospital. Mother and daughter had to stay the night in the hospital shelter.

From the moment I woke up at 5 early that morning, I contacted the other Pompe families in Ukraine. I mapped out where they were located: Lutsk, Kyiv, Cherkazy, Dnipro, Odessa. The following days we had much communication; we informed each other; reassured each other and I learned what people needed and wanted.

Five families decided to leave Ukraine, to ensure their children could continue their treatments, and to make sure they are safe. Destination addresses were given to me. I was happy to know where they were going. One family decided to stay for various reasons. They reassured me they had enough supply of treatment and could get the treatment closer to home, so they didn't need to travel for long.

Two mothers went alone with their children in the back of the car driving Poland. One mother took her 3 children (two of them having Pompe Disease) and drove via Bulgaria to Italy where her husband is employed.

While everyone was driving through a country in war, I informed the Sanofi team about which patients were leaving, and to what locations they were travelling. Sanofi could then prepare everything to make sure the patients would get their treatments in time. The hospitals in Poland, Italy and the Netherlands were notified and prepared to receive their new patients.

On Thursday, March 17th, the two children of the Odessa family received their first infusion in Florence, Italy. The families who went to Poland received their treatments in Warsaw.

Another mother, living with her 13 year old daughter and aged mother, couldn't leave as her child is on full ventilation. After we talked about powercuts, risk of collapsing healthcare infrastructure, she was convinced to go. She contacted *Doctors without Borders*. The mother gave me a mobile number of a lady working for Military Affairs in Ukraine. I contacted the physician at an expert center for Pompe in Germany. She agreed to continue the treatment of the girl. Together with Military Affairs the family's evacuation could be planned. They were transported in a wagon where a ICU was created in the *Doctors without Borders* train to let her travel as safe as possible. Two days later she arrived with her family at the treatment hospital in Germany.



Travelling with the Doctors without Borders train

The mother of Masha, the little girl, told me they had no family abroad. I answered, 'Yes you do. You have me. We are family'. I invited them to come to my home the Netherlands and then simply texted my address.

I contacted the physicians in the Netherlands and we exchanged all necessary information. The Dutch Pompe specialist was contacted by the Ukrainian physician in Kyiv so that medical information could be shared. My physician asked people in her neighbourhood if they had a place to stay for this family. I live two hours drive from Rotterdam, so it would be best if the family finally could get housing in Rotterdam. I was so happy when I heard a family volunteered to provide housing not far from the hospital.

On Thursday March 3rd Masha and her parents crossed the border with Poland. They let me know by sending a picture of them passing the border. I had tears in my eyes. They were safe.

On Saturday the 5th of March, a car with Ukrainian number plate entered my street. The fully packed car was dirty, but the people inside beautiful. We all shed tears. Finally they arrived!

While they stayed in my village, people heard about this family and donated money, clothes and toys for them.

It was clear that money was needed. A week before the father of the family had a job and suddenly had no income anymore. It was also clear that the whole situation had a high impact on them: a sick child, leaving their beloved country to save their child, leaving their parents, brother and sister. I can't even imagine it.

The family left for Rotterdam as Masha would receive her treatment there, on March 9th. The physician was well prepared thanks to the information from the Ukrainian physician in Kyiv.



The picture that brought tears to my eyes: The border from Ukraine to Poland. They were safe!



Masha



It's wonderful that countries, Sanofi employees, patient organisations, doctors and individuals are so cooperative and supportive. It shows that when we work together, caregivers and patients, patient associations, doctors and industry, we can make a difference because **'Together We Are Strong'!**