



### **Rose's Story**

My first experience traveling with Heart to Heart was absorbing, astonishing, profound. I am humbled by the enormity of describing it, because what I witnessed and experienced – well, it's incomparable. I didn't know it then, but the trip was the beginning of my engagement with an unimaginable world.

On July 4, 2004, our team of cardiac specialists lands in the city of Samara, Russia at 5 a.m., ready to work side-by-side with Russian colleagues at the cardiac hospital. Every morning for nine days, after early breakfast, a mini-bus drives us from our modest hotel on the banks of the Volga River to the hospital, where we spend the rest of the day. On numerous occasions, members of our team stay deep into the night to care for a baby in trouble. I'm surprised. *Wasn't the operation supposed to make the baby well?* Yes, ultimately, but as they recover from open heart surgery, these babies are still in need of care.

The Samara Regional Cardiac Center gives us a room to gather, eat, drink, confer, chat, relax. Room 317 looks out on the grounds of the hospital, lush, green and pleasantly dense with

plants. As for the hospital itself, Mary and Jan, the ICU nurses, tell me that it would be condemned in the United States. Gary, our pediatric cardiac surgeon, has a slightly different take on it. "Actually," he says, "it's like our hospitals were 50 years ago."

All day every day, our cardiologist Terri examines babies, and sometimes older children, selected by our Russian colleagues. Accompanied by echosonographer Val, Terri teaches the Russian cardiologists as she goes. That is the nature of this relationship: all of our specialists teach as they go. At day's end, Terri reports on her findings and makes recommendations on possible courses of treatment for each child. First thing in the morning, our pediatric intensivist Rob works with the local doctors and nurses to ready the ICU to receive babies from the operating room. The ICU is the weakest link of the newly developing children's heart program.

On Heart to Heart's first training mission to Samara, there was only one equipped pediatric ICU bed. Now there are three, but only one is fully functional. The surgical team cannot operate on more babies than there are beds equipped to receive them. As it happens, two babies remain in the ICU much longer than anticipated, so we cannot operate on as many babies as originally planned. A few parents leave with their children, worried and disappointed, to wait until we return next year. This illustrates a point that Gary makes repeatedly – that Heart to Heart's success will ultimately be measured not by how many babies we save during a mission, but by how many babies the hospital saves after we leave.

When Rob has no morning obligations in the ICU, he gives a wonderful illustrated lecture on the heart for our interpreters to further their understanding of cardiac medicine and in turn, to enhance their ability to interpret from English to Russian and vice versa. The interpreters are always in Room 317 even before we get there. They are really interpreters-in-training, honing their skills, acquiring medical vocabulary. They are young, eager, scared, lovable. Sometimes nervous about watching babies in the OR, sometimes anxious about getting it just right. They have enormous responsibility. Josie, Heart to Heart's Executive Director, often stresses that our team is indivisible. If you remove one element, one person, then everything is jeopardized. I think about that as I observe how day-by-day the interpreters acquire more vocabulary, more knowledge, and confidence. We cannot do without them; and one of our jobs is to help the cardiac hospital develop a group of skilled, reliable medical interpreters for the next several years.

In nine days, Gary, our lead surgeon, operates on five babies, always assisted by one of the Russian surgeons who is learning as he assists. Baby Anna is 18 months old, tiny, underdeveloped, her blue lips often pressed against the ample embrace of her caregiver. Abandoned at birth, Anna lives in an orphanage for sick children, where there are six caregivers for 80 children. Anna doesn't survive: the wait for surgery was too long.

Then, Baby Karina is rushed back into the OR because of excessive bleeding. Our OR nurse, Gail, donates blood on the spot to save the baby's life. By the time we leave, Baby Karina and the other babies are extubated and well on their way to recovery.

For seven days, I work up my courage to watch an operation. My six-year-old grandson, my own heart's delight, was born with Tetralogy of Fallot; his heart fully repaired when he was six months old. I thought he'd ended up with a pretty decent little heart. But I learn something from Gary. He emphasizes in various contexts that we cannot give a perfect heart to a baby born with defects, but we can give the baby a heart that will allow the child to live a healthy, normal life. I'll happily settle for that, but I'm not sure I can watch a baby on the operating table without thinking of my grandson. I'm not sure I can withstand the blood. I'm terrified. On Day 8, assured that today's operation is relatively simple, I bite the bullet. Television hospital programs have not prepared me for the reality, for the ritual, for the grandeur, or for the emotion. Suited, masked, and capped, I watch the scrubbing, suiting, gloving, and masking that the entire operating room staff undergoes. It is like a ballet. Not entirely silent, serious but not somber; now and then, a smile or a joke.

Maxim is one month old. His mother Irina tried for three years to get pregnant. Maxim's serious heart defect, transposition of the great arteries, was suspected during a medical screening. Irina says to me in Russian, "It was a nightmare to learn that he has a heart defect, to face the thought of losing him." Now Irina is apprehensive, but joyful, so pleased that her baby will be treated by highly experienced American doctors. I begin by standing far from the foot of the table on which Maxim's inert little body lies. Because Maxim's first operation will be a palliative pulmonary banding, the job of Tammi, our perfusionist, is not needed. (On our next mission, we will return to perform and teach the arterial switch operation that will fully repair Maxim's heart.) So Tammi stands very close to me (to catch me if I fall?) and narrates the proceedings for me. Gary is making and cauterizing an incision on Maxim's chest, assisted by Sergei, an experienced Russian surgeon who gently wipes up and removes the excess blood. Gail, the OR nurse, hands Gary his instruments. He doesn't have to ask, she just knows what to give him and when. He doesn't even look down, so sure that he has the right instrument in hand. They are like one person with four hands. I slowly inch closer. There is not another thought in my head, and I'm not sure I'm breathing. Almost without deciding, I find myself at the head of the operating table. I am looking down at a tiny pulsing heart. When the band is in place, Sergei begins to sew up the chest. He is a huge man whose enormous hands move with artistic grace and delicacy. I am weeping. I weep for my grandson; I weep for all the babies who will never get a decent little heart and for all those who will. I weep for the incredible intelligence, skill, and goodness – goodness – that is encapsulated in this room. I weep at the complexity and beauty of little hearts.

Throughout the day, Russian staff members and Heart to Heart team members drop into Room 317. We drink coffee, we joke, we silently look out the window. Tired. Stimulated. Exhilarated. The hospital provides a delicious lunch for us every day. Russian hospitals are notorious for lousy food (even worse than ours) or no food. Not this hospital. The medical staff assures us that the patients are fed just as well as we are. We need that good food. It is fuel for the rest of the (often grueling) day.

Late in the afternoon, the Heart to Heart and Samaran team members all meet to discuss the day's events. The Russians grill us – especially Terri, Gary, and Rob: *Why? How to explain*

*this or that decision? What could have been done differently? What else do we need?* The discussions are lively, earnest, exhausting. Shortly after the death of Baby Anna, all the surgeons get together in the middle of the day without the rest of the staff. They ask me to sit with them and interpret.

They don't really need me. Vladimir Vladimirovich, the Chief Pediatric Cardiac Surgeon at the Samara center, spent two years in an American hospital and is a superb medical interpreter. But I'm happy to be there. It is my job to observe, understand, report. Now I watch the four Russian surgeons, highly intelligent, skilled men who in their own world are accustomed to respect and authority. I watch in awe how effortlessly they let go of ego. It is as amazing as anything I've seen in these days. They are not obsequious, they do not supplicate. With great dignity, they ask for help on how to save babies' lives: *Tell us! Tell us! Show us! Give us guidelines, give us sign posts!* On- and off-duty they are people of stature. They are not well-rewarded with money or comforts. For the most part, a Russian physician's base pay is roughly \$US150 per month. Sergei's son wants to be a cardiac surgeon. Sergei tells him, *Okay, but consider it your hobby. It is not what is going to put food on the table.* The Samara cardiac surgeons have taken on other jobs in addition to their full-time obligations at the hospital. They have no choice.

Listening to our medical specialists answer our Russian colleagues' questions, observing their thought processes, I am stunned by the complexity of the heart as an organ, by the incredible number of things that can go wrong during surgery, by the awareness that pediatric cardiology and surgery is as much an art as a science. An art that requires exquisite intelligence, intuition, sensitivity, and dedication. That's what our Heart to Heart team has – and that's what the Samaran team has. Our specialists point out the deficiencies in the Samaran cardiac hospital with great tact. After all, the practice of medicine is embedded in culture, and sometimes the differences in approach are not medical, but rather a response to national conditions or to cultural imperatives.

I interview the parents of the babies selected for surgery. Often the mothers come with several family members who seem to peel off after the first day. The mother is left to face this ordeal by herself. Russians consider it normal for the mother to take on this burden alone. Except for two mothers of older children (ages 15 and 19), the other mothers are all quite young and seemingly fragile. I learn from the interviews that often these desperate mothers leave paid employment to devote themselves to keeping their children alive. In an economy like Russia's, that is a sentence of great poverty, even with state aid. A far worse fate is living with the unremitting agony of not knowing whether your child will be saved – even though the knowledge and technique to save the child exist. *Somewhere, but not for your child!* I can't stop thinking about my grandson. We all lived with high anxiety until after his operation, but we knew that he would be helped. That's the hope Heart to Heart must give to the huge population that the Samara Cardiac Care Center will one day fully serve.

Heart to Heart's medical team is hooked! Not a day passes that we don't talk about what we must do the next time we come to Samara, what kind of equipment we must somehow acquire for the hospital; how we can help them to better organize their time and resources; how to

brainstorm among ourselves to better advise them on the kinds of operations they should focus on. We can't wait to go back! Terri, our cardiologist, speaks for the entire team in an email she sends me shortly after we return:

*The trip was a very profound experience for me. While I was there I was just so impressed by all the NEED! The need for more education, more money, more equipment, more people....the list is infinite... Yet, I see that I can answer one need – education.*

Like the others in our group, Terri is moved but not daunted. She has found a Russian émigré cardiologist in Detroit who has agreed to translate masses of material she is collecting from colleagues all over the U.S. Terri says, “We will translate them and send them to Samara bit by bit, and over a year or two I will put the material into a booklet that we can distribute.” Terri is learning Russian.

Her phrase, *bit by bit*, sticks in my head.

## EPILOGUE

After a seven-year educational collaboration with Heart to Heart, the Samara Regional Cardiac Center's pediatric program became fully self-sustaining in 2009. At the time of this writing, August 2021, more than 5,000 children born with heart defects have been saved by the Samaran team. To read more about our partnership in Samara, **go to: [www.heart-2-heart.org/samara](http://www.heart-2-heart.org/samara)**



### ABOUT ROSE GLICKMAN

A published author, Rose Glickman holds a doctorate in Russian History from the University of Chicago and speaks Russian fluently (in addition to Spanish and French). After teaching Russian and Soviet history for 25 years, she began volunteering with Heart to Heart – and has since traveled with us on 11 international training missions!