

SITE: TOMSK DISTRICT: SIBERIA COLLABORATION LAUNCHED: 2006 APRIL 12-24, 2010 SURGICAL-EDUCATIONAL MISSION 5



## PATIENT PROFILE

| Child                    | Dasha L.  |
|--------------------------|---|
| Age                      | 1 year 8 months old   |
| DOB                      | August 22, 2008   |
| Birth Wt.                | 6 lbs 1 oz  |
| Current Wt.              | 20 lbs 5 oz   |
| Home                     | Novokuznetsk,<br>Kemerovo Oblast<br>250 mi from Tomsk                                     |
| Mother                   | Anya, 30 years old  |
| Father                   | Oleg, 40 years old  |
| Diagnosis                | Pulmonary atresia, VSD,<br>MAPCA (occlusions)<br>S/p Central Ao-PA shunt<br>(2009, Tomsk) |
| Open-heart<br>surgery    | Complete repair w/Contegra<br>RV-PA<br>April 22, 2010                                     |
| Discharged<br>from PCICU | April 26, 2010  |

## THE HOUSEHOLD AND THE FAMILY

Dasha lives with her parents, Anya and Oleg, and two older siblings: her sister Diana, who is 12, and her brother Roma, who is 8. The family lives in Novokuznetsk, the administrative center of the Kemerovo Province in Siberia. Anya is a stay-at-home mother; Oleg is a taxi driver.

From the 1930's until the collapse of the Soviet Union {1991}, Novokuznetsk was a major coal mining and industrial center that attracted workers from all across the Soviet Union.

## CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Anya's obstetrician detected the baby's heart defect in utero, and recommended that she terminate the pregnancy, asking, "Why do you need such a child?" {Anya cries as she recalls the conversation, clearly still very upset by it.} Anya and Oleg discussed the situation thoughtfully and chose not to terminate the pregnancy.

When Dasha was three months old, a local cardiologist referred them to Novosibirsk {200 miles away} for a full examination and diagnosis. The doctors in Novosibirsk were unable to treat Dasha because, as Anya recalls, the heart center there had used up the annual quota which allows them to treat out-of-region patients gratis. Dasha's local cardiologist suggested Anya and Oleg seek treatment for Dasha in Tomsk.

## **CURRENT CONDITION**

The family first arrived in Tomsk in November 2009. One week after Dasha's diagnosis, the first of two staged open-heart surgeries was successfully performed on her. The Tomsk team recommended scheduling her second, and more complicated, operation during Heart to Heart's surgical-educational mission in April 2010.

The Russian charity Russkii Fond Pomishchi paid for Dasha's medical care and transportation costs. Oleg drove the family to Tomsk {250 miles}, a six-hour trip by car.

On April 22, the joint Heart to Heart-Tomsk team successfully performed Dasha's second (and final) open-heart surgery. Baby Dasha's prognosis is very good.

Anya comments that she was comforted by meeting the other parents on the pediatric cardiac ward. She adds, "Patient families make friends easily, and we keep in touch."

Based on an interview conducted in Tomsk, in Russian, by Heart to Heart volunteer Rose Glickman, PhD.