

INTO the HEARTLAND CAMPAIGN

**SITE: KALININGRAD
DISTRICT: NORTHWESTERN
COLLABORATION LAUNCHED: 2013**

**SEPTEMBER 17–27, 2014
SURGICAL-EDUCATIONAL
MISSION 2**



PATIENT PROFILE

| | |
|--------------------------|---|
| Child | Makar U. |
| Age | 1 year 3 months old |
| DOB | May 31, 2013 |
| Weight | Current: 22 lbs |
| Home | Kaliningrad |
| Parents | Anna, Alexander |
| Diagnosis | Pulmonary atresia, VSD; s/p RVOT reconstruction and PDA ligation (May 2013, Kaliningrad) |
| Open heart surgery | MAPCA unifocalization, RVOT reconstruction, VSD closure September 23, 2014 |
| Discharged from PCICU | September 24, 2014 |

Based on an interview conducted by Heart to Heart board member Karen O'Brien, PhD.

THE HOUSEHOLD AND THE FAMILY

Makar's parents moved to Kaliningrad seven years ago. Alexander serves in the armed forces, while Anna stays home full time to care for Makar and his twin brother. Makar warms to strangers a bit slowly, but clearly adores his mother. "He is so affectionate with us," she says, "He loves his brother and his father, and kisses me all the time." Anna loves to sing and often sang while pregnant with the boys. Makar also loves music, and already enjoys playing with a guitar and beating on drums.

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Makar and his fraternal twin were both born with congenital heart disease (CHD). His twin's defect was less severe, and successfully repaired in infancy. Makar, however, was born with a more complicated defect that required complex, staged open heart surgeries. He was diagnosed at the Kaliningrad Federal Cardiac Center with pulmonary atresia (no direct blood flow from his heart to his lungs for oxygenation) and a ventricular septal defect (hole between left and right sides of the heart). Makar underwent his first open heart surgery on his first day of life, to reconstruct his right ventricular outflow tract (RVOT), a conduit carrying blood to the lungs for oxygen, and to close his patent ductus arteriosus (PDA ligation).

The twins exhibit developmental differences. Makar was slower to walk, and is a bit less outgoing. Anna says that his twin is physically stronger and tries to dominate, but adds that Makar has a strong personality and does a fine job of standing up for himself.

CURRENT CONDITION

The joint Heart to Heart-Kaliningrad team conducted Makar's second open heart surgery on September 23, 2014. Dr. Belov performed a complex procedure called MAPCA unifocalization, reconnecting abnormal blood vessels in the lungs to provide better blood flow. The team also performed a second reconstruction of Makar's RVOT and closed the hole between the two sides of his heart.

Makar will have follow-up exams with his cardiologist at three and six months post-operatively. As Makar continues to grow, his heart will grow correspondingly. Like all patients born with pulmonary atresia, Makar will require continuous lifelong observation and intermittent surgical interventions. As he grows, it is likely he will need an additional operation in 5-8 years, to replace his pulmonary valve. Once he reaches adulthood, Makar's full-sized heart will require less intervention.

Of note: When Heart to Heart began working in Russia in 1989, it was highly unlikely that either twin would have had access to life-saving cardiac care. Fast forward 25 years, and nearly every district in Russia is actively developing pediatric cardiac medicine. Since 1989, the annual volume of children operated on has increased more than tenfold.