



PATIENT PROFILE

Child	Makar K.
Date of birth	August 10, 2016
Weight	Current: 16 lbs; at birth: 8 lbs 3 oz
Home	Volgograd (1,400 miles from Kaliningrad)
Diagnosis	Ebstein, atrial septal defect (ASD)
Open heart surgery	Cone repair, narrowing of ASD April 11, 2017
Discharged from PCICU	April 12, 2017

Makar's story: an infant boy undergoes the Cone repair

Makar is a bubbly eight-month-old boy. He arrived to the Kaliningrad Federal Center with his mother Maria. They traveled from Volgograd, a city more than 1,400 miles away, where Maria works as a database administrator for an oil company.

Makar's heart condition was diagnosed before birth. Maria knew that she would have to be assertive in order to get him the care he needed. Although understandably nervous, she was thankful beyond words to be in Kaliningrad where her baby could receive timely access to specialized valve surgery.

Makar's diagnosis was confirmed by the Heart to Heart-Kaliningrad team: Ebstein anomaly and a large atrial septal defect (ASD). Because Ebstein anomaly is so rare, few surgeons in Russia are capable of performing the valve-sparing surgery required to correct this defect. Makar was fortunate that his cardiologist was able to contact physicians in Kaliningrad who arranged for a consultation with Heart to Heart specialists. Even though Makar had not yet reached his first birthday, his condition was severe enough to require immediate surgery. The anatomy of his heart looked favorable for valve repair. To confirm his candidacy for surgery, the Heart to Heart-Kaliningrad specialists performed diagnostic catheterization pre-operatively.

The day after his catheterization, Makar was scheduled for open heart surgery: a Cone reconstruction and a narrowing of his ASD. The operation was a success. He recovered quickly and was in his mother's arms the next day.

Many of Heart to Heart's medical volunteers on this mission were recruited from the Mayo Clinic, known for its expertise in the treatment of Ebstein anomaly. Because the Cone procedure is relatively new, it is not yet known what further

care these children may require over the long term (as adults). However, to date, surgical outcomes look good. How well each patient feels postoperatively depends not only on the quality of the valve repair, but also on the function and strength of the right ventricle. Ebstein anomaly, while known as a valve defect, is also a defect of cardiac muscular tissue. Ebstein patients' right ventricles are often thinner and less competent than those of people without heart disease. The timing of surgical intervention for Ebstein repair depends on the function of both the tricuspid valve and the right ventricle.

The vast majority of children who have undergone the Cone reconstruction at Mayo have not required valve replacement within 10 years of their initial surgery. By all accounts, Makar's prognosis is good. He will continue to have annual check ups with his local pediatric cardiologist. We wish Makar a very happy and healthy first birthday – with many more to come!

Patient story based on an interview conducted in Kaliningrad by Hannah Hunter with the help of an interpreter.

Historic Volgograd: "Hero City"

Volgograd is located along the Volga River. Industries include: shipbuilding, oil refining, and steel making. Formerly known as Stalingrad, the city became famous for its fierce resistance during the largescale decisive Battle of Stalingrad against the German Army in World War II. In 1961, Stalingrad was renamed Volgograd during the era of the Soviet Union known as "de-Stalinization."



In 1967, a statue named, *The Motherland Calls*, was erected to commemorate the nearly two million people wounded, killed, or captured in the Battle of Stalingrad. As of 2016, the statue remains the tallest sculpture of a woman in the world.