

INTO the HEARTLAND CAMPAIGN

SITE: ROSTOV-ON-DON
DISTRICT: SOUTHERN
COLLABORATION LAUNCHED: 2009

SEPT 29-OCT 16, 2010
SURGICAL-EDUCATIONAL
MISSION 2



THE HOUSEHOLD AND THE FAMILY

Four-year-old Kseniya lives with her mother, Lilia, and her father, Sergei, about 40 miles north of Rostov-on-Don. Lilia is 41 years old and Sergei is 40: by Russian standards, both quite old to have a young child. Kseniya is her parents' second child; her older sister is nineteen, living and studying in Rostov-on-Don.

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Kseniya was not a calm baby. She cried often, and her parents couldn't understand why. After she turned four, Kseniya began complaining of chest pains, which led to a cardiology appointment in May 2010, when doctors at the Rostov-on-Don Cardiac Center detected a heart murmur, performed an echocardiogram, and began diagnosing her rare condition. At the request of our Russian colleagues, the Heart to Heart team confirmed Kseniya's serious diagnosis: anomalous left coronary artery.

Kseniya's heart muscle has been continuously deprived of blood since birth. Her case is unusual and complex. Children born with this condition rarely survive past their first birthday. In the U.S., this condition is almost always detected, diagnosed, and repaired before a baby reaches six months of age.

Kseniya's mother, understanding the gravity of her daughter's condition, made the agonizing decision to delay Kseniya's open heart surgery so that it could be led by Heart to Heart's team of highly-experienced specialists in October 2010. This decision was all the more difficult since both parents are keenly aware that children born with Kseniya's heart condition have a relatively high incidence of sudden death. Like many mothers of children born with heart defects, Lilia is quick to blame herself. Our doctors reassured her that a heart defect is the most common birth defect — occurring with similar frequency all over the world, in children of mothers of all ages. Fortunately, Kseniya is otherwise healthy, and shows no developmental delays whatsoever.

PATIENT PROFILE

Child	Kseniya K.
Age	4 years old
DOB	February 8, 2006
Weight	At birth: 8 lbs 4 oz Current: 42 lbs
Home	Novoshakhtinsk Rostov Oblast 40 mi from Rostov-on-Don
Parents	Lilia, 41; Sergei, 40
Diagnosis	Anomalous left coronary artery from the pulmonary artery (ALCAPA)
Open heart surgery	Translocation of left main coronary artery, reconstruction of pulmonary artery October 9, 2010
Discharged from PCICU	October 12, 2010

CURRENT CONDITION

Although Kseniya had a mild respiratory illness immediately prior to her examination by the joint Heart to Heart-Rostov team, she recuperated quickly enough to undergo open heart surgery several days later.

Kseniya's post-operative course was uneventful. She was remarkably well-behaved and calm in the PCICU, but everyone could feel that she was sad to be separated from her mother. Still, she waited patiently for four days, often closely observing the nurses and other children nearby, or sleeping soundly. Doctors do not expect Kseniya to require further surgery. Blood flow to her heart is nearly identical to that of any other child. How wonderful that four-year-old Kseniya can grow up and lead a normal life — and that her parents no longer need to fear her sudden death.

Based on an interview conducted in Rostov-on-Don, in Russian, by Albina Popov, Heart to Heart staff.