

# INTO *the* HEARTLAND CAMPAIGN

## TOMSK III SURGICAL-EDUCATIONAL MISSION

APRIL 15-26, 2008



### PATIENT: SOFIA O.

Age	7 months old
DOB	September 8, 2007
Birth weight	6 lbs 3 oz
Current weight	13 lbs 3 oz
Home	Tomsk Tomskaya Oblast
Mother	Elena, 35 years old
Father	Vladimir, 38 years old
Diagnosis	Ventricular Septal Defect
Open-heart surgery	April 25, 2008
Discharged	May 7, 2008

### THE HOUSEHOLD AND THE FAMILY

Elena and Vladimir live in Tomsk in a three-room apartment with Vladimir's eight year-old daughter from a previous marriage. Although the couple was eager to have another child, they waited because Elena was in graduate school. Elena is now a teacher; she also conducts a chorus. Elena continues to work despite Sofia's condition, but on a reduced schedule. Vladimir is a highly-skilled designer of scientific instruments. He happily shares parenting responsibilities.

### CHILD'S DEVELOPMENT AND CONDITION

All things considered, Sofia was lucky to have been born in the Tomsk maternity hospital right next door to the Tomsk Cardiology Institute, one of the few Russian hospitals capable of treating congenital heart disease and one of Heart to Heart's sponsored sites. The Tomsk team was able to immediately and accurately diagnose Sofia's plum-sized heart's defect: there were two holes between the two chambers of her heart. Congenital heart disease is the most common birth defect worldwide, and holes between the heart's chambers are a common defect. They often close by themselves. In Sofia's case, by the time she was three months old, it was evident she would need surgery to close the holes.

Elena and Vladimir have had a terrible time accepting Sofia's condition. Sofia is adorable. She sits and crawls, and is trying to walk. She is alert and funny. She is not blue. However, she is a textbook example of a child that has "failure to thrive." She is miniscule. Until recently Elena had breastfed her, but it became clear that Sofia's caloric needs were not being met. Heart to Heart's cardiologist takes great care to explain that, because Sofia's heart is so inefficient, her heart and lungs are "working overtime." Therefore, her caloric needs are greater than the norm.

Elena and Vladimir could not believe that it was necessary – or even possible – to operate on such a tiny child. They sought second opinions; they combed the internet. In an emotional discussion with Heart to Heart's cardiologists, Vladimir asked repeatedly, "How urgent is her surgery?" The doctors pointed out that Sofia is failing to thrive and explained why. After the operation, they said, she will eat much better and grow: "There is nothing to be gained by waiting, this is the optimum moment." The parents realize that the surgery must be done immediately. Elena acknowledges, "I can't say that I am calmer yet, but I accept what needs to be done."

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