

# INTO the HEARTLAND CAMPAIGN

SITE: SAMARA  
REGION: VOLGA FEDERAL DISTRICT  
SITE LAUNCHED: 2003

OCTOBER 1-12, 2008  
SURGICAL-EDUCATIONAL  
MISSION VI



## PATIENT PROFILE

Child	Syoma K.
Age	9 months
DOB	December 25, 2007
Birth Wt.	6 lbs 10 oz
Current Wt.	19 lbs 13 oz
Home	Samara
Mother	Irina, 26 years old
Father	Vitali, 28 years old
Diagnosis	Transposition, VSD, PDA, PFO
Open-heart surgery	October 7, 2008
Discharged	October 20, 2008

## THE HOUSEHOLD AND THE FAMILY

The family lives in a two-room apartment that Irina's parents bought for them. Irina runs the household and is Syoma's primary caregiver, and Vitali is a very helpful father. Both sets of grandparents help with childcare as well.

Vitali studied computer programming and works in an auto parts supply company. Irina was trained as an engineer, working as a manager until Syoma was born.

## CHILD'S DEVELOPMENT AND MEDICAL HISTORY

For prenatal care, Irina went to the Samara Diagnostic Center, a private clinic. Doctors there performed an ultrasound 23 weeks into the pregnancy, but Syoma's serious heart defect went unnoticed.

Syoma was born at the nearby Kalinin Hospital, where the doctors were dismayed that Irina and Vitali did not know their son had a congenital heart defect. Although the Kalinin doctors feared that Syoma's defect was untreatable, they immediately sent him to the Samara Regional Cardiac Center, where Syoma had his first open-heart surgery when he was only three days old.

Since Syoma was diagnosed, Irina and Vitali have learned much about heart defects, mainly from the internet. Irina says that the information has helped a great deal; she wants to know exactly what is done during surgery. But, she confesses that the first surgery was, in a sense, easier for them to endure – because they had no idea what it entailed. The need for subsequent procedures "has been a nightmare."

Irina and Vitali knew about Heart to Heart because they have friends whose children were seen by Heart to Heart doctors. They are grateful for the tremendous progress that the local pediatric heart program has made. Irina and Vitali know a 5-year-old child with Syoma's defect who had to go to Moscow for surgery because five years ago that procedure was not yet available in Samara.

## CURRENT CONDITION

Already a veteran of four heart procedures, Syoma looks sturdy and healthy. He smiles, sits up by himself, recognizes people, and can walk in a baby walker. Irina describes him as independent, happy, and adventurous. During the echocardiogram, he squirmed energetically trying to get away, but otherwise put up with it good-naturedly.

Irina plans to return to work when Syoma turns three. But she comments that Russian preschools are reluctant to admit children with heart defects. Irina is part of an informal support group of mothers whose children have congenital heart defects. They meet, talk, and take walks with their children. They are especially supportive of each other when a child is scheduled for surgery.

*Based on an interview conducted in Samara, in Russian, by Heart to Heart volunteer Natasha Lusin, PhD.*