

SITE: SAMARA REGION: VOLGA FEDERAL DISTRICT OCTOBER 1-12, 2008 SURGICAL-EDUCATIONAL MISSION VI



## PATIENT PROFILE

Child	Anya A.
Age	5 years old
DOB	October 3, 2003
Birth Wt.	7 lbs 5 oz
Current Wt.	30 lbs 13 oz
Home	Abashevo, Samara Oblast
Mother	Svetlana, 34
Father	Andrei, 39
Diagnosis	Single inlet left ventricle S/p Pulmonary band (2004, Bakulev)
Procedure	Open-heart surgery October 9, 2008
Discharged	October 24, 2008

## THE HOUSEHOLD AND THE FAMILY

The family lives in Abashevo, an agrarian village in the Samara region. Anya lives with both of her parents (Svetlana and Andrei), her 15-year-old brother, and her grandmother. Andrei is a machine operator; Andrei's mother helps Svetlana tend their sizeable kitchen garden and livestock. Svetlana looks exhausted and older than her years. She sighs as she acknowledges that life in the countryside is difficult.

Everyone in the family helps to take care of Anya, including Svetlana's parents. Svetlana says that her son treats his sister kindly, although he doesn't fully understand how serious Anya's heart condition is.

Svetlana prefers to question the doctors in person, rather than reviewing information on the internet. She says that reading about heart defects heightens her anxiety and raises questions that she cannot answer.

## CHILD'S DEVELOPMENT AND MEDICAL HISTORY

A local doctor detected Anya's heart murmur at birth but did not realize how critical her condition was. Anya grew normally for her first month of life and then failed to thrive. When she was six weeks old, her parents took her to the Samara Regional Cardiac Center, where her heart defect was diagnosed.

In 2004, the Samara doctors sent Anya to the Bakulev Institute in Moscow, where a band was placed around her pulmonary artery {a palliative procedure that allows the child to grow in preparation for a more complicated open-heart procedure). Although this procedure went well, Anya's lips still turned blue and she continued to tire easily from any physical exertion. Every minor illness, even a cold, required hospitalization.

Early in 2008, during a routine follow-up examination, a Samaran cardiologist explained to Anya's parents that their daughter was now big enough (and healthy enough) for surgery. The doctor recommended that Heart to Heart perform the complete repair during their upcoming Fall surgical-educational mission.

## **CURRENT CONDITION**

Anya is a bright, curious child with large, thoughtful eyes. She is able to attend preschool, and her teachers say that she behaves just like all the other children. Svetlana tries to restrict Anya's physical activity, but Anya resists.

While Anya and Svetlana were waiting for Anya to have her echocardiogram, Anya played with her dolls and recited many lines of a fairy tale from memory.

Dr. Raff led the joint Heart to Heart-Samara team in performing Anya's open-heart surgery. When we asked Anya how she felt the day after her operation, she answered matter-of-factly, "I'm OK." Her recovery in the PCICU went smoothly, and she was released from the hospital two weeks later.

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