

INTO the HEARTLAND CAMPAIGN

SITE: TOMSK
DISTRICT: SIBERIAN
COLLABORATION LAUNCHED: 2006

APRIL 12-23, 2011
SURGICAL-EDUCATIONAL
MISSION 6



PATIENT PROFILE

Child	Amira I.
Age	1 year 5 months old
DOB	September 20, 2009
Weight	At birth: 5 lbs 12 oz Current: 16 lbs 9 oz
Home	Talgar Kazakhstan 940 mi from Tomsk
Parents	Tashbuvi, 33; Makhmutdzhan, 38
Diagnosis	Complete AVC, Down syndrome S/p End-to-end CoA repair, PDA ligation, PA banding (2009, Tomsk)
Open heart surgery	AVC repair, takedown of PA band April 19, 2011
Discharged from PCICU	April 21, 2011

THE HOUSEHOLD AND THE FAMILY

Amira lives with her parents, Tashbuvi and Makhmutdzhan, and two older sisters. The family rents a one bedroom apartment in Talgar, a suburb of Almaty (15 miles away). Tashbuvi is a stay-at-home mother; Makhmutdzhan works as a delivery driver. The grandparents live nearby and help take care of the children.

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

In September 2009, when Tashbuvi was 38 weeks pregnant, she had an ultrasound in Almaty, which revealed Amira's complex heart defect. Tashbuvi recalls the doctors' dire prognosis: "Your child is not going to survive birth." Tashbuvi became so distraught that she was hospitalized to avoid miscarriage; she gave birth the following week. Baby Amira's condition was critical, and she was placed in the ICU.

Fortunately, cardiac specialists from Tomsk arrived in Almaty to conduct their periodic outpatient screening. They diagnosed Amira's defect, which required immediate intervention. Amira was scheduled for urgent palliative surgery back in Tomsk to relieve her symptoms and allow her to grow enough to undergo a complete surgical repair. The Tomsk team anticipated that Amira would be ready for her second surgery some 16 months later, during Heart to Heart's mission in April 2011.

CURRENT CONDITION

Amira is tiny. She does not eat well; she turns blue when she cries; she doesn't walk yet, and has just learned to sit. She is highly susceptible to colds and fevers. Yet, despite her frailty, Amira is an extraordinarily cheerful and outgoing child. She immediately won the affection of the more than 60 cardiac specialists who observed Heart to Heart cardiologist Dr. Frank Cetta examine her.

Tashbuvi, in the Kazakh language, means *rock* or *strong*, and Tashbuvi is very calm and self-composed. She is confident in the success of the operation, saying that she fully entrusts her daughter's life to the American and Tomsk specialists.

Dr. Bert Litwin led the joint team in repairing Amira's complex, unusual form of Atrioventricular Canal. Drawing on his vast experience, Dr. Litwin provided a master class on AV Canal to more than 60 local and visiting specialists. The discussion focused on the pros and cons of various surgical approaches to correcting the malformed heart, and included descriptions of anatomical nuances that would lead a specialist to favor one possible surgical approach over another.

Amira's recovery in the PCICU was uneventful. Two days after her surgery, she was transferred to the step-down unit; and three weeks later, was released from the hospital to travel back home. The surgery has immediately improved Amira's quality of life, and her long-term prognosis for a normal lifespan is now excellent.

Based on an interview conducted in Tomsk, in Russian, by Lena Traer, Heart to Heart staff.