

SITE: CHELYABINSK DISTRICT: URALS COLLABORATION LAUNCHED: 2015 APRIL 7-19, 2015 SURGICAL-EDUCATIONAL MISSION 1



PATIENT PROFILE

| Child | Leeza S. |
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| Age | 12 years old |
| DOB | August 17, 2002 |
| Weight | At birth: 6 lbs 13 oz Current: 82 lbs |
| Home | Yekaterinburg Oblast |
| Diagnosis | Double inlet single ventricle; s/p: Glenn (Chelyabinsk, April 2012); fenestrated Fontan (Chelyabinsk, May 2012) |
| Procedure | Annual cardiology follow up for possible closure of fenestration |

Based on an interview conducted in Russian by Heart to Heart executive director Josie Everett.

THE HOUSEHOLD AND THE FAMILY

Leeza lives with her mother, her stepfather, and her three-year-old sister Polina. Her mother, Vera, is a doctor; her biological father, who lives near Leeza and her family, works in construction.

Cheery, thoughtful Leeza is very independent. She is staying on her own in the hospital for a week, while doctors perform her annual follow-up exams. Her family's home is a three-and-a-half-hour drive by car, and Leeza's mother will come to pick up her daughter over the weekend, when medical tests have been completed. Leeza willingly helps the mothers on the ward to look after their young children. She informs us she's keeping up with her homework; she does not want to fall behind in her studies. Leeza loves studying the Russian language, but finds it harder than her favorite subject – math. She dreams of becoming a lawyer because it seems to her, "They know how to do everything!"

CHILD'S DEVELOPMENT AND MEDICAL HISTORY

Leeza's heart defect was diagnosed at an early age. Her mother then tried for years, all across the country, to find the surgical treatment her daughter desperately needed. As a young child, Leeza had trouble keeping up with her friends. She could not take part in sports because every time she tried to run, she became short of breath. She also suffered from frequent dizzy spells and nosebleeds.

In 2012, when Leeza was nine, she and her mother came to the Chelyabinsk Federal Cardiac Center (CFCC) seeking treatment. Established in 2011, the CFCC had only recently begun treating pediatric cardiac patients. Leeza's case was evaluated, and she was offered surgical treatment. Shortly thereafter, the family relocated to the Chelyabinsk area to be closer to Leeza's cardiac specialists. The CFCC, as a federal center, is able to offer free or affordably priced cardiac care to patients from all over Russia. The first of Leeza's two planned operations was a Glenn repair, soon followed by a Fontan procedure. These two surgeries successfully rerouted blood flow from her heart to her lungs and body. Leeza remembers spending months in the Center recovering from her surgeries.

CURRENT CONDITION

Leeza happily "reports" that she can now run, jump, and play with her friends without feeling tired or experiencing any other symptoms. Once her follow-up exams were completed, the Heart to Heart-Chelyabinsk team discussed her current condition in a case conference. Next year, when Heart to Heart returns to Chelyabinsk, Leeza will be re-evaluated to determine the best approach to close Leeza's Fontan fenestration. This – Leeza's final procedure – may be accomplished via interventional catheterization rather than open heart surgery in the not too distant future.

^{*}Watch our video interview of Leeza at: www.heart-2-heart.org/leeza