THE HOUSEHOLD AND THE FAMILY

Roman lives with his parents, Marina and Valery, in the city of Syktyvkar. Marina’s mother, who recently suffered a stroke, also lives with them. Marina works in communications; Valery is a welder, but since his heart attack two years ago, he can no longer work full time.

Syktyvkar is the capital of the Komi Republic. Unemployment in the region, which is rich in coal, oil, and lumber, is high and on the rise.

CHILD’S DEVELOPMENT AND MEDICAL HISTORY

Doctors at the local maternity hospital discovered Roman’s heart defect when he was two days old. After two months of hospitalization, he was transferred to the Bakulev Scientific Center of Cardiovascular Surgery in Moscow (600 miles away). There it was determined that Roman’s heart has only one functioning pumping chamber – a congenital defect often referred to as single ventricle physiology. Making a heart like Roman’s functional is the greatest challenge in pediatric cardiac surgery. Within his first year of life, Roman underwent open-heart surgery – the first procedure in a multi-stage surgical approach to repair his heart.

Roman was able to begin school with classmates his age, but by the time he reached ninth grade, he found school life too challenging and opted for state-provided home tutoring.

CURRENT CONDITION

Marina never gave up hope that Roman could be cured. She discovered an on-line network for parents of children with congenital heart disease; and, through an e-mail exchange with pediatric cardiac surgeon Dr. Krivoschekov, Marina learned about treatment options for single ventricle patients at Heart to Heart’s sponsored site in Tomsk, Siberia (1,500 miles away). The Heart to Heart-Tomsk team agreed to perform Roman’s Fontan procedure together in April 2010.

Roman was present during our interview. He seems shy, but he was very positive about having the operation. He spoke of wanting to work in information technology; Marina says he spends much of his time on the computer.

Roman’s surgery on April 20 went well. The Fontan operation improved Roman’s quality of life immediately, as well as his prognosis for a normal lifespan. He was discharged from the PCICU after five days, and discharged from the hospital on May 9.

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