



Case conference: Pavel G. is examined by Drs. Nathan Taggart and Frank Cetta, veteran Heart to Heart medical volunteers from the Mayo Clinic. By conducting exams in a conference setting, real-time learning is maximized. Pavel and his parents live in Kemerovo, 125 miles from the Tomsk Pediatric Heart Center. The Center has earned the reputation for providing the most advanced pediatric cardiac care available in the Russian Federation.

“FOLLOWING” ROMAN, DASHA, AND NIKOLAI

The accepted best practice at heart centers in the U.S. is for follow-up examinations to be provided by the same specialists who initially diagnosed and recommended treatment for any given child. Accordingly, on each mission, the Heart to Heart-Tomsk team has conducted follow-up examinations on patients who have undergone surgical procedures during previous missions. This year, we share with you follow-up stories about three of these children: Roman, Dasha, and Nikolai.

We first met Roman, now 20, in 2010. He and his parents had never given up hope that one day he would receive the operation necessary to save his life. Heart to Heart was pleased to play an instrumental role in providing the surgery that had eluded this family throughout Roman's entire childhood. On the next page, we share with you Roman's medical history and his 2012 update.

Dasha's very complex heart defect was detected in utero in 2008. In 2009, our colleagues in Tomsk performed the first of Dasha's two planned open heart surgeries. Six months later, the Heart to Heart-Tomsk team jointly conducted Dasha's second open heart surgery, a valve replacement. On page 3, read about the follow-up procedure performed in 2012 to relieve the narrowing of Dasha's pulmonary arteries.

Nikolai has just turned eight. His life-threatening heart condition had been co-monitored by specialists in Tomsk and Omsk (where his family lives, 400 miles away). During our 2010 mission, the joint Heart to Heart-Tomsk team performed the first open heart procedure in Nikolai's two-stage repair. When we examined Nikolai in 2011, he was not yet ready for his second procedure. On page 4, read about this year's follow-up exam.



(Top) 2010: Roman in the PICU following his long-awaited fenestrated Fontan procedure.
(Bottom) 2012: An optimistic college student.

PATIENT PROFILE

Age	20 years old
DOB	March 8, 1992
Weight	2010: 95 lbs 2012: 102 lbs
Home	Syktvykar, Komi Republic 1,500 mi from Tomsk
Parents	Marina, 42; Valery, 42
Diagnosis	Atrial tachycardia S/p Fenestrated Fontan, PA plasty (2010, Heart to Heart- Tomsk team) S/p Stent placed in MPA (2009, Moscow) S/p Balloon angioplasty of LPA (2009, Moscow) S/p Bidirectional Glenn (1993, Moscow) HLHS, levocardia, Mitral valve atresia
2012 Follow up	Physical exam and consultation April 3, 2012
Recommendation	Immediate implantation of pacemaker

ROMAN R: FAMILY BACKGROUND

Roman lives with his parents, Marina and Valery, in the city of Syktvykar, the capital of the Komi Republic. Marina's mother, who suffered a stroke several years ago, also lives with them. The region is rich in coal, oil, and lumber, but unemployment – already high – is on the rise. Marina works in communications; Valery is a welder, but since his heart attack four years ago, he is unable to work full time.

DEVELOPMENT AND MEDICAL HISTORY

Doctors at the local maternity hospital discovered Roman's heart defect when he was two days old. After two months in hospital, he was transferred to the Bakulev Center in Moscow (600 miles away). Specialists there determined that Roman's heart had 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.

Before his first birthday, Roman underwent open heart surgery – the first procedure in a complex multi-stage surgical approach to repair his heart. He 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.

2010: PROCEDURE PERFORMED

Marina never gave up hope that Roman could get the second surgery he needed. She discovered an on-line network for parents of children with congenital heart disease; through an e-mail exchange with Tomsk pediatric cardiac surgeon Dr. Krivoschekov, Marina learned about treatment options for single ventricle patients at his hospital, Heart to Heart's sponsored site in Siberia (1,500 miles away).

In April 2010, the joint Heart to Heart-Tomsk team performed Roman's Fontan procedure. The operation immediately improved Roman's quality of life – as well as his prognosis for a normal lifespan.

2012: CURRENT CONDITION & PROGNOSIS

Roman recently developed arrhythmia, not unusual for adults after a Fontan operation. In January 2012, Roman vomited and fainted, his first symptom since his surgery in 2010. Marina immediately contacted the Tomsk Cardiology Institute – which she describes as “the best thing that ever came into our family's life.”

Roman arrives at the institute during our mission, and his case is reviewed at conference. Heart to Heart cardiologists recommend implanting a pacemaker; the Tomsk team concurs and schedules implantation of the pacemaker for the week following Heart to Heart's departure.

Despite his arrhythmia, Roman looks great. He shares with us how euphoric he has been since his surgery – simple activities that used to exhaust him are now easy. A true adolescent, he successively dyed his hair different colors. Roman is taking a two-year course at a local college with an eye to a job in a computer store and learning how to drive. Marina urges Roman to tell us his big news: He has a girlfriend.

His transformation has been difficult for his mother. Since Roman's birth, Marina has lived in acute anxiety about his health, about his survival. Little by little, she is letting go and learning to rejoice in his ability to take care of himself.

On April 12, 2012, junior surgeon Dr. Podoksenov implanted a pacemaker. Roman was discharged on April 25. Prognosis: Roman can now lead a normal life.

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



(Top) 2010: Dasha during a physical exam prior to her surgery.

(Bottom) 2012: A charming preschooler.

PATIENT PROFILE

Age	3 years 7 months old
DOB	August 22, 2008
Weight	At birth: 6 lbs 1 oz 2010: 20 lbs 5 oz 2012: 27 lbs 9 oz
Home	Novokuznetsk, Kemerovo Oblast 250 mi from Tomsk
Parents	Anya, 32; Oleg, 42
Diagnosis	Peripheral stenosis of pulmonary artery branches S/p Pulmonary valve replace- ment w/Contegra (2010, Heart to Heart-Tomsk team) S/p Pulmonary atresia, VSD repair (2009, Tomsk)
2012 Follow up	Balloon dilation of pulmonary arteries April 3, 2012
Recommendation	Follow-up exams every 6-12 months; screen for subse- quent valve replacement

DASHA L: FAMILY BACKGROUND

Dasha lives with her parents, Anya and Oleg, and two older siblings: her sister Diana, 14, and her brother Roma, 10. The family lives in Novokuznetsk, the administrative center of the Kemerovo Province in Siberia. Anya is a stay-at-home mother; Oleg is a taxi driver.

From the 1930s until the collapse of the Soviet Union in 1991, Novokuznetsk was a major coal mining and industrial center, attracting workers from all across the USSR.

DEVELOPMENT AND MEDICAL HISTORY

Anya's obstetrician detected baby Dasha's heart defect in utero, and recommended termination of the pregnancy. At the time, the doctor was likely not yet aware of recent advances in pediatric heart care available in Tomsk. In April 2010, when Heart to Heart first interviewed Anya, she cried when recalling the conversation with her obstetrician.

When Dasha was three months old, a local cardiologist referred the family to the heart center in Novosibirsk (200 miles away). Doctors there were unable to treat Dasha because, as Anya recalled, "They had used up the annual out-of-region quota which allows them to treat non-local children gratis." Dasha's local cardiologist then referred Anya and Oleg to Tomsk.

2010: PROCEDURE PERFORMED

The family first arrived at the Tomsk Cardiology Institute in November 2009. One week after diagnosing Dasha, the local team successfully performed the first of two staged open heart surgeries. Tomsk pediatric cardiac surgeon Dr. Krivoshechekov recommended scheduling the second, more complex, operation six months later, during Heart to Heart's surgical-educational mission. In April 2010, the joint Heart to Heart-Tomsk team performed Dasha's second open heart surgery.

2012: CURRENT CONDITION & PROGNOSIS

Dasha's parents' faith and their tenacity in seeking treatment for their daughter has been rewarded. She is a charming, active child with a delightful sense of humor. Anya reports that Dasha has developed normally in every way. On the children's ward, we find her sitting in a large dollhouse serving tea to dolls and stuffed animals.

Heart to Heart medical volunteer Dr. Stuart Berger performs an interventional catheterization to widen the narrowed areas of Dasha's pulmonary artery branches, removing obstruction of blood flow. Tomsk specialists consult with Heart to Heart cardiologists on Dasha's case to confirm her future medical treatment plan: She will continue to come to the Center for annual follow up; as she grows, she will require subsequent pulmonary valve replacement. Dasha's prospects are good, especially given her young age and emerging new technologies such as catheter-based valve replacement.

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



(Top) 2010: Nikolai in the PCICU following his Glenn procedure.
(Bottom) 2012: A bright and active eight-year-old.

PATIENT PROFILE

Age	7 years 11 months old
DOB	May 16, 2004
Weight	At birth: 5 lbs 7 oz 2010: 37 lbs 4 oz 2012: 48 lbs 9 oz
Home	Omsk, 400 mi from Tomsk
Parents	Svetlana, 27; Slava, 29
Diagnosis	Moderate heart failure S/p Left branch PA stenting, endovascular closure of veno-venous systemic pulmo- nary collaterals (2011, Tomsk) S/p Embolization of systemic pulmonary collaterals (2010, Tomsk) S/p Bidirectional Glenn, PA plasty (2010, Heart to Heart-Tomsk team) Unbalanced AV canal, TGA, Pulmonary atresia
2012 Follow up	Diagnostic catheterization April 4, 2012
Recommendation	Fenestrated Fontan procedure

NIKOLAI V: FAMILY BACKGROUND

Svetlana and Slava, Nikolai's parents, met when they were in their late teens. They live with Nikolai in a two-room apartment in the same building as both sets of grandparents. Omsk is an industrial city, with an automobile plant and factories that process oil, plastics, and Altai vodka. The family grows vegetables and puts up food for the winter. Slava is a technician for a gas company. He graduated with a degree in physical education, hoping for a career as a trainer or coach. We talk about the film *Million Dollar Baby*, which he enjoyed immensely.

DEVELOPMENT AND MEDICAL HISTORY

Baby Nikolai's heart defect was discovered in utero. Terminating the pregnancy was discussed, but Svetlana and Slava decided against it. When Nikolai was born, he was acutely cyanotic (blue). Nikolai's parents took him to the cardiac center in Novosibirsk (about 400 miles away) when he was six months old. Doctors there said Nikolai was inoperable, but prescribed medications.

A few years later, when Nikolai was three years old, a cardiac specialist from Omsk, Nikolai's hometown, referred him to the Tomsk Cardiology Institute.

2010: PROCEDURE PERFORMED

Nikolai underwent a physical examination, echocardiography, and a diagnostic catheterization at the Tomsk Cardiology Institute. Exams showed that Nikolai required immediate surgery. The joint Heart to Heart-Tomsk team performed surgery on Nikolai on April 19, 2010. At the request of our Tomsk colleagues, Dr. Jim Tweddell led the operation.

Slava, Nikolai's father, was alone with his son at the hospital. He explained that he is stronger, both physically and emotionally, than Svetlana. Nonetheless, during the interview he nervously twisted a towel in both hands, as if it would help him hold back his tears. The second day after his operation, Nikolai was already kicking a ball around with his father and other children. When we took his picture, he broke into a big smile!

2012: CURRENT CONDITION & PROGNOSIS

Nikolai is now a bright eight-year-old, responsive and poised. Slava talks about how active Nikolai has become since his first operation and how he continues to "catch up" from his earlier debility. Nikolai reads well and likes math. He joyfully tumbles with other little boys on the ward.

Slava speaks about the Tomsk team with respect and gratitude; one of the cardiologists functions as Nikolai's primary care doctor whom the parents can call at any time.

Following Nikolai's physical exam, Heart to Heart cardiologist Dr. Stuart Berger performs a diagnostic catheterization. The images confirm that the second stage of repair, the Fontan operation, may now be scheduled. The Tomsk team agrees to conduct the open heart surgery on their own after our team has departed.

The Tomsk team performed a fenestrated Fontan procedure on Nikolai on April 9. As of this report (early June), Nikolai had been discharged from the PCICU but was still recovering on the pediatric ward.

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