

INTO *the* HEARTLAND CAMPAIGN

SITE: CHELYABINSK
DISTRICT: URALS
COLLABORATION LAUNCHED: 2015

JULY 20–30, 2016
SURGICAL-EDUCATIONAL
MISSION 2



Operating on newborns Heart to Heart's Dr. Mark Galantowicz (center) operates side-by-side with Chelyabinsk's chief pediatric cardiac surgeon, Igor Gladyshev (right) on a six-day-old baby girl born with transposition of the great arteries. Children born with this defect must undergo heart surgery in the newborn period if they are to survive.

LIFE-SAVING CARDIAC CARE FOR EVERY CHILD IN NEED

When Heart to Heart began our work in Russia in 1990, surgeons at only two or three hospitals in the entire country were confident enough to attempt open heart surgery on young children with congenital heart disease (CHD). Performing open heart surgery on newborns – babies less than one month old – was unheard of. Twenty-six years later, Russian cardiac teams, many of them trained by Heart to Heart, perform over 7,000 open heart surgeries on pediatric CHD patients each year – 11% of them newborns. Most children throughout Russia now have access to life-saving cardiac care, but in certain regions, access remains extremely limited. Heart to Heart

remains committed to our vision for children in this part of the world: a child born with CHD – anywhere in Russia – will have access to timely, life-saving surgery. We have made steady progress toward realizing this ambitious goal, through our *Into the Heartland Campaign, 2002-2019*.

Each year, 19,000 children in Russia are born with CHD. About 2,000 of them require surgical treatment in the newborn period if they are to survive. These babies must be diagnosed in utero or soon after birth, transferred to a medical institution capable of performing cardiac surgery on newborns, and provided with attentive post-operative and

HEART TO HEART 2016 CHELYABINSK TEAM **Children's Healthcare of Atlanta:** Brenda Jarvis, senior PCICU nurse **Mayo Clinic:** Dr. Nathan Taggart,* pediatric cardiologist **Nationwide Children's Hospital:** Tamara Clark, PCICU nurse; Dr. Mark Galantowicz, pediatric cardiac surgeon; Ashley Hodge, perfusionist; Dr. Ayman Naguib, pediatric cardiac anesthesiologist; Dr. Janet Simsic, pediatric cardiac intensivist **Tomsk Cardiology Institute:** Dr. Alexander Nikolishin, pediatric cardiac intensivist; Irma Ozashvili,* interpreting coordinator **UC Davis Medical Center:** Olesya Dushkova,* surgical technician **Heart to Heart:** Natalia Lusin,* statistician & interpreter; Albina Popova,* administrative coordinator; Dr. Dmitry Ryabtsev,* interpreter; Dr. Dmitry Yaranov,* interpreter.

*Russian-English bilingual



Staged surgical repairs: two stories Both Margarita and Vitaliy were successfully operated on by the joint Heart to Heart-Chelyabinsk team during our surgical-educational mission. This was the second of three staged surgeries for each child. They will continue to receive follow-up cardiac care at the CFCC. (Left) Margarita undergoes an echocardiogram exam to confirm her diagnosis. (Right) Vitaliy in his mother's arms two days after his surgery.

follow-up care. Since the start of our *Into the Heartland Campaign*, Heart to Heart has worked to establish cardiac centers capable of operating on the hearts of newborns in strategically selected cities throughout Russia. In 2015, we began surgical education and training at the Chelyabinsk Federal Cardiac Center (CFCC), located in the underserved Urals Federal District (pop. 12 million), just east of the Ural Mountains – the 1,500 mile boundary between Europe and Asia.

Expanding access east of the Urals

Over 1,500 children are born with CHD annually in the Urals Federal District. About 150 of these children have critical defects requiring surgical intervention within 30 days of birth. The CFCC is one of the few hospitals in the Urals District capable of operating on newborns.

In July 2016, Heart to Heart conducted our second mission to the CFCC. Our surgical focus was treating newborns and infants – babies under 1 year of age, weighing less than 5 kg. This cohort of patients is known to be challenging even for the best cardiac programs in the U.S.

Most newborns requiring urgent surgery have severe heart defects such as pulmonary atresia, transposition of the great arteries, or hypoplastic left heart syndrome. These defects form in the first trimester of pregnancy and can be diagnosed prenatally via ultrasound. Many of the patients Heart to Heart examined on our trip this year had been diagnosed prior to birth. Some children were diagnosed at birth, or soon after due to their severe symptoms: lips, fingertips, and toes appearing “blue” due to extremely poor circulation (cyanosis). Other patients were not diagnosed in such a timely fashion, and ended up at the CFCC almost as if by chance.

Margarita and Vitaliy: different paths to treatment

Margarita and Vitaliy have much in common. They were both born in the winter of 2016 in the Urals Federal District. They are both small infants weighing just over 5 kg at five months of age. And they were both diagnosed with heart defects that now require them to have an open heart operation known as the Glenn procedure. But the paths that led them to the CFCC were quite different.

Baby Margarita's heart defect was detected prenatally at a routine screening. Her parents consulted many specialists to learn as much as they could about CHD and the possibility of saving their baby's life. Armed with the knowledge that Margarita's heart defect was surgically treatable, her mother, Irina, arranged to give birth at a maternity hospital close to the CFCC. Soon after birth, Baby Margarita was quickly and safely transferred there for heart surgery.

Irina is very pleased with the medical treatment her daughter received. Irina is well informed and trusts Margarita's doctors to do what's best for her baby, now and in the future.

Baby Vitaliy's journey was not so straightforward. His mother, Lyuba, also went to all of her prenatal appointments, but in the village where she lives, doctors never detected a heart problem – before or after his birth. When Vitaliy was born underweight, Lyuba's doctors assured her that he would be fine in a few weeks or months once he grew a bit. But Lyuba felt certain that something was wrong with her baby – Vitaliy was very small, his skin looked blue, and he was not gaining weight. One month after giving birth, Lyuba took Vitaliy to the nearest big city, Orenburg, for a postnatal examination. Doctors in Orenburg immediately recognized that he was sick. They were able to detect several complex heart defects by echocardiogram, and,



A delicate job Pediatric cardiac anesthesiologist Dr. Aymen Naguib (Nationwide Children's Hospital, Columbus, OH) works with the Chelyabinsk anesthesia team to carefully prepare the 2.5 kg patient for surgery – repair of truncus arteriosus, a rare form of CHD.

thanks to their established relationship with the CFCC, they knew that they needed to immediately refer him to the CFCC's pediatric cardiac team. Vitaliy was rushed to the cardiac unit by ambulance.

Vitaliy's urgent heart surgery was a success. However, Lyuba's relief and gratitude were dampened when the cardiologists explained afterwards that her baby would need two additional open heart surgeries in early childhood to render his heart functional. For Lyuba, the realization of what could have happened to her baby had she not taken him to Orenburg that day had already made her distrustful of doctors. Now, upon learning that Vitaliy needs two more surgeries, she is overwhelmed.

During our mission, we were privileged to examine and help operate on Margarita and Vitaliy: both underwent the second of their three planned surgeries, and both cases provided excellent learning opportunities for local physicians and nurses. The infants recovered well in the PCICU, and their doctors explained to the families the ongoing care their children will need as they grow. Margarita and Vitaliy will return to the CFCC annually for physical exams and echocardiograms. When they are ready, they will each undergo the Fontan operation. Their prognoses are good: they will be able to attend school, play sports, and enjoy life as other children do. None of this would have come to pass without timely surgical treatment in their first few weeks of life.

Reaching the tipping point

Today, the major challenge – for Heart to Heart and the CFCC – is to simultaneously address the backlog of untreated CHD patients living throughout the Urals District, while also learning to provide accurate and timely diagnoses for the new

babies born with heart defects every day. Heart to Heart is experienced in dealing with this challenge – it is one we have already overcome in several other regions of the country.

Russian pediatric cardiac medicine has come a long way since 1990 when there were just three centers performing open heart surgery on children. In addition to Heart to Heart's considerable ongoing support, beginning in 2008, the Russian Federal Ministry of Health made it a priority to expand access to cardiac care for both children and adults – establishing seven well-equipped, high-volume centers across the country. Today, there are 23 centers capable of performing over 100 pediatric open heart surgeries annually. Collectively, these centers provide more than 7,000 open heart surgeries each year. Heart to Heart partner sites provide 19% of these procedures.

On every Heart to Heart mission we see longtime colleagues as well as young, new faces from across Russia. Our partner sites now host annual national pediatric cardiology and cardiac surgery conferences. Four of our partner sites (St. Petersburg, Samara, Tomsk, Rostov-on-Don) have successfully completed educational collaborations with Heart to Heart, and our *Into the Heartland Campaign* is on track to conclude in 2019. We will have supported six pediatric cardiac programs through 30 years of growth and development. We are at the tipping point – in the near future, access to life-saving cardiac care will be a reality for all of Russia's children.

For now, we are keeping our eyes on the prize, working closely with our colleagues in the few remaining underserved regions of Russia to ensure that, just as in the U.S., every child in Russia will have access to life-saving cardiac care, no matter which part of the country they are born in, or how complex their form of CHD is.

FINANCIAL OVERVIEW

Financial support

Thoracic Surgery Foundation	31,000
Edwards Lifesciences Foundation	22,547
St. Jude Medical Foundation	15,500
Anonymous donor	13,000
Total Financial Support	\$82,047

In-kind support

In-kind medical services	383,170
Non-medical in-kind (see Expenses below)	18,560
Total In-kind Support	\$401,730

Total program value

Donated medical services	383,170
Expenses (excl. non-medical in-kind)	82,047
Non-medical in-kind donations (Russian)	18,560
Total Program Value	\$483,777

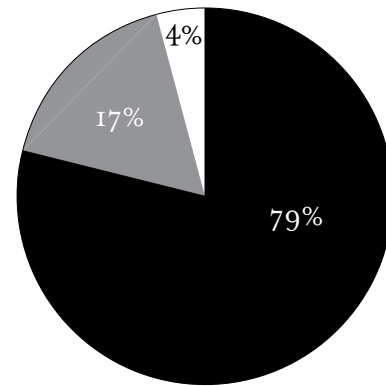
Expenses

Ground transportation, in-kind	1,200
Interpreters, in-kind	1,750
Lodging, in-kind	12,960
Meals, in-kind	1,210
Program supplies	1,534
Pre- and post-trip coordination + logistics	32,554
Travel	21,324
Travel insurance, in-kind	960
Visas, in-kind	480
Year-round program development	26,635
Total Expenses	\$100,607

Data compilation as of October 5, 2016

CHELYABINSK PROGRAM YEAR 2

Total Program Value: \$483,777



- Heart to Heart in-kind medical services \$383,170
- Expenses (excl. non-medical in-kind) \$82,047
- Non-medical in-kind donations (Russian) \$18,560

PROCEDURES PERFORMED JULY 2016

Patient exams (11)	6,545
Echo studies + readings (40)	34,296
Cath lab - diagnostic (2)	16,128
Cath lab - interventional (2)	17,380
Pediatric open heart surgeries (7)	174,173
Anesthesia (7)	54,194
Perfusion (7)	15,000
Intraoperative TEE (3)	3,600
Post-op exams / readings (13)	4,992
ICU post-op care, MD (12)	25,776
RN/tech support (ICU + OR)	10,461
Professional consulting + lectures	20,625
Total In-kind Medical Services	\$383,170

83% of the total program value consisted of goods and services donated in-kind to Heart to Heart and utilized in Chelyabinsk in Program Year 2. The remaining 17% consisted of financial support from our major sponsors and individual donors.

Thank you to our major sponsors, whose support continues to fuel our progress



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