



**Plaza San Martín, Lima** Located in the country's historic capital, this public square was inaugurated on July 27, 1921 to commemorate the 100th anniversary of Peru's independence from Spain. Plaza St. Martín features a statue of Peru's liberator, José de San Martín, on horseback as he traveled across the Andes.

## **HELPING PERU'S LEADING CARDIAC CENTER SCALE UP**

Congenital heart disease (CHD) remains the most common birth defect worldwide – 1 in 100 children are born with the condition every year. Effective diagnosis, surgical treatment, and follow-up care are vital if these children are to survive. In the United States, nearly every child with CHD receives timely care; elsewhere in the world, a patient's birth country may define their prognosis. Although it may be hard to imagine, more than 90% of children around the world still lack access to life-saving cardiac care.

To help address this global health disparity, Heart to Heart has expanded cardiac training programs to South America, beginning in Lima, Peru where 6,000 babies are born with CHD each year. Half of these children will require surgical intervention before the age of three in order to live.

As part of our *Going Global* initiative, Heart to Heart's team from nationally recognized Children's Hospital of Atlanta returned to Instituto Nacional Cardiovascular (INCOR) in March

to conduct our second full pediatric surgical-educational training mission – just six months after our last mission. Because INCOR is the country's most established cardiac center, our Peruvian colleagues bear a tremendous amount of responsibility. Peru does not yet have enough pediatric cardiac specialists to provide care for all children with CHD; the vast majority of children who do undergo open heart surgery do so at INCOR. Moreover, because CHD is not well understood throughout Peru, newborns, infants, and older children arrive to INCOR with incomplete or late diagnoses – and often very symptomatic.

The Heart to Heart-INCOR collaboration was created to scale up care for the children of Peru, first at INCOR and then through a nationwide network. In our report: a look at the strategy for this mission; a brief overview of work-to-date at INCOR; a summary of our second full pediatric team training mission; patient stories; and a glimpse at our next steps.



**Clinical training in the operating room** Dr. Laura Berenstein (anesthesiologist, Children’s Hospital of Philadelphia) demonstrates an approach to inserting an arterial line as the joint Heart to Heart-INCOR surgical team prepares a 16-month-old child for open heart surgery.

### Traditional and new approaches for VSD repair

Before our team steps off the plane in Peru, Heart to Heart and INCOR leaders have been actively planning each aspect of the mission for more than six months. To ensure program progress, Heart to Heart communicates year-round within our extensive network across the United States – San Francisco, Columbus, Atlanta, and Rochester – and back to Peru.

Heart to Heart develops annual training objectives and goals as we guide teams along the road to self-sustainability. We set our annual objectives based on multiple inputs: surgical outcomes data; empirical observation during on-the-ground missions, and information gleaned through year-round discussions with department heads and other partner site thought leaders. Our founder, Nilas Young, MD; executive director, Josie Everett; lead surgeon, Kirk Kanter, MD; and lead cardiologist, Frank Cetta, MD, were in ongoing dialogue with INCOR pediatric cardiac team leader, Miguel Arboleda, MD, and his department heads to assess INCOR’s needs and define mutual goals. After much dialogue, we jointly agreed that our second mission would focus on a full INCOR team approach to the comprehensive management of children with ventricular septal defects (VSDs) – including both open heart and percutaneous repairs.

In arriving to this agreement, many of Dr. Arboleda’s strengths as a leader were revealed: putting the needs of the full pediatric cardiac team above the needs of any individual department or team member. Modest and very engaged, Dr. Arboleda is a strong advocate for advancing the whole team’s capacity to achieve world-class surgical outcomes in VSD repair – and with good reason; there are 2,000 new cases in Peru each year.

**Ventricular septal defect (VSD)**

Shown here: A VSD is the most common heart defect. It is hole in the wall (ventricular septum) between the two lower chambers of the heart (ventricles).

In young children with VSDs, blood passes from the left side of the heart to the right through the hole. This increases the volume of blood flowing through the lungs. If left untreated, large VSDs can cause development of pulmonary vascular disease – a life-threatening condition.



**Faces of VSD** Young patients like four-year-old Santiago (left) and one-year-old Eyma (right) are two of the many children diagnosed with VSDs each year in Peru. To undergo a life-saving procedure, patients and their families must travel to the country’s capital. Luckily, Santiago is from the Independencia District in Lima, near INCOR. Eyma’s family traveled from Cutervo – a small city located more than 400 miles north of Peru’s capital.



A small VSD may cause no symptoms or problems, and many small VSDs close on their own in the first months of life. If the VSD is large enough, extra blood goes back through the lungs with each heartbeat, causing a small baby to breathe faster than normal and leading to poor feeding and reduced growth. Children with unrepaired large VSDs may develop irreversible damage to blood vessels in their lungs by as early as two years of age. In the U.S., most children have their VSDs closed through open heart surgery before their first birthday. Children with moderately sized VSDs in certain locations of the heart sometimes have the option to undergo percutaneous repair via interventional cardiac catheterization. This procedure involves a closure device being threaded through the femoral artery or vein up to the heart through a catheter to close the hole. Although it is a less invasive procedure than open heart surgery, and patients are discharged from the hospital much sooner, percutaneous closure of VSDs is only safe in 10% of the cases.

### A day in the life: on the ground at INCOR

INCOR is located in the Jesús María district of Lima – the sprawling, urban capital of Peru inhabited by 10 million people. Each day, our team of U.S. medical specialists – surgeon, cardiologists, intensivists, anesthesiologist, nurses, perfusionist, and surgical technician – arrives to the hospital ready to immerse themselves in the world of our Peruvian colleagues. Led by Dr. Kanter (surgeon, Children’s Healthcare of Atlanta/Emory University) and Dr. Cetta (cardiologist, Mayo Clinic), our 11 medical specialists – supported by Heart

to Heart administrators and medical interpreters – are found leading lectures, case presentation conferences, workshops, and clinical training all aligned with Heart to Heart’s program model.

Part of each day is spent reviewing the anatomy and physiology of VSDs. Much discussion in the lecture hall and case conferences is devoted to decision-making for treatment options – how to decide when to refer a patient for open heart surgery, and under which circumstances to refer a patient to the cath lab. In Lima today, this is especially important: our INCOR colleagues work day and night to whittle down the list of children waiting for surgery. If children with VSDs can be saved in both the operating room and cath lab, more children can be saved overall, and the program advances technologically.

- Our well-received lecture series included these topics:**
- 1 VSD physiology – if and when to close a VSD
  - 2 Intraoperative conduction issues
  - 3 Oxygen delivery/low cardiac output syndrome
  - 4 Intraoperative uses of inotropes plus effects of ventilation on cardiac function
  - 5 Surgical approach to neonate with coarctation and VSD
  - 6 How and why to conduct a morbidity and mortality conference
  - 7 Percutaneous closure of VSDs



### PATIENT PROFILE

Child	Jack P.
Date of birth	February 20, 2009
Weight	47 lbs
Home	Iquitos (630 miles from Lima)
Diagnosis	VSD, ASD, PFO
Open heart surgery	VSD patch closure and PFO surgical suture March 6, 2017
Discharged from PCICU	March 9, 2017

### Jack's story: VSD closure through open heart surgery

Jack is a calm and brave boy from the Peruvian Amazon region of Loreto. When we first met him, he was in a patient room resting in bed, quiet but friendly. His mother, Dorcas, told us that Jack appeared healthy at birth. At four months, all of that changed when he came down with what they thought was an intense flu. His family brought him to the local hospital in his hometown of Iquitos where doctors found that it was not a virus ailing him, but a heart defect. Soon after, he was diagnosed with a ventricular septal defect (VSD), atrial septal defect (ASD), and patent foramen ovale (PFO) – all more commonly known as “holes in the heart.”

Following Jack's first birthday, his father's insurance enabled the family to fly to INCOR for a medical consultation in Lima. Examinations showed that Jack's ASD had closed on its own, but the VSD remained open and problematic. He was prescribed medicine and his surgical intervention was scheduled for a later time. Two more years passed before Jack's family returned to INCOR; however, for reasons unknown, surgery was not performed. Now, at age eight, Jack has returned to INCOR with his mother for the third time. At INCOR Jack will undergo open heart surgery to close the VSD. Mother and son flew approximately 630 miles by plane from the northeastern city of Iquitos, an urban center in the Amazon, to arrive to the country's capital – the only Peruvian city where open heart surgery is performed on children.

Jack's surgery was successfully performed by the joint Heart to Heart-INCOR team. His post-operative recovery was aided by Heart to Heart's PCICU team members and went smoothly.

The open heart operation left him tired, but he still managed to give us his signature thumbs-up sign high and proud! Despite setbacks in timing, Jack is lucky – and his prognosis is good. He and his mother can now return to the rest of their family in Iquitos where Jack can begin a normal, healthy life and give his family and friends as many thumbs-up as he wishes!

*Patient story based on an interview conducted in Lima, in Spanish, by Morgan Michna with the help of an interpreter.*

**Jack's journey: from Iquitos to Lima**

The city of Iquitos is unique in that it is the largest city in the world that cannot be reached by road – it is accessible only by river and air.

Peru's 496,225 square miles are marked by diverse terrain: the mountainous regions bordering the Cordillera Blanca and Cordillera Negra, the desert regions of the south, and the jungle regions of the Peruvian Amazon. Despite the country's vast geography, pediatric cardiac surgery is currently only available in Lima.



### PATIENT PROFILE

Child	Jazmin A.
Date of birth	May 22, 2014
Weight	28 lbs
Home	Lima
Diagnosis	Ventricular septal defect
Procedure performed	Percutaneous VSD device closure March 7, 2017
Discharged from hospital	March 8, 2017

### Jazmin's story: VSD closure percutaneously in the cath lab

Three-year-old Jazmin lives with her parents, Maximo and Sonia, and her older brother. The young family is based in sprawling Lima not far from our partner site, INCOR hospital. Jazmin is a playful child who loves to dance – a pastime that has become increasingly difficult with her heart defect.

When Jazmin was born, she appeared healthy, but five days later she began showing symptoms. She was abnormally sleepy and appeared yellow. The family moved to Lima when Jazmin was two months old to seek treatment at INCOR where doctors quickly diagnosed her with a VSD and began monitoring her condition. She would later experience shortness of breath when walking and playing.

Just before Jazmin's third birthday, the joint Heart to Heart-INCOR team determined that her VSD needed to be closed urgently. Working closely with INCOR colleagues, the Heart to Heart team closed Jazmin's VSD on March 7, 2017 percutaneously, implanting a closure device in the cath lab. This procedure was brief and less invasive than open heart surgery, however, the result was the same for little Jazmin – her symptoms immediately decreased and her life was saved.

When Jazmin woke up in the intensive care unit, she asked, “Where is my brother?” Her father, Maximo, comments that before her procedure, Jazmin was never able to finish eating even a snack of bread and milk, but, within one day, her appetite improved tremendously. He also observed that she already does not tire as easily and is able to actively play around as she pleases.

#### Overview: interventional catheterization

**Interventional cardiac catheterization** is a procedure used to treat cardiovascular conditions.

During the procedure, a long thin tube called a catheter is inserted in an artery or vein in the patient's groin, neck, or arm and threaded through blood vessels to the heart.

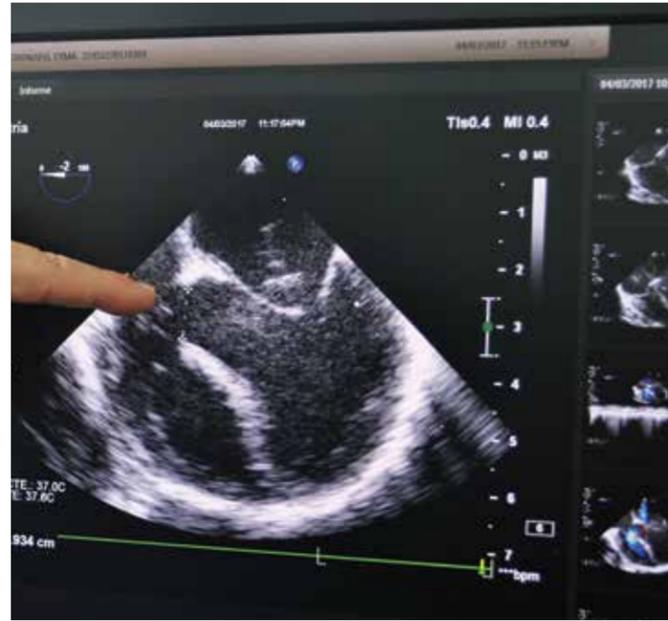
Some congenital heart defects involving holes in the heart, like VSDs, can be treated by threading a catheter up to the hole to close it – almost like a plug – instead of undergoing an open heart procedure.

(Source: Mayo Clinic website)

Only one day after undergoing her procedure, Jazmin was ready to be discharged from the PCICU step-down unit. The family will soon return home – with a healthy Jazmin who can now play and dance to her heart's content alongside her big brother.

Her prognosis is excellent: she will not likely need any further intervention and can lead a normal, healthy life. What a great way to celebrate Jazmin's third birthday!

*Patient story based on an interview conducted in Lima, in Spanish, by Morgan Michna with the help of an interpreter.*



**Advanced teaching and training** Heart to Heart cardiac specialists provided 56 teaching hours and 286 training hours during our educational mission. Teaching hours consist of didactic educational activities, such as lectures and comprehensive reviews of complex patient cases discussed in conference settings. Training hours represent hands-on training while screening and/or treating heart patients. We align all didactic and training activities to guide a new team to self-sustainability.

### The language of learning

On our mission, much of each day is spent on our feet performing clinical work side by side with our INCOR colleagues – open heart procedures in the OR, diagnostic or interventional catheterizations in the cath lab, tending to patients in the PCICU, or performing echocardiograms to diagnose patients.

Thanks to our newly developed team of exceptionally talented medical interpreters, Heart to Heart and INCOR cardiac specialists communicated seamlessly. Seven young, dedicated Peruvian doctors, completely bilingual in Spanish and English, allowed for fluid, effective communication throughout each day – especially important in high-stakes situations like open heart surgery. For Heart to Heart’s specialists to effectively transfer decades of knowledge and experience to our colleagues at INCOR requires high-level communication. Throughout each day, one of these young interpreters was at the side of each Heart to Heart specialist – in the lecture hall or in the intensive care unit – to maximize learning.

Overall, the mission was a success. The joint pediatric Heart to Heart-INCOR team performed seven open heart surgeries, three catheter-based interventions, and provided comprehensive consultations on 22 patient cases.

Although this trip represents a small step for one pediatric cardiac team, because of INCOR’s leadership position in the country, it also represents a giant leap forward for nationwide pediatric cardiac care for the children of Peru.



**Young medical talent** Pictured here are the seven interpreters – all medical doctors – who aided in our mission. From left to right: Daniel Palasz, Maria Fernanda Ortiz, Jorge Gonzales, Maria Teresa Peralta, Hernan Carcamo, Ricardo Roman, and Maria Jose Ramirez.

**HEART TO HEART 2017 LIMA PEDIATRIC CARDIAC TEAM** **Children’s Healthcare of Atlanta:** Dr. Kirk Kanter, surgeon; Ann Marie McGoldrick, perfusionist; Amanda Mendez, surgical technician; Heather Smith, PCICU nurse; Linda Steinhauer, PCICU nurse; Dr. Michael Wolf, PCICU intensivist **Mayo Clinic:** Dr. Frank Cetta, cardiologist; Dr. Nathan Taggart, cardiologist **Children’s Hospital of Philadelphia:** Dr. Laura Berenstain, anesthesiologist **UC Davis Medical Center:** Dr. JoAnne Natale, ICU intensivist **UCSF Benioff Children’s Hospital, San Francisco:** Dr. David Teitel,\* cardiologist **Heart to Heart:** Michael Berenstain, illustrator; Josie Everett,\* executive director; Lucie Everett,\* interpreter; Morgan Michna,\* interviewer and photographer; Albina Popova, mission coordinator.

\*Spanish-English bilingual



**Going for the gold** Representatives of INCOR, Heart to Heart, ESSALUD Healthcare, and the U.S. Embassy in Peru gather in front of INCOR following their meeting to discuss advancing cardiac care for children and adults nationwide. ESSALUD is one of two Peruvian healthcare leaders insuring the majority of the nation’s citizens. Founded by ESSALUD in 1992, INCOR is now the nation’s leading cardiac care institution in Peru.

### Aligning to reach the gold standard

The gold standard in pediatric cardiac medicine is treating newborns with excellent surgical outcomes. Since March 2015, Heart to Heart has been conducting a series of in-depth discussions with key stakeholders in Peru regarding how to collaboratively advance cardiac care to this gold standard nationwide. On March 8, the Heart to Heart-INCOR team, U.S. Ambassador to Peru, Brian Nichols, and head of Seguro Social de Salud del Perú (ESSALUD), Mr. Gabriel del Castillo, convened in-person at INCOR to discuss Heart to Heart’s work-to-date in Peru and the future of pediatric cardiac care in the country.

We were fortunate to meet in-person with Mr. del Castillo, who very recently assumed his leadership position at ESSALUD, one of the two largest healthcare systems in the country, providing coverage to Peru’s employed citizens. This was the second time Ambassador Nichols joined our team on-site, having last visited us in January 2016.

Lima is the only city in Peru where children can undergo open heart surgery. To effectively advance heart care nationwide, we will continue our efforts in Lima to:

- (1) Increase the capacity of their basic medical infrastructure, which already serves a large number of residents of Lima with heart disease, but cannot meet current patient needs;
- (2) Help cardiac specialists in Lima achieve surgical outcomes comparable to those at centers in the U.S. and Europe by 2020;
- (3) “Train the trainers” at INCOR, who will then join us to expand our work to Peru’s provinces during the second phase of our collaboration. Heart to Heart’s vision dovetails perfectly with ESSALUD’s recently ratified five-year strategic plan for expanding heart care nationwide;

In year two of *Going Global* in Peru, Mr. del Castillo expressed his excitement over progress made to date. He looks forward to working closely with Heart to Heart, collaborating to reach our mutual vision of nationwide heart care for Peru.

*“It is important for us to face this problem in Peru together, because no group can advance alone.”*

– LILIANA FLOR ALVARADO PARRAGA, RN  
HEAD OF INCOR PEDIATRIC CARDIAC NURSING

## FINANCIAL OVERVIEW

### Financial support

Edwards Lifesciences Foundation	66,273
St. Jude Medical Foundation	35,000
Berenstain Healthy Kids Foundation	20,000
Individual donations	9,800
UC Davis seed grant	2,600
<b>Total Financial Support</b>	<b>\$133,673</b>

### In-kind support

In-kind medical services	516,856
Non-medical in-kind (see Expenses below)	36,116
<b>Total In-kind Support</b>	<b>\$552,972</b>

### Total program value

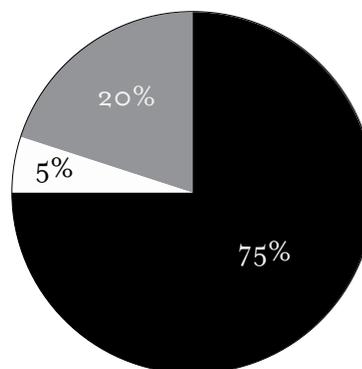
Donated medical services	516,856
Expenses (excl. non-medical in-kind)	133,673
Non-medical in-kind donations	36,116
<b>Total Program Value</b>	<b>\$686,645</b>

### Expenses

Airfare, in-kind	19,116
Ground transportation, in-kind	1,500
Lodging, in-kind	12,480
Meals, in-kind	1,940
Program supplies	3,698
Pre- and post-trip coordination + logistics	56,093
Travel	27,987
Travel insurance, in-kind	1,080
Year-round program development	45,895
<b>Total Expenses</b>	<b>\$169,789</b>

Data compilation as of June 15, 2017

## INCOR - LIMA, PERU PROGRAM YEAR 2 Total Program Value: \$686,645



- Heart to Heart in-kind medical services \$516,856
- Expenses (excl. non-medical in-kind) \$133,673
- Non-medical in-kind donations \$36,116

## PROCEDURES PERFORMED MARCH 2017

Patient exams (5)	2,975
Echo studies + readings (26)	10,316
Cath lab - diagnostic (1)	8,064
Cath lab - interventional (3)	176,962
Pediatric open heart surgeries (7)	151,316
Anesthesia (7)	66,542
Perfusion (7)	20,650
Intraoperative TEE (10)	12,000
Post-op exams / readings (10)	3,840
ICU post-op care, MD (10)	21,480
RN/tech support	10,461
Professional consulting + lectures	32,250
<b>Total In-kind Medical Services</b>	<b>\$516,856</b>

**80%** of the total program value consisted of goods and services donated in-kind to Heart to Heart and utilized in INCOR - Lima, Peru in Program Year 2. The remaining 20% consisted of financial support from our major sponsors and individual donors.

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

