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.
Ventricular septal defect (VSD)

- 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, Nils Young, MD, executive director, Josie Everett, lead surgeon, Kirk Kanter, MD, and lead cardiologist, Frank Cetta, MD, were in ongoing dialogue with INCOR pediatric cardiace 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 5,000 new cases in Peru each year.

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. Children with untreated VSD 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 within a week, both percutaneous closure of VSDs and open heart surgery have a high success rate that can save lives.

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 – surgeons, 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:

- VSD physiology – if and when to close a VSD
- Intraoperative conduction issues
- Oxygen delivery/low cardiac output syndrome
- Intraoperative uses of isotopes plus effects of ventilation on cardiac function
- Surgical approach to neonate with coarctation and VSD
- How and why to conduct a morbidity and mortality conference
- Percutaneous closure of VSDs

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 VSD 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.
Examinations showed that Jack’s ASD had closed on its own, but following Jack’s first birthday, his father’s insurance enabled the family to fly to INCOR for a medical consultation in Lima. 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 could finally 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 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. 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 could finally 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!

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 southeastern Loreto, 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.

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!
Overall, the mission was a success. The joint pediatric heart care 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. 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.

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 23 patient cases.

HEART TO HEART 2017 LIMA PEDIATRIC CARDIAC TEAM

Children’s Healthcare of Atlanta: Dr. Kirk Kantor, surgeon; Ann Marie McGoldrick, perfusionist; Amanda Mendoza, surgical technician; Heather Smith, PCICU nurse; Linda Steinhauer, PCICU nurse; Dr. Michael Wolf, PCICU intensivist; Mayo Clinic: Dr. Frank Catella, 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. Laura Berenstain, ICU intensivist

Heart to Heart: Josie Everett,* executive director; Lucie Everett,* interpreter; Morgan Michna,* interviewer and photographer; Albina Popova, mission coordinator.

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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 Peru (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;

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.

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**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
- **Total Financial Support** $133,673

**In-kind support**
- In-kind medical services 516,856
- Non-medical in-kind (see Expenses below) 36,116
- **Total In-kind Support** $552,972

**Total program value**
- Donated medical services 516,856
- Expenses (excl. non-medical in-kind) 133,673
- Non-medical in-kind donations 36,116
- **Total Program Value** $686,645

**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
- **Total Expenses** $169,789

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**

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- **Total In-kind Medical Services** $516,856

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.*