



The generous spirit at the heart of GSF and the positive impact of making healthy smiles possible for patients born with cleft goes far beyond one individual, or even one family, to reach larger communities.

THE POWER OF A HEALTHY SMILE

FROM THE GLOBAL SMILE FOUNDATION

Diana Ramirez knew that her infant son, Sebastian, needed special help and attention. He was born with a cleft lip and a cleft palate, and she was worried about the subsequent health complications that he would suffer if not given the appropriate care. Like so many parents in the developing world, Diana and her husband Javier live in a distant area of Ecuador with limited access to healthcare and virtually nonexistent cleft care.

Even though cleft is one of the most common birth defects in the world, affecting an estimated 1 in every 700 babies born in developing countries, providers in remote areas are often unfamiliar with the condition and are unable to assist parents with the specialized care their babies require.

Diana and Javier were committed to finding much-needed help for their son. When Sebastian was three months old, they traveled five hours to Dr. Roberto Gilbert Children's Hospital in

Guayaquil, Ecuador to meet the Global Smile Foundation (GSF) team. Unfortunately, they arrived on the last day of the outreach program. Volunteers had already packed up their supplies in preparation to head back to their home countries. The hospital operating rooms were also shut down by the time Sebastian's family had arrived.

Diana had learned about cleft surgery, and she insisted on talking to the GSF team about her son's care. Diana's determination was so emotionally touching and heartwarming that the GSF team relented to her request to evaluate her son. After examining Sebastian, the team reported that he was clear to undergo surgery and unpacked their bags to proceed with the operation.

"You could see it on her face," said Dr. Usama Hamdan, President and Co-Founder of GSF, recalling the moments of that day. "She was so distraught and worried for her son. We knew we had to help him."

In the decade that followed, Sebastian continued to receive comprehensive cleft care, including repair of his cleft lip, repair of his cleft palate, dental treatment, and speech therapy among other services. At every step along the way, Sebastian was under exclusive care of the GSF team, comprised of volunteer medical experts who specialize in cleft care, including surgeons, dentists, pediatricians, anesthesiologists, nurses, speech therapists, and child psychologists. Sebastian and other patients who come to GSF receive long-term care from an interdisciplinary team of



SMILING THROUGH: (Opposite page) Sebastian in 2020; (Above) Sebastian with mother Diana in 2008, and with Peri-Op Nurse and caregiver Jeanne Paolilli in 2020.

cleft specialists – the kind of care that is standard in developed the United States. GSF firmly believes that all patients deserve the best quality cleft care regardless of geographic, religious, or socioeconomic factors.

Ever since that first meeting, Sebastian's family has been part of the GSF family, and they have expressed their appreciation to the team for providing life-changing cleft care for their son. Sebastian has indeed grown up with GSF. He and his family have returned to the outreach mission site every year to see the team without fail, bringing Sebastian's two younger sisters, born in 2011 and 2013. Javier has spoken to the team to share his appreciation and experience. They also keep in touch by email and send photos of all three children at birthdays and other important life milestones.

Relationships such as the one between Sebastian's family and GSF make it easy to see why volunteers are so dedicated to GSF's mission. Treating cleft involves a range of care throughout a patient's childhood, so GSF returns to the same locations every year to support its patients. This continuity is part of what makes the GSF family so special and why they have maintained relationships with patients and families longer than any other NGO doing similar work. Dr. Hamdan and other founding members have been involved in outreach cleft care in the country for more than 34 years.

Even as GSF's work in Ecuador has expanded, the spirit of connectedness and bonding among team members, volunteers, and patients has remained strong. As more and more patients learned about GSF and the free comprehensive cleft care that their volunteers help provide, GSF decided to open a Cleft Center to provide year-round care for patients. The Center is located at Hospital León Becerra, a facility dedicated to pediatric care for children and families of low socioeconomic status. In 2012, GSF established Fundación Global Smile-Ecuador to run the Cleft Center and advance the GSF vision for sustainable cleft care in the country.

Many former GSF patients have become volunteers with Fundación Global Smile-Ecuador and provide critical support such as patient communications, public relations, and logistical help during outreach programs. One volunteer in particular, Diego De La S, became a mentor and friend to Sebastian.

Diego and Sebastian met in 2016. Diego had undergone his first surgery as an infant in 1996 with some of GSF's founding members and could talk to young patients and their families about his own experience. At age 20, Diego was nearing the end of his cleft care treatment. He met Javier and Sebastian and formed an instant friendship with the family.

“We always greet each other with hugs. I used to carry Sebastian around, but he’s too big for that now,” Diego says fondly. He remembers that Sebastian had always wanted to help during the outreach program, but he was too young. Diego often volunteered as a photographer with Fundación Global Smile-Ecuador and included Sebastian when he could.

In 2020, Sebastian finally got his chance to help during a mission and was Fundación Global Smile-Ecuador’s youngest volunteer. He worked with Jeanne Paolilli, who has volunteered as a Peri-Op Nurse with GSF for close to 10 years and had been one of Sebastian’s caregivers in the past. Sebastian helped Jeanne make ID bands for patients and assisted her as she prepared patients for surgery. Jeanne said that Sebastian was very helpful to her, “He figured out very quickly what I was doing and anticipated what I needed.”

She continued, “Sebastian is amazingly kind to our patients. He was very willing to share his experiences about having cleft lip and palate. He also spoke with the parents to make them more comfortable about their children’s care.”

Like Jeanne, many GSF volunteers return to the same locations year after year and say that watching patients grow up is one of the most special rewards of participating in GSF outreach programs.

Sebastian’s desire to assist GSF’s work follows the path of many former patients in Ecuador who have returned as volunteers. Just like Diego and many others, Sebastian has started a new cycle of “paying it forward” to future GSF patients. This generous spirit is at the heart of GSF and the positive impact of making healthy smiles possible for patients born with cleft goes far beyond one individual, or even one family, to reach larger communities.

Denise Franco Mera, President of Fundación Global Smile-Ecuador, accurately described the feeling of being part of the GSF family when she said, “It’s not what fills your pockets. It’s what fills your heart.”

And there are many hearts around the world that have been filled by the remarkable power of healthy smiles made possible by the GSF family. •

GSF relies on support from corporations, private foundations, and individuals to accomplish its mission. More information can be found at www.gsmile.org



KINDNESS IN ACTION: Sebastian with mentor and friend Diego De La S; Both have started a new cycle of “paying it forward” to future GSF patients.

FACING ADVERSITY : SEBASTIAN AND THE GSF

Sebastian began giving to others at the young age of eight. In 2016, a 7.8 magnitude earthquake hit the Manabí Province in Ecuador where Sebastian’s family lives. The damage was widespread, destroying homes and buildings for hundreds of miles, causing more than 676 deaths and 16,600 injuries. Nearly 100,000 people were left homeless.

NGOs and local groups approached GSF and Fundación Global Smile-Ecuador to help, not only because so many of their patients are from the Manabí Province, but also because they were well-known and trusted organizations. Javier approached Fundación Global Smile-Ecuador to help distribute donated goods because it was difficult to reach people who urgently needed help.



As soon as Sebastian learned about what his father was doing, he asked if he could help, “Just like GSF helped me,” he said. In total, GSF and Fundación Global Smile-Ecuador distributed more than 150 tons of food, water, and medications. They also helped build 25 homes for displaced families.

Global Smile Foundation is an NGO based in Norwood, MA whose mission is to provide comprehensive cleft care for patients in underserved areas throughout the world and to build global capacity for cleft care through empowerment and sustainability initiatives. In developing countries, the consequences of untreated cleft lip and palate are devastating, yet access to specialized care is extremely limited. GSF believes that every child born with cleft deserves the chance for a healthy smile – and a healthy life – regardless of geographic or socioeconomic barriers.

