

Saving Face

A boy with a glaring tumor on his face receives an operation at A.I. duPont Hospital for Children, but can the surgery change his life? by Shaun Gallagher

Ungrateful?

How could Fredi Condori-Hucana feel ungrateful toward this team of volunteers who had spent years trying to scrape away this curse, this “bag of worms,” as one doctor called it, that hung like a leech on his face these last five years?

They had tried to remove the tumor during a mission trip to Bolivia, then flew him to the United States for surgery.

All expenses paid. For no reason but to help a poor kid in need.

No one, least of all Fredi, could dispute their charity. He was not ungrateful.

He was just a little disappointed.

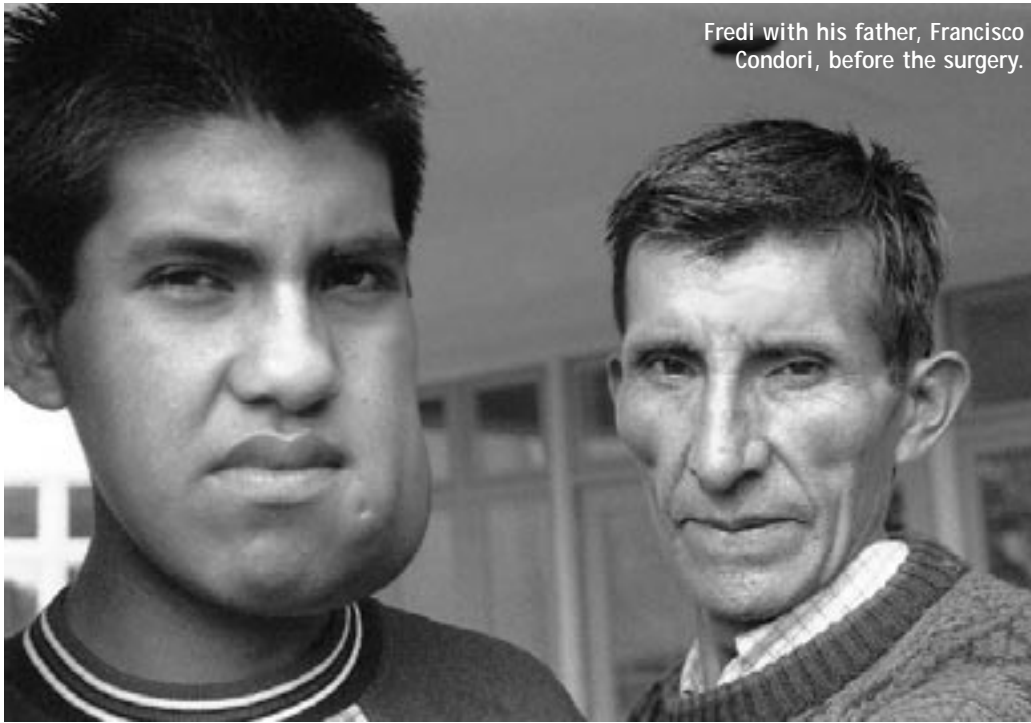
When the Delaware chapter of Operation Smile traveled to Bolivia in spring 2001, they expected to do some minor reconstructive surgery.

They met Fredi.

Fredi, then age 14, had a protrusion on his lower left cheek. It was soft to the touch and had been growing slowly. He had traveled an hour and a half by bus to see if Operation Smile could help.



Fredi Condori-Hucana at the Ronald McDonald House after surgery



Fredi with his father, Francisco Condori, before the surgery.

The doctors decided to operate. But once they opened the cheek, they found a wirey mess of engorged blood vessels tangled around Fredi's facial nerves. The medical term for the condition is a "venous malformation."

They closed him up.

When he came to, they apologized; the surgery was too complex, too outside the scope of their resources in Bolivia. Fredi had gone into surgery expecting to come out restored. Instead, the leech remained, and one more door of opportunity had slammed shut. A year later, Operation Smile returned to Bolivia. There again was Fredi, back in line for help. The bag of worms had grown.

His persistence charmed the volunteers, and the severe effects of his condition inspired them to help. But again, they lacked the capabilities to perform the surgery Fredi needed.

That's when Xavier DeCaire of Wilmington and Dr. Scott Penfil of A.I. duPont Hospital for Children, both members of the Operation Smile team, vowed to do whatever it would take to bring this boy to the United States.

Fredi, now 17, sits in a wicker chair in a bright portico at the Ronald McDonald House in Wilmington. He wears a windbreaker, hardly necessary on a warm day like this, but for Fredi, it

"I've felt ashamed," says Fredi's father. In Bolivia, a condition like Fredi's causes not pity but ostracization. Three years ago, Fredi dropped out of school to avoid his classmates' teasing.

serves a purpose. The collar is turned up, obscuring the lump that consumes the left side of his face. He props his elbow on the arm of the chair and presses his palm against the lump. He's gotten so good at hiding it that his pose looks natural.

His father, Francisco Condori, sits beside him. Petite and gaunt, Francisco looks like a rag doll. He and his family are poor, even by the standards of his country, where more than two-thirds of its people live below the poverty line.

They're also embarrassed by their son.

"I've felt ashamed," he says through Maria DeCaire, Xavier's wife, who is bilingual. In Bolivia, a condition like Fredi's causes not pity but ostracization. The Condoris have struggled these last few years against the community's prejudice. Three years ago, as the malformation grew to noticeable size, Fredi dropped out of school to avoid teasing from his classmates. For the past three years, he's been under a self-imposed house arrest.

In a few days, Fredi will have the operation that will pull out the tumor. It will

change his life enormously, he says. Once it is removed, he plans to re-enroll in school and become an engineer. He also plans to shed the windbreaker.

What about dating? I ask.

He blushes, smiles, and with his eyebrows gives a hubba-hubba.

The surgery, he's been told, should last about six hours. The doctors will open the cheek again and cut away the malformed veins that make up the lump. It won't be easy. It's not scar tissue or a cancer they're cutting away — it's working veins, which must be reconnected in the proper order. The task is made doubly difficult because the veins are twisted around Fredi's facial nerves. If one of those nerves is severed, he could lose feeling and control in parts of his face.

But Fredi does not fear the pain of surgery nor the risk of complications. He just wants the leech gone.

Fredi's surgery begins on a Monday morning in early September.

Dr. Ellen Deutch, a pediatric otolaryngologist, approaches the lump with caution. She compares it to "a handful of worms, all blood-filled, all tangled together." She's joined in the operating room by three other doctors, Jay Luft, Stephen Cook and Joseph Napoli.

In the first hour, the surgeons find the facial nerve that weaves through the knot of veins. Then they work to isolate the veins that make up the tumor. It's long work.

The operation is supposed to be completed by about 2 p.m., but at 2:45, the surgeons are still in the thick of the procedure. Francisco sits on an outside patio on the second floor with the DeCaires. He holds a blue keychain, twisting it between his fingers. Though most of the conversation is in English, he tries to follow it, smiling when everyone else does. A nurse walks out to give them a progress report.

The surgeons have freed some of the mass, but they've still got a lot of work to do, she says. Maria DeCaire translates this to Francisco, who squints his eyes, purses his lips and nods.

The afternoon drags.

At 5 p.m., three hours past the estimated wrap-up time, the surgeons are still in the operating room. The DeCaires and Francisco sit in the waiting area, pensive. Francisco flips through a People magazine. Sometimes he just places his hands back in his lap and stares at the wall.

The nurse pops in again to give another progress report.

It's going to take longer.

Francisco winces slightly.

The surgery finishes a little after 7:15, and Fredi is transported to the recovery area.

He will soon be told that the surgeons couldn't remove all of the lump.

Two and a half weeks later, Fredi is back at the hospital for the final examination by the surgeons who operated on him. It's Thursday, Sept. 25, two days before he and his father fly back to Bolivia. He sits on an exam table, staring ahead while the doctors check his scars.

The lump is far smaller now, but a part of it remains; no longer a bag of worms, but a slight slab running from below the lip and along the left jawline. Halfway to the ear, there's a modest depression.

Yet from the doctors' standpoint, the end result appears highly successful. "This was not an operation for, say, a cancer, where you have to get everything," Penfil says. "Our big concern was trying to preserve the [facial] nerve. From my perspective, that was probably the most important goal." So the surgeons removed as much as they could, until they reached a point when it was too risky to the facial nerve to slice away any more of the lump.

And at that point, they stopped.

Because a small percentage of the malformed veins remain, there will always be a bit of asymmetry to Fredi's face, Deutch says. "It's something he will always see and his family will always see, but people walking down the street won't notice." Yet the doctors knew going into the operation, and Fredi had been informed, that mild

asymmetry was likely.

Fredi, for his part, tells Norma Frier, the hospital's interpreter, that he's "so grateful." Yet the words don't match his somber eyes.

Sitting there in the exam room, he still wears his familiar windbreaker with the collar turned straight up, brushing against the now-healing ridge of his jaw.

He considers what he will say to his family when he returns to Bolivia.

He says he will try to explain away the smaller lump.

He'll tell his mother that there was still a part of the lump the surgeons had to leave, but when he gets a little older, he'll get an injection that will help shrink it.

As they listen, the doctors in the room grow uneasy. "If he was going to stay in the U.S., that is what we'd do," Penfil says. He's standing about 10 feet from where Fredi sits on the exam table. "But I just don't know that they're going to be able to do that in Bolivia."

The shrinking procedure, known as sclerotherapy, involves a series of injections to contract the remaining veins in the malformation. However, he notes, Fredi's case would require 20 to 30 injections, each spaced about a month apart, to be completely effective. That sort of treatment is all but impossible where Fredi lives, especially for a family living in extreme poverty.

Still, the doctors don't correct Fredi's assumption about further treatment.

I ask how he'd feel if he received no further treatment.

"I don't know," he says, looking down.

Fredi and his father leave for Bolivia at the end of September. "He's not excited to go home," Penfil notes. "He likes it here."

Yet Fredi does want to see his family, and he has a lot of plans for his return — things he couldn't do before the operation. He wants to play baseball. He wants to date. He wants to hang out on the corner like his friends do.

He wants to shed the windbreaker. **■**

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