Health & Medicine

The Smile Sessions

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|
Winter 2014-15

The baby with the broken face stares wide-eyed and calm, her perfectly round brown eyes floating serenely above the curling hole between her bottom lip and nose. Her image is suspended, larger than life, on a screen in a conference room at the Lancaster Cleft Palate Clinic, in Lancaster, Pennsylvania. Clinical director Andrea Smith ’05DM calls to order the weekly meeting of doctors and therapists, and draws the group’s attention to the girl’s photo.

Cleft lip and palate is a mysterious birth defect that affects one in every 575 children. The condition, which is the result of incomplete fusion early on in pregnancy, makes it difficult for an infant to swallow, clear her ears, and create the suction needed to nurse. Typically, the cleft can be corrected with a series of surgeries during childhood, but complications abound, including hearing impairments, sleep apnea, speech problems, and psychosocial issues. Cleft lip and palate is often associated with developing countries, where organizations like Operation Smile have made great strides in highlighting and combating the problem. But the incidence is the same around the world: Americans simply tend to have better and earlier access to treatment.

The Lancaster Cleft Palate Clinic opened in 1938 — the first such clinic in the world. The founder, an orthodontist named H. K. Cooper, was fond of saying, “I want to treat the whole child, not the hole in the child.” At the time, there were no other clinics in the world that allowed a variety of specialists to come together in one place — instead, different specialists typically worked in isolation to correct the multifaceted issues associated with cleft palate, often throwing one another’s work out of sync. Today, Cooper’s grandson, Ross “Rusty” Long, is the clinic’s executive director and orthodontist. The nonprofit clinic relies on private donors, many of whom are former patients who name the clinic in their wills.

Smith never intended to work with cleft palate, or even to be a dentist. “When I went to college, I started in engineering because my father was an engineer,” she says. “I liked art and science and working with my hands. My dad told me I couldn’t go to art school, so I stuck with science.” Her family dentist in Reading, Pennsylvania, offered her a job when she was fourteen, and by the time she was in high school she was taking appointments, filing records, and even cleaning teeth. She worked nights and week-ends, and full-time in the summers. By her sophomore year at Penn State, she realized she might want to be a dentist and went pre-med. When it came time to choosing a dental school, a boyfriend encouraged her to experience New York City. “I remember going for my interview and not even understanding that the dental campus was in a different place from the main campus,” Smith says. “I was so lost, but everything was so busy and exciting. My time at Columbia turned out to be the best experience of my life.”

Smith graduated from Columbia at the top of her class. Afterward, she went to UCLA for a three-year residency in advanced prosthodontics, or teeth restoration, and a consecutive one-year residency in maxillofacial prosthetics, focusing on facial restoration of cancer patients. “Often I would go to the operating room when the surgeons were taking out the cancer and I would fit the implants so they would be there when the patient woke up,” she says. The hands-on making of molds appealed to her creative side. “When I was first learning the craft, I thought — hey, this is art! I’m finally back to art!”

After UCLA, Smith wanted to return to Pennsylvania. “I’m an only child and I wanted to be closer to my parents,” she says. “I interviewed at Penn for a maxillofacial prosthodontist position and moved back, but the job fell through.” Around the same time, her second cousin happened to attend a Kiwanis meeting at which Rusty Long gave a presentation on the Lancaster clinic. “My cousin approached him after the meeting and said, ‘I have no idea if this is what she does, but my cousin needs a job.’ Rusty politely took my information. Nobody ever knows what maxillofacial prosthodontics really means, but it turned out I was exactly what they were looking for.” The clinic’s prosthodontist was eighty-two and had been trying to retire for a few years, but hadn’t found a suitable replacement. “He was a legend in the business,” Smith says, and the work he did was highly specialized. The cleft work turned out to be very similar to the cancer work Smith had been doing, and through the clinic she still performs reconstructions for cancer survivors and also for trauma victims, including many who suffer from self- inflicted gunshot wounds. The cleft-

palate clinic has an onsite lab, and Smith does a lot of her own lab work, like setting teeth for a denture or sculpting facial prosthetics for noses, eyes, and ears. “I find it very satisfying to make something fit, to be able to find a unique solution to a problem,” she says. “I thought I’d have to live in a city to be able to do this kind of work, but now I get to live a few blocks from my family. Like magic, it all fell into place, and I’ve been here five years.”

Cleft abnormalities still occur at the same rate they did in 1938, and although treatment options have grown, the road for a child born with cleft conditions isn’t much easier. “Every child in Pennsylvania is eligible for assistance with a birth defect, but often there are few doctors nearby who know how to treat cleft palate,” Smith says. Insurance presents its own hurdles; some of these procedures are considered cosmetic. “The insurance companies claim patients can lead a normal life, but what constitutes normal?” Smith says. “If you are too embarrassed to go to the corner market for milk, or to school, or to a job, how can you lead a normal life?”

The clinic is committed to serving children regardless of their ability to pay, and its patients come from twenty-five states and more than six countries. They range in age from in utero to eighteen. The clinic has two thousand active patients, including some from local Amish communities, where children with cleft are often accepted without stigma. “There is not the social pressure of mainstream society; the families often feel that their child is known in the community for the person he or she is, and the cleft palate is just a part of that,” Smith says. The Amish don’t have traditional insurance; instead, the community donates money to cover the costs of treatment.

“Many of our patients are from extremely rural areas and drive over four hours to get here,” Smith says. “We want to provide them with everything we can once they are here.” This is evident in the clinic’s weekly meeting, during which a pediatrician, speech therapist, psychologist, orthodontist, surgeon, and audiologist speak about each patient: the kids who come to get their teeth cleaned, their hearing checked, their speech measured, their ear infections treated, and their bone grafts scheduled. The doctors worry about their patients’ home life, too: bullying at school and poverty that may make it hard for a child to find transportation to the clinic.

Up on the screen, the photo of the baby with the broken face is juxtaposed with one of a ten-year-old girl with long blond hair. Her upper lip has a slight indentation, as though someone pressed a thumb there and the mark stuck. In this second photo, those round brown eyes are still wide, but she is smiling with her whole face.

It is hard to believe that this is the same girl, but as the doctors view more than two dozen patients, the before-and-after pictures are all equally stunning.

“I didn’t know exactly what I wanted to do while I was in dental school, but I knew I wanted to be the end of the line,” Smith says. “I wanted to be able to say: when all hope is lost, come to me. I’ll find a way to fix you.”

Andrea Smith ’05DM is the director of the Lancaster Cleft Palate Clinic, in Lancaster, Pennsylvania, where she practices maxillofacial prosthodontics. She is one of only 350 maxillofacial prosthodontists in the world.

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