

Twins experience a newfound freedom

Helmets allow them to take lumps without fear of danger

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By BEATRIZ TERRAZAS / The Dallas Morning News

Ahmed and Mohamed Ibrahim are resting in one bed at Medical City Dallas hospital.

Ahmed lies with his head on the pillow, and Mohamed sits facing his brother. When his father offers him a sip of soft drink from a Styrofoam cup, Mohamed throws his head back to drink, and *smack!* – his head hits the rail at the foot of the bed.

The adults clustered around the bed gasp. Then, they sigh with relief. Mohamed is unfazed. He's wearing his new protective headgear – a white two-piece helmet. And this unintended bump is exactly what the helmet was created to guard against.

"He's being a kid, and that's the glory of it," says Jeanne Pomatto, recalling that first impact. The founder and CEO of Cranial Technologies, she created the protective helmets and is excited to see that they're working.

The headgear, which weighs only 8 or 9 ounces, is the key, for now, to the formerly conjoined twins' freedom: freedom to live away from the hospital and with their family. Freedom to roll around on the floor as 2-year-olds do. Freedom to socialize and play with other children without the fear of injuring their brains, still covered only by soft tissue and growing bits of skull.

The boys were separated in October at Children's Medical Center Dallas and transferred a month later to Medical City Dallas, where they continue to recover. They face more surgeries to reconstruct their skulls, but doctors have said that with protective headgear, they can live outside the hospital. At a news briefing last month, doctors said the boys would move to an apartment near the hospital sometime in March. Last Friday, they got their helmets.

At first glance, the headgear looks deceptively simple – two molded pieces of a light, rigid plastic, a little less than a half-inch thick, that lock together with Velcro bands and that are lined with polyurethane, which looks like Styrofoam. But this one small part of the boys' care has involved people working together across three states and would have cost thousands of dollars, if it hadn't been donated.

Jeanne Pomatto has delivered the headgear herself this day.

Creating the helmets has been hard work. There is no room for error with two little boys' brains at stake.

"The No. 1 issue is how much skull is missing," she says. "There has to be a container to hold that brain without putting any pressure on the head."

In essence, she says, what doctors asked her to create was an external skull for the boys – a tall order that has turned into a labor of love for her.

"I will tell you," she says, "once you see these two little faces, how could you say no?"

Medical models

Ms. Pomatto and her staff in Phoenix, who she estimated have donated \$25,000 in work so far, have been working on the headgear with the help of plaster models provided by another company, Medical Modeling.

The Colorado company has helped the twins' doctors since the boys arrived in this country almost two years ago.

"Basically, we take medical imaging data and turn it into a physical-replica model – a model of the patient's anatomy," says Andy Christensen, Medical Modeling's president and chief technical officer. "Most times, that is the patient's bone structure."

The data are used to create a three-dimensional computer image, which in turn is used to create a life-size model.

During the twins' evaluation and treatment, Medical Modeling has created dozens of such replicas, including a full-body model of the boys, Mr. Christensen says.

"We've spent more hours and more money" on this case than on any other in the company's eight-year history, he says. The total is probably somewhere between \$75,000 to \$100,000, also all donated.

"I've gotten pulled into this case in a personal way," says Mr. Christensen, who has seen the twins several times and hopes to visit them again in the next month or two.

"We do a lot of cases, but we don't get to see the patients up close that often," he says. "It's inspiring. ... It gives me a lot of hope for a lot of these other cases. It's given me some confidence that our services make a big difference."

Every tiny curve

Several weeks ago, doctors in Dallas sent Mr. Christensen the latest CT scans of the boys' heads. The company created new life-size models that include every tiny curve and bump. Even their teeth and the raised areas where Ahmed's shunts are placed are visible.

The plaster models then went to Ms. Pomatto at her Arizona office.

Cranial Technologies has clinics in three countries and more than half a dozen U.S. states. It's best known for its trademark product, the DOC-Band, used to treat infants with misshapen heads. The bands are custom-made to apply gentle pressure where needed to reshape a baby's head.

When Dr. Kenneth Salyer, the craniofacial surgeon responsible for bringing the boys to the United States, first called Ms. Pomatto for help with the boys, she hesitated. She had never worked with twins joined at the head.

The boys' heads were misshapen from having to lie in mostly one position. Using early models from Mr. Christensen's company, Ms. Pomatto created DOC-Bands for the boys to help stop the deformity from worsening. They wore them until tissue expanders were inserted under their skin in anticipation of the separation surgery.

After the twins were separated last year, Ms. Pomatto and Mr. Christensen collaborated again. This time, she created something entirely new – headgear that would protect but not apply any pressure.

And the process has only gotten more complicated, Ms. Pomatto says.

Doctors placed shunts in Ahmed's head to drain fluid. Ms. Pomatto has had to design around them.

"There is an art form that is combined with this," she says. "I need to be able to see their face in it." Ms. Pomatto, an orthotist who has specialized in children's crania for 18 years, spent a recent weekend alone in her lab, visualizing each boy in his helmet as she tweaked the headgear on the plaster models.

She uses video clips and still photos to study how the boys move, to be sure that whatever she puts on their heads won't hinder them.

"With Ahmed, his head tilted to the side. We have to make sure he can turn his head," she says. "I try to plan ahead on all of these issues."

The biggest challenges to date have been Mohamed's skin grafts and Ahmed's shunts. There can be absolutely no pressure on these fragile spots; yet the helmets must be tough enough to protect the boys' brains in case they fall or bump into something.

'I am ecstatic'

When Ms. Pomatto arrives this morning and puts the headgear on the boys, they look at each other. They giggle. They play with their therapists for more than an hour, and they don't seem to be bothered by the helmets.

The boys' mother, Sabah Abu el-Wafa, holds Mohamed in her lap while Ms. Pomatto and Egyptian nurse Naglaa Mahmoud lay Ahmed down in his bed. He immediately begins touching the smooth plastic around his head. A few minutes later, he takes a toy keyboard and taps it against the helmet. Appearing satisfied with the tapping sound of plastic on plastic, he puts the keyboard down.

Ms. Pomatto shows the nurse how to remove the helmet. "It's easy," she says. "Open, and just lift away."

Ahmed's brown curls are damp with sweat, but there are no signs that the helmet isn't a perfect fit.

"I am ecstatic," says Ms. Pomatto.

Other children bump their heads hundreds of times in the process of growing up and exploring their world, she says. Until now, Ahmed and Mohamed have never had that kind of freedom.

"Now they can bump their heads and nothing's going to happen," she says.

Ms. Pomatto shows Mrs. Abu el-Wafa how to place the parts of the helmet on the boys, one section at a time, aligning the headgear's contours with the head.

When father Ibrahim Mohamed Ibrahim arrives at the hospital for the first time today, his sons peer at him from inside the helmets. Mr. Ibrahim smiles broadly and immediately begins touching Ahmed's head. He bends down and kisses his son.

"Thank you!" he tells Ms. Pomatto in English.

Through the Egyptian nurse, he tells Ms. Pomatto that she has given them a tremendous gift.

"Now I feel safe," he says.

