

# The Boston Globe

## The chance of two lifetimes

### Hub doctor's trip draws Haitian baby here for vital surgery

By Carey Goldberg, Globe Staff | November 3, 2008

Dumanel Luxama began his life in rural Haiti doubly unlucky. He was born with a rare deformity, a hole in his skull that let his growing brain bulge outward into a lump between his eyes as big as half a tennis ball. And an even larger cyst, swelling unseen inside his brain, threatened to suppress his vital functions and kill him.

But when he was just a few months old, Dumanel's luck began to change. Many in his family held old folk beliefs about health: They thought Dumanel's lump might have been caused by his mother's cravings during pregnancy, or an evil spirit. But his father, Almane, believed in Christianity and Western medicine. He sold his only two cows to seek the best possible help for his son.

A 14-hour bus ride from their dirt-floored house last March brought the two to a hospital in the town of Hinche. It lacked all but the simplest medical instruments, but Operation Smile and Partners in Health, both nonprofits famed for providing free health care to poor people around the world, were sponsoring a special clinic for cleft-lip patients that week.

Dr. John Meara, chief of plastic surgery at [Children's Hospital Boston](#), happened to be volunteering when Dumanel arrived and easily identified the lump that would have mystified most doctors. It was called an encephalocele (en-SEF-a-lo-seel). He had treated them in Australia, even written papers on them. They were not just unsightly, they were dangerous. Dumanel needed major brain surgery.

"We can't do this here," he said.

Partners in Health handled the red tape; Children's donated money, time, and venue. On Aug. 21, Dumanel lay at Children's on one of the highest-tech pediatric operating tables in the world as Meara and colleagues, working for free, re-engineered his brain and skull in a concert of neuro- and plastic surgery. Only in the last few years has such a complex operation become feasible, he said.

What once would have taken 24 hours was over in eight, and Dumanel was out of the intensive care unit a day or so later. Now, he bears a scalloped line of faint scars around his head and a light line across his nose, but he is crawling and pulling himself up on chairs to stand like any near-toddler and has moved on from "Ooohh," his only sound before the operation, to "Da da" and "Ma Ma."

On Tuesday, Dumanel and his father will leave to return home to their small farming community on Haiti's Central Plateau.

"Now he can start on his road in life," Luxama said gratefully during a recent follow-up visit to Children's.

Dumanel is one of only about a dozen Haitian children who have been brought to the United States for surgery this year, said Dr. David Walton, a Partners in Health physician who helped get Dumanel to Boston.

"There are literally hundreds and hundreds of these kids out there," many with congenital heart defects whose problems are never detected until it is too late, he said; others are diagnosed but still die of

diseases that could be treated with surgery. Haiti has the highest infant mortality rate in the Western hemisphere: 62 out of every 1,000 live births.

Meara emphasized that while Dumanel, of course, benefited from his medical care, so did the doctors who provided it: His case offered trainees a valuable opportunity to learn about the care of a rare anomaly and observe skills and strategies that can be applied in future complex cases.

"It's good at both ends of the airplane," he said. "It's really important to have these kinds of cases" at an institution of top specialists like Children's, "so when the next case comes along, clinicians have the experience and knowledge" to handle it.

Dumanel's surgery involved several procedures, each one of which would be considered a major operation, said Children's neurosurgeon Ed Smith. "It was a real skullbuster - no pun intended - to put together the steps and sequence of events," he said.

It was the encephalocele that brought Dumanel to Boston, but once he arrived, a routine brain scan showed that the right side of his brain had been all but taken over by an arachnoid cyst, a great bubble of fluid surrounded by spider web-like tissue that normally lines the brain to protect it.

His doctors "got the scan and said, 'Holy Moly, this is not what we were expecting at all!' "Walton said.

Smith and Meara first had to decide whether to operate on the cyst and the encephalocele at the same time. The entire neurosurgery department discussed it, Meara said, and decided it made sense.

Smith went first, to tackle the fluid-filled cyst. Imagine, he said, a big balloon, "filled with water and plopped in the kitchen sink," blocking the drain. "What we did was cut the dome of the balloon away, so there was a big pop and the fluid came out, but there is still rubber sitting over the drain at the bottom of the sink."

The fluid couldn't drain away without a second step. Using a microscope to make sure he was preserving important tiny parts of Dumanel's brain, such as the optic nerve, he created a new drainage system so fluid could flow properly down into the brain stem and spinal cord's drainage pathway.

Then Meara and Smith focused on the encephalocele, cutting away the pale, non-functional brain tissue that bulged out of Dumanel's face and repairing the dura, the brain's lining. With the lump gone, Meara had to rebuild Dumanel's skull. He moved pieces of it around and fit them together like an anatomical jigsaw puzzle. He created a nasal bone and new forehead bone for Dumanel where the encephalocele hole had been and moved Dumanel's eye sockets closer together.

Where gaps remained, he filled them in with fragments of bone. In this, a baby's skull is far superior to a jigsaw puzzle: Once the pieces are in place, they will eventually fuse together into a smooth whole. In older patients, there is no such fusing.

In general, Dumanel's risk for complications was high, from a surgical glitch to an infection. But Smith and Meara sound like they are pinching themselves as they report on Dumanel's health to date. "I'm just pleased as punch with how he's done," Smith said. "I'm hopeful that he will have fully normal function as a completely normal kid when he grows up."

Dumanel's left side remains slightly weak from the cyst, but "I'm sure with some therapy, he'll be fine," said Dr. Hermide Mercier, who has been hosting Dumanel and Almane at her Brockton home as Dumanel recovers.

"He's moving more than he used to," she said. "Now he's all over the house, pulling himself up. That's a big change."

"Da da da!" said Dumanel, who turned 1 in September. "Ba!"

Almane, 27, has been calling Dumanel's mother, Louisinette, every day, he said, "and she practically shouts, 'Come home!' "Dumanel is the couple's only child.

Last Wednesday, Meara checked over Dumanel for the last time and began to arrange for follow-up care through Partners in Health's Haiti clinics. "When you want to go home," he told Almane in Spanish, their common language, "it's possible."

Almane looked upward: "I thank God first," he said, and then looked at Meara, "and you second."

Almane hopes Dumanel will grow up to help him work on his leased farm, where he raises rice, corn, and potatoes.

"Before, he couldn't do anything," Almane said, "Now, he can do what he wants."