

Treatment is a miracle to parents, an experiment to state

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MIAMI - If only it hadn't been a cloudless Memorial Day weekend, and Miguel Angel Lorenzo's brother and cousins hadn't removed the mesh fence from the pool. If only it hadn't suddenly rained, and the boys hadn't dashed in the house and left the back door ajar just enough for an infant to squeeze through.

If only one of Miguel's cousins hadn't removed him from a playpen _ and then left him on the floor _ Miguel would not have toddled into the pool, where he floated for four or five minutes.

That's all it takes to deprive an infant's brain of enough life-sustaining oxygen to nearly kill him.

Now 28 months old, Miguel _ the baby who had just learned to say "Mama" and "Papa," but still pointed to things he wanted _ lies prone in a hospital bed that dominates his nursery, all tubes and chirping machinery. He breathes with a respirator most of the time. He is fed through an opening to his stomach.

His parents, Juan Carlos and Yusimy Lorenzo of Davie, Fla., believe they can help Miguel get better by using a medical procedure originally developed to cure the life-threatening effects of decompression sickness.

If only the hourlong treatments were not hideously expensive and, by conventional medical standards, untested.

They want the state's Medicaid insurance program to pay for the costly hyperbaric oxygen treatments _ but the state, saying the treatment is experimental, has refused. So the Lorenzos are paying for Miguel's treatments themselves _ as they fight the government in court.

The state Agency for Health Care Administration (AHCA), which oversees the program, argues hyperbaric oxygen therapy is unproven _ and, thus, a poor use for precious state healthcare dollars, particularly during dire economic times. Florida is expecting a \$3.5 billion budget shortfall for next year.

The dispute, ultimately, will be decided in court, where a three-judge panel of the Fourth District Court of Appeal in West Palm Beach is reviewing written arguments.

"This is the first time I've encountered something I can't fix," said Juan Lorenzo, 35, a former U.S. Marine who was a teenager when he arrived in South Florida from Cuba during the 1980 Mariel boatlift.

Now a technology director for a healthcare company, Lorenzo added: "It would be foolish to say Miguel can get back to where Miguel was; I'm not blind. But I will,

without doubt, get Miguel to a better lifestyle that he can appreciate."

The oxygen treatments, Lorenzo believes, are his son's only chance. "Technology doesn't offer me anything else."

Through a spokeswoman, Shelisha Durden, the healthcare agency declined to discuss Miguel's case, citing the ongoing litigation.

But at an October administrative hearing, an AHCA official said the agency is not allowed to spend taxpayer money on unproven treatments.

"Hyperbaric oxygen is not a covered service for the diagnosis of this child, which is a hypoxic brain injury," Lisette Rodriguez, who administers the state Medicaid program in Fort Lauderdale, said at the October hearing. "It is experimental, and therefore service is not covered by Medicaid."

Dr. Nina Schor, a pediatric neurologist at the University of Rochester Medical Center who is president of Professors of Child Neurology, told The Miami Herald: "There is no study that is sufficiently powered, and sufficiently consistent and well-articulated ... to draw any conclusions at all about this."

Susan Pisano, a spokeswoman for America's Health Insurance Plans, said insurance carriers have good reason to insist on scientific evidence that medical procedures work: "Demand for evidence today is, first and foremost, a patient safety question," she said, adding safety risks only emerge during rigorous testing.

"As a general rule, what drives (insurance) coverage is evidence that a therapy or service works to achieve a desired outcome," Pisano said.

The state's unwillingness to pay for the "dives," which cost \$200 for each hourlong session, has not hindered the Lorenzos, who are scraping money together to pay out-of-pocket. Their lawyers at the Florida State University law school's Public Interest Law Center adopted the family's cause after watching videos of Miguel.

"Tears came to our eyes," said Paolo Annino, an FSU law professor who leads the program. "At that moment, our class discussion changed. This was no longer a purely academic exercise on sophisticated Medicaid law, but a class committed to helping Miguel."

On a recent Tuesday morning, Yusimy Lorenzo, 32, carries a limp Miguel from her car to a waiting stroller at Ocean Hyperbaric Neurologic Center. Bundled in a white blanket against a rare morning chill, his hands remain clenched in front of him, as they've been since the accident.

Miguel's nose oozes mucous, and he gurgles as his ventilator has been unplugged for several minutes. His nurse, Elionore Jean-Jacques, suctions the little boy's nose. Yusimy reattaches his respirator, and the gurgling ceases, replaced by the soft hum of the breathing machine.

Throughout it all, Miguel stares forward. Pale blue medical sheets stretch crisply across a thin mattress inside the hyperbaric chamber, a model that is about a half-century old _ but serviceable. Yusimy gets comfortable inside the chamber, and Jean-Jacques places the toddler inside his mother's arms. Dressed in a Cars baby

shirt, Miguel lies still.

The chamber looks like a beige, slightly flattened missile, with a transparent bubble at one end large enough to allow Yusimy to sit up slightly. She brings a resuscitation bag, for emergencies, a small bell-shaped suction and a blanket into the chamber. She's wearing a cotton blouse and pants, and no bra or deodorant _ elastic and chemicals are forbidden in the pure, pressurized oxygen.

Yusimy used to be petrified of small spaces. "I either had to sacrifice my fear, and overcome it, or Miguel couldn't come here at all," she says. "Now, this is second nature."

Yusimy wipes a tiny tear from her son's cheek.

A technician, Dale Wells, slides shut the lid of the chamber and raises the pressure on a set of controls. Moments later, observers in the clinic can barely hear Yusimy sing "Row Your Boat" to her little boy as she gently moves his arms in a rowing motion.

After an hour, Wells depressurizes the chamber. Inside, Miguel is gurgling loudly again, and Jean-Jacques suctions his nose and the hole in his neck where the ventilator attaches.

After Miguel's 10th dive, he opened his eyes for the first time, and they remain open much of the time now. Since then, Yusimy said, he's tried to lift his head, begun to track sound and movement around him and shown greater flexibility in his limbs _ all minor miracles to his parents.

Yusimy smiles faintly. "Little by little," she says, "he's started to do so much that we didn't see until he started in the hyperbaric chamber."

She will return the next morning to repeat the ritual _ as she's done 95 times already.

"I would rather have him like this than not have him at all," Yusimy says. "As hard as this journey is, there's always hope."