

San Angelo boy gets help to stand, walk

New orthotic system aids independence, self-esteem

By Ami Mizell-Flint

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SAN ANGELO, Texas — Julia Pedroza held out a cracker for her 3-year-old son, Ismael, to reach for, taking one step at a time. While this task would be an easy one for many children his age, Ismael's steps are marks of huge progress, with the help of new technology.

Ismael is one of two patients at the West Texas Rehab Center using a new orthotic system designed to help wheelchair-bound children walk independently, and he is one of more than 1,000 pediatric patients using the device around the United States.

"For the first time in his life, he's able to stand up and see his mom on the other side of the room," said Eric McLarty, an orthotist at WTRC.

While progress is slow and often painstaking, McLarty and Pedroza are excited about the opportunity the new Therapeutic Ambulatory Orthotic System — TAOS — offers to Ismael and others like him.

Ismael has been a patient at WTRC since he was three months old and diagnosed with a chromosome abnormality named 1p36 deletion syndrome, a rare birth defect that affects between one in 5,000 to one in 10,000 births.

While the disorder has different levels of severity, distinctive symptoms include physical and intellectual disabilities. In Ismael's case, he cannot support his weight without assistance. He can take steps while being supported but he has a "scissor gait" in which his legs cross in front of each other as he steps.

The TAOS addresses both of those issues. The child is placed into a fitted body harness, which is then attached to a metal pole on a wheeled base. This provides body alignment for children who could not otherwise stand upright alone, and allows for proper posture and leg position.

Enabling children who could not otherwise to stand upright provides more independence, allows them to participate in activities and exercise they normally could not take part in, and provides a new self-esteem, a DVD featuring TAOS said.

"He's firing his knee extensors good today," McLarty said at a recent therapy session, "and activating a lot of the muscles needed to walk.

"This is the first time he has had the independence to do that," he said.

"The biggest problem with children who are restricted to wheelchairs is that their bodies

don't work well if they are not upright and ambulatory," said Todd Tyrell, a mechanical engineer and president of Sky Medical Inc., which designed the TAOS.

Tyrell said there are currently three base sizes to accommodate children as they grow. He said a physical therapist brought the concept to his company, but was having some problems with it. He called on his brother, also a mechanical engineer, to work with physical therapists to perfect the design.

Currently, he said, the largest base fits children up to five feet tall and 120 pounds.

"We are working on a larger base," Tyrell said, which would fit people up to five feet, eight inches tall and about 160 pounds, but have to be wary of tipping issues.

Depending on how reactive the child is in the unit, the body level of the child can be raised or lowered to enable progression in the TAOS.

The design of the TAOS "keeps his scissoring gait straight," McLarty said of Ismael, "so he can focus more on moving forward."

After working daily with TAOS for about two weeks, Ismael was able to independently move about six feet in about 20 minutes, to the delight of McLarty and Ismael's mother and grandmother.

"Inches are yards in this game," McLarty said.

"The cool thing," he said, "is that he can stand up looking at his parents, instead of them being behind him holding him up. That gives him the freedom, and an independence he's never had before."

Ismael is a typical 3-year-old, however, and sometimes will not cooperate when being placed in the system.

"If he starts fighting when we're strapping him in, it's a no-go," said Ismael's grandmother, Cynthia Morales.

Although he has those days occasionally, Pedroza said he usually "wants to go."

"Every time is just a little bit better," she said.

Aside from the TAOS, the only other freedom he has is doing an "army crawl" on the floor, Pedroza said.

"We want to give him every opportunity to get him to walk," she said.

The motivation Ismael displays trying to walk is what McLarty said made him a good candidate for the TAOS.

"It's kids like that that make it worth getting up in the morning," he said.

Although still a fairly new product — it was developed about five years ago — the TAOS is slowly gaining recognition. Most insurance companies cover most, if not all, of the cost for the device, McLarty said.

"It's still a hidden secret," McLarty said. "We want to help all those kids out there. We want parents to know what's available to the kiddos that hasn't really been there

before."

"I used to think, when is my son going to have the opportunity to learn to walk?" Pedroza said. "I think this is the answer. If it wasn't for Eric (McLarty), we wouldn't know about it at all."

"I couldn't be more pleased with his progress in just two weeks, McLarty said, "I can't wait for the next two months."



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