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Treatment creates potential for children with cerebral palsy

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With a whir of wheels on wood, 4-year-old Matt Cooper flies around the corner sporting an addictive grin.

His mother, Laura Cooper, watches as the boy sprints past in his blue gait trainer, a wheeled walker-like device for helping children with mobility. Occasionally there is a small bang, but the gait trainer is designed with bumpers on all sides to protect the child.

The walls aren't so lucky.

"He'll get some speed coming around this corner and leave some pretty good dents in the walls," Laura says.

She moves a potted plant out of Matt's route, revealing a large gash in the wall behind it that appears to be the same height as his bumpers. Yet the structural damage doesn't seem to faze the mother of three. It's a small price to see her youngest achieve mobility.

A uterine rupture during birth left Matt without oxygen for a time. The resulting brain damage left Matt with cerebral palsy, a broad term used to describe a group of chronic disorders that impair control of movement.

It is a non-progressive brain disorder, according to WebMD.com, so the damage does not worsen throughout life. There is, however, potential for improvement.

Laura and her husband, Ken, discovered an organization that could help Matt live a fairly normal life through intensive physical therapy.

Just a year ago Laura says Matt was not thriving. At age 3 he was unable to sit up and play without

assistance. In the past year they have made three visits to Now I Can, a nonprofit organization in Provo dedicated to helping children with disabilities reach their greatest potential.

"It just made him stronger overall," Laura says. "His last session there he took four steps all by himself."

'Miracle' babies



Seeing the progress Matt has made gives hope to Curtis and Kenna Seegmiller. Their daughter Abigail, a 1-year-old twin, also has cerebral palsy and is meeting with therapists at Now I Can for the first time today.

At 21 weeks, doctors told Kenna her unborn twins had a rare uterine disease where they shared a blood vessel than enabled twin-to-twin transfusions. These movements of blood between the twins could cause one or the other to hemorrhage.

Abigail was twice the size of her twin, Emrie, and the doctors were concerned that Emrie might have heart failure. The twins were born three months early via cesarean section.

Abigail came out at 2 pounds 9 ounces, but pale white. Emrie was 1 pound 13 ounces and "flaming red."

Curtis says they think there was a last-minute blood transfusion from Abigail to Emrie that saved Emrie's life. They also suspect the trauma that saved her twin's life caused Abigail's cerebral palsy.

One doctor told them Emrie shouldn't even be alive. Yet she's a normal, but small, 1-year-old girl.

"They're definitely a medical miracle," Kenna says.

The difference in the twins is obvious, though. While Emrie plays, takes long drinks from her bottle and even walks a few steps with assistance, bespectacled Abigail lies on her stomach and watches her twin.

Curtis says Abigail, like many children with cerebral palsy, is easily worn out. Even the simple act of holding her bottle can be tiring for the infant. Her father says she seems to get frustrated that she can't do the same things as Emrie.

"It's been interesting seeing her twin who doesn't have CP," he says.

Neither Abigail nor Matt have any mental disabilities, though Laura says they haven't yet ruled out learning disabilities for her son. Because cerebral palsy disrupts motor skills, Matt is unable to communicate in the same manner as most children his age. Abigail wears glasses because the motor skills disorders have caused the muscles in her eyes to tighten.

Relentless fundraising

As Abigail travels to Now I Can for the first time it's likely she will be one of the youngest patients there. Her parents are eager to help their child develop as quickly as possible.

The cost, however, is prohibitive for some. The therapy costs \$100 per hour for a four-hour session, five days a week. The Seegmillers will be there for three weeks this first visit. That's \$6,000 for just the first trip north.

Curtis works as a plumber but is also going to school at Dixie State College. In addition to the twins, the couple also has a 3-year-old girl, Elizabeth.

They have had fundraisers to pay for the visit, but they know many more visits are in their future. They also know it's essential to give their daughter the best chance to live a normal life.

"I think taking 'no' for an answer is not an option," Kenna says. "It's relentless trying to fundraise."

The Seegmillers say their Church of Jesus Christ of Latter-day Saints ward has rallied around them, donating items to multiple yard sales in order to raise funds for the visit. They have another yard sale coming up later this month after they return from Provo.

Laura understands what the Seegmillers face. Her family even organized a golf tournament to raise money for Matt's visits. When they return home after each visit with a report card that shows how much he has improved they are excited to return to Provo again.

"You walk out of there and think, 'Whatever it takes I'm going to get my child back into (the therapist's) hands,'" Laura says.

However, Laura understands that it is different for each child and there is no guarantee that each child who receives the treatment will be able to walk.

Therapy

Laura says the therapists at Now I Can fit each child with a neurosuit - an orthotic device designed to control body segments and facilitate body movements, according to Now I Can literature. The suit incorporates hooks and bungee cords to produce a variety of effects, including proper body alignment, correction of deformities, facilitation of correct movement patterns and increased muscular contraction.

In addition to therapy in the suit, the organization also offers hyperbaric oxygen treatments, which increases atmospheric pressure to allow the body to incorporate more oxygen into blood cells, blood plasma, cerebral-spinal fluid and other body fluids.

Laura says children with cerebral palsy have a lot of potential if they receive the right therapy. Matt's own pediatrician even has cerebral palsy. She applauds the Seegmillers for taking Abigail at such a

young age because it will put her that much further ahead in her treatments.

They will also return home with a personalized workout for Abigail.

"We're really excited about going up," Kenna says. "We're so lucky we don't have to go to Poland for this."

In the past, many children in the United States had to travel to Poland for treatments similar to those now found at Now I Can. The organization's pamphlet says intensive physical therapy for children with disabilities is a "relatively new idea in the United States."

Kenna says she hopes to create a greater awareness of the options available for children with cerebral palsy. She also wants to emphasize that the treatments are therapy and not surgery.

Although having a child with cerebral palsy is challenging, Laura says it has also been a good learning experience for her two older children, Kenedi, 12, and Ben, 8.

"It is a real blessing because it makes your children much more aware of other kids with special needs," she says.

Visit www.nowican.org for more information on the Now I Can organization.