

For little girl, a struggle to eat, grow

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As psychologist working in the pediatrics center at St. Peter's University Hospital in New Brunswick, Amy Kavanaugh of Hillsborough knew about children in need.

She was a 40 year old, single and successful and had been working for victims of abuse and neglect for most of her career. She felt the desire to do something.

Little did she know she was about to embark on the experience of a lifetime.

First, she was certified as a foster parent and a foster-adoptive parent. Then, through Harvest of Hope Family Service Network in the Somerset section of Franklin, she learned about the so-called "boarder babies" - children of abusing mothers forced to "board" at a hospital until a foster home can be found.

"I was not necessarily interested in special needs, but I was willing to accept drug-exposed child," Kavanaugh said.

Enter a 5-pound infant with no name, who had been born traumatically one month earlier (at 4 pounds) at University Hospital in Newark with fetal exposure to heroin, cocaine and methadone. The resulting brain damage (cerebral palsy, global developmental delays and a sensory disorder) made the little girl's future uncertain at best.

Kavanaugh had asked for a baby girl, up to 3 months old. The caseworker asked her if she would consider a baby with special needs. She said yes.

Her new daughter

She named her Emily.

"I didn't know all the issues," Kavanaugh said. "I'm glad they didn't tell me. I might have said 'wait a minute and would have missed out on Emily'"

Kavanaugh admits the past four years have been an uphill battle bordering on frustration, but she has persevered.

Emily qualified for the early intervention program in Somerset County where she received therapeutic services and physical therapy.

Early on, Kavanaugh was able to feed Emily from a bottle.

"She moved around in my arms," Kavanaugh said. "It was trial and error. I found it worked best with her back straight up."

But at 18 months, Emily developed problems with swallowing, typical for the neurologically impaired. She was aspirating liquids and had to have a tube inserted.

Last year, Emily was able to undergo speech-feeding therapy at Penn State's Intensive Feeding Therapy Program, where children attend feeding therapy sessions all day long for five weeks. After those sessions, Emily was able to move her tongue and eventually eat on her own, so the tube could be removed.

Emily did not sit independently until she was 2, and she did not start crawling until she was 2 1/2. To help with the latter, Emily received hippotherapy from Somerset Hills Handicapped Riding Center in Oldwick.



With the child on horseback, the animal's multidimensional movements approximate the movement of the pelvis during crawling.

"Within a couple months, Emily started to crawl," Kavanaugh said.

In 2005, Emily became available for adoption. The adoption was completed in October of last year. Now, five months away from her fifth birthday, Emily is ready to take her next step.

An aggressive approach

Wanting an aggressive approach to help her daughter gain more functional skills, Kavanaugh took to the Internet. There she found Euro-Peds National Center for Intensive Pediatric PT (www.europeds.org), a nonprofit hospital-based clinic in Pontiac, Mich.

The program was established in 1999 as the first clinic of its kind outside of Eastern Europe, where the concept of "suit therapy" and the universal exercise unit had its beginnings.

The clinic, part of North Oakland Medical Centers hospital (www.nomc.org), specializes in treating children and young adults who have neuromuscular disorders, including cerebral palsy, spina bifida and traumatic brain injuries.

Emily now has just completed her second week in the clinic's most intense program – 20 hours per week over four weeks, or a total of 80 hours of intensive physical therapy over one month.

The intensity of the sessions allows specially trained therapists the time to create strength, balance and coordination through repetition and therapy tools.

Suit therapy is an Eastern European-inspired tool that developed out of the design principles applied to Russian cosmonaut's spacesuits. The inside of the spacesuit provided compression while the cosmonauts were in space for extended periods.

The suite prevented muscle loss and bone demineralization when there was no gravitational pull to create compression naturally. This concept eventually was applied to patients with neuromuscular disorders, such as cerebral palsy, and stroke victims.

Kavanaugh said she has seen improvements already. At home, Emily would stay in her toddler bed until someone came for her. But in Michigan, she has already climbed down out of her full-size hotel bed.

While Euro-Peds participates in most major insurance plans, suite therapy is not covered, because it is still considered investigational in the United States.

The cost for four weeks of therapy is approximately \$12,000, not including travel and food expenses.

Helpful friends

That's where family, friends and community support continues to play a major role in meeting the expenses for Emily's therapy.

"It seems a lot of people love Emily," Kavanaugh said. "They seem to be drawn to her and want to help her."

Harvest of Hoppe has donated to Emily's charitable account.

Diana Stock, a friend of Kavanaugh's from Hillsborough, last week hosted a Lia Sophia jewelry fundraiser at the Raymond Salon and Spa (Kavanaugh's hairdresser) in the Somerset section of Franklin, donating 10 percent of the proceeds to Emily.

Care to Share, started by Tina Rear, a Hillsborough resident who has a son with autism, provides monthly support group meetings for parents of special needs children, as well as a list of services and other activities that provide education and opportunities for networking and sharing of information.

St. Peter's, too, was involved in getting Emily to Euro-Peds, allowing Kavanaugh to take unpaid family leave.

Emily's pediatrician, Dr. Gladibel Medina who works at St Peter's, has been "an invaluable source of advocacy and guidance in my quest to obtain services for Emily," Kavanaugh said. In addition, many of Kavanaugh's colleagues have donated to the fund.

In May, Linda Vandorn of Bridgewater, Kavanaugh's former teammate (and opponent) in the U.S. Volleyball league, will organize a volleyball tournament to benefit the Emily fund at the Raritan Athletic Center in Flemington, owned and operated by Richard Drake.

And Emily was also awarded a \$1,000 scholarship from the North Oakland Foundation (www.northoaklandfoundation.org).

Emily, whom Kavanaugh calls "my ray of sunshine," attends the Jerry Davis Early Childhood Center in Manville.

"She's as happy as the day is long," Kavanaugh said. " She has a wonderful temperament. She just rolls with it. She's a wonderful little girl."