

Family of Keller Navy pilot works to help disabled daughter

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BY ALEX BRANCH

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KELLER -- Her mother tries to zip her jacket against the January cold, but Kaitlyn Samuels squirms in her arms, impatient to reach the horse inside the riding ring at Rocky Top Therapy Center.

Kaitlyn is 16. Her torso is contorted by severe scoliosis. She can't speak and is unable to walk or eat without help.

A major, rare brain malformation stunted her cognitive development and, without therapy, her spinal problems could lead to surgery or death.

After years of treatment in clinical settings, Kaitlyn had grown uninterested and simply stopped participating. She usually wouldn't even try to sit up by herself.

But when placed atop a horse, Kaitlyn is transformed, according to her parents, Mark, a U.S. Navy pilot, and Jennifer Samuels of Keller.

She is eager to begin her twice-a-week sessions with physical therapist Suzanne Sessums, who guides her through exercises designed to straighten her spine.

"If we tried to do these same exercises on a therapy ball, she would start to shut down," Jennifer Samuels said. "I still do not think she realizes she is getting physical therapy out here because she just sees this as fun. It's the only thing that works."

But the therapy that has captivated Kaitlyn is also the source of a 2 1/2-year battle for benefits with Tricare, the U.S. Department of Defense's health-care program.

Tricare considers the therapy unproven and has declined to pay for it. Kaitlyn's treatments total a little more than \$8,000 a year, and the Samuelses plan to continue them with or without insurance help.

But they said they are fighting for principle: a benefit that Mark Samuels has earned through his service to his country.

Tricare paid for Kaitlyn's more traditional therapy for years, and the coverage continued for months after she started treatment at Rocky Top in 2009, Jennifer Samuels said.

In 2010, the family learned not only that Kaitlyn's treatments were no longer covered but that they had to repay \$1,300 in costs already incurred.

The treatment, known as hippotherapy, has not proved to be safe or medically necessary for her condition, Tricare contends.

The company's stance isn't unusual among insurers. Hippotherapy is commonly considered experimental, according to America's Health Insurance Plans, an industry trade association.

Still, after months of coverage, the news came as a shock to the Samuels family.

"They had all the notes about Kaitlyn's treatment from the beginning," Jennifer Samuels said. "We just thought this must be an error, and we would just go down the appeals process and get it corrected."

The family did appeal, hiring a lawyer and landing a court hearing last February. An administrative law judge ruled that Tricare should cover the therapy. But the decision was nonbinding and, in October, Tricare Management Activity, which manages the Tricare program, issued a final ruling rejecting the judge's opinion.

But the Samuelses aren't finished fighting. Last month, the law firm of Akin Gump Strauss Hauer & Feld L.L.P. took their case pro bono.

The case piqued the interest of attorney Marcella Burke, who said she wanted it in part because she comes from a military family.

Burke said she plans to appeal Tricare's decision in federal court.

"Our military serve nobly in some of the most difficult situations our world has to offer," she said. "We cannot accept anything less than the best possible health care for them and their families."

'Strange therapy'?

Doctors discovered Kaitlyn's brain malformation when she was about 7 months old. Her symptoms include seizures, feeding problems and difficulties holding herself erect, let alone sitting, standing and walking, according to documents in the case file.

Her mental level remains that of a toddler.

Without therapy, Kaitlyn's scoliosis would cause her spine to continue to curve, compressing her organs and eventually leading to surgery or death, according to filings by Colby Vokey, the attorney who handled the family's first appeal.

Because treatment in a clinic was no longer working, Kaitlyn was moved to Rocky Top, a ranch that provides rehabilitation for people with physical, mental or emotional challenges.

Leading the horse in certain directions or bending Kaitlyn backward in the saddle works her muscles to reduce the curve in her spine and stretch out her legs, said Sessums, Kaitlyn's therapist.

The cost is \$80 for each 30-minute session.

"When we put her in the clinic or therapy room, she will not hold herself up," Sessums said. "When we put her on the horse, she will sit up and we do not have to assist her at all."

Mark Samuels' benefits covered part of the therapy for a time, with the Samuelses chipping in about \$25 per session. But, by November, problems arose

Tricare asked for more documentation. The Samuelses, who also have two younger children, continued taking Kaitlyn to her treatments, believing that the coverage would eventually continue.

Finally, the company explained that the treatment would not be covered, and that the family had to repay the benefits already used, Jennifer Samuels said.

In their appeal, the Samuelses and their attorney argued that the treatment was physical therapy, just as Kaitlyn would receive sitting on any dynamic surface, such as a therapy ball. The horse was merely a different tool on which to perform the exercises, they said.

Sessums, they pointed out, had 13 years' experience as a physical therapist.

"Basically, what they said was that, because she does this on a horse, it can't be physical therapy," Jennifer Samuel said. "If you put her on a ball, it's OK. If you put her on a horse, it's not. It all seems so ridiculous."

In response to an inquiry by the *Star-Telegram*, a spokesman for Tricare said privacy laws forbid the company from discussing the healthcare of a particular beneficiary.

The appeals hearing was held last year in a Dallas courtroom. It was covered by the *Dallas Observer*, which first reported the family's situation.

Sessums and Kaitlyn's pediatric neurologist were among those who testified.

In his written ruling in favor of the Samuelses, the judge noted that Kaitlyn's therapy was not more expensive than traditional therapy because Rocky Top provides the horse and the volunteers.

He asked why, if physical therapy was allowed on a ball or in a pool, did it suddenly become "some alternative, strange therapy" when performed on a horse.

Using the horse was more beneficial to because Kaitlyn did not cooperate in a different therapy setting, he concluded.

"It would be a waste of the government's money to pay for therapy in a traditional setting, for it would provide no benefit to the beneficiary," he wrote.

More than money

The Samuelses are not the first to encounter problems with an insurer over therapy performed on a horse, said Sharon Gilbert, program coordinator for the American Hippotherapy Association. One of the organization's goals is to increase acceptance of the treatment through education.

The association defines hippotherapy as "a physical, occupational, and speech-language therapy treatment strategy that utilizes equine movement as part of an integrated intervention program to achieve functional outcomes."

"The crux of the argument should be: Was the girl improving?" Gilbert said. "Was there a medical difference in her condition as a result of her therapy regardless of the device used? If the answer is yes, they should be entitled to bill insurance for it."

Jennifer Samuel said she and her husband have repaid the \$1,300. She said she believes that Medicaid would cover the therapy but, because her husband's career requires the family to move often, they are never in a state long enough to work their way up the waiting list.

Kaitlyn missed several months of therapy as a result of the lost coverage. Then, Rocky Top received a grant that paid for her treatments until this year.

A horse breeder learned of the family's situation and offered to pay for another year of Kaitlyn's therapy.

Jennifer Samuels said the family was grateful but asked that his donation be split among Kaitlyn and several other children at Rocky Top.

The case is about more than money, she said. The Samuelses have already spent about \$5,000 on legal expenses, more than they were required to repay.

"The point is that this is part of my husband's benefits; he shouldn't have to pay it," Jennifer Samuels said. "He has earned it."

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<http://www.star-telegram.com/2013/01/18/4559119/family-of-keller-navy-pilot-fights.html>