

*Kaitlyn Samuels. Provided by Ali Wood Photography.*



AS A U.S. NAVY PILOT, Captain Mark Samuels is no stranger to battle. Now serving as Commanding Officer of NOSC (Navy Operational Support Center) in Fort Worth, Capt. Samuels has served his country faithfully his entire adult life. But he and his wife, Jennifer, are now engaged in a fight they never saw coming, against an opponent they once believed to be an ally. It's a fight with life-and-death stakes for the Samuels family that also has repercussions for every military family with a special needs child.

At the center of battle, unaware of the furor that surrounds her, their 16-year-old daughter Kaitlyn sits on horseback, happily participating in a controversial physical therapy that the Samuels say is saving her life.

Kaitlyn Samuels was born with severe congenital brain abnormalities that have rendered her profoundly disabled. "Taking care of Kaitlyn is like taking care of a 16-year-old infant or toddler,"

explains Mrs. Samuels. "We have to do everything for her—bathe her, feed her. She can't speak. She can't crawl or walk by herself, but she does walk with assistance. I can take her up and down the stairs to her room by walking behind her."

Unsure what the extent of her delays

## Kaitlyn's Law

BY ALLISON HARRELL

would prove to be, the Samuels began to pursue intensive therapy for Kaitlyn as soon as doctors detected her disabilities at eight months of age. In addition to physical, occupational and speech therapy, they pursued non-traditional therapies as well. "We were really focused on this window from birth to 3-years-old, and we took the approach that we would try everything short of a voodoo doctor," Mrs. Samuels says with a chuckle. "It did

help her for a time and she made some nice progress, but then (the therapies) would stop helping. She never liked occupational therapy unless they were working on eating, since it's so hard for her. She learned that she could put her head down and close her eyes and kind of play possum to get out of things."

In addition to her brain abnormalities, Kaitlyn suffers from severe scoliosis, which Mrs. Samuels says is the main reason she continues to require intensive therapy. "Kaitlyn has neuromuscular scoliosis, which means her brain is telling her muscles to pull over—it's just kind of a wacko message the brain is sending to the muscles. If we could explain to her how to stretch herself out of it she could help herself, but obviously that's not an option." Left unchecked, Kaitlyn's scoliosis would get progressively worse, with the increasing curvature of the spine diminishing lung capacity, popping

joints out of socket and eventually killing her by crushing her internal organs. Mrs. Samuels says surgery is an undesirable option that carries a high likelihood of failure and even the risk of death. Physical therapy to stretch Kaitlyn's muscles is the best option, but getting Kaitlyn to participate is the challenge. Mrs.

Samuels says physical therapy in a traditional environment had ceased to be effective because Kaitlyn shuts down, refusing to respond.

Licensed Physical Therapist Suzanne Sessums has been working with Kaitlyn since April of 2009 and has been a physical therapist at Rocky Top Therapy Center in Keller since 2005. In addition to her work as a physical therapist in settings that include nursing homes and the Fort Worth Independent School District, Ms. Sessums is a registered Level II Hippotherapy Instructor, meaning she is trained in the use of a horse as a therapy tool. "I am a physical therapist, and I use a horse as my therapy tool instead of a ball or a bench that I would use in a clinic.



In some cases, the horse benefits me more than what I get out of the clinic for several reasons," Ms. Sessums explains. "First of all, the movement of the horse simulates the movement of the human pelvis. I don't get that in any of the other therapy settings available to me." Ms. Sessums says that when patients such as Kaitlyn are sitting on a horse, they are required to actively engage their trunk as well as their core strength. "All of the exercises that I do in a clinic I can do on a horse. A lot of times, kids are more willing to participate on the horse because they think they are having fun and they don't realize they are actually exercising." In Kaitlyn's case, Ms. Sessums says the difference between



*Kaitlyn's family is amazed by her response to physical therapy on horseback. Provided by Ali Wood Photography.*

her response in a clinical environment versus on the horse is significant. "On the horse, she sits up completely on her own, someone just holds her ankle and that's it. I can turn the horse in small circles and constantly work, and she'll sit up for the entire 30-minute session. A couple of times we've even done 45 minutes to an hour, and she has sat up for the entire session. In a clinic with a therapy ball she would sit up for 10 to 15 seconds, and that's it."

Mrs. Samuels says she was amazed by her daughter's response to physical therapy on horseback. "She's engaged, doing all the things they want her to do in physical therapy and she's happy to do it. When she's on the horse her smile is huge, and she's sitting up straighter than

I can get her to sit up anywhere else, and she's working the whole time. There's no sign of her getting discouraged."

After a year at Rocky Top, Kaitlyn continued to be engaged and responding well to regular therapy sessions. "Kaitlyn's scoliosis was at 32 degrees. We were just maintaining that," says Ms. Sessums. "You're really not going to correct scoliosis or make it better, but you can try to prevent it from getting any worse. That was our goal with her." Then, in 2010, the Samuels family received the troubling news that TRICARE, the Department of Defense health care program, would no longer cover Kaitlyn's treatments at Rocky Top. Additionally, TRICARE was demanding repayment for \$1300 in costs the family had already incurred. One

reason the family was surprised by this decision was that Kaitlyn had been receiving physical therapy on horseback for years prior to moving to Keller, all covered by TRICARE. Explains Mrs. Samuels, "Kaitlyn's private physical therapist at the time was telling us she didn't think there was anything else she could do for her because Kaitlyn wasn't participating. She felt she had maxed out. Right after that, we moved to Maryland and I found a riding center where she could be treated by a physical therapist for every session. That was billed to TRICARE, which they paid, because the horse is a tool. The therapists were doing the same thing with Kaitlyn they were doing in the center

with a bench or a ball. They had a therapy room there, so if using the horse wasn't the best thing there were other tools available, but the horse tool worked the best for Kaitlyn. I am not merely seeking out hippotherapy," Mrs. Samuels stresses. "I am seeking out the therapy that works best for my child."

While trying to navigate the morass of insurance red tape, and faced with TRICARE's demands to pay them back for the now-revoked past coverage, the family decided to take a break from Kaitlyn's therapy at Rocky Top. When a state grant available to veterans and their families allowed them to resume Kaitlyn's therapy seven months later, the family was alarmed to discover that Kaitlyn's scoliosis had gone from 32 to 40 degrees





*The Samuels family. Provided by Ali Wood Photography.*

during her time away. "We got a clear medical picture of how much this therapy was helping her at that point," says Mrs. Samuels. "Thirty-two degrees is very manageable. Forty degrees is borderline in need of surgery. The options for Kaitlyn are therapy on the horse or a horrible surgical route that may not even work and would cost the insurance company more than that to just pay for her therapy."

In February of 2012, after a two-year battle of appeals, the Samuels family faced off with TRICARE in an independent hearing. "Our pediatric neurologist and our pediatric physical therapists all testified at the hearing," says Mrs. Samuels. "And the judge listened. He got it. He understood that she's not just riding the horse, it is truly physical therapy and the horse is merely a tool, just like a therapy ball." Despite the judge's ruling in their favor, though, the hearing was non-binding and TRICARE ignored the judge's recommendation, refusing to cover Kaitlyn's physical therapy at Rocky Top.

As the family processed this defeat, Mrs. Samuels says they ultimately decided to fight on not only for Kaitlyn,

but also for the many military families they represent. "My husband is a captain in the Navy. He makes a decent salary. We can afford to pay for her therapy, but as a commanding officer, my husband has sailors under him who live paycheck to paycheck. If TRICARE had done to them what they did to us in recouping the money, it would have taken food off their table. It wasn't pleasant for us to give all that money back, but we had the means to do it. An enlisted sailor would have not only struggled to pay TRICARE back, but their child wouldn't get therapy and they never could have afforded to get an attorney to get a hearing."

Fueled by this knowledge, the Samuels have created Kaitlyn's Foundation in partnership with Rocky Top Therapy Center to support special needs children who use horses for physical therapy. The Foundation also creates awareness about insurance coverage for military family physical therapy treatments. "Right now, Kaitlyn's Foundation is only benefiting military children at Rocky Top," says Mrs. Samuels. "But my dream is for Kaitlyn's Foundation to one day cover anyone, anywhere, who needs this therapy and

cannot get it for whatever reason."

As word spread about the Samuels' legal battle and TRICARE's decision to ignore the judge's recommendation, law firm Akin Gump Strauss Hauer & Feld LLP offered to take the Samuels' case on a pro bono basis. Their goal is to not only prove that TRICARE is misinterpreting the statute through a federal lawsuit, but to also rewrite the law to broaden TRICARE's definition of covered physical therapy services. "Akin Gump is working with Congressman Burgess, who is working on our case. We'd like this to lead to a bill—Kaitlyn's Law—that states that physical therapy is approved if the therapist is using a horse as a tool." Citizens can also lend a hand in the fight, says Mrs. Samuels, by writing to Congressman Burgess and Senators Cruz and Cornyn.

In addition to the website for Kaitlyn's Foundation ([www.kaitlynsfoundation.org](http://www.kaitlynsfoundation.org)), a Facebook page has been created to document the Samuels' fight, fittingly named "Our Military Deserve Better."

---

*Allison Harrell is a staff writer of North Texas Magazine, mom of four and an aspiring blogger.*