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Keller family battles Tricare, a military health care provider, for disabled daughter's horse therapy

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By LESLIE MINORA

Staff Writer

lminora@dallasnews.com

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KELLER — Jennifer Samuels lifts her teen daughter from her car seat, places her on her feet and wraps her arms around her. Mother behind child, they tread step by step into Rocky Top horse therapy center.

Kaitlyn, 16, was born with a brain abnormality, and her mental capacity has not developed beyond a toddler's. She has severe scoliosis and physical disabilities, and will need physical therapy her entire life. Untreated, her scoliosis could kill her.

But her insurance — which comes through Tricare, the U.S. Department of Defense's health care provider — will not cover her physical therapy on a horse, or what some refer to as "hippotherapy" or "equine therapy."

Jennifer and her husband, Mark, an active-duty Navy captain based at the Naval Air Station Joint Reserve Base Fort Worth, are advocating for Kaitlyn's Law, a federal measure to require coverage of her treatment. They are seeking the support of key local lawmakers. They are fighting against what they view as deep systemic flaws in the military's health care plan, including arbitrarily denied benefits and a murky appeals process.

Kaitlyn's therapy on a horse is no more expensive than it would be on a ball, and Tricare says it does not consider cost when determining benefits. But the insurance provider considers the treatment unproven and experimental.

"There is a lack of reliable evidence establishing hippotherapy as safe and effective," said Austin Camacho, a Tricare spokesman.

The family's case centers on whether a horse is a tool for physical therapy or a new form of therapy altogether.

Tricare covers 9.6 million beneficiaries and is federally funded. Its policies cover traditional physical therapy, but that doesn't seem to work for Kaitlyn. She caves into a deep, disengaged slouch while on a balance ball or barrel. When her therapist uses a horse, she sits up and engages.

"They make the rules, set the rules and are accountable to no one," Jennifer said of Tricare. Fighting for her daughter's benefits has been costly in both time and money, and has drawn the attention of national advocates.

"The science changes, and I don't think Tricare does a good enough job of analyzing whether it's time to consider a new treatment," said Jeremy Hilton, a Navy veteran and an advocate for military families facing illness and disability. Hilton's wife is in the Air Force at Andrews Air Force Base in Maryland, and they have a 10-year-old daughter with cognitive disabilities.

There's no way to determine how many families have faced similar issues.

"Most families would just do without," he said. "They would just walk away."

The Military Officers Association of America, which advocates on behalf of families for military benefits, is examining the Tricare appeals process and will testify before the House Armed Services Committee on its findings, said MOAA deputy director Karen Golden.

Walking in sync

At Rocky Top, Jennifer and Kaitlyn enter the barn walking perfectly in sync, as though they are a single four-legged body. Kaitlyn, small for her age, looks younger than her 16 years and can make approving or disapproving noises but cannot speak. Her open-mouthed smile is a sign that she knows where she is.

Kaitlyn attends Indian Springs Middle School in Keller. She has adored Elmo since childhood, and prefers animated movies like *The Jungle Book* and *The Little Mermaid* that her family calls "Kaitlyn's Top 10." On a Disney World trip in 2009, she loved the fast-moving spinning rides.

At the horse therapy center, volunteers lift her from a raised platform onto the horse's back and guide her in wide circles around the soft dirt arena. Her physical therapist tells them when to halt or reposition her, and stretches her backward to open her hip flexors and lengthen her spine.

Her younger sister, Danielle, 12, and brother, Jake, 9, chat about their favorite horses while they wait. For the entire half-hour session, Kaitlyn is stabilizing herself on a dynamic surface, her therapist says. It's what she would be doing on a ball, except the horse provides warmth and a better stretch for the legs.

Kaitlyn leans over to kiss the volunteers as she rides.

Judge's words

One year ago, Mark and Jennifer wheeled Kaitlyn into a Dallas federal courtroom for a hearing in front of a Department of Defense administrative judge. It was the final rung of the multilevel Tricare appeals process.

Their lawyer, Dallas attorney Colby Vokey, argued that the horse is simply a tool in physical therapy, not an unproven treatment, as Tricare contends. Kaitlyn's parents, pediatric neurologist and physical therapist all testified that her treatment is both necessary and effective.

The term "hippotherapy" is often interchangeable with "equine therapy" and "physical therapy on a horse." It is also used to describe psychotherapy using a horse, as in the treatment of post-traumatic stress disorder. Tricare defines "hippotherapy" as "a form of exercise or therapeutic horseback riding," according to Camacho, the spokesman.

Jennifer testified that Kaitlyn's therapy would be covered by a Medicaid waiver, but that because of Mark's military service, they never lived in a state long enough to get off the waiting list.

"If he was a deadbeat dad," she said, "we would not be here right now."

Among insurers, there's no steadfast rule about hippotherapy coverage.

Though hippotherapy is not categorically denied by Medicaid, it is evaluated by individual states, said Washington D.C.-based spokesman Alper Ozinal. Private insurance plans, meanwhile, often do not cover equine physical therapy, according to America's Health Insurance Plans, a trade organization.

The American Physical Therapy Association, based in Virginia, disagrees with the no-coverage policy.

"We do support the fact that hippotherapy is often used as a strategy" by a therapist, said Carmen Elliott, the director of payment and practice management. But, she said, people get lost in terminology. Just call it "physical therapy," she said.

Tricare, though, is "barred by law" from covering therapy that lacks evidence of its safety and efficacy, said Camacho. That evidence includes clinical studies, medical literature, technology assessments and various reports, including those of expert organizations.

This was the basis of Tricare lawyer Michael Bibbo's argument by teleconference from Colorado before the Department of Defense judge in February 2012.

"Congress can change the laws," he said.

Tricare recouped \$1,327.44 for Kaitlyn's therapy after denying coverage that it initially provided. The amount in dispute was far less than the family's legal fees, but for them, this was about future coverage.

Judge Calude R. Heiny, who heard the family's case, wrote an opinion firmly in their favor.

"Physical therapy done in a pool is fine, but when done on a horse, it does not suddenly become some alternative, strange therapy," he wrote. "The therapist is paid for the service she provides, not the tool she uses."

The catch: The judge's opinion was nonbinding. His role was to recommend a decision to Tricare executives. Despite the judge's recommendation for coverage, Tricare still refused.

Tricare policy and operations deputy chief Michael O'Bar issued a final decision rejecting Heiny's analysis, citing a "lack of reliable evidence establishing that hippotherapy is a proven treatment."

Vokey sent the family a letter advising that they could file a federal lawsuit but warned that it would be both expensive and time-consuming.

"We won the battle, but lost the war," he wrote. It was a setback, but the family's war wasn't over.

The battlefield

Other families across the country have faced similar battles.

Kenneth Berge, an Air Force retiree, and his wife, Dawn, filed a class-action lawsuit against Tricare to obtain coverage for their son's and others' applied behavior analysis — cognitive therapy for autistic children.

In December 2010, the Berge family alleged that Tricare's denial of coverage was "arbitrary, capricious, and contrary to law and regulation," and that the treatment was both necessary and met standards of coverage.

Officials responded that the therapy is an educational rather than medical intervention and that even if it were medical, it is not sufficiently proven.

In July 2012, a federal court in Washington, D.C., sided with the Berges, and instructed Tricare to provide coverage to them and others in similar situations. But Tricare specified that the care must be provided by a board-certified behavior analyst. Dawn Berge said the director of the facility her son attends is certified, but the staff is not. Her lawyer said this hierarchy is typical.

"We're in it for the long haul," Dawn said. "We're not giving up. We're not letting this one go." Her son still cannot receive the benefits awarded in court.

Reinforcements

Shortly before Christmas, Mark and Jennifer Samuels received an unanticipated gift. The nationwide powerhouse Akin Gump Strauss Hauer & Feld picked up their case pro bono. The time and money worries of pursuing further legal action evaporated. Jennifer counts her family as "extremely blessed."

At around the same time, Jeffrey Gural, the chairman of a New York City real estate company, donated one year of physical therapy to Kaitlyn. Her family chose to share the treatment with other military children at Rocky Top.

The family and their Houston-based lawyer, Marcella Burke, started Kaitlyn's Foundation at Rocky Top to provide treatment for Kaitlyn and others. The foundation has already received several sponsorships and donations.

With the support of Akin Gump, Mark and Jennifer are asking Texas Sens. John Cornyn and Ted Cruz and U.S. Rep. Michael Burgess, R-Lewisville, to sponsor a bill for Kaitlyn's Law, which would guarantee coverage for Kaitlyn's therapy and that of others like her.

Jennifer has been in closest contact with Burgess' staff. His office confirmed they are aware of the Samuels case and are "happy to review and do our due diligence."

While Kaitlyn's Law is her parents' priority, their strategy includes various approaches, Burke said. If legislative efforts fail, the next logical step would be filing a federal case.

As the war wages on, Kaitlyn continues her weekly therapy sessions at Rocky Top. She doesn't know that her parents are still in the throes of battle to maintain her care. She only knows that once a week, her mother walks her into the barn to meet her therapist, Suzanne Sessums.

Wearing the pink helmet her parents gave her for Christmas, she circles the riding area on her horse. Sessums stops her to stretch her back, and the volunteers reposition her.

Her core muscles, prone to tightening and contorting her body, are stretched and strengthened. When the session is over, the mother and daughter link up again. Jennifer stands behind Kaitlyn and steadies her.

They walk to their minivan, perfectly in step.

HOW TO HELP

To support Kaitlyn's Foundation, donations can be sent to:

Kaitlyn's Foundation, c.o. Rocky Top Therapy Center, 660 Keller Smithfield Road, Keller, Texas 76248.



Make checks payable to Rocky Top with "Kaitlyn's Foundation" in the memo line.

An online payment system will soon be available at kaitlynsfoundation.org.

Spirit Night for Kaitlyn's Foundation at Chick-fil-A at Alliance Town Center:

Kaitlyn's Foundation will receive 20 percent of proceeds from 5 to 9 p.m. on April 1.

Urgent Care for Kids:

The organization will donate a dollar for every "like" and \$2 for every "share" of the Kaitlyn's Foundation photo posted on the Urgent Care for Kids Facebook page.

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