

Benefits of PT-Related Pediatric Intensive Therapy - a parent perspective

Family shares daughter's experience with "Suit Therapy" for muscle strengthening, a treatment modality only recently available in Virginia.

by Leigh Bernard



Five years ago, I took a chance on a \$6,000 alternative therapy program in Miami, Fla., which turned out to be the best decision I have ever made for my daughter, Taylor. Taylor and her twin sister, Sydney, were born prematurely at 28 weeks. At a month old, after a routine head ultrasound and a confirming MRI, Taylor was diagnosed with periventricular leukomalacia (PVL). PVL is damage and softening of the white matter, the inner part of the brain that transmits information between the nerve cells and the spinal cord as well as from one part of the brain to another. PVL is one of the leading causes of cerebral palsy (CP).

As the months passed after Taylor's diagnosis, the differences between the girls' development became more and more evident. At one year, Taylor could not maintain a sitting position, much less roll over, crawl or walk. Taylor had low tone in her trunk and upper body but high tone (spasticity) in her lower extremities. Although she was receiving physical therapy (PT) and occupational therapy (OT) twice each week, it became more and more obvious that a few hours of concentrated therapy per week did not provide the muscle strengthening that Taylor truly needed to maintain what little strength she had, much less gain additional strength and improve her functionality.

In December 2002, while on an out-of-town trip, my mom read an article in a Chicago newspaper about a pediatric intensive therapy program that utilized a "suit" while engaging in repetitive, strengthening exercises. The program consisted of PT for four hours each day, five days per week for three weeks. "Suit therapy" originated in Poland and was modeled after suits that Russian cosmonauts used to maintain muscle tone in space. The suit is comprised of a vest and shorts with bungee-like cords that properly align the body

and provide resistance. The therapist has the ability to manipulate the cords in a way that will most benefit the patient.

In 2002, there were only a few clinics in the U.S. that offered this type of alternative therapy, which was not covered by insurance. I contacted Izabela Koscielny, a Physical Therapist from Poland, who brought this therapy to the U.S. and found it extremely successful for her daughter, who has CP. Izabela recommended Sunshine Therapy in Miami. Although Taylor's therapists at the time were skeptical, we packed up and drove to Miami for three weeks of intensive physical therapy in March 2003. Taylor was 16 months old. The program itself and the results were remarkable.

Each four-hour session begins with 15 minutes of sandbags and/or hot packs on the child's legs to stretch the hamstrings and any other tight muscle groups. The sandbags are followed by a full body massage, primarily focusing on the tight muscle groups. Then two hours are spent in the suit doing strengthening exercises, such as crunches and bridges. The Physical Therapist focuses on functional activities based on the child's ability; such as quadruped (crawling position), transitioning in and out of positions, sitting, kneeling, standing, crawling and walking. The clinic also has additional equipment to help with strengthening. With the use of a weight belt and bungee cords attached to a large "cage" surrounding the child, the child can maintain positions independently and practice weight bearing through standing or quadruped. They also utilize weights and a pulley system to strengthen the child's legs.

The therapeutic activities performed during the four-hour period were fairly familiar to me. However, the intensity was unique. After the initial assessment on the first day, the Physical Therapist developed a detailed therapy plan for the three-week



session. Although Taylor was working harder than she ever had, the therapists were very motivating and tried to make it as fun as possible for her. When we went to Sunshine Therapy for the first time, Taylor could not maintain a sitting position for more than a few seconds nor could she roll over. At the end of the three weeks, Taylor could maintain a sitting position for 10-15 minutes and could roll over. This was an amazing accomplishment. Now she could actually sit up with her sister and play with a toy. Her vestibular awareness, balance and strength greatly improved. We also noticed improvements in her fine motor skills and her overall alertness. Tasks that we had worked on for more than a year with two hours of Physical Therapy each week were accomplished in a three-week period.

Upon Taylor's return to Virginia, her therapists were amazed. All I could think about was when we could do this again and how much I wished we had a similar program here in Virginia. Though Sunshine Therapy created a detailed home exercise program that we could work on each day, I quickly realized that Taylor needed this intensity to improve and gain function. I liken it to an athlete who spends between two and three hours each day strengthening and training. This is a person with normal muscle tone. In the medical world, we take a child with abnormal muscle tone and give them two hours of Physical Therapy each week and expect them to progress. In reality, we're lucky if they can even maintain with that level of intensity and frequency.

Since Taylor's first intensive therapy session, she has participated in 12 more intensive therapy sessions all over the country, including Miami, Atlanta and Detroit (where Euro-Peds, the nation's first suit therapy program, is located). Our goal has been to do a session every six months. In the year leading up to kindergarten, Taylor participated in four sessions to maximize her strength before starting school. As a result of this focused effort, Taylor uses a walker as her primary mode of mobility at Henrico County's Shady Grove Elementary school in Glen Allen, Va. She uses her power wheelchair on the playground and for long distances in the community. Taylor loves school and is integrated in a regular kindergarten classroom.

In late 2006, one of Taylor's physical therapists in Richmond, Va., Cindy Richards, fulfilled her dream (and mine) and opened Richmond Hope Therapy (RHT). RHT offers traditional therapy as well as intensive therapy utilizing the suit, which is starting to be covered by some insurance plans. Taylor completed her first intensive session at RHT last year and will be attending another session in June when school lets out; we are already scheduled for a third session during

winter break next year. In addition, Taylor attends RHT weekly for a two-hour suit therapy session in an effort to maintain her functionality. In 2007, Richmond Hope Foundation was also launched. The foundation is a 501(c)(3) non-profit organization that funds therapy scholarships for children.

I have no doubt that without intensive therapy, Taylor would be wheelchair-bound. Pediatric intensive therapy has given Taylor the opportunity to maximize her potential. Her goal is to walk by herself by 5th grade. I remind her of the mini goals that we need to achieve along the way -- two tripod canes, one tripod cane, etc. However, with her perseverance and the help of an intensive therapy program, we truly believe she will walk independently one day. ■

Leigh Bernard, a physician liaison with Bon Secours in Richmond, is the mother of twin girls, one of whom has cerebral palsy. In the seven years since the girls were born, she has searched the nation for programs and therapies to help her daughter achieve her full potential. Along the way, she has become an advocate not only for her own child but also for all children with special needs. Our thanks for also providing the photos for this story.

On Saturday, July 19th, 2008, the building where the Richmond Hope Therapy Center operated, burned to the ground, leaving nothing left to salvage. With the determination and support of the patient families and the community, the doors were opened again, on August 4th, 2008.

The Richmond Hope Foundation was established two years ago to help create scholarship funds for children and families to be able to afford the intensive physical therapy that insurance frequently does not cover. The Richmond Hope Foundation is gratefully accepting donations to assist in the rebuilding process and to continue to offer scholarships for families of children with special needs.

To learn more, visit www.richmondhopetherapy.com and www.richmondhopefoundation.org or contact Cindy Richards at 804-747-4673.

