

# Family

By Stefanie Carter

For two PTs, the profession got personal when their daughter was born with cerebral palsy

# Ties

Fifteen years ago, Izabela Koscielny, MSPT, was in her final year of studies at Academy of Physical Education in her home country of Poland and expecting her first child with her husband, Richard. She was planning to start working as an athletic physical therapist upon graduation and her husband was already coaching disabled athletes training for the Paralympics. The couple was jumping into their new life together with fervor.

But fate dealt them a challenge when their daughter, Kaya, was born prematurely and was diagnosed with cerebral palsy. Suddenly, these new parents and new graduates had a whole other challenge on their hands.

"I was a gymnast for 18 years and Richard was a swimmer so we were both in a totally different world when Kaya was born," said Koscielny. "Richard was still actively competing and I was starting to coach in gymnastics. It totally changed our goals."

The couple began working toward finding ways to help their daughter. Richard, who had worked as an assistant professor, utilized his research experience to investigate every new study he could find regarding his daughter's condition. "Every year he was able to bring some more information about new research to the table," said Koscielny.

## Seeking a Cure

After a few years, the Koscielny's decided to come to the United States in search of a cure for their daughter. "We received a lot of information about the technology and about how handicap accessible this country is," said Koscielny. "I have to admit this, as much as I miss Europe sometimes with all the beautiful architectural structures; it is totally not handicap accessible."

Not long after arriving in the United States, the Koscielny's came to the realiza-

tion that there is no known cure for Kaya's condition. Their efforts turned exclusively to improving Kaya's functionality.

As Kaya got stronger, the Koscielny's began to pursue more aggressive measures to help her with functionality. "We really didn't know how we could help her. So we tried various training and anything we ever would apply seemed like it worked, but after a short time we would see a plateau. It was very frustrating," said Koscielny.

"One of the more groundbreaking studies [Richard] found in one of the physiological exercise magazines stated that an individual with cerebral palsy responds exactly the same to physical training as you or I. The training can improve strength and flexibility. The trick

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was that peak physiological response was 50 percent lower in the disabled population," said Koscielny.

Based on the research study Richard had found, the Koscielny's decided to develop a program for Kaya. "So for the typical patient, if the goal is to lose weight, the optimal training would be an hour and a half. But because our children have much lower physiological response, it means they can achieve the same benefits, it just takes twice as long. That is why our program is structured on a three-hour schedule," she explained.

In the meantime, Koscielny was corresponding with her mother in Poland who insisted Koscielny look into a new "suit" technology she'd been reading about. "My mother was sending clips from newspa-



**Izabela Koscielny, MSPT, helps a young patient stand at the Pediatric Fitness Center in Keego Harbor, MI.**

pers of this technology that can help my daughter. Of course being a skeptic, it was not easy to believe something could help my child so drastically," said Koscielny. "When Kaya was 6 years old, my father got sick so I had to fly back home and my mother took me to a clinic. When I saw the kids in the suit and talked to the parents I thought it was worth giving it a shot."

## Expanding Treatment

"The suit consists of different systems of elastic bands which are virtually responsible for mirroring the attachments of the muscle groups," explained Koscielny. "For instance, if you have a child who is tippy-toe walking then I will give the child dorsiflexion with the bands to correct that."

The suit, which Koscielny emphasized only facilitates alignment, is a technology derived from a Russian space suit design. "It does not give you alignment but gently guides you to alignment," said Koscielny.

Koscielny watched her daughter make significant progress using the suit combined with intensive physical therapy. "[In terms of therapy], I had all the knowledge I needed, but with that suit

Kaya was able to walk so much more efficiently and so much longer. Her body was so nicely aligned so her energy expenditure was so much lower," said Koscielny.

"We worked very hard for three years to transplant [the technology] here," said Koscielny. "The original Russian suit takes almost 45 minutes to put on. In America, [therapists have significant time restraints], so we decided to make the technology more user-friendly. We also made some significant changes so it qualified for a completely new patent, so now we have a patent pending."

The couple opened the Pediatric Fitness Center little more than four years ago. "Our notion is that no matter what happens—even if you achieve some of your goals—you still have to maintain a certain level of activity," said Koscielny.

Kaya is now approaching 16 years old. According to Koscielny, Kaya went from spastic quadriplegia to a diagnosis of spastic diplegia since starting the program. "We have painfully learned that anytime [the children who come to the center] become less mobile, they progressively start losing the mobility level they should maintain," said Koscielny.

### A Growing Business

The Koscielny family has found success in business and family with their program. "Four years ago there was just our little clinic here in Michigan," said Koscielny. "Now there are 86 clinics across the country and it's still growing. Our hope is that this will become a standard protocol for treatment."

Children and adults alike have come to the Pediatric Fitness Center to work with the therapists on intensive programs. Clients have a variety of diagnoses including SCI, other neurological disorders and, of course, cerebral palsy.

"We truly hope people realize, therapists especially, that it does make the most sense. [Therapists] offer such intensive therapy to our adult patients post-op. My question has always been, why not transfer that treatment to children? If you are a grown-up and have a stroke, they will rehabilitate you quite aggressively. Then why do we deny this of our children?" she said.

Koscielny said that many of the parents who have come to the center are

exactly where she and Richard were a decade ago. "Many of the doctors I went to see with my daughter would always be pessimistically cautious, saying 'There is not a chance for your daughter to walk or to achieve this and that.' If I had listened to all the negativity, I would have given up on such a fabulous opportunity for her," said Koscielny. "Today my daughter plays violin, she plays the piano with both hands and goes rock climbing. She is still severely impaired but she's become an inspiration for all the parents who come here to the center."

The breakthrough that the suit has provided many clients has made it a popular request. While not every child is a candidate to use the suit, many have benefited

### On the Horizon

While it may not have been the plan, the Koscielny family has found success pursuing their passion of helping children to achieve greater functionality and improved strength. The Pediatric Fitness Center is thriving and Koscielny is also the editor for Cerebral Palsy magazine. "I never thought about working with kids," said Koscielny. "My mother was a special education teacher for 35 years and I've seen how hard it is. It just didn't seem like I would be able to do it. Now it's my passion and it's something I wake up and look forward to every day."

Koscielny explained there are still some therapists who do not truly believe in this approach to treatment while oth-

**'With this intensive suit therapy approach, I can always guarantee the child will improve muscle flexibility, ROM and strength. With that, often comes functional skill.'**

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from it, according to Koscielny. "The tension on the suit is not significant on some of the kids, but it still provides deep proprioceptive input about where your body is in space and how it's supposed to be aligned. For most of our kids, because it provides incredible proximal stabilization, right away they gain the ability to sit or stand for the first time in their lives," she explained.

For parents, witnessing this experience is priceless. "Being a parent, I do know better than to ever give anybody any false hope," said Koscielny. "With this intensive suit therapy approach, I can always guarantee the child will improve muscle flexibility, ROM and strength."

"This is where the universal exercise unit comes in. This is a tool that not only allows you to strengthen the child, but right away when you use it as a spider device, it allows you to transfer everything you have just done to actual function activity. For someone who cares for this child and who has not seen their child stand on their own, this is a huge step, it holds promise and it's a light at the end of the tunnel," she continued.

ers are extremely enthusiastic. "Some therapists have the notion that we rob our children of their childhood. And I have to agree with this because we have to spend hours on exercises. But my response is, I have a 6-year-old who never stops moving. We're trying to keep them as active and mobile as possible," said Koscielny.

She emphasized that there is a demand for more clinics and the couple has recently helped to co-found a nonprofit organization called the American Association of Intensive Pediatric Physical Therapy. Their goals include improving technology and conducting prolonged research to make the approach more scientifically sound.

The Koscielny family has found success can often come from struggle, but Koscielny recommends perseverance above all else. "You just can never ever give up. Always keep the hope in your heart no matter how the strong winds blow against you," she said. ■

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