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Hope springs eternal for cerebral palsy patients

By Johanna M. Sampan

My eldest brother, JS, is a teacher for special children. Day after day he shares the classroom with them and treat them like any other ordinary kid in school. But of course, he treats them with more patience and understanding. He always tells me that teaching the kids bring him mixed emotions of joy, fulfillment and sometimes helplessness because he can't be there for all of them at the same time as a teacher. He also shares that he has so much love and respect for the parents of these special children who continue to show selflessness and unconditional love and affection.

Unconditional love—this is the main reason why Richard and Izabela Koscienly, both physical therapists, flew thousands and thousands of miles just to find a cure for their beautiful daughter Kaya. She was born prematurely and diagnosed with cerebral palsy—a neurological disorder that causes physical immobilization on human growth and affects the person's movement, speech, progress and posture.

"There is no cure for your daughter's situation' is what the doctors always tell me," Izabela intoned, her helplessness apparent. "But as a mother, I just couldn't accept that. I have to find a treatment for my daughter, at least something to give us hope, something to make life a little better for our daughter and the many people who share her condition," she added.

After intensive research, Izabela discovered the TheraSuit. This was inspired by Penguin-3, a suit used by cosmonauts made of synthetic material with purposefully elastic inserts intended to battle muscle atrophy. She redesigned the suit to fit to the needs of patients with cerebral palsy. It is consists of a cap, vest, shorts, kneepads and customized shoes that are attached with each other with adjustable straps and elastic bands.



Patients using the TheraSuit have shown a 94-percent improvement in fine and gross motor skills, while speech productivity and fluency is noted in 64 percent.

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It is a therapeutic aid to help in gently aligning the patient's bones and support weak muscles. It's also a breathable, soft yet forceful instrument that would help in retaining the brain to comprehend the signals from the correct movement of the muscles. It also brings body upward and uprightly.

With the TheraSuit, a patient would need to undergo an intensive program, around 3 to 4 hours a day, 5 days a week for a 3-week period or 60-hour completion of the therapy. The extensive care from specialists, together with the use of the TheraSuit and the support of the loved ones, bones become more established and stable. "Nothing comes easy, the method doesn't hurt but it's difficult," Izabela assured.

The TheraSuit method is now being offered by Quality Life Discoveries, a nonprofit organization aimed to give services to the various needs of special children. The organization is building its first and biggest cerebral palsy treatment center in the Philippines this October.

I personally tried the TheraSuit. The flexibility of the elastics helped me to move, though, even when I was feeling the weight of the piece. I sensed that my bones were aligned which allowed me to stand with a better posture.

Up to now, there is no sure-fire cure for cerebral palsy, nevertheless awareness and right information can improve a patient's situation tremendously. As for Kaya, she is now slowly becoming more and more independent—can walk and talk. She can now play the violin and enjoys rock climbing and will be taking her driving lessons soon. Amazing!♦

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