

Testimonial from Trish Schiedel - Canada

My daughter India started showing her first symptoms of something not being right at around 5 months old. She would rotate her trunk over her right hip and go red in the face. This continued daily and instead of crawling she would scoot on her bum and right hip. This is when I first talked to our doctor as I was concerned that she wasn't crawling. I was told not to worry about it as she was hitting all her milestones. By the time she was 2 1/2 years we were referred to a pediatric neurologist. She could be playing at play group and would suddenly drop to the floor and twist her trunk over the right hip. The symptoms were always the same. They decided to do an MRI of her brain which was clear. Because there was nothing significant in the MRI we were told it was a behavior and we should take her to a child psychologist. We questioned this because there was no behavior pattern to these episodes. We did however see a child psychologist who told us a 5! months old could not have come up with such a complex behavior.

Over the next several years we saw 4 pediatricians and many, many other specialists. No one could find an answer and I was told again and again that this was a behavior. I realized at age 4 that she was experiencing pain and ibuprofen helped. By the time she was 8 (in grade 3) she couldn't make it through a school day because of pain. The school would call me usually by 11:30am to come pick her up because she couldn't sit at her desk anymore. We discovered with her 4th pediatrician that her right leg was shorter. A couple years later X-rays showed that the right leg was 1.3cm shorter than the left.

In desperation I took her to Cleveland Clinic in the US. She was underweight, not sleeping well, low appetite and had chronic pain. The neurologist we were booked with (because of her symptoms) told me to stop taking her to doctors and that this was all a behavior. He wasn't the first doctor to say this to me. I told him as a mother I wouldn't stop looking for help for my daughter because this was my job.

I was beyond frustrated! I was watching my daughter suffer and not be able to thrive and enjoy her childhood.

I searched medical journals online whenever I could. I realized it was going to be up to me to do whatever research necessary to help India. The wonderful thing about researchers is that they are curious! They would email me back. I emailed Stu McGill. First on behalf of a patient of mine who had a rare tremor disorder. He was coming to my city to teach a course. I registered for his course and offered to pick him up from the airport. During the car ride I mentioned my daughter and her symptoms.

He told me he didn't think he could help but knew who could. He asked if I had heard about what they were doing in Prague. I had never heard of DNS.

I found my way to a course in Vancouver and asked Michael Maxwell if India could be a case study during the course. This was arranged and Pavel just watched India walk and said her hip was the problem. He did more assessment and diagnosed hip dysplasia and recommended a saddle seat stool for school. He also recommended she get an MRI. I had to find a new family doctor to do this as none of the specialists or pediatricians we had seen were willing to order the MRI.

Once we got it the hip dysplasia was confirmed as well as signs of arthritis in both her hips but predominantly the right one. Even with a strong family history of autoimmune disorders the pediatric rheumatologist was not willing to diagnose her also with juvenile arthritis.

India was in grade 6 when she saw Pavel and from the first day, she used the saddle seat stool she was able to make it through an entire school day!! Her life (and ours) were changed. Within 2 months we were able to wean her off of pain medication. Her appetite, sleep and mood improved. Today India is in grade 11. She is a bright, funny and loving girl! She is able to be in school full time since we got her the saddle seat stool. Meeting Pavel changed her life and our entire family. I can't put into words how grateful I am for Pavel. Nothing is worse than watching your child suffer. As a mother, to realize the doctors who are supposed to help not only are unable to, but also think you and your child are just looking for attention is truly devastating. You can imagine how relieved I was to meet Pavel and finally have an answer (and not be treated like a crazy mother!).

I am FOREVER grateful to Pavel and for DNS and the work you are all doing at the Prague Rehabilitation Center!! Thank you, thank you, thank you!!

*With lots of love and gratitude,
Trish Schiedel
Canada*