

TESTIMONIAL

Susan and Jake's story

Susan* knew something was wrong

Her son, Jake*, had been diagnosed with sensory processing disorder and hypertonia (excessive muscle tone) while also experiencing developmental delays. As he approached his fifth birthday Jake was unable to potty train. Susan worried that her son might have a tethered cord which could cause problems with bladder and bowel control. Jake's pediatrician referred them to a local neurosurgeon who, after spending only a few minutes with Jake, told her that Jake didn't meet all the criteria for a tethered cord, and he didn't recommend the imaging needed to confirm a diagnosis. Jake's pediatrician agreed with the decision.

"It was disheartening," says Susan. "I knew my son better than anyone, and I felt I wasn't being heard. I needed to find someone who would look at the whole picture, do

a thorough examination of my son and consider all of his medical history and his symptoms. I felt I had nowhere to turn." Concerned, but still hopeful, Susan remembered that her company's health plan offered second opinions and specialist referrals through a no-cost benefit called Included Health. When she connected with Included Health, her case manager took the time to learn about Jake, carefully listen to Susan's concerns, and connect the family with a leading neurologist at Boston Children's Hospital. During their first appointment, the neurologist, who was well-informed of Jake's medical history, conducted a thorough evaluation. She then referred Jake to a genetics counselor who recommended "whole exome sequencing," genetic testing that can determine the causes of Jake's symptoms. A few months later, the family finally had an answer.



"After five years of searching, we finally had an answer for Jake. I honestly feel like it could have been many more years before ever getting a diagnosis. And I'm so thankful for Included Health for connecting us with this doctor."

Susan and Jake's story

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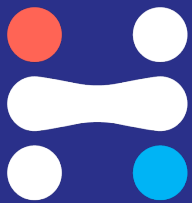


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Jake was diagnosed with KBG syndrome, a rare genetic disorder that causes short stature, dental, muscle, bone and facial differences, as well as developmental delays. With the appropriate referrals by his neurologist to different specialists, Jake was also diagnosed with autism and attention deficit hyperactivity disorder (ADHD). Imaging of his spine and brain also confirmed Susan's suspicions of a tethered spinal cord. Surgery to correct the tethered cord was scheduled and went well. Weeks later, Jake was potty trained.

Now Jake and his parents connect regularly with a care team made up of more than a dozen specialists at Boston Children's Hospital. Jake is now thriving because he and his family have the proper resources, and a supportive care team to manage his needs. Though Jake continues to have ongoing health needs, Susan knows she has Included Health in her corner to connect her son with the right experts, resources and care.

"I felt validated," says Susan. "As parents, we are our children's advocates. You need to ask questions and you need to listen to your intuition. You also need to use the resources available through your health coverage. The right doctors make such a difference and we wouldn't have found them if not for Included Health."



* Susan and Jake are HealthTrust covered individuals. Their names have been changed to preserve privacy.

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