CHRISTOPHER HERNANDEZ



Christopher Hernandez was diagnosed with Prader-Willi Syndrome (PWS) at five years old. His mother, Joanne, explained there were few places she could turn to for help or support. It wasn't until he was six that she found the program for children with PWS at Nexus Children's Hospital. After spending three months with Christopher in the program, Joanne and her son returned home to Chicago to try and make day-to-day life work.

"PWS is a hard disorder to treat since there are so many facets," she explained. "Christopher experienced physical and behavior problems. He would seek food and was extremely stubborn, so if he didn't get his way, he could become very aggressive."

Individuals with PWS lack the internal restraints that most people develop as they mature. Joanne explained her son was motivated by food, and because he didn't have the coping skills to deal with not having that desire met immediately, he would become angry.

"When Christopher turned nine, it was like a switch went off," she said. "All of the behaviors involved with someone with PWS that I read and heard about seemed to turn on at once. His aggression made it difficult for me as his mother and sole caregiver to manage him as well as my other children, husband, house, and everything else."

Joanne took Christopher to a hospital in Chicago where he saw nearly 15 specialists, but nothing worked. Many places turned her away because they weren't equipped to work with him, while others simply wouldn't prescribe certain medications that were known to help individuals with PWS.

"Around this same time, Christopher was removed from school," said Joanne. "They told me he was a threat to himself and others. His weight was also starting to get out of control, and he was having more psychiatric issues, too. He really went through a tough time."

Looking for support in her local medical community, Joanne admitted her son to inpatient psychiatric therapy. She explained, "After that, he started taking his anger out on everyone in our house and using weapons. We thought therapy would help but instead he just took away bad ideas from other kids."



As Christopher's aggression increased, Joanne felt backed into a corner. Now 11 years old, he needed help and Joanne was desperate to find a resource — but her options were limited.

"I relied on The Children's Institute of Pittsburg outpatient support for families of children with PWS. I finally felt understood," she said. "I also heard Nexus had reopened their program, and I thought to myself, that is our answer. Christopher had gained so much weight in the year of nightmares. He was up to 318 pounds."

Christopher admitted to Nexus Children's Hospital Changes Health & Wellness program later that year.

"Since we'd been at Nexus before, we were anticipating similar feedback about Christopher's progress," Joanne said. "To my surprise, he was doing better than expected and I was getting good reports. He lost weight and was working with a teacher. He also participated in different activities."

Because of the progress Christopher made, Joanne explained that she and her husband realized they wouldn't be able to capture what Nexus could give him.

"The boundaries, food security, routine, psychiatric medicine and support — all of that helped him get better and be happier," she said. "We feared bringing Christopher home would ruin all the progress he had at Nexus, so we concluded that a residential program would be best for him. That would enable him to live a more normal life and he's worked hard and deserves that."

As far as Christopher's time at Nexus Children's Hospital, he lost over 120 pounds and was able to celebrate with a party.

"The real victory is that Christopher is happy, and he's melded himself into this environment," Joanne said. "It's a really hard situation when you have a child with a disorder. You can only do so much. The way Dr. Cassidy and his staff interacted with Christopher in such a loving way made us feel better about leaving him there. I really can't say enough about the program."

