

NEXUS CHAMPION

AMBER WOODWORTH



At just 39 days old, Amber was diagnosed with Prader-Willi Syndrome, a rare genetic disorder that affects learning and behavior, and often results in health problems related to overeating and weight gain.

"When my husband Tim and I were finally given her diagnosis, the doctors said she would never live a normal life," explained Amy, Amber's mother. **"However, we decided that this disorder wouldn't define her."**

Amy and Tim knew Amber needed help, so at five months old she was enrolled in the Spokane Guilds' School. Amy explained the school gave them guidance on how to view and celebrate the things Amber could accomplish, no matter how simple they were.

Fast forward nearly 15 years. While Amber has matured, the growing up process brought with it many intense challenges from aggression and attitude problems to hoarding and weight gain.

"Amber would control everything we did," said Amy. **"She was incredibly hostile towards me and her siblings and she would steal items from around the house and hoard them. I stopped talking to her or going into her room because I didn't know if it would make her mad. She also gained a lot of weight – 75 pounds in just two years."**

Amy explained she didn't know how to stop heading down the path they were on. After seeing six specialists, all who claimed they needed to do research before they could help, both mother and daughter were at their ends.

"I remember Amber laying on her bed sobbing and saying, 'I have lost myself. I don't know who I am anymore,'" shared Amy. **"That's when I called the Prader-Willi Syndrome Association and spoke with someone who had just toured Nexus Children's Hospital."**

Three weeks later, Amy and Tim were on a plane taking Amber to Nexus' facility for the Changes Health & Wellness Program.

"We knew admitting her to the program was right and that this was the miracle Amber had prayed for," said Amy. **"We looked at this as a reboot for our whole family."**

Amber was at Nexus Children's Hospital for three months and thrived in the structured environment. She felt connected to the other children in the program as well as the staff members and she actively involved herself.

"I really liked that I made friends that I could relate to and that they could relate to me," shared Amber. **"I was also close with Ms. Paula who felt like my mother to me when I was there."**

Program staff members set health and behavior goals for Amber. While in the program, she lost 25 pounds and was evaluated for medicine to help her outbursts and anger. She also participated in daily activities that were part of a routine.

"I really had a good experience overall," shared Amber. **"We were always on walks, playing on the playground, or in the day room. I also think meeting my goals went really well."**

As part of the program, Amy and Tim were involved in counseling as well, and Amy credits the medical team for her realization of the significance of their role.

"Dr. Cassidy and Dr. Leppo opened mine and my husband's eyes to see that we needed to change," explained Amy. **"I wasn't being consistent, and our home wasn't safe because food was accessible and there wasn't a lot of structure."**

Amy said repeatedly that Nexus Children's Hospital taught her family so much to help Amber succeed at home. **"Everyone was incredible and got us on the right path towards the future. And they helped Amber work so hard. I'm so proud of her."**

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