



My Story

Real Stories from People living with Fetal Alcohol Spectrum Disorders

Taylor's Story

Taylor Allen, a 23-year-old young man with an FASD and his parents, Mark and Cathy Allen, were recently honored by the National Organization on Fetal Alcohol Syndrome (NOFAS) for their work with the FASD community in the Washington, DC area.

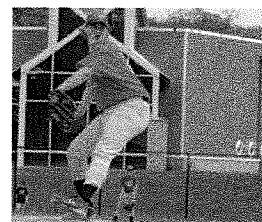
Taylor was diagnosed with an FASD in 8th grade. Before he was diagnosed, he struggled and had been misdiagnosed with attention-deficit/hyperactivity disorder (ADHD) in first grade. He lied, took things in school that did not belong to him, and recalls being disconnected and very frustrated. In the 8th grade, Taylor took a pocket knife to school and was suspended. Since it was a weapon, he had to go through the First Offender's Program and seek counseling. The counselor noticed a gap between action, reaction, and consequences, and had Taylor tested. Taylor was finally diagnosed with an FASD.

When Taylor was born, his birth mother had disclosed to the doctor that she was dealing with alcohol dependence and drank alcohol while pregnant with Taylor. This information from Taylor's parents was helpful to finally diagnose him with an FASD. After Taylor's diagnosis, the Allen family finally connected with NOFAS and the Kennedy Krieger Institute to get help for Taylor.

Some of the behaviors Taylor has struggled with include difficulty maintaining attention, inability to plan and manage time, poor problem solving skills, inability to learn from consequences, social awkwardness, anxiety, and depression. Cathy Allen, Taylor's mother, shares that "Taylor has the outward appearance of any other 23-year-old since he is on the high functioning end of the spectrum, so his FASD behaviors are often misunderstood – causing Taylor extreme anxiety and depression."

After a great deal of struggle and perseverance from Taylor and his family, Taylor earned his associate's degree in electronics from a trade school. Taylor currently works as a lead custodian at an area airport. He enjoys playing and watching baseball, tinkering with computers, reading, and spending time with his girlfriend of two years. Taylor hopes to further his education and he is working toward living independently.

In His Own Words



Taylor enjoys playing baseball in his free time.



Mark, Cathy, and Taylor

"We were like so many other families out there. We were looking for guidance and trying to find counselors, practitioners. Through NOFAS, I was able to have a voice and speak out. By talking with others who are just at the beginning of their FASD journey, we are also healing and helping ourselves – by reminding us that we are not alone.

My mom talks to families that call her all the time. They are just trying to get information, to understand, to have a shoulder to cry on. I hear these conversations. They are so emotional that I walk by and listen in and I can't help but tear up because I was there along with my dad and my mom. And I know how it was like for my mom when she made that call to Kathy [Mitchell, Vice President, NOFAS].

Now, NOFAS has empowered me. Several times a year they give me the podium to speak and tell my story. Getting up in front of a crowd to speak about FASD takes away the control that this disability had over me. I didn't know why I did a lot of things I used to do. But with this, I do know why I am doing it. For the past year, I have been leading a teen group with the help of Kathy [Mitchell, Vice President, NOFAS] and my dad. We mostly talk about what it's like to be us, our day-to-day life, things we run into. We get into how bad it feels to be misunderstood, how we just wish people would understand us. But at the end of the day, no matter how bad, we are all smiles because we've got together and met people just like us.

I want to thank NOFAS for letting us be a small part of everything they do. We are going to keep talking, keep listening, and keep educating until everyone in the world knows that you cannot drink during pregnancy."

CDC would like to give a special thanks to the Allen family and the National Organization on Fetal Alcohol Syndrome (NOFAS) for sharing this story with us. [View more personal stories at NOFAS.](https://www.youtube.com/playlist?list=PLiFZcDuldDA7k1pnjl1SHzq5p6Ka-PwJ) (<https://www.youtube.com/playlist?list=PLiFZcDuldDA7k1pnjl1SHzq5p6Ka-PwJ>)

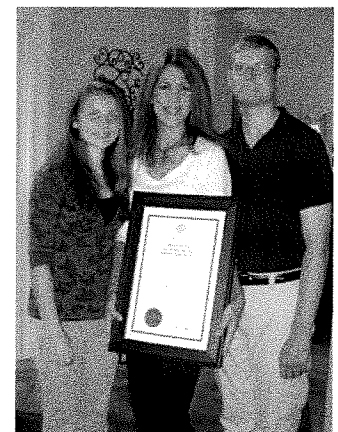
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Sasha's Story

Alexander "Sasha" Cook was adopted in 1997 at the age of five. Now at 23, Sasha and his mother, Melissa, share his story in recognition of FASD Awareness Day.

As a child and young teen, Sasha faced numerous difficulties. These included learning problems, struggles with social relationships such as interacting with classmates, difficulty with team sports since rules were too abstract, and trouble handling everyday things in life. He still remembers that being with his fellow students was "no fun."

Sasha had many evaluations and was diagnosed with multiple disabilities. Knowing



Sasha with his

he was exposed to alcohol before birth is what helped his family and doctors best understand his challenges. Typical milestones that other children reached and took for granted seemed out of reach for Sasha.

Coaching, Adapting, and Modifying Expectations

Yet despite the odds and with support from his family, friends, church, and school community, Sasha has come a long way. Sasha has shown great potential, has many strengths, works hard, and clearly shows his resilience and depth of character. "We did the majority of behavior modification at home through structure and by understanding that this is not a moral disorder but a brain-based disorder," explains Melissa.

"It is constant coaching, adapting, and modifying expectations for them, realistically.... matching their potential with their gifts and strengths. As parents, we are their external brain and our children who have FASDs can be successful in a safe, structured, organized, and under-stimulated environment that recognizes and builds on their capabilities in order to help through the challenges."

Employee of the Month

Sasha successfully completed high school and has been gainfully employed by a large national grocery chain since 2009. Over the years, Sasha has been given additional responsibilities by his employer and was also recognized for his willingness to help others. Sasha proudly shares details on the numerous awards he has received and his growing customer service skills. "I was excited to be Employee of the Month in January 2013 and now I've been promoted to work the cash register. I like the people who I work with."

Active Member of the Community

Following in his mother's footsteps, Sasha is an active member of the community. He understands his disability and helps bring support to others. Recently, he participated and helped answer questions about FASDs at the 10th annual Seminar Series for "Critical Issues Facing Special Needs and at Risk Children" hosted by the Georgia Department of Behavioral Health and Developmental Disabilities, Suicide Prevention Program and The Supreme Court of Georgia's Committee on Justice for Children.

Sasha also provided information about the National Organization on Fetal Alcohol Syndrome (NOFAS) Georgia chapter. NOFAS, a national nonprofit resource of the FASD community, is committed to preventing FASDs and supporting individuals and families living with FASDs.

As busy as Sasha stays, he still participates in fun activities including playing the piano, playing tennis with the family, and participating in a church bowling league. "Sasha is an excellent bowler and has crafted his talent for five years," continues Melissa. "As a mother raising children with FASDs, I have found that promoting physical activity through individualized sports such as bowling, tennis, and ping pong are important tools to enhance a child's daily functioning." Sasha is a very well-rounded young man and receives great family support in all his endeavors.

Melissa would like to thank the [Southeast FASD Regional Training Center \(http://www.fasdsoutheast.org/\)](http://www.fasdsoutheast.org/) and

mother, Melissa, and sister, Nadia, holding a proclamation signed by the Governor of Georgia in 2013 declaring September 9 as FASD Awareness Day.

[FASD Communities \(http://fasdcommunities.com/\)](http://fasdcommunities.com/) who have been especially helpful to her and her family in the past few years.

CDC would like to thank Sasha and Melissa for sharing their story.

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Melissa's Story

This is the story of Melissa's experience with alcohol use during pregnancy and her journey to find the best possible care for her son.

"I drank at the beginning of my pregnancy; before I found out I was pregnant. My doctor told me that it was okay to continue to drink wine during pregnancy. He said I could have a glass of wine at night with dinner. He said it might even help me relax and improve circulation. Not only did I think drinking wine during pregnancy was okay, but I thought that it could be healthy. He never asked me if I had a drinking problem, or how many drinks I have a day, or if I binge drink. There wasn't any dialogue. I really wish that my doctor would have had more dialogue or asked me questions about drinking alcohol during pregnancy.



"When my son was born he looked perfect. He has amazing strengths. He's brilliant and he's an amazing musician. However, as he got older I realized that things just weren't quite right. He doesn't like how clothes feel. He wore the same outfit for almost a year. I finally found a pair of socks that he would wear. Then the company stopped making the sock. That wouldn't be a big deal for most people, but it was a terrifying moment for me. We went through about 25 packages of socks before we found a new brand that he would wear.

"On his first day of kindergarten, the school called me because he had turned over all of the chairs that people weren't sitting in, turned over items in the kitchen area in the classroom, and thrown his shoes at the teacher.

"Most kids will get mad when they have to end play dates or sleepovers. But instead of just getting mad, my son tried to jump out of the car the other day because he had to leave a sleepover.

"When I finally realized what was going on, it was a relief, and it was horrifying, and I felt guilty, and I felt ashamed. But mostly I felt relieved to know what was going on.

"If a pregnant woman said to me, 'I drink a little bit here and there and I was told it was okay,' I would tell her that she wouldn't if she had to live just one day with the way that I feel about myself, knowing how my son has been affected by my choices.

"I am angry that I was given wrong information about drinking during pregnancy. I want to tell as many people as I can about it. You never know how much alcohol during pregnancy is too much, so why take that chance?"

CDC would like to give a special thanks to Melissa and the National Organization on Fetal Alcohol Syndrome (NOFAS) for sharing this story with us.

Watch Melissa's full story on [video \(http://www.youtube.com/watch?v=dHRZjTiFEHs&feature=youtube_gdata_player\)](http://www.youtube.com/watch?v=dHRZjTiFEHs&feature=youtube_gdata_player)