

Fetal Alcohol Spectrum Disorder: The Invisible Disability That Challenges Me Daily

In July of 2017, right before my freshman year of high school, my parents sat me down to have a conversation about my birth mother. I have always known I was adopted. Once I asked my mom if my birth mother was bad. She had answered me, “No your birth mother loved you, but on the day you were born, she could not take care of you or any other child.” That summer day, my parents explained that I was diagnosed with a specific medical condition, and this condition is difficult for some people to understand, and it was, most likely, why I am petite, have difficulty with learning, and can sometimes make impulsive decisions. They then went on to explain that the multiple challenges that I have faced were due to alcohol while my birth mother was pregnant. Her drinking had affected my developing brain. I was diagnosed with Fetal Alcohol Spectrum Disorder (FASD). While we can’t see anything different in me, the reason I had so many therapies when I was young and an IEP was due to the FASD. They believed in me; they believed I would be able to meet typical milestones of any ordinary teenager: learning to drive a car, graduating from high school, and going to college. They wanted to see me become all that I could be. My parents felt I was old enough to understand the information they were telling me. We talked about the challenges of high school that I could face. My early development was difficult because I had a ventral septal heart defect and surgery that doctors thought was contributed to by alcohol as a midline defect. My parents were able to have me evaluated by Dr. Ira Chasnoff at the Children’s Research Triangle in Chicago, IL. This contact provided my parents with direction on intervention therapy and, at age 3, I had an IEP because I was having learning and behavior delays.

FASD affected me through hyperactivity, difficulty with attention, a math disability, and when I was young, poor coordination. I was very lucky that my parents provided me with love, therapy, and never gave up on my ability to learn. When I was in fourth grade, my mom saw me counting on my fingers. In October, at a meeting with the teachers, she expressed to the math teacher that I was doing this. When the math teacher answered that it was “OK”; she had 8 other students who used their fingers, my mom found that unacceptable. My parents signed me up for Kumon that weekend. They had to start me in first-grade math because I did not know my basic facts. I stayed with Kumon through 6th grade. Throughout grammar and middle school, I had a private tutor to help me with my academic struggles. To overcome my coordination, I tried ice skating twice. The first time, in second grade, I had such a meltdown with an inclusionist that

I only took 2 lessons, then I quit. With encouragement, I tried again in 4th grade. This time I had a private instructor and group lessons. I loved to be in the ice show and continued through 8th grade. Dancing to the music became a stress release for me, even today when I am no longer skating.

While grammar and middle school provided daily learning challenges, I am proud to say high school is where I have thrived, excelled, and learned to have determination, initiative, and advocate for myself, and I have learned to accept and live with the challenges of FASD. In my freshman year, I had an amazing Biology teacher. She taught Transitional Biology, which was 1½ periods every day, with a teacher aide. I struggled, in the beginning, trying to get organized, not asking questions when I did not understand, and not completing assignments on time. My teacher asked me to come in before school. She mentored me, showing me how to organize my notebook, and helped me to develop a study plan. At first, I was told when to go to the science tutor lab to review, but by the end of the semester, I was starting to organize by myself. I was using the same strategies for other classes. I started to LOVE going to school. I also had a seminar class (study hall) with a teacher who supported me with academic questions. During my freshman year, I connected with Dr. Terry Collins, the Director of Maine Community Youth Assistance (MCYAF) that is based at my high school. This organization helps teens be successful and healthy through the prevention of adolescent alcohol and drug use. Since I had no control over my 18-year-old birth mother's choices and alcohol use, I wanted to educate myself and peers in alcohol and drug prevention. Currently, Covid-19 has temporarily placed MCYAF on pause. In the past three years, I was an active member, and last year, I was a leader in the MCYAF Townhall Meeting where a group of students organized, researched, and presented a Townhall Meeting for students, parents, school board members, city and state legislators, and community chiefs of police. This has been fundamental for me in realizing that I choose not to drink alcohol. I am hoping that we will be able to have a remote forum in 2021.

As I gained confidence in high school, I became involved in activities that I enjoyed. In the past 3 years, I have fostered over 44 rescue dogs, including a litter, this summer, of 6 puppies and the momma, for 8 weeks. All three years before Covid-19, I was a Thursday evening Catholic Charities soup kitchen volunteer. I learned how to run the family room. By September of last year, I could run the room by myself. I have always had a "beat in my head" and naturally selected percussion as my band instrument for the past 8 years. When I play my drums, xylophone, or participate in drumline, I feel this wonderful regulation. It destresses me and helps me to focus. I am so excited to be participating in the senior drumline V-show as an act captain. This is a student lead variety show for this November that will be virtual. Before

Covid-19, I participated in a theater crew. My organizations are the National Honor Society, Thespian Society, Tri-M Society, Hawk Pals (I support students with learning challenges), and Hawk Pride (I mentor 10 freshman this year with another student). Since my early childhood, preschool, and elementary school days were spent with intervention, including speech, developmental occupational and physical therapies, and doctor visits, this has influenced me to want to be a nurse who works at a children's hospital. I feel I can support children and parents. Perhaps I will even find a hospital that has a program for children with FASD. To support my plan of being a nurse, I have been accepted to and committed to the University of Wisconsin-Oshkosh for college. I am so excited to follow my dream of becoming a nurse. UWO has a unique program called Project Success. This program accepts 50 to 60 students each year with an IEP. This program will support me to succeed, with an advisor who meets with me at least once a week; the Success Office has tutors and is available to help me organize my executive function skills. I am so pleased to have been accepted to this program. I feel I will continue to thrive in college and become a nurse who helps children, and hopefully FASD children, to lead fulfilling lives like myself. I see myself as an adult volunteering at MCYAF and The Children's Research Triangle, speaking to students about how preventable FASD is and giving inspiration to parents who adopt children with FASD. Hopefully, my speaking about this will give the parents inspiration to deal with the daily challenges that FASD brings for their children. FASD is an invisible disability that is preventable by not drinking during pregnancy. Every day I face challenges that I have been fortunate to learn how to manage. By being a nurse, I feel I will be able to give back to children and others for all the support and care I have received in my life.