FASD Video Series Transcript: Rebecca

Narrator: Lived Experiences with Fetal Alcohol Spectrum Disorders.
Rebecca.

Rebecca: My name is Rebecca Tillou, and I am a 44-year-old living with an FASD.

So, I was adopted at one month old, and it was a closed adoption. So, my parents knew that my mom, my biological mom, drank during pregnancy. So, they brought me home, and I was very sick as a baby. I had constant ear infections. I had constant bronchitis. And I had failure to thrive.

There wasn't much known about FASDs at all. So, my pediatrician told my parents, she has the facial features of fetal alcohol syndrome. And my mom will tell you that growing up I was a great student. I did good in school, but what happened was my mom just felt there was something off about me. I was quirky. I preferred to play alone, and I had, you know, maybe one good friend, and I was socially weird.
So, there were things, but my parents were like, “Oh, you know, it's just genetics.” We don't know. She has unknown genetics.

I started having real academic issues when I got to college. So, I almost failed undergrad, but I passed. And then graduate school to be a speech pathologist. I actually failed because I couldn't write diagnostic reports that everyone could understand, because writing paragraphs is very hard for me. So, I failed. I failed graduate school, So that was a, you know, my parents were like, what is going on? And then my mom got a pamphlet in the mail from where I was adopted from, and it was, it had a whole page on fetal alcohol spectrum disorders. So, my mom read it. She called me and said, “This is what you have.” So, then I took it upon myself to get diagnosed at 34.

I decided, well, I want to get diagnosed because it'll answer so many questions about when I was younger. So, I went to a neurologist near my house. Doctor comes in, looks at me, and goes, “I just Googled FASD and you don't have the facial features, and I don't know anything else about it.” That shocked me. And it turned out, he's like, “Yeah, you got some executive functioning stuff going on.” I don't even know what their report said. I never got it – I don't.

So, I left there angry. And then I said, “Fine.” I looked up those who diagnose FASDs in Albany, New York, and there was one, and she took time. She took the DSM-5 or DSM-4, and looked at it, and she measured my head. I have a very small head. The social stuff I told her about, my history with time management, and impulsivity, and she took my history on my bio mom, that I knew. And then she diagnosed me with fetal alcohol effects – they don't use that anymore. She diagnosed me and I was the only adult she's ever diagnosed.

So, it was a relief because everything from my childhood that I was quirky about, made sense. My time management made sense. Not being able to read a ruler, a clock. It just, everything made sense. My math issues. Social boundaries. I'm finally learning. So that's good.

Once I got diagnosed, the pediatrician told me, “You may have been smarter, if your mom hadn't drank. Your life could have looked different.” And that struck me, but it's true. My life probably it would've been different. I have brain damage. But I consider myself successful and smart. But when she told me that, that hit me hard. And it made me angry at my bio mom, because she did this to me – that was my initial thought. But then I started to learn a little bit about alcoholism and my anger changed. So. I'm not so angry anymore. I know it wasn't her choice to hurt me. She had a disease.

If I didn't have this, I could have been a speech therapist. I could have made more money than I'm making. I could have, you know, been a better mom. But over time, over the years, it's been 10 years since my diagnosis, I have accepted that I have an FASD, but it doesn't define me. I know that's so cliche, but it's true. And I became an advocate, and I met those like me, and I met those that fight for me and us.
And so, it was hard at the beginning, but it's, and there's still days when I struggle. When I feel like, you know, it's hard out there, but it's turned from sadness and, oh, not despair, but sadness and anger to success. So, it's totally done a 180, and it's been an amazing journey so far. So, the good with the bad.

I wrote a book and it's called Tenacity. It's about search and reunion as the adoptee, and it's about FASD. It's about my journey with FASD. How my life is impacted by it. Negatively and positively. Yeah, and the advocacy that I've been doing is incredible. And that just keeps me going every single day.

I mean, I have two wonderful kids. They know my story and they support my story. One did a report on it for school. I just, I wanna be that mom that talks to my kids and then their kids. My kids talk to their friends about FASD.

Those of you out there with an FASD, if you just got diagnosed, it's not the end of the world. And you may go through feeling mad and sad and glad and happy and confused, and those are normal feelings. You need to feel them and work through them. We all have strengths with an FASD, and you will find yours if you don't know them already. It doesn't have to define you. Go out in the world and advocate because we don't have enough advocates. And it gets easier. There will be tough times. But as you learn who you are and what your supports are and how you can be successful, you will be just that. You'll be successful and you'll be wonderful. And the good times really do overshadow the bad.

Narrator: For more information, visit www.cdc.gov/fasd.