

## FASD Video Series Transcript: Diagnosis

**Narrator:** Stories and Recommendations on FASD diagnoses.

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person who is exposed to alcohol before birth. FASDs can have lifelong effects, including problems with behavior and learning, as well as physical problems.

It is estimated that up to 1 in 20 U.S. school-aged children may have FASDs.

Despite the prevalence of FASDs, many individuals and families struggle to obtain diagnoses and support from the healthcare community.

This video shares the real-life experiences and recommendations of individuals with FASDs and their families. These are the things they most want healthcare providers to know.

**Rachel:** FASD is not a curse. It's a way of being in the world differently. And that the sooner that professionals, like doctors and occupational therapists and folks realize, recognize it and then use appropriate supports, the better a child can do. And just hoping that families don't have to go through the painful journey our family did before we really embraced FASD and started working with it rather than denying or working against it.

**Annette:** My husband and I adopted our two sons. The first one was an infant, and the second one, four years later. Both as infants, we took them to the pediatricians and they said healthy, you know, but you know, later on things and their development weren't as typical. They didn't get a diagnosis until they were 14 and 18. So we had a lot of trials and errors trying to figure out what was going on with them.

**Debbie:** I really noticed when Wyatt was about in first grade, that he was really struggling academically, socially, you know, he was delayed in some ways. He had sensory processing disorder. So, I started researching myself, you know, on FASD and, and just looking, 'cause I, I did know that he had the facial features and, and started educating myself and he just, you know, fit all the, ticked all the boxes, you know, to be in an FASD category. So, I you know, went after, you know, pursuing that and didn't stop until we got it. Wyatt was 19, not quite 20, when he was diagnosed, it was like 12 years of me fighting to get him a diagnosis. We saw 10 or 12 doctors before we got his diagnosis. At least that number.

**Laura:** He saw, had lots of therapists, right? All different levels of therapist, neuropsych. And then he had, again, all these specialists, right? So, the specialist for you know, cardiologist, you know, a specialist for his eyes, a gut issue, all these different things. So cumulatively, I would say probably 15 to 20.

**Sean Patrick:** It took so long for me to get diagnosed to the point, if I would've been diagnosed earlier on, my life would've been different. Like my mom said, like it would've been completely different. If you're diagnosed late and you don't get supports early on in your life, you're not gonna be able to function normally.

**Rebecca:** 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 by that time when I was in elementary school, the whole FAS thing had gone out the window. That wasn't even on the table anymore. I started having real academic issues when I got to college. So, I almost failed undergrad. So, then I took it upon myself to get diagnosed at 34.

**Narrator:** Misdiagnosis and Missed Opportunities.

**Sean Patrick:** A lot of people do not know what FASD is, and I'm wanting to get that out into the world so people can understand why it's not like autism. It is not like ADHD, it's its complete own spectrum and how people can relate to each other in that sort of way. I've had a lot of diagnoses to the point where I can't remember all of them.

**Laura:** Starting at age, you know, two with ODD and that went into, you know, sensory processing, early childhood, all these other diagnosis, autism times three. And right now, we're kind of just talking about emotional mental health type diagnosis, right? Well, he had this whole other component of physical diagnosis, right? So, he had strabismus, he had, you know, which is exotropia, those things. He had heart murmur, orthopedic, gut issues, sleep issues. And so, to me there I was looking for something. All this has gotta be related.

**Narrator:** Documented Prenatal Alcohol Exposure Requirements.

**Annette:** And then in school I was trying to get some answers from the teachers, and they said, "Oh, don't worry about it." Fourth grade I got the school to do an, you know, a whole assessment of our oldest son. You know, they wanted to just say it's IQ. And that just didn't sit right with me because it was so bright in so many other ways. What we were concerned about in adopting children was obviously number one, not having much family history. We were concerned about drugs, drug exposure. And the one thing we didn't think about at all was the one legal drug that's available everywhere. And that's alcohol.

**Rachel:** The lack of family history is huge for parents like us because a hard diagnosis requires documented prenatal alcohol exposure. And for so many folks, I know they don't have that. If there can be a way that there can be a diagnosis without that information, because in our case, we knew she was opioid exposed and there are a lot of children who are polysubstance use exposed and alcohol because it's legal is not something that might necessarily get mentioned. And that's when we actually started pushing back to doctors. We were like, she's the poster child, she checks all the boxes. How can you look at this? All the boxes check off. And you're comparing that to a birth history that doesn't mention this. And so that was also one of the advocacy challenges for us as parents that without that in the history, it was so hard to advocate on her behalf.

**Jen:** So, we knew going home from the hospital that he had alcohol, tobacco, and meth exposure. He had spent 15 days in the NICU and when we took him home, it was basically, "Here you go, have at it mom." We had no idea that the alcohol exposure was a factor. In fact, prior to his adoption, I remember a meeting with his pediatrician. This is somebody that we know, love, and respect and still use as a provider. And I asked him, I said, "So just, I'm the kind of mom that needs to be informed, so what am I up against? Tell me worst case scenario, what can I prepare for?" And I was told that he would potentially have ADHD symptoms by the time he started school. And that other than that, we should be okay.

**Narrator:** Reliance on Facial Features Associated with Fetal Alcohol Syndrome (FAS).

**Rachel:** A lot of professionals assume there's going to be the facial dysmorphism with FASD. And that was also another thing we were told. Well, she has none of the facial characteristics, but for the vast majority of people with FASD, it is an invisible disability.

**Rebecca:** So, I went to a neurologist, 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." No joke. I walked out of there so angry. And so like, but he works with the brain, how can he not know this? So, that goes to show you, there are so many like neurologists and doctors out there that just, they were never, they never had to know about FASDs.

**Narrator:** Minimization and Dismissal of Individuals' and Families' Concerns.

**Rachel:** When we started to pose it as a possibility to professionals, they all poo-pooed it and said she doesn't have the facial features. They minimized some of the signs and I think that they were well-intentioned and they thought they were doing us a favor. Her psychiatrist initially, because there was a lot of mood dysregulation. That was sort of how it first manifested to us. And that's what she initially got treated for. The first time we raised it. He said, "Why would you want to know? There's nothing that can be done." And we persisted. And then he was a very, very kind, caring doctor and he started to listen to us and educate himself. It also gave us, as parents, sort of permission to learn more about FASD and what it really meant and how we could support her more effectively.

**Jen:** Well, when we were trying to identify even what was going on, it wasn't until he was five that a friend of mine who happens to work in child welfare, she says, "You know, Jen, I really think that you need to look into this FASD piece." And so, me being the mom that I am, I'm like done. I go home that night, I start Googling FASD Florida, which is where we are. And I came up with our diagnostic clinic that we happen to have. But other than that, I didn't even know to be looking for something prior to having that conversation with her. I even made an appointment with our pediatrician when we're in the middle of big struggles. And I just said, I need help. And I was told I wasn't stern enough as a parent and I was told to go read a book. I left that appointment in tears.

**Annette:** And so, I do remember making an appointment with the school psychologist to try to go get some help, you know, wondering, you know, what, what I might do to help him. And her first question was, "So, how are things at home? How are things between you and your husband?" You know, so from the school's perspective, we were doing things wrong as parents. And of course, I was questioning myself because I was a working mom. I wasn't there all the time.

**Narrator:** Benefits of Diagnosis.

**Patima:** I went through so much stuff that I shouldn't have gone through as a child just because they wouldn't give me a diagnosis. And that in the long run would've saved me from so much pain.

**Debbie:** It was really an emotional time, too. It was, it was great to have the diagnosis, but it was also, there was a lot of grief and loss in, in that and, and actually knowing,

**Wyatt:** I remember that I was probably excited that I got my diagnosis. This made me feel more comfortable. And like I was heard and like me and my mom were heard, actually.

**Sean Patrick:** It was a major relief. I was like, oh my gosh, I don't have so many diagnosis anymore. I didn't really understand it at first, but then when I started learning about it and I started advocating for myself, I started being like, oh, now, now I see like, oh gosh, wow. This is why I've been like this my entire life.

**Laura:** It connected all those dots for physical and mental health. Absolutely.

**Sean Patrick:** And it kind of just really opened up the door for like new possibilities, if you know what I mean. Like, it's just like, boom, I can do things now. 'Cause I know what kind of diagnosis I have.

**Laura:** It was absolutely pivotal getting his diagnosis, because it allowed me, again, to look at this whole body diagnosis of FASD. And then not only that, but it allowed me to be a better advocate to parent him differently.

**Sean Patrick:** But ever since I got this diagnosis, asking for help is like, oh, I can ask for help. It allows me to express my own self and allows me for others who have FASD, not to feel alone.

**Patima:** It was, ah, I haven't, I now have a name for this thing. You know, not just wondering, oh, what do I have? How, how will this, you know, keep affecting my life. But now I can point to, this is one of the many obstacles that I live with.

**Rebecca:** 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, I still struggle with those. It just, everything made sense. My math issues, social boundaries, I'm finally learning. So that's good. But yeah, it just, it all made sense.

**Jen:** Before we had his diagnosis, his trajectory was very unknown. I didn't know if we were looking at significant behavior needs. I didn't know if he would be able to be successful in a classroom. But the moment that they told me he had fetal alcohol syndrome, it was a kick to the gut because I knew that that meant he was gonna have lifelong challenges. But it was also very validating because I knew there was something off. I just couldn't pinpoint what it was. So again, I didn't know what I didn't know, but I knew something was off and I just really wanted to be able to help him. So as hard as it was to get his diagnosis, it was also very freeing because then we had a direction. Once we got his diagnosis, we were able to kind of flip the script on that. We were able to put him in a place where he could be successful. I call it, name it, to tame it so I can label and identify what his needs are. Then I can help tame those behaviors.

**Narrator:** For more information, visit [www.cdc.gov/fasd](http://www.cdc.gov/fasd).