FASD Video Series Transcript: Sean Patrick and Laura

Narrator: Lived Experiences with Fetal Alcohol Spectrum Disorders. Sean Patrick and Laura.

Sean Patrick: My name is Sean Patrick. I like to create things. I do some painting. I make Lego Lightsaber hilts.

Laura: So, I am Laura, and mom to Sean, as well as self-advocate.

Sean Patrick: I want to share my story, because 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 is its complete own spectrum, and how people can relate to each other in that sort of way.

Laura: Not until I got my diagnosis last year did I realize all the ways that I have compensated for my challenges. We got our diagnosis a little bit late. We wouldn't have had to struggle like we did if we would've got a diagnosis early, right? We could have had the early intervention and all those other things. And I think both of us, our trajectories would've taken a different way, right? If we would've had the early diagnosis, and wouldn't had to go through some of those challenges.

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, you don't get supports early on in your life, you're not gonna be able to function normally, which really can relate to how my life has been. I've had a lot of diagnosis to the point where I can't remember all of them.

Laura: Starting at age two with ODD (Oppositional Defiant Disorder), and that went into 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, which just exotropia, those things. He had heart murmur, orthopedic, gut issues, sleep issues. And so to me, I was looking for something, all of this has gotta be related. And so when he got that FASD diagnosis, that truly connected all the dots of both his physical and mental health. He's had lots of therapists, right? All different levels of therapists, neuropsych. And then he had, again, all these specialists, right? So, the specialist for his, you know, cardiologist, a specialist for his eyes, a gut issue, all these different things. So cumulatively, I would say probably 15 to 20.

Sean Patrick: Well, after being given multiple diagnosis, I received my diagnosis in my mid-teens. It was a major relief. I was like, [Sean Patrick gasps] "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 I see. Like, oh gosh, wow. This is why I've been like this my entire life."

Laura: It connected all those dots as far as 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," 'cause in the past, I would've never ask for help. I hated doing it. It made me feel like stupid and all that kind of thing.

Laura: Before my diagnosis, I didn't ask for those helps. I just struggled and it was hard, and it took a lot of energy out of me, and I didn't feel like I could be my best because I was too busy trying to keep up. And now, I have that diagnosis and I can ask for support, and I get those supports. It allowed me to have a better understanding of Sean Patrick and why it is, since he's had his diagnosis, I completely understood a lot of the supports that he needs because they are a lot of the same supports that I need. He went to his first PCP. He mentions to her, "I'm Sean. I have FASD. Are you familiar with FASD?" And her first response to him was,

Sean Patrick: "If I wanted to learn about FASD, I would've looked it up in DSM-5."

Laura: Sean just shut down. Just shut down and sat in his seat. He was mad. He was frustrated. And so, then I clicked into family navigation program and got all the information that we provide for mental health providers and professionals, that sort of thing. I sent it all to her and our staff and said, "Thank you so much for seeing us. We certainly appreciate it. With regards to FASD, I wanna share this information with you going forward." And in 24 hours, I get a phone call from the physician herself saying, "Thank you so much for sending this information to me. You and your son are definitely the experts." So, it was a great, what could have been ugly, right? It really turned into a positive experience for that physician as well.

Sean Patrick: My life today is awesome. It's amazing. But becoming an FASD advocate, getting to travel, meeting other people, it helps me to understand myself and others who are impacted by FASD.

Laura: Why are we here? To create more opportunities, right? To spread that awareness, that advocacy. If you're getting this diagnosis, embrace yourself. All those strengths that you have, that you've made it, whether it's 5 years, 20 years, 50 years. You've done so many wonderful things without even knowing. And now that you do have that diagnosis, again, asking for those support so that you can continue to do those and have those same successes, but without so much energy and effort having to go into it. With FASD, we all have strengths, we all have challenges, and it's focusing on those strengths. What is that individual's superpower? I could see with

Sean; his superpower is that he's never met a stranger. He will go talk with anyone and everyone. And so, let's turn that into a positive, and with that FASD message.

Sean Patrick: Because in my world, there are no strangers, unless they're strangers. [Sean Patrick and Laura laugh]

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