

FASD Video Series Transcript: Patima and Rachel

Narrator: Lived Experiences with Fetal Alcohol Spectrum Disorders. Patima and Rachel.

Patima: I am Patima Sing-Eisen.

Rachel: My name is Rachel Sing and I'm the proud mom of Patima. 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.

Patima: Or even not knowing you have it.

Rachel: Right.

Patima was not highly verbal as a child and it took her very intense work with a therapist in middle school to identify emotions that she was experiencing and what to call them. So, in our family we referred rather awkwardly to Patima having a brain condition, when her sibs would ask, "Why this? Why that?" And we'd say, "Well, she has a brain condition that explains these outbursts, these rage episodes." I mean there were all kinds of things that it was, it was challenging to explain to younger siblings.

A lot of professionals assume there's going to be the facial dysmorphia 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.

Patima: But you know, difficult not knowing why, you know, I would act like this or why I wouldn't be like a quote, unquote, normal child.

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. 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.

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. And that's when we actually started pushing back to doctors. We were like, "She is 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 our behalf. So, I mean the diagnosis

was a very long process and I think like a lot of families, we were in search of this silver bullet for years, you know, this therapy, that intervention.

Patima: I have vague memories of trying all the different medications, trying to have some sort of semblance of normalcy. This medication doesn't work or it's too much, too little. Try to find the right combination. We saw more than 20 medical professionals to try and get the name for my diagnosis.

Rachel: 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. And he finally came up with, it was not a hard diagnosis, but he did write a letter for the school district saying that she had all the indicators of ARND (Alcohol-Related Neurodevelopmental Disorder) and that for us was, 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.

Patima: It was, "Ah, I now have a name for this thing." You know, not just wondering, "Oh, what do I have? 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. Can't make it go away. You can just deal with it like how you would deal with any other thing. The unknown is scary. That's just human nature. We have fear, we fear what we don't know. We wanna know what things are. So, we name 'em. And, with that name comes knowledge. And with that comes problem solving and all things that we humans love to do. It's a way to make things less scary for us.

Rachel: You know, if you told us 10 years ago that this is who Patima would be today, it was hard to imagine. And so, for doctors and other medical professionals to know this is, it's a very different developmental trajectory. Once we started hearing about that as well, we became more hopeful that it's a different curve. So, there are so many strengths Patima has, that I think are.. [Rachel pauses]

Patima: the result [Patima interjects]

Rachel: somewhat associated with FASD. She has this incredible resilience. She has an incredible ability to persist. She's a fabulous artist because when she loves something she just keeps at it and keeps doing it. And I think that's another thing that medical practitioners need to know as well, that it's a whole child. And so there's gonna be beautiful talents and strengths that that child has that may or may not be associated with FASD. We don't know, probably there needs to be research on FASD and all the, the all the cool strengths that come with it, as well as all the challenges. 'Cause we tend to focus on the deficits and the challenges.

Patima: You can't stop it, but you can help it. You can help regulate it, help them figure out what these emotions are. You learn. Just as you learn words, just as you learn how to write. You learn what these emotions are called 'cause you see other people have them. If you can get the child to either verbalize or draw a picture or like

act out what they're feeling, it will help. Getting it out of their system. Getting it just out in the open so they don't hold onto it. 'Cause they don't know what it is.

Rachel: It's been an emotional journey.

Patima: It has.

Rachel: Yeah. Well, we love you so much.

Patima: You're gonna make me blush.

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