Williams syndrome: "It's like music in your heart"

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Nathan Brighthouse

Usually in May, Nathan Brighthouse joins in the Walk for Williams in Salt Lake City, helping raise awareness about Williams Syndrome. This year the event was canceled due to COVID-19. “It’s terrible,” he said.

Since he can’t go on the walk, Nathan offered an interview to let people know about the genetic condition he lives with. It includes heart problems, developmental delays and learning difficulties.

His message about Williams Syndrome: “It’s amazing. It helps people feel happy, and it makes me happy because it’s like music in your heart.”

If you know Nathan—and a lot of people do—you probably know how infectious his happiness is. He is friendly, and he remembers you even if he hasn’t seen you for a long time. He likes to hug a lot. And his friends know how much he loves soap. “Hand washing. … People make me laugh when they do it.” The Spirit Goat made a special soap for him called Nathan’s Choice. It has lavender in it. He likes the color, and he said the lavender is good for his anxiety, too.

Nathan works two part-time jobs, though both are on hold due to the pandemic. “I miss everything about my jobs right now,” he said. He plays basketball, goes on walks and gets on Facebook to help pass the time.

He is pleasant to be around, but he also really struggles when he is frustrated. When he was little, his family had to learn to watch for it. Times were different then—information on Williams syndrome was hard to come by.

“We didn’t even have internet access,” said his mother, Kerry. “We had to go to a medical library to look up the terms. … I remember going out into the garage and we had just bought a new van. I kept seeing these dents on the side.” She wondered how they got there—and later found out Nathan was hitting his head there when he was upset.

Frustration is still very hard for him. There are other challenges, too. “He’ll just take off and start talking to somebody, and that’s been true since he was really, really little,” Kerry said. Nathan loves people; it’s something he has in common with many others who have Williams syndrome. “Mostly they’re just a joy to be around,” Kerry said. “Sometimes it does require patience because they have a hard time with appropriate personal space.”

Social media has brought Nathan in contact with many friends, and with some who tried to take advantage of a kind heart. “Friends” have asked him for money, and it took him a while to understand why his family said he shouldn’t respond. “Now he knows that if somebody asks that, they’re not a friend, they’re a fraud,” Kerry said.

On the other hand, Nathan’s Facebook friends have supported him, too. Several have posted about Williams syndrome. (Full disclosure: I’m Nathan's friend, and he messaged me on Facebook to let me know this was Williams syndrome awareness month.)

When he calls someone his dear or his friend, he is sincere. When he’s happy, he’s truly happy. It’s even been the subject of scientific study. Researchers funded by the Williams Syndrome Association wanted to better understand what makes people with Williams syndrome happy, and whether there was something that triggers it that could be used to help people with depression. Nathan participated in that research.

When he was little, the Williams Syndrome Association was one of the few places where his family learned about the condition Nathan was born with. Another was the Center for Persons with Disabilities’ Up to 3 Program.

Today the information is much easier to find—so much that it can be overwhelming. “You have to break away and enjoy your child for who they are, and not just somebody with Williams Syndrome,” Kerry said.

Want to learn more? Visit the Williams Syndrome Association website.