Looking at autism from all angles, including through the lens of a video camera

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Dr. Frampton Gwynette talks with Kristina Blake as she edits a video for MUSC's Autism News Network. Credit: Sarah Pack

Kristina Blake has come a long way in a short time. But you'd never know it to watch her expertly editing a video newsletter on a laptop

computer she calls "Precious." She looks like she's been doing this her whole life. The video is for the Autism News Network at the Medical University of South Carolina. Blake is one of its stars.

"Hi, I'm Oprah. Welcome to the 'Oprah Winfrey Show,'" she said in the video, with a twinkle in her eye. It was April Fools' Day.

Blake looked confident on camera, standing on what appeared to be a news set but was actually a digitally generated background and desk. She shot the video at her house in Goose Creek.

A few years ago, Blake was feeling the opposite of confident when she joined the group for adults with autism spectrum disorder at the Medical University of South Carolina (MUSC) that runs the Autism News Network. "When I first started, I did not want to be here. I had so much anxiety built up, that I would just fall down [in a faint]," Blake said.

"But I've been in the group for probably over four years, and I've adapted to it. And then when I started getting involved in doing the newsletters, posting, everything like that, I started getting more confident. My thing is to let people know about this program because I don't want it to fall apart. So I'm doing all I can to let people know that it's important to me. Being in this group has definitely changed my life."

Her success showcases one of many ways MUSC Health's Institute of Psychiatry supports people with autism, during Autism Awareness Month. That support comes as genetic research could be a game-changer; tests for autism build buzz; the neurodiversity movement drives discussion; technology offers new options.

Genetic research

Frampton Gwynette, M.D., a psychiatrist specializing in autism and

attention-deficit/hyperactivity disorder, is a professor in the Department of Psychiatry and Behavioral Sciences at MUSC. He oversees the program for adults with autism and the Autism News Network.

He's also assisting principal investigator Laura Carpenter, Ph.D., an expert in developmental pediatrics, with MUSC's role in the national SPARK study. The project seeks to "improve the lives of people with autism by identifying the causes of autism and informing more effective therapies, treatments, services, and supports."

"For so long, in genetics, there really wasn't a payoff," Gwynette said. "They've poured billions and billions and billions into it, and there still hasn't been a huge genetic breakthrough in terms of interventions for people with autism spectrum disorder."

SPARK can change that, he said, because of its size. It has 100,000 people with autism and 175,000 family members participating, making it the largest autism study ever. The researchers are collecting and analyzing medical, behavioral and genetic information.

The goal is to learn more about the causes of autism to develop new treatments and actions that might prevent problems that can come with autism spectrum disorder. "It's probably going to change the way we look at autism," Gwynette said.

Tests for autism

Doctors usually diagnose autism by looking at a person's developmental history and behavior. But new methods are in the works.

Gwynette said a polygenic risk score is one promising possibility. "You can, based on DNA results, do a blood test, and based on analysis of different genes, figure out if this person's at significant risk for autism,

based on their gene score."

Then, there's a hair test. StrandDx-ASD looks at the chemicals in a strand of hair to screen for environmental exposures, including levels of some metals that doctors believe are associated with autism, and how the person regulates some nutrients. A peer-reviewed study in the Journal of Clinical Medicine found that it worked more than 80% of the time. The company that makes it, LinusBio, is seeking full approval from the Food and Drug Administration.

Brain fingerprinting, using medical imaging methods to create a map showing how different areas of the brain interact, is another possibility. Researchers at Stanford University came up with an algorithm that uses artificial intelligence to look at a brain fingerprint to try to predict whether a person has autism and how severe that person's symptoms may be. They say big data studies will be the next step in studying brain fingerprinting.

Meanwhile, other scientists have developed a test that looks at metabolites in blood to predict whether a person has autism. They say it worked 95% of the time in a study involving 131 kids with autism. More research is underway.

Gwynette said any test that gives families and doctors an early alert that a child has autism spectrum disorder would be valuable. "Early is usually defined at 18 months to 36 months. That's a really important window, because at that point, if somebody has autism, they haven't fallen too far behind their peers yet. There's more plasticity in the brain, so they can respond more robustly to interventions like behavioral therapy, speech therapy and physical therapy."

Neurodiversity

While all of that research is underway, some people with autism spectrum disorder are embracing their differences. The neurodiversity movement holds that it's normal for brains to function differently, and society should stop stigmatizing it, find ways to accommodate those differences and see people with autism and other neurological differences as an important part of our society.

"In the past, autistic could be seen as a derogatory term. But the neurodiversity movement is really interesting because some people don't want to be neurotypical or forced to receive therapies with a goal of being neurotypical," Gwynette said.

One neurodiversity advocate, Temple Grandin, was diagnosed with autism as a child. Now an animal expert, scientist and author, she said her ability to think in pictures is a gift that helps her solve problems neurotypical brains might miss.

On the flip side, some families who have loved ones with severe autism oppose the neurodiversity movement. They see autism as a disability that needs treatment to ease suffering. Promoting neurodiversity, in their view, undermines what they're going through.

Gwynette said there's a balance to strike for a condition with a wide range of manifestations. "I think it gets down to how we define impairment. If you look in the Diagnostic and Statistical Manual of Mental Disorders, there's not only criteria that have to be met, but there has to be impairment.

"So it's not only you have these characteristics, but they're causing a problem for you. You could have them and not feel like they're causing a problem for you. But if you don't have any friends, and you're being bullied all the time, and you have really bad sensory issues, and you know it's getting in the way of your quality of life, that's something you

need help with."

Technology offers new options

Gwynette said technology offers new ways to give that help. "It's a great augmentation to behavioral therapies. For instance, if you're doing speech therapy and you have an iPad, you can touch the picture of a car and the iPad will say 'car.' And you can start to acquire language more efficiently that way."

He said wearable technology such as watches can help families keep track of children who tend to wander, a common problem with autism. They may take off because they like to explore or because a situation upset them. "Wandering is one of the most dangerous things in the field—especially around water. Technology can help you know where your child is. That's important."

Gwynette said his team also uses technology to record people with autism role playing so they can watch the video and see how they're reacting and behaving.

Then, of course, there's the Autism News Network, where Kristina Blake and her colleagues produce videos, podcasts, broadcast and internet radio content and live events aimed at a mass audience. It's designed to offer social skills and vocational training for the participants and show others the viewpoint of adults living with autism.

Blake said you can see in the videos how much the MUSC-based network has helped her. "At first, I was so nervous that I had to be fed things to say, whether it was from Dr. Gwynette or somebody else. And then we had to cut that part out and just leave me in. But now, I'm doing it on my own. I'm the one that's in charge of the video. So I come up with the stuff now, and then I usually just pretty much go with the flow

with it. I enjoy it so much that even though I get nervous at times, I'm determined to do it."

Gwynette is thrilled by her progress. "I wish I could get a tape measure and measure her improvement. Anyone can see it."

Provided by Medical University of South Carolina