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Bright Futures

Articles and Updates from Phoenix Children's

March 30, 2022

On the Spectrum: Proactive, Personalized Care for Children with Autism

[Autism Spectrum Disorder \(ASD\) \(/blog-tag/autism-spectrum-disorder-asd\)](#) | [Barrow Neurological Institute at Phoenix Children's \(/blog-tag/barrow-neurological-institute-phoenix-childrens\)](#)

Challenges with verbal and non-verbal communication. Difficulty with social interactions. Repetitive behaviors. Attention deficit disorder. Learning disabilities. Tourette syndrome. All of these issues and more can affect children with autism spectrum disorders (ASD). Stemming from a neurological disorder, ASD is a developmental disability that typically appears during the first three years of a child's life, and the symptoms can be as individual and complex as the children themselves.

April is Autism Awareness Month, and treating children with ASD as the unique individuals they are is at the heart of the [Autism Clinic \(https://phoenixchildrens.org/autism-clinic/conditions-we-treat\)](https://phoenixchildrens.org/autism-clinic/conditions-we-treat) at [Barrow Neurological Institute \(https://www.phoenixchildrens.org/centers-programs/barrow\)](https://www.phoenixchildrens.org/centers-programs/barrow) at Phoenix Children's, the only comprehensive program of its kind in a children's hospital in Arizona.

"Our clinic is called the **Autism Precision Medicine Clinic** because of our attention to the specific patient," says neurologist Richard E. Frye, MD, PhD, chief of Neurodevelopmental Disorders and director of the clinic. "Our focus is on identifying and addressing each child's precise medical issues early, including those that may not be obvious, and then working with the child and their family to apply the best evidence-based treatments and behavioral interventions."

Innovative treatment helps Cheston speak his first words

Cheston, 11, was born with several medical issues and diagnosed with ASD at age 2. His family was new to Arizona and didn't know where to turn for help. A friend referred them to the [Developmental Pediatrics Program \(https://www.phoenixchildrens.org/centers-programs/developmental-pediatrics-program\)](https://www.phoenixchildrens.org/centers-programs/developmental-pediatrics-program) at Phoenix Children's.

"Cheston was newly diagnosed in 2014, and we didn't know what to expect. I didn't really understand what we were dealing with at first," recalls his mother, Hope. "At the clinic, they listened to our story and figured out where we were having the biggest challenges. They gave us a roadmap of what we needed to do for Cheston and walked us through the process."

Cheston was extremely hyperactive and nonverbal. He also experienced seizures. Typical medications for hyperactivity disorder made his behavior worse. So, he was prescribed alternative medications more specific for controlling hyperactivity in ASD, which he is still taking.

"His mind had been going so fast that he couldn't keep up, and he would get frustrated," says Hope. "The medicine calmed him enough to the point where he started to talk. After a few months of treatment, he came into the room and said, 'It's time for my shower.' Those were his first words."

Cheston also struggled with transitions, and changes would trigger seizures.

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“They educated us how to communicate with him and to deliver information the way he needs it, not how we think we should do it,” says Hope. “We also learned to let him work his way through, and there’s really not much he’s afraid to do now.”



Cheston met Daisy when he was having a challenging week, and the meeting led to a precious bond between

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Making earlier diagnosis a priority

Autism symptoms can range from mild to severe. While symptoms usually start when children are toddlers, an ASD diagnosis may not be made until years later, often making symptoms more difficult to manage. The earlier in life a child is diagnosed, the sooner they can begin treatment.

Phoenix Children's is leading the effort to diagnose autism early through the [Early Access to Care Arizona \(https://phoenixchildrens.org/earlyaccesstocarearizona\)](https://phoenixchildrens.org/earlyaccesstocarearizona) program. Here, pediatricians are trained to provide timely diagnosis and comprehensive care to children with ASD rather than referring them to diagnostic centers, which often have waitlists of six to eight months.

Vitamin and supplement clinical trials show promising results

Dr. Frye also leads several clinical trials to develop new treatments for children with ASD. Researchers have found that antibodies in the blood prevent folate (vitamin B9) from reaching the brain in some children with ASD, causing more developmental disorders. The study treats children ages 2 ½ to 17 years old with leucovorin calcium, a prescription type of folate that can bypass the antibodies to access the brain. So far, the 24-week clinical trial has shown promising improvement in language, communication and social interactions.

Meghan, 7, was officially diagnosed with ASD in 2019, but she had been showing symptoms, including hyperactivity, delayed speech and other developmental and social issues for many months, and was in a developmental preschool class. Her mother, Marie, learned about Dr. Frye's clinical trial through a social media group, and Meghan joined the study.

"We didn't know for the first three months if she was taking leucovorin calcium or a placebo, but we were almost convinced she was taking it because we saw significant changes within two weeks of her starting the study," says Marie. "It was pretty dramatic – not only with her language, but also with her interactions and social skills."

Marie adds that even people who didn't know Meghan was in the study commented about the spike in her language and communication skills. Now, as one of Dr. Frye's patients, Meghan continues to take leucovorin calcium.

"Dr. Frye is one of the few doctors in the country who does this type of research, and we feel very lucky to live nearby and see him on a regular basis," says Marie. "There is a good amount of behavioral support for kids with autism, but behavior is a symptom. He's doing important research on the biology of ASD and what actually happens in the body to really improve the quality of life for patients and families."



Drawing is one of Meghan's favorite activities. She especially enjoys drawing colorful animals and animated characters.

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Dr. Frye also leads another clinical trial to research a combination of nutritional supplements specifically designed for children who have both ASD and mitochondrial dysfunction, as Cheston does. Mitochondria are the structures within the body's cells that help them function properly and produce energy.

"Mitochondrial dysfunction is one of the medical disorders that has been consistently associated with ASD," says Dr. Frye. "It may be one factor that explains the diverse symptoms we see in some children."

The study aims to determine whether the supplements improve mitochondrial function and ASD symptoms, as they do for Cheston. Some children with ASD have mitochondrial dysfunction but may not know it. That's why the clinical trial will first test children for the disorder.

The Autism Precision Medicine Clinic at Phoenix Children's is also part of the Autism Speaks [Autism Care Network](https://autismcarenetwork.org/) (<https://autismcarenetwork.org/>), which collects and shares information from routine medical visits across North America. This continuous learning system expedites innovation and brings more personalized, effective treatments and therapies to local providers years earlier than traditional research.

"Dr. Frye is amazing. He's treated so many children and knows what they need. He watches Cheston and tells us how to adjust his environment," says Hope. "Cheston actually enjoys his visits to the clinic now. They get so excited when they see him doing better."

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