

COPING WITH AUTISM SPECTRUM DISORDER

RICHARD ELIAS NOTICED SOMETHING was off-track soon after his third son, Peter, was born 13 years ago. He just couldn't put his finger on it.

Over time, red flags started unfurling. Peter didn't make eye contact or attempt to make sounds. He didn't smile and his development was sluggish.

Richard and his wife, Amy, learned the truth when Peter was 18 months old: Their son was autistic. At first, they didn't know what that meant.

"Back then, people didn't have the awareness they have today," said Elias, who now heads up Autism Support of Kent County.

Since then, a patchwork of evidence suggests, but does not confirm, that autism may be linked to genetic disorders, inflammation in the central nervous system or undetermined environmental factors.

What is known and what isn't

What experts do know is one child in every 150 will be diagnosed with the neurodevelopmental disorder. Autism affects boys four times more often than girls.

In varying degrees, autism makes it difficult for children to communicate, form relationships and grasp abstract concepts. For some, a touch may feel like a flame, lights may be blinding, normal-level sounds may seem unbearably loud and common smells repulsive.

There is no cure for autism. It is a life-long disease that ranges from mild cases in which the autistic person can live independently to severe forms where they require social support and medical supervision throughout their lives.

"These kids with autism are very, very

loving and very intelligent," said Elias, president of ASK, which offers support groups for parents. "In a lot of ways, they have very special skills for certain disciplines."

Amid an alphabet soup of treatments, parents sometimes find it difficult to sift therapies that work from snake oil.

Elias denounces what he calls pseudoscience, taking particular aim at model and activist Jenny McCarty's claim that vaccines cause autism. Or that chelation therapy (removing heavy metals from the body) or a gluten-free diet offer cures.

"A gluten-free diet may improve a child's symptoms, but there's no cure," said Elias. "They may be able to function better, or have better speech, but that's not a cure."

Autism is known as a spectrum disorder, meaning it can affect each person in different ways and in varying degrees, said Dr. Tony Richtsmeier, behavioral pediatrician at Spectrum Health's Helen DeVos Children's Hospital.

Each autistic child manifests characteristics that fall somewhere within the spectrum, exhibiting a range of challenges with communication, social interaction, patterns of behavior, interests and activities.

"This is a true spectrum disorder, so you have children who are extremely high functioning and some who are extremely impaired," said Richtsmeier. "Some can make tremendous gains with minimally intensive therapies, and some, with multiple therapies, make limited progress."

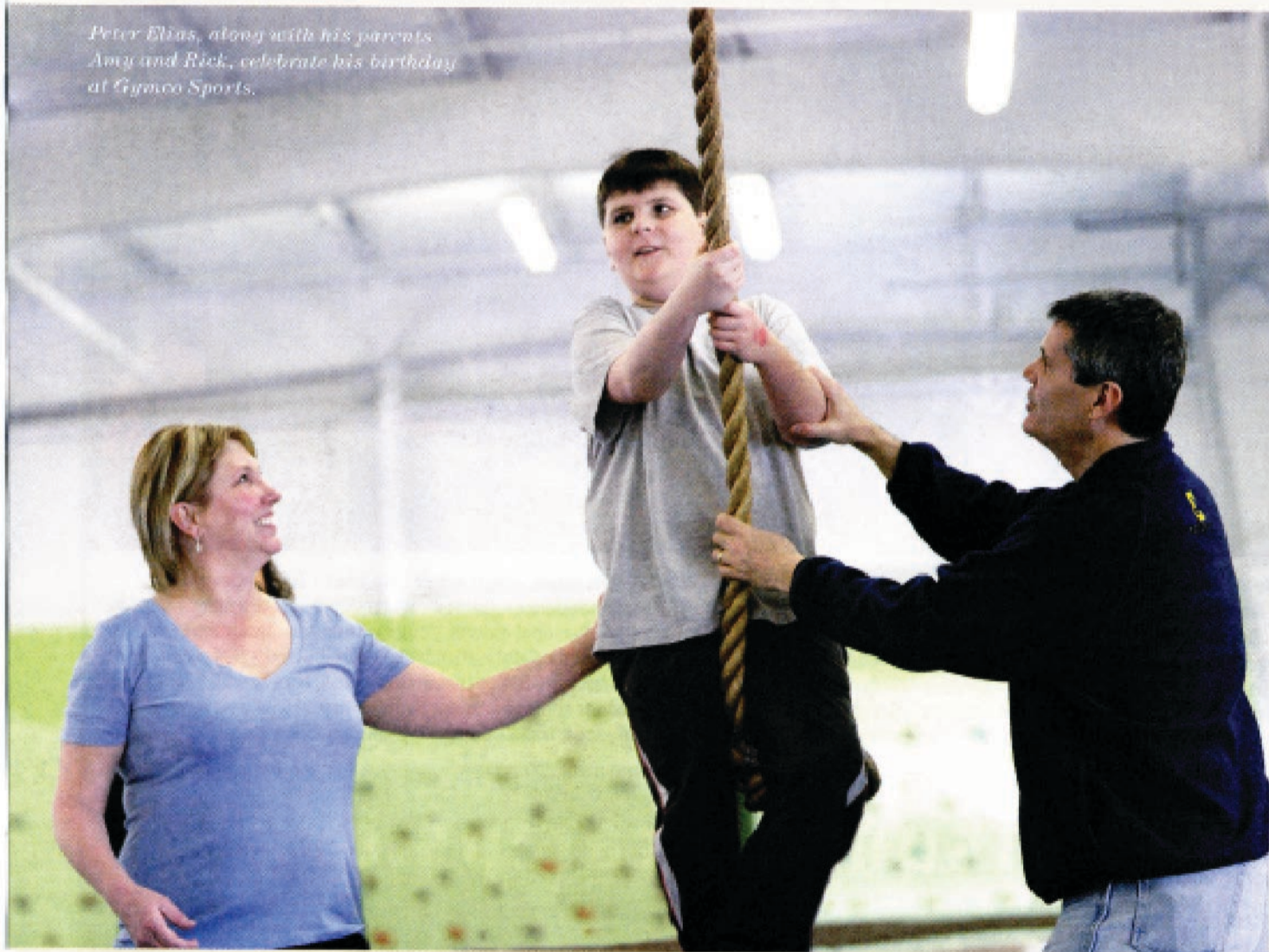
"There are many factors that might affect a particular child's response and progress. It does seem certain that early intervention is one important issue for these children."

Music and communication skills

At the Franciscan Life Center in Lowell, music is used to develop better communications skills, said Sister Mary Margaret Delaski, director of the center's music therapy program.

"It's pretty wonderful when you can get eye contact, and you know that through beating a drum, communication is going on even though they can't speak," said Delaski. "Even those who have a

Peter Elias, along with his parents Amy and Rick, celebrate his birthday at Gimco Sports.





hard time focusing on anything — music holds their attention.”

Music’s repetitive nature appears to key into an autistic child’s pattern of learning.

Singing and playing the piano, guitar or percussion instruments, used in tandem with visual aids, is an effective way to improve motor, communication and social skills, Delaski said.

“Then, of course, it’s fun,” she said. “Often these children have so many stresses in their lives. This is one time they’re having fun because life is not too easy for them.”

Neurofeedback reflects inefficiencies

Some parents claim success with neurofeedback. Also known as neurotherapy, this technique provides real-time feedback on brainwave activity measured by sensors on the scalp, typically in the form of a video display, sound or vibration.

This provides the clinician with information on how the brain is performing and reflects its inefficiencies, said Molly Raaymakers, neurotherapist for Neurotherapy Associates of West Michigan in Grand Rapids.

When brain activity changes in the direction desired, a positive feedback “reward” is given to the individual, she said. Reward, or reinforcements, can be as simple as the change in pitch of a tone or as complex as the movement of a character in a video game.

“The brain, for whatever reason, gets a number of ‘hicups’ in how it’s able to perform and function,” said Raaymakers. “By identifying how the brain is getting stuck, we are able to get the brain to self-correct.”

Relationship Development Intervention

Nicole Beurkens, director of Horizons Developmental Remediation Center in Caledonia Township, said her family-based approach to helping autistic children begins with making no promises.

“We don’t talk about cures,” said Beurkens. “We tell parents our goal is help them work with their child, where their autism is no longer an obstacle for them.”

TYPES OF AUTISM SPECTRUM DISORDER

Autism is not a one-size-fits-all definition. There are actually three different types of autism spectrum disorders, according to the Centers for Disease Control:

Autistic disorder (also called “classic” autism): This is what most people think of when hearing the word “autism.” People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.

Asperger syndrome: Those with Asperger syndrome usually have some milder symptoms of autistic disorder. They might have social challenges and unusual behaviors and interests. However, they typically do not have problems with language or intellectual disability.

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS, also called “atypical autism”): People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all, may be diagnosed with PDD-NOS. They usually have fewer and milder symptoms than those with autistic disorder. The symptoms might cause only social and communication challenges.

Topping Beurkens’ list is helping autistic children develop genuine friendships and learn language, communication and social interaction skills so they gain the highest level of independence possible.

“A lot of people give lip service to that,” said Beurkens. “What really happens is the experts don’t look far enough in the developmental sequence, and try to teach skills much higher than what the child is really ready for. We have to go back in the developmental process and make sure foundations are there.”

Beurkens starts with a program called Relationship Development Intervention to determine where the child is functioning developmentally, and how well he or she is interacting with their parents.



With the help of his brother, Luke, and his father, Rick, Peter Elias crosses a balance beam.

CD, video games can help

A virtual tractor or spacecraft helps some children whose environment is overstimulating them. Some autistic children may appear deaf or develop perseverant behaviors like hand flapping. Others may have difficulty with balance.

Vision Audio Inc. of Joppa, Md., has created therapeutic audio CDs and computer video games to assist those with autism spectrum disorders, said Bill Mueller, audio engineer, game developer and president of Vision Audio.

In 1996, Mueller created CDs called the Electronic Auditory Stimulation effect, or EASE, series to help autistic children learn how to cope with noise.

"They are not simulation games but driving and flying games, games where you drive a vehicle into a challenging environment that causes the horizons to be constantly moving," said Mueller. "This challenges the child to maintain their orientation while their car may be rolling and tumbling."

Helping autistic children adapt to normal sounds that may make them jump is the music CDs' mission. "We create an environment where we have a generally subdued background noise level, which in this case is muted music. So the music is played through a filter and high frequencies are turned down, and for very short and very intense movements, we open that filter up and let those high frequencies come through, and then we shut them off again," said Mueller.

"What that does is stimulate the child's auditory pathways to the brain but it does not over stimulate the pathways so the child doesn't want to run away screaming. It's a short, high-intensity auditory stimulation."

The sounds are introduced in very small doses, said Mueller. Eventually, the child learns that they're not harmed by these noises. The brain learns to accept it and eventually ignore it, which is the goal.

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"That give us a specific sense of what gaps are in their development and what we need to work on," said Beurkens. She usually meets with parents twice a month so she can help them change the way they are interacting with their child.

Families are encouraged to provide video footage so Beurkens and her staff can provide constructive feedback to make sure they're on the right track. They re-evaluate every six months to make sure they're making progress.

Parents are searching for something that is going to improve the day-to-day quality of life for their child.

"They're looking to make things easier, to be more effective and competent in parenting their children," she said. "They're looking for somebody to guide them so they don't have to feel so alone in trying to manage their child's needs and ease their worries in what the future might hold."

Horseback riding benefits

Some parents say horseback riding builds muscles and strengthens hand-to-eye coordination. It also helps the child learn shapes and colors and follow directions, and is a great self-esteem booster, said Sarah Engel, horseback-riding trainer for a year-round therapeutic program at Lamoreaux Ridge Equestrian Center in Grandville.

"It gives them a sense of pride and accomplishment," Engel said. "There's incredible benefits to just sitting in the group with other people. Sometimes they bond more to the horse and sometimes to the people — other riders and side walkers who are there helping them in case they need extra strength for balance."