



BEAUTIFUL LITTLE MINDS

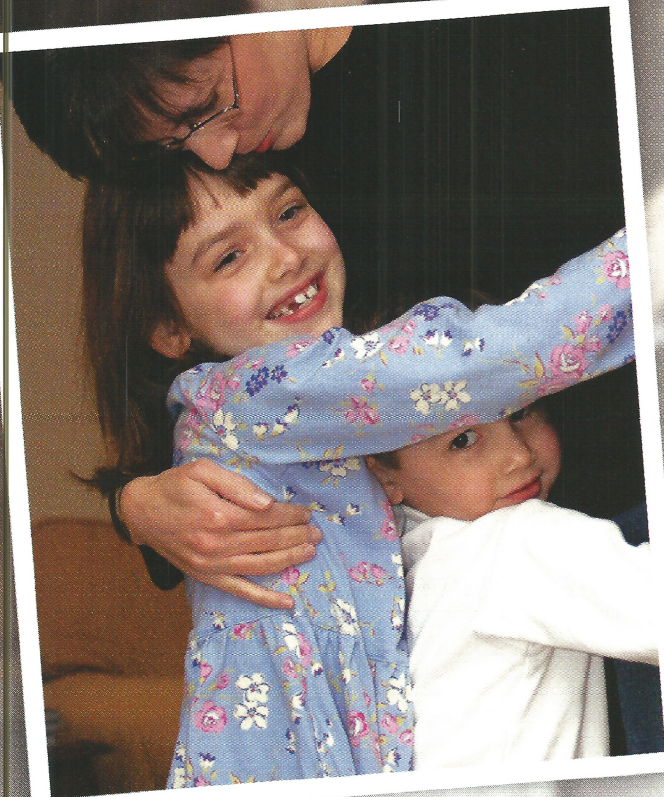
COLLEEN PHELAN KNOWS THAT HER SON

Patrick said "I love you" to her for the first time on September 7 at 8:15 p.m., when he was three years old. She also knows that her daughter Megan finally said "Mom" on December 11 at 2 p.m., when she was two years and nine months old. Phelan's oldest child, Katie, reached these milestones, too, but she didn't memorize the dates and times. This is because Megan and Patrick have autism, and Katie does not.

"My autistic kids' victories often touch me in ways Katie's can't," says Phelan. "These milestones are so difficult for them. Megan's first 'Mom' meant more to me than Katie's did, because it was so much harder for her to learn. And when Patrick said he loved me, just the fact that he could even view me that way was extra precious."

Parents of typical children take for granted that they can have daily, emotional interaction with their kids. We don't always feel a special thrill when our children look us directly in the eyes, we don't get teary eyed when our children answer our questions and converse. We take for granted that they can go with us to restaurants, stores, and other people's houses, that they get potty trained before they start school, that they can eat what they want, and we can leave them with a teenage babysitter from the neighborhood when we have to go to the dentist.

written by Lynn Prowitt-Smith / photography by Kristin Burke/Peter Baker Studios



Parents of autistic children take nothing for granted, and they learn to celebrate every victory, no matter how small. If you want to witness the most extreme examples of human nature's ability to adapt, triumph over adversity, find silver linings, and harness the power of love, meet a family that lives with autism.

WHAT IS AUTISM?

Autism is now referred to as Autism Spectrum Disorders (ASDs), which represents a group of pervasive developmental disabilities

(PDDs) that affect a person's ability to process their experiences. ASDs are generally diagnosed before the age of three, but can be noticeable in the first year of life. The new use of the term spectrum is significant because it describes the very wide range of ability and symptom combinations that exist. The common threads for ASDs, according to the Autism Society of Connecticut, are threefold: First, impairment in understanding and expressing verbal and non-verbal communication; second, problems relating socially; and third, behaviors that may be repetitive, seemingly without purpose, or inappropriate.

"ASDs encompass a group that spans from kids who have a really, really low IQ to those who are very high functioning," says Isis Bartels, M.D., a Fairfield resident and pediatrician at Willows Pediatrics in Westport. "Some of those kids will have nothing except problems with social interactions, and other kids will have motor skill problems or they'll have a learning disability or something else." Other telltale indicators are a propensity for repetition and rigidity, such as obsessively arranging objects or following very specific routines. "But there's always a social deficit and problems in communication—that's the substrata."

No two kids on the spectrum are exactly alike, but the themes are consistent. Many have trouble with eye contact, have delayed or limited speech, can easily memorize things they hear and then repeat them over and over. It's common for children with autism to become extremely attached to a certain toy or object. Also often associated with ASDs are sensory integration issues—problems processing sound or tactile sensa-



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tions, for example—and exacerbating food sensitivities, such as intolerances to gluten and casein, virtually omnipresent components of wheat and dairy.

WHAT CAUSES IT?

This question is a source of great frustration and debate, and theories abound but definitive answers are scarce. A widespread and persistent theory was that the MMR (Measles, Mumps, Rubella) vaccine triggered autism. Next, people began to suspect a mercury-containing preservative used in vaccines called thimerosal. But conclusive research reveals no causal relationship between vaccines and autism. "Study after study has shown and disproved that there's any cause with regard to the MMR," says Bartels. "Kids who don't get the MMR have as much autism as kids who do get the MMR. And it's the same with the mercury."

Thanks to new research—findings that show brain differences in people with autism and very recent confirmation of a genotype that increases the risk of autism more than two-fold—science is inching closer to a better understanding of what causes this neurological derailment. If one identical twin has autism, the other has a 60 percent chance of having it, which confirms a genetic component. One recent study showed that older fathers, ages 40 to 49, are nearly six times more likely to have offspring with autism, regardless of the mothers' age. This implicates chromosomal damage. What is known so far points to only one certainty, and that is that ASDs result from some combination of genetics and environmental influences.

>> story continued on page 36

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"Clearly, there's the genetic link, and then I think with a lot of these children there is some insult to their systems that triggers a change their neurological development," says Melissa Van Buren, Ed.D., a developmental specialist who evaluates and treats children with special needs from all over Fairfield County. "There are so many accounts of the first couple of months to a year seeming quite normal and then usually you hear about illnesses, repetitive ear infections, or some other insult to their system."

According to the Autism Society of Connecticut, research is being conducted in the following areas: immune system dysfunction, gastrointestinal disturbances, vaccine reactions, metabolic disorders (gluten and casein intolerance), yeast and fungal imbalances, sensitivities to food additives, environmental pollution, and viral infections.

THE PREVALENCE MYSTERY

Current statistics say that about one percent of the population has an ASD. But a more alarming number is this: One in 104 boys is "on the spectrum," and 67 children are diagnosed every day. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to strike boys than

girls. According to Autism Speaks, autism's largest advocacy organization, more children will be diagnosed with autism this year than with AIDS, diabetes and cancer combined.

When you ask people who work with autistic children, many are convinced that there are significantly more autistic children today than there were 10 or 20 years ago. "My experience is that we're seeing many more children on the spectrum these days," says Van Buren. Speech pathologist Denise Leverty, who works for the Shelton-based Child and Family Network, has been working with autistic kids for 13 years, and she concurs: "Ten years ago, we saw one autistic kid every three months, if that. It was very rare. Now, we pick up one to two kids a week who are on the spectrum."

However, in a baffling paradox, the science does not show an actual increase in prevalence, only in diagnoses. Says Bartels: "I really think that the increase in diagnoses is due to the fact that we are analyzing it better and defining it better more than anything else. It's not that they weren't there before, it was just called mental retardation and that was it. Now we're categorizing the different types of developmental delay, so autism has come into greater focus."

WHEN AUTISM HAPPENS

Mark and Susan Durham of Fairfield came to the conclusion that something wasn't right with their twin boys, Ethan and Henry, when they were around 18 months old. "Too many suspicious things were going on at once," Susan says. "We were sending the boys to a daycare a few

days a week and it became even more apparent. Ethan [who is more affected than Henry] was happier walking the perimeter of the play area and not really interacting. We could see that he was going to be kind of marching to his own beat."

The most striking change, though, was a dramatic alteration in eating. "It was Ethan more than Henry," says Mark,



who has been a stay-at-home dad with the boys for five years. "He went from eating all kinds of stuff to basically eating cereal and crackers, anything that was brown and crunchy, or cheese. Ethan basically existed for about two and a half years on nothing but graham crackers and shredded cheese." This turned out to be a telltale sensory integration issue, and Ethan has worked with a therapist and his parents to desensitize his mouth to other textures. "Every week, we sat there and for half an hour he screamed his head off while the speech therapist tried to get him to take just a little taste of pudding or some other soft food," says Mark. After about four months, the therapy was successful and both boys, now in first grade at Dwight Elementary School, eat a wide variety of foods.

"The first year was terrible, a nightmare," says Mark. Susan went back to work, because Mark had been laid off and she could more easily go back to her job than he could find a new one. "I didn't even know what questions to ask. This was a whole new area for me. I

studied economics in school, I have an MBA and worked in business for 13 years. This was completely new, trying to deal with nonverbal beings and toilet train them and all this other stuff, and these problems on top of it. And then, you know what? I'm a guy. I don't get called for play dates. I'm not going out for coffee with the girls at Starbucks and trading babysitters and all. It's harder."

Fairfield mother, Kristin George, learned that her son, Matteo, was autistic before he was two years old. "At Matteo's 18-month appointment, our pediatrician suggested having him evaluated," she says. "I went home and started reading, and I knew immediately. There were descriptions of odd little behaviors. He loved to look at books, but when he wanted us to read to him he would grab a book and then back into our laps—put his back to us and just back in. That was mentioned in this book that we read. It's something a lot of kids do. Also, he could do puzzles at 12 months old—another very common feature—would spend long periods of time building with blocks.

I just thought he was so smart—'oh, my child, he can focus so well, and look at his fine motor skills!' In fact, again it was a repetitive behavior, building something and knocking it down, over and over. Back then, if you had mentioned autism to me, I would think of someone banging their head against the wall, not a kid who giggled and enjoyed being cuddled. I didn't realize there was such variation."

When Matteo suddenly started speaking at 2 years and three months old, his first words were the letters of the alphabet. A month or two later, he began saying some other words and Kristin, too, got to hear those extra precious words. "One of the first things I taught him to say was 'I love you' because those were three words that I really needed to hear!"

The Phelan's two children were diagnosed on the spectrum within a year of each other. "Megan [the older child] was born with her autism," says Colleen Phelan. "But for Patrick—and this is common for kids who are regressors [autistic children who show normal behavior to a certain point and then regress]—he had a



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ECC, an individualized plan is created and the child goes on to kindergarten in their school district or, as part of the magnet program, to one of the schools with a special ASD-targeted classroom. These classes currently exist at Dwight, Osborn Hill and Jennings. Connecticut public schools have more than 2,150 students in kindergarten through 12th grade with an ASD.

"Fairfield and Greenwich are arguably the two best school districts in Connecticut for autistic kids, especially in the preschool years," says Colleen Phelan. "If you have a child with autism, you're going to try to get to a handful of school districts and avoid some others like the plague. Greenwich is number one but Fairfield is arguably number two."

And it's not only the services. "Fairfield has a big emphasis on diversity," says Kristin George, "and teaching kids that there are other children who have differences and it doesn't make them any less valuable as a friend. As a result, the kids here are very accepting and compassionate."

EARLY DIAGNOSIS AND BREAKING HEARTS

What happens during the time a child is in the Birth to Three program, preschool (at the ECC or elsewhere), and in kindergarten, is especially crucial, because most experts agree that the window of opportunity for dramatic improvement begins to narrow around the age of five.

"Every single study shows that the quicker you identify the problems in these young brains and remediate, the better the outcome," says Dr. Bartels. "Here's the tricky part about it—especially early on when they're babies, it's the absence of normal behavior rather than the presence of abnormal behavior that tells you. The babies will respond; it's not like there's something wrong with them. In many cases, you just assume it's something they're going to do a little later. At four months, we ask if the baby is rolling over, interacting with you, laughing. And most parents will say, yes, the baby is laughing. But you don't know if the laughing is in response to the parent or to an object that amuses him."

Picking up the signs is one thing, but breaking the news is another. "Sometimes I already know that something is wrong with the child, but the parent's heart can't take it," says Bartels. "You have to tread very lightly. Sometimes you have to wait, you drop little hints, and you hope that they'll buy into it so that you can get the child into a program and move forward. But after all, it's their child. Sometimes these parents need time to put their hands around it."

Even after they get their hands around it, it's a long, stressful road. "There's all the uncertainty," says Kristin George. "Will he be able to graduate from high school, go to college? Will he have friends? Will he be able to have relationships? Will he be happy? Will he be able to have a job and live independently? Who will take care of him if and when something happens to us? Will our daughter [Teresa, who is typical and in first grade at Jennings] be able to cope? I'm sure parents of typical kids feel anxiety about those types of things too, but it's magnified. The stress is pretty unbelievable."

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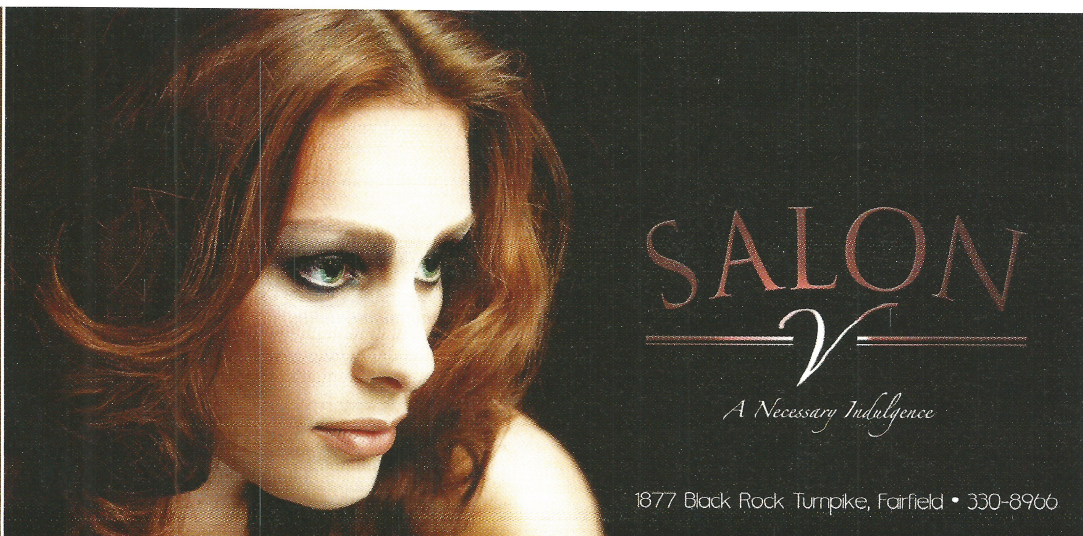
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ON THE SPECTRUM

Autism is now categorized into five spectrum disorders, which more specifically pinpoint a child's abilities, disabilities, and symptoms.

CELEBRATING THEIR SUCCESSES

Though the window of greatest opportunity for these kids may be limited, they do make progress—often surprising their parents and the experts. “Megan astounded the researchers at Yale, where she took part in a study,” says Phelan. “With her first visit there when she was two, she was given the PPD NOS [see sidebar below] diagnosis with the warning that she could be severely affected. She was just there a year ago for the follow up and they couldn’t get over the improvement. Today, Megan is in kindergarten at Dwight with very limited supports.”

ASPERGER'S DISORDER (ALSO CALLED ASPERGER'S SYNDROME)

This “high functioning autism” is characterized by a lack of social skills, difficulty with social relationships, a restricted range of interests or activities, but normal or above normal intelligence and at least adequate language skills. However, communication subtleties such as humor, irony, idioms, tonal inflections, or non-verbal communication may escape their understanding. Asperger's tends to be diagnosed later than the other ASDs because it is subtler.

PERVASIVE DEVELOPMENTAL DISORDER NOT OTHERWISE SPECIFIED (PDD NOS)

Sometimes called just PDD, or atypical autism, this diagnosis means the child does not fully meet the criteria of symptoms or does not have the degree of impairment that would clearly place them in another category of developmental or psychiatric disorders. PDD does suggest significant impairments, however, in communication, socialization and behaviors.

AUTISTIC DISORDER

Sometimes referred to as early infantile autism, childhood autism, or simply autism. This category is for people who may have some degree of mental retardation and fall within the moderate to severely impaired range for communication, socialization and behaviors.

RHETT'S DISORDER

Also called Rhett's Syndrome, this occurs mostly in females where typical development lasts to approximately six to 18 months and then a change in behavior, regression in speech and/or reasoning, or loss of other previously acquired skills is noticed. Gross motor skills and use of hands may deteriorate into repetition of movements that generally look like constant hand wringing or hand washing.

CHILDHOOD DISINTEGRATIVE DISORDER (CDD)

CDD is characterized by normal development for at least the first two years, followed by definitive regression (sometime before the age of 10) in several areas of functioning, including social language skills, gross motor skills, and bladder/bowel control. Children will have all the indicators of autism, but not the history that would be typical of an ASD.

Adapted from the Autism Society of Connecticut

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