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# 6 Facts You Need to Know About Autism

There are lots of frightening rumors about what causes this mysterious brain disorder in children. We asked leading experts across the country for the very latest news.

By Jan Sheehan

## Facts Every Parent Should Know

Nancy Wiseman had a feeling early on that something wasn't quite right with her daughter. When Sarah was 6 months old, she stopped babbling, and by 10 months, she was silent. By 18 months, the increasingly aloof toddler no longer responded to her name, and she resisted being held, kissed, or touched. "I felt that I was losing my child a little more each day," says Wiseman, of Merrimac, Massachusetts. When Sarah wasn't saying any words or even making sounds that resembled words by 20 months, her grandmother, a school psychologist, suspected that the girl might actually be deaf. Instead, Wiseman was devastated to learn that her daughter had autism. "The diagnosis really knocked the wind out of me," she recalls, "but I was relieved to finally know what was wrong."

Although the severity of autism can vary widely, many children with the neurological disorder -- which typically appears in the first three years of life -- have problems speaking, interacting with others, sharing affection, and learning. Thanks to the tireless efforts of parents and advocates, public awareness of autism has grown tremendously since it was first identified in 1943, but it is gaining even more attention today than ever before. Congress has held hearings on the condition. Public-health agencies are spending millions to study it. Researchers at countless universities are racing to find the causes and best treatments.

"There are many unanswered questions," says Alice Kau, Ph.D., an autism expert at the National Institutes of Health, which funded more than $74 million in autism research in 2002, as compared with only $22 million in 1997. Still, researchers are beginning to make progress in unraveling this baffling disorder, and the number of resources available for families is increasing. Here, six facts about autism that every parent should know.

### 1. RATES ARE ON THE RISE

Autism is ten times more common today than it was in the 1980s, according to the Centers for Disease Control and Prevention. More than three in 1,000 children in this country have autism to some degree. In California, the number of kids with autism in the state's social-services program nearly doubled between 1998 and 2002, surpassing cases of childhood cancer, juvenile diabetes, and Down syndrome. Nationwide, autism strikes three to four times more boys than girls; the rates are about the same for kids of all races.

Although there seems to be an autism epidemic, most experts attribute the increasing prevalence to improved diagnosis and reporting. The definition of autism has been expanded in the past decade to include a wider spectrum of problems with communication and social interaction. "Ten years ago, many children with mild autism were simply not diagnosed," says Adrian Sandler, M.D., a developmental-behavioral pediatrician at Mission Children's Hospital, in Asheville, North Carolina, and chair of the American Academy of Pediatrics' committee on children with disabilities. Plus, there are more state and federal programs for autistic kids, giving doctors an incentive to diagnose and refer them. However, there may be additional, unknown reasons for the spike in autism rates, and researchers are investigating everything from environmental toxins to viruses to food allergies.

### 2. KIDS ARE GETTING DIAGNOSED SOONER

There's no laboratory or medical test for detecting autism, so doctors must rely on behavioral signs. In the past, many were reluctant to label a child as autistic until symptoms became obvious. "The average age for diagnosis had been about 3 1/2, with many children diagnosed much later," says Amy Wetherby, Ph.D., director of the Center for Autism and Related Disabilities at Florida State University, in Tallahassee. But that's changing.

One reason is that pediatricians are becoming more aware of autism. At the same time, autism specialists are better at identifying early telltale signs such as a lack of babbling or pointing. "Most children with autism will show some signs of developmental disruption by their first birthday," says Rebecca Landa, Ph.D., an autism researcher at Baltimore's Kennedy Krieger Institute.

And while no one is yet diagnosing autism in children that young, doctors can now make a reliable assessment by 24 months -- when a child's brain is still rapidly developing. "If we can intervene while a child's brain is very immature, it will be much easier to help change her behavior," Dr. Wetherby says.

**3. AUTISM IS A GENETIC DISORDER**

Although autism was once believed to be the result of improper parenting, researchers now believe that genes -- not psychological factors -- are to blame. If a couple has one autistic child, there is a 5 to 10 percent chance that siblings will have some sort of autistic disorder. With identical twins, the likelihood is 60 percent. Even though profoundly autistic people rarely have children, researchers often find that a relative has mild autistic symptoms or a high-functioning autistic-spectrum disorder known as Asperger's syndrome.

Experts believe that autism is the result of multiple genes -- anywhere from three to 20 -- interacting with each other. This may explain why the symptoms and severity of the disorder vary greatly. These genes may cause a baby's brain to develop abnormally in utero or make him more susceptible to unknown triggers. "There is probably a combination of genetic and environmental influences," says Catherine Lord, Ph.D., director of the Center for Autism and Communication Disorders at the University of Michigan, in Ann Arbor. Although the genes linked to autism have not yet been pinpointed, intense research is under way.

## Research, Early Signs and Treatment

**4. THERE IS NO KNOWN SCIENTIFIC LINK BETWEEN VACCINES AND AUTISM**

There's been widespread controversy about a possible connection between vaccines and the soaring autism rates. Some parents of children whose autistic symptoms first appeared shortly after their measles-mumps-rubella (MMR) immunization are convinced the shot was the cause, but repeated studies have failed to find scientific evidence. Although one small, heavily publicized British study published in 1998 suggested a link, ten of the 13 authors publicly retracted the findings this March, saying they were unreliable. (The lead researcher reportedly had a conflict of interest because he was also working with lawyers filing a suit against vaccine manufacturers.)

Because the MMR vaccine is routinely given at 12 to 15 months -- when the first symptoms of autism often become noticeable -- the apparent association is a coincidence, says *Parents* adviser Neal Halsey, M.D., director of the Institute for Vaccine Safety at Johns Hopkins University, in Baltimore. Up to 40 percent of children with autism typically experience regression at 12 to 18 months; they start developing normally but then suddenly lose communication and social skills.

Even so, some pediatricians have been offering the option of delaying the vaccine until 21 to 24 months of age to ease parents' worries. By then, toddlers are typically talking, so autism can be ruled out. But Dr. Halsey warns that this trend could be more harmful than helpful, because it leaves children unprotected from potentially fatal illnesses.

The possibility that mercury poisoning might cause autism has also been in the news. Since the

1930s, a preservative called thimerosal, which contains small amounts of mercury, had been used in some childhood vaccines (not MMR). Although mercury is known to be harmful to the brains of infants and young children, most vaccine experts say the amounts used in the preservative were too tiny to cause neurological damage. Nevertheless, manufacturers voluntarily began removing thimerosal in 1999, and by the end of 2001, none of the routine vaccines given in early childhood contained the preservative. The preservative is now used only in flu shots and some vaccines given to adults and adolescents.

**5. LARGE HEAD SIZE IS A RED FLAG**

Recent findings published in the *Journal of the American Medical Association* suggest that the brains of children with autism develop differently from an early age. Researchers discovered that most infants who were later diagnosed with autism had small head circumferences at birth but had heads -- and brains -- much larger than normal by 6 to 14 months. "Some of them went all the way up to the 90th percentile in just a few months," says study coauthor Natacha Akshoomoff, Ph.D., an assistant professor of psychiatry at the University of California, San Diego. Those who ended up with the most severe form of autism were found to have the most dramatic acceleration of brain growth during infancy.

Pediatricians don't always measure head circumference at well-baby visits, so it's wise to request it. However, don't panic if your baby's head size is above the norm. Some babies just have big heads. "Rapid head growth is not a way to diagnose autism," Dr. Akshoomoff points out, "but it means that a child should be watched closely to be sure that she meets speech and behavioral milestones."

**6. EARLY TREATMENT IS CRUCIAL**

There is no known cure for autism, but intensive therapy helps a child learn a wide range of skills -- from making eye contact to hugging to having a conversation. And the sooner a child begins, the better. A panel of experts convened by the National Academy of Sciences in 2001 recommended that children should have 25 hours of therapy per week as soon as autism is suspected. Because children with autism have very different behaviors and abilities, the most effective approach takes into account a child's unique challenges and encourages healthy development through play, rather than just trying to change specific symptoms. "Intervention can take many forms, from going to a regular preschool to a parent's working with her child over the course of a normal day to direct therapies from well-trained teachers and professionals -- all depending on the child," Dr. Lord says.

Thanks to early intervention, some children -- like Nancy Wiseman's daughter, Sarah -- make remarkable progress. "At the very least, we're able to lessen the severity of symptoms," says Dr. Lord, who chaired the expert panel. "The latest studies show that almost 80 percent of kids with autism now have some speech by age 9, whereas only 50 percent of these kids were talking 20 years ago." And though past research suggests that most autistic children have below-average cognitive abilities, a recent study found that early treatment raised children's IQ scores by about 20 points, to almost normal levels. Those who started therapy as toddlers were also more likely to attend regular kindergarten.

One of the biggest remaining challenges is the shortage of trained therapists and spots in special-education programs and schools for children with autism. To address this problem, the federal government recently announced a ten-year plan to provide adequate services.

While there's still much about autism that remains a mystery, research scientists are making new discoveries every day. In fact, they say, it may be possible to cure autism one day -- perhaps through gene therapy even before a child is born. But for now, early diagnosis and therapy offer the best hope. "There's no doubt that today's generation of autistic kids will be better off than previous generations, because they're getting help sooner," Dr. Wetherby says.

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