

What is autism?

Autism is a complex brain disorder that affects a child's ability to communicate, respond to surroundings, or form relationships with others. Autism is a developmental disorder of the brain that occurs in people of all racial, ethnic and social backgrounds. Children with autism are not unruly kids who choose not to behave.

Generally diagnosed at age 2 or 3, few disorders are as devastating to a child and his or her family. Many children with autism will never be able to tell their parents they love them.

While some people with autism are mildly affected, most people with the condition will require lifelong supervision and care and have significant language impairments. In the most severe cases, affected children exhibit repetitive, aggressive and self-injurious behavior. This behavior may persist over time and prove very difficult to change, posing a tremendous challenge to those who must live with, treat, teach and care for these individuals. The mildest forms of autism resemble a personality disorder associated with a perceived learning disability.

First described over 50 years ago, the incidence of autism is rising steadily. While criteria for diagnosing autism have changed over time and the number of cases reported have increased, studies indicate that:

- An estimated one in 1,000 children have autism
- Two to five children per 1,000 show some form of the disorder
- As many as 1.5 million Americans today are believed to have some form of autism.
- Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a rate of 10-17 percent per year.
- Changes in how autism is diagnosed, criteria for diagnosing autism and number of cases reported may account for some of the increases in incidence of the disorder.
- Autism is four times more prevalent in boys than girls.
- If a family has one child with autism, there is a 5 to 10 percent chance that the family will have another child with autism.
- If a family does NOT have a child with autism, there is only a 0.1 to 0.2 percent chance that the family will have a child with autism

[Source: Centers for Disease Control (CDC), National Institutes of Health (NIH), National Alliance for Autism Research (NAAR)]

What causes autism?

While identified over 50 years ago, no one is sure what causes the disorder. Researchers believe this is probably a combination of genetic and environmental factors. One thing is certain – autism is an extremely complex disorder. It is likely caused by multiple gene changes throughout the genome; probably 10 or more genes are involved.

Various studies have been done to identify the cause of the disorder and multiple theories have been proposed:

- Under certain conditions, a cluster of unstable genes may interfere with brain development resulting in autism.
- Problems occurring during delivery.
- Environmental factors such as viral infections, metabolic imbalances, and exposure to environmental chemicals; harmful substances ingested during pregnancy.
- In 1998, British researchers published a controversial paper suggesting a link between the growing number of autism cases and the standard childhood vaccine for measles, mumps and rubella (MMR). The possibility of a relationship between vaccines and autism is being debated to this day.

- Long since disproved, in the 1950s and 1960s, doctors believed autism was a psychological disturbance caused by detached, or uncaring “refrigerator” mothers.

Is there a cure for autism?

No. There is no cure, but if a child is provided with special education, significant improvements may be made in the child’s social development.

There is no blood test or diagnostic scan that can diagnose the disorder. Physicians rely on behavioral observations to make their diagnosis.

While the public has become more aware of the disorder in recent years, autism research remains one of the lowest funded areas of medical research by both public and private sources.

How long have we known about autism?

People have lived with autism throughout history – published descriptions of behavior resembling autism date back to the 18th century. A number of researchers and doctors have studied autism over more than 50 years:

- 1943 – Dr. Leo Kanner was the first person to describe a specific condition as autism.
- 1940s – Dr. Bruno Bettelheim suggested that detached, uncaring “refrigerator” mothers caused psychologically disturbed children to develop autism, a belief that most doctors held through the 50s and 60s.
- 1964 – Dr. Bernard Rimland provided evidence that proved autism was a biological condition, proving that Bettelheim was wrong, thus liberating mothers from years of shame and guilt.
- 1977 – Dr. Susan Folstein and Dr. Michael C. Rutter published the first autism twin study, revealing evidence of a genetic basis for autism.
- 1991 – Drs. Catherine Lord, Michael Rutter and Ann LeCouteur published the Autism Diagnostic Interview.
- 1992 – The American Psychiatric Association released the Diagnostic and Statistical Manual (DSM-IV), which refined diagnostic criteria for autistic disorder.
- 1993 – The World Health Organization released a similar diagnostic manual known as the International Classification of Diseases (ICD-10).
- In 1994, the National Alliance for Autism Research (NAAR) was established, becoming the first organization in the U.S. dedicated to funding and accelerating biomedical research into the autism spectrum disorders.
- 2003 – NAAR and the NIH unveil the *NAAR Autism Genome Project*, a public/private research partnership that is the largest research collaboration ever to focus on the genetics of the disorder, with the hope of finding the underlying causes of autism.
- 2004 – The first phase of the *NAAR Autism Genome Project*, the genome scan, is launched. The scan will utilize DNA Array technology and be conducted by Translational Genomics Research Institute in conjunction with Affymetrix, Inc. A second scan based on microsatellite is also scheduled and will be conducted by the Center for Inherited Disease Research (CIDR).

Why hasn’t anything been discovered, even after so much research has been done?

Autism is an extremely complex disorder. Studies have revealed that it has a genetic component, but environmental factors are also thought to be involved.

While studies have been done for a long period of time, researchers have not had sufficiently large patient populations to provide insight into the underlying disease

Where can I get more information about autism?

<http://www.naar.org>

<http://www.nih.gov>

<http://www.cdc.gov>