

Autism Unraveling The Mystery

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Autism's mysteries remain as numbers grow

STORY HIGHLIGHTS

- Autism is a brain disorder whose cause is still unk
- It will be diagnosed in more than 25,000 children t
- Symptoms: lack of social interaction, communicati
- Early diagnosis and intervention are critical for tre

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By Val Willingham
CNN

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ELLCOTT CITY, Maryland (CNN) -- It remains one of the greatest mysteries of medicine. Although autism will be diagnosed in more than 25,000 U.S. children this year, more than new pediatric cases of AIDS, diabetes and cancer combined, scientists and doctors still know very little about the neurological disorder.



GASTON FAMILY

Until they were 18 months old, the Gaston triplets seemed like normal, healthy babies.

Unlike childhood diabetes or pediatric leukemia, there is no blood test, no scan, no image that can detect autism. Diagnosis relies totally on behavioral observation and screening. And that's not easy.

According to the National Institute of Neurological Disorders and Stroke, three distinctive behaviors characterize autism: lack of social interaction, problems with verbal and nonverbal communication, and repetitive behaviors or narrow, obsessive interests. But children with autism display these symptoms in many different ways, some as mild as avoiding eye contact, while others are totally immersed in a world of their own.

Dr. Gary Goldstein, president of Kennedy Krieger Institute, one of the leading U.S. facilities for autism research and treatment, says although doctors know more about autism than ever, plenty of

questions remain unanswered. Over the past few years, it has become clear that genetics play a big role in the development of autism. But researchers believe something -- a trigger -- sets off autism in a child.

"It's a combination of being genetically vulnerable, and then having some kind of social or toxic exposure that tips you over," Goldstein says. If scientists find that trigger, they could find the missing piece of the autism puzzle.

Unraveling the mystery



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It's that missing puzzle piece that frustrates families with autistic children. When the Gaston triplets of Ellicott City, Maryland, were born seven years ago, their parents, Lynn and Randy, were thrilled. For years, they had been trying to have children. After in vitro fertilization, Lynn gave birth to identical twins, Hunter and Nicholas, and a fraternal brother named Zachary. Though they were born prematurely, they grew to be healthy, happy babies. Then something changed.

At around 18 months, the boys began to display unusual behaviors. Zach became compulsive, lined up cereal boxes and toys; he wouldn't socialize and kept to himself. Hunter would roam the house at night and

scream at the top of his lungs. Nick just stopped talking.

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Lynn asked her pediatrician about it. Her sons' doctor said she was overreacting and they should wait and see. But Lynn and Randy were sure there was something wrong with their children. It was frustrating for Lynn, who watched her children change every day before her eyes. "It was almost as if somebody turned the switch off. It was like the first 18 months of their lives didn't happen."

As months passed, the Gastons became frustrated as doctor after doctor told them to wait. That was unfortunate, because doctors now know that the sooner [autism](#) is diagnosed, the better chance the child has for getting successful treatment.



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The Gastons had never heard of autism before their sons were born. Now they were raising three autistic children. That was tough enough, but even after the diagnosis, it was hard to find any information on the condition. That's because until recently, very little information on autistic children has been widely available. The [Centers for Disease Control and Prevention](#) have been collecting data only since 2001, the year the Gaston triplets were born.

Lynn expressed her frustration: "It's not like you can look up autism in the phone book. I couldn't go to the Yellow Pages and find a doctor, and didn't even know what doctor to go see. I thought my pediatrician was going to handle all this."

The Gastons keep asking themselves, "Where is the trigger?" They've each looked into their family history and found no autism.

Some parents believe that thimerosal, a preservative found in childhood vaccines that virtually every child gets, causes autism, because many children were diagnosed after they were vaccinated. But most medical experts increasingly doubt that theory, because even though the chemical has been removed from virtually all vaccines, the number of cases of autism is rising.  [Interactive: Understanding autism »](#)

"You remove thimerosal from all but the flu vaccine, which isn't given to children under 6 months of age, and the incidence of autism only increases. So you just have piece of evidence after piece of evidence after piece of evidence that really disproves this notion," said Dr. Paul Offit, chief of the Infectious Diseases Division at Children's Hospital of Philadelphia, Pennsylvania.

Although the Gastons don't express their opinions on vaccines, Randy makes a point: "There's something that's affecting these children at that age, and it's unfortunate that families are left to their own devices to find out what is going on."

For now the Gastons remain dedicated to getting their sons the best care possible, which can be expensive. They sold their house in order to pay bills for therapy and doctors that total in the hundreds of thousand of dollars.

Health Library

- MayoClinic.com: [Autism](#)

They are also involved in autism awareness groups and try to help other parents of autistic children understand what their children are going through. Just recently they shot a public service announcement to promote a new project developed by the Kennedy Krieger Institute, called [IAN](#), or interactive autism network, an online project that can help autism researchers link with families of autistic children as well as with other scientists. The hope is that IAN will alert families to local and national autism research projects they can participate in.

But minus the projects and the doctors and the therapists, the Gastons, like many families with autistic children, believe it all comes down to the attention they give their children that makes the real difference. ([Read the Gastons' Web page](#))

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"Early intervention is key, because brain development starts before birth," says Dr. Pat Levitt, director of the Vanderbilt Kennedy Center for Research on Human Development in Nashville, Tennessee.


"During the ages of 0 to 5 years, there is a tremendous amount of change that occurs in the brain and brain chemistry."

In October, the American Academy of Pediatrics set up new guidelines to help pediatricians recognize the early signs of autism, in order to diagnose the disorder and get children into treatment as soon as possible.

Unfortunately, that didn't happen for the Gastons. Their boys were 4 years old before doctors at Kennedy Krieger confirmed the family's fears. All three sons had some variation of autism.

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To say it's been difficult for the Gastons is an understatement. But above all, they love each other and work to give their children as much happiness as possible.

As Randy Gaston says while Zach turns to give him a hug and a smile, "The one thing he has to know for the rest of his life is that I did everything for him. That's what it comes down to. I love him." [E-mail to a friend](#) 

Val Willingham is a producer with CNN Medical News.

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