

Progress slow but sure in fight against autism

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Autism knows no boundaries. A complex neurobiological disorder that limits social interaction across a spectrum of degrees, autism-spectrum disorders are diagnosed in one in 110 children in the United States, and one in 70 boys.

Labeled a national public-health crisis by the federal Centers for Disease Control and Prevention, autism rates have increased 600 percent in the past two decades, and the disorder remains largely mysterious and complicated.

Despite all of the negative news, a faint light of hope can be seen at the end of the tunnel, as a wave of scientific studies and progress is bringing closer the ultimate goal of effectively diagnosing, preventing, treating and, perhaps, even curing the disorder.

Much of the recent advancement can be attributed to nonprofit organizations like Autism Speaks, which has quickly become North America's largest autism science and advocacy organization since Nantucket summer resident Bob Wright, former head of NBC Universal, and his wife Suzanne started it in 2005. The Wrights, whose grandson Christian is on the spectrum, have raised both money and awareness of the disorder and the need for research, and in 2008 alone, their organization provided \$33 million in research funding.

And the research keeps on coming. According to a study released on Monday by Autism Speaks, the risk of autism among younger siblings of a child with autism is much greater than previously reported. According to Alycia Halladay, director for environmental research at Autism Speaks, the take-home message from the study is that there is now a more accurate benchmark for recurrence rates in younger siblings who have an older sibling on the spectrum.

"Previous numbers put it at 3 to 10 percent," Halladay said. "This new study, which is the largest to-date of this group, had used more comprehensive and detailed assessments and updated this number to close to 19 percent. The other studies that have been published years ago had used very small sample numbers of about 20-50. This study had combined data from 12 different sites across the United States and Canada, so there were over 600 younger siblings with an older sibling affected by autism."

The study, called the "Recurrence Risk for Autism Spectrum Disorders: A Baby Siblings Research Consortium Study," states "19 percent of younger siblings of children with ASD (Autism Spectrum Disorder) developed autism, a rate significantly higher than the general population. If there were two children with ASD in the family, the risk of the third sibling developing ASD increased to more than 32 percent."

The risk of diagnosis for a male infant who had an older sibling with ASD was almost three times greater

than the risk for female infants: 26 percent compared to 9 percent.

Halladay said this study was much more detailed in comparison to others that had been done in the past, and that the older siblings received comprehensive assessments, as did the younger ones, and the families were closely monitored by clinicians, whereas in previous studies, it varied as to the type of diagnosis being done and who had made that diagnosis.

"The bottom line is we feel, the scientific community feels, that this is a much more accurate number and an accurate rate for this group," Halladay said. "Family history is a very strong risk factor for autism, so the message that we want to send to parents is if you have a child, an older child with autism and a younger child, you should be vigilant about monitoring their development.

"You should not give up when trying to talk to a pediatrician about your concerns. Clinicians and health providers should listen. This is a risk factor; they should listen to the parents and they should monitor these patients closely, because the earlier the child can be identified, the sooner they can get intervention."

Genetics, environment both considered

Halladay added that some of the researchers involved in this study are now involved in research that looks at prenatal and early neonatal factors, both genetic and environmental, in looking at outcomes. They have been studying families that have one child and another on the way, researching a woman's prenatal exposure, what medicine's she's taking, what kind of household products they use, where they live and all of these different non-genetic factors in addition to genetics.

"They're actually able to examine them in a way that no other research project has been able to do before," said Halladay. "Family history is one risk factor, but there are many risk factors, and a new twin study showed that not only is genetics involved, but also a very strong non-genetic component. Examining what those environmental factors are is going to be very important.

"In 2005, Autism Speaks funded a pilot study to see whether or not prenatal exposures could be looked at. So for many years, these investigators have been looking at methodology to study environmental exposures."

Additional studies have already generated data from large groups that focus on environmental factors. Some of the targets have included prenatal exposure to some medications like antiepileptic drugs that have proven to be a risk factor for developing autism. A large number of children developed symptoms similar to autism, and this is a coincidental finding that Halladay said they are following up on.

More recent findings have centered around a number of other factors like maternal and paternal age. As a parent's age increases, so does their risk of having a child with autism.

"But this is again a risk factor, not a cause," Halladay said. "I'm not saying older parents need to be warned that their child will develop autism, it's just another one of the many risk factors."

Yet another risk factor currently being examined is a follow-up of a study out of California that used advanced technology to link where children are conceived with their distance from major roadways. The idea is, and the results showed, that the risk of autism increases if the residence of conception was closer to a major roadway.

"One of the hypothesis is diesel fumes, particulate air matter and exhaust are pollutants that may influence child development in many different ways, and many could be a factor in the development of autism. This definitely needs to be followed up on," Halladay said.

A study from the University of California-Davis MIND Institute in Sacramento, Calif. used medical records and estimates of folic acid consumption through food sources, and found that women who took prenatal vitamins prior to becoming pregnant were at less risk of having a child affected, Halladay said.

"This shows that following doctor's instructions and paying attention to doctor's recommendations actually is very beneficial when it comes to autism outcome."

No rest in ongoing battle

The Wrights know all too well how important it is to be consistent and follow your instincts, even when a doctor says nothing is wrong. They began paying enormous medical bills out of their own pockets for their grandson and used their connections at Yale and Columbia-two major centers for pediatrics-and New York Presbyterian Hospital, but there was just no treatment.

"The resources available were between thin and nonexistent, with no national connection and very little local," said Bob.

"There were local spots where there was help, primarily in California and New Jersey, and there were others, but those two stand out. It was very disorderly, there was no insurance to speak of anywhere in the nation. The best chance was through a church group or a state agency like in California or New Jersey. There was no direct federal help and it was not organized."

So the Wrights began traveling around the country trying to determine if they could make a difference. They found an organization in New York made up of parents of children with autism that had been quite active, and that became the start for them, Bob recalled. They went to a couple of meetings and decided that they were going to form a new organization from scratch.

"We wanted to combine science, medical and a lot of awareness, which nobody was doing," he said. "I was raising money for that purpose. So that group we joined said to me, 'Why don't

you take over our organization? That can be your start and we can give you direction.' We found groups like that and brought them into the umbrella of Autism Speaks. Groups generally had some components, but not others. We wanted to broaden out."

Against all odds, Autism Speaks is prevailing. Sitting in their Nantucket home just last week, the Wrights went through a roller-coaster of emotions, but were both smiling when they recalled the milestones they've reached in just the last six years.

In addition to raising over \$200 million in autism awareness advertising money for the National Ad Council and \$1 billion for autism research, in August of last year, Gov. Deval Patrick signed An Act Relative to Insurance Coverage for Autism (ARICA) bill at Fenway Park, making Massachusetts the 23rd state to legislatively expand autism insurance coverage. Until the Wrights' lobbying efforts, most families were forced to individually pay for prescribed treatments totaling well over \$50,000 a year, many of which weren't covered by insurance nor provided to children by their school districts, which are legally obligated to provide relevant speech, occupational and behavioral therapy.

"A lot of doctors were not talking about it," said Suzanne. "It came from nowhere to huge and it swept right by them. The implication is how can you be a pediatrician and not know about it? Because it's not taught in medical school. Residencies in pediatrics didn't cover it. The amount of things written about autism was very there. There's a lot of defensiveness with dealing with an existing problem, so we went around and said we don't care. This isn't a trial, we're here to figure out what you guys can do, what you're willing to do. Raise your hand, go to your state AMA meetings and get this on the calendar."

For the future of Autism Speaks, the Wrights hope to go global. They're aware that they can't fund the whole world, but they take credit that they derived, from the United States, awareness, early diagnosis and treatment and the scientific pass and relationship between where the government helps and where individuals have to help. They are now gearing up for Nantucket's big event: The annual Walk Now for Autism on Saturday at Jetties Beach. Registration begins at 8:30 a.m.

"If you get involved with autism, time is your enemy, so you continue to push and push and get what is due to this community that was never gotten, and now we're getting what we need for our families," Suzanne said. "The community here on Nantucket has been so supportive, the walk is huge now, we have an autism resource center. We're trying to help as much as we can. Being on an island is isolating enough, and with a child with a disability, it can be even more difficult."

To read more about the current studies at Autism Speaks, or about the organization itself, visit www.autismspeaks.org