

Turn your passion for exercise into a profession.
Become a Personal Trainer.
Center for Continuing Education & Professional Advancement



LOCATION FINDER

Find the Long Island
Press near you.

Enter zip below



Search

Search

Advanced Search

[News](#) | [Features](#) | [Sports](#) | [Columnists](#) | [A&E](#) | [Lifestyle](#) | [DoThis](#) | [Blogs](#) | [BestOfLongIsland](#) | [PowerList](#)

[home](#) : [features](#) : [our children's brains](#)

Tuesday, June 01, 2010

9/8/2005 5:45:00 PM

[Email this article](#) • [Print this article](#)

Our Children's Brains Part I: Autism

Why Is It On The Rise?

By [Ela Schwartz](#)

Luke Gilmore has come a long way in the past few years. The 5-year-old boy used to avoid eye contact and would spend his time staring out the window or racing distractedly around the house. Now he plays with other children and can even identify about 40 words by pointing them out to his teachers. But Luke's father, John Gilmore of Long Beach, says his son hasn't spoken a word since he was about a year old.

Luke has been diagnosed with autism, a neurodevelopmental disorder whose causes remain unknown.

Gilmore believes Luke's autism was caused by mercury poisoning via three vaccines containing thimerosal, a mercury-based preservative used in childhood vaccines since the 1930s. In 1999, the U.S. Public Health Service recommended that manufacturers reduce thimerosal content from about 25 micrograms per shot to trace amounts, although older vaccines may still be on the market. But the government has not officially identified mercury as a cause of autism. Indeed, many medical professionals and even other parents like the Gilmores say the correlation isn't clear.

Luke's parents began noticing changes after his first vaccination, at the age of 2 months, when he developed eczema and asthma. After another round of vaccinations, at 8 months of age, Luke stopped making eye contact and would alternate between being "spacey and hyperactive," says Gilmore. At about 1 year, Luke got his third round of vaccines and "all hell broke loose," as his father puts it.

"He'd just bounce off the walls constantly, had gastrointestinal problems and his eczema was out of control," Gilmore remembers. "We knew something was really wrong. We'd seen three distinct changes in our son after three rounds of vaccines."

Gilmore is not alone in his belief that autism is a medically caused catastrophe. Many parents with autistic children have joined groups that seek to eliminate mercury from vaccines altogether. Gilmore is president of one such group-the New York Metro chapter of the National Autism Association. Others include the Coalition for SAFE MINDs (Sensible Action For Ending Mercury-Induced Neurological Disorders), No Mercury and Generation Rescue, all of whose members say their children were developing normally until regressing into the desolate world of autism between the ages of 2 and 7.

Their proactivity was rewarded this summer when Gov. George Pataki signed into law a bill limiting the use of thimerosal in vaccines for pregnant women and children. The bill was powered by Assemb. Harvey Weisenberg. A former educator, Weisenberg is familiar with the needs and issues facing children with physical and mental disabilities. Determined to

improve the quality of life for disabled people and their families, he spearheaded the recently passed legislation that limits the amounts of thimerosal in vaccines given to children under 3 or pregnant women.

"Although there's no evidence thimerosal is the cause, we're aware mercury is toxic and poison, so why inject this into a child?" he says. But some parents say this isn't enough. They want thimerosal banned in all 50 states and financial compensation for what they consider to be injuries caused by vaccines.

"I have three children with autism, so clearly there's a genetic basis," says Michele Iallonardi of Hauppauge. "But I believe that my children would not have autism if they hadn't been exposed to thimerosal. Some people are genetically predisposed-their bodies don't have the ability to get rid of the thimerosal injected into them with their vaccines. My children are a perfect example."

Iallonardi says her eldest son, Jackson, 4, suffered developmental delays from early infancy, and because he had health problems, doctors recommended two dosages of the flu shot when he was 2 years old. "His behaviors got worse," she says, "and about a month later he was diagnosed with autism."

After that, Iallonardi stopped vaccinating her twins, Bennett and Luca, now 2, when they turned 3 months. She says their autism is not as severe as that of their sibling.

AUTISM ASCENDING

Autism was first described in the 1940s, but the condition was poorly understood and little known until the 1990s. At first, autistic children were thought to suffer from schizophrenia or emotional trauma. Then, aloof and unloving "refrigerator mothers" were blamed for their children's odd behavior.

Now considered a spectrum disorder, autism ranges from its "classic" state to Asperger's Syndrome, characterized by social and communication difficulties but average to superior intelligence. Children with the disorder may exhibit repetitive behaviors as well, such as hand-flapping, head-banging or rocking back and forth. Those with classic autism generally don't speak, seem unaware of the outside world and often require institutionalization.

According to the Centers for Disease Control and Prevention (CDC), autism rates have climbed from about one in 2,500 children in the 1980s to between one and four in 500 today, but it's unclear whether the number of cases is rising or greater public awareness and broader diagnostic criteria have brought more cases to light.

Densely populated Long Island has a high number of autistic children. May-Lynn Andresen, a registered nurse and the senior administrative manager at the Fay J. Lindner Center for Autism at North Shore-Long Island Jewish (NSLIJ) Health System in Bethpage, is the parent of a child with an autism spectrum disorder. Based on stats provided by the CDC, Andresen estimates that there may be as many as 18,000 autistic children in Nassau, Suffolk and Queens. "Autism is a big issue for us here," she says.

EVIDENCE OF HARM

David Kirby, a Brooklyn-based journalist, first heard about the thimerosal theory in 2002. He was skeptical until learning that a rider tacked on to the Homeland Security Act-dubbed the "Eli Lilly Protection Act" after the primary manufacturer-absolved pharmaceutical companies from liability for damages caused by the vaccine additive. The rider was repealed in 2003.

Kirby chronicled the experiences of parents who formed the Coalition for SAFE MINDs in Evidence of Harm-Mercury in Vaccines and the Autism Epidemic: A Medical Controversy. Published in April 2005, the book investigates claims that the FDA failed to total up the amounts of thimerosal in the increasing number of vaccines given to children and conduct safety studies, thus exposing children to amounts of thimerosal that far exceeded federal safety limits.

The book also alleges that the CDC manipulated data from the federal Vaccine Safety Database to eliminate a statistically significant link between thimerosal and autism, ADHD and speech delay, and that the CDC refused to disclose data and records until required to

do so under the Freedom of Information Act. Kirby says government officials refused requests for interviews.

"I would have been willing to publish anything they had to say," he says, stressing that "evidence" of harm is not the same as "proof." People should reach their own conclusions after reading the book, in which Kirby does not take an anti-vaccine stance, he adds.

"If I had children, I would have them vaccinated," Kirby says. "Children can lose their sight or hearing, become disfigured, even die from these diseases."

Thanks to vaccinations, few of us recall the days when catching diseases such as diphtheria or measles was a childhood rite of passage. Smallpox has been eradicated; polio is rarely seen outside of the Third World. But when vaccination rates drop, diseases regain a foothold, as Japan, England and Sweden discovered when whooping cough and measles re-appeared after parents fearful of side effects stopped inoculating their children.

IN SEARCH OF ANSWERS

While there have been many studies aimed at unearthing the causes of autism, none has proven a link between the disorder and thimerosal. For the most part, the medical community attributes autism to genetic factors, and statistics do show a correlation. According to the CDC, if one child in a family has autism, the odds that a sibling will be affected increase significantly.

The National Institutes of Health (NIH) and independent researchers, who are trying to identify genes that could cause autistic symptoms, say these traits often run in families. That's something many parents of autistic children acknowledge, even as they insist there's more to blame for the condition than just chromosomes and genes.

Not everyone in the autism community believes that mercury's to blame. Many cite the fact that the CDC and other public health organizations conducted five major epidemiological (large-population) studies examining the health records of hundreds of thousands of children in the United States, the United Kingdom, Sweden and Denmark. According to the Institute of Medicine (IOM), which pored over the data, those studies show no proof that autism is linked to thimerosal.

Proponents of the theory that thimerosal and autism are linked counter that the IOM failed to give equal weight to biological and toxicological laboratory studies showing the negative neurological effects of thimerosal.

"Autism could be caused by any number of factors, but the potential for thimerosal to be one of them is there, based on research done by qualified professionals," says Chris Petrosino, the parent of a son with autism and co-president of the Nassau/Suffolk chapter of the 500-members-strong Autism Society of America, which supported the legislation to remove thimerosal from vaccines.

Those on the other side of the fence say mercury-blaming parents are upset-seeing your child regress into autism is traumatic-but that emotion is no substitute for science and facts.

Retired Roslyn dentist Marvin Schissel is an adviser to the American Council on Science and Health and the National Council Against Health Fraud. His adult son was diagnosed with autism spectrum disorder at age 25. Schissel sees no point in funding more thimerosal studies, since the preservative has been removed from most vaccines and studies have shown no concrete connection.

"Why keep wasting money and energy with this issue when we could be investigating other, more promising areas?" Schissel asks.

Marty Schwartzman, too, has his doubts about the thimerosal theory. The Bayside resident, president of the Long Island chapter of the National Alliance for Autism Research (NAAR), says his twins, Allyson and Robby, now 12, did not show signs of regression after receiving vaccinations.

"They were both delayed, but then, for some reason, Allyson took off," Schwartzman says. Now a typical seventh-grader, Allyson wants to work with autistic children when she grows

up. Her brother has autism and attends the School for Language and Communication Development in Glen Cove.

Schwartzman, however, considers himself open-minded and doesn't discount any potential links to the disorder that affects his son. "I go to a lot of presentations and read papers [about autism], and [many things] sound plausible, but I'm not a chemist and I don't understand the structure of cells," he says. "I think we need to explore the cause of autism to the fullest extent."

Those who do blame thimerosal are encouraged by new developments. The Los Angeles Times published a Merck company memo warning of the dangers of high mercury doses through increased immunizations. The memo was dated 1991, eight years before the FDA recommended that thimerosal be removed from vaccines.

In California, autism rates are dropping, in keeping with the prediction of lower rates after thimerosal's phase-out. The University of Texas found that school districts in environments with high mercury levels had the highest rates of special-education services, and that autism rates increased by 17 percent for every 1,000 pounds of mercury released. The emissions came from coal-burning plants, with Texas releasing more than any other state.

FUTURE FALLOUT

Autism affects more than the child diagnosed with it. Parents exhaust themselves trying to fill the child's needs. Siblings feel neglected. Financial and marital woes often set in because insurance seldom pays for expensive newer therapies and one parent may have to quit work to care for the child.

And our society is responsible for caring for a staggering number of autistic individuals. Robert Krakow, an attorney who represents vaccine-injury cases and is the father of a child with autism, is also chairman of the board of Lifespire, a not-for-profit organization that provides housing and services for 5,000 disabled adults in the New York City region. Krakow says that if you multiply the cost of special-education services for a child over several years, then add about \$225,000 that's spent per year on each adult resident at an institution, the cost comes out to about \$13 million to care for an autistic individual who requires housing and services over his or her lifetime.

Andresen says that huge numbers of developmentally disabled Long Island children need to be helped and supported, brought in to local school districts and protected from teasing and bullying. "Communities need to rally and provide opportunities for them to practice social skills in different environments and support them with jobs," she says. "We need to understand that it truly takes a village."

TWO LONG ISLANDERS ADVANCE THEIR CAUSE

Giving Autism A Voice

By Ela Schwartz

Oyster Bay resident Evelyn Ain's story is similar to those told by many parents who become well-acquainted with autism. Her son Matthew was a normal toddler, babbling, smiling and drinking out of a cup. When he was about 10 months old, he stopped talking and began withdrawing.

"He looked like he was in a fog," says Ain. "It got to the point where a stranger couldn't come into the house without Matthew freaking out."

Her son's pediatrician found nothing wrong. His neurologist measured Matthew's head and checked his reflexes. Evaluators sent by the Nassau County Health Department's Early Intervention Program said he might be "a little autistic," Ain says.

Neurologists told her they refused to diagnose autism before the age of 2, but Ain was determined to resolve once and for all whether or not Matthew had the disorder. She brought her son, then 18 months old, to the Kendell Speech and Language Center in

Kendell, Fla., to be evaluated by a speech/language pathologist board-certified in behavioral analysis.

The Center confirmed Ain's suspicions and diagnosed Matthew with autism.

"I died right there," she says. "But I was able to come back to Long Island and get him the services he needed."

Concluding that many parents were looking for answers, support and empowerment, she launched *Spectrum Magazine for Parents of Children With Autism and Developmental Disabilities* in 2004. The magazine is now national, with a circulation of 60,000.

"*Spectrum* is a way to bring families together on a larger level and provide a community," Ain says. "Autism is nothing to be embarrassed about. Our families just have different lifestyles. We choose schools differently, travel differently, live differently."

In April this year, the magazine shed a spotlight on its national debut at the Garden City Hotel. Guests at the gala included Anthony Edwards, formerly of *ER*, and Assemb. Harvey Weisenberg (D-Long Beach), who received the Lifetime Achievement Award.

The publication has grown by leaps and bounds already: What began as a three-person operation in 2004 now employs about 25 people across the country. Ain looks forward to the magazine's continued growth.

"I'd love to see *Spectrum* go international and have a Spanish-language edition to reach Latin American communities," she says.

Cris Italia, editor-in-chief of *Spectrum*, says the magazine's mission is not just to keep parents of autistic children abreast of research and treatments. It's also to spark ideas about fun activities these parents can enjoy with their autistic youngsters. "We don't want to be all gloom and doom," Italia says. "We write about trips to take and games to play. We provide hope."

-Michele Pepe contributed to this story.

Related Links:

- [The Our Children's Brains Series](#)

Turn your passion for exercise into a profession.
Become a Personal Trainer.

Center for Continuing Education & Professional Advancement



Long Island Press & LongIslandPress.com, All rights reserved.
Software © 1998-2010 1up! Software, All Rights Reserved