GENERATIONRESCUE

RESCUEWIRE: **For Immediate Release**
May 10, 2005

UPI ASKS, "WHERE'S ALL THE AUTISTIC AMISH?"

Generation Rescue commends UPI Investigative Journalist Dan Olmstead for taking an honest look at the relationship between mercury and autism.

In a five-part series, United Press International Investigative Reporter Dan Olmstead explores the assertion that autism is genetic by studying one of the few remaining communities in the United States that does not routinely vaccinate their children: The Amish. His story appears below.

United Press International

April-May, 2005

The Age of Autism: The Amish anomaly

By Dan Olmsted
UNITED PRESS INTERNATIONAL

Lancaster, PA, Apr. 18 (UPI) -- Part 1 of 5. Where are the autistic Amish? Here in Lancaster County, heart of Pennsylvania Dutch country, there should be well over 100 with some form of the disorder.

I have come here to find them, but so far my mission has failed, and the very few I have identified raise some very interesting questions about some widely held views on autism.

The mainstream scientific consensus says autism is a complex genetic disorder, one that has been around for millennia at roughly the same prevalence. That prevalence is now considered to be 1 in every 166 children born in the United States.

Applying that model to Lancaster County, there ought to be 130 Amish men, women and children here with Autism Spectrum Disorder.

Well over 100, in rough terms.

Typically, half would harbor milder variants such as Asperger's Disorder or the catch-all Pervasive Development Disorder, Not Otherwise Specified -- PDD-NOS for short.

So let's drop those from our calculation, even though "mild" is a relative term when it comes to autism.

That means upwards of 50 Amish people of all ages should be living in Lancaster County with full-syndrome autism, the "classic autism" first described in 1943 by child psychiatrist Leo Kanner at Johns Hopkins University. The full-syndrome disorder is hard to miss, characterized by "markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activities and interests," according to the Diagnostic and Statistical Manual of Mental Disorders.

Why bother looking for them among the Amish? Because they could hold clues to the cause of autism.

The first half-dozen articles in this ongoing series on the roots and rise of autism examined the initial studies and early accounts of the disorder, first identified by Kanner among 11 U.S. children born starting in 1931.

Kanner wrote that his 1938 encounter with a child from Mississippi, identified as Donald T., "made me aware of a behavior pattern not known to me or anyone else theretofore." Kanner literally wrote the book on "Child Psychiatry," published in 1934.

If Kanner was correct -- if autism was new and increasingly prevalent -- something must have happened in the 1930s to trigger those first autistic cases. Genetic disorders do not begin suddenly or increase dramatically in prevalence in a short period of time.

That is why it is worth looking for autistic Amish -- to test reasoning against reality. Largely cut off for hundreds of years from American culture and scientific progress, the Amish might have had less exposure to some new factor triggering autism in the rest of population.

Surprising, but no one seems to have looked.

Of course, the Amish world is insular by nature; finding a small subset of Amish is a challenge by definition. Many Amish, particularly Old Order, ride horse-and-buggies, eschew electricity, do not attend public school, will not pose for pictures and do not chat casually with the "English," as they warily call the non-Amish.

Still, some Amish today interact with the outside world in many ways. Some drive, use phones, see doctors and send out Christmas cards with family photos. They all still refer to themselves as "Plain," but the definition of that word varies quite a bit.

So far, from sources inside and outside the Amish community, I have identified three Amish residents of Lancaster County who apparently have full-syndrome autism, all of them children.

A local woman told me there is one classroom with about 30 "special-needs" Amish children. In that classroom, there is one autistic Amish child.

Another autistic Amish child does not go to school.

The third is that woman's pre-school-age daughter.

If there were more, she said, she would know it.

What I learned about those children is the subject of the next column.

***

The Age of Autism: Julia

By Dan Olmsted
UNITED PRESS INTERNATIONAL

Leola, PA, Apr. 19 (UPI) -- Part 2 of 5. Three-year old Julia is napping when I arrive at the spare, neat, cheerful house on Musser School Road near the town of Leola in Lancaster County.

She is the reason I have driven through the budding countryside on this perfect spring day, but I really do not need to meet her.

In the last column, I wrote about trying to find autistic Amish people here in the heart of Pennsylvania Dutch country, and noted there should be dozens of them -- if autism occurs at the same prevalence as the rest of the United States.

So far, there is evidence of only three, all of them children, the oldest age 9 or 10. Julia is one of them. I found out about her through a pediatrician in Richmond, Va., Dr. Mary

Megson. I had been asking around for quite some time about autism and the Amish, and she provided the first direct link.

Megson said she would give my name to this child's mother, who could call if she chose. A few days later the phone rang. It was Stacey-jean Inion, an Amish-Mennonite woman. She, her husband Brent and their four children live simply, but they do drive a vehicle and have a telephone. After a few pleasantries, I told her about my trying to find autistic Amish.

Here is what she said, verbatim:

"Unfortunately our autistic daughter -- who's doing very well, she's been diagnosed with very, very severe autism -- is adopted from China, and so she would have had all her vaccines in China before we got her, and then she had most of her vaccines given to her in the United States before we got her.

"So we're probably not the pure case you're looking for."

Maybe not, but it was stunning that Julia Inion, the first autistic Amish person I could find, turned out to be adopted -- from another country, no less. It also was surprising that Stacey-jean launched unbidden into vaccines, because the Amish have a religious exemption from vaccination and presumably would not have given it much thought.

She said a minority of Amish families do, in fact, vaccinate their children these days, partly at the urging of public health officials.

"Almost every Amish family I know has had somebody from the health department knock on our door and try to convince us to get vaccines for our children," she said. "The younger Amish more and more are getting vaccines. It's a minority of children who vaccinate, but that is changing now."

Did she know of any other autistic Amish? Two more children, she said.

"One of them, we're very certain it was a vaccine reaction, even though the government would not agree with that."

Federal health officials have said there is no association between vaccinations and autism or learning disabilities.

"The other one I'm not sure if this child was vaccinated or not," she added.

During my visit to their home, I asked Stacey-jean to explain why she attributed the first case to vaccines.

"There's one family that we know, their daughter had a vaccine reaction and is now autistic. She was walking and functioning and a happy bright child, and 24 hours after she had her vaccine, her legs went limp and she had a typical high-pitched scream. They called the doctor and the doctor said it was fine -- a lot of high-pitched screaming goes along with it.

"She completely quit speaking," Stacey-jean said. "She completely quit making eye contact with people. She went in her own world."

This happened, Stacey-jean said, at "something like 15 months." The child is now about 8.

For similar reasons, Julia Inion's Chinese background is intriguing. China, India and Indonesia are among countries moving quickly to mass-vaccination programs. In some vaccines, they use a mercury-based preservative called thimerosal that keeps multiple-dose vials from becoming contaminated by repeated needle sticks.

Thimerosal was phased out of U.S. vaccines starting in 1999, after health officials became concerned about the amount of mercury infants and children were receiving. The officials said they simply were erring on the side of caution, and that all evidence favors rejection of any link between Autism Spectrum Disorders and thimerosal, or vaccines themselves.

Julia's vaccinations in China -- all given in one day at about age 15 months -- may well have contained thimerosal; the United States had stopped using it by the time she was born, but other countries with millions to vaccinate had not.

Stacey-jean said photographs of Julia taken in China before she was vaccinated showed a smiling alert child looking squarely at the camera. Her original adoptive family in the United States, overwhelmed trying to cope with an autistic child, gave Julia up for re-adoption. The Inions took her in knowing her diagnosis of severe autism.

I tried hard -- and am still trying -- to find people who know about other autistic Amish. Of the local health and social service agency personnel in Lancaster, some said they dealt

with Amish people with disabilities, such as mental retardation, but none recalled seeing an autistic Amish.

Still, I could be trapped in a feedback loop: The Amish I am likeliest to know about -- because they have the most contact with the outside world -- also are likeliest to adopt a special-needs child such as Julia from outside the community, and likeliest to have their children vaccinated.

Another qualifier: The Inions are converts to the Amish-Mennonite religion (Brent is an Asian-American). They simply might not know about any number of autistic Amish sheltered quietly with their families for decades.

It also is possible the isolated Amish gene pool might confer some kind of immunity to autism -- which might be a useful topic for research.

Whatever the case, Stacey-jean thinks the autistic Amish are nowhere to be found.

"It is so much more rare among our people," she said. "My husband just said last week that so far we've never met a family that lives a healthy lifestyle and does not vaccinate their children that has an autistic child. We haven't come across one yet."

"Everywhere I go (outside the Amish community) I find children who are autistic, just because I have an autistic daughter -- in the grocery store, in the park, wherever I go. In the Amish community, I simply don't find that."

***

The Age of Autism: Witness

By Dan Olmsted
UNITED PRESS INTERNATIONAL

Lebanon, PA, May. 10 (UPI) -- Part 3 of 5. Frank Noonan is a family doctor in Lancaster County. When I met him for lunch last Saturday, he was still in golfing togs from his weekly game -- "Saturdays are my 'I can breathe' day," he says. Even so, he stayed after our meal to meet a cancer patient who phoned him at the restaurant.

People such as the Amish. As a family practitioner, Noonan sees patients of all ages. He combines traditional and alternative medicine in an "integrative" blend to suit the individual. The Amish like that approach -- they prefer to see just one doctor for all their care, and their first resort is herbs and supplements, not prescriptions and pills. For one thing, most don't have insurance.

Based on movies like "Witness" and the image of the Amish in horse-and-buggies, many people -- myself included -- assume they have virtually no contact with such outside influences as modern medicine.

Not so.

Noonan has been a doctor in Lancaster County nearly 25 years and about a third of his patients are Amish, making his Amish practice one of the area's largest. He has seen "thousands and thousands" of the county's 22,000 Amish residents and others who live nearby.

I found him through an Amish-Mennonite mother of an autistic child adopted from China. She told me she has seen almost no autism among the Amish, but that I should talk to Noonan because he has treated so many Amish for so long.

Based on my reporting so far, there is evidence of only three or possibly four Amish with autism in Lancaster County, where there should be dozens at the 1-in-166 prevalence in society at large. One of them is the adopted Chinese child. Another was described as having "a clear vaccine reaction" at 15 months, after which she became autistic. I have not met that child and can't vouch for that description.

When I called Noonan three weeks ago, he seemed surprised by my question about Amish autism but agreed to think about it, check around and tell me what he found. At lunch, Noonan said he hesitated to offer an opinion when I first called because it had never occurred to him.

But now, he said, he realized something.

"I have not seen autism with the Amish," Noonan told me. "And I say that having seen a ton of Amish patients. I may be able to think in all those years of maybe one case of (Amish) autism I've had."

"I've checked with some of my colleagues," he added, "and they all tell me it's very, very sporadic that we'll see a case of autism among the Amish."

From 2000 to 2003, Noonan also saw patients at the Wellness Center, which is operated by the Amish and Mennonites. About 90 percent of those patients are Amish, Noonan said, and he saw thousands of them. But still he saw no autism.

"Absolutely none, in the almost three years I was there. We would have seen it. It's not something they would hide. They're not like that."

Noonan said he sees "a fair amount of mental retardation among the Amish." A significant percentage of people with autism have mental retardation as well as severe speech and hearing problems. Wouldn't they show up on the radar of those who track and treat such issues?

And wouldn't autistic Amish see Noonan for the same inevitable illnesses and injuries that bring the rest of their family to him?

I tried various ways to find gaps in Noonan's account. Perhaps autistic Amish children were seeing pediatricians or specialists as opposed to family doctors ...

"The Amish don't go to specialists like we do," he responded. "The Amish go to family docs for all their pediatric care. So at least in Lancaster County, where I practice, almost all pediatrics among the Amish is done by family docs."

"You'll find all the other stuff, but we don't find the autism," Noonan said. "We're right in the heart of Amish country and seeing none. And that's just the way it is."

In my last column, I said this interview was a tipping point between absence-of-evidence (not finding many autistic Amish) and evidence-of-absence (finding there might not be many).

The case is still open, but does anyone disagree that Dr. Noonan makes a compelling witness?

The Age of Autism: Mercury ascending

By Dan Olmsted
UNITED PRESS INTERNATIONAL

Washington, DC, May. 17 (UPI) -- Part 4 of 5. A year ago, the prestigious Institute of Medicine slammed the door on the idea that mercury in vaccines bore any relation to autism. "The overwhelming evidence from several well-designed studies indicates that childhood vaccines are not associated with autism," the chairman of the IOM panel, Harvard scientist Marie McCormick, told reporters last May 18.

The panel went further: It took the unusual step of urging that research money go instead to more "promising" areas. You can't slam a door much harder than that.

But 12 months later, that door seems slightly ajar. One big doorstop is the new 441-page book by David Kirby called "Evidence of Harm," a compelling portrayal of parents and scientists who have pushed the vaccines-autism theory. They contend that a mercury-based preservative called thimerosal, in an increasing number of vaccinations, triggered an autism epidemic in the 1990s.

Thimerosal was phased out of U.S. childhood vaccines beginning in 1999.

One memorable vignette in Kirby's book is a meeting between several of those advocates and Dr. Julie Gerberding, who had been director of the Centers for Disease Control and Prevention less than two years.

Last May 12, a week before the IOM report, Gerberding flew in from Atlanta to meet them -- at her request -- in the Rayburn House Office Building on Capitol Hill. Rep. Dave Weldon, R-Fla., a medical doctor who is a persistent critic of thimerosal and the CDC's handling of the issue, also was present.

Taking turns, the parents and scientists methodically laid out their case.

Mady Hornig of Columbia University described how mice with an autoimmune genetic predisposition develop autistic-like behaviors after being injected with thimerosal-containing vaccines.

"Hornig played the videos for Gerberding, who suddenly appeared stunned," Kirby recounts in his book. "She brought her hands to her face in disbelief.

"Dave Weldon had a similar reaction. He stopped Hornig in the middle of her ghastly presentation. 'Wait a minute,' he said. 'Am I to understand you correctly? You injected these mice with the same amount of mercury, relatively speaking, that infants receive in vaccines, and you saw these kinds of mutilatory behaviors? You saw this mouse eat through the cranium of his cellmate?'

"'Yes,' she replied calmly."

The Institute of Medicine saw the same presentation before issuing its report but rejected it as unconvincing.

Gerberding was polite but noncommital, Kirby writes. As she left, she said, "I am not afraid of controversy, and I am determined to follow the science."

Call it coincidence, but it's striking how much less dismissive of thimerosal concerns the CDC is these days, compared with the Institute of Medicine and others.

The National Network for Immunization Information, for instance, launched a pre-emptive broadside against "Evidence of Harm." That group represents the mainstream medical establishment, including the American Academy of Pediatrics, the American Nurses Association and the American Academy of Family Physicians. Their members, it should be noted, were among those who administered the vaccines in question on the recommendation of the CDC.

"Warning: Controversial vaccine book," the NNII statement was headlined. "Reporter David Kirby has recently written a book ... purporting that there is a link between thimerosal and autism and other developmental disorders."

That's a bit of an overstatement, considering the first two sentences of Kirby's book: "Does mercury in vaccines cause autism in children? Anyone hoping to find proof that it does in the pages that follow is advised to put this book down now."

The NNII asserted that "extensive evidence shows no link between vaccines and neurodevelopmental disorders, including autism. This evidence is based on well-established scientific studies.

"Continued attempts to link vaccines and autism run the risk of diverting attention away from efforts to understand the cause or causes of autism," the group said.

The CDC also issued a release on Kirby's book. Its thrust was different -- that the book is a "look back" to a time when thimerosal was in childhood vaccines.

"Given the historical nature of the book, it is important to emphasize that today, with the exception of some flu vaccines, none of the vaccines used in the U.S. to protect preschool children against 12 infectious diseases contain thimerosal as a preservative.

"As the IOM concluded in a recent report, the vast majority of studies, which have involved hundreds of thousands of children in a number of countries, have failed to find any association between exposure to thimerosal in vaccines and autism; that is, they have failed to find any evidence of harm," the CDC said.

It's worth noting the contrasts in the statement. The doctors and nurses group says "extensive evidence shows no link." Dr. McCormick at the Institute of Medicine says "overwhelming evidence" shows no link.

But the CDC, which unlike such groups has ongoing access to the actual data, merely states that studies so far "have failed to find any association."

"CDC continues to support research related to autism," the statement said, "including studies designed to examine the possible causal association between autism and other possible environmental causes, including thimerosal-containing vaccines. ... Research in these areas is ongoing."

Ongoing research that includes thimerosal as a possible cause of autism? Supported by the CDC?

Put simply, the CDC isn't ruling out anything -- contrary to the Institute of Medicine's declaration that more research on thimerosal is a waste of money, contrary to the medical establishment's pronouncement that continuing to look could cause harm.

Consider Gerberding's comments April 28, 2004, at a House subcommittee hearing: "We don't have the evidence to show that the thimerosal preservative is a risk, but you know we have an open mind about that."

Apparently the Institute of Medicine's findings three weeks later didn't completely reassure her, because this February -- almost a year after the IOM report -- she said the same thing in an interview with NBC.

"Right now, the scientific evidence doesn't provide any framework for concluding that thimerosal or immunizations in any way affect autism," she said. "But we have to have an open mind about that."

An open mind, not a closed door. Ongoing research, not ending research. That's quite a difference. Experts who are certain thimerosal didn't cause the autism epidemic may want to have a word with Dr. Gerberding.

Next: Mercury, the Amish and the autism epidemic.

The Age of Autism: Mercury and the Amish

By Dan Olmsted
UNITED PRESS INTERNATIONAL

Washington, DC, May. 20 (UPI) -- Part 5 of 5. The cases of autism among the Amish that I've identified over the past several weeks appear to have at least one link -- a link made of mercury.

That's not something I expected to encounter. I had been looking for an unvaccinated population to test the controversial idea that vaccines, and in particular the mercury-based preservative called thimerosal, could be behind the apparent rise in autism cases over the past decade.

The concept: If the Amish have little or no autism, it might point a finger at something to which they have not been exposed.

Most of the medical establishment, it must be stated upfront, considers the idea that thimerosal could have played a role in the rise of autism disproven and dangerous. As noted in the last column, however, the director of the Centers for Disease Control and Prevention says she has "an open mind" about that possibility.

So do I, having come across correlations that made me want to look more closely at thimerosal. For instance, the first child diagnosed with autism in the United States was

born in 1931, the same year thimerosal was first used in a vaccine. And autism diagnoses exploded in the 1990s, the same decade children got an increasing number of thimerosal-containing vaccines (it was phased out starting in 1999). Tantalizing, but proof of nothing.

So I turned to the 22,000 Amish in Lancaster County, Pa. I didn't expect to find many, if any, vaccinated Amish: they have a religious exemption from the otherwise mandatory U.S. vaccination schedule. When German measles broke out among Amish in Pennsylvania in 1991, the CDC reported that just one of 51 pregnant women they studied had ever been vaccinated against it.

To cut to the chase, what I've found to date is very little evidence of autism among the Amish in Lancaster County, far below the 1 in 166 rate of Autism Spectrum Disorders the CDC cites for children born in the United States today. I don't discount the idea that they might be more difficult to find or diagnose, and I'm still looking.

I did find three or possibly four children with autism and, weirdly, a possible link to vaccinations. One was a child adopted from China, where she got all her vaccinations before being vaccinated all over again when she got to the states. Her Amish-Mennonite mother said she believes that vaccine load caused her autism. The mother told me about another child who had what she described as an immediate vaccine reaction that left her autistic at age 15 months.

That mother said a minority of younger Amish have begun getting their children vaccinated, though a local doctor who has treated thousands of Amish said the rate is still less than 1 percent.

The pattern I was noticing then took an interesting twist. From a doctor's posting on an alternative health Web site, I learned about several cases of autism among Amish children who had not, in fact, been vaccinated.

I called that doctor, Lawrence Leichtman, at his office in Virginia Beach, Va. A pediatrician and geneticist who has been widely published in medical journals, he told me he was treating six unvaccinated Amish children and adolescents -- three from Pennsylvania, including one from Lancaster County; two from Ohio, and one from Texas.

That seemed to render any relationship between autism and mercury exposure in the Amish less likely. But, not after what Leichtman said next.

"By the way," he volunteered, "four of these six kids all have elevated mercury. The only two that don't, one of them is from Texas and one is from Iowa. But all of the people in Pennsylvania and one of the people in Iowa have elevated mercury."

Given what I had already come across in Lancaster County, I wanted to hear more about that. Were the mercury levels significantly higher? I asked. "Oh yes," he responded.

What did he think was going on?

"The people in Pennsylvania, I've actually tracked back on them," Leichtman said. "There's definitely a plume from one of the coal-fired power plants that just goes right over them. And the one in Iowa, it's a little less obvious because actually he's in the Amana Colonies, but I have seen reports of the area around Amana having elevated levels of mercury in the environment."

As it happens, the Pittsburgh Post reported last week that Pennsylvania has four of the nation's 10 "dirtiest power plants." Mercury is a byproduct of coal combustion.

Leichtman also believes that northern states "get most of the prevailing wind that comes across the Pacific. You get that trans-Pacific flow which is all Chinese mercury. We're getting a load of Chinese mercury, as far as I can tell."

Leichtman's comments meant that the two people I talked to, who knew anything about autism among the Amish, independently brought up mercury exposure -- in vaccines and in the environment-- as the cause of most of the cases.

That's a link others have made, although not to the Amish, whose autism prevalence has apparently never been studied:

- "We believe that thimerosal and environmental mercury -- which are worldwide pollutants -- are behind the surge" in autism in the 1990s, wrote Sallie Bernard in 2002. She is a founder of the group Safe Minds, which wants mercury out of all medical products. Bernard co-authored a controversial 1999 study about thimerosal, "Autism: A novel form of mercury poisoning."

- "In the end it is mercury in the brain that causes such problems, and that mercury can come from several sources," said Boyd Haley, chairman of the chemistry department at the University of Kentucky and another maverick on thimerosal.

"Therefore, a logical approach is to think that all mercury exposures are additive, even if some may be more causative than others."

Haley cited a recent Texas study, first reported by United Press International in March, that found an association between autism rates and exposure to industrial mercury emissions in Texas counties. One county with high autism but low exposure to mercury emissions turned out on closer inspection to be the site of a huge abandoned mercury mine, the researchers found.

Leichtman believes the damage to children is being done by environmental mercury, not the mercury in vaccines (my own research makes me think that if it's either, it's both). He said he can detect elevated mercury levels in about half his 500 autism patients.

"Environmental mercury is horrible," he said, "and I think that's where it's coming from. To me, people with autism are the canaries in the coal mine. A lot of them are reflecting the damage from all of that."

Leichtman, like a number of other doctors, is trying to flush mercury out of autistic children through a process called chelation (key-LAY-shun).

Chelation as a treatment for autism is unproven and controversial (what about autism is not unproven and controversial?), and it carries a risk of serious side effects. Chelation has been used for 40 years in cases of heavy metal toxicity, including lead poisoning.

But does it help children with autism?

"The people in Pennsylvania wouldn't take chelation," Leichtman said, and noted the Amish aversion to medical procedures and drugs. "One in Iowa did. He certainly did better."

We'll look at chelation and its implications in the next column.