

Chelation Benefits/Risks: Helping Autistic Children

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The unorthodox practice of chelation
No one knows what causes autism, but one theory has ignited an intense
debate

By John Larson
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NBC News
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Autism is a mysterious and devastating disorder that is believed to affect
as many as 500,000 children in this country. No one knows for certain what
causes autism, but one theory - chelation- has sparked controversy. Now,
Jim

Adams wants to put that theory to the test. In a desperate quest for
answers, he is using his scientific know-how to test a controversial therapy
called "chelation." And he has a special reason for taking on this mission -
his daughter Kim. This report aired Dateline Sunday, June 4, 7 p.m.

Kim Adams knows every word, every move, every pause by heart because
she has
watched this same video thousands of times.

Kim Adams, autistic girl: Barney's Birthday!

Like many diagnosed with autism, she is trapped in a world of repetition and ritual.

For example, her father Jim knows his daughter will want two braids because it is Wednesday. Kim insists on wearing two braids and a dress to school every Wednesday.

Her need for order is extreme. Even a minute change in routine, like a spot appearing on her father's shirt, can make her world feel frighteningly out of whack.

Kim Adams: Daddy's shirt.

Jim Adams, Kim's father: Oh, daddy's shirt is dirty.

Kim Adams: Mommy, daddy's shirt is dirty.

Marie Adams, Kims mother: That's okay.

At 13 years of age, Kim is still a child who needs help with life's most basic skills. She can't brush her teeth without a list of directions, or make her bed without a series of pictures.

Jim Adams: My little girl was diagnosed with autism at age two-and-a-half. We were told it was a lifelong, incurable disorder. There was nothing we could do for her, that it was just a matter of time until we'd probably have to institutionalize her. It was absolutely crushing.

Jim and his wife, Marie immediately ruled out institutionalizing Kim. And although already raising two other children, they began doing everything they could for Kim - special diets, special teachers, special classes. While she appeared normal, Kim couldn't speak, couldn't follow simple instructions, and made little eye contact.

Marie Adams: Then as she got older, you know her anger, her tantrums, her aggression - she used to hit, kick, bite. When she was older, she knocked holes in the walls.

A professor of chemistry at Arizona State University by day, Jim Adams studied autism at night, learning about brain development and damage, how the brain interacts with vitamins, minerals and metals.

He sought out others concerned with the rising number of children being labeled autistic - parents and scientists who also wondered how a condition

that was diagnosed in only one in 100,000 children in the 1980s was two decades later diagnosed in as many as one in every 175 American children.

He started hearing stories about damage done to people exposed to methyl mercury, the kind found in thermometers and in polluted environments.

There

was the mercury spill in Japan that led to mercury laden fish and Minimata disease, affecting many who ate the fish.

He heard about Pink Disease, also called Acrodynia, a mysterious condition that afflicted children in this country roughly a hundred years ago. The symptoms included social withdrawal and lack of language. The condition disappeared almost overnight when a certain type of teething powder which contained mercury was removed from the market.

Jim Adams: There is no doubt that the mercury in the teething powders was what caused Acrodynia, and that symptoms of Acrodynia were pretty similar to symptoms of autism.

John Larson, Dateline correspondent: What's your basic idea here? That mercury causes autism or that somehow makes it worse?

Jim Adams: We think that it's a combination of a genetic susceptibility leading to a decreased ability to excrete mercury. So that these kids are not necessarily dosed to high levels of mercury, but that simply, they are a small subset of the population that they have unusual genes, that they just can't excrete mercury very well.

Larson: Jim's suspicion that mercury might somehow be connected to the rise

in the number of children diagnosed with autism places him near the center of one of the most hotly contested and politically charged medical debates of our time - one that has pitted activist parents against federal health officials and vaccine manufacturers, because mercury in children often comes from vaccines.

Vaccines -- those life-saving miracle drugs that have successfully fought back everything from polio, small pox, and diphtheria, to measles, mumps and

rubella. It began to be phased out a few years ago, but until then, most infant vaccines included something called ethyl mercury in a preservative called thimerasol.

Although different from methyl mercury, the kind found in pollution, ethyl mercury in high enough doses, can also damage the nervous system.

Jim Adams: Thimerasol was introduced into vaccines before the FDA even existed. It was just grandfathered in. And then as children began receiving more vaccines in the vaccination schedule, the amount they received kept growing and growing until 1999 when Congress asked the FDA to evaluate the amount of mercury in all the pharmaceutical products.

What the Food and Drug Administration discovered was that along with getting more shots, by 1992, children were also getting more mercury. The vaccines undoubtedly were protecting the children from a variety of deadly diseases, but were they also causing autism in some children?

In order to answer that question, the Centers for Disease Control and Prevention commissioned two reports into the issue, both of which dismissed thimerasol as the problem. Dr. Tanya Popovic is the CDC's Associate Director for Science Research.

Tanya Popovik, CDC Associate Director for Science Research: Top-notch scientists have reviewed everything and anything that is available and have really in their latest report said that they reject causal association of thimerasol in vaccines and autism.

The American Academy of Pediatrics and many other scientists also reject the link between vaccines and autism and are concerned the debate over mercury will discourage parents from vaccinating their children.

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Producer: Why do a story on an unorthodox practice?

But despite the stance of mainstream science, thousands of parents, and even some scientists, claim there is a growing body of evidence to suggest there might be a connection between mercury and autism.

And they point to the benefits of a radical new treatment to help make their case.

Julia Berle, mother of autistic child: It saved my child.

This mother and thousands of other parents have turned to a process called chelation.

Chelation involves ridding the body of metals, including mercury. In its most aggressive form, it is done intravenously, but most parents give their autistic children a milder oral medication, or as in this case, a cream that is absorbed through the skin. The chelation agent binds to the mercury, which is then passed through the system.

Originally approved for treating lead poisoning, there are parents who claim chelation has helped cure their children's autism.

The parents share stories and home videos of what they describe as their children's recoveries.

Some report their children going from agitated repetitive behaviors to simply being calmer and able to focus. From being unable to use language, to being able to express themselves- from almost complete withdrawal, to interacting with their families again. But most doctors aren't buying those stories of near-miraculous recovery.

Dr. Jay Berkelhamer, president of American Academy of Pediatrics: The usefulness of chelation therapy in treating autism is nil.

Dr. Jay Berkelhamer is the President of the American Academy of Pediatrics. Like most doctors Dateline spoke with, he pointed out the process can be dangerous. Performed intravenously, it even led to one death.

Dr. Berkelhamer: Chelation therapy is potentially toxic. The chelation material that are used to remove these metals from the bloodstream can affect the liver and the kidney.

The reason most doctors agree with the American Academy of Pediatrics is because they don't believe mercury from vaccines is the problem in the first place. They say some autistic children may just outgrow the problem, or improve from behavioral and other therapies, but that autism isn't cured by removing metals from a child's system.

CONTINUED: Testing the theory

But despite the position of mainstream science on chelation, for Jim Adams and some other scientists, the verdict is still out.

Jim Adams: It's a very controversial topic. There have been a number of epidemiology studies looking at it, Some showing absolutely no link, some showing a very strong link. It depends, I think, very much on who does the research. I think the most critical issue is looking into thimerasol.

So Jim Adams has decided to do just that. Along with Dr. Matt Boral of the Southwest College of Naturopathic Medicine - an accredited school of alternative and integrated medicine - he has designed the first double-blinded, placebo-controlled study of chelation. The mission: to answer the question of whether chelation really works, or whether it's just the wishful thinking of desperate parents.

John Larson, Dateline correspondent: You've got strong feelings about the connection between mercury and autism. Are you the guy who should be doing

this study? Will critics come out and say, "Well, here, he just proved what his suspicions were?"

Jim Adams: I think that if someone else were to do the research, I'd be thrilled. But the fact is no one else has done it and thousands of families are out there using it. And so, because it's pretty much the most highly ranked treatment according to a survey of 23,000 families, I think there's a lot of good reason to do it.

But he already knows chelation does not work for everyone.

Chelation did not help his daughter, Kim, perhaps Jim says because it was done too late. But regardless of why it didn't work, he wants to know if chelation can help any autistic children. After all, he is not just a chemist in search of knowledge, but a father who knows the desire for a cure.

John Larson: What happens in the end, after all this hard work? If you find that there really is no relation between mercury and autistic behavior. Will you be disappointed?

Jim Adams: Disappointed, yes. But whatever way it turns out, we'll report it. If it doesn't help, we'll report it. And if it does, we're gonna report that, too.

Public health officials stress the need to vaccinate children against known diseases. Today most American children under the age of two years are automatically vaccinated with mercury-free vaccines, and parents can ask their pediatricians about getting thimerasol free vaccines for their older children. Some experts also suggest requesting mercury-free flu shots for pregnant women, infants and children.

Jim Adams predicts he'll have the final results of his study by the end of the year, and we'll have them first, here on Dateline. You should know that most children under the age of two are now automatically given mercury-free vaccines, and parents can request those shots for their older children as well.