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Debated autism therapy gives hope to parents

Iowa boy improves with mercury-removal treatment

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Le Claire, Ia. - Gavin Wilken is out in his backyard, unknowingly demonstrating extraordinary accomplishments.

The 6-year-old is goofing around with his little sister, Lindsey. He's talking. He's laughing. He's playing chase.

Their mother, Tami Wilken, watches from the kitchen, expressing amazement at how normal Gavin seems. You should have seen him a few years ago, she says. He quit speaking. He failed to respond to his name. He would hold a pen in front of his face and spin it for hours on end.

The troubles began subtly when Gavin was 17 months old. "He started swaying in front of the wall," Wilken says. "At first, I thought, 'How cute, he's playing with his shadow.' But there was no shadow."

Doctors, who at first saw nothing wrong, concluded Gavin had autism. The brain condition can rob children of their personalities, and it can tear families apart. Most doctors say they're unsure what causes autism, and they can't explain why the number of new cases has soared over the past 20 years. They have little to offer in treatment or in hope.

Tami Wilken says she knows the answers. She has joined an increasingly vocal and controversial movement of parents who believe their children's autism was sparked by mercury, which until recently was included in many vaccines as the base component of the preservative Thimerosal. Wilken has taken the belief a step further, seeking out an aggressive treatment, called chelation, to remove the metal from Gavin's body.

She knows mainstream medical leaders disagree with the theory and the treatment. "If their oath is to do no harm, why are they pushing mercury into my child but not letting me take it out?" she asks.

Doctors skeptical of treatment's benefits

Vaccine controversy

BAN: Last year, Iowa became the first state to ban mercury-based preservatives from most vaccinations.

SCIENCE: Dr. Rizwan Shah of Des Moines said the small amounts that used to routinely be included in vaccines have never been scientifically linked with autism.

PARENTS: Yet an increasingly vocal and controversial movement of parents believe their children's autism was sparked by mercury, which until recently was included in many vaccines as the base component of the preservative Thimerosal.

VACCINATIONS: Iowa grade schools require that children be vaccinated, but parents may apply for medical or religious exemptions.

This spring, Gavin became one of 125 children put forward as success stories by a new national group urging parents to use chelation to relieve their children of autism. The group, Generation Rescue, has taken out full-page ads in USA Today and the New York Times, declaring that "Autism is Preventable and Curable."

The effort concerns many physicians, who worry that it could make parents needlessly fearful of vaccines and that it could lead desperate families to spend tens of thousands of dollars on a treatment that they say probably doesn't help and could hurt.

Doctors often start the discussion by saying they understand why parents of autistic children are frustrated with the lack of explanation and treatment for the growing problem. Federal researchers say that between 1994 and 2003, the number of school-age children classified as having autism or related disorders exploded from 22,664 to 141,022. Official estimates say as many as one in 166 children are affected. Although many experts say that much of the jump in cases is due to more aggressive diagnosis of the condition, most agree that there also has been an actual increase.

Dr. Patricia Quinlisk, Iowa's state epidemiologist, says large studies have concluded there is no link between mercury and autism.

"Thimerosal is not the cause of autism," she says. "Therefore, I don't think taking it out is the answer." Several European countries took the preservative out of their vaccines years ago, she says, and their autism rates continue to grow.

American drug makers began removing the controversial ingredient from most of their vaccines a few years ago. "The anti-vaccine people took that as proof something was wrong," Quinlisk says. In fact, she says, the manufacturers did it because authorities feared that even baseless concerns could make parents avoid important vaccinations.

"No way could it be a coincidence"

Chelation, the treatment being used on Gavin, has been around for many years. It mainly has been used for people who have suffered from lead poisoning or industrial accidents involving heavy metals. Chelation medications are designed to bind with the metals, which the body then can excrete.

Possible side effects include loss of helpful minerals, such as zinc and iron. Gavin has been taking various forms of the treatment for four years. His current medicine is a cream that his parents spread on his arm every other day. They give him vitamins and other supplements to try to replace lost minerals.

Tami Wilken, who works part time at the International House of Pancakes, and her husband, Bill, who drives trucks for FedEx, have spent \$65,000 to \$70,000 on treatment for their son.

It is worth it, they say. Gavin resumed speaking within two weeks of starting chelation. Within a year, he was using six-word sentences. This past school year, he was in a regular first-grade class with the help of a teacher's aide. They hope that by third grade, he will be able to handle classwork on his own.

Quinlisk and many other doctors say some autistic children improve on their own, for unknown reasons. So the fact that some kids get better while on a given treatment proves nothing, they

argue.

Tami Wilken doesn't buy it. "Absolutely not," she says. "There is no way it could be a coincidence."

Source of autism remains unclear

J.B. Handley, Generation Rescue's founder, doesn't buy it either. Handley, who lives in Oregon, has an autistic son who he says is improving while having chelation treatment.

Authorities are so intent on vaccinating children that they've covered up the harm, and studies concluding otherwise are tainted by the influence of drug companies, Handley says.

Handley contends that all autism is caused by mercury and that because of the preservative that used to be common in vaccines, "an entire generation has been poisoned," he says.

That cuts against conventional wisdom, which holds that autism is a complicated, varied condition that probably has multiple causes.

Handley says the symptoms of autism are strikingly similar to those of mercury poisoning. That's why he believes chelation works.

The treatment has caused controversy before. In 1998, the Iowa Board of Medical Examiners suspended a West Des Moines doctor partly for using chelation as a treatment for heart disease and diabetes. The doctor still hasn't had his license restored.

Under state rules, the treatment may be used only to treat heavy-metal poisoning. Ann Mowery, the licensing board's executive director, says she hasn't heard of any Iowa physicians using the treatment for autism. She says the board hasn't ruled on whether that would be a permitted practice, because the subject hasn't been brought up.

Gavin's physician, Dr. Robert Filice of suburban Chicago, knows his "alternative" therapy is outside the medical mainstream. But he says he's not worried about getting in trouble for it because chelation is intended to take out heavy metals, and that is precisely how he's using it.

Filice is not sure that all autism cases are caused by mercury poisoning, but he believes that even small amounts of the metal can harm children who for genetic reasons have trouble excreting it.

The doctor says he's treated about 20 autistic children with chelation, and about half of them have shown dramatic improvement. "There's no guarantee that they're going to respond. But it's such a safe therapy, with the potential benefits being so great, I would tend to err on the side of treating somebody, just to see what happens."

Such talk leaves many people wondering if chelation is the answer, or if it is just the latest straw for desperate parents to grasp.

More research urged on mercury's role

Count Steven Muller among the undecided. Muller is executive director of the Homestead, a Runnells autism treatment agency. He sympathizes with families who are reaching out for

unusual solutions.

"It's great to have people pushing the envelope, because if they don't, the world stays flat," he says. "But I've also heard people say that all autistic kids can be cured, thereby raising false hopes for families that probably always will be dealing with this."

Muller's agency relies heavily on behavioral therapies to help autistic children and adults get along in the world. He believes there is enough suspicion to justify continued studies of Thimerosal's possible role. Even now that the preservative has been removed, he suggests that doctors should consider spreading the shots out, instead of giving them in bunches. That might lessen possible complications, he says.

"But when parents say, 'I'm not going to vaccinate my kids,' that's the wrong approach," Muller says. "You do need to vaccinate your kids."

Muller is wary of expensive, unproven treatments. He has seen families go into debt to pay for all kinds of approaches, from swimming with dolphins to taking complicated vitamin therapies. Some might work for a few kids, he says, but not for everyone.