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AUTISM TREATMENT



AMANDA DIFUCCI, 6, has shown rapid improvement since she began taking an alternative treatment for her autism. Her development skills limited a year, she now plays energetically with other children. Her parents credit the use of a chelation agent that is removing mercury from her body.

PHOTOS BY LORI VAN BUREN/TIMES UNION

A risk or remedy debate

Parents of autistic child cite progress as medical community urges caution

By **MATT PACENZA**
Staff writer

CASTLETON-ON-HUDSON — On Saturday, Amanda DiFucci will have a princess party for her seventh birthday.

A year ago, before her parents tried a controversial medication to treat her autism, such a celebration would have been impossible. Their

daughter, who was first diagnosed with autism when she was 4, never played with other kids. She had endless tantrums. She spoke like a toddler, using single words.

Today, nine months into treatment with DMPS, a "chelation" agent that leaches heavy metals like mercury out of Amanda's body, she has shown rapid improvement, according to her kindergarten teacher.

"There was a burst of development," said Amy DeWeerd of Green Meadow Elementary School in East Greenbush. "Her language is much

more developed. She's much more expressive. She's always playing with someone. She's one of the group for sure."

Sara DiFucci firmly believes her daughter's autism was caused by mercury poisoning, most likely from a preservative called thimerosal, which until several years ago was added to vaccines to keep them sterile. She now also believes chelation will help her daughter fully recover, by removing mercury from her body.

Please see **AUTISM A5** ▶



PAINTING a picture on the deck of her home, Amanda DiFucci is showing few signs of autism since being on a new therapy. Her mother, Sara, sits in the backyard with her.

AUTISM: Parents see marked improvement

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Those are extremely controversial opinions that fly in the face of the established wisdom of nearly the entire medical community. Numerous studies show no link between vaccination and autism. Most professionals also reject therapies like chelation which are unproven — and possibly harmful.

"There's a lot of documentation that chelation done in the wrong way is actually dangerous," said Dr. Anthony Malone, a pediatrician affiliated with Albany Medical Center who specializes in developmental and behavioral disorders.

All sides in the debate over autism agree about one thing: It has become an epidemic. It now affects about 1 out of every 166 American children, a six-fold increase over the past decade. It's more common than multiple sclerosis or childhood cancer.

Authorities don't know exactly why there is much more autism today. Even 10 years ago, autism was barely on anyone's radar.

"A good portion of the increase is earlier diagnosis and better recognition," said Malone. "There also appears to be a real increase."

DeWeerd reports that in her first 15 years teaching kindergarten, she had two children in her classes with autistic disorders. In the last three years, she's had five such children.

The term autism covers a range of conditions, called autism spectrum disorders. That includes everything from the most severe form, called autistic disorder, to a milder form, Asperger syndrome, and another called pervasive developmental disorder.

Children with these disorders have limited communication skills, impaired social abilities and "restricted, repetitive and stereotyped patterns of behavior," according to the National Institute of Mental Health.

Amanda could not ask questions or have conversations. She would repeatedly slap her head and pull at the neckline of her shirt. Loud noises sent her into frenzies for hours. She had a strong aversion to most foods, and would violently fight efforts to eat anything outside of a few mainstays.

"It was like an episode of 'Fear Factor,'" said Sara DiFucci, 34, of trying to feed her daughter.

For years, parents of autistic children like the DiFuccis have fought to challenge the majority opinion about autism. Whether

mercury from vaccines caused autism seemed settled after a definitive 2004 National Institute of Medicine report which found that the mercury hypothesis "lacks supporting evidence and are theoretical only."

The parents and their allies say those studies are flawed. They point to more recent research, such as a 2004 Columbia University study which found that some mice develop autistic-like behaviors after being injected with vaccines containing thimerosal.

The parents, sometimes referred to as the Mercury Moms, have founded organizations like Defeat Autism Now!. Recently, the DiFuccis and others parents created Generation Rescue, which believes autism can be cured.

They believe mercury harms those kids who have a genetic disorder that doesn't allow them to excrete heavy metals. So the mercury they bring in, from fish or from thimerosal, stays in their bodies, wreaking havoc.

"The thinking is that there is a subset of children that have a genetic vulnerability or susceptibility to toxics," said Dr. Kenneth Bock of the Center for Progressive Medicine in Albany and the Rhinebeck Health Center, the one area practice that endorses chelation and other detoxification approaches.

Bock does not recommend DMPS, the medicine the DiFuccis are using with Amanda, because it is not currently approved by the U.S. Food and Drug Administration. The FDA's Web site says the compound "appears to be relatively nontoxic."

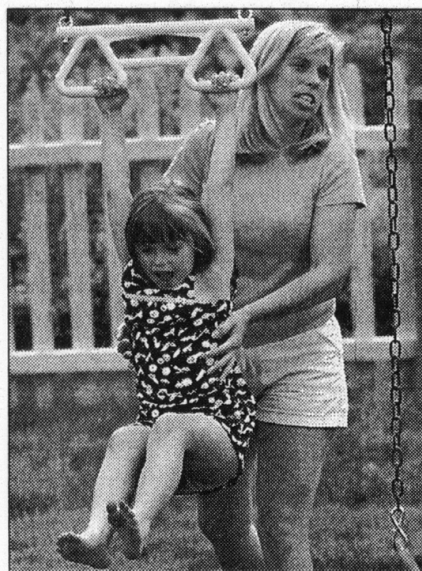
Sara DiFucci and her husband, a manager with General Electric in Pittsfield, decided last fall to begin chelation with DMPS, a topical liquid applied to the skin. It is not covered by insurance and costs them between \$2,000 and \$6,000 a year.

The DiFuccis said they are careful to make sure DMPS isn't hurting their daughter. Every other month, Amanda gets a full battery of tests to make sure her blood levels and organ function remain normal.

For DMPS, the DiFuccis went to Dr. Rashid Buttar, an alternative medicine physician in North Carolina who claims remarkable success with the compound. Buttar told Congress last May that 22 of 31 patients with autistic disorders whom he treated with DMPS had recovered.

One such child is the 2-year-old son of J.B. Handley, a founder of Generation Rescue.

"As a parent, it's the difference



LORI VAN BUREN/TIMES UNION

SARA DIFUCCI gives her daughter a push on a swing at their home in Castleton-On-Hudson. Amanda, 6, showed some severe signs of autism when she was younger, but her development has improved greatly, her mother and teacher say.

between being in a deep dark cave and having bright light and oxygen," said Handley, an investment banker in San Francisco.

Skeptics have seen dramatic claims made about earlier autism treatments that didn't hold up after more rigorous testing.

Barbara Quinn, a nurse clinician who works with Malone at Developmental Pediatrics in Latham, remembers when a mother with a recovered child went on a morning talk show crediting secretin, a hormone therapy.

"We were flooded with calls, parents asking, 'Why weren't we doing secretin?'" said Quinn. "But then later, literature showed kids had seizures with secretin."

Alternative therapy research is tough to do, its backers say.

"The problem is that there isn't a lot of funding for this type of research," said Bock. One controlled study on DMPS is about to begin at Arizona State University.

The professionals who work with autistic children say they'll flock to any therapy, even chelation, if good research shows it is safe and effective. "If something was out there, I'd be dancing on the roof," said Quinn.

Some professionals who hear the DiFuccis' or the Handleys' stories say they wonder if the chelation wasn't just coincidental with the children's improvement. Other children with autistic disorders may experience rapid improvements, although they remain uncommon.

The long-term prognosis for children with autism varies. For those with mild to moderate

cases, research suggests about 10 to 20 percent can recover fully, according to Malone.

The one therapy endorsed by nearly all medical professionals is behavioral teaching, which emphasizes intensive structured learning for children.

Most of the parents who claim success with chelation also had their children do such work, leading professionals to wonder why parents credit the chelation.

"It's hard to tease out the intervention that led to the improvement," said Kristin V. Christodulu, director of the Center for Autism and Related Disabilities at the University at Albany, which provides resources to parents and school professionals in the Capital Region.

Sara DiFucci rejects the idea other therapies may be responsible for Amanda's improvement. The DiFuccis stopped the other therapies they were trying, like vitamins and behavioral work, just before they began chelation in October.

The debate about autism and mercury may actually be settled soon. Since thimerosal was removed from all vaccines but the flu shot by 2002, the numbers of children with autism should start to go down, if the Mercury Moms are right.

"Late 2006 should be the first time that rates go down," said Handley. "If they don't, our hypothesis will need to be reexamined."

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