

THE WALL STREET JOURNAL.

A Radical Approach to Autism

Some Physicians, Families Tout Metal-Stripping Drugs, But Benefits Are Unproved

By AMY DOCKSER MARCUS

Staff Reporter of THE WALL STREET JOURNAL

February 15, 2005; Page D1

One of the most frustrating struggles in children's medicine has been the long-running, and often controversial, effort to treat autism.

Now, some parents and physicians are touting an approach that could be the most controversial yet: using drugs that strip the body of metals.

The treatment, called chelation therapy, has been used for decades to detoxify people contaminated with metals through industrial accidents or environmental exposure. The drugs have potentially serious side effects -- including bone-marrow and liver problems -- because they also strip necessary minerals such as iron and zinc from the body. But advocates of the technique say the drugs can significantly reduce autism's devastating symptoms such as lack of emotion and repetitive behaviors. Some go so far as to say that autistic children treated with chelation can return to normal health.

The practice grew out of the belief among many autism experts that heavy metals -- especially mercury-based preservatives in childhood vaccines -- are to blame for autism. An Institute of Medicine report in May 2004 found no link between autism and vaccines. But the theory got a boost last year after a toxicologist who treated his own son with a chelating medication testified before a congressional subcommittee chaired by Congressman Dan Burton of Indiana. Rashid A. Buttar told the committee that 19 of the 31 patients in his North Carolina clinic using the medication, called TD-DMPS, for more than a year had a complete loss of their autistic symptoms. The results haven't been published, though Dr. Buttar says he is working toward that.

The practice of chelation as a treatment for autism has been greeted with anger by many in the mainstream medical establishment, who decry the potential side effects and note that there are no published clinical trials demonstrating that it works. Some contend that children who seem to improve after therapy were likely misdiagnosed as autistic to begin with, or simply have a milder form of autism.

Many autistic children who have been treated with chelation were undergoing numerous other treatments as well, including in Dr. Buttar's research. That makes it "difficult to tease out the effect of chelation," says Marie McCormick, professor of maternal and children's health at the Harvard School of Public Health. Only clinical trials are likely to resolve the debate, adds Dr. McCormick, chairwoman of the committee that wrote last year's IOM report on vaccines.

The traditional approach to treating autism has focused on intensive behavioral therapy, special education and speech training. Autism, which affects as many as one of every 166 U.S. children, according to the Centers for Disease Control and Prevention, is a developmental disorder that affects a child's communication, creative play and social interaction.

There is no way to know how many autistic children are undergoing chelation. The CDC reported last year that 60,000 Americans use some form of chelation therapy. But it isn't known how many are being treated for lead poisoning or other diagnoses. Representatives for the CDC and the federal Food and Drug Administration said they had no comment on the use of chelation therapy for autism.

Word-of-Mouth

Thus parents embarking on chelation are relying primarily on anecdotal reports through the Internet and other word-of-mouth avenues. The story of Lenny Hoover, 6 years old, from Royal Palm Beach, Fla., is one that advocates of chelation therapy often cite.



Paulette Martin/FilmMagic

Lenny Hoover's parents say chelation helped reverse his autism. He now attends regular kindergarten.

Charles Hoover, Lenny's father, says his son was diagnosed with mild to moderate autism at the age of 2. The Hoovers first put Lenny on a wheat- and dairy-free diet, in the hope this would reduce his gastrointestinal problems, which are a common issue for autistic patients. They started him on intensive behavioral therapy. When he was 28 months, they also began chelating him after tests showed Lenny had elevated tin, nickel and arsenic in his urine. They mixed a medicine called DMSA into his juice, which he had to drink every eight hours for three days, with 11 days off. He did 38 rounds of chelation following this schedule.

"We had a heck of a time getting him to drink it," said Mr. Hoover. "It smells like sulfur and is horrendous."

But Lenny started making such rapid gains that they eventually stopped behavioral therapy. By the time Lenny was 5, the local school determined that he had no developmental delays. He started a regular kindergarten last fall. Says Mr. Hoover, "We lost our son, then we got him back."

A number of Web sites and autism support groups offer information to parents on chelation. A Yahoo chat group about chelation and other biomedical treatments for autism, Chelatingkids2, has more than 1,800 subscribers, according to co-founder Ann Brasher. The Autism Research Institute, an advocacy group in San Diego that supports the idea that vaccines are the primary source of mercury poisoning in autistic kids, says that in its most recent parent survey, 73% of the 187 parents who said they use chelation therapy reported that it was helpful. Today, the institute, which says it is funded mainly by individual contributions, is set to release a report recommending chelation as "one of the most beneficial treatments for autism and related disorders."

Question of Diagnosis

Some critics argue that patients such as Lenny Hoover may have been misdiagnosed -- that such children were actually at the high-functioning end of the spectrum of autistic disorders or were never even autistic. Mr. Hoover says that Lenny demonstrated typical autistic behavior. Lenny had lost his speech ability, slept only a few hours at night, and in home videos he is seen spinning around in a circle, over and over again.

Mr. Hoover acknowledges that it is difficult to say conclusively which of the therapies used on Lenny was helpful. He says that the diet, behavioral therapy and chelation all helped his son, but that he believes chelation was a key. At this point, Lenny eats a regular diet and hasn't done any chelation since July 2003, when his parents decided he wasn't making further gains from the therapy.

Off-Label Use

There are many medications used for chelation. Some, such as DMSA -- a chemical compound made by a variety of manufacturers including Epochem Co. in Shanghai -- are FDA-approved for other treatments including lead poisoning. Doctors who prescribe these to treat autism are using them off-label, which is allowed for already-approved medications. Others aren't FDA-approved. But pharmacists can compound them for individual use at a physician's request. The drugs can be given in several ways, as creams, pills or via shots or intravenous infusions. Regimens vary in frequency, dosage and length of treatment.

Before starting chelation, patients undergo testing to measure their exposure to heavy metals. Doctors disagree on the best way of testing metal exposure. Options include hair, urine and blood tests. Critics say these tests can have high false-positive rates. The Autism Research Institute supports the use of a so-called provocation test, which involves giving a chelating agent followed by urine or stool collection to see whether heavy metals were excreted.

Chelation therapy isn't cheap, with medications running \$100 to \$200 a month. Testing also can be expensive, costing \$1,000 to \$2,000 to get started, and \$1,200 to \$2,400 a year in monitoring. Insurers don't cover chelation therapy for autism or other off-label uses.

New Studies

The metal-cleansing treatment also is gaining ground as a treatment for a range of conditions besides autism, including Alzheimer's and heart disease. A preliminary study published in Archives of Neurology in December 2003 found that removing metals accumulating in the brain of Alzheimer's disease patients using the chelating drug, clioquinol, appeared to slow the progress of the disease. Two institutes of the National Institutes of Health last year opened a clinical trial that so far has enrolled more than 500 patients to test whether chelation therapy benefits patients with heart disease.

Later this year, investigators at Arizona State University in Tempe, Ariz., will launch a clinical trial involving 80 autistic children ages 3 to 9. Half of the children will

receive DMSA, the treatment approved by the FDA for lead poisoning. The other half will receive a placebo. The trial aims to demonstrate whether chelation therapy can improve the symptoms of autism.

Chelation Agents

Some pros and cons in three of the most commonly used chelating agents in autistic children:

NAME	PROS	CONS
DMSA Sodium 2,3 dimercaptopropane- 1 sulfate	In the oral form, approved by the FDA for treating lead poisoning in children as young as 1. It can remove a wide range of metals, including lead and mercury.	Long-term use can potentially cause bonemarrow suppression or liver damage. It strips zinc, a beneficial mineral, and supplements may be needed. It can cause gastrointestinal problems to worsen.
DMPS 2,3 dimercaptosuccinic acid	It causes fewer gastrointestinal problems than other agents and may be more effective at eliminating mercury than DMSA. It now comes in a cream form, which is easier to use.	DMPS is not FDA-approved although physicians can have it individually compounded for patients. It has potentially serious side effects and blood and urine need to be regularly monitored.
TTFD Thiamine tetrahydrofurfuryl disulfide	In studies, it had a good safety record. In a small study of 10 children on the autism spectrum, most improved clinically. It comes in cream form.	It is not approved by the FDA, although physicians can have it individually compounded for patients. It has a strong odor described as "skunklike" even in cream form, and has a bad taste in powdered form making it difficult to give to children who cannot swallow a capsule.

Source: Autism Research Institute's Defeat Autism Now Project