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## PERSONAL JOURNAL.

THE WALL STREET JOURNAL.

### A Radical Approach to Autism

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

By AMY DOCKSER MARCUS

ONE OF THE MOST frustrating struggles in children's medicine has been the long-running, and often controversial, effort to treat autism.

Now, a growing number of 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 like 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 hearing sponsored 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 over 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 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 mis-

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Paulette Martin/FilmMagic

### *Treating the Body vs. the Mind*

By RACHEL ZIMMERMAN

MANY PARENTS of autistic kids have long argued that something other than the disorder itself was causing some of their children's problems. Now, mainstream medicine is beginning to acknowledge that.

The idea, embraced by a growing number of top specialists, is to treat medical conditions that are common in autistic children. These problems—which include gastrointestinal disturbances, sleep

disorders and food allergies—may be contributing to the children's behavioral difficulties. While such conditions are frequently treatable, they often go undetected due to lack of physician awareness and the children's poor language skills.

Major hospitals, from Massachusetts General to the Cleveland Clinic, have begun aggressively treating underlying medical problems in autistic children, and researching how

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## Some Doctors Tout Metal-Stripping Drugs

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diagnosed 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. Spokespersons for the CDC and the federal Food and Drug Administration said they had no comment on the use of chelation therapy for autism.

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.

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, mixing 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 now offer information to parents on chelation. A Yahoo chat group, Chelatingkids2, has over 1,800 subscribers, according to co-founder Ann Brasher. The Autism Research Institute, an advocacy group in San Diego that sup-

### Chelation Agents

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

NAME	PROS	CONS
<b>DMSA</b> 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 bone-marrow suppression or liver damage. It strips zinc, a beneficial mineral, and supplements may be needed. It can cause gastrointestinal problems to worsen.
<b>DMPS</b> 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.
<b>TTFD</b> 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

ports the idea that vaccines are the primary source of mercury poisoning in autistic kids, says that in its most recent parent survey, 73% of parents who use chelation therapy reported that it was helpful. Today, the institute is set to release a report recommending chelation as "one of the most beneficial treatments for autism and related disorders."

Some critics of chelation argue that patients like Lenny Hoover may have been misdiagnosed—that such children were ac-

### Before chelation, patients undergo testing to measure exposure to metals.

tually at the high-functioning end of the spectrum of autistic disorders or were never even autistic. Mr. Hoover says he doubts it, and that Lenny demonstrated typical autistic behavior. Lenny had lost his speech ability, and in home videos he is seen spinning around in a circle, over and over again. He had constant tantrums and slept only a few hours at night.

Mr. Hoover acknowledges that it is difficult to say conclusively which of the therapies used on Lenny was helpful. He says that all three therapies—the diet, the behavioral therapy and chelation—helped his son, but that he believes chelation was a key. At this point, Lenny eats a regular diet and has not done any chelation since July 2003.

There are many medications used for

chelation. Some, like DMSA—a chemical compound made by a variety of manufacturers including EPOCH Co. Ltd in Shanghai—are FDA-approved for other treatments including lead poisoning. Doctors who prescribe these to treat autism are using them off-label. Others, like one called DMPS, are not FDA-approved; physicians must request that these be individually compounded by a pharmacist. 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.

The majority of patients undergoing chelation for autism are children, say doctors who administer the treatment. Doctors involved in the movement say children under age three have the best chance of improvement of symptoms.

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 if heavy metals were excreted.

Autistic children are sometimes prescribed chelating agents even if tests don't reveal high levels of mercury. The reason: Some chelation advocates say that traditional blood tests miss metal exposure that might have taken place in utero or during the child's first year of life.

Chelation therapy isn't cheap, with medications running \$100-\$200 a month. Testing can also be expensive, costing \$1,000-\$2,000 to get started, and

\$1,200-\$2,400 a year in monitoring. Currently, insurers don't cover chelation therapy for autism, heart disease, Alzheimer's or a range of other off-label uses.

Chelation is also 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. Many patients with heart disease receive weekly intravenous infusions of a chelating drug, EDTA, out of belief that it can reverse heart disease.

Two institutes of the National Institutes of Health last year opened a clinical trial that has so far enrolled over 500 patients to test whether chelation therapy benefits patients with heart disease. And a number of health spas around the country offer chelation as a treatment to generally cleanse the body and improve overall health.

Later this year, investigators at Arizona State University in Tempe, Ariz., will launch a clinical trial involving 80 autistic children ages three to nine. Half of the children will receive DMSA, which is approved by the FDA for treating lead poisoning in children as young as one. The other half will receive a placebo. The trial aims to demonstrate whether or not chelation therapy can improve the symptoms of autism.

The positions of two toxicologists illustrate the sharp divide among scientists on this subject. Michael Shannon, a pediatric toxicologist at Children's Hospital Boston and a professor of pediatrics at Harvard Medical School, says he has been chelating children, primarily for lead poisoning, for 20 years. He says he has evaluated 30-40 children with autism and found evidence of mercury poisoning in only one child, who he said was eating a high-seafood diet.

Dr. Shannon says that he has treated autistic children for lead poisoning, largely because autistic children are very oral and they may be chewing on paint. But even after the lead levels returned to normal, he says. "I have not seen evidence that chelation reversed their autism."

On the other side of the spectrum is Dr. Buttar, who testified before the congressional subcommittee last year. Dr. Buttar, who is also vice chairman of the American Board of Clinical Metal Toxicology, talked about his son, Abid Azam Ali Buttar. At 36 months, the child had no verbal communication, would not respond when called, and spent hours staring at the fan.

In an effort to treat his son's developmental delay, he and a partner developed a cream formulation of the chelating drug, DMPS. At the age of 5, Dr. Buttar says his son now beats him at chess, reads simple words, has an extensive vocabulary and does math in his head. In some children, autism "can be fully and permanently reversed," Dr. Buttar said in his congressional testimony.



## Treating Medical Conditions Common to Autism

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these problems may be linked to the disorder's symptoms. The movement got a big push this month when six hospitals joined together to form the Autism Treatment Network, aimed at coordinating an approach to a wide range of potential physical problems.

When 10-year-old Becky Sullivan began biting holes in her wrists and hitting her own face so hard that it bruised, two psychiatrists and a neurologist told her mother the outbursts were behavioral problems caused by her autism. One suggested an antipsychotic medication, but that didn't stop the aggressive behavior.

Her mother then took Becky to Massachusetts General Hospital in Boston, where a pediatric gastroenterologist found that Becky's esophagus was severely inflamed and covered with ulcers. Her violent behavior likely resulted from frustration with her inability to communicate the excruciating pain, the doctor concluded. Acid-reflux medicines halted the problem almost immediately. "She's a whole different kid," says Becky's mother, Jacquelyn Sullivan of Quincy, Mass.

Autism is a broad term used to describe a spectrum of developmental disorders marked by language difficulties and emotional withdrawal. Currently, there is little agreement about what causes it, or why its incidence appears to have increased tenfold over the past decade. Desperate parents have often stumbled through a morass of conflicting medical and behavioral advice, from intravenous supplements to swimming with dolphins.

### Guidelines for an Exam

The Autism Treatment Network, which recently began meeting, plans to draw up national guidelines for a thorough physical examination aimed at catching medical problems that appear to disproportionately affect autistic children. The hospitals plan to gather data on patients and publish findings on the prevalence of different medical disorders in autistic children. Centers participating in the network include Baylor College of Medicine, Houston; Cleveland Clinic Foundation, Cleveland; Columbia University Medical Center, New York; Massachusetts General Hospital, Boston; Oregon Health & Science University, Portland, Ore.; and the University of Washington Medical Center in Seattle.

"What we are trying to standardize is the concept that children with autism can and do have health-care issues just like typical kids and they deserve the same degree of attention, evaluation and treatment," says Margaret Bauman, a pediatric neurologist at Massachusetts General Hospital and a member of the committee that will oversee the new consortium.

### Health Issues and Autism

The six hospitals in the Autism Treatment Network are working to address some of these medical problems, which may be causing behavioral problems in autistic children. Contact [www.autismtreatmentnetwork.org](http://www.autismtreatmentnetwork.org) or (503) 783-2710.

CONDITION	BEHAVIOR	COMMENT
<b>Gastrointestinal disorders</b>	Aggression; injuries to self and others	Treatment with acid-reflux medication can lessen pain and discomfort.
<b>Sleep problems</b>	Irritability, moodiness, trouble concentrating	Doctors may investigate whether a melatonin deficiency is to blame.
<b>Food allergies</b>	Belly aches, anxiety, rashes	Some families find eliminating wheat and dairy can improve symptoms.
<b>Metabolic disorders</b>	Exhaustion, seizures, delayed motor development	Some physicians are trying supplements, such as B vitamins and antioxidants, that may aid metabolic functions.

Sources: Autism Treatment Network physicians

One of the first priorities of researchers will be to settle—through clinical study—the hotly debated question of whether certain medical conditions, such as acid reflux, diarrhea and other gastrointestinal maladies, are more common in autistic children than in other kids.

For example, sleep deprivation, which can cause irritability and social difficulties in healthy people of all ages, appears at least at first blush to be more common in autistic children. One small study found that more than 66% of autistic children suffer from insomnia or other sleep disturbances, compared with only 30% of typical children, says Kyle Johnson, co-director of the pediatric sleep clinic at Oregon Health & Science University.

The autism network will soon begin collecting data on children and adolescents' sleep patterns. Researchers may also look for potential causes of the sleep problems, such as defects in the production of melatonin, a brain hormone that induces sleep, which preliminary work suggests may be produced at lower levels in autistic children. Some parents already treat their autistic children with over-the-counter supplements, but there's little proof they work.

Another area getting increased attention is food allergies. Scientists at Massachusetts General and across the country have begun looking for the reason that many autistic people appear unable to tolerate certain foods, such as wheat and dairy. Early research suggests the children have very "permeable guts," a term that means the intestines allow certain substances to cross into the bloodstream that would normally be blocked, says Timothy Buie, the gastroenterologist who treated Becky Sullivan.

One theory of how this relates to autism is that the small proteins of wheat and milk

could bind to cell receptors in the brain and alter a child's mental state.

Richard Fade, a Medina, Wash., venture capitalist and parent of an autistic child who helped organize and raise funds for the new consortium, says he eliminated wheat and dairy from son Mitch's diet four years ago. The then-6-year-old's temper tantrums and anxiety decreased dramatically, and the unpleasant rashes on his body went away, his father says. The dietary change didn't cure his autism, diagnosed at age 2, notes Mr. Fade, but "there's a night-and-day difference in what he can do."

Another area the network will research is so-called metabolic disorders, where the body can't properly break

down important biochemicals. One related problem that appears to affect a small percentage of autistic children is a malfunction in the mitochondria, small intra-cellular bodies that produce the energy needed to fuel the body, says Marvin Natowicz, a medical geneticist in the neurology department at the Cleveland Clinic. A mitochondrial malfunction could be responsible for the extreme exhaustion found in some autistic children, Dr. Natowicz says. It could also be somehow causing other symptoms as disparate as seizures, significant diarrhea and even constipation.

### Supplements and Vitamins

Some physicians have tried giving high doses of certain vitamins such as B2, B1 and C, which are believed to aid aspects of mitochondrial function. Another approach is to give supplements such as antioxidants or carnitine, an amino-acid derivative, which scientists believe can neutralize the buildup of certain compounds if the mitochondria aren't working properly. The consortium plans to gather data on children with a series of tests to screen for chromosomal and metabolic disorders.

Until more is known, many doctors say parents with autistic children who are acting out should press their pediatricians to keep looking for possible medical causes—and seek multiple opinions from specialists if necessary. "If the kid is being aggressive, self injurious, or otherwise exhibiting odd behavior or symptoms, parents should be unwilling to accept that as 'autism' behavior until proven otherwise," Dr. Buie says.