

Autism treatment: Risky alternative therapies have little basis in science

November 24 2009, By Trine Tsouderos and Patricia Callahan

James Coman's son has an unusual skill. The 7-year-old, his father says, can swallow six pills at once. Diagnosed with autism as a toddler, the Chicago boy had been placed on an intense regimen of supplements and medications aimed at treating the disorder.

Besides taking many pills, the boy was injected with [vitamin B12](#) and received intravenous infusions of a drug used to leach mercury and other metals from the body. He took megadoses of [vitamin C](#), a hormone and a drug that suppresses testosterone.

This complex treatment regimen -- documented in court records as part of a bitter custody battle between Coman, who opposes the therapies, and his wife -- may sound unusual, but it isn't.

Thousands of U.S. [children](#) undergo these therapies and many more at the urging of physicians who say they can successfully treat, or "recover," children with [autism](#), a disorder most physicians and scientists say they cannot yet explain or cure.

But after reviewing thousands of pages of court documents and scientific studies and interviewing top researchers in the field, the Chicago Tribune found that many of these treatments amount to uncontrolled experiments on vulnerable children.

The therapies often go beyond harmless New Age folly, the investigation found. Many are unproven and risky, based on scientific research that is

flawed, preliminary or misconstrued.

Laboratory tests used to justify therapies are often misleading and misinterpreted. And though some parents fervently believe their children have benefited, the Tribune found a trail of disappointing results from the few clinical trials to evaluate the treatments objectively.

Studies have shown that up to three-quarters of families with children with autism try alternative treatments, which insurance does not usually cover. Doctors, many linked to the influential group Defeat Autism Now!, promote the therapies online, in books and at conferences.

Intensive regimens are so common that one doctor recently joked at an Autism One conference in Chicago that "you know you have a child with autism if ... your child takes more pills than your grandmother."

The Tribune found children undergoing daylong infusions of a blood product that carries the risk of kidney failure and anaphylactic shock. Researchers in the field emphatically warn that the therapy should not be used to treat autism.

Children are repeatedly encased in pressurized oxygen chambers normally used after scuba diving accidents, at a cost of thousands of dollars. This unproven therapy is meant to reduce inflammation that experts say is little understood and may even be beneficial.

Children undergo rounds of chelation therapy to leach heavy metals from the body, though most toxicologists say the test commonly used to measure the metals is meaningless and the treatment potentially harmful.

Last year, the National Institutes of Health halted a controversial government-funded study of chelation before a single child with autism was treated. Researchers at Cornell University and University of

California, Santa Cruz, had found that rats without lead poisoning showed signs of cognitive damage after being treated with a chelator.

Doctors associated with the autism recovery movement often say they know that more research is needed on their treatments, but they can't wait because children need help now.

"We feel some urgency that we can't wait for 10 or 20 years," pediatrician Dr. Elizabeth Mumper, medical coordinator for the Autism Research Institute, testified in a special federal court that examined the issue of autism and vaccines. The nonprofit institute is the parent organization of Defeat Autism Now!

Other physicians -- as well as scientists and bioethicists -- disagree.

"They really should be seeing treatment of patients with unproven therapies as dangerous experimentation," said pediatrician Dr. Steven Goodman, a clinical trial expert at the Johns Hopkins Berman Institute of Bioethics. "The problem with uncontrolled experiments ... is that it is experimentation from which we can learn nothing."

Many parents who try alternative therapies cite an analogy popularized by a luminary of the movement, a physician who wrote a book on recovering children from autism. They say they feel as if their child has jumped off a pier. Science hasn't proved that throwing a life preserver will save the child, but they have a duty to try, right?

Critics say that's the wrong way to think about it.

"How do they know the life preserver is made of cork and not lead? That is the issue," said Richard Mailman, a neuropharmacologist at Penn State University. "However desperate you are, you don't want to throw your

child a lead life preserver."

One in 100 U.S. children is diagnosed with autism spectrum disorder by age 8, according to the U.S. Centers for Disease Control and Prevention. That figure has increased in recent decades, though experts do not know whether more children actually have autism or more cases are being diagnosed.

There are no cures for the disorder, which is characterized by communication problems, difficulties interacting socially and rigid, repetitive behavior.

Researchers do not know what causes most cases of autism. They suspect the diagnosis actually applies to different disorders that create similar symptoms, but in most cases scientists cannot yet tell one from another. Research has yielded clues, but the search for hard answers continues.

By contrast, clinicians and others in the recovery movement readily offer explanations, treatments and hope.

Autism is not a mysterious disorder of the mind, they say; it is related to a complex array of medical problems. Address those undiagnosed immune, digestive, neurological and metabolic issues, and the symptoms of autism may improve, Jane Johnson, executive director of Defeat Autism Now!, wrote in an e-mail.

Johnson said more than a thousand parents have contacted the Autism Research Institute to say their children have recovered or nearly recovered from autism. "It is growing by word of mouth," Johnson said of the movement. "If you see a child improve dramatically using our approach, you might jump in yourself."

Both Johnson and Teri Arranga, director of Autism One, said solid science supports their approach to autism; Arranga sent the Tribune a list of hundreds of studies. Autism One, whose Web site declares "Our Children Get Better," sponsors conferences in the U.S. and Canada.

But the science cited by the recovery movement was extensively reviewed by some of the world's top scientists in a unique venue known as vaccine court. The government formed the court to address claims from people who think vaccines caused them harm, including families that blame children's autism on the shots.

The scientists who testified sharply criticized the research behind alternative treatments, using words like "careless" and "misleading."

"So much of what's said doesn't make scientific sense," testified Dr. Robert Rust, a chaired professor of neurology at University of Virginia. "There is what I regard as cherry-picking, picking little pieces from the paper and ignoring the rest of it, and in some instances I think misrepresenting what the paper says."

Mailman, the Pennsylvania neuropharmacologist, who also testified, said in an e-mail that "it was the scientific offensiveness that I felt most keenly."

The scientists found no proven value in many specific therapies for autism, from sauna treatments to chelation to the ingestion of worm eggs.

"There is no evidence for (the treatments') efficacy, no evidence for the reason for them to work," testified Dr. Eric Fombonne, head of the division of child psychiatry at McGill University and a prominent autism expert. "There (are) no published studies which would suggest that (they) would change the course of autism."

Notably, Arranga's list included studies authored by Dr. Mark Geier, a geneticist, and his son, David Geier. Dr. Geier opened clinics across the U.S. that promote treatment of autism with Lupron, a powerful testosterone suppressor. When the Tribune profiled the Geiers earlier this year, top pediatric endocrinologists deemed their work to be baseless.

No other treatment is more emblematic of the world of alternative therapies for autism than chelation. It is also a potent example of the approach's flaws and risks.

Chelation is one of the highest-rated treatments on the Autism Research Institute's parent survey, and a Defeat Autism Now! consensus statement calls removing metals from the body "one of the most beneficial treatments for autism and related disorders."

Parents trade stories and advice about chelation on large Internet groups. One Yahoo! group has more than 8,000 members. The treatment takes many forms, including creams for the skin, capsules, suppositories and intravenous infusions of powerful medicines usually reserved for people with severe metal poisoning.

Families often embark on this course after seeing test results that make children with autism look like they spend their days playing in smelting plants.

For example, a boy named Jordan King was chelated after his lab reports showed apparently high levels of mercury and tin, according to vaccine court testimony.

It was "shocking" to see tin turn up, Rust testified.

"It's seen almost exclusively in people who spend their careers for long periods of time working with tin ... especially when people are working on tin with hot torches," Rust said.

In fact, Jordan's troubling results were based on a lab test that is common in the world of alternative autism treatments and is practically guaranteed to give incredible results. It's called a provoked urinary toxic metals test, and here's how it works.

First, a child is given a chelating drug that "provokes" the body to excrete some of the metals that nearly everybody -- healthy or not -- has in the body in trace amounts. Those metals are excreted in urine, which is sent to a lab offering these tests.

Nobody knows what normal results of this test would look like, toxicologists say. There is no accepted reference range. Nonetheless, the lab sends back color-coded charts that show alarming peaks of metals graphed against a meaningless reference range that was calculated for people who had never been given a chelator.

"That is exactly the wrong way to do it," said Dr. Carl R. Baum, director of the Center for Children's Environmental Toxicology at Yale- New Haven Children's Hospital. "There is a whole industry that preys on people's fears of heavy metal poisoning."

Though most labs note that the reference range used is for unprovoked results, the apples-to-oranges comparison still can set off panic in parents.

With Jordan and another child whose case was examined in vaccine court, "there was absolutely no reason to chelate them for any mercury-related reason," testified Dr. Jeffrey Brent of the University of Colorado, Denver, former president of the American Academy of

Clinical Toxicology.

Alarmed by the rise in the use of the provoked test to justify chelation, the American College of Medical Toxicology this summer criticized its use as "fraught with many misunderstandings, pitfalls and risks."

Toxicologist William Shaw, lab director of The Great Plains Laboratory in Lenexa, Kan., said determining appropriate reference ranges for provoked tests will take more research but noted that it is difficult to get such studies approved by ethics boards and to get parents to enroll their children.

Both Shaw and Johnson of Defeat Autism Now! said the labs are identifying real problems, saying they have seen children benefit from chelation. Johnson also pointed to improved test results.

"Our only bedrock here is the observation by clinicians and parents that their children get better when they are given agents which are known to remove heavy metals from the body," Johnson wrote in an e-mail.

But that kind of anecdotal evidence is "at best good for generating hypotheses," Baum said. "Where's their control group? Their randomized controlled trial?"

Baum and other toxicologists urge physicians in the alternative movement to do standard, unprovoked tests for metals. "I guarantee you the results ... will not be so dramatic," Baum said.

In fact, a study published in the peer-reviewed journal *Environmental Health Perspectives* in October found that children with autism had lower levels of mercury in their blood than those developing typically. The reason? The children without autism ate more fish, a source of mercury.

Chelation's popularity as a treatment for autism is driven by the unproven idea that the disorder is tied to accumulation of heavy metals in the body. Mercury, once common in vaccines as part of a preservative called thimerosal, is often pegged as the culprit.

Yet the federal Institute of Medicine reported in 2004 that a review of dozens of studies had failed to show a link between vaccines, thimerosal and autism. Subsequent studies also found no connection. After thimerosal was removed from childhood vaccines except for some flu shots, autism diagnoses continued to rise.

Last spring, after hearing hundreds of hours of testimony, three "special masters" presiding over vaccine court ruled conclusively that they found the argument that the measles-mumps-rubella vaccine and thimerosal cause autism unpersuasive.

"Sadly, the petitioners in this litigation have been the victims of bad science, conducted to support litigation rather than to advance medical and scientific understanding of autism spectrum disorder," special master Denise Vowell wrote.

Even when tests show normal or low levels of metals, doctors who support chelation as an autism therapy sometimes take the results as proof that the child is poisoned. Their hypothesis is that the child cannot excrete metals, and that is why they do not show up in tests.

Colten Snyder, another child whose case was evaluated in vaccine court, underwent chelation after tests on his blood and hair over six years came back normal for mercury, court records state.

Given that the boy was immunized with vaccines containing thimerosal, "his hair mercury was exceptionally low," said his physician, Dr. J. Jeff Bradstreet of Florida. "That's pathological." Bradstreet also disputes that

all of the test results were normal.

Toxicologists and experts on vaccines said studies show that if a vaccine contains mercury, the metal is quickly excreted.

Colten went "berserk" after being given a chelator, according to a nurse whose notes were cited in court records. He also had incontinence, night sweats, headaches and back pain. Bradstreet testified that the boy did not do well with chelation but later said it is "impossible to know" what caused the problems.

In her decision, Vowell sharply criticized Bradstreet: "The more disturbing question is why chelation was performed at all, in view of the normal levels of mercury found in the hair, blood and urine, its apparent lack of efficacy in treating Colten's symptoms and the adverse side effects it apparently caused."

Pediatric toxicology experts say all chelation drugs carry risks -- even when used to treat severely lead-poisoned children. Treatment with the medication is carefully monitored, as some drugs can dangerously deplete the body of essential metals, toxicologists said.

When rats with no lead exposure were treated with succimer, a common chelator given to children with autism, the animals showed lasting impairments of cognitive function and emotional regulation, said the study's lead researcher, Barbara Strupp at Cornell University.

Strupp said that finding raises concerns about administering chelators to children with autism unless they clearly have elevated levels of heavy metals. "I was just astounded and concerned for these kids," she said.

After she learned that the National Institutes of Health planned to conduct a clinical trial of chelation in children with autism, she alerted

the researchers to her findings. The study was later canceled.

"Really, they are putting their children at serious risk," Baum said.

Harvard pediatric neurologist Dr. Martha Herbert, who has given speeches at Autism One conferences, is often cited by advocates in the recovery movement as proof that people with stellar credentials support them.

Herbert said she endorses the movement's push to look at environmental toxins as a possible factor in autism and supports researching whether various treatments can improve the health of children with the disorder. Chelation, she wrote in an e-mail, "is a very special case" and should not be used "to praise or damn other approaches."

In an earlier e-mail she wrote that she would sue the Tribune if she was portrayed as "an uncritical booster and fan of potentially dangerous unorthodox treatments."

"I'm not defending chelation," Herbert said in an interview. "I will sue you if you say that."

James Coman says he is so concerned about the possible long-term effects of his son's treatments, including chelation, that he filed complaints with state medical boards against the boy's two Defeat Autism Now! doctors, Dr. Anjum Usman of Naperville, Ill., and Dr. Daniel Rossignol of Melbourne, Fla.

"I worry very much," Coman said as his son played nearby with his younger brother and a neighbor's children. "There may be latent physical harm," he said. "We don't know."

Coman said he thinks his son, now a playful, funny and outgoing 7-year-

old, would have progressed developmentally without any medical treatments.

His wife declined to be interviewed but has said in court documents that she believes the boy's many alternative therapies benefited him. She argued that her son's treatment must continue on a regular basis.

"Abruptly halting medications (he) has been on for years will do great harm to the child," she said in court documents.

But the boy has stopped some of his treatments, according to court records, and Coman says he has not regressed.

Rossignol declined to be interviewed for this story. Usman's practice, True Health Medical Center, said it would not comment on a specific case, citing office policy and laws designed to protect patient privacy.

"We base our treatment protocols on the lab results, parent reports and physical examination of our patients -- nothing out of the ordinary in the practice of medicine," Usman wrote in a separate e-mail. "I am deeply troubled by any suggestion that the medical profession should not treat the medical problems these children clearly face."

Both family practice doctors are stars of Defeat Autism Now!, having trained thousands of clinicians, according to Johnson. They are listed on the group's online clinician registry, a first stop for many parents of children with autism seeking [alternative treatment](#).

To be listed, doctors need only attend a 13-hour seminar held by the Autism Research Institute, sign a statement saying they agree with the group's philosophy and pay a \$250 annual fee.

Johnson told the Tribune that doctors linked to her group mostly focus on diet and vitamins. Yet a recent clinician seminar held in Dallas

covered many highly technical specialties: immune problems, digestive issues, methylation abnormalities, mitochondrial dysfunction and detoxification.

As long as doctors continue to attend seminars every two years, they can remain listed. As of this month, 350 physicians, naturopaths, chiropractors, nurses and others were listed on the Defeat Autism Now! U.S. registry for state-licensed health care providers.

Many sell supplements to patients, which most practitioners consider a serious conflict of interest. Of 300 U.S. Defeat Autism Now! clinicians who answered a question about supplement sales for the registry, 80 percent indicated they sold the products to patients. Some even sold proprietary formulas.

"This is one of the most ... grave violations of our code of conduct, codes and ethics," Rust, the neurologist, testified in vaccine court.

A disclaimer on the registry site states that the Autism Research Institute does not "guarantee competence, skill, knowledge, or experience" of those listed. Johnson said the providers sell supplements to ensure quality control.

One physician on the registry was Dr. Roy Kerry of Pennsylvania. In 2005, a 5-year-old with autism had a heart attack and died while being intravenously chelated in his office, according to court records.

Less than a year later, Kerry was added to the registry. In 2008 he voluntarily surrendered his medical license pending criminal charges of involuntary manslaughter in connection with the boy's death, according to the Pennsylvania Board of Medicine.

Those charges were dropped, but in July of this year the state board

suspended his license for six months, with 2{ years of probation, state records show.

Kerry's lawyer, Al Augustine of Chicago, said there was no proof chelation killed the child and that Kerry agreed to the suspension to avoid the cost and emotional hardship of contesting it.

Defeat Autism Now! continued to list the doctor until Nov. 5, a day after the Tribune inquired about his inclusion.

Johnson said the group had already planned to drop him this month because he had not filled out paperwork on his medical license.

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Citation: Autism treatment: Risky alternative therapies have little basis in science (2009, November 24) retrieved 16 April 2024 from <https://medicalxpress.com/news/2009-11-autism-treatment-risky-alternative-therapies.html>

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