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## The autism “biomed” movement: Uncontrolled and unethical experimentation on autistic children

David Gorski on November 23, 2009

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Ever since I first discovered the anti-vaccine movement, first on Usenet, specifically on a Usenet newsgroup devoted to discussing alternative medicine (misc.health.alternative, or m.h.a. for short) and then later on web and on blogs, there have been two things that have horrified me. First, there are the claims that children suffer all sorts of harm from vaccines, be it being made autistic (with the attendant “autism epidemic” caused by vaccines), suffering neurological damage, immune system damage, and all manner of other adverse consequences. There is no good evidence for these claims (although, as has been documented right here on this very blog time and time again, anti-vaccine activists will trot out all manner of awful studies to support their contentions), but that doesn’t keep useful celebrity idiots like [Jenny McCarthy](#), [Jim Carrey](#), [Don Imus](#), or [Bill Maher](#) from repeating the same myths over and over again. Worse, the permeation of society with these myths about vaccines has led to declining vaccination rates and the [resurgence of potentially deadly vaccine-preventable diseases](#). It began first in the U.K. in the wake of Andrew Wakefield’s trial [lawyer-funded, incompetent, and possibly fraudulent](#) “research,” and has [spread to the U.S.](#), thanks to Jenny McCarthy and her ilk, who [won’t take responsibility](#) for their words and actions.

Even worse, the myth that vaccines cause autism has led to ideas. Dangerous ideas, and not because they “challenge” medical orthodoxy. These ideas are dangerous because they have direct consequences for children with autism. These consequences take the form of subjecting children to unscientific treatments that are ineffective at best and harmful at worst, sometimes even life-threatening. Indeed, I have [written about case histories](#) in which children were subjected to injections of “stem cells” into their cerebrospinal fluid by lumbar puncture and various other “treatments,” as well as [chemical castration in combination with chelation therapy](#). That latter bit of quackery is something I wrote about years ago, but that the mainstream press only just noticed earlier this year. Better late than never, I guess. Even better than that, though, the same reporting team at the [Chicago Tribune](#) that reported on Mark and David Geier’s advocacy of liverpox to treat autistic children back in May 2008; the result of that story does not appear to

advocacy of Lupron to treat autistic children back in May. Sadly, the result of that story does not appear to have been actions by the State of Maryland to take away Dr. Mark Geier’s medical license or to go after his son David for practicing without a license. Neither does it appear to have resulted in insurance companies going after them for prescribing an expensive drug for an indication for which it is not appropriate. What it does appear to have done, however, is to inspire the same journalist, Trine Tsouderos, along with another journalist from the *Chicago Tribune*, Patricia Callahan, to pursue an even bigger target that Mark and David Geier, namely the entire “autism biomed movement,” which is for the most part rank quackery, in the following articles:

- [Autism treatments: Risky alternative therapies have little basis in science](#)
- [Autism treatment: Success stories more persuasive to some than hard data](#)
- [Questionable treatments for children with autism](#)

This is another rare case of excellent reporting on this issue, and I hope that this report (another installment of which was published early this morning after I had written this post) will grab the attention of more reporters and news outlets, leading to shining a light on the dark underbelly of the autism biomed movement.

The aspect of this report that I most like is that Ms. Tsouderos gets it. She understands what I and other critics have been saying all along, namely that the autism biomed movement is almost all pseudoscience and quackery and that much of it “amounts to uncontrolled experimentation on children.” This is a message that has been a hard sell, because most lay people (and, sadly, a lot of doctors) do not understand clinical trials, clinical trial ethics, and why the physicians and “healers” promoting these unsupported therapies are in essence doing uncontrolled, poorly done, and poorly monitored clinical research, whether they recognize that’s what they’re doing or not. The [rules and laws built up over decades](#) exist for a reason, to protect patients and human research subjects from harm and risk as much as is possible. Because of their emotional and ideological investment in such therapies, they throw out rules in such a way that they’d find utterly unacceptable if a mainstream scientist or even worse—gasp!—big pharma were to do. The story sets up this concept right from the beginning:

“ 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

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 Tribune found that many of these treatments amount to uncontrolled experiments on vulnerable children.

Remember how many times Jenny McCarthy has said of her son, “Evan is my science”? Indeed, take a look at this [transcript](#) from an interview she did a couple of years ago (sadly, the original video no longer seems to be on the web):

“ You know, I could in two months turn Evan completely autistic again. I could do it completely through diet. And maybe getting some vaccine boosters. Through diet, I could load him up again with all the things that will aggravate the damage that was done. Right now, what happened now was that I healed him to the point where he got everything back to this baseline level and it stays there like this. But I mess with it at all—boom!

Combine McCarthy's frequent invocation of the mantra that “Evan is my science” plus the attitude that if she were to stop doing everything combine to demonstrate that this is indeed “experimentation” with therapies, as documented by the Trib (and that have been documented here many other times), that are at best unproven and implausible and at worst ineffective and potentially dangerous:

“ 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.

The justification for using chelation therapy to treat autism is two-fold. First, claim its adherents, children are either “mercury-toxic” or “heavy metal-toxic.” Originally, back in the days when Generation Rescue used to [proclaim boldly](#), ““There is no such thing as autism. Autism is a misdiagnosis for mercury poisoning.” These days, even J.B. Handley has moved the goalposts and now attributes autism to a more vague “overload of heavy metals, live viruses, and bacteria,” due to “the tripling of vaccines given to children in the last 15 years (mercury, aluminum and live viruses); maternal toxic load and prenatal vaccines; heavy metals like mercury in our air, water, and food; and the overuse of antibiotics.” The second rationale is a dubious, unreliable, and unproven diagnostic test in which children are given chelating agents and then the levels of mercury and other metals are measured in urine samples. Surprise, surprise! These levels are virtually always elevated (mainly because that’s what chelation therapy does, binds metals and leads to their excretion in the urine, even in normal children. These “provoked urinary toxic metals tests” are virtually guaranteed to show “elevated” levels of various metals, particularly because often the “normal” ranges used for these tests are based children who have not recently had a chelating agent administered:

“ 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.

Indeed. It’s inherently deceptive to do medical tests this way. Whether that deception is due to the incompetence of the “biomed” doctors doing them or outright dishonesty probably depends upon the specific practitioner. In any case, study after study has failed to find evidence that elevated mercury or heavy metal levels has any relationship to autism. Moreover, representatives of the labs doing such tests even admit that they’re not clinically validated. Their excuse for not working on clinical trials to validate them? About as lame as it gets:

“ 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.

Except that, [as Prometheus has pointed out](#) time and time again, autism is a disorder of developmental delay, not developmental stasis. Autistic children can and do “get better,” a significant fraction of them even so far as to lose their diagnosis and an even large fraction of them improving enough to be able to be productive members of society when they grow up. That’s why anecdotes about autistic children “recovering” after chelation therapy are [inherently unreliable](#), not to mention that there’s no control group

against which to compare. Indeed, in an [accompanying sidebar](#), Ms. Tsouderos points out several things that need to be driven home again and again. Anecdotes are inherently unreliable, particularly in a condition that waxes and wanes as much as autism. She emphasizes, as did Prometheus, that 10-20% of children with autism may make so much progress that they become indistinguishable from their peers and "lose" their diagnosis.

Three other points stand out. First is the reaction of a luminary of the autism biomed movement to this story, specifically Dr. Martha Herbert. ([We've met her before.](#)) I'm rather amused at how she [responded](#) to e-mail exchanges about chelation therapy, after pointing out that she supports "biomed" treatments for autism:

“ 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.”

That quote's not going to endear poor Dr. Herbert to the biomed movement at all, I suspect. On the other hand, because she so desperately wants to be the “respectable” face of the autism biomed movement, Dr. Herbert does need to try to protect what's left of her academic reputation, and supporting obvious quackery like chelation therapy for autism would not help her in that endeavor.

The second point was that it's really, really easy to become a [Defeat Autism Now!](#) (DAN!)-certified biomed practitioner and to be listed as such. First off, you don't even have to be a physician! You can be a [nutritionist](#), [naturopath or a homeopath](#), chiropractor, or nurse. Then all you have to do is to attend a 13-hour seminar held by the [Autism Research Institute](#), sign a statement agreeing with the group's philosophy regarding autism, and then pay \$250 a year. After that, you, too, can push supplements, give chelation therapy, and promote whatever biomed woo you want to desperate parents!

Finally, it was interesting to see what happened to Dr. Roy Kelly, an ENT doctor turned DAN! doctor whose incompetence and quackery killed an autistic child back in 2005. Unfortunately, his license was only suspended for six months, with two and a half years probation. In my opinion, it should have been permanently revoked because he has proven himself to be practicing outside the standard of care in a way that killed a child. Amusingly, however, he registered as a DAN! doctor a year after having killed an autistic child and continued to be listed until, well, I'll let the story tell:

“ Less than a year later. Kerrv 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 1/2 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.

Such are the standards for DAN! doctors. Even worse, that Dr. Kerry only had his license suspended for six months as a result of what looks to me like gross negligence demonstrates the utter ineffectiveness of our system for licensing and monitoring doctors. Another luminary of the autism biomed movement, Dr. Rashid Buttar, in addition to selling autism "biomed" in the form of "transdermal chelation therapy" (sometimes jokingly referred to as "Buttar's butter") and even apparently [urine injection therapy](#), provided unproven cancer "cures" for years for many patients, charging huge sums for them. The North Carolina State Medical Board has [tried unsuccessfully to strip Dr. Buttar of his medical license](#). In any case, it does look amusingly not coincidental that DAN! didn't drop Dr. Kerry from its roles until reporters from the Trib started sniffing around. If only the Pennsylvania State Medical Board were less reluctant to discipline wayward physicians like Dr. Kerry.

Not surprisingly, the autism biomed movement (or, as it is in my opinion, the autism quackery movement) wasted no time striking back. Indeed, within a couple of hours of the Trib story going live on its website, the anti-vaccine crank blog Age of Autism posted a notice to "[Tell the Chicago Tribune They Are Wrong](#)." Instantly, the [comments section of the Trib story](#) was flooded with outraged boosters of "biomed" autism therapy. The dogmatism and pseudoscience on display are truly depressing to contemplate. But AoA wasn't done. Yesterday, Kent Heckenlively, the AoA blogger who hit his daughter's grandfather up for \$15,000 to [take his daughter to Costa Rica for dubious "stem cell" injections](#) into her cerebrospinal fluid, next likened the Trib story to "[playing the 'telephone' game](#)," complaining that the Trib didn't take seriously

the "studies" that he had referred Ms. Tsouderos to. Of course, real experts had told her the value of those studies, which is basically nil. I will give Mr. Heckenlively credit for melting my irony meter into a dripping, quivering pool of molten metal and rubber by saying that Ms. Tsouderos, "gives the appearance of thinking without actually engaging in the activity." That statement, better than anything else, sums up the savvier members of the anti-vaccine movement. The less savvy members can't even give the appearance of thinking, at least not of thinking critically and scientifically.

Autistic children have paid the price. They will continue to pay the price until somehow, some way, science-based medicine, rather than anecdote- and pseudoscience-based medicine can prevail. Autistic children deserve no less than the best scientific medicine that can be brought to bear on helping them to develop and alleviating their symptoms. They most certainly don't deserve the unethical and uncontrolled experimentation to which far too many of them are being subjected.

## Author

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