

## **Autism and Vaccinations: The Evidence to Date**

For years, frightening stories have been appearing in print, online and on the airwaves about a possible link between early childhood vaccinations and the onset of autism. These reports often refer to the “controversy” surrounding this question.

While it is certainly true that there is controversy, there is no substantive argument about the evidence surrounding vaccines and autism. At this point, after ten years of research and dozens of large scale studies in multiple countries, the medical/scientific community (that is, the medical/scientific community that embraces the scientific method, with its emphasis on peer review, objective measurement, and testing of all hypotheses) is unanimous in its finding that no credible evidence exists that would support a connection between vaccinations and autism.<sup>1</sup>

Of course, nobody can prove a negative. One can’t prove that no little green men live on the moon, but we humans have devised a scientific method that can tell us, with reasonable certainty, if there is sufficient evidence to say that something is probable or not probable. At this point, the evidence strongly suggests that vaccines do not cause autism, do not contribute to the cause of autism, have no role in the onset of autism. In fact, in March of 2005 Japanese scientists reported that after withdrawing the MMR vaccine for a segment (or cohort) of the population (a cohort that was matched with other cohorts for similarity of age and other relevant variables) autism cases did not fall, but actually rose for that segment.<sup>2</sup>

And yet, in spite of all the epidemiological studies and all the research and all the complicated scientific papers that have been produced on this topic, there are still many people who insist that there is such a connection. In part this is because the nightly news and the talk shows don’t really go into the complicated papers or the research. They tend to give sound bites then set up shouting matches between “for and against” commentators. He or she who can shout the loudest or who has the most sympathetic story wins. In a contest between a tweedy science type from the Center for Disease Control, droning on about data and research, and a passionate parent who is convinced her child was poisoned by vaccinations, it’s highly likely that the parent is going to win far more support in the court of public opinion.

But truth about the physical material world in which we live, about the action of pharmaceuticals on human development or human behavior, does not depend on whether one is a parent or a professional or a journalist; it does not depend on who is more attractive, who can attack with more biting sarcasm, or who can “frame the narrative” in the most appealing manner. Rather, this kind of medical scientific truth resides in some objective reality, some verifiability, some confirming data. How do particular claims hold up in the real world? What is the quality of the evidence being presented to support this argument? Does the evidence continue to look robust and convincing when brought into the light of skeptical inquiry? Do these claims make sense? Have they been subjected to rigorous peer review and replication studies? If so, what were the results?

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<sup>1</sup> For a summary of this evidence see page 5 of this essay.

<sup>2</sup> Honda, Hideo et al. (2005). No effect of MMR withdrawal on the incidence of autism: a total population study. *Journal of Child Psychology and Psychiatry*, 46:6, 572–579

What follows is an historical/critical summation of this controversy. It is not an analysis of the biochemical research published in dozens of academic and scholarly papers. Such analysis is available elsewhere for interested readers.<sup>3</sup> Rather, the purpose of this essay is:

- To summarize the major findings to date of that research.
- To explain the origin of the controversy, setting it into an accurate historical context.
- To discuss the importance of evaluating the “quality of the evidence” behind any new theory about causation and treatment for autism.
- To propose, for parents and professionals and journalists alike, a framework for decision-making and discernment regarding such theories and claims.

### **Origin of a controversy**

There are two theories about vaccinations and autism. One was first proposed by Dr. Andrew Wakefield, a British surgeon specializing in gastrointestinal disease. In 1998, Dr. Wakefield published an article in The Lancet, speculating that the Measles Mumps Rubella (MMR) vaccine somehow was implicated in the onset of autism. The second theory is that thimerosal, a form of ethyl mercury used as a preservative in vaccines prior to the early 2000’s, contributed to the onset of autism. Speculation about the effects of thimerosal, fueled in part by cautionary statements issued by reputable organizations about safe and unsafe levels of mercury, included the possibility that the preservative damaged immune systems and neurological functioning. Politicians from both sides of the aisle, including Dan Burton, grandfather of a child with autism (and someone who had previously become known for his loud support of laetrile, the fringe therapy for cancer<sup>4</sup>), as well as the environmental activist Robert F. Kennedy Jr., joined the chorus of voices linking mercury and vaccines. Journalist David Kirby’s incendiary book, Evidence of Harm<sup>5</sup> added more fuel to the fire.

Wakefield’s theories received widespread media attention and triggered what became an international panic over the use of the MMR vaccine. Overnight, parents were besieging their doctors with questions about vaccine safety. The release of the study led to a steep decline in Great Britain’s vaccination rate and a subsequent outbreak of measles.<sup>6</sup> By January 2003 vaccination among two-year-olds in Britain had fallen to 78.9%, below the 95% level needed to protect the population<sup>7</sup> and cases of measles began to rise. The fear spread exponentially, not only to the United States, but all over the world.

Upon closer examination however, Wakefield’s research was looking more and more flawed. It is hard to understand how any reputable scientist, researcher, or MD could allow such material to be published; especially in light of the very serious repercussions that he surely must have known would follow. More to the point, it’s hard to know how The Lancet editors could

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<sup>3</sup> For what is probably the most comprehensive discussion available today of the pharmacological/biomedical research into the question of vaccines and autism, see Autism’s False Prophets, by Paul A. Offit, MD. Columbia University Press. September 2008.

<sup>4</sup> Offit, Paul, Autism’s False Prophets. Columbia University Press, September 2008. pp 26-27.

<sup>5</sup> Begley, Sharon with Jeneen Interfandi: “Anatomy of a Scare.” Newsweek. Mar 2, 2009.

<sup>6</sup> Researchers Reject Famous MMR-Autism Study. Jennifer Warner. WebMD Medical News. March 2004

<sup>7</sup> MMR: Key Dates in the Crisis. Brian Deer. The Sunday Times. February 9, 2009

have published such a study. In fact, in 2004, The Lancet editor, Richard Horton, (although still trying to defend his decision to publish the essay) did admit that he had not known about Wakefield's "fatal conflicts of interest."<sup>8</sup> A month later, 10 of 13 of Wakefield's coauthors on the study published a "retraction of an interpretation" concerning the study. The fact that so many of his colleagues were now trying distance themselves from this study is particularly noteworthy as retractions are rare in this type of research. The retraction stated, in part:

We wish to make it clear that in this paper no causal link was established between (the) vaccine and autism, as the data were insufficient. However the possibility of such a link was raised and consequent events have had major implications for public health. In view of this, we consider now is the appropriate time that we should together formally retract the interpretation placed upon these findings in the paper...<sup>9</sup>

And what were some of these conflicts of interest? Brian Deer, an investigative journalist writing for the Sunday Times of London, was unearthing more and more evidence not only of professional conflicts of interest also of grave methodological flaws and serious ethical violations in the way Wakefield was conducting his research. According to the documents and evidence uncovered by Deer:

- Most of the children participating in Wakefield's study – purportedly selected at random for his "objective study" – were engaged (through their parents) in an attempted lawsuit against the manufacturers of the MMR vaccine.
- Wakefield himself had received funding for this research from a personal injury lawyer, Richard Barr, who represented these children.
- Wakefield and Barr, far from conducting a disinterested evaluation of a possible hypothesis, were actually trying to gather evidence for their lawsuit.
- The children were subjected to intrusive, dangerous tests, including painful lumbar punctures and colonoscopies, without proper informed consent.
- Wakefield had recruited children at his son's birthday party - some as young as four years old, and some of whom he later jokingly recounted had vomited or cried - and paid them five pounds each for samples of their blood.<sup>10</sup>

In 2005, the General Medical Council of Great Britain charged Wakefield and two of his colleagues with ethical and professional misconduct.<sup>11</sup> Wakefield refused to back down, taking his case to the public, and garnering wide support with his claims that he was being persecuted for speaking out in defense of children. The claims and counterclaims are still dragging on to this day. But in February of 2009, The Sunday Times of London reported that evidence presented to the General Medical Council had revealed that Wakefield had "changed and misreported results in his research, creating the appearance of a possible link with autism."<sup>12</sup>

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<sup>8</sup> Richard Horton. Quoted in BBC Online News, February 22, 2004.

<sup>9</sup> Murch SH, Anthony A, Casson DH, *et al* (2004). "Retraction of an interpretation". *Lancet* 363 (9411). March 2004.

<sup>10</sup> Deer, Brian: The MMR Investigation: Summary of allegations concerning serious professional misconduct on the part of Andrew Wakefield and colleagues: Fitness to Practice Panel. <http://briandeer.com/mmr/lancet-summary.htm>

<sup>11</sup> Offit, Paul. *Op. cit.* p. 52.

<sup>12</sup> Deer, Brian, Hidden Records show MMR truth. The Sunday Times. February 8, 2009

The investigation revealed that no measles virus whatsoever had been detected in any of the subject children, contrary to Wakefield's stated assertion in his paper. In other words, according to this Sunday Times report, it appears that that critical data were simply made up.<sup>13</sup>

Faced with increasing accusations and mounting evidence of malfeasance, malpractice and fraud, Wakefield's response was to threaten his critics - including journalists, The Lancet, the General Medical Council and the Chief Medical Officer in Great Britain. To date, however, most of these lawsuits have been dismissed, and he has been forced to pay defendants' legal fees. And yet, he continues to practice and preach about the dangers of vaccines. Meanwhile the incidence of measles continues to rise, as more and more parents refuse to vaccinate their children. As of this writing, two British boys have died of this once near eradicated disease. While awaiting final outcome of these General Medical Council hearings, Wakefield now lives and works in the United States, where he enjoys a devoted following.<sup>14</sup>

But even his most ardent supporters may begin to lose their trust in him as more and more information comes to light: For instance, even before he published his now infamous study, Wakefield had been working on the development of his own alternative vaccine— a vaccine to treat (even cure) not only inflammatory bowel disease but autism. Here is how he describes this work, taken from another (later) Patent Application:

The present invention relates to a method for the diagnosis of regressive behavioural disease (RBD also referred to as "Regressive Developmental Disorder") or Autism. In my earlier Patent Application No. WO 96/30544 I have described how persistent measles infection whether of a wild type or vaccine mediated is the origin of some forms of IBD [Inflammatory Bowel Disease.]... I have now discovered a combined vaccine therapeutic agent which is not only most probably safer to administer to children and others...but which also can be used to treat RBD ["Regressive Behaviour Disorder, or Autism"] whether as a complete cure or to alleviate symptoms. [Emphasis added]<sup>15</sup>

And what about thimerosal? Once doubts began to surface about the Wakefield hypothesis, those who insisted that vaccines just "had" to be the culprit in autism started focusing on the preservative thimerosal. But there was a problem with this theory as well. Thimerosal had begun to be phased out of vaccines in 1999 for children under age 5. And yet the prevalence of autism cases still continued to rise even after thimerosal was removed. Still, in an attempt to allay the growing fears, the putative thimerosal link was studied and studied and studied again. So far, there has been no credible study lending any support to the theory.<sup>16</sup> The largest of these studies, which tracked all Danish children born between 1990 and 1996, compared children vaccinated with a vaccine containing thimerosal to children vaccinated with a thimerosal-free vaccine. If indeed thimerosal was linked to autism, one would expect a higher

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<sup>13</sup> Ibid.

<sup>14</sup> Dr. Wakefield, along with Dr. Arthur Krigsman, Dr. Bryan Jepson, and Dr. Doreen Granpeesheh, offers treatment for children with developmental disabilities at "Thoughtful House" in Austin Texas.

<sup>15</sup> United States Patent Application: US 6534259B1. Wakefield. March 18, 2003.

<sup>16</sup> National Network for Immunization Information. March 2008. Mercury in Vaccines: Summary of Articles. [http://www.immunizationinfo.org/immunization\\_science](http://www.immunizationinfo.org/immunization_science).

rate in the group who received the vaccine containing thimerosal compared to the group receiving the preservative free vaccine. In fact, there was no difference in rates of autism occurrence between the two groups.<sup>17</sup>

### **Study after study, but who is reading them?**

With the evidence supporting Wakefield's theories evaporating into scandal, and the thimerosal link proving speculative at best, one would think that the controversy would die a natural death, but this did not happen. Nothing dissuaded those who insisted on a connection that somehow, in some yet undetected manner, vaccines had to be the culprit. Here in the United States, Robert F. Kennedy, Jr. and Congressman Dan Burton continued to ratchet up the rhetoric, accusing the government and "Big Pharma" of poisoning children, then trying to cover up the evidence. Other politicians such as John Kerry, John McCain and Joe Lieberman expressed strong reservations about vaccine safety. Celebrities and stars jumped onto the bandwagon. Deirdre and Don Imus became vocal supporters of the cause. Senator Lieberman announced that he was "for the parents" in this controversy. Parents reached out to other parents on the internet, and founded organizations to protest what they saw as a government/pharmaceutical conspiracy. Money poured in to these agencies, and more and more parents started refusing vaccinations.

Government agencies and the medical establishment, meanwhile, in an effort to take parental concern seriously, keep launching study after study to address the concerns. (It is perhaps important to point out that while these efforts were no doubt well intentioned; the reality is that they diverted huge resources of funds, time and expertise: resources that could perhaps have been put to better use in the care and education of children with autism.) In any case, in 2001, the **National Institute of Child Health and Human Services** issued this statement:

The Institute of Medicine (IOM) at the National Academy of Sciences, at the request of the Centers for Disease Control and Prevention (CDC) and the NIH, conducted a review of all the evidence related to the MMR vaccine and autism...The IOM concluded that the evidence reviewed did not support an association between autism and the MMR vaccine.

And again in 2004, the **Institute of Medicine** conducted another review of literature on the vaccination/autism question, and again found that "the body of epidemiological evidence favors rejection of a causal relationship between thimerosal-containing vaccines and autism." They further found that: "potential biological mechanisms for vaccine induced autism that have been generated to date are only theoretical."

As this controversy drags on and on, the national organizations concerned with child health continue to speak clearly:

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<sup>17</sup> Hveiid, A. Stellfeld M., Wohlfahrt, J. Melbye, M. Association between thimerosal containing vaccine and autism. Danish Epidemiological Science Centre, Department of Epidemiology Research, Statens Serum Institut, Copenhagen, Denmark. *Journal of the American Medical Association, (JAMA) 2003 Oct 1; 290 (13):1763-6*

- **The Centers for Disease Control and Prevention (CDC)** “Many studies have looked at whether there is a relationship between vaccines and autism. The weight of the evidence indicates that vaccines are not associated with autism.”<sup>18</sup>
- **The National Institutes of Health:** “There is no conclusive scientific evidence that any part of a vaccine or combination of vaccines causes autism, even though researchers have done many studies to answer this important question. There is also no proof that any material used to make or preserve the vaccine plays a role in causing autism. Although there have been reports of studies that relate vaccines to autism, these findings have not held up under further investigation.”<sup>19</sup>
- **American Academy of Pediatrics (AAP)** “Scientific data does not show a link between vaccines and autism.”<sup>20</sup>

But these reports only infuriated the anti-vaccine people. The argument was deteriorating into an “us versus them” conflict, and evidence, facts, or objective findings did not seem to matter a great deal. Anahad O’Connor and Gardiner Harris, science writers for the New York Times, uncovered disturbing evidence of hostility against researchers who reject the vaccine/autism connection.

Since the [Center for Disease Control] report's release, scientists and health officials have been bombarded with hostile e-mail messages and phone calls. Dr. McCormick, the chairwoman of the institute's panel, said she had received threatening mail claiming that she was part of a conspiracy...An e-mail message to the C.D.C. on Nov. 28 stated, *"Forgiveness is between them and God. It is my job to arrange a meeting,"* ....Another e-mail message, sent to the C.D.C. on Aug. 20, said, *"I'd like to know how you people sleep straight in bed at night knowing all the lies you tell & the lives you know full well you destroy with the poisons you push & protect with your lies."* ...In response to the threats, C.D.C. officials have contacted the Federal Bureau of Investigation and heightened security at the disease control centers.<sup>21</sup>

Arthur Allen, writing in the online journal Slate, describes the mounting hysteria:

...Anti-mercury activists jumped on the transcript of a 2000 meeting at which the study was scrutinized to argue that something improper was going on. The transcript shows no such thing. But the activists unleashed a public-relations campaign alleging a government and "big pharma" cover-up...That, in turn, proved to be eye candy for environmental groups...Anti-pollution lawyer Robert F. Kennedy Jr. zealously jumped on the thimerosal bandwagon in an "expose" published in Salon and Rolling Stone...Even the women's

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<sup>18</sup> See <http://www.cdc.gov>. Commenting on the Hannah Poling case, which the anti-vaccine crowd hail as a “concession” by the government, Dr. Julie L. Gerberding, director of the CDC, said “Let me be very clear that the government has made absolutely no statement indicating that vaccines are a cause of autism. That is a complete mischaracterization of the findings of the case and a complete mischaracterization of any of the science that we have at our disposal today.”

<sup>19</sup> <http://www.nichd.nih.gov/publications/pubs/autism/mmr>

<sup>20</sup> <http://www.aap.org/healthtopics/autism.cfm>

<sup>21</sup> O’Connor, A. and Harris, Gardiner. On Autism’s Cause, It’s Parents vs. Research: *New York Times*. June 25, 2005

division of the Methodist Church has gotten in on the act, presumably on the grounds that it is fighting for social justice by decrying mercury poisoning, although there was no mercury poisoning, and social justice would be better met by promoting confidence in vaccines... Kennedy, who wrote blithely in the Huffington Post during the trial that "overwhelming science" had confirmed the link, continues to believe it. So does Rep. Dan Burton, R-Ind., whose circuslike hearing room aired many such claims. Neither cites any solid studies, because they do not exist.<sup>22</sup>

Paul Offit, MD, has also documented multiple threats not only against the journalists, parents, and researchers who question about the supposed connection between vaccines and autism, but against their families. Two of the journalists he interviewed, as well as he himself, received threats against their children.<sup>23</sup>

### Why?

What is going on here? Do those who resist these studies believe that all these organizations are "anti parent?" Do they believe that all of them are making money off bad vaccines? If the pharmaceutical industry wanted to make money off of sick children, it would seem more logical to abandon vaccines, which prevent illness – then they could rake in millions providing drugs for all the deadly diseases that would come surging back. Are the government agencies conspiring with the pharmaceutical companies to hide the fact that their policies and their products had harmed children? Even if there were any evidence for this conspiracy theory, why would journalists who spoke out against the vaccine autism link want to hide that horrible evil? What would they have gained by that complicity, other than the harassment, attack and intimidation they have already suffered? Why does this belief that vaccines caused autism persist in spite of all evidence to the contrary?

It may be that some are motivated by the hope of large monetary settlements in lawsuits against vaccine makers or the government, but this cannot be the entire or only explanation for this continuing conviction. In fact, there seem to be no easy answers, and no single answer to the question of "why?" Controversies such as this are multi-faceted, and go beyond the obvious motivators. They include genuine and deeply held fears about the safety of any substance we give or inject into young children. They include an intense need to understand, to find the reason why something has happened to a beloved child. They include media sensationalism and simplifications, malfeasance on the part of some, dishonesty on the part of others; the value (or lack thereof) that that we place on scientific literacy in our culture. It would probably take a book or two to try to examine all the social and cultural factors at play in these types of conflicts.

But it does bear mentioning that one of the underlying problems that have plagued the autism community for decades is the self-aggrandizing zeal of people who see themselves as "saviors" of the oppressed. What does this mean? Years and years ago, Dr. Lorna Wing, of the

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<sup>22</sup> Allen, Arthur. True Believers: Why there's no dispelling the myth that vaccines cause autism. *Slate*. July 29 2007.

<sup>23</sup> Offit, op.cit. pp 116-119. See also: Donald G. McNeil, Jr. "Book is rallying resistance to anti-vaccine crusade." *New York Times*. Jan. 12, 2009. <http://www.nytimes.com/2009/01/13/health/13auti>.

British Autism Society, coined a phrase to describe this phenomenon. She called it the Victim/Villain/Victor syndrome. At the time, the phrase was used to describe the “victims,” – children with autism; the “villains,” their mothers and fathers, who were held to be the villains under the flawed psychodynamic theories of that generation; and then there were the “victors” – the rescuing savior therapists who came in to repair the emotional damage wrought by Mommy and Daddy. Today, the roles have remained; they are just filled by different actors. Today the Villain is Big Pharma/Big Government, conspiring to harm innocent children (the Victims.) The Victors are the parents and their supporters - celebrities, politicians and talk show hosts, all rushing in the *save the children!*

This reincarnation of the “victim/villain/victor” roles, which have proved so seductive in the past, may shed at least some light on the pervasive tendency in our culture to frame this argument in terms of being “for” or “against” the parents. In controversies such as these, where individuals such as parents of autistic children are pitted against large and faceless institutions, popular sentiment interprets any skepticism about therapeutic beliefs as a statement “against parents” and “for the establishment.”

One recent example that a mother shared with ASAT, the Association for Science in Autism Treatment, may suffice to make the point: This mother reported a casual conversation with her physical therapist, who, knowing that she had an interest in autism, asked her what she thought about the vaccine controversy.

“I think the evidence does not support that connection,” she said.

The physical therapist was clearly taken aback, and communicated his disapproval:

“I’m for the parents!” He announced sternly.

“I am a parent,” the mother replied.

Given the history of autism, it is not surprising that popular opinion tends to come down strongly on what it perceives to be the side of the parents. After the debacle of the “refrigerator mother” theory, which blamed autism on cold parents, how could anyone dare question parental judgment? Nobody wants to be on the wrong side of this argument again. People want to be on the side of those whom they perceive as vulnerable, wronged. Hollywood has understood this, and movies and books have followed, hammering away at that theme. As Board members of ASAT have noted before, films such as Lorenzo’s Oil, whose message was that mothers and fathers could figure out the answer to a complex fatal disease much more effectively and efficiently than a universe of doctors and researchers, only stoked this anti-establishment zeal. There is a cultural tendency now to always give the benefit of the doubt to “the little guy,” over anyone having anything to do with any institution, corporation, or agency.

Combine that cultural inclination with the fact that the media is not explaining the science and the general population does not always have either the time or the background to go deeply into the science, and the result is predictable. As of this moment, the “vaccinations cause

autism” belief has a new champion, Jenny McCarthy, whom the media identifies as “the actress and former Playboy model,” who, convinced that both vaccines and digestive problems had a part to play in her son’s development of autism, wrote a book on the topic, a book that was embraced uncritically by talk show hosts and television producers far and wide. In her appearances in these shows she is rarely challenged; rather her ideas about vaccines, ‘yeast overgrowth, “crystal children”<sup>24</sup> “indigo moms,”<sup>25</sup> her son’s “hypersensitivity to air and water” etc. are accorded rapt attention and respect.

National Public Radio, which prides itself on its intellectualism, offers more of the same emotion-charged “reporting.” Recently, a special Federal Court rejected petitioners’ arguments in three cases where families were claiming that vaccines had caused autism in their children,<sup>26</sup> This was all over the news, not only because of the astonishing fact of having a vaccine tried in a court of law, but because the three cases were closely watched by thousands of parents waiting to bring their own lawsuits, and thousands of other interested parties, representing both sides of the vaccine/autism debate. Now, the mandate of a Federal Court is to evaluate evidence placed before it and reach a judgment based on the merits of the evidence and strength of the argument. The Federal court not only rejected petitioners’ argument in the three cases; it did so resoundingly. Here is language from just one of the rulings:

...the evidence was overwhelmingly contrary to the petitioners’ contentions. The expert witnesses presented by the respondent were far better qualified, far more experienced, and far more persuasive than the petitioners’ experts, concerning most of the key points. The numerous medical studies concerning these issues, performed by medical scientists worldwide, have come down strongly against the petitioners’ contentions. Considering all of the evidence, I found that the petitioners have *failed* to demonstrate that thimerosal-containing vaccines can contribute to causing immune dysfunction, or that the MMR vaccine can contribute to causing either autism or gastrointestinal dysfunction.

Upon release of these decisions, NPR responded with an interview of a journalist discussing something he called “the emotional truth” of parents versus the “scientific truth” of research. A listener would not be faulted for wondering if he was positing some kind of equivalency between these two concepts. What exactly is “emotional truth?” The journalist never defined this, but even granting that there is such a thing as “emotional truth,” perhaps this is something more germane to the universe of feelings and beliefs rather than to objective facts about the human nervous system and the effect of vaccinations on that system.

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<sup>24</sup> Jenny McCarthy. Louder Than Words, a Mother’s Journey in Healing Autism. Plume. (reprint edition) 2008.

<sup>25</sup> Crystal Children and Indigo children (along with Crystal and Indigo adults), originate in New Age beliefs. Here is one description taken from a site called StarChild: “Crystal Children began to appear on the planet from about 2000, although some date them slightly earlier. These are extremely powerful children, whose main purpose is to take us to the next level in our evolution, and reveal to us our inner power and divinity. They function as a group consciousness rather than as individuals, and they live by the “ Law of One” or Unity Consciousness.” Crystal and Indigo people are said to have an aura, and be able to read minds.

<sup>26</sup> United States Court of Federal Claims. Autism Decisions and Background Information. Feb. 12, 2009. <http://www.uscfc.uscourts.gov/node/5026>

Another disturbing characteristic of media coverage of this Federal ruling was that at least a few journalists kept talking about how “this ruling has dealt a major blow to parents” - once again reinforcing the assumption that all parents believed in this theory and that to attack the theory was to attack parents.

Parents, however, can be just as prone as rogue researchers to an excessive self confidence, lack of discernment and lack of humility.

**PR.com Interviewer: I’ve heard you say that God chose you to have an autistic child. Why? Why did God choose you?**

Jenny McCarthy: It’s amazing how God puts certain people in the packages that no one would possibly expect. That if I look back at all my books, I always wondered why I became a best selling author of mommy and baby books. That seems so funny to me. I became this mom who was telling it like it is and every book was “The Naked Truth About... *something*.” And it couldn’t have happened to a better person, because I was going to come out and give my naked honest truth about autism and have the balls to get on these shows and say what I’m doing. I definitely know that I was the *one!*<sup>27</sup>

**PR.com: What has been your greatest lesson in this whole experience, dealing with Evan’s autism?**

Jenny McCarthy: My greatest lesson is always to trust the mommy instinct. Always trust yourself. Always trust the gut instinct. It will never let you down.

Unfortunately, “gut instinct” has let parents down, and will continue to do so unless it is counterbalanced by a healthy dose of reason, skepticism and discernment. Parents have been taken in by self-aggrandizing saviors and false promises ever since autism was identified. One glance at the history of autism is enough to deflate the notion that “gut instinct” is a reliable guide to treatment choices. One glance at the booming “alternative medicine” industry in this country indicates that there has been and probably always will be a market for fringe therapies, promises of miracle cures, and snake oil salesmen<sup>28</sup> – in short, for big promises backed by slim evidence. ASAT has been tracking this problem for years, speaking out about the outrageous therapeutic claims in the autism world – often inspiring some hate mail of our own, alas. Nevertheless, we, the parents and professionals of ASAT, continue to fight for a rational, science-based approach to autism.

Not that the fight is easy, or anywhere close to being won. People seem much more compelled to accept at face value what celebrities and models tell them about the genesis of autism rather than anyone who drones on with boring facts and figures about epidemiology, biochemistry or neurology. A researcher who pays young children to participate in a fatally flawed study is more credible, apparently, than all the scientists of the CDC, NIH, or the American Academy of Pediatrics combined. Politicians who have no grasp of the research grandstand and pontificate, spreading fallacies and fomenting rage. Women’s church groups

<sup>27</sup> PR.com: Alison Kugel. Interview with Jenny McCarthy. October 9, 2007.

<sup>28</sup> See: Margaret Taylor Singer and Janja Lalich: Crazy Therapies: What are they? Do they work? Jossey Bass. 1996.

decide that vaccines are an instrument of injustice in the world. Parents fight with each other on internet chat rooms, only adding to the bewildering pain that many are dealing with already as they try to figure out what is best for their kids.

But is this really the way we should be framing this discussion, conducting this conversation? Does this dangerous dismissal of science and research and medical training and keen minds and authentic authority really help our children? Do we really want these questions being determined by shouting matches rather than rational objective discussion of the truth? As Daniel Patrick Moynihan once said: *“Everyone is entitled to his own opinion, but nobody is entitled to his own facts.”* The fact is that the vaccine/autism connection has been about as thoroughly debunked as it is possible to debunk anything. From large scale population studies to individual case analyses, nobody has succeeded in providing anywhere near convincing evidence of any causative link between the two.

### **Where do we go from here?** **Cultivating discernment**

All parents, caregivers, educators and professionals involved in the care and education of people with autism want to make sure that they are making the best possible decisions for a child, until he or she might become capable of making those decisions independently. How do we go about making sure that our decision making is informed as much as possible not only by love and compassion, but by truth? Here are just a few recommendations from ASAT, which has been involved for over a decade now in the struggle to increase effective intervention and education, and to bring science based accountability to the search for autism’s causes and treatments. By the way, it is perhaps important to mention that our Board and Advisory Board consists of parents and family members of people who have autism, professionals who are involved in clinical work with children and adults who have autism, researchers whose knowledge of this field runs deep, and other caring citizens.

**1. We need to focus on facts, not on identity politics:** It is not helpful to frame this discussion as: “You’re either on the parents’ side, or you’re not.” First of all, as mentioned already, not all parents have bought into this vaccine myth: some are appalled at seeing the conversation hijacked by hysteria and self promotion rather than by a rational consideration of facts and evidence. Secondly, it is not supportive of parents, it’s not helpful to them, it’s not “being on their side” to keep propagating fallacies about autism. Thirdly, nobody, including parents, is infallible. Over the years, parents have both been victimized by false expertise and they have helped to sustain such false expertise, for instance, by supporting all kinds of dubious treatments that eventually were discredited. The reality is that we all have to be very humble about how much we know and don’t know. Professionals who abuse their authority and inflate their expertise should not be trusted to make pronouncements about autism or its treatments. Neither should we “believe” in every theory that a parent proposes on the Internet or in People Magazine. Bruno Bettelheim did not know what he was talking about when it came to autism genesis or treatment but neither does Jenny McCarthy, whose knowledge about the topic stems, as she asserts, “from the University of Google.”<sup>29</sup>

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<sup>29</sup> PR.com: Alison Kugel. Op. cit.

**2. Let us become more aware of what constitutes “good science” and what constitutes pseudoscience.** Since people can be fallible, and everyone can make mistakes, we need to rely on some system of fact finding in the real world. The scientific method is not designed to answer some questions, such as “Does God exist?” Or “What is love?” but it is designed to answer questions about biology and chemistry, the brain and the body. Unfortunately, there is good science and then there is junk science, and in a world of instant information and competing claims, we all need to become a bit more adept at discriminating between the two. Parents and “laypeople” are taking on more and more of their own research into medical, educational and treatment issues in autism, which can be empowering and good, or it can lead to and prolong yet more disasters like the secretin debacle, the ongoing scandal of facilitated communication or the current vaccine controversy. What constitutes “good science?” That is another question that would take a few tomes to answer, but here are at least some hallmarks of strong scientific research. (Material in italics is taken verbatim from an article by Gina Green, PhD, Advisory Board member of ASAT; explanatory comments are by ASAT editors.)<sup>30</sup>

**The least ambiguous evidence** that a treatment is effective is evidence that includes:

- *Controls for several alternative explanations.* This means that a child’s improvement may or may not have been due to the treatment under consideration, and researchers will have “controlled” for those explanations – eliminated them one by one in a systematic fashion so that only the one explanation remains.
- *A comparison of treatment outcome with outcomes that occur with no treatment or other treatments.* One has to be sure that the outcome observed is a direct result of the treatment under question, and is not something that would have occurred even if no treatment were provided or another treatment were provided.
- *True experimental research design.* This does not mean testimonials or personal stories, compelling though they may be. True experimental research design usually includes careful baseline observations and descriptions of the symptoms, behavior or phenomenon that is being evaluated. It includes observations about antecedent conditions, the environment under which the behavior is occurring or the test is being conducted, as well as the systematic elimination of all possible alternative explanations for effects reported. It entails accurate analysis and reporting of independent variables that may have affected experimental outcomes, and many other types of controls and procedures to safeguard the experiment’s internal validity.
- *Replication by independent investigators.* Finally, strong and robust research will have included “external validity,” or some capacity for generalization “*which refers to the confidence with which the results of an experiment can be applied to people and situations other than those involved in the experiment.*” In the case of the Wakefield research there has been no external validity or generalization of results because there was no internal validity of his experiments to begin with.

And what does “**most ambiguous evidence**” look like? Weak or speculative evidence would usually be based on

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<sup>30</sup> Gina Green. *Evaluating Claims about Treatments for Autism.* in: *Behavioral Intervention for Young Children with Autism. A Manual for Parents and Professionals.* C.Maurice, S.C. Luce and G.Green, Eds. Pro Ed. 1996.

- Subjective reports (testimonials, anecdotes, personal accounts or uncontrolled observations)
- No comparisons
- No measurements or indirect measurements only
- Case studies, descriptive research, no true experimental design

But if one still feels unsure about the quality of the research supporting a certain treatment, it may help to have the checklists below on hand. The first is from the extremely valuable site [www.quackwatch.org](http://www.quackwatch.org), founded by Stephen Barrett, MD, an internationally recognized champion of scientific literacy and a consumer advocate. The origin of the second is unclear, but may have appeared years ago in a pamphlet published by the American Arthritis Foundation - apparently because Arthritis, like autism, is also subject to its own parade of miracle treatments and cures.

### **A) Comparison of Science with Pseudoscience**

#### **Science**

Their findings are expressed primarily through scientific journals that are peer-reviewed and maintain rigorous standards for honesty and accuracy.

Reproducible results are demanded; experiments must be precisely described so that they can be duplicated exactly or improved upon.

Failures are searched for and studied closely, because incorrect theories can often make correct predictions by accident, but no correct theory will make incorrect predictions.

As time goes on, more and more is learned about the physical processes under study.

Convinces by appeal to the evidence, by arguments based upon logical and/or mathematical reasoning, by making the best case the data permit. When new evidence contradicts old ideas, they are abandoned.

Does not advocate or market unproven practices or products.

#### **Pseudoscience**

The literature is aimed at the general public. There is no review, no standards, no pre-publication verification, no demand for accuracy and precision.

Results cannot be reproduced or verified. Studies, if any, are always so vaguely described that one can't figure out what was done or how it was done.

Failures are ignored, excused, hidden, lied about, discounted, explained away, rationalized, forgotten, avoided at all costs.

No physical phenomena or processes are ever found or studied. No progress is made; nothing concrete is learned.

Convinces by appeal to faith and belief. Pseudoscience has a strong quasi-religious element: it tries to convert, not to convince. You are to believe in spite of the facts, not because of them. The original idea is never abandoned, whatever the evidence.

Generally earns some or all of his living by selling questionable products (such as books, courses, and dietary supplements) and/or pseudoscientific services

### **B. Pseudoscientific Therapies: Some Warning Signs:**

- High “success rates” are claimed.
- Rapid effects are promised
- The therapy is said to be effective for many symptoms or disorders.
- The theory behind the therapy contradicts objective knowledge and sometimes common sense
- The therapy is said to be easy to administer, requiring little training or expertise.
- Other, proven treatments are said to be unnecessary, inferior or harmful
- Promoters of the therapy are working outside their area of expertise
- Testimonials, anecdotes, or personal accounts are offered in support of claims about the therapy’s effectiveness, but little or no objective evidence is produced
- Catchy, emotionally appealing slogans are used in marketing the therapy
- Belief and faith are said to be necessary for the therapy to “work.”
- Skepticism and critical evaluation are said to make the therapy’s effects evaporate
- Promoters resist objective evaluation and scrutiny of the therapy by others.
- Negative findings from scientific studies are ignored or dismissed
- Critics and scientific investigators are often met with hostility, and are accused of persecuting the promoters, being “closed minded,” or having some ulterior motive for debunking the therapy.

**3. And finally, and perhaps most importantly, we need to understand that correlation does not equal causation.** Because autism typically manifests itself when a child is around one to three years old, the same age range at which most vaccines are administered, this correlation reinforces, for many, the certainty of causation. But “my child was perfectly normal and then he had a vaccination and then became autistic” is not proof of anything; rather, it indicates confusion about coincidence and causality. If ice cream sales increase in August, and crime rates go up in August, it’s not that ice cream causes crime rates to rise. Operating under such a (false) assumption, we should ban any medication, any surgery, any antibiotic, any dental intervention, any hospitalization, any baby dose of Tylenol or aspirin within the first two to three years of life, since that is when children first begin to manifest signs of autism.

The bottom line is this: In Japan, they took away the MMR vaccine, they took away the thimerosal, and the rates of autism did not decrease, they increased. It is time to lay this straw dog to rest.

### **Conclusion:**

The vaccine controversy is only one more chapter in a long and difficult history that will be written one day about the genesis, diagnosis, treatment of autism in our country and indeed in the world. Tragically, that history has been colored by a long parade of fads, fallacies, dubious and at times very harmful interventions. Let us be careful about accepting yet another “miracle breakthrough” treatment, especially one that springs from yet another astonishing and improbable hypothesis about causation. From the wasteland of Freudian psychoanalysis for autistic children to the scandal of facilitated communication; from the fads of auditory integration therapy, vitamin therapy, dolphin therapy, radical diets, hyperbaric oxygen chambers,

secretin therapy, holding therapy, drum therapy, and now chelation therapy there have been no fewer than 100 – that is 100 – “alternative treatments” offered for sale on the internet and embraced by parents. The vast majority of these treatments have almost no peer reviewed research to speak of, no credible replication, no application whatsoever to the symptoms of autism. True, some of them may be fairly harmless: many children (those who have autism and those who do not) would delight in the experience of swimming with dolphins, whether or not there is any peer reviewed research indicating any effect on any symptom of autism. But some of these interventions have been shown to be most harmful, and they bleed time and money and resources away from families. Withholding vaccinations can and does have real repercussions not only for our own children but for others’ children as well.

Real progress has been made and will continue to be made toward that goal of giving all children greater independence, language and the ability to make choices and decisions for themselves. But that progress will continue only if we learn from history. Let us be careful about accepting at face value yet another astonishing new theory about autism’s genesis, a theory that contradicts all the careful research that has already been built up, painstakingly, by reputable researchers, slowly solving the puzzle of this mysterious condition.

In the current controversy over vaccinations, journalists, politicians, parents and celebrities would do well to pause a moment, and reflect: Are we helping or hurting parents when we accept, without extremely careful weighing of all available evidence, yet another sensational new “discovery” in autism? Are we helping or hurting children with autism? As a recent article summarizing the controversy has stated:

It is bad enough that the vaccine autism scare has undermined one of the greatest successes of preventive medicine and terrified many new parents. Most tragic of all, it has diverted attention and millions of dollars away from finding [autism’s] true causes and cures.<sup>31</sup>

Parents and scientists need the expertise of the other if we are to maximize the growth and development of children who happen to be diagnosed with autism. Each group deserves respect when they speak about what they know and remain humble about what they don’t. Parents know their child. Today, when treatments still consist largely of behavioral/educational intervention, parents can and must be seen as vital partners in the process of helping a child maximize his or her potential for self expression and independence. Scientists, researchers and clinicians, meanwhile, have their own authority, an authority that is critical to an increased understanding of causes and treatments. They too should be listened to with respect and attention. Science and parental love can work hand in hand when each is willing to acknowledge the scope and the limits of each other’s experience. Autism is a developmental, neurological condition, ranging from mild differences to devastatingly serious impairment in functioning. Only through careful research, - not popular opinion, not rogue “researchers” - will we continue to grow in our understanding. It is scientific research, coupled with the undying and unconditional love of parents, that will continue to forge an enlightened path as we seek to help the children and families who grapple with this diagnosis.

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<sup>31</sup> Begley, Sharon, “Anatomy of a Scare.” op.cit.