



## ASAT Board of Directors

David Celiberti, Ph.D., BCBA  
**President**

Jenna Glennon, M.A.T., BCBA  
**Vice President**

Elizabeth Dyer, M.A., CCC-SLP  
**Treasurer**

Kathryn Dobel, J.D.  
**Secretary**

Megan Atthowe, RN, MSN, BCBA

Preeti Chojar, MCA

Marianne Clancy

Joseph Forgione, M.B.A

Beth Glasberg, PhD, BCBA

Barbara Jamison, B.A.

Robert H. La Rue Jr., Ph.D. BCBA

Mary E. McDonald, Ph.D., BCBA

Joshua K. Pritchard, MS, BCBA

Tristram Smith, Ph.D.

Bridget Taylor, Psy.D., BCBA

Mary Beth Walsh, Ph.D.

Barbara Wells

ASAT  
PO Box 188  
Crosswicks, NJ 08515-0188

E-mail: [info@asatonline.org](mailto:info@asatonline.org)  
[www.asatonline.org](http://www.asatonline.org)

This column of the newsletter will showcase resources and tools that consumers can use to better understand and access science-based treatment for autism.

In this issue of *Science in Autism Treatment*, Stacey Sipe has reviewed *A Parents' Guide to Research*.

This will be a recurring column in the newsletter.

**Kate Fiske, Ph.D., BCBA**  
**Consumer Corner Coordinator**  
**Science in Autism Treatment**

## Autism & Vaccines: 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

"no credible evidence exists that would support a connection between vaccinations and autism"

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

*Continued on page 5...*



## Consumer Corner: Review of "Life Journey Through Autism: A Parent's Guide to Research"

**Stacey Sipe, Special Education Teacher**

As part of my training toward certification as a BCaBA, I have visited the website of the Organization for Autism Research ([www.researchautism.org](http://www.researchautism.org)) and have become familiar with many of its free publications. I was particularly drawn to *Life Journey Through Autism: A Parent's Guide to Research*, as I am spending increasing amounts of time reviewing autism treatment research. Reading through published research can often be a challenging and intimidating experience. I can not help but wonder how overwhelming it may be for parents of children with autism as they try to digest the technical aspects of the research literature, discriminate rigorous, well-designed research from poorly executed research, and make sense of the treatment implications of published findings.

*A Parent's Guide to Research* represents the collaborative effort of the Organization for Autism Research (OAR) and Danya International, Inc. The publication is very comprehensive, well written, and presented in an organized and understandable format.

This resource begins with an introduction that details how to use the guide and highlights the key sections. Its preview sets a tone of clarity and ease that is consistent throughout the guide, which is important for a resource intended for a parent audience. Descriptions of subsequent sections follow:

How to be a savvy consumer of source of autism information offers specific strategies for accessing published research. This section is particularly well organized, listing several websites for accessing research and tips for effective Internet searches for research articles.

Understanding the science model delineates the 5 basic types of research studies (case studies, correlational studies, longitudinal studies, experimental studies, and clinical trial studies) and summarizes their respective advantages and disadvantages.

A uniform framework for evaluating research walks parents through the purpose and content of the various sections of published research and summarizes what the reader should be looking for when reading them. Helpful examples are offered throughout, as well as some caveats surrounding potential conflicts of interest.

The current state of autism research describes the array of current autism research and cautions readers to be wary of claims of "miracle" cures for autism.

Directions for future research offers parents some insight into the types of questions that warrant further scientific inquiry.

The Glossary provides clear and concise definitions of terms that parents will encounter when reading through research articles. Such terms can be quite intimidating to those not familiar with the language of research.

Several Appendices are presented in this guide, including

*Continued on page 18...*

## Interview with Dr. Stephen Barrett, Quackwatch Founder— David Cellberti, Ph.D., BCBA

As many of our readers are aware, pseudo-scientific treatments are not exclusive to autism. We had the opportunity to interview Dr. Stephen Barrett, M.D., a staunch advocate for science and a formidable opponent of quackery. Given Dr. Barrett's longstanding efforts in these areas, it seemed fitting that he would be the first to be interviewed in Science in Autism Treatment.

**Q:** Please tell us about your early experiences challenging medical quackery? How were your views perceived by your colleagues at that time?

**A:** In the late 1960s, I began a broad-based, local group that included health professionals and laypersons who met

regularly to discuss problems related to health fraud and quackery. Our initial focus was on misleading chiropractic advertising and anti-fluoridation scare tactics. Publicity about our activities eventually led to the formation of several similar groups and a national organization emerged from those efforts. Our work has always been appreciated by science-based professionals and their organizations.

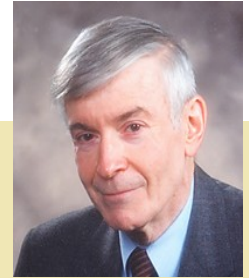
**Q:** That sounds like a very local, grass roots beginning. What led up to the creation of Quackwatch.org?

**A:** I began writing about my findings in the early 1970s and eventually developed a sideline career as a medical editor and investigative journalist. Over a 20-year period, I gradually increased my

journalistic activities and decreased my psychiatric work until I completely retired from psychiatry in 1993. In 1996, after completing three major books, I started a Web site to make some of my findings more available. As the Internet developed, my enthusiasm multiplied because investigations that used to take months could often be completed in a few days or even a few hours. In addition, I receive a steady stream of e-mail messages that ask questions and report questionable activities.

**Q:** Can you share some information about the impact that your website has had?

**A:** The Quackwatch network has more than 4,500 pages. Our home pages alone receive *Continued on page 6....*



## Tributes to Dr. Edward "Ted" Carr - David Cellberti, Ph.D., BCBA

Earlier this summer, the autism community lost one of its finest. Dr. Edward Carr and his wife, Dr. Ilene Wasserman, were killed by a drunk driver on June 20, 2009. Dr. Carr was a Professor in the Department of Psychology at the State University of New York at Stony Brook, and was recognized internationally for his decades of research related to the assessment and treatment of challenging behaviors in persons with autism.

I first met Ted Carr over 20 years ago when I was a college senior at Stony Brook interested in enrolling in his small seminar on autism. Fortunately for me, I passed the

interview process that he put in place. Without a doubt, my decision to pursue this career was a direct result of his class. He was an incredible professor; witty, intelligent, and he had the uncanny ability to bring to life concepts and findings from published research. He was kind enough to write a letter of recommendation on my behalf. During the interview process for graduate school, I quickly learned that this incredible professor was also widely known and esteemed in the broader professional community. As I progressed in my career, my appreciation and respect for his work only grew.

This is a profound loss for our community. Although I know he had more to teach us, his legacy will continue through his students, his brilliant writings, and the transformational impact he has had on how we conceptualize treatment. Ted has left an indelible imprint on autism treatment, and his work will forever be part of the fabric of what we do. I have asked a few individuals to share some of their thoughts about Ted and his tremendous impact on the field: Drs. Ray Romanczyk, Paul Chance, Joanne Genser, Jane Carlson, and Len Levin.

*Another tribute on page 7....*



## Board Member Bio: Mary Beth Walsh, Ph.D. - Josh Pritchard, MS, BCBA

Each issue, an ASAT Board Member will be asked some questions so that the readers can become more familiar with the ASAT leadership. This first issue begins with Mary Beth Walsh, Ph.D....

**Q:** What got you involved with ASAT?

**A:** I joined the ASAT Board of Directors in the fall of 2006, recruited to the cause by a behavior analyst who had worked with my younger son who has autism. However, I knew of the organization for years before hand, and used to receive and

enjoy the old newsletter. As a long time parent-advocate of effective intervention, I've directed many parents to the ASAT website, in particular our Research Summaries on Autism Treatments, and was glad to be able to volunteer with the Website Committee.

**Q:** What line of work did/do you do and how does it relate to the ASAT Mission?

**A:** I teach in a graduate program in Roman Catholic pastoral ministry, and hold a doctorate in theology and ethics. This may seem to some to have little to do

with ASAT's mission; however, to my mind, the right of individuals to effective intervention and treatment, and the rights of parents to accurate information based on science are both deeply ethical issues. In addition to being an advocate of science-based intervention for individuals with autism, I also advocate for the inclusion of individuals with autism in communities of faith, and have co-edited a resource booklet, [Autism and Faith: A Journey into Community](#) available [here](#)



Mary Beth with her son

*Continued on page 18...*

**Comments on Spreckley and Boyd (2009) — Jonathan W. Kimball, Ph.D., BCBA**

*Efficacy of applied behavioral intervention in preschool children with autism for improving cognitive, language, and adaptive behavior: A systematic review and meta-analysis* by Michele Spreckley and Roslyn Boyd

Spreckley and Boyd (2009) have written a meta-analysis of the efficacy of “applied behavior intervention” (ABI) programs for preschoolers with Autism Spectrum Disorders (ASD). Their article stirred much interest and conversation among a variety of individuals concerned with education and treatment for children with autism in the state where I work, because of their conclusion that “there is inadequate evidence that ABI has better outcomes than standard care for children with autism” (p. 338). An implication of this statement is that the authors compared ABI to another uniform type of intervention, when in fact they did no such thing. At this time there is no universally accepted form of “standard care” analogous to what exists for other disorders or illnesses. We only have the most general guidelines recommending features that *any* comprehensive program should have (e.g., National Research Council, 2001). Spreckley and Boyd did not refer to such guidelines nor did they demonstrate, for children who were not receiving ABI, that any uniform type of care was delivered across the studies they evaluate. On the other hand, specific behavior analytic interventions employed in comprehensive treatment programs for children with autism are well represented in hundreds of

peer reviewed studies conducted over several decades and carried out by researchers worldwide (Baer, 2005; Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996). In what follows I will explain my skepticism concerning the validity of Spreckley and Boyd’s conclusion, and discuss why it ought not to have significant impact on autism treatment, research, or policy. I am a clinician, and more, a well-informed consumer than a producer of research, and it is in this capacity that I will discuss Spreckley and Boyd. I will not, therefore, provide a nuanced critique of their meta-analysis: With respect to this article my intention is as much to inoculate as to illuminate.

A meta-analysis involves combining effect sizes (i.e., the quantitative expressions of response to treatment relative to results for a comparison group or to pre-treatment performance) reported across several studies for a given variable. Results thus aggregated have greater statistical power and thus, it is believed, lead to more valid conclusions about a treatment’s effects than they would if studies were considered individually. Spreckley and Boyd sought to examine comprehensive behavior analytic intervention in terms of its effects on cognitive, adaptive, and language development of children with ASD (incidentally, what they referred to as ABI, is otherwise known as early intensive behavioral intervention [EIBI] or, in an unfortunate conflation of discipline and intervention, “ABA”). One of their criteria for including a study in

the analysis was that it must have been a randomized or quasirandomized controlled trial (RCT), which requires random assignment of participants to treatment or comparison groups. Randomly assigning some children to receive treatment and others to receive none or less treatment is very difficult to accomplish ethically in research with human participants, and therefore just four studies met all criteria: Eikeseth, Smith, Jahr, and Eldevik (2002); Eikeseth, Smith, Jahr, and Eldevik (2007); Sallows and Graupner (2005); and Smith, Groen, and Wynn (2000). These studies are but a fraction of the behavioral research that has been conducted with children with autism—a fact to which we will return below. At any rate, based on their statistical analysis of these four studies the authors concluded “that ABI did not result in significant improvement in cognitive, language, or adaptive behavioral outcomes compared with standard care” (pp. 341-342).

For each of the four variables Spreckley and Boyd examined—IQ, receptive and expressive language, and adaptive behavior—they took the aggregated scores from respective studies, combined them, and compared the result with similarly aggregated scores for comparison groups.

**“With respect to this article my intention is as much to inoculate as to illuminate.”**

*Continued on page 8....*

This section of the newsletter highlights questions regarding important clinical issues and responses from prominent professionals. We hope you enjoy their insights and recommendations!

Each future issue of this newsletter will showcase two Clinical Corner responses.

**Lori Bechner, M.A., BCBA**  
**Clinical Corner Coordinator**  
**Science in Autism Treatment**

**Clinical Corner: Toilet Training**

**Can the principles of applied behavior analysis be used to toilet train a child with an autism spectrum disorder?**

*Answered by Frank Cicero, Ph.D., Director of Psychological Services at Eden II Programs*

Here is the good news... children with autism can be toilet trained through the exact same methods that are used with typically - developing children. And what are these methods? Applied behavior analysis! If you have ever toilet

trained a typically- developing child you probably used a combination of praise and rewards for going on the toilet, explaining your expectations, removing the child’s diaper, prompting to the toilet on some type of schedule, rushing him or her to the toilet when they seemed like they needed to go, and teaching how to notify you that he or she needs to use the bathroom. You might or might not have added in some form of

punishment or verbal reprimand for accidents. Well...here is my advice for toilet training a child on the spectrum...use exactly the strategies that I just described.

So then, why does it seem so much more difficult? One of the biggest obstacles is simply getting started. Because parents think that toilet training will be very difficult, and something so different than anything else they have taught their child in the past,

*Continued on page 4....*





## Clinical Corner: Toilet Training continued....

they delay training. Toilet training for a girl typically is recommended to begin at around two years of age. For a boy it is a little later (about two and a half). When it comes to a child with a developmental disability it is difficult to use these age guidelines. Instead, a child is ready to begin training when they can hold urine in the bladder for at least 1 hour, can remain seated on a toilet for at least three minutes, have an awareness of the relationship between following instructions and getting rewarded, and do not have significantly interfering problem behavior. Another challenge with toilet training a child on the spectrum is the absolute need for consistency and intensity of training once you begin. The more intense you implement a

plan, the quicker you will see results. For the most intense procedure, I recommended toilet training for at least 6-8 hours per day. I also usually implement the training directly in a bathroom with the child wearing the least amount of clothing possible (usually underwear, shirt and socks). In this way, he or she can easily get to the toilet when needed and also you, as the trainer, can easily and quickly see when they are beginning to have an accident.

Toilet training consists of four main components: prompting to the toilet on a schedule, rewarding success, teaching how to request, and quickly prompting to the toilet at the start of an accident. For the schedule, I usually recommend

starting with 30 minutes. The child sits on the toilet and tries to urinate for 1 minute. If the child is successful, immediately provide him/her with a very powerful reward with verbal praise. If the child is not successful, simply prompt him/her to try again in 30 minutes. In order to teach requests, prompt the child to request the bathroom each time you are about to prompt him/her to the toilet. You can use whatever communication system (i.e. verbal speech, picture exchange, signs etc.) your child is used to and does best with.

Now, what to do with the accidents? Accidents in toilet training

“Accidents in toilet training are a good thing. In fact, without accidents, you will only be reinforcing prompted trips to the toilet”

this is not always the case. When a child is trained for urination, but

are a good thing. In fact, without accidents, you will only be reinforcing prompted trips to the toilet, thereby resulting in a child that is schedule trained instead of independent. You have two choices here, prompting/reinforcement or punishment. I usually recommend the first choice, prompting/reinforcement instead of punishment, at least in the beginning of training. Try encouraging a lot of drinking during training hours. Within the first second of the child having an accident, produce a loud verbal startle such as “HURRY, HURRY, HURRY.” This is not a reprimand, but should be stated in a very loud, surprising, urgent tone of voice. The idea is to temporarily produce a startle response in the child so that urination is reflexively held for a brief moment. In that moment, you physically prompt the child to the toilet, where you instruct him or her (now in a very calm voice) to continue their

urination. If they continue (which is likely), you reward the behavior with a reward and verbal praise. In this way, you turned an accident into a positive teachable moment. Continue with these strategies until the child begins to show fewer accidents, goes more on the schedule and begins to independently request. Throughout training it is very important to collect data on accidents and successes, so that you can make data-based decisions along the way. Fade the intensity of the schedule, fade out of the bathroom and ultimately fade the tangible rewards. With this intensive treatment program, I have seen complete training in as little as 1 week, however do not get discouraged if your child takes longer. What about training for bowel movements? Good news....you often get bowel training along with urination training without doing any additional procedures. Bad news...

continues to have bowel accidents, you need to figure out the reason behind the problem before you can treat it. Is it simply a lack of knowledge? An ingrained ritual or routine? Noncompliance? A medical problem such as constipation? The nature of the accidents will guide your treatment. Very briefly, if the problem is a lack of knowledge, a reinforcement / punishment procedure should work. This procedure is similar to the procedure that I described for urination training, except that it is rarely implemented for 6-8 hours per day. Instead, you bowel train only when the child is likely to need to have a bowel movement. If the problem is more consistent with a ritual or noncompliance, you need a traditional behavior plan more than a toilet training intervention. And finally, if the problem is medical in nature, follow the recommendations of a physician or dietician.

### ASAT Advisory Board

F. J. Barrera, Ph.D., BCBA  
 Stephen Barrett, M.D.  
 Martha Bridge Denckla, M.D.  
 Curtis Deutsch, Ph.D.  
 William V. Dube, Ph.D.  
 Deborah Fein, Ph.D.  
 Eric Fombonne, M.D.  
 Richard Foxx, Ph.D., BCBA  
 Gina Green, Ph.D., BCBA  
 William Heward, Ed.D., BCBA  
 Ronald Kallen, M.D.  
 Alan Leslie, Ph.D.  
 Bennett Leventhal, M.D.  
 Johnny L. Matson, Ph.D.  
 Joyce E. Mauk, M.D.  
 Catherine Maurice, Ph.D.  
 Bobby Newman, Ph.D., BCBA  
 John Pomeroy, M.D.  
 Stephen Porges, Ph.D.  
 Sharon Reeve, Ph.D., BCBA  
 Joyce Rosenfeld, M.D., FACEP  
 Arthur Toga, Ph.D.  
 Paul Touchette, Ph.D.  
 Roberto Tuchman, M.D.



The Organization for Autism Research will be holding its 7<sup>th</sup> Annual Applied Autism Research and Intervention Conference on October 23-24, 2009 in Arlington, VA. With the theme “Evidence-Based Education and Intervention across the Lifespan,” attendees will hear from 23 leading autism professionals regarding issues from early childhood to adulthood.

This event is designed to provide parents, educators, clinicians, students, and researchers with access to the latest in autism intervention research and evidence-based practice. BCBA, APA, and ASHA Continuing Education Units are available. Early Bird and group rates are available until September 23<sup>rd</sup> and registration is limited. For more information, please visit [www.researchautism.org/news/conference](http://www.researchautism.org/news/conference).

## Autism and Vaccines continued....

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?

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 M.D. 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 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 co-authors 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> 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

*Continued on page 10....*

## Interview with Dr. Stephen Barrett, Quackwatch Founder continued....

more than 1 million hits per year, and our e-mail newsletter has nearly 11,700 subscribers. Search engines rank our articles very high, probably because thousands of other sites link to us. Many people thank us for steering them away from scams and schemes. We also get lots of hate mail from people whose cherished beliefs we criticize.

**Q: Aside from the significant impact of your website, what do you consider among your greatest successes in countering pseudoscience?**

*A: My college textbook, Consumer Health: A Guide to Intelligent Decisions, now in its 8<sup>th</sup> edition, has helped educate many teachers of health education.*

**Q: It is wonderful to hear that your textbook has been revised and improved upon so many times. It speaks to the forever evolving nature of science and how it informs best practices.**

As you know, the field of autism is fraught with medical and non-medical treatments that lack any scientific basis. Is the degree unique to autism or fairly rampant across other disorders?

*A: There are quack approaches for preventing and treating virtually everything. I don't know of any published comparative statistics. However, it is clear that the percentage of families with a child with autism who have been significantly victimized is very high and that many of them are involved in legal and political actions that are very costly to our society. In fact, the volume of inquiries about autism-related quackery led to the creation of [www.autism-watch.org](http://www.autism-watch.org) in 2004.*

*During the past few years, anti-vaccine activists have been causing trouble not only for families of children with autism but for parents in general. Much of the problem is fueled and facilitated by a small network of misguided physicians, without whose participation the worst sorts of exploitation—*

*such as chelation therapy—would not be prevalent.*

*The most effective vaccine opponent is actress Jenny McCarthy. Her ideas that vaccinations cause autism and that children get too many too soon are dead wrong. She's dangerous because she does not come across as an extremist. She understands almost nothing about medical science. But with continual promotion by Oprah Winfrey and Larry King, she has managed to reach young parents on an emotional level by talking about her personal experiences. Newsweek recently published a cover story criticizing Oprah for providing a forum for bad health advice.*

**Q: It is unfortunate that you and others have had to work so hard to debunk quackery when the onus should be on treatment proponents to provide legitimate data to substantiate their claims. What lessons should advocates of scientifically validated treatments of autism learn from the resilience of pseudoscientific treatments?**

*A: There are several lessons to be learned: 1) Quacks never sleep; 2) Most people do not see quackery as a serious threat; 3) Most professionals are too busy (or too nervous about being attacked) to get involved; and 4) Unfortunately, the Internet makes it possible for anyone to publicize misinformation.*

**Q: Very succinct and very true. As we have seen with facilitated communication, proponents of pseudoscience never go away as well. What do you see as the most serious issue to combat in autism currently?**

*A: Chelation therapy for nonexistent "heavy metal toxicity." It's expensive, carries some physical and psychological risk, and encourages false beliefs that vaccinations are dangerous. In fact, I have created <http://chelationwatch.org/> to warn the public about chelation therapy.*

**Q: Aside from helping consumers be as knowledgeable and aware of research and the distinction between science and pseudoscience, what can be done to weaken the influence of pseudoscience in autism?**

*A: One is to develop well-written articles about each of the treatment modalities offered. Some individuals and groups have addressed some topics, but more need to be covered.*

*The second is to seek out frequent and extensive media exposure showcasing science-based treatment. We also need to discourage talk-show hosts (most notably Oprah Winfrey and Larry King) from providing a platform for anti-vaccination scare tactics.*

*The third is to mobilize people who have been victimized to strike back. Thousands of parents have been tricked into believing that their child with autism is suffering from heavy metal toxicity and needs to be chelated. The main device used to do this a provoked urine test for heavy metals. The article at <http://www.quackwatch.org/t> explains why provoked testing is a fraud. Parents who understand this should complain to the licensing boards about the doctors who use such tests.*

**Dr. Barrett, we appreciate this opportunity to talk with you about these important matters. You have been a persistent voice for science and your impact has been significant. Your efforts have had an incredible influence on not only the autism community, but by those impacted with any disorder who have been distracted and misguided by pseudoscience.**

---

*Stephen Barrett, M.D., a retired psychiatrist who resides near Chapel Hill, North Carolina, has achieved national renown as an author, editor, and consumer advocate. An expert in medical communications, Dr. Barrett operates Quackwatch, Autism Watch, and 21 other Web sites and edits Consumer Health Digest (a free weekly electronic newsletter). He has written more than 2,000 articles and delivered more than 300 talks at colleges, universities, medical schools, and professional meetings. His 50 books include *The Health Robbers: A Close Look at Quackery in America* and seven editions of the college textbook *Consumer Health: A Guide to Intelligent Decisions*. He is listed in *Marquis Who's Who in America* and received the 2001 Distinguished Service to Health Education Award from the American Association for Health Education. His media appearances include *Dateline*, *The Today Show*, *Good Morning America*, *ABC Prime Time*, *Donahue*, *CNN*, *National Public Radio*, and more than 200 radio and television talk show interviews.*

“Quacks Never Sleep”



### Chelation Treatment for Children with Autism—Joyce Elizabeth Mauk, M.D.

One of the unfortunate byproducts of the media hype relating autism to vaccines is renewed interest in chelation as a treatment for autism. Chelation refers to a medical procedure that uses chemicals to remove heavy metals from the bodies of children with autism. The agents most commonly used are Calcium Disodium ethylenediamine-tetraacetic acid (Ca-EDTA), Dimercaptosuccinic acid (DMSA) and 2-3-dimercaptopropane-1-sulfonate (DMPS). These man-made molecules all have a high affinity to bond metals and remove them from the body via urine when the drug itself is excreted. In addition to these more traditional chelation agents, I have found Internet references to the use of the herb cilantro and certain types of clay for chelation.

The administration of metal-binding molecules to treat autism is based on speculation that mercury poisoning (via administration through immunization, mercury-containing dental fillings or environmental exposure) causes autism. Therefore, the rationale is that removing the toxic metal will cure the autism or lead to an amelioration in the symptoms of autism.

It is important to note that chelation has some legitimate uses. In particular, it is indicated for removing lead from children with severe lead poisoning, and many papers in the medical literature confirm its efficacy for this purpose. Of note, however, chelation is also an unproven, but widely-prescribed treatment for atherosclerosis. There are also industrial uses for these chemicals.

Determining whether or not chelation is an appropriate treatment for autism is predicated on chelation proponents obtaining and publishing high-quality scientific evidence to support their assertions. Medical scientific evidence is published in legitimate peer-reviewed scientific publications. Scientists submit publications with a hypothesis to test and present their evidence to prove or disprove it. Editors have experts in the field review papers and decide if they are appropriate for publication. This process can lead to delays in making new scientific information available to the public or treating physicians, but there are many safeguards in this process. There is also a hierarchy of quality of scientific studies with case reports, testimonials and expert opinion being at the lowest level of quality and with randomized

case-control studies with high numbers of participants as the highest. Also, good scientific studies have clear outcome measures (for example a decrease in the counts of abnormal behavior, an increase in skills learned, etc) as opposed to reporting a subject being generally “better”. They control for other competing variables, i.e. no change in medication, diet, or therapeutic intervention during the course of the study. Also the evaluators of outcomes should be “blind” to the treatment condition, not knowing if the child has received the active agent (chelator) or not.

Whether or not exposure to heavy metals causes autism requires conducting careful studies to identify patterns that would suggest causality such as a temporal association of cause and effect (e.g., whether mercury exposure is followed immediately by signs of autism), a plausible biologic mechanism, and a dose response relationship (e.g., whether higher levels of mercury exposure increase the risk of autism). Existing scientific evidence does not support mercury as a cause of autism, and suggests instead that a number of genetic variations are most likely responsible for the condition.<sup>1,2</sup>

*Continued on page 14...*

### Tribute to Dr. Edward “Ted” Carr – Paul Chance, Ph.D. Former ASAT Advisory Board Member

Ted was a professor of psychology at the State University of New York in Stony Brook, a fixture there since the seventies. He taught courses in ABA --applied behavior analysis-- and did research on the treatment of children with developmental disorders, particularly autism. Although autism is presumed to have a biological origin, ABA is so far the only treatment that has met scientific standards of effectiveness. Basically it helps children learn, through special forms of instruction, the social and cognitive skills that most children pick up incidentally. Ted not only used ABA to help children with autism get control over themselves and their lives, he also trained dozens of graduate students to do this work. And through his research he provided new insights into developmental disorders and new techniques for their treatment.

He is perhaps best known for his work on the functional nature of aberrant behavior. Years ago Ted discovered that some of the most challenging and bizarre behavior of children with autism was likely to occur when they were performing a task they found difficult. For example, when asked to make his bed, one boy made mistakes such as putting the sheet on top of the blanket. When asked to correct his mistake, he would become agitated and bite himself and hit his mother. This ended the bed-making task. The “dysfunctional” behavior was actually quite functional: It allowed the child to escape a frustrating situation. In other instances, the function of the behavior might be to obtain attention or a treat.

Ted realized that in a sense the child was communicating his or her desires. He also realized that

there was nothing bizarre about the desires themselves: We all want to get out of unpleasant situations sometimes, we all want to obtain rewards. What was bizarre was the way the child communicated these desires. Ted theorized that if he taught these children more appropriate ways of communicating what they wanted, their inappropriate behavior might decline. They might learn to say, “I need help” or, if they could not speak, they might learn to point or make a gesture. Ted found that when he taught children with autism alternative ways of letting people know what they wanted, the screams, violent outbursts, and self-injurious behavior typically declined sharply.

After the fact, such insights may seem obvious, but that is the nature of insight. I can tell you that the idea that children with autism often behave bizarrely to communicate and that they can be taught more appropriate ways of communicating was not obvious to the hundreds of psychiatrists, psychologists, pediatricians, and parents who worked with autistic children decades ago.

To do this kind of work takes an extraordinary person, and that is what Ted Carr was. Years ago when Ted had a sabbatical, I asked him how he had used the time. He said that he spent part of it in Europe, working with children who were deaf, blind, and mentally retarded. I said, “That doesn’t give you much to work with, does it?” He said, “No, but you do what you can.”

That was Ted Carr. He did what he could. Fortunately, that was a lot.

*Another tribute on page 8...*

“That was Ted Carr. He did what he could. Fortunately, that was a lot.”  
~Paul Chance

**Tribute to Dr. Edward “Ted” Carr — Joanne Gerenser, PhD., CCC-SLP, Executive Director, The Eden II Programs**

I was so saddened when I heard the news that Ted Carr and his wife Ilene were killed in a car accident in Long Island. I first met Ted when he was our keynote speaker many years ago at the New York State Association for Behavior Analysis. I had read much of his work and was so excited to actually be able to have the chance to meet him. We then presented together a variety of times over the years. Whenever the hosts of the conference planned a speakers’ dinner, I always made sure I grabbed the chair next to Ted’s. I can honestly say that every single time we chatted, I learned something new that somehow influenced my work with children with autism in a positive way.

As I sat down to write this tribute to Ted I tried to decide what to focus upon. Should it be the incredible work he did in functional behavior assessment? What about his

brilliant work in the development of functional communication training? Or maybe it should be about his work as a highly respected teacher, both at State University of New York at Stony Brook and in the community at large through his workshops and lectures? Perhaps it should focus on the work Ted and his students did on quantifying such elusive concepts as happiness, friendships, and other essential factors that contribute to a good quality of life. I decided that it would not be possible to even touch upon on all of the important contributions that Ted made to the field of applied behavior analysis and to the lives of people with autism and their families. There are simply too many and doing so would truly require a book.

So instead, I will focus on the three things I truly admired most about Ted. The

first was his willingness to listen and to discuss issues. Although Ted and I may not have always agreed on all issues in the treatment of individuals with autism, he always listened with great interest, respected my opinions and generously provided me with his wisdom and perspectives. The second thing that I loved about Ted was how much he cared about the quality of life of people with autism and their families. I believe that this was clearly the driving impetus for all of his work. Finally, one can not write about Ted without discussing his sense of humor. I am so grateful that I had the opportunity over the past decade to spend time with Ted, laugh at his dry sense of humor, and learn from one of the best. He will be truly missed, but his contributions to the field will be a part of us forever.

*Other tributes on page 9 and 11....*

**Comments on Spreckley and Boyd (2009) continued....**

While four studies met their inclusion criteria, data only happened to be available from different combinations of three studies for each of the four variables. When these data are examined more closely, a startling realization dawns: Sallows and Graupner (2005) is included in the analysis of all four variables, and in every case, the mean score in that study favors the comparison group over the treatment group. Later in the text, Spreckley and Boyd tell us “The results of this review should be interpreted with caution because [for two studies, Sallows & Graupner, 2005, and Smith et al., 2000] *the content of the intervention was the same for the comparison group, although at reduced intensity (80% and 16%)*” (p. 343, emphasis added). In other words, Sallows and Graupner’s comparison group—the one favored in the analysis—*was also receiving “ABI”!* The comparison was really between clinic-directed vs. parent-directed behavioral programming (the latter actually having 82% of the overall hours [T. Smith, personal communication, June 30, 2009]). The higher parent-directed comparison score considerably lowered the average for Spreckley and Boyd’s aggregated “treatment” group for all four variables. This low average was the principal basis for Spreckley and Boyd’s statement that “Current evidence does not support ABI as a superior intervention for children with ASD” (p. 342). Their bold conclusion—never mind the unsubstantiated and ideologically hand-tipping closing remark that “the overwhelming majority of children with ASD change over time as part of their development as opposed to change resulting from an intervention” (p. 343)—thus went well beyond the data and seemed to ignore their own admonition to interpret the results with caution.

I think it would be widely acknowledged that what is measured and evaluated in autism treatment is behavior. Further, it has been argued that children with autism are unique, as different from each other as from typically developing children. Some of the research that employs inferential statistics with aggregated data reminds me of a metaphor facetiously related by one of my professors, who said that

if medical research were practiced in a manner that disregarded individual uniqueness, we could put every participant’s blood into the same vessel and just run one test. As James Johnston (1988) wrote, “Behavior exists only between individual organisms and their environments, and in order to be effective, experimental studies must respect this fact... This means that if experimenters do anything that contaminates, dilutes, or otherwise distorts measures of behavior change, there is likely to be some deleterious effect on the inferences that can be drawn from the data. Among other actions, this caveat clearly includes the variety of measurement and data processing techniques that result in collating individual data into some group amalgam” (p. 2).

What Spreckley and Boyd did, in discussing the results of their meta-analysis, was to draw conclusions based on an amalgam of already amalgamated data. When done well, this method of analysis can be appropriate to retrospectively assess the degree of confidence we should have in extant data, and by extension, the conclusions drawn from those data (see Reichow & Wolery, 2009, for a more comprehensive meta-analysis and more humble conclusions). When it comes to learning about behavior, however, this method is like inserting yet another mattress between the princess and the pea. If the Sallows and Graupner data were to be eliminated from the analysis, the conclusion would be quite different yet probably no more enlightening: in terms of behavior, individual differences would still be lost, with no accompanying gain on the statistical side because any analysis would be suspect due to an insufficient number of participants. Adding a much larger sample of children in order to increase statistical power, however, would also increase the heterogeneity of the sample. A large sample would then entail the use of additional statistical procedures to help determine the extent to which heterogeneity influences the generalizability of the findings—which seems like taking one pill to help manage the undesirable effects of another.

Despite Spreckley and Boyd’s faulty conclusion, their argument

*Continued on page 9...*



was really not about efficacy, but about evidence itself. By “evidence,” Spreckley and Boyd were primarily referring to a particular *kind* of experiment, the RCT, as the grail of research, as the one true means of producing valid data for making sound conclusions about reported effects. Much has been written about insufficient RCT data to support comprehensive behavioral intervention (cf. two fine articles by Reichow & Wolery, 2009, and Rogers & Vismara, 2008), but I think this concern is to some extent misplaced or premature. Reichow and Wolery may have been technically accurate when they said that “Without comparisons between EIBI and empirically validated treatment programs, it is not possible to determine if EIBI is more or less effective than other treatment options” (p. 39), but while comparison may constitute one kind of worthwhile pursuit, it has its own shortcomings.

First, comparison studies are as much an actuarial endeavor as a clinical one. The chief aim of such research is “to estimate dividends and risks for general categories based on statistical records alone, that is, without attempting to understand the reasons for each event so as to allow prediction in a more individualized fashion” (Johnston, 1988, p. 3). Well-conducted RCTs can indeed help identify individual characteristics that, statistically, seemed to enhance or impede response to a given treatment—valuable information indeed—but if a specific participant does not respond to that treatment, researchers are more often left merely with ignorance than with alternatives. The autism community would be better served by studies that seek to match child characteristics with the most promising type of treatment program, as Sherer and Schreibman (2005) did with Pivotal Response Training and a more structured behavioral approach (some benefitted from the former, others, the latter—these are individual judgments and cannot be made *a priori* on the basis of aggregated data).

Second, when it comes to treatment of children with autism, there is really very little to compare. There is much data supporting the efficacy EIBI, while the amount of experimental research produced by non-behavioral programs is minimal at present (Schreibman, 2005). There is no law requiring the use of behavioral techniques for children with autism; there is, however, a federal law (the Individual’s with Disabilities Education Act) mandating that practices be based on “peer-reviewed research,” and when it comes to children with autism, most of the extant research is behavioral.

At this point, I must clarify what is denoted in speaking of “EIBI” and “behavioral research.” Saying a child received EIBI is like saying a child received college. I think Don Baer (2005) put it very well:

“ABA [EIBI] acknowledges from the outset of each case that each

child with autism requires a unique sequence of behavior changes made by different procedures to maximize his or her chances of achieving the best outcome possible. ABA is, as far as I know, the only approach that has always measured its outcomes objectively, reliably, and validly. Approximately 500 published studies show that one or a few of the many behavior changes children with autism require can be made by ABA programming. True, perhaps 300 of those 500 studies lacked a convincing experimental design and formal evidence of reliable measurement, but the other 200 replicated their results and extended them with good measurement and convincing designs. ABA is, as far as I know, the only approach that has evaluated outcomes in well-controlled clinical trials.... ABA has produced unprecedented good results...[and] no other approach has proved that it can do nearly as well, as far as I know (p. 6).”

In this paragraph, Baer not only suggested that no two children will, or ought to, receive identical intervention components under the umbrella of EIBI, but also indicated the single-subject nature of behavioral research. What characterizes EIBI is less any given intervention, which may happen to have been developed by behavior analysts, and more that the effects (dependent variables) of every intervention (independent variable) are measured frequently and reliably. An instructional method is employed because (a) it has a documented track record of effectively teaching specific skills under similar circumstances in the past, and (b) it remains effective in its current use with a child, as demonstrated by regular monitoring of performance data. In other words, individual outcomes matter more than whatever specific technique reliably produced them, but it happens that we know more about behavioral methods because their outcomes have been so extensively measured—sometimes well enough that alternative explanations for the change can be confidently ruled out.

Spreckley and Boyd’s concern was not only with the kind of available evidence—RCTs versus single-subject research—but also with the amount of available evidence. This is not an academic consideration, when federal law calls for the use of empirically supported practices but does not spell out how much peer-reviewed research is enough. Spreckley and Boyd chose to apply a strict “threshold” standard, an all-or-nothing judgment whereby an intervention program that is not supported by a certain number of RCTs is not considered to be supported at all. In contrast to this, there are also hierarchical standards of evidence, such as those of the American Psychological Association, which place interventions,

*Continued on page 19....*

### Tribute to Ted Carr — Raymond G. Romanczyk, Ph.D. BCBA-D

In the two weeks since Dr. Carr’s death, understandably many tributes and reviews of Dr. Carr’s work and contributions have been presented to honor this important contributor to the field of autism. I still recall vividly his paper “The Motivation of Self-injurious Behavior: A Review of Some Hypotheses” back in 1977 and how it served to place into strong focus the importance of antecedent and well as consequence in the behavioral equation. His work has been incorporated into, and influenced, the many different forms of behavioral approaches. He leaves behind legions of students, colleagues, and families he has touched so profoundly. His professional legacy will endure for a very long time.

But aside from his enormous professional contributions, I grieve for my friend Ted. We met more than 35 years ago as energetic wide-eyed graduate students, well before autism was a hot topic. I remember Ted for his kindness, energy, and wit, and that I always had fun when I saw him. Some say he had a dry sense of humor. I just thought he was hysterical with his keen insight based

humor that had an incredible ‘bite’, but he was always playful, genuine, and engaging. I recall fondly the verbal jousting matches we had right from time we first met, that prefaced each of our subsequent contacts, whether sitting in a restaurant or at a formal committee meeting. The topics were usually not about professional issues, but would be wide ranging, usually focused on the absurdities of life. The joust would last 5 or 10 minutes until we would both say ‘uncle’ and call it a draw, resting a bit after the interchange. We would then talk about important things, and for Ted that was always about family, before we would have to move on to the professional issues at hand. I will miss Ted the person very much.

“I remember Ted for his kindness, energy, and wit, and that I always had fun when I saw him.”  
~Raymond Romanczyk

*Raymond Romanczyk is a SUNY Distinguished Service Professor Director - Institute for Child Development Binghamton University*

## Autism and Vaccines continued...

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 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 (see table on page 12)

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

*continued on page 12....*

## Dancing for Autism: Irish Dancers Promote Autism Awareness and Support the Association for Autism Treatment



In April 2009, Autism Awareness Month, Irish dancers in the Mid-Atlantic Region of the US stepped forward to participate in a charity dance benefitting ASAT at The Lady of Knock

Feis competition held in Kutztown, PA, hosted by Oonagh McCune. There was a remarkable turn-out in this charity dance which was offered to Irish dancers registered in competitive events held during the day long Feis. Dancers of all ages, boys and girls, from beginners to champions joined together and took to the stage side-by-side. Dancer after dancer performed their treble reel in solo performances down the line. The fast-paced whirlwind of graceful

dance moves and rhythmically tapping feet engaged all, inspiring cheering and hand-clapping by the audience. It was truly a festive performance! We would like to thank Oonagh McCune for choosing ASAT as the beneficiary of the April 2009 charity dance! We are very grateful to the dance school teachers and families who promoted the event and to the many Irish dancers who chose to participate.

From left to right:

Katie Godek of the O'Grady Quinlan Academy of Irish Dance in Bethlehem PA., Caitlin Kelly of Kerry Dance NY in Warwick NY, Bridget Butler of the O'Grady Quinlan Academy of Irish Dance in Bethlehem PA

**Edward G. Carr, Mentor— Jane I. Carlson, Ph.D and Len Levin, Ph.D.**

**Mentor (men-tawr, -ter), noun.** 1. *A wise and trusted counselor or teacher;* 2. *An influential senior sponsor or supporter.*

Ted was our mentor. We had the distinct honor and pleasure of being Ted’s graduate students at the State University of New York at Stony Brook. We are among the fortunate few who were able to spend years working so closely with this warm, witty, wonderful, brilliant man. He was our mentor in the truest sense of the word. Always approachable, Ted was incredibly generous and open with us as students and as people. Through his skill as a researcher, we learned how to think about problems, the technical aspects of planning and implementing research projects, and the art of technical writing. Through his incredible empathy towards others, we learned the importance of service, of the quality of a person’s life, and the persistence that it takes to address problems that really matter.

Ted was incredibly supportive of us as young professionals. He involved us in a variety of projects and activities to ensure that we were well rounded as professionals. He introduced us to his colleagues and collaborators and encouraged us to reach out to others whose work we found interesting. He’d say, “Call him/her and introduce yourself. Tell them you’re my student.” When we did, we were always greeted warmly and often regaled with a funny story of that person’s time with Ted. Even quite recently, more than a decade out of graduate school, colleagues would say that they’d seen Ted and when he heard that they worked with one of us, he would sing our praises.

In the initial wave of grief that followed Ted’s death, many of us who had studied with Ted reached out to one another. We communicated across the country via e-mail and telephone to once again share our common experience. Many of the conversations began with tears and ended with laughter as we recounted the days working in the lab, meetings centered around the consumption of chocolate, and our sometimes hilarious misadventures as young researchers. We also talked about the themes that ran through our individual relationships with Ted; the lessons that he taught us individually and collectively that set us on a path to become mature professionals. We discovered that, across the continent and quite independently from each other, we began many of our training sessions with parents and direct service staff with the same lecture on systems of truth; a philosophy of science lecture that was a Ted Carr standard and creates a context for thinking about evidence-based practice. As we struggled to put into words what Ted meant to us as individuals, we were struck by the depth with which the lessons imparted during those graduate school years had affected our professional lives.

Many tributes will be written to Ted, and all of them well deserved. Ted was truly a giant in the field of autism and

developmental disabilities and his work has had an immeasurable impact on research and practice. Much will be written about his numerous publications, his involvement in professional activities, and the honors and awards he collected throughout his career. We pay a different sort of tribute to Ted; a tribute to the important role he played in our lives, his role as mentor. It would be impossible to impart all of the lessons learned from our years working with Ted so we’ve selected a group of “Ted-isms” to share that represent a sample of the wisdom that he passed along.

**“There are no treatment packages, cookbooks, or recipes.”**

Ted taught his students that analysis was paramount and there are no short cuts. In Ted’s uniquely entertaining, engaging, and ultimately enlightening way, he would frequently mock less sophisticated intervention agents by dramatizing a scenario (doing something like a Woody Allen impression) during which a frazzled psychologist would frantically flip through a textbook saying to himself, “What am I supposed to do for aggression? The book says to use Time-out... Done!”

There would be some laughter and then Ted would become very serious and say something like, “...A prescription for failure.” The brilliance of this guiding principle goes beyond the analysis of problem behavior. In 2009, many of us still encounter so-called ABA-based programs for children with autism in which every single child in the program receives the same treatment package: the same exact augmentative communication system; unvarying teaching procedures for every target objective; identical visual supports/schedules; etc. Every child in the program receives the same recipe. Ted taught us to avoid such an approach; inevitably,

that approach is a prescription for failure.

**“The bad data point is often the most interesting.”**

In graduate school, the focus is on a set of research products and, as we well know, research does not always go as anticipated. The odd outlier data point can often extend a phase of a project and heighten the anxiety of a graduate student facing a deadline. Ted would say, with a wry smile, “So, what did you learn from that?” He would empathize and then help us to understand that failure in treatment research can be as informative as success. Analyses of the things that don’t go according to plan can become the impetus for the next treatment innovation. With the signature grin returning, he would occasionally express this idea another way: “There’s a reason it’s called re-search.” **“Write so that people who need the information can understand it.”**

Writing for an audience of colleagues is an important vehicle for sharing information. Equally important to Ted was writing in a way that was accessible to the person who would ultimately need to solve a problem, implement an intervention, teach the skill: the parent, the teacher, the direct service worker. Ted would have us hand over our

*Continued on page 18....*



*Ted Carr’s Lab (1993), from left to right: Seated: Gene McConnachie, Theresa Giacobbe-Greico, Jane Carlson Standing: Len Levin, Darlene Magito McLaughlin, Nancy Langdon, Christopher Smith, Scott Yarbrough, and Ted Carr*



## Autism and Vaccines continued...

## National Organizations and their positions on Vaccines:

<b>The Centers for Disease Control and Prevention (CDC)</b>	"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>
<b>The National Institutes of Health (NIH)</b>	"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>
<b>American Academy of Pediatrics (AAP)</b>	"Scientific data does not show a link between vaccines and autism." <sup>20</sup>

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 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, M.D., 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 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 to *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

"I'm for the Parents!" he announced sternly.

"I am a parent" the mother replied.

*Continued on page 13...*

## Autism and Vaccines continued...

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.

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 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

*Continued on page 14....*

## Autism and Vaccines continued...

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>

## Chelation Treatment for Children with Autism continued....

Typically, physicians who prescribe chelation will test baseline levels of heavy metals in the urine of patients and then test the urine again after the administration of the chelation drug. However, this may not be a valid assessment. One published report of a child with environmental mercury toxicity (presenting with acrodynia, or burning pain associated with mercury toxicity) showed that urinary level did not reflect clinical improvement after chelation<sup>3</sup>. Another study of children with autism concluded that since DMSA chelation did not lead to high excreted levels of mercury, the children with autism did not have a high body burden of the metal<sup>4</sup>.

A recent search of the scientific literature via Medline found no randomized controlled trials of the use of chelation for the treatment of autism. A proposed study that was to be funded by the NIMH was cancelled. Several papers outlining only the opinion of the authors (listed as "pre-pilot") advocate a role for chelation as a treatment for autism based on personal experience.<sup>5,6</sup>

Individuals or parents making decisions

about introducing a drug intervention such as chelation must weigh risks to benefits. There are no known scientifically-validated benefits of the administration of chelating agents, yet there are some reported risks. Known side effects of these chemicals include: Two reported deaths (presumably from hypocalcemia induced by using an incorrect drug administered too quickly); hypocalcemia; and depletion of beneficial metals (zinc, iron). Ten percent of DMSA-treated patients show evidence of gastrointestinal issues including elevation in liver enzymes. In short, there is not enough scientific evidence available at this time to advocate a role for chelation of heavy metals in the treatment of autism, and there is potential for adverse side effects.

*Joyce Elizabeth Mauk, M.D.*  
*Advisory Board Member,*  
*Association for Science in Autism Treatment*  
*President/CEO and Medical Director*  
*Child Study Center, Fort Worth, Texas*

**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.

Continued on page 16...

### References

1. Nelson, K. B., & Bauman, M. L. (2003). Thimerosal and autism? *Pediatrics*, 111(3), 674-679.
2. Stehr-Green, P., Tull, P., Stellfeld, M., Mortenson, P. B., & Simpson, D. (2003). Autism and thimerosal-containing vaccines: Lack of consistent evidence for an association. *American Journal of Preventative Medicine*, 25(2), 101-106.
3. Gattineni, J., Weiser, S., Becker, A. M., & Baum, M. (2007). Mercury intoxication: Lack of correlation between symptoms and levels. *Clinical pediatrics*, 46(9), 844-846.
4. Soden, S. E., Lowry, J.A., Garrison, C. B., & Wasserman, G. S. (2007). 24-Hour Provoked Urine Excretion Test for Heavy Metals in Children with Autism and Typically Developing Controls, a Pilot Study. *Clin Toxicol (Phila)*, 45(5), 476-481.
5. Patel, K., & Curtis, L. T. (2007). A comprehensive approach to treating autism and attention-deficit hyperactivity disorder: A pre-pilot study. *Journal of Alternative and Complementary Medicine*, (New York, N.Y.), 13 (10), 1091-1097.
6. Kidd, P. M. (2002). Autism, an extreme challenge to integrative medicine. Part 2: Medical management. *Alternative Medicine Review: A Journal of Clinical Therapeutic*, 7(6), 472-499.



# ASAT is proud to unveil the 2009.... Real Science, Real Hope Sponsorship Initiative

ASAT believes that individuals with autism have the right to effective treatments that are scientifically demonstrated to make meaningful, positive change in their lives. It can be challenging for families to find accurate information about the efficacy of various interventions for autism. For that reason, central to ASAT’s mission, is the goal of disseminating accurate information about autism treatments. ASAT works toward a time when all families will be empowered to identify and choose the most effective, scientifically-validated interventions for their child, and all providers can be guided by science when selecting and implementing their interventions.

There are many organizations, who, along with ASAT, are concerned about the plethora of treatments that lack scientific support - and the burden this then places on families and service providers who are struggling to make decisions about treatment. The following organizations have indicated their support for ASAT and its mission to disseminate accurate, scientifically-sound information about autism and treatments for autism, and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

These sponsorships not only provide financial support used specifically for our dissemination efforts, but also send a clear message that ASAT’s vision is shared by others within the professional community. The funds provided by the ASAT sponsors will help support a number of directed efforts undertaken by ASAT this year (e.g., a pediatrician education program, a journalist/ media education program, and public awareness of our newsletter and website).

ASAT’s sponsors have indicated their support of the following tenets:

1. That all treatments for individuals with autism should be guided by the best available scientific information.
2. That service providers have a responsibility to rely on science-based treatments.
3. That service providers should take steps necessary to help consumers differentiate scientifically-validated treatments from those that are not.
4. That consumers should be informed that any treatment which is not scientifically supported should be pursued with great caution.
5. That objective data should be used to guide clinical decision making.

The tasks of educating the public about scientifically-validated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of our sponsors.

If you are interested in becoming a sponsor, please visit the sponsor page on our website at [http://asatonline.org/about\\_asat/sponsors.htm](http://asatonline.org/about_asat/sponsors.htm)

## Participating Organizations in Real Science, Real Hope

<p><b>CHAMPION \$2,000</b> Ask a Behaviorist</p> <p><b>BENEFACTOR \$1000</b> Rethink Autism</p> <p><b>ALLIANCE \$500</b> Alpine Learning Group, Inc. Different Roads to Learning Eden II Programs ELIJA School New England Center for Children New Haven Learning Centre for Children Virginia Institute of Autism</p>	<p><b>PATRON \$200</b> Beacon Services Behavioral Directions Brooklyn Autism Center Academy Connecticut Center for Child Development (CCCD) Educational Partnership for Instructing Children (EPIC) Evergreen Center Institute for Educational Planning Lizard Children’s Learning Centre Reed Academy Room to Grow SKF Books Somerset Hills Learning Institute</p>
--	---

## ASAT’s Mission

Our mission is to disseminate accurate, scientifically sound information about autism and treatments for autism and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

**IMPORTANT DISCLAIMER:** ASAT has no formal relationship with any of the sponsor organizations. Furthermore, their stated endorsement of the above tenets is not verified or monitored by ASAT. Although ASAT expects that all sponsoring organizations will act in accordance with the above statements, ASAT does not assume responsibility for ensuring that sponsoring organizations engage in behavior that is consistently congruent with the statements above.

## Autism and Vaccines continued...

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:

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 (on p 17) on hand. The first is from the extremely valuable site [www.quackwatch.org](http://www.quackwatch.org), founded by Stephen Barrett, M.D., 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.

**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, and 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>1</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.

### Footnotes

<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

Continued on page 17...

**A. COMPARISON OF SCIENCE AND PSEUDOSCIENCE**

Science	Pseudoscience
Their findings are expressed primarily through scientific journals that are peer-reviewed and maintain rigorous standards for honesty and accuracy.	The literature is aimed at the general public. There is no review, no standards, no pre-publication verification, no demand for accuracy and precision.
Reproducible results are demanded; experiments must be precisely described so that they can be duplicated exactly or improved upon.	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 searched for and studied closely, because incorrect theories can often make correct predictions by accident, but no correct theory will make incorrect predictions.	Failures are ignored, excused, hidden, lied about, discounted, explained away, rationalized, forgotten, avoided at all costs.
As time goes on, more and more is learned about the physical processes under study.	No physical phenomena or processes are ever found or studied. No progress is made; nothing concrete is learned.
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.	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.
Does not advocate or market unproven practices or products.	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.

**Autism and Vaccines continued...**

<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

<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

<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).

<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

<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

<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>.

<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>

<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.

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

<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.

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



**Edward G. Carr, Mentor— continued....**

papers to other students from different orientations, people in the community, our parents, to ensure that the concepts being presented were clear and comprehensible. “If a classroom teacher or parent can’t understand what you’ve done, you haven’t done anything.”

**“Systems of truth”**

Ted was a scientist working in an applied field with interdisciplinary teams whose members were often not trained in the methodologies of science. Ted was a psychologist whose broad range of colleagues in the larger field of psychology were comprised of many different orientations, many not rooted in a scientist/practitioner model. Ted was an advocate working with families who were desperate for assistance and relief and who would often turn to “alternative” treatments with the hope of obtaining better outcomes for their children. While Ted’s diplomacy skills with respect to navigating the dynamics of an interdisciplinary team meeting, for example, were unparalleled, we can only presume that these situations were some of the setting events for his semi-annual lecture on systems of truth.

At the beginning of every semester, in every course that Ted taught, he described the process by which we determine whether or not something is “true.” He talked about three systems of truth: the Authoritarian system, the Phenomenological system, and the Empirical system. When we adhere to the Authoritarian system of truth, we believe that a statement is true because an expert or reliable source expresses that the statement is fact. When we adhere to the Phenomenological system of truth, we believe that a statement is true because our experience, albeit, our subjective experience, confirms that the statement is true. When we adhere to the Empirical system of truth, we believe that a statement is true because direct measurement following the systematic manipulation of independent variables yields reliable data that strongly suggest that the statement is true. In other words, when we adhere to the Empirical system of truth, we rely on results obtained via experimentation and the scientific method to guide our decision-making with respect to selecting interventions and modifying systems to achieve our desired outcomes.

As we mentioned above, many of Ted’s students still use this taxonomy in

our lectures and workshops today. It empowers parents as they are faced with contradictory recommendations from professionals. It inspires students and staff to pursue careers dedicated to evidence-based practice. It is the philosophical foundation on which this organization, the Association for Science in Autism Treatment, is based.

Ted’s death leaves a huge hole in our lives. He won’t be there now to bounce around a research idea or to offer advice on a professional problem, but his voice will continue to inform the work we do every day. He’s shaped the way we analyze problems, the way we design intervention strategies, the way we communicate about our work, and the service we provide to people with autism and their families. His teachings have become part of our DNA; who we are as professionals and as people. For this we are forever in his debt. Ted Carr was our mentor; he was our friend.

---

*Jane I. Carlson, Ph.D., BCBA-D  
The Groden Center*

*Len Levin, Ph.D.  
Coyne and Associates*

**Board Member Bio: Mary Beth Walsh, Ph.D.—continued....**

**Q: What experience do you have with autism treatment? How do you think ASAT can help with that?**

**A:** *When my son was diagnosed, I was very lucky to make contact with a gifted and kind behavior analyst (Dr. Sharon Reeve, BCBA-D, of ASAT’s Advisory Board) who helped me educate myself about autism treatment and science, and who, more importantly, helped my son tremendously and set our whole family on the right path. But over the last eight years I’ve come to realize my family’s story is extremely unusual. Where we live in New Jersey, we are lucky to have a lot of supports, from a respected advocacy organization committed to science, Autism NJ [www.autismnj.org](http://www.autismnj.org) to some excellent*

*evidence-based schools for children with autism, and including great graduate programs that train teachers in science based intervention for autism. This abundance of resources is not the norm. It’s my personal belief that those of us who have been able to access excellent services for our children have an obligation to help other parents.*

*As Chair of the ASAT Website Committee, I am privileged to be able to read and respond to the emails that come into the [info@asatonline.org](mailto:info@asatonline.org) account from parents around the globe, and I know that most families have a much harder time finding evidence based treatment for autism, or even getting to see what this looks like in real life. At ASAT we receive emails from parents in Oman, Bangladesh, and*

*Brazil, and I am always struck by the tremendous lengths parents are willing to go to in pursuit of effective intervention. Too often the scarcity of science-based intervention for children with autism fuels parental desperation for “anything that works” and allows for the proliferation of quack-based interventions and opportunists willing to prey on vulnerable families, especially during the early, confusing, anxiety-filled years immediately post-diagnosis. Reading the emails we receive at ASAT always recommit me to our mission to provide accurate information about the science behind proposed autism treatments, and to work to increase access to effective, evidence-based interventions for all individuals with ASDs.*

**Consumer Corner continued....**

a description of the various theoretical perspectives on autism, information about participating in research, and some sample research articles with embedded sidebar comments that label the various sections of the study. The worksheets are invaluable tools for culling out essential information and include both a basic and more detailed template.

I am grateful that OAR has compiled such a wonderful resource for parents. This guide is several years old, but it continues to be useful to those parents beginning their search as well as those wishing to delve deeper into research. Although this guide is clearly targeted toward parents, I believe this resource will also be immensely helpful to teachers and other providers learning to navigate the research on autism.

As a special education teacher, I am well aware of the vast array of treatments that are offered to parents of children with

autism. Parents armed with skills in identifying and understanding sound research studies will also prompt educators and other service providers to use evidence-based practices and perhaps exercise greater scrutiny when considering the dozens of treatments that lack scientific support. If parents are able to better access and understand research, they will be in a better position to make sound choices to help their children realize their fullest potential reliable. An educated consumer base will undoubtedly support the advancement of both science and practice.

A free copy of *A Parent’s Guide to Research* can be downloaded by visiting the following link:  
<http://www.researchautism.org/resources/reading/index.asp>

---

*Stacey Sipe, Special Education Teacher  
Granite Street Elementary School, Millinocket, Maine*

### Comments on Spreckley and Boyd (2009) continued....

whether investigated via group comparison or single-subject research, along a continuum from “well established” to “probably efficacious” to “experimental” (Detrich, 2008, p. 29). These standards are merely arbitrary conventions, a matter of consensus within a given field, and with respect to single-subject research we are “just beginning the process of determining the professional standards that allow demonstration of an evidence-based practice” for special education (Horner et al., 2005). Horner et al. (2005) suggested five criteria that must be met in order for an intervention that has been effective in single-subject research to be considered evidence-based, one of which proposes that:

“A practice may be considered evidence based when (a) a minimum of five single-subject studies that meet minimally acceptable methodological criteria and document experimental control have been published in peer-reviewed journals, (b) the studies are conducted by at least three different researchers across at least three different geographical locations, and (c) the five or more studies include a total of at least 20 participants (p. 176).”

Parents, providers, and policy makers will find very many specific behavioral interventions that meet this standard.

It is the dual standards and models of research—threshold vs. hierarchical, actuarial comparisons of programs vs. single-subject evaluation of interventions—that the much-cited National Research Council (NRC) report (2001) attempted to reconcile. On one hand, the report applied a very high threshold standard to evidence itself, and even Spreckley and Boyd were correct that there is negligible RCT research on any general approach to teaching children with autism (in fact, for many putative treatments there is no research at all). On the other hand, the NRC applied a hierarchical standard to specific instructional interventions, and on this basis made numerous more or less qualified recommendations, almost all of which happened to be supported by behavioral research. It is not necessarily that these interventions are inherently superior to other methods—any judgment of that kind is indeed premature. Rather, they are simply supported by a preponderance of evidence that meets conventional standards for being well-established and that does, therefore, offer firm enough footing for policy. In suggesting otherwise, Spreckley and Boyd’s logic would seem to be not only unsupported by conventions of psychology and special education, but also, in proffering a nearly impossible standard of evidence, potentially harmful. Tobacco companies once chose to adopt a similarly impossible standard and on the basis of that self-serving choice disputed that there was adequate “evidence” that cigarettes “caused” lung cancer—despite compelling and continuously mounting

demonstrations of a relationship. Spreckley and Boyd’s putatively scientific claim could be exploited to argue against providing behavioral intervention, and in the supposed absence of evidence, authority is left as the only arbiter of treatment decisions.

Jonathan W. Kimball, Ph.D., BCBA  
Woodfords Family Services  
Portland, Maine

#### References

Baer, D. M. (2005). Letters to a Lawyer. In W. L. Heward, T. E. Heron, N. A. Neef, S. M. Peterson, D. M. Sainato, G. Cartledge, R. Gardner III, L. D. Peterson, S. B. Hersh, and J. C. Dardig (Eds.), *Focus on behavior analysis in education: Achievements, challenges, and opportunities*. Columbus, OH: Pearson.

Detrich, R. (2008). Evidence-based, empirically supported, or best practice? A guide for the scientist-practitioner. In J. K. Luiselli, D. C. Russo, W. P. Christian, and S. M. Wilczynski (Eds.), *Effective practices for children with autism*. New York: Oxford University Press.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism: A 1-year comparison controlled study. *Behavior Modification, 26*, 49-68.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: A comparison controlled study. *Behavior Modification, 31*, 264-278

Horner, R. H., Carr, E. G., Halle, J., McGee, G., Odom, S., & Wolery, M. (2005). The use of single-subject research to identify evidence-based practice in special education. *Exceptional Children, 71*, 165-179.

Johnston, J. M. (1988). Strategic and tactical limits of comparison studies. *The Behavior Analyst, 11*, 1-9.

Matson, J. L., Benavidez, D. A., Compton, L. S., Paclawskyj, T. & Baglio, C. (1996). Behavioral treatment of autistic persons: A review of research from 1980 to the present. *Research in Developmental Disabilities, 17*, 433-465.

National Research Council. (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

Reichow, B. & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders, 39*, 23-41.

Rogers, S. J. & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology, 37*, 8-38.

Sallows, G.O., & Graupner, T.D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation, 110*, 417-438.

Schreibman, L. (2005). *The science and fiction of autism*. Cambridge, MA: Harvard University Press.

Sherer, M. R., & Schreibman, L. (2005). Individual behavioral profiles and predictors of treatment effectiveness for children with autism. *Journal of Consulting and Clinical Psychology, 73*, 525-538.

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation, 105*, 269-285.

Spreckley, M., & Boyd, R. (2009, March). Efficacy of applied behavioral intervention in preschool children with autism for improving cognitive, language, and adaptive behavior: A systematic review and meta-analysis. *The Journal of Pediatrics, 338-344*.

## ASAT Committee Members

In addition to our Advisory Board, a number of individuals lend their time and talents to support ASAT's mission and initiatives.

#### ASAT Newsletter

Lori Bechner, M.A., BCBA  
Kate Fiske, Ph.D., BCBA  
Germaine Ibrahim, M.Ed.

#### ASAT Public Relations

Diane Carballo, B.S.  
Jennifer Hieminga, M.Ed.  
Lewis Mazzone, M.A.  
Rebecca McKee, M.S., Ed.  
Audrey Meissner, M.Ed., BCBA  
Sage Rose, Ph.D.  
Connie Russo, Ph.D.

#### ASAT Finances Committee

Paul E. J. Pangburn, B.S.

#### ASATonline.org

Kerry Ann Conde, B.A.  
Amanda Wadsworth, M.S. Ed.

#### Media Watch

Geoff Debery, M.A., BCBA  
Florence DiGennaro Reed, Ph.D., BCBA  
Daphna El-Roy, Ph.D., BCBA  
Regina Claypool-Frey, B.S.  
Hannah Hoch, Ph.D., BCBA  
Sharon Reeve, Ph.D., BCBA

*Coming Soon this Fall*



- Review of Sabrina Freeman's book, *The Complete Guide to Autism Treatments*
- Interview with Tom Zane and Suzanne Letso
- Overview of ASAT's Media Watch
- 2 Research Reviews
- Clinical Corner: Early Intervention
- Clinical Corner: FBAs
- Consumer Corner
- Autism SIG Consumer Guidelines
- Debut of "Talk about Ethics" with Mary Jane Weiss
- .....And more!



www.asatonline.org



**ASAT** Real Science, Real Hope  
ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Over 10 Years of  
Education  
Advocacy  
Information

To support ASAT's mission and make a significant difference in the lives of children with autism and their families, please complete this form and remit it to:

The Association for Science in Autism Treatment  
P.O. Box 188 Crosswicks, NJ 08515-0188

Amount of my Gift  \$25  \$50  \$100  \$250  \$500  \$1000  \_\_\_\_\_  
(Please make check payable to ASAT)

Name \_\_\_\_\_ Phone (\_\_\_\_) \_\_\_\_\_

Address \_\_\_\_\_

Email \_\_\_\_\_

- Yes, I give permission to publically acknowledge my donation by including the following information on ASAT printed material or website.
  - Donor Name
  - In Honor of / In Memory Of \_\_\_\_\_  
*circle one*
- No, I prefer that my donation is not listed in ASAT material.

ASAT offers a Free Newsletter  
Science in Autism Treatment

- I have already subscribed at [www.asatonline.org/signup](http://www.asatonline.org/signup)
- Please add me as a subscriber