

## **How do I explain my decision to use science-based treatments for autism when friends and relatives often insist I try something new?**

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When friends or acquaintances hear about our experiences with autism, quite often the first thing they ask is, “What is your opinion of vaccines?” Then, in many cases, that person asks if we have heard of or read anything about Jenny McCarthy and how she cured her son’s autism. The vaccine debate is an issue that lingers on, despite numerous scientific studies that find no evidence to support a link between vaccines and autism and even in the face of the recent retraction of Andrew Wakefield’s article by the *Lancet* (a very rare occurrence by this highly reputable journal).

As citizens, we respect any individual’s right to his or her own opinion and, specifically, for parents of children with autism to make decisions for their child regarding treatment. The late Senator Patrick Moynihan eloquently said, “Everyone is entitled to their own opinions, but not their own facts.” As scientists, we believe that objective data and evidence should guide treatment options for all diseases and disorders, and autism is no exception. It is simply a matter of fact that theories, hypotheses and individual experiences do not provide adequate information to guide treatment decisions.

Sadly, the controversies surrounding vaccines have detracted attention from the most important of conversations: How do we effectively help children who are *already* diagnosed with autism? Although applied behavior analysis is the treatment for autism that has the most empirical support, we are rarely ever asked our opinion of this therapy, or if it is effective.

Every few weeks or so, some “new” treatment (or “repackaging” of a known treatment) will gain the attention of consumers. In an ideal world, all treatment providers would make a commitment to science and evidence-based practices, and the media would make a commitment to responsible journalism. Until these ideals become reality, those who do understand science-based treatments should do what they can to inform and educate parents about the benefits of scientifically validated treatment, and the use of data to guide decision-making when assessing autism treatments.

Given the large numbers of television programs, newspaper articles, and websites putting forth “miracle cures” and “breakthroughs,” it is not surprising that parents frequently receive advice and suggestions from extended family members, neighbors, and co-workers, particularly after a news item is broadcasted, printed, or otherwise disseminated. Many of these individuals have the best intentions and are eager to share what they believe is “cutting edge” information about autism. In other cases, the advice is sometimes provided in a manner that comes across as critical of what you are choosing to do or not do for your child (i.e., there may be the implication that you may not be doing enough as a parent to help your child with autism). If the information is offered by a more casual acquaintance, it may be

best to simply thank him or her for their interest and concern and move on; however, such a strategy may not fare as well with individuals with whom you have a closer relationship. In these cases, you might consider sharing the following:

- There are dozens of “miracle cures” and “breakthroughs” for autism that manage to receive widespread media attention, even if they have not been proven effective;
- It is important to be critical of all available information, regardless of the **source**, and to recognize that not all information on the internet is reliable and accurate;
- There is a large body of scientific research published in peer-reviewed journals that supports the choices that you have made;
- Numerous task forces (some are listed at the end) have looked closely and objectively at the available research and have determined that the vast majority of autism treatments lack scientific support;
- Autism treatment is a multi-million dollar industry and many treatment proponents rely heavily on sensationalism and extraordinary claims to “sell” their products;
- Interventions that are actually shown to be the most effective often receive the least amount of media attention; and
- For most other medical conditions, a provider that disregards proven intervention and uses a fringe treatment may actually be sued for malpractice (you may even consider drawing an analogy to a medical condition of particular interest to the person providing the advice).

Of course, you may also consider addressing this matter proactively. This would involve explaining your choices and commitment to science-based treatment to more significant family members and friends on your terms and at your convenience. It may be helpful to view this discussion as a series of tiny conversations.

We both serve on the board of the Association for Science and Autism Treatment (ASAT). You may consider sharing links to websites such as [asatonline.org](http://asatonline.org), which will help your family members and friends separate the wheat from the chaff.

This response would not be complete without offering some of the resources available through our organization. Many of you may not be aware of ASAT’s website, [www.asatonline.org](http://www.asatonline.org). We would like to draw your attention to a few components of the website that bear relevance to this discussion.

- Summaries of Scientific Research on Interventions on Autism  
[www.asatonline.org/intervention/treatments\\_desc.htm](http://www.asatonline.org/intervention/treatments_desc.htm)
- What is Evidence-Based Practice and Why Should We Care?  
[www.asatonline.org/intervention/articles/evidencebasedpractice.htm](http://www.asatonline.org/intervention/articles/evidencebasedpractice.htm)
- Recommendations of Expert Panels and Government Task Forces  
[www.asatonline.org/intervention/recommendations.htm](http://www.asatonline.org/intervention/recommendations.htm)

Please note that ASAT’s newsletter, *Science in Autism Treatment*, is a free publication. To sign up, go to: [www.asatonline.org/signup](http://www.asatonline.org/signup). It is our hope that readers will better understand the role that science should play in the treatment of autism, the importance of data in driving decision making, and how to identify pseudoscience.

Some other helpful resources:

- Interventions for Autism Spectrum Disorders: State of the evidence. (A collaboration of the Maine Department of Health and Human Services & the Maine Department of Education.) [www.muskie.usm.maine.edu/](http://www.muskie.usm.maine.edu/)
- Report of the MADSEC Autism Task Force (2000)  
[www.madsec.org/LinkClick.aspx?fileticket=YmikqkW4tFk%3d&tabid=81](http://www.madsec.org/LinkClick.aspx?fileticket=YmikqkW4tFk%3d&tabid=81)
- New York State Department of Health Clinical Practice Guideline for Autism and Pervasive Developmental Disorders  
[www.health.state.ny.us/community/infants\\_children/early\\_intervention/disorders/autism/](http://www.health.state.ny.us/community/infants_children/early_intervention/disorders/autism/)
- National Professional Development Center's Evidence-Based Practices for Children and Youth with Autism Spectrum Disorders (ASD)  
<http://autismpdc.fpg.unc.edu>
- Autism Watch  
[www.autism-watch.org/](http://www.autism-watch.org/)