Autism 101 for Vaccine Advocates

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Every Child By Two hopes that you find the *Autism 101 for Vaccine Advocates Guide* very helpful. We would really appreciate your feedback. Please visit [www.ecbt.org/autism101survey.htm](http://www.ecbt.org/autism101survey.htm) to fill out a very short online survey.

To view the archived *Autism 101 for Vaccine Advocates* webinar, visit [ecbt.org/resources/rc_ecbtandpartners.cfm](http://ecbt.org/resources/rc_ecbtandpartners.cfm)

This Guide is supported through funding provided by the Centers for Disease Control and Prevention through cooperative agreement 1U38IP000455-01.
It can be frustrating to still be talking about autism and vaccines when as medical and public health professionals we know all these points are true...

1. There are dozens of studies looking at the relationship between autism and vaccines, and none indicate a link. You can read the studies for yourself here: http://www.autismsciencefoundation.org/autismandvaccines

2. The study that originally connected autism and the MMR vaccine, conducted by Andrew Wakefield, was retracted in early 2010.

3. Andrew Wakefield was stripped of his medical license and his report was deemed “an elaborate fraud”.

4. The Vaccine Court has denied all claims in the Autism Omnibus Hearings, writing “this case is not a close case...the overall weight of the evidence is overwhelmingly contrary to the petitioners’ causation theories."

5. More and more children are getting sick from vaccine preventable diseases like measles and pertussis.

Even with all these facts, some parents may still question the safety and efficacy of vaccines.

Some parents are also still unsure of the connection between autism and vaccines. According to a Harris Interactive/HealthDay poll published in January 2011:

- **18%** of Americans say vaccines cause autism
- **30%** of Americans aren’t sure

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Physicians are feeling the effects, according to a Journal of Preventative Medicine study published in May 2011:\(^8\):

- **79%** of physicians report at least one vaccine refusal
- **8%** report refusals for more than **10%** of children in their practice
- **89%** report at least one request to spread out vaccines
- About one-third of physicians say vaccine discussions are negatively affecting their job satisfaction

The science on autism and vaccines is clear, but still some parents are not getting the message. Better communication with parents about vaccines is necessary. Our traditional frameworks for communicating science are no longer adequate. We need a new way of talking to parents and we need to understand what does cause autism so we can better explain what doesn’t.

**Autism 101**

For many years, we thought once the studies exonerating vaccines as a cause of autism were published that parents’ concerns would be allayed. But this has not been the case. The good news is there are new studies helping us start to understand what does cause autism. By sharing some of this information with parents we may further be able to calm their fears regarding vaccines.

**The Types of Autism**
Autism is a group of brain-based disorders that affect a person’s behavior as well as social and communication skills. These disorders include:
- Classic Autism
- PDD-NOS
- Asperger Syndrome
- Rett Syndrome
- Childhood Disintegrative Disorder

Together these are referred to as Autism Spectrum Disorders\(^9\). Typically when we talk about autism, we are talking about classic autism, PDD-NOS and Asperger Syndrome.

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What is Autism?
Regardless of the classification of autism, every person diagnosed with autism has some level of impairment in three areas:

- **Social** - interest in people, joint attention, imaginative play
- **Communication** - language, speech
- **Behavior** - repetitive behaviors, tantrums, aggression

The connection of social, language and behavior is a very simplified view of what autism means for a family. When a child has autism families are most often dealing with a wide-range of medical conditions and behaviors. There are many more associated symptoms and syndromes, like anxiety, depression and aggression, and co-morbidities like sleep disturbance and epilepsy.

What Causes Autism?
We can’t pinpoint an exact cause of autism yet, but scientists have been hard at work looking for the causes of autism and also developing new treatments for autism. Many scientists are testing theories that autism results from a combination of genetic and environmental factors. What we do know is that the brain’s development is off course.

We know that about 15% of autism is attributable to specific genetic causes, meaning in that in about 1 in 6 children with autism we can identify a genetic abnormality that explains their autism.

We are discovering that the genes that are linked to autism are involved in the formation and function of neural synapses - which are the spaces between neurons that enable communications signals to be transmitted through the brain.

Recently, scientists have discovered that differences in brain structure of an ASD child can be seen prenatally, as early as in the second trimester. What they have found is that an overproduction of brain cells in the frontal lobes of the brain creates patches of functional abnormality. Too many cells are created, and the genes responsible for sorting and differentiating the needed cells from the unneeded cells are

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compromised. This relatively new knowledge will be essential to developing early biomarkers for autism.

Several studies have shown that specific drugs are successful in reversing the deficits associated with autism, at least in mice\textsuperscript{12}. By creating mouse models that mimic the genetic anomalies found in autism, we are able to test new drugs and see if they help to correct the problems we see. FDA clinical trials of these drugs in humans are currently underway.

While there are some enviromental factors ruled out, like ultrasounds and vaccines, there are several environmental factors that have been implicated. Valproic acid taken during pregnancy and rubella exposure during pregnancy have both been shown to increase the chance of ASDs. Studies are underway to test the effects of fertility drugs, anti-depressants taken during pregnancy and pesticides.

**How is Autism Diagnosed?**

The number of children being diagnosed with autism is now \textbf{1 in 110}, a large increase over past decades. It is still unclear whether this rise is a true increase in incidence or the result of better diagnosis. Diagnostic criteria for autism has been expanded over the past years, and better awareness of autism has meant increased availability of services.

The good news is that we are able to diagnosis children younger and younger. In some studies, children as young as 6 weeks old are able to be reliably diagnosed (this is well before the infant has received most vaccines)\textsuperscript{13}. There is also a new, simple screening tool for pediatricians to use on all 12 month old babies\textsuperscript{14}. The AAP recommends routine screening for autism at 18-month and 24-month well-baby examinations\textsuperscript{15}.

Diagnosis is still made based on behavior, parent questionnaire, and clinical observation. We don’t have no medical test yet, but scientists are looking for biomarkers.


The CDC lists these Red Flags for Autism\textsuperscript{16}
\begin{itemize}
  \item Does not babble or coo by 12 months
  \item Does not gesture (point, wave, grasp) by 12 months
  \item Does not respond to name by 12 months
  \item Does not say single words by 16 months
  \item Does not say two-word phases on his or her own by 24 months (not repeating)
  \item Has any loss of any language or social skill at any age
\end{itemize}

Why is Early Diagnosis Important?
Early intervention works. Children with autism in a good early intervention program can make meaningful gains in skills. In fact with early treatment, \textit{30-50\%} make enough gains to be mainstreamed by kindergarten. Scientists can effectively screen children as early as 12 months\textsuperscript{17}, and recent studies have even found that some diagnoses can be made as at 6 to 8 weeks\textsuperscript{18}. It’s important to note that early Intervention programs vary by state, so check with your local organizations.

What Do We Know About Risk?
Recent science has made great strides into determining risk factors for ASD diagnoses. The following have been found to be proven risks for an autism diagnosis:
\begin{itemize}
  \item Genetics – Identical twins, who share all their DNA, show a higher autism concordance rate than fraternal twins, further validating that autism is a genetically based disorder
  \item Male children\textsuperscript{19} - Boys are diagnosed \textbf{four times} more frequently than girls
  \item Siblings - Studies have shown that there is a \textit{20\%} chance that a younger sibling of a child with autism will also be diagnosed with autism\textsuperscript{20}
  \item “Older” parents - Higher maternal and paternal age at conception adds to risk of ASD diagnosis\textsuperscript{21}
  \item Prenatal Exposures- Exposure to rubella virus (but not rubella vaccine) or valproic acid during pregnancy increases risk that the child with be diagnosed with autism
\end{itemize}

\textsuperscript{16} CDC. “Act Early.” Last reviewed December 10, 2010. \url{http://www.cdc.gov/ncbddd/actearly/index.html}
Autism Treatments

There have been major advances in evidence-based treatments. These are just some that have been shown to be effective in clinical trials. Usually people with autism need a combination of these therapies to succeed:

- **Applied Behavior Analysis Therapy** - Several ABA models have good evidence behind them, including discrete trial training, relationship development intervention, pivotal response training and “Early Start Denver Model”\(^{22}\)
- **Speech Therapy**
- **Occupational Therapy**
- **Physical Therapy**
- **Pharmacological Interventions** - The FDA has approved Risperdal\(^{23}\) and Abilify\(^{24}\) for symptoms associated with autism. Other drugs are currently undergoing FDA clinical trials in humans

Children with autism are often being treated with several concurrent treatments. According to a report from the Interactive Autism Network (IAN), on average children with autism are receiving five simultaneous treatments\(^ {25}\). About 5% of children currently receive no treatment at all, while others receive dozens. One child in the survey was receiving 56 concurrent treatments.

Unfortunately, parents of children with autism are often lured with promises of improvement by charlatans or quacks looking to make a quick buck. Here are some treatments for which there is little or no evidence of efficacy:

- Music Therapy (AIT)
- Horseback Riding Therapy
- Special Diet (Gluten and Casein Free)
- Vitamin Supplements
- Secretin Injections
- Anti-Fungal Agents
- Chelation
- Giant Electromagnets
- Hyperbaric Oxygen Therapy
- Holding Therapy
- Nicotine Patch
- Medical Marijuana

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\(^{25}\) IAN & Kennedy Krieger Institute. 2008
Parents of Autistic Children

Parents of children with autism often have more stress than typical parents or even parents of children with other disabilities. They often experience stress related to their child’s poor social relatedness and behavioral problems, their child’s sleep problems, and from lack of resolution with diagnosis.

This stress, combined with fierce love for their children, may lead parents to use non evidence-based interventions. You may hear anecdotal reports from parents or the media that certain treatments work. In fact, parents are often so eager for new treatments to work that they report tremendous improvements even for children on placebo.

Additional Resources

IACC
Every year, the federal Interagency Autism Coordinating Committee (IACC) writes a strategic plan to guide federal and private spending on autism research26. This document is a blueprint for the most pressing issues in autism science and is a great resource for the public health community. The IACC also publishes an annual Summary of Advances in Autism Spectrum Disorder Research27 which reports on new findings that have made the most impact on the field.

Government Pages
- National Institute of Health (NIH) -
- Health Resources and Services Administration (HRSA) -

Autism Science Foundation

The Autism Science Foundation (ASF) is a nonprofit organization dedicated to science and evidence. ASF funds autism research directly, and supports families by reinforcing the message that no science currently exists to indicate that vaccines cause autism.
- Website: [http://www.autismsciencefoundation.org](http://www.autismsciencefoundation.org)
- Blog: [http://www.autismsciencefoundation.wordpress.com](http://www.autismsciencefoundation.wordpress.com)
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