



### Making the CASE for Vaccines:

### A new model for talking to parents about vaccines

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...

- 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.html
- The article that originally posited a relationship between autism and the MMR vaccine, conducted by Andrew Wakefield, was retracted in early 2010<sup>1</sup>. Andrew Wakefield was stripped of his medical license<sup>2</sup> and his report was deemed "an elaborate fraud."<sup>3</sup>
  - The Vaccine Court has denied all claims in the Autism Omnibus Hearings<sup>4</sup>, writing, "this case is not a close case. The overall weight of the evidence is overwhelmingly contrary to the petitioners' causation theories."
- 3. More and more children are getting sick from vaccine preventable diseases like measles<sup>5</sup> and pertussis.<sup>6</sup>



Even with all these facts, some parents may still question the safety and efficacy of vaccines. Physicians are seeing the effects, according to a Journal of Preventative Medicine study published in May 2011<sup>7</sup>:

• Nearly 8 out of 10 physicians report at least one vaccine refusal from a parent.

<sup>&</sup>lt;sup>1</sup> ABC News. "Lancet Retracts Controversial Autism Paper." <a href="http://abcnews.go.com/Health/AutismNews/autism-vaccines-lancet-retracts-controversial-autism-paper/story?id=9730805">http://abcnews.go.com/Health/AutismNews/autism-vaccines-lancet-retracts-controversial-autism-paper/story?id=9730805</a>

<sup>&</sup>lt;sup>2</sup> The New York Times. "British Medical Council Bars Doctor Who Linked Vaccine with Autism."

http://www.nytimes.com/2010/05/25/health/policy/25autism.html

<sup>&</sup>lt;sup>3</sup> CNN. "Retracted autism study an 'elaborate fraud,' British journal finds." http://www.cnn.com/2011/HEALTH/01/05/autism.vaccines/index.html

<sup>&</sup>lt;sup>4</sup> "About the Omnibus Autism Proceeding." <a href="http://www.hrsa.gov/vaccinecompensation/omnibusproceeding.htm">http://www.hrsa.gov/vaccinecompensation/omnibusproceeding.htm</a>

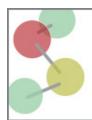
<sup>&</sup>lt;sup>5</sup> CDC. "Measles --- United States, January--May 23, 2014."

https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6322a4.htm

<sup>&</sup>lt;sup>6</sup> CDC. "Pertussis Epidemic – Washington Outbreaks 2012."

https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6128a1.htm

<sup>&</sup>lt;sup>7</sup> "Prevalence of parental concerns about childhood vaccines: the experience of primary care physicians." http://www.ncbi.nlm.nih.gov/pubmed/21496754





 8% report refusals for more than 10% of children in their practice.

Parents are also still unsure of the connection between autism and vaccines. According to a <u>Harris Interactive/HealthDay</u> poll published in January 2011<sup>8</sup>:

- 18% of Americans say vaccines cause autism.
- 30% of Americans aren't sure.



Families with one child with autism are also less likely to vaccinate younger siblings, based almost entirely on their belief of the autism – vaccine connection<sup>9</sup>. However, a study disproved this fear, showing that autism diagnosis did not change by putting children on an alternate MMR schedule.<sup>10</sup> Other factors which may influence the decision to vaccinate are mandates and allowable exemptions. While overall up-to-date vaccine rates are around 95%, almost half of US states dipped below that, endangering those who cannot receive vaccines due to age or preexisting medical issues like leukemia.<sup>11</sup>

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.

### New 4-Step Framework for Communicating Vaccine Science: The CASE Model

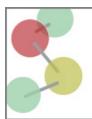
It is important to listen carefully to the concerns parents raise regarding vaccines and autism. They may have heard scary things on TV or from friends, and their fears are very real. It's our job as medical and public health professionals to explain the science in a new way. The **CASE Method** combines emotional

<sup>&</sup>lt;sup>8</sup> "Vaccine-Autism Link: Sound Science or Fraud?" http://www.harrisinteractive.com/newsroom/pressreleases/tabid/446/mid/1506/articleid/674/ctl/readcustom%2 Odefault/default.aspx

<sup>&</sup>lt;sup>9</sup> "Survey of vaccine beliefs and practices among families affected by autism spectrum disorders." https://www.ncbi.nlm.nih.gov/pubmed/22387922

<sup>&</sup>lt;sup>10</sup> Autism Occurrence by MMR Vaccine Status Among US Children With Older Siblings With and Without Autism. http://jamanetwork.com/journals/jama/fullarticle/2275444

<sup>&</sup>lt;sup>11</sup> Vaccination Coverage Among Children in Kindergarten — United States, 2013–14 School Year. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6341a1.htm





and scientific talking points to sway parent's emotional response and help them face the issue more logically.

Keep in mind that parents will evaluate the message and the messenger. It is important to maintain a professional and compassionate tone when discussing vaccines with a parent. They are scared and looking for more information.

#### Next time you have a concerned parent, try the CASE Method:

- <u>Corroborate</u>: Acknowledge the parents' concern and find some points on which you can agree. Set the tone for a respectful, successful talk.
- About Me: Describe what you have done to build your knowledge base and expertise on this issue.
- **Science:** Describe what the science says.
- Explain/Advise: Give your advice to patient, based on the science.

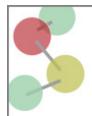


# Examples of how to use the CASE Method with common vaccine concerns:

"I heard on TV that vaccines cause autism"

- **Corroborate**: There's certainly been a lot of coverage on television about vaccines and autism so I can understand why you have questions.
- **About Me**: I always want to make sure I'm up to date on the latest information so that I can do what's best for my patients, so I've researched this thoroughly. In fact, I just returned from a professional conference where we reviewed the data at length.
- Science: The scientific evidence does not support a causal link. The CDC, the AAP, the NIH, the IOM (etc.) all reviewed the data and all reached the same conclusion. Dozens of studies have been done. Here's what we do know about what causes autism....
- Explain/Advise: Vaccines are critical to maintaining health and wellbeing. They
  prevent diseases that cause real harm. Choosing not to vaccinate does not
  protect children for autism, but does leave them open to diseases. Kids need
  these vaccines.



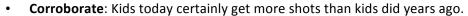


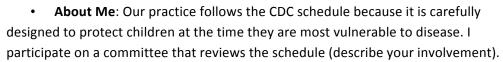


"Measles isn't so bad. I had chicken pox and I was fine."

- Corroborate: I can understand why you might feel that way. I had chicken pox myself.
- **About Me**: Until last year, I had never seen a case of HIB or measles, but now, as vaccine rates decline, these diseases are making a comeback. My colleague in San Diego was telling me about what's going on in CA regarding the whooping cough epidemic.
- **Science**: These diseases have come back in areas where vaccination rates are low. Last year, six children died of HIB and this year in California nine babies have died of pertussis.
- **Explain**: We care about our patients and don't want to practice substandard care. All our patients need to be vaccinated. My own children are fully vaccinated.

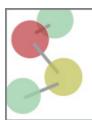
"I want to spread out the shots so they won't overwhelm my child's immune system."





- **Science**: Although kids get more shots today, they actually receive fewer antigens than when they got fewer shots, because technology has enabled us to make vaccines that have only the part of the cell that induces immune response.
- **Explain**: We want all the kids in our practice to be immunized so that they have the greatest chance for a long, healthy life. My own children are fully vaccinated. Science has shown that autism risk is no different if the vaccines are spaced out vs. given together.







### Welcome to 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 that in addition to learning that vaccines **don't** cause autism, 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 allay their fears regarding vaccines.

#### The Types of Autism

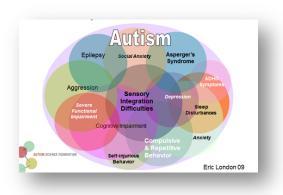
Autism is actually a group of brain-based disorders that affect a person's behavior as well as social and communication skills. These disorders include classic autism, Pervasive Developmental Disorder – Not

Otherwise Specified (PDD-NOS), Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Together these are referred to as Autism Spectrum Disorders.<sup>12</sup> Typically when we talk about autism, we are talking about classic autism, PDD-NOS, and Asperger Syndrome.

#### 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 agression, and comorbidities like sleep issues and epilepsy.

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<sup>&</sup>lt;sup>12</sup> CDC. "Facts about ASDs." <a href="http://www.cdc.gov/ncbddd/autism/facts.html">http://www.cdc.gov/ncbddd/autism/facts.html</a>





#### What Causes Autism?

Scientists have been hard at work looking for the causes of autism and also developing new treatments for autism. We know that 15% of autism is attributable to specific genetic causes, meaning in 15% of children with autism we can identify a genetic abnormality that explains their autism, and that number rises as better genetic technologies are developed. We are discovering that the genes involved in autism are involved in the formation and function of neural synpases. Synapses are the spaces between neurons that enable communication signals to be transmitted through the brain. 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. Several studies have shown that specific drugs are successful in reversing the deficits associated with autism, at least in mice. FDA clinical trials of these drugs in humans are currently underway.

However, genetics are not the only contributor to autism risk. Research has shown an increased risk to certain prenatal, but not postnatal, environmental exposures. For example, prenatal exposure to high levels of air pollution has been consistently linked to autism<sup>13</sup>. Drugs taken during pregnancy, like valproic acid, an anti-epileptic medication, is associated with increased risk<sup>14</sup>. Importantly, getting the flu or other serious infection with a fever doubles the risk of having a child with autism.<sup>15</sup> Most scientists agree that it is the interaction of genes and environment that leads to an autism diagnosis. Many of the neural pathways that these environmental chemicals target are the same as those controlled by the genes associated with autism, leading to a combination of things that influence risk. Vaccines, however, have not been shown to target the signalling from cell to cell, and the way the neurons shape and connect during development.

#### How is Autism Diagnosed?

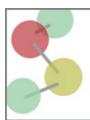
We are able to diagnosis children younger and younger. In some studies, children as young as 6-12 months old show signs and symptoms of autism and later receive a diagnosis (this is well before the infant has received most vaccines).<sup>16</sup> There is also a new, simple screening tool for pediatricians to use

<sup>&</sup>lt;sup>13</sup> A Systematic Review and Meta-Analysis of Multiple Airborne Pollutants and Autism Spectrum Disorder. https://www.ncbi.nlm.nih.gov/pubmed/27653281

<sup>&</sup>lt;sup>14</sup> "Prenatal valproate exposure and risk of autism spectrum disorders and childhood autism." https://www.ncbi.nlm.nih.gov/pubmed/23613074

<sup>&</sup>lt;sup>15</sup> "Autism after infection, febrile episodes, and antibiotic use during pregnancy: an exploratory study". https://www.ncbi.nlm.nih.gov/pubmed/23147969

<sup>&</sup>lt;sup>16</sup> "Early Identification of Autism Spectrum Disorder: Recommendations for Practice and Research. https://www.ncbi.nlm.nih.gov/pubmed/26430168





on all 12 month old babies<sup>17</sup>. The AAP recommends routine screening for autism at 18 and 24 months of age.

### The CDC has listed these Red Flags for Autism<sup>18</sup>

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not respond to name by 12 months
- Does not say single words by 16 months
- Does not say two-word phases on his or her own by 24 months (not repeating)
- Has any loss of any language or social skill at any age



#### 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, 30-50% make enough gains to be mainstreamed by kindergarten. These gains can be sustained for many years after the initial intervention is delivered.<sup>19</sup> It's important to note that Early Intervention programs vary by state so check with your local organizations.

#### **Autism Treatments**

There have been major advances in evidence-based treatments<sup>20</sup>. These are just some that have been tested to be effective. Usually people with autism need a combination of these therapies to succeed:

Applied Behavior Analysis (ABA) Therapy. Besides the typical ABA procedures, several new models based on the theories of ABA have shown to be effective. These include relationship development intervention, pivotal response training, naturalistic behavioral interventions including "Early Start Denver Model" and "JASPER." 22



<sup>&</sup>lt;sup>18</sup> CDC. "Act Early." http://www.cdc.gov/ncbddd/actearly/index.html

<sup>&</sup>lt;sup>22</sup> "Preschool Deployment of Evidence-Based Social Communication Intervention: JASPER in the Classroom." https://www.ncbi.nlm.nih.gov/pubmed/26936161





Parent-mediated social communication therapy for young children with **autism** (PACT): long-term 19 randomised controlled trial. https://www.ncbi.nlm.nih.gov/pubmed/27793431

<sup>&</sup>lt;sup>20</sup> Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder: A Comprehensive Review https://www.ncbi.nlm.nih.gov/pubmed/25578338

<sup>&</sup>lt;sup>21</sup> UC Davis. Early Start Denver Model. http://www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/





- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Social Skills Training
- Video Prompting
- Pharmacological interventions. The FDA has approved Risperdal<sup>23</sup> and Abilify<sup>24</sup> for symptoms associated with autism, but not the core symptoms.

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:

- Camel milk
- Special Diet (Gluten and Casein Free)
- Vitamin Supplements
- Secretin Injections
- Anti-fungal agents
- Chelation
- Giant electromagnets
- Hyberbaric Oxygen Therapy
- Holding Therapy
- Nicotine Patch
- Marijuana (and not for the parent)
- Snake Oil (yes, actual snake oil)



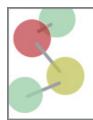
Sometimes parents or the media will report anecdotal evidence that these treatments work. We believe this phenomenon is due to the high placebo effect we see in autism trials. Parents are so eager for a treatment to work that they often report tremendous improvements even for children on placebo.

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<sup>&</sup>lt;sup>23</sup> PubMed Health. http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000944/

<sup>&</sup>lt;sup>24</sup> PubMed Health. http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000221/





#### **Additional Resources:**

Every year, the federal Interagency Autism Coordinating Committee (IACC) writes a strategic plan to guide federal and private spending on autism research. <sup>25</sup> 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 Research, <sup>26</sup> which reports on new findings that have made the most impact on the field.

The following websites are helpful resources.

National Institutes of Health:

- https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml
- https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet

Center for Disease Control and Prevention:

https://www.cdc.gov/ncbddd/autism/index.html

Health Resources and Services Administration:

https://mchb.hrsa.gov/maternal-child-health-initiatives/autism

#### **Autism Science Foundation**

The Autism Science Foundation is a nonprofit organization dedicated to science and evidence. ASF funds autism research directly, and also support families by reinforcing the message that no science currently exists to indicate that vaccines cause autism.

Website: www.autismsciencefoundation.org

Blog: www.autismsciencefoundation.wordpress.com



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https://iacc.hhs.gov/publications/strategic-plan/2013/

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 $<sup>^{25}</sup>$  IACC Strategic Plan for Autism Research – 2013 (currently being updated).

<sup>&</sup>lt;sup>26</sup> IACC. "Summary of Advances in Autism Spectrum Disorder Research." https://iacc.hhs.gov/publications/summary-of-advances/2015/