

# Understanding Autism

Dr. Todd Huffman

McKenzie Pediatrics, P.C.

2010

## Introduction

Public awareness of autism has risen considerably since the turn of the new millennium, largely resulting from increased media coverage, and a rapidly expanding body of scientific knowledge.

Parents and caregivers understandably have many concerns over what they read on the Internet, and hear in the media and from friends. Information on autism abounds, some of it true or partly true, some of it entirely false, and all of it very confusing.

Autism is a congenital perception and information-processing disorder of the brain. The disease is characterized by limited social communication and stereotypical or ritualized behavior. Boys are affected much more frequently than girls.

Autism can be associated with low intelligence, but also with above-average intelligence. Autism and mental retardation can occur together, but also independently of one another and are determined to a great extent by hereditary factors. Some of the responsible genes have already been identified, but the precise genetic mechanisms that lead to autism have not yet been fully explained.

## Diagnosing Autism

Not everything is known about these complex, puzzling, and lifelong disorders – far from it. What is known, though widely unrealized by the public, is that autism is not a singular condition, just as a cold is not a singular condition. Autism is a **spectrum disorder**, with wide variability with respect to the presence and intensity of symptoms.

Although ASDs are complex, biologically-based neurodevelopmental conditions with strong genetic underpinnings that are highly heritable, their exact etiology is unknown. Just as there are hundreds of viruses that cause the common cold, there are many known and doubtless many more unknown causes – most of them genetic – of autism.

In the medical lingo, autism is a *multi-factorial inherited disorder with multiple genetic causes*. At least one autism-linked abnormality has been found on almost every chromosome.

\*\*\*

Just as the symptoms of the common cold are varied and diverse, so, too, are the symptoms and timing of autism. Some children have mild symptoms, others quite severe. Some children show symptoms very early in life, others later, and suddenly.

By definition, autism must show itself by the third birthday. Most autistic spectrum disorders are not even suspected until between age one and three years, when the parents begin to realize that their child is not communicating as expected for their age, and as compared to their peers or older siblings.

Unfortunately, however, the average age at diagnosis remains 4 years, and possibly older in socio-economically disadvantaged groups. This despite that most forms of ASD begin to show during infancy, as retrospective analyses of family home videos often reveals.

\*\*\*

Regrettably, there are as yet no certain biological markers of autism, no blood tests that can determine the presence of autism. And autism does not announce itself in the delivery room.

Instead, doctors diagnose autism using a set of behavioral indicators that have evolved over the six decades since the term “autism” was first applied to childhood disorders of social interaction, by Leo Kanner in 1943. Today, the term actually applies to three diagnostic groups of developmental disability, which doctors refer to as **autism spectrum disorders** (ASDs).

While such grouping implies that each represents a degree of severity of the same entity, there is actually no evidence for this. They might very well have unrelated causes. The idea that autism may not be a single disease but rather several has gathered support in recent years from evidence supplied by magnetic resonance imaging of the brains of autistic children.

### **Basic Features of Autism**

Although the three forms of ASD – Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder not otherwise specified (PDD-NOS) – certainly differ, they share three main features. Children with an ASD have:

- **impairments in social skills**
- **impairments in communication**
- **restricted interests and repetitive behaviors.**

The popular image of autism is strongly colored by an entity called **Asperger Syndrome (AS)**. AS has become a common – perhaps too common – diagnosis assigned to young and often school-aged children who have difficulty relating to their peers.

Unlike classic autistic disorder, people with **AS** often have above-average or even superior intellectual functioning. As children, they show no delays in the development of linguistic and cognitive abilities. People with AS may, in fact, have superior verbal fluency, and they often have strong, though unusually focused intellectual interests.

However, without exception they have impairments in *social* skills. They are not intuitively able to read other people’s feelings, or detect or respond to social cues. This often leads them to become labeled “odd”, or “different” by their teachers, peers, or even their parents.

\*\*\*

By contrast, children with **Autistic Disorder** don’t talk much; when they do, they often talk to themselves, or merely echo what they hear. To varying degrees they are withdrawn and inaccessible, seeming to regard people as unwelcome intruders. Eye contact is infrequent, and parents’ bids for attention are often ignored.

Children with autistic disorder were often described as “easy babies”, content with being alone, needing little attention except when hungry, tired, or soiled. Some autistic children, on the other hand, were described as extremely fussy and irritable as babies, owing to their extreme intolerance to environmental stimuli.

In regards to intelligence, children with autistic disorder vary from the gifted to the severely challenged. They often have an excellent memory, but they lack imagination, choosing to interpret what is said to them concretely.

Children with autistic disorder often play in a repetitive manner. They may demonstrate obsessive-compulsive-like behaviors. They demand that their toys and clothes remain in the same place every day. They commonly do not cope well with transitions, or changes in routine. They are also very intolerant of strong sensory stimuli.

Finally, children with autistic disorder may become aggressive, self-injurious, or resort to self-stimulatory behaviors, which serve to calm them. As a result, these children's socially inappropriate behaviors make it difficult for families to go out in public places.

## Statistics of Autism

Autism spectrum disorders occur in all demographic groups. The disorders know no racial, geographic, or social boundaries.

The CDC's best estimate of the current prevalence of ASDs for 8-year-old children in the United States is approximately **6.6 per 1000**. About one-third of these children have autistic disorder, the remainder some other form of ASD (Asperger Syndrome, or PDD-NOS).

*Prevalence* is a measure of the status or burden of a disorder among a defined population at a particular point in time.

In Canada, ASD prevalence rates are reported as 6.5 per 1000, with the individual rates 2.2 per 1000 for AD, 1.0 per 1000 for AS, and 3.3 per 1000 for PDD-NOS.

\*\*\*

**More boys than girls** are consistently found to be affected with ASDs, with male-to-female ratios ranging from 2:1 to 6.5:1. The male-to-female ratio is even higher for high-functioning autism and AS, ranging from 6:1 to as high as 15:1. **The male predominance also strongly suggests a genetic role in the inheritance of autism.**

ASDs occur more commonly among siblings of an affected child. Estimates of **recurrence risks, based on family studies of idiopathic** (cause unknown) **ASDs are approximately 5-6% (range 2-8%) when there is an older sibling with an ASD** (a 20-fold higher risk than in the general population), and even higher where there are already two children in the family with an ASD.

Another important clue that points to genetic factors underlying autism is the **concordance in identical twins: this is as high as 90%**. The fact that this concordance is not 100% suggests that there are other factors (perhaps environmental) that contribute to the etiology of autism.

\*\*\*

**Advanced paternal and (especially) maternal age have been shown to be associated with an increased risk of having offspring with an ASD**, possibly because of de novo (spontaneous) mutations and/or alterations in genetic imprinting. The risk of an ASD is 1.7 times greater if the mother is age 35 years or older. This lends credence to the theory that autism has a genetic basis. As you get older, your DNA more easily mutates. For example, women who are older are more likely to have children with Down syndrome, which is purely genetic.

Interestingly, the risk of an ASD is 1.8 times greater if the child is a first-born. There is no clear understanding of why this would be.

## Is Autism On The Rise?

It is clear that more cases of autism in recent years are being recognized, but it is not clear whether more cases of autism are actually occurring.

Most experts feel that autism has in fact *not* become more common, that there exists no real "epidemic" of autistic spectrum disorders. Rather, they believe, the "rise" can be explained largely by that physicians are applying the diagnosis far more commonly and correctly than in the past.

In other words, an autism *diagnosis* epidemic indeed exists, but an autism epidemic is not so clearly evident.

In other words, the rising prevalence of autism is believed largely an artifact of the gradual broadening in recent decades of the definition of the disability to include children with milder, more subtle symptoms. Children once described as “quirky” or “unusual” or “eccentric” are today more likely to be diagnosed with an ASD, especially AS. Heightened awareness of autism among parents and doctors has certainly aided this phenomenon.

\*\*\*

The prevalence of autism and, more recently, ASD is closely linked to a history of changing criteria and diagnostic categories. Autism first appeared as a separate entity with specific criteria in the DSM-III in 1980. In 1987, the DSM-III-R listed broadened AD criteria, and the new sub-threshold category of PDD-NOS, both of which promoted inclusion of milder cases. The DSM-IV in 1994 included AS for the first time.

Again, before 1980 there were no standard criteria for autism. Any diagnosis of autism was based on the definition of each individual physician. People now labeled autistic in the past might have been given some other diagnosis. Indeed, a 2008 study found that a surprising number of adults who were diagnosed as children as having developmental language disorders would today be diagnosed as having an ASD.

Similarly, a number of studies have revealed that as autism has “increased” in recent decades, there have been equivalent declines in cases of “non-specific mental retardation”. This is a phenomenon known as **diagnostic substitution**. Children once labeled as “retarded” are now more likely to be given the more specific diagnosis of “autistic”. This is *not* to say that all or even many autistic children are cognitively delayed.

\*\*\*

Researchers hypothesize that increased surveillance and sociological factors also play a significant role, as supported by a 2010 Columbia University study (Berman, Liu, & King). They found that the risk of being diagnosed with an ASD correlated closely with social proximity to another family with a child with an ASD diagnosis.

A child who lives within 250 meters of another child who has been diagnosed with an ASD is 42% more likely to be diagnosed with an ASD than a child living greater than 1000 meters away. Researchers hypothesize that being close to a family with an ASD child provides access to information that allows other parents to more efficiently mobilize their resources to seek an ASD diagnosis.

\*\*\*

It should be noted, however, that the data cannot entirely rule out a small true increase in autism prevalence. It should also be noted that autism prevalence has increased *uniformly* in all age groups; if an environmental cause were at work, affecting young brains, then younger age groups should have disproportionately increased.

One final note: There is also a financial impetus to include children in the wider definition, so that their treatment will be covered by insurance.

### **What About The Department Of Education Statistics?**

Vaccine critics often point to Department of Education data to support their claim that autism rates are rising more quickly than experts have reported.

However, school districts use criteria for “diagnosing” autism that differ from, and are less stringent than, criteria used by medical professionals. This results in flawed data. DoE data unfortunately does not provide anything close to accurate information about the actual prevalence of autism in the school-aged population.

It is also important to understand that Autistic Disorder did not become a diagnosis for which children became eligible to receive special education services until passage of the **Individuals with Disabilities Education Act** (IDEA) in 1990.

IDEA obliged states to administer their programs in the most integrated settings appropriate to the needs to the person with disabilities. Before the IDEA was enacted, children were labeled as having conditions such as MR, learning disability, speech impairment, or emotional disturbance to obtain eligibility for services. After IDEA, children with autism, especially those with co-morbid MR and behavior problems who might have been institutionalized in the past, began to attend community schools and to be “counted” in educational prevalence data.

This again reflects the phenomenon of **diagnostic substitution**, whereby the number of children receiving special education under other categories has *decreased* over the same period that the number of children who’ve been labeled as having an ASD has *increased*. **Which, again, is why educational administrative data should not be considered for epidemiologic studies.**

## Causes of Autism

In discussing etiology (cause), sub-typing ASDs as either **idiopathic** or **secondary** is helpful.

Most individuals with an ASD have the **idiopathic** type, meaning that they do not have a co-morbid medical condition known to cause an ASD. Children with idiopathic ASDs demonstrate variable behavioral phenotypes, are somewhat less likely to have co-morbid Global Developmental Delay and/or Mental Retardation, and generally do *not* have dysmorphic (abnormal physical) features that herald a recognizable syndrome.

The only exception to the general lack of physical signs of an idiopathic ASD is **macrocephaly** (enlarged head circumference), found in 20-30% of children with idiopathic ASDs, and supported by MRI studies showing that 90% of toddlers with an ASD have increased brain volumes. **Children later diagnosed with an ASD have been shown, as a group, to have average or below average head circumference** (also known as occipito-frontal circumference, or OFC) **at birth, with acceleration in brain growth during the first year of life, leading to above-average head circumference, or overt macrocephaly, by late infancy or toddlerhood.**

\*\*\*

Neuropathologic studies of brain tissue from people with autism have revealed several abnormalities throughout the brain. The most consistent neuropathologic findings suggest pathology that arises in utero, as early as 20-24 days after conception.

Environmental exposures may act as central nervous systems teratogens in early gestational life. Because many of the developmental brain abnormalities known to be associated with ASDs occur during the first and second trimesters of pregnancy, environmental factors (eg, teratogens such as **thalidomide** and **valproic acid**) are more likely to play a role in the fetus via maternal factors.

It is also possible that maternal illness (eg, **rubella**) during pregnancy plays a role.

\*\*\*

Regardless of the mechanism, **the evidence is convincing that most cases of ASDs result from interacting genetic factors. However, the expression of the autism gene(s) may be influenced by**

**environmental factors, which may represent a “second-hit” phenomenon that primarily occurs during fetal brain development.**

Put more simply, there may be a genetic susceptibility that interacts, at least in some cases of an autism spectrum disorder, with environmental factors. Said differently, environmental factors may modulate already existing genetic factors responsible for the manifestation of ASDs in individual children.

Bottom line is that over the past few decades of study, it has become more and more apparent that the etiology of ASDs is multi-factorial with a variety of genetic and, to a lesser extent, environmental factors playing a role.

\*\*\*

Evidence is today overwhelming that the cause of autism has a *substantial* genetic component. Scientists are discovering a growing number of complicated genetic abnormalities (mutations) that correlate with susceptibility to autism. Perhaps as many as ten or more genes or chromosomal abnormalities may relate to the various symptoms of autistic spectrum disorders.

It's not like sickle-cell anemia, where a single gene has a single mutation, or cystic fibrosis, where a single gene has many mutations. With ASDs, it appears that at least several genes have varying mutations.

As discussed earlier, evidence clearly shows a high degree of heritability within families. While the overall chance of having a child with an ASD currently stands at 0.6 percent, the chance of having a second child with an ASD – what doctors call the sibling recurrence risk – lies between 15 and 20 percent.

Furthermore, twin studies demonstrate that if one non-identical twin has an ASD, the other will have it also about 10 percent of the time; for identical twins, the chance exceeds 90 percent.

However, the majority of autistic spectrum disorders occur in individuals without a family history of an ASD. Researchers therefore believe that some or many cases of autism are the result of new and spontaneous genetic mutations, but much more remains to be discovered about the genetic basis of autism.

### **Are There Other Causes of Autism?**

This is where things get a bit tricky, especially when it comes to information read on the Internet, or heard on the morning talk shows or from friends and acquaintances. It must be remembered that autism is not a singular thing. It is a **spectrum** – in other words, there are a wide range of symptoms or features of autism, and each of these features may range from mild to severe.

The diagnostic criteria for autistic spectrum disorders cast such a wide net that many children with other primary medical conditions or diseases that have developmental consequences, or lead to developmental regression, will be labeled as “autistic”, when in fact “autism” is not their primary disease, rather a consequence of their primary disease.

Confused? Even physicians get it a bit mixed up.

To put it a different way, **some children (less than 10% of children with ASDs) early in childhood begin to show genetic syndromes or develop diseases, sometimes suddenly, that affect their development in such a way that it is slowed, stopped, or caused to regress.** The resulting developmental disabilities can sometimes then fit into the criteria of one of the autistic spectrum disorders, and the child is labeled “autistic”.

While in a sense they are “autistic”, nonetheless autism is not their underlying condition. Rather, the child has a sort of “**secondary autism**”, if you will.

Conditions known to predispose children to developmental disabilities that meet diagnostic criteria for an ASD include epilepsy, Fragile X Syndrome, Inborn Errors of Metabolism, Rett Syndrome, Childhood Disintegrative Disorder, Tuberous Sclerosis, Prader-Willi Syndrome, Angelman Syndrome, severe lead poisoning, congenital rubella, and rare disorders of mitochondrial function, among others.

### Neurogenetic Syndromes Associated With ASDs

- Fragile X; most common known genetic cause of AD and of MR in males. The phenotype includes MR, macrocephaly, large pinnae, large testicles (particularly after puberty), hypotonia, and joint hyperextensibility. Approximately 3-4% of children with an ASD have Fragile X, and 30-50% of children with Fragile X have an ASD.
- Tuberous Sclerosis
- Phenylketonuria
- Fetal Alcohol Syndrome
- Angelman Syndrome: (15q deletion)
- Rett Syndrome; should be considered in all females with autistic-like regression, especially if they have microcephaly, seizures, and hand-wringing stereotypies. Confirmed by DNA testing in 80% of cases. Much less common in males, where it may be comorbid with Klinefelter Syndrome.
- Smith-Lemli-Opitz Syndrome: auto-recessive, 1:20000, metabolic error in cholesterol biosynthesis, usually presents with multiple congenital anomalies/FTT/MR
- Down Syndrome: 6-7% of children with Down Syndrome meet criteria for one of the ASDs
- CHARGE Syndrome: 50% meet criteria for one of the ASDs

**Epilepsy** – which is another catch-all word, like “autism” – is a common, and under-recognized, cause of developmental disability. There are many types of epilepsy, otherwise known as seizure disorders, which are disruptions of the electrical activity of the brain. The peak age at which epilepsy develops is early childhood, the same time of life when autism is diagnosed.

Many children with epilepsy do not have the classic jerking that everyone thinks of when thinking of a seizure. Many seizure disorders are “sub-clinical”, meaning that they are difficult to recognize without electroencephalographic testing (an EEG).

Doctors know that as many as *one-third* of children diagnosed with autistic disorder have an abnormal EEG. What we don't know is how many children diagnosed with an ASD actually have a “secondary autism”, secondary to a seizure disorder. More remains to be learned about this connection.

### Do Vaccines Cause Autism?

In a word, no. The notion that vaccines cause autism has been clearly and soundly disproved. Still, the issue is reported in the media and across the Internet as a controversy.

It is understandable why parents might think vaccines create autism. Autism symptoms are usually first noticed between the ages of 12 months and 3 years. Of course, these are about the same ages when children receive a number of vaccines, though most are received before the first birthday.

In addition, we give many more vaccines to infants and toddlers now than we did in the past, though the number of **antigenic particles** – germ particles stimulating an antibody response – is a *tiny fraction* of the number of even three decades ago.

In 2004, the Institutes of Medicine – a branch of the non-partisan and non-governmental National Academy of Sciences – released a report concluding that no evidence exist linking vaccines with the development of autism. Since 2004, the evidence against such a link has become even more overwhelming.

Therefore the continuing public “controversy”, in the face of overwhelming scientific evidence from over 200 scientific, peer-reviewed, reproducible studies from more than a dozen different countries, must be considered an intentional misinformation campaign.

### **Don't All Those Vaccines Overwhelm The Immune System?**

Viruses are made of proteins. Larger viruses contain more proteins than do smaller viruses. Smallpox, one of humankind's largest viruses, contains about 200 proteins. Children a century ago who received inoculations against smallpox therefore received 200 challenges to their immune systems.

By contrast, the measles, mumps, and rubella viruses are quite small, containing ten, nine, and five proteins, respectively, for a total of 24 challenges. Small potatoes compared to smallpox.

Today, upon completion of a series of fourteen different vaccines, children have been exposed to a sum total of 177 germ proteins, less than if they were exposed to a single smallpox virus! Even as recently as the 1960s, when vaccines were not nearly as purified as they are today, there were over 3200 germ proteins given children between just five vaccines (smallpox, diphtheria, tetanus, pertussis, and polio).

If immune system overload were the cause of autism, with far fewer immunologic challenges in modern vaccines, shouldn't we be seeing the rates of autism decreasing, not increasing? **The notion of “immune overload” simply is not valid scientifically.**

One more surprising fact: the human body's immune system fights off an average of 10,000 germs **every day**. With each of those germs having many proteins, the total number of daily immunologic challenges likely exceeds 100,000!

Rest assured that your child's body is up to the challenge of handling the sum total of 177 germ proteins spread out over the first twelve years of life. Vaccines given in the first two years of life are a raindrop in the ocean of what infants' immune systems successfully encounter in their environment every day.

### **What About Thimerosal?**

Thimerosal (sodium ethylmercury thiosalicylate; a.k.a. Methiolate) is an organic mercury-containing preservative that was used from the 1940s until 2001 as an additive to vaccines. It was very effective at preventing bacterial and fungal contamination, which was especially important for multi-dose vials entered and re-entered by medical professionals.

It is still found today in many other medications and products, including some throat and nose sprays, and some brands of contact lens solution.

Interestingly, before the reduction of thimerosal in the United States, the maximum allowable exposure for infants, as set by the FDA, was 187.5 micrograms; the most thimerosal that children would receive in getting their entire complement of childhood vaccinations was 137.5 micrograms.

Many routinely recommended childhood vaccines have never contained thimerosal, including the MMR (measles-mumps-rubella) vaccine, IPV (inactivated polio vaccine), the varicella (chickenpox) vaccine, and the pneumococcal (Prevnar) vaccine. Some brands of Haemophilus influenzae type b (Hib) and diphtheria-tetanus-pertussis (DTaP) vaccines also have never contained thimerosal as a preservative.

Despite years of study in the U.S. and in countries from around the globe, there has been found no evidence of a link between thimerosal in vaccines, and autistic spectrum disorders. Even still, as a precautionary



measure thimerosal was removed in 2001 from all routinely recommended vaccines manufactured for administration to infants in the U.S.

The last batches of thimerosal-containing vaccines expired in January 2003.

**Despite that thimerosal has disappeared, autism remains.** Since 2003 the number of cases of children with autistic spectrum disorders has continued to rise. No better proof of the lack of a link between thimerosal and autism could indeed exist.

Consider this: If cars are an important cause of auto-related deaths, removing them from the highway ought to significantly decrease them. If thimerosal was a strong driver of autism rates, removing it from vaccines ought similarly to result in a significant decrease in autistic spectrum disorders. It has not.

\*\*\*

As it was, the thimerosal-autism link never made much sense to scientists. Thimerosal contains ethyl mercury, which is different from the *methyl* mercury that we all think of when we think of “mercury”. If the addition of a single consonant seems to matter little, consider the headaches and hangovers caused by the ethyl alcohol contained in beer and wine, and the blindness and death caused by methyl alcohol, otherwise known as wood alcohol.

These two forms of natural mercury differ greatly. Ethyl mercury decomposes much more quickly than methyl mercury. It is cleared from the body seven times faster. And it is too large a molecule to easily pass into the brain, whereas methyl mercury passes with much less difficulty.

In (methyl) mercury poisoning, the characteristic motor findings are ataxia (inability to walk) and dysarthria (difficulty with speech), along with tremors, muscle spasms and pain, and weakness. Autism has no motor findings in common with mercury poisoning; in fact, no motor findings are common among autistic spectrum disorders, excepting occasional clumsiness and low muscle tone.

Methyl mercury poisoning also causes a classic constriction of the victim’s vision. Victims also suffer from peripheral neuropathy, causing pain and numbness in the hands and feet. Skin eruptions are common, as is a very low platelet count. The victim’s kidneys and the immune system can also be damaged.

None of these symptoms are known in autistics, and none of these organ systems are affected.

We are right to worry about mercury. Methyl mercury exists in too high an amount in some types of fish, and ingesting too much mercury can cause permanent brain and organ damage. But parents should be reassured that autism was not caused by exposure to the low amounts of ethyl mercury in vaccinations. All children, including siblings of autistic children, should be vaccinated, as there is absolutely no evidence of mercury poisoning in children.

### **What About The MMR Vaccine?**

In 1998, a British physician by the name of Andrew Wakefield joined twelve co-authors in publishing a report in the British medical journal *The Lancet* describing twelve children with an ASD and gastrointestinal symptoms. In eight cases, parents reported that the symptoms began within two weeks after the children received the MMR vaccine.

Wakefield and his colleagues hypothesized that this might be a *new type* of autism, characterized by gastrointestinal symptoms and developmental regression caused by the MMR vaccine. No proof was offered of a link, and the study group was so small as to be almost meaningless. Nevertheless, the news media picked up the title of the report (“Vaccine may trigger disease linked to autism”), and the rest, as they say, is history.

\*\*\*

Many have heard some version of this basic storyline: Hero physician finds that autism is linked to a vaccination, and is blacklisted by the medical profession for daring to report it. Most, however, do not know what happened next.

In 2004, ten of Wakefield's co-authors formally retracted their hypothesis, assuring the public that no link between MMR and autism was established.

In January 2010, the General Medical Council (GMC), which oversees doctors in Britain, found that Wakefield "showed a callous disregard" for the "distress and pain" of children, and found that in regards to his study his "conduct...was dishonest and irresponsible. In total, he was found guilty of more than 30 charges.

In February 2010, The Lancet formally retracted Wakefield's controversial paper. Dr. Richard Horton, editor of The Lancet, said in retracting the paper that "it's the most appalling catalog and litany of some of the most terrible behavior in any research and is therefore very clear that it has to be retracted."

Dr. Paul Offit, a world-renowned authority on the science of vaccines, and author of *Autism's False Prophets*, said it best after The Lancet's retraction: "[The Lancet retraction] was too little, too late. Wakefield's study gave birth to the notion that vaccines causes autism. And it was wrong. But it's hard to close Pandora's Box once you've opened it. It's hard to unscare people once they're scared. The paper should never have been published. It has causes people to refuse vaccines, to be hospitalized for vaccine-preventable diseases, to die from those diseases. They've retracted it because the information was fraudulent, but the retraction won't bring those children back."

In a different interview, Offit said: "The Lancet published a hypothesis that was unsupported and has since been disproven by careful scientific study. But there is no undoing the harm of that original paper. Many parents abandoned the MMR vaccine. As a consequence, hundreds of children were hospitalized and four were killed by measles. This retraction will do nothing to change that."

Harsh, but true words.

To make matters worse, Wakefield was found prior to his "study" to have taken over \$1 million from a personal-injury lawyer representing parents with children diagnosed with an ASD. Wakefield has since joined a fringe religious group in the United States that pushes scientifically ridiculous therapies for autism.

\*\*\*

In 2010, the British GMC found Dr. Wakefield "guilty of serious professional misconduct"; he was stripped of his medical license on May 24, 2010.

Wakefield's sins: 1) falsification of data; 2) fraudulent methodology; 3) did not get his study approved by an ethics committee before carrying it out; 4) cherry-picked his child subjects, from a birthday party, paying them to participate, and 5) did not disclose his relationship with attorneys involved in suing on vaccine-based claims.

Yet as a result of Wakefield's claim, the MMR scare attracted so much media attention that MMR immunization rates fell in a number of countries, leading to subsequent outbreaks of mumps and measles in Great Britain, Germany, Switzerland, and the U.S. Hundreds have been hospitalized, and up to a dozen deaths from measles have been reported.

\*\*\*

Like the claim against thimerosal, Wakefield's claim against the MMR vaccine made little intuitive sense to scientists and doctors. After all, autism rates in the United Kingdom had already been on the rise prior to the introduction of the MMR vaccine in 1988.

His claim that the virus in the vaccine caused injury to the gut, allowing proteins to pass into the bloodstream that then harmed the brain, could never be demonstrated, despite many tests on the brain and spinal fluid of autistic children. And study upon study – from locales as diverse as the UK, Finland, California, Georgia, Denmark, and Japan – has confirmed that the rate of autism is the same in populations of children having received and having not received the MMR vaccine.

Besides, if the administration of the MMR vaccine led to the development of an ASD, why is it that in not one of the very many countries where MMR is given to children are we seeing an epidemic of autism occurring in four and five year-olds after receiving their second MMR vaccination?

In the United Kingdom, MMR vaccination rates dramatically fell to 81% in the years after Wakefield's fraudulent "study" was published, and are only now beginning to increase. Rates need to be consistently above 95% to create "herd immunity". Meanwhile, measles cases in England and Wales rose steadily through 2008, affecting as many as 1400 children annually, before slightly falling in 2009. As many as a dozen children whose parents elected not to immunize them against measles have died as a result.

Study after study has exonerated MMR. The notion that MMR causes autism has had its day in scientific court. More than 20 subsequent studies from around the globe have been conducted since Wakefield's paper – ALL consistently found no link. There is no "controversy".

For more information, read online the excellent articles by Brian Deer published in the British Medical Journal (5 January 2011) and by Susan Dominus published in the New York Times Magazine (20 April 2011).

### **What If There Is A Conspiracy To Hide The Truth?**

There exists no vast international conspiracy to hide the "truth" about vaccines.

Ponder the ridiculousness of it: hundreds of thousands of public health scientists, academic researchers, medical journal editors, pediatricians, and family physicians the world over in league with vaccine manufacturers foreign and domestic, not to mention agencies of the United States government (the CDC, and FDA), to hide from parents and the public at large evidence of having collectively inflicted a devastating disease upon millions of children, children whose welfare these professionals have otherwise devoted their lives to protect.

Ponder further the ludicrous notion that of a vast, secret, corrupt international cabal of hundreds of thousands of individuals joined year upon year in absolute solidarity, maintaining a leak-free silence over the terrible secret they share. These same conspirators are even so devious as to knowingly give these dangerous vaccines to their own children and grandchildren, as part of a grand scheme to convince the public of their safety.

Preposterous, wouldn't you agree? If the link between vaccines and autism were not necessarily proven, but at least strongly suggested, there would be reason to reconsider how and when we vaccinate children. No true advocate for children would think otherwise. But the science simply is not there.

Look at it from another perspective: the business perspective. Vaccine administration is not always cost-effective for pediatricians, especially those who are in smaller practices. In fact, from a purely business standpoint, vaccines don't make much sense at all – administration is often poorly reimbursed, and vaccines *prevent* infections and the resulting income-generating outpatient visits and hospitalizations that would go along with them!

## Why Do Fears About Vaccines Causing Autism Persist?

Despite the singular, consistent, reproducible, and clear results of hundreds of studies from around the globe, many parents remain fearful of vaccines. Even as science the world over has dismissed it, the idea of a vaccine-autism link continues to gain cultural currency.

Why? The first answer: **the media**, which has as its primary motivation to sell advertising to earn profit, which happens most lucratively when media entertains, and creates controversy to heighten interest in its products. It doesn't hurt that ours is a culture dominated by cynicism and hungry for scandal.

What makes an interesting television program may not, of course, be the same as what makes good science. Media reporting often highlights the fantastical, making it seem commonplace when in fact it may be rare, or even nonexistent. The media are experts at distorting the ability of viewers to engage in accurate risk assessment.

The media also keeps the vaccine-autism myth alive by following the journalistic mantra of "balance", by perpetually presenting two sides of an issue even when only one side is supported by the science, and even long after one side has been discredited. Even then, the media does not often achieve the balance it supposedly desires, as evidenced by programs that feature vaccine opponents without equally featuring scientific experts.

We must avoid the false balancing that derails much of what passes for reporting these days. Truth is not a matter of popular vote, and it is disingenuous to offer so-called "balance" reporting by virtue of presenting "he-said, she-said" summaries.

\*\*\*

The next answer to the question of why vaccine fears persist: **the alliance of fringe scientists, personal-injury lawyers, and well-intentioned but ill-informed advocacy groups, politicians, and celebrities**. All are given a platform by the media, and by talk-shows and prime-time "news" programs in particular. Scientists, on the other hand, are not.

Due to the vocal nature of this alliance, parents are being coerced and confused into questioning the safety of vaccines based on flimsy, irreproducible science. The incessant scaremongering is to some degree intentional, launched and maintained by media-relations firms hired by personal-injury lawyers as well as some advocacy groups. They know that it is much easier to scare someone than to unscare them.

Personal-injury lawyers, in particular, are out to dent public confidence in immunizations. After all, it's good for their business. An illustration in fact: most reports of "autism" to the government's voluntary vaccine side-effect reporting system (VAERS) haven't come from doctors, nurses, or nurse practitioners; most have come from personal-injury lawyers! Lawyers are manipulating this system to show "increases" in autism that are based on litigation, not on health research.

\*\*\*

To the vast majority of lay people who are parents, the science of medicine and vaccines and the immune system is hard to understand, and the anti-vaccine movement has, more or less successfully, framed the issue as "big pharma" protecting its interests, and a conflict between "brave maverick" doctors against government and the global medical community.

It is difficult communicating science to a public that is unfortunately more easily convinced by fear, and a desire to find a unifying cause for autism, than by science and reason. It is also difficult to reassure a public that has trouble distinguishing cause from coincidence, and understanding that temporal association alone does not imply causation.

We all hear stories, most of them twisted with the telling and re-telling, about an individual who developed some sort of medical problem just after vaccination. We almost never hear about the millions upon millions

of children who were vaccinated but had nothing bad happen to them. From the public perspective, these success stories are simply not newsworthy. From the scientific perspective, they are essential.

Science will ultimately uncover the causes of autism, and perhaps even find means for preventing some number of those causes, but in the meantime doctors and scientists will have to become better at explaining the science that excludes vaccines as one of these causes. Simply relating the facts of science isn't enough, no matter the overwhelming weight of evidence that shows that vaccines don't cause autism. When scientists find themselves just one more voice in a sea of "opinions" about a complex scientific issue, misinformation takes on a life of its own.

\*\*\*

And science alone will not convince some parents. Distrust of vaccines is part of a broader cultural trend that favors "science by consensus" – if many people make the same claim, it must be true.

Unfortunately, modern technology has made it difficult to determine exactly how many people are in the crowd. Near universal access to the Internet and other social media has made it surprisingly easy to find stories of children who were completely normal until they were vaccinated. Given that most children in the U.S. are completely vaccinated, any adverse event that occurs in the first year to eighteen months of life is likely to occur within weeks of a vaccination.

But let's put this into perspective. For instance, if 10 million women are given a vaccine, 86 will develop optic neuritis in the next 6 weeks. If all 10 million are pregnant, 16,684, will have a spontaneous abortion. All of this is true – even if the shot is a placebo. This illustrates two things. First, as epidemiologists know but the public may not, sequence does not mean consequence. More importantly, as human beings, we have trouble grasping the big numerical picture – it is more natural to assume a relationship with the shot than to contemplate thousands of lost pregnancies caused by chance alone, or to something other than the shot.

\*\*\*

Sharon Kaufman, a professor of medical anthropology at the University of California, San Francisco, makes a life's work out of studying trends related to health and aging. She has spent years examining the vaccine-autism controversy, interested in understanding how cultural factors shape issues of trust, risk, and responsibility as they relate to science.

Kaufman sees the persistence of the vaccine-autism theory as a consequence of how individuals manage risk in modern society. People must trust experts to protect them from risk, whether they're getting on an airplane or vaccinating their kids, she explains. When faith in experts erodes, personal responsibility prevails. "People think if you blindly follow experts, you're not taking personal responsibility," she says.

\*\*\*

The final answer to the question of why vaccine fears persist: **the Internet**, where no view is too outrageous to masquerade as fact.

Parents who say they've "done their research" mean they've perused a number of web sites on the Internet. But that's not research. Information on the Internet is typically unfiltered – anyone can say anything, and health advice can be terribly misleading.

Because of the Internet, everyone is an expert, or no one is. As a consequence, there is no "truth" as defined by experts. Rather, there are many opinions misrepresented and misinterpreted as truth. It doesn't help that people are far more likely to be swayed by a personal, emotion experience they read on the Internet (or see on television) than by results of large epidemiological and scientifically reproducible studies.

Consider this: if you are having trouble with your car, you do not take to the Internet to study motor engineering. You take your car to a garage and ask a mechanic to repair it. In a similar way, we put our trust in numerous people we encounter in our everyday lives. If we did not, society would collapse.

Which is why it is all the more peculiar our selective withdrawal of trust from medical professionals. For many parents, the advice given by their child's pediatrician or family physician about vaccines is just one more opinion in a sea of opinions offered on the Internet.

### **Is Autism Treatable?**

While autism diagnoses have soared, valid treatments are few. The prognosis for truly normal function is guarded, even with early and intensive therapy. **Behavioral therapy** is the mainstay of therapy. Behavioral therapy uses imitation, repetition, and frequent feedback to teach children appropriate behaviors.

Although these programs can help, they are laborious and tedious, and progress is typically torturously slow. Worse, they can be quite expensive, and are often not covered by medical insurance. Or therapy may not be close by for parents.

Since standard therapies require much time to see progress, some parents understandably may be willing to grasp at the promise of a "quick fix". They succumb to the common, understandable desire to find something – anything – that might help.

Which is why there exists a prolific cottage industry of unnecessary tests, lucrative consulting fees, and scientifically unproven and potentially harmful therapies. Snake-oil salesmen litter the Web, selling untested treatments that are combine pseudoscience and fraud.

In other words, **a cottage industry of false hope.**

As many as 75% of autistic children are receiving alternative treatments, most or all of which are bogus, even risky. Parents want to believe these therapies work because they desperately want their children to get better. They don't want to watch them struggle anymore. They're tired of the glacial pace of medical research, tired of slogging through endless hours of behavioral therapy, and tired of watching their child improve at rates so slow it's difficult to tell whether they're improving at all. They want something new, something now; something that will immediately release them from the prison of autism.

And so they turn to scientifically unsupported "biomedical" therapies:

- elimination diets (Feingold diet, gluten- and casein-free diets, the ketogenic diet)
- secretin therapy
- vitamins and supplements (Vitamins A, B6, B12, and C; folate; magnesium; omega-3-fatty acids)
- famotidine (Pepcid) for undiagnosed GERD
- hyperbaric oxygen chambers
- Lupron
- OSR#1 (a toxic unapproved drug marketed as a harmless dietary supplement for autistic children)
- and/or heavy metal "cleansing" (chelation therapy, which is potentially dangerous and may even cause death).

But what is most baffling to child health professionals is that the same parents who are skeptical of the scientists and public health officials who "failed" to find that vaccines "cause autism" haven't been similarly skeptical of this vast array of autism "therapies", all of which are claimed to work, and all of which are based on theories that are ill-founded, poorly-conceived, contradictory, or disproved. Most every alternative autism therapy has not been tested for safety or efficacy in autism

### **A Final Word: The Omnibus Autism Proceeding**

In the U.S., because of rising litigation that jeopardized the vaccine program and threatened to drive pharmaceutical companies out of the vaccine business, Congress passed the National Childhood Vaccine Injury Act of 1986 (Public Law 99-660), which created the National Vaccine Injury Compensation Program (VICP).

The idea was to create an alternative to the tort system through which people injured by vaccines could be efficiently compensated. Vaccine litigants, if denied compensation, could still sue in conventional courts, but all claims for compensation had to go first through the VICP.

Beginning in 2001, parents, with the assistance of a blooming cottage industry of personal-injury lawyers, began filing petitions with the Secretary of Health and Human Services under the Vaccine Injury Compensation Program (VICIP), for compensation for harm to their children from vaccines. Parents were alleging that certain childhood vaccinations might be causing or contributing to autistic spectrum disorder.

Specifically, it was alleged that cases of autism, or neuro-developmental disorders similar to autism, may be caused by the MMR vaccination, by thimerosal, or by some combination of the two.

As the number of litigants claiming that vaccines caused their children's autism ballooned to close to 5000, threatening to bankrupt the VICP unless massive infusions of new money from Congress were provided, the Office of Special Masters (OSM) of the U.S. Court of Federal Claims held a series of meetings in mid-2002, resulting in its issuance of Autism General Order #1 in July 2002, in which the OSM established the procedure for addressing the Omnibus Autism Proceeding (OAP).

As part of this proceeding, litigants were to choose what they considered to be the best cases representing their hypothesis of causation by which vaccines could produce autism and other neurodevelopmental disorders. The court would hear these cases, make rulings, and then these rulings would be used as the basis for all similar cases that would follow.

In the end, over 5300 cases alleging a causal relationship between such vaccinations and autism disorders were filed in the Program. The first evidentiary hearing for test cases was held in June 2007, then again in October and November 2007. Final hearings were held in July 2008.

\*\*\*

The first decision was rendered in February 2009. In all three test cases in which a link between the MMR vaccine and autism was accused, despite the "best" that the anti-vaccine litigants could throw at the courts the Special Masters decisively rejected all three hypotheses of causation.

In a 174-page decision, Special Master George Hastings rejected all of Petitioners' contentions, observing that "this case is not a close case. The overall weight of the evidence is overwhelmingly contrary to the petitioners' causation theories." A more emphatic refutation is hard to imagine.

Regarding some 23 expert witnesses who testified or submitted reports, Special Master Hastings stated that "[t]he 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 Special Master concluded, "the petitioners have . . . failed to demonstrate that vaccinations played any role at all in causing problems."

A Federal Appeals Court upheld the rulings in August 2009, stating that "...Petitioners' arguments linking injuries to thimerosal and the MMR vaccine are without merit. Accordingly, the Court affirms the Special Master's February 12, 2009 decision."

And then, in a further blow to the anti-vaccine movement, the three Special Masters ruled in March 2010 in three separate cases that thimerosal does not cause autism. Groups of organizations that believe vaccines cause autism expectedly dismissed the rulings, believing the Special Masters, as government judges, to not be impartial.

### **Where Can I Find More and Reliable Information?**

- Cambridge Center for Behavioral Studies ([www.behavior.org/autism](http://www.behavior.org/autism))
- Asperger's Disorder Homepage ([www.aspergers.com](http://www.aspergers.com))
- Autism Asperger Publishing ([www.asperger.net](http://www.asperger.net))
- Autism Cares ([www.autismcares.org](http://www.autismcares.org))
- Autism Education Foundation ([www.autismlessons.org](http://www.autismlessons.org))
- The Autism Research Institute ([www.autism.org](http://www.autism.org))
- The Autism Society of America ([www.autism-society.org](http://www.autism-society.org))
- Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org))
- CDC Autism Information Center ([www.cdc.gov/ncbddd/autism](http://www.cdc.gov/ncbddd/autism))