

Communicating With Parents About Autism and Vaccination: *10 Tips*

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2009 National Immunization Survey

For recommended childhood vaccines...(one or more doses)	Proportion of parents
Neither delayed nor refused	60.2%
Only delayed	25.8%
Only refused	8.2%
Both delayed and refused	5.8%

Sources of dissatisfaction

Even with very detailed explanations,
parents who
feel they are **not treated with respect** or
have **unrecognized or unaddressed fears**
feel **unhappy** about the amount of
information provided.

Jenny McCarthy on Rosie's Show



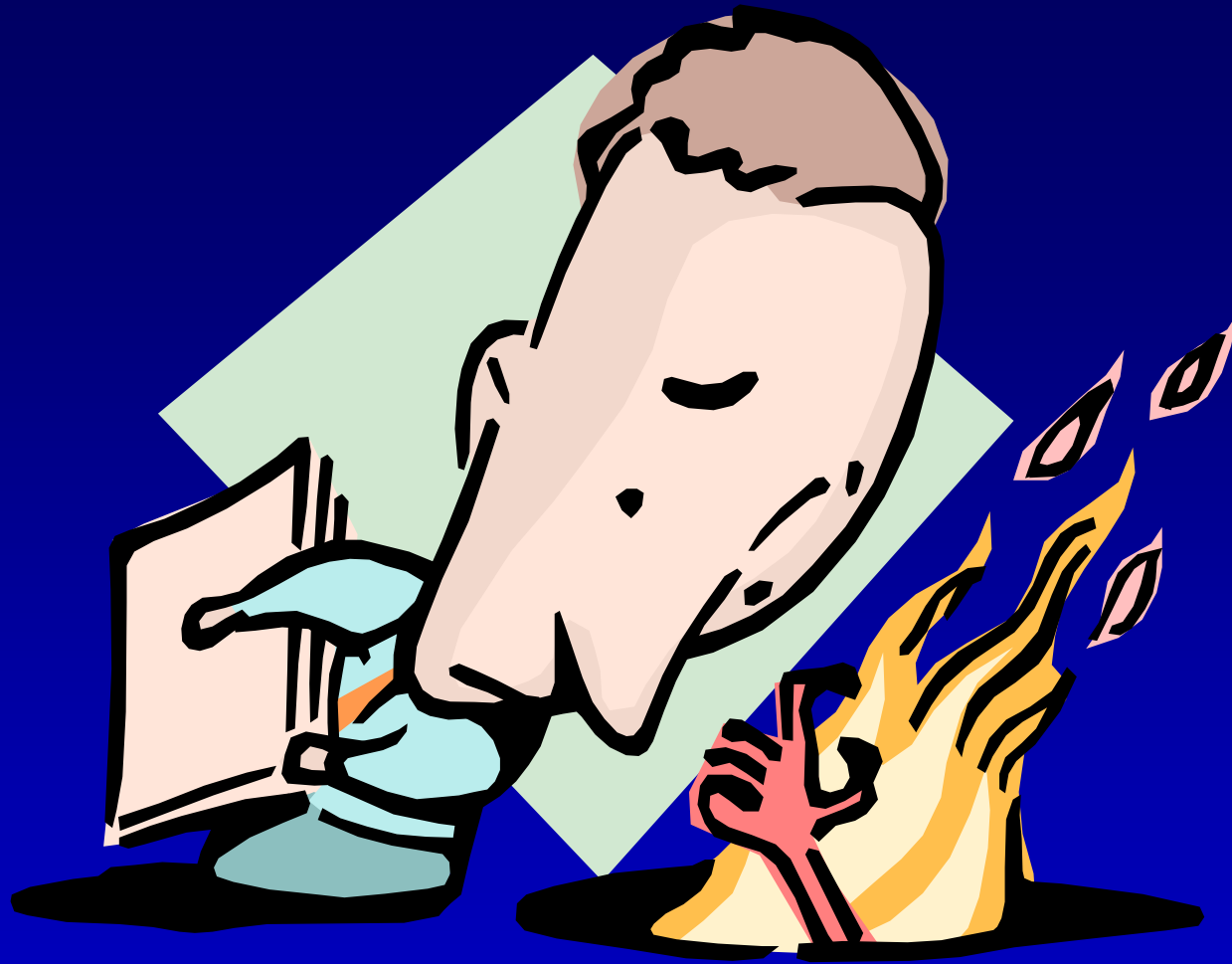
Learning Objectives

- Discuss 10 tips for communicating about vaccines with parents who are unsure
- Review the C.A.S.E. method for communicating
- Highlight great tools for getting more information



Tip #1. All it takes is perfection

It's hard to communicate well when you are stressed, tired, etc. The tips I'm sharing are *aspirations*!



These are my confessions:

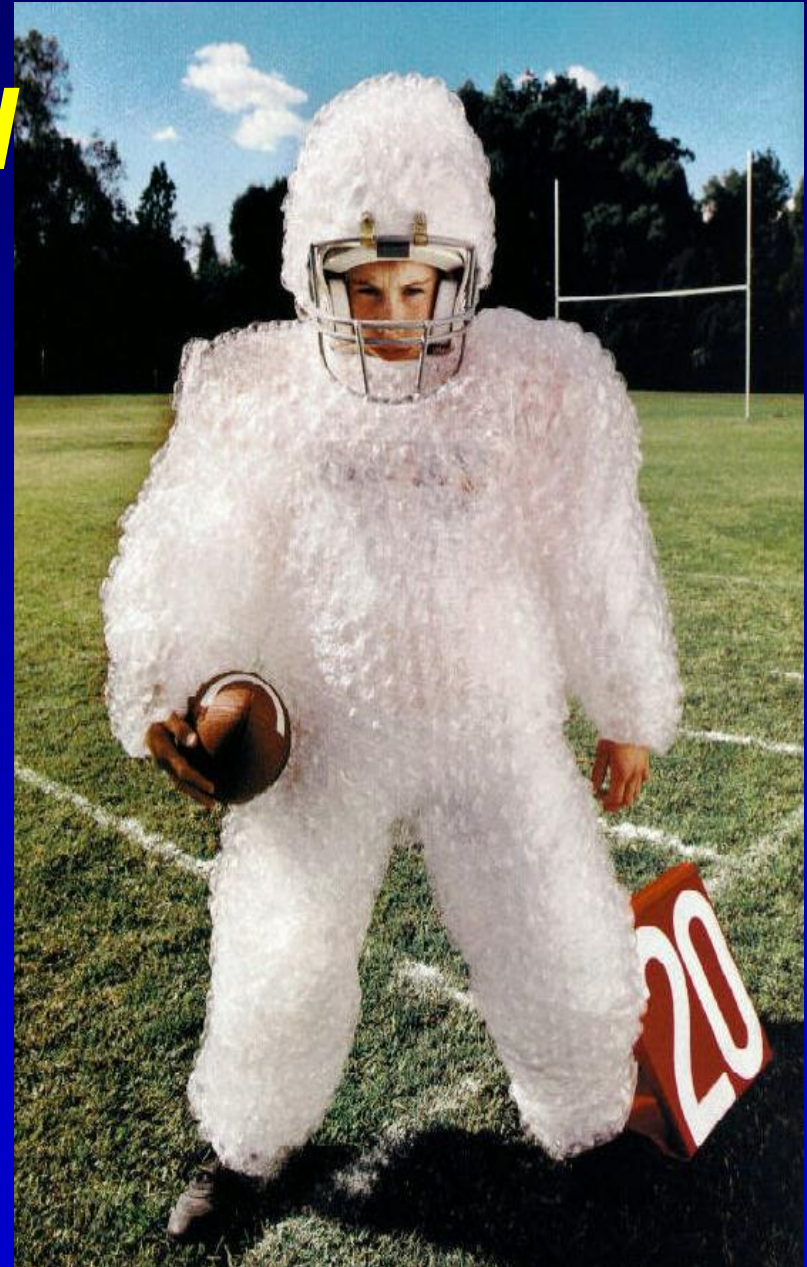
I am not a great communicator. Many days (or parts of days) I find relationships to be a strain.

Tip #2-Good communication starts with listening

- *Listen* with curiosity & non-judgmental attitude
- Put aside our motivation to seem smart, “be right”, “win”
- Check for what they believe now
- Hear the fear



**Remember what we *all*
want for our children:**



Humiston's 2nd Brain Theory



AKA the Parent Brain Theory

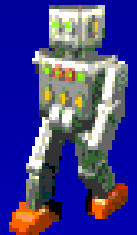


Tip #3-One size *communication* does not fit all

- Mailed survey of U.S. parents in January 2001
- 90% of parents (n=1820) were classified into a of distinct parent groups:
 1. **Vaccine Believer** parents who were convinced of the benefit of vaccination
 2. **Cautious** parents noteworthy for a high emotional investment in their child
 3. **Relaxed** parents characterized by a less involved parenting style and some skepticism about vaccines
 4. **Unconvinced** parents distinguished by distrust of vaccinations and vaccination policy

Tip #4-Let them know you care

- Factors predictive of **effective communication** between providers and patients/parents are the perception of interest, caring, warmth, and responsiveness
- Parents' **most frequent criticisms** of health care practices concern relationships with practitioners
- These relationships have a dramatic effect on parental **satisfaction, recall of instructions and treatment adherence**
- Greater trust and a better relationship with the provider have more of an effect on **patient recall and satisfaction** than written instructions or even the amount of time spent



In the past, 1 element of doctor-parent-child communication was recognized

- **Informativeness**: quantity and quality of health info provided

The 3 elements of doctor-parent-child communication

- **Informativeness**: quantity and quality of health info provided
- **Interpersonal sensitivity**: affective behaviors that reflect the provider's attention to, and interest in, the parents' and child's feelings & concerns
- **Partnership building**: extent to which the provider invites parents (and child) to state their concerns, perspectives, and suggestions during the consultation

New 4-step Framework for Communicating Science: Making the CASE for Vaccines

- **C**orroborate: Acknowledge the parents' concern and find some point on which you can agree. Set the tone for a respectful, successful talk.
- **A**bout Me: Describe what you have done to build your knowledge base and expertise
- **S**cience: Describe what the science says
- **E**xplain/Advise: Give your advice to patient, based on the science

<http://blip.tv/public-health-live/making-the-case-for-vaccine-safety-a-new-model-for-communicating-with-parents-4569317>
Minute 14:45 to 22:30



Tip #5-Be prepared

Vaccine Concerns

See <http://www.immunize.org/concerns/>

Responding to Questions and Concerns about Vaccines – Resources for Health Professionals

http://www.immunize.org/concerns/ IAC Vaccine Concerns

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IAC Resources

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Talking About Vaccines

Responding to Concerns About Vaccines

The purpose of this section is to provide medical professionals with background information and practical resources that will help them discuss immunization with concerned parents or patients. Because people question vaccination for different reasons, we have divided this section into different topics.

Talking About Vaccines

- [Importance of Vaccine](#)
- [Talking with Parents](#)
- [Vaccine Safety](#)

Vaccine Concerns

Adjuvants & Ingredients	Responding to Dr. Sears' Alternative Schedule	Mitochondrial Disorders
Alternative Medicine	Measles, Mumps, Rubella (MMR)	Religious Concerns
Autism	Multiple Injections	Thimerosal

IAC Resources

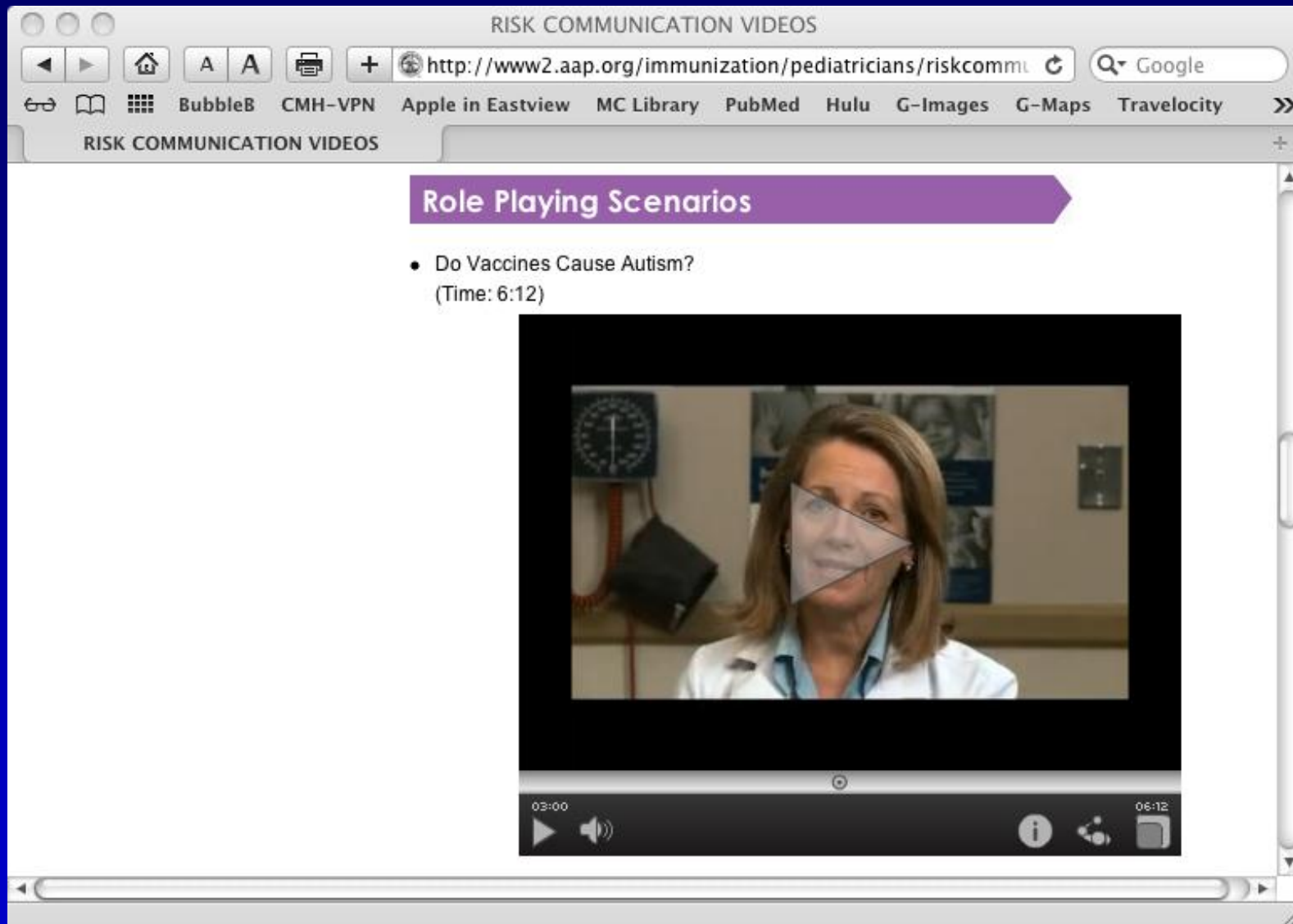
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<http://www2.aap.org/immunization/pediatricians/riskcommunicationvideos.html>

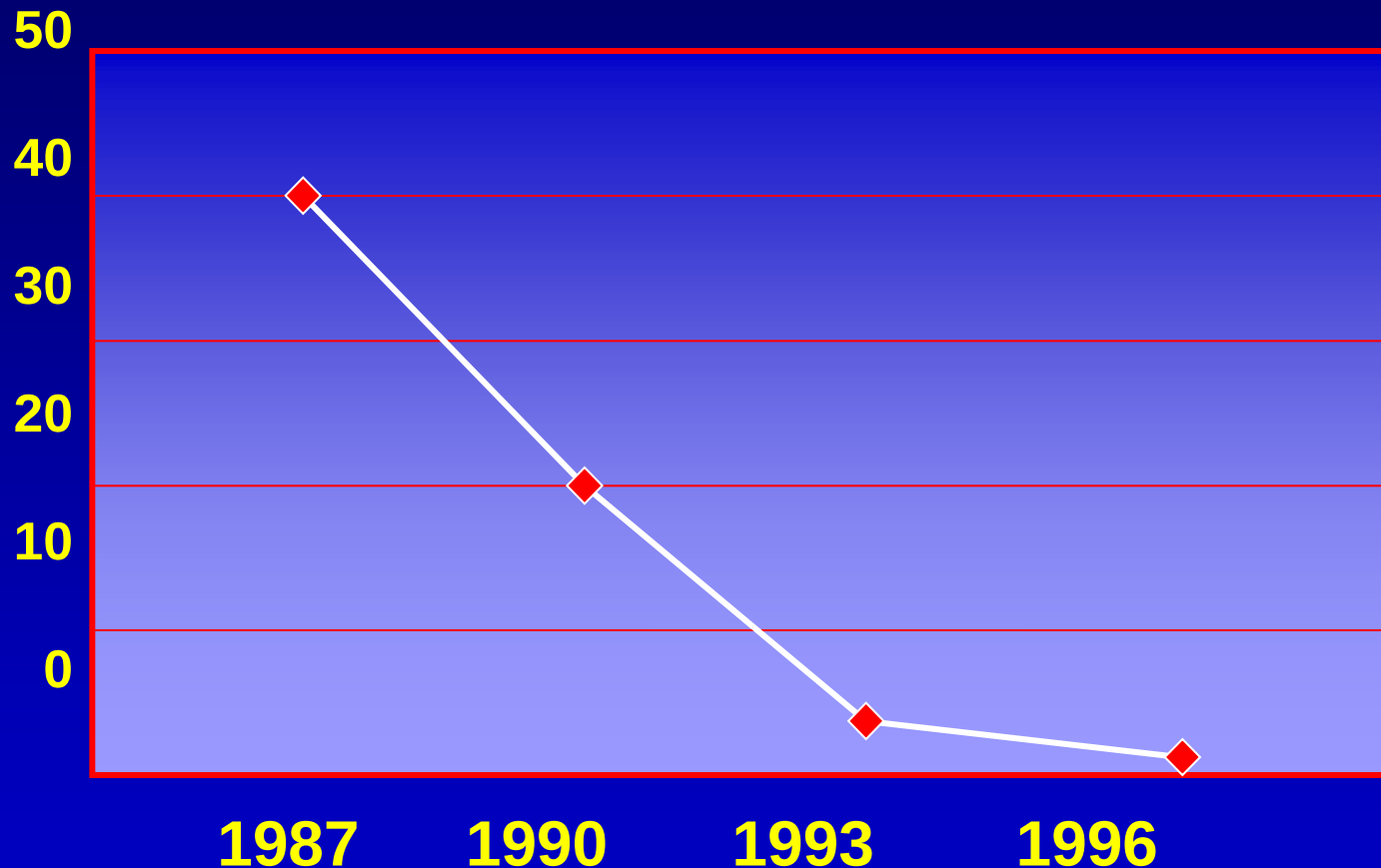


These videos show a provider using the CASE method in an office setting. (simulated)

Tip #6-Use English (not medicalese)

Tip #7-Use visuals

Vaccine protection from *Hemophilus influenza* type b (Hib)

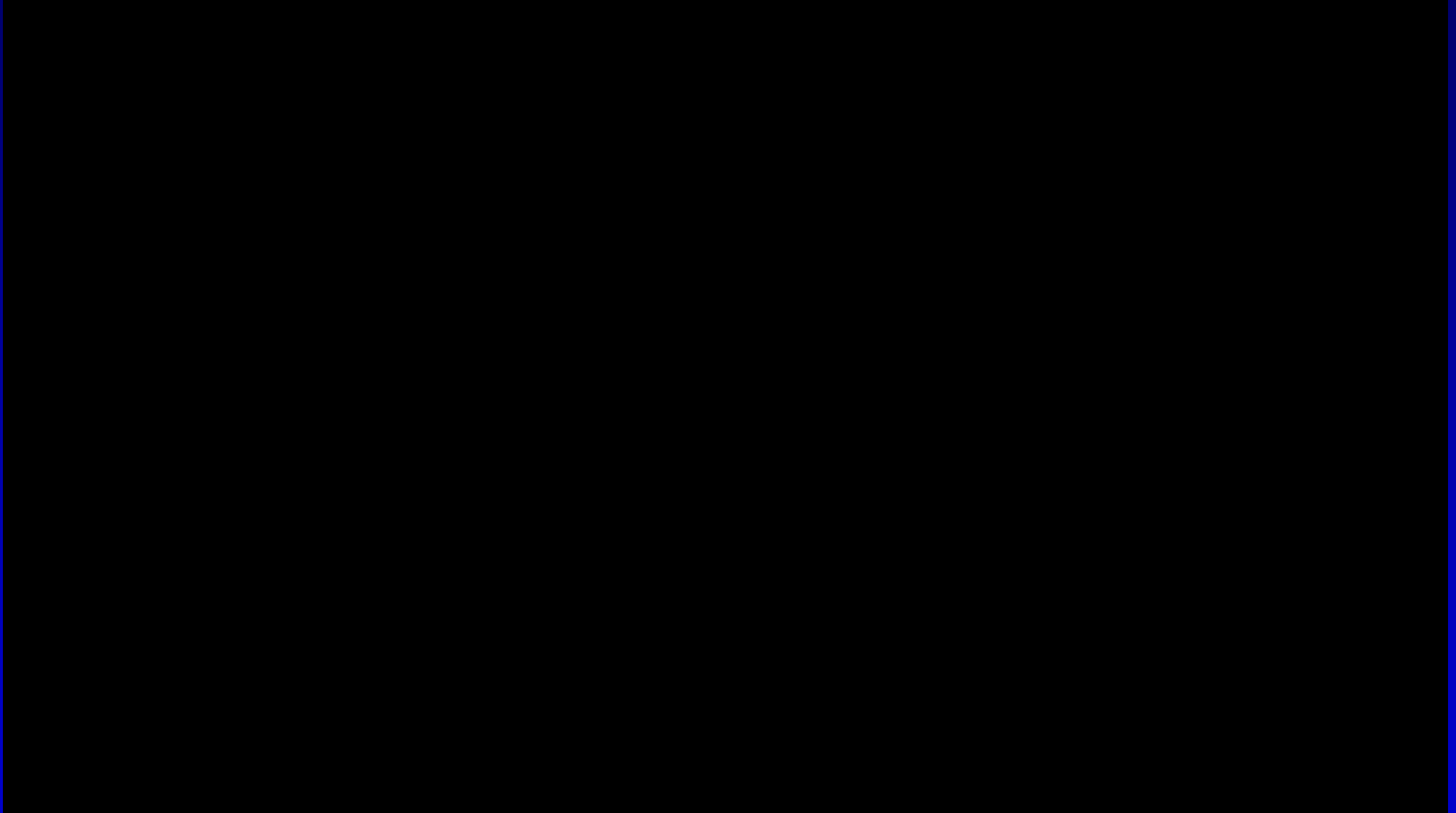


Estimated annual incidence of invasive Hib per 100,000
Children < 5 years of age, 1987-1996



Penn & Teller on Herd Immunity

(warning: 2 bad words)



Whole Brain Teaching

- Emphasis on **active learning** -- learner makes connections that tap both hemispheres
- Managing the **emotional climate** – to reduce “primal thinking” that occurs during distress
- **Images** are basis for comprehension

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Some of these images are quite graphic



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Disease & Vaccines

The latest recommendations, news, information, and resources from IAC



IAC Videos

Educational videos and PSAs

PowerPoint Presentations

Presentations on immunization issues and vaccine-preventable diseases

Unprotected People Reports

Case reports and testimonials about people who have suffered or died from vaccine-preventable diseases

Video of the Week

IAC's weekly selection of PSAs and videos that raise awareness of immunization issues

IAC Image Library



The Immunization Action Coalition's (IAC) gallery of digital images includes pictures of health professionals vaccinating children, teens, and adults; images of people affected by vaccine-preventable diseases; micrographs of viruses, bacteria, and pathology specimens; and slideshows of global immunization campaigns, past and present.

Use these photos to educate staff and patients about the importance of vaccination.

Global Immunization Campaigns

Photo galleries, images, and historic pictures of global immunization campaigns. See first hand the effort to immunize the world's children against life-threatening diseases.

[Browse Campaign Galleries](#)

BILL & MELINDA GATES foundation

The Global Health CHRONICLES



Polio Eradication in Pakistan

Other Image Libraries

Public Health Image Library

CDC's database of photographs, illustrations, and videos

American Academy of Pediatrics

Collection of photographs of children affected by vaccine-preventable diseases

Images from the History of Medicine

Database for archival posters, illustrations, portraits, and photographs

Tip #8-Use check back

Ask parents (and the child when appropriate) to repeat what they understood in their own words, and clarify info & plans



What does
the parent
think?

What I say:
Corroborate
About my prep
Science
Explain/Advise

Tip #8-Use check back

2nd chance:
What I meant
to convey

What does
the parent
think?

What does
the parent
think I said?

What I say:
Corroborate
About my prep
Science
Explain/Advise

Tip #9-Use re-inforcers

Clear Answers & Smart Advice About Your Baby's Shots

By Ari Brown, MD, FAAP

Dr. Brown received her medical degree from Baylor College of Medicine in Houston, Texas; she did her pediatric residency at Harvard Medical School/Boston Children's Hospital. In private practice since 1995, Dr. Brown is perhaps best known as the coauthor of the 411 parenting book series — *Expecting 411: Clear Answers and Smart Advice for Your Pregnancy, Baby 411, and Toddler 411* (Windsor Peak Press).

In response to the recent media attention given to vaccines, autism, and other controversies concerning vaccines, the Immunization Action Coalition (IAC) has reprinted a special excerpt from *Baby 411* that answers these questions and more. IAC thanks Dr. Brown for this clearly written information, but mostly, we are grateful for her continued advocacy for safe and effective vaccines.

Vaccines. Autism. Controversy. As a new parent (or parent-to-be), it's hard not to hear the great debate in parenting circles these days—do vaccines cause autism? If not, what causes autism and why is it on the rise?

Q: What is autism?

Autism Spectrum Disorder (ASD) is really a collection of several disorders that have three abnormal areas in common: social skills, communication skills, and repetitive or obsessive traits. Specialists use the terms ASD and Pervasive Developmental Disorders (PDD) interchangeably. To add even more confusion, Pervasive Developmental Disorder, not otherwise specified (PDD-NOS), and Asperger's Syndrome also are other categories that fall under the ASD umbrella.

There is a very broad range of severity within ASD. A child may have normal intelligence and language, but be socially awkward and have panic attacks if his sandwich is cut in triangles instead of squares. Or a child may appear out of touch with reality and spend his entire day rocking and flapping his hands. Both children have ASD. As you might suspect, children with severe problems as in classic autism are diagnosed much earlier than kids who can communicate but have trouble with social skills, as in Asperger's Syndrome.

Children are usually diagnosed by 18-24 months of age when language delays are obvious. Many children with Asperger's Syndrome may not be diagnosed until preschool (or sometimes even later). However, clues to the diagnosis appear long before that time. Some early clues include: not smiling back at people, poor eye contact, not called by name, and not trying to communicate/connect/engage with other people by 1 year of age.

There also are some unusual behaviors. Cuddling may not be soothing. Bright lights and noises often bother them. Because they are bugged by the outside world, they may turn inward and find comfort in repetitive behaviors (rocking, head banging, spinning). Autistic children may have little interest in playing with toys. Or they may play in an odd way—such as using a phone as a comfort object.

Bottom line: Children with autism have autism long before their first birthdays, even though their "official" diagnosis usually occurs in their second year of life.

Q: I have a friend whose child has autism. She said he was "perfectly normal" until he was about 18 months old. Does this happen?

A small minority of ASD children have completely normal milestones and then regress, which is known as "late onset autism." These children most likely have a distinct genetic abnormality that turns on or off without any trigger.

However, for most kids with ASD, parents and doctors just miss (or dismiss) the early signs in the first year of life and the child's atypical development only becomes apparent at 18 months.

Doctors rely heavily on parents to point out concerns. And parents (especially first-timers) don't know what is normal and what isn't. The mother of one of my ASD patients told me that she only realized how unusual her son's development was after she watched her second child, without ASD, breeze through her milestones. Even the most vocal ASD mom of all, Jenny McCarthy, agrees. Her son was 5 months old when he first smiled at her (that's abnormal), when all of her friends' babies smiled at 2 months of age (that's normal).

Some parents report that their ASD child spoke a few words and then "lost" the ability to say them. If you delve a bit deeper, the child may have randomly said a few things, but was not consistently using words like "juice" or "no" to communicate his needs.

There is growing research in language development that looks at brain anatomy. Primitive brain parts control early language development from birth to 18 months. At 18 to 24 months, the mature brain parts turn on and language takes off. With autistic children, mature language does not take off. But from a parent's perspective, it may look like a loss of skills.

Q&A

VOLUME 1 • SUMMER 2008

Vaccines and Autism: What you should know



Vaccine Education Center at
The Children's Hospital of Philadelphia

Some parents of children with autism are concerned that vaccines are the cause. The center on three areas: the combination measles-mumps-rubella (MMR) vaccine; thimerosal, a mercury-containing preservative previously contained in several vaccines; and the number of vaccines babies receive too many vaccines too soon.

What are the symptoms of autism?

Symptoms of autism, which typically appear during the first 3 years of life, include difficulties with behavior, social interaction, and communication. Specifically, children with autism have difficulty interacting socially with parents, siblings, and friends; have difficulty with transitions and need to play in repetitive behaviors such as hand flapping or spinning; have a preoccupation with activities or toys; display a preoccupation with noise and sounds; and have heightened sensitivity to noise and sounds. Autism disorders vary in the type and severity of symptoms, so two children with autism may have quite different symptoms.

What are the causes of autism?

One of the most common theories about the causes of autism is that it is caused by a combination of genetic and environmental factors. Research has shown that autism is more common in children with a family history of autism, suggesting a genetic component. However, environmental factors also play a role. For example, children born to mothers who had a fever during pregnancy or who took certain medications during pregnancy are at a higher risk of developing autism.

Research also has shown that children with autism have differences in their brain structure and function. These differences may be caused by genetic factors or by environmental factors. For example, children with autism have a higher incidence of seizures, which may be related to the brain differences.

www.immunize.org/pdfs/080608.pdf • Item #P2068 (1/12)

www.immunize.org • www.vaccineinformation.org

For the latest information on all vaccines, visit

麻疹、流行性腮腺炎及風疹疫苗

您 需 要 了 解 的 資 訊

1 為什麼要接種疫苗？

麻疹、流行性腮腺炎及風疹是嚴重的疾病。

麻疹
• 麻疹病毒引發皮疹、咳嗽、流鼻涕、眼睛腫痛以及發燒。
• 它可導致耳部發炎、肺炎、癲癇（抽搐及目光呆滯）、大腸潰瘍以及死亡。

流行性腮腺炎
• 流行性腮腺炎病毒引發發燒、頭痛以及腺體腫大。
• 它可導致耳聾、腦膜炎（大腦及脊髓發炎）、睾丸或卵巢腫痛，在罕見的情況下還會危及生命。

風疹（德國麻疹）
• 風疹病毒引發皮疹、輕度發燒，以及關節炎（絕大部分發生在婦女身上）。
• 如果某位婦女在妊娠期感染了風疹，她可能會造成或者新生兒會有嚴重的先天性缺陷。

如果您的孩子可能因接觸其他得了這些病的人而染上這些疾病，這些疾病是通過空氣傳染。

麻疹、流行性腮腺炎及風疹 (MMR) 疫苗可以預防這些疾病。

接種MMR疫苗的孩子中絕大部分不會得這些病。如果我們停止接種疫苗，更多的兒童就會患這些疾病。

2 哪些人應該接種MMR疫苗以及應該在甚麼時候接種？

兒童應該接種2劑MMR疫苗

- ✓ 第一劑應在12-15個月大時接種
- ✓ 第二劑應在4-6歲時接種。

以上是我們推荐的接種疫苗的年齡，但是只要兒童第二次接種疫苗的時間與第一次接種時至少間隔28天，就可以在任何年齡時接種。

有的成人也應該接種MMR疫苗：
通常，于1956年之後出生的年滿18歲的人應該至少接種一劑MMR疫苗，除非他們能夠證明他們已經接種過疫苗或者已經患過這些疾病。

詳細情況請諮詢您的醫生或護士。

MMR疫苗可以在接種其他疫苗時同時接種。

3 有的人不能接種MMR疫苗或者應該推遲接種時間

• 曾經對雞蛋、一種稱為新癬癬的抗生素有危及生命的過敏反應，或者從前接種MMR疫苗時發生危及生命的過敏反應的人不應再次接種。

• 那些在預定接種MMR疫苗時患有中等或嚴重疾病的人通常應該等到痊愈后再接種疫苗。

• 妊娠期間的婦女應該在生產后再接種MMR疫苗。婦女不宜在接種MMR疫苗後的3個月內懷孕。

• 有的人應該詢問其醫生是否應該接種MMR，這些人包括：

- 患有HIV/AIDS，或其他影響免疫系統的疾病
- 正在接受對免疫系統有影響的藥物（如類固醇）治療，療程達2周以上
- 患有任何種類的癌症
- 正在接受X光或藥物治療癌症
- 曾服用過血小板凝集（一種血液不正常的症狀）

• 最近接受輸血或者其他血液產品的人應該向其醫生詢問他們在甚麼時候可以接種MMR疫苗

請向您的醫生或護士索取更多的資訊。

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



Facts for Parents About Autism and Vaccine Safety From the American Academy of Pediatrics (AAP)

The AAP understands that vaccine safety is an ongoing concern for parents of young children, and supports ongoing research in this area. In addition, the AAP supports further research into the causes of autism. The following information is to help parents and caregivers to understand some of the common issues and questions surrounding this topic.

WHAT IS AUTISM?

- Autism is not a specific disease, but rather a collection of disorders of brain development called "autism spectrum disorders," or ASDs.

Autism has a strong genetic basis.

- Studies show that the incidence of autism has risen. The apparent increase in autism may be due to a combination of factors. For example, more and more behaviors and disorders are being included in the definition of ASD than in the past. Also, the public and the medical profession recognize these disorders more often.

Audiotapes

- **Allows parents to :**
 - Repeatedly listen to the info
 - Share accurate info w/ others who could not be present
- A study found that **tapes made during outpatient visits**
 - Were listened to by parents nearly universally
 - Grandparents listened to them 53% of the time
 - 70% were listened to >1 x
 - The tapes were found to be helpful >99% of the time
- **Medicolegal concerns** – unfounded to date
Tapes often reveal much more info was shared than either party realized; tapes may be protective

Tip #10-Involve the whole office

Why involve everyone?

- If you don't, your message may be undermined
- Champions are born when people understand the mission
- Agree on specific vaccine communication tasks for receptionist, nurse, physician
- >1 person asks for parents' questions



Communicating With Parents About Autism and Vaccination: *10 Tips*

- 1. All it takes is perfection 😊**
- 2. Listen; hear the fear**
- 3. 1 size communication does not fit all**
- 4. Let them know you care**
- 5. Be prepared**
- 6. Use English (not medicalese)**
- 7. Use visuals**
- 8. Use check back**
- 9. Use re-inforcers**
- 10. Involve the whole office**



A Few Great Tools



Strategies to Overcoming Barriers with Vaccine Hesitant Parents

- **Understand the parent's concerns**
- **Understand the parent's influences**
- **Establish open, non-confrontational dialogue**
- **Provide unambiguous, easily understood answers**
- **Provide accurate info about vaccines**

8 Provider “Competencies” for Health Care Communication

1. Develop a partnership with the patient
2. Establish or review the patient's preferences for info
3. Establish or review the patient's preferences for his or her role in decision making
4. Ascertain and respond to the patient's ideas, concerns, and expectations
5. Identify choices (including those suggested by the patient) and evaluate research in relation to the individual patient
6. Present info and assist the patient to reflect on the impact of alternate decisions with regard to his or her lifestyle and values
7. Negotiate a decision with the patient
8. Agree on an action plan & complete arrangements for follow-up

- Guide to immunize.org -

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NGO Immunization Websites

- Allied Vaccine Group www.vaccine.org
 - Immunization Action Coalition (IAC)
 - Vaccine Education Center of Children's Hospital of Philadelphia (VEC of CHOP)
 - National Network for Immz. Information (NNii)
 - American Academy of Pediatrics (AAP)
- Vaccine Safety Institute www.vaccinesafety.edu

CDC National Center for Immunization & Respiratory Diseases

- Call the hotline at 800-232-4636 (800-CDC-INFO)
- Email questions to nipinfo@cdc.gov
- See <http://www.cdc.gov/vaccines/>
- <http://www.cdc.gov/vaccines/pubs/pinkbook/index.html>

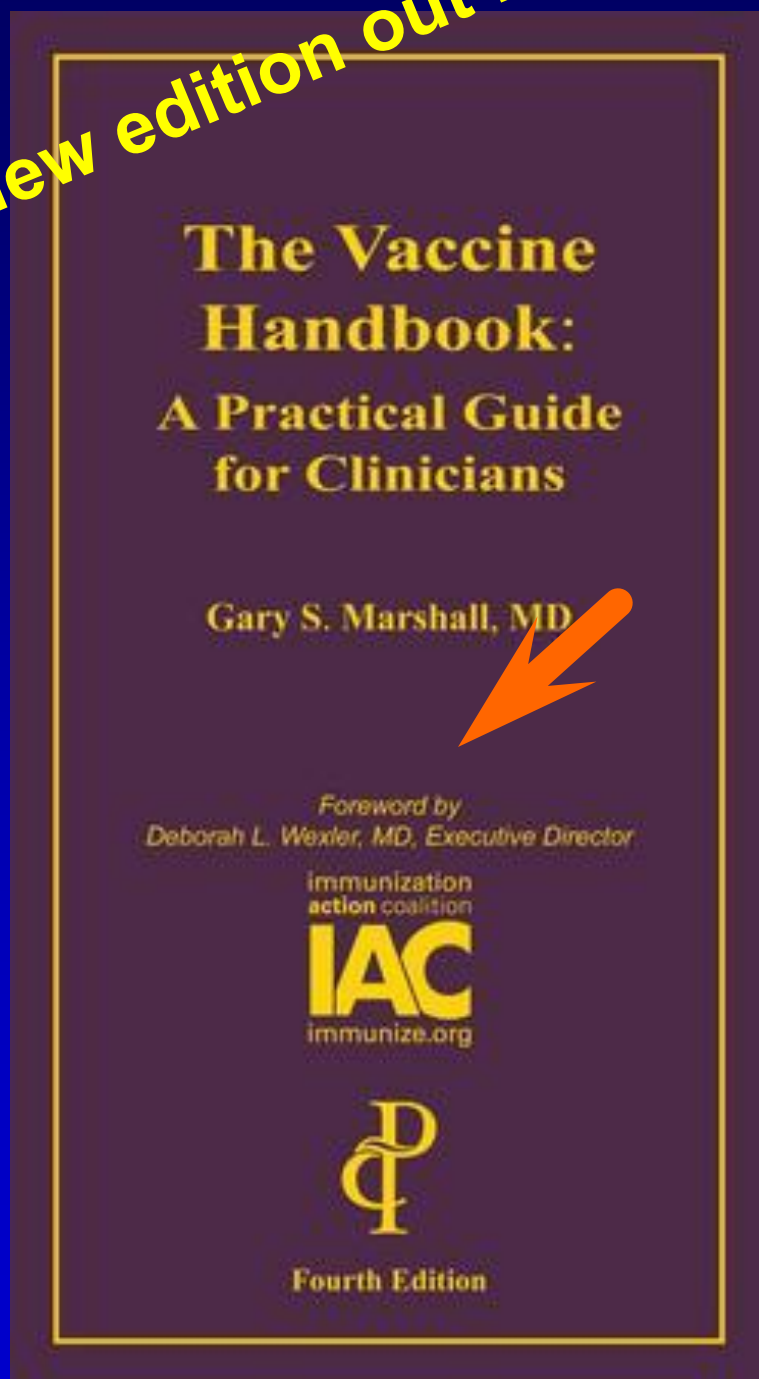


New edition out now!

Web site for TVH is:

<http://www.pcibooks.com/books/view/49>

- Authoritative, user-friendly guide to vaccination for healthcare workers
- Easy to navigate
- Info on:
 - Vaccine infrastructure
 - Standards and regulations
 - Business aspects of vaccine practice
 - General recommendations
 - Schedules
 - Special circumstances
 - How to address a vaccine concerns



Offit, Paul A (2008)

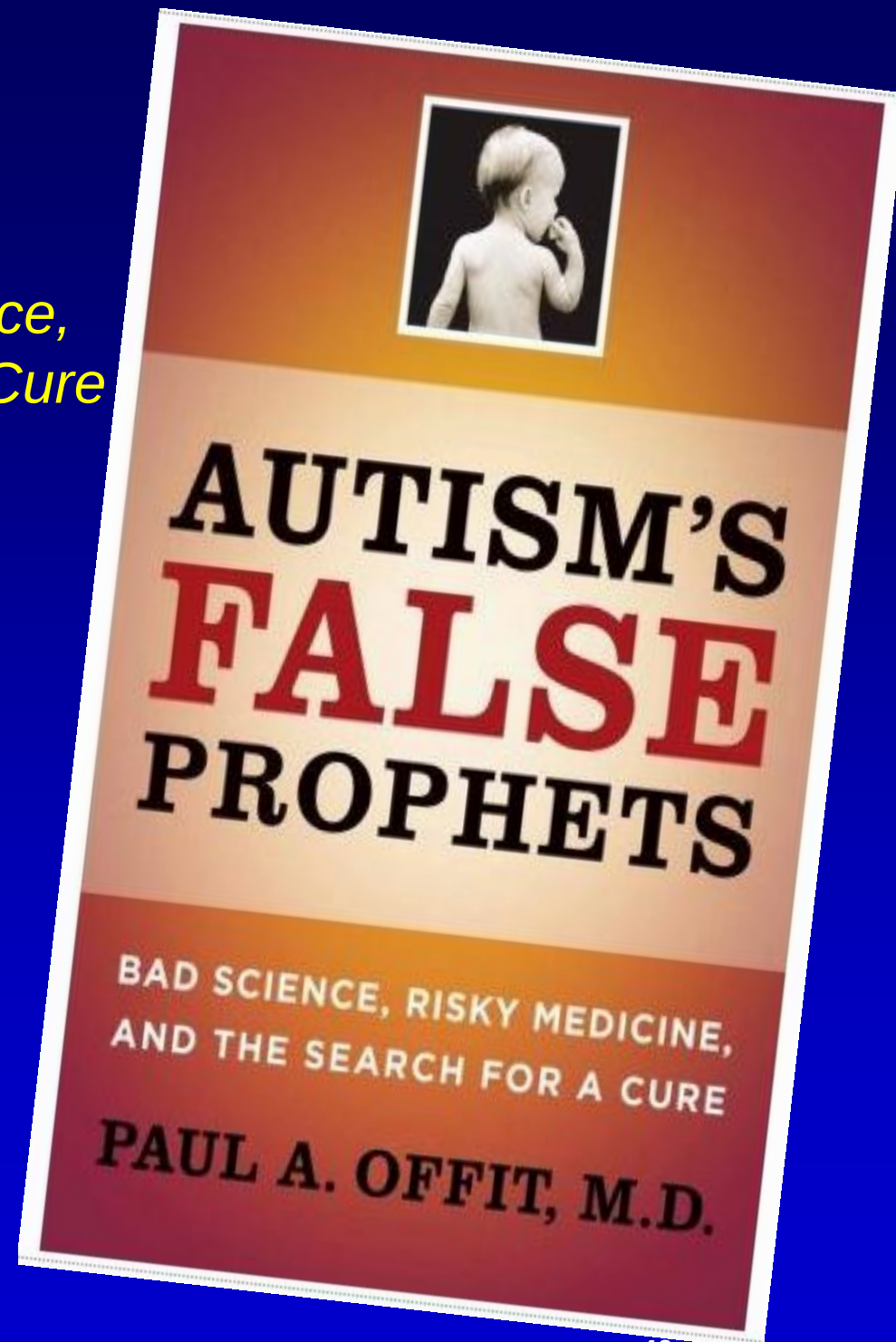
Autism's False Prophets: Bad Science, Risky Medicine, & the Search for a Cure

Columbia University Press

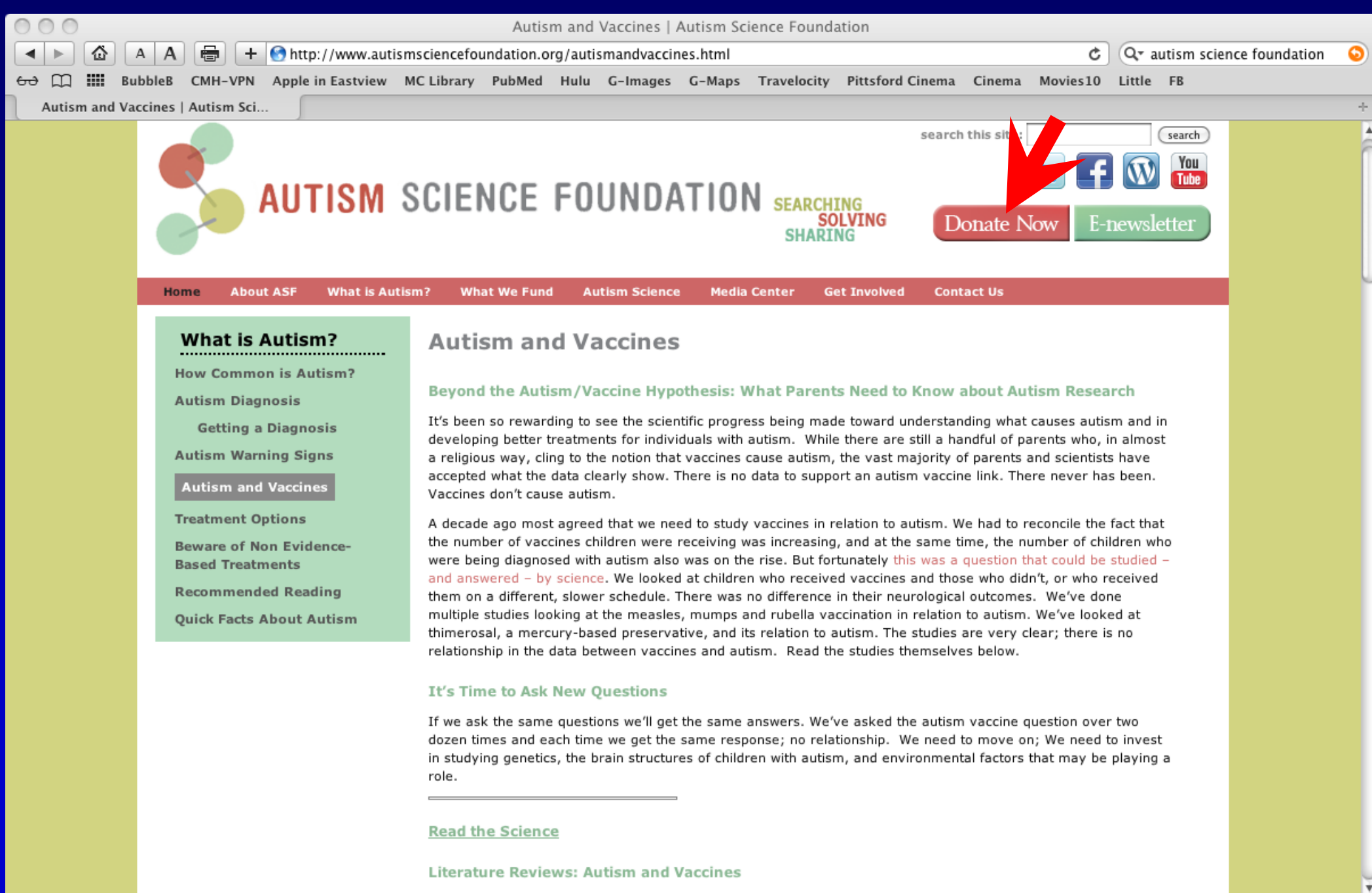
Profits go to autism research

See also

Vaccines: What You Should Know
(third edition)



<http://www.autismsciencefoundation.org/autismandvaccines.html>



The screenshot shows a web browser window with the URL <http://www.autismsciencefoundation.org/autismandvaccines.html>. The page features the Autism Science Foundation logo, a search bar, and social media links. A red arrow points to the search bar. The main content area is titled 'Autism and Vaccines' and includes a sidebar with navigation links.

Autism and Vaccines | Autism Science Foundation

search this site: search

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What is Autism?

- How Common is Autism?
- Autism Diagnosis
 - Getting a Diagnosis
 - Autism Warning Signs
 - Autism and Vaccines**
- Treatment Options
- Beware of Non Evidence-Based Treatments
- Recommended Reading
- Quick Facts About Autism

Autism and Vaccines

Beyond the Autism/Vaccine Hypothesis: What Parents Need to Know about Autism Research

It's been so rewarding to see the scientific progress being made toward understanding what causes autism and in developing better treatments for individuals with autism. While there are still a handful of parents who, in almost a religious way, cling to the notion that vaccines cause autism, the vast majority of parents and scientists have accepted what the data clearly show. There is no data to support an autism vaccine link. There never has been. Vaccines don't cause autism.

A decade ago most agreed that we need to study vaccines in relation to autism. We had to reconcile the fact that the number of vaccines children were receiving was increasing, and at the same time, the number of children who were being diagnosed with autism also was on the rise. But fortunately **this was a question that could be studied – and answered – by science.** We looked at children who received vaccines and those who didn't, or who received them on a different, slower schedule. There was no difference in their neurological outcomes. We've done multiple studies looking at the measles, mumps and rubella vaccination in relation to autism. We've looked at thimerosal, a mercury-based preservative, and its relation to autism. The studies are very clear; there is no relationship in the data between vaccines and autism. Read the studies themselves below.

It's Time to Ask New Questions

If we ask the same questions we'll get the same answers. We've asked the autism vaccine question over two dozen times and each time we get the same response; no relationship. We need to move on; We need to invest in studying genetics, the brain structures of children with autism, and environmental factors that may be playing a role.

[Read the Science](#)

Literature Reviews: Autism and Vaccines

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