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AUTISM SCIENCE FOUNDATION



Making the CASE for Vaccines: A new model for talking to parents about vaccines

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Nurse Training on Immunization Project
 Center for Public Health Continuing Education
 School of Public Health
 University at Albany

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Why are We Still Talking About Vaccines and Autism?

- Science *clearly* shows no link; many good studies
- Media Loves Controversy
- Anti-vaccine Movement Has a Celebrity Spokesperson

**Existence of Good Science Suggests
 Problem is Communication**

Traditional Framework for Communicating Science

- Identify the information essential for decision-making
- Formulate message, drawing on the research

Traditional Framework for Communicating Science

- No data support a causal relationship between vaccines and autism.
 - Here are the studies
- Vaccines save lives. Therefore your child needs to be vaccinated.

No Longer Enough

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

- **Corroborate:** Acknowledge the parents' concern and find some point 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
- **Science:** Describe what the science says
- **Explain/Advise:** Give your advice to patient, based on the science

People behave rationally when:

- They get relevant information in a concise, comprehensive format that seems credible
- They feel their concerns are heard
- They feel control over their decision
- They do not feel belittled

Parents evaluate the message and the message deliverer

Barriers

- Not enough time with each patient (not reimbursed for this)
- The media captures public attention; I can't compete with Jenny
- Parents come in with bad information from the internet (Dr. Bob's Schedule)
- Anecdotes are powerful

Top Three Parent Concerns about Vaccines

- Vaccines Cause Autism
- The diseases are not so bad (better to fight them naturally)
- Too Many Too Soon (let's slow down the schedule)

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...
- **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. None show a link. In fact, the latest autism science indicates...
- **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. Hey, I had chicken pox myself
- About Me: The vaccine program has been so successful and a lot of the diseases that we feared, like polio, are no longer a concern. Until last year, I had never seen a case of HIB or measles, but now 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. In my practice.....
- Science: These diseases have come back in areas where vaccination rates are low. Last year, 5 children died of HIB. Five cases of mumps have been diagnosed in NYC. 9 California babies died this year of pertussis.
- Explain: We care about our patients and don't want to practice substandard care. All our patients need to be vaccinated. My children are fully vaccinated.

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

- Corroborate: Kids today certainly get more shots than kids did years ago
- About Me: Our practice follows the CDC schedule because it is carefully designed to protect children at the time they are most vulnerable to disease. I recently returned from a meeting, or I served on a committee that reviewed the schedule...
- 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. Plus, the immunological challenge from a vaccine is nothing compared to what kids fight off every day. An ear infection is a bigger immunological challenge. "Drop in the ocean"
- 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.

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

- Corroborate: Acknowledge the parents' concern and find some point on which you can agree. This sets the right tone
- About Me: Describe what you have done to build your knowledge base and expertise
- Science: Describe what the science says
- Explain/Advise: Give advice to patient, based on the science

Welcome to Autism 101



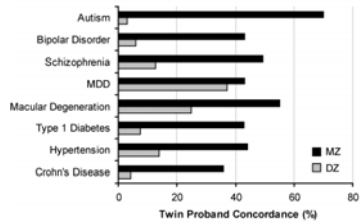
Autism Spectrum Disorders

- Autism Spectrum Disorders (ASDs) are a group of developmental disabilities.
 - Classic Autism
 - PDD-NOS
 - Aspergers Syndrome
 - Rett Syndrome
 - Childhood Disintegrative Disorder
- Impairment in 3 domains
 - Social (interest in people, joint attention, imaginative play)
 - Communication (language, speech)
 - Behavior (repetitive behaviors, tantrums, aggression)

What do we know?

- International Meeting for Autism Research (IMFAR)
- IACC 2010 Strategic Plan for Autism Research
- Genetics/High Heritability
- "Genes to Treatment" Model:
 - Genes—Proteins—Develop Compounds—Test in Animal Models
 - Genes focused on development and function of synapses

High Heritability of Mental Disorders



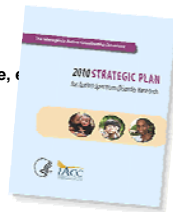
Insel, 2009

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What do we know?

- Diagnosis/Biomarkers
 - Eye tracking (Klin, et al)
 - Pattern of head growth (Courschesne, et al)
- Biologic Underpinnings
 - FMRI (Schultz, et al)



What do we know?

- Causation
 - Genes; Copy Number Variations (Sebat, State, Hakonarson, Buxbaum, et al)
 - Environment (IOM identified over 80 targets)
 - Maternal Rubella
 - Maternal Thalidomide
 - Maternal Valproic Acid
 - Prenatal Maternal Immune Response
- Treatment
 - Evidence based interventions; Applied Behavior Analysis
 - Testing interventions in real world (Mandell, Kasari, et al)

Red Flags for Autism



- 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 phrases on his or her own by 24 months (not repeating)
- Has any loss of any language or social skill at any age

Early Intervention

- Kids can make meaningful gains in skills
- 30-50% make enough gains to be mainstreamed by kindergarten
- Early Intervention programs vary by state
- IDEA: Individuals with Disabilities Education Act
 - Individualized Educational Program (IEP)
 - Free and Appropriate Education (FAPE)
 - Least Restrictive Environment (LRE)

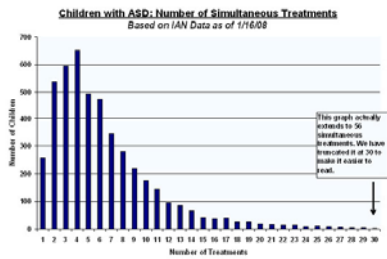
Treatment: Evidence and Anecdote

- Applied Behavior Analysis Therapy
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Social Skills Training
- Pharmacological interventions (Risperdal, Abilify)
- Special schools & School-Based Interventions
 - TEACCH, ABA, Floortime, Intensive Language Instruction

Other Treatments (Non Evidence based)

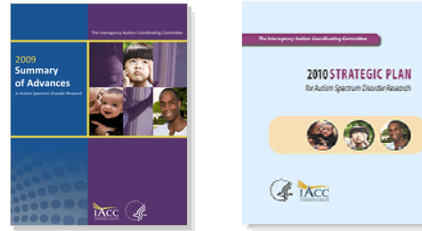
- Music Therapy (AIT)
- Horseback Riding Therapy
- Special Diet (Gluten and Casein Free)
- Vitamin Supplements
- Secretin Injections
- Anti-fungal agents
- Chelation
- Hyperbaric Oxygen Therapy
- Holding Therapy
- Marijuana (and not for the parent)
- Snake Oil (yes, actual snake oil)

Simultaneous Treatments



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Autism Research



<http://iaccc.hhs.gov/summary-advances/2009/index.shtml>

Autism Science Foundation's Mission

- Support autism research by providing funding and other support to scientists and organizations conducting, facilitating, publicizing and disseminating high quality autism research.
- Support families by reinforcing message that no science (over two dozen studies) indicates a causal link between autism and vaccines
- Founded by parents and scientists, working together



- **Web** www.autismsciencefoundation.org
- **Blog** www.autismsciencefoundation.wordpress.com
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- **YouTube** AutismScienceFdn

Additional Resources:

- www.cdc.gov
- www.immunize.org
- www.pkids.org
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