


**AUTISM
SCIENCE
FOUNDATION**

*Autism 101: Understanding and
Communicating about Autism*

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Autism Science Foundation


Kentucky Immunization Summit
October 16, 2015



**Why Are We Still Talking About Autism
& Vaccines?**

- Dozens of studies disproving any link
- Lancet retracted Andrew Wakefield's original paper
- Andrew Wakefield stripped of his medical license
- Andrew Wakefield's original report deemed "an elaborate fraud"


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**Why Are We Still Talking About Autism
& Vaccines?**

- Vaccine Court denies all claims in the Autism Omnibus Hearings
 - "This case is not a close case. The overall weight of the evidence is overwhelmingly contrary to the petitioners' causation theories".
 - Plaintiffs were "misled by physicians who are guilty, in my view, of gross medical misjudgment"
 - "To conclude that Colten's condition was the result of his MMR vaccine, an objective observer would have to emulate Lewis Carroll's White Queen and be able to believe six impossible things before breakfast."

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And yet....

- In a typical month, 93% of physicians reported some parents of children <2 years requested to spread out vaccines
- 21% reported $\geq 10\%$ of parents made this request.
- 40% reported this issue had decreased their job satisfaction.

Kempe, A et al. (2015) Physician Response to Parental Requests to Spread Out the Recommended Vaccine Schedule *Pediatrics*.

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And yet....

- 6% of survey respondents believed vaccines cause autism in children
- 52% were unsure

Gallup Poll, 2015

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You've Got the Power!

- 85% of parents surveyed listed healthcare professionals in their top three information sources for vaccine decisions ¹
- Parents reported trusting healthcare providers the most for vaccine safety information (76%) followed by government experts (23%) and family and friends (15%) ²
- Parents who receive immunization information from their doctor are less likely to have concerns about vaccines than parents who get information from friends, family members, or books and are 80% less likely to follow alternative immunization schedules ³

1. Kennedy, A. et al. (2011) Confidence about vaccines in the United States: understanding parents' perceptions. *Health Affairs (Project Hope)*.
2. Freed GL, et al. (2011) Sources and perceived credibility of vaccine safety information for parents. *Pediatrics*.
3. Wheeler M, Battersheim A. (2013) Parental vaccine concerns, information source, and choice of alternative immunization schedules. *Hum Vaccin Immunother*.


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Traditional Framework for Communicating Science

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

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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

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What do we need?

- Need to be able to respond to parents who say:

"You can't tell me vaccines don't cause autism unless you can tell me what does cause autism"

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Welcome to Autism 101



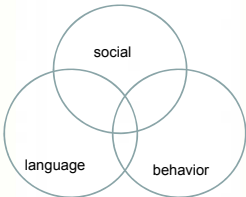
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Autism Spectrum Disorders

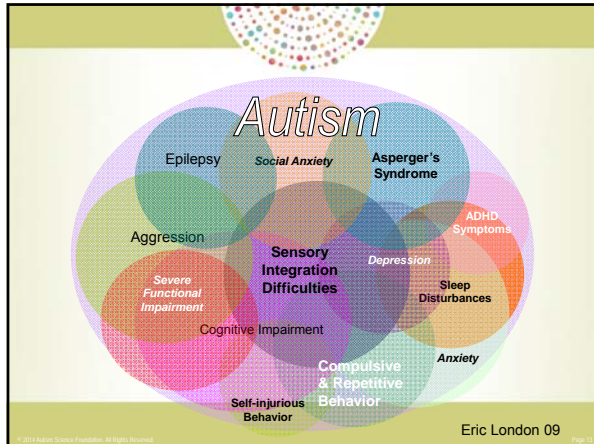
- Autism Spectrum Disorders (ASDs) are a group of developmental disabilities.
- Impairment in Social Communication
 - Social (interest in people, joint attention, imaginative play, practical/useful language)
 - Restrictive/Repetitive Behavior (tantrums, self-injury, aggression, narrow interests)

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What is autism?



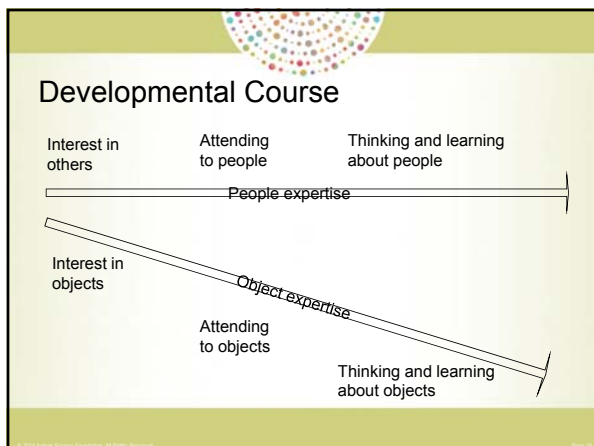
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What Causes Autism?

- We don't know
- Genetics
- Environment
- Developmental trajectory off course
 - Due to primary social impairments, individuals with autism do not attend to faces in early childhood.
 - As a result, they fail to develop expertise in people. This is reflected in face processing impairments and atypical brain activity.

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Diagnosis

- Diagnosis can be made earlier and earlier
- Diagnosis is made based on behavior, parent questionnaire, clinical observation
- No medical test; looking for biomarkers
- Every child with autism is different, but yet share certain similarities

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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

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Other symptoms/co-morbidities

- Epilepsy
- Sleeplessness
- Aggressive or Withdrawn
- No language or overabundance of language

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Early Intervention

- Early now means as young as 6 months of age
- Kids **can** make meaningful gains in skills
- 50% make enough gains to be mainstreamed by kindergarten
- Progress after EIBI continues even after the intervention has ended
- 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)

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What do we know about risk?

- **Twin Studies**
 - Identical twins (58-95% concordance) vs. Fraternal Twins (21%-60%)^{1,2}
- **High Sibling Recurrence Risk**
 - ~20% chance of second child receiving ASD diagnosis if first child has been diagnosed with ASD; previously ~10%³
- **Premature infants**
 - 3-8% prevalence of ASD⁴
- **Males diagnosed four times more often than females.**⁵
 - Do females have some protective factor?
- **Higher maternal and paternal age at conception confers added risk**⁶


¹ Hallmayer, J. et al. (2011) Genetic Heritability and Shared Environmental Factors Among Twin Pairs with Autism. *Arch Gen Psychiatry*.
² Cohen, E. et al. (2010) Heritability of Autism Spectrum Disorder in UK population-based twin sample. *JAMA* 305: 414-423.
³ Ozonoff, S. et al. (2011) Recurrence Risk for Autism Spectrum Disorders: A Baby Siblings Research Consortium Study. *Pediatrics*.
⁴ Sanderson, T. et al. (2011) Sex Differences in Autism. *PLoS One*.
⁵ Kuzhneva, M. et al. (2014) Prevalence and neonatal factors associated with autism spectrum disorders in preterm infants. *J of Pediatrics*.
⁶ Savaris, S. et al. (2010) Autism risk associated with parental age and increasing age difference between parents. *Molecular Psychiatry*.

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Is it the environment?

- Several environmental factors have been demonstrated to increase risk
 - Exposure to air pollution during pregnancy
 - Valproic Acid taken during pregnancy
 - Rubella exposure during pregnancy
- Others have been studied and ruled out
 - Anti-depressants taken during pregnancy
 - Pet Shampoo
 - Ultrasound
- Environmental Factors currently being studied
 - IOM identified over 80 toxicants worthy of study
 - Flame retardants to pesticides
 - Focus is on prenatal (2nd trimester) exposure

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What do we know about causes?

- For most of ASD, combination of genetic and environmental factors
- 15% of autism attributable to specific genetic causes
 - Genetically-defined autisms. Fragile X syndrome, Tuberous Sclerosis, IDIC15 and Phelan McDermid all have >60% diagnosed autism
- Imaging Studies and Genetics converging on neural synapses
 - "Synaptopathy"¹ – common feature in above disorders
 - Formation and Function – genes regulating brain cell outgrowth, connections
- Synaptic Protein Discoveries Leads to Novel Therapeutics
 - Animal Models of Autism
 - Clinical Trials in Humans (arbaclofen, oxytocin)

¹ Brosse, N et al. (2010) Synaptopathy: dysfunction of synaptic function? *Biochem Soc Trans.*
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What do we know about biology?

- Differences in brain structure seen as early as 6 months of age, prior to symptom onset¹.
- Altered brain activity is also seen prior to onset of behavioral symptoms
- Postmortem data indicate that brain structure differences originate in gestation².
- There is an overproduction of brain cells in the frontal lobe, creating patches of functional abnormality. "Failure to prune"
- Have discovered genes responsible for "dysregulation" or failure to govern and sort the number of cells generated.
- This new knowledge is essential to developing early biomarkers of risk to autism as well as biological methods to improve diagnosis.

¹ Wolff JJ et al. (2015) Altered corpus callosum morphology associated with autism in the first 2 years of life. *Brain.*
² Skoner R et al. (2014) Patches of disorganization in the neocortex of children with autism. *N. Engl J Med.*
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What do we know about diagnosis?

- Number of children being diagnosed now 1 in 68
 - Increase due to many factors
 - Broader diagnostic criteria
 - Better awareness and recognition by parents, doctors
 - Better access to services for ASD
- Children diagnosed at 18 months **stay diagnosed** at 3 years
- About half of those with atypical behaviors who did not reach diagnosis at 18 months did so at 3 years.
- New, simple screening tool for 12 month old babies
 - Prior to 12 months, signs and symptoms are predictive but not absolute

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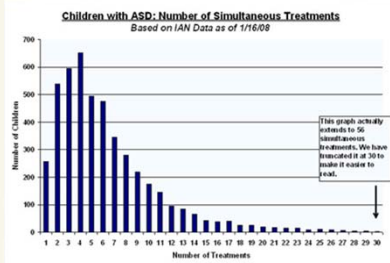
Treatment: Evidence and Anecdote

- Applied Behavior Analysis Therapy
 - Naturalistic Behavioral Intervention like Early Start Denver Model
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Social Skills Training
- Pharmacological interventions (Risperdal, Abilify)
 - Oxytocin and IGF-1 in Human Clinical Trials
- Special schools & School-Based Interventions
 - TEACCH, ABA, RDI (Relationship Development Intervention), PRT (Pivotal Response Training)

Beware of the Cure du Jour

- Music Therapy (AIT)
- Horseback Riding/Swim with Dolphins Therapy
- Special Diet (Gluten and Casein Free)
- Mega-Vitamin Supplements
- Secretin Injections
- Anti-fungal agents
- Chelation
- Giant electromagnets
- Bath Salts
- Hyperbaric Oxygen Therapy
- Holding Therapy
- Nicotine Patch
- Marijuana (and not for the parent)
- Ecstasy

Simultaneous Treatments






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 science has ruled out a causal link between autism and vaccines
- Founded by parents and scientists, working together

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