




# What Does the Future Hold for Autism Families?

Jill Escher

 **AUTISM SOCIETY**  
Improving the Lives of All Affected by Autism  
San Francisco Bay Area

Escher Fund for  
**Autism**   
Humans start as molecules  
[GermlineExposures.org](http://GermlineExposures.org)

**CLARADON**  
PROPERTIES, LLC

**First, a little bit about...**



**RESOURCES**

**Nonprofit Guide**

ism. Here are just a few dozen of them:

**abilities united** Abilities United, Palo Alto, [www.abilitiesunited.org](http://www.abilitiesunited.org)  
 Provides a variety of programs for kids and adults with disabilities, including aquatic therapy, education and therapy services, socialization and basic skill learning, occupational training, and adult day programs.

**Addison Pensak JCC** Addison Pensak JCC: Special Needs Programs, Los Gatos, [www.svjcc.org/special-needs/programs-for-children-with-special-needs](http://www.svjcc.org/special-needs/programs-for-children-with-special-needs)  
 Provides programs for kids and teens with special needs to have fun, make friends, and participate in an array of activities including sports, swimming, and arts and crafts.

**ANOVA** Anova, Marin County, [www.anovaducation.org](http://www.anovaducation.org)  
 Anova is a non-profit organization serving children with autism and related social, emotional, and behavioral challenges. In addition to three K-12 campuses in Santa Rosa, San Rafael, and Concord, CA, Anova provides innovative educational and behavioral services, early intervention, and paraprofessional support throughout 15 counties across California.

**Azure Family Concerts** Autism Fun Bay Area and Azure Concerts, San Francisco.

**Palo Alto, www.aufuninbayarea.org**  
 Sponsors free professional musical performances, from classical to jazz, tailored to people on the autism spectrum or have similar challenges, and their families and caregivers. The website also lists a calendar of Bay Area autism-friendly events.

**AUTISM SOCIETY** Autism Society San Francisco Bay Area, Bay Area-wide, [www.stautismsociety.org](http://www.stautismsociety.org)

An all-volunteer, grass-roots organization of parents, family members, friends and professionals working for the well-being of local autism families, with an emphasis on expanding the limited lifespan care options for the dramatically increasing numbers of adults with autism.

**Bay Area Autism Consortium**, <http://bayareautismconsortium.com>

A collaboration among researchers from the area's leading research and clinical centers—University of California-San Francisco, Stanford University, Kaiser Permanente Division of Research, the California Department of Public Health, SRI International, Children's Hospital Oakland Research Institute, and the Children's Health Council.

**CALENDAR**



**NEWSLETTER**

**Sign up**



Conference links, handsome men in women's restrooms, criminal justice for adults with autism and more for January 2017....

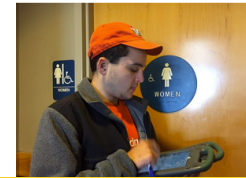
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**SFASA16 Conference Recap**

"This was an amazing event. I hope there will be more events like this one to empower us parents to get more involved to change the hard reality that is facing us and our children."  
 —SFASA16 attendee



**BLOG**



**Yes, that's a large handsome man in the women's room**



**Immersed: An unflinching view of severe autism**



**For adults with autism, the many layers of "community"**

## April 15 Dance-a-thon



- Groooooovy multi-beneficiary fundraiser

## Coming up

### March-May Webinar Series



- Employment
- Police encounters
- ECT
- ASD Research
- Sexuality, hygiene
- Social opportunities

### March 23 Cannabis Klatch Sold out



### December 2 2017 Conference



- At Stanford University
- Registration in September

# Conference Archives



Artwork courtesy of Tyler Bell, SomethingToSayArt.com

**2014: A Place for Us: Supported Housing Solutions for Adults with Autism/DD**



**2015: Let a Thousand Flowers Bloom: The Bay Area Adult Autism/DD Programs & Housing Summit**



**2016: Into the Future: An Adult Autism/DD Planning Workshop**

Now, onto...

## What does the future hold for autism families?



“Hmmm...  
I see autism in  
your family.”

# “Autism is a whole family condition.”

—Jim Ball, ASA



**Nonverbal ASD**



**Deeply affected**

And ... extended family, employers, taxpayers, school districts, social welfare systems, justice system, health care system, friends, and on and on....



## Prediction One:

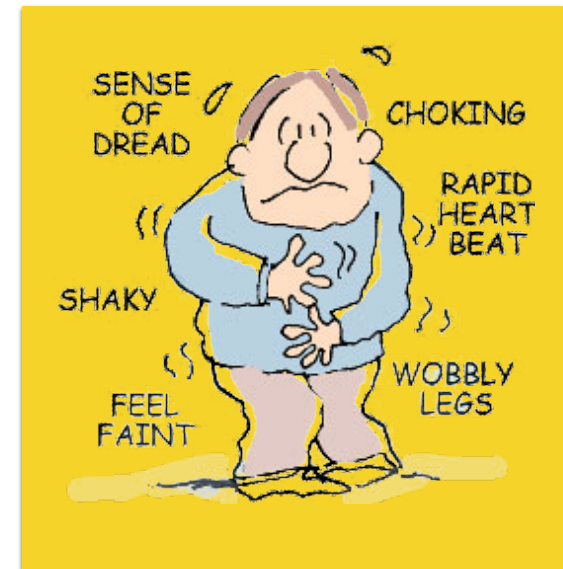


**A growing panic...**



## A Growing Panic: Why?

1. California's autism **population is exploding**.
2. Children with autism become **adults with autism**. Autism is a remarkably treatment-resistant condition.
3. Autism **parents are aging** and often bear **crushing responsibility**.
4. Adult care can be staggeringly **expensive and complicated**.
5. Limited **public resources**; restrictive eligibility criteria.
6. **Outdated policy** headed in wrong direction.





**Prediction Two:**



**Bye-bye autism Kool-Aid**

**“It’s just better ascertainment.”**



**“It’s just diagnostic shift.”**

**“Even Einstein was autistic.”**



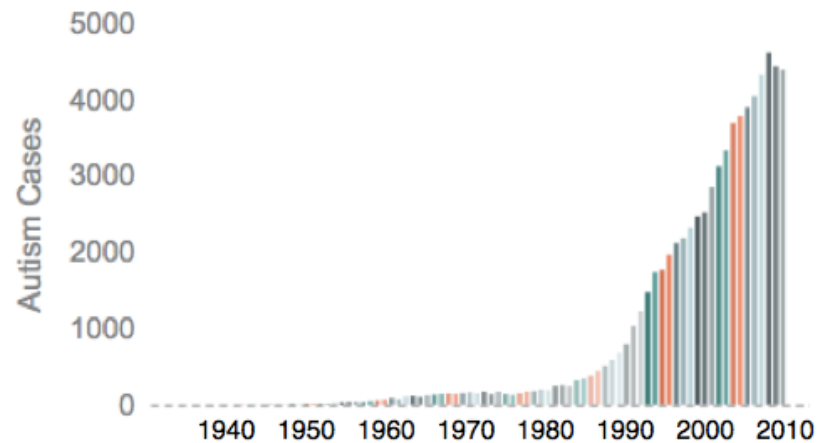
**“Autism’s always been around,  
just hidden under other labels.”**

**“Autism is a gift, handed down through  
the generations from our ancestors.”**

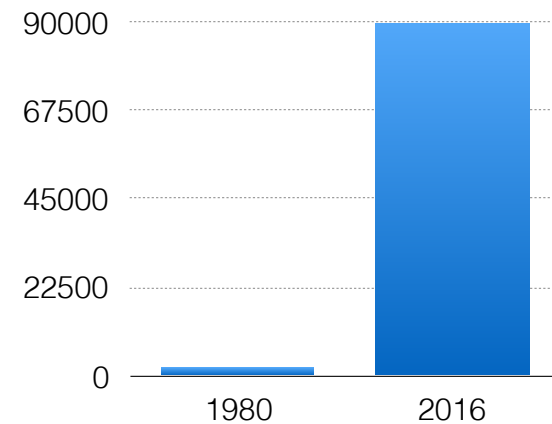


## Calif DDS Autism Soon = 100,000

DDS Autism Cases by Birth Year



DDS Autism Cases: 1980 v 2016

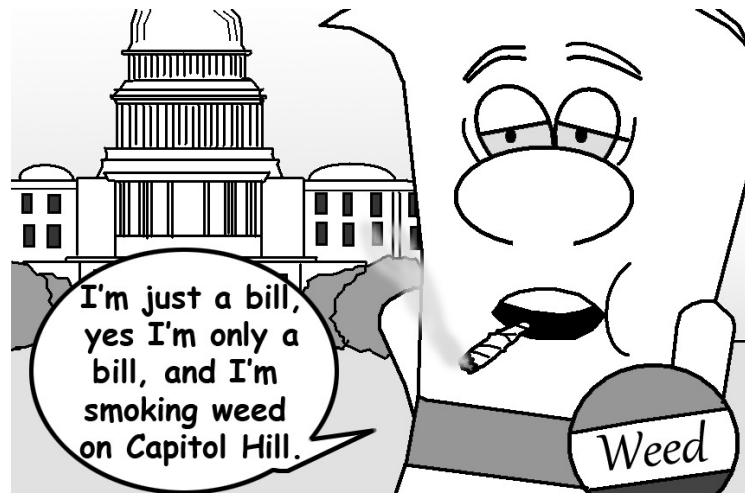


- Early 1980s: 2,000± DDS autism cases. Today **91,000**.
- Within 20 years California DDS **adult autism will quadruple**

**The increase is real, the social services implications are dire.  
We are facing a national emergency.**



## Prediction Three:



**Shaking up tired old policy**

# Beastly, Outdated, Smokin' Weed Policy

1. Federal Government's **Quiet War Against Adults with Autism** (Medicaid restrictions).
2. **Questionable priorities** (prisons, walls, trips to Mars); while ignoring autism tsunami, essential human services.
3. No federal or state **housing plan**.
4. State focus on spending for less than .5% of DD population; **little long-term planning** for 95.5%.

What to do...?



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**With this unprecedented crisis  
and must bring federal and state policy into the  
21st century of autism.**



**One priority...**



## Prediction Four:



**Tons of “institutions” (no not like that)**



# We must strengthen autism-serving “institutions”



State “Institution” (big “I”) v. Community “institutions” (small “i”)

- **How?** Tax reforms and incentives
- Smarter funding streams
- Empower parents to create housing / programs



## Prediction Five:



**The break-up (of sorts)**

## Our Land of Vague Fuzzies



**He's "sick."**

A head cold? Stage 4 lung cancer? Hangover?  
Acute lead poisoning? A tummy bug? Ebola?



**He's "on the spectrum."**

A prodigious memory? Nonverbal and self-injurious? Social anxiety? Needs 24/7 care due to severe mental disability?

# The Matrix: A More Refined, Realistic View of "Autism"

Socio-adaptive functioning

Normal SA

Borderline SA

Moderate SA

Severe SA

Deficits Independent

Deficits Continuous support

Deficits Intensive support

Thinking/  
Learning/IQ

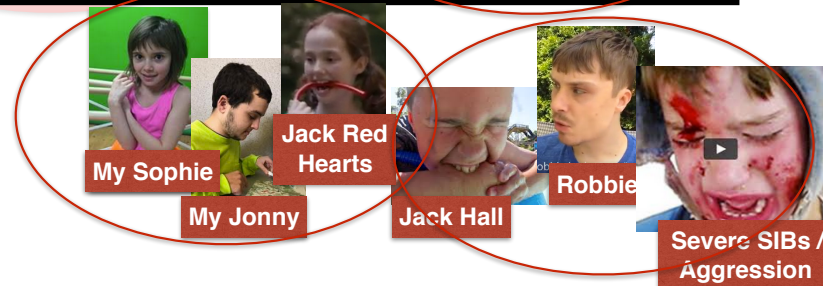
Normal IQ  
Normal language

Borderline/  
Mild Intel.  
Disability  
Slow/unusual  
language

Moderate ID  
Some language

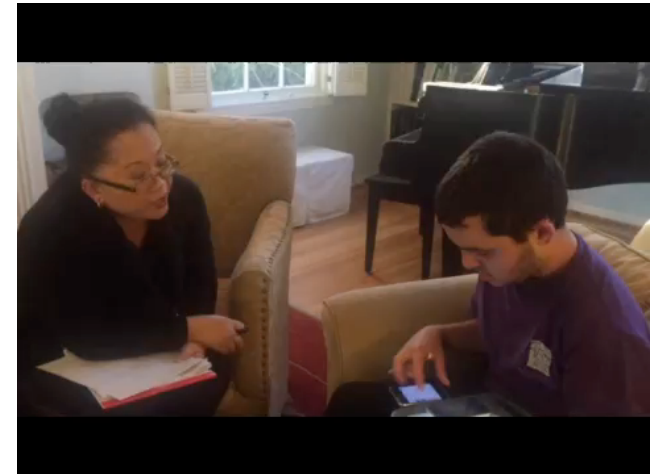
Severe ID  
Minimal or no  
language

Profound ID



## Beware of over-grouping and euphemism.

For example, my son is no “**self-advocate**” with mere “**learning differences.**”



**Neurodiversity** is a helpful construct to build acceptance, highlight strengths, and empower individuals who don't fit cognitive norms.



But “natural”? We must not ignore the **biological pathology** of autism and other DDs.



## Prediction Six:



**Smarter Science**

## Another hat: Research philanthropist



Past grantees include: Harvard University • UCSF • UCSD • UCLA  
University of Bristol • Child Health and Development Survey  
University of Copenhagen • Rockefeller University • Brown University  
Autism Speaks • Linkoping University • University of Chicago  
Stanford University • Florida State University • North Carolina State University  
Colorado State University • Keystone Symposia • Gordon Research Conferences •  
International Society for Autism Research  
Environmental Mutagenesis & Genomics Society • and more

# What's causing autism?

## GENES

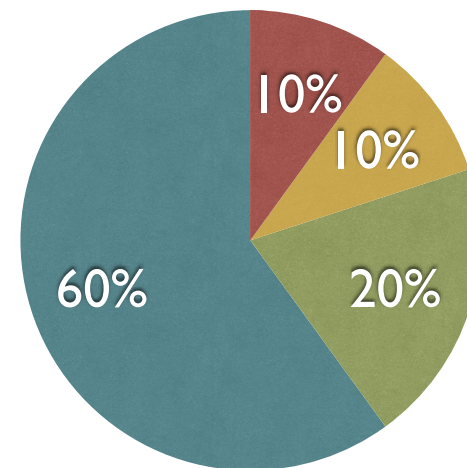
100s of genes contribute—about 10% of cases can be attributed to known genomic errors, **10% more forecast**

## PROXIMAL FETAL STRESSORS

le, prematurity, multigravidas, hypoxia, certain drugs, infection, maybe 10-20%

## UNKNOWN

Probably at least 60% of cases, but **strong evidence of heritability** (among sibs)





# **Poll: For the unknown causes — what side am I on?**

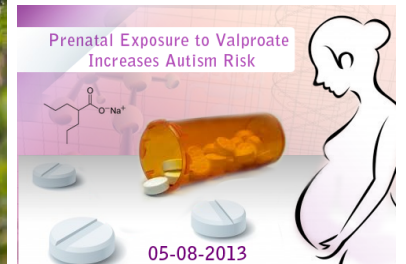
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**GENES/INHERITANCE**



OR

**ENVIRONMENT HARMING THE FETAL BRAIN**



# Genetics\*

\*Because a lot of (bad) stuff happens to our genes.

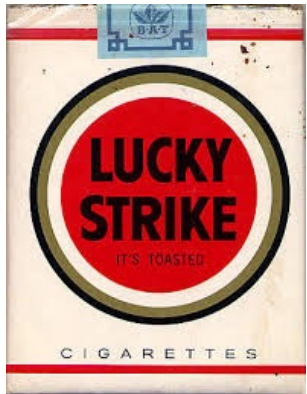


- Mutations
- Regulatory genome
- Epigenetics
- Cytoplasmic stuff

- Loads of **toxic culprits** from the past
- Particularly in **early critical windows** (when our eggs/sperm were forming)
- Small errors can have outsize impacts on **neurodevelopment**

# “Time Bomb” Hypothesis of Autism, an Example

A pregnancy exposure affects 3 generations at once



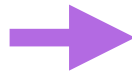
Grandmother exposed to toxicant as adult

Daughter exposed as fetus

Future grandchildren **exposed at genetic level** via germ cells

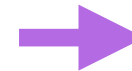
**1965**

Woman smokes while pregnant with her daughter. Errors occur in the daughter's eggs.



**1995**

30 years later, the daughter conceives with one of those eggs and then gives birth to a baby boy.



**1997**

Two years later, the boy is diagnosed with autism. **Doctors say “It's genetic.”**

**A 32-year lag between gene exposure and “genetic” pathology.**



## My “time bomb”?

I was born in 1965 in Los Angeles.  
Like all girls, I was born with all my eggs.



Some decades later, from those eggs, I had three beautiful, genetically normal children from three low-risk, full-term, normal pregnancies.

Two are nonverbal autistic, no one knows why.



Son, 18



Daughter, 10

# Three miraculous discoveries

1.

Handwritten medical record from 1965, titled "PRE-NATAL CARE". It contains a table with columns for date, gestational age, and treatment details. The text is written in cursive and includes notes about the patient's condition and the administration of synthetic progestins and estrogens.

In **2010**, I obtained my mother's **1965 obstetric records**. What did they mean?

2.

## Prenatal Exposure to Synthetic Progestins and Estrogens: Effects on Human Development

June Machover Reinisch, Ph.D.,<sup>1</sup> and William G. Karow, M.D.<sup>2</sup>

Seventy-one offspring of mothers administered combinations of synthetic progestins and estrogen for the maintenance of at-risk pregnancy were evaluated for their performance on IQ and personality tests. Siblings born of untreated pregnancies acted as controls. Hormone-exposed subjects were partitioned into three treatment subgroups dependent on the ratio of progestin to estrogen administered to their mothers during pregnancy. No difference in IQ was obtained among the three treatment subgroups even when scores were adjusted for sibling score and prenatal and perinatal complications. Responses to the personality questionnaire provided significant differences among the three groups. The group exposed to the progestin regime (progestin alone or in combination with very low doses of estrogen) and the estrogen regime (higher doses of estrogen than progestin) were most dissimilar. Progestin regime exposed subjects were characterized as more independent, sensitive, self-assured, individualistic, and self-sufficient. In contrast, the subjects exposed to the estrogen regime were more group oriented and group dependent. Analysis of difference scores generated by subtracting the score of an unexposed sibling from that of the exposed cosibling provided similar results. A general discussion is presented on the efficacy of hormone treatment for pregnancy maintenance, augmented fetal wastage of males, birth order and treatment, maternal knowledge of treatment and its possible postnatal effects on the offspring, and drug effects on the fetus.

**KEY WORDS:** synthetic progestin; estrogen; diethylstilbestrol; humans; personality; IQ; pregnancy maintenance; prenatal.

In **2011**, I discovered I had been a **subject in a study** (Reinisch 1977) examining fetal effects of synthetic steroid hormone drugs.

3.

Handwritten medical record from 1965, titled "Card 4-Drugs Taken During Pregnancy (Steroids & Thyroid)". It contains a table with columns for date, gestational age, and treatment details. The text is written in cursive and includes notes about the patient's condition and the administration of synthetic progestins and estrogens.

In **2013**, I obtained records from the Kinsey Institute detailing my **heavy exposure to synthetic steroid hormone drugs**.

## So what?

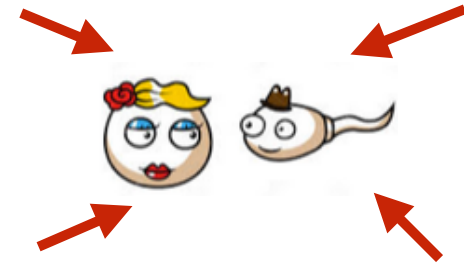
There are likely **three**, not **two**, primary ways to think about autism causation:



1. **Genetics**—  
naturally occurring  
random mutation in  
genes



2. Direct risks to the  
developing **fetal brain**  
(somatic)



3. **Genomic or gametic errors**—**induced by outside factors (time bomb)**

## **In summary, a psychic rap**



**Panic we're not faking  
Kool-aid—no more partaking  
Policy we'll be shaking  
“i”nstitutions we creating  
Spectrum needs some breaking  
Smarter science is in the making**

**Thank you**