

Triggers for tics and Tourette syndrome



What **everyone** should know



Latitudes.org

Association for Comprehensive
NeuroTherapy (ACN)



Sheila Rogers DeMare, MS
Director





My inspiration





“Latitude”

means freedom of action or choice



Latitudes.org

StopTicsToday.org

Webinar Focus

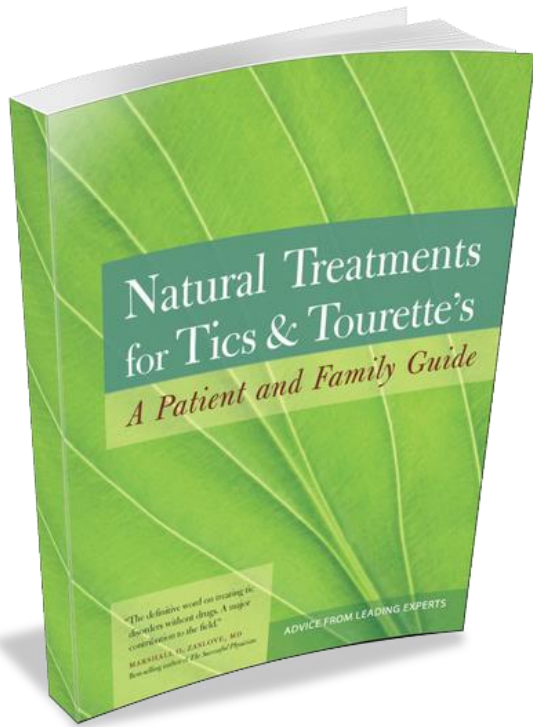
When conventional medicine gets it wrong

Finding triggers means new hope

Discoveries from the tic community

Tips and tools for your search

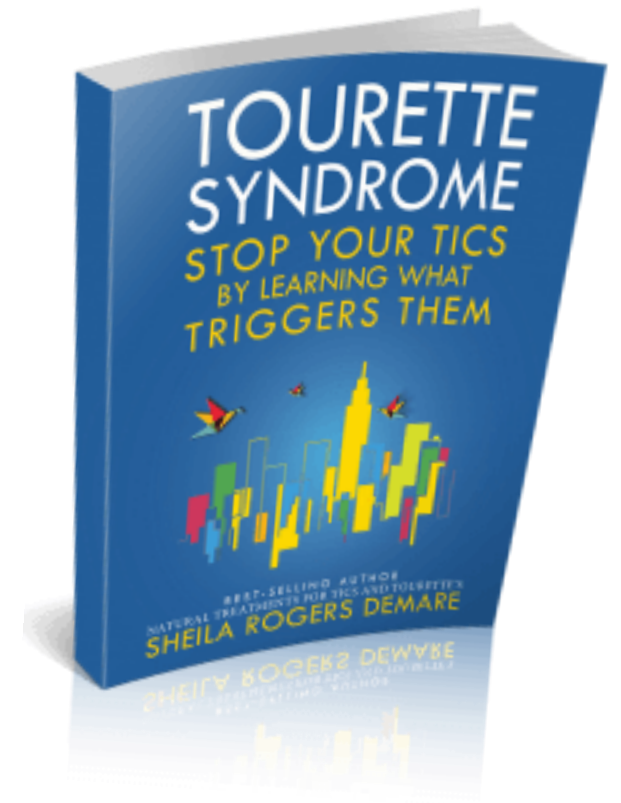




Natural Treatments for Tics and Tourette's: A Patient and Family Guide

On Amazon

Tourette Syndrome: Stop Your Tics by Learning What Triggers Them



A note to me from a concerned mother

*“Have you met with national
organizations or talked with
Tourette parents?*

Because you have it all wrong”



Background of Sheila's efforts

School psychologist and mother of a child with Tourette's

Liaison on natural therapies to the national Tourette Association medical board for several years

Founder and director of ACN and editor of *Latitudes* for 25+ years

Featured in media and at conferences. Met with support groups, co-author on published Tourette research, author of two books on natural approaches to tics and Tourette's



ACN's advisory board

Mary Ann Block, MD; Integrative medicine

Marne Glaser, MA; Electromagnetic Safety

Christopher Grayson, MBA; Research compliance

James Greenblatt, MD; Psychiatry

Devin Houston, PhD; Enzyme therapy

Helen Irlen, MA; Scotopic sensitivity

Ricki Linksman, MEd; Accelerated learning

Siegfried Othmer, PhD; EEG Biofeedback

Mona Rae; Behavioral Interventions

Sherry Rogers, MD; Environmental medicine

ACN's advisory board, *continued*

William Shaw, MD; Laboratory research/testing

William Shrader, MD; Environmental medicine

Vijendra Singh, PhD; Neuroscience & Immunology

Dana Ullman, MPH; Homeopathy

Judith R Ullman, ND; Homeopathy

William Walsh, PhD; Orthomolecular Medicine and Research

Rose Winter, AIA; Green Building and LEED Certification

Mark Young, PhD; Psychology

Marshall Zaslove, MD; Neurology/Psychiatry



I just finished reading your book on triggers for tics. I want to thank you for your expertise, research, and diet information. . . We still have challenges but you have helped my son tremendously and naturally. So keep doing what you do. It matters.



Your work helped my daughter become tic-free after a diagnosis of Tourette's. It gave me the courage to take control of her health and find a solution in a world where the best pediatric neurologists were closed-minded. A documentary on this could transform thousands of lives.



Check your mindset



What we want to hear at the doctor's office



**“Let’s find out why you have these tics
and see what could help you.”**

**Instead, what we hear
at the doctor's office**

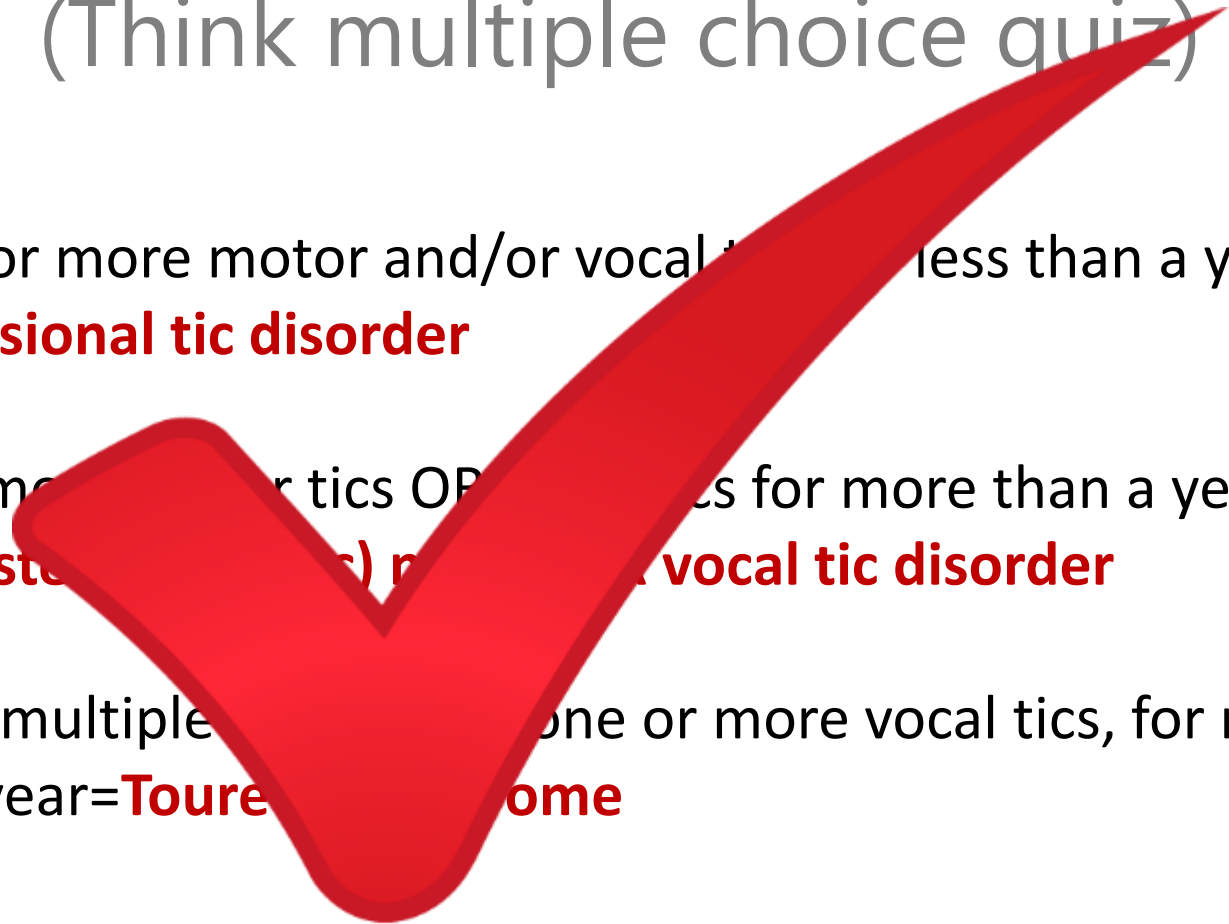


“Hm-m-m Let's give a diagnosis for those tics”

Diagnosing tics

(Think multiple choice quiz)

1. One or more motor and/or vocal tics, for less than a year = **provisional tic disorder**
2. 1 or more motor tics OR 1 or more vocal tics for more than a year = **persistent (chronic) motor or vocal tic disorder**
3. Both multiple motor and one or more vocal tics, for more than one year = **Tourette syndrome**



Classic advice for Tourette's

Tell teachers and family. Try to reduce stress

It's genetic and there is no cure

Drug side-effects can be worse than the tics

Tics will come and go. We call that 'waxing and waning'

There's really nothing you can do



Time
for a
reality
check





“My brother suffered with Tourette’s while growing up.

When my son started having tics I checked to see what was new.

Wow.

Basically nothing.”

News flash!

The current approach
to tics is not helpful

In fact, can be harmful



**The #1 most misleading concept
if you want to find triggers**

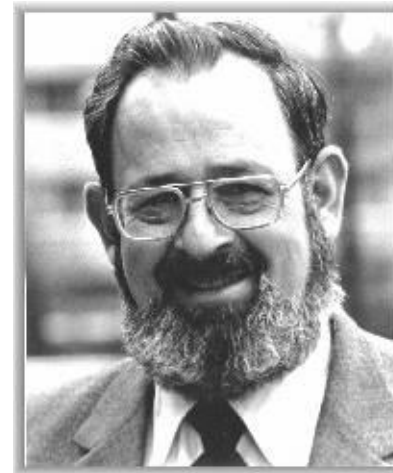


**The “mysterious”
waxing and waning
of symptoms**

When medicine gets it wrong



Peptic ulcers
Drs. Barry Marshall &
Robin Warren



Autism
Dr. Bernard Rimland



**It's genetic and
there is no cure**

**Tics will
mysteriously
come and go.**

**There's really
nothing
you can do**

Embracing a new
way paradigm to
understand
Tourette syndrome



This advice turned our lives around

Tics are a symptom. They are the body's way of saying, 'Something is wrong inside. Won't you fix it?'

Dr. Richard Macdonald
Neuromusculoskeletal medicine specialist

Tourette Syndrome Pioneers



**THERON
RANDOLPH**



**MARSHALL
MANDELL**



**DORIS
RAPP**

DR RANDOLPH

DR MANDELL

DR RAPP

Their NEW findings:

Tourette syndrome is an immune,
allergic, and environmental condition



It can't be
environmental.
It's neurological!

DID YOU KNOW?

Science says Tourette syndrome is a **genetic AND environmental** disorder.

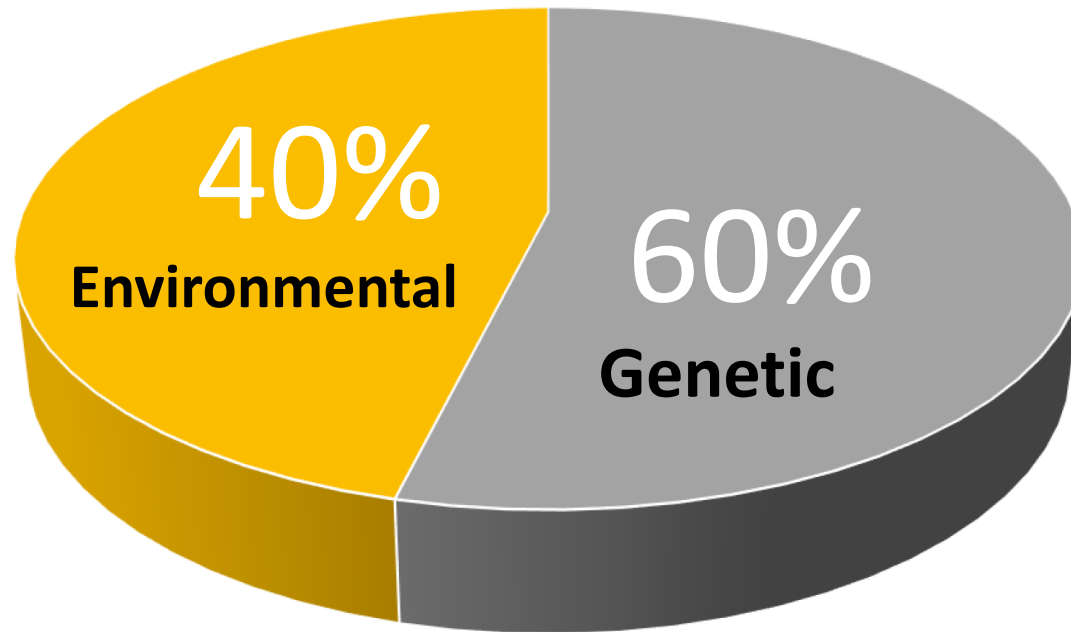
Hoekstra PJ, Dietrich A, Edwards MJ, et al. "Environmental Factors in Tourette Syndrome: *Neurosci Biobehav Rev*. 2013 Jul;37(6):1040-9.

Mathews CA, Grados MA. "Familiality of Tourette syndrome, OCD, and ADHD: heritability analysis in a large sib-pair sample." *J Am Acad Child Adolesc Psychiatry*. 2011 Jan; 50(1):46-54

Hoekstra PJ, Dietrich A, Edwards MJ, et al "Clinical differences between subjects with familial and non-familial Tourette's syndrome: a case series. *Int J Psychiatry Med* 1998;28(3):341-51.

Researchers suggest:

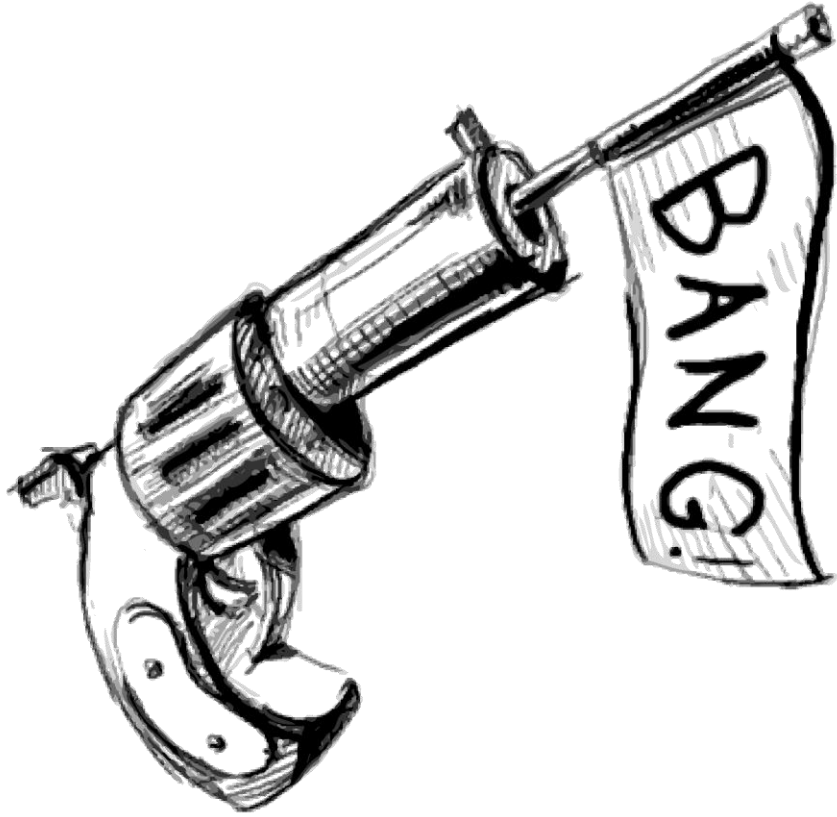
Tourette's is 60% genetic
and 40% environmental



There's a saying:



Genetics
loads
the gun. . .



and the
environment
pulls the
trigger.



We can't control what
genes we receive



But we can change
our environment.

So, what are triggers?

**ANIMAL
ALLERGY**

**INDOOR
ENVIRONS**

**FOOD
AND
DRINK**

**PARENTAL
HEALTH/
DELIVERY**

**CHEMICALS
DRUGS**

**STRESS
THOUGHT
EMOTION**

**WEATHER
SEASONS**

**FRAGRANCE
ODORS**

**TEMP
CHANGE
HEAT**

INFECTION

**SENSORY
INPUT**

**POLLENS
DUST MOLD
INHALANTS**

Conditions with recognized symptom triggers

ADD and ADHD

Anaphylaxis

Anxiety

Arthritis/Gout

Asthma

Atrial fibrillation

Autism

Colitis

COPD

Crohn's disease

Depression

Eczema

Epilepsy

Essential tremor

Fibromyagia

GERD

Hay fever

Headache

Hives

Irritable bowel

Lupus

Migraine

PANDAS/PANS

Parkinson's disease

Psoriasis

Rosacea

Trigeminal neuralgia

Ulcerative colitis

Research shows that kids with Tourette Syndrome often have other physical complaints. Unfortunately these aren't investigated to discover the *cause* of the tics.

4X increase in migraines

visual defects

**hypersensitivity to
light and touch**

vomiting

headaches

nausea

night terrors

cramps

**problems falling
asleep and waking**

“feeling sick”

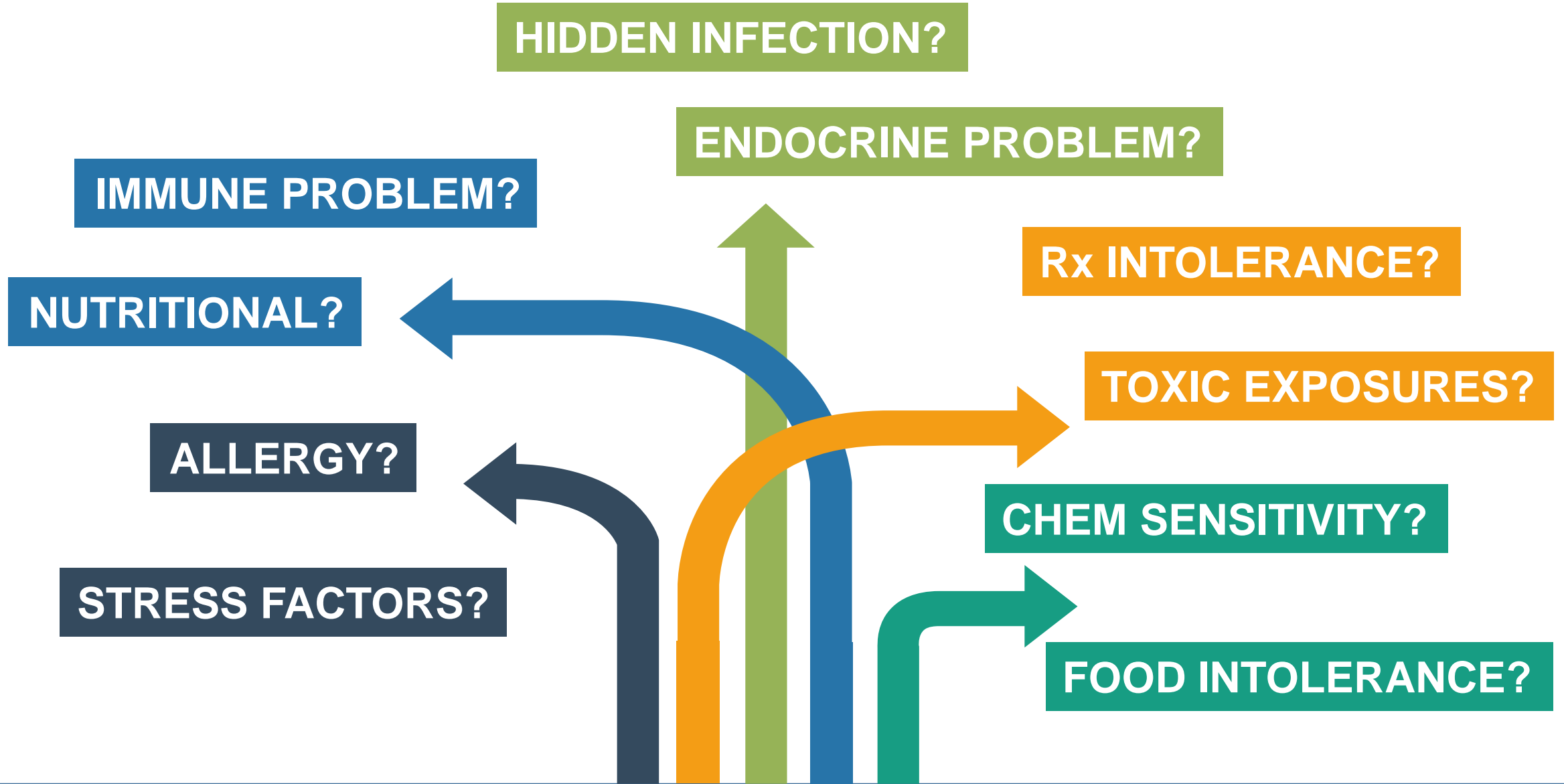
aches and pains

heat sensitivity

talking in sleep



Make a diagnosis



The first list of triggers for
Tourette's from ACN's
2004 survey of 1794 people.



Since then hundreds of doctors, patients,
and families have shared their findings.

First survey on triggers for tics

- Alcohol
- Artificial colors and flavors
- Artificial sweeteners
- Caffeine
- Chlorine
- Chocolate
- Cleaning chemicals
- Clothing / fabric
- Corn, orange juice, wheat,
- Dairy
- Dental related
- Dust
- Flashing lights / bright or fluorescent lights
- Foods (numerous)
- Fumes from fuel
- Heat (temperature increase)
- Infections (bacterial/viral)
- Medications
- Miscellaneous toxic chemicals
- Molds
- New carpeting
- Noise
- Paint and thinners
- Perfumes/scented products
- Pets
- Pesticides
- Pollens
- Preservatives/MSG
- Smoke
- Stress
- Sweets/sodas
- Video games
- Yeasty foods
- Vaccines (specific)


Source: ACN Latitudes



Whoa! How can
there be so many
triggers for tics?

Trigger lists always include items that have aggravated *some* people, but that doesn't mean they affect everyone.





Barabas G, Matthews WS, Ferrari M "Tourette's syndrome and migraine" Arch Neurol. 1984 Aug;41(8):871-2

4x the incidence of migraine

Triggers for migraine

- Aged cheeses
- Alcohol
- Aspartame
- Baked goods
- Caffeinated beverages
- Chocolate
- Dairy foods
- Fruits (avocado, banana, citrus fruit)
- Preservatives
- Processed foods
- Salty foods
- Skipping meals or fasting

- Meats containing nitrates
- Medications: oral contraceptives and vasodilators
- MSG
- Onions
- Peanuts and other nuts/seeds
- Processed, fermented, pickled, or marinated foods

Foods with tyramine

Chicken livers
Figs; certain beans
Red wine; aged cheese
Smoked fish

Sensory issues

- Smell of perfume
- Smell of paint thinner
- Secondhand smoke
- Bright lights and sun glare
- Loud sounds

Other

- Change in weather/pressure
- Changes in wake-sleep patterns
- Intense physical exertion
- Stress

Potential triggers to investigate





From a cardiologist in the 1980s

An exposure to fluorides doubled my daughter's tics. . . a diesel motor running increased her tics . . . Exposure to paint doubled her tics for six hours . . . Exposure to paraffin in a small restaurant with many burning candles produced nonstop tics until we left.

continued

From a cardiologist in the 1980s, continued

In my opinion, her sensitivity to chemicals produces a marked increase in the intensity and frequency of her symptoms.

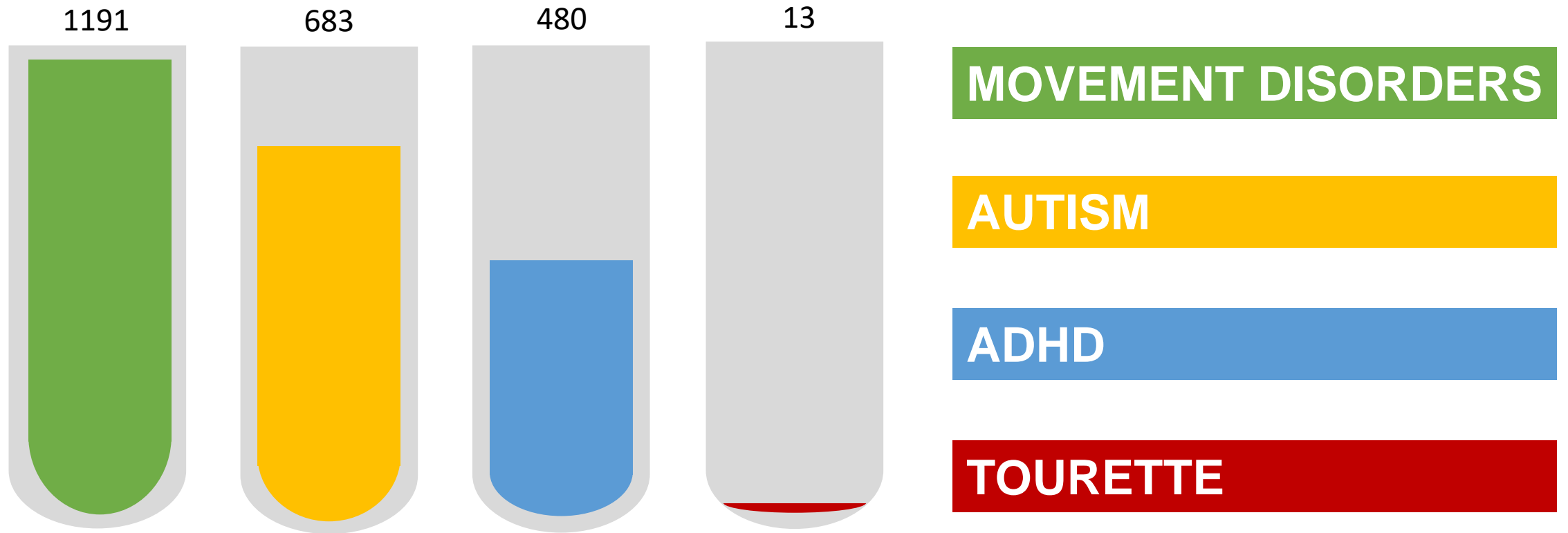




I'm a clerk at a Canadian post office, and one night I was sorting bundles of magazines entitled Cosmetics. I was looking at this title word on cover after cover. Then my Tourettic mind started looking at it from a different angle. I saw the title become "cos-me-tics," pronounced "cause me tics." And it's true—they can cos me tics!

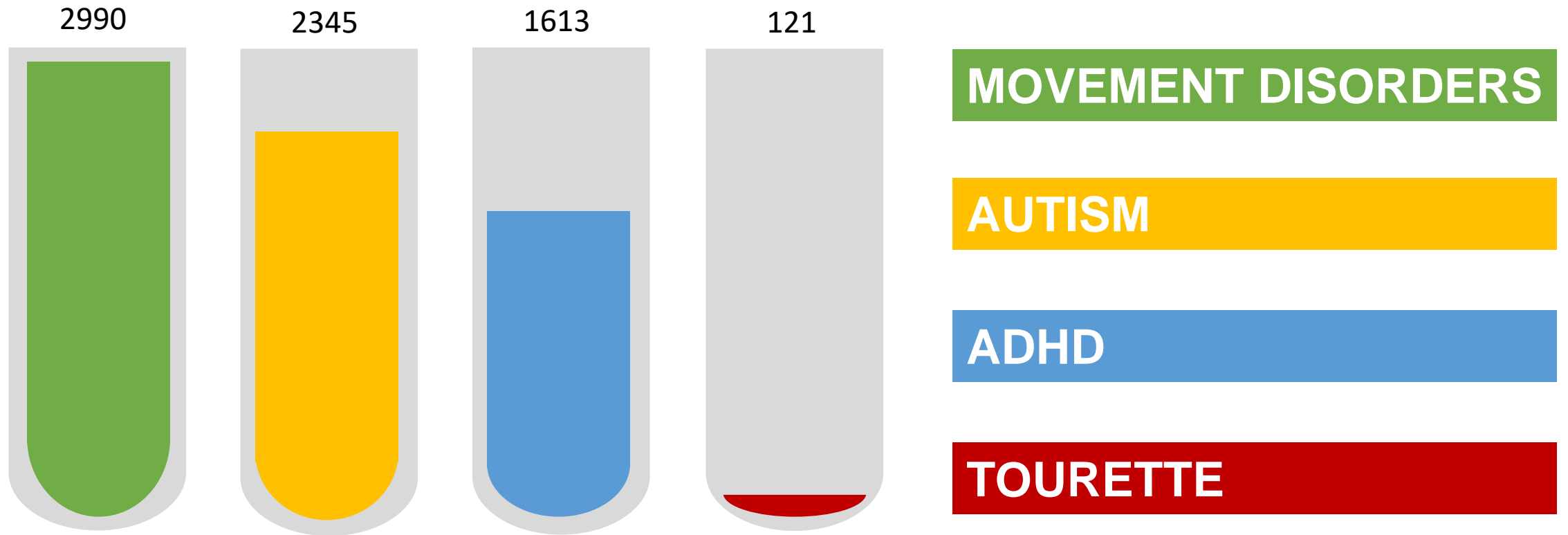
Relative research interest in diet

The # of studies found with a PubMed search for the condition and nutritional therapy March 2019



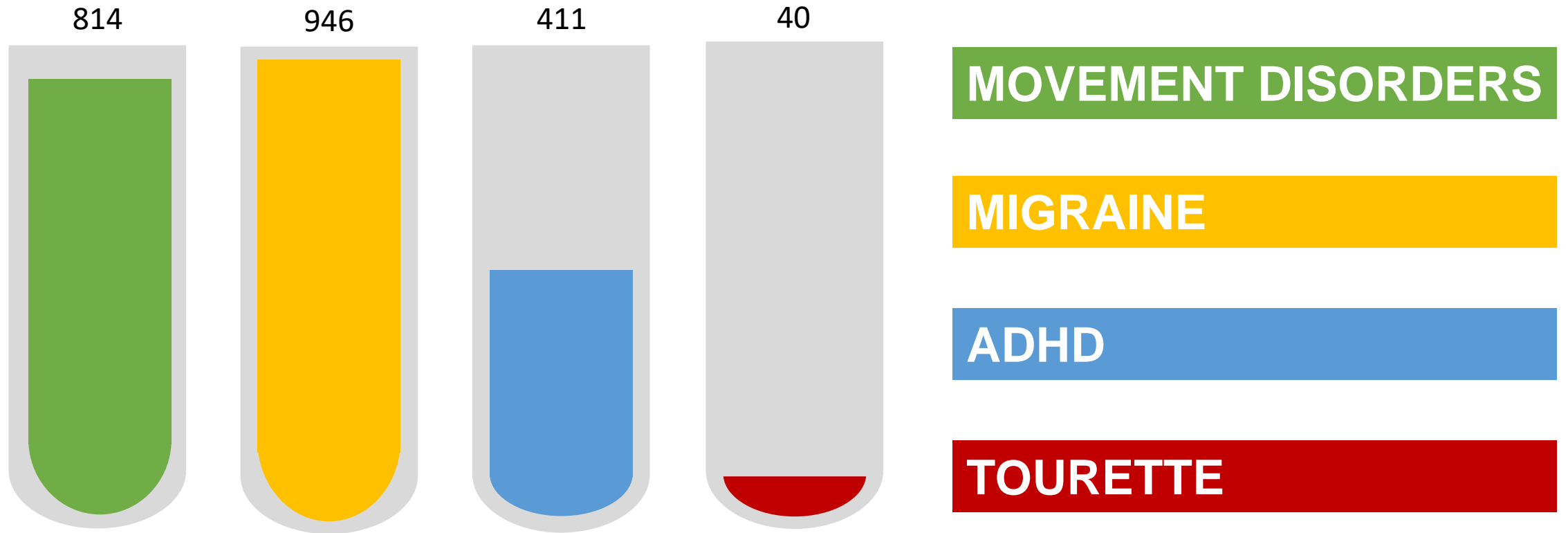
Relative research interest in environment

The # of studies found with a PubMed search for the condition and environment March 2019



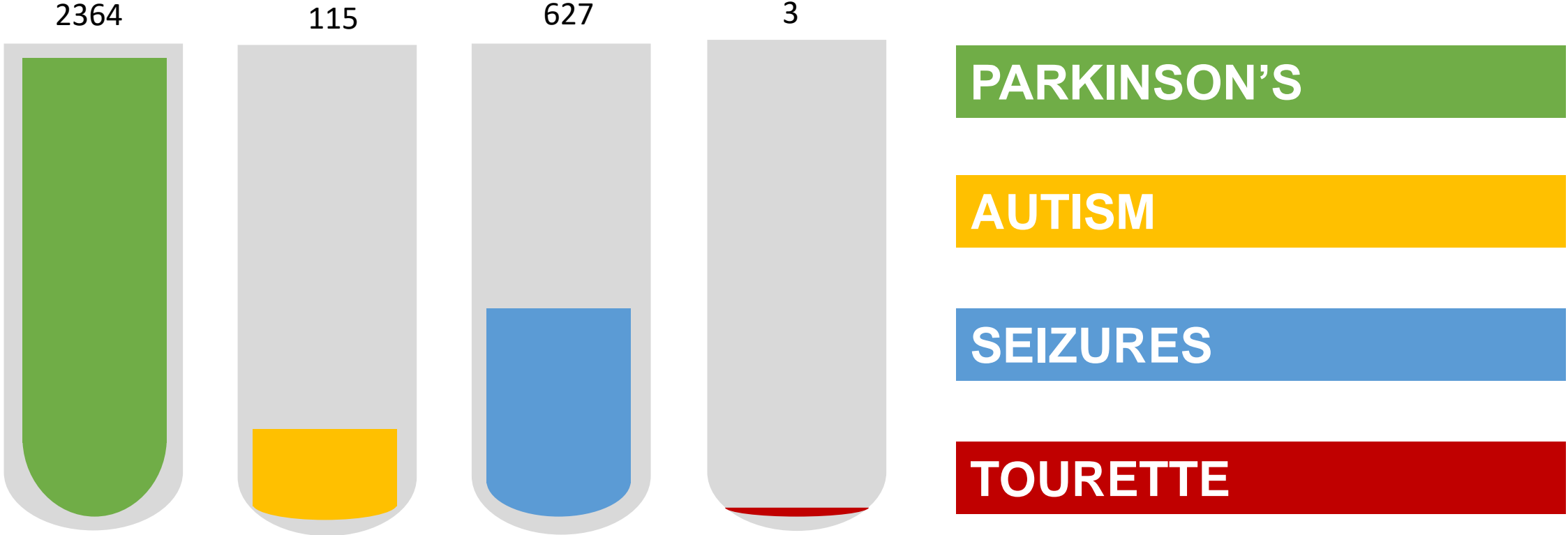
Relative research interest in allergy

The # of studies found with a PubMed search for the condition and allergy March 2019



Relative research interest in pesticides

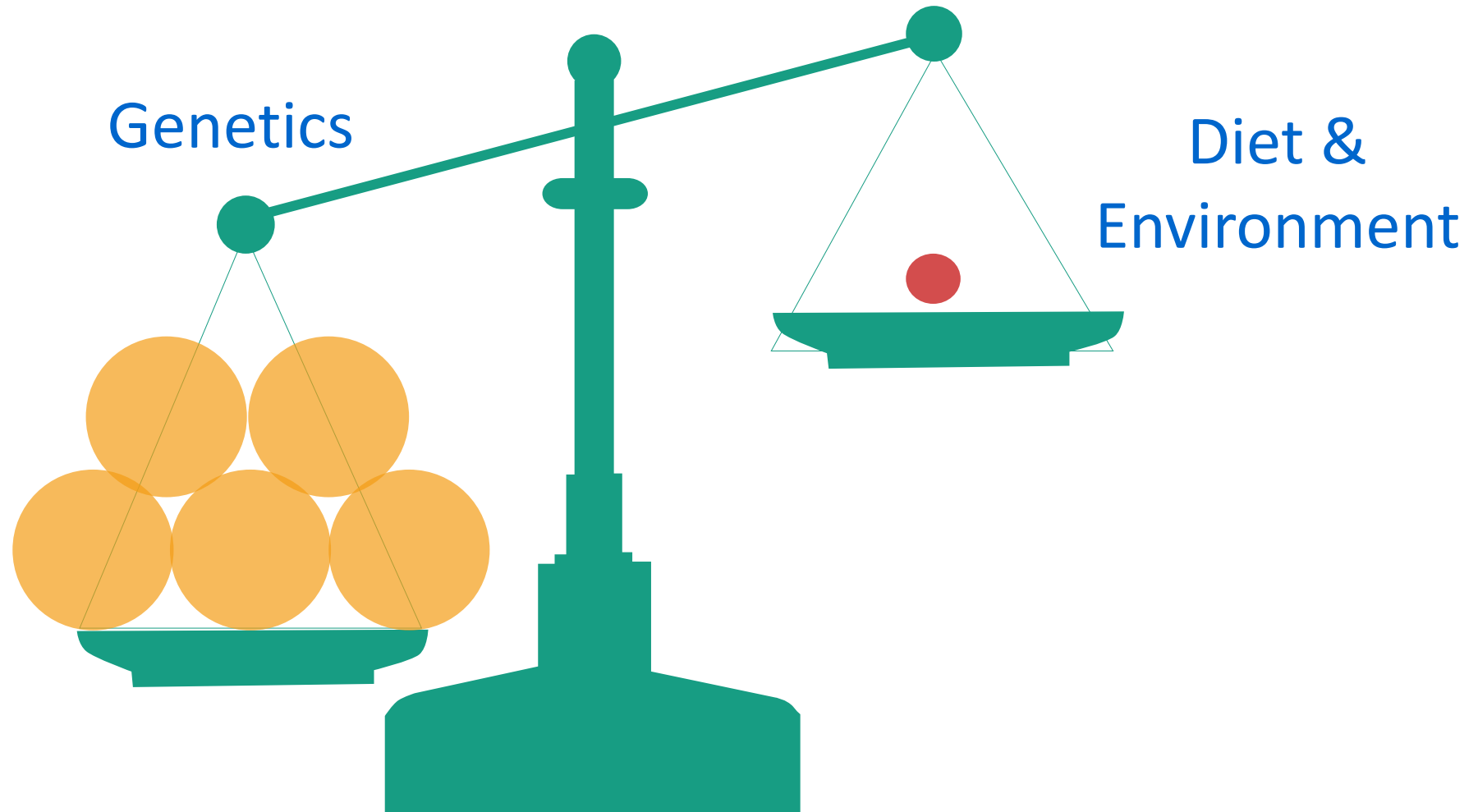
The # of studies found with a PubMed search for the condition and pesticides March 2019



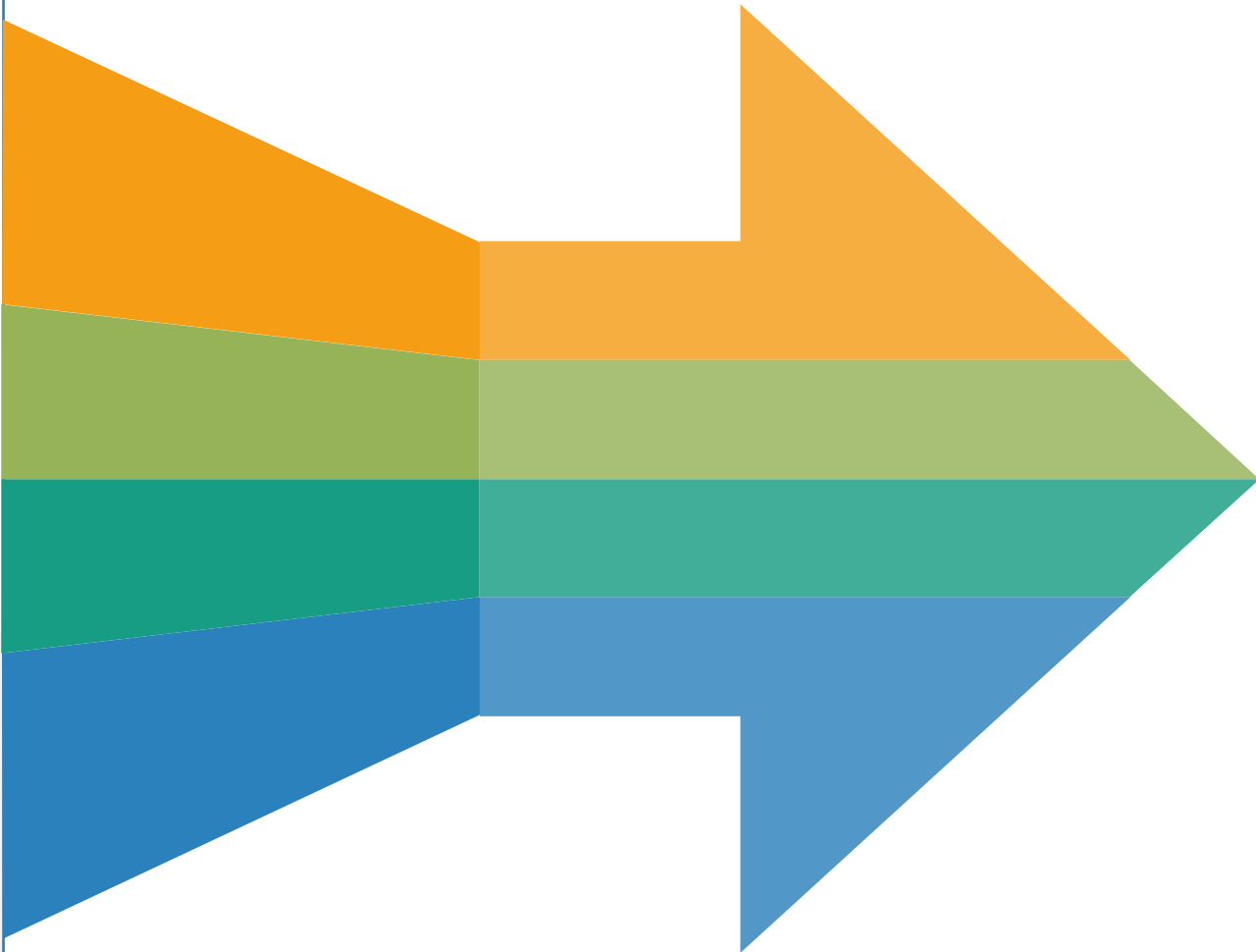
Conventional medicine has ignored the role of diet and the environment in tics. Meanwhile it has little else to offer.



The imbalance in research on tics



So very slow...



“In general, it takes **two generations** for new ideas to be accepted — perhaps **even 50 years in medicine** because of the huge monolithic medical establishment that has **one mission: to preserve its own territory.**”

Abram Hoffer, MD

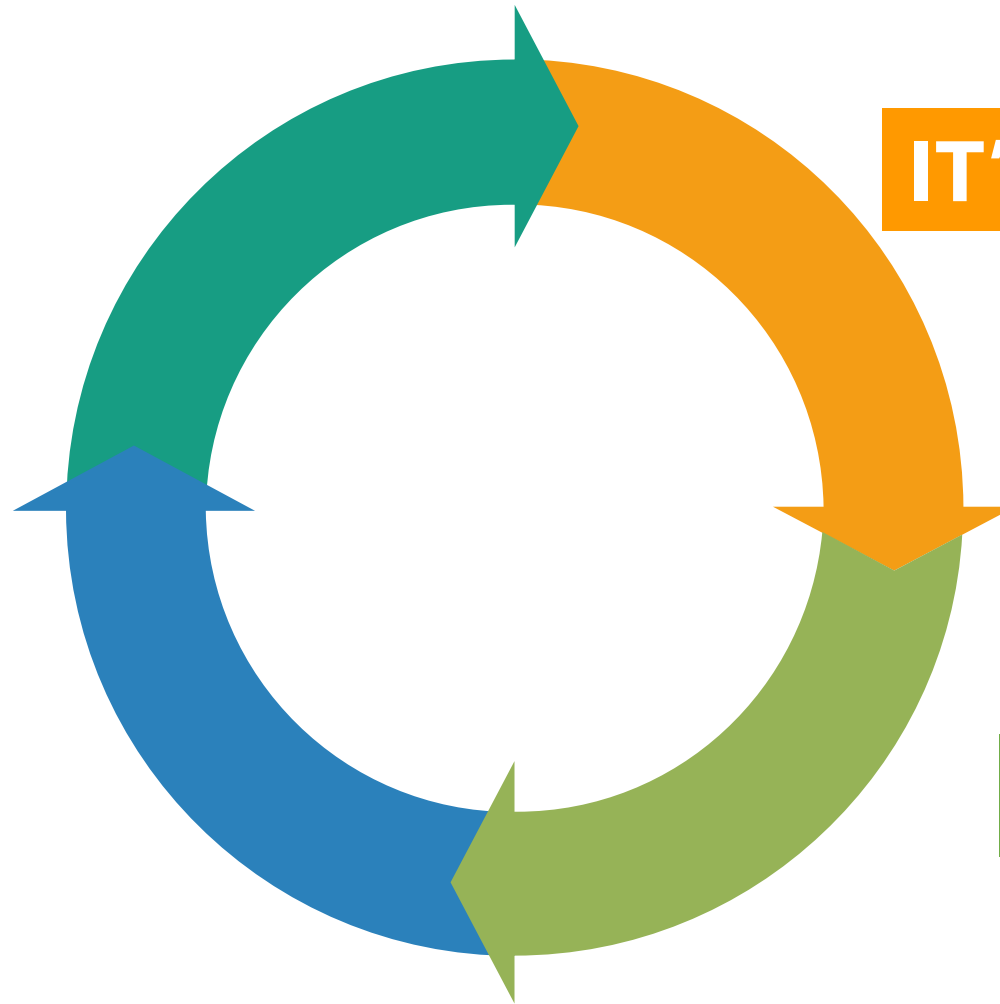
A Circle Going Nowhere

IT'S GENETIC

IT'S A MYSTERY!

NO ANSWERS

NO RESEARCH



Hypersensory Sensitivities in Tourette's



Temperature

Odors/Chemicals

Touch/Movement

Visual/Auditory

Food and Drink Influence in Tourette's



Food allergy

Intolerances

Sugars

Additives

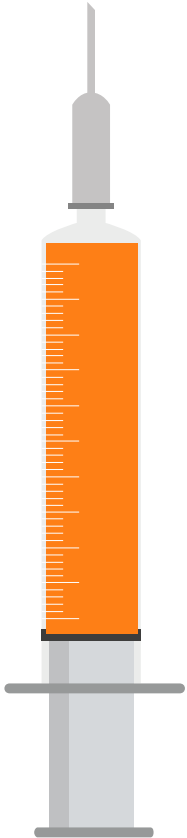
What vaccine studies say

Tics and thimerosal 1

Safety of thimerosal-containing vaccines: a two-phased study of computerized health maintenance organization databases.

... cumulative mercury exposure from thimerosal-containing vaccines ... Results ... **cumulative exposure at 3 months resulted in a significant positive association with tics.**

Verstraeten, Davis, DeStefano et al; Pediatrics. 2003 Nov;112(5):1039-48.



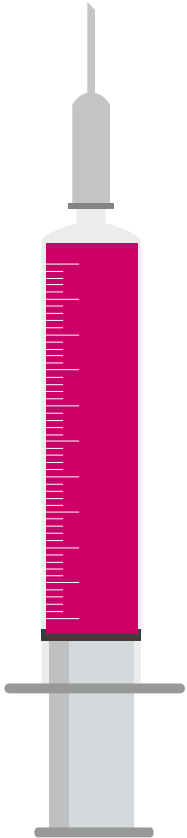
What vaccine studies say

Tics and thimerosal 2

Thimerosal exposure in infants and developmental disorders: a retrospective cohort study in the United Kingdom does not support a causal association.

With the possible exception of **tics**, there was no evidence that thimerosal exposure via **DTP/DT vaccines** causes neurodevelopmental disorders.

Andrews, Miller, Grant et al *Pediatrics*. 2004 Sep;114(3):584-91.



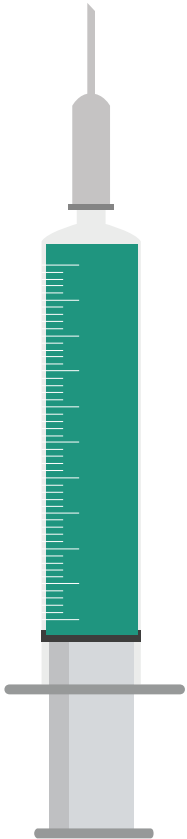
What vaccine studies say

Tics and thimerosal 3

*A two-phased population epidemiological study of the **safety of thimerosal-containing vaccines: a follow-up analysis.***

... **significant associations between cumulative exposures to thimerosal** and the following types of neurological disorders: unspecified developmental delay, **tics**, attention deficit disorder (ADD), language delay, speech delay, and neurodevelopmental delays in general.

Geier & Geier *Med Sci Monit.* 2005 Apr;11(4):CR160-70. Epub 2005 Mar 24



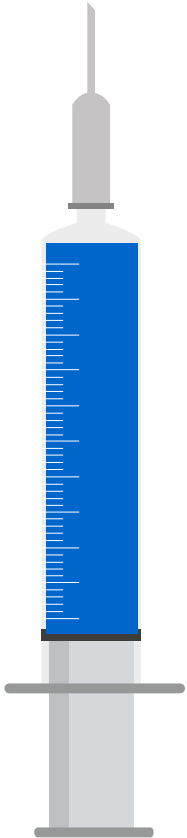
What vaccine studies say

Tics and thimerosal 4

Thimerosal exposure in infants and neurodevelopmental disorders: an assessment of computerized medical records in the Vaccine Safety Datalink.

Consistent significantly increased rates . . . tics, attention deficit disorder, and emotional disturbances **with mercury exposure from thimerosal containing vaccines.**

Geier & Geier J Neurol Sci. 2008 Aug 15;271(1-2):110-8. Epub 2008 May



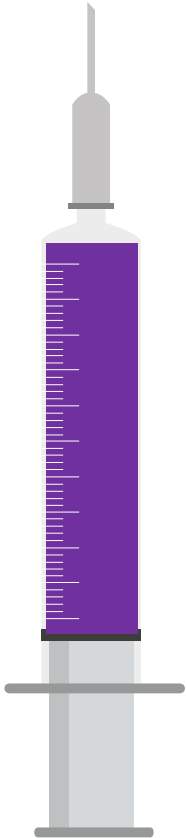
What vaccine studies say

Tics and thimerosal 5

Thimerosal exposure in early life and neuropsychological outcomes 7-10 years later.

The authors found . . .there was a **small, but statistically significant association between early thimerosal exposure and the presence of tics in boys.**

Pediatr Psychol. 2012 Jan-Feb;37(1):106-18. doi: 10.1093/jpepsy/jsr048.





Most vaccines in USA since 2001
are thimerosal-free. All are
available without the
mercury preservative (says CDC)

Insist on them

If living in another country
be proactive and
check your options

Questions from the thimerosal studies

1. If ethylmercury can trigger tics, what other toxins can do so?
2. How long do tics, caused by thimerosal, continue?
3. What should be done to remedy a toxic overload?
4. What happens if these children are given a flu shot containing ethylmercury every year? And how does the same shot affect the fetus in a pregnant woman?

Challenges in Trigger Monitoring





Getting started
with diet change



Food additives were causing tics, with artificial colors at the top of the list, artificial flavors next. . . All the neurologists and psychiatrists we saw thought we were imagining this.



Challenges and opportunities at school and other activities.



Your website was enormously helpful to me. I started an elimination diet for my son and we discovered that his tics are brought on by gluten, corn, and cane sugar. MSG does it also.

A close-up portrait of a man with short, slightly messy grey hair and light-colored eyes. He is wearing a dark green V-neck sweater over a light-colored t-shirt. He is looking off-camera to the right with a slight, thoughtful smile. The background is a blurred outdoor setting with green foliage and a wooden fence. The image is framed by a solid green border on the left and right sides.

It's never too late
to find triggers



... I discovered that they all contained various amounts of sodium phosphate, sodium erythorbate, and/or sodium nitrate(s). I was obviously sensitive to these chemical additives.

continued

continued

I suggest readers who suffer from tics and Tourette's be conscious of what they eat, and read the labels of food products. I encourage experimentation with foods and other factors that alter or modify a person's tics, tensions, and anxiety—and keeping good records.



Nothing produces such dramatic relief as identifying an allergic trigger and eliminating it.

Dr. Leo Galland, *The Allergy Solution*

Is the home allergy-free?



Make bedrooms an allergy-free sanctuary



- Dust-proof beds and floors
- Use natural bedding & furniture
- Check for electronics
- Look for mold
- No scented products or candles
- Pets?
- Consider a quality air purifier

Pollens and molds



Use natural unscented laundry products



Toxic chemicals are used on parks, athletic fields, and golf courses

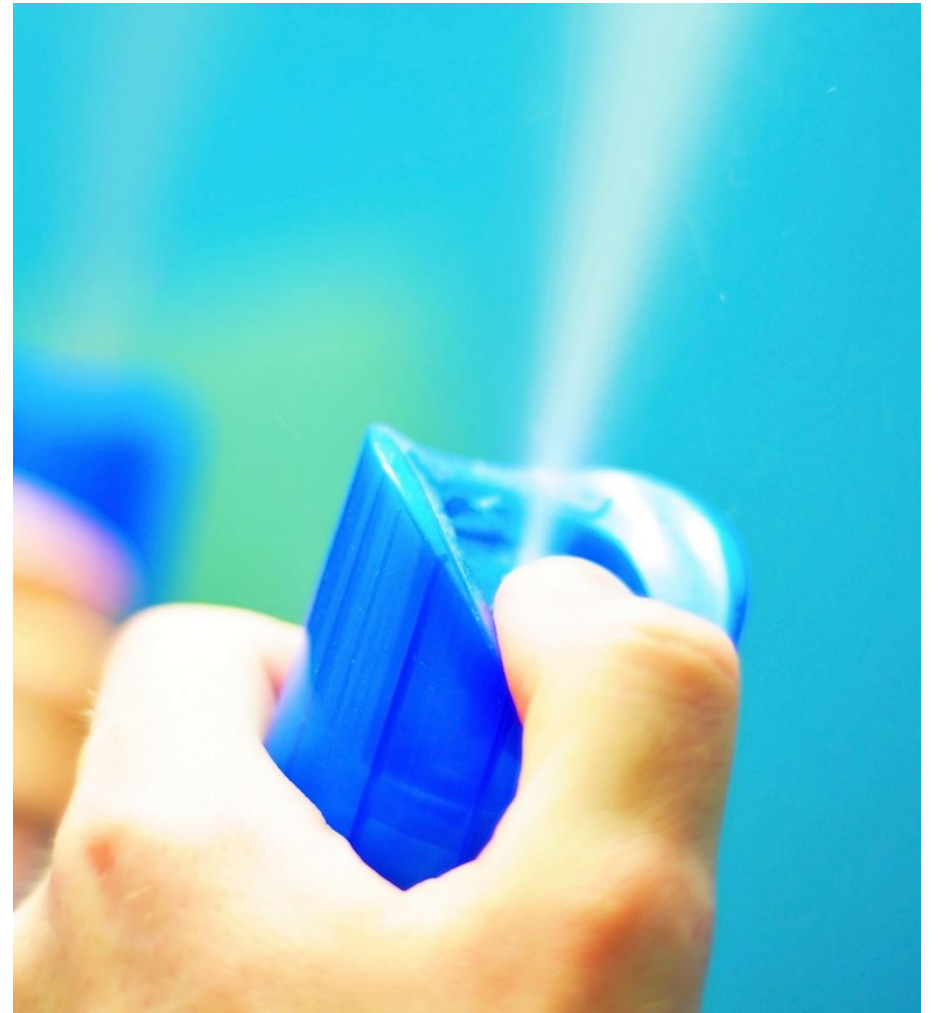


Beware the new car smell. It has toxic volatile organic compounds

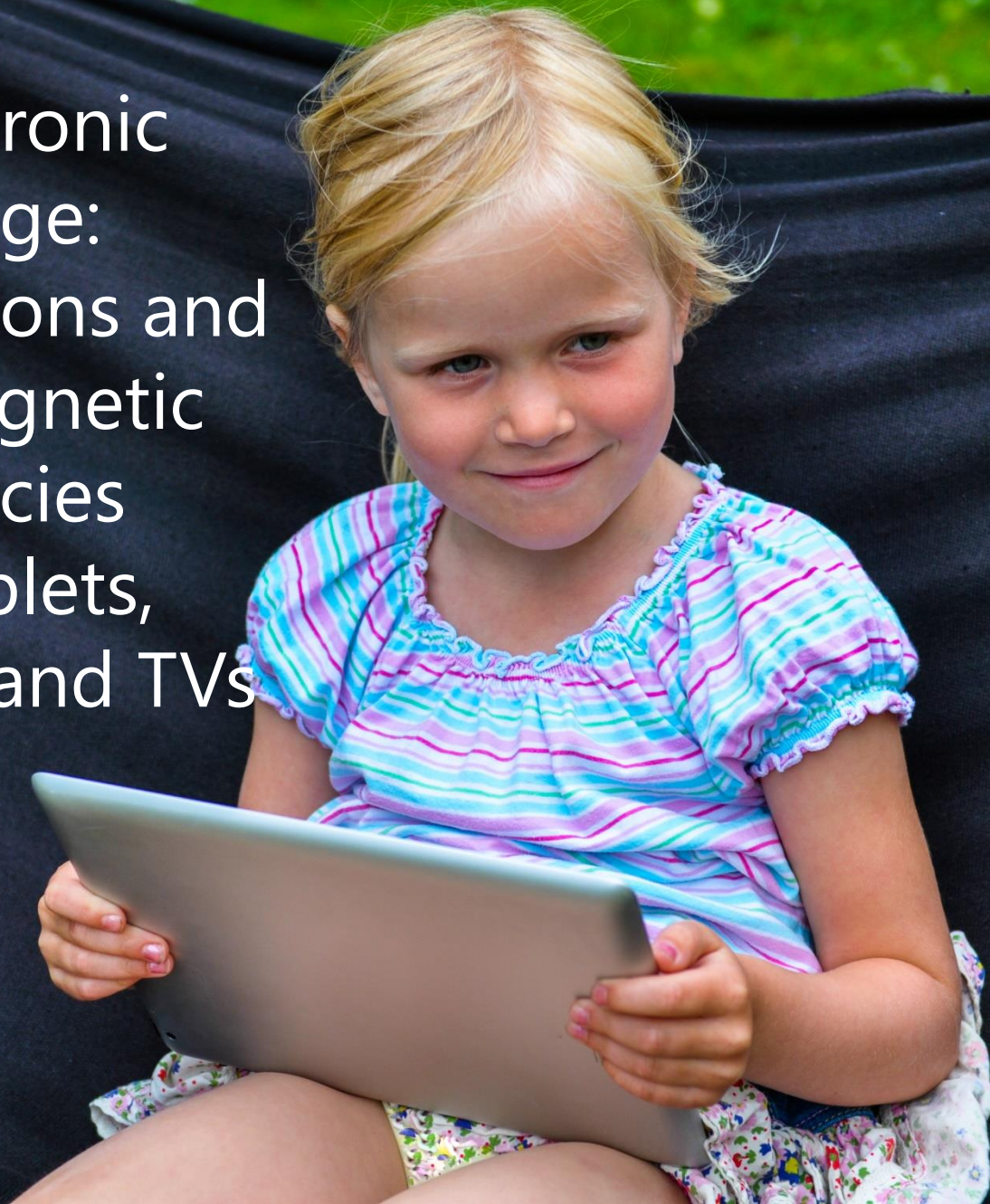
Minimize exposure to gas smells, exhaust and pollution.



Avoid air fresheners,
plug-ins, and conventional
scented candles



The electronic
challenge:
Visual reactions and
electromagnetic
frequencies
from tablets,
computers and TVs





Natural cleaning products are easy to find.

From gerbils to hamsters, and cats to dogs,
many pets can aggravate allergies



Read labels on personal products



Monitor
stress and
fatigue



5 steps for success



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Attention Deficit Disorders

- Symptoms & Diagnosis
- Prevention & Treatment
- Families Speak Out
- Resources & Research

Tourette Syndrome & Tics

- Symptoms & Diagnosis
- Prevention & Treatment
- Families Speak Out
- Resources & Research

PANDAS & PANS

- Symptoms & Diagnosis
- Prevention & Treatment
- Families Speak Out
- Resources & Research

OCD

- Symptoms & Diagnosis
- Prevention & Treatment
- Families Speak Out
- Resources & Research

Learning Disorders

- Symptoms & Diagnosis
- Prevention & Treatment
- Families Speak Out

Autism

- Symptoms & Diagnosis
- Prevention & Treatment

Depression

- Symptoms & Diagnosis
- Prevention & Treatment

Electrohypersensitivity

- Symptoms & Diagnosis
- Prevention & Treatment
- Families Speak Out

Other Conditions

- Anxiety
- Lyme Disease
- Seizures

What makes me tic?

Circle what you think

Name _____ Date _____



Computer or tablet



Food or drink



Sunlight



Swimming pool



Being in school



Reading



Car or bus rides



What else?



Feeling sick



Clothes



Too hot or too cold



Allergies



Watching TV

(c) Latitudes.org A supplement to *Tourette Syndrome: Stop Your Tics by Learning What Triggers Them*

- Computer or tablet
- Sunlight
- Food or drink
- Reading
- Swimming pool
- Being in school
- Feeling sick
- Car or bus rides
- Clothes
- Too hot or too cold
- Allergies
- Watching TV

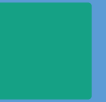
Click below to download charts
and get helpful links

<https://latitudes.org/njcts-triggers>



... Please don't let this letter end up in a wastebasket. I feel strongly others could be helped.





THANKS





QUESTIONS?

