

Healing Tourette Syndrome

A new paradigm

Sheila Rogers DeMare, MS



Tourette Syndrome Conference
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Sponsored by the
Brad Cohen Tourette Foundation

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www.Latitudes.org

ACN Latitudes



Who we are
How we started
What we do

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www.Latitudes.org

ACN's advisory board

Mary Ann Block, MD; Integrative medicine
 Marne Glaser, MA; Electromagnetic Safety
 Christopher Grayson, MBA; Research compliance
 James Greenblatt, MD; Psychiatry
 Helen Irlen, MA; Scotopic sensitivity
 Ricki Linksman, MEd; Accelerated learning
 Siegfried Othmer, PhD; EEG Biofeedback
 William Rea, MD; Environmental medicine
 Sherry Rogers, MD; Environmental medicine
 William Shaw, MD; Laboratory research/testing *Continued*

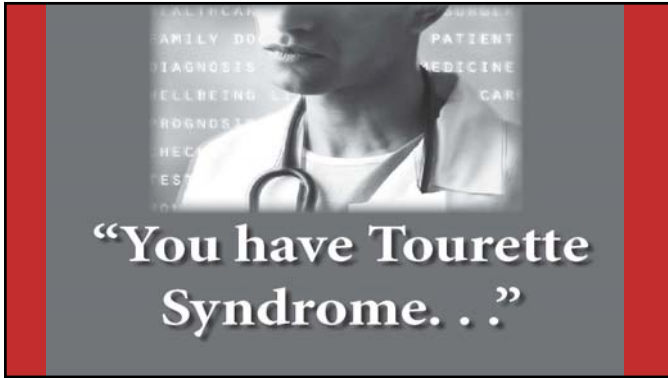
ACN's advisory board, *continued*

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
 Mona Wimmer; Behavioral Interventions
 Rose Winter, AIA; Green Building and LEED Certification
 Mark Young, PhD; Psychology
 Marshall Zaslove, MD; Neurology/Psychiatry

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who's
 drinking
 the
kool-aid?





Classic advice on Tourette syndrome

- Tourette's is genetic and there is no cure
- **Try to reduce stress**
- Tics will mysteriously come and go: waxing & waning
- **Tell teachers, friends and family**
- Medications are available, but the side-effects can be worse than the tics themselves
- **Remember, no one ever died from Tourette syndrome**

Did you know?

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.

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.

Don't

let your child hear comments from the doctor like: "Your son **has Tourette syndrome** and **there is no cure.**"



"Why would you tell us to lie to our children? **There is no cure—that's the truth!**" -- A concerned mother and

Tourette association advocate



“Have you **contacted** the National **TSA** or similar organizations or talked with **Tourette parents** . . . because **you have it all wrong.**”

May 2016

I was the “liaison” on alternative therapies to the Tourette Syndrome Association for several years.

I am also in regular contact with patients, families, and physicians regarding Tourette’s.



Sheila Roger Demare
Director, Association for Comprehensive NeuroTherapy
www.Latitudes.org

Don’t

believe that tics and Tourette’s are only genetic and there’s nothing you can do except medicate.

Do

look at tics as **symptoms** of a **body imbalance** that needs to be addressed and **fixed**, not just something to be subdued with drugs.

2

The role of the environment



What's the "environment" in medicine?

The term environment includes:

Physical, chemical, biological, and social influences

- Parental health / prenatal conditions / delivery
- Food and drink
- Infection
- Chemicals and drugs; odors, fragrances
- Allergens, pollens, dust, molds, dander
- Seasons / temperature change
- Indoor environments
- Stress / thoughts / emotion
- Sensory input

What is Environmental Medicine?

Environmental medicine: Addresses adverse reactions to an environmental excitant in **air, food, water, and drugs**; these are frequently found in the **home, work, school, and play environments**.

Exposures to these agents may adversely affect one or more organ systems and this effect is **commonly not recognized by individuals and their physicians**.

American Academy of Environmental Medicine
www.aaemonline.org

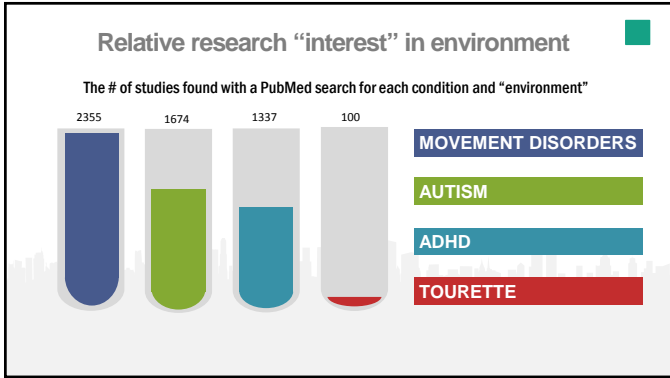
Research on Tourette's
and the environment

- A summary of current findings
- What's missing?

1. Some of our slides in this presentation show the results of searches on PubMed.gov in May 2016
2. **The # of articles shown is greater than the actual number of studies that focus on that topic**
3. The graphs were developed to give a comparison of current medical conditions and related research interest

Research interest

The environment
Movement disorders
ADHD
Autism
Tourette



Research interest

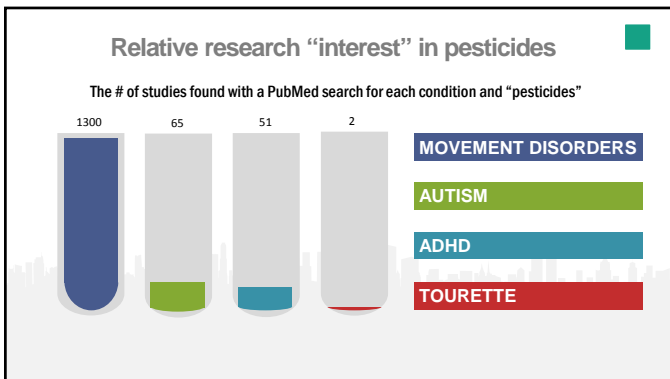
Pesticides

Movement disorders

ADHD

Autism

Tourette



The patient's exposure history

- Home, school, office
 - A/C and heating system
 - Bedroom
 - Pets
 - Personal care products
 - Geographic area and pollens
- Dust and mold exposures
 - Hobbies, lifestyle
 - Chemicals, foods, addictions
 - Activity level, medication use
 - Stress, emotional issues

Dr. Albert Robbins



What the doctor needs to do for tic disorders

3



“First, do no harm.”



Examine and evaluate



“Allergic individuals may not tolerate chemicals or drugs well, due to detoxification problems, systems overload, and multiple environmental intolerances.” Dr. Albert Robbins



Without an environmental history

- Environmental cause(s) may be missed
- The treatment prescribed may be inappropriate
- The causes and aggravating factors will continue, and the illness may progress and become irreversible

Albert Robbins, DO

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"
heat sensitivity	aches and pains
	talking in sleep

Possible comorbid conditions with Tourette's

- Depression
- Learning problems
- Sensory disorders
- Anxiety
- Personality disorders
- Oppositional defiant disorder
- Sleep disorders
- Migraine

Lab tests to consider: Albert Robbins, DO

<ul style="list-style-type: none"> • Allergy evaluation • Nutritional evaluation • Toxic metals evaluation • ASO titers for hidden Strep • Test for other infections • Stool studies for parasites/yeast • Urinalysis • Immune studies 	<ul style="list-style-type: none"> • Thyroid studies • C-reactive protein (CRP) • Comprehensive metabolic panel • Complete blood count • Total IgE and IgA • Copper • Ceruloplasmin <p><i>Select tests based on clinical evaluation</i></p>
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Recommendations by William Shaw, PhD
Director, Great Plains Laboratory

- People with Tourette's, OCD, ADHD and/or chronic tic disorders may also have allergies, anxiety, autoimmune disease, chronic pain, eating disorders, headaches, cognitive difficulties, restless leg syndrome, and/or poor immunity
- These conditions are typically associated with oxidative stress, mineral deficiency, and microbial imbalance

Lab tests to consider: William Shaw, PhD

Priority

- GPL-TOX Toxicology panel
- Glyphosate
- Organic acids test
- Metals hair test
- Copper / zinc profile
- Streptococcus antibodies profile
- Igg food allergy test + candida
- Advanced cholesterol profile

Recommended

- Inhalant allergy test
- Food allergy test
- Comprehensive stool analysis
- Comprehensive fatty acids test
- Gluten/casein peptides test
- Amino acids urine test
- Vitamin D test

Medical workups for tic disorders

ALBERT ROBBINS, DO

JON PANGBORN, PhD

WILLIAM SHAW, PhD

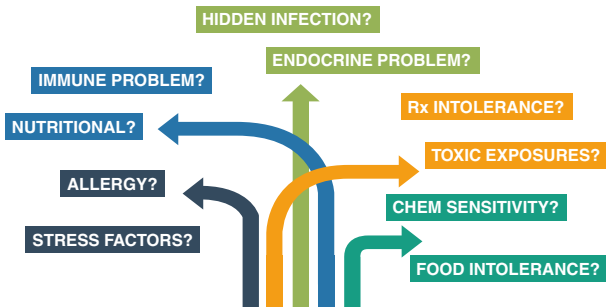
INTEGRATIVE

See: www.Latitudes.org/medical-workups-tics




After a thorough medical evaluation, a doctor should refer out when he/she can't help a patient or when a different specialty is needed.

Make a diagnosis



4

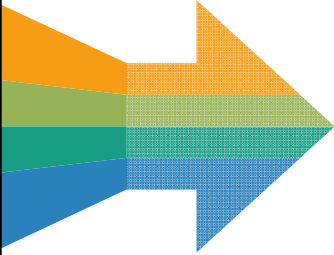
Change medicine in



“Discovery consists of seeing what everybody has seen, and thinking what nobody has thought.”

Albert Szent Györgyi
1937 Nobel Laureate
in Physiology and Medicine

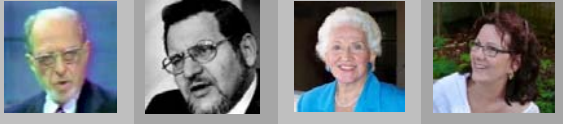
So very slow...



“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

Tourette Super Stars



RANDOLPH **MANDELL** **RAPP** **WAKEM**

Theron Randolph, MD



- The father of environmental medicine
- The first to link Tourette syndrome symptoms to food reactions in a patient; 1970s
- Criticized for proposing Multiple Chemical Sensitivities, a condition that is just now being accepted

Marshall Mandell, MD



- 30+ years ago, saw that allergens, toxins, and foods could trigger tics in many with Tourette's. Spent 1000+ hours, treated 23 patients *free of charge* to confirm findings.
- Shared findings at '80s international medical symposium on Tourette's. "No one asked a single question or ever contacted me," he said.

"I predict that nutritional, allergic, and immune factors will be found to be key factors in the development of tics. Unfortunately, by [the time this is accepted by mainstream medicine] **thousands of families*** will have suffered needlessly."

Marshall Mandell, MD

(Written for *Latitudes* more than 20 years ago)

***Dr. Mandell should have said millions of families worldwide!**

Doris Rapp, MD



- Popularized environmental medicine; best-selling author of *Is This Your Child?*
- Brought a boy with Tourette's on the "Phil Donahue Show"; showed how foods, allergens and chemicals could trigger symptoms
- Reviled by medical community; Could not get the Tourette Syndrome Association to respond

"I spent a fortune on videos [of kids with symptom reactions]. But people said the kids were acting. . . then they said the kids were tired or irritable, they needed a nap. Finally I said, 'Doris, forget it...they are never going to believe you.' But I say, academics ought to listen to what we're saying. If they can't help patients, why won't they at least let us try to help?"

Doris Rapp, MD

Quoted in Allergic to the Twentieth Century

Ginger Wakem



- Healed her son's severe case of Tourette's working with an environmental physician
- Started an alternative therapy network. Communicated with parents, forward-thinking doctors, and the Tourette Syndrome Association (TSA)
- Frustrated with lack of response from the TSA, she passed the effort to Sheila Rogers [DeMare]

“It was very labor intensive . . . What bothered me most was that I couldn’t get through to the Tourette Syndrome Association. I had been willing to take up the cause. But I was losing the battle if I couldn’t get the physicians on the TSA boards to listen; they controlled the message. They never changed their stance on recognizing the role of allergy. They never alerted families to the fact that there were things they could try that might make a difference for their child.”

Ginger Wakem

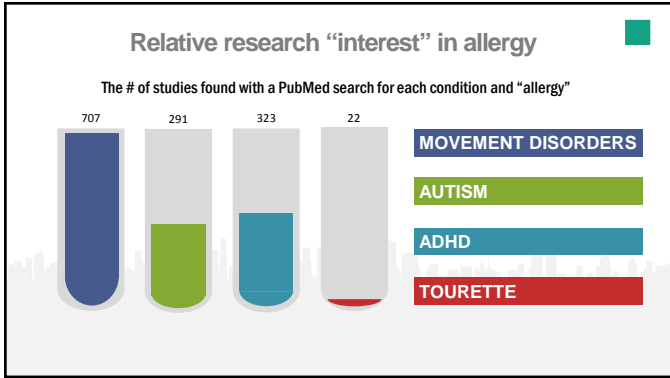
3 ways of dealing with new information in medicine

- ➔ Ignore it
- ➔ Explore it
- ➔ Silence it

Research interest

Allergy

Movement disorders
ADHD
Autism
Tourette




5

A fresh approach


way Embracing a new paradigm to treat Tourette syndrome





Conventional approach to Tourette syndrome

- A short checklist = a diagnosis of Tourette's
- This label drives drug treatment to subdue tics
- The patient is not properly examined and potential causes of symptoms are not explored



A new and better approach to Tourette syndrome

- Recognizes that Tourette's is not a single condition
- Medical evaluations identify causes of tics and related symptoms
- Causes may be multiple and individualized
- Medical status drives therapy, with the goal of healing the body

Old paradigm # 1

- Belief that tics were caused by hysteria, emotional problems, or evil spirits.
- **Primary treatment:** Psychotherapy.

Current paradigm #2

- Genetic factors are emphasized as the cause of tics
- **Primary treatment:** medications with significant side-effect risks and limited effectiveness

New paradigm #3

- Tourette syndrome is recognized as a multi-faceted condition with subgroups
- Patients receive a thorough medical evaluation
- Environmental triggers are explored, and avoidance therapy is employed for any identified
- **Primary treatment** is based on individualized medical needs, with a comprehensive, integrative approach

Do

know that causes for Tourette's can include **immune** responses with **allergic** and **infectious** reactions, and **chemical** and **food** sensitivities, to name a just a few.

Don't

accept waxing and waning as mysterious symptoms over which you have no control.

Do

consider **seeing a professional** to learn if **infection**, nutrient **imbalances**, or **allergies** are affecting symptoms. Structural imbalances may also be involved.

Don't

use standard medications for tics without being aware of potential side effects.

6

Triggers and TILT

What are triggers?

With our 2004 survey of 1794 people, the first comprehensive list of tic triggers was developed.

Conventional medicine has ignored our findings and not pursued the topic.





34+ "triggers for migraine"
 Source: MayoClinic.com; MedlinePlus (NIH)

<ul style="list-style-type: none"> • Aged cheeses • Salty foods • Processed foods • Skipping meals or fasting • Aspartame • MSG • Alcohol • Caffeinated beverages • Baked goods • Chocolate • Dairy foods • Fruits (avocado, banana, citrus fruit) 	<p><i>Foods with tyramine</i></p> <ul style="list-style-type: none"> • Red wine; aged cheese • Smoked fish • Chicken livers • Figs; certain beans <p>Meats containing nitrates</p> <p>Onions</p> <p>Peanuts and other nuts/seeds</p> <p>Processed, fermented, pickled, or marinated foods</p> <p>Medications: oral contraceptives and vasodilators</p>	<p><i>Sensory issues</i></p> <ul style="list-style-type: none"> • Smell of perfume • Smell of paint thinner • Secondhand smoke • Bright lights and sun glare • Loud sounds ○ Stress ○ Change in weather/ barometric pressure ○ Intense physical exertion ○ Changes in wake-sleep patterns
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4 "triggers for tics" on conventional sites
 Source: NIH; Tourette Syndrome Association May 2016 (Tourette Association of America)

- Stress
- Fatigue
- Tight collar
- Hearing someone else's tic

Um-m-m, where's the rest?
Sorry, that's it folks!

34+ "triggers for tics" on Latitudes.org

ABC order based on our major survey and reports received
Individual responses will vary, and the list does not include all possibilities

- 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 (multiple)
- 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; please *search on Latitudes.org*

Do

look for triggers for tics that go
beyond stress, fatigue and anxiety.



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.

It's worth exploring what your triggers might be, even if you only have a few.



Why are there **so many** potential triggers? Understanding a proposed condition called **TILT** helps explain it.

TILT= Toxicant Loss of Tolerance

Defined by Claudia Miller, MD



Miller, CS "Toxicant-induced loss of tolerance--an emerging theory of disease?" *Environ Health Perspect* 1997 Mar; 105 (Suppl 2): 445-453.

“TILT, our most recent medical model for disease, might be thought of as the **21st Century theory of disease**. Instead of germs or biological proteins, TILT implicates **synthetic chemicals or chemical mixtures** as causal agents. . .



“Why has medicine been so late to recognize TILT? **First**, the exposures that initiate TILT are very **new in human history**—since World War II.



“Further, TILT involves **three stages**, which has made it **all but impossible for patients or their doctors** to track what is going on:
(next page)

The 3 Stages of TILT

- 1) Initiation by a **chemical exposure** that causes breakdown in tolerance
- 2) Followed by **triggering of symptoms** by common **foods**, everyday **low level exposures**, and **drugs**
- 3) Finally **masking**, which hides the relationship between exposures and triggers.



Claudia Miller, MD

Do

keep a journal to note if foods, allergens, sensory issues or chemical exposures are aggravating tics.

Don't

expose yourself to scented products, standard cleansers, pesticides and other items toxic to the nervous system.

7

Prevention and Treatment

Do

consult a **neurologist** to rule out a number of **physical conditions** that may cause tics.



PANDAS, PANS and Lyme

Update and Resources

Patient satisfaction with treatments for Tourette syndrome A 2009 study

- 104 consecutive Tourette syndrome patients
- 60% were taking Tourette medications
- Of those, 30% experienced some type of side-effect
- Only 46% were satisfied with current treatment.
- 56% saw improvement with alternative approaches

Kompoliti K1, Fan W, Leurgans S. Complementary and alternative medicine use in Gilles de la Tourette syndrome. *Mov Disord* 2009 Oct 15;24(13):2015-9.

Potential treatments for tic symptoms

- Avoidance of tic triggers
- Nutritional therapy: diet and supplements
- Allergy therapy
- Immune therapy
- Detoxification
- Body work
- Stress reduction
- Body-mind connection therapies; Cognitive behavior therapy
- Biofeedback

Tips for detoxification of chemicals

William Shaw, PhD; Great Plains Laboratory

- 1) Exercise frequently to develop sweating. Use a towel to remove sweat frequently; chemicals may be reabsorbed back into the body
- 2) Use infrared (IFR) sauna therapy to sweat out toxins for stored and acute exposures
- 3) Take supplements of folate, B6, B12, and Trimethylglycine (TMG). They help reduce homocysteine that inhibits the ability of paraoxonase to detoxify organophosphate pesticides
- 4) Oral or intravenous glutathione helps remove toxins, as do chlorella and activated charcoal

Continued

Tips for detoxification of chemicals: *continued*

- 5) Drink purified water – by distillation, deionization, or reverse osmosis. Store in glass containers, preferably, or in plastic containers with 1, 2, or 5 designations on the bottom.
- 6) Adding lemon to water helps with detoxification. There are also many detox herbal teas available, including ingredients like dandelion root, licorice root, and burdock root.
- 7) Use chelation therapy if there is significant body burden of toxic metals.

William Shaw, PhD
Director, Great Plains Laboratory

Research interest

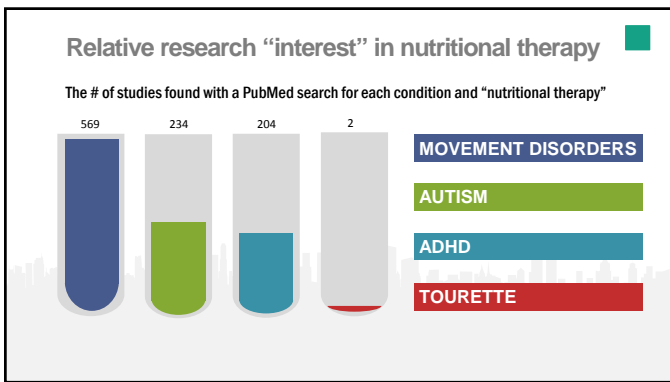
Nutritional therapies

Movement disorders

ADHD

Autism

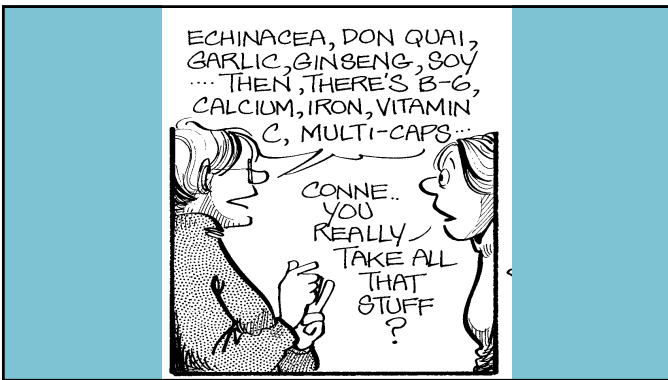
Tourette



The important gut-brain connection

- Leaky gut
- Identifying and treating imbalances
- Digestive enzymes









Don't
 assume that all natural therapies
 are safe and effective. Get
 professional guidance when needed.

Nutritional Subgroups in Depression
William Walsh, PhD



The Five Biotypes of Depression, and
 Advanced Nutrient Therapies

Nutritional therapy | Epigenetics | Methylation

Recommended: [Watch on YouTube](#)

Nutrient individuality and needs



Because of genetic differences in the way our bodies process foods, **most of us are quite deficient in certain nutrients and overloaded in others.** Even with an ideal diet, most of us have certain nutrients that are at very low levels with many times the RDA required to achieve a healthy balance.

Neurotransmitters problems



Most neurotransmitter problems appear to be genetic in nature and involve abnormal absorption, metabolism or storage of key nutrients. . . Nutrient therapy can be very potent and does not involve side effects, since no molecules foreign to the body are needed.

William Walsh, PhD

Nutritional imbalances



The most common nutrients in overload:

Copper Iron Folic acid
Calcium Methionine Manganese
Choline Omega-6 fatty acids

Of course, these same nutrients may be deficient in other persons.

William Walsh, PhD

Essential Fatty Acids



Biochemical individuality also exists with oils, and certain persons are innately low in omega-6 oils.

A review of symptoms and specialized plasma and red-cell-membrane lab tests can identify individual needs.

William Walsh, PhD

Results of fish oil study for Tourette syndrome

Gabbay V1, Babb JS, Klein RG et al, A double-blind, placebo-controlled trial of ω -3 fatty acids in Tourette's disorder *Pediatrics*. 2012 Jun;129(6):e1493-500

Treating bi-polar disorder with fish oil and inositol

- New small study: 24 subjects (almost half dropped out)
- Subjects had moderate level of symptoms
- Findings: Fish oil plus inositol worked better than either alone

A randomized clinical trial of high eicosapentaenoic acid omega-3 fatty acids and inositol as monotherapy and in combination in the treatment of pediatric bipolar spectrum disorders: a pilot study. *Clin Psychiatry*. 2015 Nov;76(11):1548-55

Marvelous magnesium

- Available types
- Dr. Carolyn Dean on benefits
- Why it's worth a try
- Adding B6

Tips to calm the nervous system

- Nutrients
- Herbs
- Holistic therapies

8

Diet *and* food issues

- Intolerance and food allergy
- Additives
- What's up with gluten?

- Testing for food reactions
- Elimination diet
- Recommendations

Dietary compliance
Getting help with our behavior charts



9

Sensory hypersensitivities

Heat Touch Odors Movement
Auditory
Visual & Irlen syndrome

Electrosensitivity
What we know
What you can do

Feedback *and*
testimonials

10

11

Resources

Please keep in touch
and share your ideas

acn@Latitudes.org

www.Latitudes.org
