

Starting Medical Intervention

For parents of children diagnosed with autism

Agenda

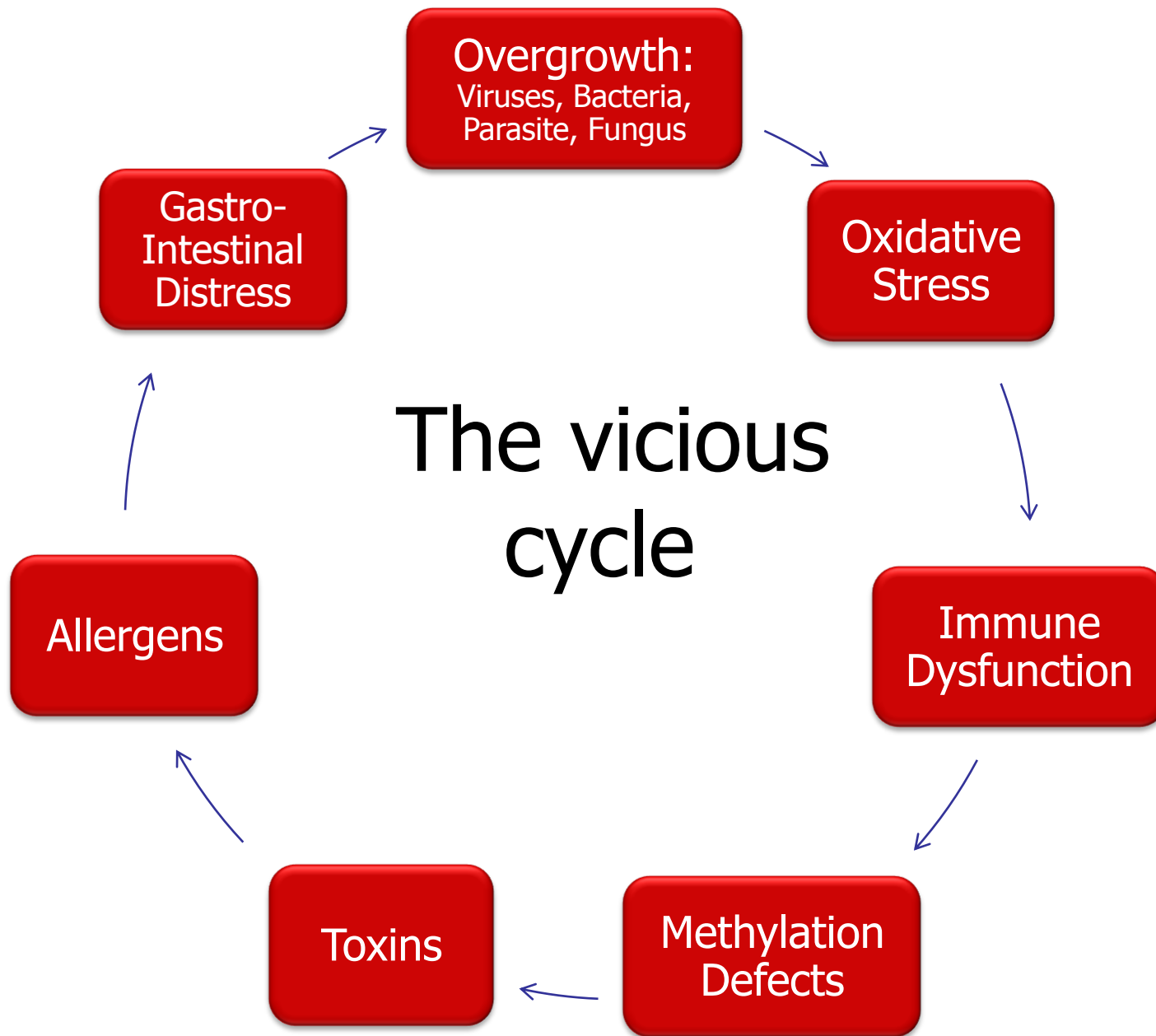
- Why treat?
- Steps to treatment
- Documentation & tips
- The treatments (including supplements & diet)
- Your homework
- Questions & Answers

My credentials



Why ASD treat medically?

- Science demonstrates children with autism have many other health problems
<http://tacanowblog.com/2012/10/15/many-children-with-autism-have-other-health-problems/>
- Am. Academy of Pediatrics has a complete guide on treatment and gastro issues
<https://www.tacanow.org/family-resources/aap-standards-of-care/>
- Cases of recovery include medical treatment not just therapies.



No one set protocol

- A very common question: “What did YOU do to heal YOUR child?”
- Unfortunately, each child has a DIFFERENT COMBINATION of Co-morbid conditions, resulting in a treatment plan unique to their needs!
- What works for one child, may not work for the next.
- The topics we’ll discuss here today are the most common and effective treatments used with ASD kids, especially the children recovered from Autism.
- For more on the “tried and true” best-practices treatments, see TACA’s Autism Journey Blueprints at <http://www.tacanow.org/family-resources/autism-journey-blueprints/>

Can These Problems Be Fixed?

- Before you panic, not all children with autism have all these problems!! But rather, individuals with autism typically have a combination of the above disorders that CAN be addressed through proper medical testing and treatment.
- *Most all of these problems CAN BE FIXED over time or mitigated and managed*
- *Hard work, consistent efforts and TIME to heal can make all the difference*

Steps to Treatment

Step 1: Save Money

- Know who pays for what
 - ✓ Use your resources wisely
 - <https://www.tacanow.org/family-resources/who-pays-for-what-a-guide/>
- TACA On a budget series
 - <https://www.tacanow.org/family-resources/autism-on-a-budget-series/>
- Be prepared – prepared folks spend less
- Insurance reimbursements
 - <https://www.tacanow.org/family-resources/health-insurance-coverage-on-a-budget/>

Step 2: Figure out “what”, “who” & “how”



- What are your child’s issues?
 - ✓ Think Match.com with other families and the specialist who can help
- Who can help you find answers?
 - ✓ What issue is handled by WHICH specialist?

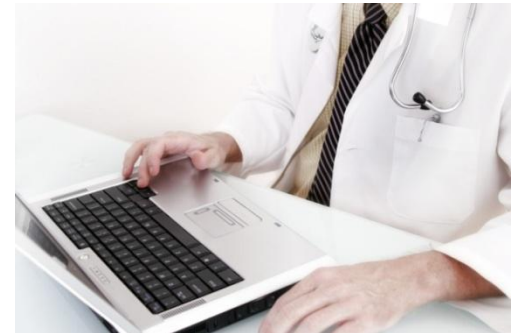
Step 3: Travel for meetings



- Parent education via meetings and conferences save you time and money
- TACA Meetings: Free, extremely valuable and driving too!
- Traveling to conferences, there is always a way:
 - ✓ Secure frequent flyer miles
 - ✓ Call and ask if you can volunteer

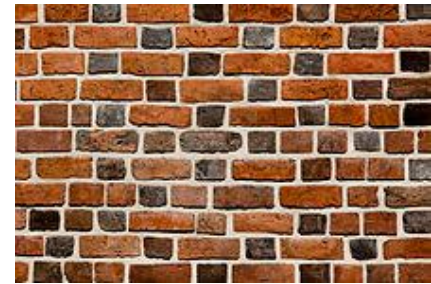
Step 4: Doctors

- These specialists are not always in your state. “Close does not equal best”
- If you are traveling for a meeting or conference – ask for an appointment with a desired speaker
- Plan your vacations, family visits or trips around your appointments!
- Hello Skype!
- GO TO CONFERENCES
armed with your files & greet them



Step 5: Breaking Down Wait List

- Laugh off Wait list! Know this:
 - ✓ Most people either walk away or put there name on the list and never follow up
- Improve your odds!
 - ✓ Fill out all the paperwork
 - ✓ Drop it off or send it via USPS Priority and call to follow up
 - ✓ Get to know the scheduler or office manager
 - ✓ Show them you are committed by checking in to fill in a cancellation



Step 6: Create A Plan



- Set up a plan and start somewhere!
 - ✓ Five things your child does that needs to stop
 - ✓ Five things your child needs to learn

TIP: Check your IEP / look at standard milestones
- Develop the plan around your family's needs
 - ✓ i.e. Water safety based on where you live!
- Use the TACA Blueprints as a guide
<https://www.tacanow.org/family-resources/autism-journey-blueprints/>

Documentation & Tips

Tips for making it happen

- Relatives frequent flier miles or hotel points
- Gifts for holidays and birthdays
- Go to your church
- Create a fund

START WHERE YOU ARE.
USE WHAT YOU HAVE.
DO WHAT YOU CAN.

- ARTHUR ASHE

- ARTHUR ASHE

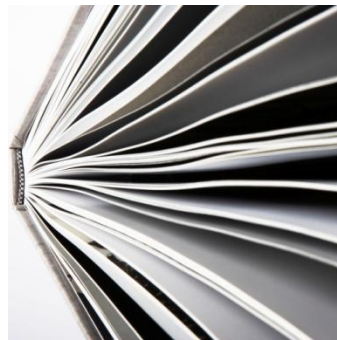
Best Practices & Lessons Learned

- Planning
- Reading ahead
- Written agenda
- Get copies of labs, birth records and pediatrician's file + recent IEP sent ahead of time
- Organize your binder
- If the doc is wrong or behind – call them on it!



Document

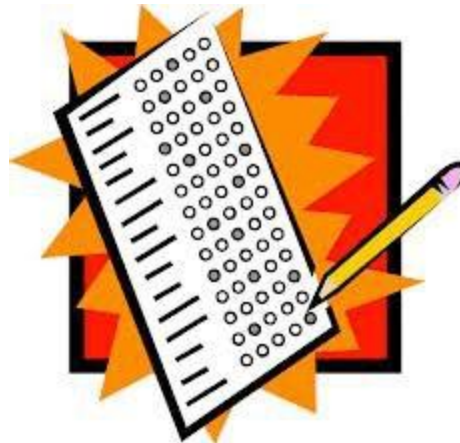
- Document - daily
<http://www.tacanow.org/medical/calendar.htm>
- Organize & Plan
 - ✓ Binders
- Re-Assess every 6 months your plan



ATEC - Why

- Autism Treatment Evaluation Checklist is important
- Evaluate – 2 times or more a year with the ATEC

<http://www.autism.com/ari/atec/index.htm>



Testing

Standard Testing

- Formal assessment and diagnosis: neurologist, behaviorist, speech & OT
- Tests to rule out genetic disorders: Fragile X and Rett Syndrome, MTHFR, Wilson's Disease, mitochondrial dysfunction, Chiari1, PON1. Perform MRI & unsedated 24-hour EEG.
- Baseline Testing: Comprehensive Digestive Stool Analysis, lipids, Amino Acids, IgG and IgE food and environmental allergies, Organic Acids Test, Liver Function, Comprehensive Metabolic Panel, Complete Blood Count, Red Blood Count, zinc, 25-Hydroxy Vit D, blood and urine Immune panel, hearing, celiac, thyroid panel

Secondary Testing

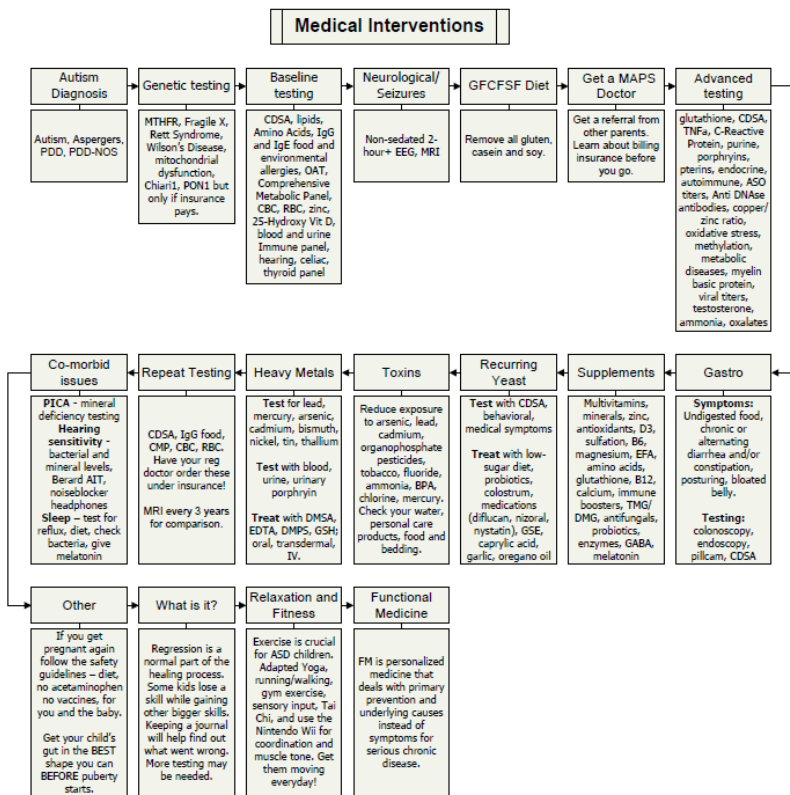
- Glutathione, CDSA, TNFa, C-Reactive Protein, purine, urinary porphryins, pterins, endocrine, autoimmune, ASO titers, Anti DNase antibodies, copper/ zinc ratio, oxidative stress, methylation, metabolic diseases, myelin basic protein, viral titers, testosterone, ammonia, oxalates
- Don't worry what these mean yet, just take the list to your doctor.

The Treatments

What are the treatments?

7

Autism Journey Blueprint®
A visual foundation of best practices for your child



This document is a "sample" checklist to consider in planning intervention for a child affected by autism. Please note, the order and action items will vary by child.

This is only a sample. Please consult with your child's development and medical team for what is appropriate for their individual needs.



TACA Autism Journey Blueprints
As a guide:
http://www.tacanow.org/wp-content/uploads/2012/04/AJ-Blueprints-Medical-Intervention_updated_4.30.12.pdf

Basic Biomedical Treatments

- Food Allergies
- GFCFSF Diet
- Vitamin/Mineral Supplements
- High-Dose Vitamin B6 and Magnesium
- Essential Fatty Acids
- Gut Treatments
 - ✓ Antifungals
 - ✓ Probiotics
 - ✓ Digestive Enzymes
- Amino Acids
- Melatonin
- Thyroid Supplements
- Sulfation
- Glutathione
- Chelation
- Immune System Regulation
- Antivirals & Antibiotics

Food Allergies

- IgE is Histamine type allergy (redness, rash)
- IgG is Immune response allergy
- You should get BOTH IgG and IgE food allergy testing (the most number of foods you can get tested), (use only blood tests).
- Get quantitative tests that measure severity of allergy, not just positive/negative.
 - ✓ Foods that test low can be rotated in/out of diet.
- Even if your child doesn't show allergies to gluten, casein and soy, you should still remove them from the diet as they affect ASD kids differently.
- Read More at <http://www.tacanow.org/family-resources/food-allergy-testing/>

Dietary Intervention

- **GFCFSF** is the first step in dietary intervention. It solves the peptide issue from leaky gut.
- The most effective diet is **SCD-CF**: Specific Carbohydrate Diet, casein-free, because it not only addresses GFCFSF but also yeast as it does not allow most carbohydrates.
- There are other diet options such as Rotation Diet, GAPS, Low-Oxalate Diet, Body Ecology Diet, etc.

Yeast Overgrowth

- Yeast is an infection in people with weak immune systems. To effectively kill it, you must cut off it's food supply, or it will just keep coming back
- **Test** with CDSA, behavioral, medical symptoms
- **Treat** with low-sugar, low carbohydrate diet, probiotics, colostrum, medications (diflucan, nizoral, nystatin), GSE, caprylic acid, garlic, oregano oil
- More at <http://www.tacanow.org/family-resources/what-is-yeast-overgrowth/>

What does Yeast look like?

- **Physical Signs**

- in the mouth, in the form of thrush
- on the skin such as diaper rash or eczema
- red ring around the anus
- rash or cracking between the toes or joints

What Does Yeast Act Like?

- **Behavioral signs**
- Headaches
- Inappropriate laughter
- Sleep disturbances
- Unexplained intermittent crying episodes
- Belly aches
- Constipation
- Bed wetting
- Gas pains
- Fatigue
- Depression
- “Fogginess”
- Inattention
- Hyperactivity
- Anger, aggression
- Increased self-stimulatory behavior
- High-pitched squealing
- Increased sensory defensiveness
- Climbing/jumping off things
- Sugar cravings
- Confusion
- Lethargy

The Yeast Beast

- Yeast - caused by a carbohydrate heavy diet – is the number one reason we see kids not progress.
- Kids who are “picky eaters” and self-limit to certain foods, colors, textures are addicted to carbs. Once the carbs are limited/removed, the kids expand their diet.
- Diet is paramount, but unless the yeast is under control, your child won't get better.
- Yes, you can give antifungals, but as long as you feed the child too many carbs, the antifungals, which are hard on the liver, are only a stop-gap measure. The yeast will never go away until you clean up the diet.

Gastrointestinal (GI) Issues

- **In studies it is estimated 35%-70% of people with ASD have treatable GI conditions.**
- **Symptoms:** Undigested food, chronic or alternating diarrhea and/or constipation, posturing, bloated belly, self-injurious behaviors.
- **Testing:** colonoscopy, endoscopy, pillcam, CDSA
- **First treatments:** GFCFSF Diet, yeast treatment, digestive enzymes, supplements for gut motility
- More at <http://www.tacanow.org/family-resources/the-poop-page/>

Heavy Metals

- Heavy Metal toxicity is common in ASD kids (and is likely causal). You must do proper testing and medical treatments to remove the metals.
- Heavy Metal toxicity is a serious medical condition that requires serious medical intervention, called chelation. Chelation has been an approved treatment since the early 1900's.
- Read more at:
<http://www.tacanow.org/family-resources/chelation-and-autism/>

Diet & Supplements

Common ASD Supplements

- Multivitamins
- Minerals
- Zinc
- Antioxidants
- D3
- Sulfation
- B6
- Magnesium
- Essential Fatty Acids
- Amino acids
- Glutathione (GSH)
- B12
- Calcium
- Immune boosters
- TMG/ DMG
- Antifungals
- Probiotics
- Enzymes
- GABA
- Melatonin

Supplementation and Diet

- **Before we start - A few hints:**
- 1) Following a gluten free / casein free diet is an important part of supplementation. (Diet discussion will provide details)
- 2) Proper eating – a balanced diet needs to be a part of the process. This is an on-going battle with ALL children. We as parents need to strive for balance with protein, carbs, sugars, veggies/fruit in our kids good health.
- 3) Do your best to eliminate or control these items in your child's diet:
 - ✓ Yeast · Refined sugars · Dyes / Additives / "natural flavors"
- 4) Testing for what supplements are missing from your child's body is important.
- 5) Work with a qualified doctor: www.medmaps.org
- 6) Save on supplements!! Become a TACA Member!
<http://www.tacanow.org/become-a-taca-member/>

Supplements (cont.)

- You can order these supplements from Kirkman LABS in hypoallergenic, GF CF free, no artificial flavors - I recommend www.kirkmanlabs.com or New Beginnings from GPL because they work primarily with kids that have special needs. They do GREAT, INCREDIBLE phone consults to walk you through and explain everything. They even have a PARENT INFORMATION GUIDE that describes all their products in detail and the RDA for your child. This guide is free on the www.tacanow.com web site under MEDICAL.
- Now, with all good things are rules. Parents need to follow directions given by supplement manufacturers.

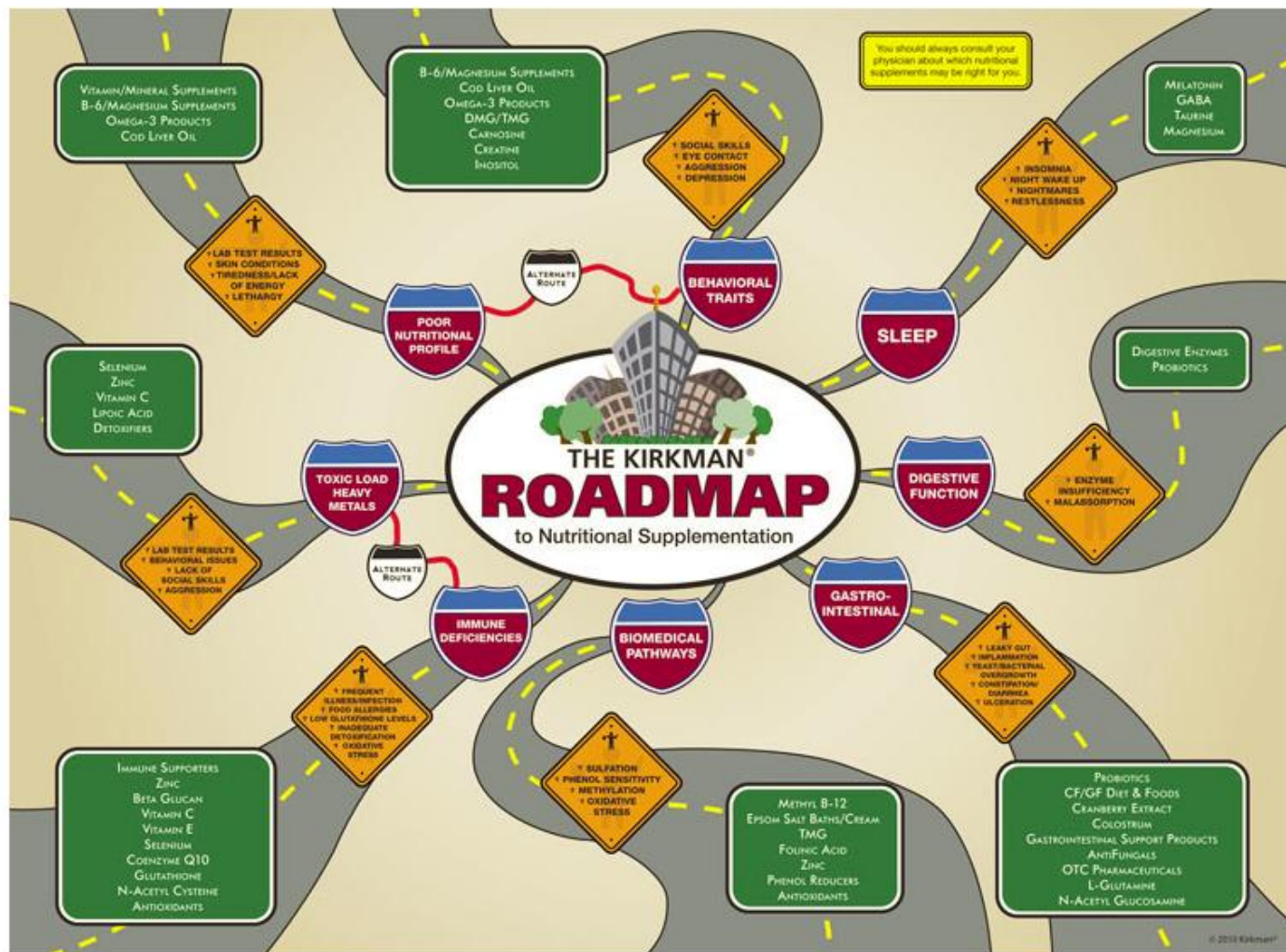
Supplement Rules #1

- 1) Do not overload kids. Only give them the RDA (recommended daily allowances) for their weight and age per a doctor. (NOTE as your child ages your doctor may or may not try “super dosing.” Proceed with caution.)
- 2) Because most of our kids have a leaky gut, these supplements will not absorb properly. Be strict gluten free / casein free (GFCF) diet and this will be repaired over TIME (1 year or more). Then these supplements will actually work!
- 3) Add one supplement at a time three weeks apart. Document, document, document!! (Check for changes in behavior, rashes, difference in sleep patterns, introduction or amplification of self stimulatory behavior, or mood swings.)
- 4) Ideas for getting supplements in your child:
 - ✓ SEE www.tacanow.com web site under MEDICAL
 - And http://www.kirkmanlabs.com/about/buttons/taking_supplements.html

Supplements Rules #2

- 5) Buy small samples. Check to see if they work. We have 4-5 LARGE JARS of supplements that did not work that costs \$35-45 dollars **EACH - down the drain!**
- 6) Ask what supplements should be taken with food, not with other supplements, by themselves or at night.
 - ✓ a. for example - ProBio Gold is better to be taken ALONE and right before bed to help digestion.)
- 7) Sometimes, supplements – even in the smallest quantities, can over load a child's system. It is OK to take "supplement vacations". Take a break 2-3 times a year where you remove all supplements. Add one back in three days apart and document your child's reactions and behaviors each day!
- 8) A negative reaction to a supplement can be behavior that will pass or can be a truly negative reaction. As a parent, know the difference of a reaction if you should:
 - ✓ a. Stop the supplement immediately
 - ✓ b. Or wait and see how your child behaviors with a smaller dose adjustment

What Supplements Do What?



<http://www.tacanow.org/family-resources/kirkman-what-supplements-help-what/>

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Important Supplement Notes

- 1) Supplement vacations: When you have the diet, allergy, intolerance issues down and your child takes a step back, take them off all supplements for a "supplement vacation". For about 1-2 weeks no supplements. Then you add them back in 1 at a time, 3 days apart. You can easily see if one supplement is bothering your child. In addition, you sometimes need a break from all of them.
- 2) At a conference: "My son used to take all his supplements just fine. In fact, he has been fine with the supplements for the last year. Now whenever I give him his supplements he immediately throws up." The answer: **STOP GIVING HIM SUPPLEMENTS!** What you supplemented last year, may not be what the body needs THIS year.
- 3) What ONE child receives in supplements is not what ALL children should receive. Supplement what your child needs with a doctors support and tests.
- 4) BEWARE Of additives!! Especially in supplements! These dyes, colors, flavors, and un needed additives can be harmful to our kids! Also it is recommended veggie caps vs. gelatin caps.

Diet

- There are different statistic floating let me give you one I am familiar with personally: 85% of the families in TACA have children responding well to a “dietary” intervention
- **DO NOT IGNORE THE POWER & INFLUENCE OF THIS INTERVENTION!**
- These interventions include:
 - ✓ www.gfcfdiet.com / www.autismNDI.com
 - ✓ www.scdiet.com
 - ✓ www.feingold.org & Low Oxilate Diet
 - ✓ TACA provides an overview on all including rotation diet and allergy elimination at www.tacanow.org
- Diets do not have to be forever if the problem can be fixed
 - ✓ Unfixable: Celiac disease, IgG/IgE Allergies, Colitis, IBS, and others...
 - ✓ Sometimes these are fixable: some can to mitigated by meds. or detox

Diet - continued

- Many DAN doctors consider a GFCF / SCD / Feingold or Allergy elimination diet as a FOUNDATION to medical treatment.
 - ✓ Some doctors will not accept you into their practice if your child is a candidate for a diet and you do not execute.
 - ✓ For my family – the “diet” was key to my son’s success.

How are treatments selected

How are Treatments Selected?

- Based on family history & patient intake (symptoms and history)
- Medical tests (current and past)
- What the child has respond to positively and negatively provides important clues
- Doctors should make a case for going after the priorities based on the parents/child issues
 - ✓ You should help set priorities
 - ✓ A good doctor will help you prioritize as a team
- Special note on “low hanging fruit” and why it is important to tackle these items first.

Treatment issues

- Almost **all** treatment recommendations by doctors have a side affect
 - ✓ Read up on medications & treatments besides what the doctor says in an appointment
- Know what is a “liveable” side affect vs. a negative side affect to stop a treatment
 - ✓ When do you call the “bat phone”?
- Clear evaluation guidelines should be provided by the doctor and understood by the parent

Treatment Notes

- Cure du Jour
 - ✓ There are 1-3 of these every year
- A trial of a treatment today may not complete preclude a trial later
 - ✓ Caveat - Unless the initial trial was a disaster!
- Research and refinement of treatments
 - ✓ New treatments or new variations on old treatments are coming out each year
- And the old adage – what works for one does not work for all
 - ✓ Understand why a treatment is proposed for your child and why a treatment IS NOT

Taking Treatments Home

– Leave Armed



- Ask for demonstrations
- It only helps if it goes in – ask doc for specifics – take notes &/or leave with that info.
- Have clear guidelines of treatments (dose, frequency, possible side affects, when to call for help, what to look for.)
- One day at a time – % of success

New Treatments



- Basics first
- Unless medical tests drive towards new treatments

Your home work



Finding a doctor

1. Search and watch YOUTUBE videos
2. Go to TACA meetings
3. Meet them at conferences

Tip: Be sure to bring your kids medical binder and ask questions!

Preparing for your first Doctors appointment

Before	Day of appointment
1) Get recommendations for which doctors.	10) Arrive at least 20 minutes before – have snacks
2) Send your medical files & fill out paperwork. Send ahead of time. Keep a copy.	11) It takes a village – have help at your appointment (note taker, babysitter, talking in front of kid)
3) Start the diet	12) Go in order!
4) Get connected w/ TACA friends	13) Prioritize (sleep & poop)
5) Start reading	14) Be prepared – have an agenda
6) Know what your insurance covers?	15) Medical tests (bring old test, prioritize new w/ doctor)
7) Write down concerns	16) Supplements
8) Have an idea of a PLAN	17) Ask for emergency contract info & know when to use it!
9) Get in sync with your spouse	

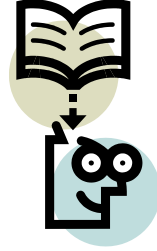
After the Appointment

Know the next steps

- Be in good standing
- Save your receipts
- File insurance claims by co-morbid treatments
- Set up the next interaction
- Document everything!

<https://www.tacanow.org/family-resources/how-to-prepare-for-a-maps-doctor-appointment/>

Reading



- The Parents Role in Biomedical Intervention:

<https://www.tacanow.org/family-resources/art-of-managing-professionals-appointments/>

- The Art of Managing Professionals

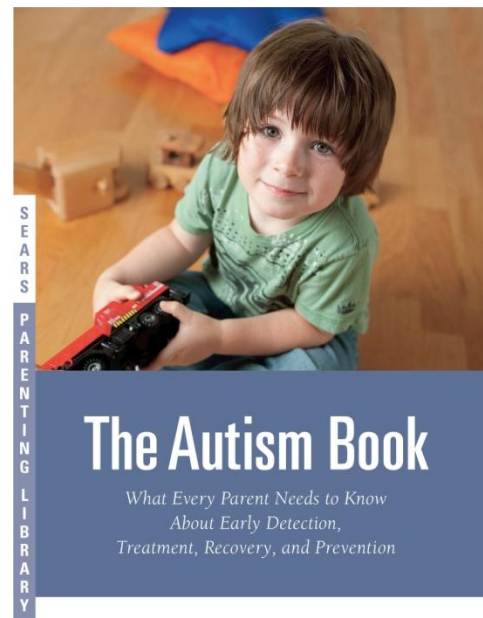
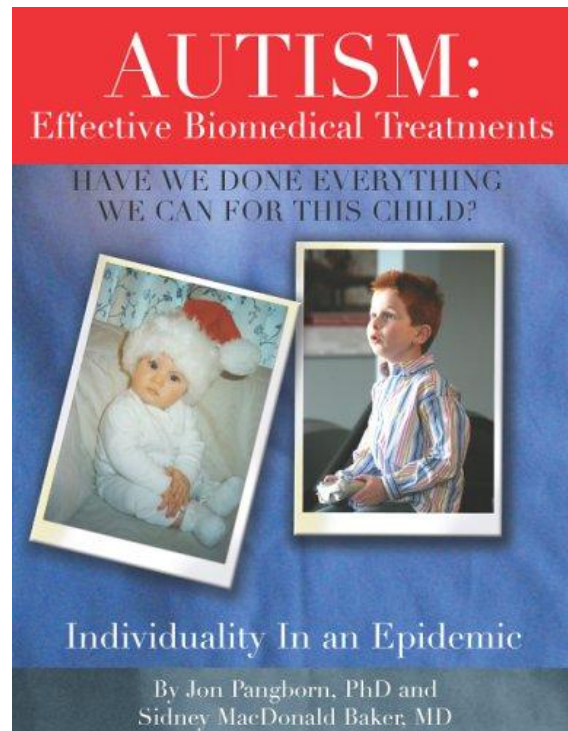
<https://www.tacanow.org/family-resources/the-parent%E2%80%99s-role-in-biomedical-treatment-for-autism-spectrum-disorders/>

- Books

- ✓ Dr Bob Sears – The Autism Book

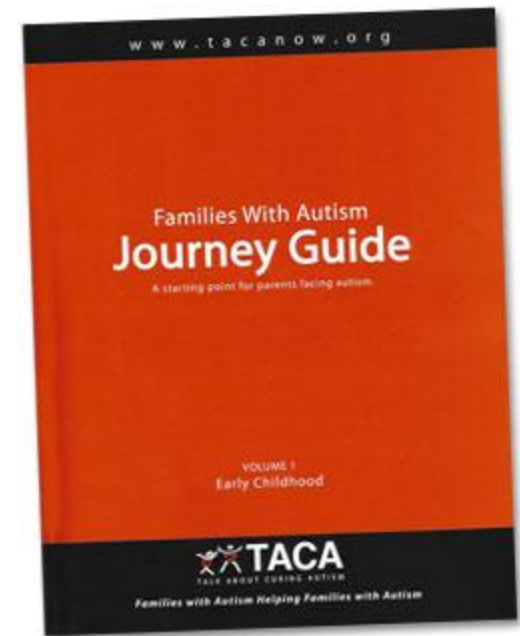
- ✓ Pangborn/Baker: Autism: Effective Biomedical Treatments

- ✓ TACA Autism Journey Guide



Robert W. Sears, MD, FAAP

Author of *The Vaccine Book*



Teens and Adults and Biomed

- **Is there an age where biomed stops working?**
NO!
- Biomedical Interventions are not just for the very young. The beautiful thing about biomedical intervention is that there is no “window” during which biomed will only work, but rather we’ve seen many families start biomed with teens and adults with great success. As always, health is the main goal we strive for with our children, so even if recovery doesn’t happen, every child deserves to be healthy and biomed is the path to health.
- Read more at <http://www.tacanow.org/family-resources/teens-with-asd-biomed-older-child/>

Create your plan!

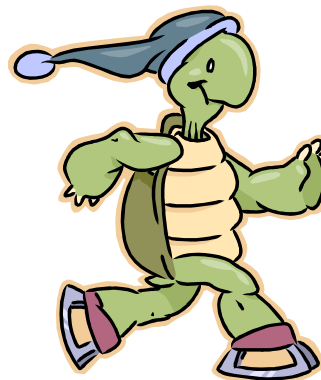
Its all about Step 6!

- Top 5 issues
- Top 5 needs
- Use the TACA Blue prints as your guide!



Sprint vs. Marathon

- Rarely does biomedical testing and treatments net results overnight
- Hard, consistent efforts pay off over time
- Spend your money wisely. Use existing resources (state, federal & private first)



Your homework

- 1) Get a TACA mentor
- 2) Surround yourself with positive parents
- 3) Make your checklist of items important for your child
- 4) Document your child's baseline (i.e. ATEC, video, medical tests) & prioritize issues.
- 5) **NEVER LOSE HOPE!**



In Conclusion

Remember: **PLUG IN TO TACA!**

- Get out in your community. Here is how:
 - ✓TACA Chapter meetings & coffee talks
 - ✓TACA Mentor
 - ✓TACA Facebook and Live Chat
 - ✓Email / Phone
 - ✓TACA USA Yahoo Group
 - ✓TACA Real Help Now Conferences
 - ✓And more webinars!

Everything is available at www.tacanow.org