Medical Intervention for Autism – Where to start

By Lisa A Jeff’s mom
Agenda

• Presentation will be broken into three sections:
  – Section one: How to start biomedical therapies for your ASD child
    • This is the longest section (90% of the presentation)
  – Section two: A brief overview on what I did for my son, where he started and where he is today.
  – Section three: The video.
Then the close with question & answers
Disclaimer

• I have no credentials! I am just a mom – not a doctor.
• This presentation should not be used as medical advice.
• Always use a doctor before pursuing any intervention
• Always remember, what works for one child does not work for every child with autism spectrum disorders
• We have little support, little knowledge, little data on what works – we are the leaders forging the path to tomorrow’s answers
Biomedical Intervention
How to Start…
Biomedical intervention should be part of a comprehensive and complete intervention plan
A complete intervention plan includes:
- Biomedical interventions (with dietary interventions)
- One on one behavioral intervention: (i.e. ABA, speech, occupational therapy, floortime, TEAACH, RDI, VBA)
- Social interventions (i.e. preschool, social skills programs, outings into the community)

Biomedical interventions rarely show overnight success — success comes from consistent, prolonged efforts

Find a doctor for this journey — good relationship chemistry and communication is key to success

Doing biomedical with other interventions is OK — We cannot wait for “single therapy” environments!

There is no silver bullet geared towards a comprehensive approach

The specific needs for each child is always different!
Medical: What Happened to Our Kids?

- A few words on “myths and legends” – where are the facts?
  - There still is a lot of debate on this issue – each kid is affected differently (due to a myriad of unique issues)
  - Got a decade? I don’t suggest waiting for the debate to be complete

- The current theory:
  - Genetic predisposition + Vaccines (multi-viral, too many at once and too many additives such as thimerosal/mercury & aluminum) and/or OTHER ENVIRONMENTAL ASSAULTS = AUTISM

- Pushing for medical research to figure out what broke our kids will help fix them

- What can you do now?
  - Work with a doctor that has experience with autism & common biomedical issues and treatments
  - Go slow and get on the alternative medicine band wagon
  - DO NO HARM!
What Can be Wrong? (Part One)

• According to world renowned Autism specialists Dr Jerry Kartzinel http://www.pppvonline.com/ he reports that after treating over 1,000 patients there are many biological issues could be affecting autistic children. Here is a list of those common issues:

• **Common Gut Issues**
  – Inflammatory bowel disease
  – Reflux
  – Improper food absorption
  – Dysbiosis of the gut (due to bacteria and yeast issues)
  – Sulphanation defect
  – Nutritional problems (including improper protein absorption)
  – Food opioids (this is the need for a gluten/casein free GFCF diet!)
  – Gastritis
  – Leaky gut
What Can be Wrong? (Part Two)

- Brain & Blood Disorders
- Seizures
- Purine disorders
- Methylation defects (or disabled)
- Heavy metal toxicity & detoxification issues
- Persistent virus(es) (i.e. measles, lyme, etc)
- Brain blood perfusion
- Brain autoimmunity
- Elevated Ammonia levels
- Serotonin & Melatonin defects (which leads to sleep disorders)
- Thrombophilia (tend to clotting of blood)
- Omega 3 deficiency
- Testosterone regulation
- Dopamine effect
- And finally chromosomal issues (this is rare)
What Typically is wrong

- Inability or poor detoxification
- Inflammation gut & /or brain
- Methylation Impairment
- Viral and / or Fungal Issues
- Other – not yet discovered
- Brain Abnormalities and other issues
  - Incls: Rhetts, seizures, Chiari Malformation, Fragile X, LKS
And the real problem

KIDS WHO HAVE IT ALL OR
MULTIPLE ISSUES:

• Inflammation gut & /or brain
• Methylation impairment
• Oxidative stress
• Viral & fungus issues
• Inability or poor detox.
• Brain abnormalities & other issues
• And OTHER (yet to be discovered)

EACH CHILD HAS A DIFFERENT COMBINATION
- Researchers are yielding important new clues everyday
Can These Problems Be Fixed?

• Before you panic, **not all autistic children have all these problems**!! But rather, autistic children 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**
Step 1: Finding a Doctor

• General note:
  – the differences between traditional docs vs. DAN doctors

• Some general doctors do not go beyond the AAP Standards of Care for Autism (they are weak at best.)

• Some general doctors do not believe that autism is treatable (AVOID)

• Some general doctors DO have an open mind and want to learn and help (SEEK OUT & FIND THESE!)
Step 1: Finding a doc (cont.)

- DAN Doctors – (list on [www.autism.com/ari](http://www.autism.com/ari))
  - They have been to at least ONE DAN! Conference (detailed resume on this website)
  - Look for doctors that speak at conferences and been mentioned at support group meetings!
- Look beyond the “one trick pony” doctors
- A few words on wait lists
- Talk to as many parents as possible for recommendations and why they like a resource is the a great referral.
What doctors & Specialists do WHAT??

- General pediatrics are needed for the common children issues
  - Colds, flus, ear infections, check ups, emergencies
- DAN doctors for alternative treatment plans (NOTE: general ped and DAN doc can be the same person. This path is recommended if possible.)
- Specialists such as: gastro’s, allergists, neurologists, opthomologists, audiologists and others that specialize is specific issues as it relates to your child are very important to the process.
  - These docs are typically recommended by your DAN or Pediatrician
- Be sure to share ALL tests results with all doctors on the team!
Doctor / Patient Relationship

- Ways doctors work with you
  - Visits (should be at least 1 to 2’s a year)
    - There should be some good chemistry with your child and the doc.
  - Phone consults (as often as needed)
  - Emergencies –
    - A policy for after hours and urgent needs should be understood
  - Emails (Some docs offer this, some don’t. This communication should occur as often as needed)

- Types of services
  - Case review & initial consult ($$$$ at first)
  - Lab results consults
  - Treatment & planning
  - Emergencies

- Get to know services fees up front before you start any services!

- A note about disclaimers & contracts
Step 2: Do Medical Tests

- Medical tests provide important clues to finding what is wrong AND what to do. **Without them you are flying blind.** GET **“SIGHT!”**
- Tests are not always perfect – take heed and have a good doctor for interpretation and next steps
- They provide mile markers in the ground to look at year after year for progress and evaluating interventions
**What Med Tests can do**
Confirm a hypothesis or treatment path

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Recommended Medical Tests

- Urine Peptides
- Urine Organic Acid
- Comprehensive Stool Analysis
- Genomics
- Complete Viral panel including - Lyme
- Toxic Metals / Red Blood Cell Elements
- Vitamin Panel (could be part of another test)
- Essential Fatty Acids RBC test (blood)
- Lymphocyte Subsets TH1/TH2
- Food Allergy Panel
- Plasma Sulfate & Plasma Cysteine
- Liver & Kidney Functions (from any lab)
- Immunoglobin profiles (depends on your doctor)
- Thyroid Study (from any lab)
- Ammonia Levels (from any lab)
- Blood clotting profiles (from any lab)
- Anti Mylen Basic Protein
- MAJOR TESTS: 24 hour EEG, MRI, Spect Scan (after age 6) and Landau Klefner/Fragile X, Rhetts Syndrome

There are thousands more.....

ALL tests above require a doctor’s prescription
Medical Testing Notes

• Each doctor has a preference with labs
  – Some will review tests done by other doctors or previous years or labs
  – Some won’t! ($$$)

• Health insurance comments:
  – Remember to look into CALIF. STATE LAW AB 88
  – Check with your insurance provider on coverage **BEFORE** starting a therapy or getting a test done regarding reimbursement
  – NO will always be the first answer and it is **NOT** the last!

• Testing done annually:
  – Allergy and food sensitivities
  – Comprehensive stool
  – Plasma sulphate / cysteine
  – Liver / kidney functions

• Testing done more frequently (if issues or chelating):
  – Comprehensive stool
  – Toxic metals (when chelating)
Step 3: 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) Working with a qualified doctor (DAN! Doctor [www.autism.com/ari](http://www.autism.com/ari) or see resources on [www.tacanow.com](http://www.tacanow.com) for Southern California doctors)
Supplements (Part II)

• Some of the most commonly missing and desperately needed supplements for children on the spectrum are:
  – Calcium
  – Zinc
  – Magnesium (Citrate & Glycenate)
  – Cod liver oil (make sure it is tested and MERCURY FREE SOURCE)
  – Essential fatty acid (EFA Powder)
  – Selenium
  – Probiotics (ProBioGold)
  – B6 (SuperNuThera) & B12
  – TMG or DMG
  – Vitamin C, E & CoQ10
  – L-Glutathione (supplement or topical crème or IV or nebulized)
  – Methionine
  – Taurine & Folinic Acid (amino acids)

• The “Sometimes” Needed / and “Sometimes Very Helpful” Category are:
  – And sometimes, a digestive enzyme (Enzymaid Complete w/ DPPIV)
  – Colostrum / Transfer Factor
  – Magnesium Sulfate crème or Epsom salt baths for children who are sensitive to phenols

• NOTE: THERE ARE THOUSANDS OF CHOICES!
Supplements (Part III)

- 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](http://www.tacanow.com) web site under MEDICAL
  And [http://www.kirkmanlabs.com/about/buttons/taking_supplements.html](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.)
  – b. Do not take digestive enzymes with a probiotic! (The enzyme will digest the probiotic without any effect on your childs system!)

• 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 behaves with a smaller dose adjustment
What Supplements Do What?

AUTISM

- Omega 3, CLO, Nutritional Vitamins, E, Minerals, Amino Acids
- SNT Nu-Thera, DMG & TNG
- Poor Nutritional Profile Deficiencies
- Sleep Disorders
- Immune Deficiencies
- Enzymatic Pathway Deficiencies
- Heavy Metals Toxicity
- Digestive Issues
- Enzymes
- Probiotics
- Colostrum
- GABA
- Magnesium, Sulfate, Amino Acids
- Lipotropics
- DMG
- Chelation Products
- TACA
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 DAN! conference in San Diego a parent asked a question of Dr Jeff Bradstreet; "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 doctor's support and tests.

4) BEWARE Of additives!! Especially in supplements! These dyes, colors, flavors, and unneeded 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](http://www.gfcfdiet.com) / [www.autismNDI.com](http://www.autismNDI.com)
  - [www.scdiet.com](http://www.scdiet.com)
  - [www.feingold.org](http://www.feingold.org)
  - TACA provides an overview on all including rotation diet and allergy elimination at [www.tacanow.org](http://www.tacanow.org)

- Diets do not have to be forever if the problem can be fixed
  - 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 the DAN protocol.
  – 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.
Step 4 – The Treatments
Common Medical Interventions

- Metal Detoxification (chelation)
- Anti-fungal & anti-virals
- Gastro assessment and treatments
- Assessment & Treatment for Metabolic Disorders
- Secretin (topical & IV)
- Nutritional Therapies (Supplements) & Diet(s)
- Nasal or Injectable MB-12
- Oral, topical, nebulized & Push/IV (GO IN THIS ORDER) Vitamin C, Glutathione (and NAC)
- Hyperbaric Oxygen Treatments (HBOT)
- Growth Factor and Trans. Factors
- IV & Oral Immunoglobin therapies
- Bio & Neurofeedback
- Somatic & Listening Therapies (Tomatis, AIT, Berard)
- Craniosacral & Chiropractic Therapies
- Pharmacology (last step please)
  - There are many, many more…. These are the most common
- Do not set off to try them all! Medical tests will tell you what to do and what is a “maybe later”!


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
Step 5: Evaluating Interventions
Evaluating Treatment Options

• Most important part of evaluation – DOCUMENTATION
  – See http://www.tacanow.com/calender.htm

• Document the big FIVE: sleep, behavior, stools/pees, rashes?, stims

• Great eval system www.autism.com/atec. Weakness: it does not do a good job for younger children and is not calibrated as a child ages.
  – Keep ATEC score print outs in a file or email

• Binders are your friend!
  – Keep a new section for each test period

• Get different opinions!!
  – Ask therapists, teachers, friends, family their thoughts week by week. Take data on their input
Web & Book Resources

• WEB:
  – Thoughtful House – www.thoughtfulhouse.org
  – Generation Rescue – www.generationrescue.org
  – ICDRC www.icdrc.org / www.gnd.org (great intake form on this site)
  – ARI: www.autism.com/ari (GO TO A DAN! Conference or buy tapes!)
  – And TACA www.tacanow.org

• BOOKS:
    • Buy one for you and your doc
  – CHILDREN WITH STARVING BRAINS: Dr Jaquelyn McCandless
  – EVIDENCE OF HARM – David Kirby
  – WHAT YOUR DOCTOR DOES NOT TELL YOU ABOUT VACCINES
    – Dr Stephanie Caves
  – TREATING AUTISM – Dr. Steve Edelson & Dr. Bernard Rimland
  – AUTISM EFFECTIVE BIOMEDICAL TREATMENT (Have We Done Everything We Can For This Child? Individuality In An Epidemic)
    by M.D. Sidney Baker, Ph.D. Jon Pangborn
Step 6: Troubleshooting
When (not if) Something Goes Wrong – Part I

• When Something is Going On - Strange Behaviors, a Plateau, an Old Self Stims
  – This is a tricky process: supplements, dietary interventions, food allergies, additives, sleep issues, medical intervention, daily behavioral therapy – it is a lot to worry about! You are always seem to be checking, changing, deleting, adding ideas to your child’s daily intake, interventions and program. Never a dull moment!
  – Occasionally, with progress and success – set backs can happen. Set backs come in several shapes and sizes. ABOVE ALL DO NOT PANIC!!

• Here is the checklist I use when something does not seem quite right: http://www.tacanow.com/whatisit.htm
When Something Goes Wrong (Part II)

• FOR DETAILS: http://www.tacanow.com/whatisit.htm
• 1) Too much sugar / yeast issues
• 2) Gluten/casein OR FORBIDDEN FOOD Infraction
• 3) Phenol overload
• 4) Allergy/intolerance to a food or foods
• 5) Dyes / natural flavors
• 6) Or the supplements don't work for your child's chemistry!!
• 7) Dark Circle / Bruises Sleeping issues
• 8) IT IS IN THE POOP!! CONSTIPATION OR DIARRHEA
• Bottom line, it always about bowel movements! Here are some ideas to consider for constipation or diarrhea. http://www.tacanow.com/poops.htm
• 9) It is the treatment itself. Know the warning signs of what is wrong and what is a sign of treatment. Know when to stop and when to get through it. COMMUNICATION WITH YOUR DOCTOR IS KEY!!!
When Something Goes Wrong

• SORRY – MORE ABOUT POOPS: (Part III)
  – STOOL IMPACTION and constipation can be incredibly painful for our kiddos. An x-ray of the abdomen can demonstrate that the stools are beyond impacted and require MEDICAL ATTENTION. Look for distended tummies, night wakenings, and behaviors as clues and please see your doctor for help. Good gastro doctors can make a huge difference for our kids.
  – And for DIARRHEA or constipation: contact your doctor. Prolonged diarrhea or constipation is NOT ok for children. (MANY ASD kids bounce back and forth.)
  – Increased aggression or anxiety

• NOTE: IF A SYMPTOM CARRIES A FEVER, LONG PERIODS OF IRREGULAR BOWEL MOVEMENTS, EXTREME CHANGE IN BEHAVIOR, LOSS OF SLEEP OR APPETITE, PLEASE CONTACT YOUR DOCTOR IMMEDIATELY.
By the way – what happened?
Vaccines

- You and your family need to read this book
- This book & his talk will give you details.
Part II: Jeff Overview

• Case study of one
Part II: Medical Case Study

- A boy named Jeff
  - Original diagnosis Sept 1999: Autism – moderate to severe
  - Follow up diagnosis include Apraxia & Auditory processing disorder
  - Prognosis: The usual – no hope, no treatment, no cure. 1st three doctors told us to institutionalize our son
  - Did not speak from 15 months to almost 5 years of age
  - Many many biomedical issues including: poops, sleep, rashes, stims & extreme behaviors
  - Skill sets: at 2.5 years of age all levels were 3-6 month old levels
Part II: Medical Case Study

Biomedical Interventions used (based on medical tests!)

- **Diet!** Organic, clean, natural, no dyes / preservatives or additives.
- Supplementation: MB-12, TMG, Levocourin, Lipoceutical & Nebulized Glutathione, Methionine, Calcium, Selenium, CoQ10, Vitamin C & E, Zinc, Cod Liver Oil
- Chelation: 4 years worth – DMSA, EDTA, TTFD & TD-DMPS
- IV products: Glutathione, NAC, Vitamin C, Secretin (started w/ topical/oral – then went to nebulized)
- Prescriptions: for yeast Ketakonozole & Diflucan (get compounded!! Note: these are pulsed not constant.)
- Full endoscopy & colonoscopy with prescribed Pentasa (inflammation), Prevacid (reflux) and Singular (immune regulation, allergies) with daily doses of Georges Aloe
- Epsom salt baths

- **Traditional therapies provided – serious 1-on-1 hours!**
  - Applied Behavioral analysis & Social skills training – [www.lovaas.com](http://www.lovaas.com)
  - Speech – [www.apraxia-kids.org](http://www.apraxia-kids.org) (Aug communication was used during non-verbal days: [www.dynavoxsys.com](http://www.dynavoxsys.com), [www.pecs.com](http://www.pecs.com))
Part II: where is Jeff Today

• ATEC score March 2000 - **106**
• ATEC score January 2005 & 2006 & 2007 **10**
• Biggest issues remain: Auditory Proc., Speech & Social Skills (like a 4-6 year old & varies daily)
• Typical 3rd grade with a part time aide – age appropriate levels academically
• Achieve Jeff’s true potential – final destination unknown
• He is not a diagnosis – he is a child with a promising future AND
  **We will never give up**
Part II – Jeff next steps

• Biomedical: Look for answers in existing diseases & medical conditions:
  – Stroke
  – Inflammation
  – Gut
  – Methylation & detox

• Traditional therapies: Continue what we are doing in:
  – Aide in school – in phase 4 (of 5)
  – Speech – as much as possible in everything we do
  – 13-15 hours of home / mostly theory of mind, advanced / abstract concepts & some curriculum pre loading (Lindamood Bell programming to teach and acquire useful skills in reading comprehension & problem solving)
  – Social skills focus
Part III: The short video

- Progress
Medical Presentation:
in closing
Conclusion

- Biomedical treatment and care must be **PART** of your intervention plan for an autistic child. In addition to biomedical intervention please consider one on one behavioral intervention including but not limited to: ABA, VBA, Speech, OT, play skills, Social skills. For additional information on THERAPY OPTIONS please see the THERAPY link on the [www.tacanow.org](http://www.tacanow.org) website. **Both a biomedical intervention AND BEHAVIORAL therapy plan are part of a total solution for your child.**

- Positive change will happen and recovery is possible. Believe in nothing less.
Question & Answers

• You can make a difference in a child’s life!