

Dr Stoller's PATIENT HANDBOOK

Welcome to the Hyperbaric Medical Center of New Mexico—a place where you and your family can find answers and hope for your child with brain injury and or developmental issues.

Dr. Stoller is currently consulting on patients with brain injury and children misdiagnosed as having autism, PDD-NOS, ADHD, etc. These labels are incorrect in most cases as affected children have a mitochondrial dysfunction and damaged detoxification kinetics. It would be better to call what they have Mitochondrial Neuro-Gastro-Immune Encephalopathy /Encephalomyopathy (MNE). Dr. Stoller will not be the primary care physician for your child, but many times will work with your primary care physician to provide the best possible care for your child.

THIS HANDBOOK WAS DESIGNED TO ANSWER QUESTIONS YOU MAY HAVE ABOUT YOUR CHILD'S TREATMENT. PLEASE READ IT CAREFULLY.

The goal of our evaluation is to document that your child has a medical problem, specifically related to mitochondrial dysfunction and possible mutations in certain key enzyme systems related to detoxification. Our intervention is aimed at healing the main areas of injury affecting the child with MNE or other developmental problems caused by mitochondrial dysfunction. Four of the main problems that children with MNE face are inflammation, metal toxicity, immune dysregulation, and oxidative stress.

The brain is the nerve center for the body, and has two major jobs.

1. Regulating all body functions
2. Processing the stimuli and instructing the body how to respond

If impaired due to inflammation or toxicity, the brain may not perform these vital functions.

The gut (the gastrointestinal tract) has 3 major jobs.

1. Absorption of nutrients
2. Eliminating toxins from the body
3. Immune system assistance

If the gut is inflamed, these jobs are done improperly.

An impaired immune system is the other area we see as a concern in many of our children. Reactivity to food, seasonal allergens and environmental exposures are addressed if this is an issue for your child.

COMMONLY PRESCRIBED LAB TESTS

This list explains some of our more frequently used tests, but should not be considered all inclusive. Because each child's treatment is individualized, the tests ordered for your child may be different from those shown below.

- 1. UPPA**
This is the Urine Porphyrin Profile Analysis. Many affected children spill porphyrins in their urine which is an indication of metal or pesticide toxicity as well as mitochondrial dysfunction as the porphyrins are made in the mitochondria.
- 2. Nutrigenomic (Methylation Cycle) testing**
This looks at various enzymatic point mutations in the metabolic cycle that is crucial in detoxification
- 3. Cysteine and Sulfate level**
These are essential in the process of Glutathione production and detoxification. Checking the levels will allow the doctor to decide which supplements may need to be added or reduced.
- 4. Anne Connolly**
This lab tests for antibodies to brain endothelial cells. If positive, it indicates an inflammatory response in the brain.
- 5. Ammonia**
This by-product of amino acid and protein metabolism is toxic to the brain if is highly elevated. It can be elevated for many reasons, including mitochondrial dysfunction which impairs the body's ability to properly eliminate the ammonia.
- 6. Lactic Acid**
This is one of the waste by-products resulting from a chemical reaction when the body metabolizes glucose for energy. The amount can be high in the body for various reasons, ranging from extreme exercise to mitochondrial dysfunction.
- 7. Immune studies**
These tests determine the status of the immune system, indicating immune deficiency, immune dysfunction and antibody responses.
- 8. Anti-Gliadin AB**
This test shows the presence of antibodies when there is a reaction to gluten.

10. Androgens/Testosterone

These hormones are measured because some children have been found to have high levels, resulting in precocious puberty and/or aggressive behavior.

11. TSH (thyroid stimulating hormone)

Testing indicates the level of hormone in the circulating blood.

13. Neopterine/ Oxidative Stress

These tests are usually performed by Laboratoire Philippe Auguste in France along with the UPPA. Inflammation in the brain or gut (neopterine), or oxidative stress. High oxidative stress can indicate tissue damage due to free radicals.

14. OAT (organic acid test)

This urine test shows the presence of yeast and fungal and bacterial metabolites. If elevated, this may indicate imbalance of the gut flora.

15. UTM (urine toxic metals)

This lab tests the urine collected after a chelation dose to determine the effective pull of the metal toxins from the tissues.

16. CSA (comprehensive stool analysis)

This includes various tests to determine the presence of bacteria, parasites, yeast or other metabolites in the gut.

INTERVENTIONS

These may be considered, or we may add other things to this list.

- Supplements including vitamin and mineral replacements, amino acid replacements, digestive enzymes, probiotics, etc.
- Medications including Methyl B12, anti-fungals, antibiotics, anti-seizure meds, etc. Some over the counter medications may also be used.
- HBOT - hyperbaric oxygen therapy
- Sauna
- Chelation
- IVIG
- Dietary changes
- Occupational/ Physical therapy
- Speech therapy
- ABA or other behavioral therapies

DO'S AND DON'TS

- DO call ahead for an appointment as schedules fill very quickly.
- DO call us 24 hours in advance if you must cancel an appointment. You will be billed for late cancellations or “no shows” appointments
- DON'T fail to call us in the event of a missed/cancelled appointment to reschedule. Follow up is very important.
- DO email the medical assistant with brief concerns or questions, but limit them to things she can respond to quickly (such as prescription refills) as she is assisting Dr. Stoller in seeing patients throughout the day.
- DON'T email if your child is acutely ill. Take him/her to a local physician, or if it is an emergency, call 911.
- DO fill out and send in your **follow-up form**. Dr. Stoller requires that this form be completed and returned prior to each office or phone consult. This enables you to organize your concerns and questions, and saves you time and money at the time of your consult.
- DON'T forget to list all current meds and supplements and the pharmacies you use with their phone number.
- Never Give up, Never Surrender.

AVOID COMMON HOUSEHOLD EXPOSURES TO POTENTIAL TOXINS.

- Tap water - Have your tap water tested for metals and bacteria.
- New clothes or linens - Wash all new clothes and linens before using to remove chemicals that may have been used to treat them.
- Epsom salts - Most of the Epsom salts you buy have metals including lead and mercury.
- Additives, preservatives, and dyes in food - Please read your labels and be on the lookout for offending items.
- Fish - Many fish remain high in mercury and can be a source of repeated exposure.
- Cleaners, dish soaps, etc. - Read your labels. Avoid ammonia products.
- Bug repellent - DEET is not a recommended repellent as it is a neurotoxin.
- Sunscreens, lotions, bath products - Again, read the labels and avoid the products that have long lists of ingredients. Also, avoid “thalates” in the products.

- Swimming pools - If you take your child swimming, use precautions to avoid extreme exposure to chlorine. These include rinsing well after swimming, use of Mag Sulfate cream and activated charcoal.

READ THE LABELS ON ALL FOOD ITEMS TO ENSURE THEY ARE PERMITTED ON YOUR CHILD'S DIET.

These are some websites that may be helpful when implementing a new diet: Also check out www.TACANOW.org

- GFCF - www.autismndi.com with Karen Serrousi and Lisa Lewis
www.gfcfdiet.com
- Specific Carbohydrate Diet - www.pecanbread.com
- Low Oxalate Diet - www.lowoxalate.info

FREQUENTLY ASKED QUESTIONS

- 1. When do I need to call or come back to see Dr Stoller?** As your visit comes to a close, your doctor or PA will tell you when he wants to talk with you again. Generally, 6-8 weeks is recommended for follow up as this gives the doctor an opportunity to hear about progress or problems with the current plan of care. It is important to note that those children who follow up regularly generally have a higher level of progress than those who do not follow up regularly. That is the only way your practitioner will know if the treatment plan is working, or if it needs to be changed. If your child is chelating, you must make sure to check labs every 3-4 months (or more often if the doctor directs it), as these medications are ones that can affect the liver, so close checks should be made to ensure your child's safety. Please call us if they are due, and we are happy to send you a prescription for the tests and kits if necessary. It is extremely helpful to our staff if the parents keep track of when the labs are due and proactively seek to get them when needed.
- 2. Why do I need to complete a follow up form every visit?** This allows you to organize your questions and identify areas of progress, concern, or regression in a way that will help the doctor review the items of importance before visiting with you. The more organized the visit, the more money and time you will save. Please list on each follow up form all medications and supplements, their doses, and when you give them. Also include a current weight and a local pharmacy that we can call if the doctor orders a commercial brand medicine.
- 3. My child was ordered Methyl B12 injections. Is there a video or website I can look at to teach me how to give these shots?** There is a

website (www.drneubrand.com) that has a section called “videos.” Click on “examples of giving a shot.” You can find videos that show the technique to use and offer helpful information when learning how to administer MeB12 injections.

- 4. My child has been ordered several supplements. Where do I start?**
Generally, it is recommended that you start one supplement at a time and in a reduced dose. Start with one quarter to one half of the full dose and gradually increase it over 4-5 days before starting the next supplement. The reason for this is to ensure that the child tolerates the supplement or medicine well, and you can observe the child for positive reactions as well. If you give too many things at once and the child does not tolerate it, you have no way of knowing which supplement or medicine he/she did not tolerate.
- 5. My child has just started chelation; how quickly should we expect him/her to demonstrate improvement?** Some children respond favorably right away after starting chelation treatment. Other children may demonstrate irritability, fatigue or hyperactivity. Responses vary from child to child. If your child demonstrates difficulty breathing, or any other severe reaction, call 911. If he/she develops a rash or other mild reaction, you can stop the medicine and try oral Benedryl. It should be noted that improvements are generally seen over months.
- 6. My child has started antifungal therapy for yeast overgrowth in the gut. Why does she look sluggish and grumpy today?** When there is an overgrowth of yeast, and an anti-yeast medicine is started, you may notice the child’s behavior gets a little worse before it gets better, or he/she may become sluggish or irritable. This is typically due to “die-off” of yeast and release of exotoxins. This can last from one day to 3-5 days, at which time you can expect an improvement in behaviors. Hydrating the child may help as well as use of activated charcoal. Talk to your doctor if you have any questions about how to give activated charcoal.

We recommend that you take many notes between visits so that you can track how your child does from visit to visit. Note trends in behavior, weight gains or losses, and whether you notice more language or eye contact, etc. We also suggest that you record your consult and take notes as well. Many times it is hard to remember all the details later.

There will be questions we have not addressed here, and when those come up, write them down so you remember to talk about them with your doctor. We are happy to help as much as we can, and offer as much support as we are able.

FOLLOW-UP FORMS

Our office requires that you fill out and return a follow-up form prior to every office or phone consult, thus letting your doctor know your concerns and questions ahead of time.

FOLLOW-UP APPOINTMENT FORM FOR DR. Stoller

**TO BE FILLED OUT BY THE PARENT OR RESPONSIBLE PERSON SIGNING THE
CONSENT FORM**

EMAIL COMPLETED FORM TO info@hbotnm.com OR FAX TO 916 732-9033

PLEASE NOTE THAT THIS FORM HAS TWO PAGES

Date of appointment:

Date of last visit or contact:

Patient Last Name:

First Name:

Date of Birth:

Approximate Weight:

Height:

Please list any allergies to any medicines or supplements:

Pharmacy Name:

Pharmacy Phone Number:

Reason for today's consultation (e.g. I want to discuss lab results, etc):

Please list any positive (good) changes since last contact:

Please list any negative (bad) changes since last contact:

Please list any persistent, unresolved, troubling behaviors and/or symptoms (e.g. diarrhea, constipation, poor feeding, etc):

What therapies are currently being used (e.g. ABA, OT, Speech, Sensory, etc)?

Have you used hyperbaric oxygen therapy for your child? If so, how many cycles, what pressure and over what period of time?

Have you used metal detoxification or chelation? If so when and what agent(s)?

Is your child in school?

Do you have school concerns?

What prescribed medications (not OTC supplements) are being taken? List all Prescription or Supplements that come from a Pharmacy. Please provide the name of the drug, the dose of the medication (e.g. 25 mg etc), and the time(s) of day given.

Are you giving any non-prescription medications (e.g. anti-histamine)? Please provide the name of the drug, the dose of the medication (e.g. 25 mg etc), and the time(s) of day given for each:

What supplements are being taken? Please provide name of supplement, dose (quantity being taken) and time of administration for each:

Is your child on a diet restriction – like gluten and casein elimination?

Does your child self-limit foods or does your child have texture or smell problems with food?

Describe the common foods being consumed:

Please describe how your child is doing with the following:

Sleep Patterns:

Bowel Habits:

Eye Contact:

Receptive Speech:

Expressive Speech:

Fine Motor:

Gross Motor:

Stereotypias (stimming):

Play and Interaction with peers: