## Summary – Tummy Troubles Alex Flores, MD

Dr. Flores is a pediatric gastroenterologist. He is Chief of the Pediatric Gastroenterology Department at Tufts Floating Hospital and works to support patients with mitochondrial disease who have particular issues with GI dysfunction.

Although it can be difficult to find physicians who specialize in GI dysmotility AND mitochondrial disease, Dr. Flores has been researching this issue for thirty years and calls GI motility his area of expertise. During his 15 years working with the Digestive Center at the Floating Hospital he has developed innovative techniques and tests to assess GI motility that often occurs in patients with mitochondrial disease.

When it comes to mitochondrial disorders, there are a heterogeneous group of symptoms and problems. Mito problems deal with the impairment of energy production that affects every organ in the body and commonly destructs the functionality of the GI tract. Mitochondria provide energy for the cell and are involved in every process that exists in the human body. Dr. Flores is interested in the gastrointestinal issues that are associated with mitochondrial disease particularly.

### CAUSES OF MOST COMMON GI SYMPTOMS AND DISMOTILITY

Mitochondrial disorders can have a deleterious effect on the central, autonomic, and enteric nervous systems and contribute to a patient's dysmotility. Some symptoms of dysmotility are: Upper GI tract (swallowing impairment), gastro paresis (stomach paralysis), intestinal pseudo-obstruction (dysmotility of the small bowel), pancreatic insufficiency, gallbladder dysfunction, biliary dyskinesia, refractive constipation, and sphincter dysfunction.

### WHY IS DISMOTILITY SO COMMON WITH MITOCHONDRIAL DISEASE?

Mitochondrial function affects every organ in the body. Mitochondria organelles in cells synthesize ATP, which provides the energy required by every organ and body system. The inability for mitochondria to function disturbs homeostasis, affecting the liver, pancreas, small intestine, and colon. Without mitochondria to produce energy, the GI tract can shut down.

#### IN PATIENTS, CHILDREN AND ADULTS WHO HAVE LIMITED MOBILITY, GI ISSUES ARE ALSO A PROBLEM. WHAT IS THIS RELATED TO?

Even in-utero, it is known that the autonomic nervous system develops from the same place as the central enteric nervous system, which is located on top of the kidneys. The two systems are inherently tied together, and an abnormality in one causes a dysfunction in the other. Therefore, physiologically, this exchange makes sense.

#### ARE THERE RECOMMENDATIONS THAT ARE GENERAL STANDARDS OF CARE OR PRACTICES THAT YOU FOLLOW?

It is necessary to recognize that every mitochondrial disease patient may have a different presentation and group of symptoms. Some patients suffer from multiple systemic issues, in which cause the root cause of the problem should be thoroughly investigated. Consider how allergies, malabsorption, and other abnormalities can skew results.

# ARE THERE OTHER CLINICIANS YOU RECOMMEND THAT HAVE EXPERIENCE WITH MITOCHONDRIAL DISORDERS THAT AFFECT THE GUT?

It is hard to find professionals educated in both realms of dysmotility and mitochondrial disease. However, there are clinics in Boston, Milwaukee, Columbus, Cincinnati, and Louisiana that are known for their expertise in these areas.

### WHAT ARE SOME GENERAL RECOMMENDATIONS FOR NUTRITION?

Many patients benefit from avoiding the long chain fatty acids and including medium chain fatty acids (such as coconut oil) in their diet so that food is easier to digest. In addition, some patients benefit from a high lipid, low-carb diet, especially those with Complex I deficiency. There are many specific diets depending on your individual symptoms, but the HIGH LIPID, LOW CARB diet is considered a general rule to follow. Aggressive fluid management is also critically important.

# ARE THERE TRIGGERS YOU TELL PATIENTS TO AVOID THAT CAUSE PAIN OR WORSENING OF SYMPTOMS?

Fasting can be an issue and should be avoided, even for short periods of time. Even though eating may be difficult, a patient should never cease ingesting nutrients. Unrelated illnesses such as infections, respiratory problems, migraines, IBS should be treated as these can make a patient's dysmotility worse. Stress contributes (even in children) to dysmotility symptoms as well.

### **ADVICE FOR PARENTS**

Supplements and vitamins known as the "mito cocktail" which include coenzyme Q10 and other antioxidants are helpful. Also, be aware that some mitochondrial and dysmotility medications can be expensive. Be educated. Know your doctor and research yourself to know exactly the best possibilities and treatments for your children. It is the parents' involvement in the community that really makes a difference in bringing greater awareness of this disease to the rest of the world. There is also a symptom guide for clinicians (www.MitoAction.org/guide) on the MitoAction website that is helpful to consult and to show your doctor in order to learn more about this complicated disease.

### **ADDITIONAL QUESTIONS & ANSWERS**

- Are there medications that should be avoided by people with dysmotility? Dr. Flores believes that many antidepressants could be dangerous and should be avoided because they are known to further slow motility. Barbituates and NSAIDS (Aleve, Motrin) and aminoglycocides are also potentially harmful. Consult a doctor before you use common cold medicines and any off-the-shelf medications in accordance with your motility disorder.
- Is Senna safe for constipation in people with Mito? Senna can bring about painful side effects. Dr. Flores often prescribes Amitizia because it does not cause cardiac dysrhythmia and has no other known side effects. For constipation, glycol compounds in laxatives, such as Glycolax and Mirolax are also effective.

Dr. Alex Flores, Tufts Floating Hospital for Children

(617) 636-3266

aflores@tuftsmedicalcenter.org.

Additonal presentation by Dr. Flores, found on the Tufts Medical Center website Children's Hospital in Columbus, OH: Dr. Carlo Dilorenzo {(614) 722-2000} is another well-known expert in motility.

To hear more from Dr. Alex Flores, the expert on motility and mitochondrial disorders, consult the Tufts medical center website or "Google" Alex Flores gastroenterology. There are some informative presentations about dysmotility available to people seeking more knowledge on this complicated issue.