Living with mitochondrial disease presents many twists and turns and a maze of questions. UMDF is pleased to offer answers to some of those questions as taken from Ask the Mito DocSM at: www.umdf.org. Please note that information contained in Ask the Mito DocSM is for informational and educational purposes only. Such information is not intended to replace and should not be interpreted or relied upon as professional advice, whether medical or otherwise.

Responders for this issue include: Fran D. Kendall, M.D., of Virtual Medical Practice in Atlanta, GA and Northside Alpharetta Medical Campus in Alpharetta, GA and Mary Kay Koenig, M.D., of The University of Texas Health Science Center at Houston, Houston, TX.

The Question is...

Our son, age 12, was diagnosed with mitochondria Complex I, II, IV at 12 months. He has low tone, amblyopia, and presents deficits in speech, language, fine motor, bowel control, and cognitive and tests within mental retardation ranges at school. He is currently taking methylphenidate ER 20 mg for attention deficit. There has been slight improvement with the medications but still requires CONSTANT re-direction or one-on-one attention with all activities. We are considering increasing his dosage, but cautious due to side effects. What treatments other than the traditional ADD medications are necessary and/or appropriate in the background of mitochondrial disease? How much does the mitochondrial disease cause symptoms that mimic ADD? Based on his 5 ft, 91 lbs, would you recommend an increase in dosage? Or even changing his prescription?

Response from Fran D. Kendall, M.D.:

The decision to medicate a child with ADD/ADHD spectrum issues is a difficult one and is not typically something I do or recommend unless all other avenues of treatment such as educational modification with, for example, one-on-one teaching assistance has been tried. If all other avenues fail and the ability to learn is severely impacted in a child who has the capacity to do so but cannot, due to ADD/ADHD, then I am supportive of ADD/ADHD medication. Methylphenidate ER 20 mg per day is often a starting dose for this medication. However, modification of current dosage or the decision to switch to another medication must be determined by a treating physician who will weigh the risks and benefits of doing so.

The Question is...

I am 49 years old. I was diagnosed with mitochondrial myopathy five years ago, although I have had symptoms for 21 years. My balance has gotten worse to the point I must use a cane. I had some tests that showed the vertigo was coming from my Central Nervous System. I also have some hearing loss, kidney failure (lost one kidney to cancer some years ago), sleep apnea, seizures and increased BP and pulse rate. Many of these symptoms started very recently. Can these symptoms be attributed to worsening mitochondrial disease? What do you suggest I do?

Response from Mary Kay Koenig, M.D.:

All of the symptoms you are describing are symptoms commonly seen in people with mitochondrial disease and unfortunately, most adult patients do tend to have worsening of their symptoms over time. My recommendation to you would be to do everything possible to optimize your health status. A good “check-up” at the PCP can go a long way towards improving how you feel. In your case specifically, make sure to control your seizures, have a sleep study and/or use CPAP to improve sleep quality, and see a cardiologist to assess your elevated blood pressure and heart rate. Additionally, I would suggest seeing a physical therapist to help you develop a safe, low-intensity exercise plan. Studies have shown that routine exercise can improve quality of life in people with mitochondrial disease. Lastly, ensure that you are taking adequate doses of CoEnzyme Q10. Although not proven effective, most people with mitochondrial disease describe benefits in energy levels with it.