Summary – Dysautonomia: Body Temperature, Heart Rate, and More!
Dr. David Holtzman

What is dysautonomia? For many, it is a one-word description that explains some of the most troublesome and puzzling symptoms that adults and children with mitochondrial disease experience. The autonomic nervous system functions to moderate and allow adaption of the body to everything in our environment. The autonomic nervous system, when functioning properly, regulates the response to very basic changes such as temperature, walking, sitting, sleeping, eating, desiring, and digesting food, thirst, etc. Dysfunction of the autonomic nervous system, also known as dysautonomia, can present some of the greatest daily quality of life challenges for people who are affected.

Dr. Holtzman is a member of the MitoAction medical advisory commitee and brings experience not only as an active clinical pediatric neurologist at Massachusetts General Hospital, but also as an established PhD researching mitochondrial physiology and mitochondrial function. Dr. Holtzman also teaches students in many areas including Harvard Medical School.

The impact and presence of dysautonomia may be under-appreciated in mitochondrial disease community, although the majority of patients may find that some symptoms, especially those related to body temperature regulation, could be related to autonomic dysfunction. Dr. Holtzman begins by underscoring the difficulty in understanding and treating symptoms related to dysautonomia, as the autonomic nervous system is a vast and diffuse system that can be influenced by many factors, including anxiety, thyroid function, endocrine function, stress, hormone changes, etc. It is important that any patient, adult or child, experiencing troublesome or puzzling dysautonomia symptoms consult with their physician, as it is quite possible that such signs and symptoms are actually related to organ function. For example, while changes in baseline body temperature, thirst, fainting, dizziness, fatigue, bowel or gut dysfunction (diarrhea, constipation, dysmotility) could be related to autonomic nervous system dysfunction, these very same signs and symptoms could be related to specific organ issues as well.

It is not immediately clear why mitochondrial dysfunction would affect the autonomic nervous system, although the two are surely related. The mitochondria affect certain abilities of the autonomic nervous system, including the ability to sense temperature (the mitochondria are important in providing additional energy needed to generate heat). The functions of the muscles rely on the mitochondria, as does the brain. In this way, the relationship is complex and can be difficult to understand. It is probably more helpful to think about some of the symptoms of dysautonomia instead.

One common and confusing result of dysautonomia for many people is related to body temperature. It is not uncommon for mitochondrial disease patients to have some abnormal regulation of body temperature, resulting in either a lower or higher baseline body temperature (commonly 96-97 degrees) or a marked inability to tolerate heat or cold. In this way, abnormal sweating is another characteristic of dysautonomia.

Sweating as an autonomic nervous system function occurs in order to cool the body (sweating independent of environmental temperature is related to the sympathetic nervous system, as a response to anxiety, fear, stress, etc.). The absence of sweating occurs in some individuals, making them very sensitive to over-heating in warmer climates. Conversely, some people may sweat excessively regardless of the environmental temperature. Hydration is useful in both instances. Keeping the body well-hydrated with plenty of liquids is a very important preventive measure for the majority of people with mitochondrial disease. Recognizing that probability of heat and cold intolerance and the potential consequences (often fatigue or pain) makes it important for patients and families to use good planning when going outdoors, getting into a hot car, swimming or bathing, etc.

Some people are troubled by changes in blood pressure and heart rate. Dizziness, lightheadedness, fainting, changes in heart rate, nausea and anxiety are a few of the most common and troublesome complaints. Dr. Holtzman emphasizes the importance of identifying how these symptoms could be related to actual anxiety as opposed to dysautonomia, as anxiety symptoms are more easily treated. Sometimes changes in position can also be difficult, such as sitting up from lying down. This is also called postural orthostatic hypotension (POTS) and affects many people with and without mitochondrial disease (learn more at POTS place).

"I just thought I was crazy for feeling this way," said one MitoAction member on the call. Be assured, you are not crazy, and the symptoms associated with dysautonomia can be very confusing and really challenging as they affect how one feels and even how well one can function! There are patients whose primary symptoms of their underlying mitochondrial disorder are related to autonomic nervous system irregularities. Still, many people wonder when to react and seek medical help. First, know the patient's baseline. For example, if a person's baseline temperature is around 97 degrees, a temp of 100 degrees is more concerning than in a person with a normal baseline temperature of 98.6 degrees Farenheit. The same idea applies to heart rate, blood pressure, and daily function. Second, always respond by consulting a doctor the first time that any unusual symptoms occur. In addition, **rest and good fluid intake are two keys to managing mitochondrial disease**, as well as autonomic nervous system dysfunction.