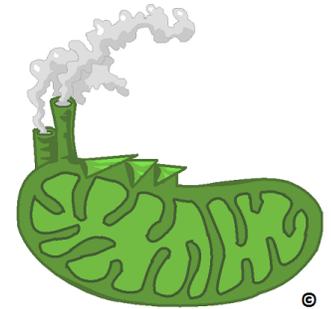




Factsheet: Mitochondrial Disease

What is it?

Mitochondrial diseases are a group of progressive metabolic, often neurological, disorders that result from defects in the mitochondria. The mitochondria are commonly referred to as the “power house” of every cell in the body that contain genetic material. It is responsible for creating more than 90% of the energy needed to support growth and sustain life. In a healthy person, the mitochondria produce oxygen to convert foods into energy. With a mitochondrial disorder, food cannot be converted and instead of getting energy, the person will be fatigued in 3 main areas of the body including the heart, brain and skeletal muscles. Mitochondria failure therefore results in energy deprivation and chronic fatigue. There are many mitochondria disorders and each disease has its own unique symptoms.



What are the signs and symptoms?

Mitochondria disorders are notorious for not following a set pattern. The heart, brain, lungs and muscles are most affected because they require the most energy. Other effects can include GI issues like reflux and constipation, failure to thrive, diabetes, blindness, deafness, and heat/cold intolerance. A “red flag” for mitochondrial disease is when an individual has 3 or more organ system problems. However, sometimes it is referred to as an “invisible disease.” The following table was created using the *United Mitochondrial Disease Foundation (umdf.org)*.

<p style="text-align: center;">Brain</p> <ul style="list-style-type: none"> • Seizures • Developmental delay • Mental retardation • Features of autism • Cerebral palsy 	<p style="text-align: center;">Heart/Liver/Pancreas</p> <ul style="list-style-type: none"> • Cardiomyopathy • Heart blocks • Hypoglycemia • Liver failure • Diabetes
<p style="text-align: center;">Muscles</p> <ul style="list-style-type: none"> • GI reflux • Diarrhea or constipation • Hypotonia 	<p style="text-align: center;">Nerves</p> <ul style="list-style-type: none"> • Weakness • Pain • Temperature instability
<p style="text-align: center;">Ears/Eyes</p> <ul style="list-style-type: none"> • Blindness • Strabismus • Deafness 	<p style="text-align: center;">Systematic</p> <ul style="list-style-type: none"> • Failure to thrive • Fatigue • Respiratory problems

Suggested school accommodations

Conserving energy and learning to pace are important strategies in the classroom. Working with the child in order to organize their actions and reactions will make a significant difference in their readiness to learn.

- Ongoing communication
- Flexible schedule
- Shortened days/weeks
- Limit stressors
- Multiple sensory learning supports
- Monitor for memory loss
- Auditory/Oral accommodations
- Supervision in halls
- Extra set of books at home
- Educational aid or 1:1
- Hand hygiene for all to prevent infection
- Energy conservation strategies
- Provide support
- Limit physical demands like writing,
- Climate control environment
- Limit physical activities when needed
- Frequent breaks
- Designated and safe rest area
- Hydration, carrying a water bottle
- Snacks available, no fasting
- Extended lunch or snack times
- Limit time on transportation related to fatigue

SHNIC school nurses information:

Specific health issues for individual health care plans

- Name of mitochondrial disorder, severity
- Body parts and functions affected
- Current medication list including PRN medications for pain
- Last hospitalization
- Nutrition orders including snacks and fluid goals
- Feeding tube orders for use and replacement per county policy, if applicable
- Fever protocol
- Orders for temperature control parameters or cold stress/hot stress
- Seizure action plan
- Orders for rest breaks or nap times
- Repositioning for muscle cramping
- Communication about other illness/infection in the school

Resources & Manuals

United Mitochondrial Disease Foundation

<http://www.umdf.org>

Teacher/Education resources

<http://www.umdf.org/site/pp.aspx?c=8qKOJ0MvF7LUG&b=7934659>

Mito Action

<http://www.mitoaction.org>

Energy for education– Youtube video

<http://www.mitoaction.org/energy-4-education>