Mitochondrial Disease Fact Sheet

Who is MitoAction?
MitoAction is a Boston-based 501(c)3 charity incorporated in 2005 (tax id 55-0899427), that provides support, advocacy and educational resources FREE for all patients and caregivers affected by mitochondrial disease. MitoAction is entering its fifth year and is the ONLY dedicated support and advocacy organization for those living with the disease. Visit our website: www.MitoAction.org.

What is Mitochondrial Disease?
Mitochondrial disease is a chronic, genetic disorder that occurs when the mitochondria of the cell fails to produce enough energy for cell or organ function. Mitochondria are responsible for creating more than 90% of the energy needed by the body to sustain life and support growth. When they fail, less and less energy is generated within the cell. Whole systems begin to fail, and life is severely compromised.

How common are mitochondrial diseases?
The incidence is about 1:4000 individuals in the U.S., similar to that of cystic fibrosis. Mitochondrial dysfunction has also been implicated in autism, diabetes, Parkinson’s disease, Alzheimer’s disease.

What are the symptoms of Mitochondrial Disease?
“Mito” commonly manifests with devastating symptoms such as stroke, muscle pain, extreme fatigue, and organ failure. Depending on how severe the mitochondrial disease is, the illness can range in severity from mild to fatal.

How are mitochondrial diseases diagnoses and treated?
There is no single laboratory or diagnostic test that confirms a diagnosis of mitochondrial disease. Blood DNA and/or muscle biopsies are the best means of diagnosing patients.

Is there a cure for mitochondrial disease?
There are no cures for mitochondrial diseases, but treatment can help reduce symptoms, or delay or prevent the progression of the disease. Researchers internationally are working hard to better understand mitochondrial disease.

What is MitoAction’s mission?
- To improve quality of life for children and adults affected by the disease.
- To raise awareness about mitochondrial disorders, and their relationship to other diseases.
- To provide specific and practical materials that help patients to manage their symptoms.
- To aggregate and connect the international mitochondrial disease community and to engage pharmaceutical industry working toward therapeutic approaches to mitochondrial disorders.
- To create tools which empower patients and caregivers to be advocates for themselves or their children.