Mitochondrial Disease Leadership Creed for Physicians, Researchers, Patient Advocates and Organization Representatives

We believe that mitochondrial disease is a very real and potentially devastating diagnosis. We believe that adults, children and families who suffer from this disease deserve support. We believe in transparency of diagnosis and treatment and collaboration in the clinical decision making process. We insist on direct and thoughtful communication between all healthcare providers involved in the mitochondrial disease patient’s care and believe that parents should not be burdened with the role of medical liaison. We recognize that such open communication between all providers enhances a patient’s medical care and can help to prevent unfortunate allegations of misconduct which can be destructive for the patient and family and their relationships with the medical community. We support international research efforts to improve the standards of diagnosis, treatment and basic understanding of the disease.

We encourage open discussion about the challenges facing the patients as well as the physician community who care for those with mitochondrial disease. We wrestle with the difficulties that these patients and families face and pledge to do our best to address them in a manner which is direct, honest and helpful. We honor the patients and families suffering as pioneers alongside us in this new and rapidly growing arena.

We recognize that mitochondrial disease is a complex diagnosis and that patients and families are often under duress during their diagnostic odyssey. We too are frustrated by the lack of treatment options available for our patients. We believe that awareness and education on multiple levels are critical. We strive to improve communication between physicians and healthcare providers about mitochondrial disease in an effort to improve our patient’s lives. We envision a future in which children and adults with mitochondrial disease will be better understood and will have viable, life-saving treatment options within their reach.

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