Dear Clinician:

Thank you for your interest in the Mitochondrial Care Network (MCN), a joint effort of the Mitochondrial Medicine Society (MMS), the United Mitochondrial Disease Foundation (UMDF), MitoAction and Foundation for Mitochondrial Medicine (FMM). By completing this application you are taking the first step in joining an exciting initiative that offers clinical and scientific challenges, opportunities and rewards! Additionally, you will play a **pivotal role** in identifying underserved patients and providing badly needed services for them, as well as contributing to an expanding knowledge base that promises better care for the future.

The growing interest in a Mitochondrial Care Network demonstrates that **'if we build it, they will come,' and we fully anticipate steady growth in patient numbers, even in centers with very small mitochondrial disease populations now.** For this reason, when selecting sites for Mitochondrial Care Centers, emphasis will be placed on the following areas more than on existing patient numbers:

- Institutional support;
- Enthusiasm for the program; and,
- Willingness to work collaboratively to ensure the creation a successful, sustainable network of mitochondrial clinical centers.

I. Background and Purpose

The MCN will formally unify clinicians who provide medical care to individuals with mitochondrial disease; to define, design and implement best practices in mitochondrial medicine, building on current consensus guidelines for mitochondrial diagnosis* and care**; and to optimize management and care to improve patient outcomes.

The MCN's goals include establishing an outstanding standard of continually improving care for mitochondrial disease in the United States, while integrating a formal infrastructure for research and clinical trials.

The MCN will be an organized group of individual Mitochondrial Medicine Centers (MMCs) that:

- Offer proper evaluation and diagnosis for primary mitochondrial disease;
- Provide comprehensive medical care to individuals with primary mitochondrial disease;
- Foster patient education; and
- Engage in active participation in clinical research and mitochondrial registries (NAMDC, MCDR)

II. Application Eligibility

Any clinician in the United States who provides care to patients with mitochondrial disease can apply to join the MCN. Factors for consideration will include patient volume (both current and prior), multidisciplinary approach and hospital/center support. The MCN Governance Board is responsible for final decisions on eligibility of initial pilot phase and expansion of the MCN.

* Parikh S, Goldstein A, Koenig MK, Scaglia F, Enns GM, Saneto R, Anselm I, Cohen BH, Falk MJ, Greene C, Gropman AL,
Haas R, Hirano M, Morgan P, Sims K, Tarnopolsky M, Van Hove JL, Wolfe L, DiMauro S. Diagnosis and management of
mitochondrial disease: a consensus statement from the Mitochondrial Medicine Society. Genet Med. 2015 Sep;17(9):689-701. Review. PMID:25503498. Available at bitl.ly/mitoconsensus

**Parikh S, Goldstein A, Karaa A, Koenig MK et al. Patient care standards for primary mitochondrial disease: a consensus
statement from the Mitochondrial Medicine Society. Genetics in Medicine. advance online publication 27 July 2017. doi:10.1038/gim.2017.107. Available at bit.ly/mitocare

A diverse group of Centers for the pilot phase will be selected to determine the full scope, clinical priorities, implementation of standards of care and desired outcomes of the MCN.

III. Overview of MMC

As a part of the MCN process, centers should be committed to the following: continuing education of colleagues, medical trainees and mitochondrial patients/families through conferences; partnering with other MCN Centers to optimize care; participating in MMS clinical research projects; participating in patient registries; and fostering relationships with regional and national patient advocacy groups.

A. Principles of MMC (see table)

- Accept patients who have, or may have, mitochondrial disease and provide ongoing care.
- Accept, or have specific referral sites, for patients of any age, whether adults or children. Those centers that focus only on either pediatric or adult care must demonstrate access to continuity of care across age groups and facilitate the provision of care, regardless of age.
- Have a center director with significant clinical experience and a commitment to the implementation of current consensus guidelines for mitochondrial care and a goal to maintain standards of care when appropriate.
- Be responsive to patient queries. Have a designated medical staff member (local Center Coordinator) who will be the point of contact for both patients and for staff at the MMS.
- Schedule new patient appointments in a timely manner in accordance with medical needs.
- Make appropriate referrals to specialists (either within or outside the MCN MMC facility) who are familiar and experienced with consensus guidelines in adult and pediatric care of individuals with mito.
- Have ready access to select subspecialists as outlined
- Have knowledge of ongoing clinical research and provide information to facilitate the patient's participation in ongoing registries and clinical trials.
- Complete an Annual Report to the MMS Governance Board on MCN MMC activities.
- Distribute the MCN Patient Satisfaction Survey to all mitochondrial patients

B. Benefits to becoming an MMC

Participation in this effort is anticipated to offer a number of benefits including:

- The opportunity to collaborate within an organized network of US centers to improve mitochondrial patient care.
- Collaboration between the MMCs, including sharing of resources and information, systematic data collection and optimization of patient outcomes.
- An opportunity to contribute to the ongoing development of the Standards of Care for mitochondrial clinical care as developed by the MMS.
- An opportunity to join key opinion leaders to coauthor publications impacting forward thinking solutions and opportunities in mitochondrial care
- Potential increase in a center's mitochondrial patient numbers: MCN MMCs will be listed on the MMS and patient advocacy group's websites and in printed materials.
- Becoming an integral part of mitochondrial research and clinical trials network and community.
- The MCN will have a central coordinator who will assist in administrative and research activities and facilitate overall network interactions.

C. MCN Oversight

Initially the MCN will run under the oversight of the MCN Governance Board consisting of members of the executive team from the MMS and the Patient Advocacy Groups (UMDF, MitoAction and FMM). Additional stakeholders will be added as appropriate.

IV. MCN Application Process

Please complete the online Mitochondrial Care Network Application form and submit.

A. Deadline

The initial RFA period will run through February 28, 2018. All applications will be reviewed by the MCN Governance Board for selection for the pilot phase.