North American Mitochondrial Disease Consortium (NAMDC)

Research Areas

Tool Development

Resource

At a Glance

- Status: Active Consortium
- Year Launched: 2010
- Initiating Organization: NIH Rare Disease Clinical Research Network
- Initiator Type: Government
- Rare disease
- Location: North America

Abstract

Mitochondrial diseases are a challenge because they are probably the most diverse human disorders at every level: clinical, biochemical, and genetic. Although severity varies, by and large these are progressive and often crippling disorders. The North American Mitochondrial Disease Consortium (NAMDC), working closely with United Mitochondrial Disease Foundation (UMDF), is working to address these difficult issues.

Mission

The challenge for the NAMDC is the extraordinary clinical spectrum of mitochondrial diseases, which all too often leads practitioners to either underdiagnose (“What is this complex disorder?”) or overdiagnose (“This disorder is so complex that it must be mitochondrial!”). Yet mitochondrial diseases cause similar metabolic defects and presumably share—albeit to different extents—the same mechanisms. Thus, the availability of a mitochondrial patient registry and consortium will have a powerful impact in multiple ways, as already documented by similar organizations operating in Europe.
NAMDC’s aims are as follows:

**Structure & Governance**

This consortium is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research, National Center for Advancing Translational Sciences. The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing. Through the RDCRN consortia, physician scientists and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Funding and scientific oversight for the RDCRN are provided by NCATS and 10 National Institutes of Health components: Eunice Kennedy Shriver National Institute of Child Health and Human Development; National Cancer Institute; National Heart, Lung and Blood Institute; National Institute of Allergy and Infectious Diseases; National Institute of Arthritis and Musculoskeletal and Skin Diseases; National Institute of Dental and Craniofacial Research; the National Institute of Diabetes and Digestive and Kidney Diseases; National Institute of Mental Health; the National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

**Patent Engagement**

The RDCRN NAMDC Contact Registry is a way for patients with mitochondrial disease and their family members to learn about NAMDC research studies they may be able to join. Participation is completely voluntary, and participants may withdraw at any time. There is no cost to join the Contact Registry.

**Links/Social Media Feed**

Homepage  
http://www.rarediseasesnetwork.org/NAMDC/

**Points of Contact**
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