

How do I participate?

If you are diagnosed with a mitochondrial disease or are suspected to have a mitochondrial disorder you can be enrolled into the registry by contacting any NAMDC member site nearest you (see next page for list of participating centers). In the event that you are unable to travel to any of the NAMDC sites, you can contact the NAMDC Clinical Coordinating Center to be enrolled remotely by web or telephone contact.

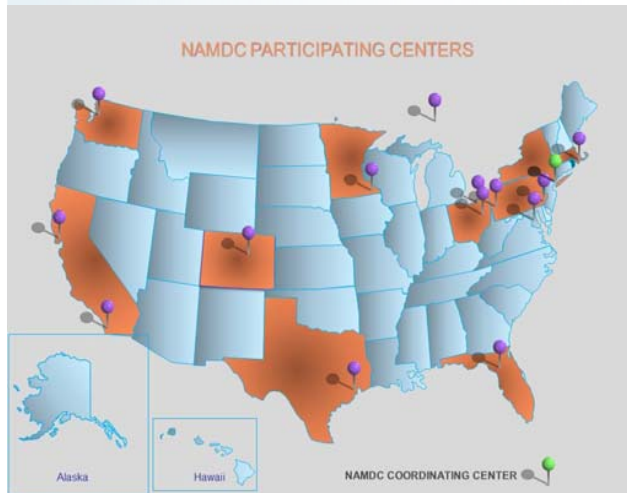


NAMDC Clinical Coordinating Center

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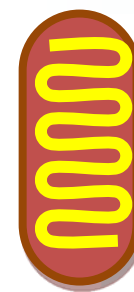
<http://www.namdc.org>
Phone: 212-342-2336
Fax: 212-305-3986
E-mail: NAMDC@columbia.edu



NAMDC Participating Centers

Columbia University Medical Center
Seattle Children's Hospital
Mayo Clinic
Cleveland Clinic Foundation
Case Western Reserve University School of Medicine
Hamilton Health Sciences
University of Florida College of Medicine
Baylor College of Medicine
University of California San Diego Medical Center
Akron Children's Hospital
University of Pittsburgh
Stanford University
Children's National Medical Center
Children's Hospital of Philadelphia
Children's Hospital of Colorado
Massachusetts General Hospital

Visit [<http://www.rarediseasesnetwork.org/cms/NAMDC>] for contact information of participating sites' nearest you.



NAMDC Clinical Patient Registry

Together against
mitochondrial disease



What is Mitochondrial Disease

Mitochondrial diseases comprise a group of rare (about 1 in 5,000) but very serious genetic disorders. They are caused by defects in mitochondria, the powerhouses of human cells. Symptoms vary widely and can include muscle weakness, seizures, mental retardation, dementia, hearing loss, blindness, strokes, diabetes, and premature death.

Although some mitochondrial diseases are evident at birth, a mitochondrial disease can develop at any time during a person's life.

Most mitochondrial diseases are progressive and have poor prognoses and few available treatments.

What is the NAMDC Clinical Patient Registry?

The NAMDC Clinical Patient Registry collects information to help scientists learn more about mitochondrial diseases and their potential causes. The Registry is maintained and operated by the North American Mitochondrial Disease Consortium (NAMDC) consisting of several centers of excellence in the study and treatment of mitochondrial disease.

These "centers of excellence" collaborate with each other and with participating patients to collect vital information and conduct research on mitochondrial diseases.

NAMDC is supported by the National Institutes of Health (NIH) and is a member of the NIH Rare Disease Clinical Research Network (RDCRN) . NAMDC collaborates with the United Mitochondrial Disease Foundation (UMDF/MDCR).

What kind of information is collected?

NAMDC clinicians collect clinical information that support your diagnosis, and add your contact information to the registry. If you agree, you will receive notifications about research participation. Patients who participate in the registry make it possible for researchers to create new studies, find new treatments, and work for the improvement of quality of life of those affected by these rare conditions.

Is my personal information safe?

Yes, the NAMDC Coordinating Center will not give participant names or other personal identification to other participating centers or researchers. NAMDC and non-NAMDC researchers may however access your **de-identified** data to pursue research upon approval by the NAMDC Research Committee.

All data collected for the NAMDC Registry will be stored in an encrypted database.