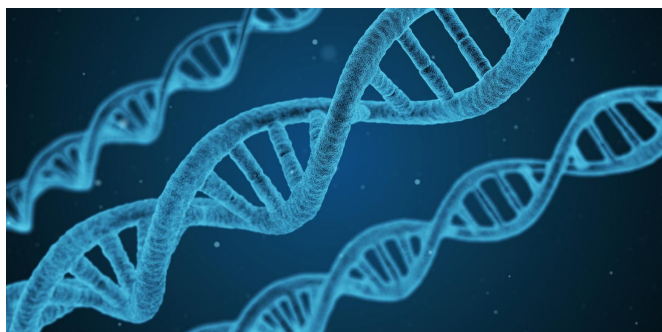


New clinical care guidelines issued for patients with mitochondrial disease

25 October 2017



Credit: CC0 Public Domain

Physicians who see patients with mitochondrial disease now have a practical new tool—a set of guidelines for managing and caring for those patients. Occurring in at least one in 4,500 individuals, mitochondrial disease is caused by defects in genes affecting the function of mitochondria, crucial energy-producing structures found in every cell. This complex disease can affect nearly every organ or system in the body.

"Standards of care are not uniform across centers or clinicians. To take just one example, clinicians need to know how often to order laboratory tests to monitor the health of [patients with mitochondrial disease](#)," said study co-leader Amy Goldstein, MD, newly appointed clinical director of the Mitochondrial Medicine Frontier Program at Children's Hospital of Philadelphia (CHOP), and current president of the Mitochondrial Medicine Society (MMS), which issued the consensus statement. "Our guidelines reflect expert consensus based on our current knowledge of [mitochondrial medicine](#)."

The MMS patient care standards for primary mitochondrial disease appeared online July 27, 2017 in *Genetics in Medicine*. The study leader and corresponding author is Sumit Parikh, MD, of

the Cleveland Clinic Children's Hospital.

The MMS previously issued consensus criteria in 2015 to guide diagnosis of mitochondrial disease. It subsequently surveyed over 200 clinicians worldwide who see mitochondrial patients, and found that 99 percent of those practitioners, including neurologists, geneticists and metabolic experts, wanted additional guidelines to assist in managing patient care. In addition, said Goldstein, "patients and families have been asking for a guidelines document to bring to their own physicians."

For the current study, the MMS appointed an international panel of 35 mitochondrial medicine specialists to review current knowledge and develop recommendations.

Reflecting the systemic impact of energy deficiencies caused by impaired mitochondrial function, the group's recommendations address a broad range of medical specialties, including cardiology, neurology, [critical care medicine](#), nephrology, endocrinology, audiology and ophthalmology.

In addition, the guidelines address special issues encountered by patients during pregnancy and high-altitude travel, and also compile a list of medications, such as statins and acetaminophen, that must be used with caution or avoided in patients with mitochondrial disease.

While the current guidelines are the first set of published recommendations for patient management and clinical care decisions, the authors recognize that as mitochondrial medicine continues to evolve, the guidelines will need to be updated.

These guidelines represent an important step in the effort to standardize health care and optimize health outcomes for [mitochondrial disease](#) patients.

They also establish a baseline from which meaningful clinical trials can be launched to evaluate new treatment interventions.

More information: Sumit Parikh et al, Patient care standards for primary mitochondrial disease: a consensus statement from the Mitochondrial Medicine Society, *GENETICS in MEDICINE* (2017).
[DOI: 10.1038/gim.2017.107](https://doi.org/10.1038/gim.2017.107)

Provided by Children's Hospital of Philadelphia

APA citation: New clinical care guidelines issued for patients with mitochondrial disease (2017, October 25) retrieved 6 June 2021 from <https://medicalxpress.com/news/2017-10-clinical-guidelines-issued-patients-mitochondrial.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.