

# **Development and Validation of a Genetic Counseling Teaching Aid for Mitochondrial Disorders**

**Monica Dandapani, Allison Cirino, Susan Hiraki, Katherine B. Sims,  
Jeff Milunsky, MaryAnn Whalen Champion**  
Boston University School of Medicine, Boston, Massachusetts

One goal of genetic counseling is to facilitate patient learning and enable informed decision-making. Information about many genetic concepts can be difficult to grasp, so genetic counselors often make use of teaching aids to help communicate key points. There are a number of teaching aids already available to help explain inheritance patterns, prenatal testing options, and hereditary cancer risk. However, there are currently no teaching aids available to address mitochondrial disorders. The genetics, biology and pathogenicity of mitochondrial conditions are complex, driving the need for such teaching aids. The aim of this study was to create a teaching aid that facilitates patient learning about mitochondrial conditions and to assess whether knowledge about mitochondrial conditions improved after an educational session using the teaching aid. The teaching aid was designed for use by genetic counselors, but could also be used by other health care professionals or by educators in a classroom setting. The teaching aid was developed based on current knowledge of mitochondrial conditions and was modeled after existing teaching aids. An iterative process was used in which the aid was first piloted in an educational session with a subject group of genetic counselors and genetic counseling students, and was then amended based on open-ended feedback that was gathered after the presentation. The efficacy of the teaching aid was tested with individuals affiliated with mitochondrial support groups and/or patients and parents of patients with mitochondrial disorders. Improvement in knowledge was measured using pre- and post- session multiple-choice questions about mitochondrial disease. Satisfaction was assessed using both multiple choice and open-ended questions about the participant's overall impressions of the educational session. Open-ended comments were analyzed for recurring themes. This study showed that this teaching aid is an effective tool for improving knowledge about mitochondrial conditions.