

GNEM SYMPOSIUM SPEAKER SERIES

presented by The Neuromuscular Disease Foundation

"Multidisciplinary Clinics (virtual and in-person) for GNE myopathy"



Dr. Tahseen Mozaffar with Carol Gelbard, LCSW



June 19, 2020 9am PDT/12pm EDT



Dr. Tahseen Mozaffar with Carol Gelbard, LCSW Introduction & Summary Slide for: "Multidisciplinary Clinics (virtual and in-person) for GNE myopathy"

An Overview of what to expect in this talk:

Intro: (bullet form)

- 1. What is your relationship to NDF? (In your case you've been funded for two years to study___)
- 2. What we will learn from this presentation today? (What problem are you trying to solve?)
- 3. How does this study fit in with our bigger scientific mission? (In your case, how will it support gene therapy or drug development etc.)



Speaker Series #61920

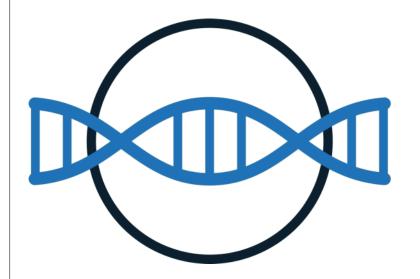


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for GNE myopathy"

Key Takeaways:

Importance for multidisciplinary care in GNEM

- It is important to have a wholistic approach to care of GNEM patients
- 1. These visits can be done once a year, either in person or virtually
- 2. Currently there are opportunities to do these visits virtually from all over the US using a variety of video platforms
- 3. These multidisciplinary visits provide a unique opportunity to not only take good care of patients but develop natural history and longitudinal data in disease course, collect valuable biological specimens and create a repository and interact with industry partners to create research trials and studies in GNEM



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