MDF DM Days at Virginia Commonwealth University

• Nicholas Johnson, MD, MSCI, FAAN
• Vice Chair of Research
• Division Chief, Neuromuscular
• Associate Professor of Neurology
The Myotonic Dystrophy Program at VCU: Clinical

- Adult myotonic dystrophy clinic on Tuesdays at the NOW building
- Pediatric myotonic dystrophy clinic every other Wednesdays at CHoR downtown
DM Program Clinical

• Both clinics include multidisciplinary support:
  • Physical therapy
  • Speech therapy
  • Social work
  • Respiratory therapy
  • Care coordinators
  • Dietician
  • Genetic counseling (soon)
Both clinics have care providers with experience in myotonic dystrophy

• Pediatric:
  • Eugenio Montaserio, MD
  • Amy Harper, MD
  • Mathula Thangarajh, MD, PhD
  • Nicholas Johnson, MD, MSCI

• Adult:
  • Nicholas Johnson, MD, MSCI
  • Kelly Gwathmey, MD
  • Scott Vota, DO
Myotonic Dystrophy research team

• Nicholas Johnson, MD, MSCI
  • Leads the natural history studies in DM1, CDM, prevalence study
• Mathula Thangarajh, MD, PhD
  • Focus in cognition in DM
• Melissa Hale, PhD
  • Focus on disease mechanism in DM1
• Kiera Berggren, SLP
  • Focus on speech and swallowing in DM
• Brittney Holmberg (Project manager)
• Jeneane Henry, RN (clinical research support)
• Sarah Valkovci (study coordinator)
• Liz Diaz (study coordinator)
• Kameron Bates (bioinformatics)
• Erin DeSpain (grants and contracts)
Overview

• Scientific Updates
• Rehabilitation in DM
• Cognition in DM
• Updates from MDF
• Research updates
• Lunch
• Speech therapy
• NORD