



THE JOURNEY TO DIAGNOSIS

— FOR PEOPLE WITH MITOCHONDRIAL DISEASE —

A recent study published in *Neurology: Genetics* documented the complex journey to diagnosis for people with rare mitochondrial diseases. Follow the patient journey and learn about some of the common challenges they face as brought to light by the study.



MOTIVATING SYMPTOM TO SEEK A DIAGNOSIS

- 1 WEAKNESS
- 2 FATIGUE
- 3 DIFFICULTY WALKING
- 4 DROOPY EYELIDS
- 5 IMPAIRED COORDINATION



NUMBER OF CONSULTATIONS WITH DOCTORS



PARTICIPANTS CONSULTED AN AVERAGE OF 8 DOCTORS ON THEIR JOURNEY TO A DIAGNOSIS



DIAGNOSIS OF MITOCHONDRIAL DISEASE

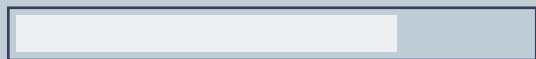
MORE THAN HALF

OF RESPONDENTS REPORTED RECEIVING AT LEAST ONE ALTERNATIVE DIAGNOSIS BEFORE THEIR FINAL DIAGNOSIS

55% OF PARTICIPANTS RECEIVED THEIR MITOCHONDRIAL DIAGNOSIS FROM A NEUROLOGIST

AT 22%, MYOPATHY WAS THE MOST COMMON MITOCHONDRIAL DISEASE DIAGNOSIS REPORTED BY PATIENTS

72% JOINED A PATIENT ADVOCACY GROUP AS A RESULT OF THEIR DIAGNOSIS



85% FOUND PARTICIPATION IN AN ADVOCACY GROUP WAS BENEFICIAL



ROLE OF PATIENT ADVOCACY FOLLOWING DIAGNOSIS

To learn more, read the full article at [Neurology: Genetics](#).