

ALL ABOUT NEMALINE MYOPATHY

NM IS A RARE MEDICAL CONDITION THAT CAUSES MUSCLE WEAKNESS & VARIES IN SEVERITY FROM MILD SYMPTOMS TO PREMATURE MORTALITY.



Weak Body Muscles: People with Nemaline Myopathy may need wheelchairs or other physical support to get around.



Weak Face & Throat Muscles: Individuals with NM may have trouble speaking or swallowing.



Weak Breathing Muscles: People with NM may need the help of breathing machines.



NM doesn't affect brain development or cognitive functions like learning and thinking.

FACT NM

CAN BE CAUSED BY MUTATIONS IN ONE OF 12 KNOWN GENES. MOST CASES ARE CAUSED BY MUTATIONS FOUND IN THE NEB GENE (50%) AND ACTA1 GENE (15-25%).

DID YOU KNOW?

NEMALINE MYOPATHY AFFECTS AN ESTIMATED 1 IN 50,000 PEOPLE. CURRENTLY NO TREATMENTS EXIST.



LEARN MORE ABOUT NM!



WHAT IS

A FOUNDATION BUILDING STRENGTH FOR NEMALINE MYOPATHY

DONATE HERE!



AFBS is a 501(c)(3) nonprofit organization dedicated to finding treatments for Nemaline Myopathy (NM), while also providing support and resources to individuals and families with NM, building community through in-person and virtual gatherings, and organizing conferences where researchers and patients gather to share knowledge.

Currently no treatments or disease modifying therapies exist, but AFBS is working aggressively to change this. AFBS is committed to advancing research by:



RESEARCH

Funding Priority Research

- Gene Therapy
- Small Molecule (Drug) Therapy
- Developing a greater understanding of NM
- Developing disease management therapies & technology

Assisting with **Genetic Confirmation Testing** to support patients in receiving the best possible care.



TESTING



NM BIOBANK

Funding the **NM Biobank**, the world's foremost repository of Nemaline Myopathy tissue samples.

Supporting individuals with NM in adding their information to the **Congenital Muscle Disease International Registry** where their data can help inform scientists' understanding of the disease.



CMDIR

A MESSAGE FROM OUR EXECUTIVE DIRECTOR:

"With increased awareness comes increased understanding, and with understanding comes progress. Let's shine a light on Nemaline Myopathy and pave the way for breakthroughs!"

-Jen Tozer

