

# NEMALINE MYOPATHY RESOURCE KIT

## At a glance

If you or someone you know has been diagnosed with Nemaline Myopathy (NM), this resource kit is for you. Created by [A Foundation Building Strength](#) (AFBS), a nonprofit organization dedicated to biomedical treatment discovery for NM, this kit provides helpful resources and information for affected individuals and their families. Click on the hyperlinked, underlined text for additional information.

## WHAT IS NEMALINE MYOPATHY?

[Nemaline Myopathy \(NM\)](#) is a genetic disorder caused by mutations in one of 12+ genes that primarily affects skeletal muscles, which are used for movement. Muscle weakness is often most severe in the muscles of the face, neck, body core, and muscles close to the center of the body (proximal muscles), such as those of the upper arms and legs. The condition commonly affects other organs and body systems too.

## TOOLS TO EMPOWER YOUR HEALTH

Connecting with others on a similar journey is a powerful support. We are stronger together.

You can join the [NM community](#) in many ways:

### FOLLOW + JOIN

- Follow AFBS on [Facebook](#) + [Instagram](#)
- Follow the [Nemaline Myopathies page](#)
- Join the Facebook discussion group: [Nemaline and Congenital Myopathy Community](#)

### CONNECT WITH AFBS

- [Sign up](#) for the AFBS e-newsletter to get updates on news, research, events and more
- Complete the [AFBS NM Contact Survey](#)

### ATTEND

- Learn more about [AFBS social gatherings](#) + other [events](#)
- Attend a [SciFam Conference](#)
- Tune into a [webinar](#)

### DOWNLOAD

- Download [The Care of Congenital Myopathy: A Guide for Families](#)
- Download and print a set of [NM Awareness Cards](#) to share with new acquaintances, bringing awareness to NM

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## ADVANCE NEMALINE MYOPATHY RESEARCH

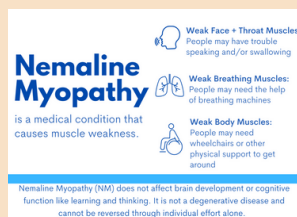
The road to treatment begins with YOU. AFBS is removing barriers to treatment development. Take the following steps to advance NM research:

- 1** Join the **International Registry**: Contribute to the information needed to conduct important NM research
- 2** Get **Genetic Testing** to confirm your diagnosis: Fill out this short **interest form** to get started. Contact [stacy@buildingstrength.org](mailto:stacy@buildingstrength.org) for additional support.
- 3** **Donate Tissue Samples**  
Contact [Stacy.Cossette@childrens.harvard.edu](mailto:Stacy.Cossette@childrens.harvard.edu) for next steps
- 4** Make sure your clinicians are using the **medical code for Nemaline Myopathy: G71.21**

Remember, the road to treatment begins with you. Take control of your health and access the resources provided by AFBS to empower yourself and your loved ones.

### NM AWARENESS CARDS

The [NM Awareness Cards](#) are a helpful tool to share with curious on-lookers, new acquaintances, or anyone that is not aware of what NM is. This card will help bring more awareness to NM in your community. [ORDER YOUR FREE CARDS HERE](#)

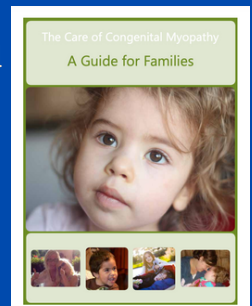


### THE CONGENITAL MYOPATHY CARE GUIDE

AFBS provides valuable resources to help you get the best care possible.

**[The Care of Congenital Myopathy: A Guide for Families](#)** is a free,

comprehensive resource for those with any form of NM. It consolidates the expertise and experience of medical professionals and affected families from all around the world into one helpful guide.



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