



A FOUNDATION BUILDING STRENGTH

For Nemaline Myopathy

FUNDRAISING GUIDE

Thank you for your interest in fundraising for A Foundation Building Strength, to find treatments for Nemaline Myopathy and change lives. This guide will help you get started with your fundraising plans.

ONLINE FUNDRAISING

Online fundraising gives you the ability to raise funds online, using specialized online fundraising tools. These tools allow you to:

- Register your fundraising page online
- Personalize your fundraising page
- Email your friends and family to ask for donations (utilizing customizable email templates)
- Recruit others to join you
- Track fundraising progress
- Share your passion for funding NM research via social media

To get started, visit <https://buildingstrength.networkforgood.com/projects/27134-fund-treatments-for-nemaline-myopathy>. Click “Start Fundraising Now!” and follow the step-by-step instructions to create your fundraising page. Once logged in, you can customize and personalize your page. (AFBS can also set up a customized fundraising page just for you. Contact jtozer@buildingstrength.org if interested.)

To start fundraising, you can utilize the fundraising email templates to recruit individuals to join you and to ask for donations.

Using social media is a great way to expand your reach when asking for donations and recruiting participants. Sample social media posts are included when you set up your fundraising page. Keep your followers updated by posting, and sharing photos of your fundraising efforts while engaging and asking them for support. Continue posting updates of your progress until you reach your goal!

When someone makes a donation online, they will automatically receive an email confirmation and can use this for tax purposes. In addition, sending a personal thank you email to each donor is a great way to show your appreciation. A template email for thanking donors is provided within your fundraising page. You can also customize your fundraising page to be notified when someone makes a donation, or you can log into your page to view your fundraising progress.

If someone wants to mail their donation, they can send a check to A Foundation Building Strength, 3825 El Camino Real, Palo Alto, CA 94306, noting the fundraising event or fundraiser’s name.

FUNDRAISING TIPS

Ask personally. Share your own story about why you are fundraising for NM.

Ask everyone! The golden rule of fundraising is simple, you raise money when you ask for it. So ask everyone you know, both individuals and businesses.

Be specific. Let your donors know your fundraising goal and how much time you have to meet it.

Share it! On social media and include your fundraising page link in your email signature.

Ask confidently. You are not asking for money for yourself; you're asking for funds to help find treatments for NM.

Double your money! Ask your employer about their matching gift program and suggest this with your donors too.

Try these fun ideas to boost donations and make an even bigger impact on the lives of those with NM:

- SoulCycle fundraising event
- Walk & Roll walk-a-thon
- Host a party (private dinner, Superbowl, Oscars, Kentucky Derby, etc)
- Hold an auction or raffle
- Ask a restaurant or business to host a promotion for AFBS (portion of sales, donation jar, etc)
- Turn a gift to you, into a gift to AFBS: Birthday/Wedding Donations
- Bake sale
- Lemonade stand
- BBQ fundraiser
- Game night
- Yard sale

ABOUT AFBS & NEMALINE MYOPATHY

A Foundation Building Strength (AFBS) was founded in 2008 with a mission to help find treatments and a cure for Nemaline Myopathy (NM), an as-yet incurable, congenital, hereditary neuromuscular disorder that causes weakened muscles, hypoventilation, and many other symptoms.

AFBS is the only organization in the world that funds research specifically for NM. Because there is so little funding for rare disease research, every dollar donated has a huge, tangible impact.

It is estimated that approximately 6,500 people in the U.S. are currently diagnosed with NM. Sadly, 66% of severe cases of NM will die before age 2.

RESEARCH PROGRESS

In 2017, AFBS was able to fund **8 new research projects** throughout the world.

Many children with NM can't breathe on their own because the muscles necessary to do so are too weak to expand and contract the lungs and diaphragm. One new research project will test actual NM patients to discover if training inspiratory muscles works to improve diaphragm function.

AFBS provides a critical role as a resource and support system for families who are affected by NM. Its role in ushering in families' engagement in the Congenital Muscle Disease International Registry and tissue repository has been critical in allowing researchers to access people for their work.



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