

**A FOUNDATION  
BUILDING  
STRENGTH**

For Nemaline Myopathy

**FUNDRAISING  
TOOLKIT**

Together we can make a difference for those  
living with Nemaline Myopathy



Thank you for giving your time and efforts to fundraise for AFBS. By fundraising, you play a leading role in providing hope to those affected by Nemaline Myopathy. With the funds you raise, you will make it possible to further our mission of finding treatments, and ultimately a cure, for Nemaline Myopathy.



AFBS was founded in 2008 and is the **only organization solely for NM**. Founded by NM parents, AFBS is highly driven to efficiently and effectively progress NM research.



Because there is so little funding for rare disease research, every dollar donated has a huge, tangible impact.

**What is Nemaline Myopathy?**

A group of neuromuscular disorders that cause muscle weakness of varying severity. Many people with NM can't breathe, swallow, speak, or walk on their own.

**Lifespan**

Varies greatly. In severest cases, children with NM die before age two. In mild cases, individuals may appear unaffected but have a tendency to tire quickly from exercise. Most cases of NM require some form of mechanical breathing support, feeding support and/or mobility support.




**Estimated # of people affected: 1 in 50,000 live births**

# CURRENT NEMALINE MYOPATHY RESEARCH PROJECTS

## Improving Myosin Function to Treat Nemaline Myopathy

Introduce superior form of myosin to the muscles of NM mouse models.

Institution: King's College London  
Investigator: Dr. Julien Ochala

## CMD-Tissue Repository

Funding to support the congenital muscle disease tissue repository.

Institution: Medical College of Wisconsin  
Investigator: Michael Lawlor, MD

## CRISPR/Cas9 Gene Editing

Reintroducing DNA material to correct gene variation.

Institution: Hospital for Sick Children  
Investigator: James Dowling, MD, PhD and Hernan Gonorazky, MD

## Use of Abnormal Protein Expression to Improve Prognostication and Treatment Study Design in Nemaline Myopathy

Analyzing protein expression in mouse models to better understand the NM biological processes

Institution: Medical College of Wisconsin  
Investigator: Michael Lawlor, MD

## Modulating Myosin to Improve Muscle Strength in Nebulin-Based NM

Increase myosin force generation by gene therapy and myosin activator that targets slow myosin.

Institution: University of Arizona  
Investigator: Jhan Lindqvist, PhD

## Pre-Clinical Evaluation of the FDA Drug Collection

Test FDA approved drugs on zebrafish then test promising ones on mice

Institution: Monash University  
Investigator: Robert Bryson-Richardson, Tamar Sztal, Nigel Laing and Kristen Nowak

## Diaphragm Contractility

Assess exercise effect on diaphragm function.

Institution: VU University Medical Center  
Investigator: Coen Ottenheijm, PhD, Baziel van Engelen and Jonne Doorduyn

## Targeting Kelch-Regulated Pathways

Finding new molecular pathways to treat NM.

Institution: Brigham and Women's Hospital  
Investigator: Vandana Gupta, MD

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## EXCITING RESEARCH UPDATE

Dr. Gupta has found a mechanism by which Kelch proteins, a specific protein in muscle, regulates the stability and function of skeletal muscle. She has created zebrafish models with a similar genetic code to humans with NM. The fish with NM show weakness by swimming very slowly or not at all. When Kelch proteins are absent, the fish were slower and weaker. **She discovered that by reducing the toxic proteins by increasing Kelch protein in the fish, they swam faster and longer, demonstrating improved muscle function.**

# GETTING STARTED

Steps for a Successful Fundraiser:

1

## **Set Your Fundraising Goal**

- The average daily cost to support one NM research project is \$200. How many days of research will you support?

2

## **Gather Support**

- Get your friends and family involved. As a team, identify talents and skills that can help your fundraising efforts.

3

## **Determine How You Are Going to Raise Funds**

- Is it summer? Hold a car wash. Like to cook? Have a bake sale. We can help – check out our fundraising ideas (page 6). Use your personal skills and creativity to come up with the idea that works best for you and your supporters.

4

## **Create a Plan**

- Pick a date
- Create a timeline
- Make a list of tasks and assign them to your support team
- Identify how you will promote the event
- Collecting donations online? Create an AFBS fundraising web page (see page 8)

5

## **Spread the Word**

- Promote your event with local media. See media advisory template for help (page 10)
- Place fliers in your places of work, play, school, etc.
- Utilize social media and share online! View our social media tips for ideas (page 9)

6

### **Share Your Successes**

- Thank each of your contributors, volunteers and sponsors.
- Share photos of your fundraiser with AFBS. We'll highlight it on our social media and newsletter
- Share your results on social media to let your supporters and friends know the impact they made

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### **Submit your Contributions to AFBS**

- Submit your donations online or by mail

Checks can be made payable to A Foundation Building Strength. Mail to:

A Foundation Building Strength  
3825 El Camino Real  
Palo Alto, CA 94306

Thank you acknowledgements from AFBS will be sent once we receive donations.

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### **AFBS is Here to Help**

- We're always available to help you create a successful event. Email [info@buildingstrength.org](mailto:info@buildingstrength.org) for any support needed before, during or after your fundraiser.

# FUNDRAISING IDEAS

## Ideas for Everyone



**Commemorate:** Celebrate your birthday, anniversary or wedding by requesting donations to AFBS in lieu of gifts.



**Bake Sale:** Encourage everyone to bake their favorite treat and then sell, sell, sell. This one works well where there are a lot of people in one spot.



**Auction:** Obtain contributed items from local businesses and auction them off to the highest bidder.



**Restaurant Night:** Check with local restaurants. Many of them already have programs in place that allow you to raise funds for the cause of your choice. Each restaurant will have specific rules so be sure to inquire.



**Cycle:** Find a local spin studio (Cyclebar, Rush Cycle, etc) and recruit friends to fundraise and participate in a fun ride.



**Run:** Look at the local 5k run/walks and marathons in your community. Submit AFBS to be a charity partner, recruit friends or just run on your own!



**Lemonade Stand:** Perfect for hot summer days! All you need is lemonade, cups, ice and a money box and you're ready to go.



**Recycle Program:** Raise funds by recycling different products! Check out [fundingfactory.com](http://fundingfactory.com) for more information.



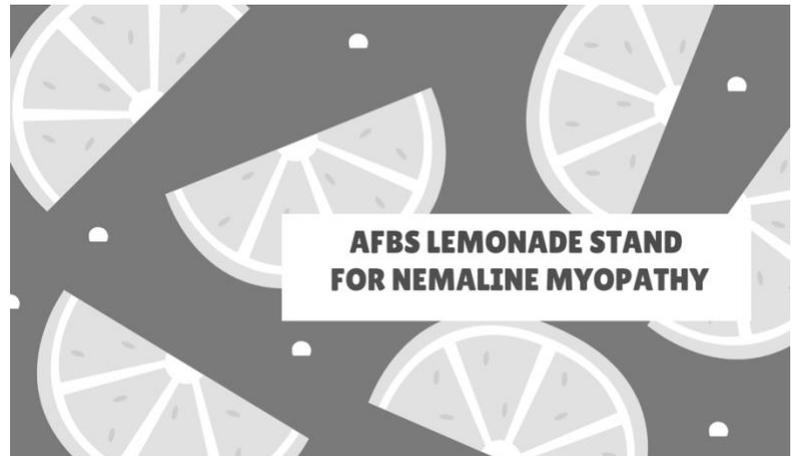
**Your Own Idea:** Use these ideas as a jumping off point. Be creative and work with AFBS. We are always looking for new, successful, fun ideas so if you have one please share!

# PLAN AN AFBS LEMONADE STAND

You can be part of our efforts to find treatments for NM, one cup at a time! Follow these simple steps to register your lemonade stand and make it a success.

REGISTER AT

<http://buildingstrength.org/organize-event/>



## Let's do this!

Once registered, choose your location, date and time. Children are encouraged to participate every step of the way!

## Spread the word.

When you register, you'll be creating your very own page for your stand. You can share your page with friends on social media and email. It's a great way to invite people to stop by your lemonade stand or even receive donations from people who may not be able to make it that day! Put up fliers and get the word out.

## Have fun!

Rather than putting a price on each cup of lemonade, simply ask for a donation of any amount. Be sure to let your supporters know that you can accept checks (payable to A Foundation Building Strength) or cash.

Consider adding on a raffle or bake sale at your event to maximize donations. Be creative!

## Now what?

After your event, send in your donations. We'll update your personal fundraising page with your donation total.

# CREATING YOUR FUNDRAISING PAGE

Creating an AFBS fundraising page is fun and easy! To get started, go to <http://buildingstrength.org/organize-event>. In a few simple steps you can personalize your page with a photo and your story. Next, email the link to friends and family so they can visit your page and engage in your cause. You'll receive automatic updates each time someone donates and your team can track your progress online.

Once you've set a goal, encourage your friends and family to get involved and donate online. Be creative in spreading the word.

We'll provide you with the online tools you need to achieve your goal. And you can feel good knowing you are truly making a difference for NM research. Get started by connecting with AFBS at [info@buildingstrength.org](mailto:info@buildingstrength.org).

**Hike a 14er to Build Strength for NemaLine Myopathy**  
Sign up as a fundraiser to support Jaxon and all those with NM

Start Fundraising

\$10,580 TOWARDS \$10,000

Help Us Find Recurring Donors

"We love you all!!"  
A SUPPORTER OF STEPHANIE ENGLISH  
GAVE \$100

"Best of luck! Love the Madsen family"  
MEGAN MADSEN  
GAVE \$25

I donated in support of this campaign on [Chuck English's](#) page.  
CHUCK ENGLISH  
GAVE \$250

105% TOWARDS OUR GOAL

5 FUNDRAISERS

50 DONATIONS

0 RECURRING DONORS

By most accounts Jaxon is a typical 6 year old boy-he loves robots and legos, farting and burping, thinks he is the funniest person in our family, and has secret handshakes with his friends from school.

But along with his diagnosis of NemaLine Myopathy comes a great deal of differences-he wakes up every morning and has respiratory therapy to clear his lungs because his muscles are

YOUR FRIEND HERE!  
GIVING \$50 PER MONTH!

You can help us get more recurring donations by starting a fundraiser!

Start Fundraising

# SOCIAL MEDIA TIPS

First, send out emails to your friends and family encouraging them to join your efforts and contribute! \*Hint\* send multiple emails...often times people want to give, but lose the email or forget so a reminder email is a great thing!

Then promote your event through social media. In addition, add pictures and share your personal story explaining WHY you are passionate about raising funds for AFBS!

## Facebook

- Post information about your fundraiser on your Facebook profile. Be sure to include details so your friends can get involved
- "Like" the A Foundation Building Strength Facebook page (@buildingstrength)
- Create an Event and/or a Fundraiser on Facebook and invite your friends

## Sample Posts

- A Foundation Building Strength is the only organization in the world exclusively focused on funding NM research. Support me as I strive to raise \$XXX to help provide a treatment for NM
- I'm excited to host an event for AFBS, and I could use YOUR help. Please support my efforts!
- I'm raising funds for AFBS in honor of {insert personal story}. Support me today!
- I'm halfway there! Thanks to generous supporters, I've raised \$XXX towards my goal of \$XXX. Don't miss your chance to support my efforts. Donate Now!



# MEDIA ADVISORY TEMPLATE

Fill out the details in the following template and send it to our local paper for publication at least three weeks in advance of your event to be listed in your community event calendar.

## FOR IMMEDIATE RELEASE:

## CONTACT:

Date of Release:  
Today's Date

Your name, Phone, Email address

\*\*\*\*\*MEDIA ADVISORY\*\*\*\*\*

## HEADLINE OF YOUR EVENT IN ALL CAPS HERE

- Who and What:** *Example: Your name, (or organizations name) will hold (name of your event) to benefit A Foundation Building Strength, the only organization worldwide dedicated to exclusively funding Nemaline Myopathy research.*
- Where:** *Example: Cycle Bar Culver City*
- When:** *Example: 10am, Saturday, June 24, 2019*
- Why:** *Example: Children like (insert name if honoring a specific person) depend on A Foundation Building Strength to find treatments, and ultimately a cure, for Nemaline Myopathy. Every donation helps bring us closer to improving the lives of those living with NM. Join us for (name of event) as we raise funds and awareness for Nemaline Myopathy.*

## About A Foundation Building Strength

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. Sadly, 66% of severe cases of NM will die before age 2.

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.

# DONATION REQUEST LETTER TEMPLATE



**A FOUNDATION  
BUILDING  
STRENGTH**

For Nemaline Myopathy

Dear [Name],

Join me in making a difference for all those affected by Nemaline Myopathy, a very rare, neuromuscular disease that causes weakened muscles, resulting in extreme difficulty eating, walking and even breathing. I'm organizing an event, [EVENT NAME] on [DATE] at [LOCATION] to benefit A Foundation Building Strength (AFBS), the only organization in the world that funds research specifically for NM. My goal is to raise [FUNDRAISING GOAL AMOUNT].

This event will support promising research to move all those affected by NM closer to treatment and an easier, healthier and longer life.

[INCLUDE PERSONAL STORY ABOUT NM AND WHY YOU'RE FUNDRAISING]

Currently no treatments or disease modifying therapies exist for NM and few potential candidate drugs have been identified. With your support, we can change this and make a difference for all the children and young adults battling this devastating disease.

Check out my fundraising page and please consider making a donation: [INSERT FUNDRAISER PAGE URL LINK]. To make an even greater impact, you can set up a personal page to fundraise for this campaign.

Thank you for considering a donation to [EVENT NAME]. If you have any questions, please contact me at [EMAIL] OR [PHONE].

Sincere thanks,

[YOUR NAME]

# DONATE TO CHANGE LIVES

A FUNDRAISER for  
NEMALINE MYOPATHY RESEARCH



**A FOUNDATION  
BUILDING  
STRENGTH**  
For Nemaline Myopathy

The mission of A Foundation Building Strength (AFBS) is to find treatments, and ultimately a cure, for Nemaline Myopathy (NM). NM is a rare neuromuscular disorder that causes muscle weakness of varying severity. Many people with NM can't breathe, swallow, speak or walk on their own.

## DONATION COLLECTION & ACKNOWLEDGEMENT

- The event organizer must make sure all donations are accounted for and submitted to AFBS, to ensure AFBS can send an acknowledgment letter to each donor.
- AFBS accepts donations by cash, check, or credit card.
- The easiest way to accept credit card donations is to set up an AFBS fundraising page for your event.
- For security reasons, please redeem cash for a bank cashier's check, then submit that cashier's check to AFBS with a list of the names, addresses, and donation amounts for these donors.
- All checks must be made payable to A Foundation Building Strength
- AFBS will automatically send an acknowledgment letter for all \$250+ donations received by check or credit card, as long as donor's contact information is included. For donations at any amount needing acknowledgment letter, be sure to provide each donor's name, address, and amount of donation, so we can send an acknowledgment.
- As the organizer, please remember to thank everyone who helped make your event a success—the donors, the volunteers, the venue, and sponsors.

