



A FOUNDATION BUILDING STRENGTH

For Nemaline Myopathy

THE CHALLENGE

Nemaline Myopathy (NM) is a rare congenital muscle disease characterized by hypotonia, weakness and depressed or absent deep tendon reflexes. Normal everyday activities such as breathing, eating, and walking can be extremely challenging for NM patients.

6,459 people in the U.S. are diagnosed with **Nemaline Myopathy**

66% of severe cases will die before age 2

148,000 people in the world have **Nemaline Myopathy**

1 in 108 people of Ashkenazi Jewish heritage is a carrier of **Nemaline Myopathy**

2%

of \$157 Million of NIH funds are allocated to rare disease research, only \$3.7 Million

**National Institutes of Health*

THE SOLUTION IS RESEARCH

OUR MISSION IS TO FIND TREATMENTS FOR NEMALINE MYOPATHY AND RAISE AWARENESS FOR FAMILIES OF THOSE AFFECTED BY THE DISEASE

A Foundation Building Strength 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.



2015 EXPENSES: \$509,026

82% ■ Research

18% ■ Administrative

HIGH IMPACT PROJECTS

- GENE THERAPY FOR NEBULIN-BASED NEMALINE MYOPATHY
- EVALUATING THERAPEUTIC APPROACHES FOR ACTA1 NEMALINE MYOPATHY
- FUNDING FOR CONGENITAL MUSCLE DISEASE TISSUE REGISTRY FOR ACCESS TO NM SAMPLES FOR RESEARCH

» 11 Grants awarded in 2015

» 22 Grants awarded since 2009

\$1.517 Million in research grants awarded since 2009

WE WOULD LIKE TO THANK OUR 2,035 SUPPORTERS, 32 VOLUNTEERS, 11 FUNDED SCIENTIFIC INVESTIGATORS AND ALL OF THE FAMILIES AFFECTED BY NEMALINE MYOPATHY.

If you would like to support A Foundation Building Strength, visit www.buildingstrength.org or send a check to 3825 El Camino Real, Palo Alto, CA 94306



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