



Neurofibromatosis Incorporated Northeast

9 Bedford Street Burlington MA 01803

Incorporation Year: 1988

www.nfincne.org

Organization Contact: kpeluso@nfincne.org Karen Peluso

Diseases Disorders & Medical Disciplines Birth Defects & Genetic Diseases



Current

CEO/Executive Director: Mrs. Karen Peluso

Board Chair: Mrs. Lori Ryan RN, MS Clinical Research Supervisor

Mission Statement: The mission of Neurofibromatosis Northeast is to find effective treatments and the cure for neurofibromatosis (NF) by promoting scientific research, creating awareness, and supporting the patients and families who live with NF.

Needs Statement: Lack of awareness of NF is one of our greatest challenges, and with high visibility, better understanding and more resources would follow. In addition, educational materials and support collateral – for both medical professionals and patient families – is an unmet need that we intend to fill. Finally, medical research to CURE NF must be funded and supported. This year, hope to do the following: 1. Systematically reach out to clinicians treating NF patients in New England and NY, to create connections, educate them on the benefits we can provide their patients, and create a list of medical resources for our patient families. ~ \$25,000. 2. Update and expand our written resources to share with clinicians' offices across our target area, so that newly-diagnosed families are offered immediate information, guidance, and direction about NF and NF Northeast. ~ \$35,000. 3. Revamp our website to include broader educational resources for our patient families. ~ \$35,000 4. Further advertise our #TheWordIs and Beauty Mark Nation campaigns, aimed at bringing greater visibility and awareness to NF. We continue to look for a national, high-profile sponsor to partner with us and make this a global brand. ~ \$50,000 5. NF Northeast wants to CURE NF. We must continue to lobby for federal support through the Department of Defense and NIH, and will focus increased time advocating for continued national funding to medical research. Last year, we successfully lobbied for \$15 million in federal research funding. We also need to support seed research for new NF research projects. ~\$200,000.

Impact Statement: This past year, Neurofibromatosis Northeast enlisted the help of Community Consulting Group to perform an in depth and thorough evaluation of our best practices, our weaknesses, our successes and future goals. With their guidance, we have: Hired a Patient & Clinician Outreach Coordinator in New York State, whose goal is to increase penetration in the NY community, both with patient and family support and clinician outreach and connection; Hired a Development Officer, whose goal is to broaden NF Northeast's fundraising efforts, to reduce reliance on events and to increase support on an individual, corporate and foundation basis; Expanded our Board of Directors, bringing on two new Board members; Created a Family Support Group, whose goal is to bring NF families together in small-group settings in an effort to create organic, authentic opportunities for NF families to connect, learn and lean on each other; Increased outreach to NF specialists and clinicians, with the goal of increasing clinicians' awareness of NF Northeast and consequently, increasing clinician referrals of patient families to NF Northeast. Successfully advocated for continued Federal funding for NF research, through local and national advocacy including direct physical presence in Washington DC lobbying for continued Federal support of crucial NF research through the Department of Defense and NIH. This year, Neurofibromatosis Northeast intends to continue following the suggestions Community Consulting Group. We plan to increase our connection with NF clinicians in our target states. We will establish relationships with clinicians in major medical centers throughout the Northeast, in order to increase awareness of NF Northeast for both the clinicians and for the patients and families they see. We will continue to attract new members for our Board of Directors to help lead the charge and strengthen our relations with the biotech and pharmaceutical companies as well as our base of support. We saw great success last year with our #TheWordIs campaign, in which we highlight the lack of name recognition for neurofibromatosis, despite the disease affecting more people than cystic fibrosis and muscular dystrophy combined. In this campaign, we encourage the use of the full word, with the hope of making neurofibromatosis a household word. In helping to make neurofibromatosis more well known, we will raise awareness and public and financial support, and plan to continue to grow this program. In addition, we will continue to search for a high profile partner to help market Beauty Mark Nation and increase awareness of NF. We plan to launch new events, including a Steps2Cure CT and additional events in New York State, while reexamining and growing our current core group of fundraising events. We will strive to attract new sources of funding, including researching new potential corporate and foundation support.

Full-time Staff: 2

Volunteers: 150

(excludes part-time staff)

Programs Detailed on Profile

Research and Advocacy

NF Awareness

NF Patient and Family Support

Projected Revenue: \$825,500.00

Projected Expenses: \$822,180.00

Fiscal Year	2016	2015	2014
Total Revenue	\$773,174	\$723,905	\$764,324
Total Expenses	\$675,354	\$704,591	\$681,191

Top Funding Sources

Fiscal Year	2016	2015	2014
Top Funding Source & Dollar Amount	--	--	--
Second Highest Funding Source & Dollar Amount	--	--	--
Third Highest Funding Source & Dollar Amount	--	--	--