



**The Giving Common**  
An Initiative of the Boston Foundation

# Neurofibromatosis Incorporated Northeast

9 Bedford Street Burlington MA 01803

**Incorporation Year:** 1988

[www.nfincne.org](http://www.nfincne.org)

**Organization Contact:** [kpeluso@nfincne.org](mailto:kpeluso@nfincne.org) Karen Peluso

Diseases Disorders & Medical Disciplines Birth Defects & Genetic Diseases

**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 higher visibility better understanding and more resources would follow. The Beauty Mark Nation campaign has been an exciting way to increase awareness for the NF Community. Now, we need to bring it further afield and make it a global brand, and to do that we need a high-profile sponsor to partner with us. To accomplish this lofty goal we need dedicated and additional resources and are looking for funding of \$50,000.

For the most part, much of our event based fundraising and support activities are limited to the greater Boston area and we need to expand our reach all over New England and New York state. There are many unidentified NF patients and families in those areas that could benefit from our knowledge base and resources. To do this we need to update and distribute our educational materials more widely and to do that the organization needs \$45,000.

**Impact Statement:** Accomplishments:

As a result of an increasingly successful awareness and outreach program, we have expanded our Board of Directors and the NF Community significantly and had a number of new events and NF walks established in cities and towns that had none previously. At the same time, a number of our longstanding special events have grown substantially with increased participation. Such events help bring the NF community closer and serve the families well.

NF Northeast continues to sponsor children/teens to attend Camp New Friends, a camp where NF patients can be with others who are like them, and our scholarship program to assist students with NF as they pursue their education after high school continues to award small bursaries to help defray costs.

As the organization is dedicated to promoting NF research, to that end we again successfully advocated for continued Federal funding for NF research. Through our advocacy program, we were able to help increase the number of Congressional members voicing support for continued Federal funding. On a local level we provided financial support to the Harvard Medical School Center for NF and Allied Disorders as well as the NF Clinics at Boston Children's Hospital and Massachusetts General Hospital.

Goals:

Despite neurofibromatosis affecting more people than cystic fibrosis and muscular dystrophy combined, our greatest challenge continues to be the lack of name recognition. All too often we hear the statement "I've never even heard of NF". To address that, we aim to build our public awareness campaign further, and in particular, partner with a high profile spokesperson to help market Beauty Mark Nation and increase awareness about NF.

We will continue to attract new, high profile 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 will strive to attract new sources of funding so that we can allocate more towards research as well as supporting those families afflicted by NF.

**Full-time Staff:** 3

**Volunteers:** 150

(excludes part-time staff)

## Programs Detailed on Profile

Research and Advocacy

NF Awareness

NF Patient and Family Support

**Projected Revenue:** \$853,126.00

**Projected Expenses:** \$849,679.00

Fiscal Year	2015	2014	2013
Total Revenue	\$723,905	\$764,324	\$529,721
Total Expenses	\$704,591	\$681,191	\$587,559

### Top Funding Sources

Fiscal Year	2015	2014	2013
Top Funding Source & Dollar Amount	--	--	--
Second Highest Funding Source & Dollar Amount	--	--	--
Third Highest Funding Source & Dollar Amount	--	--	--