



# The Giving Common

An Initiative of the Boston Foundation

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

## Neurofibromatosis Incorporated Northeast



Current

### General Information

9 Bedford Street  
Burlington, MA 01803  
(781) 272-9936

**Website**

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

**Organization Contact**

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

**Year of Incorporation**

1988

## Statements & Search Criteria

### **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.

### **Background Statement**

The organization was founded in 1988 (as Neurofibromatosis, Inc., Mass Bay Area) by a group of individuals who were in some way affected by NF. The grass roots effort began around a kitchen table, and the founding Board of Directors was a "band of warriors" who were inexperienced in running a non profit organization, but were driven by their passion to find treatments and the cure for NF.

For the first 10 years the organization was run by volunteers until a part time Executive Director was hired. Today, NF Northeast employs a full time Executive Director, a full time Special Events Director, a full time Patient Outreach Coordinator and 2 part time employees. In 1997 we changed our name to Neurofibromatosis Northeast to reflect the area we serve (New England and New York State).

Our Board of Directors is made up of leaders from the community, industry as well as families affected by NF. We work closely with the National Network, but are governed independently.

We raise approximately 70% of our revenues at special events, with the remainder coming from corporate and individual support.

## **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.

## **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.

### **CEO/Executive Director Statement**

When our organization was founded very few people had even heard of neurofibromatosis (NF), a debilitating and disfiguring tumor disorder. Since then our organization has emerged as a leader in the movement to create awareness and promote research, and in the process, has become a well-known resource for NF patients. We are heartened by the fact that today NF research has moved to the forefront of the biomedical revolution, due in part to our efforts, and also because NF is related to other conditions such as cancer, brain tumors, learning disabilities and many other disorders which affect the general population.

To drive NF research we award grants to peer reviewed scientific research projects that are looking for the cure or treatments for NF. We also provide support to the NF Clinics at Massachusetts General Hospital and Boston Children's Hospital.

We are advocates for federally funded NF research and work with members of Congress to continue and improve NF research programs.

Our Patient Outreach Coordinator responds to inquiries from newly diagnosed patients or their families and provides: literature, referrals to NF specialists, and introductions to a strong support network of patients and families. We also offer symposiums and webinars for NF patients and caretakers.

Knowing that increased awareness of neurofibromatosis will ultimately bring us closer to the cure for NF, we recently created the Beauty Mark Nation. Learn more at [beautymarknation.org](http://beautymarknation.org). Beauty Mark Nation is a light hearted reference to the cafe au lait spots that are the hallmark of NF1. It is our hope that the Beauty Mark Nation name and logo will become a global symbol, and help bring NF out of the shadows and into the public's consciousness.

Our goal is to secure a worldwide sponsor of the Beauty Mark Nation, and we are reaching out to prominent health, beauty and fashion companies asking them to take the bold step to sponsor this awareness campaign. We need a major brand to join forces with the Beauty Mark Nation because NF patients matter and have stayed in the shadows for too long.

## **Board Chair Statement**

*Commitment, Compassion and Collaboration. These are the cornerstones of NF Northeast!*

Strong leadership has built a solid foundation over the years from which the organization is poised to take advantage of new opportunities and successes!

Recently having been elected Chair of the Board of Directors is an honor. My first connection with NF Northeast was 14 years ago as a parent reaching out to the organization for information and support. Now that I have been a member of the Board of Directors for over 8 years, served as Chair of the Medical and Science Committee and sat on the Strategic Planning Committee, I have a clear understanding of where the organization has been, where it is today and where it should be tomorrow.

NF Northeast is emerging as an increasingly powerful player within the life sciences/biotech field and is highly regarded as a national leader in advocacy, awareness and patient support. In recent months, NF Northeast staff and representatives have been invited to raise awareness and understanding of neurofibromatosis to a wider audience by participating in panel discussions at the State House as well as making presentations to venture capital companies who are specifically looking at rare diseases.

The Board of Directors is fully committed to driving the organization to new heights and we have welcomed a number of new directors to help lead the momentum of growth and success. Going forward, it will be important to expand across several areas, including broadening our presence in the Northeast region, increasing the Medical & Science Committee activities, including awarding more research grants, continuing to provide educational and family/patient support opportunities, and NF advocacy.

We will increase collaboration between NF organizations, biotech and pharmaceutical companies, academia, federal entities, such as the National Institutes of Health, Department of Defense, Food and Drug Administration, and other rare disease organizations where a combined voice is more powerful than a singular one.

My sincere thanks to all of our volunteers and committee members - the organization could not operate without you! Events large and small have fueled the organization and strengthened the NF community. Please come take part in an event, volunteer at another and help us grow the organization further. There is much to be done as we strive for treatments and a cure for neurofibromatosis and I ask for your continued support in making that goal a reality!

## Service Categories

Birth Defects & Genetic Diseases

Nerve Muscle & Bone Diseases Research

## Geographic Areas Served

We serve NF patients and their families throughout the Northeast region (New England and New York) as well as anyone who is not represented by an NF group in their area of the country.

Please review online profile for full list of selected areas served.

# Programs

## **Research and Advocacy**

### **Description**

NF Northeast has provided research grants to scientists at leading institutions around the country. We are the impetus behind the creation of The Harvard Medical School Center for NF and Allied Disorders (CNfAD). Along with research support at the CNfAD we also provide the salary of a Clinical and Research Coordinator who is the liaison between the NF clinics at both Mass General Hospital and Children's Hospital Boston and the research lab.

Since 1996 we have worked closely with members of the House and Senate to seek increased funding for research not only at the National Institutes of Health (NIH) but also through the Department of Defense Congressionally Directed Medical Research Program (CDMRP). Karen Peluso, Executive Director of NFNE, has presented testimony before the House Appropriations Subcommittee on Labor, Health and Human Services and Education as well as the Senate and House Appropriations Subcommittees on Defense.

### **Budget**

225000

### **Category**

Medical Research, General/Other Birth Defects, Genetic Disorders & Developmental Disorders Research

### **Population Served**

Children and Youth (0 - 19 years), Adults, Families

### **Program Short Term Success**

Within the last four years a nation-wide clinical trials infrastructure has been established and clinical trials to test drugs to treat NF symptoms are now underway. The NF Clinical Consortium was created by the Department of Defense funding. Army officials administering this program have indicated that they could easily fund more applications if funding were available because of the high quality of the research applications received.

The success we have achieved so far is testimony to the partnership between grass roots advocacy groups, legislators and the scientific community.

**Program Long term Success**

NF involves the uncontrolled growth of tumors along the nervous system, which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer and death. NF is the most common neurological disorder caused by a single gene and is more common than muscular dystrophy and cystic fibrosis combined. However, because of NF's close connection to many common diseases and disorders, such as cancer, learning disabilities, heart disease, memory loss, and brain tumors, research on NF stands to benefit 175 million Americans in this generation alone. We must continue to invest in research and build on the successes of this program if we are to continue to advance towards treatments and cures for NF and the numerous diseases associated with it.

**Program Success Monitored By****Examples of Program Success**

Advocacy has become one of the most important ongoing programs of our organization, and our efforts have paid off. Since 1996 we have helped to generate \$230 million dollars for NF research through the Department of Defense, and NF research advances made by the DOD have been dramatic.

Each year we also request the inclusion of report language on NF research at the National Institutes of Health in the Labor-HHS-Education Appropriations bill. This language serves as a directive from Congress to the NIH to study NF within numerous institutes including NCI and NINDS,

## **NF Awareness**

### **Description**

Neurofibromatosis affects more people than cystic fibrosis and muscular dystrophy combined yet most people have never even heard of it. NF's virtual anonymity in the eye of the general public has limited our volunteer development, fund raising capabilities, and our ability to effectively serve NF patients and their families. Determined to make neurofibromatosis a household word, we have launched an awareness campaign using social media, print, radio ads and billboards. We conduct educational, social and fundraising events and we sponsor and attend medical conferences. We also look for other opportunities for media exposure such as the "Neurofibromatosis Awareness Month" proclamation signings by all of the Governors in the Northeast.

In 2011 we created the Beauty Mark Nation, a lighthearted and fun way to command public attention, challenge public perception and create a high degree of visibility for the NF cause. This bold commitment will ultimately bring us closer to the cure for NF!

### **Budget**

40000

### **Category**

Diseases, Disorders & Medical Disciplines, General/Other Birth Defects, Genetic Disorders & Developmental Disorders

### **Population Served**

Children and Youth (0 - 19 years), Adults, Families

### **Program Short Term Success**

A short term success would be when we talk about neurofibromatosis people will not say "I've never heard of it".

### **Program Long term Success**

The long term success of our awareness program would be the development of treatments to stop the ravages of NF. With greater awareness more research dollars will follow. Research into NF will not only benefit those patients who live with it, but because of NF's close connection to many common diseases and disorders, such as cancer, learning disabilities, heart disease, memory loss, and brain tumors, research on NF stands to benefit 175 million Americans in this generation alone.

### **Program Success Monitored By**



## **Examples of Program Success**

One of the first signs of neurofibromatosis (type1) on a baby are café au lait birthmarks. They are harmless and often just called ‘beauty marks”, but in reality they are the hallmark of a genetic condition that can be debilitating, disfiguring and deadly.

In 2011 we launched the Beauty Mark Nation which has been well received in the United States as well as many countries around the world. We entered Beauty Mark Nation into Ragan’s Healthcare and PR Marketing Contest and received Honorable Mention in 2012. Our next step is to secure a prominent sponsor from the health, beauty or fashion industry to partner with the Beauty Mark Nation. A major brand will display the Beauty Mark Nation logo on their product, and this bold commitment will command public attention and create a high degree of visibility for the NF cause. This will ultimately bring us closer to the cure for NF!

## **NF Patient and Family Support**

|                                     |  |
|-------------------------------------|--|
| <b>Description</b>                  | <p>When patients contact NF Northeast's office, our Patient Outreach Coordinator provides printed materials, referrals to doctors, hospitals and clinics and, if requested, will arrange introductions to other families in the area who are living with the uncertainties of NF. We have a large and caring network of NF patients and families who are a valuable resource for others who are dealing with the frightening diagnosis of NF.</p> <p>We provide sponsorships for children/teens to attend Camp New Friends. Camp is a safe haven for children with neurofibromatosis who are quite often isolated and anxious about their disability or disfigurement. At camp their disfigurement or physical challenges are accepted, and they have an opportunity to build self-esteem and establish connections with others who live with NF. In 2012 we initiated our NF Scholarship Program and have provided scholarships for students who are continuing their education after high school. Applications for scholarships are accepted between January 1st and April 15th.</p> |
| <b>Budget</b>                       | 50000  |
| <b>Category</b>                     | Diseases, Disorders & Medical Disciplines, General/Other Birth Defects, Genetic Disorders & Developmental Disorders  |
| <b>Population Served</b>            | Children Only (5 - 14 years), College Aged (18-26 years), Families   |
| <b>Program Short Term Success</b>   | During the past year we expanded our Patient Outreach Program and achieved significant milestones, most notably identifying over 100 new NF patients and families to whom we provided services and support.  |
| <b>Program Long term Success</b>    | One day NF patients will go to doctors who understand their condition and have the therapies to stop tumor growth and improve their quality of life. NF children will not be bullied and patients will not be discriminated against in the workplace. The general public will understand what NF is, show empathy towards patients and support research and programs.  |
| <b>Program Success Monitored By</b> |  |
| <b>Examples of Program Success</b>  | We will know we have been successful when NF patients won't feel ashamed and alone, and the stigma of having NF has been lifted. Parents won't be afraid to tell the teachers that their child has NF, and the general public will know about NF and understand its ramifications.   |

# Management

## CEO/Executive Director

|                           |                     |
|---------------------------|---------------------|
| <b>Executive Director</b> | Mrs. Karen Peluso   |
| <b>Term Start</b>         | June 1992           |
| <b>Email</b>              | kpeluso@nfincne.org |

### **Experience**

Karen Peluso, Executive Director of Neurofibromatosis Northeast has been involved with the NF effort since 1982. She served as a member of the Board of Directors of the National Neurofibromatosis Foundation and was Co-President of the Massachusetts NNF Chapter from 1985 to 1987. During that time she and her husband received the NNF's Courtemanche Award for Leadership. Karen was a member of the founding Board of Directors of NF Incorporated (later renamed the NF Network), and has served as the Executive Director of NF Northeast since 1992. She is committed to promoting NF research and making neurofibromatosis "a household word". Karen works with members of Congress to promote NF research at a National level and has presented testimony before both the House and Senate Appropriations sub committees. In 2006 she received the "Changing Peoples Lives Award" from the Grand Circle Foundation in recognition of her NF advocacy. In 2013 the Board of Directors of NF Northeast created the Karen Peluso Advocacy Fund in her honor. Karen holds a MEd from Cambridge College where her integrated studies focused on nonprofit management.

## Staff Information

|                        |     |
|------------------------|-----|
| <b>Full Time Staff</b> | 3   |
| <b>Part Time Staff</b> | 2   |
| <b>Volunteers</b>      | 150 |
| <b>Contractors</b>     | 0   |

## Staff Demographics - Ethnicity

|  |   |
|--|---|
| <b>African American/Black</b>          | 0 |
| <b>Asian American/Pacific Islander</b> | 0 |
| <b>Caucasian</b>                       | 5 |
| <b>Hispanic/Latino</b>                 | 0 |
| <b>Native American/American Indian</b> | 0 |
| <b>Other</b>                           | 0 |

## Staff Demographics - Gender

|                    |   |
|--------------------|---|
| <b>Male</b>        | 1 |
| <b>Female</b>      | 4 |
| <b>Unspecified</b> | 0 |

## Formal Evaluations

|  |          |
|--|----------|
| <b>CEO Formal Evaluation</b>                         | Yes      |
| <b>CEO/Executive Formal Evaluation Frequency</b>     | Annually |
| <b>Senior Management Formal Evaluation</b>           | Yes      |
| <b>Senior Management Formal Evaluation Frequency</b> | Annually |
| <b>NonManagement Formal Evaluation</b>               | Yes      |
| <b>Non Management Formal Evaluation Frequency</b>    | Annually |

## Plans & Policies

|  |                   |
|--|-------------------|
| <b>Organization has a Fundraising Plan?</b>                                  | Under Development |
| <b>Organization has a Strategic Plan?</b>                                    | Yes               |
| <b>Years Strategic Plan Considers</b>  | 3                 |
| <b>Date Strategic Plan Adopted</b>   | Jan 2015          |
| <b>Does your organization have a Business Continuity of Operations Plan?</b> | No                |
| <b>Management Succession Plan?</b>   | Under Development |
| <b>Organization Policy and Procedures</b>                                    | Yes               |
| <b>Nondiscrimination Policy</b>  | Yes               |
| <b>Whistleblower Policy</b>  | Yes               |
| <b>Document Destruction Policy</b>   | Yes               |
| <b>Directors and Officers Insurance Policy</b>                               | Yes               |
| <b>Is your organization licensed by the Government?</b>                      | No                |
| <b>Permit?</b>   | No                |

## Awards

### **Awards**

| <b><u>Award/Recognition</u></b>                                  | <b><u>Organization</u></b>                    | <b><u>Year</u></b> |
|--|---|--------------------|
| Honorable Mention - Beauty Mark Nation - Best Marketing Campaign | Ragan's Healthcare PR & Marketing Awards 2012 | 2012               |

# Board & Governance

## Board Chair

|                            |                              |
|----------------------------|------------------------------|
| <b>Board Chair</b>         | Mrs. Lori Ryan RN, MS        |
| <b>Company Affiliation</b> | Clinical Research Supervisor |
| <b>Term</b>                | Jan 2015 to Dec 2018         |
| <b>Email</b>               | loriryan340@msn.com          |

## Board Members

| <b>Name</b>                  | <b>Affiliation</b>                      | <b>Status</b> |
|------------------------------|---|---------------|
| John Driscoll                | Retired                                 | Voting        |
| Paul Epstein DMD             | Dentist                                 | Voting        |
| Henry Kay                    | U.S. Partner of Medica Venture Partners | Voting        |
| Melissa Malerba              | Teacher                                 | Voting        |
| John Manth                   | Hilbert College                         | Voting        |
| Cynthia Robinson Markey Esq. | Court officer                           | Voting        |
| David Rokoff                 | Community Volunteer                     | Voting        |
| Robert Ryan                  | Morgan Stanley Smith Barney             | Voting        |
| Lori Ryan RN, MS             | Clinical Research Supervisor            | Voting        |
| John Shea                    | Hospital Management                     | Voting        |
| John Thomson PhD             | Consultant                              | Voting        |
| Nicole Ullrich MD, PhD       | Boston Children's Hospital              | Voting        |
| Jessica Wolfe PhD            | BluePond Wellness LLC                   | Voting        |

## Board Demographics - Ethnicity

|  |    |
|--|----|
| <b>African American/Black</b>          | 0  |
| <b>Asian American/Pacific Islander</b> | 0  |
| <b>Caucasian</b>                       | 13 |
| <b>Hispanic/Latino</b>                 | 0  |
| <b>Native American/American Indian</b> | 0  |
| <b>Other</b>                           | 0  |

## Board Demographics - Gender

|                    |   |
|--------------------|---|
| <b>Male</b>        | 9 |
| <b>Female</b>      | 4 |
| <b>Unspecified</b> | 0 |

## Board Information

|  |      |
|--|------|
| <b>Board Term Lengths</b>                          | 3    |
| <b>Board Term Limits</b>                           | 2    |
| <b>Number of Full Board Meetings Annually</b>      | 4    |
| <b>Written Board Selection Criteria?</b>           | Yes  |
| <b>Written Conflict of Interest Policy?</b>        | Yes  |
| <b>Percentage Making Monetary Contributions</b>    | 100% |
| <b>Constituency Includes Client Representation</b> | Yes  |

## Standing Committees

Finance

Development / Fund Development / Fund Raising / Grant Writing / Major Gifts

Strategic Planning / Strategic Direction

Governance and Nominating

# Financials

## Fiscal Year

|                                   |              |
|-----------------------------------|--------------|
| <b>Fiscal Year Start</b>          | Jan 01, 2016 |
| <b>Fiscal Year End</b>            | Dec 31, 2016 |
| <b>Projected Revenue</b>          | \$853,126.00 |
| <b>Projected Expenses</b>         | \$849,679.00 |
| <b>Endowment?</b>                 | No           |
| <b>Spending Policy</b>            | N/A          |
| <b>Credit Line?</b>               | No           |
| <b>Reserve Fund?</b>              | Yes          |
| <b>Months Reserve Fund Covers</b> | 24           |

## Detailed Financials

### Revenue and Expenses

| <b>Fiscal Year</b>    | <b>2015</b> | <b>2014</b> | <b>2013</b> |
|-----------------------|-------------|-------------|-------------|
| <b>Total Revenue</b>  | \$723,905   | \$764,324   | \$529,721   |
| <b>Total Expenses</b> | \$704,591   | \$681,191   | \$587,559   |

### Revenue Sources

| <b>Fiscal Year</b>                              | <b>2015</b> | <b>2014</b> | <b>2013</b> |
|---|-------------|-------------|-------------|
| <b>Foundation and Corporation Contributions</b> | --          | --          | --          |
| <b>Government Contributions</b>                 | \$0         | \$0         | \$0         |
| <b>Federal</b>                                  | --          | --          | --          |
| <b>State</b>                                    | --          | --          | --          |
| <b>Local</b>                                    | --          | --          | --          |
| <b>Unspecified</b>                              | --          | --          | --          |
| <b>Individual Contributions</b>                 | \$184,592   | \$241,747   | \$116,856   |
| <b>Indirect Public Support</b>                  | --          | --          | --          |
| <b>Earned Revenue</b>                           | --          | --          | --          |
| <b>Investment Income, Net of Losses</b>         | (\$3,703)   | \$1,971     | \$5,936     |
| <b>Membership Dues</b>                          | --          | --          | --          |
| <b>Special Events</b>                           | \$530,516   | \$520,606   | \$406,929   |
| <b>Revenue In-Kind</b>                          | \$12,500    | --          | --          |
| <b>Other</b>                                    | --          | --          | --          |

### Expense Allocation

| Fiscal Year                             | 2015      | 2014      | 2013      |
|---|-----------|-----------|-----------|
| Program Expense                         | \$576,839 | \$567,502 | \$467,728 |
| Administration Expense                  | \$92,877  | \$72,202  | \$80,181  |
| Fundraising Expense                     | \$34,875  | \$41,487  | \$39,650  |
| Payments to Affiliates                  | --        | --        | --        |
| Total Revenue/Total Expenses            | 1.03      | 1.12      | 0.90      |
| Program Expense/Total Expenses          | 82%       | 83%       | 80%       |
| Fundraising Expense/Contributed Revenue | 5%        | 5%        | 8%        |

### Assets and Liabilities

| Fiscal Year           | 2015      | 2014      | 2013      |
|-----------------------|-----------|-----------|-----------|
| Total Assets          | \$556,488 | \$533,747 | \$444,904 |
| Current Assets        | \$550,514 | \$525,704 | \$439,584 |
| Long-Term Liabilities | \$0       | --        | \$0       |
| Current Liabilities   | \$70,677  | \$67,250  | \$61,540  |
| Total Net Assets      | \$485,811 | \$466,497 | \$383,364 |

### Short Term Solvency

| Fiscal Year                                       | 2015 | 2014 | 2013 |
|---|------|------|------|
| Current Ratio: Current Assets/Current Liabilities | 7.79 | 7.82 | 7.14 |

### Long Term Solvency

| Fiscal Year                        | 2015 | 2014 | 2013 |
|------------------------------------|------|------|------|
| Long-Term Liabilities/Total Assets | 0%   | 0%   | 0%   |

### 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  | --   | --   | --   |

## Capital Campaign

Currently in a Capital Campaign?

No

## Comments

### Foundation Staff Comments

Financial summary data in the charts and graphs above are per the organization's audited financials. Contributions from foundations and corporations are listed under individuals when the breakout was not available.