



The Giving Common

An Initiative of the Boston Foundation

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Neurofibromatosis Incorporated Northeast



Current

General Information

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

Website

www.nfincne.org

Organization Contact

Karen Peluso 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 part time Patient Outreach Coordinator, a part time Development Officer, a part time Development Assistant, a part time Gift Processor and a part time book keeper. 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, foundation and individual support.

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.

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.

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. 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 over \$3 million in research grants to scientists at leading institutions around the country. Most grants are "seed grants" which allow a scientist to gather knowledge and data they will use to apply for large grants from National Institutes of Health (NIH) or the Congressionally Directed Medical Research Program (CDMRP) through the DOD. We also provide support to the NF clinics at both Massachusetts General Hospital and Boston Children's Hospital.

Since 1996 NF Northeast has worked closely with members of the House and Senate to assure continued and increased funding for NF research at the NIH and the CDMRP. We are proud of our success in particular with the CDMRP which has received appropriations over \$300 million for NF research since the program began. 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

250,000

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 \$245 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 an ongoing 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!

In 2017, we created #TheWordIs campaign, in which we encourage people to SAY the word neuro-fibro-ma-tosis, in an effort to destigmatize the word and in turn, the disease. Many people have trouble saying the word, but in encouraging people to say the word, we are bringing awareness and acceptance to neurofibromatosis. We have filmed children and adults alike mispronouncing -- and then pronouncing correctly -- the word "neurofibromatosis" and have shared these videos through various social media venues.

Budget

50000

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!

We are also working to secure more visibility of our #TheWordsIs campaign. With increased funding, one potential example of success would be filming professional TV spots featuring this campaign and broadcasting on local and even national television spots. Increased national awareness of NF is crucial to securing funding for the medical research to CURE NF.

NF Patient and Family Support

Description	<p>When patients contact NF Northeast's office, our Patient Outreach Coordinators in Boston or New York provide 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 have an active NF Families and Community Committee whose mission is to create local communities of peer support among NF patients and their families throughout the northeast states. Events such as play groups, BBQ's and coffee chats have been organized by the committee and have resulted in emerging support networks and volunteer run events.</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.</p> <p>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> <p>In 2018, we hope to increase and improve our print resources for patients, and to expand our online educational resources for patients, to provide information about NF and its many implications (learning disabilities resources, school IEP management, symptom management, physician resources, current research, and more).</p>
Budget	75000
Category	Diseases, Disorders & Medical Disciplines, General/Other Birth Defects, Genetic Disorders & Developmental Disorders
Population Served	Children Only (5 - 14 years), College Aged (18-26 years), Families
Program Short Term Success	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. In addition, in 2017, we hired a new Patient Outreach Coordinator in New York state to further service our patient families in New York, who have been underserved to date.
Program Long term Success	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 and show empathy towards patients and support research and programs.

Program Success Monitored By

Examples of Program Success

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

Executive Director	Mrs. Karen Peluso
Term Start	June 1992
Email	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 NFFF Chapter from 1985 to 1987. During that time she and her husband received the NFFF'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

Full Time Staff	2
Part Time Staff	5
Volunteers	150
Contractors	0

Staff Demographics - Ethnicity

African American/Black	0
Asian American/Pacific Islander	0
Caucasian	7
Hispanic/Latino	0
Native American/American Indian	0
Other	0

Staff Demographics - Gender

Male	0
Female	7
Unspecified	0

Formal Evaluations

CEO Formal Evaluation	Yes
CEO/Executive Formal Evaluation Frequency	Annually
Senior Management Formal Evaluation	Yes
Senior Management Formal Evaluation Frequency	Annually
NonManagement Formal Evaluation	Yes
Non Management Formal Evaluation Frequency	Annually

Plans & Policies

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

Awards

Awards

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

Board & Governance

Board Chair

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

Board Members

Name	Affiliation	Status
Alexandra Powers Cellucci	Home Health Care	
John Driscoll	Retired	Voting
Paul Epstein DMD	Dentist	Voting
Henry Kay	U.S. Partner of Medica Venture Partners	Voting
Andres Lessing	Blue Cross Blue Shield	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

African American/Black	0
Asian American/Pacific Islander	0
Caucasian	13
Hispanic/Latino	0
Native American/American Indian	0
Other	0

Board Demographics - Gender

Male	9
Female	6
Unspecified	0

Board Information

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

Standing Committees

Finance

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

Strategic Planning / Strategic Direction

Governance and Nominating

Community Outreach / Community Relations

Financials

Fiscal Year

Fiscal Year Start	Jan 01, 2017
Fiscal Year End	Dec 31, 2017
Projected Revenue	\$825,500.00
Projected Expenses	\$822,180.00
Endowment?	No
Spending Policy	N/A
Credit Line?	No
Reserve Fund?	Yes
Months Reserve Fund Covers	24

Detailed Financials

Revenue and Expenses

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

Revenue Sources

Fiscal Year	2016	2015	2014
Foundation and Corporation Contributions	--	--	--
Government Contributions	\$0	\$0	\$0
Federal	--	--	--
State	--	--	--
Local	--	--	--
Unspecified	--	--	--
Individual Contributions	\$202,649	\$184,592	\$241,747
Indirect Public Support	--	--	--
Earned Revenue	--	--	--
Investment Income, Net of Losses	\$2,010	(\$3,703)	\$1,971
Membership Dues	--	--	--
Special Events	\$506,515	\$530,516	\$520,606
Revenue In-Kind	\$12,000	\$12,500	--
Other	\$50,000	--	--

Expense Allocation

Fiscal Year	2016	2015	2014
Program Expense	\$538,684	\$576,839	\$567,502
Administration Expense	\$100,676	\$92,877	\$72,202
Fundraising Expense	\$35,994	\$34,875	\$41,487
Payments to Affiliates	--	--	--
Total Revenue/Total Expenses	1.14	1.03	1.12
Program Expense/Total Expenses	80%	82%	83%
Fundraising Expense/Contributed Revenue	5%	5%	5%

Assets and Liabilities

Fiscal Year	2016	2015	2014
Total Assets	\$658,222	\$556,488	\$533,747
Current Assets	\$654,317	\$550,514	\$525,704
Long-Term Liabilities	--	\$0	--
Current Liabilities	\$74,591	\$70,677	\$67,250
Total Net Assets	\$583,631	\$485,811	\$466,497

Short Term Solvency

Fiscal Year	2016	2015	2014
Current Ratio: Current Assets/Current Liabilities	8.77	7.79	7.82

Long Term Solvency

Fiscal Year	2016	2015	2014
Long-Term Liabilities/Total Assets	0%	0%	0%

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	--	--	--

Capital Campaign

Currently in a Capital Campaign?

No

Comments

CEO Comments

As we enter our 30th year, NF Northeast is at a pivotal point in our history. Since our inception as a small, all-volunteer group run at a kitchen table, we have grown into an organization with a budget of almost a million dollars. Last year alone, we served as a resource for over 13,600 NF patients in the Northeast, had over 2,000 participants attend NF Northeast events, had over 40,000 visits to our website, awarded over \$175,000 in research grants and NF Clinic support, visited over 200 Congressional offices and advocated -- successfully -- for over \$15 million in federal funding for critical neurofibromatosis research. Clearly, we have grown and our impact is impressive.

However, now is our time to truly take off. With NF affecting one in 2,500 individuals and no clear treatment or cure yet on the horizon, we need to make neurofibromatosis a household word, and with the awareness will follow the funding for research that is needed to CURE NF. To that end, we need to make ourselves a bigger presence for both NF families and the clinicians serving them. In the coming years, our goal is to grow in every way. Our plan is to personally connect with every clinician treating NF patients in the Northeast and NY and establish ourselves as the organization to

which the clinicians refer their NF families. We have systematically increased our online presence, and we intend to invest in our print, online and social media presence so that we become the key resource for NF families.

This will take a huge investment of both time and money, and we will be seeking significant funding to help bring our organization to the next level in our mission to CURE NF.

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.