



NF Network

- **The NF Network** was founded in 1988 as Neurofibromatosis, Inc. by three regionally independent local NF Organizations.
- They created a national organization that serves as an umbrella to facilitate collaboration on national activities and a networking of shared resources.
- Allows for autonomy to be retained by the individual regional organizations.



Leading NF Advocacy, Building NF Community



Promoting NF Research

- Nationwide program advocating for federal NF research funds
- Active participation in scientific and medical meetings and conferences
- Seed grants available to NF researchers
- Promotion of patient participation in clinical trials



Building the NF Community

- Dissemination of electronic and print NF materials
- Educational meetings and webinars
- Peer counseling and social gatherings
- Referrals to NF Clinics



Funding our Mission

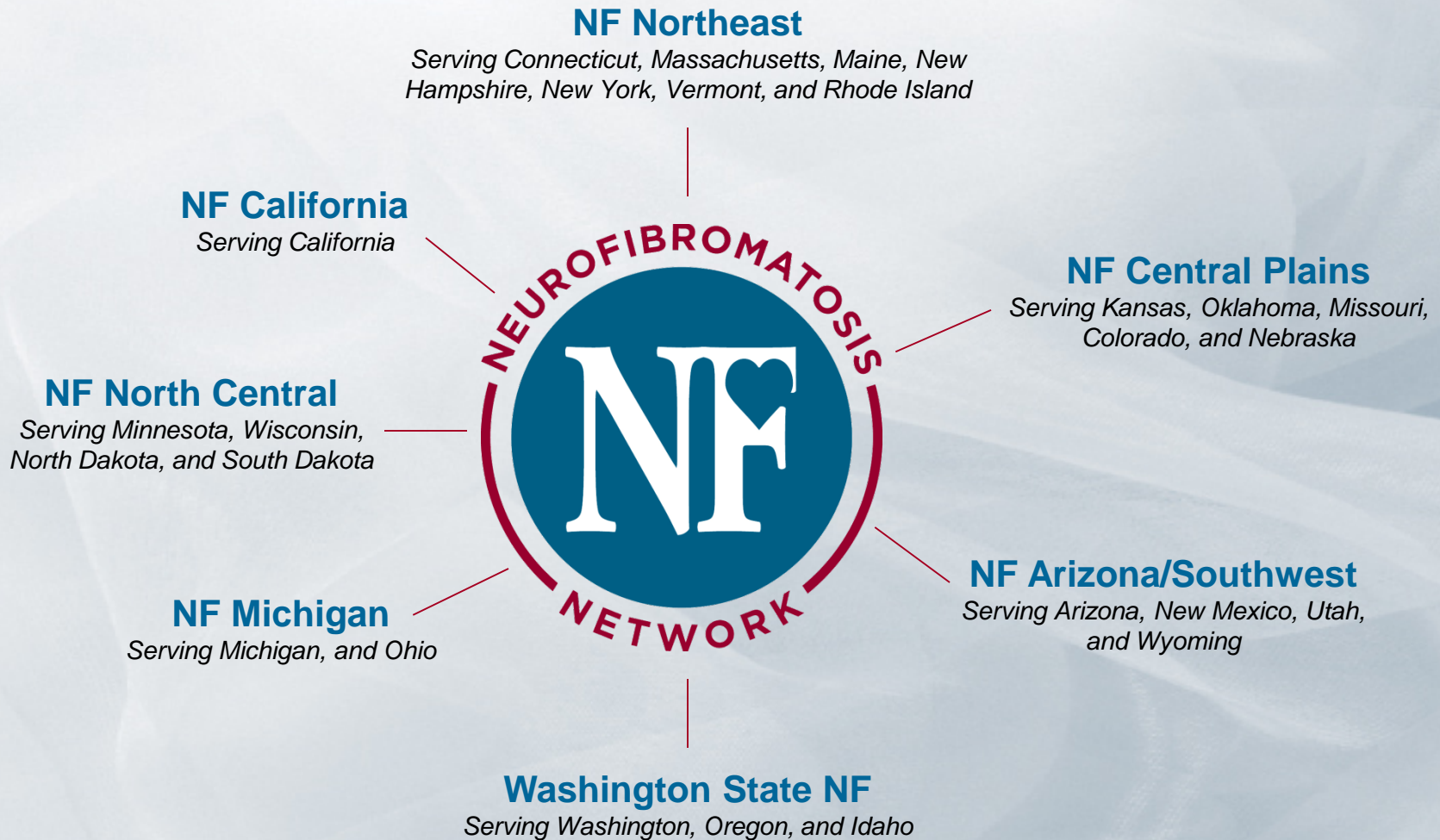
- 25 Years of individual and CFC donations
- National fundraisers
- Great Steps4NF community walk programs
- Support of state and regional member organizations



NF Network Mission

To find treatments and a cure for neurofibromatosis by promoting scientific research, improving clinical care, providing outreach through education and awareness, while offering hope and support to those affected by NF.





The national NF Network services all states where there is no local representation.

NF Northeast

Serving Connecticut, Massachusetts, Maine, New Hampshire, New York, Vermont, and Rhode Island



NF Central Plains

Serving Kansas, Nebraska, Colorado, and Oklahoma



NF California

Serving California



NF Arizona

Serving Arizona, New Mexico, Utah, and Wyoming



NF Michigan

Serving Michigan and Ohio



Washington State NF

Serving Washington State



NF Community and Education

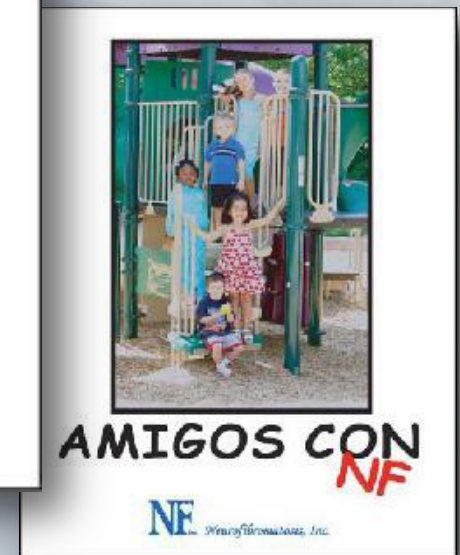
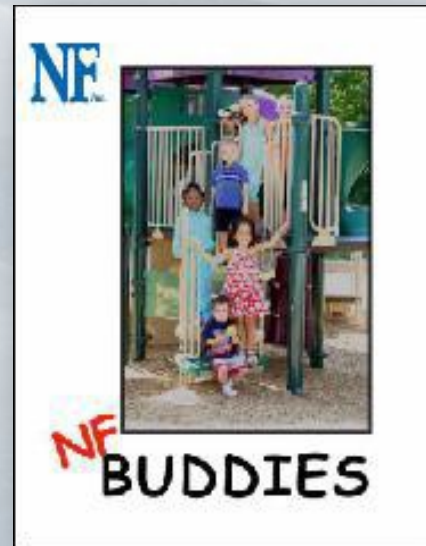
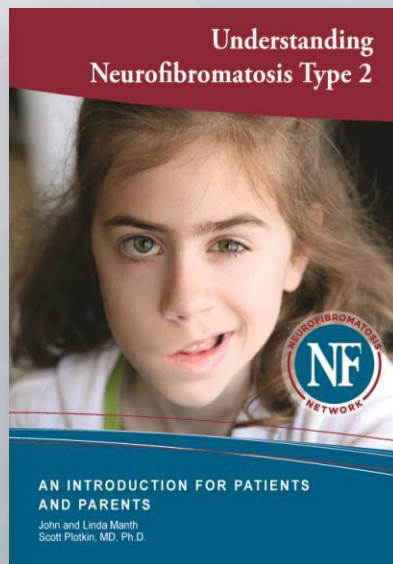
Educational Meetings/Symposiums



NF Community and Education

Publications:

- ***“Understanding Neurofibromatosis”*** booklet
- ***“Understanding Neurofibromatosis Type 2”*** booklet
- ***“Buddy”*** book for children in English and Spanish



NF Community Support/Outreach

We provide patient resources and individualized assistance to new NF contacts.

- **Camp New Friends - VA**
- **Camp New Focus - MI**



Camp New Friends

Check out the Kids having fun 2016!
Brochures for 2017 will be out this winter.

<http://www.nfnetwork.org/nf-happenings/camp-new-friends>



NF Community Support/Outreach

NF Community Building events

- NF Chats
- Beach Days
- Holiday parties
- Family Days at the ball park
- Events which create NF Networking opportunities



NF Research

Advocacy: Grassroots advocacy program to promote federal funds for NF research. Started in 1996 and have successfully advocated for over \$300 M through the Army's NF research program and inclusion of NF Research language for NIH.



Organizations participating in NF Network Advocacy Program Leadership Council

NF Network

NF Northeast

NF Midwest

Washington State NF Families

NF North Central

Texas NF Foundation

Participating Organizations

Littlest Tumor Foundation

NF Central Plains

NF Upper Midwest

NF Michigan

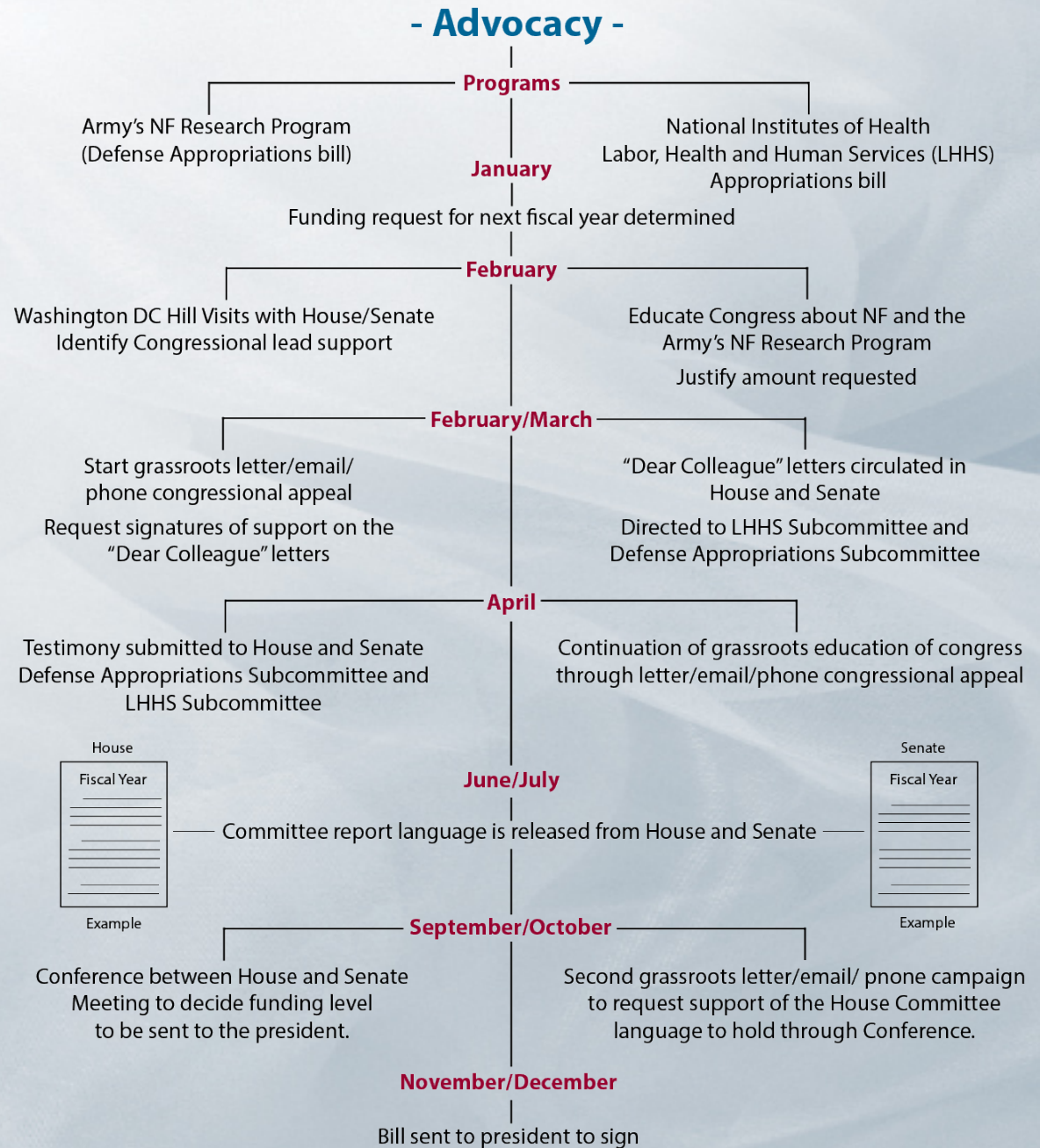
NF California

NF Arizona



2017 Advocacy Program

NF Network Acquiring Federal Funding for NF Research



CONGRESSIONAL SUPPORT FOR “DEAR COLLEAGUE” LETTERS

United States Senate
WASHINGTON, DC 20510

March 25, 2015

Chairman Thad Cochran
Defense Appropriations Subcommittee
122 Dirksen Senate Office Building
Washington, DC 20510

Ranking Member Richard Durbin
Defense Appropriations Subcommittee
115 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Cochran and Ranking Member Durbin:

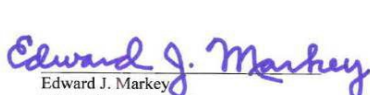
We write to request that you include \$15 million in the Fiscal Year 2016 Department of Defense Appropriations bill for the Neurofibromatosis Research Program (NFRP). Significant advances in Neurofibromatosis (NF) research have been made over the past several years, due in large part to the Army's program, and leading researchers are now on the threshold of a treatment and a cure for this terrible disease.

NF affects 1 in 2,500 people and is the most common neurological condition caused by a single gene and affects more people than muscular dystrophy and cystic fibrosis combined. NF can cause a myriad of devastating clinical problems including nerve and brain tumors, disfiguring skin growths, bone defects that may require limb amputation, unmanageable chronic pain, deafness, blindness, cardiovascular defects, vascular disease, and learning disabilities. NF gene mutations are also important 'drivers' of cancers in the lungs, liver, brain and breast. Research on NF stands to benefit 175 million Americans in this generation alone given its close connection to many common diseases.

In addition, Neurofibromatosis research addresses areas of great clinical need directly affecting the health of our soldiers, including bone fracture and repair, vascular disease, wound healing and nerve regeneration, behavior and psychosocial issues, learning disabilities, muscle weakness, and pain. Recognizing NF's importance to both the military and to the general population, Congress has given the NF Research Program strong bipartisan support. The Army's NF Research Program funds innovative, groundbreaking research which would not otherwise have been pursued, and has produced major advances in NF research, including conducting clinical trials in a nation-wide clinical trials infrastructure created by NFRP funding.

The Army's highly successful Neurofibromatosis Research Program has shown tangible results and direct military application with broad implications for the general population. Continued funding is needed to continue to build on the successes of this program, and to fund this promising research thereby continuing the enormous return on the taxpayers' investment. We respectfully request that you include level funding of \$15 million for the Neurofibromatosis Research program in the FY 2016 Department of Defense Appropriations bill.

Sincerely,


Edward J. Markey
United States Senator


Tammy Baldwin
United States Senator

Congress of the United States
Washington, DC 20515

March 25th, 2015

The Honorable Rodney Frelinghuysen
Chairman
Subcommittee on Defense
Washington, DC 20515

The Honorable Peter Visclosky
Ranking Member
Subcommittee on Defense
Washington, DC 20515

Dear Chairman Frelinghuysen and Ranking Member Visclosky:


We write to request that you include \$15 million in the Fiscal Year 2016 Department of Defense Appropriations bill for the Neurofibromatosis Research Program (NFRP). Significant advances in Neurofibromatosis (NF) research have been made over the past several years, due in large part to the NFRP, but continued investment is necessary to advance treatments and find a cure for the numerous diseases associated with NF.


NF is a genetic condition that includes three disorders: NF1, NF2 and Schwannomatosis. NF1, the most common form, affects 1 in 2,500 people. NF is the most common neurological disorder caused by a single gene and affects more people than muscular dystrophy and cystic fibrosis combined. NF can cause a myriad of devastating clinical problems including nerve and brain tumors, disfiguring skin growths, bone defects that may require limb amputation, unmanageable chronic pain, deafness, blindness, cardiovascular defects, vascular disease, and learning disabilities. NF gene mutations are also important 'drivers' of cancers in the lungs, liver, brain and breast.

In addition, NF has become a clinical 'model' for advancing medical research and the genetic information learned from NF holds the key to understanding a number of health issues that benefit the war fighter as well as the general population, including cancer, bone fracture and repair, vascular disease, wound healing and nerve regeneration, behavior and psychosocial issues, learning disabilities, muscle weakness, and pain. Recognizing NF's importance to both the military and to the general population, Congress has given the NF Research Program strong bipartisan support. The NFRP funds innovative, groundbreaking research which would not otherwise have been pursued, and has produced major advances in NF research, including conducting clinical trials in a nation-wide clinical trials infrastructure created by NFRP funding.

The highly successful Neurofibromatosis Research Program has shown tangible results and direct military application with broad implications for the general population. Continued funding is needed to continue to build on the successes of this program, and to fund this promising research thereby continuing the enormous return on the taxpayers' investment. We respectfully request that you include \$15 million for the Neurofibromatosis Research program in the FY 2016 Department of Defense Appropriations bill.

Sincerely,


Luis V. Gutierrez
Member of Congress


Louise M. Slaughter
Member of Congress

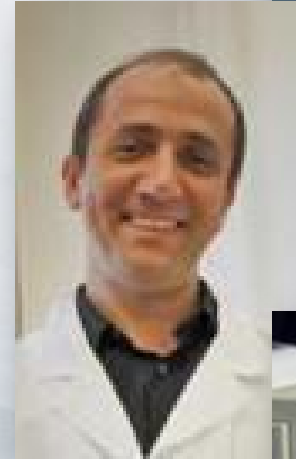
Research Funding

NF Research

- Direct investments in seed grants for basic research
- Clinical research
- Clinical care coordinators

Funded

- By individual regions
- Through a collaborative effort of the regions



Creating Awareness

NF HOPE CONCERT

6TH ANNUAL BENEFIT for **NEUROFIBROMATOSIS**



NF is what my son has, but
it's not who he is.

-Jenn



NF Awareness Challenge | May 2012
Join the NF Awareness Challenge on Facebook.



I have NF. NF doesn't have me.
NF Awareness Challenge | May 2012
Join the NF Awareness Challenge on Facebook.



I know someone who has NF.
#NFAwareness Challenge | May 2012
Join the Challenge on Facebook.

Creating Awareness

Join the Beauty Mark Nation!

