



Neurofibromatosis Midwest 2013 Annual Review

WE'RE HERE.
WE CARE!



Our Balanced Approach
to Improving Lives

Clinics

9 neurofibromatosis clinics
in our 6 state region

Awareness

Materials, merchandise,
events, and media exposure

Research

Research grants and lobbying
for federal funds

Education

Symposia, webinars, website,
and educational materials

Support

Phone support, free packets for the
newly diagnosed, events, and camp

NF Midwest CARES about children, adults,
and families living with neurofibromatosis and
looks to improve their lives through these five areas.

Our MISSION is CARE

NF MIDWEST IS HERE

We are local and have been part of the NF community for over 30 years—since 1982. Our efforts focus on improving the lives of adults, children, and families in the six state region we serve.

NF MIDWEST CARES

We were founded by, and our Board is directed by, people who are personally affected by NF. Some have since lost their loved ones with NF but remain dedicated. NF is a lifelong, life affecting, and continually evolving disorder. NF Midwest is here for it all—from diagnosis on—and we want it all—**C**linics, **A**wareness, **R**esearch, **E**ducation and **S**upport!



WE'VE BEEN THERE

Everyone on our staff has at least one loved one with NF. We know what it is like to live with NF. We understand the struggles of adults who face pain, depression, loneliness, and discrimination.

As parents, we have watched our kids **struggle. We've lived in fear, but through it** all we have learned from our experiences. NF Midwest has spent over 30 years fighting all the different types of NF battles. We have a good idea of what the NF community needs and have a personal interest in the results.

In the last three decades we have come a long way in improving the lives of people with NF and are excited **by the possibilities of the future. We wish this wasn't** a journey that we had to make, but are thankful for the dedication of those who are making it with us.

MISSION STATEMENT

NF Midwest is committed to improving the lives of children, adults, and families impacted by neurofibromatosis. Our continued focus and foundation is on Clinics, Awareness, Research, Education and Support in the states of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and the eastern half of Missouri.



WHAT IS NEUROFIBROMATOSIS?

Simply put, the neurofibromatoses (NF) are a grouping of genetic disorders (including NF1, NF2 and schwannomatosis) affecting approximately 1 in 2500 people that can cause tumors to grow on nerves in or on the body. They can cause a variety of other complications depending on the type of NF. NF affects all races, ethnicities and genders equally. Also, while it is genetic, approximately 50% of people with NF are the result of a “spontaneous mutation”. **This means ANYONE can be born with NF.**

For more information visit www.nfmidwest.org or call 630-945-3562 for an educational packet.

Our COMMUNITY

OVER 12,000 PEOPLE IN OUR REGION HAVE NF

Our NF Midwest community includes the over 12,000 children and adults in our region who have neurofibromatosis, plus their countless family members, loved ones and friends. Their needs and experiences with NF are as diverse as the disorder they battle.

HOW NF AFFECTS OUR COMMUNITY

Internal Tumors	Dermal Tumors
Learning Disabilities	Cancer
Amputation	Complete hearing loss
Vision loss	Facial disfigurement
Depression	Paralysis
Scoliosis	Seizures
Poor motor skills	Speech problems
Orthopedic issues	Severe pain
High blood pressure	Bone deformities
Hydrocephalus	Loss of balance
Heart defects	Attention deficit disorder
Autism	Headaches
Discriminationand more

OUR CARE REGION 6 STATES



NF NETWORK AFFILIATE

NF Midwest is an affiliate of the NF Network, which includes a national organization and regional organizations. We collaborate with them in our advocacy efforts, share resources, and work together on mutual interests that improve the lives of people with NF.

NF Midwest is wholly independent. We hold our own 501(c)3 status and have our own bylaws and policies.



CLINICS the cornerstone of CARE

Clinics with doctors and specialists who have extensive experience in caring for people with NF, and knowledge about neurofibromatosis is especially important as NF complications can be varied, severe, and complex.

NF Midwest's top priority is making sure that those with NF get the best care. We work to create, identify, and support clinics in our region. As of 2014, we are pleased to have nine clinics in our six state region of Illinois, Indiana, Iowa, Wisconsin, Kentucky and eastern Missouri. With the latest addition of a clinic in Louisville, Kentucky, we now have coverage in every state.

NEW CLINICS

NF Midwest was happy to announce the addition of two new clinics in January 2014.



Alexander Asamoah MD

One is through the University of Louisville Weisskopf Child Evaluation Center's Genetics Unit where they are now seeing children and adults with NF. Dr. Alexander Asamoah, a geneticist, formed this specialty clinic. The clinic will allow for genetic evaluation and management in addition to an ophthalmology evaluation on the same day.

The other clinic is in Chicago's Loyola University Health System with locations in Burr Ridge and Maywood. They will see both children and adults. The clinic director, Dr. Nikolas Mata-Machado, served a neurology fellowship under Dr. James Tonsgard at the University of Chicago NF Clinic.

We look forward to strengthening and supporting these clinics.



Nikolas
Mata-Machado, MD

CONSORTIUM CLINICS

In 2006 the NF Clinical Trials Consortium was formed to conduct clinical trials to improve the quality of life of people with NF. The Consortium consists of thirteen patient recruitment sites, four collaborating sites, and an Operations Center at the University of Alabama at Birmingham.

In our region we are fortunate to have four NF Consortium Clinics. They include Washington University in St. Louis, Indiana University in Indianapolis, University of Chicago and Lurie Children's Hospital in Chicago.

9

CLINICS

Lurie Children's Hospital, Chicago

University of Chicago, Chicago

Loyola University, Chicago

Washington University, St. Louis

Cardinal-Glennon, St. Louis

Children's Hospital, Milwaukee

Indiana University, Indianapolis

University of Iowa, Iowa City

Louisville University, Louisville

1,600

NF PATIENTS
In 2013

AWARENESS leads to UNDERSTANDING

POPE AWARENESS CAMPAIGN 2013



CLAUDIO PERVEPA/LANDOV

"True charity requires courage. Let us [...] help those in need."

- Tweeted by Pope Francis, Sept 2013

Awareness by the public about the complexities of NF and the impact it may have on someone who is affected will lead to more understanding and compassion. Too often people in the NF community find themselves struggling to explain what NF is. Some find themselves stared at and discriminated against because of their tumors. Some find it difficult to find and hold jobs because of learning disabilities, pain or other severe complications. The difficulties of the neurofibromatoses are overwhelming enough without the extra burden of a public **that doesn't understand.**

Awareness can be life changing. NF Midwest wants to change lives.

SPREADING THE WORD

- We regularly use social media to spread the word. This includes Facebook, Twitter, Google and other venues.
- NF Midwest has developed materials to educate the public. This includes our popular ***Faces of Neurofibromatosis brochure.*** We also have two "fold-over" business cards. One raises general awareness and the other gives those who find themselves stared at an opportunity to share and teach.
- We maintain an active website that includes information for public education and awareness.
- Our awareness merchandise offers an easy way to "wear the word" via various clothing. We also have other merchandise that brings the cause to the public.
- We often have human interest stories in newspapers, on television newscasts and through other avenues.
- Our staff and volunteers speak to various organizations. This has included schools, Congress, conferences for nurses, medical and nursing students, Rotary Clubs, banquets and much more.
- We conduct regular awareness campaigns.



RESEARCH at the center of CARE

Research for treatments for the many complications of the neurofibromatoses has always been a priority of NF Midwest. NF Midwest has been funding research since 1983 and gave the initial boost to many of the pioneers of NF research—many of whom continue their work today.

We also support programs such as the REiNS (Response Evaluation in Neurofibromatosis and Schwannomatosis) Initiative. REiNS seeks to develop standard responses and treatments for the neurofibromatoses. Go to www.reinscollaboration.org.

NF Midwest CARES and works to improve the quality of life of people with neurofibromatosis. This includes finding treatments and a CURE!

RECENTLY FUNDED

- Genetic exome sequencing research into the cause of excessive fibromas in NF1 at Massachusetts General Hospital and Harvard Medical School
- Basic research in the mechanisms of NF2 at Ohio University
- Cognitive study of children with NF1 aged 2 to 6 at the University of Wisconsin
- Clinical research with database support at the University of Chicago



COGNITIVE STUDY

This year we saw the results of a study that we have funded for two years with Bonnie Klein-Tasman of the University of Wisconsin. Dr. Klein-Tasman is dedicated to increasing our understanding of the cognitive, emotional, and behavioral characteristics of children with neurofibromatosis type 1.

As a result of her work, Dr. Klein-Tasman and her team published two journal articles. One in the *International Journal of Pediatrics* and the other in the *Journal of the International Neuropsychological Society* in 2013.

An immediate benefit of this study was that 65 children from the Midwest received free neuropsychological testing, which can be expensive. Forty to sixty percent of children with NF1 have a learning disability. These studies are informative and helpful in understanding how the individual child learns.

FREE TESTING FOR
65
CHILDREN WITH NF1



The **BEGINNING** of a CURE



\$300M
IN FEDERAL RESEARCH
DOLLARS IN 10 YEARS

NF ACTIVISM

Every February since 1996 a group from NF Midwest joins others from NF Network Advocacy Partner organizations and storms Capitol Hill to lobby for the federal funding of NF research. This year was our 18th year!

NF Midwest has been a part of this advocacy work from the beginning. In just the last 10 years alone, the donations and fundraising events of the NF Midwest community have enabled us to contribute almost \$250,000 to lobbying efforts **which have resulted in over 300 million dollars (that's \$300,000,000!)** in NF research through the Congressionally Directed Medical Research Program (CDMRP) and the National Institutes of Health (NIH).

It's only because of the work and support of our wonderful NF Midwest community and champions that we are able to move neurofibromatosis research forward.



Members of the NF Network Advocacy Partners in Washington DC in February 2014

NF MIDWEST PARTNERS WITH TECHNOLOGY FIRM

NF Midwest is extremely excited to partner with PreScouter, a technology discovery firm, to find innovations in neurofibromatosis research.

PreScouter is generously donating its services in 2014 to further NF Midwest's long-term objectives to create academic collaborations, thereby accelerating neurofibromatosis research, resulting in better technologies reaching NF patients faster.

PreScouter finds and connects small start-ups, academics, and other sources of scientific and technical advancements with corporate R&D labs that can help develop their work.

EDUCATION

Education is the most powerful weapon
which you can use to change the world.

~ Nelson Mandela

Education is the most powerful weapon we can use to change the lives of people with NF. Continued education is especially important because NF is a complex, highly variable disorder with complications that change throughout life.

NF Midwest aims to enable every individual and family challenged by NF to be well armed with knowledge and information so they can be a strong partner in their care and an advocate for their condition.

OUR EDUCATION ARSENAL

- A new comprehensive, dynamic website that provides NF families a previously unseen level of information with constant updates of webinars, meeting announcements, articles, research updates, materials and more
- Premier symposium for over 24 years featuring experts from around the world
- *Ask the Doctor* sessions to help patients and family members get their questions answered in an informal setting
- Easy to understand articles about the various complications and concerns of NF called “be iNformed”
- The *Understanding Neurofibromatosis (3rd edition)* booklet published by NF Midwest in 1993 and now used worldwide. This was the first comprehensive book on the neurofibromatoses for NF patients and families.
- FREE packets of information for the newly diagnosed in our region
- Special materials to share with medical professionals and school staff to educate them on NF



SYMPOSIUM

NF Midwest is well known for holding a family education symposium in October for over 24 years. We average 150 people each year and invite highly qualified NF experts from around the globe. We have always underwritten this program to keep the registration fee very low, as our priority is educating and bringing together NF families and individuals.

SUPPORT...a life ring

Supporting people with NF is really the most important part of what we do. In the end clinics, awareness, research and education are all about supporting the NF community and making lives better.

Our staff and board consists mainly of people who are personally touched by NF in one way or another. We know that the very best and most immediate way to improve the lives of people with NF is by being there for them and helping them to develop a lifelong support system.

OUR SUPPORT

- Private, but active Facebook group exclusively for people with an interest in NF in our Midwest region. The group allows individuals to share and help each other. It is closely monitored and our staff and volunteers step in to offer sound advice or information as needed.
- We take calls at the office and even on our cell phones at night and on weekends. We have counseled people approximately 250 times the last year.
- **We are part of the NF Network's Inspire board which is the most active discussion board for NF in the world.**



- NF Midwest financially supports Camp New Friends, a summer camp for kids and young adults ages 7 to 23. We send an average of 14 kids a year to this camp.
- Our NF community finds support at our many events such as the Great Steps 4NF walks, the annual symposium, and the various NF *Family Days*.
- We encourage and build local support groups within our region .

55

KIDS TO CAMP
IN FOUR YEARS



85

NEW FAMILIES
SERVED IN 2013



GREAT STEPS 4NF WALKS

RALLIES FOR NF!

Our Great Steps 4NF walks are truly rallies for the cause. They not only raise funds, they bring together NF families, and raise awareness.

NF Midwest started the Great Steps 4NF tradition and now other NF Network organizations throughout the United States hold Great Steps events.

In 2013, we held five Great Steps 4NF walks throughout our region. This included the world's largest walk for neurofibromatosis in Naperville, Illinois where the granddaddy of all NF walks enjoyed it's 12th year.



GREAT STEPS 4NF 2014 LOCATIONS

Chippewa Falls, WI
Naperville, IL
Effingham, IL
Madison, WI
Fort Wayne, IN

Includes the
LARGEST WALK
For NF in the U.S.A.



DOIN' IT 4NF EVENTS

We are extremely grateful for our amazing champions and the businesses and friends who supported them as they held events in 2013 to raise funds and awareness. The NF Midwest community is kind, generous and dedicated to the NF cause and to each other. Events such as (but not limited to) golf outings, corner collecting, trivia night, hostess parties, and poker night describe the many ways some NF champions have raised money and awareness.

We're all "doin' it 4NF" and we're in it to win it!

FUNDS and FINANCIALS

HOW DONATIONS ARE USED

As an organization staffed and directed mainly by those with a personal interest in neurofibromatosis, our funds are used wisely and efficiently for the benefit of the whole NF community.

A donation to NF Midwest is a donation to CARE which includes clinics, education, research, education and support for NF1, NF2, and schwannomatosis. General funds are used for all of these areas.

SPECIFIC FUNDS

To allow for the development of specific initiatives, NF Midwest has several funds to which a donation can be directed.

- **General Research Fund**
- **NF2 Research Fund**
- **Martin Ginsberg Research Grant**
- **Camp and Kids Programs**
- **Scholarship Fund—NEW**
- **Care Fund for Clinical Support—NEW**

We take great care to use funds in the way directed by our donors. If any donor would like to establish another specific fund we would be happy to discuss this.

Board of Directors

Dennis Pilkinton, President
Steve Griest, Vice President
Jean Nolan, Secretary
John O'Donnell, Treasurer
Gail Mavrogenes
Patrick Cullen

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Nikolas Mata-Machado, MD
Loyola University of Chicago
Heather Radtke, MS, CGC
Children's Hospital of Wisconsin
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University of Iowa Hospitals and Clinics

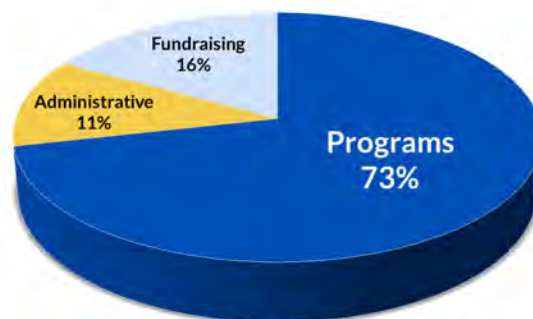
HOW YOU CAN CARE

People with NF are in need of care and support. You can be the difference and there are so many ways that you can help.

Make a single donation today at www.nfmidwest.org/donate, become a member of our Monthly Giving Circle, give through your workplace, attend an event, or volunteer.



REVENUE - FY2013



EXPENSES - FY2013

NF Midwest is a wonderful resource for us right here...They provide excellent NF informational packets and web based educational programs so people with NF in their lives can learn about the newest medical information and research discoveries about NF... NF Midwest, as a smaller more local foundation, can provide support in a more personal way that is also very important to our well being and hope.

~ Roxanne T.

...my Mom found NF Midwest, she calls them our life ring and for good reason, they saved us in more ways than they or anyone else could imagine. We were no longer alone. They sent us information, talked to us, gave us a breath when everyone else seemed to have taken it away. I guess that might be hard for people to understand but trust me when I say my NF is much easier with them in my corner.

~ Myshell R.

So glad I found this group, I always thought I was alone until now.

~ Nickie F.

Thanks again for directing the annual NF symposium. Your hard work & dedication to the cause is really appreciated.

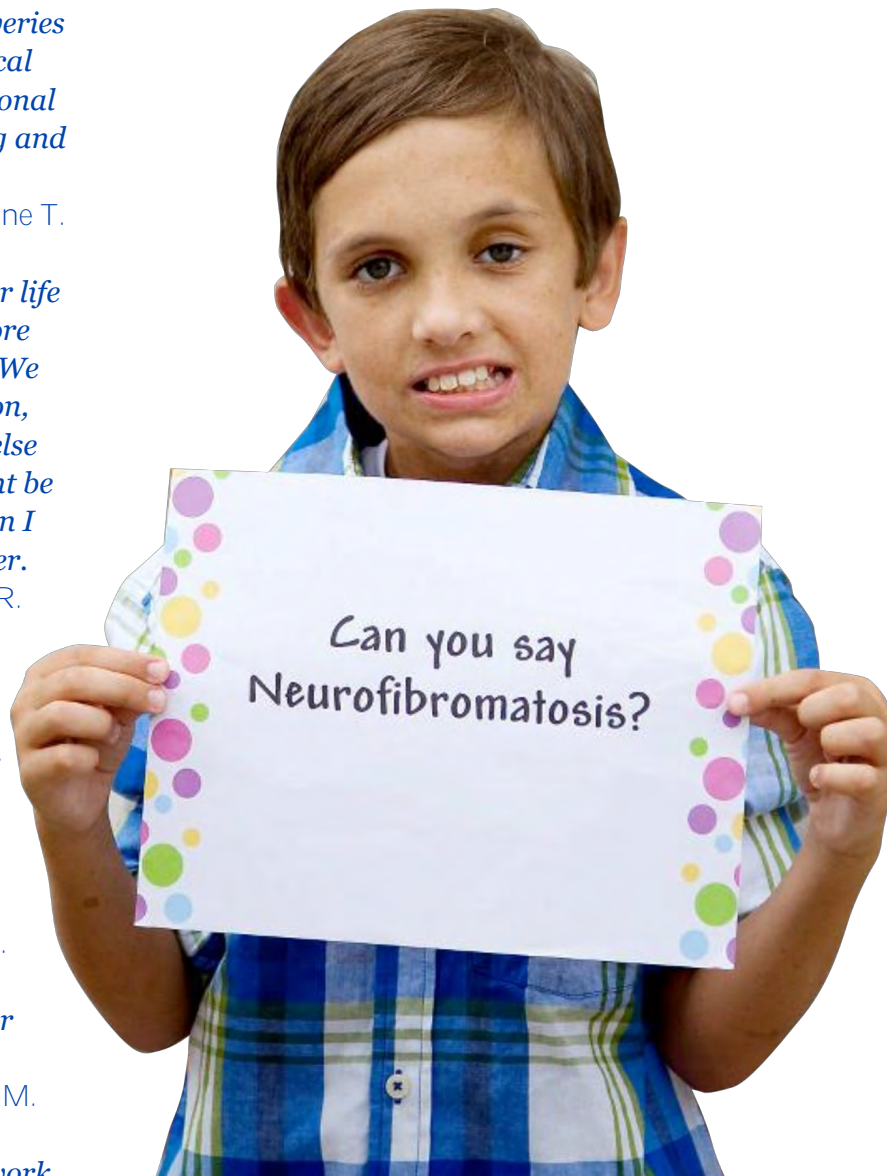
~ Brad D.

NF Midwest has truly been a beacon through our journey with NF.

~ Andrea M.

Thanks for all that you do for NF. You clearly work extremely hard for the cause and [we] will be forever grateful for that. Thank you!

~ Sue M.



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