



A Publication by NF Midwest for Neurofibromatosis Families

Neurofibromatosis Newsletter



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Published 2 times a year

April is "Ask The Doctor" Month

Sign up for one of our FREE sessions at nfmidwest.org!

Get your NF questions answered or listen to the questions of others at a casual meeting with an NF expert and NF families. Refreshments will be served and the event is FREE. Sorry, but child care will not be available. Register in advance at nfmidwest.org or call the office at 630.945.3562.



REGISTER NOW

Sunday, April 15th 2:00-4:00 pm

[Shriners Hospital for Children](#)

Chicago, IL

Note this is Central Standard Time

REGISTER NOW

Saturday, April 21st 10:00 am-12n

[IUPUI Campus](#)

Indianapolis, IN

Note this is Eastern Standard Time

Be iNformed
webinars and more.

OOPS!

Please LOOK
at these dates
carefully. The dates on
our recent postcard
were transposed.

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Step Forward for the NF Cause

The time to register for a walk for NF is now!

This year there are at least 6 opportunities in the Midwest to put your best foot forward and raise awareness and funds for neurofibromatosis. So far we have 5 physical walks and there is also the opportunity to sign-up for a Fantasy Walk. If you'd like to learn more about *steppiNForward* to raise NF awareness, raise funds for the cause and meeting others with NF, check it out at greatsteps.org.



You have 6 Opportunities to Step Forward for the NF Cause

★ [Naperville, Illinois](#)—June 2nd ★
Naperville Riverwalk

The GRANDADDY of Them All!

The biggest walk for neurofibromatosis in the entire country!

[Malden, Missouri](#)—April 28th
Malden Community Center

[Effingham, Illinois](#) - June 16th
Community Park

[Madison, Wisconsin](#)—May 19th
Token Creek Park

[Fort Wayne, Indiana](#)—Sept. 8th
Eel River Elementary School

Sign-Up Your Team Now at www.GreatSteps.org



Don't have a Great Steps for NF walk near you; your Saturdays too filled with other activities; or your body just plumb tired? You can still help raise awareness and funds by signing up for a [Fantasy Walk](#). This fun, new concept involves creating your own fantastical journey and bringing your friends along for the ride. In the process, you spread the word about NF and raise funds for the cause. Please check it out on our website at nfmidwest.org or give us a call at 630.945.3562.

Mission Statement

NF Midwest is an organization dedicated to the support and education of people affected by the Neurofibromatoses; to the education of health care providers; and to the investment in research.

Disclaimer

Neurofibromatosis Midwest does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep our members informed. We strongly advise that you check any drugs or treatments mentioned with your physician.

NF Midwest

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St. Charles, IL 60174
1.630.945.3562
www.nfmidwest.org
info@nfmidwest.org

Be sure to mark us a "safe sender."

Comprehensive Neuropsychological Evaluations for Children with NF1

By [Jill Isenberg, Ph.D., ABPP](#)

Children with NF1 are at risk for the development of learning and cognitive problems (e.g., difficulties with thinking, reasoning, memory, language, attention, etc.). Indeed, more people with NF1 will report school problems and academic failure than will experience serious physical complications associated with the disease. Cognitive problems have been described as the most significant cause of impairment across the lifespan for individuals with NF1.

Children with NF1 often receive psychoeducational testing through their school district to determine if the child qualifies for special education services as a result of learning or cognitive problems. Psychoeducational testing typically includes an evaluation of a child's intellectual ability (IQ) and academic achievement. In addition, if concerns are present, additional testing related to speech-language skills, fine- and gross-motor development, and emotional/behavioral functioning may be provided.

Importantly, children with NF1 are at risk for deficits in cognitive domains that typically are not assessed through [psychoeducational evaluations](#). For example, children with NF1 are at-risk for the development of problems with sustained attention and [executive functioning](#) skills. Executive functions refer to a wide-range of skills that allow the individual to manage and regulate his or her behavior and includes skills such as organization, planning ahead, problem-solving, inhibition of inappropriate behavior, and emotional regulation. Further, children with NF1 may develop problems with visual and verbal memory, visual-spatial processing, and social perception/interactions. Deficits in each of these domains are likely to interfere with a child's functioning; however, difficulties in these areas may go undetected in the traditional psychoeducational evaluation.

A comprehensive [neuropsychological evaluation](#) typically involves assessment of the domains that are covered in psychoeducational evaluations (e.g., intelligence and academic achievement) and also includes evaluation of a wide range of other cognitive skills. By evaluating all of the domains in which children with NF1 may demonstrate deficits, a comprehensive neuropsychological evaluation has the potential to identify all of the areas of difficulty that are impacting a child's learning. A full understanding of the child's cognitive strengths and weaknesses facilitates the development of a thorough intervention plan for use at home and school that is designed to maximize the child's functioning.

Neuropsychological evaluations are conducted by a neuropsychologist. A neuropsychologist holds a doctoral degree (Ph.D.) in Clinical Psychology or a related field and receives specific pre- and post-doctoral training in brain development and brain-behavior relationships. Thus, a neuropsychologist is positioned uniquely to understand how a particular disease that impacts the brain (such as NF1) will influence an individual's behavior in a variety of settings. A pediatric neuropsychologist specializes in understanding how conditions (such as NF1) impact the developing brain.

If you suspect that your child has cognitive deficits that are impacting his or her learning, you should talk with your child's NF1 physician regarding his or her potential need for a neuropsychological evaluation. Adults with NF1 also may benefit from a comprehensive neuropsychological evaluation, which may assist with post-secondary education and vocational training. Your NF1 physician may know of a neuropsychologist in your area. Your insurance company also may be able to identify a neuropsychologist in your area who is covered by your plan. The website for the [American Board of Professional Psychology](#) provides a searchable directory of board certified neuropsychologists that may identify a provider in your area (go to www.abpp.org, click on "find a board certified psychologist," select clinical neuropsychology, and input information about where you live).



July 15-21, 2012

Last year 14 kids attended [Camp New Friends](#) from the Midwest. At camp they learned to work as a team, built friendships and learned about their condition so that they could become effective partners in their own care. Upon their return, the sense of confidence, accomplishment and self-esteem was quickly evident from the smile on their faces to the swagger in their step.

Located in [Massanetta Springs, VA](#), Camp New Friends offers adolescents and teens (ages 7-16) and Transitional Youth (ages 17-25) with NF seven days and six nights of summer fun and social connections. It is presented by Brainy Camps of Children's National Medical Center.

Registration is online at: www.brainycamps.com.

Cost is \$750 per camper and includes a \$150 non-refundable deposit. NF Midwest has financial assistance available. Please contact our office for more information.



Great friends return from Camp New Friends in 2011!

Advocacy in Action

NF Advocates Descended on Capitol Hill

Thank you for your personal letters urging federal funding for NF research. On Feb. 6th and 7th a team of NF activists from the Midwest personally delivered those letters and often met with staff to make sure your stories were heard. This year activists from the Midwest included our director Diana Haberkamp, Aron and Meagan Buchanan from [NF Minnesota](#), and Tracy Wirtanen from the [Littlest Tumor Foundation](#) in Wisconsin.

This year's push is for 16 million to be allocated to the [NF Research Program](#) through the [Department of Defense's Congressionally Directed Medical Research Program](#). We are also encouraging the inclusion of language in the Labor, Health and Human Services appropriation for more neurofibromatosis research.

The NF Coalition, which includes [NF Network](#) organizations and [Texas NF](#), has been the national leader in advocating for federal research dollars since 1996. Because of these efforts over \$225 million dollars has been allocated to the Army's NF Research Program (NFRP) through the CDRMP. The success of this very targeted neurofibromatosis research has led to the development of a number of drugs which are now being tested in NF patients. Promising NF research funded through the CDRMP frequently leads to additional grants from the [National Institutes of Health](#), increasing the NF share of federal funding dollars.

It's Time to be Heard!

Now that we are back from DC will you to make sure our FY13 request is being heard?

The best way to get the message to your representative and senators is to meet with them or one of their staff members personally. Obviously, this can be daunting. Writing or calling will also be effective. This year we need you to contact your representative and senator. We are looking for 16 million to be included in the Defense Appropriation bill through the CDRMP for NF research and that language be included in the Labor, Health and Human Services bill encourage NF research.



Go to nfnetworkadvocacy.org to send a simple, quick email to your Congressmen about supporting NF research. If you have an interest in taking your advocacy efforts further, please contact the NF Midwest office.



Advocates for NF gather before heading out to congressional offices.

Welcome Jenny Perkins

Our New Development Director

We are so excited to have added a new set of hands to the NF battle. Jenny Perkins joined us in December in the new position of Development Director. Jenny is helping to develop and oversee our various fundraising and awareness events; working with people on their various community events; and developing a larger base of individual and business donors. Raising our fundraising and donor base is crucial in our efforts to support NF clinics in the Midwest; fund research; create educational opportunities; send kids to camp; advocate for federal research funding and to offer general support and referral information to NF families.



The addition of Jenny also frees up the rest of the staff to focus more on programs that benefit the NF community. This includes, but is in no way limited to, working with area NF clinics, exploring research opportunities, expanding advocacy, and being available to help NF individuals and families with questions and concerns.

Register your Email and be iNFormed

Please drop us an [email](#) or check out our [website](#) and register so you can take advantage of all of the benefits we offer, such as:

- Invitations to NF related webinars
- Timely email delivery of our Newsletter in color and with helpful links.
- Early symposium invitation and updates
- Access to information booklets and articles
- Action alerts
- Access to the NF discussion forum on Inspire
- Updated calendar of events

ILLINOIS



**May 20th in
Schaumburg!**

Join us for a day of fun and fellowship for all ages at the Chicago area NF Family Day event. This is a great way to meet other families and individuals with NF.

When: May 20, 2012

Where: [Gameworks Schaumburg](#)

Cost: People with NF are **FREE!**

\$10.00 per person for food only.

\$16.00 for food, 1 hour game play + 20 credits

REGISTER NOW

Find more details at nffamilydaychicago.eventbrite.com.

Chicago Area Golf Benefits

REGISTER NOW

For last years prices
until May 1st!

Take a Swing at NF

Friday, August 10

[Prairie Landing](#), West Chicago, IL

Chip in Fore NF

Wednesday, August TBD

[Cog Hill](#), Lemont, IL

Registration isn't open yet for this event

MISSOURI

Washington University Symposium

Enjoy this free event on May 4th!

Washington University NF Center is holding its first NF Symposium on Friday, May 4, 2012 at the Washington University School of Medicine Eric P. Newman Education Center (EPNEC) from 8:00 am- 4:00 pm. Keynote speakers will be **Dr. Luis Parada** and **Dr. Bruce Korf**. In addition, there will be invited talks from Washington University NF Center researchers, clinicians and trainees. To register, visit <http://nfccenter.wustl.edu/research/nf-center-research-symposium/>

Meet Us at the Zoo

Join others NF individuals and families May 5th at the [St. Louis Zoo](#).

It's that time again! We're kicking off NF awareness month with a 2nd Annual NF family fun day on May 5th, "Meet Us at the Zoo". Come out and have a fun family day with others and spread awareness of NF. Please bring a picnic lunch to enjoy in the park. Bring your family, friends and neighbors. We meet at the north gate at 10 am. Please wear an NF shirt. If you're late, don't worry, just look for someone with an NF t-shirt and/or a name tag with an NF ribbon on it. See you at the Zoo! Any questions feel free to contact: Rebecca Damschroder at crzybusymomof2@hotmail.com or Christina Thomas at cltq4d@mail.mizzou.edu.



INDIANA

Fort Wayne Friends

Commit now to the Great Steps Walk on Sept. 8

The [Fort Wayne Committee](#) is holding their 2nd annual Great Steps for NF Walk on September 8th at Eel River Elementary school. If you'd like to join the Fort Wayne Committee or meet more people who care about NF in Fort Wayne, please email them at fortwayne@nfmidwest.org.

Indianapolis "Ask the Doc" Meeting

Get questions answered by an "NF Professional" and network with others interested in NF1. Saturday, April 21, 10:00 am-12 noon EST at IUPUI Campus. Find more information at nfmidwest.org.



Fort Wayne Friends - September 2011.

WISCONSIN

Madison Great Steps for NF Walk

Be there on Saturday, May 19 at 9:00 am

Madison's [Great Steps for NF](#) walk will be held on May 19 in Token Creek County Park. If you'd like to help please give us a call or send an email to Wisconsin@nfmidwest.org.

Children's Hospital NF Symposium

Don't miss this educational opportunity on April 28

The [Children's Hospital of Milwaukee](#) is holding an NF Type 1 symposium on Saturday, 4/28 at the Health Research Center Auditorium of the Medical College of WI. The time is not set yet.

Step Foward!

Join or Form an Area Committee!

Anyone can start a local committee to help the NF cause. NF Midwest will do as much of the work as possible, but we need "boots on the ground" to build the NF community in your area. Give us a call at 630.945.3562. if you'd like more information.



Step Forward for the NF Cause!

There are so many opportunities for you to step forward for NF. They are on these pages, on our website and in your mind. If you have an idea for a fundraising and/or awareness raising event, we'll help you DO IT!

Run4NF

You can pick any run of any size, anywhere and raise money for NF!

We have a lot of fantastic *Great Steps for NF* walkers out there. They are walking to fight NF, raise public awareness and to enjoy the day with other NF families. But what about those that want to RUN? Now there is a way for those that have a slightly quicker pace to raise money and awareness too. We have 5 runners that have decided to use their marathon experience to benefit NF Midwest. Andrea Miller is running the Chicago [Rock 'n' Roll Marathon](#) on July 22. Nikki Jendras, Katie Sullivan, Simon Camaj and Michael Blaha are running the [Chicago Marathon](#) on Oct 7th. They will be joining the Brown family, Jeff, Derek and Hilary, from New Hampshire. Good luck to all of our marathon participants! If you are interested in running a marathon and doing it for a great cause, contact Jenny at jenny@nfmidwest.org.

How About a Fun Run?

Perhaps you wanted a marathon that's not quite as demanding as the Chicago Marathon. Well, hopefully you'll see the colors of the rainbow as you wipe the mud out of your eyes and run for your life. What? Try out one of these "fun runs" and use the event as your own fundraiser. Ask your friends and family to sponsor you in your adventure.

What does Mud, Zombies, And Rainbows have in common?

www.runforyourlives.com A zombie infested 5k obstacle course race. Midwest locations include Indianapolis or St. Louis.

www.downanddirty mudrun.com 5k and 10k courses filled with military-style obstacles. Located in Chicago, this event also has courses for 4-13 year olds.

www.thecolorrun.com The only race you will finish more colorful than a rainbow. Located in Chicago,

this race makes you colorful, not dirty.

There are a lot of local fun or regular runs. Check the internet to find one near you.

Participate in any sort of run while raising funds and awareness for NF and NF Midwest will support you while you support the cause.

Please, call or email Jenny for more information at jenny@nfmidwest.org or 630.945.3562.

How much do I need to Raise?

If you...

-  raise \$500, Run4NF will reimburse your race registration
-  raise \$1500, Run4NF will reimburse your race registration and one night hotel (max \$100)
-  raise \$2500, Run4NF will reimburse your race and two nights hotel (max \$200)
-  raise \$5000, Run4NF will reimburse your race, 2 nights hotel (\$200) plus credit \$200 for air travel

Community Events

Some of our Great Steps teams are holding community fundraisers to boost their fundraising totals. *Note: ANYONE can host a community event, not just Great Steppers.* A community fundraiser is an event that is set up and run by an individual or team, with little involvement by NF Midwest. Great for a number of reasons, the people that put them together usually have a network of family, friends, co-workers, neighbors, etc that they involve in the event. In this way these events raise awareness and involve more people beyond NF Midwest's reach, bring NF families together, and raise much needed funds which can also go toward a team.

Some of the great events that have already taken place include a [vendor night](#) in November with seven home party consultants by **4Kate**. An educational, but extremely fun Trivia Night for the **Austinators** in January. A Tastefully Simple party, with the bonus of a raffle basket for the Naperville GS walk by **Logan's Heroes** and **Jacob's Warriors** annual [Buffalo Wild Wings](#) day.

More great events are planned; please consider supporting them if you can. For more information on the events below please contact the office:

Team Kourtney is cooking up a Lasagna Dinner on April 21st in Van Wert, OH.

Team Monkey is holding a Corner Collection in Tinley Park, IL on May 5th and 6th.

Colour Line Hair Studio of Geneva is holding an event [Celebrating Silas](#) on March 19 at McNally's Irish Pub in St. Charles, IL

If you need [great ideas](#) for community events, need help getting an idea going or would like us to put your event on our website, Facebook and Twitter... contact Jenny at jenny@nfmidwest.org.

We Need You!

We're looking for volunteers, raffle prizes and sponsors!

The NF awareness and fundraising season is here. Most of this work falls in the months of April through September. This time of year offers a great opportunity for you to join in on the efforts and help the NF cause, while also meeting others and getting close to the NF action. Please volunteer your time or your services. Let us know your interest and we'll find a place for you in the fight.

Because we hold so many events during this time, we are also always in need of [sponsorships](#) and [raffle](#) items. Think about who you know that might have merchandise and event tickets for raffle and auction. Think about who you know that might have reward points from a reward card and might want to use them up for a good cause. Think about who you know that has a connection to an executive in a business that would like the opportunity to step forward for the NF cause.

Symposium 2011 Wrap-up

You're invited to our next great Midwest Symposium on October 13!

Thanks to your generous support NF Midwest is able to hold a large, educational symposium for NF families and interested parties. We held our 21st symposium in St. Louis, MO on October 15th.

Thank you to our wonderful speakers including Pat Furlong of the [Parent's Project Muscular Dystrophy](#) who gave us an excellent presentation on advocacy; Dr. Gutmann from the Washington University NF Center in St. Louis; Dr. Hingtgen from the Indiana University School of Medicine and NF Clinic; Dr. Ashok R. Asthagiri from the NIH; Dr. Chicoine, Dr. Hullar, Dr. Isenberg and Dr. Potts from Washington University School of Medicine & NF Center; Dr. Raizer from Northwestern Brain Tumor Institute, Chicago; and Dr. Kent Robertson, Indiana University School of Medicine.

A big thank you to our volunteers including Michelle Mellencamp from the [Indiana University NF Clinic](#) and our various volunteers from [Washington University's NF Center](#). Thank you to Anita Thurman and especially to Sarah Thurman for watching over our Kids Group. As always, we couldn't get this done without our very special NF2 coordinators, Susan Buono, Laura Didier and Steve Reason.



**2012 Midwest Symposium
October 13**

Our 2012 Midwest Symposium is scheduled for October 13 at the [Northern Illinois University Extension Building](#) in Hoffman Estates, IL. This is a western Chicago suburb with easy access from the I-90 interstate and is about 30 minutes from O'Hare Airport. We are already working on an exciting agenda. Please, let us know if you would like to help. Be sure to mark your calendars now and keep an eye out for more information. This might be the perfect reason to get yourself signed up for email updates at nfmidwest.org.



St. Louis Symposium 2011!



NF Network 2012 WEBINAR SCHEDULE

The NF Network has scheduled many informative [webinars for 2012](#). Please, check our website or nfnetwork.org for reserving a spot.

Brainy Camps/Camp New Friends

Wednesday, April 11, 2012

Speaker: Sandra Cushner Weinstein

Children's National Medical Center, Washington, DC

Optic Gliomas in NF1

Wednesday, May 9, 2012

Speaker: Robert Listernick, MD

NF Clinic Director, Children's Memorial Hospital, Chicago

NF1 and Aging

Wednesday, June 6, 2012

Speaker: John J. Mulvihill, MD

Genetics, Oklahoma University Medical Center

NF2 (Closed Captioning Provided)

Wednesday, July 11, 2012—Speaker: TBA

Webinars may also be recorded for viewing at a later date. Webinars that you may have missed include:

[NF1 and School Issues](#)

[How to Meet and Talk with your Congressmen about NF Research Funding](#)

NF2 and Facial Reanimation

Not available as a recording

To receive timely updates of these and other events it is very important that we have your email. If we don't already have it, please, send it to us now at info@nfmidwest.org.

Running 12 4NF!

Man running 12 half-marathons in 2012 for NF.

Michael Blaha is a super man in more ways than one. After learning that a former student, John, had NF1, Michael has dedicated his mind and body to running not 1, not 2, not 3.....but 12 half-marathons PLUS the full Chicago marathon for the NF cause. He is not only a man of steel, but a man with a pure and super heart!



To show appreciation for Michael's super effort, please make a donation at firstgiving.com/fundraiser/michaelblaha. Also check out his blog at Run4NF.blogspot.com.

**Text "follow nfmidwest" to 40404
for text updates on your phone!**

Give it a try!



NF Q&A Corner

Q: My doctor didn't order an MRI. Shouldn't I have one regularly?

A: NF specialists usually do not recommend MRI's as part of a routine evaluation. They are more often ordered if an abnormality is suspected due to the presence of symptoms. This is because the presence of an abnormality doesn't mean it has to be treated. Treatment is more often determined by symptoms.

Q: Can I have both NF1 and NF2?

A: Since NF1 and NF2 are found on different genes it is HIGHLY unlikely, but not entirely impossible to have both. It would be similar to having NF1 and cystic fibrosis. Genetically, NF1 and NF2 are different disorders.

NF2 Clinical Trial

RAD0001 Phase II Trial

In 2012 House Research Institute will sponsor a three-year, Phase II clinical trial, evaluating the efficacy of the drug RAD001 (otherwise known as everolimus). Following an identical protocol, the clinical trial will be conducted simultaneously in Los Angeles, California, and Paris, France. In Los Angeles, the trial will be under the direction of Dr. Giovannini. Find more information [here](http://clinicaltrials.gov) at clinicaltrials.gov (Identifier #NCT01345136).

NF2 Websites

The two sites below are excellent for finding everything about, and everything going on with, NF Type 2. Be sure to sign up for the Compass quarterly newsletter at Advocure2.org. It is phenomenal.



nf2crew.org



advocurenf2.org

University of Chicago in Palos Heights

NF Clinic hours available on Wednesdays

In addition to clinic hours on Thursdays and Fridays in Chicago, the University of Chicago NF clinic also sees patients in Palos Heights on most Wednesdays and occasional Fridays. You may find this clinic more convenient in ease of access and location. To make an appointment in Palos, call Mark at 708-448-8000.

May is NF Awareness Month! What are your plans to raise awareness? Call and let us know or to ask for ideas on how you can help!

Events are being added so fast in the NF Midwest community that it is impossible to keep everyone totally up-to-date. We do the best we can and will do the best we can for any community events that you decide to hold.



March 15 St. Charles, IL [Parent's Meet & Greet](#)

March 19 St. Charles, IL [Celebrating Silas](#) at McNally's Irish Pub

April 15 Chicago, IL [Ask the Doc](#)

April 21 Indianapolis, IN [Ask the Doc](#)

April 21 Middle Point, OH Lasagna Dinner Team Kourtney

April 28, Milwaukee, WI Educational Meeting

April 28 Malden, MO [Great Steps for NF Walk](#)

May 5 St. Louis, MO [Family Day at the Zoo](#)

May 5 & 6 Tinley Park, IL Corner Collecting By Team Monkey

May 19 Madison, WI [Great Steps for NF Walk](#)

May 20 Schaumburg, IL [Chicago Area NF Family Day](#)

June 2 Naperville, IL [Great Steps for NF Walk](#)

June 16 Effingham, IL [Great Steps for NF Walk](#)

July 15-21 Virginia [Camp New Friends](#)

August 10 West Chicago, IL [Take a Swing](#) at NF Golf Benefit

August TBD Lemont, IL [Chip in Fore](#) NF Golf Benefit

Sept 8 Fort Wayne, IN [Great Steps for NF Walk](#)

October 7 Chicago, IL Chicago Marathon

October 13 Hoffman Estates, IL NF Midwest Symposium

What's Your 6 Degrees of Separation?

Everyone one has a connection to at least one celebrity or at least knows someone who does. Who can you connect to help the NF cause?



We're looking for celebrities to doodle for National Doodle Day. National Doodle Day is part of Neurofibromatosis (NF) Awareness month, where celebrity doodles are available for auction on eBay during the month of May to raise money to benefit the NF Network. If you have a connection, please let us know. All we need to do is get a packet to them with a page to doodle on and they send it back.

Also, please spread the word to everyone you know about the auction. If they don't know a celebrity, they might like to have a connection by way of purchasing a celebrity doodle.

Find more details at doodledayusa.org.



Beauty Mark Nation™
United to Cure Neurofibromatosis

Join the Beauty Mark Nation at
beautymarknation.org

Neurofibromatosis (NF) affects three times as many people as cystic fibrosis and muscular dystrophy combined. Yet, most people have never heard of NF. We need to change that! The [Beauty Mark Nation](http://beautymarknation.org) is rising up and joining forces to make a difference because – NF patients do matter and have stayed in the shadows for too long.

One of the first signs of neurofibromatosis (type1) are café au lait birthmarks. While harmless and often just called ‘beauty marks’, in reality they are the hallmark of an unpredictable, genetic condition that can vary in severity.

Just as those who know and love cancer patients will shave their own heads in solidarity and support of their loved ones in treatment, those who know and love NF patients can show their solidarity and support by donning beauty marks—temporary tattoos, face paint, body paint, “war paint”.

Spread the boundaries of the Beauty Mark Nation by wearing the tattoos or other war paint. 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!

Contact [NF Midwest](http://nfmidwest.org) for tattoos and other things you can do as a member of the Beauty Mark Nation.



Did You See Something You Liked?

Do you see value in our newsletter and what we do? Can you support our efforts with a small [donation](http://nfmidwest.org/donate) of \$5, \$10 or \$20?

Midwest Area NF Clinic Information

For more doctors go to www.nfinc.org

[Children's Memorial Hospital](http://www.childrensmemorial.org)

(Children Only)
Chicago, IL

773-880-4462
Joel Charrow, MD
Robert Listerick, MD

[Indiana University NF Clinic](http://www.indiana.edu)

(Children and Adults)

Riley Hospital for Children
Indianapolis, IN 46202-5119

Cynthia Hingtgen, MD, PhD (Director)

317-948-7450

for scheduling & information

Yvonne Hayden, RN (Clinic Coordinator)

University of Chicago

(Children and Adults)

Chicago & Palos Heights, IL

James Tonsgard, MD (Director)
773-702-6487

Cynthia MacKenzie, RN
773-203-2344

General Inquiries & Research

773-702-6169 (Chicago)
708-448-8000 (Palos Heights)
Appointments

www.uchicagokidshospital.org/nf

or

www.uchospitals.edu/specialties/neurology/neurofibromatosis.html

St. Louis Children's Hospital

(Children and Adults)

[NF Center](http://www.nfcenter.wustl.edu)

St. Louis, MO

314-454-6120

www.nfcenter.wustl.edu

David H. Gutmann, MD (Director)
Anne Albers, PNP

Children's Hospital of Wisconsin
(Children and Adults for first evaluation)

[NF and RASopathy Center](http://www.childrenshospital.org)

Milwaukee, WI

414-607-5280

877-607-5280

Donald Basel, MD

Dawn Siegel, MD

Heather Radtke, MS (Clinic Coordinator)

NF Midwest is registered as a 501(c)3, not for profit organization in the State of Illinois. Currently our coverage includes the states of Illinois, Iowa, Indiana, Wisconsin, Kentucky, Tennessee and eastern Missouri.