



A Publication by NF Midwest for Neurofibromatosis Families

Neurofibromatosis Newsletter

Volume 33, Issue 1

Spring 2014

Published 2 times a year



2014 NF Midwest Symposium *A Day of Learning And Socializing*

October 25, 2014
8:30 to 4:00
Hoffman Estates, IL



NF Midwest has been holding a premier [symposium](#) for NF families, affected individuals and other interested people for over 24 years. We host experts from all over the world and spend the day learning from them and each other. The price is always affordable and the day is always enjoyable and informative. Mark your calendars now and look for more details soon.

Ask The Doc—Indy

Saturday, April 12, 2014
11:00 am-2:00 pm EST
REGISTER NOW
Cost is \$5.00

Don't miss our annual [Ask the Doc](#) session in Indianapolis. This is an excellent opportunity to get your questions answered and to meet the doctors from the Indianapolis NF clinic.

For more information or to sign-up call 630.945.3562 or go to www.nfmidwest.org/atd_indy.



2013 Annual Review

Inside of this issue of NF Midwest's newsletter you will find our 2013 Annual Review. This review shows the work that NF Midwest does and continues to do for the NF community. [See it online.](#)

NF Midwest C.A.R.E.S.

We have also unveiled a new acronym to clarify our mission. Our [mission](#) has NOT changed. We remain committed to the NF community and our new mission acronym is about how NF Midwest C.A.R.E.S. with **C**linics, **A**wareness, **R**esearch, **E**ducation and **S**upport.

University of Wisconsin Research Collaboration

We are excited and proud to announce our collaboration with the University of Wisconsin-Madison, Biotechnology Center. The [UW Biotechnology Center](#) and NF Midwest are currently in the process of establishing new NF research at the University of Wisconsin. This partnership marks a strong step forward in bringing new research techniques and NF awareness to one of the most prestigious research institutions in the world.



Board Of Directors

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



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 **C**linics, **A**wareness, **R**esearch, **E**ducation and **S**upport in the states of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and the eastern half of Missouri.

NF Midwest C.A.R.E.S.!

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
473 Dunham Road, Suite 3
St. Charles, IL 60174
1.630.945.3562
info@nfmidwest.org
Be sure to mark us a "safe sender."
www.nfmidwest.org

If You Want to be Remembered—Do Something Memorable.

What will your Legacy be?

Planned giving donors make a real difference in improving the lives of people with neurofibromatosis and sustaining the work of NF Midwest.

A planned gift is a gift made as part of your financial plan, retirement plan or estate plan and there are many options available. They can sometimes reduce your tax burden and certain vehicles can provide income for you or a loved one.

Please contact NF Midwest or your financial planner to learn more about them. Possibilities include:

Outright Gifts

- Cash
- Stock & Mutual Funds
- Personal Property

Gifts Beyond Your Lifetime

- Bequests/Wills
- Life Insurance Policy
- Retirement Assets

Gifts That Pay You Income

- Charitable Gift Annuity
- Charitable Remainder Trust

LEAVING A LEGACY

Irma (Toni) Napolilli, who passed away in September 2012 at the age of 94, and her husband, Francis, who preceded her in death, have left NF Midwest and the neurofibromatosis community a very generous gift through a [Charitable Remainder Unitrust](#) (CRUT).

The Napolilli's were very hardworking, caring individuals as well as dedicated parents to their four children, including a daughter with neurofibromatosis type 1. They admired the work of NF Midwest for many, many years and always sought to be more involved in our programs and to support our work. Finally in managing their estate and planning for retirement, they formed a trust that would help them maintain income through their later years and ultimately benefit NF.

There are not enough words to describe our gratitude. As an organization staffed by people with a personal interest in NF, we look forward to using these funds wisely and carefully for the benefit of the neurofibromatosis community.



Consistent Giving Keeps Hope in Motion.

Set your giving on auto pilot!



Don't forget about [monthly giving](#). We have many people who have joined our monthly giving circle and you can help us grow it. We have people who give \$10, \$50 or \$100 a month.

A monthly donation is a painless, effortless way to support neurofibromatosis and NF Midwest. Your monthly generosity gives NF Midwest a reliable income stream so that we can focus more of our resources on the battle of neurofibromatosis. To set up monthly giving give us a call or click [here](#).

NF Family Wellness Retreat...

for NF Families (first come basis) at the Imago Dei Village, Clintonville, WI August 15-18, 2014. Cost is \$100 per family. For more info call (920) 475-6599 or email info@littletumor.org. [MORE INFO](#)



NF Midwest has a special, new club for exceptional fundraisers called the **iNFINITY Club**. Living up to it's name this club is for

people who give to the NF cause always and forever. This club has four levels and consists of people, family or teams who have gone above and beyond in their giving and/or fundraising over the years. We have started this club by going back retroactively to 2009. Please forgive us for any inaccuracies or if we have missed anyone.

Platinum \$200,000+

Someone is coming soon. Is it you?

Gold \$100,000+

Francis and Irma Napolilli

Silver \$50,000+

Austinators Team Doodle

Bronze \$25,000+

Ali's Gaitors	2 Addi's	Jacob's Warriors
Cole's Crew	Team Lauren	

Camp New Friends



Camp **N**ew **F**riends is a weeklong summer camp held in West Virginia for kids with NF. Run by Brainy Camps Association and developed by the Center of Neuroscience and Behavioral Medicine at **Children's National**

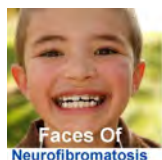
Medical Center, Camp NF helps to reduce the stigma and isolation that kids with NF often experience. The camp also helps them make friends, find support, learn more about their condition and develop adaptive behaviors.

We are excited to send 14 kids from the Midwest region July 21– 27. Some of these kids received camp and/or travel assistance through NF Midwest which would not be possible without the support of our donors.

Applications for camp and requests for financial aid, **MUST** be made through Brainy Camps at www.brainycamps.com. Space is limited. It is filling up quickly so apply soon!

NF Awareness Store

Now including awareness material!



Spread the word and wear the word! Check out NF awareness merchandise and material at NF Midwest's Awareness Store at nfmidwest.org/store. We now have extra awareness materials available for purchase in addition to t-shirts, hoodies, wristbands etc. Look for **more awareness items soon. It's up to us to make the public aware of neurofibromatosis!**

If you would like to hold a fundraising and/or awareness event. Please, let us know and we can get material out to you at no charge.

Thanks for Contacting Congress

In February we once again stormed the hill in Washington DC for federal research dollars. The NF Midwest team included Diana and Karissa Haberkamp, Ryan Geier and our longtime, dedicated activist Susan Buono. Thank you to everyone who wrote letters for us to bring. We delivered everyone of them. Also, thank you to everyone (and their **extended network**) who **"clicked"** when we requested it and **sent their requests for funding through our "petition" site.** We are very hopeful that we will get another \$15 million for NF research through the Congressionally Directed Medical **Research Program.** If you'd like to learn more about how you can help in the future please give us a call.

New Additions on Our Website

We are constantly adding to www.nfmidwest.org and making it a leading site for NF information and community. We still have a lot to do and will never stop working to make it better. Here are a few of the **NEW** things you will now find on it.

- Our [Awareness Store](#) now includes material as well as merchandise.
- You can now **"subscribe" to our blog** so that when we post you will automatically received an update.
- Transcripts and material from our symposium
 - [Socialization slides](#)
 - [NF2 Kissil Transcript](#)
- New Articles
 - [Applying for Disability Benefits with NF](#)
- New Webinars and Videos
 - [Neurofibromatosis 2 and Technology—Transcript](#)
 - [The Genetics of Neurofibromatosis Type 2](#)
 - [Video - Tumor Suppressor Research—Webinar Recording](#)

And more (because we're sure we missed something!)

To really be in the NF Loop:

1. **Make sure we have your CURRENT email**
2. **Join our NF Midwest Facebook Group** - The group is private and limited to people in our region with a high interest in NF and NF Midwest. Go to nfmidwest.org/facebookgroup to request to join.
3. **"Like" our NF Midwest Facebook page at facebook.com/nfmidwest**
4. **Follow us on Twitter at twitter.com/nfmidwest**
5. **Get our Twitter updates as text by texting "follow nfmidwest" to 40404.** You may send an "unfollow nfmidwest" text if it gets to be too much.
6. **Check our website www.nfmidwest.org regularly**
7. **Subscribe to our blog at www.nfmidwest.org/subscribe**



Activists in Washington, DC (from L-R) Diana, Karissa, and Susan

YOU CAN DO IT 4NF!

Do It 4NF in 2014! The neurofibromatosis cause needs you. No matter your talents or time, there is definitely something you can DO 4NF!



ILLINOIS

Upcoming Events

Great Steps Naperville and Effingham—Illinois will once again have two [Great Steps 4NF](#) events this year. The largest NF walk in the country in [Naperville](#) on June 21st and the 7th annual walk in [Effingham](#) also on June 21st.



Birdies for Charity—Here's an event you can participate in from your couch and possibly win a car! For John Deere's [Birdies for Charity](#) all you need to do is make a pledge and guess at the number of birdies that will be made during the [John Deere Classic](#). A 2014 Chevy Cruze will be awarded to one person who guesses the right amount.

John Deere underwrites the entire expense so 100% of your donation goes to the cause, PLUS a yet to be determined bonus of 5% to 8%. Call or look for info online.

Family Day—A member of the Chicago area NF Midwest chapter is working on a Family Day. If you would like to help, please let us know.

Golf Benefits—Two golf benefits are scheduled for the Chicago area in August. Please ask your friends who golf (or try to golf) to join us and consider any associates that might like to be a sponsor. More information may be found on our website under [EVENTS](#).

[Chip in Fore NF](#)—Thursday, August 7th at Cog Hill Golf Club, Lemont, IL

[Take a Swing at NF](#)—Friday, August 8th at Prairie Landing Golf Club, West Chicago, IL

They Did It 4NF!

Thirty-One Gifts—[Jessie Bodel](#) sold Thirty-One Gifts and donated her profits to the cause.

Si's Super Guys—Obtained a great \$5,000 donation from a local business.

Naperville Marathon—We had a wonderful turnout for the Naperville Marathon Run4NF team. Thanks to our spirited runners and fundraisers! [PHOTOS](#)



2013 Chicago area NF Family Day



Joan Pilkinton, Great Steps 4NF founder, is still doin' it 4NF – loading up discounted candy for the famous Naperville Great Steps “Goodie” Walk!



Please consider a donation to help with the cost of creating this newsletter.

Use the enclosed remittance envelope or donate at www.nfmidwest.org/donate.

If we can't help ourselves, who will?

MISSOURI



Color Me a Cure 4NF — Saturday, April 19th

Alex's Angels are doin' it again 4NF! This time with a [Color Me a Cure 4NF](#) 5K/1 Mile Family Fun Run/Walk to benefit NF Midwest. The event will include raffles and a silent auction. The event is at Malden City Park, Malden, MO. Registration is from 8:00-9:00 am. Mail entry and payment to: Crystal Presson; 3404 State Hwy 25, Malden, MO 63863

Central Missouri Support Meetings —The [Central Missouri](#) (formerly Columbus) chapter holds monthly meetings on the 3rd Thursday of every month at the Columbia Public Library. For more info contact us or email the chapter at CentralMissouri@nfmidwest.org.

Family Day—The [Central Missouri Chapter](#) is working on a St. Louis area family day. For more info or to help please contact us or email the chapter at CentralMissouri@nfmidwest.org.

They Did It 4NF!

Great article on NF published—Members of NF Midwest's Central Missouri Chapter got a [fantastic article](#) written about neurofibromatosis in the Columbia Daily Tribune. The author Jodie Jackson, Jr. was approached by the Chapter many months ago about writing it and it ended up being perfectly timed and tied to the Pope's embrace of a man with neurofibromatosis. This article not only explained neurofibromatosis and specifically its affect on two area families, it also nicely highlighted the need for local care and support - a mission of NF Midwest and it's chapters. We applaud this wonderful effort by Central Missouri and appreciate the Thomas and Ridgel families sharing their stories and putting a face to NF. Thank you also to Jodie Jackson, Jr. and the Columbia Daily Tribune.

Spoke to a High School Genetics Class—Christina Thomas from Central Missouri took the time to teach kids about NF in a high school genetics class.

WISCONSIN

Upcoming Events

Links for Lauren—Monday, August 25th

[Aerotek](#) is holding the 2nd Annual *Links for Lauren* Golf Benefit at the prestigious [Nakoma Golf Club](#) in Madison, WI. Proceeds will benefit NF Midwest and the neurofibromatosis cause.

Madison Great Steps 4NF Walk /5K Run—May 10th

Don't miss the 5th annual Great Steps 4NF walk (now with a [5K run!](#)) at the [Capital Brewery Bier Garten](#) in Middleton. [MORE INFO OR REGISTER](#)

Chippewa Falls Great Steps 4NF Walk—May 17th

West Central Wisconsin is getting a Great Steps 4NF walk! The Inaugural Chippewa Falls walk is scheduled on NF Awareness day, May 17th, 2014. Our energetic Chair is Crystal Reith. Email Crystal at wcwisconsin@nfmidwest.org if you'd like to help "do it 4NF". [MORE INFO OR REGISTER](#)

Milwaukee Adult Support Group—TBD

NF Midwest is working with the Milwaukee chapter of CTF on the development of a support group for adults with NF at [Waukesha Memorial Hospital](#). We will keep you posted with details—make sure that we have your email or to check our website regularly.

They Did It 4NF!

Badger Game Concessions—Ryan Geier arranged for a fantastic opportunity for NF Midwest and the neurofibromatosis cause. NF Midwest volunteers worked a concession stand at three University of Wisconsin Badger football games and a portion of the proceeds went to NF Midwest. Thank you to all our wonderful volunteers!



INDIANA

Upcoming Events

Ask the Doctor Indianapolis— On Saturday, April 12th from 11:00 to 2:00 the Indianapolis chapter is hosting an *Ask the Doctor* session at Indiana University. Drs. Lisa Smith, Laurence Walsh and Michael Ferguson of the NF Clinic will be taking questions for 2 hours and there will be an hour of socializing afterwards. There will be free child-care for children 3 and up. The cost is \$5 per adult and there is a \$5 parking fee. For more info or to register, call 630.945.3562 or go [here](http://www.nfmidwest.org).

Evansville Meetings—The next meeting of the NF Midwest Evansville Chapter is Tuesday, June 17, 2014 from 6:00 - 8:00 at the Roca Bar North, 12301 Hwy 41 N, Evansville, IN. For more info email Jane at Evansville@nfmidwest.org.

Great Steps Fort Wayne— The 4th annual *Great Steps for NF Walk* will be held Saturday, September 13th at the Eel River Elementary School. Please sign-up early and show your support at www.greatsteps.org.



**Fort Wayne Walkers
2013**

Important Clinic Message

It is VERY important to visit your "NF clinic" regularly, but if can't and it has been a while, PLEASE try to provide that clinic an update of your condition, especially if there have been changes in your health. Having an accurate database of how individuals with NF are affected is important for knowledge of the NF community with regards to care and also for research. For instance, it is helpful for the clinic to know if you have developed cancer, seizures, unexplained high blood pressure, depression, anxiety, or any other health problems. Also, please let the clinic know if a former patient has passed away.



On October 19th we are very fortunate to have at least 7 runners participating in a [Detroit Marathon](http://www.detroitmarathon.com) for NF Midwest and neurofibromatosis. We thank them for thinking of us and the NF community!

IOWA



A booth at the Liberty Fall Festival by the 2ADDIS. They did it 4NF!

KENTUCKY

NF Midwest is excited to have a new NF clinic in Kentucky through the University of Louisville. Look for more details on page the back page. If you would like to have an event to help this clinic and children and adults with NF in Kentucky, please let us know.

Never Forgotten



This past fall has been a difficult one as we have lost several people to NF, including a former board member, plus another non-affected former board member.

We know that there were more whose names or info we don't have. Because of the exceptional difficulty of the last several months we do want to acknowledge these losses and rededicate ourselves to improving the lives of those with NF and appreciating the work that so many put in for the cause.

Lisa Wilkins—Dec 4, 1979—June 7, 2013
Caitlin Ostrom—Sept. 14, 1993—Nov. 22, 2013
Jazlyn Pearcy—May 14, 2008—Dec 22, 2013
Steven Le Claire—Aug 5, 1982—Jan 28, 2014

Former Board Members

Marcy Perlman—Oct. 27, 1957—Dec 6, 2013
Laura Forbes—June 30, 1931—Feb. 11, 2014

Great Steps 4NF 2014 Registration is open!

If you have never participated in a Great Steps 4NF walk, this is the year to start. If you have been a part of these exciting events, then you already know that this is the best way to rally for the special NF person in your life, raise money, raise awareness and have a great day-all at the same time! Get your team together, fundraise and join us for a GREAT day!

Madison, WI – ([2013 PHOTOS](#)) We are back at the popular Capital Brewery and Bier Garten (Middleton) for another year with an added surprise, a 5K Run4NF! The walk and the run happen at the same time but registration for the 5K run is separate. So basically you can [RUN](#) or WALK 4NF! [REGISTER FOR 5KRUN](#)

Chippewa Falls, WI – This is the Inaugural Great Steps 4NF in west central Wisconsin. The Reith family has been working extremely hard at putting together a great walk for this area. [Alex and Cora](#) of WAXX 104.5 will be your hosts.

Naperville, IL – ([2013 PHOTOS](#)) This is the 13th year for the original Great Steps 4 NF walk, the **longest running and the biggest NF walk in the country**. Join us at the beautiful Naperville Riverwalk for food, fun, music, raffles and special treats along the walkway with our famous “goodie walk”.

Effingham, IL – ([2013 PHOTOS](#)) Join the Didier family in year number 7 at Effingham Community Park. Enjoy the camaraderie of other NF families, the huge raffle and a yummy bake sale. Oh the bake sale!

Fort Wayne, IN – ([2013 PHOTOS](#)) The Taylor family is planning another awesome walk this year. Even though this walk is in September, it's not too early to register and start fundraising. The earlier you start, the more people you connect with which means more awareness.

Contact Jenny at 630-945-3562 or jenny@nfmidwest.org with any questions.



**REGISTER
NOW**

at

www.GreatSteps.org

Madison, WI

In the Capital Brewery Bier Garten

May 10

[Register Now](#)

Chippewa Falls, WI

W/Alex & Cora of WAXX 104.5

May 17

[Register Now](#)

Naperville, IL

Famous “Goodie” Walk

June 21

[Register Now](#)

Effingham, IL

Includes Awesome Bake Sale

June 21

[Register Now](#)

Fort Wayne, IN

Amazing Raffle!

Sept. 13

[Register Now](#)



Neurofibromatosis Midwest

473 Dunham Road, Suite 3
St. Charles, IL 60174

Non-Profit Org
U.S. Postage
PAID



630-945-3562

Fax: 630-689-1213

www.nfmidwest.org

E-Mail: info@nfmidwest.org

Save paper and our expense. If you would no longer like to receive mailings such as these, please call us or send us an email.

2 New NF Clinics Added in the Midwest

NF Midwest is excited to announce the addition of two new clinics in our six state region. Both of these clinics opened their doors in January.



**UNIVERSITY OF
LOUISVILLE**

One is through the University of Louisville [Weisskopf Child Evaluation Center's](#) Genetics Unit where they will see children and adults with NF. Dr. [Alexander Asamoah](#) received a WHAS Crusade for Children grant in order to create this specialty clinic. Currently the clinic will be held once a month. The clinic will allow for genetic evaluation and management in addition to an ophthalmology evaluation on the same day for new patients (children and adults) who may have the diagnosis of NF-1, as well as for patients already diagnosed. Kelly Jackson, MS CGC, a genetic counselor, will be coordinating the clinic. She can be reached at 502-852-5681.



**LOYOLA
MEDICINE**

*Loyola University Chicago
Stritch School of Medicine*

The other opened in the [Loyola University Health System](#) in the Chicago area with locations for appointments in Burr Ridge and Maywood where they will see both children and adults. The clinic director, Dr. Nikolas Mata-Machado, has a deep interest in patients with neurofibromatosis and served a neurological fellowship under Dr. James Tonsgard at the University of Chicago where he learned a great deal about NF and NF patients in Dr. Tonsgard's large NF clinic. In fact, Dr. Mata-

Machado is on the cover of our third edition of [Understanding Neurofibromatosis](#). Dr. Mata-Machado speaks fluent Portuguese and Spanish. To make an appointment call 888.LUHS.888 or visit [loyolamedicine.org](#).

We look forward to working with and supporting these clinics. You can help support them by fundraising and also by using the clinics and giving us your feedback.

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 and the eastern half of Missouri.