

NF Midwest Collaborates on New Young Adult Leadership Program

...because the neurofibromatosis cause needs **New Fighters** and young **iNFluencers**!

For the last year NF Midwest has been working on a vital collaboration with the Texas Neurofibromatosis Foundation (Texas NF) and the Littlest Tumor Foundation (LTF) to pilot a [Young Adult Leadership Program](#). This program's mission is to empower the next generation of NF leaders by engaging their unique strengths and teaching successful leadership skills, so that they can advocate for research, raise awareness, educate the public, and support and represent the NF community.

NF Midwest helped to coordinate and co-fund this program and sent four people from the NF Midwest community to participate. Emily Newell from Wisconsin; Sabrina Jones and Rachel Campana from Illinois; and Erik Geiman from Kentucky participated in four days of training and lobbying in Washington DC in January. This was an incredible experience for us all! Please read more details on our website at www.nfmidwest.org/blog/young-adult-leadership-program.



Young Adult Leaders and Mentors meet with Senator Tammy Baldwin in her Washington, DC office.



A Young Leader shares her story and gets a high five from Congresswoman Gwen Moore (WI).



Young Leaders Emily Newell, Sabrina Jones, Rachel Campana, Erik Geiman.

Grant to University of Chicago for Clinical Trials

In November, NF Midwest awarded a grant of \$60,000 to the University of Chicago to support their work in NF1, NF2, and schwannomatosis clinical trials. The University of Chicago has proven to be one of the premier sites for NF clinical trials. When all 22 of the NF consortium sites were evaluated last year, the University of Chicago was ranked #2 for enrollment, compliance, and scientific contribution. They also enrolled more patients than any other US center on two recent clinical trials. Yet, they were underfunded and required urgent funds to provide for the necessary staff.

Currently, the University has plans for four different trials. These will be on [Selumetinib](#), [Springworks PD0325901](#), [Cabozantinib](#) and [Binimetinib](#).

We couldn't have done it without our donors!



Another Program to Make Sure No One Fights Alone New NF Midwest Care Impact Grant

In the interest of improving care, NF Midwest has created a new grant program called a Care Impact Grant. NF Midwest Care Impact Grants provide up to \$10,000 to individuals or organizations for a program or project that directly impacts and improves the care of adults and children with neurofibromatosis and/or schwannomatosis in NF Midwest's region of Illinois, Indiana, Iowa, Kentucky, Wisconsin, or the east half of Missouri.

The Care Impact Grant program reflects NF Midwest's commitment to make sure that No One Fights Alone. We need to work together to achieve this and we know that physicians, clinics, social workers, and other members of our community have ideas about new and important ways to serve the NF communities. A Care Impact Grant can help make that happen.

The NF Midwest Care Impact Grant program seeks to fund projects that will make a tangible difference in the lives of people with NF. Grant applications must meet program requirements and will be selected through a review process. This program is supported by the proceeds of Great Steps 4NF Walks and generous individual donors.

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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.

2018 Scholarship Recipients

In 2018, NF Midwest awarded six academic scholarships to adults with neurofibromatosis or schwannomatosis. The program provides \$1,000 scholarships to students from our service area who are diagnosed with NF and are pursuing a post high school education. Applications are scored based on participation in NF Midwest and a demonstrated drive to succeed despite the challenges associated with living with NF. Aspects such as academic record, community service, and teacher/employer recommendations are also considered.



This was the 4th year of our scholarship program which was launched with funds from a charitable trust left to NF Midwest by Frances and Irma Napolilli but relies on the generosity of donors to continue. Please, consider a donation or a fundraiser so that we can continue to support our adults in their quest to improve!

Our 2018 scholarship recipients were:

Eric Filipiak; Natalie Hazbun; Delaney Kissel; Lindsey Wegner; Alicia Villalobos Tovar; Karli Olszowka.

NF Docs at the University of Illinois (Chicago)

Dr. Mata-Machado and Dr. Maraka

The University of Illinois in Chicago now has two doctors regularly treating patients with NF. Dr. Nikolas Mata-Machado is treating children. Call 312-996-7416 for an appointment. Dr. Stefania Maraka is seeing adults. Call 312-355-0510 for an appointment. The clinic has told us that they are accepting all forms of Illinois Medicaid and can often see people from other states with Medicaid. While this clinic is in the city of Chicago, it has easy access right off of I-290.



Bring your tent, your RV, or grab a hotel room and join us for a day of fun and music!

**SamJam4NF, Unplugged in the Prairie
September 21st in Carlinville, IL**

Enjoy Progressive Bluegrass, Americana and Roots music, plus food trucks, beer, and bags!
Find out more and order tickets at www.samjam4nf.com.

**Call NF Midwest for
complimentary tickets for NF families.**

This event is presented by the Oswald Family and Friends for the benefit of NF.

**Please, Help Support the
Cost of this Newsletter and
the NF Midwest Mission!
Make a Donation...**

at www.nfmidwest.org/donation
or mail a check to NF Midwest,
473 Dunham Rd, Suite 3, St.
Charles, IL 60174!

Any amount makes a difference!



NF Midwest Awarded Grant for Care...3 years in a row!

NF Midwest has once again been awarded \$20,000 from the [Driven to Care](#) program which is funded by the [Diane and Bruce Halle Foundation](#), the philanthropic arm of [Discount Tire](#). This funding helps to support our Care and Outreach Program and to help ensure that **No One Fights Alone!** Thank you to Jonathan and Erin, parents of a child with NF, for recommending us for this program. Also, thank you to Chandra and all the wonderful members of the regional Driven to Care team. These are amazing, caring people, and Discount Tire is a company that truly gives back!



No One Fights Alone When We **All Party Together!**

Join NF Midwest at a Great Steps Walk 4NF and you are guaranteed a good time!
Sign-up now at www.greatsteps.org to raise funds, awareness, and to improve the lives of everyone with neurofibromatosis and schwannomatosis!



Be a Hero! Find a Sponsor!

The NF Community needs corporate and small business support. Please think of who you know in the business community that might like to sponsor a walk or provide a material donation for raffle or giveaway! Email us at info@nfmidwest.org.

Register for any walk at www.greatsteps.org

Missouri/Columbia NF Walk

Saturday, May 4th @Peace Park, Mizzou Campus

A pair of dedicated volunteers, Christina Thomas and Kristi Saylor, are working to hold the first Great Steps Walk4NF in Columbia. If you have ANY ability to attend, they'd appreciate your support in their efforts.

Wisconsin/Madison NF Walk

Saturday, May 18th @Capital Brewery

It's always a fun morning in the beer garden at [Capital Brewery](http://www.capitalbrewery.com). Look for an amazing raffle and silent auction this year....and quite possibly some dancing. If you'd like to help or get involved in some way with NF in Madison, email Tim at Madison@nfmidwest.org.

Illinois/Naperville NF Walk

Saturday, June 1st @The Riverwalk

Join us for the largest walk for NF in the country! We usually have approximately 70 families with NF and close to 1,000 people. It's really more of a party in the park, with a little walk in the middle where you actually get to collect "goodies" as you walk! There's music, food, ice cream, costumed characters, bounce houses, dancing, great raffle prizes, and more!

Indiana/Fort Wayne NF Walk

Saturday, September 21st

Come out to [Parkview Field](http://www.parkviewfield.com), home of the [MiLB TinCaps](http://www.milbtincaps.com) baseball team, for the 8th annual Great Steps Walk 4NF in Fort Wayne. This is a fun walk inside the stadium. You'll enjoy food, music, raffles, and more! The Fort Wayne committee is energized and ready to go. If you'd like to join them in organizing this event or others, please send an email to fortwayne@nfmidwest.org.

Individual Fundraiser Recognition Gifts

Recognition prizes will be given to INDIVIDUAL fundraisers based on what they raise through their online fundraising page. The gifts are not "cumulative", meaning fundraisers only receive the one gift that is in their fundraising category. This puts the FUN in FUNdraising.

\$500 NF Midwest Pocket Flashlight

\$1,000 NF Midwest Baseball Hat

\$2,500 NF Midwest Flashlight + Hat + 10 Raffle Tickets

Team Recognition Gifts

If a TEAM raises over \$5,000 the team captain will receive a "Top Fundraising" flag and patch and their choice of an NF Midwest jacket, 4 free tickets to our Fall Top Golf Event, or 4 free tickets to our symposium and Friday night get together.

If a TEAM raises over \$10,000 the team captain will receive a "Top Fundraising" flag and patch and their choice of TWO of the following — an NF Midwest jacket, 4 free tickets to our Fall Top Golf Event, or 4 free tickets to our symposium and Friday night get together.



The TOP FUNDRAISING team of all the walks will choose the color combination for next years t-shirts!

In 2018 Caitlin's Promise was our top fundraiser and chose dark gray shirts with bright yellow print. Who will choose 2020's colors and what will they be?



**BE SURE TO RAISE FUNDS TO HELP YOUR LOVED ONE OR
TEAM WIN SPECIAL RECOGNITION PRIZES!**



New Board Chair

Denise Dulceak was elected in October to serve as the Chair of the NF Midwest board. This is a two-year term. Denise who has served on the NF Midwest board for 3½ years, has a son, age 10 with NF type 1. She has a Bachelors Degree in Biomedical Science and works at the

DuPage Eye Surgery Center. Denise has a great passion for the NF cause and the NF Midwest community. She especially believes in a community that works together so that **No one Fights alone.**



Care and Outreach— Andrea Miller

In January, Andrea Miller stepped into the position. Andrea has been involved with NF Midwest for nine years. Andrea and her husband currently live in NW Illinois with their 16-year-old son that has NF1. He was diagnosed as a baby, so

she has years of personal experience with NF1. One of the things that drew her to NF Midwest all of those years ago was our education and the generosity of support. Those are some things that she intends to continue to cultivate.

As Outreach and Care Coordinator Andrea's main priority is to keep in touch with individuals in our community; to be a resource for information and guidance whenever possible; and to ensure that **No one Fights alone.** She will also be working with leaders in our local groups, and as a liaison to our NF Clinics to help improve care.

Camp New Friends August 3-9



This year NF Midwest donors helped send 14 kids to Camp New Friends in Virginia.

Camp New Friends is an amazing, safe place to make friends, to develop self esteem, and for kids with NF to learn to care for themselves as well as others.

Chicago based NF Kids arrive back home in August 2018.

Applications for camp and for assistance are taken by Camp New Friends Brainy Camps and reimbursed by NF Midwest. Please contact us if you'd like more information or go to brainycamps.com.

We're One Step Closer to a Possible Drug for Plexiform Tumors

Great news! Selumetinib, one of the MEK inhibitors that has been reducing plexiform tumors in clinical trials, has received "[Breakthrough Therapy Designation](#)" (BTD) from the FDA. This does not mean the drug is approved, but it's another big step. Some consider it a "Pre-approval stamp".

According to the FDA drugs with BTD status benefit from....

- Fast Track designation features
- Intensive guidance on an efficient drug development program
- Organizational commitment involving senior managers



NF Midwest Super Hero Pen—Give one! Gift One!

Be a hero and keep hope in motion by joining our Monthly Giving Circle. For a limited time, sign up for at least \$10 a month and we will send you a NF Midwest Super Hero Mop Topper Pen AND send one to a loved one or a physician with a No One Fights Alone Card and a note saying it was from you. For each additional \$10 we will send another pen to another doctor or loved one.

Sign up for automatic monthly giving at nfmidwest.org/donation.



Memorials Received

In the past year NF Midwest has received memorials in memory of the people listed below. They are not necessarily people who have passed away from NF, but memorials requested in lieu of flowers.

Norma Bergen
Christopher Lambrecht
Eugene Rudoy
Shirley Beitman
Michael Taylor
Robert Ramsay
Joshua Ernst



Angela Carlson
Suzanne Klug
Michael Scholz
Dorothy Whitehurst
Bob Perkins
Paula Martin

Memorial

Donations

Leave a Legacy

We've been very fortunate to have a few generous benefactors remember NF Midwest in their end of life plans. This has allowed us to expand or develop new programs. If you've set up a plan to benefit NF Midwest, neurofibromatosis and schwannomatosis please let us know if you want us to recognize you in our Legacy Society. This may include listing NF Midwest as a recipient in whole or in part of your estate, your life insurance, or in a remainder trust.

We Take Stock and IRA/401C Transfers

Sometimes it may be financially beneficial for tax reasons, or just for convenience, to transfer a gift in the form of stock or from an IRA or 401C. NF Midwest is able to take gifts in this way. If you, or someone you know, would like to give in this way please call the office at 630-945-3562 or email info@nfmidwest.org.

2019 NF Midwest Symposium & iNfo Fair Set for November 9th!



The next [NF Symposium and iNfo Fair](#) will be held November 9th in Hoffman Estates, IL. We are still setting up speakers, but look for it to be full of learning and friendship.

Our hope is to have several topics about cutaneous neurofibromas, plus possibly something on learning disabilities or socialization. Let us know if there are topics you'd like to see.



Mark Your Calendars Now!

The NF Midwest Dream Team



If you have a great interest in supporting the mission of NF Midwest and have some time to dedicate to it, you could be a Dream Maker by joining our Dream Team. The Dream Team meets to discuss the needs of NF Midwest and to find solutions. This could mean helping with a project, serving on a committee, providing expertise, etc. You also may know someone in your sphere of influence that might be able to help.

For instance, in previous meetings we mentioned the need for help with Google Adwords and someone to design graphics, etc. Morgan Prato mentioned that the company she works for may want to help with Google Adwords at no charge and that she can create graphics and help in other ways. Morgan has become a Dream Maker on the Dream Team! There are jobs big and small and a niche for everyone who would like to help.

Dream Makers receive frequent emails regarding the needs of NF Midwest and are invited to meetings (often online) to discuss the programs of NF Midwest and the needs of the NF Midwest community. We don't expect Dream Makers to make every meeting, but to be engaged. This means replying to emails, being ambassadors for the mission, and talking about the work of NF Midwest. Only people who demonstrate the time and availability to participate on a regular basis, and who are able to respond in a timely manner, will remain on the Dream Team.

We've had meetings online and in person to introduce people to the concept of the Dream Team. If you're interested in learning more, we'd be happy to have a private meeting with you online or in person.

Be iNformed...

1. Make sure we have your **CURRENT** email and aren't blocked.
2. Join our private NF Midwest Facebook Group—This is limited to people in our region—Go to facebook.com/nfmidwest.
3. Join our NF Midwest NEWS Facebook Group—This is open to anyone. Go to www.facebook.com/groups/nfmidwestnews.
4. "Like" our NF Midwest Facebook page at facebook.com/nfmidwest.
5. Follow us on Twitter at twitter.com/nfmidwest.
6. Get our Twitter updates as text by texting "follow nfmidwest" to 40404. Send an "unfollow nfmidwest" to unsubscribe.
7. Check our website www.nfmidwest.org regularly.

Check out WWW.NFMIDWEST.NEWS
to read many old posts on NF news,
education and more!

More Advocates!

More Congressional Support!

Thanks to your letter writing and the volunteer advocates that descended on Capitol Hill in February (and to our Young Adult Leaders who were there in January) Congressional letters of support for NF funding received more signatures than ever before! The work of our NF Midwest community helped secure \$15 million in funding last year for 2019 and our January and February advocates started the work for funding in the 2020 budget.



NF Midwest volunteer advocates this year included (from L to R) Karissa Haberkamp, Denise Dulceak, Rachel Campana, Heather Reyes, Diana Haberkamp, Ryan Nelson, Matt Dulceak, and Susan Buono.



Over 80 NF Advocates, and one guide dog, took on Capitol Hill in 2019 Advocates.



We must all work together, to make sure **No One Fights Alone!**

Please, think of the ways that you can be a part of this support system whether it is a donation, a fundraiser or as a volunteer. Contact us and we'd love to bring you into the fight and help you #Dolt4NF!

Do It Yourway



Just #Dolt4NF

#Dolt4NF

Raise Funds and Awareness for the Cause!

We are very dependent on the grass root, passionate fundraising of our NF Midwest community and friends.

Please consider holding a #Dolt4NF event and/or creating a fundraising

page for NF Midwest in 2019! Funds are used to improve the lives of people in the Midwest through **C**linics, **A**wareness, **R**esearch, **E**ducation, and **S**upport or (**C.A.R.E.S.**).

Get your network of friends and family to join you and be sure to do something fun! Also, take photos and send them to us.

We look forward to sharing your events in our next newsletter and can't wait to see the clever and fun ways you come up with to #Dolt4NF!

Find tips and ideas for events and how to create your own fundraising page on our website, pick up the phone (630.945.3562), or shoot us an email at info@nfmidwest.org. We'd be thrilled to talk to you about your ideas!

NF2 Action Committee (NF2ACT!)

For approximately 10 years NF Midwest has had a special NF2 Committee that works on NF2 programming for NF Midwest. This especially includes the topics at our annual symposium and for NF2 related grants. Susan Buono, Laura Didier, and Steve Reason have served on this committee consistently through the years. We invite anyone who is interested to join this committee as we look to expand NF2 education. If you are interested, please call 630-945-3562 and ask for Diana or email info@nfmidwest.org.



We'd Love to See Someone in the NF Community Win a Car!

Steve and Diane Reason have once again enrolled NF Midwest in the John Deere Classic Birdies for Charity. This is basically a raffle

to win a 2 year lease on a 2019 Lexus NX. All you have to do is pledge a donation and guess a number. NF Midwest will receive your entire donation PLUS 5 to 10% more! You may also win other prizes. You need to [submit your pledge](#) and guess by July 6th.

Email Steve at steveNF2@frontiernet.net to submit your pledge or look for a pledge form online at www.nfmidwest.org. You may also make your donation and guess online on at the Birdies for Charity site at www.birdiesforcharity.com/ and search for Neurofibromatosis Midwest or #1815.

Local Meetings/Groups



Below is information on groups that meet regularly for support and/or socializing. If you want to be notified of future events from the groups below, or other groups, please email andrea@nfmidwest.org. You may ALSO email the group leader when possible, but be sure to let Andrea know of your interest. Also, join NF Midwest's private [Facebook group](#) for more

timely updates.

Note: There are other groups that are occasionally meeting that aren't listed here, plus new groups popping up all the time. If you'd like to put a group or social event together, please email andrea@nfmidwest.org.

Kentucky Support Group

Please join the Kentucky NF Support Group for an afternoon of fun, food, and friendship at the Thomas family farm on Saturday, July 13, 2019 from 12-4pm.

The Thomas family will provide hamburgers, hot dogs, condiments, tea, and lemonade. Everyone is asked to bring a chair and a dish for everyone to share.

The pool will be open!! Be sure to bring your swimsuits and towels! In addition, there will be yard games for kids and adults, horse back riding (with assistance), and four wheeler and dune buggy rides! Don't forget the best of all...meeting New Friends!

Please RSVP to Camillia at camnkyler@gmail.com or call (270)735-6033. This will help with the food count.

For more info about the Kentucky NF Support Group, please email kentucky@nfmidwest.org.

Central Missouri Support Meetings

The Central Missouri group usually holds a meeting on the 3rd Wednesday of every month at the Columbia Public Library from 6:30 to 8:00 pm. For more info, contact us or email CentralMissouri@nfmidwest.org.

Fort Wayne Family Night

The NF Midwest Fort Wayne group is holding a family night at the Tin Caps baseball game against the South Bend Cubs on Friday, May 17, 2019. Come out meet others, raise awareness, and have some fun. There are two ticket prices. For \$15 you receive a game ticket, plus game favors, and raffle tickets. The game starts at 7:00 pm. It will be a fun night with postgame fireworks and a Super Hero Theme! Email fortwayne@nfmidwest.org to sign-up or for more information.



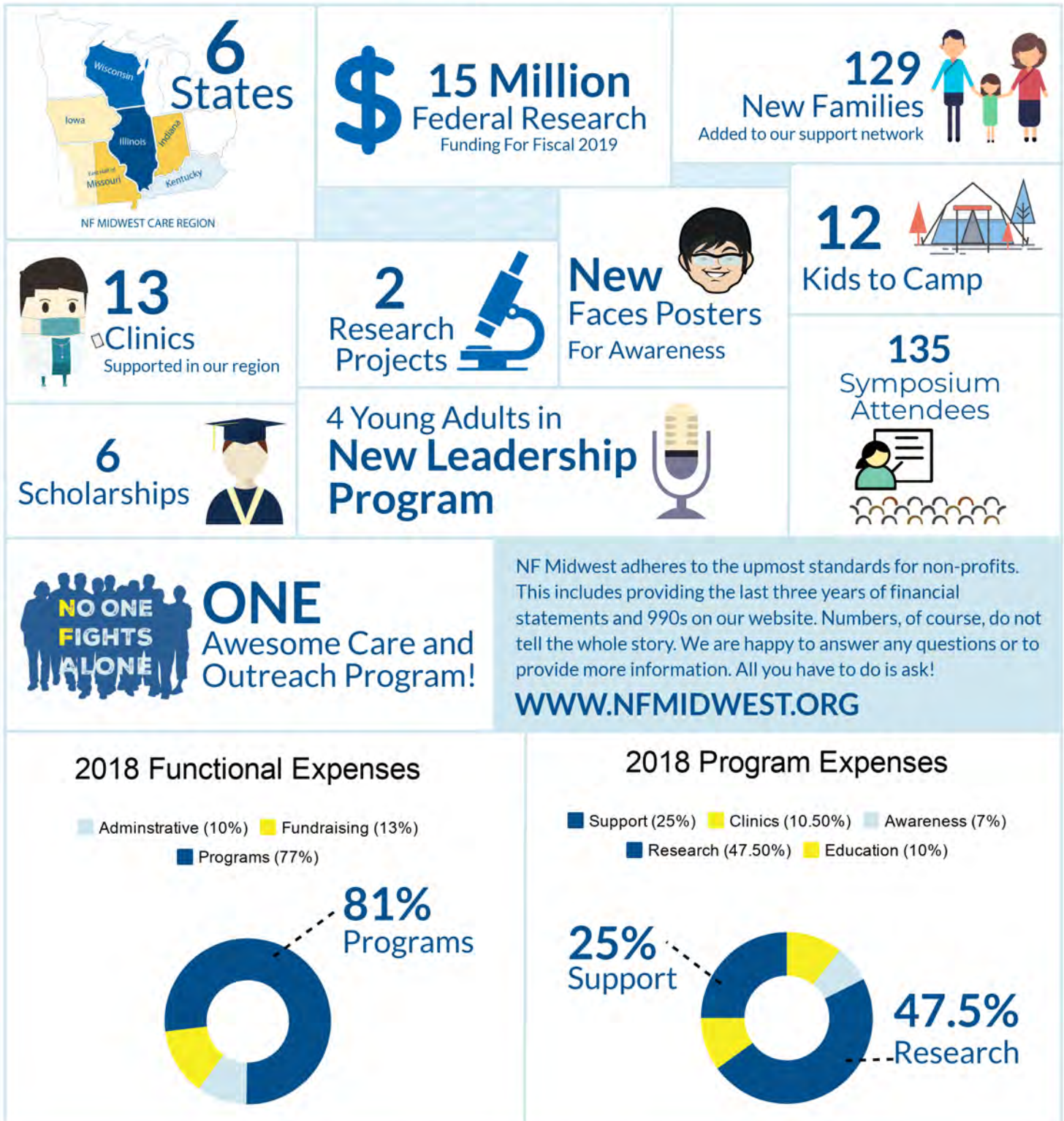
May 17th



C.A.R.E.S.

Celebrating 37 Years!

Of Improving the lives of children and adults with neurofibromatosis and schwannomatosis. NF Midwest C.A.R.E.S. by focusing on Clinics, Awareness, Research, Education, and Support.





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

Non-Profit Org
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630-945-3562

www.nfmidwest.org
info@nfmidwest.org

Please make a donation now in honor of your loved one or friend with neurofibromatosis or schwannomatosis. Donations will be credited to the family or team!

Thank You To...

Our Donors

Who make the mission possible!

Our Volunteers

Who move the mission!

The Oswald Family and SamJam4NF

To Pete, Sam, Pete 2, and their friends and family for creating and continuing SamJam4NF! What an amazing event!

Susan Buono

For serving MANY years on our NF2 Action Committee and for many years of lobbying in DC.

Darlene Woldt

For years of helping with the Madison Walk.

Lesli Wegner For the many years of putting together the food for the GS Walk4NF in Naperville and serving on the board.

Mary Chapman

For your years of helping with the GS Walk4NF in Madison. We love the creative ways you put together the raffle!

Tim Eberle The energizer bunny...you're rocking the Madison Walk 4NF and going gangbusters on raffle prizes, etc.

Steve Reason For ONCE AGAIN arranging the Birdies for Charity fundraiser!

Julie Rutter For helping with the vision for the Dream Team and years of fundraising!

Denise Dulceak

For serving on the board, the Dream Team lobbying, and all the other MANY things you do!

Linda Bell For the photos and ideas for our project.

Mike Forbes For all your years of doing what you can and for speaking up for the NF adult community.

Heather Reyes For chairing our scholarship committee and for joining us to lobby in Washington, DC.

Brad Duthie

For dropping off office supplies and just offering to help!

Joan Scott

A tireless volunteer who helps at the office whenever we need her!

Levi, Ali, Sam, Jay, Jenny, Stacy, Matt, Tori, Ify, and Janna

For providing great stories and photographs for our Faces of NF Awareness project!

Christina Thomas and Kristi Saylor

For starting a new walk in Columbia, MO.

Jeanette Dentro

For helping at the symposium and other events and for being an inspiration!

Morgan Prato For your awesome help with graphics; our website; and Google ads!

The Board To the NF Midwest Board — Gail, Gordon, Charles, Pete, Denise, and Lesli.

To Those We Forgot We are blessed with so many who help. We appreciate you all!

NF Midwest's Mission

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.