

## We're Hanging in There, but We Need Your Support



There's no denying that it's been a TOUGH year and a half for everyone, including NF Midwest...and especially the NF community. We thank everyone who has helped and supported us through this crisis. We've learned a lot and found a few "COVID Linings" in the mayhem and sadness. For instance, we've brought back sweatpants, and we've learned that we can have our groceries brought to our car or our home, so we don't have to endure long lines shopping and the temptation of goodies at the checkout.

More importantly, we've had some lessons and experiences from this pandemic that I believe have improved our programming and brought together our community. We've touched and communicated with more people and in more impactful ways simply because we have all learned how to Zoom! We've brought people and experts together in NF Power Hours, Parents Groups, and Open Chats. We've had volunteers with expertise help us from California to Canada! We've found new and creative ways to raise funds and awareness. Most importantly, we found that we are there for each other even when we can't physically be together.

Another plus is that we resurrected the "Hang in There" cat to remind us all that we could be a poor little kitty dangling all alone from a tree. If they can hang in there, we can too because *No One Fights Alone* in our NF community. COVID's not over yet, and we're not done either!

We do, however, need financial support. Smaller nonprofits like NF Midwest are struggling. A recent report predicted that 38% of nonprofits could close in the next several years. Please, consider all the various ways you may be able to help.

*Diana Haberkamp, Executive Director*

## Recent NF Midwest Grants to Support Care and Research

### NF Midwest Collaborates to Fund NF2 Gene Therapy Research at Indiana University



NF Midwest, [NF2 BioSolutions](#), NF Northeast, and NF Michigan have combined forces to fund a USD 100,000 Gene therapy project at Dr. Wade Clapp's Lab at Indiana University.

This funding expands on research that was also funded by NF Midwest at the University of Massachusetts and Nationwide Children's Hospital.

### Care Impact Grants

NF Midwest Care Impact Program recently provided funds to three NF providers to improve care or access to care.

**Lurie Children's Hospital's** NF clinic received funds to assist patients with counseling, travel assistance, parking, meals, and lodging.

**Dr. Stefania Maraka**, who is seeing adult patients with NF at the **University of Illinois in Chicago**, received funds to support patients who need and can't afford childcare in order to get to appointments.

Funds were also granted to **Dr. Mata-Machado**, who sees children with NF at the **University of Illinois in Chicago** to assist with travel and similar needs.

**Financial assistance through these funds must be requested through the clinics and will be evaluated and awarded by them.**

## WE HAVE BEEN EMAILING QUITE REGULARLY. IF YOU HAVEN'T RECEIVED ANYTHING FROM US THERE'S PROBABLY A REASON!!

Even if you think we have your email, it's possible that our emails are being blocked or that you OPTED OUT. So if you have not been receiving emails from us, don't hesitate to contact us at [info@nfmidwest.org](mailto:info@nfmidwest.org) or call 630-945-3562. Also, we communicate almost weekly with our "affected" families and individuals about events and news. If you haven't been receiving those emails and would like to, please get in touch with us to put you on the "list."



## THEY WALKED THEIR WAY!



Last summer (2020), NF Midwest couldn't hold any walks, so we held a Walk that Wasn't in which teams and individuals were encouraged to fundraise and raise awareness in their own ways and then join us at a **Celebrathon** in October. This summer, we could step out a little bit more but still couldn't come together in larger walks. So we invited our community to **Walk4NF Your Way**.



*The Albrecht family (Strollin' for Roland) stopped by in Madison and mom picked up her NF Midwest jacket for raising over \$2500!*

May 1st, we were able to have a real-life, in-person walk in Columbia, MO (YEA!) in a beautiful park on a beautiful day. It was fantastic to be together with people and fun to have a raffle!

On May 15th, we invited the people of Madison, WI, and really anywhere to come to a hotel, pick up their t-shirts on Friday afternoon or Saturday morning, and then "walk their way." Some people walked near the hotel while others held walks and barbecues with friends and family elsewhere.

On June 5th, we invited people in the Chicago area (or anywhere!) to pick up shirts at the NF Midwest office and do their own thing. Again many teams and individuals participated, and again, we were online with people checking in. At noon for both the Madison and Naperville walks, we had a raffle.

These hybrid virtual walks were all done to bring some normalcy back to the community and raise much-needed funds.

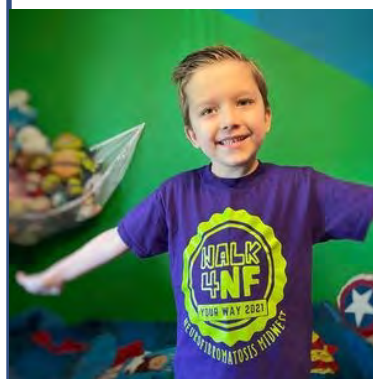
### Individual Fundraiser Recognition Gifts

Recognition prizes are given to INDIVIDUAL fundraisers based on what they raise through their online fundraising page. This puts the FUN in FUNdraising and helps with awareness.

- \$100 Walk T-Shirt
- \$500 NFM Baseball Hat
- \$1,000 NFM Baseball Hat + Contigo Stainless Steel Bottle
- \$2,500 Awesome NFM Jacket + Hat + Bottle



### Top Fundraising Team Chooses the Colors!



*Maverick shows off the tshirt colors he chose for 2021.*

For the last few years, the top fundraising team of all walks chooses the t-shirt colors for the following year. In 2020 we didn't have a walk; instead, we held a virtual *Walk that Wasn't* event, and MavMan's Sidekicks earned the honor of choosing the colors for 2021 by raising over \$11,000! Maverick famously joined us virtually with his mom in purple against a bright green wall to tell us the t-shirt would be purple and the ink green! The

Celebrathon was a lot of fun, and we'll be doing it again on October 17<sup>th</sup>. In the meantime, we wait to see what team will raise the most!!

### Fundraising Team vs. Individual

Raising over \$7,185, Laura Haslam (Jay Walkers) was our top INDIVIDUAL fundraiser our *Walk That Wasn't* event in 2020. In the past, the top individual and the top team have been the same, with the captain of a team raising the most and making their team the top team. In 2020, this didn't happen because MavMan's Sidekicks had several team members raising funds individually, which made the fundraising efforts fun to watch!

### How They Raised Funds

Our top fundraisers last year included teams and individuals of people passionate for the NF cause. How they raised funds varied, but the most successful either created fun events such as online drawings for donations and/or found large sponsorships or business donations. For instance, Annie Hartigan received a donation from a Toyota dealer and a match donation from the Toyota corporation. In addition, our top fundraisers often ask and in every way they can—via email, social media, snail-mail, and maybe even in line at the DMV—though we don't think any are that crazy!

**Mark your calendars for Sunday, October 17th when we will hold our 2nd annual online CELABRATHON!**





Join us online at 5 PM CST on Sunday, October 17th, for another Celebrathon celebrating the NF Midwest community. The event will last approximately an hour and will highlight the events and programs of NF Midwest, but most importantly, our fundraisers and our volunteers.

The walk team that raised the most funds this year will announce their color choice for next year's walks!

We will be holding a raffle in which individuals or teams may submit raffle prizes and receive credit for any entries for their prize to go towards their fundraising for next year. Also, the group or individual whose prize gets the most funds will get a prize and pride.

Contact us to participate and submit your prize!

Abby and the Amazing Absters have already submitted a Nintendo Switch as their entry!

For more info, please keep checking our website, our Facebook group, and in your email for messages from us. If you are not receiving regular notifications from us and want to, please let us know. Our email is [info@nfmidwest.org](mailto:info@nfmidwest.org).

**Starting sometime in mid-September we will be posting prizes in which people can buy entries to win. Go to [nfmidwest.rallyup.com/celebrathon](http://nfmidwest.rallyup.com/celebrathon) to learn more or participate.**



In lieu of walking in 2021, the *Walk That Wasn't Celebrathon* was held in October 17th online! We had a great time. It was a learning experience for us all and great way to come together. In the weeks ahead of the event we had submissions from people to help put together some videos about NF and a couple of musicians that submitted work. If you'd like to watch the virtual event you can do so at [www.nfmidwest.org/youtubechannel](http://www.nfmidwest.org/youtubechannel).

## Top 2020 Walk that Wasn't Fundraisers

### Top Teams

MavMan's Sidekicks	11,231
The Jay-Walkers	7,295
Hartigan's Heroes	6,100
Audrey's Army	4,05
Ellie's Crew	3,755
Pete's Dragons	3,600
Team Eberle	2,821
Willow Strong	2,526
Strollin' for Roland	2,238
Christopher's Crusaders	2,195

### Top Individuals

Jay Haslam	7,185
Annie Hartigan	5,875
Dayna Cano Qazi	5,525
Jennifer Licato	4,860
Maverick Cano	4,310
Gail Mavrogenes	3,600
Jessica Rheault	3,155
Tim Eberle	2,821
Marie Faust	2,501



### Top Teams

Jay Walkers	13,105
Ellie's Crew	5,023
Trace's Tacklers	4,010
MavMan's Sidekicks	3,280
Christopher's Crusaders	3,250

### Top Individuals

Jay Haslam	10,195
Jessica Rheault	4,318
Linda Czerkies	3,265
Judy Hall	3,000
Dawn Pederson	2,874

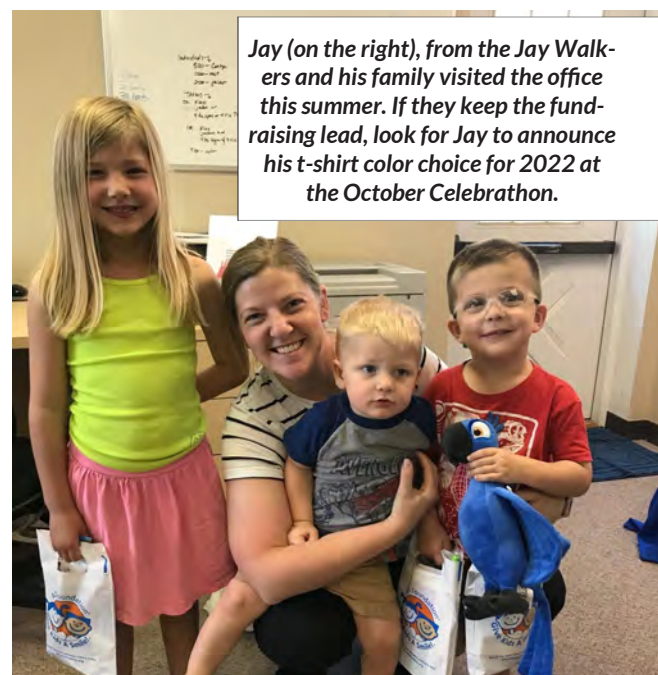
## IT'S NOT TOO LATE TO PARTICIPATE

WALK YOUR WAY

Any Day, Any Way

SIGN-UP TO FUNDRAISE, GET A T-SHIRT, AND PRIZES. ENDS SEPTEMBER 25TH

It's not too late to help raise funds and awareness in 2021 to get a walk t-shirt and to earn recognition gifts. Simply register for our **Any Day, Any Way and Walk4NF Your Way** by September 25th. To receive a t-shirt, you must pay \$25 or raise \$100. You can register as an individual or join or create a team. However, you or at least one person on your team must make and share a fundraising page. T-shirts will be sent to your captain after September 25th or to you if you are fundraising as an individual. Please email [Maggie@nfmidwest.org](mailto:Maggie@nfmidwest.org) for more information or go to [www.nfmidwest.org/walk4nf](http://www.nfmidwest.org/walk4nf).





## Story of SamJam By Peter Oswald

I'm sometimes asked, "How did SamJam come to be?"

It began with Sam. My son, Sam, has dealt with NF since his diagnosis at age 4. Now 36 years old, Sam has weathered scoliosis and a spinal fusion, two brain tumors, knee surgery, eye surgery, chronic pain, and a MPNST. Diagnosed seven years ago, the nerve sheath tumor (MPNST) required two surgeries to remove and included removing the sciatic nerve. He also had radiation and chemo. Sam endured the treatment and was declared cancer-free.

To celebrate his successful treatment, Sam's older brother, Peter, and I planned a music festival to recognize Sam's recovery, raise funds for the NF cause, and make people more aware of NF. Our first-year event featured six bands (all progressive bluegrass, Americana, and roots music), a beer tent, and food vendors. At the close of the event, we had raised enough money to make a \$22,000 donation to NF Midwest! Not only did Sam have a great time at the event, but everyone wanted to know if it was an annual event.



Since that time, we have held SamJam Music and Brewfest each year (except 2020 with COVID-19) to raise money and promote greater public awareness of NF. We organized as a non-profit organization in 2015 so people could make tax-deductible donations, and the support of local sponsors and donors has been great each year.

This year's [SamJam4NF](http://www.samjam4nf.com) will be held on August 28, from noon to 11:00 p.m., at the Macoupin County Fairgrounds in Carlinville, IL. As a new twist for this year, we are planning an "end-of-summer-bash" with five tribute bands, along with the beer tent, food trucks, and camping. Held outdoors with professional staging, sound, and lighting, attendees will enjoy music tributes to Neil Young, John Prine, Jimmy Buffet, Rolling Stones, and Grateful Dead.

Is it worth the work? Absolutely! The chance to entertain people who love music and Sam is a great opportunity. In addition to the monetary donations, helping people become more aware of NF and the challenges for NF patients makes it all worthwhile. For all the details, check out [www.samjam4nf.com](http://www.samjam4nf.com).

## Join Diana at the 2021 SamJam4NF Music and Brewfest End of Summer Bash on August 28th



Diana and her husband are motoring to SamJam in an RV! Come out and join them for a fun, relaxing day with live music, excellent food trucks, and a beer tent. Bring your lawn chairs and blankets to enjoy an end-of-summer celebration on the lawn at the Macoupin County Fairgrounds in Carlinville. Adults - \$20, Students - \$10, under 16, free! Free tent camping and trailer hookups are available at a reasonable fee. Join in the fun! Learn more at [www.samjam4nf.com](http://www.samjam4nf.com). Email [info@nfmidwest.org](mailto:info@nfmidwest.org) about free tickets for people with NF or schwannomatosis.



## DIY/Personal Fundraising

Raise awareness and funds by creating your own Personal Do-It-Yourself (DIY) event. Holding a personal event is a great way to give more than your personal donation and raise funds to support Clinics, Awareness, Research, Education, and Support. A DIY event can be a big event, such as SamJam or something simple like a party or game night at your home. Your imagination only limits the ideas! If you find your imagination lacking some luster talk to some friends or ask us ([email Maggie@nfmidwest.org](mailto:email Maggie@nfmidwest.org)).

Funds raised may be put towards your walk goal, and even if you don't participate in a walk, you can earn recognition gifts etc.. Here are some examples of DIY fundraising.

- Facebook Fundraisers
- Drive-thru Dinner
- Painting party
- A Non-Event Event
- Raffle Drawings
- Backyard BBQ
- Game Party
- Disco is Back Party

## Grandma Selling Art to Support NF Midwest



Kalona Rheault has been selling her artwork and plants to support the mission of NF Midwest, with funds from her proceeds going towards Ellie's Crew in honor of her granddaughter who has NF1. Kalona's [Heart to Hand](http://www.facebook.com/Heart-to-hand-107522701389169) is a great DIY fundraiser as it creates awareness, works with someone's passion, and raises funds!

Check out her work at  
[www.facebook.com/Heart-to-hand-107522701389169](http://www.facebook.com/Heart-to-hand-107522701389169)

Thank you, Kalona!!



## More Online Educational and Support Opportunities

Not only have we learned how to run Zoom meetings and reach out online, but our community has also learned how as well. Let's call it one of the few "COVID LININGS" or how lemons have turned into lemonade.

We have Power Hours and Parent Group meetings, and we're looking to add more for adults! Also, we've collaborated with other orgs more on webinars and learning opportunities, and in November, we will have a virtual iNfo Fair! If you aren't receiving emails about these opportunities, please let us know!



## Improved Searching on our Website and More Articles and Resources

NF Midwest has added an improved search function to the [LEARN](#) section of our website. On the backend, we will be able to add more resources efficiently, and on the front end, a new search function will allow you to find

information more readily. We generally only include material and resources for the lay audience. In other words, we avoid science-heavy material and look for material that can more directly impact our community. If you have any suggestions of material or resources to add, please [let us know!](#)

Be sure to check it out at [nfmidwest.org/learn](http://nfmidwest.org/learn).

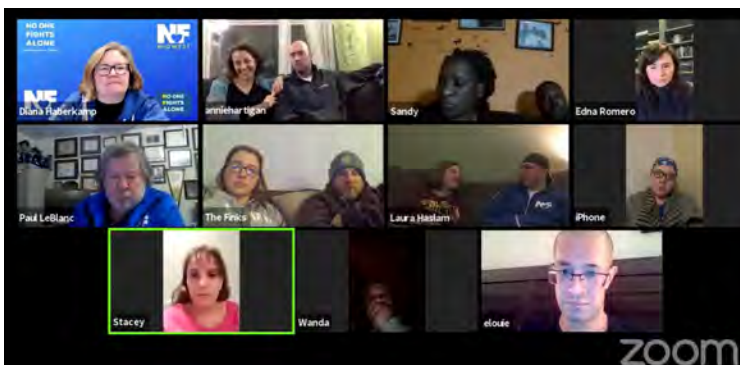
## NF Power Hours

The Covid-19 pandemic has had a tremendous impact on us all. Perhaps the most affected area, aside from medical implications, has been people's ability to meet and congregate. For a community such as NF Midwest, this is a potentially devastating realization. NF Midwest is an organization that thrives on connection and togetherness and ensuring that **No one Fights alone.**

To remain connected, NF Midwest began hosting virtual meetings called **NF Power Hours**. Each power hour focuses on a specific subject and leaves space for all to join in, even those mainly unaffected by the highlighted topic. Some of the subjects covered so far in our Power Hours have included cutaneous neurofibromas, schools and IEP's, socialization in NF, SSI/SSDI-Disability, ABLE accounts, special needs trusts, a specialist in early childhood intervention, adults with NF, Medicaid and Medicare, talking to your children about NF, and simple open chats.

Power hours have a conversational design where everyone is invited to participate but never pressured, making it the perfect place for those who may be uncomfortable or unfamiliar with virtual meetings.

Some power hours are presented live in our private NF Midwest Facebook group and may be viewed by NF Midwest community members.



**Parents of Children with NF**  
2nd Thursday of Each Month  
8pm CST

joins in the discussion. However, we also welcome new concerns or questions.

You must register once, and there is no need to register again. Please, register at [www.nfmidwest.org/parentsgroup](http://www.nfmidwest.org/parentsgroup).

## Parent Group

The NF Midwest community now has a group of parents meeting regularly online....USUALLY the third Thursday of every month at 8 pm CST. To keep the Parent Group fresh and interesting, there's usually a specific topic and sometimes an expert to

## NF Collective: Transitioning to Adult Care Document and Webinar



The NF Collective has published a "[Guide for NF Patients and Caregivers Transitioning to Adult Care](#)." In February, the Collective also held a webinar on the subject that featured young adults

from across the country. You can download the document or view the webinar at [nfcollective.org/resources](http://nfcollective.org/resources).

The NF Collective consists of several NF organizations working together to address various needs within the NF community. It currently includes NF Midwest, Littlest Tumor Foundation, Neurofibromatosis Northeast, NF Team, Texas Neurofibromatosis Foundation, Neurofibromatosis Network, and the Children's Tumor Foundation.

## November 13th iNfo Fair

We are aligning our stars, meaning our presenters, for an online all-day iNfo Fair on Saturday, November 13th. If this comes together, it will be in place of our annual fall symposium. Please, mark your calendars and be on the lookout for more information. Again, make sure you are receiving our emails.

## We Need Your Help! We Need Board and Committee Members!

If you're interested in furthering the mission of NF Midwest with your time and talent consider joining a committee, our Dream Team, or the [Board](#). Please contact Diana or a board member and we can discuss the many ways you can help!

## 2021 NF1 Diagnostic Criteria Update

*Genetics in Medicine*, the official journal of the American College of Medical Genetics and Genomics recently published an update of the diagnostic criteria for neurofibromatosis type 1. The new criteria are the result of years of work and collaboration of over 90 neurofibromatosis (NF) experts from around the world. The goal of the new criteria is to allow for earlier and more accurate diagnosis of NF1, leading to improved care. Publication of new criteria for neurofibromatosis type 2 and schwannomatosis is planned for late this year. We have highlighted the changes to the NF1 diagnostic criteria in the table below in bold..

### ORIGINAL DIAGNOSTIC CRITERIA (1988)

A diagnosis of NF1 can be given if an individual has two or more of the following manifestations:

- Six or more café-au-lait macules (brown skin spots)
  - greater than 5mm in pre-pubertal children
  - greater than 15mm in post-pubertal individuals
- Freckling in axilla (armpit) or groin
- Two or more neurofibroma tumors of any type, or one plexiform neurofibroma
- Two or more iris Lisch nodules (iris hamartomas)
- Optic glioma
- A distinctive bony lesion: dysplasia (abnormal growth) of the sphenoid bone behind the eye, or dysplasia of long bones, often in the lower leg
- Having a close relative (parent, sibling, or child) with NF1

### UPDATED DIAGNOSTIC CRITERIA (2021)

A diagnosis of NF1 can be given if an individual has two or more of the following manifestations:

- Six or more café-au-lait-macules\* (brown skin spots)
  - greater than 5mm in pre-pubertal children
  - greater than 15mm in post-pubertal individuals
- Freckling in axilla (armpit) or groin\*
- Two or more neurofibroma tumors of any type, or one plexiform neurofibroma
- Two or more Lisch nodules **or two or more choroidal abnormalities**
- Optic **pathway** glioma (tumor of the visual pathway)
- A distinctive osseous lesion such as: sphenoid dysplasia; **anterolateral bowing of tibia (tibial dysplasia); or pseudarthrosis of a long bone**
- **A pathogenic NF1 gene variant (no longer using term "mutation")**
- A parent with NF1 by the above criteria

**\*At least one of the two pigmentary findings (café-au-lait macules or freckling) should be bilateral.**

## 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. We thank the families who thought of NF Midwest in their time of grief.

*Amber Virgin*

*Dustin Wood*

*Brian Korf*

*Bruno Dalmaso*

*Karnal Phegley*

## Memorial Donations

## NF Midwest Lobbied for 20 Million in NF Research Funds

In February, NF Midwest, other NF organizations, and many volunteers lobbied virtually by meeting online with staffers from the US House and US Senate about funding for NF research.

Thanks to these efforts, the House of Representatives has approved twenty million dollars for NF research through the Department of Defense (DOD) Congressionally Directed Medical Research Program for fiscal year 2022! There are still more steps in the process, but this is the biggest. Keep an eye out for when and how to contact your Representatives and Senators in Congress to push for NF funding and support.

## Studies Looking for Participants

There are almost always studies and surveys looking for participants from the NF community. These can be vital to helping research.

Here are some [studies](#) currently looking for participants.

- Adults age 40+ are needed for a genetic research study. No travel is necessary. Learn more at [www.nfmidwest.org/blog/nf-study-of-genetic-mutations](http://www.nfmidwest.org/blog/nf-study-of-genetic-mutations).
- People with NF1 are being sought to participate in a trial to evaluate a chronic pain management mobile app. No travel is needed. Find out more at <https://www.nfmidwest.org/blog/participate-in-nf1-pain-study-app>.

To find more opportunities to participate in research, go to [www.nfmidwest.org/blog/category/research-posts](http://www.nfmidwest.org/blog/category/research-posts), or [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and sign up on the NF Patient Registry [www.nfregistry.org](http://www.nfregistry.org).

## Consider These Unique Ways to Donate

- Become an automatic monthly recurring donor
- Donate stock directly or from your IRA or 401C
- Add NF Midwest to your will or as a benefactor of your life insurance
- If you can make a larger donation, considering funding a match challenge



## 2021 Scholarship Recipients

NF Midwest has awarded three \$1,000 post-secondary academic scholarships and one new **Distinguished Service Scholarship** to four adults affected by neurofibromatosis or schwannomatosis.

Also, this year the NF Midwest Board established a special **Distinguished Service Scholarship Award**, which provides extra funds to applicants who have demonstrated an outstanding contribution to the NF cause and the mission of NF Midwest. The very first award of this kind has been given to Ali Didier. Ali's past volunteer work, dedication, and spirit in the face of challenges and adversaries is the inspiration behind this award which may be awarded to others in the future. In addition to Ali, three other very worthy applicants have been awarded regular scholarships. If you'd like to apply for a 2021-2022 scholarship, look for the application process in January 2021.

**Our 2021 scholarship recipients were:**

**Ali D. (Bolingbrook, IL)** will be a Sophomore at Rochester Institute of Technology. She is pursuing a degree in accounting.

**Braxton S. (North Manchester, IN)** will be a Sophomore at Manchester University. He is pursuing a degree in English.

**Madelyn M. (Verona, WI)** will be a Freshman at the University of Wisconsin - Whitewater. She has not yet decided on a major.

**Phillip E. (Kirkwood, MO)** will be a Freshman at Augustana University in Sioux Falls, SD. He is majoring in Science, Technology, Engineering, and Math (STEM).



## May Awareness Videos

In May, several individuals and families did interviews to share their stories during NF Awareness Month. Dayna Qazi graciously volunteered to create and post these videos and other NF month social media postings. Dayna worked as a great interviewer, and our participants did an incredible job.

If you'd like to watch these videos, they are on NF Midwest's Youtube channel at [www.nfmidwest.org/youtubechannel](http://www.nfmidwest.org/youtubechannel) (how easy and obvious is that URL?).



**Washington DC  
Jan 2 -6, 2022**

## 2022 Young Adult Leadership Program

The NF Young Adult Leadership Program ([NFYA](http://NFYA.org)), a collaboration between NF Midwest, Littlest Tumor Foundation, and Texas NF has scheduled its next leadership session for Washington, DC Jan 2 -6, 2022. This program offers young adults (18 or older) the opportunity to learn to advocate, develop leadership skills and personal strengths, and help the NF community find effective treatments for NF 1, NF 2, and Schwannomatosis. If you're interested in participating and/or would like to learn more, please contact Diana Haberkamp at [diana@nfmidwest.org](mailto:diana@nfmidwest.org) or call 630-945-3562.

## Thanks to Kara and Dayna

For hosting our March 17th **Irish for a Cure Lucky Day Drawing**. Also, another thanks to Kara for being the parent moderator of our Parents Group. These two put the Fun in fundraising.



## Board Of Directors

Denise Dulceak, Chair  
Peter Oswald, Vice Chair  
Dena Hasselberg, Secretary  
Gail Mavrogenes



## Professional Advisory Panel

Scott Hunter, PhD  
University of Chicago Hospitals

Bonita P. Klein-Tasman, Ph.D.  
University of Wisconsin

Robert Listernick, MD  
Lurie Children's Hospital of Chicago

Nikolas Mata-Machado, MD  
University of Illinois

Jason Marker, MD  
Beacon Health System/Family Practitioner

James Tonsgard, MD  
University of Chicago Hospitals

### 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.



## New Merchandise

Check out our "a-wear-ness" merchandise at our store at [www.nfmidwest.org/store](http://www.nfmidwest.org/store). We have some new items, including two new t-shirts. One is a new No One Fights Alone shirt and the other a new FN NF shirt. You'll also find hoodies, facemasks, bandana, and wristbands.



Neurofibromatosis Midwest  
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Non-Profit Org  
U.S. Postage  
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630-945-3562  
[www.nfmidwest.org](http://www.nfmidwest.org)  
[info@nfmidwest.org](mailto:info@nfmidwest.org)

If you have the means **PLEASE** make a donation **NOW** in honor of your loved one or friend with neurofibromatosis or schwannomatosis at **NFMIDWEST.ORG/DONATE**.



#### Our Donors

If not for you, we could not keep up the work during these difficult times.

#### Our Volunteers

For hanging there and stepping up to help whenever you can.

**To Those We Forgot** You matter and were thankful...we're also often forgetful, overwhelmed, and distracted...but we love you!

**Steve Reason** For arranging the Birdies for Charity fundraiser again in 2021 event through this crazy time!

**Kara Cano** For leading our new Parents Group!

**Dayna Qazi** For helping to put video together of TWTW and for 2021 May Awareness!

**Kara/Dayna Duo!** For the two of them together hosting out Irish for a Cure Lucky Day Raffle and for all your support and ideas.

**The Oswald Family and SamJam4NF** To Pete, Sam, Pete 2, and their friends and family for their ongoing work on SamJam4NF! We look forward to August 2021!

**Kyanne Baker** Who has no NF "connection" yet volunteered to help with HTML/CSS and did a great job!!

**Dawn Pederson** For giving input to our fundraising committee.

**Tim Eberle** Who has chaired the Madison walk for many years and is now stepping down...but not out!

**Julie Rutter** For walking us through another 2nd PPP loan and for finding sponsors!

**Mary Chapman** For your years of work on the Madison walk, providing input on our fundraising committee, and for showing up when we need you!

**Christina Thomas and Kristi Saylor** For your Columbia, MO support group and the walk (so excited that we're having an actual walk in May!

**Jonathan H.** Our Salesforce volunteer!

**Morgan Prato** For your continued help with graphics and marketing!

**Sharon Arens and Susan Caris** For your work and dedication on the Fort Wayne walk and family night...though neither came to be.

**Laura Haslam** For joining the CDMRP Peer Review panel and for doing some great writing for us!

**Cara Calloway** Our Canadian virtual volunteer for getting us through our first virtual event—the Walk that Wasn't.

**George Stafford** From SCORE for getting us started with some new strategic planning.

**Jessica Rheault** For proofreading whenever we need you...as you can tell (LOL). She doesn't proofread everything—so it's not her fault!

**Jason Helvey** For being the Emcee of our 2021 *Celebrathon* last October.

**The NF Midwest Board** Denise, Pete, Dena, and Gail.

### 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.