

Leading the Fight for Options in Treating Dermal Neurofibromas

NF Midwest gets new insurance procedure codes approved.

For two years NF Midwest has been working closely with Dr. Taylor, a father of an adult with NF, to clarify what many call *electrodesiccation* or what should more accurately be called the **electrosurgical removal of neurofibromas in high quantities under general anesthesia**. Our immediate goals were to better define what is meant by “electrodesiccation” and to improve insurance coverage by getting new insurance procedure codes that better delineate the difference between getting a few removed vs. many removed.

Our combined determination paid off and we are very excited to announce that the American Medical Association (AMA) approved two new temporary Current Procedural Terminology (CPT) Codes for the high quantity removal of neurofibromas through electrosurgery or “destruction”.

CPT codes are used to identify what medical service or procedure was performed. Not to be confused with ICD (International Classification of Diseases) codes which are used to identify the disease, complication or symptom that is (or are) being treated. Insurance companies need to know what procedure was used to determine payment. The CPT code provides this information.

The existing CPT codes do not differentiate well enough between the different techniques for removing neurofibromas or between removing several to removing hundreds. This can cause some confusion and issues with insurance coverage.

The new CPT codes are temporary and in effect until the end of 2022. Having these codes does not guarantee payment by insurance. In fact, it hasn't been determined what monetary value insurance companies are going to put on these new codes. It is believed that insurance will at least pay at the same rate as they did previously. Surgeons who remove neurofibromas in the way described by the codes will have to use the correct code. If thirty or more surgeons use the codes before they expire they may become permanent which we hope will greatly improve NF1 care.

We hope that these new CPT codes will help us to identify more surgeons who will perform “electrodesiccation” and will lead to better studies on the impact of removing many neurofibromas.

NF Midwest believes that enough isn't being done, or studied, regarding the most common complication of neurofibromatosis type 1 and that treatment options for adults who are most often affected by a lot of neurofibromas need to be better explored.

For more information on the new CPT codes please look for NF Midwest's [article](#) on removing neurofibromas on our website.

MORE INFO ON [TYPES OF NEUROFIBROMAS](#)

New NF Navigator/Social Worker: **Dedicated to Care!**



Jasmine Mitchell, MSW

NF Midwest is truly focusing on CARE and is thrilled to have hired Jasmine Mitchell, a social worker, to support individuals and families in our NF Midwest community.

Jasmine will be a patient navigator who is available to help patients and parents better navigate and understand the complexities of neurofibromatosis. She will be a community and social navigator available to help in locating resources for health insurance, social security disability benefits, job accommodation, financial assistance, transportation, school accommodations, and more.

We're very excited to extend this valuable service to the community. The first year of this program is funded by a bequest from [Francis and Irma Napolilli](#). Your support will help it continue and to grow. Please consider a donation or a monthly recurring gift. Together we can improve the lives of people with NF. [Email Jasmine!](#)

If you'd like to make a donation to our CARE program go to www.nfmidwest.org/donate.

A Big Heart!

NF Midwest has a new logo with a more prominent heart right in the middle of NF. It signifies NF Midwest's dedication to caring for, and supporting, the families and individuals with neurofibromatosis in the Midwest.



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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.

NF Midwest Works to Secure Federal Funding for NF Research

Thanks to our passionate NF community and donors, NF Midwest, along with other organizations, secured \$15 million federal funding for NF research through the Congressionally Directed Medical Research Program ([CDMRP](#)) for fiscal year 2016. We started working on this funding source almost 20 years ago and it has played a pivotal role in NF research including funding the [NF Clinics Consortium](#) through which most NF clinical trials are now conducted.

Our advocacy continues! In February, we once again stormed Capitol Hill, this time asking for 18 million. We need you to continue to respond to our alerts when we ask for personal letters or emails to your Congressional representatives.

Midwest Dream Team

Representatives from NF organizations in the Midwest form the informal "Midwest Dream Team". Getting ready to lobby on the hill are advocates from NF Midwest, NF Upper Midwest and the Littlest Tumor Foundation.



NF Midwest Scholarships



2015 Scholarship Recipients Austin Denny and Evan Carr

NF Midwest is proud to announce the continuation of our scholarship program in 2016. Established in 2015 with funds donated by the Napolilli family, the program offers \$1,000 scholarships to students pursuing undergraduate or vocational programs of study.

To qualify, students must have an NF diagnosis, be entering or continuing undergraduate (Associate's, Bachelor's or Vocational) school on a full or part-time basis at an accredited, US-based institution, and live in NF Midwest's service region of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and eastern Missouri.

In our inaugural year, two awesome young men, Austin Denny and Evan Carr each received a \$1,000 scholarship. Evan is from Marion, IL and used his scholarship for his first semester at Anderson University in Indiana where he is studying biochemistry. One day he would like to establish his own neurological disease research center. Austin, from Fond Du Lac, WI is seeking a certificate in Business Administration from North Central Technical College in Wausau, WI. He has an interest in computers and technology repair.

There is no limit to the things you do in life. It may take me longer than most people to complete, but that does not mean that I will not complete it. — Austin Denny

If you'd like to be a recipient of one of our 2016 scholarships [apply now](#). The application deadline is May 31st. Please contact us or go to our website for more information.

May 17th Open House

16th through 20th Savers Donation Drive



Savers Thrift Shop is partnering with NF Midwest for a donation drive. Your unwanted items can help fund CARE for people with neurofibromatosis. Monday, May 16th thru Friday, May 20th. Call for more information.

Join us for our Open House on Tuesday, May 17th All Day until 7pm.

Visit Our Office!!!

Welcome to Three New Board Members

Since last spring NF Midwest welcomed three new board members to our board of directors.



Pete Oswald joined the board in March of 2015. He is currently Director of Public Relations and Marketing at Blackburn College in Carlinville, IL. Pete has a varied background in non-profits as a director of a crime commission in Eastern Iowa, executive director of the Clayville Folks Arts Guild and as a founding member of the Summer Repertory Theatre at Blackburn. He also served twelve years on the local school board and in 2014 he and his family started SamJam4NF. Pete has an adult son, Sam, with NF1.



Denise Dulceak joined the board in September. Denise is mom to Jonathan who has NF1 and has been involved with NF Midwest since her son's diagnosis. She has a bachelors degree in Biomedical Science and is a licensed massage therapist and Reiki Master. Currently Denise works for the DuPage Eye Surgery Center. Denise is passionate about the cause and the work of NF Midwest and looks forward to helping others and raising awareness.



In November, Heather Reyes joined the NF Midwest board. Heather has a Master's Degree in Mathematics Teacher Leadership from Aurora University. She spent six years teaching middle school mathematics and currently does some teaching as an adjunct professor for Aurora University while focusing on raising her two young daughters, Olivia and Astrid. Olivia was diagnosed with NF-1 shortly after her first birthday, Heather has been involved with NF Midwest ever since.

In October Jean Nolan stepped off the board. We thank her for her wonderful years of work and hope she joins us again in the future.

If you would like to be contacted by the board for ways that you too can be involved, please contact [NF Midwest](#).

Earn NF Incentive Prizes!

Raise much needed funds through a [Great Steps 4NF walk](#) or through your own event and you can earn special prizes. Over \$1,500 earns you a bag chair; over \$3000 and you can also have a super comfy *Doin' It 4NF* sweatshirt blanket; over \$5,000 and you receive our annual *Top Fundraiser Club* flag.

Prizes may be substituted by NF Midwest if needed.

Modeling the Doin' It 4NF Sweatshirt Blanket, the 2015 Top Fundraiser Flag and the Doin' It 4NF bag chair (in the background)

Camp New Friends



Your generous donations enable NF Midwest to fund kids from our region who need help with travel and tuition to attend [Camp New Friends](#) in West Virginia.

Applications must be made through Brainy Camps at www.brainycamps.com.

The opportunity to go to this special camp for kids with NF is available for every child with neurofibromatosis. It's an amazing place to make friends, to develop self esteem and to learn to care for themselves as well as others.

This year camp is July 24– July 30.

[View videos](#) from past campers on our website!

[See Photos](#) from last year!

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.

Josephine Basile

Dorothy Borchardt

Ruth Darda

Erica Evans

Marie & Kermit Foertsch

Erwin Gordon

Mary Margaret Hemmerick

Darrin Joss

Beverly (Thompson) Jones

Alexis Mendez

Mother and Father of Dr. Robert Patterson

Virginia Lee Plume

Carol Schmidt

Amanda Stewart

Memorial

Donations



She Gave Up Her Gifts for NF

When Sophie from LaGrange, IL turned 11 this last fall, she asked her guests to make donations to NF Midwest instead of giving her gifts. Thank you Sophie!

Sophie is truly inspirational!



Symposium and iNFO Fair (see [PHOTOS](#))

On Saturday, October 25th, NF Midwest held their 25th NF Educational Symposium. In our decades old determination to arm people with knowledge, this year we added an iNFO fair which includes tables and experts on various topics.

The day was absolutely amazing! We had Rick Guidotti, a former fashion photographer and now a one man force bringing Positive Exposure to genetic disorders. Rick gave a great presentation and took wonderful photos. Annette Bakker from Children's Tumor Foundation also presented about NF research. Other speakers and our iNFO tables covered such subjects as learning disabilities, fibroma removal, SSI/SSDI and Insurance, genetics, fine motor skills, and NF2 research including an update on research and treatments from Dr. Jaishri Blakeley of Johns Hopkins.

There was lots of food, goodies and socializing! Be sure to mark your calendars now for our NF Symposium and iNFO Fair scheduled for November 5th.



Diana Haberkamp, NF Midwest Executive Director; Annette Bakker, President of CTF and Gail Mavrogenes, Chair of the NF Midwest Board get snapped by Rick Guidotti.

Like What You Read? Support the Cost of this Newsletter and the NF Midwest Mission!

[Make a donation](#) now to cover the cost of developing this newsletter and to support the NF Midwest mission. \$500, \$100, \$50, \$20....any amount makes a difference!

Ways to Donate

There are so many ways to provide financial support to NF Midwest and the neurofibromatosis cause. Please, consider at least one of these ways in 2016.

Monthly Giving Circle – Set up an easy, recurring [monthly donation](#) and receive a free NF Midwest t-shirt.

Honor or Memorial – These [donations](#) include a donation notification letter to the family or friends of the individual donated in honor/memory of.

Team or Family – Donate to the fundraising efforts of a Great Steps team or family.

Personal Fundraising – [Hold your own event](#) or campaign to raise funds for neurofibromatosis. We can provide a personal fundraising page. Consider raising for birthdays, weddings, or your own special event.

Planned Giving - Here are a few options for [planned giving](#). Please consult your own financial advisor or attorney.

Wills and Living Trusts – Include a bequest to NF Midwest in your will or living trust, to ensure that we can continue our mission for years to come.

Beneficiary Designations – Name NF Midwest as a beneficiary to receive assets such as retirement plans and life insurance policies after you're gone.

Charitable Trusts and Annuities – There are several different mechanisms that can offer tax advantages and/or fixed payments to you while also benefitting NF Midwest.

Donor Advised Funds – Recommend a gift to NF Midwest through your donor advised fund.

Workplace Giving - Companies are often very generous and supportive of their employees charities. There are many ways to leverage your place of employment to help NF.

Payroll Deduction – Your company may offer payroll deduction for non-profits. This may be through United Way or other such organizations and you can select NF Midwest. If you work for the Federal government you may have a deduction made as part of the CFC. Our number is 75126.

Matching Funds – Check with your employer to see if they will match any donation you make to NF Midwest.

Workplace Fundraising – See if your employer will allow you to do some fun events to raise funds.

For some of these giving options you may need the following info:

Legal Name: Neurofibromatosis Midwest

Address: 473 Dunham Rd, Suite 3, St. Charles, IL 60174

Federal Tax ID Number: 22-2580173

Upcoming Illinois Events

4th Smiles for Sarah Sox Outing—Sunday, May 22

Join the Panozzo Family Sunday, May 22th to watch the White Sox vs. Royals on Sunday. Before the game there will be a party in the parking lot including games of bags and more. Tickets are only \$20. Contact Jim at JimPanozzo@yahoo.com or call 708-612-0609.

Take a Swing 4NF—Friday, September 9th

at Prairie Landing Golf Club, West Chicago, IL. This will be the 18th running of this event which raises funds to send kids to Camp New Friends and for other kids related programs. New sponsors and golfers are always welcome!

Illinois Doin' It 4NF!

Bowling Fundraiser— The GS4NF Naperville Team, Jonathan's Journey held a bowling event at Wheaton Bowl on April 16th to raise funds for their team.

Birdies for Charity—Steve and Diane Reason once again set up Birdies for Charity which offers people a chance to guess the number of Birdies at the John Deere Classic golf tournament to win a car. They raised over \$2000!!

Pocket's Fundraiser—Last May the GS4NF Naperville team, Lindsey's Lifesavers, organized an event with Pocket's in Aurora in which 50% of sales for the day were donated to their team.

Wine and Painting Party—The Naperville GS4NF team Jonathan's Journey held a wine and painting party at the Chilled Palette in Geneva last April.

Tailgate Party— One of our supporters has regularly held a tailgate party with friends before a White Sox game. As this event has grown they found themselves making a profit that they donated between three charities, including NF Midwest. NF Midwest received \$650, plus another \$650 as a company match!

You too can [fundraise](#) for the NF cause!



Illinois

Naperville—Saturday, June 4th (see [photos](#) from 2015)

Last year the Naperville walk represented almost 70 families with NF and had close to 1,000 people! It was truly a party in the park and a perfect, sun shiny day! After a quick breakfast and a 3 mile walk we enjoyed music, pizza, hotdogs, ice cream, and some great raffle prizes. The highlight of the day was all of the Superheroes and Princesses who came by to walk, dance & take photos.

Sign-up now for the 15th year of the LARGEST WALK for NF in the country at www.greatsteps.org. This includes our popular "goodie give-away" stops along the walk.

Effingham—Saturday, June 18th (see [photos](#) from 2015)

Last summer the Didier family, friends and volunteers held their 8th Annual Great Steps 4NF Walk. About 150 people participated and four new teams joined the fun. Coming from all over central and southern Illinois, western Indiana and even the St. Louis area, we enjoyed breakfast, pizza, snacks and drinks, sale of baked goods and NF merchandise.

Join us for another great day of food, fun, raffle....oh an a little stroll on June 18th. It's always a good time!

Taylorville—Saturday, September 10 (see [photos](#))

The Layton family and friends put together an awesome inaugural walk and 5K in Taylorville last September. The energy and community was inspiring. Twelve teams and 110 walkers enjoyed the sunny brisk day while meeting others and raising awareness for NF! There was live music, bounce house, cotton candy machine, bake sale, 50/50 & a silent auction. It's amazing people had time to walk!

They're doing it again at Manners Park on September 10 and it is sure to be more amazing! Come out and show the area what NF is all about.

SamJam, Unplugged in the Prairie—September 17th

The Oswald family and friends are holding their 3rd [SamJam4NF](#), Unplugged in the Prairie all day music fest in Carlinville, IL.

What a great time! Last year we had a few NF families and a whole lot of music lovers at this fantastic event. Make the trip from wherever you are and enjoy progressive bluegrass, Americana and Roots music, plus food, beer, and bags!

Make plans now to join us! Find out more and order tickets at www.samjam4nf.com.



Two New Wisconsin NF Clinics

We have two new clinics that we are now referring people to in Wisconsin. The clinic director's at these clinics have experience in neurofibromatosis and a passion for helping people with NF. The clinics are:

UW Cancer Center at ProHealth Care

N16 W24131 Riverwood Drive
Waukesa, WI 53188

Clinic Director: Hendrikus Krouwer, MD

Appointments: 262.696.5690

Dr. Krouwer is a neuro-oncologist. He only see adults.

American Family Children's Hospital

2nd Floor

1675 Highland Avenue

Madison, WI 53792

Clinic Director: Neha Patel, MD

Clinic Coordinator: Abby Roth RN BSN CPHON

Appointments: 608.263.6420 Option #3

Dr. Patel sees children only as part of the Comprehensive Pediatric Neurocutaneous Disorders Clinic.

There are now four clinics that we have identified in Wisconsin. The other two are Children's Hospital of Wisconsin (414.607.5280) and Froedtert Hospital (414.805.0994) in Milwaukee.

Wisconsin Doin' It 4NF

Picnic in the Park 4NF in Bloomer

The West Central NF group held a picnic at North Park in Bloomer in July. The picnic was to bring NF families and individuals together to share stories, support each other and most of all have fun.



Aydin and mom and dad!

Team Aydin Bowling for a Cure

In January the GS4NF Chippewa team, Team Aydin, held a bowling fundraiser and raised more than \$8,000 for their Great Steps team and the NF cause!



Wisconsin

Sign-up to walk TODAY at greatsteps.org

Madison, WI - Saturday, May 7th (see [photos](#))



The 6th annual Great Steps 4NF Walk was held at the Capital Brewery with 22 teams and 190 walkers. The day was awesome with the sun shining and perfect temperatures. After a light breakfast and a quick walk we enjoyed pizza, raffles and silent action prizes. Special thanks to Tim Eberle and Maitri Meyer for putting together this great event in 2015.

We have a great committee working on the Madison walk this year. If you'd like to help or get involved in some way with NF in Madison, email Tim at Madison@nfmidwest.org.

Chippewa Falls, WI - Saturday, May 14th

(see [photos](#) from 2015)

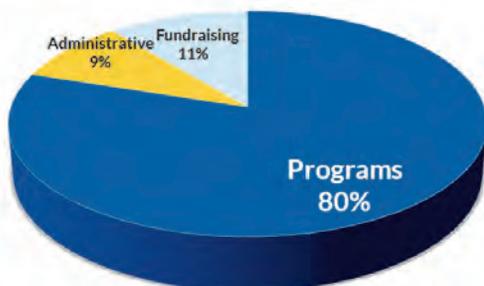
The 2nd Great Steps 4NF Walk at Irvine Park had over 200 walkers from 14 teams. What and this an amazing day! Alex & Cora from WAXX 104.5 kept everyone moving with great music and Andrea Albers from NEWS 18 was there to interview walkers for a news story! Tons of food, tons of raffles and tons of fun was had by all!



Crystal Reith leads a great team of volunteers including her family, Dave & Sandy Reischel, Heather Hakes, Rick and Mary Ann Wold. Be sure to join them this year!

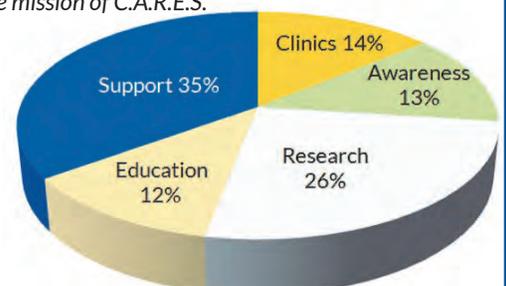
If you have a prize or raffle donation for the Chippewa walk, or want more information about the West Cen-

2015 Expense Breakdown



2015 Program Breakdown

Below shows where NF Midwest spends your donations for the mission of C.A.R.E.S.



INDIANA

Lunch with the Docs—SIGN-UP NOW!

Our Indiana group has scheduled another *Lunch with the Docs*. This is a popular, casual event in which you can ask NF doctors and specialists questions about NF and socialize with others.

Experts in attendance will include doctors and specialists from the Indianapolis NF clinic at Indiana University including Dr. Walsh, Dr. Nunes, Dr. Shih and Dr. McDonald.

There will be a kids group for children ages 4 to 13 with crafts and games.

For more information or to sign-up call 630.945.3562 or go to www.nfmidwest.org/indylunch2016.

Lunch with the Docs

Indiana University, Indianapolis

Saturday, May 14, 2016

11:00 am-2:00 pm EST

Cost is \$5.00 for adults/children are FREE
(cost includes lunch)

Evansville Meetings—The Evansville NF Midwest chapter regularly holds meetings. For more info email Jane at Evansville@nfmidwest.org.

IOWA

Taco Dinner 4NF

A couple of families and individuals came together and held a taco dinner in East Moline at Leisure Time Billiards in August. Dustin Dorsey, Jamie Dornbush, Wendy Buikema and other volunteers raised almost \$3,000!

MISSOURI

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.

Color Me a Cure

In May, 2015 the Presson Family and Alex's Angels once again held a fun Color Me a Cure 4NF 5K/1 mile Family Fund Run/Walk in Malden, MO.

Fredbird, the St. Louis Cardinals mascot came out for the Valley Park GS4NF Walk.



Indiana

Fort Wayne GS 4NF Walk —Saturday, July 9th

The 5th Annual Great Steps 4NF Walk in Fort Wayne was held at Eel Elementary School with 15 teams. The rain stopped just in time



for the day to begin! We enjoyed a sunny day with kid's games, bags and great raffle prizes! Team Pauly rocked it with their homemade walkway signs – what a great way to raise awareness! A big thank you to Liz and Ryan Taylor for leading the event and to our committee including Susan Caris, Ken Boice, Ben Cunningham, Sharon Arens, Ezra Konaing.

Fort Wayne will be holding its 6th annual walk in a new location at Parkview Field on July 9th. If you are looking to help

please email info@nfmidwest.org.

Indianapolis GS 4NF Walk —Saturday, Aug. 13th

The Indianapolis area is holding their first Great Steps 4NF Walk at Hummel Park in the suburb of Plainfield on Saturday, August 13th. Corky Mayo is chairing this walk. If you'd like to help or get involved in NF in Indianapolis send her an email at indy@nfmidwest.org.

KENTUCKY

Get it Started in Kentucky

If you'd like to do something for NF to raise awareness and funds, NF Midwest would love to help. We have at least one family in Western Kentucky looking for people to connect with and to build an NF community. Email info@nfmidwest.org or call 630.945.3562.

Valley Park GS4NF Walk

In September Gina Wilburn, her family and Trisha Brennen held a tremendous walk in Trailhead Park in Valley Park, MO. There were 7 Teams and 220 people joining DJ Dave who kept the crowd moving. Fredbird (the Cardinal Mascot) and a clown were also on hand for entertainment. Plus, face painting, a bounce house, tons of food and an equal amount of raffle prizes! The outpouring of support was amazing! (See [Photos](#))





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

Non-Profit Org
 U.S. Postage
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630-945-3562
 www.nfmidwest.org
 info@nfmidwest.org



**Sign-up for
 Your Walk
 Today!**

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.

**Meet Michelle!
 Ready to Work With You to Raise Funds and Awareness**

We have a new Event/Awareness Event Coordinator. Yes, that is all one person who is ready to help our NF Midwest community do all they can for the neurofibromatosis cause. Meet Michelle Phillips-Trademan. [Email Michelle!](#)



Michelle Phillips-Trademan

Hey Ya'll!

A southern transplant, I moved to Chicagoland to be with a cute bald dude that I fell in love with. After 20 years of marriage our baby is of the furry type that barks and plays Frisbee! After years in the Meeting Planning, Convention & hotel business, I have been an entrepreneur for the past 20 years. My passion of the Arts in Face/Body painting and window painting equals my love for the art of business in Marketing/PR! That's why I'm so excited to be able to utilize those talents in bringing awareness to NF in our region and help to raise funds for a cause that has been overlooked long enough! I'm looking forward to working with and meeting you all soon!

- Michelle -

WHERE WILL WE SEE YOU?

2016 Great Steps 4NF Walks

- Madison, WI • May 7
- Chippewa Falls, WI • May 14
- Naperville, IL • June 4
- Effingham, IL • June 18
- Fort Wayne, IN • July 9th
- Indianapolis, IN • August 13th
- Taylorville, IL • September 10

Lunch with the Docs in Indy
 May 14th

Take a Swing 4NF Golf Benefit
 September 9th

SamJam 4NF
 September 17th

NF Symposium and iNFo Fair
 November 5th

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.