



A Publication by NF Midwest for Neurofibromatosis Families

# Neurofibromatosis Newsletter

Volume 30, Issue 1

Winter-Spring 2011

Published 2 times a year

## Great Steps Teams Are Off and Running



It's [Great Steps](#) season again and teams are already raising money for the NF cause! If you'd like to learn more about steppin' out to raise NF awareness, while raising funds for the cause and meeting others with NF, check it out at [greatsteps.org](http://greatsteps.org).

Recent events included **Jacob's Warriors' Buffalo Wild Wings Benefit** and **Peanut's Gang's Red Robin Benefit**. Teams have various events in the works including a [vendor day](#), [bowling and bag toss event](#). If you're looking for ideas or want to know what works the best, give us a call. We have the scoop!

### Pick a Date! Pick a Place! Join the Great Steps Movement!

[Madison, Wisconsin](#) - May 21st  
Token Creek Park

[Effingham, Illinois](#) - June 18th  
Starting in Community Park

[Naperville, Illinois](#) - June 4th  
Naperville Riverwalk

Fort Wayne, Indiana—TBA  
Carroll High School

Sign-Up Your Team Now at [www.GreatSteps.org](http://www.GreatSteps.org)



## April is "Ask The Doctor" Month!

Do you have a question you would like answered by a health care professional with NF expertise? Do you wonder what other people's questions about NF are? Do you have a need to know how others find ways around the obstacles that NF can cause? Come join us for a casual morning or afternoon of learning. A panel of medical professionals with an expertise in NF will be available to answer your questions.

Refreshments will be served and the event is FREE. Sorry, but child care will not be available.

Saturday, April 2, 2011 10:00 am-12n

Sunday, April 17, 2011 2:00-4:00 pm

**Register NOW** IUPUI Campus  
[Indianapolis, IN](#)

**Register NOW** Shriners Hospital for Children  
[Chicago, IL](#)

## NF Type 2 "Ask the Doctor" Online Webinar

**Register NOW**

Join us for a NF2 "Ask the Doctor" [Webinar](#) on Tuesday, April 5th at 8:00 pm ET, 7:00 CT, 5:00 PT. Dr. Scott Plotkin, director of Massachusetts General Hospital's Neurofibromatosis Clinic will be our presenter. The 1 1/2 hour webinar will discuss NF2 management and research and include a question and answer time. Please contact the office at [info@nfmidwest.org](mailto:info@nfmidwest.org) for more information or check online at [nfmidwest.org](http://nfmidwest.org) for updates. Captioning is provided by NF Midwest and NF Northeast.

## Get Timely Updates And Make us a "Safe Sender"

If you missed an event because our newsletter was a little late, be sure to get email updates by signing up online at [nfmidwest.org](http://nfmidwest.org) or sending us your email information at [info@nfmidwest.org](mailto:info@nfmidwest.org). Also, [make sure](#) we aren't going to your "junk" or "spam" folder.

### Board Of Directors

Dennis Pilkinton, President  
Steve Griest, Vice President  
Ken Schoening, Treasurer  
Jean Nolan, Secretary  
Gail Cooper  
David Evans  
John O'Donnell

### Executive Director

Diana Haberkamp

### Mission Statement

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

### Disclaimer

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

**NF Midwest**  
473 Dunham Road  
St. Charles, IL 60174  
1.630.945.3562

[info@nfmidwest.org](mailto:info@nfmidwest.org)  
Be sure to mark us a "safe sender."  
[www.nfmidwest.org](http://www.nfmidwest.org)



Our offices have moved and our phone number has changed. Please, be sure to update your address books and cell phones. If you have old return envelopes for donations you may continue to use those until August.

**473 Dunham Rd, Ste 3  
St. Charles, IL 60174  
Phone: 630.945.3562  
Fax: 630.549.0671**



### Advocacy in Action

January 31st and February 1st, NF Midwest advocates, Susan Buono and Julie Rutter joined our executive director, Diana Haberkamp and a crew of others from the NF Coalition to educate Congress about the importance of federal funding for neurofibromatosis re-

search. Meetings were held at well over 100 offices and drop-ins were made at many more, as NF advocates blanketed the hill. NF Advocates asked for language in the Labor, Health and Human Services, Education appropriations encouraging NF research and, more importantly, for funding through the Department of Defense's [CDRMP](#) (see below).

Thank you to everyone who wrote personal letters to their congressmen. We were happy to hand deliver them. Thank you also to Julie and Susan for giving their time and voice to the effort.

The NF Coalition, which includes NF Inc. organizations and Texas NF, has been the national leader in advocating for federal research dollars since 1996. Because of these efforts over \$200 million dollars has been allocated to the Army's [NF Research Program](#) (NFRP) through the CDRMP. The success of this very targeted neurofibromatosis research has led to the development of a number of drugs which are now being tested in NF patients. Promising NFRP research results frequently lead to additional grants from the National Institutes of Health, increasing the NF share of federal funding dollars.

### Helpful Social Security & Disability Site

The Social Security and Disability Resource Center website ([SSDRC.com](#)) provides a detailed overview of how the federal disability system works (social security disability and SSI) and also provides answers to many questions that applicants typically have, but often have trouble finding answers to. For the most part, the site is based on the author's personal experience as a former disability-medicaid caseworker, and also as a former disability examiner for the social security administration.

### What is the CDRMP

You have often heard us talk about the [CDRMP](#). This stands for Congressionally Directed Medical Research Programs. For NF, this program has been a major lifeline.

CDMRP has its roots fifteen years ago, when there was considerable frustration with the lack of "real world" research for mitigation / treatment options for NF. The National Institute of Health (NIH) did research on NF along with many other conditions, but the research was focused on basic science, rather than on treatments for the condition and understanding how it impacts those who have it.

With bipartisan support, CDMRP came into being as a way for Congress to specifically fund innovative research that would have near term treatment application. Over the years, the programs have expanded to include Breast Cancer, Leukemia, Autism, and several other conditions. Under the program, Congress designates the funds for specific research, and the defense department then allocates funds to deserving grant proposals. All grant proposals are peer reviewed, and grant recipients are required to collaborate with one another to avoid silos of information.

**Funding for the program has ranged from \$8 million to a high of \$25 million; current 2010 funding was just under \$14 million. Key current initiatives include:**

- Study complications of NF with high mortality such as neoplasms and cerebrovascular abnormalities.
- Research complications of NF with high morbidity such as skeletal maladies, learning deficits, hormone associated effects, and pain.
- Refinement and standardization of imaging techniques, molecular and cellular markers, and quality of life metrics for use in future trials.
- Translational research such as the development of pre-clinical testing of therapeutic agents for the treatment of NF.
- Research focus areas such as wound repair, nerve regeneration, stress and inflammation, cognitive dysfunction, health-related quality of life, and neurofibromin protein.

For more details, visit the CDMRP web site at [www.cdmrp.army.mil](http://www.cdmrp.army.mil).

### Community Events

A lot of our families hold [events](#) in their community to raise NF awareness and funds for the NF cause. Please, let us know if you'd like some ideas for holding one or have one planned. While we aren't always able to advertise the event in a timely fashion, we do our best to post them on our website; on our facebook page at [facebook.com/nfmidwest](http://facebook.com/nfmidwest) and Twitter at [twitter.com/nfmidwest](http://twitter.com/nfmidwest) and through email blasts. So please make sure that you are plugged in by providing us with an email and [signing up](#) for those sites.

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

## Destination: Milwaukee Marathoners Run4NF

Start training your feet to pound the pavement or hands to clap in support! NF Midwest is proud to support [Derek Brown](#) in his mission to run a marathon in every state to raise awareness for the NF cause. He's doing so in honor of his brother who is affected by NF, and plans to bring him to Wisconsin in October. Derek looks forward to putting the Wisconsin feather in his cap by running in Milwaukee's [Lake Front Marathon](#) on Sunday, October 2.

You can support him in this effort by joining him in the run or by helping us plan a carbo-loading dinner/fundraiser the night before for all of our NF runners. If you'd like to run you must register directly at [milwaukee-lakefrontmarathon.org](#). [Registration](#) is open now. Please let us know if you intend to run or if you'd like to help plan the party by dropping us an [email](#) or giving us a call at 630.945.3562.

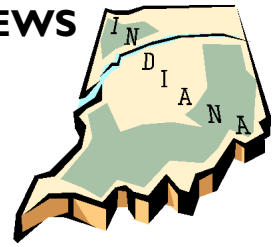
According to Derek, his father, Jeff Brown, motivated him to start running by "dragging him out to Chicago to run the Chicago Marathon." Derek ran the 2010 race with a team of runners dedicated to raise NF awareness.

"It was quite the experience and I enjoyed every second. That's how my marathoning career began," says Derek in his story on the [nfnetwork.org](#) blog.



*Derek Brown poses with his cousins and running mates, Sarah Brown and Hilary Ritter.*

## INDIANA NEWS



### Fort Wayne Friends

Recently, several people in the **Fort Wayne, IN** area, independent of each other, contacted NF Midwest seeking information and counseling. With their permission and encouragement, NF Midwest put these individuals in contact with each other. They are now in the process of forming a group for local fundraising and mutual support.

Their first meeting, an informal gathering at **Panera Bread** in Fort Wayne, was held on Saturday, Feb. 26th.

If you'd like to join up with this group, or are simply seeking more information, please email them at [fortwayne@nfmidwest.org](mailto:fortwayne@nfmidwest.org).

### Indianapolis "Ask the Doctors" Meeting

We are very sorry to those of you who may not have been notified in time regarding our "[Ask the Doctor](#)" meeting in Indianapolis. Please, sign up for email updates if you are able at [nfmidwest.org](#) and/or make sure we are not going in your junk folder. Otherwise, if you'd like to be personally notified of Indiana events give us a call and we'll see what we can do.

## WISCONSIN NEWS



### Madison Great Steps

We are very excited about our 2nd [Great Steps for NF](#) walk to be held in Madison on May 21 in the [Token Creek County Park](#). If you'd like to help please give us a call or send an email to [Wisconsin@nfmidwest.org](mailto:Wisconsin@nfmidwest.org).

Be sure to sign-up for the walk soon at [www.greatsteps.org](http://www.greatsteps.org) so that we can start raising funds and awareness in Wisconsin.

### Milwaukee Marathon

We are looking for energetic go-getters to help us plan an event the night before the Milwaukee Lakefront Run. The event can be a simple pasta dinner to welcome Derek Brown who is trying to run a marathon in every state in honor of his brother with NF. Email us at [Wisconsin@nfmidwest.org](mailto:Wisconsin@nfmidwest.org).

### Start a Chapter! Make a Difference!

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

**Get more timely and detailed news by signing up for email updates at [nfmidwest.org](http://nfmidwest.org) and make sure we're not blocked from your IN box!**



July 10-16, 2011



*"They say you can leave camp, but camp never really leaves you." - Paul Newman*

Camp New Friends provides opportunities for children and young adults with neurofibromatosis to gain confidence and build self-esteem. The campers learn about their condition from experts in the field and become effective partners in the management of their care. At Camp New Friends, children and teens become part of a team, while learning and having fun in a safe and supportive environment.

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

Registration is online at: [www.brainycamps.com](http://www.brainycamps.com)

Cost is \$750 per camper and includes a \$150 non-refundable deposit. Neurofibromatosis Midwest has financial assistance available. Please contact our office for more information. Email [info@nfmidwest.org](mailto:info@nfmidwest.org) or call the office at 630.945.3562.

### Letter from a camper's grateful mom

*Hello there, my NF family,*

*I just wanted to share a little note on my experience with Camp New Friends. At first I was very nervous about Joey going to camp. After talking to other families and calling the camp, I soon found that peace. As a parent I waited by the phone anticipating Joey's arrival to the camp. After he got there he was so excited and full of great joy. Although I missed him very much being gone, he came back with a new sense of belonging and pride. He had made some real close bonds and is still in contact with these children. Joey has always been an outgoing kind of kid, however he came back so super-charged and so excited about life. Wow, what a connection he had with the staff, new friends, and all who helped. We could never thank you enough for the sense of pride, joy, happiness, and inspiration you have given Joe. You are true angels and a blessing to us and a stepping stone to an amazing future to many children; you have made a huge difference in Joe's life and mine.*

*Thank you,  
Jennifer Accordino*

### Meet Us at the Zoo

Come out and [enjoy the day](#) with a group of fun people at the St. Louis Zoo on **Saturday, April 2nd**. NF families and adults with NF will gather at the North Entrance at 10 am and explore the zoo from that point.

This event will be a wonderful opportunity for kids to meet other kids with NF, and for adults both with and without NF to meet each other.

We plan to wear [NF shirts](#) for a dual purpose— to meet others with NF and to raise awareness for other zoo visitors. So if you have an NF shirt, please wear it. If not, wear a blue or green shirt if you can.

General Admission to the zoo is free with a \$12.00 parking charge per car. However there is limited free parking as well.

For additional information please contact Michael Forbes at [rmichaelforbes@yahoo.com](mailto:rmichaelforbes@yahoo.com); Rebecca Damschroder at [crzybusymomof2@hotmail.com](mailto:crzybusymomof2@hotmail.com) or Christina Thomas at [cltq4d@mail.mizzou.edu](mailto:cltq4d@mail.mizzou.edu).

Information about the St. Louis Zoo can be found at <http://www.stlzoo.org>.



### Get Ready to Roll at our Chicago Family Day on May 14!

**Register NOW**

Don't miss the 3rd annual Chicago area NF Family Day held this year at Brunswick Zone in Lake Zurich, IL from **2:30 to 5:00 pm**, presented by NF

Midwest Chicago Chapter. Both adults and children are encouraged to enjoy a couple hours of fun and friendship plus bowling and pizza. This event is FREE for those affected by NF. All others pay a minimal cost of \$10 each. The price includes bowling, shoes, pizza and drinks. Please register in advance through our website [nfmidwest.org](http://nfmidwest.org), or [nffamilyday-chicago.eventbrite.com](http://nffamilyday-chicago.eventbrite.com) or call the office at 630.945.3562.

This event is a great way to meet other NF families within your own community and to promote NF Awareness month!



**Save the Date**

### Planned Golf Benefits

#### Take a Swing at NF

Friday, August 12  
Prairie Landing, West Chicago, IL

#### Chip in Fore NF

Wednesday, August 24  
Cog Hill, Lemont, IL

## Symposium 2010 Wrap-up

NF Midwest's annual symposium, held October 16th at the NIU campus in Hoffman Estates, IL, was attended by over 150 people, including 26 teens and children who participated in breakout discussion groups and organized activities.

We'd like to thank our wonderful speakers including: Dr. [James Tongsgard](#), University of Chicago, and Dr. [David Gutmann](#), Washington University, who spoke about recent advances in NF1 Research and Clinical Trials; Dr. [Hubert Weinberg](#), New York board-certified plastic surgeon, who discussed removal of fibromas through electro-desiccation; Sandra [Cushner-Weinstein](#), Children's National Medical Center, who addressed adaptive coping and resiliency; Dr. [Andrew Fishman](#), Northwestern Memorial Hospital, and Dr. [Matthias Karajannis](#), New York University, who presented NF2 clinical perspectives and patient care delivery; Dr. [Vijaya Ramesh](#), Massachusetts General Hospital, who updated research on mTor/P13K; ; Ellyce Anapolsky, [Health and Disability Advocates](#), who gave an overview of public benefits; and our panel of people with NF1 who gave us their perspectives on dealing with the disorder.

Thanks to our dedicated volunteers: Mike Bukowski for his technical expertise; and energetic kid-wrangers, Bria Pilkinton, Karissa Haberkamp, Meagan Geffe, Lisa Sprovieri, and Kristen and Craig Skinner; and to our NF2 coordinators, Susan Buono, Laura Didier and Steve Reason.

## New location for 2011

### Symposium set for Oct. 15 in St. Louis

This year the our symposium will be held on Saturday, October 15th at the [Renaissance St. Louis Airport Hotel](#). We are already working an exciting agenda. Please, let us know if you would like to help. Be sure to mark your calendars now and keep an eye out for more information. This might be the perfect reason to get yourself signed up for email updates at [nfmidwest.org](#).



## Ras/MAPK Conference

We are currently working on a short educational meeting in conjunction with the RAS/MapK conference to be held in the Chicago area in July. Drs. Maria Acosta and Alcino Silva will be attending that conference and our hope is to have them present to NF families on Sunday, July 31. Unfortunately as of this printing, we are still working on this and there will not be another newsletter before that. If we do succeed in setting this up it will be at the Westin O'Hare Hotel in Rosemont. To get timely updates we again urge you to sign up for email updates at [nfmidwest.org](#). You may also want to join our facebook page at [facebook.com/nfmidwest](#). Also, you can text "follow nfmidwest" to 40404 for text updates.

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

**Give it a try!**

## Pre-Existing Condition Insurance Plans

If you think you're uninsurable, you may be in for some good news. The Affordable Care Act, the health insurance law passed in March 2010, created a new program – the Pre-Existing Condition Insurance Plan. The program makes health insurance available to you if you have been denied insurance coverage because of a pre-existing condition.

The [Pre-Existing Condition Insurance Plan](#) (PCIP) is administered either by your individual state or by the Dept. of Health and Human Services. Twenty-seven states, including Illinois, Wisconsin, Iowa and Missouri have state-run plans. Twenty-three states, including Indiana, Kentucky and Tennessee have plans run by HHS. The program is designed help those who meet these three conditions:

- Uninsured for at least six months
- Have a pre-existing condition or have been denied coverage because of a health condition
- Are a U.S. citizen or are residing here legally

The program may be able to help you until 2014, when a new competitive marketplace called an Exchange will offer you access to affordable health insurance choices.

The state-run programs vary in cost from state to state, but cover primary and specialty care, hospital care and prescription drugs. In the HHS-covered states, the federal government contracts with a national insurance plan to administer benefits. There are three plan levels available, and families can enroll their eligible children in PCIP at child-only rates.

There is a comprehensive and user-friendly website, [healthcare.gov](#), that provides a wealth of information on insurance-related issues, including details about what's available in each state.

## Dr. Tongsgard receives Humanitarian Award from University of Chicago



Dr. Tongsgard received the Social Work Humanitarian Award 2011 from University of Chicago Medical Center. Dr. James Tongsgard, Director of the University of Chicago [NF Clinic](#), was presented the first Social Work Humanitarian Award from the University of Chicago Medical Center's department of Social Services. He was recognized as a strong compassionate advocate for his patients and families, addressing all their needs,

not just their medical concerns. While this award was not specifically for his work in neurofibromatosis, Dr. Tongsgard has dedicated much of his career to the NF cause. For over 25 years he has shown great commitment and concern for our NF community. We know that he is most deserving of this award and salute him.

## LD and Response to Intervention

*“What do you mean my child with NF won’t be evaluated for an IEP because of RTI?”*

Sixty percent of people with NF have a learning disability including Attention Deficit Disorder. With that in mind, many parents have gone or will go to their public school district to request an evaluation for a [504](#) or an [IEP](#) (Individual Education Plan). An IEP falls under the [Individuals With Disabilities Education Act](#) (IDEA), which mandates that states allow, as part of their criteria for determining whether a child had a [Specific Learning Disability](#) (SLD), the use of Response to Intervention (RTI). According to a [memo](#) from the United States Department of Education, **Response to Intervention cannot be used to delay or deny an evaluation for eligibility under the IDEA.**

What does this mean? It means that when parents request an evaluation for their child, the school district cannot deny or delay the evaluation because they are doing RTI. If a disability is suspected, school districts are obligated to determine if the student is eligible for services under IDEA. Remember, information collected from RTI is used for eligibility under the Specific Learning Disability category and children with NF may be eligible under other disabilities such as [Other Health Impairment](#). Refer to your state special education department for more information.

Resources:

[www.idea.ed.gov/explore/home](http://www.idea.ed.gov/explore/home)

US Department of education, Office of Special Education Programs (OSEP)

[www.wrightslaw.com](http://www.wrightslaw.com)

Great resource for special education law

[www.nfcenter.wustl.edu](http://www.nfcenter.wustl.edu) (under patient resources)

A [brochure](#) from Washington University, St. Louis  
“Addressing Academic Concerns: A Guide for Parents of Children with Neurofibromatosis 1”

[www.isbe.state.il.us/SPEC-ED/html/parent\\_rights.htm](http://www.isbe.state.il.us/SPEC-ED/html/parent_rights.htm)

Illinois Parent Guide -Educational Rights and Responsibilities: Understanding Special Education in Illinois

## LD/ADD Adult Resources

If you are an adult facing the challenges of learning disabilities or attention deficit disorder, there are numerous resources available on the internet.

The **Learning Disabilities Association of America** has a comprehensive website, [ldanatl.org](http://ldanatl.org) that covers a variety of topics relevant to both children and adults. Resources for assessments, evaluations and literacy; civil rights; workplace issues and social/emotional aspects are provided. The Association holds an annual conference, and has chapters in many states.

Another site, [ldonline.org](http://ldonline.org), provides links to articles, books and forums for adults with learning disabilities.



## NF2 Crew assembles online resource list

The [NF2 Crew](#) is an online-based support community for individuals affected by NF2, their families and friends. Their mission is to reach out to affected individuals by providing links to NF2-related social and informational sites. The ever-growing list includes links to insurance, research, doctors, financial assistance, travel and blogs. They welcome worthwhile additions to the list. The list can be found [www.nf2crew.com/Links.html](http://www.nf2crew.com/Links.html).

## NF2 Con 2011 in Las Vegas

The Las Vegas Con is back with a vengeance! This year the NF2 Crew will hit the [MGM Grand](#) from **June 9th to 11th** for several days of Sharing, Caring and Friendship!



You can book your rooms now; instead of a group rate we are encouraging everyone to find the best deals they can. Average rate for a room at MGM this weekend is about \$120, a great deal!

We will have a suite at the MGM Grand for our annual Crew party as well as to have a central location to hang out throughout the weekend.

The weather should be gorgeous, so be ready to hang out by the pool during the day and enjoy Crew parties at night!

The NF2 Crew was created back in the 90's to give people with NF2 a place to find our three tenets: **Caring, Sharing, and Friendship**. The Crew has grown and branched out over the years, but the NF2Con is our original annual social gathering where we finally get to hang out with the people we chat with every day!

For people with NF2 and their family members to come together for a weekend of fun and excitement! Check out [www.nf2crew.com](http://www.nf2crew.com) for more information.

## Schwannomatosis Support Group

We are looking to form a [schwannomatosis](#) support group or action committee on a local or national level. If you are interested in the opportunity to be a part of such a group or know of an existing group, call us at 630.945.3562 or drop us an email at [schanno@nfmidwest.org](mailto:schanno@nfmidwest.org).

Schwannomatosis is a form of neurofibromatosis that is not well understood. Patients with schwannomatosis have benign (non-cancerous) tumors called schwannomas that form on many nerves in the body. Many people with schwannomatosis also have very severe pain. Only 10% of patients with schwannomatosis inherited the disease from a family member. Scientists do not completely understand the genetics of schwannomatosis.



## NF Q&A Corner

**Q:** *Having been affected all my life with many of the common, and some of the more rare manifestations of NF, I feel that scientists could learn much from a thorough examination of my body after I'm gone. How do I go about donating my body to medical research?*

**A:** While donating an NF affected body to research can be very helpful, it is a very complicated and sensitive issue. Ideally the affected person should have been followed by a physician who is very active in NF research, so that an accurate history has been established. Also, the donation of a body needs to be arranged ahead of time with the facility that will be doing the research and there can be quite a bit of logistics involved. If you are interested in donating your body to research, it is best to discuss this with your NF doctor. They may be able to better direct you.

**Q:** *Should people with NF be concerned with radiation from x-rays, CAT scans, etc?*

**A:** Simple routine x-rays or occasional CAT scans are nothing to worry about. Radiation therapy, however, is a concern and should be avoided unless radiation therapy is perceived to be an important part of treatment, as is the case in some breast cancer patients.

## eNuF NF Merchandise

Heather gray t-shirts	\$12.00
Women's blue t-shirts	\$14.00
Bracelets	\$ 1.00
License Plate Frames	\$ 1.00



Call 630.945.3562 or email [info@nfmidwest.org](mailto:info@nfmidwest.org) to place an order. Shipping will be figured and added to all purchases.

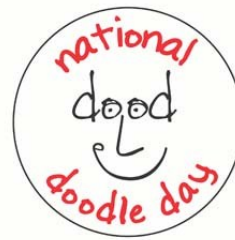
## Fall Fundraiser Reaps Rewards

Last October, the family and friends of Benjamin Shipley (*Ben's Buddies*) organized an elegant and well-attended **Fall Harvest Benefit**. The event, held at a private residence, was touted as "A Celebration of Wine, Food and the Fall Season."

Among the guests attending were marathoner Derek Brown and his teammates, Sarah Brown and Hilary Ritter. Derek is the young man from Connecticut who plans to run a marathon in every state in honor of the NF cause.

While glasses were raised, NF awareness was raised as well. Each guest went home with a goody bag that included, along with the customary treats, an invitation to participate in the upcoming [Great Steps](#) for NF walk, either as a walker or a donor.

## What Celebrities Do You Know?



We're looking for celebrities to doodle for National [Doodle Day](#). National Doodle Day is part of Neurofibromatosis (NF) Awareness month, where celebrity doodles are available for auction on eBay during the month of May from May 12-22 to raise money to benefit [NF, Inc.](#) Celebrities participating this year are Jeff Bridges

(actor, *True Grit*), Julianne Moore (actress, *The Kids Are Alright*), Julianna Margulies (actress, *The Good Wife* on CBS) and Kathryn Bigelow (director, *The Hurt Locker*).

We are always looking for more celebrities. Please think about any connections you may have. Also, please spread the word about the auction to your friends, family and co-workers.

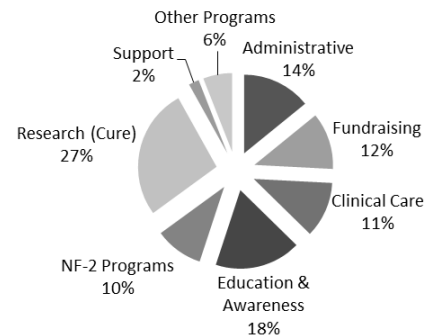
## NF Midwest Financials

Last year approximately 74% of NF Midwest's expenses, or \$205,000, went to programs. This included the areas of education and awareness; research; clinical care; support; and NF2 research and education. Of this, over \$111,000 was allocated in direct grants to research and clinical care. We also allocated \$27,000 to advocacy. Please, see the chart for our expense breakdown. If you have any questions please give us a call, and thank you to everyone who furthered the NF cause this past year.

## DONATE NOW!



- **Monthly Gift**—Join our monthly giving program and become an NF Midwest Partner.
- **Single Gift**—Make a single gift donation.
- **Memorial Gift**—Arrange for a gift to be made in memory of a loved one
- **Honor Gift**—Honor accomplishments or celebrate special events and holidays with a gift to NF Midwest.
- **Matching Gift**—Find out if you can double or triple your donation through your workplace giving.
- **Gift Planning**—Donate to a named fund or learn how to make a tax saving gift through your will, trust or other estate plans.



## Donating is Easy:

**By Phone:** (630) 945-3562

**By email:** [info@nfmidwest.org](mailto:info@nfmidwest.org)

**Via our website:**  
[www.nfmidwest.org](http://www.nfmidwest.org)

**By Mail:**  
NF Midwest  
473 Dunham Rd, Suite 3  
St. Charles, IL 60174

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

Non-Profit Org  
U.S. Postage  
**PAID**  
Mt. Prospect, IL  
Permit #65



630-945-3562  
Fax: 630-549-0671  
E-Mail: [info@nfmidwest.org](mailto:info@nfmidwest.org)

## Midwest Area NF Clinic Information

For more doctors please call 630.945.3562

### Children's Memorial Hospital

*(Children Only)*  
2300 Children's Plaza  
PO Box 59  
Chicago, IL 60614

773-880-4462  
[Joel Charrow, MD](#)  
[Robert Listerick, MD](#)

### Indiana University NF Clinic

*(Children and Adults)*  
Riley Hospital for Children  
669 West Drive, RR208  
Indianapolis, IN 46202-5119

[Cynthia Hingtgen, MD, PhD](#) (Director)

317-948-7450  
for scheduling & information

Yvonne Hayden, RN (Clinic Coordinator)

### University of Chicago

*(Children and Adults)*  
5839 S. Maryland Avenue MC3055  
Chicago, IL 60637

[James Tonggard, MD](#) (Director)  
773-702-6487

Cynthia MacKenzie, RN  
773-203-2344  
General Inquiries & Research

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

[www.uchicagokidshospital.org/nf](http://www.uchicagokidshospital.org/nf)

or

[www.uchospitals.edu/specialties/neurology/neurofibromatosis.html](http://www.uchospitals.edu/specialties/neurology/neurofibromatosis.html)

### St. Louis Children's Hospital

*(Children and Adults)*  
NF Center  
Neurology Department  
Washington University  
Campus Box 8118  
St. Louis, MO 63110

314-454-6120

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

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

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

Distributed courtesy of Innovative Mail Services, Inc., Mt. Prospect (847) 827-9081