



A Publication by NF Midwest for Neurofibromatosis Families

Neurofibromatosis Newsletter

Volume 29, Issue 1

Winter/Spring 2010

Published 2 times a year

Funding for CARE and a CURE

We are very excited to have already committed funding to three projects in 2010. Careful thought and consideration were given in funding these grants. Two of them involve supporting research and clinical care at University of Chicago NF Clinic and Washington University's NF Center in St. Louis, MO for a total of over \$65,000. The other is a \$25,000 grant for NF-2 basic science at Massachusetts General Hospital.

The Martin Ginsberg Grant was awarded to the University of Chicago's NF Program. The *Neurofibromatosis (NF) Program at the University of Chicago* was established in 1989 by Dr. James Tonsgard to advance clinical care and research for NF. The core clinical group includes Dr. James Tonsgard and clinicians in various specialties. The

NF Midwest funds CARE and CURE at two clinics!

University of Chicago NF clinic has seen close to 1500 patients and maintains a detailed database of each patient visit with more than 489 data points. The data provides an longitudinal record of the patients. This includes not only a listing of characteristics of the patient, but also the progression of the disorder and the effect of

treatments over time. This valuable data helps scientists and physicians understand how often a particular complication may occur and what treatment if any, may be the most effective. At the UoC, NF Midwest is funding a nurse/data manager to maintain the database and to submit and supervise clinical research protocols. This grant also funds a nurse for Saturday clinics.

The *Washington University Neurofibromatosis Clinical Program* was established in 1994 by Dr. David H. Gutmann, MD, PhD. In 2004, Dr. Gutmann founded the *Washington University Neurofibromatosis Center* (www.nfcenter.org), a comprehensive center composed of over twenty-five clinicians and laboratory scientists focused on accelerating the pace of scientific discovery and its application to the care of individuals with NF. Currently the university sees over 400 NF patients a year. In order to better serve NF families and to function as a regional resource for children and adults

(Continued on page 2)

Ask The Doctors

Do you have a question you would like 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 afternoon of learning. A panel of medical professionals with an expertise in NF will be available to answer your questions.



Ask the Doctors
April 18th, 2009
2:00 – 4:00 pm

Shriners Hospital, Chicago, IL
(on Chicago's western border by Oak Park)



To register or for more information, call the NF Midwest office at 630.932.8111; drop an email to register@nfmidwest.org or register online at www.askthedoctors.eventbrite.com.

Don't miss another event. Sign up for email updates at nfmidwest.org!

Inside This Issue

Great Steps Walks

Ask the Doctors

3 Research Grants Awarded

Community Fundraisers Making a Difference

NF-2 News

Parents Action Committee

NF Adults Group

Camp New Friends

Participate in Run4NF

Camp New Focus

August NF Gathering

Ravioli Eating Contest

Mission Statement

NF, Inc. 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, Inc. 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, Inc. Midwest
PO Box 1923
Lombard, IL 60148
1.630.932.8111
info@nfmidwest.org
www.nfmidwest.org

Care and Cure (Continued from page 1)

with NF, Neurofibromatosis Midwest is funding the part-time position of NF Clinic Care Coordinator. This individual will function as a point of contact for NF families with the aim of improving care and working with clinical research.

After much consideration, our NF2 Action Committee (NF2ACT) has awarded an NF2 research grant to James Gusella, PhD and Vijaya Ramesh, PhD at the Center for Human Genetic Research at Massachusetts General Hospital. Drs. Gusella and Ramesh will be receiving a \$25,000 grant to further explore the mTor pathway to gain understanding of

the pathogenesis of NF2 meningioma. They expect that the results of the study will provide a definitive answer as to whether the intracranial injection meningioma model is effective for testing drugs and whether there is evidence in this first set of tests that either rapamycin or PI-103 is a viable candidate for human testing in Phase 0 or Phase I clinical trials.

As a regional organization, we want to provide the best care to people with NF in our area while still pursuing the hope of a cure and better treatments. Our main criteria for funding clinical care/research are (1) having clinical options for both children and adults and (2) being currently involved in research or clinical trials. As such, our grants for CARE to the University of Chicago and Washington University are also grants for a CURE.

New Board President Elected

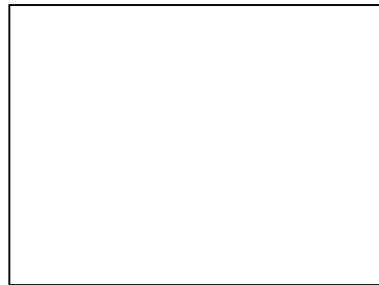
On October 13, the NF Midwest Board of Directors held their annual election and new officers were seated. Our new president is Dennis Pilkinton. Dennis, is the Chief Operating Officer of Crown Corr Inc. in Indiana. An active leader in our Great Steps Walks for the last 9 years, Dennis joined the board in 2008. Dave Haxby, a long standing board member and past president is now Vice President. Our new treasurer is Ken Schoening. Ken, also joined the board in 2008 and is president and owner and president of A-1 Packaging Solutions, Inc. Our new secretary, Jean Nolan, is new to the board. Jean is Vice President and Insurance Broker with the Nolan Agency, Inc. in Lombard. She is also an active member and past president of the Lombard Rotary. Also new to the board is Steve Griest. Steve has also been active in our Great Steps Walk for the last 9 year. He is General Manager of the Chicago Office of Harmon, Inc. Re-elected directors are Gail Cooper, Dave Evans and Gordon Cummings.

If you'd like to attend one of our board meetings, we generally meet quarterly with the next meeting scheduled for Tuesday, April 13th. Please, give us a call at 630.932.8111 for more details.

Congress approves 13.75 million dollar funding for NF Research

Congratulations your letter writing has paid off! The 2010 Defense Appropriations bill passed with \$13,750,000 for the Army's Neurofibromatosis Research Program. Our request to Congress was for \$20 million and while we were excited that House included \$25 million in their bill it was knocked down to \$13.75 million in conference. While the funding for fiscal year 2010 is down from what we'd like, it's not surprising in these difficult times. Last year, Fiscal Year 2009, the Army's NF Research Program received \$10 million so we are please with the increase.

We are already started our campaign for 2011 funding with a visit to see your Representatives and Senators in Washington, DC in February.



Place a new picture

Passing of Murtha; thanks Harkin, et al.

Contact Information

Office: **1.630.932.8111**
 Fax: **1.630.932.8119**
 Website: **NFMidwest.org**
 Office Email: **info@NFMidwest.org**
 Diana Haberkamp,
 Executive Director: **Diana@NFMidwest.org**
 Joan Pilkinton,
 Assistant Director: **Joan@NFMidwest.org**

Board Of Directors

Dennis Pilkinton, President
 Dave Haxby, Vice President
 Ken Schoening, Treasurer
 Jean Nolan, Secretary
 Gail Cooper, Director
 Gordon Cummings, Director
 David Evans, Director
 Dave Haxby, Director

Our NF Family Camp Experience

From The Bukowski Family

Have you heard about those adventure vacations where you go hiking, bicycling, or kayaking as you explore nature with a personal guide, ending each day with a room already made for you and a meal already prepared? They're a great way to get out and do something a bit different while on vacation, but they can be pricey. Still, it's something my family has long wanted to do, so we jumped at the opportunity to attend the inaugural NF family camp in September. By the end of the activities-packed weekend, it felt like a cross between an NF conference and an adventure camp experience. Oh, yeah—and the kids thought it was way cool, too.

We started our adventure off by driving up the western Michigan coastline, eventually veering off towards Grand Rapids (home of former President Gerald Ford). The camp was about an hour north of Grand Rapids and was nestled on 680 wooded acres that served multiple community purposes. Once we checked in to our cabin (everybody stayed in either one or two adjoining cabins, depending on their family size), we went to the Eagle's Nest (or mess hall) for dinner. Afterwards, we had a bonfire, at which point introductions—and the fun—began.

There were about half a dozen families there, with children ranging in age from preschoolers through teenagers. Every family had at least one child affected by NF, some of whom had more severe complications that they were dealing with than others.

This NF family camp—officially named Camp New Focus—was conceived by Brenda Arnott as an alternative camping experience for NF-affected children who are not able to attend the NF, Inc. camp held annually in Virginia (formerly, Maryland). It has been on her heart to provide an experience in the Midwest for kids dealing with NF that would like to go to camp closer to home. Camp New Focus was born out of that desire.

After breakfast on Saturday morning in the cafeteria, we all headed out to a nearby building for a lesson on the high ropes confidence course. Now, when I say, "high ropes", I really mean HIGH! Some of the ropes and platforms the kids had to jump around on were over 20 feet up in the air—yikes! The kids were also offered the opportunity to jump off a platform that was 18 feet high. (That may not sound like much, but it's like jumping off the roof of a house.) This was probably the highlight of the trip for our family, as all of us either jumped or swung off that platform. Although there was a safety harness on each person on the high ropes course, it was still a bit unnerving—but Donna's encouragement (she was our coach on the ground), Paul's strength (he was holding the safety harnesses), and Danielle's quickness (she was the one who came to rescue us when we were stuck or frozen with fear) helped all of us to have a terrific time.

While the kids were busy building-up their confidence, the parents were offered a reprieve by attending a mini-NF conference in another nearby building. There, a doctor and others familiar with NF discussed different aspects of the disorder, as well as different ways to deal with the stress

2009 Symposium

Over 180 people attended our annual symposium held October 17th at a new location in Hoffman Estates, IL. This included approximately 160 adults of which approximately 35 participated in the NF2 break-out, 17 teenagers in the Teen Group and 11 children in the Kids Group.



Symposium attendees enjoyed visiting during the buffet lunch.

We'd like to thank our wonderful speakers including: Mike Forbes and Marie Drew who gave us their personal perspectives on living with NF1 and NF2; Bonnie Klein-Tasman, PhD from the University of Wisconsin-Milwaukee for up-

dating us on her research of cognitive issues in children with NF; Dr. Cynthia Hingten, University of Indiana, for her overview of NF and for explaining her research on NF and pain during the research panel; Dr. Fawn Leigh, Massachusetts General Hospital, for serving on the NF-1 research panel and for giving the NF2 group an update on NF2 research at MGH; Dr. Robert Leiberson, Stanford University, for presenting the use of cyberknife on NF2 tumors; Dr. Marco Giovannini, House Ear Institute, for updating us on his NF2 research with mouse models; Kelly Lowry, PhD, a Child Psychologist at Children's Memorial, for working with our teen group; and to Dr. Listernick, Children's Memorial, and Dr. Tongsgard, University of Chicago, for their help in putting this symposium together and for the information they provided on research.

Please mark your calendars now for our next symposium at the same location on October 16, 2010.

Donation Envelope

Included in the newsletter this month is a donation envelope. If you send in a donation and would like it credited to a specific Great Steps team or family, please include a note with that information.

NF Awareness Month

May is NF Awareness month. Please look for opportunities to spread awareness. Hold an event or even simply set-up an awareness table. For more information on holding a community event, go to www.nfmidwest.org/events.

Congressional Support

It is with great sadness that we received news of the passing of Representative John Murtha (PA). Rep. Murtha was a long-time champion for spending on NF research through the Congressionally Directed Medical Research Program.



We've received support from many other Senators and Representatives for NF research through the CDRMP and for language encouraging research through the National Institutes of Health. Please, check with us regarding the support from your Congressional representatives and be sure to thank those who _____

We also want to thank Senators Tom Harkin (IA) and Dan Inouye (HA) for their leadership in this effort on the Senate Defense Committee. In the House we owe a great debt of thanks to C.W. Bill Young (FL).



*Marcy Perlman and friend,
Van, enjoy the night.*



Kane County Cougars NF Family Day

An evening of Fun, Food and Friends!

Sunday, May 16, 2010

Pregame Catered Picnic: 11:30 A.M.

Game Time: 1:00 P.M.

Cost (For NF Affected Families): \$20 per adult, kids (under 17) \$5

Cost (for others): \$25 per adult, kids (under 17) \$15



Waiting for a homerun!

Join us at our 2nd NF Family day held once again at the Kane County Cougar stadium on May 16th. NF Midwest has reserved a private outfield deck, where Cougars staff will set up, cook and clean up while you enjoy a catered picnic. After the picnic enjoy the game with a unique view of the field. The price is reduced for NF affected families and is \$20 per adult and \$5 for children under 17. We also welcome friends at \$25 per adult and \$15 per child.

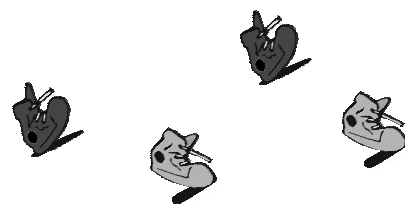
The Kane County Cougars are a class A affiliate of the Major League Oakland Athletics. Who knows, you may see a future all-star player or even a past one!

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

Reserve your tickets now. 1-630-932-8111 or by e-mail office@nfmidwest.org. You may also register online at _____ . Tickets will be mailed approximately one week before the game or arrangements will be made at will call. Space is limited. Handicap access is available.



Great Steps
for NF
2010



Get Ready For Great Steps 2010! Now in 3 Locations, plus a Virtual Walk!

Get ready, get psyched, get to making a difference and prepare to participate in Great Steps 2010! If you haven't joined in this fun event before, we'd love to see you this year. You now have the choice of three different locations on three different dates as walks will be held in:

Naperville, June 5th
Madison, WI June 12th
Effingham, June 19th

The more people that come out to walk, the louder the roar we can make for the NF cause. Last year we had over 1000 walkers in Naperville! Last year Effingham raised over \$8,000. This year we want central Illinois to know about the NF cause. Join this initial Great Steps walk and be the start of something wonderful!

Information about the walks are available at nfmidwest.org and greatsteps.org. Be sure to visit the site and come back frequently for updates. Also, registration brochures have been mailed, please let us know if you didn't receive one. In the meantime, we are always in need of raffle and other prizes, plus donations of food and miscellaneous sundries. We also have openings for company sponsorships. Please, think of who you know that may be able to help us out.

If you have any questions please give us a call at 630.932.8111 or drop an email to info@nfmidwest.org.

Needed for the Walks

Clown
Breakfast Goods
Newspaper Ads
Water
Raffle & Prizes such as...

Cubs Tickets
Sox Tickets
Free Hotel Rooms
Gift Certificates

Much More!



This year NF, Inc. Midwest and a very special donor sent 7 kids to Camp New Friends at their new location in Virginia. All but one were new to the experience.



NF Adult Group (NAG)

Our NF-1 Adult Group continues to meet regularly. Choosing to be proactive and taking NF head on, this group develops fundraisers, increases awareness and finds support in friendships and socializing. Meetings are generally planned a month in advance. If you'd like to be notified of NAG happenings please contact the office at 630.932.8111 or drop an email to nag@nfmidwest.org.



NF2 News From NF2 Crew

NF2 Action Team (NF 2 ACT)

Initial Meeting February 7

Do you or someone you know want to make a difference in the NF2 cause and the NF2 community? Then consider joining our newly forming NF2 committee.

This committee will guide NF, Inc. Midwest in NF2 related activities, events, research and support. Our initial meeting is set for Saturday, February 7th at 12:00 Noon. We will be meeting at our office at 145 S Main, Lombard, Illinois. Though you may have missed this meeting do to the timing of our newsletter, if you are interested in making a commitment to the cause and the group, please let us know. In the future, we hope to set-up a way to communicate and meet online.

Please, let us know of your interest by calling 630.932.8111 or sending an email to nf2@nfmidwest.org.

Community Fundraising

Consider a community or family fundraiser to raise funds and awareness for the NF cause. Community/Family Fundraisers are events that are put on by NF Midwest members or their friends and family to benefit NF research or support various programs. Often these are in honor of a loved one affected by NF or for a Great Steps team. They can be anything from a slightly time consuming event such as a golf outing to something simpler like a home party. No matter what the event, they are always fun and bring awareness to the NF cause! In the past couple of months we have received donations from the following Community/Family Fundraisers:

Giovan's Ravioli Eating Contest

The Angela's Angels Naperville GS team benefitted from Giovan's Ravioli Eating contest held September 10th. This is the 3rd year that owner _____ held this event in honor of his long-time customer Angel Szoldatits who has NF2.



Jorge Abaroa takes on the meatball eating competition.

This year the fun was multiplied by at least three as _____ threw in 3 more side competitions. They included eating 3 big meatballs blinded-folded, feeding canollis to a partner while you were both blind-folded and _____, Of course, there was also

the ravioli eating contest of who could eat the most ravioli's. Be sure to mark you calendars to come out for this event this fall.

4KATE Events

To raise funds for their team and awareness for the NF cause, the 4KATE Naperville GS team held a vendor night in November (see article to the right) that helped others get their holiday shopping done. 4KATE also teamed up with the _____ team for a bowling benefit in February.

Buffalo Wild Wings Night

Jacob's Warriors Naperville GS Team received funds for their team by encouraging friends and family to eat at BWW in Oswego on Feb. 15th. Their team received 15% of each food purchase for every patron that presented a special fundraising ticket.

Jump!Zone

The A-Team (Naperville GS) held a fun night of jumping and playing to benefit their team and NF Midwest on Feb. 15th at the Jump!Zone in Niles, IL.

4KATE VENDOR NITE

By Vikki Medlik

On November 14th team 4KATE held a vendor night at my home in Tinley Park to raise money for NF. The six vendors that were there, for everyone's shopping pleasure, have donated a percentage of their sales to NF. We also held a raffle and had a \$5 Wheel of Fortune game where every spin was a winner.

Vendor night was the brain child of my sister-in-law Kim Daniels. I have to say I was very nervous about holding this event and I was afraid it would turn out to be more work than what we could raise. I am happy to say it turned out surprisingly well and was worth all the effort. Not only did we raise over \$1,000 for NF but I met 2 other moms (hi Dena, hi Sue - Thanks for coming!) who have children with NF that live within a few blocks of me. To me that was the best part of the evening.

The turn out for the event was great and everyone had a good time. We had a lot of people say that they would attend something like this again so we are considering doing the vendor night again next year around the same time.

The vendor night left us with a very positive outlook and has made me a little more at ease about proceeding with other events. So, please keep an eye out for more events we will be hosting - Bowling on February 20, 2010 and a Sock Hop possibly in May. If you are interested in attending or for more information you can contact me at vmedlik@sbcglobal.net.

Neurofibromatosis, Inc. Midwest
PO Box 1923
Lombard, IL 60148

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



630-932-8111
1-800-322-NFNF (IL Only)
Fax: 630-932-8119
E-Mail: info@nfmidwest.org

Midwest Area NF Clinic Information

For more doctors go to www.nfinc.org

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 Tongsgard, MD (Director)
773-702-6487

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

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

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.org
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

