



NF Inc. Minnesota E-News

From the NF Inc. Minnesota Chapter

March 2006

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NF Inc. Minnesota Chapter Meeting to be held on April 22nd

NF Inc. Minnesota is joining together with Children's Hospitals and Clinics of Minnesota and Gillette Children's Specialty Healthcare to present the first meeting of Family Connections, a networking and resource group for families and people with Neurofibromatosis, Tuberous Sclerosis, and other related conditions.

Join us for an exciting and relaxed morning! A speaker from PACER will discuss Healthcare Advocacy and how to obtain the right care for children and adults with NF.

DATE: Saturday, April 22, 2006

TIME: 10:00 – 11:30 a.m.

PLACE: Children's Hospital and Clinics of Minnesota – St. Paul Campus, Gardenview Building (by Red Ramp), and room number 1053/1054. Free weekend parking in the underground Green Ramp on Smith Avenue.



Bring the whole family! Childcare and refreshments will be provided – please let us know if you can come and how many children you will be bringing. **To RSVP and for more information**, please email or call [Elizabeth Sigveland](#) at (651) 220-6745.

Your Help Is Needed: Promote NF Research

You can help us promote government funded NF research by writing to your Senators and Congressmen. We are requesting

\$25 million for FY2007 from DOD to continue the Army's highly successful Neurofibromatosis Research Program (NFRP). We are also seeking inclusion of Report Language on NF research in the Labor, Health and Human Services, and Education Appropriations Bill. **A sample letter and Congressional listing is provided below.**

- [Sample Letter](#)
- [Find Your Elected Official](#)
- [2005 House HHS](#)

NF Inc. Minnesota encourages you to write your Senators and Congressmen! Please email John Everett at johne@cipmn.org and let him know that you contacted your officials today!

Understanding Neurofibromatosis: An Introduction For Patients and Parents



The second edition of the Understanding Neurofibromatosis pamphlet by Dr. James Tongard is now available from the Illinois Neurofibromatosis Chapter.

This information is for families who have recently been told that one member may have Neurofibromatosis (NF). When you were first told about NF, you may only have heard the word Neurofibromatosis and nothing else. As some of the initial shock wears off, you will want to know more about this disorder or group of disorders because NF really is more than a single disorder. This pamphlet will explain what NF is, what causes NF, what your family will need to do about it, and who can help.

To order your copy, contact Illinois Neurofibromatosis, Inc., PO Box 1923, Lombard, IL 60148, (630) 932-8111 or (800) 322-NFNF.

NF 1 and Tibial Dysplasia Study

The division of Medical Genetics at the University of Utah has been involved in Neurofibromatosis type 1 (NF1) research since 1983, when Dr. John Carey collaborated with investigators at the University of Utah to map the NF1 locus. Subsequently Dr. Viskochil, working with Ray White, cloned the NF1 gene. Since that time we have been heavily involved in various research projects to better understand the biology of NF1 and how to improve the lives of individuals with NF1. One of our interests over the past 8 years has been the bone problems that are observed in NF1. These include scoliosis, long bone bowing with or without fracture and non-healing (pseudarthrosis), sphenoid wing dysplasia, bone cysts, and short stature.

Dr. Carey is leading a multicenter study through the Intermountain Shriners Hospital looking at the day to day life issues in NF1 individuals with tibial bowing/pseudarthrosis. Dr. Viskochil is leading a study looking at the molecular aspects of the bone of the leg from patients with tibial pseudarthrosis with undergo surgery. These studies are currently underway.

Dr. Carey and Dr. Viskochil hope that through their current and future studies they will be able to find answers to help develop treatments for the bone problems associated with NF1. They are indebted to the NF1 individuals and families for participating in this research.

We are now almost two years into the study and are looking for more people to participate. We need:

- Adults who have NF1 and Tibial Dysplasia
- Children (ages birth to 18) who have Tibial Dysplasia
- Children (ages birth to 18) who have NF1

If interested in participating in this study, please contact Jeanne Sibert or Susan Geyer at Shriners Hospital for Children, Intermountain, (801) 536-3500.

NF International Summer Camp Program

New Camp (Ages 12-18)

July 15 – 21, 2006

Campers will spend a few days at Camp K, enjoying the ropes course, arts and crafts as well as fun day trips to see AAA baseball games, visit 12,000 foot Snowbird mountain, lots of swimming, hiking, horse back riding, camp fires, dances, a talent show, fishing and more. A unique feature of our camp is the visit to the University of Utah's Eccles Genetic Science Learning Center, take a tour of a working genetics lab, perform hands-on experiments and have the chance to talk one-on-one and ask questions of an NF researcher. The kids always enjoy being scientists for a day and learning about NF and genetics in a fun, interactive way.



Reunion Camp (for kids who previously attended Camp)

July 22 – 28, 2006

The purpose of this camp is to reunite old campers. Reunion camp gives an opportunity for friends to catch up. Campers will enjoy activities similar to those of the New Camp and also participate in new and revised program.

For more information, contact the [Children's Tumor Foundation](#) at (800) 323-7938.

NF Inc. Announces Camp New Friends July 16-22, 2006

NF, Inc., in collaboration with Children's National Medical



Center, conducts Camp New Friends, a summer camp for those affected by NF, in Adamstown, Maryland. The next Camp New Friends is July 16 - 22, 2006. Children 7 through 15 years of age, with NF1 or NF2, are encouraged to apply as campers. Those 18 or older may apply as Counselors or as Counselors-in-Training.

To request further information or register for Camp New Friends 2006, please print, complete, and return our [camp form \(pdf\)](#). You can also obtain more information about the camp by emailing NFMidAtlantic@aol.com; or contact Sandy Cushner-Weinstein, PT, LCSW-C, at Children's National Medical Center, by phone at 202-884-5142, or via email at scushwei@cnmc.org (please use "NF Camp" in the subject line). Further details regarding the camp will be posted here as they become available -- please check back!

May is National NF Awareness Month

We invite you to help us spread the word about Neurofibromatosis and the important work that we do here at NF Inc. Minnesota. Help us educate the community by inserting a short paragraph about NF in your church bulletin or your local paper. For more information on how you can help, please contact NF Inc. Minnesota at (651) 225-1720.

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NF Inc. Minnesota PO Box 18246
Minneapolis, MN 55418
(651) 225-1720