



# NF Inc. Minnesota E-News

From the NF Inc. Minnesota Chapter

April 2006

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



## You're Invited!

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, come and share your knowledge with other families – and have fun doing it!

- Child supervision will be provided – please RSVP how many children will be attending as well as their ages

**DATE:** Saturday, April 22, 2006

**TIME:** 10:00 – 11:30 a.m.

**PLACE:** Children's Hospitals and Clinics of Minnesota – St. Paul Campus, Gardenview Building (by Red Ramp), Room numbers 1053/1054. Free weekend parking in the underground Green Ramp on Smith Avenue. [\\*See enclosed map\\*](#)

**TOPIC:** A speaker from PACER will come and discuss Healthcare Advocacy, and how to obtain the right care for children and adults with NF.

- Refreshments will be served – please RSVP so we can be sure to have enough

for everyone!

To RSVP and for more information,  
Please call Elizabeth Sigveland at 651-220-  
6745

### **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. The following information can be inserted or edited into your church bulletin or local paper:

Neurofibromatosis is a potentially debilitating genetic disorder that causes tumors to develop in nervous system tissues. NF is the most common neurological disorder caused by a single gene, affecting one in 4,000 births. Fifty percent of all people with NF have no family history of the disorder. A person with NF has a 50:50 chance of passing the defective gene on to his/her child. NF is worldwide in distribution and affects both genders, all races and ethnic groups equally.

During Neurofibromatosis Awareness Month, we invite people and organizations throughout the world to join us in observing this important occasion by learning more about neurofibromatosis, which affects so many people in our communities.

Neurofibromatosis Inc – Minnesota is a nonprofit organization dedicated to individuals and families affected by neurofibromatosis. NF Inc – Minnesota provides information, education and support to individuals and families with NF, the

medical community and the general public.

For more information, contact NF Inc. Minnesota at 651/225-1720 or visit our website at [www.nfincmn.org](http://www.nfincmn.org).

## **Management of the Patient and Family with Neurofibromatosis 2: A Consensus Conference Statement**

### **Introduction**

Neurofibromatosis 2 (NF2) is an autosomal dominant disease whose hallmark is the development of bilateral vestibular schwannomas (VS).

Schwannomas also occur on the other cranial, spinal and peripheral nerves. Other manifestations are intracranial, spinal and optic nerve sheath meningiomas, and low grade ependymomas and gliomas of the central nervous system (CNS). A consensus conference on NF2 was held in October 2002 at the request of the UK Neurofibromatosis Association, with particular emphasis on vestibular schwannoma (VS) surgery. In this report, we review current knowledge about NF2 and present the consensus statement. For a copy of this article, please contact Terri at [tskor@earthlink.net](mailto:tskor@earthlink.net).

### **The Dr. Mia MacCollin Fellowship**



The Dr. Mia MacCollin Fellowship has been established by NF, Inc., NE to provide for a Fellow to work alongside the NF Clinic Director, Dr. Scott Plotkin, at Massachusetts General Hospital in Boston. Recognizing

the lack of physicians who specialize in

neurofibromatosis, the Fellowship is a means to educate physicians to insure accurate diagnosis and care management for NF patients.

Dr. Mia MacCollin began seeing patients at the Neurofibromatosis Clinic at Massachusetts General Hospital in 1993 and shortly thereafter became the Clinic Director. A highly regarded authority on neurofibromatosis, she has conducted extensive NF research at the Massachusetts General Hospital Neuroscience Center and published numerous papers on NF1, NF2 and Schwannomatosis. Dr. MacCollin is leaving the Boston area in June and will be moving to Oregon.

### **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 base-ball 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

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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](mailto: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](mailto: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!

**Thunderbird Charities and  
Neurofibromatosis, Inc. of Arizona  
Presents the NF World Round UP!**

NF Inc. of Arizona and Thunderbird Charities presents the NF World Round UP! in Prescott, Arizona on July 21- 26, 2006. The main purpose of the camp is to give the teens a wonderful summer experience, while at the same time giving them the opportunity to be with peers who also have NF and share their experiences, hopes, and fears. Camp activities will include; horseback riding, zip line, sporting activities, swimming and hiking.

For more information or an application, contact Justin Nesmith at 480.945.9650 or email [camp@nfaz.org](mailto:camp@nfaz.org).

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