



be informed

2009 Neurofibromatosis Symposium

Saturday, October 17, 2009

8:00 AM to 4:00 PM

Northern Illinois University
Hoffman Estates, Illinois

Join us for an exciting day in which you will meet other families dealing with NF and hear specialists tell us about the latest progress in NF research, current treatment options, and practical advice for living with NF.

TOPICS AND AGENDA*

8:00 – 9:00 am Registration, Continental Breakfast and Socializing

NF General Session

- **Living with NF: Personal Perspectives**— Marie Drew and Mike Forbes, **Neurofibromatosis Fighters**
- **NF Overview**—Cynthia Hingtgen, MD, PhD, University of Indiana

NF-1 Breakout

- **Attention, Executive Function, and Learning Disabilities in Neurofibromatosis Type 1**
Scott Hunter, PhD, University of Chicago, Associate Professor of Psychiatry, Behavioral Neuroscience & Pediatrics
- **Cognitive Issues in Neurofibromatosis Type 1**
Bonnie Klein-Tasman, PhD Associate Professor of Psychology at the University of Wisconsin-Milwaukee
- **Survey of NF-1 Clinical and Basic Research (Panel)**
Panel includes: James Tonsgard, MD, PhD, University of Chicago
Robert Listernick, MD, Children's Memorial Hospital
Cynthia Hingtgen, MD, PhD, University of Indiana
Fawn Leigh, MD, Massachusetts General Hospital
Yuan Zhu, PhD, University of Michigan

Topics to include, but not limited to: - **Plexiform trials and imaging**
- **Neurofibromatosis Type 1 Animal Models**
- **Genetics of NF and NF "look a likes"**
- **Pain in NF-1**

NF-2 Breakout

- **Preclinical Mouse Models of Neurofibromatosis Type 2: The Potential for Prediction.**
Marco Giovannini, MD, PhD House Ear Institute, University of Southern California Los Angeles
- **The Use of Cyberknife on NF-2 Tumors**
Robert Leiberson, MD, Stanford University Medical Center, CA
- **NF-2 Research at Massachusetts General Hospital**
Fawn Leigh, MD, Massachusetts General Hospital

Teen Session (for children ages 12 to 18)

- **Living with NF**
Kelly Lowry, PhD, Child Psychologist, Children's Memorial, Chicago
This optional session will be provided sometime during the day for children enrolled in the Teen Group. The permission form on the registration sheet must be filled out and signed in order for a child to participate. If we don't have a permission form they will attend the younger children's group while the *Living with NF* session is going on.

***Topics and order of events are subject to change**

KIDS GROUPS

CHILDRENS GROUP (Ages 5-11) - A fun day is provided for children ages 5-12. This childcare will be provided FREE of charge, but you must make a reservation.

TEEN GROUP (Ages 12-18) Bring the older kids for a day of fun, games and the optional Living with NF session. This is a great chance for your kids to meet others with NF. Siblings are also welcome! We ask that you donate \$10 per child, if possible. Reservations required.

Please let us know if your children have any special needs so that we can accommodate them better.



Photo courtesy of Rick Guidotti, Positive Exposure

ACCOMMODATIONS AND TRANSPORTATION

HOTEL Chicago Marriott Northwest, 4800 Hoffman Boulevard, Hoffman Estates, Illinois 60192 has a block of rooms reserved under NF, Inc. Midwest for \$85, plus tax. A shuttle bus is available to the NIU Building. Limited rooms are available. To make a reservation, call 1-800-395-5921 or 1-847-645-9500.

TRAVEL BY CAR See map in this brochure for directions.

TRAVEL BY AIR NIU is 20 miles from O'Hare International Airport; 40 miles from Midway Airport.

SPECIAL NEEDS

- The National Association of Development Disabilities Council might be able to help if you are financially unable to afford travel and registrations fees. Each state has its own Council with differing requirements and amounts of aid available. To find out more contact the Council in your state by calling 202-347-1234 or go to www.naddc.org.
- The NF Midwest Symposium will have CART services for the hearing impaired that will follow the shared and NF-2 sessions only. If you need CART services for the NF-1 session, please let us know.
- If you have any other special needs, please let us know as soon as possible.

ADDRESS AND DIRECTIONS

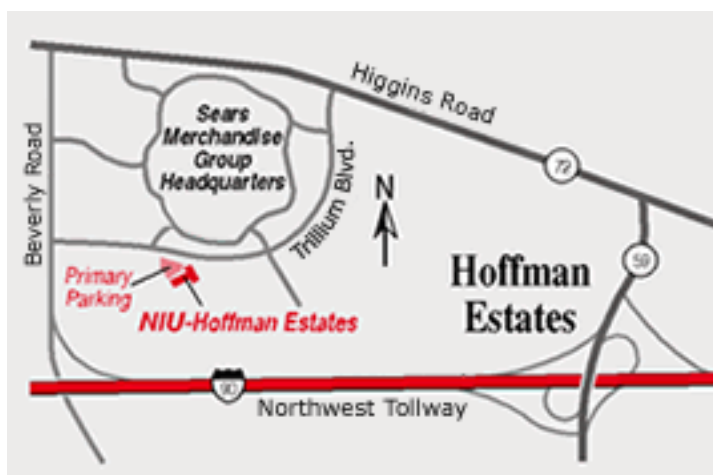
Northern Illinois University (NIU)—Hoffman Estates
5555 Trillium Blvd.
Hoffman Estates, IL 60192
Phone: (847) 645-3000

From I-90 Eastbound

Exit Route 59 north (left) to Higgins Road (IL Rt. 72). Turn west (left) onto Higgins Road. Turn south (left) onto Beverly Road. Turn east (left) onto Trillium Boulevard. The NIU Hoffman-Estates is on the right, across from the Sears Merchandising Group Headquarters.

From I-90 Westbound

Exit Beverly Road north (right) to Trillium Boulevard. Turn east (right) onto Trillium Boulevard. The NIU Hoffman-Estates is on the right, across from the Sears Merchandising Group Headquarters.



Note: You cannot turn left into the NIU lot from Trillium Blvd. You should come in from Beverly Road.

REGISTRATION

Please list the names and addresses of all attendees in your party below and include ages of any children.

Registration deadline is October 10, 2009

(please print clearly)

Name _____ Phone _____ Email _____

Address _____ City _____ State ____ Zip _____

Please include the names and addresses of ALL attendees below. Use a separate piece of paper if necessary.

REGISTRATION: FEE \$20.00/person (includes lunch); Children ages 5-11 Free; Teens ages 12-17 \$10 Donation suggested (Financial assistance available)

of Adults _____ # of Teens _____ # of children _____ Ages of children _____

Special Needs _____ Captioning needed? _____

Our interest is in NF-1 _____ NF-2 _____ Other _____

Please publish our contact information in a directory to be distributed to all attendees? _____

LIST OF ATTENDEES

I understand that NF, Inc. Midwest, its presenters, and/or news organizations may be photographing and videotaping this event. I agree that any photographs, videotapes or other images containing my likeness, or that of my children, are the sole property of the photographer and NF, Inc. Midwest. I authorize the foregoing accounts, for publicity, in promotional material, and for any other lawful purpose. All attendees signatures are required below and represent acknowledge of the above statement.

Name _____

Name _____

Address _____

Address _____

Phone # _____ Age _____

Phone # _____ Age _____

Signature _____

Signature _____

Name _____

Name _____

Address _____

Address _____

Phone # _____ Age _____

Phone # _____ Age _____

Signature _____

Signature _____

PAYMENT

Enclosed is total payment of \$ _____ for _____ adult (\$20) and _____ child (\$10)

We accept: check MasterCard Visa Amer. Express Card # _____

Expiration Date _____ 3DC (from back of card) _____

Signature _____

Please accept our donation of \$ _____ to help others attend.

Mail your registration form and payment to:
NF Inc., Midwest
 PO Box 1923
 Lombard, IL 60148-1923

OR fax or phone in your registration to:
 Phone: 630-932-8111
 Fax: 630-932-8119
 Email: info@nfmidwest.org

TEEN SESSION WAIVER

I would like my child(ren) _____ age(s) _____
Name(s)

to participate in the special session for adolescents ages 12 to 18. I understand this session will be moderated by a professional and that this may include information specific to their disorder and will allow for open discussion between the participants.



Parent's Name Printed

Signature

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

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PAID
Mt. Prospect, IL
Permit #65



630-932-8111
1-800-322-NFNF
Fax: 630-932-8119
E-Mail: info@nfmidwest.org
www.nfmidwest.org

be informed!



**Neurofibromatosis
2009**

Fall Symposium

**October 17, 2009
Hoffman Estates, Illinois**

**New Location
&
New special session for teens**