



be informed

2010 Neurofibromatosis Symposium

Saturday, October 16, 2010
8:00 AM to 4:00 PM

Northern Illinois University
Hoffman Estates, Illinois

Register
now!

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*

Please check out www.nfmidwest.org/symposium2010 for possible changes or additions.

8:00 – 8:45 am Registration, Continental Breakfast and Socializing

- **Introduction to Neurofibromatosis**
David Gutmann, MD, PhD, Washington University, MO
- **Overview of Public Benefits**
Health & Disability Advocates, Chicago

The following breakout sessions run concurrently.

Breakout #1/NF-1 Focus

- **Recent Advances in NF1 Research and Clinical Trials**
David Gutmann, MD, PhD, Washington University, MO
James Tonsgard, MD, PhD, University of Chicago
- **Removal of Fibromas through Electro-Desiccation**
Hubert Weinburg, MD, Plastic Surgery, New York
- **Promoting Resiliency**
Sandra Cushner-Weinstein, MSW, Children's National Medical Center, Washington DC
and Brainy Camps/Camp New Friends
This will run concurrently with the NF2 breakout and will be optional to those with an NF2 interest

Breakout #2/NF-2 Focus

- **mTor/P13K Research Update**
Vijaya Ramesh, PhD, Massachusset's General Hospital
- **NF2 Clinical Perspectives and Patient Care Delivery**
Matthias Karajannis., MD, New York University Medical Center
Andrew Fishman, MD, Northwestern Memorial Hospital, Chicago
- **Open Discussion: *What are the components of a patient friendly, efficient NF2 clinic?***

Teen Session (for children ages 12 to 18)

- **Kids Speaking Out**—*Sandra Cushner-Weinstein MSW, Social Worker, Children's National Medical Center, Washington, D.C.* This optional session will give NF children and their siblings a chance to talk about NF, living well or anything they'd like. It is for the children only and will run approximately 1 hour. No parents will be allowed. 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 *Kids Speaking Out* session is going on. If you'd like your younger child to attend please call us for permission.

**Topics are not in order of the actual schedule and may be 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 12-17) 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 Midwest for \$89, 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

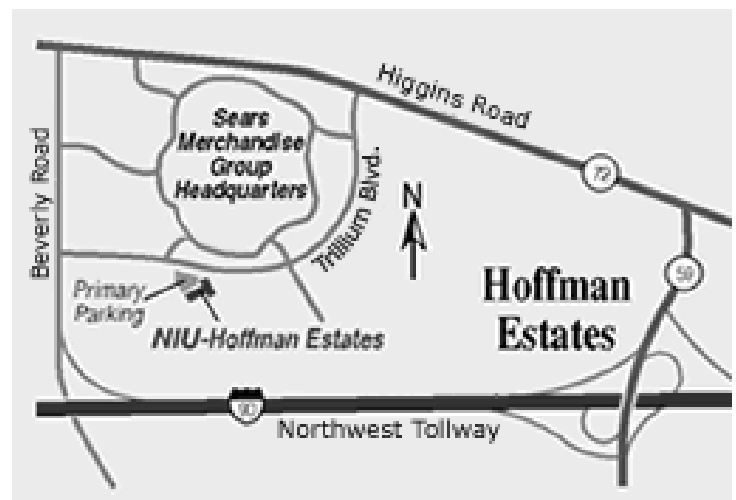
Northern Illinois University (NIU)—Hoffman Estates
5555 Trillium Blvd.
Hoffman Estates, IL 60192
Phone: (847) 645-3000

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 8, 2010

(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 (Financial assistance available)

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

Special Needs _____ Captioning needed? _____

May we publish your name, address and phone in a directory of attendees to be distributed to other attendees? _____

LIST OF ATTENDEES

I understand that NF 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 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 acknowledgement 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 our donation of \$ _____ to help others attend.

Mail your registration form and payment to:

NF Midwest
PO Box 1923
Lombard, IL 60148-1923

OR fax or phone in your registration to:

Phone: 630-932-8111
Fax: 630-932-8119

TEEN SESSION WAIVER

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

Name(s)

to participate in the special session, *Kids Speaking Out*, for adolescents ages 12 to 18. I understand that 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 Midwest
PO Box 1923
Lombard, IL 60148

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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

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**Neurofibromatosis
2010
Fall Symposium**

**October 16, 2010
Hoffman Estates, Illinois**