



2014 Neurofibromatosis Symposium

Register

Saturday, October 25, 2014

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 living with NF and hear specialists tell us about the latest progress in NF research, current treatment options, and practical advice.

The day includes continental breakfast, lunch, and afternoon snack.

Register online at www.nfmidwest.org/symposium2014

TOPICS AND AGENDA*

Please check out nfmidwest.org/symposium2014 for possible changes or additions.

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

[CART](#) (Captioning will be provided for MOST sessions, email us for more info at info@nfmidwest.org)

- **Introduction to Neurofibromatosis** — [Robert Listernick](#), MD, Lurie Children's Hospital, Chicago
- **Motivational Speaker** — [Dave Evans](#), NF1 Fighter
- **Patient Reported Outcomes (PROs): What they are and how they affect clinical trials and treatment** — [Staci Martin](#), PhD, National Institutes of Health; [James Tonsgard](#), MD, University of Chicago
- **New Approaches to Pain Management** — Staci Martin, PhD, National Institutes of Health
- **Volumetric Assessment of NF Related Tumors** — [Eva Dombi](#), MD, National Cancer Institute
- **Transitioning to Adult Care** — [Parag Shah](#), MD MPH, Lurie Children's Hospital and LaRabida Children's Hospital
- **Learning Disabilities in Adults with NF1** — [Megan Scott](#), PhD, University of Chicago plus a panel of NF1 Adults with LD
- **Malignant Peripheral Nerve Sheath Tumors (MPNST) in NF1** — Eva Dombi, MD, National Cancer Institute
- **NF2 Basics, Research Updates, and NF2 Clinical Care at Loyola** — [Nikolas Mata-Machado](#), MD Loyola Medical Center, Chicago
- **Mutations and Biological Behavior of NF2-Associated Schwannomas and Meningiomas and Potential Therapies** — [Long-Sheng Chang](#) PhD, Ohio State University College of Medicine

Teen Special Session (for all children ages 12 to 18 with permission)

- **Transitioning to Adult Care** — Parag Shah, MD MPH, Lurie Children's Hospital and LaRabida Children's Hospital

****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 5-11. 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 a special teen session (optional). 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.

Teens, with permission, may attend a session especially for them about transitioning to adult care.



ACCOMMODATIONS AND TRANSPORTATION

HOTELS [Hyatt Place Chicago/Hoffman Estates](#), 2750 Greenspoint Parkway has a block of rooms reserved under NF Midwest for \$90.00, plus tax. A shuttle bus will provide transportation to and from the NIU Building upon request. Limited rooms are available. To make a reservation, call 847-839-1800 press 3 for Reservation and ask for NF Midwest or go to www.nfmidwest.org/hotel.

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.

TRAVEL FROM CHICAGO This year we would like to try to help people who may not have cars travel to the symposium from the city. If you are traveling from the city and need help please contact us so we can see if special arrangements can be made.

SPECIAL NEEDS

- The NF Midwest Symposium will have CART services for the hearing impaired that will follow the shared and NF2 sessions only. If you need CART services for the NF1 session, please let us know.
- Financial assistance is available
- 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

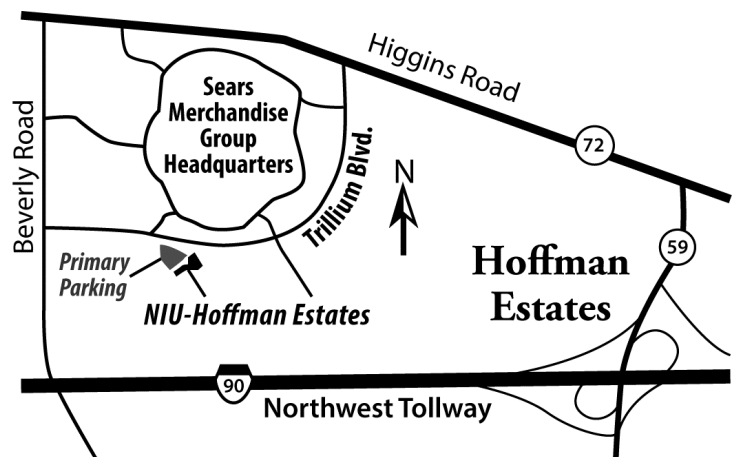
Phone: (847) 645-3000

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 21, 2014

Register online at www.nfmidwest.org/symposium2014

(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 includes continental breakfast, lunch, afternoon snack, socializing and knowledge!

\$25.00/person; Children ages 5-11 Free; Teens ages 12-18 \$10

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

Special Needs _____ Captioning needed? _____

Which breakout will you be attending? _____ NF1 _____ NF2 (Required)

May we publish your name, address and phone in a directory of attendees to be distributed to other attendees? _____ Yes _____ No

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.

Name _____

Name _____

Address _____

Address _____

Phone # _____ Age _____

Phone # _____ Age _____

Name _____

Name _____

Address _____

Address _____

Phone # _____ Age _____

Phone # _____ Age _____

PAYMENT

☐ Enclosed is total payment of \$ _____ for
_____ adult (\$25) and _____ teen (\$10)

We accept: ☐ check ☐ MasterCard ☐ Visa ☐ Amer. Express

Name on Card _____

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

473 Dunham Rd Suite 3
St. Charles, IL 60174

OR fax or phone in your registration to:

Phone: 630-945-3562

Fax: 630-689-1213

CHILDREN'S SESSION WAIVER

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

Name(s)

to participate in the special teen session about transitioning to adult care to be presented by Dr. Shah.



Parent's Name Printed

Signature

Neurofibromatosis Midwest

473 Dunham Road

Suite 3

St. Charles, IL 60174



630-945-3562

info@nfmidwest.org

www.nfmidwest.org



iNFormed4NF
www.nfmidwest.org

24th Annual Neurofibromatosis Symposium

**October 25, 2014
Hoffman Estates, Illinois**

***Learn from the EXPERTS!
Share with the EXPERIENCED!***

Leading physicians and researchers will teach and update us on NF while we socialize, strengthen and learn from each other.

Don't miss it!