

# November 9th, 2019

Saturday, 8:00 am to 4:30 pm; Northern Illinois Building, Hoffman Estates, IL

## Neurofibromatosis Symposium & iNFo Fair!

Presented by NF Midwest

*You don't want to miss  
this opportunity!*

*Join us for a day of learning and sharing at our 2019 NF Symposium and iNFo Fair. There will be plenty of opportunities to meet others. Plus, we will have special tables for extra iNFo and questions.*

### TOPICS AND AGENDA\*

---

8:00 – 9:00 am Registration, Continental Breakfast, and Socializing  
CART (Captioning will be provided for MOST sessions. Email us for more info at [info@nfmidwest.org](mailto:info@nfmidwest.org).  
Speakers may be added or changed. Look for updated information at [www.nfmidwest.org/symposium](http://www.nfmidwest.org/symposium).

### SCHEDULED PRESENTATIONS

*(Topics are NOT in order of the actual schedule or in any order of importance and may be subject to change)*

- **New NF1, NF2, and Schwannomatosis New Diagnostic Criteria**
- **Regional Clinic Info and Trial Updates**
- **Encouraging Social Connections and Adaptive Behaviors. How Parents Can Help!**—Sandra Cushner-Weinstein LICSW, Children's National Medical Center in Washington, DC; Director of Brainy Camps and Camp New Friends
- **Gene Therapy/Gene Editing**—Robert Kesterson, PhD, University of Alabama, Department of Genetics

### NF Type 1 Topics

- **Surgical Management of Cutaneous Neurofibroma: Current Therapy and Future Directions** – Lu Le, MD PhD, University of Texas Southwestern Medical Center
- **Drug Treatment of Cutaneous Neurofibromas: Past, Present, and Future**—Ashley Cannon, MS, CGC, PhD, University of Alabama
- **Translational Research Update on Cutaneous Neurofibromas**—Matt Steensma, MD, Spectrum Health, Francis S Collins Scholar
- **Research Update: Photodynamic Therapy on Cutaneous Neurofibromas**—Medical College of Wisconsin
- **Optic Gliomas/Research and Treatment Update**—Robert Listernick, MD, Lurie Children's Hospital and NF Clinic, Chicago, IL

### NF Type 2 Topics

- **Hearing Rehabilitation in NF2: Auditory Brainstem and Cochlear Implantation**—Kevin Peng, MD, Otologist/Neurotologist, House Clinic. Los Angeles, CA
- **Discoveries from Synodos for NF2**—Long-Sheng Chang, PhD, Nationwide Children's Hospital and The Ohio State University College of Medicine
- **NF2 BioSolutions: Accelerating Gene Therapy Research for Neurofibromatosis Type 2**—John Manth, NF2 BioSolutions Board Member

## INFORMATION TABLES

---

We will have tables of various iNformation on topics related to NF, plus opportunities to visit with our presenters to ask more questions. We will be bringing virtually all the material we have available, with copies for you to take. Examples of iNformation provided includes (there will be much more!)...

- NF Clinics and their clinical trials
- New Health Supervision Guidelines for Children with NF1
- Care Guideline for Adults with NF1
- Participating in Research
- Learning Disabilities and School Issues
- Medical Imaging for NF1: Radiation Exposure
- Autism Spectrum Disorder Symptomatology in Children with NF1
- Insurance Coverage for Neurofibroma Removal by NF Midwest
- Procedure Codes for Removing a High Quantity of Neurofibromas
- Info on Various Complications in NF1 including...
  - Optic gliomas, seizures, scoliosis, pain, vascular disease, brainstem tumors
- Making a Difference—Raising Funds and Awareness

## KIDS GROUPS

---

**CHILDRENS GROUP (Ages 5-12)** 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 13-18)** Bring the older kids for a day of fun, games, and just hanging out. 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.

The kids will be served pizza for lunch.

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



## 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 sessions, please let us know.
- Financial assistance is available from NF Midwest for people from our region who are in need and we waive the registration fee for people traveling more than 90 miles. Our region includes Illinois, Wisconsin, Indiana, Iowa, Kentucky and the eastern half of Missouri. If you are not from our area, you will have to contact your local NF organization or another institution that may be able to assist you. Please, call us if you need assistance from us or in reaching another organization.
- If you have any other special needs, please let us know as soon as possible.

## ACCOMMODATIONS AND TRANSPORTATION

---

**HOTELS** A block of rooms is available at the Chicago Marriott Northwest/Hoffman Estates for \$89 a night. A shuttle can take you to and from the venue if needed. Make a reservation at [www.nfmidwest.org/hotel](http://www.nfmidwest.org/hotel) or call (847) 645-9500 and ask for the NF Midwest group rate. There are also many other hotels in the area.

**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** 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.

**TRAVELING MORE THAN 90 MILES** If you are traveling more than 90 miles and are in our region, or NF Upper Midwest's region, (this includes Illinois, Indiana, Iowa, Kentucky, Minnesota, Missouri, North Dakota, South Dakota, or Wisconsin) as a service to both of our communities we will waive your fees. Use the coupon code "90miles".

## ADDRESS AND DIRECTIONS

---

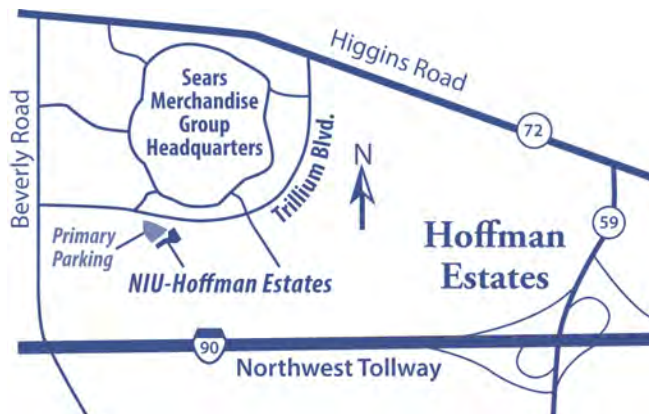
**Northern Illinois University (NIU)—Hoffman Estates**  
5555 Trillium Blvd.  
Hoffman Estates, IL 60192  
Phone: (847) 645-3000

### 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 will have to make a U-turn or come in from Beverly Road.

## FRIDAY NIGHT GATHERING!

---

**This year we are holding a special social event  
on Friday night before the symposium!**

Details are still in the works, but the event will be free and probably at the hotel.  
Please, mark during registration whether or no you are interested in attending.

## REGISTER ONLINE!

---

Please register online at  
**[www.nfmidwest.org/symposium](http://www.nfmidwest.org/symposium)**  
or  
call the office at **630-945-3562**.

**Registration deadline is November 6, 2018**

**Please register as early as possible!**

**Symposium Registration Fees include Continental Breakfast, Lunch, & Snack**

**\$25.00—per adult over 18**

**\$10—Teens ages 13-18**

**FREE—Children ages 5-12**

**Bowling—\$15**

Children under 5 are not allowed, though we MAY make an exception for 4 year olds (please call).

*Note: The cost for the symposium and bowling are well below our actual costs. We do all we can to make this event affordable for the NF Midwest community. If you'd like to help defray the costs, please make a donation at [www.nfmidwest.org/donate](http://www.nfmidwest.org/donate).*

**Help NF Education by donating at [www.nfmidwest.org/donate](http://www.nfmidwest.org/donate)**



**Neurofibromatosis Midwest**

473 Dunham Road, Suite 3  
St. Charles, IL 60174

630-945-3562

info@nfmidwest.org

www.nfmidwest.org

**Register Now!**

...Or donate to support the  
symposium and future  
educational events for NF!



# Neurofibromatosis Symposium & iNFo Fair!

Presented by NF Midwest

## November 9th

Saturday, 8:00 am to 4:30 pm

Northern Illinois Building

Hoffman Estates, IL

***Plus Friday Night  
Gathering!***

Socialize, strengthen and learn from  
Leading experts and each other.

***Don't miss it!***

