

# October 20th, 2018

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

Plus

Bowling and Buffet

Fun Night

Friday, October 19



# Neurofibromatosis Symposium & iNFo Fair!

Presented by NF Midwest

Join us for a day of learning and sharing at our 2018 NF Symposium and iNFo Fair. There will be plenty of opportunities to meet others. Plus, we will have special tables for extra iNFo information and questions.

**Includes continental breakfast, lunch, and afternoon snack.**

## 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)*

- **Resiliency Through Stress Management and Lifestyle Modification Skills** — Presented by Eric Riklin, doctoral student in clinical psychology, who has a craniofacial condition and has endured 25 surgeries.
- **Supporting Well Siblings** — Presented by Jill Weissberg-Benchell Ph.D., Prof. of Psychiatry and Behavioral Medicine at Northwestern University's Feinberg School of Medicine and Lurie Children's Hospital of Chicago.
- **Challenges of Finding Adult Care** — This will be an open discussion with a panel of physicians, and patients and caregivers in the audience. (Will run concurrently during Supporting Well Siblings)
- **Understanding Employment Rights** — Presented by Hannah Walsh, Employment Rights Helpline Attorney at Equip for Equality.

### NF Type 1 Topics

- **Living with NF1-What should you know?** — Neha Patel, MD, pediatric neurooncologist from the University of Wisconsin, Madison and Director of the NF1 clinic at American Family Children's Hospital will provide a detailed overview on NF1 and the care her clinic provides to NF1 children.
- **Care Guidelines for Adults with NF1** — Presented by David Stevenson MD, Professor at Stanford University in the Division of Medical Genetics and contributor to the new guidelines for the care of adults with NF published by American College of Medical Genetics and Genomics.
- **Strategies for Working Executive Functioning Through Play** — Presented by Alix Tonsgard the Early Learning Specialist at the DuPage Children's Museum.

### NF Type 2 Topics

- **Facial Retraining** — Presented by Jackie Diels, OT, a leading authority on facial neuromuscular retraining (NMR), a non-surgical therapeutic approach to the treatment of facial paralysis, paresis and synkinesis.
- **NF2 in Pediatrics** — Robert Listernick, MD from Lurie Children's Hospital will share his clinical experiences and advice for NF2.
- **NF2 Current and Upcoming Clinical Trials** — James Tonsgard, MD from the University of Chicago will update the group on current and upcoming NF2 clinical trials.

## 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...

- Participating in Research
- Learning Disabilities and School Issues
- Info on Various Complications
- Pain
- NF Clinics and How to Find a Doctor
- Neurofibroma Removal
- Making a Difference—Raising Funds and Awareness

## 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 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.



***We have a special visitor this year!***

### HANDS-ON PLAY EXHIBITS

This year Jill Samonte, Accessibility & Inclusion Specialist from the DuPage Children's Museum, will be on the premises, and in the kid's room, with hands-on portable and tabletop exhibits for the children and parents to interact with such as super big Tinker Toys.



## 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.

## ACCOMMODATIONS AND TRANSPORTATION

**HOTELS** Hyatt Place Chicago/Hoffman Estates, 2750 Greenspoint Parkway, has a block of rooms reserved under NF Midwest for \$89.00, 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 and ask for the NF Midwest group rate or go to [www.nfmidwest.org/hotel](http://www.nfmidwest.org/hotel). 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. Look for that option at online registration.

## ADDRESS AND DIRECTIONS

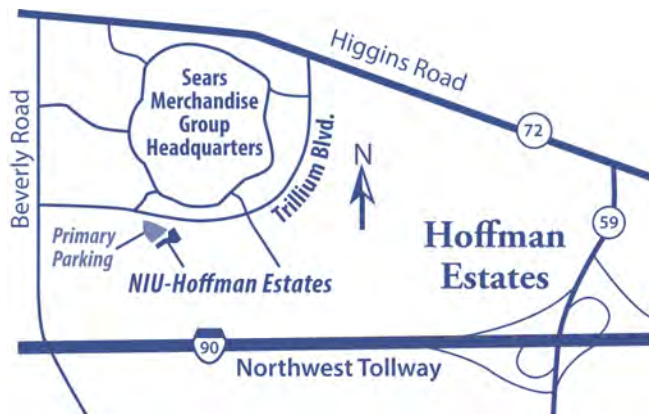
**Northern Illinois University (NIU)—Hoffman Estates**  
5555 Trillium Blvd.  
Hoffman Estates, IL 60192  
Phone: (847) 645-3000

### 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 BOWLING AND BUFFET!

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



Please join us on October 19th for  
**A FUN NIGHT OF BOWLING AND BUFFET**  
from 6:30 to 8:30 at the Main Event, 2575 Pratum Avenue, Hoffman Estates, IL. This will cost an additional \$15 but includes the buffet, bowling, and shoes! Register when you register for the symposium (see below)!

## 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 October 17, 2018**

**Please register as early as possible!**

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

**\$25.00—per adult over 18**

**\$10—Teens ages 12-18**

**FREE—Children ages 5-11**

**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!



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### ***Plus October 19th Bowling and Buffet!***

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

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

