

**Kick-off Event: Eat, Meet, then Have a Seat!**  
**First of the Keith Keirse Learning Series**

We'll start off with a spaghetti dinner for all. Afterwards, while kids and teens participate in a fun, interactive program led by Johnny and Adam's Rhythm and Music, adults will participate in a session led by Dr. William Rosenberg,



Neurosurgeon and Founder of the Center for the Relief of Pain.

Sunday, March 10, 2019  
Matt Ross Community Center  
8101 Marty St.  
Overland Park, KS 66204  
5:00 p.m.

No charge, but reservations are required.

Click [here](#) to reserve your spot!



# MIDWEST CITY, OKLAHOMA



NEUROFIBROMATOSIS  
NETWORK  
Coffee Chat 

## Join us!

The Neurofibromatosis Network and our Oklahoma advocates invite you to join us as we come together to share our stories, make new friends, and learn more about neurofibromatosis.

Contact Breanna at  
[bbronowskistutsman@nfnetwork.org](mailto:bbronowskistutsman@nfnetwork.org) or  
630-510-1115 for more information, or  
RSVP at the link below!

**Saturday, March 2nd**

Beginning at 4:00pm

**Santa Fe Steakhouse**

7101 SE 29th St  
Midwest City, OK 73110

**RSVP** at [www.nfnetwork.org/coffee-chat-with-the-nfnetwork-ok/](http://www.nfnetwork.org/coffee-chat-with-the-nfnetwork-ok/) or  
call the NF Network 630-510-1115!

Neurofibromatosis Network • 213 S. Wheaton Avenue, Wheaton, IL 60187 • 630-510-1115

[www.nfnetwork.org](http://www.nfnetwork.org)

Join the NF Network and our Oklahoma advocates as we come together to share stories, meet new friends, and learn more about neurofibromatosis. Come visit with us at 4:00 p.m. on Saturday, March 2, at Santa Fe Steakhouse in Midwest City, OK. We look forward to seeing you there! **To RSVP, contact Breanna at [bbronowskistutsman@nfnetwork.org](mailto:bbronowskistutsman@nfnetwork.org).**

## Up on the Hill

The halls of Capitol Hill were filled with voices of NF advocates on February 11 and February 12, 2019. Organized by The NF Network, the group was 80+ strong and included people from more than 20 states. Advocates met with their Representatives and Senators, urging them to support NF research through the National Institutes of Health and the Congressionally-Directed Medical Research Program.

Two volunteers from NF Central Plains travelled to Washington, D.C. this year as participants: Rachel Mindrup and Sharon Loftspring. In total, they visited nearly 30 Congressional offices covering Kansas, Nebraska, Colorado, Oklahoma, and parts of Missouri. Their goal was not only to secure \$15 million of funding for NF research, but to raise awareness by sharing stories from the legislators' constituents.

Results of The NF Network's collective efforts will be posted as soon as they're made known. Many thanks to those of you who wrote letters about your NF experience. Your voices matter!

## Research Update: NF and Sleep Issues

Researchers at Washington University School of Medicine in St. Louis have been studying the sleep problems often associated with NF1. Learning disabilities and attention problems are also common in children with NF1, and both may be worsened by poor sleep patterns.



Using mice genetically-modified to mimic NF, researchers sought to understand why some children have difficulty falling or staying asleep, and others don't. They fitted onto the mice miniature versions of the caps people wear for sleep studies, enabling the researchers to measure the brain waves and identify sleep patterns.

Dr. David Gutmann, head of the NF Center there and the study's senior author, said that a better understanding of the cells and proteins that are involved will lead to better ways to treat insomnia. For more details about the study, go to <https://nfcenter.wustl.edu>.