



NF Central Plains

dedicated to awareness, education, and support
for those affected by Neurofibromatosis



Fall Fun for All, Don't Forget to Register and Join Us!!

Join us at the Overland Park Arboretum and Botanical gardens for NF Central Plains' Fall social gathering.

We have reserved a pavilion so we can meet as a community for snacks, activities, and surprises before setting off to explore all there is to see.

Sunday, October 28, 2018

2:00 p.m. (you can stay and explore the park until closing 5:00 p.m.)

179th & Antioch Rd

Overland Park, KS

This one's on us! NF Central Plains will cover the cost of admission for you and up to 5 family members or friends. Additional guests are welcome to attend for \$3 per individual.

To reserve your spots, send an email by October 21, to nfcentralplains@gmail.com with your name and the number of guests attending so we can have an accurate head count.

SEE YOU THERE!

NF1 and NF2 Research Updates

A recent study of brain scans performed on children with NF1 at Washington University School of Medicine found that the frequency of brain tumors in the NF1 population was more than three times higher than previously estimated. Brain MRI scans of children with NF1 characteristically show unidentified bright spots (“UBOs”) that are generally thought to disappear in teenage years. Until now, it was unclear whether these abnormalities should be a cause for concern. Researchers recently developed a set of criteria to distinguish tumors from other bright spots. Applying these criteria will help doctors identify probable tumors. This does not mean that all NF1 children should be scanned regularly, however. It does mean that doctors will be able to interpret MRI scans more accurately and determine which abnormalities are most likely tumors in need of monitoring.



Founded in June 1, 2018, NF2 BioSolutions is a 100% volunteer-run nonprofit organization dedicated to finding an effective treatment or cure for NF2 through the use of gene therapy and immunotherapy. Its core team is composed of people who have been directly affected by NF2 through personal or family experience. The organization also aims to raise awareness of NF2.

According to its website, NF2 BioSolutions uses two main approaches with respect to gene therapy for NF2. The first is to use a viral vector to introduce a “suicide” gene into tumor cells. Once this gene is incorporated into tumor cells, it induces the cell to die, a process called apoptosis. The second approach is to introduce a new and functional copy of the NF2 gene which encodes for the protein Merlin.

For more information, visit nf2biosolutions.org

Meet Jenina Sorenson



When you meet Jenina Sorenson, you can't help but notice her enthusiasm and bright outlook. Jenina was born in Columbia, Missouri, but moved to Springfield while in high school. She earned her degree in elementary education from Central Missouri State University, and has worked in the education field ever since.

Her career started in the Kansas City public schools where she taught for four years before working as an instructional coach for other teachers in the Hickman Mills school district.

It was during Jenina's first years of teaching that neurofibromas began forming. Her dermatologist diagnosed her with NF, and referred her to a neurologist. He discovered a mass in her pituitary gland, unrelated to the NF. In 2012, Jenina underwent surgery to remove it. Days before her surgery, she completed her masters degree in elementary school administration where she earned a 4.0!

Looking for adventure, Jenina accepted a teaching position in Dubai where she taught third grade at an American school. "It was an amazing experience," she recalled.

Jenina returned to Kansas City, and is currently a certified physical education instructor for Kindergarten through fourth graders at the Hope Leadership Academy, a charter school in Kansas City, Missouri. She especially loves working with eight and nine year-olds.

Although Jenina has struggled with learning disabilities and anxiety, she manages to stay positive. When asked how she does it, she replied that she surrounds herself with friends who are supportive, and she exercises regularly. She is also currently enrolled in a clinical trial focusing on stress management for NF patients. Realizing that "everyone has a story" has been beneficial.

Q: How do I meet other NF individuals and families outside of Kansas City?

NF, Inc. Central Plains wants to meet you where you are! Several members of the NF community have expressed an interest in hosting activities in different locations around Kansas City proper, and we heard you. NF, Inc. Central Plains is coming your way.



We'll do the work of arranging a meeting to brainstorm about events that interest the NF families in your area. **BUT WE NEED YOUR HELP.** If you live in the vicinity of Lawrence or Lee's Summit, please send your contact information to nfcentralplains@gmail.com. Someone will get in touch with you with more details on how you can get involved and meet local NF individuals and families.

If you are interested in starting a group in your area, let us know. We can help try to make it happen!

Advocacy Success!

It's official! Thanks to your advocacy efforts, we are pleased to announce that \$15 million has been allocated to NF research through the Congressionally Directed Medical Research Program for Fiscal Year 2019. The NF Network has been advocating for continued research through the National Institutes of Health and the CDMRP for over 20 years with continued success, securing over \$600 million during that time.

But this can't be achieved without your help. Over the next several months, we will be asking you to create letters sharing your personal story with your representatives in Congress. They will be hand-delivered when the NF Network advocates make the trip to Capitol Hill in February. Be on the lookout for more detailed instructions to help you get started.

