



NF Central Plains

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



Ten Years of Great Steps Make Us NF Strong!!

Over 200 people gathered at Macken Park in North Kansas City on Saturday, June 2, 2018, for the 10th Annual Walk for NF. Chaired by Jill Meyer and Shelly Chavez, this year's event included some old favorites plus some new features: face painting, a live auction, carnival-like games, hoola-hoop contests and a DJ. Those with NF were honored with medals, and every participant received a mini-bundt cake as a special anniversary take-away. Yvonne Glass, event coordinator from the NF Network, recognized Brandi Marley for her family's efforts in getting the Walk off the ground years ago, and the current chairs, sponsors and volunteers for their dedication.

Over \$20,000 plus dollars in proceeds raised from the successful event will help fund the NF Network's advocacy efforts and NF Central Plains' patient outreach. Please support our generous sponsors: Excel, Carmax, Joshua's Pest Control, Nothing Bundt Cakes, Blue Cross Blue Shield, University of Kansas Health Systems, State Farm, Validity, Goodfellas, and Consolidated Communications.



To view photos from the day of the event use the following link: <https://leelajphotography.smugmug.com/RileysRun/i-s3nC5BN>

NF1 and NF2 Research Updates

A working group of NF1 experts has recently completed and published new guidelines for the clinical care of adults with NF1. The report covers several possible manifestations of NF1, summarizes them, and provides recommendations for optimal care. To view the entire article, visit <https://rdcu.be/MFHJ>.

Scientists of diverse areas of expertise were convened by the Children's Tumor Foundation to discover new therapeutic strategies to treat schwannomas and meningiomas in NF2 patients. Their findings can be viewed at: https://www.eurekalert.org/pub_releases/2018-06/ctf-sfn061418.php



Inspiration In Person

Meet Keith Keirse. Why? Because he is an inspiration.

Keith grew up in Butler, Missouri, and attended Central Missouri State for college where he studied business management. For nearly 30 years, he worked in the real estate title insurance industry.

Keith spent most of his adult life in Kansas City, but took a detour in 2002. He moved to Arkansas to enjoy life in a beautiful lake house in a wooded community with his wife, Jan. They moved back to Kansas City in 2009 to be closer to their daughter and two grandsons.

In the spring of 2015, when he was well into his 60's, Keith was diagnosed with NF. Looking back at his health history, he says, there were several indicators: Lisch nodules, cafe au lait spots, and various nerve tumors. "Nobody ever connected the dots," commented Jan. Keith underwent major surgery at Mayo Clinic then to remove a large tumor in the upper part of his chest and shoulder, resulting in the loss of his right arm.



Recently, when he received a less-than-positive prognosis from his doctor, Keith turned lemons into lemonade. He and Jan threw a party. Over 160 people attended, representing all aspects from Keith's life — college friends, veterans, fellow volunteers, colleagues and civic leaders — all came to roast and toast this amazing individual.

Have his medical issues and NF diagnosis stopped Keith from leading a full life? Absolutely not! When asked what the "secret sauce" is that fuels his positive outlook, Keith replied, "I have a

wonderful wife who pushes me, and I mean that respectfully.” Jan added, “We both have a deep faith.” Keith and Jan agree that they have lived a blessed life, and have chosen not to waste time and energy on things they can’t change. Whatever happens is part of the “cycle of life,” they explained.

Keith wants his legacy to be that he helped those facing medical challenges to look at life through a positive lens. He and Jan have attended several NF Central Plains events, and in the short time we’ve known them, they have already done just that.

Pose a Question

Question: What is the difference between a *Cutaneous Neurofibroma* and a *Plexiform Neurofibroma*?

Answer: *Cutaneous or Dermal Neurofibromas* include both subcutaneous (under the skin) and cutaneous (on top of the skin). The former can appear in toddlers, whereas the latter don’t show up before puberty, and often much later. They can number from a handful to hundreds. They are benign but can be tender.

Patients may opt for removal by surgery or electrodesiccation.

Plexiform Neurofibromas grow internally on nerves in 30%-50% of NF1 cases. They can arise in childhood and grow throughout life. Although they are largely benign, they can become malignant. They may require surgery, although this can cause nerve damage and must be done by a surgeon experienced with NF1.



SUBMIT YOUR QUESTIONS to nfcentralplains@gmail.com. (Please limit your questions to topics of general interest as NF Central Plains is not qualified to give individual medical advice)

Opportunities to Participate in Research Studies

Resiliency in adults — Researchers at Massachusetts General Hospital are looking for adults with NF1 or NF2. For more information, contact Christopher Funes at cjfunes@mgh.harvard.edu.

Reading disabilities — Researchers at Vanderbilt University are looking for NF1 patients, ages 8-21. For more information, contact Ariel Leonard at 615.875.5534.

Attitudes toward facial transplants — Researchers at Stevenson University are looking for NF patients. For more information, contact Rivka Glaser at rglaser@stevenson.edu.