

# THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER

*Making a Difference Together*

## WASHINGTON UNIVERSITY NF CENTER RESEARCHERS GENERATE A NEW MODEL FOR CHILDHOOD BRAIN TUMORS

### WELCOME!

The Washington University Neurofibromatosis (NF) Center is composed of clinicians and laboratory scientists focused on accelerating the pace of scientific discovery and its application to the care of individuals with NF.

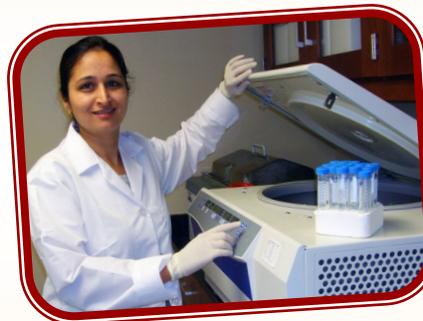
Our mission is to galvanize and promote research on NF, achieving significant breakthroughs in the diagnosis and treatment of this condition. We believe that these breakthroughs are possible when researchers, medical professionals, and families partner together.

The Washington University Neurofibromatosis (NF) Center comprehensive care team offers detailed patient evaluations and assessments. They work seamlessly with families, referring physicians, allied health professionals and other agencies to deliver the most advanced medical services available to children and adults affected by NF.

# NF CENTER

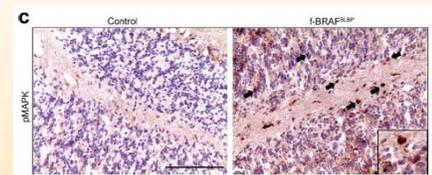
Washington University  
Neurofibromatosis Center

Visit our website at: <http://nfcenter.wustl.edu>



Aparna Kaul, PhD, and her colleagues have recently generated a new mouse model for pediatric low-grade brain tumors similar to those that arise in children with NF1. Molecular studies from the laboratory of Dr. David Gutmann and other's previously identified the genetic cause for the most common brain tumor in children, called pilocytic astrocytoma (glioma). Using a variety of methods, these teams showed that these tumors result from a specific change in the DNA that joins the halves of two genes to create a new "fusion" gene that causes cells to grow faster and form gliomas.

In the most recent study, Dr. Kaul and her associates generated a mouse in which this fusion gene is expressed in the brains of mice. They show that expression of this fusion gene in the mouse brain causes an increase in the number of glial cells in the specific brain region where the majority of these tumors arise.



The availability of this unique mouse strain will facilitate the generation of new mouse brain tumor models to expedite the identification and testing of promising therapies to treat these common cancers in children.

## SAVE THE DATE!

CLUB NF  
OCTOBER 5, 2013

Join us at fuNFest in  
Vandalia, IL!

BEAT NF  
NOVEMBER 1, 8, & 15, 2013

Join us for our jazz music  
therapy program for children  
with NF1 ages 3-5!

CLUB NF  
DECEMBER 7, 2013

Join us for a cooking and  
table manners event at  
Schnuck's!

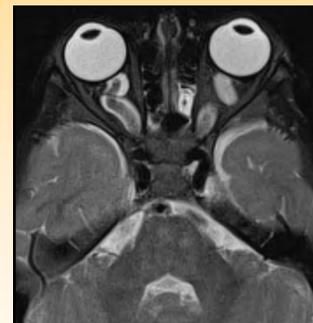
## RESEARCH AT THE WASHINGTON UNIVERSITY NF CENTER

### WASHINGTON UNIVERSITY NF CENTER RESEARCHERS PUBLISH STUDY ON OPTIC NERVE TORTUOSITY IN CHILDREN WITH NF1

Optic nerve tortuosity, or thickening of the optic nerves, is often reported in children with NF1; however, it is not clear whether this finding means that a tumor will eventually form.

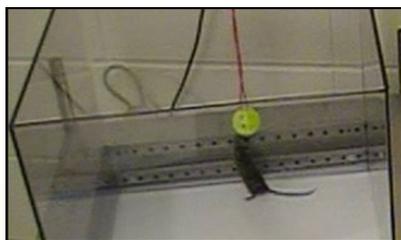
In the currently study, Joyce Ji, a medical student at the Washington University School of Medicine sought to find the best way to measure optic nerve thickness in children with NF1. To do so, she developed an optic nerve tortuosity index.

She found that all children with NF1 had thicker optic nerves than did children without NF1, and that the tortuosity index was a superior way to measure optic nerve thickness in children.



### WASHINGTON UNIVERSITY NF CENTER RESEARCHERS CHARACTERIZE NEW BEHAVIORAL PROBLEMS IN *Nf1* MOUSE MODEL

David F. Wozniak, PhD and his colleagues at the Washington University NF Center collaborated on a recent study aimed at identifying and characterizing the spectrum of behavioral deficits in NF1. Using a novel genetically-engineered *Nf1* mouse strain, their findings revealed abnormalities in many different types of behaviors, ranging from exploring new objects in the environment to odor preferences.



In this report, Wozniak joined forces with Charles F. Zorumski, MD, the Samuel B. Guze Professor and Head of the Department of Psychiatry, and David H. Gutmann, MD PhD, the Donald O. Schnuck Family Professor. This multi-disciplinary effort employed numerous methods, including electrophysiology and neurochemistry techniques, to characterize these behavioral deficits. The information garnered from this initiative will be invaluable for the design and interpretation of ongoing mouse studies aimed at treating these problems first in small-animal models and later in people with NF1.

### WASHINGTON UNIVERSITY NF CENTER RESEARCHER INVESTIGATES PAIN BEHAVIOR IN *Nf1* MICE

Daniel O'Brien, a graduate student in Dr. Robert Gereau's laboratory in the Department of Anesthesiology recently published a study on pain and itch behavior in a mouse model of neurofibromatosis type 1.

Using mice with an inherited mutation in the *Nf1* gene, Dan and his colleagues showed that sensitivity and scratching following exposure to painful or itchy stimuli were normal in these mice. This work suggests that reduced *Nf1* gene function (as seen in people with NF1) is not sufficient to increase pain or itch sensation in mice. Future studies will focus on understanding how pain or itch sensitivity is controlled by the *Nf1* gene.

The manuscript appeared in a recent issue of the *Journal of Pain*.

LEARN MORE ABOUT  
RESEARCH AT THE  
WASHINGTON UNIVERSITY  
NF CENTER



## FOR OUR FAMILIES

### WASHINGTON UNIVERSITY NF CENTER DANCE NF PROGRAM A HUGE SUCCESS



On Saturday August 10, 2013 the Washington University NF Center, funded by the St. Louis Children's Hospital Foundation, had its first ever Dance NF event.

Dance NF was created to teach families how to use dance to work on delays often seen in children with NF1. Designed by one of the Washington University NF Center summer interns, Sam Karlow, Dance NF proved to be a tremendous success with our families. "I wanted to share the benefits of dancing with our families. Dancing exercises your mind and body and connects you to others. And it's fun!" says Sam, a rising junior at Washington University who studies psychology as well as dance. She plans to attend medical school in the future.

Sam spent her summer researching dance therapy as well as the delays children with NF1 experience so she could create a tailor-made event for our families. Her final product included multiple games that encouraged movement, flexibility, balance and attention. While Sam worked with the children, the parents had the opportunity to meet with Sarah Ann Patz, MA, who spoke with parents about the importance of encouraging body awareness and core strength through dance.



In addition to using dance therapy techniques, Sam decided to give her event a circus theme. She invited St. Louis Children's Hospital clowns to the event who played with the children and gave them glitter tattoos. Each child also made an animal mask and chose an animal to portray for their final dance performance. "I didn't want the final performance to be a *performance* with memorized steps and perfect meter," says Sam,

"Dance therapy is about encouraging body awareness and being comfortable in your own skin. I wanted the kids to feel like there were no wrong answers when it comes to movement."

### AUGUST 2013 CLUB NF: LEARNING AND GROWING TOGETHER



On August 3, 2013, the Washington University Neurofibromatosis (NF) Center in collaboration with the St. Louis Children's Hospital Foundation hosted their August Club NF Event: Learning and Growing Together! at the Des Peres Lodge. The August program focused on gross motor skills and balance through gym games and swimming.

The morning began with the children playing balance games in the gym with the therapists, while the parents had an opportunity to engage in a Family Think Tank session to discuss opportunities for expansion and improvement in the Washington University NF Center. Following this, the children returned and all shared lunch.

After lunch, families and therapists headed to the swimming pool! Games played in the pool included collecting as many floating ping



## WASHINGTON UNIVERSITY NF CENTER EVENTS

### FUNFEST: JOIN OUR RAGE DONATE AGAINST NEUROFIBROMATOSIS

fuNFest is an annual family festival sponsored by Amanda and Brain Walk, a Washington University NF Center family, in support of research at the Washington University NF Center. Each year the event features food, drinks, music and games including a yearly favorite—"cow patty bingo". In addition, this year the Washington University NF Center will host their October Club NF event at fuNFest! Stop by our booth to play games with us and to learn about what it is like to be a child with NF1.

Join the Walk family and the Washington University NF Center at Gatch Lake in Vandalia, IL on October 5, 2013 from 12PM—6PM for a great time and help us spread NF awareness!

For more information, please email Kirsten Brouillet at [brouilletk@neuro.wustl.edu](mailto:brouilletk@neuro.wustl.edu) and join the fuNFest Facebook page and Facebook event!

**FUNFEST**  
JORDAN

JOIN OUR RAGE DONATE AGAINST NEUROFIBROMATOSIS



### FOLLOW OUR BLOG!

Check out the new section of our website dedicated to keeping you up-to-date with patient stories, research advances and Washington University NF Center events.

### BEAT NF

Brought to you by the Washington University NF Center in collaboration with the Music Therapy Department from Maryville University, Jazz St. Louis and the St. Louis Children's Hospital Foundation, we are proud to announce a Music Therapy Program for children with NF1 ages 3 to 5 and their parents. Join us the first three Fridays in November to work on motor skills, social skills and attention skills through music.

Space is limited to 12 children for this initial event. If you are interested in learning more, please contact Kirsten Brouillet at [brouilletk@neuro.wustl.edu](mailto:brouilletk@neuro.wustl.edu) TODAY!



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