

THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER

Exceptional Care through Groundbreaking Research

GOVERNOR NIXON AND MAYOR SLAY PROCLAIMS MAY 2014 NF AWARENESS MONTH

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.

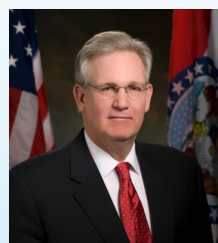


Jay W. Nixon, governor of Missouri, and Francis G. Slay, Mayor of St. Louis, proclaimed May 2014 Neurofibromatosis Awareness Month in Missouri.

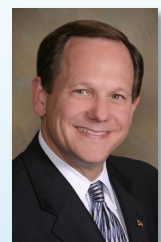
In doing so, Governor Nixon and Mayor Slay acknowledged all individuals living with NF, as well as the work researchers at the Washington University NF Center undertake daily in an effort to find new and better treatments for individuals living with NF.

Additionally, the proclamation highlighted the Washington University NF Center Research Symposium, held on May 16, 2014, which celebrated two decades of outstanding research in NF at the Washington University NF Center.

We extend our gratitude to Governor Nixon and Mayor Slay for helping us raise NF Awareness. Please join us in celebrating NF Awareness throughout the year.



Governor Nixon



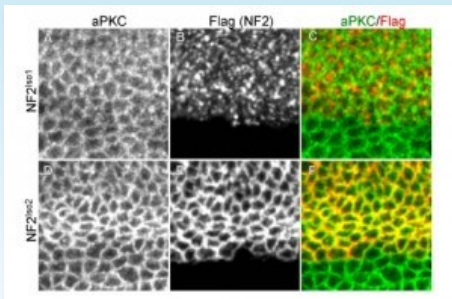
Mayor Slay

SAVE THE DATE!

<p>CLUB NF AUGUST 2, 2014</p> <p>Join us for swimming at Des Peres Lodge!</p>	<p>CLUB NF OCTOBER 4, 2014</p> <p>Club NF attends the annual fuNFest in Vandalia, IL!</p>	<p>BEAT NF FALL 2014 SESSION</p> <p>Join us at the St. Louis Gym Centre for jazz music therapy!</p>
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RESEARCH AT THE WASHINGTON UNIVERSITY NF CENTER

NEW STUDY USES THE FRUIT-FLY TO UNDERSTAND *NF2* GENE FUNCTION



Investigators at the University of Chicago employed the common house fly (*Drosophila*) as a model system for determining how genetic mutations in the neurofibromatosis type 2 (*NF2*) gene disrupt its function. Dr. Richard Fehon and his colleagues, including David H. Gutmann, MD, PhD at the Washington University NF Center, used *Drosophila* to test whether the normal human *NF2* gene as well as patient-derived *NF2* gene mutations could rescue defects observed in flies lacking *Nf2* gene function. Their exciting findings were recently reported in the journal PLoS One.

The use of *Drosophila* as a model organism offers many opportunities to understand how the *NF2* gene functions in the intact animal.

WASHINGTON UNIVERSITY NF CENTER TRAINEE PRESENTS RESEARCH FINDINGS AT NATIONAL MEETING

Graduate student, Anne C. Solga, MS, has been completing exciting new work on the role of the tumor microenvironment in dictating NF1-associated glioma growth. Ms. Solga, a graduate student in the laboratory of David H. Gutmann, MD, PhD, was chosen to showcase her studies at the 2014 American Association for Cancer Research Meeting in San Diego this week.

Immune system-like cells, called microglia, are one of the important cell types responsible for mediating the growth of NF1-associated optic gliomas in mice. Anne, working with former post-doctoral fellow, Winnie Pong, PhD, employed RNA-sequencing to identify genes expressed in these glioma associated microglia. This discovery effort was performed in collaboration with Dr. Elaine R. Mardis and her team at the Genome Institute at Washington University.

Anne found new growth factors made by these microglia, which she is currently exploring in more detail. Her ongoing investigations are aimed at determining how these proteins control tumor growth as an initial step towards developing treatments that block their tumor-promoting activities.



iPAD APP THERAPY CLINIC LAUNCHED!



Some children with NF1 experience developmental delays that can make some aspects of school and everyday life difficult. One way to address these issues is to use technology, such as the iPad, to enable access to alternative opportunities for education and personal growth. But how can you learn about everything the iPad can do to help your child?

Our Occupational Therapist, Nicole Weckherlin, has begun offering iPad instruction and training sessions for children and families with NF1. The goal of these private sessions, made possible through St. Louis Children's Hospital Therapy Services, is to teach families with NF1 how to use the iPad (or other tablets that support the same apps) to improve productivity and communication skills while promoting independence.

While the Apps for NF1 section of our website is a fantastic online resource for apps to address developmental delays often experienced by children with NF1, a session with Nicole Weckherlin, OTR/L promises to be an opportunity for personalized recommendations for the best apps and iPad utilization for your individual child.

MAKING A DIFFERENCE TODAY!

COURTNEY'S CORNER: PROMOTING YOUR CHILD'S SLEEP HYGIENE

As the sun stays up later and summer nears, bedtimes often become much more difficult to enforce. Compound this fact with emerging data that children with NF1 display increased rates of poor sleep patterns and you have a recipe for nightly battles and sleepy children.

Children are naturally curious and full of energy; however, with this energy comes a lack of insight about when the fun and exploration should stop and the body should be given time to rest, repair and learn. This is where parents step in! Our job is to reassure our children that the fun will return tomorrow, but that our bodies need lots of time to recover from daily activities.

Setting and maintaining bedtimes that are consistent is called sleep hygiene. In many regards, sleep hygiene is as important as brushing teeth and bathing. Sleep is the time when we repair our cells, grow our muscles, lay pathways in our brain and process what we have learned during our day. Without enough sleep, our bodies simply aren't given the chance to develop and grow to their full potentials.



How can you tell if your child is getting enough sleep? Children should wake by themselves in a relatively good mood. If waking up is a struggle, then bedtime may be too late. Sometimes fatigue can be displayed by poor behavior or decreased attention. If your child becomes more impulsive, less attentive or more physical around dinner time or is difficult to calm for bed, bedtime may be too late. Although a child can never be forced to fall asleep, there are several tips you can follow to ease the transition to bedtime and set your child up for a successful night sleep:

- No caffeine, especially close to bedtime. Remember, many sodas (even several varieties of root beer) have caffeine as does tea.
- Establish a quiet bedtime routine and follow it everyday.
- Make bedtime the same time every night and try to wake up at the same time every morning (even on the weekend).
- When kids get too tired, they have a hard time falling asleep. Pay special attention to your child during the evening hours. As soon as they are rubbing their eyes, having more trouble controlling their emotions or are more impulsive, realize that they may be tired.
- A child's room should be for sleeping. A nice rule of thumb is that all things that need a cord (including a TV and video games) should be in public areas of the home, not bedrooms.
- If you think your child is not getting enough sleep, move their bedtime earlier by about 15 minutes at a time. You will not likely convince a child to go to bed at 7:30PM in one day if they are used to staying up until 9:00PM.



Recommended Hours of Sleep by Age Group*

Infants	14 to 15 hours per night
Toddlers	12 to 14 hours per night
Preschoolers	11 to 13 hours per night
Grade-school children	10 to 11 hours per night
Teenagers	9 to 10 hours per night

**Recommended by the American Academy of Sleep Medicine.*

Courtney Dunn, PT DPT is a Physical Therapist in the Washington University NF Center

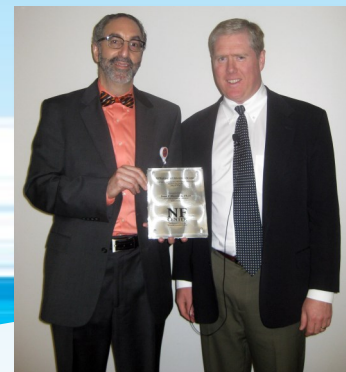
WASHINGTON UNIVERSITY NF CENTER EVENTS



Dr. Holtzman, Chair of Neurology, gave the introductory remarks



Dr. Epstein spoke about heart defects and NF1



Dr. Morrison spoke about NF1-associated tumors

2014 WASHINGTON UNIVERSITY NF CENTER RESEARCH SYMPOSIUM WAS A TREMENDOUS SUCCESS

The second Washington University NF Center Research Symposium, held on Friday, May 16, 2014, was a tremendous success with over 180 medical professionals, researchers and families in attendance.

Keynote speakers Jonathan Epstein, MD, and Sean Morrison, PhD, discussed their research on NF1-associated heart disease and NF1-associated tumors, respectively, while Kent Robertson, MD PhD, described ongoing clinical trials for plexiform neurofibromas in NF1.

Researchers from the Washington University NF Center spoke about the genetics of brain tumors, personalizing medicine for individuals with NF1, understanding developmental delays in NF1, and the progress of the NF1 Patient Registry Initiative (NPRI).

During this day-long event, medical professionals, researchers and families had the opportunity to learn about the exciting research being performed at Washington University.

We extend our sincerest gratitude to all who presented at and attended the 2014 Washington University NF Center Research Symposium.

STAY CONNECTED!

WEBSITE



FACEBOOK



YOUTUBE



We want to hear what you think! For questions or to submit ideas for future Washington University NF Center newsletters, please email: [Alicia Vallorani at vallorania@neuro.wustl.edu](mailto:vallorania@neuro.wustl.edu)