

THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER

Making a Difference Together

TEAM NF PRESENTS CLINICAL MANAGEMENT MODEL AT THE 2013 CTF CONFERENCE

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.



Washington University
Neurofibromatosis Center

Several members of the Washington University NF Center were chosen to present their approach to the evaluation and care of children with neurofibromatosis type 1 (NF1). Anne Albers, Dr. Courtney Dunn, Nicole Weckherlin and Dr. Jill Isenberg coordinated a wonderful mini-symposium during the annual Children's Tumor Foundation meeting in Monterey, California.

At this conference, Anne Albers provided an excellent overview of our program while Jill Isenberg related our recent studies on attention deficit and executive function. Nicole Wecherlin presented her initiatives using iPad apps as therapy for children with behavioral and cognitive problems. Finally, Courtney Dunn outlined the unique resources developed by Team NF staff, including Club NF.

Congratulations to all the presenters for a fantastic session!



SAVE THE DATE!

BEAT NF

JULY 29—AUG 2, 2013

A one week music therapy intensive for our children ages 3 to 5 and their parents!

CLUB NF

AUGUST 3, 2013

Join us for swimming followed by a lunch (provided by us) to share ideas for expansion of the Washington University NF Center activities!

DANCE NF

AUGUST 10, 2013

A 3 hour Dance Therapy intensive for our children ages 5 to 10 and their parents!

RESEARCH AT THE WASHINGTON UNIVERSITY NF CENTER

WASHINGTON UNIVERSITY NF CENTER RESEARCHERS PUBLISH NEW STORY ON THE ROLE OF THE MICROENVIRONMENT IN NF1 BRAIN TUMOR FORMATION

Previous studies from the Washington University Neurofibromatosis (NF) Center and other research groups have shown that brain tumors contain both cancerous and non-cancerous (stromal) cells. Current brain tumor therapies are focused on stopping the growth of the cancer centers, but largely ignore stromal cells. One of these stromal cell types is an immune system-like cell, called microglia. Microglia constitute as many as half of the cells in NF1-associated brain tumors

To determine whether microglia are important for NF1-associated brain tumor formation, Winnie Pong, PhD, a postdoctoral researcher in the laboratory of David H. Gutmann, MD PhD, used *Nf1* genetically engineered mouse strains. She found that the microglia in these tumors express a particular protein (CX3CR1) important for their movement and migration. She then partly disabled the *CX3CR1* gene in *Nf1* optic glioma mice, and found that impairing microglia function delayed brain tumor development.

These exciting results establish a critical role for these stromal cells in the formation of optic nerve gliomas. This report was recently published in the journal *Annals of Neurology*.

WASHINGTON UNIVERSITY NF CENTER RESEARCHERS PUBLISH STUDY ON HEIGHT ASSESSMENTS IN CHILDREN WITH NF1

Abby Hollander, MD and her colleagues recently published a study that examined short stature in children with NF1. Heights were recorded from children with NF1, their parents and their siblings, allowing Hollander to calculate each child's expected height based on his or her parent's heights. The study showed that children with NF1 were not only shorter than the general population, but were also shorter than their expected heights and shorter than their unaffected siblings. This research firmly establishes a central role for the *NF1* gene in determining height in children with NF1.

This study was recently published in the *Journal of Child Neurology*.

NF1 GENOME PROJECT REACHES 300 PARTICIPANTS

In late December 2010, the Washington University Neurofibromatosis (NF) Center established the NF1 Genome Project (NF1GP). Now, two and a half years later, the NF1GP has over 300 participants. The Washington University NF Center extends its gratitude to the individuals with NF1 who have donated DNA. These samples will allow Washington University NF Center investigators to study how changes in DNA predispose certain people with NF1 to specific medical problems.

Although the NF1GP has reached a significant point in its history, it is still vitally important for those with NF1 to continue to provide additional DNA samples to this project. We have set a goal of 1,000 specimens over the next several years.

With exciting advances in the field of genome science, now is the time to work together, researchers, clinicians and families alike, to find the best possible treatments for people with NF1.



GET INVOLVED IN RESEARCH!
Check out our current clinical studies

THANK YOU, WASHINGTON UNIVERSITY NF CENTER FAMILIES!

WASHINGTON UNIVERSITY NF CENTER FAMILY HOLDS 5K RUN FOR NF



Brooke Chelew always knew her younger sister had Neurofibromatosis Type 1 (NF1), but she never worried about it until the day her sister had a seizure. From that moment on, Brooke made it her mission to teach herself and her community about NF1.

In February, Brooke, along with her mother Kim, first approached the Washington University NF Center about sponsoring a 5K Race to raise awareness about NF. Quickly, their ideas blossomed into the first annual *Quest for a Cure: Run for NF*.

Aided by a core team of young women from local high schools including Ursuline Academy, St. Joseph's Academy, Cor Jesu Academy and Crossroads College Preparatory School, Brooke and her family planned and organized this exciting event. Despite the dreary weather on race day, April 27, 2013, 196 individuals came out to Queeny Park to run and show support.

We thank Brooke, her family and her team for their generous support of the Washington University NF Center!



iNFFamily[®]

Check out the new section on our website dedicated to talking to kids about NF1!

WASHINGTON UNIVERISTY NF CENTER FAMILY RAISES NF AWARENESS

The Walk family partnered with Megan Diekemper, owner of Diekemper Photography, in order to raise awareness about NF.

Every year, Ms. Diekemper hosts an event called *Tutus & Ties*, where children have their pictures taken in tutus or ties, and the proceeds are donated to a worthy cause.

When Amanda and Brain Walk heard about this event, they contact Diekemper Photography, explaining what NF is and how much it would mean to them if their cause could be supported.

Touched by their story, Ms. Diekemper was thrilled to help support NF awareness, and made the Washington University NF Center the focal point of her 2013 *Tutus & Ties* event.

We thank the Walk family and Megan Diekemper for their generous support of the Washington University NF Center!



WASHINGTON UNIVERSITY NF CENTER EVENTS

The Washington University NF Center is launching multiple exciting initiatives this summer and we hope you will be apart of them!

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 one week Music Therapy Intensive for children with NF1 ages 3 to 5 and their parents. Join us everyday July 29—August 2, 2013 from 9:30AM to 11:30AM for the chance 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 TODAY!

BEAT NF



DANCE NF

Brought to you by the Washington University NF Center in collaboration with the St. Louis Children's Hospital Foundation, we are pleased to provide a one morning Dance Therapy Intensive for children with NF1 ages 5 to 13. Join us on August 10, 2013 from 10AM to 1PM for the chance to work on motor skills, social skills and attention skills through dance.



If you are interested in learning more, please contact Kirsten Brouillet at brouilletk@neuro.wustl.edu TODAY!

FAMILY THINK TANK

Do you have a vision for future activities and resources at the Washington University NF Center? Join us after Club NF on Saturday August 3, 2013 for lunch and discussion. We will walk you through all the resources currently available for our families and you can let us know how we're doing! Bring your ideas and creativity to help us plan.

We will have two sessions, one for parents and one for kids. After the meeting, feel free to head back to the pool with your all day swim pass!

Interested in learning more? Please contact Alicia Vallorani at vallorania@neuro.wustl.edu.

STAY CONNECTED!

FACEBOOK

"Like" The Washington University Neurofibromatosis (NF) Center to follow us and get regular updates about everything we're doing from research to Club NF!



THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER WEBSITE



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

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