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Washington University Neurofibromatosis (NF) Center

Making A Difference Together



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 Receives Department of Defense Clinical Trials Grant

The Washington University NF Center was awarded a grant from the Department of Defense to participate in the NF Clinical Trials Consortium. This consortium is composed of eleven clinical programs worldwide focused on evaluating promising new treatments for NF1 and NF2.

Coordinated by Dr. Bruce Korf at the University of Alabama –Birmingham, this large multi-center collaborative group aims to rapidly assess the effectiveness of novel therapies for bone abnormalities, brain tumors, plexiform neurofibromas, malignant peripheral nerve sheath tumors, and cognitive problems in children and adults with NF1 as well as brain tumors in individuals with NF2.

“The ability to evaluate promising new a treatment in a rapid and efficient manner is a major advance for our families living with NF1 and NF2”, says Dr. David Gutmann, Director of the Washington University NF Center.

Save the Date!

Club NF

[November 3 & 10]

Join us for the fall Club NF on promoting social development through musical theater and drama.

Club NF

[January]

Join Team NF for the first Club NF event of the New Year

Washington University
Neurofibromatosis Center

**NF
CENTER**

nfcenter.wustl.edu

Meet the Team

Over the summer the NF team welcomed two new team members, Alicia Vallorani and Emily Mangi. Alicia is assuming the responsibilities of the team's Clinical Research Assistant. Emily will be the Program Coordinator for the Washington University Neurofibromatosis (NF) Center.

Alicia Vallorani, Clinical Research Assistant

Alicia graduated from Knox College in 2011 with a bachelor's degree in Psychology. She works directly with Dr. Gutmann MD, PhD, as well as multiple other physicians in order to ensure quality clinical research is available for individuals with NF. Alicia consents individuals for participation in multiple studies including the NF1 Genome Project and ensures proper collection of all data.

Emily Mangi, Clinical Program Coordinator

Emily is a 2008 graduate of Southern Illinois University of Edwardsville. She received a bachelor's degree in Health Education, and minor in Psychology. She works directly with Dr. David H. Gutmann, MD, PhD, to coordinate the numerous events, activities and clinical studies currently offered by the Washington University Neurofibromatosis (NF) Center. Emily also orchestrates Club NF events.



Congratulations Team!

Washington University NF Center Trainee Awarded Fellowship Grant

Tao Sun, PhD was recently awarded a Young Investigator Award from the Children's Tumor Foundation to further his groundbreaking work on defining the molecular basis for the higher rates of brain tumors (gliomas) seen in boys with NF1. Dr. Sun is a post-doctoral fellow with Joshua Rubin, MD, PhD, Associate Professor in Pediatrics and Co-director of the St. Louis Children's Hospital Neuro-Oncology Program. Together, they have developed a unique model of Neurofibromatosis-1 (NF1)-associated glioma formation that demonstrates a sex-dependent pattern similar to children with NF1. Currently, Dr. Sun is focused on determining how sex-dependent differences in growth control pathways, including the cyclic AMP pathway, define the differences between male and female brain cells important for brain tumor formation.

Congratulations to Dr. Sun on this prestigious award.



Club NF Promotes Physical Activity

On August 11 & 18, 2012, The Washington University NF Center in collaboration with St. Louis Children's Hospital Foundation hosted a summer session of Club NF. The summer program highlighted the benefits of participating in physical activity to improve motor coordination, gross motor skills, attention, body strength, visual perception and sensory processing. The activities included an indoor tee-ball game, fun races, and playing with a giant parachute.

Parents had the opportunity to participate in a focus group aimed at increasing our understanding of the needs of our families who are raising a child with NF1. This education activity was organized by Karen Balakas, PhD, RN, CNE.

The day finished with a swim session for the families.

If you would like to attend any future Club NF programs, please contact Emily Mangi at mangie@neuro.wustl.edu



Stay Connected

For the most update information on Club NF and the Washington University NF Center stay connected with our websites.

To follow us on our Facebook page "Like" The Washington University Neurofibromatosis (NF) Center

Make sure to visit the Washington University NF center website too!

www.nfcenter.wustl.edu

Get Involved in Research

Washington University Neurofibromatosis (NF) Center reaches 250 participants in the NF1 Genome Project

The Washington University Neurofibromatosis (NF) Center has established a one-of-a-kind NF1 Genome Project. The NF1 Genome Project is a DNA bank that collects blood samples from individuals affected with NF1 to learn how changes in the DNA may predispose people with NF1 to specific medical problems.

With advancing technology in the field of genome science, scientists and physicians at the Washington University NF Center are working together to determine how subtle changes in our DNA lead to the wide variety of medical problems seen in people with NF1. Knowledge gained from these studies may one day help doctors and scientists better predict who will develop these problems, and may lead to the design of more effective drug therapies.

To learn how to participate, contact Alicia Vallorani at NFClinicalStudies@neuro.wustl.edu. For more information on all our clinical research studies, visit our website (<http://nfcenter.wustl.edu>)

Shop For NF

Schnucks eScrip Community Card Supporting the Washington University Neurofibromatosis (NF) Center

The Washington University NF Center is thrilled to partner with Schnucks Markets, Inc! Every time you shop at Schnucks, use this card and a percentage of your bill will be donated to the Washington University NF Center! This is FREE and will fund outstanding research and programs for individuals with NF at Washington University.

Cards can be obtained at any Schnucks customer service desk.

For more information and how to register your card, visit our webpage, <http://nfcenter.wustl.edu/giving/shopforNF/>



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We want to hear what you think! For questions or to submit ideas for future NF Center newsletters, please email Emily Mangi (mangie@neuro.wustl.edu)