

SPRING 2012

# Washington University Neurofibromatosis (NF) Center

*Making A Difference Together*



## Welcome!

The Comprehensive NF Center at Washington University 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 common condition. We believe that these breakthroughs are possible when researchers, medical professionals, and families partner together.

The Neurofibromatosis Center's 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 with NF.

## Save the Date For the First Annual NF Center Symposium

The Washington University Neurofibromatosis Center proudly announces the first Washington University NF Symposium on May 4, 2012 in the Eric P. Newman Education Center (EPNEC).

The morning session will highlight basic science research performed by faculty in the Washington University NF Center. Our keynote speaker will be **Dr. Luis F. Parada**, an internationally-recognized leader in neurofibromatosis research. Dr. Parada is the Diana & Richard C. Strauss Distinguished Chair in Developmental Biology at the University of Texas Southwestern Medical School.

The afternoon session will focus on clinical research performed by faculty in the Washington University NF Center. Our keynote speaker will be **Dr. Bruce R. Korf**, one of the world's leading authorities on neurofibromatosis. Dr. Korf is the Wayne H. and Sara Crews Finley Professor of Medical Genetics and Chair of the Department of Genetics at the University of Alabama Birmingham.

Following the afternoon session, we welcome you to meet our keynote speakers and members of the Washington University NF Center faculty at an informal reception beginning at 4 o'clock.

*Sponsored by the Chelew Family*

## Save the Date!

### NF Symposium

**[May 4]**

Join us at the Eric P. Newman Education Center (EPNEC) for our first annual NF Symposium.

### Club NF

**[May 12 & 19]**

Come learn the benefits of gardening & fine motor skill development in kids with NF1.

### Club NF

**[August]**

Join us in August for our Summer session of Club NF to learn about the benefits of swimming for kids with NF1.





## Club NF Goes Rock Climbing

In February, Club NF visited Upper Limits in St. Louis to learn how to rock climb. We learned about gross motor skill development and how to address academic concerns commonly seen in kids with NF1. To see photos from the event, visit <http://nfcenter.wustl.edu>.

## Team NF Members Featured in St. Louis Children's Hospital Blog

Washington University Neurofibromatosis (NF) Center team members Courtney Dunn, PT, DPT and program coordinator, Taylor Ferguson were recently featured in the St. Louis Children's Hospital patient care blog, *From The Bedside*.



## The NF Center is Now on Facebook

Washington University Neurofibromatosis (NF) Center is now on Facebook. "Like" us to receive the most up-to-date information and updates about Team NF and the NF Center.

## NF Center Researchers Examine Motor Delays In Children With NF1

Courtney Dunn, PT, DPT, lead Physical Therapist for the NF Clinical Program at St. Louis Children's Hospital, recently completed a study to examine motor delays in children with NF1.

Using a simple developmental screening tool, called the "Parents' Evaluation of Developmental Status: Developmental Milestones" or PEDS-DM, Dr. Dunn worked with Saint Louis University medical student Elizabeth Soucy to demonstrate that two-thirds of children with NF1 have developmental delays. The most common delays were found in the areas of gross motor, fine motor, and math skills. These findings were recently published in the *Journal of Child Neurology*.

Based on these findings, Dr. Dunn and her colleagues in Team NF have expanded Club NF activities to specifically focus on these areas of delay in children with NF1. Future studies included correlating motor delays with other areas of performance as well as with brain MRI findings.

## NFitness

Fitness and Development are important considerations in early childhood. To provide current and practical information about your child's development and fitness needs during this critical period of their life, our Team NF Physical Therapist, Dr. Courtney Dunn, has created a series of short fact sheets. Visit <http://nfcenter.wustl.edu> to learn more about NFitness.





## NF Center Researcher Receives Grant to Identify Genetic Risk Factors for Brain Tumors

Joshua Rubin, MD, PhD was recently awarded a Children's Discovery Institute (CDI) grant to discover genetic modifiers of brain tumor development in children with neurofibromatosis type 1 (NF1).

Nearly twenty percent of children affected with NF1 will develop a brain tumor (optic glioma) during the first ten years of life. Unfortunately, it is currently not possible to determine who will develop an optic glioma and who will not. In addition, vision screening in young children is challenging, and brain imaging does not predict which child might experience vision loss.

Previous studies have indicated that other genetic factors, called genomic modifiers, may be responsible for predisposing some children with NF1 to brain tumor formation.

Working with Jingqin (Rosy) Luo, PhD in the Department of Biostatistics and David H. Gutmann, MD, PhD in the Department of Neurology, Dr. Rubin has completed preliminary studies which revealed subtle genetic changes (single nucleotide polymorphisms, SNPs) associated with optic glioma development in children with NF1.

Leveraging these early successes, Dr. Rubin is now assembling a new international consortium to evaluate SNP-based diagnostic tools for identifying children at highest risk for glioma formation.

The goal of this exciting project is to develop accurate predictive biomarkers for glioma development and clinical progression. The availability of a future SNP-based diagnostic test would allow physicians to identify children at highest risk for optic glioma formation and begin treatment prior to vision loss.



## Drummer Matt Wilson to Perform at Children's Hospital

Matt Wilson will be joined by Terell Stafford on trumpet. His appearance at St. Louis Children's Hospital is in partnership with the Washington University Neurofibromatosis (NF) Center and Jazz St. Louis.

**WHO:** Matt Wilson and Special Guests

**WHAT:** Performance for patients and families

**WHEN:** Wednesday, March 21, 2012 at 11:00 am

**WHERE:** Child Life Playroom  
St. Louis Children's Hospital  
One Children's Place  
St. Louis, MO 63110

*Matt Wilson is a Grammy-nominated, New York-based drummer and is one of today's most celebrated jazz artists. He is universally recognized for his musical and melodic drumming style as well as being a gifted composer, bandleader, producer, and teaching artist. In addition, Wilson's dedication to jazz has helped establish him as a beloved world ambassador for the music, on and off the bandstand.*



## Get Involved in Research

We, at the Washington University NF Center, are recruiting families to participate in ongoing clinical research studies. Your involvement in these studies will accelerate the pace at which new treatments are developed.

### Attention Deficit in Children with NF1

Dr. Jill Isenberg is leading a study to define the spectrum of attention deficit issues facing children with NF1. Dr. Isenberg is an experienced pediatric neuropsychologist interested in developing assessment tools for identifying children most at risk for attention deficit.



### Short Stature in NF1

Dr. Abby Hollander is leading a study to determine how best to identify children with NF1 whose short stature might be caused by a growth hormone deficiency. Dr. Hollander is a pediatric endocrinologist. Your participation involves getting your family's height measured as part of your routine visit to the NF Clinical Program at St. Louis Children's Hospital.

For more information on all our clinical research studies, visit our website (<http://nfcenter.wustl.edu>).

## Calling All Artists!

On Friday, May 4, 2012 the Washington University NF Center will be hosting our first annual NF Symposium. We would like to feature artwork from our amazing NF Center kids.

Parents, if your child is between the ages of 1 day and 18 years of age, please ask him or her to create a piece of art to be displayed at the upcoming NF Symposium. The artwork can feature NF-related themes, or whatever inspires your child.

All artwork submissions will be displayed proudly at this exciting event. If your son or daughter is interested in donating a piece or art to the NF Center Symposium, please contact Taylor Ferguson, [fergusont@neuro.wustl.edu](mailto:fergusont@neuro.wustl.edu).

*All art submissions can be mailed to:*  
**Washington University School of Medicine**  
**Department of Neurology**  
**Attn: Taylor Ferguson**  
**Campus Box 8111**  
**660 South Euclid Avenue**  
**Saint Louis, MO 63110**

*Please send all art submissions by April 27, 2012*

We want to hear what you think! For questions or to submit ideas for future NF Center newsletters, please email Taylor Ferguson ([fergusont@neuro.wustl.edu](mailto:fergusont@neuro.wustl.edu)).