

THE 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.



MCDONNELL FOUNDATION GRANT AWARDED FOR INNOVATIVE BRAIN TUMOR ECOLOGY COLLABORATIVE PROJECT

The grand objective of the proposed Brain Tumor Ecology Collaborative (BTEC) is to initiate and foster a highly interactive scientific forum including mathematic modelers specializing in complex systems, integrative cell and molecular biologists working on processes key to establishing and maintaining cellular communities, and cancer researchers interested in understanding the brain tumor microenvironment. The proposed initiative will enable these scientists to connect and pool their collective expertise and insights to create alternative conceptual frameworks and experimental designs for new types of studies which would result in a better understanding of glioma behavior. Importantly, this collective will be comprised of individuals who recognize an unprecedented opportunity to build an infrastructure, including a virtual tissue space and collaborative web-based on-line forum to integrate datasets from multiple research groups and experimental methods spanning multiple strata, encompassing molecular, cellular and tissue-based data, allowing exploration of these interconnected and complex information sources in a dynamic and seamless manner.

SAVE THE DATE!

WINTER CLUB NF
JANUARY 26 and
FEBRUARY 2 2013

JAZZ ARTIST
MAY 2013

SPRING CLUB NF
MAY 2013

RESEARCH AT THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER

UNRAVELING THE LINK BETWEEN SEIZURES AND NF1

Judith Weisenberg, MD Adam Ostendorf, MD, and David H. Gutmann, MD, PhD, are currently investigating the link between seizures and Neurofibromatosis Type 1 (NF1). Using an extensive clinical database, including almost 20 years of data, the researchers are searching for links between seizure types, seizure response to medicine, and characteristics of neuroimaging and EEG results to further examine the increased prevalence of seizures in this population. Using this information, physicians hope to find predictors of seizures in patients with NF1, identify optimal treatment strategies, and ultimately understand the brain dysfunction caused by this disease.

TWO STUDIES COMPLETED BY COURTNEY DUNN, DPT, PT

THE ASSOCIATION BETWEEN LOW TONE AND BRAIN TUMORS

Courtney Dunn, DPT, PT and her colleagues recently reported an association between low motor tone and brain tumors in children with neurofibromatosis type 1 (NF1). In this study, recently published in the Journal of Child Neurology, Dr. Dunn showed that a specific type of reduced muscle tone may be an indicator of brain tumors in some children with NF1. While these results are exciting, they require further study to determine whether this finding can be used to screen children most likely to harbor optic gliomas. A prospective study is currently planned to examine the value of this clinical observation in the management of children with NF1.

DEVELOPMENTAL DELAYS AND NF1

Courtney Dunn, DPT, PT and her colleagues recently completed a study of 124 children with neurofibromatosis type 1 (NF1) to learn more about the progression of developmental delays during childhood. Her findings, published in the Journal of Child Neurology, show that school-age children exhibit more areas of delay than infants or preschool-age children. Importantly, Dr. Dunn's work demonstrates that gross motor delays are found in all age groups and do not improve as children get older. Based on her findings, early screening and intervention is essential for those children with NF1 and gross motor delays.

THE NF1 PATIENT REGISTRY INITIATIVE (NPRI) REACHES 1000 PARTICIPANTS

The NF1 Patient Registry Initiative (NPRI), established by the Washington University Neurofibromatosis (NF) Center in May of 2011, has enrolled over 1000 participants as of December 2012. The online registry was launched to assemble a large patient population to better understand the range of medical and social consequences in people living with NF1. This information may one day help clinicians to develop personalized treatment strategies that improve the quality of life for individuals living with NF1. To date, individuals from all 50 states, the District of Columbia, and 43 countries have participated. If you have NF1 or are the parent of a child with NF1, you can sign up for the registry at <https://nf1registry.wustl.edu/>.

OTHER STUDIES CURRENTLY RECRUITING

- * **NF1 Genome Project:** Blood samples are collected and DNA is extracted for future research aimed at identifying children at greatest risk for specific medical problems associated with NF1. Participation is open to all ages. Blood draws can be performed during a sedated MRI.
- * **NF1 Brain Trust Project:** Small skin biopsies are donated to the Washington University Neurofibromatosis (NF) Center in order to generate brain nerve cells used to discover better treatments for learning, memory and behavior problems associated with NF1. Neurofibromas removed by our plastic surgeon can be donated.

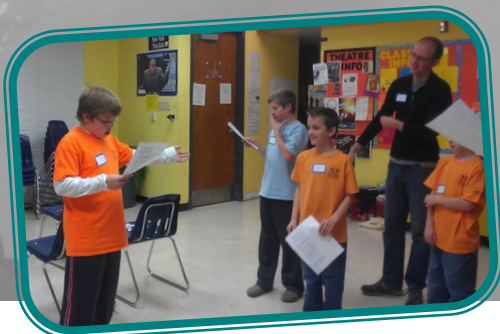
FOR OUR FAMILIES



CLUB NF PARTNERS WITH STAGES ST. LOUIS TO PROMOTE CONFIDENCE, GROSS MOTOR SKILLS AND ATTENTION

On November 3 and 10, 2012, the Washington University Neurofibromatosis (NF) Center in collaboration with the St. Louis Children's Hospital Foundation partnered with STAGES ST. LOUIS to host the Fall 2012 session of Club NF. The Fall program highlighted the benefits of participating in theatre as a means of building self-confidence while improving motor skills and attention. Members of STAGES ST. LOUIS led theatre games and taught participants scenes and dances from *Seussical* —the musical comedy based on the beloved children's books by Dr. Seuss. The morning's activities culminated in a showcase for the parents.

While the kids were making theatre magic, parents had the opportunity to participate in a focus group aimed at increasing our understanding of the needs of our families who are raising children with NF1. This educational activity was organized by Karen Balakas, PhD, RN, CNE.



CLUB NF 2013

Get excited for Club NF 2013 sessions! Plans for the Winter and Spring sessions are well underway. On January 26 and February 2, 2013 learn the benefits of playing games with family and friends. Challenge each other to get active and play your best! In May, get ready to cook! We can't wait to see you there!

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!



APPS FOR NF

Check out our recommended Apps for kids with NF by scanning the QR Code with your iPhone or iPad. Learn about great tools for teaching skills from organization to classroom productivity.

THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER WEBSITE

Visit our website at:
www.nfcenter.wustl.edu

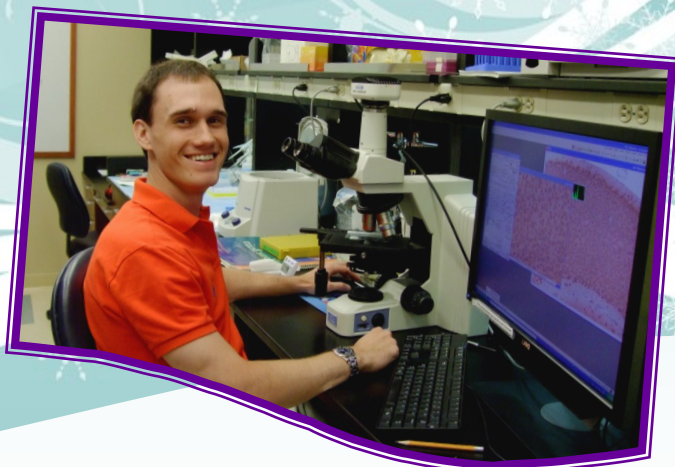
WASHINGTON UNIVERSITY
NEUROFIBROMATOSIS CENTER
MAKING A DIFFERENCE TOGETHER

CONGRATULATIONS TO OUR WASHINGTON UNIVERSITY NF CENTER RESEARCHERS!

WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER TRAINEE AWARDED FELLOWSHIP GRANT

Hugh Bender was recently awarded a Young Investigator pre-doctoral research fellowship from the Children's Tumor Foundation to further his work to define how the NF1 protein, neurofibromin, controls the growth of brain stem cells. Mr. Bender is a graduate student in the laboratory of Dr. David H. Gutmann. For his PhD thesis, Hugh is focused on determining the mechanism underlying neurofibromin regulation of RAS activity relevant to normal brain development as well as brain tumor (glioma) formation.

Congratulations to Mr. Bender on this prestigious award.



WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER INVESTIGATORS FEATURED PROMINENTLY AT THE 2012 SOCIETY FOR NEUROSCIENCE MEETING

Washington University Neurofibromatosis (NF) Center was well represented at the 2012 Annual Society for Neuroscience Meeting in New Orleans.

David H. Gutmann, MD, PhD, the Donald O. Schnuck Family Professor and Director of the Washington University NF Center chaired a symposium, entitled "Neurofibromatosis: Modeling CNS Dysfunction". Along with Dr. Gutmann, this exciting session included Dr. Luis Parada (University of Texas – Southwestern), Dr. Alcino Silva (University of California – Los Angeles), and Dr. Nancy Ratner (Cincinnati Children's Hospital).

The Society for Neuroscience chose this symposium to highlight as an invited article to be published in the *Journal of Neuroscience*.

In addition, several Washington University NF Center researchers presented their new scientific findings.

Kelly Diggs-Andrews, PhD presented her research on the role of the *Nf1* gene in mouse behavior and brain nerve cell function. Dr. Diggs-Andrews was also the recipient of the St. Louis Society for Neuroscience Chapter Postdoctoral Travel Award.

David Wozniak, PhD also showcased his research on abnormal behaviors in *Nf1* genetically-engineered mouse models. Together with Dr. Gutmann's team, Dr. Wozniak has identified attention and learning deficits in *Nf1* mutant mice relevant to children with NF1.

SHOP FOR NF!

THE WASHINGTON UNIVERSITY NEUROFIBROMATOSIS (NF) CENTER AND BRAVELETS™



The Washington University NF Center has partnered with Bravelets™ to help support research and programs for individuals with NF at Washington University. With every bracelet purchased, \$10 will be donated to fight Neurofibromatosis!



For more information, visit the Washington University Neurofibromatosis (NF) Center Brave Page at <http://bravelets.com/product/wunf/>