Dr. Gutmann Receives 2012 Friedrich von Recklinghausen Award

We, at the Washington University Neurofibromatosis (NF) Center, are proud to announce that Dr. David H. Gutmann, MD, PhD, Washington University NF Center director, was recently awarded a prestigious lifetime achievement award by the Children’s Tumor Foundation (CTF). The Friedrich von Recklinghausen Award is a great honor bestowed to those who have made significant contributions to neurofibromatosis research and clinical care. The award has been given to an outstanding physician or researcher in the neurofibromatosis field since 1989. Dr. Gutmann’s colleagues in the neurofibromatosis research and clinical care field nominated him for this honor.

It comes as no surprise to us at the Washington University NF Center that Dr. Gutmann has been given this honor due to his long standing and preeminent role in the areas of neurofibromatosis research and clinical care. Those familiar Dr. Gutmann know it was only a matter of time before he became the recipient of the Friedrich von Recklinghausen Award. His continued passion and inspiration of others is unmatched. He continues to inspire his team and colleagues with his never-ending enthusiasm and drive to achieve the greatest feats for the NF community.

Dr. Gutmann established the Washington University NF Center in 2004 and has been treating patients with NF at St. Louis Children’s Hospital since 1994. The Washington University NF Center is comprised of over thirty investigators and boasts the involvement and support of over fifteen departments. The Washington University NF Center team, lead by Dr. Gutmann, has received over 30 collaborative grants in the past six years and has published over sixty manuscripts. Dr. Gutmann has also written and published over 300 peer-reviewed manuscripts and written over fifty book chapters.

He received the prestigious Friedrich von Recklinghausen Award in New Orleans, Louisiana at the annual NF Conference and was also invited as a distinguished guest speaker for the event.

Save the Date!

Club NF
[August 11 & 18]
Join us for the summer session of Club NF to learn about the benefits of swimming for children with NF1.

Family Picnic
[September]
As a back-to-school event, join us for an outdoor picnic complete with educational resources and fun!

Club NF
[October]
Join Team NF outdoors for a harvest themed Club NF complete with pumpkins and outdoor fun & games.
NF Center Trainee Receives Prestigious American Brain Tumor Association Award

Dr. Yi-Hsien Chen, a post-doctoral fellow in Dr. David Gutmann’s research laboratory, was recently awarded a fellowship from the American Brain Tumor Association (ABTA).

Dr. Chen received his PhD degree in Genetics from the University of Nottingham where he studied the genes that control stem cell function in amphibians. Dr. Chen joined Dr. Gutmann’s laboratory in 2010 and began investigations aimed at understanding how genetic mutations found in pediatric brain tumors control stem cell function. Based on his research on the NF1 gene, Dr. Chen is now studying how a related brain tumor-causing genetic change (mutation) controls neural stem cell growth and differentiation. The title of his grant is, “Identification of Cellular and Molecular Targets for KIAA1549:BRAF-Induced Pediatric Glioma Therapy”.

We congratulate Dr. Chen on this outstanding achievement.

NF Center Researcher Awarded Grant to Study NF1 Brain Tumors

Dr. Sonika Dahiya, Assistant Professor in Pathology at the Washington University School of Medicine, was recently awarded a grant to examine brain tumors (gliomas) arising in children and adults with NF1. As part of an international team of investigators led by Dr. Anat Stemmer-Rachamimov from the Massachusetts General Hospital, Dr. Dahiya, working with Dr. David Gutmann, will perform an extensive analysis of these tumors in an effort to develop a classification scheme best suited for individuals with NF1.

“We are very excited about this endeavor”, says Dr. Gutmann.” We hope that the results from this study will provide the most accurate prognostic information to physicians caring for individuals with NF1 affected by these tumors.”

The Children’s Tumor Foundation funded this international consortium study.

Kimberly Johnson, MPH, PhD Awarded American Cancer Society Institutional Research Grant

Kimberly Johnson, MPH, PhD, Assistant Professor in The Brown School of Social Work was recently awarded a grant from the American Cancer Society for her proposed studies on Neurofibromatosis type 1 (NF1).

Dr. Johnson is spearheading work at the Washington University NF Center to develop a large international registry of individuals with Neurofibromatosis Type 1 (NF1). The one-of-a-kind registry will enable research aimed at understanding environmental and genetic risk factors that influence early onset cancer development in individuals with NF1.

With funding from the American Cancer Society, Dr. Johnson and her colleagues will establish new internet-based methods to increase enrollment in the NF1 Patient Registry Initiative (NPRI). These studies are designed to identify children and adults at greatest risk for specific medical problems in NF1. These studies may help clinicians to develop personalized treatment strategies that improve the quality of life for individuals living with NF1.
NF Center Nurse Practitioner is a Finalist in St. Louis Magazine “Excellence in Nursing Award”

The NF Center is proud to announce that Anne Albers, PNP, MSN, was selected as a finalist for this year’s *St. Louis Magazine*’s “Excellence in Nursing Awards.”

“They tirelessly and selflessly care for others with a special, gentle diligence that only someone in their profession could possess. They are the many exceptional nurses in our community, and *St. Louis Magazine* will honor their dedication and caring at our third annual Excellence in Nursing Awards. It is the least we can do to show our gratitude for the excellent nurses at our communities’ schools, hospitals, nurseries, colleges, and clinics who touch the lives of St. Louisans each and every day.”

“It was an especially challenging year for the ‘Excellence in Nursing’ judges, as each nurse nominee had superior recommendations and impressive backgrounds. However, the judges were able to narrow down the nominees to 71 finalists across 18 categories.”

We extend our congratulations to Anne!

The Washington University Neurofibromatosis (NF) Center Research Symposium was an Overwhelming Success

On Friday, May 4, 2012, the Washington University Neurofibromatosis (NF) Center hosted its first NF research symposium attended by over 180 physicians, researchers, therapists, medical professionals and families.

The morning session highlighted basic science research performed by faculty in the Washington University NF Center. The keynote speaker was 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 focused on clinical research performed by faculty in the Washington University NF Center. The keynote speaker was Dr. Bruce 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, Team NF welcomed attendees to meet the keynote speakers and members of the Washington University NF Center faculty at an informal reception.

We hope to see everyone at the next Washington University NF Center Symposium. Stay tuned for details in the coming year.

Matt Wilson Performs at St. Louis Children’s Hospital

On Wednesday, March 21, drummer Matt Wilson and his band Arts & Crafts performed at St. Louis Children’s Hospital Child Life Playroom for patients.

Terell Stafford joined Matt on trumpet while Martin Wind was on bass and Gary Versace was on the Hammond organ. His appearance at St. Louis Children’s Hospital was a joint partnership between the Washington University Neurofibromatosis (NF) Center and Jazz St. Louis.

Matt and Arts & Crafts performed selected songs from their repertoire including Scenic Route and Bubbles. These songs were some of the children’s favorites and involved audience participation. The children were encouraged to add to the sound with their own musical instruments during the song about taking the scenic route. The kids also played with bubbles while the band played their bubbles song. Doc ICU from Clown Docs even joined in the fun by playing a musical instrument and doing a dance for the children.

Both the band and the children had a great time and look forward to Matt Wilson and Arts & Crafts next visit.
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.

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

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NF1 Patient Registry Initiative

The Neurofibromatosis Type 1 (NF1) Registry is a 30-minute questionnaire that will collect information to help doctors and researchers better understand the range of medical and social problems experienced by children and adults with NF1. If you have been diagnosed with NF1 or are the parent/guardian of a child (minor) with NF1, you are eligible to join this registry. The information gained from your participation may one day help doctors develop personalized treatments that improve the quality of life for individuals living with NF1. Visit [http://nf1registry.wustl.edu](http://nf1registry.wustl.edu) to participate.

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Sleep Disturbances in NF1

Dr. Amy Licis is leading a study to define the types of sleep problems seen in individuals with NF1. Dr. Licis is a pediatric neurologist and specialist in sleep disturbances. Your participation involves answering questions as part of your routine visit to the NF Clinical Program at St. Louis Children’s Hospital.

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Club NF Visits the Missouri Botanical Garden

In May, Club NF visited the Missouri Botanical Garden for the spring session of the highly popular play-based therapy and educational series. Team NF hosted Nicole Weckherlin, OTR/L who discussed iPhone/iPad based media and how to apply that to the lives of children with NF1. Jenny Brandt from the St. Louis Children’s Hospital Child Life program also spoke to parents about the challenges parents face raising children with NF1 and what resources are available to help.

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“Run For Eric” Team Races for NF Center

Eric Dominguez was two years old when he was diagnosed with Neurofibromatosis type 1 (NF1). Since that time, his family has become a passionate advocate for NF research. To raise funds for research and to promote awareness about NF1, the Dominguez family created a group called “Run for Eric”.

Each year, they travel to different locations around the globe to participate in marathons. In previous years, the “Run for Eric” team has participated in the Antarctic Marathon “End of the Earth of the Earth for a cure,” the Disney Marathon, the Marine Corps Marathon and the New York Marathon.

The Dominguez family and friends are on a mission to raise one million dollars for NF research. Thus far, they have raised over $274,000.

To help them reach their goal of one million dollars, the Run for Eric team will be heading to Kenya in June 2012 to participate in their first international marathon.

To learn more about Run for Eric and how to support their cause, visit [http://www.nfrunforeric.com/](http://www.nfrunforeric.com/).

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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).