

MESSAGE FROM THE DIRECTOR

The beginning of each new year affords us an opportunity moment to reflect upon our successes in the preceding year and to establish our goals for the year ahead. 2016 marks the 12th year of the Washington University NF Center and 22 years of supporting families in the NF Clinical Program at St. Louis Children's Hospital. As director, I am very fortunate to work with a large team of dedicated clinicians, researchers and strategic community partners whose sole collective purpose is to provide the best possible services to children and adults with NF.

In this issue of our quarterly newsletter, you will find updates on all of the core components that comprise the Washington University NF Center, which allow us to provide you and your family with the best care possible.

As we embark on another new year, it is our vision to help change the standard of care for children and adults with NF. We believe that this is only possible when researchers and clinicians work together with families living with these conditions. Using this cross-disciplinary approach, our clinicians provide optimized and personalized care for families, our research investigators aim to discover novel risk assessment and management strategies, and our complementary care programs, like Club NF, empower and maximize each individual's capabilities. In this manner, we deliver exceptional care through groundbreaking research.



David H. Gutmann, MD, PhD
Donald O. Schnuck Family Professor
Director, Washington University NF Center



NF CENTER NEWSLETTER: VOLUME 1, 2016

EXCEPTIONAL PATIENT CARE

With the departure of Anne Albers, PNP and Vicki Kuchnicki, Patient Care Coordinator in 2015, we welcomed two new members to the team. Jessica Heuring, RN joined Team NF as our nurse coordinator, and Dr. Stephanie Morris, MD, a talented pediatric neurologist, is partnering with Dr. Gutmann to care for children in the NF Clinical Care Program at St. Louis Children's Hospital.

Beyond in-clinic patient care, we have worked hard over the past year to improve the services we provide. In late 2015, we launched a completely redesigned website (nfcenter.wustl.edu), which contains updated, easy to find educational resources for families affected by NF. We are also expanding our extensive inventory of educational brochures, and plan to release new patient notebooks early this year to enable families to easily track everything related to their NF care.

Discover all of the resources available for you at:
nfcenter.wustl.edu/family-resources

EXCEPTIONAL CARE through GROUNDBREAKING RESEARCH:

2015 PROGRESS & 2016 GOALS



GROUNDBREAKING RESEARCH

Washington University NF Center investigators made numerous research advances in 2015. Dr. Angela Hirbe (Division of Medical Oncology) employed advanced genomic sequencing to discover a new gene important for malignant peripheral nerve sheath tumor development, while Dr. John Constantino (Division of Child Psychiatry) completed the world's largest study of autism in children with NF1. Dr. Corina Anastasaki used skin cells from people with NF1 to generate stem cells as reprogrammable sources of human brain neurons, and Dr. Yi-Hsien Chen identified one of the reasons why some NF1 brain tumors fail to respond to conventional and new investigational therapies. Dr. Anne Solga used advanced sequencing methods to identify a key growth factor made by immune system cells in NF1 mouse optic gliomas that controls tumor growth, and Dr. Kimberly Johnson (Brown School of Social Work) found that allergic conditions are associated with a reduced risk of brain tumors in children with NF1.

Thanks to continual support from our patients and their families, we have been able to expand the resources necessary to galvanize future research progress, including the NF1 Genome Project, Clinical Patient Database, Brain Trust and the Patient Registry Initiative.

Looking ahead, on April 1, 2016, leading researchers from around the country will join us for our third biennial Washington University NF Center Research Symposium where new discoveries in the world of NF will be highlighted.

Learn more about our research advances at: nfcenter.wustl.edu/research

COMPLEMENTARY CARE PROGRAMS

This year, we look forward to continuing our collaboration with Jazz St. Louis, focusing on refining and expanding Beat NF, our jazz music-motor therapy program for toddlers with NF1 and related disorders.

For Club NF, our play-based therapy program for children with NF1 in grades K - 8, we are implementing new therapy activities to encourage the development of skills often delayed in children with NF1, and are excited to work with the Go! St. Louis Read, Right & Run Marathon coordinators for our April 2016 Club NF event.

To offer complementary care programs for children of all ages with NF1, last fall, we partnered with Dr. Kimberly Sirl in Pediatric Neuropsychology to launch Teen NF, a social skills program for teenagers with NF1. The pilot session was met with great enthusiasm, and we have a second session planned for later this year.

View our upcoming events at: nfcenter.wustl.edu/events

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EXCEPTIONAL CARE *through*
GROUNDBREAKING RESEARCH

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