# Neurofibromatosis Center Funding Opportunities

Washington University in St. Louis



The Washington University Neurofibromatosis (NF) Center is committed to excellence in patient care, research, and education. Our center is staffed by adult and child neurologists, adult and pediatric oncologists, nurses, occupational and physical therapists, and numerous researchers. Our multidisciplinary approach allows us to provide the most up-to-date care for our families, while performing groundbreaking research aimed at changing the way we care for people with NF.

In addition to providing exceptional care for children and adults with NF, we aim to identify novel ways to predict what medical problems will arise in any given person and discover new therapies to prevent or more effectively manage these problems. Our clinical faculty actively collaborate with scientists from many different disciplines across the university, including cancer biologists, neuroscientists, biostatisticians, immunologists, information scientists, and radiologists.

Gifts from visionary donors foster creative scientific investigation and enable the high-risk, high-reward studies and initiatives necessary to make breakthroughs that advance the care of people with NF.

#### **NF Undergraduate Scholars Program**

#### \$6,000 annually per student

In order to cultivate the next generation of NF researchers, we have established a comprehensive mentorship program for undergraduate and post-baccalaureate students. Scholars choose a research project, participate in community engagement programs for children with NF, present at conferences, and shadow clinicians in an outpatient setting. Over the past 20 years, we have mentored more than 75 scholars, all of whom have successfully matriculated to graduate schools as PhD or MD students.

#### **Precision NF Modeling Initiative**

#### \$20,000 annually

The goal of this program is to create accurate models of tumors and neurodevelopmental delays in children with NF1. These translational platforms will be used to (1) detect medical problems early, (2) define the basis for learning, attention, and behavioral deficits, and (3) identify and evaluate new therapies.







#### NF Center Graduate Student Fellowship

#### \$50,000 annually per trainee

Funds to support graduate students in the critical early phases of their training are difficult to secure. This phase of training is expensive with limited grants available. A fellowship program provides stipend support and funds for travel to scientific conferences while helping us build a pipeline of the next generation of NF researchers.

#### **Patient Navigator** \$80,000 annually

Patient navigators offer unbiased assistance to patients and their families during visits to different medical specialists. They serve as critical liaisons to obtain educational and other resources and help coordinate clinical studies aimed at improving the care of people living with NF.





#### NF Center Postdoctoral Trainee Fellowship \$85,000 annually per trainee

Postdoctoral Fellowships allow us to recruit best-inclass talent to promote new learning and creative research ideas. Support for postgraduate training is expensive with limited grants available. In order to capture future NF researchers in the final phases of their training, this fellowship program will provide stipend support and funds for travel to scientific meetings.



#### Innovative Therapy Programs \$150,000 annually

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At the Washington University NF Center, we believe that the care of people with NF extends beyond the hospital. For this reason, we have developed numerous therapy and life skills programs for children with NF. These include a jazz music therapy program for toddlers (Music Heals), a motor therapy program for school-age children (Club NF), and a life skills program for teenagers (Totally Teen). We also host an annual Family Day and NF Camp to foster healthy development and a sense of community. Importantly, to facilitate the transition from St. Louis Children's Hospital to Barnes-Jewish Hospital, we created a specialized program for adolescents and young adults.



#### **Dedicated Clinical Research Assistant** \$100,000 annually

Clinical trials are an essential tool used to determine drug efficacy, establish standard treatments, and learn how to safely use a treatment for specific populations. This individual will enroll both children and adult patients in NF-related clinical studies and trials in accordance with institutional and federal regulatory guidelines, providing seamless integration across the lifespan.



#### **NF1 Genome Project**

### \$250,000 annually, but any amount helps with this essential program

Over the past decade, we have established a DNA bank in collaboration with our families with NF1. We wish to use this novel resource for genome sequencing to identify new risk factors that might help us better predict specific problems that are likely to arise in individuals with NF1.

Specific project costs include:

- DNA sequencing: \$150,000
- Annual DNA collection/processing: \$5,000
- Genetic analyst: Salary + fringe \$95,000



#### **NF1 Precision Medicine Project**

## \$500,000 annually, but any amount helps with this essential program

We have established a risk assessment pipeline with Dr. Philip Payne, founding director of the Institute of Informatics. The goal of this project is to identify potential risk factors using artificial intelligence/machine learning methods, which are then experimentally validated in the laboratory for use in realtime risk assessments of patients in the outpatient clinic.

Specific project costs include:

- Laboratory personnel: Salary + fringe \$200,000
- Bioinformatician: Salary + fringe \$120,000
- Research costs: \$180,000

# Your gift will accelerate the pace of discovery and change the lives of people living with NF.

Our clinical program is internationally recognized, not only for our commitment to providing outstanding patient care, but also for advancing discovery and improving medical care through research. Your support enables us to perform high risk/high reward research, hire talented staff, and conduct the work that will one day allow us to personalize the way we care for people living with NF.

If you are interested in learning more about how you can directly support our mission, please contact Emily Williams, Senior Director of Medical Advancement, at <u>williams.e@wustl.edu</u> or 314-935-2660. She will partner with you to find impactful ways to advance our research initiatives.

On behalf of the many individuals with NF, thank you for helping make these discoveries possible.



Questions? Contact Emily Williams Phone: 314-935-2660 Email: <u>williams.e@wustl.edu</u> Washington University in St. Louis School of Medicine