

# What is neurofibromatosis?

Neurofibromatosis (NF) is a set of complex genetic conditions that can affect nearly every organ system in the body. NF causes tumors to grow on nerves throughout the body and in the brain. Other problems can include learning issues and bone deformities.



## Who we are?

The NF team at St. Louis Children's Hospital is led by **Dr. David H. Gutmann** and nurse practitioner, **Anne C. Albers**. Dr. Gutmann is an internationally-recognized expert in NF, and was a member of the research group that identified the entire *NF1* gene. He has twenty years of experience in the care of children and adults with NF, and directs a large basic science research laboratory working on NF. Dr. Gutmann also founded and leads the Washington University Neurofibromatosis Center ([nfcenter.wustl.edu](http://nfcenter.wustl.edu)), a collaborative research center composed of clinicians and laboratory scientists focused on accelerating the pace of scientific discovery and its application to the care of individuals with NF.

Ms. Anne Albers is a pediatric nurse practitioner with expertise in the care of individuals with NF. She works very closely with Dr. Gutmann to ensure that all possible services are provided to patients and their families. She also assists in coordinating services between the members of the multidisciplinary team.

## What we do.

Neurofibromatosis affects different people in different ways. As a team, we work with our patients and their families to care for the whole person.

To do so, all team members at St. Louis Children's Hospital and Washington University meet regularly to discuss current standards of care and to discuss exciting new developments. These meetings not only include health care professionals, but also research scientists.

Through regular communication, our team is able to provide the most up to date and progressive treatment plans.

Our care is:

- **Multi-disciplinary.** Many of your team members work in clinic with Dr. Gutmann. Most others are just down the hall.
- **Compassionate.** We understand that NF can affect many aspects of life. We strive to provide support and resources to address these issues.
- **Up To Date.** Our team members are also part of the Washington University Neurofibromatosis Center of Excellence. This physician and research team focuses on advancing knowledge and treatments for NF.
- **Family-centered.** You are your child's best advocate and champion. Do not hesitate to contact us with questions or concerns, no matter how large or small.

Our **NF Team** is composed of numerous specialists who are experts in the care of children and adults with NF.

These include:

- Audiologists
- Cardiologists
- Dermatologists
- Endocrinologists
- Neurologists
- Neuropsychologists
- Neuroradiologists
- Neurosurgeons
- Nurse Specialists
- Occupational Therapists
- Oncologists
- Ophthalmologists
- Orthopedic Surgeons
- Otolaryngologists
- Pain Specialists
- Physical Therapists
- Plastic Surgeons
- Radiation Oncologists
- Social Workers
- Surgical Oncologists

## Available resources.

In order to provide the best resources for our families with NF, we have developed several important resources.

These include:

- Personalized patient binders
- A booklet written specifically for families newly diagnosed with NF
- A booklet written specifically for teenagers with NF
- Information sheets on specific problems seen in children and adults with NF
- A continuously updated Website with online resources about research breakthroughs ([nfcenter.wustl.edu](http://nfcenter.wustl.edu))

The NF Clinical Program is also an active member in the **NF Clinical Trials Consortium**. New treatments for children and adults with NF are offered as part of these ongoing clinical studies.



Neurofibromatosis Clinic  
St. Louis Children's Hospital  
One Children's Place  
St. Louis, MO 63110

Phone: 314.454.KIDS (5437)  
Fax: 314.454.2523

*"Making a Difference Today"*



**As a TEAM, we work  
with our PATIENTS and  
their FAMILIES to care  
for the WHOLE PERSON.**

Children's  
HOSPITAL • ST. LOUIS  
BCH HealthCare

Washington<sup>®</sup>  
University in St. Louis  
Physicians

Welcome to the  
Neurofibromatosis  
Clinic

Children's  
HOSPITAL • ST. LOUIS  
BCH HealthCare