

This brochure answers common questions patients and their families ask about Neurofibromatosis Type 2 (NF2) and Schwannomatosis (SWN). It will provide a brief summary of these conditions and explain the services offered at Siteman Cancer Center.

Individuals with NF2/SWN benefit from the midwest's only program specializing in NF2/SWN patient care – the Washington University NF2/SWN Clinical Program. This program is a joint project of the Washington University NF Center and Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine.



## SITEMAN CANCER CENTER LOCATIONS

Washington University Medical Campus

Barnes-Jewish West County Hospital

Barnes-Jewish St. Peters Hospital

South St. Louis County

Northwest HealthCare

Memorial Hospital Shiloh

Call **800-600-3606**

or visit **siteman.wustl.edu**  
to schedule an appointment  
or learn about our locations.



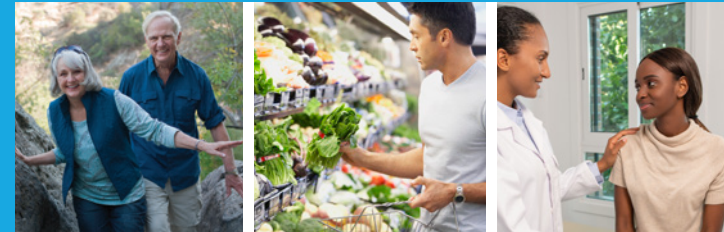
Siteman Cancer Center complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex.

Atención: hay servicios de asistencia de idiomas disponibles a su disposición sin costo.

Lláme al 314-747-5682 (TTY: 1-800-735-2966).

注意：免费提供语言协助服务，如有需要敬请致电  
314-747-5682 (TTY: 1-800-735-2966)。

## NEUROFIBROMATOSIS TYPE 2/ SCHWANNOMATOSIS CLINICAL PROGRAM



Information for patients  
and family members



## WHAT IS THE DIFFERENCE BETWEEN NEUROFIBROMATOSIS TYPE 2 AND SCHWANNOMATOSIS?

Neurofibromatosis Type 2 (NF2) is a genetic condition affecting approximately 1 in 40,000 people. NF2 can cause several different types of tumors to form within the nervous system, including schwannomas, meningiomas and ependymomas. In addition, individuals with NF2 are prone to developing cataracts. These medical problems can result in vision loss, deafness, balance problems, weakness and pain. Some of the tumors can be life-threatening, and require prompt treatment by an experienced team of medical professionals.

NF2-related SWN affects 1 in 20,000 individuals, whereas other types of SWN affect 1 in 70,000. The most common tumors are called schwannomas, which can involve the spinal cord and peripheral nerves. Pain is a main presenting symptom.

Individuals with NF2/SWN can pass this condition to their children. In this regard, there is a 50% chance of inheriting this condition from an affected parent and genetic testing is available. However, up to one half of patients have no family history of NF2/SWN and are the first member of their family with this condition.



## NF2/SWN CLINICAL PROGRAM AT WASHINGTON UNIVERSITY SCHOOL OF MEDICINE

The Washington University NF2/SWN Clinical Program has three major goals:

- Medical care for people with NF2/SWN across the lifespan
- Provide counseling and other resources for patients and family members
- Coordinate research to develop new treatments for NF2/SWN

A dedicated group of physicians and other health care professionals from a broad spectrum of medical specialties — including neurosurgery, otolaryngology, neurology, medical oncology, radiation oncology, neuroradiology, plastic and reconstructive surgery, audiology, neuro-ophthalmology, anesthesiology (pain management), physical therapy, and social work — coordinate patient assessments and provide treatment using a comprehensive approach. We believe that a team model is the best way to bring the most effective care to individuals with NF2/SWN.

## NF2/SWN RESEARCH

Washington University is a world-renowned medical center with extensive research facilities and experience. These research facilities are directly benefiting our patients. Ongoing work has concentrated on using chemotherapeutic agents to arrest the growth of tumors and cochlear implantations to preserve or restore hearing. As a founding member, we are active participants in the NF Clinical Trials Consortium.

All general questions regarding the NF2/SWN Clinical Program at Washington University School of Medicine may be directed to: [NFClinic@wustl.edu](mailto:NFClinic@wustl.edu). For assistance coordinating appointments, please call 314-362-3577 or 800-600-3606.

