Washington University Neurofibromatosis (NF) Center



PROVIDING CARE FOR OUR FAMILIES ACROSS THE LIFESPAN

Both children and adults with Neurofibromatosis (NF) require comprehensive and coordinated medical care. Since the problems that children with NF face are sometimes different from those seen in adults, it is necessary to have both pediatric and adult experts. To provide seamless care across the lifespan, we have assembled a dedicated group of pediatric and adult specialists who work together as a team. In addition, we begin the adolescent/young adult transition process with our teenagers at 14 years of age to ensure a smooth transfer of care from St. Louis Children's Hospital to Barnes-Jewish Hospital.

NF1 CLINICAL PROGRAM

Children with NF1 are seen in Pediatric Neurology by our dedicated team of childhood experts. This includes:

- physicians
- nurse coordinator
- occupational therapist

For children with NF-associated nerve sheath tumors and nervous system tumors, the care team will include pediatric oncologists.

Adults with NF1 are seen by a dedicated neurologist. Adults with plexiform neurofibromas and malignant peripheral nerve sheath tumors are managed by a medical oncologist. Those with brain tumors are followed by a neuro-oncologist.

ADOLESCENT AND YOUNG ADULT TRANSITION CLINICAL PROGRAM

Our adolescent/young adult (AYA) transition program begins when teenagers turn 14 years old. At that time, we:

- assess the child's specific needs
- determine which specialists they require at Barnes-Jewish Hospital
- establish yearly milestones and goals to allow for a seamless change in care

Each child requires their own plan, as some will easily transition, while others might require a slower adaptation period.

SCHWANNOMATOSIS (SWN) CLINICAL PROGRAM

Children and adults with Schwannomatosis (SWN) are cared for by a team of physicians tailored to their specific medical problems. The team's collective experience in treating large numbers of patients with these uncommon conditions allows them to deliver specialized care tailored to the patient's individual needs.

Washington University Neurofibromatosis Center

CLINIC LOCATIONS

Pediatric NF1 / SWN Care

St. Louis Children's Hospital, Suite 2130

One Children's Place

St. Louis, MO 63110

Phone: 314-454-6120

Pediatric Specialized Care

Plexiform Neurofibromas and Nervous System Tumors

St. Louis Children's Hospital, 9th Floor

One Children's Place

St. Louis, MO 63110

Phone: 314-454-6018

Adolescent and Young Adult (AYA) Program

St. Louis Children's Hospital, Suite 2130

One Children's Place

St. Louis, MO 63110

Phone: 314-454-6120

Adult NF1 Care

Center for Advanced Medicine (CAM), 6th Floor

Center 40 Building

1600 S. Brentwood Blvd

Brentwood, MO 63144

Phone: 888-996-4894

Adult SWN Care

Center for Advanced Medicine (CAM), 6th Floor

4921 Parkview Place, Suite C

St. Louis, MO 63110

Phone: 314-362-3577 or 800-600-3606

Adult Specialized Care

Plexiform Neurofibromas, MPNST, Schwannomatosis

Center for Advanced Medicine (CAM), 7th Floor

4921 Parkview Place

St. Louis, MO 63110

Phone: 314-747-1171







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