



## OUR UNIQUE APPROACH

Formal therapy is the next best step when a specific delay has been identified, and the child or family has a very focused goal they would like to achieve. However, to support the general development of children with NF1, we offer experiences that enhance all areas of development in community settings. We pair parents with NF1 care professionals to support open communication, so children continue to grow outside of the hospital walls.

## PLAY-BASED THERAPY: CLUB NF

Provided by the Washington University NF Center in partnership with the St. Louis Children's Hospital Foundation, Club NF is a free, bi-monthly, play-based therapy program for children in Kindergarten through 8th grade who have been diagnosed with NF1. Our therapists use everyday activities to work on skills often delayed in children with NF1.

## JAZZ MUSIC-BASED THERAPY: BEAT NF

The Washington University NF Center, in collaboration with our partners at Jazz St. Louis and the St. Louis Children's Hospital Foundation, created Beat NF to provide a therapy program to address frequently delayed skills in toddlers with NF1.

This free, one-of-a-kind jazz music motor therapy curriculum uses jazz music and physical therapy to:

- Promote social, attention, and motor skills
- Foster healthy parent-child interactions
- Encourage peer relationships and jazz appreciation

*This brochure is provided through the generosity of the Doris and Donald Schnuck Fund for Children in need and the St. Louis Children's Hospital Foundation*

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**NF**  
CENTER

EXCEPTIONAL CARE through  
GROUNDBREAKING RESEARCH

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# THErapy SERVICES

A GUIDE FOR PARENTS OF CHILDREN  
WITH NEUROFIBROMATOSIS TYPE 1



children's  
HOSPITAL • ST. LOUIS  
BJC HealthCare

Washington  
University in St. Louis  
Physicians

children's  
HOSPITAL • ST. LOUIS  
BJC HealthCare

Washington  
University in St. Louis  
Physicians

## DISCOVER THERAPY SERVICES

Children with NF1 face a variety of challenges throughout development, many of which go unrecognized. Parents of children with NF1 often report similar concerns with their child's development:

- Inability to ride a bicycle
- Pain and fatigue when walking longer distances
- Trouble playing on team sports
- Struggles with handwritten activities at school
- Difficulty tying shoes and managing clothing fasteners
- Trouble staying on task while attempting to read or complete homework

When these challenges relate to motor skills, language development or self-help skills, pediatric therapists offer solutions. Physical, occupational and speech therapists are licensed health care providers, who are available to expertly support your child's development.

Through the Washington University NF Center Clinical Program and Therapy Services at St. Louis Children's Hospital, you have access to a wide array of therapy services to assist you in addressing developmental concerns, should they arise. The best way to keep your child on the track to success is early detection and treatment of these delays.



## OCCUPATIONAL THERAPY

Occupational therapists (OTs) are fine motor specialists who address the use of the smaller muscles of the body: those used for writing, typing, dressing and feeding. OTs are also experts in a variety of organization, sequencing and social skills, which generally fall under the umbrella of executive function.

For children with NF1, these executive function delays are often a large focus of OT services. OTs can also suggest alternate methods of written communication, including the use of computers and other assistive technology devices.

## SPEECH THERAPY

Speech-language pathologists (SLPs) develop treatment plans which address all aspects of language, including many areas in which children with NF1 are at risk for experiencing delays:

- Production of sounds
- Organization and expression of thoughts
- Understanding spoken language and following directions

In addition, children with NF1 frequently have a "nasal" quality to their word production. They may also struggle with articulation errors in spoken words, making their speech hard to understand. As children age, they often struggle with the more refined aspects of communication, including understanding body language, detecting social cues and difficulty following multistep tasks.



“Technology can provide children with NF1 an opportunity to achieve higher levels of success in the classroom.”

- Nicole Weckherlin, OTR/L



“We believe that NF should never hold you back. Our therapists specialize in supporting your child to achieve their goals.”

- Courtney Dunn, PT, DPT

## TECHNOLOGY-BASED THERAPY

Technology can play an important and useful role in the lives of children with NF1 by enhancing the school experience, promoting independence and supporting fine motor development. OTs can evaluate your child's technology needs and work with your child to help optimize the use of these devices.

## PHYSICAL THERAPY

Physical therapists (PTs) focus on gross motor skills that use the larger muscles of the body: those important for walking, running, jumping and playing sports.

When working with children with NF1, the largest concerns related to gross motor skills include decreased coordination, balance, strength and endurance. Weakness of the core (the muscles of the belly, back and hips) is one of the key reasons for this decreased balance. PT services benefit children with NF1 by:

- Improving weakness and coordination to increase balance
- Enhancing motor skills to allow greater participation in sports and other activities
- Supporting proper alignment of the spine, legs and feet to decrease pain

## ONLINE THERAPY RESOURCES

- Courtney's Corner Physical Therapy Blog
- Nicole's Nook Technology-Based Therapy Blog
- NFitness Therapy and Development Section