

Introduction to the Cognitive and
Social Development of Children with
Neurofibromatosis Type 1

LEARNING with **NF1**



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THROUGH RESEARCH

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LEARNING with NF1

About half of those diagnosed with neurofibromatosis type 1 (NF1) experience some form of learning disability. Imagine how confusing school would be if everything you read was pushed together like this. Or if the words began and ended in random places. Or if the words danced all over the page. Or if you couldn't connect letters with the sounds they make.

Problems like this may make learning difficult, but they don't have to make it impossible. And having a learning disability does not mean that the child is stupid, or lazy, or unable to learn. It does mean that a child may learn in a different way from his or her classmates. And it also means that, with work and support, the child can close the learning gap.

This guide is written to help the parents and caregivers of those children to understand what to look for. We can help your child to take the first steps towards overcoming learning disabilities.



NF1 Basics

The term “neurofibromatosis” covers three different genetic conditions that cause tumors to form around the nerves: neurofibromatosis type 1 (NF1), neurofibromatosis type 2 (NF2), and schwannomatosis.

NF1 is the most common form. It affects 1 in every 3,000 people born worldwide. It’s caused by mutations in the gene for neurofibromin, a protein that cells use to receive a variety of internal signals—including a signal that tells cells when to stop growing and dividing. Without this control, the cells can multiply around the nerves, producing the tumors commonly found in NF1.



Neurofibromin also appears to be involved in processing nerve signals, including signals inside the brain and those that send messages between the brain and the muscles. So problems with neurofibromin may, in some cases, affect how the brain gets information from the world, processes and stores that information, and how it sends signals back out to interact with the world (through actions or speech, for example).

The symptoms associated with NF1 vary greatly from person to person, and the course of the condition can be difficult to predict. In about half of NF1 cases, the affected gene is inherited from one of the child’s parents, with the other half of NF1 cases arising spontaneously. Almost all such mutations are caused by natural errors in how the body copies DNA during growth, and how it “proofreads” to correct those copying errors. They are not caused by drugs, alcohol, X-rays, or anything the child’s father or mother may have done. NF1 is not a cancer, and it is not contagious.

Learning Basics

In order to learn, we need to take information in, put it in a form that makes sense, connect it with previous things we've learned, store it, and then find it, pull it back out, and act on it. These steps can be looked at this way:

1. **Information comes in** through the senses: sight, hearing, touch, smell, and taste, for example.
2. The brain holds them in temporary storage (**working memory**) while it figures out what to do with them.
3. Then we encode this information, **putting it in a form that makes sense**.
4. We then **store the information** and make connections with other things we know.
5. At this point, we can be said to understand the information, to have **learned** it.
6. Learning becomes useful when we can **find it in our memory**, pull it back out, and use it to help make sense of new situations and information.

Controlling all this activity, sort of like a traffic cop, is the executive function (EF), a set of complex brain activities that develop as we grow. The executive function is what helps us pay attention, set priorities, make plans and keep them, control emotions, achieve goals, and manage daily routines.

Cognitive Difficulties in NF1

Since neurofibromin seems to play a role in transmitting and processing nerve signals, it may affect operations at any of the stages of learning.

Some children with NF1 may misperceive auditory or visual information. Or they may have problems absorbing, processing, retrieving, or communicating



Seven Sensitive Systems

Commonly Affected Areas

- Visual Perception
- Language
- Motor Skills
- Attention
- Behavior
- Executive Function
- Social Skills

different types of information. Up to 90% of NF1 patients will need some educational assistance, and about 50-60% of the NF1 population struggles with learning difficulties. It is important to be aware of the cognitive difficulties your child may face so that you can find ways to champion his or her learning and development. Early intervention can help create beneficial routines and habits to help your child succeed.

Visual Perception

Difficulty processing visual information is one of the most common cognitive problems seen in children with NF1. When we look around, our eyes are taking in information about what is in front of us. Our brain then puts these pieces together, so that we can recognize objects and people. Children with NF1 may have difficulty reading maps, understanding graphics, assembling puzzles, copying shapes, copying information down from a blackboard, or reading words in the correct order. They may tend to skip lines, reverse or rotate letters, or omit words when writing. This obviously affects classroom performance.

HELPFUL TIPS

Improve Visual Perception

For Playing:

1. Build an obstacle course in the back yard, using cones, balls, ladders, or whatever you have at hand. Let the child learn by navigating the course.
2. Put a plastic letter in an opaque bag, and have the child identify the letter by feel.

For Homework:

1. Use graph paper for math homework, to help keep the numbers in line.
2. Show the child how to keep his or her place while reading, by using a 3x5 note card under each line of text.

Language

Some children with NF1 have difficulty understanding speech or writing. They may have problems following directions or instructions, understanding the meaning and content of speech, discriminating between sounds, or understanding word meanings. Children with NF1 may also have trouble expressing themselves aloud or on paper. Their grammar and sentence structure may be poor. They may have limited content in their speech. They may confuse the meanings of written words and misinterpret grammar. They may have difficulty participating in conversations, and struggle to find the right words when they do speak.

HELPFUL TIPS

Promote Language Understanding

- Provide ample time for the child to respond to what you say.
- Repeat instructions.
- Avoid yes/no questions.
- Play games involving naming (e.g. “I Spy”).
- Use the child’s name when trying to get his or her attention.
- Use visual prompts and pictures.
- Demonstrate meaning with actions.

Motor Skills

People use their gross motor skills to control movements that use large muscles—walking, for example, or picking up and moving a chair. They use fine motor skills when precise movements of small muscles are called for—perhaps to pick up a pencil or write a sentence. About 50% of children with NF1 have some problem with both gross- and fine-motor control, and about 30% receive occupational therapy to improve their motor skills. Children with NF1 may seem clumsy and may find everyday tasks challenging. They may bump into things or fall more often than their peers. Many have trouble playing sports. Some have difficulty with handwriting, drawing, and copying.

HELPFUL TIPS

Improve Motor Skills

- Encourage playing with playdough or clay to make figures.
- Make bracelets that involve beading and tying knots.
- Make collages, and practice cutting pictures out of magazines.

Attention Difficulties

We pay attention to different things in different ways, using different parts of the brain. Some children with NF1 will concentrate so hard on one activity that they ignore the rest of their environment, and may have difficulty letting go of one task to move on to a new one. Others may have the opposite problem, and have trouble paying attention to one task for any length of time. Children with attention problems may find it difficult to complete lengthy activities in the classroom or at home. Children with NF1



may sometimes have attention issues without the hyperactivity and behavior problems often associated with attention deficit; in these cases, attention problems may go unnoticed without formal cognitive testing.

The ability to pay attention is a critical factor in academic performance, and identifying and addressing attention deficits early is extremely important.

Behavior Difficulties

Children with NF1 may experience many different types of behavioral difficulties, with issues like impulsivity, hyperactivity, inattention, and inflexibility. Many children with NF1 may also respond inappropriately in social encounters, or have difficulty interpreting facial expressions or body language. Children with NF1 may therefore seem shy and awkward around peers, and may have trouble making friends. On top of this, children with NF1 may experience greater levels of anxiety, withdrawal, and depression.

When you try to manage your child's behavioral difficulties, it is important to fully investigate their causes, as treatments may vary greatly. It is not uncommon for children with NF1 to undergo neuropsychological testing.

Manage Your Child's Behavior/ Attention Difficulties

HELPFUL TIPS

- Give the child choices, but limit their number. Too many options may overwhelm the child. Offering two options and letting the child choose can help her feel in control.
- Let your child know what to expect. Outlining a schedule for activities in advance can help him prepare for a transition from one activity to another, decreasing confusion and frustration.
- Reinforce positive behavior. Like all children, those with NF1 seek attention, negative or positive. Rewarding your child's successes and positive efforts encourages more such behavior in the future.
- Be consistent. Again, many children prefer routine and structure, and this seems particularly beneficial for many children with NF1. Pick realistic consequences for bad behavior, consequences that you are ready to impose and the child can comply with. Apply them consistently.
- Pick your battles. Trying to micromanage your child's behavior will leave both you and your child exhausted. Start by picking a few problematic situations to work on.

Executive Function

Children with NF1 frequently have problems with tasks that require executive functioning. They may have a hard time organizing materials to complete homework assignments, figuring out how much time a task will take, and setting deadlines. As a rule, it helps to give clear, direct instructions with frequent reassurance and explicit feedback.

Executive functions may be best understood as an umbrella term that encompasses a number of related skills necessary for purposeful activity. Executive functions include the ability to:

- Initiate behavior
- Focus on that behavior
- Select the relevant tasks needed to complete a goal
- Organize a means to solve problems
- Change problem-solving strategies in a flexible manner
- Monitor and evaluate behavior and emotions
- Manipulate information in immediate memory (working memory)

Difficulties in executive functions are often a hidden source of academic underachievement.

HELPFUL TIPS

Improve Executive Function



Baking cookies

A simple task like baking cookies can help children develop problem-solving skills, bilateral skills, visual motor skills, safety awareness, body awareness, and fine motor skills. Baking requires many processes that seem simple but require organization and forethought: reading the recipe and following directions, wearing oven mitts to put the cookie

1. Establish a “Daily Home Schedule” by introducing one task at a time.
2. Break the day down into time slots for all of the main tasks your child does in a day. Include after-school activities, homework time, chores, free time, dinner, and preparing for bed. Here is an example to get you started.

Get up in the morning	7 :00 AM
Leave for school	8 :00 AM
Arrive home from school	2 :00 PM
Snack and play time	2 :15 PM
Homework	3 :30 PM
Soccer Practice	4 :30 PM
Dinner with the family	6 :30 PM
TV time	7 :30 PM
Get ready for bed	8 :30 PM
Lights out	9 :00 PM

3. Set time limits for each task, and reward the child for following the schedule.

sheet in the oven, keeping track of the ingredients on the counter or table to avoid knocking them over, rolling dough into small balls or spreading it flat, and cutting out shapes using cookie cutters.

Steps:

1. Plan which ingredients to use.
2. Calculate the amount needed of each.
3. Measure them.
4. Follow written directions or verbal instructions.
5. Be patient (which is to say, have self-control).

Social Skills

Some children with NF1 have difficulty forming friendships and may be rejected by their peers. Nearly 40% of children with NF1 struggle with social interaction and communication. In some children, language development may be delayed, or they may not be able to communicate effectively even when their speech is adequately developed. They may not use or respond well to non-verbal signals. They may have few age-appropriate peer relationships. Or they may appear to lack spontaneous sharing and imaginative play.



HELPFUL TIPS

Plan a Play Date & Develop Friendship

Start by listening to your child. The more positive and trusting your relationship, the more likely it is that your child will accept your guidance. If your son or daughter is upset about a friendship problem, be empathetic. You can help your child find the right playmates by volunteering at your child's school. It's an opportunity to network and to suggest play dates. Do not be disappointed if your child does not get invited to other play dates; take it as an opportunity to organize your own.

1. Before the Play Date:

Prepare by putting away anything that might cause conflict, such as a favorite toy. If your child has repeatedly acted in a way that causes you concern, remind him in advance about the appropriate behavior.

2. Plan Activities:

Plan enough activities so that you leave little or no unstructured time. Even though you have a plan, make it seem as though your child is the

ADHD: Understanding the Connection with NF1

The symptoms of Attention Deficit Hyperactivity Disorder (ADHD)—behavioral difficulties, attention difficulties, and executive function deficits—are also often seen in children with NF1. Some signs of ADHD are:

- **Hyperactivity:** The child fidgets or squirms when asked to sit still, and runs around or climbs when inappropriate.
- **Impulsivity:** The child has trouble waiting for his or her turn, shows emotions without restraint, and interrupts others' conversations.
- **Inattentive:** The child frequently makes careless mistakes, has trouble organizing tasks, or has difficulty paying attention for more than a few minutes.

Overall, about one third of children with NF1 meet the diagnostic criteria for ADHD. Even so, it is important to remember three things:

- These ADHD-like symptoms, like so many other symptoms of NF1, often present themselves in a variety of ways, both with and without hyperactivity.
- Not all children with NF1 have these ADHD-like symptoms.
- Not every child who shows ADHD-like symptoms actually has ADHD.

one in charge. For example, when it is time to switch activities you can ask your child, “Do you think it is a good time to watch a movie or play outside?”

3. Be Ready:

If any conflict arises, be ready to smoothly intervene and redirect. Be on hand with snacks and other distractions, but remember not to get overly involved.

4. Leave Them Wanting to Come Back:

Limit the length of the get-together. An hour is sufficient for a seven-year-old child, particularly if this is the first play date with a friend. You want to end while everybody is still having fun!

5. Overall:

After the play date is over, give your child feedback. Keep the ratio of positive to negative remarks as high as possible. There should always be about four times as much praise as criticism (and the criticism should always be constructive).

Still, children with NF1 are at higher risk than the general population for developing ADHD. Although many children may seem restless, a diagnosis of ADHD should be considered when the symptoms begin to affect school performance, or if the child experiences symptoms to a greater degree than other children her or his age. For those children with ADHD, it may be helpful to develop a distraction-free zone, in which they can complete tasks or assignments. Allowing ample time for breaks and movement may help them to stay focused when they are working on tasks that require more than 20 minutes per item.



How to Interpret and Use ADHD Resources

ADHD is more common in the general population than NF1 (in the 4 to 17 age range, about 1 child in 11 is currently diagnosed with ADHD), and there are many resources for adults and children with this diagnosis. Even children who do not have ADHD may have problems that can benefit from strategies used to treat ADHD. Your NF expert may refer you to the ADHD websites, books, and apps. To get the most out of these resources, remember:

- Focus on specific skills. There are many suggestions for how to work on organizational skills, time management, completing school work, and attention. Rather than looking at the big picture, it may be helpful to focus on specific everyday tasks you would like to improve.
- Find what works for you. Your child may not fit all the criteria for ADHD, so some of the recommended ADHD management tools may not apply in your case. Try out different strategies to find those that best suit your child.

- Don't get bogged down in the details. It can be frustrating and exhausting to search through resources that seem to target a completely different disease. Many children with NF1 do not demonstrate the hyperactivity associated with ADHD and are not at risk for addiction and drug abuse (unlike some with ADHD). Focus on the symptoms that overlap most with your child's, and ignore those that do not.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is being recognized in children with NF1. The scientific community recognizes that autism characteristics do not fit within rigid categories; rather, they range along a broad spectrum of symptoms and behavior. A significant number of children with NF1 display symptoms often associated with ASD, and these symptoms may interfere with some functions of daily life. They may include problems with flexibility and transitions, repetitive behaviors, and being regarded by others as different (with unusual social communication, motivation, awareness, and cognition). The NF scientific community is continuing to learn more about ASD in children with NF1.

Strategies for Parents and Caregivers of Children with NF1

Give Yourself a Break

Managing the health and development of your child can be exhausting and overwhelming, but it is important to remember that making time for yourself throughout the week will help your child reach his or her full potential. You will not only feel rejuvenated and parent more effectively, but you will also be modeling a balanced lifestyle for your children. Taking a break will help you re-focus and find new ways to tackle your daily challenges.

Positive Conflict Resolution

Although your child's behavior may often seem irrational, having a conversation about it may help her or him learn how to verbalize rather than act out. Instead of sending the child to a time out, offer an opportunity to calm down in a safe and comfortable place first. Having a positive space for calming can help children work through their feelings positively, rather than negatively. If you notice that acting out is becoming more frequent, have the following conversation in a positive setting (such as over a favorite snack).

First, ask your child to explain what she or he is trying to express with the outburst: what does the child want and why. Second, you and the child should come up with three potential solutions that would address the child's needs and avoid the flare-up. Third, decide on one solution together. Keep in mind that you may have to compromise with your child, and that the solution may be helping the child learn when to take a break.

HELPFUL TIPS

Make the Most out of Mealtimes

- Give your child countdown warnings ahead of transitions to mealtimes, with notifications at perhaps 15, 10, and 5 minutes before the activity change.
- Give your child an active role. Involving your child in cooking or setting the table for the meal gives her or him a feeling of involvement (“agency”). Cooking, for example, gives the child an incentive for taking part in the meal, so she or he can see how the creations taste.
- Modify your expectations. Your child may need to take periodic short breaks throughout the meal. Plan for these to take place between courses. Let your child know when it will be break time, and provide a timer so the child can keep track of exactly how long the break will be.
- Prioritize. Decide on which parts of the meal you most want your child to partake in. Even if he or she cannot finish the full meal at the table, focus on the positives of participating in the major parts.

Services for Children with Special Needs

For young children

Early Intervention Programs (EIP) are federally funded services available in every state to identify children who may need extra help to meet developmental milestones. Each state runs the program in its own unique way, but a free evaluation is available to every child under 3 years of age.

For school-aged children

It is important to build a positive relationship with the administrator and teachers at your child's school. Communication is the key, and reaching out to your child's teachers early will show that you are invested and involved in your child's education.

- When you contact your child's teachers, set goals for what you hope to accomplish. Any interaction more detailed than a simple introduction deserves a parent-teacher conference.
- When you plan for the conference, be sure to set a date that is convenient for both you and the teacher, and make a simple agenda.
- Multiple conferences may be necessary if you have more than one issue to discuss.
- During the conference, be sure to stay positive, stay on task, and find out what you can do at home to help reinforce what your child is learning in the classroom.

Do not get discouraged if your child needs to work on many areas. Many NF1 children struggle in school. Communicating with your child's teacher is only the first step.

Types of Assistance

Occupational Therapy/Physical Therapy/ Speech Therapy

To receive either physical therapy (PT), occupational therapy (OT), or speech therapy services, the child must be eligible for special education services, and it needs to be apparent that the child will benefit from them. To read more about eligibility for special education services, see the "Legal Rights" section of this brochure, to follow.

- Occupational Therapy is for children who struggle with visual perception, written communication skills, play skills, task organization, and feeding.



- Physical Therapy is for children who have difficulties moving from place to place, positioning themselves during activities, or minimizing pain.
- Speech Therapy is for children who have difficulty with articulation, language processing, cognitive or other developmental delays, and motor planning problems.

Types of Accommodations

Children with NF1 may need, and qualify for, changes to help them learn better.

These accommodations may include:

- Assistive technology, including writing aids, computers, or keyboard devices.
- Testing accommodations, including extending the test time, providing oral and written directions, or offering headsets to muffle noise, among many other measures.
- Room modifications, including room dividers to reduce distractions, providing a variety of work surfaces (desk, blackboard, and floor, for example), or seating the child close to the teacher.
- Adaptive physical education, to help the child learn to cope with the challenges of impaired motor skills.

Transition Services

People with NF1 can also benefit from services to help them transition to life beyond school. Transition service plans must be included on the child's Individualized Education Plan (IEP) from the age of 15 onward. They are designed to help prepare students for life after high school, and may include vocational assessments, training in daily-living skills, and community experience.

Legal Rights

Parents are in the best position to advocate for their child when they have educated themselves about the process, the laws, and their rights. Parents are encouraged to consult with the child's teachers and the school's special education department. State your concerns about your child's educational needs, and do it in writing. If your child has NF1 and is struggling in school because of a learning difficulty, a 504 Plan or an Individualized Education Plan (IEP) may be a good option at any time from kindergarten through 12th grade. Here, in brief, are some of the provisions.

Individualized Education Plan (IEP)

The IEP is a personalized education plan required under IDEA, the Individuals with Disabilities Education Act. The IEP is used for children who need special education services in addition to the general curriculum.

To qualify for an IEP, the child typically has to undergo a number of assessments and evaluations to document the areas in which she or he needs assistance. Though documentation from medical providers is often included, it is not required. The law provides for an additional, independent evaluation at the school district's expense if parents disagree with the first evaluation.

Children with NF1 typically qualify for an IEP under the special education disability classification of "other health impaired" (OHI). Once in place, the IEP provides for modifications, accommodations, and specialized instruction that change how and what your child is taught.

The IEP documents the child's current performance, sets out annual goals, and outlines the necessary special education and related services, classroom accommodations, and transition services. It also spells out how progress will be measured, and may prescribe participation in state and district-wide tests. The IEP is both results-oriented and time-sensitive. It should be reviewed and updated at least once a year.



The 504 Plan

The 504 Plan (named for Section 504 of the Rehabilitation Act of 1973, which bans discrimination against public school students with disabilities) protects students who have a disability that substantially limits one or more major life activities—such as learning, reading, thinking, writing, and concentrating. The act prohibits the exclusion of persons with disabilities from federally funded programs or activities. The 504 Plan can be used to formally document a disability, and to make accommodations or modifications to the learning environment.



There is no standard 504 Plan—every student has different needs and should receive a different plan. The plan can include computers and other technologies, extending time or allowing privacy for test-taking, prescribing verbal or non-verbal cues, and supplying the child with note-takers or other help.

Section 504 does not require specialized instruction, and does not provide for independent evaluations at the district's expense. What it does do is require schools to eliminate barriers that prevent the student from participating fully in the programs offered in the curriculum. A 504 plan might be a good option if your child is not eligible for other services under an IEP.

Transition into Adulthood

As your child moves into the teenage years, start involving him or her in important medical decisions. Eventually, your child will need to assume responsibility for their own healthcare. Your child will need to maintain active health insurance—which can be on your own medical plan until the child reaches the age of 26. It is recommended that adults with NF1 see their NF1 specialist at least once every 2 years.



Life after Graduation

The most important thing for any child, with or without NF1, is finding a path that will make him happy. Talk to your child about what she envisions for her life, and discuss the steps she can take to reach those goals. Some options include community colleges, technical institutes, and undergraduate colleges/universities. Keep in mind that higher education is not for everyone, and many people also choose to enter the workforce directly.

Thinking of Going to College

High school students interested in college should meet with a guidance counselor

to discuss options. It is helpful to work with school advisors to ensure that proper accommodations can be made for taking standardized college entrance examinations. A 504 Plan or IEP should be sufficient to establish disability and justify the accommodation.

The NF1 diagnosis is one more factor to add to the college-selection mix. Most colleges should be able to make accommodations for those with learning difficulties, but be sure to look into these options as early as possible, both during the college search and after acceptance.

Social Life

As your child grows older, keeping up relationships will take work and planning. It is important to help your child understand this, and how to balance a social calendar with work and school commitments.

Family Planning

Because NF1 is a genetic disease, and a person with NF1 has a one-in-two chance of passing the trait on to a child, it is recommended that young men and women with NF1 discuss their family planning choices with a genetic counselor before having children.

Encourage Older Children to Manage Their Own Healthcare

HELPFUL TIPS

- Encourage them to make their own doctor appointments.
- Help them develop a plan for how to get from home to the doctor's office and back—whether by driving themselves, getting rides from family or friends, or public transportation.
- Highlight the importance of keeping their own medicine log.
- Promote independence in healthcare decision-making.
- Encourage them to keep their own medical records folders.

Resources

WEBSITES

The Children's Tumor Foundation website (ctf.org) The website of the oldest and largest national foundation for NF in the United States. Here you can find information on NF, research news, NF specialists, educational events, patient brochures, family events, and many other ways to support the NF community.

The NF Registry (nregistry.org)

A patient-centered resource for sharing your experiences as a way to help guide NF research. You can find clinical trials that you may want to consider participating in, see how your NF experiences compare to those of others, and be a part of an international NF awareness effort.

National Research Center for Learning Disabilities (www.nclد.org)

For more information on legislation and regulations that affect the education of a child with a disability.



The Individuals with Disabilities Education Act/IDEA (idea.ed.gov)

A resource for more information about your legal rights.

US Department of Education, Early Intervention (www2.ed.gov/programs/osepeip/index.html)

A resource for information about services for very young children.

Think College (www.thinkcollege.net)

Resources for college-bound individuals with intellectual disabilities.

College Scholarships (www.collegescholarships.com)

A resource where you can search for scholarships and programs for individuals with disabilities.

BOOKS

Neurofibromatosis: A Handbook for Patients, Families, and Healthcare

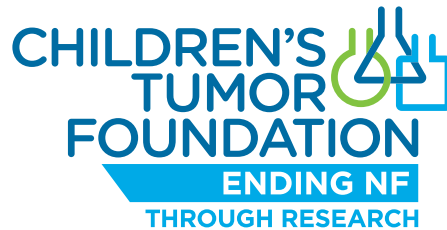
Professionals, 2nd edition. By Bruce R. Korf and Allan E. Rubenstein. New York: Thieme, 2005. Information about the natural history and genetics of NF, as well as management and research.

The NF Parent Guidebook: How to Help Children with Learning Challenges Associated with Neurofibromatosis Type 1

A booklet to teach parents how to manage the education of their children with NF1. Available for purchase or download at ctf.org.



Thank you for taking the time
to learn about neurofibromatosis.



Founded in 1978, the Children's Tumor Foundation (CTF) is a highly recognized national nonprofit 501(c)(3) organization dedicated to finding treatments for NF.

Our Mission:

Drive research, expand knowledge,
and advance care for the NF community.

Our Vision:

End NF.

To become involved and learn about local Foundation activities in your area, please visit our website or contact us at the address or number below.

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