



**ADDRESSING ACADEMIC  
CONCERNS: A GUIDE FOR  
PARENTS OF CHILDREN WITH  
NEUROFIBROMATOSIS 1**

**children's**  
HOSPITAL • ST. LOUIS  
BCH HealthCare



## WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis (NF) is a set of complex genetic disorders that can affect nearly every organ system in the body. There are two types of NF: neurofibromatosis type 1 (NF1) and neurofibromatosis type 2 (NF2). NF1 is ten times more common than NF2. People with NF1 do not get NF2. These are two different medical conditions.

NF1 affects approximately one in every 3,000 people. This makes NF1 more common than cystic fibrosis and hereditary muscular dystrophy combined.

A diagnosis of NF1 is made following an extensive physical exam. Your NF doctors are looking for birthmarks (cafe-au-lait macules) and freckling in the armpits or groin area. Other signs of NF1 include neurofibromas (benign tumors affecting nerves throughout the body), optic gliomas (brain tumors involving the optic nerve), and specific bone abnormalities.

Once a child or adult is diagnosed with NF1, your NF medical team closely monitors children and adults for specific signs and symptoms. Importantly, NF1 affects people differently in infancy, school-age children, and adults. For this reason, young children and adolescents require yearly visits with an NF specialist. In adulthood, visits may become less frequent.

Although NF1 increases the risk of tumor growth, individuals are expected to generally live a full and active life, with a relatively normal life expectancy. However, due to the complicated nature of NF1, your child should be cared for by a team of specialists, each an expert in the management of NF1. Every member of the team has a particular role. Together, your NF team aims to help you obtain the highest level of health, function and quality of life for your child.

## What School Issues Exist In Children With NF1?

Learning problems are common problems in children with NF1. Despite relatively normal intelligence and learning potential, over half of children with NF1 have some form of learning difficulty.

Children with NF1 often experience learning problems because of a “short-circuit” or dysfunction in one or several of the channels in the brain. A dysfunction in any step may interfere with subsequent steps in the learning process, thus leading to problems in a child’s ability to perform up to their potential in the classroom. When this occurs, steps are needed to either strengthen the area of weakness (through interventions) or work around the dysfunction (through accommodations).

Interferences in a child’s learning may result from problems getting information into the brain (input), processing information, retrieving information, and/or communicating information (output).

Children with NF1 may have difficulties with input, causing “misperceptions”. A child with normal vision or hearing may still have a visual or auditory perceptual disability. Perceptual disabilities often leave a child feeling confused, anxious and/or frustrated. A child with a perceptual disability may reverse letters, have problems positioning objects in space, or have difficulties distinguishing subtle differences between similar sounds. In addition, children with perceptual disabilities may misperceive social cues and body language. Problems with input may also take the form of attention problems. Children with NF1 are at high risk for problems with attention, and they sometimes have trouble holding their attention over a period of time (e.g., 10-15 minutes). Because of this, it is often necessary to present information to them multiple times and to provide as much structure and organization to the material presented as possible.



Children with NF1 may also have difficulties with processing information, leading to problems putting together information in their minds. These problems in “integration” include difficulties putting things in an order that make sense (sequencing), figuring out the meaning of symbols and words (abstraction), and organizing new information and relating it to previously learned information (organization).

Children with NF1 may also have problems with memory. There are two general types of memory – short term and long term memory. Children with NF1 are more likely to experience problems with short term memory. For this reason, some children with NF1 may not be able to immediately remember information they have learned, even though they can successfully demonstrate learning the next day. Similarly, children with NF1 may be inconsistent with their memory, demonstrating knowledge about something one day but not the next. This pattern of performance is due to inefficiencies in their ability to retrieve information from memory. Utilizing recognition format examinations (e.g., multiple choice; true/false) is often helpful in circumventing this difficulty. In addition, providing extended time for assignments and examinations can be helpful. Speeded activities (e.g., time-tests) should be avoided as much as possible.

## What to Do If You Suspect Learning Problems

If your child is experiencing problems with academic performance, you should consider the following steps:

1. Speak to your child about it.
  - How does your child feel about school?
  - Does your child notice these difficulties?
  - What does your child think may be the problem?
2. Talk to your child’s teacher(s).
  - Is the problem in all academic areas or only in specific subjects?
  - Are there any problems with behavior in the classroom?
  - Does your child appear focused in class?
  - Is your child participating in class?
  - What steps are the teachers willing to take to help your child?

## Involving Teachers/Educators When You Think There Might Be a Problem

Including your child's teachers as well as others involved in his/her education is critical to your child's success. Not only will you learn more about your child, but the teachers can suggest other strategies to use at home and at school, and can assist you with making a [referral](#) for [formal evaluation](#).

It is important to build and maintain a positive relationship with your child's teachers. Begin by letting teachers and other school staff members know that you look forward to working with them. Let your child know that you are ALL working together to help him/her succeed. Pay attention to any notes and/or graded work that is sent home for your review. Let the teachers know from the start that you want to work with, not against, them, so your child will perform better in the classroom. Do not feel you are intruding or asking for special treatment. You are simply indicating that you are truly concerned about your child's education.

The first contact with your child's teacher, in many ways, is the most important. This is the time you are building rapport and developing a relationship of trust. Therefore, an appropriate time and setting is important for the first brief encounter. A phone call, a note, or, best of all, an initial face-to-face meeting effectively initiates this process.

A good time to contact your child's teacher is during the first week of school. This gives you an opportunity to meet one another and to establish a positive relationship from the start. When meeting with a teacher, keep the discussion constructive.

When arranging a conference with the teacher, the ten guidelines below may help make this time a positive and productive experience: ([http://www.childdevelopmentinfo.com/learning/parent\\_teacher.shtml](http://www.childdevelopmentinfo.com/learning/parent_teacher.shtml); Taken from the Child Development Institute: Establishing a Parent-Teacher Relationship)





**Guideline 1:** Identify the purpose for the conference. Is it to become acquainted? Is it to alleviate your concerns about your child's poor attitude towards reading and/or school? Or is it to receive a report card and test scores? Each of these situations is vastly different and requires different types of preparation.

**Guideline 2:** Communicate the purpose for the conference. If you are requesting the conference, immediately tell the teacher the purpose. This helps to alleviate any imagined fears the teacher may have about your request to hold a conference.

**Guideline 3:** Arrange the conference at the teacher's convenience. The teacher then has sufficient time to plan, allowing them to bring the necessary information to the conference. An unplanned conference can turn out to be a waste of time for both the teacher and parent, and can cause feelings of frustration.

**Guideline 4:** Plan for the conference. Write out the areas and questions you want to cover during the conference. Combine, delete, and clarify these questions, and, finally, prioritize them. By using this process, your most important questions will be answered in a clear, succinct manner. Moreover, the teacher's responses will likely be more helpful and to the point.

**Guideline 5:** Restate the purpose of the conference at the onset. Try to stay on one topic since your time together is limited.

**Guideline 6:** Display a positive attitude during the conference. Be aware that not only what you say reflects your attitude, but also your tone of voice, facial expression, and body movements. A loud voice may imply dominance. Rigid posture may suggest anger or disapproval. Always listen attentively and show your enthusiasm.

**Guideline 7:** Remain open and supportive throughout the conference. Don't become antagonistic or defensive; otherwise the conference outcome can be disastrous. Strive for cooperation between you and your child's teacher. Even when teachers present a negative side of your child's behavior or inform you of other problems, try to remain objective. This can be difficult when it is your child, but he/she will experience as many or more difficulties if you and the teacher don't try to find a way to work together to solve these problems.



**Guideline 8:** Make sure that specific suggestions are provided to increase your child's success in the classroom. If your child is doing well, find out what you can do to ensure continued success and progress. If he/she has difficulties, make sure the teacher goes beyond merely pointing out a problem. The teacher needs to provide ideas for eliminating or reducing the difficulty. Many parents have been discouraged or aggravated because teachers point out problems but don't provide solutions. Don't let this situation occur! If immediate suggestions can't be provided, then a follow-up conference is needed.

**Guideline 9:** Ask for examples of daily work to better understand your child's strengths and weaknesses. By reviewing your child's work, you will learn if progress has been made since the last conference. Have any weaknesses become worse? If improvement hasn't been made, are other methods or materials being used? As a parent, what should you be doing at home with your child?

**Guideline 10:** Clarify and summarize each important point as it is discussed. Thus, both teacher and parent are better able to develop a mutual understanding and agreement.

Keeping good records and documentation of meetings and interventions that have been tried will be useful for future reference as you work with the school to help your child. It is suggested that you document everything.

Be on time, be positive, and be prepared for school activities and meetings. Stay involved during the school year. Make a point to show up and participate in events such as science fair, back-to-school night, and open houses.

## Consider Further Evaluation

You should consider more formal services if you and your child's teacher are not successful. There are two primary pathways for establishing formal educational services:

### 504 Plan

- Refers to Section 504 of the Rehabilitation Act of 1973
- Prohibits the exclusion of persons with disabilities from federally funded programs or activities
- Provides modifications and accommodations in the classroom to allow the student an equal opportunity to perform to his/her potential
- Does not include specialized instruction

### Individualized Education Plan/Program (IEP)

- Based on the Individuals with Disabilities Education Act (IDEA) (1990; reauthorized in 1997 and 2005)
- Provides modifications, accommodations, and specialized instruction
- Changes how a child is taught
- Students qualify for an IEP only if they are actually experiencing learning problems in the classroom
- Children with NF1 typically qualify for an IEP under the special education disability classification of Other Health Impaired/Impairment (OHI)
  - To qualify under OHI, a student must have a chronic or acute medical condition (like NF1) that results in limitations in alertness, strength, or vitality which adversely affects his/her performance in the classroom. This must be documented in an evaluation (either by the school district or a psychologist in the community)
  - Determination of a student's eligibility for an IEP is always a team decision among designated school staff and the parents

## Developing an Individualized Education Plan (IEP)

Once you have notified the school that you would like your child to be considered for an IEP, the school district will convene an IEP Team meeting



with the parents, teachers, special education coordinator, and likely other staff members (e.g., school psychologist, speech-language therapist, principal, etc.)

The IEP Team will discuss your child's performance and determine what additional information is needed before deciding if your child qualifies for special education services (IEP). Additional information will likely include the following:

- Classroom observation
- Consultation with your child's healthcare professionals (e.g., NF specialist)
- Psychoeducational testing (intelligence, achievement, and maybe language or motor testing)

The IEP Team will reconvene after all of the data are collected to decide, as a team, if your child qualifies for special education services (IEP), based on the special education laws of the state. If eligible for special education, an IEP will be generated by the team that will include the following information:

- Explanation of your child's disability
- Educational goals
- Therapeutic goals (if he/she receives speech/language therapy, physical therapy, or occupational therapy)
- Classroom placement (mainstream versus special education)
- Location of services and minutes per week
- List of academic accommodations and how often they will be utilized

It is important to remember that the IEP process takes time. The teachers will need at least four weeks of documentation and background information to identify problem areas so that specific interventions can be suggested. Agreed upon interventions are tried for several weeks and then the child is reassessed to see if these interventions are effective and successful. If not, a different set of interventions may be tried, based on what was observed as working or not working. All aspects will be reviewed, which is why this may be a lengthy process. In addition, each state has its own policies, standards, and processes for carrying out the requirements set by Individuals with Disabilities Education Act (IDEA).

## Legal Rights of Students and Parents

Parents are in the best position to assist their child in receiving appropriate services when they have educated themselves about the process and their rights. If there are concerns about whether the student's rights are being violated, parents are encouraged to consult with their state Department of Education.

The IEP process can be overwhelming and complicated. Parents may need help understanding their child's needs. If they need help, specialists (called advocates) are available to help.

Parents can contact their [State Learning Disabilities Association](http://ldaamerica.org/state_chapters/index.asp) at [http://ldaamerica.org/state\\_chapters/index.asp](http://ldaamerica.org/state_chapters/index.asp) or [State Parent Training and Information Center](http://www.taalliance.org/centers/) at <http://www.taalliance.org/centers/>.



## Other Resources

Washington University  
Neurofibromatosis Center  
<http://nfccenter.wustl.edu>

Missouri Special Education  
[www.dese.mo.gov/divspeced](http://www.dese.mo.gov/divspeced)

Illinois Special Education  
[www.isbe.state.il.us/spec-ed](http://www.isbe.state.il.us/spec-ed)

### Parent Advocacy Groups:

Missouri Protection  
and Advocacy Services  
(573) 659-0678 or  
(800) 392-8667

MPACT (Missouri):  
(816) 531-7070 or  
(800) 995-3160 or  
(877) 876-2831

Family Matters (Illinois)  
(217) 347-5428 or  
(866) 436-7842

National Research Center  
on Learning Disabilities  
[www.nrcld.org](http://www.nrcld.org)

Missouri First Steps Office  
(866) 583-2392  
<http://www.dese.mo.gov/divspeced/FirstSteps/index.html>

Department of Elementary and  
Secondary Education  
Division of Special Education  
P.O. Box 480  
Jefferson City, MO 65102-0480  
(573) 751-5739

RELAY in Missouri  
(800) 735-2966

The Children's Tumor Foundation  
95 Pine Street, 16th Floor  
New York, NY 10005  
(800) 323-7938  
Email: [Info@ctf.org](mailto:Info@ctf.org)  
Internet: [www.ctf.org](http://www.ctf.org)

Neurofibromatosis, Inc.  
PO Box 66884  
Chicago, IL 60666  
(800) 942-6825  
Email: [admin@nfnetwork.org](mailto:admin@nfnetwork.org)  
Internet: [www.nfnetwork.org](http://www.nfnetwork.org)

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