A GUIDE FOR THOSE LIVING WITH NF1

Diagnosed with Neurofibromatosis Type 1 (NF1)

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CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

A Message from the Children's Tumor Foundation

This booklet is designed to help you on your journey living with neurofibromatosis type 1 (NF1). Whether this is a recent diagnosis or a previous one, you will find information and support here to help you and your loved ones.

The Children's Tumor Foundation (CTF) hopes this guide will answer some of the most common questions that people living with NF1 and their caregivers have about coping with a diagnosis, understanding how NF1 occurs, recognizing common and less common symptoms, and managing care while living a full life.

We are also here to help you connect with other patients and families, and share opportunities for you to be part of the active and vibrant NF community around the world.

"I strongly believe that while having NF has been a difficult journey, it has taught me to push forward and persevere through whatever life may throw in my way and has truly made me the complete person I am today."

—David, who lives with NF1, pictured here with his two daughters Genna and Rosie, who also live with NF1

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Newly diagnosed with NF1

At the Children's Tumor Foundation (CTF), we know that receiving a diagnosis of neurofibromatosis type 1 (NF1) can be overwhelming and a lot to process all at once. People deal with difficult or unexpected news in different ways. For some families, the diagnosis comes as a complete surprise in a child who otherwise appears healthy. For others, it may have been a long road to finally reach the diagnosis.

Some people take in the information slowly, giving themselves the time to absorb the information in pieces. Others seek to learn as much as they can as soon as possible. Either is perfectly normal, with no right or wrong way to handle this news.

It is important to know that you are not alone. NF1 is one of the most common genetic disorders, and there are many families who can offer insight and support. The Children's Tumor Foundation, along with your healthcare providers and loved ones, is available to help as you adjust to the diagnosis, and give you the tools needed to manage NF care.

Previously diagnosed with NF1

Coping with a diagnosis of a genetic condition such as neurofibromatosis type 1 (NF1) can be difficult at any stage of life. Families must continually learn new things and adjust their coping strategies as a patient's unique challenges change over time. For instance, the considerations at the initial diagnosis may be very different from those that are applicable many years later, and as one transitions into adulthood.

It is important to recognize that new questions, fears, and anxieties may appear and may sometimes surprise you. The Children's Tumor Foundation, along with your healthcare providers, is here to help you throughout the NF journey.

"NF has given me the strength to overcome anything life has to throw at me. It has taught me to appreciate everything in life, and that I need to continue to grow as a person every day to overcome this."

—Samantha, who lives with NF1

Types of NF

NF refers to a group of genetic conditions that cause tumors to grow on nerves. These are lifelong conditions that affect all populations equally, regardless of gender, race, or ethnicity. People who have NF can lead full lives, but they often require specialized medical care by a team of healthcare providers familiar with the disorder. One type of NF does not change into another type.

Neurofibromatosis type 1 is the most common form of NF, occurring in about 1 in every 2,500 births. Even though individuals have NF1 when they are born, it may not be diagnosed right away because some manifestations (signs or features) only appear over time. In addition, some healthcare providers not familiar with early NF1 manifestations, may struggle to recognize important features.

This brochure is specific to NF1. If you are uncertain about the type of NF you have, please contact your healthcare provider. You can learn more about all types of NF at the Children's Tumor Foundation website, at ctf.org.

—Diane, Sean, and NF Hero Jadien

did you know?

Neurofibromatosis type 1 (NF1) is the most common type of NF, and affects approximately 1 in every 2,500 people.

Introduction to NF1

Neurofibromatosis type 1, or NF1, can affect multiple organs of the body. The most common signs are found on the skin, typically in infancy or early childhood. Café-au-lait macules are small, flat, brown spots that can occur anywhere on the skin. Freckling can occur in the groin or under the armpits. The appearance of these skin findings often leads a doctor to suspect a diagnosis of NF1.

In addition to skin spots and freckling, there may also be neurofibromas (benign growths on the peripheral nerves of the body) that are sometimes observed early but can also develop over time. About 50% of people who have NF1 also have learning difficulties. Fragility or curving of leg bones and of the spine (scoliosis) may occur in some individuals who have NF1. Benign spots on the colored part of the eye (Lisch nodules) may also appear.

Occasionally, tumors may develop in the brain, on cranial nerves, or on the spinal cord. Although NF tumors are usually not cancerous, they may cause problems by affecting nerves or pressing on nearby body tissues. Sometimes a benign tumor may become malignant (cancerous), but for most people who have NF1, a malignant tumor will never develop.

Most individuals who have NF1 lead healthy lives with relatively mild or manageable symptoms. Although two-thirds of people who have NF1 do not have any major medical complications, some may have more significant health issues. Some uncommon, but serious, NF1-related complications include malignancy (cancer) and problems with the narrowing of the blood vessels. Although these situations are not typical, they are serious and must be monitored by healthcare providers familiar with NF1.

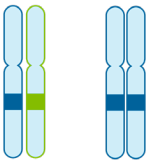
The manifestations of NF1 are very different for each individual. It is difficult to predict how mild or severe the impact of NF1 will be or what medical concerns will develop over time, and it is therefore important to connect with and be followed by a specialist in NF1. Dealing with this uncertainty can be scary and frustrating for patients and their families.

If you think you need assistance coping with NF1, please seek support through the Children's Tumor Foundation or from your healthcare provider.

What causes NF1?

You may wonder what caused you or your child to have NF1. **It is important for you to know that you did nothing wrong; NF1 is related to a genetic change, and is not the result of anything that a parent or person living with NF did or did not do.**

How genetic changes happen:



A pathogenic *NF1* gene variant

- Neurofibromatosis type 1 is caused by a change, or pathogenic variant (previously called a mutation), in a gene (a sequence of DNA)
- We all have two *NF1* genes, inheriting one from our father and one from our mother. In general, NF1 refers to the condition and *NF1* (in italics) refers to the gene
- The *NF1* gene has a very long genetic sequence, and even a small change can disrupt its normal activity
- The *NF1* gene is located on chromosome 17 and is responsible for the production of neurofibromin, a protein that prevents cells from growing too quickly
- A person with NF1 has a pathogenic variant in the *NF1* gene that interferes with the normal production of neurofibromin
- Having abnormal or not enough neurofibromin is the cause of clinical manifestations associated with this condition

In 50% of individuals who have NF1, the *NF1* gene variant is inherited from a parent who has the condition. In the other half of cases, a new change in the *NF1* gene occurs even though neither of the parents has the condition. This is referred to as a spontaneous, sporadic, or *de novo* case of NF1.

Neurofibromatosis type 1 is not caused by anything a parent does or does not do before or during a pregnancy. It is also not a condition that can be detected in a routine prenatal screening during pregnancy. **NF1 is not contagious; you cannot spread it or catch it from another person.**

did you know?

A child can inherit NF1 from a parent, but about half of the time, a child with NF1 is the only person in the family who has NF1.

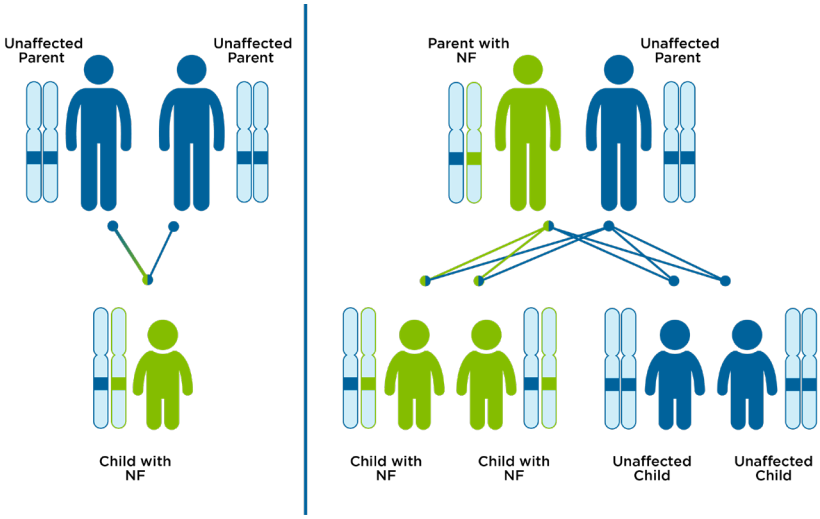
"Having NF was just normal for me. But when I actually learned about it, I was at the age when I was just kind of like, 'Oh, I'm different.' One of the things that I do with CTF is go to camp every year. At NF Camp, I can go and be around other kids with NF. It's great."

—Olyviah, pictured here with her brother Frankie, both of whom live with NF1

The likelihood of having another child with NF1

If one parent has NF1, each time that parent has a child, the chance of the child having NF1 is 50%. It is similar to flipping a coin—**each pregnancy has a 50/50 chance**. You may get heads or tails for each flip, but your previous coin flip does not affect the likelihood of getting heads or tails in the future.

If neither parent has NF1, the couple is unlikely to have another child who has NF1. Because the genetic variant was not inherited from the mother or father, the risk for another occurrence is thought to be less than 1%.



For questions about risks and pregnancy options, it is helpful to speak with a genetic counselor or knowledgeable healthcare provider.

did you know?

The *NF1* gene is responsible for the production of neurofibromin, a protein that helps control cell growth.

Genetic Testing

Genetic testing is also called molecular or DNA testing. Because NF1 is caused by a genetic change (called a pathogenic variant), your doctor may recommend genetic testing of the *NF1* gene. This specialized testing can be performed on blood, saliva, or other tissues. Genetic testing may be helpful in certain situations. It can be helpful to confirm a diagnosis, to determine whether other family members have NF1, and to provide information during reproductive decision-making.

There are limitations to genetic testing, and it does not detect NF1 in all individuals with the condition. In most cases, genetic testing does not predict the severity or specific complications a person will experience. The decision to undergo genetic testing is a personal one. A genetics healthcare provider or a genetic counselor can help you with this decision. Additional information about genetic testing is available at **ctf.org/genetictesting**.

"People with NF are affected in so many different ways, but they all have NF. We need to make as many people aware of NF as possible."

—Aiden, who lives with NF1

NF1 diagnostic criteria

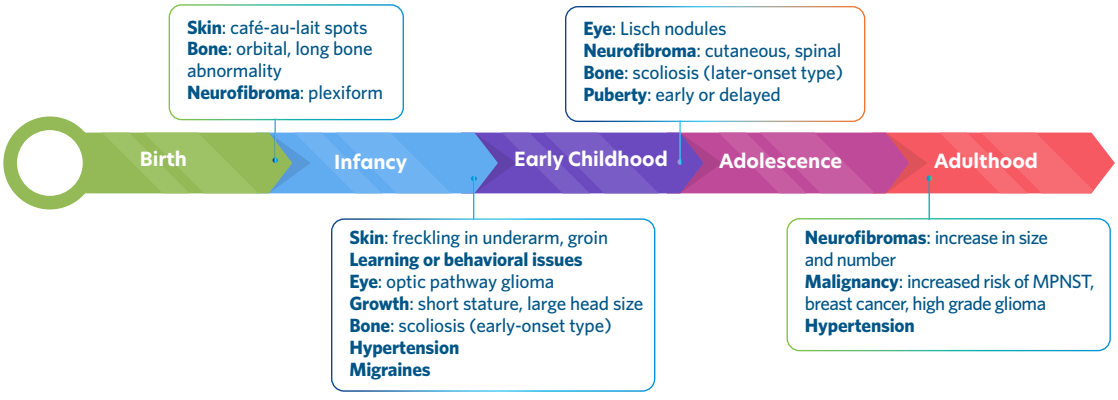
In 2021, an international group of neurofibromatosis experts published an update to the criteria that is needed to confirm a diagnosis of neurofibromatosis type 1 (NF1). **A diagnosis of NF1 can be given if an individual has two or more of the following manifestations:**

- Six or more café-au-lait macules (brown skin spots)*
- Freckling in the axilla (armpit) or groin*
- Two or more neurofibroma tumors of any type or one plexiform neurofibroma (a larger, more extensive tumor)
- Two or more Lisch nodules (benign colored spots in the eye) or two or more abnormalities in the choroid (vascular layer of the eye)
- Optic pathway glioma (a tumor of the optic pathway in the eye)
- Osseous lesion (bony lesion), such as sphenoid dysplasia (abnormal growth) of the bone behind the eye, or dysplasia or pseudarthrosis of the tibia (long bone in the leg) or other long bones
- A pathogenic *NF1* variant revealed by genetic testing
- A parent with NF1 based on the criteria above

*At least one of the two pigmentary manifestations must be present on both sides of the body.

Some of the manifestations of NF1 are age related and may not be present early in life. Therefore, sometimes a diagnosis cannot be confirmed in a young child based on a doctor's physical examination. However, this doesn't mean the child is free of NF1. When a child meets only one of the criteria above, some doctors and families take the "wait and see" approach, monitoring the child over time to see if additional features of NF1 develop. Other times, genetic testing may be considered.

Approximate timing of possible NF1 manifestations



Recognizing signs and symptoms

No one person will have all the possible signs and symptoms, or manifestations, of NF1. The features vary between individuals, and no two cases are alike. Even individuals within the same family may have different presentations. Many people with NF1 are quite mildly affected and have few medical problems. However, there is a wide range of possible manifestations and severity. In most cases, there is no way to predict which symptoms will appear in any one individual. The possible manifestations of NF1 are outlined below.

Skin

Café-au-lait spots or café-au-lait macules. Café-au-lait spots are flat, light brown spots on the skin which are not harmful or painful. They do not indicate the severity of NF or where a tumor might develop. Individuals with NF1 usually have six or more café-au-lait spots.

Eyes

Optic pathway tumor. An optic pathway glioma, or OPG, is a tumor that develops around the optic nerve, which is the nerve that connects to the eyeball and passes information about vision to the brain. An OPG develops in about 15-20% of children who have NF1. Children are most at risk to experience symptoms from an optic pathway glioma when they are younger than six years. Most of the time, optic pathway gliomas do not cause any symptoms and do not require intervention, but sometimes they can affect vision or cause other medical issues and require treatment.

Lisch nodules. Lisch nodules are small brown bumps that occur on the iris of the eye (the colorful part of the eye). They typically do not develop until the teenage years. These nodules generally do not affect vision, but are very useful in the diagnosis of NF1.

Bones

Bone abnormalities. Scoliosis (curvature of the spine) occurs more frequently in children who have NF1 and should be monitored throughout childhood and adolescence. Although rare, bowing of the lower leg or problems with other bones can occur in some individuals who have NF1. Severe bowing of the leg bones may require bracing or other treatments.

Peripheral nerves

Neurofibromas. A neurofibroma is a type of tumor that forms bumps along nerves anywhere in the body. There are several types of neurofibromas associated with NF1:

Cutaneous/subcutaneous neurofibromas are the most common types of neurofibromas in NF1. These are benign tumors that develop along a nerve on the skin (cutaneous neurofibromas) or under the skin (subcutaneous neurofibromas) which appear as lumps or bumps on the skin, or bumps that you can feel below the skin surface. There is no way to predict when, where, or how many neurofibromas may develop. Some people who have NF1 may have only a few neurofibromas while others may have several. These types of neurofibromas do not become cancerous and are not usually associated with serious medical problems. Sometimes they can cause tenderness or mild pain.

Spinal neurofibromas are those that grow on the nerves around the spinal cord. Because they are so close to the spinal cord, they can sometimes cause pressure or symptoms such as weakness, numbness, or tingling.If symptoms develop, it is important to tell your doctor, as surgery may be needed.

Plexiform neurofibromas occur in approximately 30% to 50% of individuals living with NF1. Like cutaneous neurofibromas, plexiform neurofibromas also grow along nerves, but they can be more complicated. On the skin surface they have a mixed or lumpy texture and can grow extra hair. They can become entangled with surrounding structures, such as muscles, blood vessels, and organs of the body. Sometimes they can cause disfigurement and disability.

Unlike cutaneous neurofibromas, plexiform neurofibromas are thought to be present at birth and grow slowly over time. They can be located inside the body or appear on the surface of the skin. Plexiform neurofibromas should be monitored closely by patients and their medical providers. They have the potential to become malignant and form into a cancer called a malignant peripheral nerve sheath tumor (MPNST), which occurs in approximately 10-12% of patients with a plexiform neurofibroma. To learn more about plexiform neurofibromas, visit **ctf.org/pns**.

There is an approved treatment for some individuals with inoperable plexiform neurofibromas that may help stop tumor growth and even shrink the size of these tumors in some people. To learn about treatment options, visit **ctf.org/treatments**.

Hormone system

Delayed or early puberty. Most people who have NF1 start puberty within the expected age range, but some may undergo precocious (early) or delayed puberty. This is an important finding to mention to your healthcare provider, because it may be a sign of an NF-related complication.

Growth concerns. Many individuals living with NF1 are shorter than expected for their family. In addition, some may have a larger head size than expected based on their height and weight. Usually, these findings are not due to any underlying medical problems, but it is important to monitor growth, physical development, and head size throughout childhood under the care of providers familiar with NF1.

Vascular system

Hypertension (high blood pressure). Hypertension occurs more commonly in individuals who have NF1 and can lead to serious complications if left untreated. In addition, there are other types of NF1-related complications that can cause elevations in blood pressure. It is very important to be seen by a doctor familiar with NF1 if blood pressure is elevated.

—NF Hero Tristan, who lives with NF1

More information and additional resources about NF can be found on the Children's Tumor Foundation website at **ctf.org/education**.

NF1-associated learning challenges

Learning difficulties are one of the most common challenges faced by individuals with NF1. Although the frequency of intellectual disability is low, as many as 50% of people with NF1 will experience some difficulties with learning. Memory, attention, visual-motor function, and spatial orientation are the areas that are commonly affected. There can be problems processing information and trouble with executive functioning skills, which include planning, management, attention, and organization. These symptoms may vary, though, and do not happen in all individuals who have NF1.

Learning difficulties can impact daily functioning for individuals with NF1. For those who have learning difficulty, early intervention can make a big difference. These issues are not progressive, but can be apparent as a child advances in school and is challenged more. Working with a student's teachers to address these concerns is vital and can have a big impact and positive rewards.

To further support families of children living with learning disabilities and their teachers, the following resources are freely available at **ctf.org/education:**

- **Learning with NF1**
- **NF1 Guide for Educators**
- **The NF Parent Guidebook**

did you know?

Approximately half of children and adults with NF1 have learning challenges, and may require some form of learning assistance.

"Learning disabilities are often associated with NF1, and watching Denver struggle through school has made me realize that I too struggled with those same learning disabilities, which is what made getting through school so difficult. I've learned to be more patient with Denver; I know what he is going through, and it's hard work."

—Katy, mom to Denver, both of whom live with NF1

Healthcare providers who specialize in NF

Since there is currently no cure for neurofibromatosis (NF), medical management focuses on the early detection of complications and the management of symptoms. Because symptoms vary between individuals, the treatments and types of healthcare providers who provide care can vary as well.

It is important to see healthcare providers who are familiar with NF. Because NF1 involves many different systems of the body, many healthcare providers from several different specialties may be involved in providing NF care. This is done most conveniently at a clinic that specializes in the treatment of NF. There is a list of NF specialty clinics on the Children's Tumor Foundation website, at **ctf.org/doctor**. As part of the treatment plan, a referral may be made to a variety of healthcare professionals who are experts in different NF1-related areas.

Many NF clinics offer coordinated care so that specialists are in communication with one another. Sometimes patients can see more than one healthcare provider in the same day. These may be physicians, advanced practice providers, and other types of providers in the following fields:

Cardiology. Cardiologists specialize in the heart and major blood vessels.

Dermatology. Dermatologists evaluate and treat conditions of the skin, hair, and nails.

Genetics. Medical geneticists have expertise in the diagnosis, management, and treatment of genetic disorders. Genetic counselors provide education and counseling about genetic disorders and discuss the options for reproductive decision-making.

Neurology. Neurologists are trained in the diagnosis, management, and treatment of conditions affecting the brain and nerves.

Neuropsychology. Neuropsychologists specialize in evaluating behavior and cognitive function. They can help make recommendations to a school when an individual has learning challenges.

Oncology. Oncologists specialize in the diagnosis and treatment of different types of benign and malignant tumors.

Ophthalmology. Ophthalmologists diagnose, monitor, and treat conditions affecting the eyes and vision-related structures.

Orthopedics. Orthopedists are involved with conditions involving the muscles and bones, including the spine.

Psychiatry/psychology. Psychiatrists diagnose and treat emotional and behavioral problems, and psychologists provide counseling and other behavioral interventions to help patients deal with these concerns.

Surgery. There are different types of surgeons who may be involved in the treatment of NF.

- *General surgeons* are trained in a broad spectrum of conditions involving almost any area of the body
- *Neurosurgeons* specialize in conditions involving the brain and spinal cord
- *Plastic surgeons* specialize in cosmetic or aesthetic concerns
- *Orthopedic surgeons* specialize in managing bone problems

Therapy. There are different types of therapists who may be involved in the treatment of NF.

- *Occupational therapists* assist patients with everyday activities and fine motor abilities, including writing skills, dressing, and using utensils
- *Physical therapists* assist patients with motor skills involving body strength and movements, such as walking
- *Speech therapists* assist patients with oral function and speech

did you know?

The patient is an important member of the healthcare team. Being active, involved, and educated will make a difference toward NF care.

Telling Others

Sometimes, family members struggle with what to say to others about neurofibromatosis type 1 (NF1). This may be because they do not know where to start or how much to say. They may also be worried that they or their child may be treated differently when an NF1 diagnosis is revealed.

Although everyone has his or her own ideas and comfort level for sharing personal information, there are some things to consider that may help make the process easier. Involving the child in the conversations and decision-making process about whom to tell and what to say may be helpful, as well as an empowering and valuable experience for the child.

Whom to Tell

Often, the diagnosis is shared primarily with family members and close friends. Because NF1 may affect school performance, sharing the diagnosis with teachers, counselors, and the school nurse may be necessary and can help ensure that the child receives any extra support and services they may require.

For older children and adults, it may be helpful to tell their employer, especially if there may be absences from work for doctor appointments or other NF1-related health concerns.

In other instances, it is not uncommon for the diagnosis of NF to come up, especially if an individual has visible signs of NF1 on the outside of the body, learning difficulties, or behavioral problems that are noticeable to others.

Talking with Children

Neurofibromatosis type 1 can be a difficult topic to discuss with a child. When and how to tell a child about the diagnosis varies according to the child's age, cognitive ability, emotional state, and maturity level. Some parents seek the advice of a healthcare provider to help share the information, while others prefer to do it on their own.

Regardless, it is important that the information is accurate. Being open and honest is critical. When a child feels a parent is not forthcoming or hiding something, it can lead to trust issues and increased anxiety, as the child may make incorrect assumptions or seek information elsewhere.

Children of any age often respond to the mood of others around them. Therefore, it is important to consider the way a parent has accepted and reacted to the diagnosis when in front of the child. Although having NF1 is a serious matter, it is helpful to remain calm during these discussions. There should also be adequate time allowed for the conversation as it should not be rushed.

Discussions about an NF diagnosis are often ongoing conversations that build over time. At younger ages, a child may need only basic information such as the name of the disorder, the parts of the body that are affected, how it will be treated (if at all), and how his or her life will be affected in the short-term. If the child has a specific question, parents may limit their response to address only the specific question the child is asking without a detailed explanation, unless the child asks more questions or needs clarification. As a child gets older, more facts can be provided, and as an individual becomes a young adult, genetics and inheritance are often reviewed.

The Children's Tumor Foundation has a series of educational resources developed for children and their parents, many of which feature our fun Moxie & Sparx mascots. These educational children's books, comics, coloring pages, and fun activities may help you speak to your child about NF1 and help children learn to talk about it themselves. Learn more at **ctf.org/kids**.

Sample Message to Family and Friends

Dear family member/friend,

We want to share with you that our child has a diagnosis of neurofibromatosis type 1.

Neurofibromatosis type 1, or NF1, is a disorder that occurs in approximately 1 in every 2,500 births. The severity and features of NF1 vary greatly from person to person. Neurofibromatosis type 1 is a genetic disorder that people are born with, although it may not be diagnosed right away because some of the features develop over time. Typically, the most noticeable sign of NF1 is the appearance of light brown patches on the skin called café-au-lait spots. Neurofibromatosis type 1 can also cause benign growths called neurofibromas, which are usually not cancerous. Some people who have NF1 may also have learning disabilities.

People who have NF1 require specialized medical care, but they usually enjoy full, active lives. Neurofibromatosis type 1 is caused by a genetic (DNA) change, but this change is not always inherited. NF1 is not contagious, and was not caused by anything that a parent did wrong. Doctors and scientists are working towards understanding more about NF1 and its treatment. There is more information at www.ctf.org if you want to learn more.

We appreciate all of your love and support.

Sincerely,

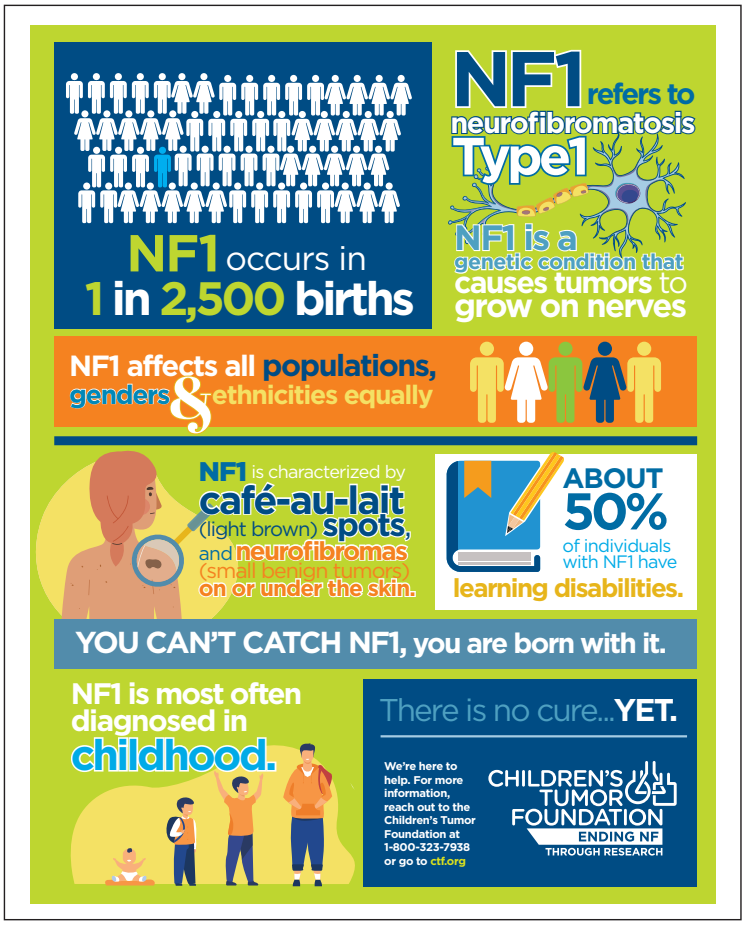
Your name

Additional Support and Resources

We hope that reading this guide has been helpful. As you continue your NF journey, you may have a range of emotions. Some people struggle to make sense of their feelings, or they may be in denial of the diagnosis. Acceptance of difficult news is a process and takes some people longer than others. Individual family members may move through the process at different times, so it is important to communicate and be understanding of each other. Instead of fighting against these feelings, it is important to recognize them and determine how to take care of yourself and your family.

As part of our mission, the Children's Tumor Foundation is dedicated to creating and sharing educational resources for patients and families with all types of neurofibromatosis. A full collection of resources on the various symptoms of neurofibromatosis type 1 (NF1) and the concerns specific to affected patients, teens, adults, teachers, parents, and families can be freely downloaded at **ctf.org/education**.

While searching for information about NF1, your doctor is your best resource. If you come across information that you find confusing, or if you just have questions, be sure to speak with your healthcare provider.



CTF educational materials for you and your family

- To help guide parents of children who have NF1 and its associated learning, behavioral, or social challenges, CTF developed the **NF Parent Guidebook**, a home-based, 160-page resource designed to provide support and education to you and your family. The NF Parent Guidebook is a place to find ideas, strategies, and suggestions for parents and children. This resource is available to freely download at **ctf.org/nfparentguidebook**.

- For children living with NF1, along with their siblings and friends, you can find an engaging collection of **Moxie & Sparx** comics, videos, and activities, as well as CTF-sponsored children's books and accompanying parents' gudes, at **ctf.org/kids**.

- To further support families of children living with learning disabilities and their teachers, **Learning with NF1** and **NF1 Guide for Educators** brochures are available at **ctf.org/kids**.

- To help support teens, the Children's Tumor Foundation hosts a week-long camp each summer for teens and young adults with all types of NF. Find out more at **ctf.org/camp**. Our **Just for Teens** brochure about NF1 is also available at **ctf.org/education**.

- Although NF1 is most often diagnosed in childhood, it is a lifelong condition and the Children's Tumor Foundation is here for NF patients of all ages. A brochure specifically for **Adults with NF1** is available at **ctf.org/education**.

- The Children's Tumor Foundation is a global organization, and is working to translate our educational resources, including this one, into various languages. To learn more, go to **ctf.org/translations**.

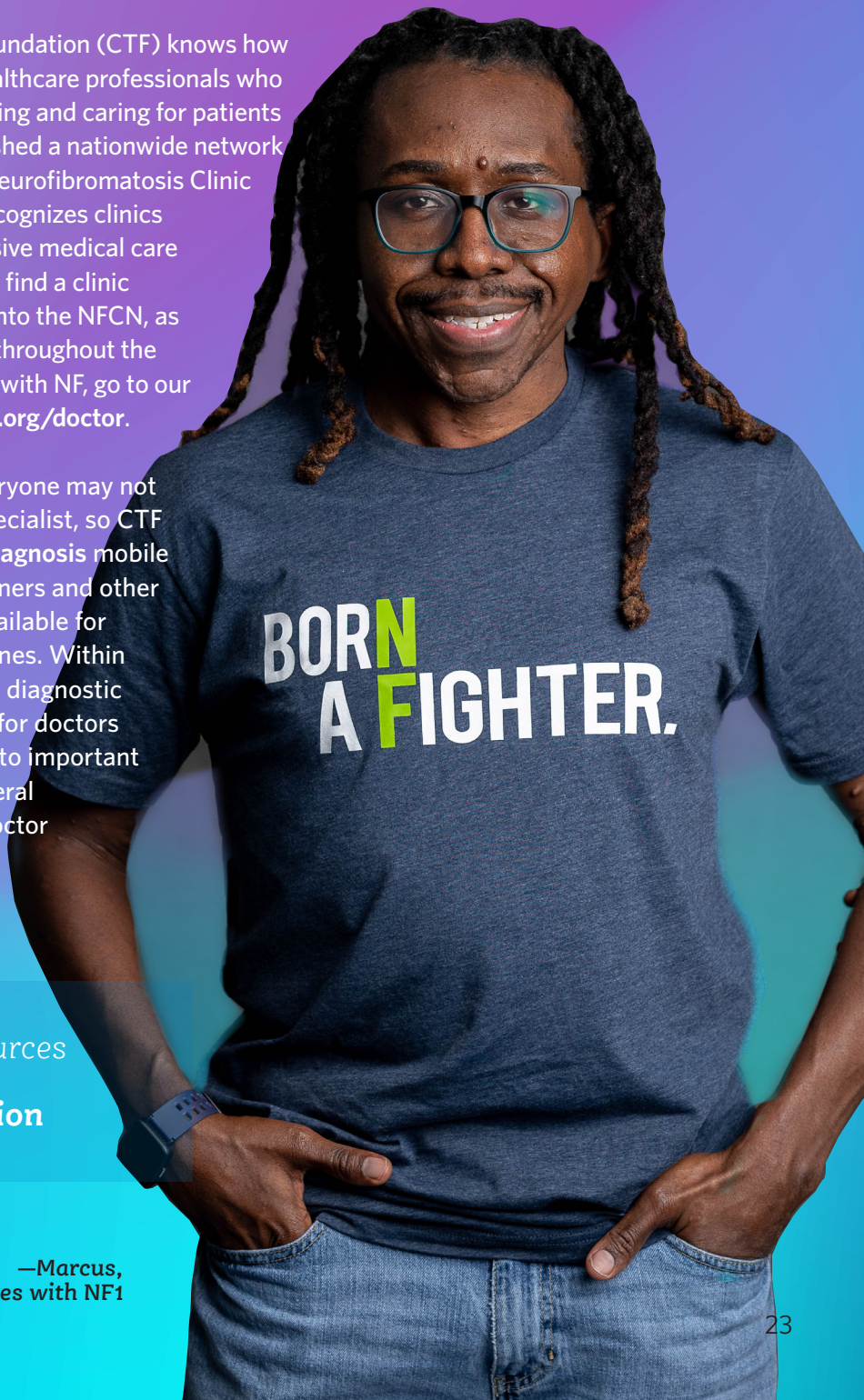
- It may be comforting and useful for you to read stories about others living with NF and their families. The CTF newsfeed at **ctf.org/news** frequently posts **Stories of NF**. You may also enjoy reading stories from NF Heroes of all ages at **ctf.org/nfheroes**.

- Numerous videos featuring NF1 patients of all ages can be viewed on the Children's Tumor Foundation and Make NF Visible YouTube channels.
  YouTube.com/ChildrensTumor
  YouTube.com/MakeNFVisible

Finding NF care

The Children's Tumor Foundation (CTF) knows how important it is to find healthcare professionals who have experience diagnosing and caring for patients with NF. CTF has established a nationwide network of NF clinics called the Neurofibromatosis Clinic Network (NFCN) that recognizes clinics that provide comprehensive medical care to individuals with NF. To find a clinic that has been accepted into the NFCN, as well as other specialists throughout the country who are familiar with NF, go to our **Find a Doctor** page at **ctf.org/doctor**.

We understand that everyone may not have access to an NF specialist, so CTF has developed the **NF Diagnosis** mobile app for general practitioners and other healthcare providers, available for iPhone and Android phones. Within the app is up-to-date NF diagnostic information specifically for doctors and clinicians with links to important publications for the general practitioner. Ask your doctor to go to **ctf.org/nfapp** for more information.



Additional resources can be found at **ctf.org/education**

—Marcus,
who lives with NF1

"Being part of the NF Registry allows me to join the battle in eliminating the suffering that is caused by having NF. It's a personal choice that I have made to participate in the fight to end NF."

—Alwyn, who lives with NF1

The NF Registry

The NF Registry is a patient-driven resource for accelerating research and finding treatments for all forms of neurofibromatosis (NF). This safe and effective tool will empower NF patients and their caregivers by inviting them to take an active role in advancing NF research.

When you join the NF Registry you have access to the latest discoveries about the many ways living with NF can affect individuals and families. This will help you and your family find the best possible care. As an NF Registry participant, you complete a yearly health survey. This data helps researchers study how NF affects everyone differently and how NF changes over time. You can then choose whether to receive personalized emails about any or all of the following topics:

- Clinical trials and research studies relevant to you or your child
- Updates to NF care recommendations
- Research announcements and news
- Surveys designed to get patient input on key NF challenges
- Educational materials specific to you
- Resources to help you on your path with NF

The NF Registry's first principle is that patients are always in control of their own information. You only share what you want to share, and you control the permissions on when or if you are to be contacted. All information is carefully protected with the strictest privacy protocols in place.

Even if you choose not to be contacted, your participation helps researchers learn from the real experts – NF patients and families.

To learn more or join the NF Registry, go to **nfregistry.org**

did you know?

Joining the NF Registry will give you access to the latest NF research, and can alert you to clinical trials and research studies relevant to you.

The Children's Tumor Foundation

Regardless of whether your neurofibromatosis (NF) is a new diagnosis or you have known about it for a long time, the Children's Tumor Foundation (CTF) wants to help guide and support you along your journey. Founded in 1978, the CTF began as the first grassroots organization dedicated solely to the goal of finding treatments for NF. Today, the CTF is a highly recognized global nonprofit foundation, the leading force in the fight to end NF, and a model for other innovative research endeavors.

Our mission: To drive research, expand knowledge, and advance care for the NF community

Our vision: To end NF

Get Involved

The Children's Tumor Foundation offers many opportunities to help you manage your NF, learn more, feel supported, and know that you are not alone.

- **Learn the facts.** Read and share the information in this brochure, and visit our website at **ctf.org** to learn more or find an educational symposia (either in-person or in a virtual setting) to gain more knowledge about NF.

- **Download the NF Care patient app.** For NF patients and caregivers, the Children's Tumor Foundation NF Care apps contain quick access to the CTF newsfeed, research updates, patient resources, and more. A mobile app specifically for patients with NF1 will be freely available for iPhone and Android users at **ctf.org/nfapp.**

- **Sign up for research.** Join the NF Registry at **nfregistry.org** to learn about and participate in advanced scientific research for NF. Read more on page 25 of this brochure.

- **Become involved.** National programs such as Shine a Light NF Walk, NF Endurance, Classrooms that Care, and NF Camp are great ways to empower yourself, meet others, increase awareness, and support NF care and research. Learn more at **ctf.org/getinvolved**.

- **Spread the word.** Families and organizations from around the world participate in NF Awareness Month each May, and join the Children's Tumor Foundation's **Make NF Visible** and **Shine A Light** activities and campaigns. You can share our infographics and videos on social media, secure a proclamation in your local town or state, light up a local landmark, and even advocate for NF research funding. Learn more at **ctf.org/nfawareness**.

- **Form connections.** Reach out to CTF to see if there is a contact or event in your area. We have many volunteers and staff members across the country who are available and want to help support you. To speak to someone directly, email us at info@ctf.org or call 1-800-323-7938.

- **Stay informed.** Visit the CTF website at **ctf.org** to stay informed about NF research or find a calendar of events. You can sign up for our newsletter or our email list by going to **ctf.org/signup**.

- **Get Social.** In addition to in-person events around the country, you can connect with NF patients and families on any of the Children's Tumor Foundation social media channels.

  Facebook: facebook.com/childrenstumor
  Twitter: twitter.com/childrenstumor
  Instagram: instagram.com/childrenstumor
  YouTube: youtube.com/childrenstumor
  LinkedIn: linkedin.com/company/children's-tumor-foundation

- **CTF Europe.** Children's Tumor Foundation Europe, which launched in 2018, has been hard at work driving research, expanding knowledge, and advancing care for the over 250,000 Europeans living with neurofibromatosis. Find out more at **ctfeurope.org**.

"I want my friends to know that I have NF, because I want people to know that I'm a little different and that I have more tumors around my body."

—Alex, who lives with NF1

We encourage families to use only reputable websites and not perform general online searches for NF, which may be inaccurate or show worst-case scenarios. In addition, we advise against receiving personal medical advice from social media platforms. Individuals should talk to their healthcare provider about specific questions regarding their health or complications of NF.

References

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Contributors

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We're here to help.

For more information about NF1 and all types of NF, please contact the Children's Tumor Foundation.

—Michelle, who lives with NF1

Sponsored by AstraZeneca

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

CHILDREN'S TUMOR FOUNDATION
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