

“NF1 is something  
I was born with.  
It causes birthmarks  
and benign skin  
tumors, but it’s  
not contagious.”

- Nikki, age 20

Just for Teens: **Living with NF1**

A special thank you to the many children, teens and adults we have followed in our NF/RASopathy Center at Children's Hospital of Wisconsin. Each of your families has touched our lives and taught us so much, and we admire your strength and perseverance. We created this booklet just for teens because we believe knowledge is power – knowledge of the disorder, knowledge of the available resources and knowledge of how you can take charge of your health and your life. We hope you'll read on for important information on how you can overcome NF1 and thrive.

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## What is neurofibromatosis type 1 (NF1)?

You may have just found out that you have NF1 or maybe you've been seeing doctors for your condition for a long time. Either way, we hope to answer some of the questions you might have about living with NF1.

NF1 is actually fairly common, even though many of your friends and classmates have probably never heard of it. One in every 3,000 people has NF1 – you could know someone else at school with this condition and not even realize it. Some people with NF1 may have more obvious signs or complex medical problems, while others may not.

It's important to understand that NF1 symptoms can change as you get older. You may notice more skin issues, like lumps appearing under your skin. No matter how small, it's important to note these changes and mention them to your doctors. Your NF clinic team can help you deal with these changes and answer any other questions.

## Genetics: How do you get NF1?

You may be wondering why NF1 happened to you. Well, the answer is in your genes, which are the instructions that tell your body how to grow and develop. The gene that causes NF1 is called *NF1*. This gene usually stops the growth of tumors by making proteins. If there is a change (scientists call it a mutation) in the *NF1* gene, the gene doesn't have the right information to work properly, so the protein can't stop the growth of tumors like it should. People with NF1 have one nonworking gene and one working gene on the 17th pair of chromosomes. The beauty of life is that everyone is different. If everyone were the same, life would be boring!

You could've inherited this gene change from a parent, or the change might have happened on its own. But no matter where it came from, it's not your fault or your parents' fault. We all have a lot of different genes and mutations that can cause health problems or simply affect the way we look – it's just part of life.

### Quick facts

- NF1 is also called von Recklinghausen's disease, named after a German doctor.
- NF1 varies from person to person, just like no two people look exactly alike.
- NF1 is caused by one gene of the 20,000 that everyone has.

## What does NF1 look like?

Although you need to have only two of these characteristics (see related box) to know that you have NF1, you could have more than two. That's OK; it helps make you who you are. Some of these features simply affect your appearance, while others cause medical problems. Most are not life threatening. Each one is described in the next section to help you better understand your condition and recognize any changes that may or may not happen to you.



Cafe-au-lait spots

### Café-au-lait spots

These flat brown birthmarks are called café-au-lait spots because their color is similar to the color of coffee with milk. One of the features of NF1 is having at least six of these spots, though some people have many more. Even some people without NF1 may have a few of these spots. Café-au-lait spots don't cause any health issues, but they can cause some people to feel self-conscious. Usually you develop all of the café-au-lait spots you will ever have before you're a teen. Having more café-au-lait spots doesn't mean that you will have more medical problems.



Freckling

### Freckling

NF1 freckles are usually located in the creases of your skin, such as your armpits and groin area. These freckles are very similar to café-au-lait spots because they're the same color, but they're usually smaller and clustered in a specific area. These freckles don't cause any medical problems. Some of your friends or classmates may have similar freckles, perhaps on their face or arms (especially if they have red hair and light skin). You may see more freckles as you get older.

## Diagnostic criteria of NF1 - you must have at least two of the following:

- Close family member with NF1 (mom, dad, brother or sister)
- Six or more café-au-lait spots
- Freckles in the armpit or groin
- Either two or more neurofibromas and/or one plexiform neurofibroma
- Lisch nodules on the eyes
- Optic glioma
- Specific bone problem

## Neurofibromas

These little lumps on or under your skin often appear during the teen years and into adulthood. They're actually bumps on your nerves. Nerves are kind of like electrical impulses that tell your body when to move, if you're in pain, etc. Since your body has nerves everywhere, you could get a neurofibroma anywhere. Some may look like a mosquito bite, while others can be of varying sizes, shapes and textures. Some are so small that it's hard to see them, or they could be just below the skin, where you can only feel them. They can also itch, sometimes before you even know they're there! Unlike mosquito bites, they don't go away, though they may get temporarily smaller or bigger, like during exercise.

You may develop more neurofibromas as you get older. They are NOT cancerous and usually don't cause medical problems, but you might find them annoying if they rub against your clothes or shoes. If you bump them, neurofibromas can sometimes send a shooting pain, almost like hitting your funny bone. But if they become painful even when you don't bump them, mention it to your doctor. Neurofibromas can be removed surgically or with laser therapy. However, it's important to remember that these surgical procedures often leave a scar and may have other risks or complications, and the neurofibromas could grow back later.



Neurofibromas

## Plexiform neurofibromas

Plexiform neurofibromas are a special kind of neurofibromas that have many blood vessels and may involve deeper nerves. Plexiform neurofibromas are usually something you were born with, but you might not even know you have one because it could be deep below the skin. They usually grow slowly and become noticeable later on. Sometimes they can cause the area to become misshapen.

Unfortunately, because they have so many vessels and nerves, plexiform neurofibromas are often difficult to remove by surgery. They also tend to be easily aggravated, so if you try to remove or reduce them, they could grow back even larger. For that reason, surgery is not often done.



Plexiform neurofibroma\*

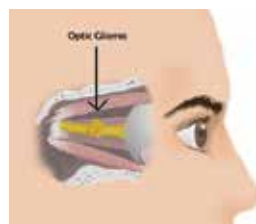
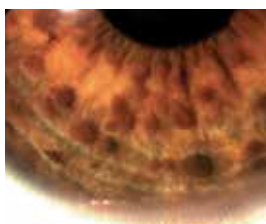
Like regular neurofibromas, plexiform neurofibromas are usually benign (not cancerous), but with plexiforms, there is a small chance that they may turn into a malignancy, or cancer. Just remember, we all have a chance of getting cancer, but because you have NF1, the chance of that is slightly higher. It's very important to talk to your doctor about any plexiform neurofibromas you may have, especially if they cause pain, numbness (tingling or loss of feeling), or weakness (you have a hard time moving a part of your body).

## Lisch nodules

Lisch nodules are small raised freckles on the iris, the colored part of your eye. They have no effect on your vision and don't cause any medical problems. Most people with NF1 will develop these eye freckles at some point, usually before the age of 20. Most people wouldn't even notice Lisch nodules unless they were looking at your eye with a special light scope. If an eye doctor ever mentions that you have Lisch nodules, remember that it's not a big deal!

## Optic glioma

Unlike Lisch nodules, an optic glioma can cause medical problems. It is a growth along the optic nerve, which connects your eye to the rest of your brain. An optic glioma is inside the brain, so doctors usually find it when doing an MRI (a test that uses special equipment to take pictures of your brain). An eye doctor may spot other signs of an optic glioma, such as increased pressure or unusual blood vessels in your eyes. Since your optic nerve helps you see, an optic glioma could cause problems with your eyesight. The optic glioma might also push on the pituitary gland, another important part of your brain. If your pituitary gland isn't working properly, your hormones can be out of whack, causing a sudden growth spurt or early puberty changes. Most optic gliomas occur between the ages of 4 and 6, so it would be unusual for someone your age to suddenly develop one. Regardless, it's very important to let your doctor or eye doctor know if you notice any changes in your vision.



Examples of Lisch nodules are shown in the first three images\*. Far right is optic glioma\*\*.

\* Lisch nodules photos courtesy of Deborah M. Costakos, MD, Children's Hospital of Wisconsin.

\*\* Optic glioma diagram created by Shawna Joachim, clinical research coordinator, Medical College of Wisconsin.

A portrait of a young man with short, dark hair and a slight smile, wearing a white polo shirt. The background is a blurred outdoor setting with green foliage and a building. The text 'Cody, age 20' is overlaid on the left side of the image.

Cody,  
age 20



## Bone problems

There are two types of bone problems associated with NF1. Both are very rare and are usually seen in young kids. Sphenoid dysplasia involves a bone around your eye, and tibial dysplasia affects a bone in your lower leg. Most teens already know if they have either of these conditions. If your doctor hasn't mentioned a bone issue, then you probably don't need to worry about it.

## Other things people who have NF1 may have:

### Scoliosis

There are two types of scoliosis (curved back) that can occur with NF1: dystrophic scoliosis (more severe and develops at a younger age) and nondystrophic scoliosis (less severe and more common). You would probably know by this age if you have the more severe type. The less severe type can happen in teenagers with or without NF1 as they go through their growth spurt, though scoliosis occurs more often in teens with NF1. If you start to have back pain or someone notices that your back isn't straight, contact your NF specialist. This can be easily checked with an X-ray.



Image of Scoliosis

### Blood pressure

It's important for everyone, not just those with NF1, to monitor their blood pressure, because high blood pressure (hypertension) can cause a weakening of blood vessels and lead to a stroke. Most of the time, hypertension is not caused by an underlying medical problem and can be easily treated. However, there are serious medical complications that can occur with NF1 that can cause high blood pressure, so you should note your blood pressure at every doctor's visit. If your blood pressure is ever high or can't be controlled well, talk with your NF specialist.

### Learning difficulties

Learning disabilities affect 50 percent of people with NF1. It's nothing to be embarrassed or ashamed of – having a learning disability does not make you less smart. We all learn in different ways. Sometimes people, with or without NF, need some extra help in school. Others might have a hard time focusing or sitting still in class. This is common in people without NF1, too. Make sure to talk to your NF specialist if you're struggling in school - he or she might have some ideas on how to help.

## What should a teen be prepared for?

As you go through adolescence, your body is going through many changes. You're becoming more independent. Your parents used to give you a bath, watch over you and were aware of any physical changes. But now, you probably like your privacy. So, keeping track of any changes that could be related to NF1 is becoming YOUR responsibility. You need to know what to look for and whom to talk to about your concerns.

These days you may want to spend more time with your friends or by yourself than with your parents – that's normal. It's also normal if you don't tell your parents every last thing about your life.

However, when it comes to NF1, it's really important to tell your parents if you notice any changes. They can help you determine if you should call the NF clinic. Anything that is new (or different for you) should be watched. Check out the box on the right for specific times to call your NF doctor.

### When to call your NF doctor

- Increasing size or texture (feel) of a neurofibroma
- Increasing pain
- Itching in one area of the body
- Changes in your vision
- Tingling or numbness that doesn't stop or keeps coming back
- Whenever you have questions

## What to say when people ask questions or tease you

Friends and classmates may ask about your condition. Just as you might notice someone who has something different about them (like pink hair), others might notice you have more birthmarks than usual and be genuinely curious about the reason. It's up to you to decide how many details you want to share.

Other kids might tease or make rude comments. Try not to let them bother you. Remember, we can't control what others do or say, but we can control how we react. If you think they're making fun of you, just give a quick response and walk away. It's normal to feel hurt over mean comments, but don't give those kids the satisfaction of seeing that they bothered you, and hopefully they'll quit soon.

Regardless of people's intentions, it's good to have a response ready for these situations. Write something down and practice saying it a few times. That way, if someone catches you off guard, you won't be as flustered. Also remember to take a few deep breaths – this will keep you calm. Check out the next page for some ideas.

## Phrases to practice

You might want to give just a short, factual response — remember, you know more than they do. Or if it feels right, you might want to use humor to show that their comment hasn't bothered you. Whatever you decide to say, make sure it feels natural for you.

**If someone points out your café-au-lait spots and says something like:**

“Wow, why do you have those spots all over you?”

**You could say:**

“It's no big deal; they're just birthmarks.”

**Or you could make a joke, followed by a factual explanation:**

“I'm part leopard. Seriously, though, they're just birthmarks called café-au-lait spots.”

**If someone says:**

“I don't want to catch whatever it is that YOU have.”

**You could say:**

“Yeah, well, you probably don't know that it's not contagious.”

**Or:**

“Wow, that's rude. But you don't need to worry because it's not contagious.”

**For closer friends or people who seem interested, you might say:**

“NF1 is something I was born with, and it causes birthmarks and benign skin tumors, but it's not contagious.”

## Your future

You're at a crucial point in your life, and how you transition from childhood through adolescence will help determine how well you succeed and thrive as an adult. But it's also an exciting time as you start making plans for the future.

## Setting goals

It's important to set goals. They might be educational goals (graduating on the honor roll), career goals (becoming a mechanic, pilot or teacher) or personal goals (traveling the world or starting a family). Your NF team can help you set goals and offer support to help you achieve your dreams. And your NF1 diagnosis offers you one advantage: You already have experience facing and conquering challenges. That strength and persistence will pay off!

## Marriage and family

When thinking about relationships and starting a family, NF1 may or may not play a role in your decisions. Either way, it's important to discuss your condition with your significant other once you're in a serious relationship. Just like other couples, you may decide to have biological children, adopt a child or not have kids at all. When you get to that point, talk to your NF team or a genetic counselor so you have the facts to make an informed decision. For more information, see the box below.

### Having kids and NF1

Just because you have NF1 doesn't guarantee that your kids will get it – though it is possible. You have two genes, a changed (nonworking) *NF1* gene and a regular (working copy) of the *NF1* gene. If you pass on the nonworking gene, your child will have NF1 (though no one can say how mild or severe it will be). If you pass on the regular working copy of the *NF1* gene, your child will not have NF1. So, it's like flipping a coin: You may get heads, you may get tails; the odds are 50 percent, or 1 in 2. The odds are the same every time you have a child. You could have all heads, all tails or any combination. This is referred to as **autosomal dominant inheritance**.



Kevin,  
age 17

## **Final thoughts: How to thrive with NF1**

Growing up (with or without NF1) is hard. Sometimes having NF1 can be isolating. You might feel all alone, but that's not true! There are many teens with NF1 who might even live in the same city as you. Also, never forget that there are people who care about you: your parents, your siblings, your friends and your NF care providers. And there are a lot of positive ways you can use your diagnosis to help others. You might want to consider:

- **Participating in local events** – There are NF walks, runs, meetings and camps.
- **Writing or presenting a report on NF** – One teen from our clinic gave a class presentation about NF1. She learned more about NF while educating others who always wondered about her diagnosis.
- **Organizing a fundraiser for NF** – Two teenage boys started a penny drive at their school. Another girl set up a fashion show at her high school. They all have earned funds for NF research and increased awareness of NF1. Another young man with NF1 paints pictures and sells them for different charities.

Reach out for help if you need it. Some teens find it helpful to talk to a school counselor or therapist, and your parents and NF clinic team are always there to listen, too. There also are online chats and resources available so that you can connect with others with NF1.

## **Most importantly, always remember that NF1 is only a small part of who you are – it doesn't define you.**

You have many interests, talents and strengths that make you unique, and you can thrive with NF1.



Anna,  
age 20

## Have other questions not addressed in this booklet?

Call your NF clinic. They're here to help.

### Clinic information

NF clinic contact \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

### Support groups

- Children's Tumor Foundation: [ctf.org](http://ctf.org)
- NF Network: [nfmidwest.org](http://nfmidwest.org) and [nfnetwork.org](http://nfnetwork.org)



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