

# SUPER EMERSON

*A Book About NF1  
For Kids*



CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

# A NOTE FOR PARENTS



This resource is designed to help you talk with your child about their neurofibromatosis type 1 (NF1) diagnosis. It can be used with the “Talking to your Child about NF1” caregiver guide to help you decide how and what to tell your child about their condition. This resource is about a child with NF1 and provides an overview of NF1. Please review this book ahead of time to make sure you are comfortable with the amount and kind of information presented.

Throughout this book, there are “**Sparx Facts**” and “**More from Moxie**” sections with detailed and more complex information. Every child can take in different amounts of information at different times. There may be sections you wish to skip and return to later, or maybe your child is ready to read all the information. If you need help navigating what is developmentally appropriate, please consult the “Talking to your Child about NF1” guide or talk with your NF1 healthcare provider.

There are interactive activities that can be done throughout the book. Some children find it helpful to do related activities while reading, and some find it distracting. Do whatever helps your child the most!

**Written by Ryan Brown-Ezell**, Genetic Counseling student at The University of Alabama at Birmingham with assistance from Ashley Cannon, PhD, MS, CGC, Madeleine Franchi, MS, LCGC, Heather Radtke, MS, CGC, and Georgina Schlub, FHGSA, PhD.

## **Illustrations by Liz Lathem.**

Additional contributions by Jennifer Janusz, PsyD, ABPP-Cn, Susanne Preinfalk, Vanessa Younger, and patient representatives Stacey DeCillis, Jackson DeCillis, and Connie Sorman.

References for this resource and for “Talking About NF1 With Your Child” can be found at [ctf.org/superemerson](https://ctf.org/superemerson)

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Hello! My name is Emerson, and I am 6 years old. My favorite color is green, and I like playing basketball with my friends.



I have one dog named Lulu and one  
cat named Oscar.

I live with my mom, grandpa, big sister, and little  
cousin. My sister is 10 and loves dancing.



My cousin is 3  
and likes playing  
with his food.  
Even though we  
do not get along  
sometimes,  
I still like  
them.



*What about you?  
Who are your friends and family?*



# ABOUT ME:



*Use this page  
to tell me  
about you!*



- What is your name?

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- How old are you?

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- What is your favorite color?

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- What are some of your favorite things to do?

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- Who is in your family?

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- Who do you live with?

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- What are some things you like?

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- What are some things you do NOT like?

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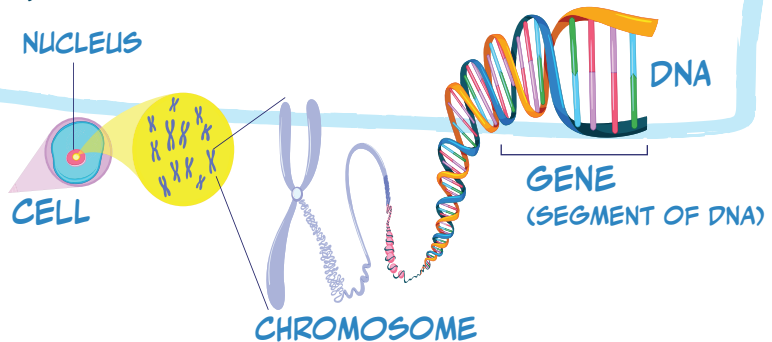
I also have something called neurofibromatosis type 1. It can be hard to say, so I like to break it into smaller pieces:

nur-row-fi-bro-ma-toe-sis

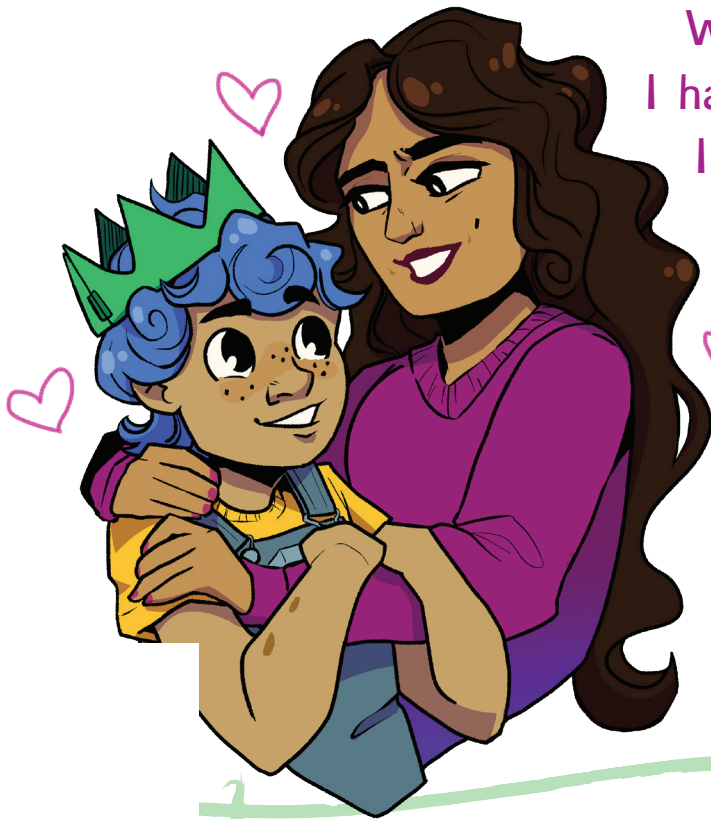
Neurofibromatosis Type 1, or NF1 for short, is what gives me the bump on my leg and the brown spots on my skin.

### SPARX FACTS:

Your body is made up of trillions of cells. Inside each cell are packages of genetic information called chromosomes. When you stretch those chromosomes out, you find a string of DNA. Sections of DNA called genes are responsible for different roles in your body. The *NF1* gene's job is to prevent cells from growing too much. When there is a change in the *NF1* gene, it cannot do its job, which leads to NF1.



Some people's parents, brothers, or sisters also have NF1, but I am the only one in my family. Does anyone in your family have NF1?



When my mom told me I had NF1, I was worried I did something wrong. She hugged me and said I did nothing to cause NF1.

### SPARX FACTS:

Everyone gets half of their genes from their mom and half from their dad. This process is called inheritance.

Some people inherit NF1 from their parents, while other people are the first ones in their families to have NF1.



Even though there are lots of people who have NF1, just like me, we all look different. I have a bump on my leg called a neurofibroma (nur-row-fi-bro-muh) and many spots on my skin called café au lait (ka-fay-o-lay) spots.



### SPARX FACTS:

Some people have very few NF1 features, while others have many. Here are some common features:

- Café-au-lait spots (brown skin spots often referred to as birthmarks)
- Freckling, especially around the armpit or groin
- Neurofibromas (tumors that grow on nerves)
- Optic glioma (tumors of the optic pathway that sometimes cause vision issues)
- Learning difficulties or behavior problems
- Softening and curving of bones

### MORE FROM MOXIE:

Café au lait is a type of skin spot, but it is also a type of coffee and translates to “coffee with milk.” Be careful talking about café au lait spots in a coffee shop, you might get a hot drink!



I love learning about new things like outer space, fashion, and the great big ocean! One day I want to meet a dolphin so we can splash through the waves together.

Sometimes it is hard for me to focus during school, and I miss things the teacher says. I get the wiggles and it is hard for me to sit still.

At other times, I have a hard time understanding the work. I told my teacher that sometimes we go too fast, and I feel like I am left behind.



She thanked me for telling her and told me to make sure to ask questions if there is something I do not understand.





Everyone learns differently, and it may take me time to figure out how I learn best. For now, I get extra help from my teachers so I can learn the things I want to know.

### SPARX FACTS:

Learning difficulties are common, especially for people with NF1. It is important that you talk to your parent or caregiver and teacher about any challenges you have. There is nothing wrong with asking for help. Everyone's brain works in different ways, which makes our world unique!



WHAT DO YOU LIKE TO LEARN ABOUT?

*I like to learn about:*

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Sometimes people do not know about NF1 and I get to be the first one to tell them!


I tell them that I have a condition I was born with called NF1. It is part of what makes me, me, just like my brown eyes.



NF1 is the reason that I have the bump on my leg, the spots on my skin, and why sometimes learning is hard.

But there is still so much I can do!  
Having NF1 is just one of my superpowers.





I also know that unlike the flu or a stomach bug,  
NF1 is not contagious.

The things connected to NF1, like the bump on my leg,  
might change over time. I could get more spots, more  
bumps, or nothing could change at all!

I need to make sure to tell an adult if I find any new  
lumps or bumps, have pain or itching, have trouble  
seeing, or find it hard to do the things  
I could do before.

I wish I could know exactly  
what is going to happen in the  
future. My mom said that no  
matter what happens, my  
family will always watch  
over me and love me,  
which made  
me feel better.  
I know my  
doctor will also take  
care of me.





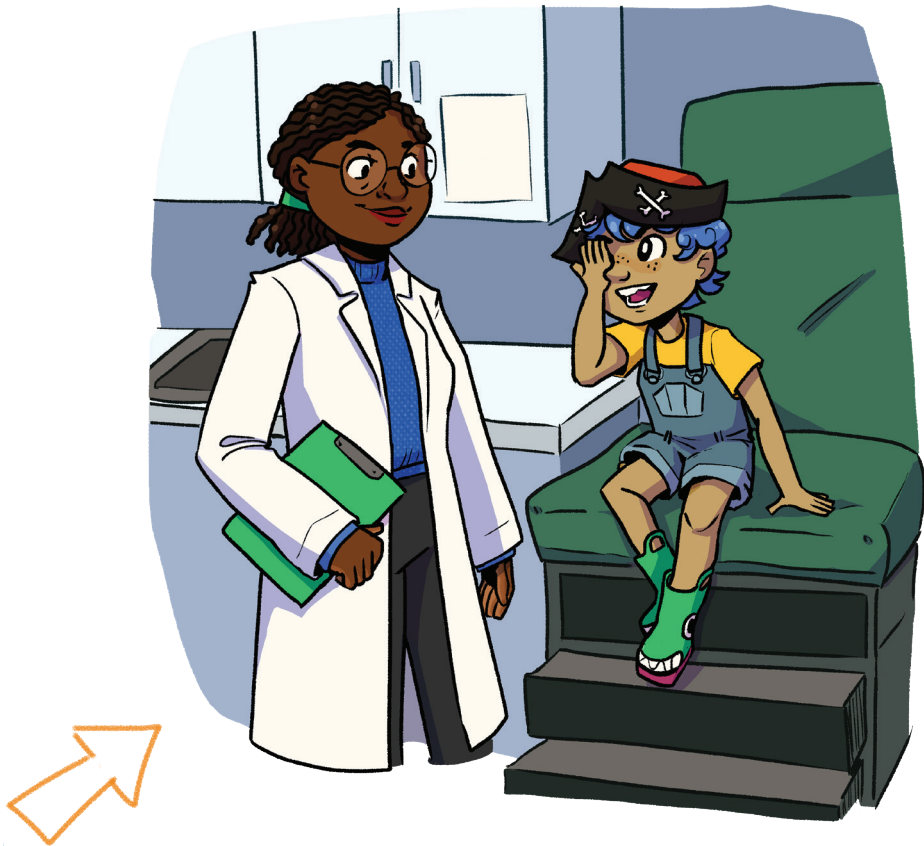
Sometimes I feel excited about what changes will happen, other times I feel nervous. Talking to my family and other people who help me makes me feel better.

Here is a picture of the people who I can talk to.



### WHO CAN YOU TALK TO?

*Draw a picture of them here:*



This is my doctor, Dr. Dawson! I have lots of doctors and they all work together to make sure I am healthy. Dr. Dawson looks at my eyes to make sure everything is a-okay! Her favorite color is rainbow, and she likes carrots. She uses some of the biggest words I have ever heard. I am pretty sure she makes some of them up.

I do fun tests when I am at her office like covering one of my eyes and seeing what I can see with the other. Sometimes when I do this, I feel like I am a pirate. Arr matey!

I get nervous sometimes when I go to the doctor and I hold my mom's hand super tight. Then I remember! I take a deep breath for four counts... 1, 2, 3, 4... hold it for four more... 1, 2, 3, 4 ... then blow out all of my jitters into a bubble. I feel better!



**EMERSON TOOK FOUR COUNTS OF DEEP BREATHS IN, HELD IT FOR FOUR COUNTS, AND THEN BREATHED OUT TO FEEL BETTER.**

*What are some things that you do that make you feel better?*

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Because I have NF1, I go to the doctor more than some of my friends. Sometimes it doesn't feel fair! Then I remind myself that there are other kids out there with NF1, just like me, who also

go to the doctor a lot. Other kids go to the doctor for other things too, like my friend who is in a wheelchair.

My doctors make sure that we do the right tests and that nothing is missed. I can point out anything on my body that feels uncomfortable or is new. Dr. Dawson told me to ask questions if I ever do not understand and she will explain. You can ask questions too!

### MORE FROM MOXIE:

You know your body better than anyone else and are going to be the first one to notice physical or emotional changes. Let your doctor and a trusted adult know about any changes, such as a new lump or bump, a change in size of your bumps, a new pain, or trouble seeing.

Your mental health is just as important as your physical well-being. Sometimes kids can feel worried or sad, and it is important to figure out ways to help decrease your stress and work with any uncomfortable emotions. If you need help, please reach out to a trusted adult.







Even though having NF1 makes me different from some people, I have a lot in common with my friends.

NF1 is a small part of what makes me, me. But I also love to play basketball, cuddle with my dog, and spend time with my family. These are also a big part of what makes me who I am.

Everyone in the world has different superpowers! One of mine is that I know what it's like to have NF1. I can also throw a ball really far, learn new things with my grandpa, give the best hugs, and love with all of my heart.

WHAT IS SOMETHING SPECIAL ABOUT YOU?  
WHAT IS YOUR SUPERPOWER?

*Draw a picture of yourself below,  
or describe what makes you, you!*

A PICTURE OF ME:



MY SUPERPOWERS:

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## OTHER RESOURCES FROM THE CHILDREN'S TUMOR FOUNDATION

Available at [ctf.org/education](https://ctf.org/education)

### **Moxie and Sparx Flashcards**

Help teach others about NF! Download our NF Flashcards featuring our mascots Moxie and Sparx sharing facts about NF. These are perfect for teachers to give a lesson on NF, NF Heroes to share with their classmates, and parents to help answer questions from their kids. Download, print double-sided, cut out, and spread knowledge of NF.

### **Café Au Lait: A Story of NF1 and My Special Spots**

Available for purchase at the CTF Store, this 36-page picture book tells the story of Enzo as he learns about NF1 and his café au lait spots.

### **Moxie and Sparx Explain NF1**

A short comic book for kids explaining NF1 with CTF mascots Moxie and Sparx.

### **Color Jam Coloring Book**

These coloring pages feature our mascots, Moxie and Sparx, who are working with the Children's Tumor Foundation to end NF.

## FOR PARENTS

### **Talking to your Child about NF1**

A companion to Super Emerson, this guidebook for parents offers research-backed suggestions and tools for sharing information with your child about a diagnosis of NF1.

### **NF Parent Guidebook**

A 160-page guidebook for parents of children living with NF1 from the Children's Tumor Foundation, which includes activities for children and their parents

## ABOUT THE CHILDREN'S TUMOR FOUNDATION

Founded in 1978, the Children's Tumor Foundation (CTF) began as the first grassroots organization solely dedicated to finding treatments for NF. Today, CTF is a highly recognized global nonprofit foundation and a leading force in the fight to end NF.

**Our Mission:** Drive research, expand knowledge, and advance care for the NF community

**Our Vision:** End NF

Read more about this resource at [ctf.org/superemerson](https://ctf.org/superemerson). For more information about the Children's Tumor Foundation, visit [ctf.org](https://ctf.org) or reach out to us at [info@ctf.org](mailto:info@ctf.org)



# SUPER EMERSON



A Book About NF1  
For Kids

Emerson loves costumes, their pet cat, and their favorite superhero cape. Join this blue-haired hero who learns what it means to have a diagnosis of neurofibromatosis type 1 (NF1), and explains the condition in a fun, easy-to-understand way for kids.

This resource is designed to help you talk with your child about their NF1 diagnosis. It can be used with the “Talking to your Child about NF1” caregiver guide to help you figure out how and what to tell your child about their condition.



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