

Katie Finds Her Courage

A Book for Children with NF 1



A note to parents

This book has been written for families who have a child with neurofibromatosis type 1 (NF1). As NF1 affects every individual differently, deciding what to tell a child and finding the ‘right’ words can be challenging. It is our hope that through this story, your child can learn about NF1 in words that children can understand. The story is followed by activities. You might want to point out that, by doing the activities, this book will become unique to your child and may help him or her express feelings and better understand the disorder. It is also our hope that *Katie Finds Her Courage* will help facilitate future conversations about growing up, friendships, and living one’s life fully.

*As children tend to refer to NF1 as NF, for the purposes of this story, we use the term NF within the book.

A note especially for you...

If you have been told that you have NF, you may have a lot of questions. For example, “What exactly is NF?” “How did I get it?” “Will it go away?”

Katie Finds Her Courage was written to help you understand NF better. Remember that your own experiences may be very different than Katie’s. Be sure to talk with your parent(s) or your doctor about any questions or worries that you have after reading this book.

We hope that you enjoy Katie’s story, and that you too find that special courage that is always within you!

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Chapter 1

A New School

My name is Katherine. My family calls me Katie. You can call me Katie too. I turned eight in December.

We just moved to a new town. I have a new home, new neighborhood and new classmates. School is hardest of all because I don't have friends there yet. The truth is, I am not sure I like this change at all! I really do like my teacher though. Ms. Lopez is very friendly and always smiling.

After my third day at school, Ms. Lopez asked me to come up to her desk. Worried, I asked, "Did I do something wrong, Ms. Lopez?"

"Oh no, Katie. I'm sorry if I worried you," Ms. Lopez said, "I just wanted you to know that I am very glad that you are in our class. How do you like school so far?"

I hesitated. I really did not want to hurt Ms. Lopez's feelings. "It's okay," I finally said.

"Are you making friends?" asked Ms. Lopez.

"Umm....not really," I replied. "I don't think anyone really wants to be my friend."

Ms. Lopez was quiet for a moment, then said, "I can see how that could be very hard for you. Let me think about ways I might be able to help."

At school the next day, Ms. Lopez announced a big assignment. "Class, we are going to start working on a project. Everyone is going to write a short book about themselves. We will call these books the 'All About Me' books.

When the books are finished, each of you will have a chance to read your book to the class. For homework tonight, start thinking about what you would like to say about yourself in your book.”

On the way home, I thought about all the things I could say in my book. Ms. Lopez had given each student in the class a worksheet to start collecting information.

“All About Me” Information

Name:

Age:

My family:

Where I live:

What I like to do:

What I don't like to do:

My favorite foods:

My favorite books:

When I got off the bus in front of my house, the cutest dog with lots of little spots and adorable floppy ears came running to greet me. Mocha is my puppy and my very best friend. She is always full of licks and happy yelps as soon as she sees me. Mocha and I ran towards the house together where my mom was waiting to greet us.



“Hey sweetie, how was your day?”

“It was OK,” I replied. “Ms. Lopez said we will be writing a book about ourselves and then sharing it with the class.”

“That’s exciting,” Mom said. “What a great way for the class to get to know each other!”

Just then I heard my big brother David coming down the stairs. “Hey there, Squirt,” he said. “What’s this about you being an author?” he asked as he searched the fridge for a snack.

“We’re writing a book about ourselves in school but some of it will be homework,” I explained.

“That sounds like fun. More fun than what I’m doing. I have to pick a topic to present to the class for our health section,” David groaned.

“What are you going to talk about?” Mom asked.

“I was thinking I may talk about NF,” David said. “Or maybe I will talk about how bad soda can be for your teeth. I saw an ad where someone left a tooth in a cup of soda and within days, it rotted away!”

“Those are both great ideas, David” Mom encouraged. “Although the NF idea sounds like a good way to teach the class about it and to share what it is like for you to have NF,” she continued.

“Yeah. Especially since not a lot of people know about NF,” David replied.

“Katie, will you write about having NF in your book?” Mom asked.

“No, I don’t think so,” I mumbled.

“Why not?” asked David.

I shrugged. “I just don’t want to.”

“Well, I sure could use some help with the artsy stuff for the poster I have to make,” David said looking at me. “And I need to make certificates to give my classmates after the presentation. How about this? If you help me with my project then maybe I can help you with your book, and you can use the certificates too if you change your mind about including NF.”

I wasn’t sure that I wanted to write or talk about something that made me feel different, but I did like the idea of helping David. He never asked for my help.

“Okay. I guess I could help a little,” I finally said.

Just then, Mocha dropped a toy at my feet and started tugging at the bottom of my jeans.

“Guess Mocha wants your attention,” David said. “Come to my room after dinner, OK?”

“Sure,” I said as I ran outside to play with Mocha. After dinner David and I sat down at the computer and started working. We found a couple of websites about NF to help us.

“NF. What does it stand for?” David asked me.

“Neurofibromatosis (nū’rō-fi’brō-mă-tō’sis),” I said proudly. I had heard this word a lot and it had taken a long time before I was able to say it correctly!

“Great. But what is Neurofibromatosis?”

“It’s something that gives us spots on our skin and makes us go to the doctor’s office,” I said as I pet Mocha, who was trying to squeeze herself under the desk.

“Right again,” David said, “but I think I’ll have to add a little more information than that. Neurofibromatosis (called NF for short) is a term used to talk about genetic disorders. Hmmm,” David sighed. “I guess I’ll have to talk about genes.”

“Jeans? Mom puts our jeans in the washing machine, David. Plus, I’m not sure our jeans have much to do with NF,” I said feeling really smart again.

“Oh, Katie. You are so cute!” David said.

“**G-e-n-e-s** (not j-e-a-n-s) are found in our cells and they decide what we inherit (get) from our parents such as the color of our hair.”

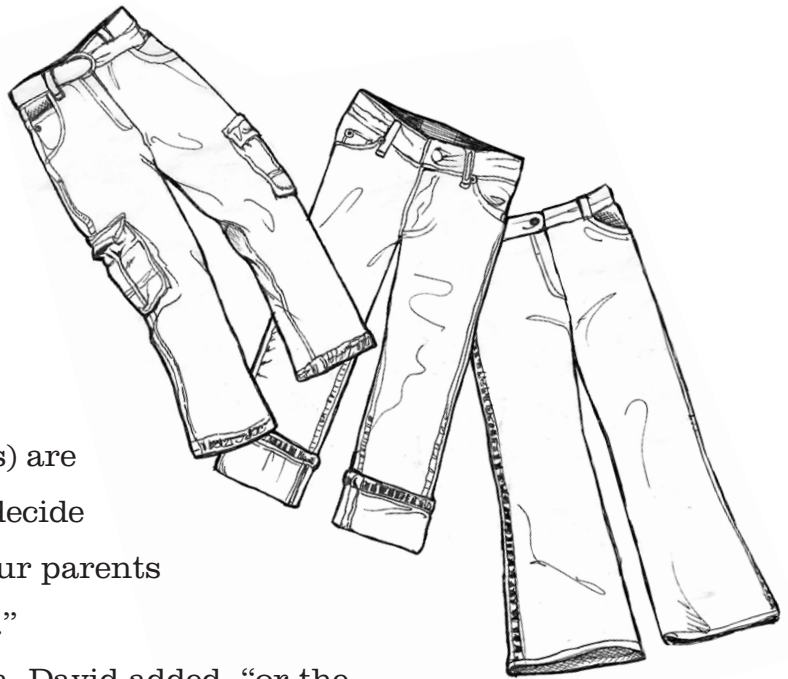
Looking over at Mocha, David added, “or the markings on a dog’s fur.”

“You mean Mocha got her spots from her mom or her dad?”

“Yes, she did,” David said. “And we inherited our looks and other traits from our parents too.”

“Oh, I get it,” I said giggling, “I got Mom’s brown eyes and you got Dad’s big feet!”

“Gee, thanks Squirt,” David grinned. “You are right, though. And in addition to Mom’s brown eyes and Dad’s big



feet, one other thing we inherited is NF.”

“We did? I wondered how we caught it,” I said.

“NF is not something people can catch Katie. I thought that too when I first learned about it. In fact, I better write this fact on my poster.

You cannot get NF by being around someone else who has it.

“Well, why did they give it to us?” I asked, now concerned and a little confused.

“Mom and Dad never meant for us to have it, Katie.” Dad has NF, so there was a chance that we would inherit it from him. We did, but he never wanted us to have it too.

“Some people who have NF don’t have a parent with it. In fact, half of all people who have NF got it ‘spontaneously,’ which means that their parents did not have it. They just got it because their genes changed.”

“Huh?” I asked puzzled.

“I know... this can be confusing stuff. Just remember that nothing you did made you have NF and that Mom and Dad did not mean for us to have it. It is nobody’s fault that people have NF, OK?” David asked.

“Got it,” I said. I knew our parents would never purposefully do anything to us that could be harmful.

“Bedtime, Katie!” I heard Dad say from downstairs.

“Okay!” I shouted back.

“Guess that’s enough for tonight,” David said. “Thanks for your help, Squirt.”

“No problem,” I said as Mocha and I left the room to get ready for bed.

Turn the page if you would like to see what I wrote in my journal.

Katie's Journal

Dear Journal,

Tonight I worked with David on his school project. He is telling the class about his NF. I could never do that!

Did you know that it is not my fault that I have NF?
And that Dad did not mean to give it to me? It has to do with our ~~jeans~~ genes...

Chapter 2

Visiting Dr. Miller

I was in the middle of a good dream when Mocha jumped up on the bed and woke me up.

“Good morning, Katie,” Mom said as she popped her head in the room. “Time to get up.”

“I’m up, Mom” I said, and then grumbled to myself, “I don’t like mornings!”

When I went downstairs to eat breakfast, Mom reminded David and I that we had appointments with Dr. Miller.

“What time is the appointment?” Dad asked, as we each ate a bowl of our favorite cereal.

“1:00,” Mom answered.

“Oh man,” I said, “That means I’ll miss Art class. But at least I won’t have to miss lunch. It’s my favorite today—pizza and brownies!”



“Glad you won’t miss your very nutritious lunch today Katie,” Dad replied. “I’m sorry I won’t be able to get away from work to join you, but you can tell me all about the appointments at dinner tonight.”

Later that day, on the way to the doctor’s office, David asked why we had to see Dr. Miller.

“Well, Katie is due for a check-up,” Mom replied, “And Dr. Miller wants to look at the plexiform that has been

bothering you, David,”

“His plexiWORM?” I gasped with a mouth full of cookies. “What is THAT?”

“PlexiFORM (**PLEX-i-form**),” David said. “That’s what this big bump on my leg is called.”

“Oh!” I replied. “Are the smaller bumps called Plexi-whatevers too?”

“No. The bumps on your skin are neurofibromas” mom said. “Has the plexiform been bothering you, David?”

“It’s been hurting a little....but don’t worry about it, Mom,” David said.

“It is important that we tell Dr. Miller, David,” Mom insisted.

“I know,” David said sounding annoyed at being reminded.

“Why does it hurt?” I asked my brother.

“Dr. Miller says the reason it hurts is because the plexiform grows along the nerves in my leg,” David started to say.

But I didn’t hear David. We had just parked the car and I saw Dr. Miller walking into the building. I ran over to give her a big hug hello. Dr. Miller was always so nice to me!

During my check-up, Dr. Miller seemed to be looking at one of the spots on my arm.

“What are these called again?” I asked.

“Café-au-lait spots,” Dr. Miller said. “That is French for ‘coffee with milk’. They are called that because their color is like the color of coffee and milk.”

“Oh yeah...” I said looking around the room at all the medical equipment.

As Dr. Miller continued to examine me, I said, "In the car coming here, David was talking about his plexiform. How come I don't have one of those?"

"NF is different in every person, Katie - even within the same family," Dr. Miller explained. "We don't know why some people have plexiforms and others do not."

"How do you know that David and I have NF?" I asked.

"Good question. You sure are smart," Dr. Miller said. "We don't have one test to determine if a person has NF so we look for a lot of different things like plexiforms, freckle-like spots on your eyes called Lisch Nodules (**LISH Nod-ule**), café-au-lait spots, or neurofibromas," Dr. Miller smiled. I could tell she was surprised by how many questions I was asking.

"Alright Katie, hop down here and let's see how tall you are," she said.

"It looks like you've grown a bit since last time."

"Really? I'm still short. I'm the shortest person in my class," I said. "Is that because of NF?"

"People that have NF are often shorter than other people," Dr. Miller said. "It could also be because your mom and dad are not very tall. As long as you continue to grow at your own pace, there is nothing to worry about Katie," she said. "Everyone grows differently. I'm proud of you for asking questions. Do you have any more for me?"

"Nope—that's all I got for today!"

"Well, you look wonderful. Why don't you go to the playroom while I spend a little time with your brother."

I jumped down from the table and scooted out the door to see if the computer in the playroom was available.

When we left the doctor's office, I noticed that David looked upset.

"What's wrong?" I asked him.

"Dr. Miller said that my plexiform may have grown. She wants me to see a specialist. If my leg gets weaker, contact sports could be difficult for me. I already run slower than most of my friends."

"Dr. Miller said other things too David," Mom said reassuringly.

"Like what?" David asked.

"She said that just because you have a plexiform doesn't mean that you cannot do sports. You should continue to do whatever you feel comfortable doing. But, if you are in a lot of pain or get tired, you can take a break. And, if your leg is bothering you, it's a good idea to think about some other things that you're good at and enjoy doing."

"Eating!" I blurted. "You're always good at eating!"

"Very funny," David said.

"There is a lot that you can do," Mom said. "You love bowling. You write really well. And you love taking pictures."

"We do have an awesome bowling team," David said. "I guess it couldn't hurt to see if I can join the team."

When we got home, I went outside to play with Mocha until dinner time. Mocha knew several tricks and she FINALLY learned to roll over. Before we started eating dinner that evening, I showed off Mocha's new skill while Mom and Dad talked about the visit with Dr. Miller.

As Mom marked down the next doctor's appointment on the calendar, I asked why we had to go again.

"You don't have to go next time, Katie," Mom replied. "This is an appointment for David. He is going to have a special test called an MRI to look at his plexiform."

"An MRI?" I asked. "Is that the tube-like machine that I laid down in last year?"

"That's right. I forgot that you had one too."

"That sure was noisy!" I said as I remembered what it was like.

"I kind of like them," David said. "It is cool that they can see parts of my body that otherwise can't be seen."

But my attention had switched to the television. There was a show on that some of the kids were talking about at school and I asked if I could stay up to watch it. Mom wouldn't budge.

"I think you still have a little homework to do before bed. Go upstairs and get started. I'll be up in a minute to help," Mom said.

Turn the page if you would like to see
what I wrote in my journal.

Katie's Journal

Dear Journal,

David and I went to Dr. Miller's office today. I asked all sorts of questions. I hope Dr. Miller thinks I'm smart! Mom wouldn't let me watch the TV show that EVERYONE else gets to watch!

Help Katie remember what she learned today by matching the following:

A Neurofibroma is

at their own pace.

Everyone grows...

different

An MRI is used...

to see parts of the body we
can't see with our eyes

NF is _____ in everyone,
even people in the same family

like a small bump.

Chapter 3

I'm NOT Sick

The next day at school, everyone in my class was working on their 'All About Me' books.

"Well, class, it looks like you are making great progress on your books!" Ms. Lopez said. "I think that we can start reading them to the class in the next few days."

As we were sitting on the floor writing and drawing in our books, Jack looked over my shoulder at what I was writing and asked, "What is N-F?"

I didn't know what to say.

"Umm, it's just something I have."

"Are you sick?" Jack asked.

"No," I almost yelled, "But I do have to miss school sometimes to visit the doctor."

"Why would you have to go to the doctor if you weren't sick?" Jack asked.

I started to tell him but Ms. Lopez announced that it was time to put our things away before going home for the day.

I was so embarrassed! Jack's reaction about what he saw in my book made me feel different. I wasn't sick! I decided right then to take that part out of my book!

After school, when Dad asked about my day, I got upset. "I'm worried that if people know I have NF they will think I am sick and different. I am taking it out of my book!" I said.

"Most people have never heard of NF, Katie. NF may be one thing that makes you different from your classmates



What is N-F?

who don't have it, but there are a lot of things about you that are similar to the other kids in your class," Dad said. "When you hear what some of the other kids wrote in their books, you'll see how similar you are to them," he tried to assure me.

Just then, David stormed into the house and loudly plopped his books on the table by the front door.

"Oh dear," Mom said, "Are you OK, David?"

"Good news and bad news!" he exclaimed.

After getting a snack, David started with the good news. He was chosen "student of the week" for his progress in science and it was announced over the loudspeaker at school that morning. Then, David got to the bad news. He explained that he spent an hour in the library trying to read his homework assignment but he only got through 10 pages. A new video game was out and David's friend Alex had invited a group of kids over to his house to play it. David still had so much homework that he didn't think he would finish in time to go to Alex's house.

"We're proud of you for trying, David," Mom said. "Try not to get upset with yourself. If you stay at Alex's for no more than one hour, I can help you get through the rest of your reading tonight."

"Really? Thanks, Mom. Thanks, Dad. Have I told you that you are the greatest parents in the whole wide world?" With that, David was out the door.

When he was gone, I asked, "Does David have a hard time with reading like I have a hard time with math?"

"Yes," Mom said. "Dr. Miller said that some people with NF can have trouble with certain kinds of school work, but she also said that no one has a mind that can

do everything perfectly.”

“If we have trouble with math or reading, does that mean we’re not very smart?” I asked feeling worried.

“No, no, both you and David are very smart. Having trouble with certain subjects, like reading or math, or with certain parts of learning, like paying attention, does not mean that you are not smart,” Mom reassured me. “There are many ways to be smart. You are really good at lots of things, like spelling and training Mocha. You should never feel bad about the way your own mind works.”

I thought about that for a while and decided to go look for Mocha. She had more tricks to learn!

As promised, David came home in an hour, and he was in a MUCH better mood. He worked hard with Mom on his reading assignments. Before bed, Dad said, “Sounds like you both had a long day. What do you say we have some ice cream?”

“Yeah!” I shouted and ran to the freezer. As dad took out bowls, David talked about his health project.

“We had some library time to work on our projects at school today. Mine is going really well. Actually, I’m almost done!”

“How will you start your presentation?” Mom asked.

“I think that I’ll start by talking about how many people have NF,” David replied.

“How many people have it?” I asked trying to keep Mocha from licking my ice cream.

“About one out of every 3,500 people,” David answered.

“Gee,” Mom said, “I never knew that. You see, we can learn something every day, no matter how old we are!”



“What else are you going to say?” Dad asked.

“I’ll probably talk about some of the signs of NF and how they affect me,” David continued.

“How do they affect you?” I asked.

“Well, I have that plexiform in my leg, which can be painful...and I have to go to lots of doctors which means I might miss some school...and that I may have to take a break from certain activities,” David said while finishing his second bowl of cookie dough ice cream.

As David was talking, I was deciding what I wanted to write in my journal for the night.

Turn the page to read part of my journal. Shhhh! It’s a secret. And if you want to know what David is thinking about, you can read some of his thoughts, too.

Katie's Journal

Dear Journal,

I just finished some delicious ice cream!

Did you know that David has trouble reading? I sure didn't! I guess it can be part of having NF. That may be why I have trouble in math.

Did you know that you can teach your parents things? I had thought they knew everything!

I think David is still worried about his plexiform. I'll be extra nice to him tomorrow. I didn't even yell at him for almost finishing up all the ice cream!

David's notes to himself

I wish my leg didn't bother me but I'm happy that the bowling team is still open! I'm thinking about other sports that may be easier for me to do. I saw a golf game on TV and I think I might be good at that. I am really good at miniature golf! I'm also going to see if I could take pictures for the school yearbook. I shouldn't let my leg keep me from doing things I love to do. But, why does Mom always seem to be right? It gets annoying. But at least I did teach her one thing the other day—she had no idea how many people get NF each year until I told her.

Chapter 4

Peter and Math

The next day at school, half the class shared their ‘All About Me’ books. I was working hard to keep track of the ways that I was similar to my classmates.

“All About Me” Information

Jack: has a big brother, his favorite color is green, he likes to go to the movies

Sally: likes ice cream and hates bugs

Peter: does not like doing math but loves art

I could not wait to go home and tell my parents all the things I had in common with my classmates.

“Mom, Mom!” I shouted, “Jack has a big brother too, and Peter doesn’t like math either, and...”

Then I saw David sitting down at the table. He wasn’t eating his usual big snack. “Hey David, what’s wrong?”

I asked remembering my vow to be extra nice to him.

“I just didn’t have a great day,” David mumbled.

“What happened?” their Mom asked.

“This one kid kept making comments about my leg.”

“That must have been really hard,” mom said softly.

“When he first said something, it made me feel really angry and I think he wanted to start a fight. The next time he came over and said that my leg looked weird, I think he was expecting me to cry.”

“So what did you do?” I asked.

“I just looked at him and said ‘So?’ and then he walked away.” With some pride, David grinned and added “I don’t think he knew what to say back.”

“Sounds like you handled that really well David.” Mom smiled. “Maybe after your presentation in class people will be more understanding,”

“Sure hope so,” David said. “It’s just so frustrating sometimes!”

“What about your day Katie?” Dad asked.

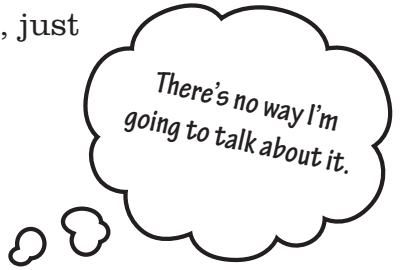
“People started reading their books out loud.” I said. “It’s my turn tomorrow.”

“Are you excited?” Mom asked.

“Yes, but I decided that I’m not going to talk about NF.”

“Whatever you decide is fine, Katie. But how about we add a few sentences about it in your book, just in case? That way, if you change your mind, it will be there. If you decide not to read that page, you can just skip it,” Mom said.

“Fine,” I said. But to myself I thought



*There's no way I'm
going to talk about it.*

As we worked on writing about NF together, Mom asked if it would be a good idea to have some extra support in case I did tell the class about NF. She thought that the students might come up with some difficult questions. I told her she didn't have to worry about it because I wasn't going to talk about NF to the class anyway. She didn't tell me she decided to call Ms. Lopez in the morning to see if David could come listen to me read my book.

*Do you want to see what I wrote
in my journal, tonight?*

Katie's Journal

Dear Journal,

Today some of the class shared their All About Me books. I'm not as different as I thought I was! But no one else has NF... and after Jack's reaction, I don't think that I should tell anyone. Should I? I don't think I'm that different. But, what if they think I am after I tell them? No, I won't say ANYTHING about having NF!

All About: Katie

My favorite color: green

My favorite thing to do: play with my dog, Mocha

My favorite school subject: writing

My least favorite subject: MATH

My family size: 4 and a dog!

My favorite food: pizza

My favorite dessert: ice cream

Chapter 5

What Should Katie Do?

The next morning I awoke again to Mocha's good morning licks. I rolled out of bed and stumbled downstairs for breakfast.

"Good morning, Katie," Mom said smiling. "All ready to read your book to the class?"

"Yes," I said. "But remember, I decided that I am not reading that page about NF."

"Morning Squirt," David said overhearing this conversation as he was coming down the stairs. "You don't have to say a lot about it Katie. Just ask the class if they have ever heard of NF. Then tell them you have it. If they ask any questions, you can use your own words to explain it."

"No way," I said thinking to myself, "Everyone likes David. Easy for him to say I can do this."

"Last night I made cupcakes for you to take to school, Katie," their mom said. "Since all the books will be finished today, I thought everyone would probably like a special treat to celebrate," she said.

I smiled. 'At least we could agree on that. Everyone loves cupcakes,' I thought to myself.

Later that morning, as the students were reading their books, I kept thinking, "Surely it will be my turn next." I wanted to get it over with but I ended up being very last!

As I walked to the front of the room, I noticed my heart was beating extra fast. When I turned to face the class, I was

surprised to see David seated in the back. ‘Wow! It’s nice that David’s here!’ I thought. ‘But he must really want me to talk about NF...’

I felt my heart pounding as I began to talk. My voice was shaky too. I don’t remember how I started but I know I told the class all about my favorite things to do, favorite foods, and my family and of course, all about Mocha. When Ms. Lopez asked if I was done, I didn’t know what to say. I thought about how smart Dr. Miller thought I was when I was asking so many questions and how David had helped me prepare for today. I gulped and after a long silence, said, “I also have something called NF.”

Then I took a deep breath.

“Does anyone know what that is?” I asked.

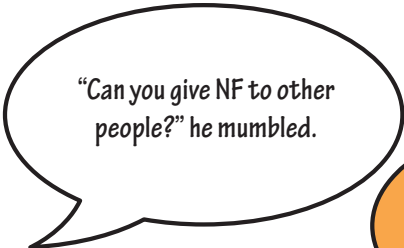
No one answered.

“NF stands for neurofibromatosis,” I explained.

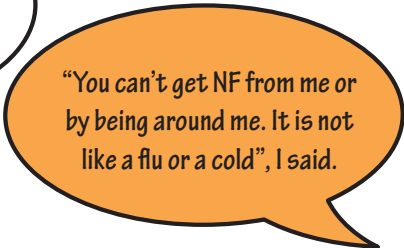
For the next few minutes, I shared what I had learned with David and Dr. Miller during the past week.

When I had nothing left to say, I said, “Does anyone have any questions?”

Jimmy was the first person to raise his hand.



“Can you give NF to other people?” he mumbled.



“You can’t get NF from me or by being around me. It is not like a flu or a cold”, I said.

"Does Mocha know how to roll over?" Jack asked.

"She just learned how to roll over. It took forever for her to learn that trick!" I explained.

"What is it like having NF?"

"Really, I am just like all of you. I go to school, love to get together with friends, play on the computer, go to the movies, and I think about what I want to be when I grow up. NF is just part of my life. The more I learn about it, the less scary it is."

"How do you get rid of NF?"
Megan asked.

"NF doesn't go away," I said. "But I haven't had many problems with it at all. My brother has had to see doctors a lot more than I have."

Ms. Lopez spoke next.

"Katie's brother has joined us and has offered to help answer some questions too."

David spoke up from the back of the room.
"I have NF too. The only real problem that I have is this plexiform tumor (pointing to his leg) which can be really annoying."

Jessie asked,
"Do you have cancer?"

"No, I do not have cancer, but that is a good question. Cancer tumors grow differently and can spread. What I have in my leg may get bigger but won't spread."

The room was quiet for a little while. A few people asked about how long David and I knew we had NF. There were also more questions about Mocha's tricks.

When they were finished, Ms. Lopez said, "You all did a really great job writing your books and reading them to the class. You know more about each other now - both similarities and differences. Ms. Lopez began writing some notes on the blackboard.

"Some ways that you are similar are that most everyone..."

Likes pizza
Has brothers or sisters

Wants more recess time
Has a favorite color

"Who can remember ways that you are different? If you recall, I shared that I have to wear special glasses when I read, and not too many other people in our class need to do that," Ms. Lopez said. Carin was the first person to speak.

"Bryce is allergic to peanuts and bee stings."

"Jake has a scar on his elbow from when he broke it," Amy called out.

"And Carin has to wear ear plugs when she swims," Bryce said.

"Patrick has a big scar on his knee from falling off his bike," Mark offered.

"Lucy has diabetes," Susie said.

"I can't sit still for very long. And no one has as many freckles as I do." Travis said.

“Great examples! Learning about each other is kind of like reading a book: If you only read a little of it, you never get to know the whole story.

Patrick raised his hand. “Yes, Patrick?” Ms. Lopez said. “If you had only read one page of my book, you might not have learned that I have twin brothers,” Patrick said.

Carin called out, “OR that I might have to move again next year.”

Jack spoke next. “If we only heard one page of Katie’s book, we might not have learned about her NF.”

“You are all correct. So, what is the most important lesson we learned from hearing each other’s stories?” Ms. Lopez asked.

Jack darted his arm straight up again. “We learned that even at our age, we can write our own books,” he blurted. “That is true”, Ms. Lopez said. “Anything else?”

Lucy called out, “We should learn about each other.”

“Very good, Lucy,” said Ms. Lopez. “Any other thoughts?”

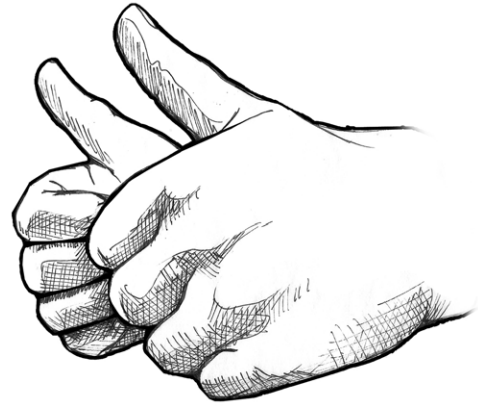
I surprised myself when I added, “You really don’t know a person just from what you see on the outside.”

“Excellent, class,” Ms. Lopez concluded. “I am so proud of all of you.”

“We’re going to take a short break now,” Ms. Lopez said. “Katie brought cupcakes to share with everyone.” As I went to get the cupcakes, I remembered the certificates David and I made for our classmates. As each person picked a cupcake, they also received their

very own certificate to complete.

I looked back at David just in time to see him leaving the classroom. He gave me a smile and a high thumbs up as he walked out the door.



Everyone loved the cupcakes. My mom had put different animals on each one. There was even a dog that looked like Mocha on one of them and a sugar free cupcake for Lucy!

As they sat around eating the cupcakes and comparing the animals on top, I told a few of the girls more about Mocha. After they heard about some of the tricks that Mocha could do, they all wanted to come over to play with her.

Before leaving to go home, Ms. Lopez came up to me and said that she would never forget what I had taught the class today - that I had taught them something very special.

I felt so proud. All the courage I needed today had been inside me all along!

CONGRATULATIONS

**For being knowledgable
about NF!**

This certificate is awarded to

Who now is an expert on neurofibromatosis type 1

It's
Official!

date



By reading this book you now know a lot about NF too!
This is your personal invitation to write about yourself.

“All About Me” Information

Name: _____

Age: _____

Grade: _____

Color of eyes: _____

Hair color: _____

My favorites: _____

Color: _____

Game: _____

Food: _____

Animal: _____

Person: _____

Book: _____

Place to be: _____

Thing to do: _____

These are the ways that I am like Katie:

These are the ways that my life or my NF is different than Katie's:

Three good things about me are:

One thing I do not like about me is:

These are important people in my life:

This is what I wish my friends or classmates would understand about NF:

These are the questions I still have:

This is the advice I would give to other kids who just learned they have NF:

Can you find...

all the words related to NF in the word search?

**hint: words can be diagonal and some go backwards as well*

NEUROFIBROMATOSIS

P	G	C	C	U	X	D	D	P	X	I	N	R	S	K
L	R	I	I	H	H	F	O	Z	P	E	N	O	E	A
E	W	R	T	L	U	B	H	X	U	M	B	T	N	G
X	A	M	E	H	L	D	U	R	C	A	N	C	E	K
I	Z	G	N	K	B	J	O	J	N	N	Q	O	G	S
F	B	J	E	Y	P	F	M	H	A	D	R	D	O	S
O	N	K	G	C	I	L	E	A	R	N	I	N	G	H
R	L	W	I	B	T	I	A	L	U	A	E	F	A	C
M	I	V	R	C	H	E	C	K	U	P	T	P	M	P
T	U	O	M	E	T	N	Q	I	J	N	I	U	T	S
V	M	Z	Z	H	U	T	P	M	P	A	R	Y	F	Z
A	D	U	G	H	H	Q	A	H	Q	Z	E	A	C	Y
H	S	I	L	X	K	M	I	W	R	G	H	V	T	O
E	E	N	N	Z	H	I	S	N	P	V	N	T	U	Y
H	R	B	O	W	J	S	L	T	U	F	I	Y	R	N

CAFÉ-AU-LAIT

CHECKUP

DOCTOR

GENES

GENETIC

MRI

INHERIT

LEARNING

HEIGHT

NEUROFIBROMA

PLEXIFORM

UNIQUE

Appendix

The following pages can be referred to or used as needed

Contents:

42-43 Glossary

44-46 Information for Educators

47 For More Information

48-49 A Note About Teasing

Glossary

The findings below lead doctors to diagnose someone as having NF.

Neurofibromatosis Type 1

- Lisch Nodules
- 2 or more neurofibromas or one plexiform neurofibroma
- Optic (eye) nerve tumor
- Family history of NF
- Bone abnormality
- Freckling under the arms or groin
- 6 or more café-au-lait spots

Café-au-lait spots: “Café-au-lait” means “coffee with milk” in French. Named for their color, these are spots on the skin commonly found on people with NF.

Freckling under arms or groin: Just having freckles does not mean that someone has NF. These freckles are in areas that do not normally get sunlight—areas usually covered up by clothing.

Neurofibromas: Often seen as small bumps, neurofibromas may be painful if they are pushing on a nerve. The number of neurofibromas someone has varies although most people get more during puberty and later in life.

Plexiform neurofibromas: A special neurofibroma that grows along large nerves. Sometimes these “plexiforms” may be obvious because of swelling, but other times they are very deep inside the body so they are harder to see. They can grow large though, and if this happens, you may be able to see them. They can also be painful and surgery may be used to help reduce their size and manage pain.

Lisch Nodules: These are tiny tan bumps, like freckles, on the eye. They are harmless and do not cause pain or problems with vision.

Optic nerve tumor (optic glioma): Growth involving cells of the optic (eye) nerve, the nerve that connects the eye to the brain. It can cause problems with vision or hormone production although problems usually occur between the ages of 4-6. MRIs may be used to check for an optic glioma.

Bone abnormality: This means that a bone is shaped differently. Usually there are two types found in NF: a curvature of longer bones (such as the shinbone) or different bone structure around the eye. Both are present at a young age if they are going to appear.

Family history: Someone else in the family is known to have had or have NF

Information for Educators

It is our hope that the following pages may add to your understanding of NF and aid in discussion with parents, colleagues, and children.

SUMMARY

Neurofibromatosis encompasses both NF1 and NF2, genetic conditions involving nerve tissue. The focus of this book has been NF1 (commonly referred to as NF), which is more common than NF2.

A unique aspect of NF is that it varies greatly in severity and complications. Therefore it is important to remember that everyone's experience with the disorder is individually based.

Individuals with a diagnosis of NF may have behavioral and cognitive concerns. It is important to discover the individual's own experience with NF to determine the degree to which he or she is affected.

Discussion with parents:

Even though you may have researched NF on your own, it is important to obtain the family's perspective. It may be helpful to ask parents the following:

- 1.** How does NF affect your child? (not the majority of children) Consider: cognitive abilities, behavior, physical limitations, social impact.
- 2.** What are your child's strengths? Does he or she have any limitations?
- 3.** What concerns do you have for your child?
- 4.** What is your child's understanding of his or her NF?
Is there anything you would or would not like discussed in the classroom?
- 5.** How can I help your child to succeed?

Using this Book as a Teaching Aid

This book is intended to provide information about some of the physical findings and complications of NF1 as well as the social effects which may accompany it.

Children may be very curious about physically noticeable findings such as neurofibromas--especially if the child has a prominent bone deformity. Children may be afraid of such differences or even fear that they will get or “catch” NF. While it is not important that they retain specific details about the disorder, it is important to ease their mind of fears and address their questions as honestly as possible.

Children with disfigurements may also be subject to teasing. In order to not isolate the child during a discussion about NF, it may be helpful to extend the conversation to recognizing themes that emerge among similarities and differences. Helping children find commonalities can greatly improve interaction.

When considering talking about NF with a class, it is important to discuss this with the child’s parents and to consider the child’s views and wishes. Both the parents and the child may be able to help guide your discussion.

For more information about NF

The Neurofibromatosis Association

www.nfauk.org

The Children's Tumor Foundation

www.ctf.org

Neurofibromatosis Inc.

www.nfinc.org

National Institutes of Health

www.nih.gov

For more information about *Katie Finds Her Courage*, contact:

Lori Wiener, Ph.D. 301-451-9148

Brigitte Widemann, M.D. 301-496-7387

Why Do People Tease?

They do not understand

They are nervous or afraid

They want others to think that they are funny or powerful

They want to make themselves feel better

Write in your own reason

So What Can You Do?

Help them understand

Respond with “So?”

Show that the teasing words are meaningless to you—that they don’t upset you. This way there is nothing encouraging them to continue teasing you.

Write down what people say. See how silly it is and come up with what you could say back.

Leave the insult with the teaser. In other words, if you get really mad, walk away.

Write in your own way to deal with teasing.

Notes

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



National
Cancer
Institute

U.S. Department of Health
& Human Services

National Institutes of Health

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