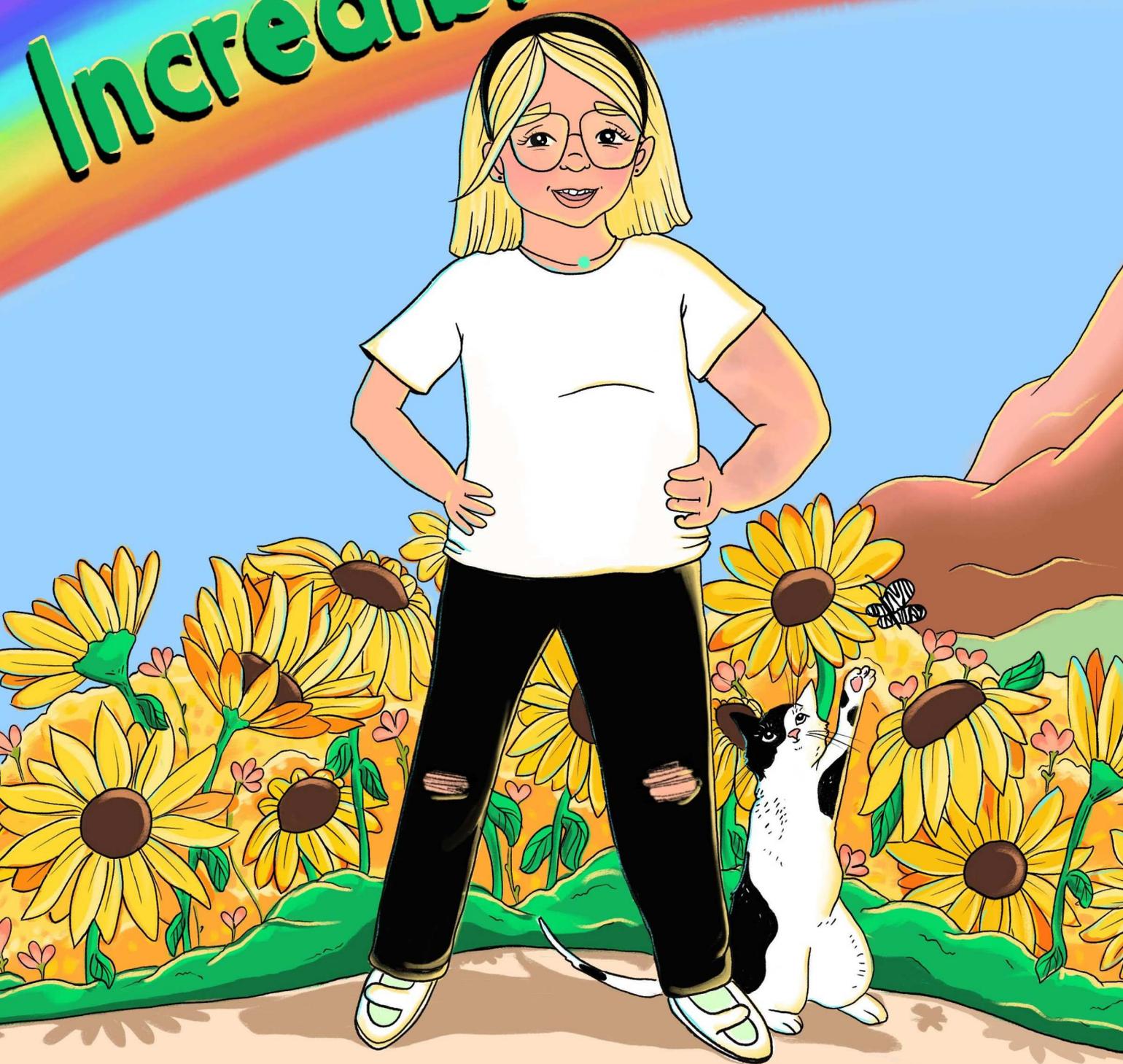


# Incredible You!





# Incredible You

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In collaboration with  
CLOVES Syndrome  
Community

Picture this: a bright, vibrant world filled with an endless array of rich, sparkling colors. A rainbow fills the wide blue sky, and the golden sun casts a heavenly glow on everything below it. There are hundreds of exotic flowers and trees, even types that you have never seen! All of your favorite things are there for you to enjoy. You'd never want to leave!





Now, picture this: a dull, dark place where everything is the same shade of gray. The sky looks like a storm is brewing; the ground is not grass but hard cement, and all of the plants are the same shade of boring gray. You can't even tell the people in this world apart because they all look the same. Where is the fun?

Which world would you want to live in? The first one, full of color and life? Or the second one, where it's gray and everything is the same?

I would want to live in the first world, wouldn't you? Well, good news: We do live in that world! There may not be a rainbow filling the sky every day, but our world is full of color and, most important of all, everything on this planet is different. Now hold onto that word. You're going to hear it a lot throughout this book.

My name is Kate. I'm ten years old and I have CLOVES Syndrome. You might know all about CLOVES Syndrome because maybe you have it too? Or maybe you have another PIK3CA Related Overgrowth Syndrome? Or perhaps you have a friend or a brother or sister with one of these conditions?

I'm going to share my experiences living with CLOVES Syndrome. I'll explain how people with CLOVES are unique in many ways, and also how we're not so different from everyone else.

I'm going to take you on a journey. We'll learn about CLOVES Syndrome, and about ourselves! We'll learn about everything from what the word CLOVES means, to what it's like meeting other people with PIK3CA Related Overgrowth Syndromes, and more! And, along the way, you're going to discover just how incredible you really are!



CLOVES is an acronym made up of a lot of big words. The C stands for Congenital (something you are born with); L is for Lipomatous (lumps and bumps made of fat); O is for Overgrowth (body parts that grow faster than others), V is for Vascular malformations (lumps and bumps made of tissue and veins and vessels), E is for Epidermal nevi (rough, bumpy patches of skin) and S is for Spinal or Skeletal issues. CLOVES Syndrome happens when a particular gene in a person's body undergoes a mutation before they're even born. That gene is named PIK3CA, which is why another name for CLOVES (and other conditions like it) is PIK3CA Related Overgrown Syndrome (or PROS, for short.) Some people with CLOVES Syndrome prefer the term PROS because it's more representative of the wide array of ways mutations to the PIK3CA gene can be represented in people's bodies.

It's a lot to learn, but it's also very important to know. The long, confusing words may look a little scary, but to sum it all up, CLOVES and PROS are really just fancy names for a very unique body. And that's how I try to explain it to other people!

I was born with a big bump under my arm (called a lymphatic malformation...that's a type of vascular malformation) as well as big lumps and bumps on my back and tummy. My feet are very wide and one of my legs grows faster than the other. Everyone with CLOVES Syndrome has lumps, bumps, and overgrowth in different ways and on different parts of their body. Even though we all have CLOVES Syndrome, none of us are the same!

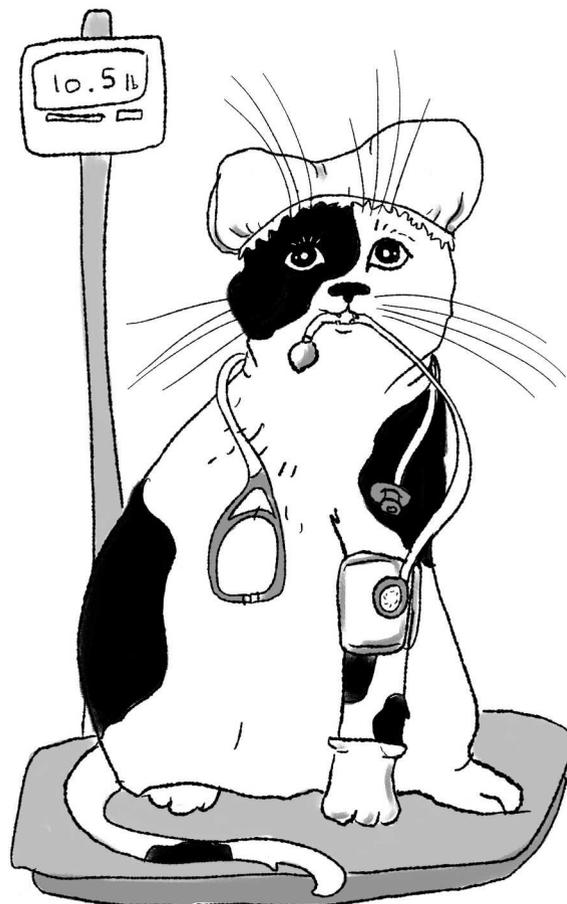
PIK3CA Related Overgrowth Syndromes are very rare--and CLOVES is just one of the many expressions of PROS! The world's population is about seven billion, and the number of people with CLOVES Syndrome represents such a small percentage of the world's population, it's nearly impossible for people to comprehend it. Pretty amazing, huh?

It's important for everyone to learn about their own bodies, and it's especially important for those of us with CLOVES (and other PROS). The more you know about you, the more comfortable you will be!

**KID SPEAK:** CLOVES is a funny word. And it's even harder to explain in kid language. I just say my body has a lot of lumps and bumps on it. Or that some of the parts of my body are larger than other parts.

People with CLOVES Syndrome usually spend more time at the doctor than most of their friends or family members do. For me, I have all of the regular check ups and visits like anyone else, but I also see a team of doctors who know all about CLOVES and PROS. You may have lots of different specialists (doctors who specialize in parts or systems of the body.) Over time, you'll become very familiar with your doctors and nurses, and the other members of your medical care team, just like I have!

Even though being at the doctor or hospital a lot can be hard, I am grateful for the doctors and nurses who help me manage my condition so I can enjoy my favorite things! Our doctors work hard to help us stay healthy and comfortable in our bodies, no matter what it takes.





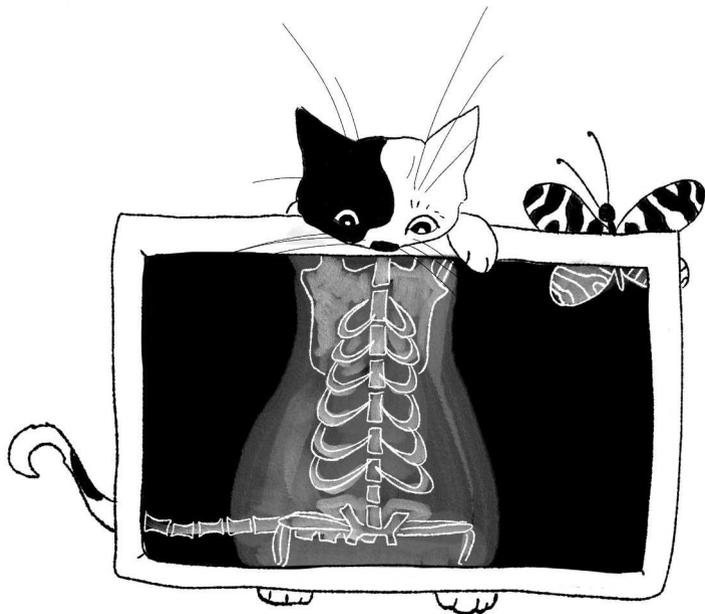
When I think about going to the doctor, the first thing that comes to mind is something called an MRI. What's an MRI you ask? An MRI is an important tool doctors use to find out information within your body that cannot be seen during a regular checkup. You may have had one of these before, but if you haven't, I'm going to tell you all about it.

MRI stands for Magnetic Resonance Imaging. An MRI uses magnets to take pictures of the tissue and blood vessels inside your body. Isn't that cool?

You may have MRIs regularly because it's very important for the doctors to keep an eye on your blood vessels, bumps, and body tissues as you grow to help keep you healthy. But it really depends on what your medical team recommends. Just like everyone with CLOVES Syndrome is different, your doctors may want different kinds of images for you than they do for me!

It's important to stay very still while you're having an MRI so the machine can take really good pictures. So, depending on your age and comfort level, you may have some medicine beforehand to make you sleep. Or you may feel comfortable enough to stay awake and have an MRI without medication. It's up to you, your parents or caregivers, and your doctors. In either case, the nurses will have you lay down on a bed with a pillow, and they will even give you warm blankets if you ask. The MRI machine is very loud so they will give you earplugs to protect your ears. If you stay awake, they may let you listen to music--or even watch a movie! If this is your first MRI, it may look a little strange and it makes some weird noises, but you will get used to it in no time.

I'm old enough now that I choose to be awake and not have medication during my MRIs. Sometimes I pretend that I am going on a trip, and I'm riding in an airplane, to keep myself calm and still....and sometimes I even fall asleep.



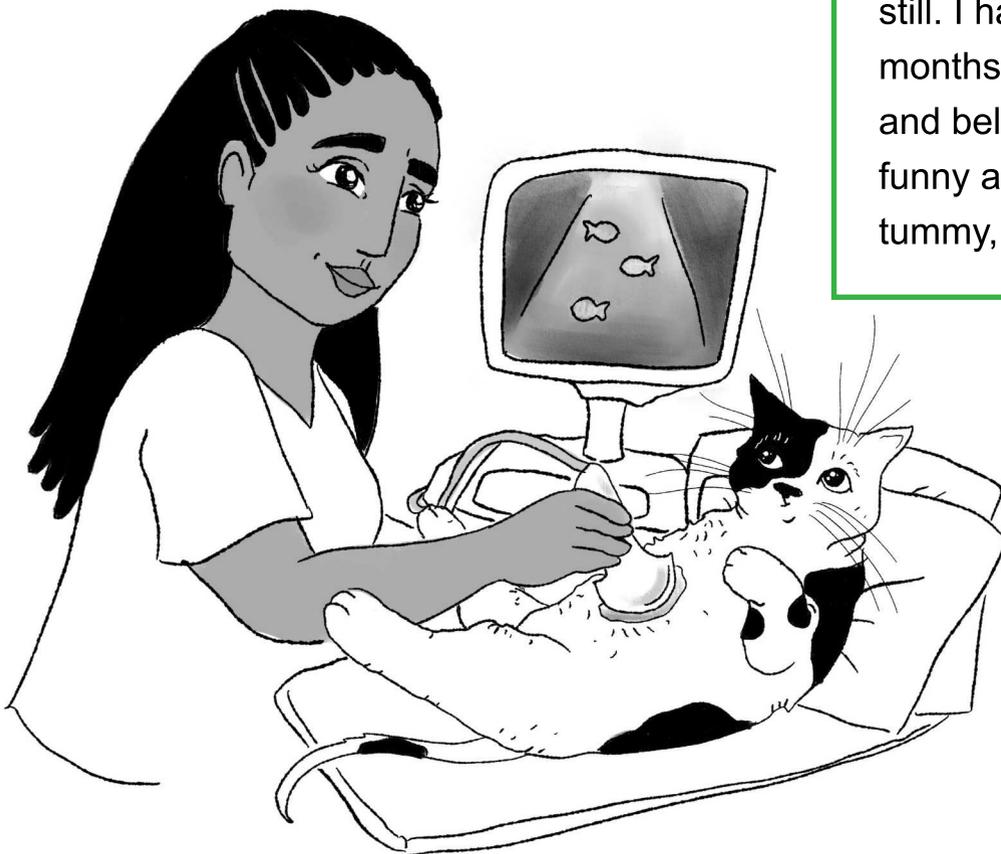
Let's move on to another important kind of exam! It's an X-ray. You may visit an orthopedic doctor (a doctor who specializes in bones) if CLOVES has affected your legs, feet or spine. At some appointments you may get something done called an X-ray.

What's an X-ray, you ask? Well, it's kind of similar to an MRI, but a lot simpler. Where an MRI took pictures of your tissue and blood vessels, an X-Ray takes pictures of your bones! The X-ray looks like a really big camera, and it sounds like one too. It's much quieter (and quicker!) than an MRI.

If you have ever broken a bone in your body, you've probably had an X-Ray. You have to be nice and still while the X-Ray takes pictures, but it's easy, and it doesn't hurt at all. You may lay on a table, or stand up, depending on what kind of pictures the doctor has requested. Once the X-Ray is done, the doctor will put the pictures on a light or they may look at them on a computer so they can see a clear picture of your skeleton! Yes, your skeleton! Isn't that cool? If you want to learn more about your body, you can ask your doctor to show you your X-Rays images.

Ultrasounds are another tool doctors use to see what's going on inside your body. Young kids with CLOVES Syndrome have ultrasounds so the doctors can get a clear picture of their kidneys to check for certain things. Ultrasounds use a wand, with some warm jelly on it (not like the kind of jelly you eat! A different kind of jelly). The nurse puts the jelly on your skin, and gently rubs the wand over the parts of your body that the doctor wants pictures of. The pictures come up on a T.V. screen as she's taking them. It's pretty amazing!

**KID SPEAK:** I don't mind Xrays, but it's hard being still. I have MRIs every six months to look at my back and belly. Ultrasounds feel funny and squishy on my tummy, but they don't hurt.



Next I'm going to tell you about something you may or may not be familiar with: surgery. There are all kinds of surgeries, each meant to help with different things on or in a person's body. There are so many kinds, in fact, that I can't possibly talk about them all, so I'm going to tell you about one of my surgeries and what it was like for me.

I've had surgery on my feet and legs. Other people with CLOVES Syndrome have had surgery on the lumps and bumps on their bellies or back, on their arms, hands, and other parts of their bodies. Whether you need surgery, and if so, what kind of surgery really depends on you and what you need to live a happy and healthy life.

I had surgery a few years ago on my right leg that was growing too fast. The surgery I had was to help slow down the growth.

On a surgery day, your day will start early. You are one of the most important people in the hospital when you are scheduled for surgery. Everything about a surgery is handled with extreme care by the doctors and nurses. For that reason, they want you at the hospital early in the day so they can get ready for your surgery and make sure everything is ready to go--including you!

First, the nurses will ask you to change out of your own comfortable clothes and put on a crisp hospital gown. Your hospital gown is your best friend. Yes, you read that right. It's not very fashionable, but it helps by making the part of your body having surgery easy for the doctors to get to and work on.

Someone may check your vitals (take your blood pressure, heart beat, height, weight). Next you may see a doctor called an Anesthesiologist.

An Anesthesiologist is a doctor who is very important before, during, and after your surgery. He or she may ask you questions and write things down on a clipboard while you're waiting. Their job is to give you a medicine known as anesthesia that will put you into a long, quiet, and painless sleep during the surgery. The anesthesiologist has to ask you all of these questions so that they know how best to give you the medicine so you stay healthy and stable throughout the surgery. This is a very important job.



Finally, after more visits from more nurses who ask you simple questions, the doctor who is doing the surgery will come in. He or she will ask even more questions to you and your parents. Then they will talk to you about what they hope to accomplish during your surgery and ask if you have any question. If there is anything you don't understand, you can ask them to explain it. It's normal to feel nervous or worried during all of this. A little bit later, I will share some of the things I do when I am worried.

After all of this, you will see your Anesthesiologist again. They'll explain each step as they help you go to sleep. They may put a small mask over your mouth and ask you to breathe deeply. They will talk to you and before you know it, you will be asleep for your surgery.

The next thing you know, you'll be waking up in the recovery room. You get to see your family, and rest in an even more comfortable bed. It will all feel so quick, it will take a second for you to realize that the surgery is over! The best part after surgery is ice cream (or at least I eat ice cream after I have surgery!)

Some pain after surgery is normal, but while you are in the hospital, the nurses will make sure that you are comfortable and feeling good. When you go home after surgery, usually you will have to rest and take it easy for a certain amount of time (depending on what kind of surgery you had and what your doctor says you can do). You'll take medicine the doctor's prescribe to help you stay comfortable and healthy while you heal.

Sometimes healing can take a while, but eventually, you'll get back into the swing of everyday life again!





Have you ever been somewhere and noticed people staring or giving you curious looks when they see your body is different? It's really hard to know what to do when that happens, isn't it?

Many people with CLOVES have experienced this. It takes strength, patience and confidence to work through those feelings and situations. I know how difficult, embarrassing, or just plain rude it is to be looked at by people that don't understand what CLOVES or PROS is.

When this happens, you might have a lot of different feelings. You might feel embarrassed, or even mad. You may want to leave the situation, or you might feel like being direct and asking the person what they are staring at. You may want to ignore the whole thing. Some days, you may feel like calmly talking to the person who was staring and telling them about your condition. Other days, you might want your friend or family members to help you explain it--or you might not want to talk to anybody at all! There are all kinds of ways to deal with people who are staring or curious, and what feels right to you will change from day to day, and situation to situation. The most important thing to remember is that however you want to respond is valid and okay. Listen to your feelings--you're the best judge of what you need to feel safe and happy!

What I've learned is that most people are just curious. This syndrome is so very rare that most people have never seen someone with CLOVES Syndrome, or any of the PIK3CA Related Overgrowth Syndromes. Like your parents probably told you, it isn't polite to stare, but some people just can't help it. They might not be trying to be rude, but it's still hard to deal with!

Now, there are always going to be people who outright ask you the question, “What happened to you?” or “why do you have a {big hand, scars, lumps on your back?}” or “does it hurt?” If you feel like it, you can answer their questions and have a conversation about PROS. You can say something like “This is how I was born.” But, just like before, how you respond all depends on how YOU feel and how YOU want to deal each day.

You are unique--extra unique! Sometimes being unique can be hard, but it can be amazing too! I'll say this again, and again: Embrace your uniqueness and be proud of who you are!

This is how I was BORN!





Now, you probably have friends at school or from other activities that you are involved in--maybe sports, Girl or Boy Scouts, youth groups, or just your neighborhood friends. When you think about the close friends that you have now, you might remember that you got to know one another because you had some of the same interests. Once you got to know each other, you realized that you wanted to be friends. It was easy when you were very young, but now that you're older it can feel harder to find and make friends. If you go to a new school, like when you enter middle school for the first time, it may feel intimidating to walk around those brand new hallways and pass by those brand new faces that have never seen someone with CLOVES before. But you know what? People who want to be your friend will be kind; they will want to learn from you and they will begin to understand in a very short period of time.

Believe me, when people really get to know you, your interests, talents, and your personality will stand out to them. They'll respect--and even love!--your differences because that's what true friends do. Anyone who doesn't treat you with respect isn't worth your time or worry.

Just be yourself. Your true self will shine brighter than any differences that may exist between you and your friends. Just be you!

**KID SPEAK:** My best friends have learned all about CLOVES Syndrome. They appreciate me because I am kind and caring and a good friend. My friends and I have a great time together--they accept me for who I am, lumps, bumps, and all!

Do you play any sports? I used to play soccer, and I absolutely loved every minute of it. Now I play basketball, and I love that even more.

I can do it, and so can you! If you want to run, go for it. If you like to kick a ball around a field, knock yourself out (not literally). Anything you want is right there in front of you. Do what you want when you want. Nothing should restrict you from doing what you love.

You may have to do some things in a different way, or at a different pace than other people, depending on how your CLOVES affects your body, but that shouldn't stop you from doing what you love. You may need a few more breaks than your teammates, or you may have to sit out for a round when playing freeze tag or kickball with your friends, but that doesn't mean you can't jump right back in as soon as you're ready.

Being with friends and being active is a great way to stay healthy, strong and positive. Maybe you aren't into sports, but you love singing in choir, or acting in plays. Maybe you love photography, or volleyball, drawing or building things. Maybe you like writing stories. Whatever it is, keep doing it. Find activities you love and pursue them! And if you're not the best at it? Don't quit! Keep going, whether it be just for fun or simply to spend time with your friends or teammates.

You are strong, bright, and full of amazing skills. And you'll meet other amazing people while you do the things you love. So keep on going, even when it's challenging. You never know, maybe you'll unearth some new qualities that you never even knew you had.



We've talked about CLOVES Syndrome and PROS themselves, and some of the social challenges that come along with it, and how I deal with them! Now I want to talk about some of the ways people with CLOVES customize things--like shoes and clothing--to make life easier.

If you have a larger foot and/or leg, you will understand when I say it isn't easy to find shoes or clothing that fits right and looks good.

Since I was very young, I've only been able to wear certain tennis shoes that actually fit onto my larger foot. When I was little, that was no problem at all. I didn't care; I just kept on playing and doing my thing.

But as I got older, I didn't like the tennis shoes that fit me anymore! In middle school, I wanted outfits that looked cute and stylish. I liked sleek skinny jeans and chunky sweaters--and those tennis shoes really didn't fit my look.

I had a hard time with this. It took time, and some experimentation, but with my parents' help, I finally found a solution: I found a cute pair of mary janes that would accommodate the shape of my feet. My parents went online and ordered a large size that would fit to my larger foot. Then, to help fine tune the fit, they extended the leather strap that goes over the top of my foot. My mary janes look cute, and fit comfortably!



My CLOVES makes finding shoes tricky, but for some people with larger legs or a larger size of other parts of their body, adapting clothing to be comfortable might be more important. That can mean making the leg of one side of a pair of pants larger, adding extra space to the waistband, or widening the arm holes on a shirt. It's all about what you need! It's great if you have a family member or friend with a sewing machine, because they can help to make clothes feel better for your body. As you get older, you can learn how to alter your own clothes, or even sew whole garments to make them exactly what you want!

There are so many ways to customize things like shoes and pants to keep you comfortable and confident. Sometimes it just takes a little ingenuity. Now days, there are even designers who are creating collections of adaptive clothing that are as functional as they are stylish--right off the rack!



If you ever find that you aren't able to find what you need, do some research. With the power of the internet, anything is possible! You can find new ideas for customizing existing garments or shoes, and I've also found companies and individuals who are open to making just what you need if you're willing to work with them and provide measurements, tracings, photos, etc. They might be able to make exactly what you've been dreaming of.



I want to be just like everyone else--just a regular kid, and I want everyone else to see that in me too.

You know this already, but there are some challenges that come with having CLOVES Syndrome. The challenges vary a lot from person to person. For me, I have had a lot of surgeries and I have to see about 8 specialists (doctors who specialize in a certain area of the body) on a regular basis. That means I go to a lot of appointments. I also have a lot of bumps on my body, and scars that are visible when I wear a bathing suit. Sometimes I have a hard time with the questions that people ask and going to the doctor so often, and just being a patient all the time.

I also get worried about all of the regular kid stuff like school work, tests, after school activities, and if my friends aren't getting along. Sometimes it feels like way too much to manage.

But I'm here telling you my story, so you know that I have come up with ways of dealing and coping and getting through the hard times. I bet you have also come up with lots of ways of dealing when you are worried or stressed.

We all deal with things differently. Some people talk about what is bothering them or what they are worried about. Other people are more quiet and just share or speak when they are ready. I call the way that I deal with things (like worries, doctor appointments, sadness) My Tool Box. I wanted to share some things that I do when I am having a hard day.



**My support system** - For me, my support system is my mom and dad and my big brother, my grandparents, aunts and uncles and, of course, my friends. It is good to remember I have people in my life who love me, who I can ask for help when I feel overwhelmed, or who I can just talk to about life.

**Doing what I love** - Sometimes staying busy with things I like to do, means that I have less time to sit and think about everything else stressing me out. This is a good coping mechanism for me for short term worries, like an upcoming surgery or test (as long as I still make time to study of course!)

**Relaxation** - I work with my therapist on ways to relax and stay calm. It's hard to do, but it helps! I have a meditation app for kids that I love.

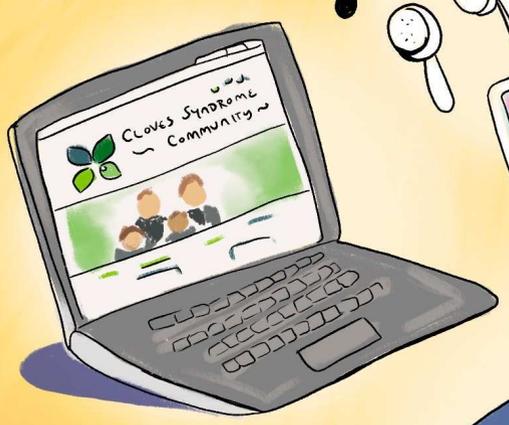
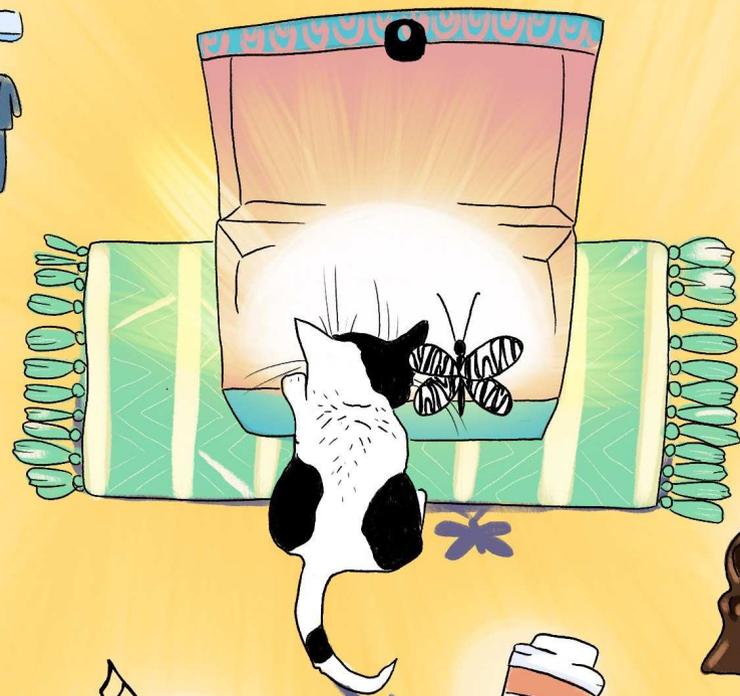
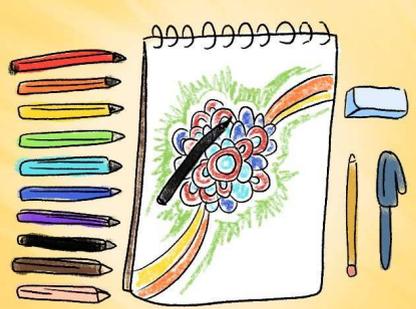
**Medication** - Sometimes medication created for worries or depression can help if you are having a really hard time, or are overwhelmed and struggling. Talk to you parents and doctors about this to learn more.

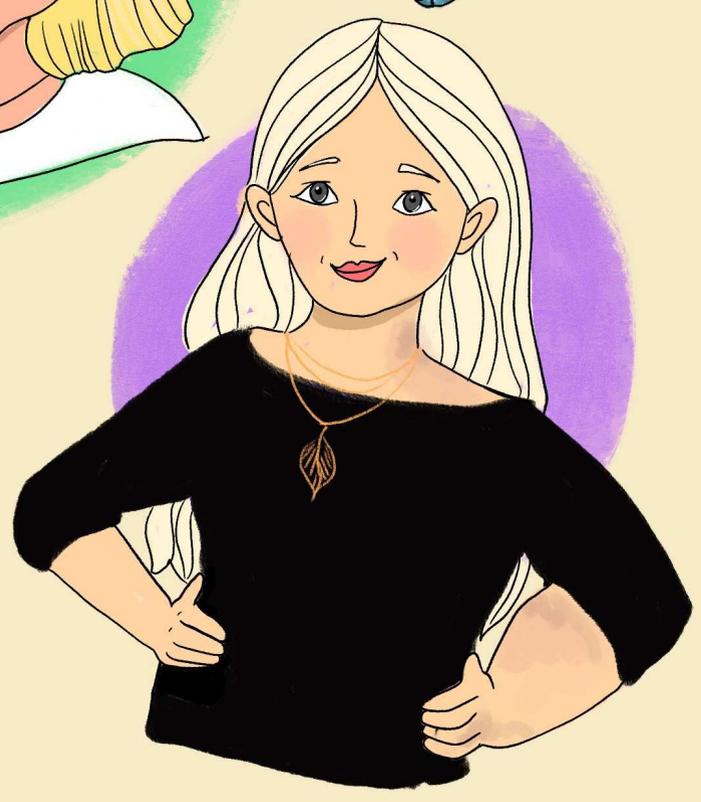
**Getting regular exercise** - This is a known stress buster! Sometimes just going on a ten minute walk helps me feel better.

**Eating well and staying hydrated** - I love treats and junk food, but I feel best when I also try to eat lot of fruits and veggies and protein. Water is really important to drink throughout the day (or at least, that's what my mom says!)

**Sleep** - This is pretty obvious, but getting a good amount of quality rest every night is really important for all people - kids and adults alike. Did you know that not getting enough sleep can make you feel more anxious? So go snore it up, people!

**Connecting with other people who have CLOVES** - Talking to, emailing with, or writing other kids with CLOVES is a lot of fun. Meeting them in person at the CLOVES conference or at Betsy's Camp is even more awesome. There are lots of ways to connect with other people these days. Talk to you parents about what options are okay for you.





Well, I think that just about wraps up everything I wanted to share! There's just one more thing: it's always a great feeling to meet others like you.

You may be too young now, but when you're at the right age and your parents have approved, join our Facebook page! In our online group, you'll find other kids just like you. We like to chat and share with each other, and we're up for just about anything you'd like to talk about. Just go to Facebook and search "CLOVES Syndrome Community", and a page called "Welcome CLOVES Community" will pop up. Join that page and begin getting to know the others in the group by making an introduction post! Or, if you don't have Facebook yet, ask your mom or dad to join the group! That way they can contact other parents if they ever have any questions or concerns. It's always comforting to talk to someone that has something in common with you.

Another great place to visit online for information and support is the CLOVES Syndrome Community website. If you are allowed to go on the internet, type in [www.clovessyndrome.org](http://www.clovessyndrome.org). It's a site that tells you almost everything about CLOVES. If you can't access the internet, ask your parents to go on and check it out! It's a great website, and lots of questions can be answered if you visit it every so often.

***Keep your head up and just be yourself. That's all you ever need to be. You have an amazing future ahead of you, and I know that you will embrace every opportunity to meet that future. You are unique in the best way possible, and you will reach so many new heights in your lifetime. Don't let anything stop you, because...***

You are



# Incredible!



## Love science? Want to impress your friends with big words?

How did CLOVES come about and why is it so rare? This may be the most difficult question to answer because of how confusing the explanation can get! If you like science, I know you'll be right with me as I explain it because the cause of CLOVES Syndrome is as scientific as it gets!

Let's start here: At the beginning of this book, we talked about how wonderful it is that every person looks different, right? Have you ever stopped to wonder why that is or how it happens?

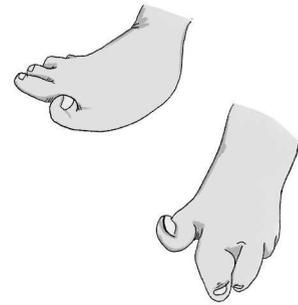
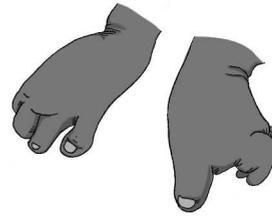
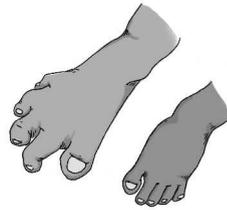
Well, every person in this world has their own pattern inside their body! You have a pattern in your body that led to all of your physical characteristics--everything from the color of your hair, to the length of your big toe. And I have a completely different pattern! Everyone in the entire world has their own unique pattern, which is the reason why each person has a unique set of physical traits.



Now, here comes the interesting part. The pattern that each and every one of us has is known as DNA. DNA is located inside every cell that makes up your body.

You may have learned this in science class, but if you haven't gotten there yet, cells are incredibly important. They make up everything that is living, including you! The crazy thing is, you can't even see cells! They are so small that no person can see them without using a special microscope. And do you know why they are so very important? Because they keep you alive! They make up your organs (like your heart), your skin, and even your hair! They are a very special part of your body.

Here are how some scientists at Genome Research explain it: "The answer lies in a molecule called deoxyribonucleic acid (DNA), which contains the biological instructions that make each species unique. DNA, along with the instructions it contains, is passed from adult organisms to their offspring during reproduction" ([www.genome.gov](http://www.genome.gov)) . So, let's review before we move on to what DNA and cells have to do with PROS. Basically, you have millions of tiny little important cells in your body, and your pattern, DNA, is located in these cells. Now, the whole pattern is your DNA--and each piece of the pattern, is called a gene.



So what does this all have to do with CLOVES, and PROS? These syndromes are caused by something that happens to your DNA that doesn't usually happen, known as a mutation (or a change).

PROS is caused by a somatic ("somatic" means it wasn't passed down from your mom or dad) mutation in the gene (the piece of the DNA pattern) called PIK3CA. PIK3CA helps the body control how it grows.

The mutation increases the activity of the gene, which is why people with CLOVES or a PIK3CA Related Overgrowth Syndrome (PROS) have parts of their body that are larger than others. The mutation can affect only a few cells or a lot of cells, and can affect the cells in different parts of the body, too.

The word "mutation" sounds pretty scary, but it really isn't. All "genetic mutation" means to scientists is a change to the genes that make up the DNA in a person's body. In fact, a recent study found that the average person has around 400 mutations in their genes--most people just don't know it! ([https://www.cell.com/ajhg/fulltext/S0002-9297\(12\)00538-1](https://www.cell.com/ajhg/fulltext/S0002-9297(12)00538-1))

So, let me give you an example. Since my right leg is bigger than my left leg, that means that the cells in my right leg were changed by this mutation. If you looked at my DNA under a microscope, you would see that the PIK3CA gene in the cells in my right leg are different than the ones in my left. Does this make sense? So the mutations can affect any part of your body, like one or both legs, feet, arms, hands, and even your torso or head.

It all sounds very complicated--and it is!--but you really will understand it with some effort and research. It can be confusing, but it's also incredible! We are lucky to have some amazing researchers from all over the world working hard to better understand CLOVES, and the entire spectrum of PIK3CA Related Overgrowth Syndromes. They are even beginning to discover ways to slow the condition down without surgery!

So there you have it: a crash course on the complicated science behind CLOVES syndrome. To learn more, visit CLOVES Syndrome Community at [www.clovessyndrome.org](http://www.clovessyndrome.org)





