

# Meet The PROS!



Ages 8-12

FEATURING  
**The PROS**

**STEVE**



**CHLOE**



**FATIMA**



**RAUL**



**JESSICA**



CO-STARRING:

**PROFESSOR P**





Aw, come on, Mom.

No. Phones. At. The. Table. Period! You know the rules.

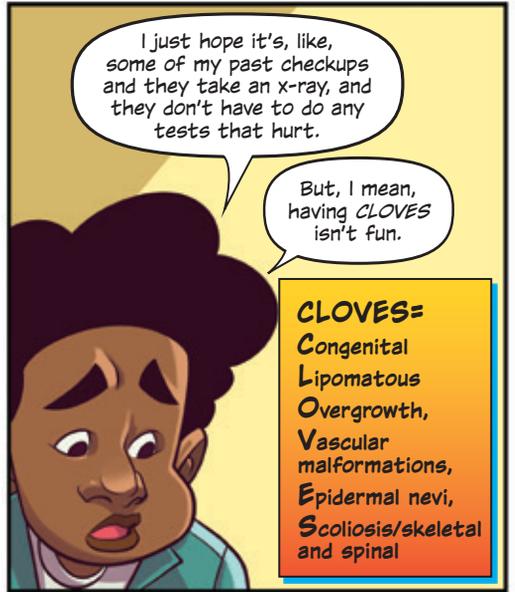
Ooh, big bro's in trouble!

Listen to your mother, Steve... and Sarah, be nice to your brother.



Steve, did you tell your teachers you'll be out tomorrow?

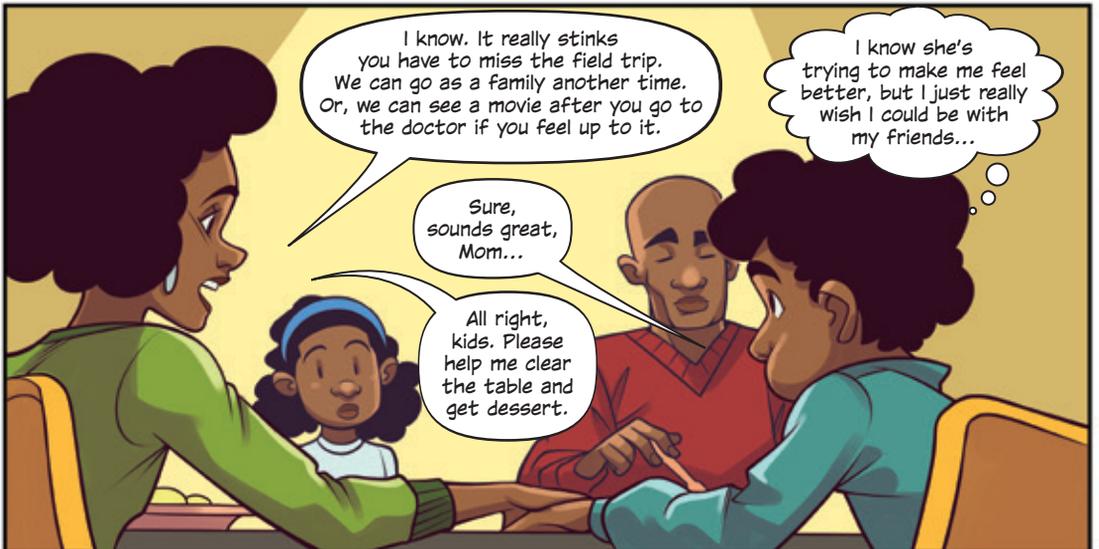
Yeah, they know I have another doctor's appointment and have to miss our class trip.



I just hope it's, like, some of my past checkups and they take an x-ray, and they don't have to do any tests that hurt.

But, I mean, having *CLOVES* isn't fun.

**CLOVES=**  
Congenital  
Lipomatous  
Overgrowth,  
Vascular  
malformations,  
Epidermal nevi,  
Scoliosis/skeletal  
and spinal



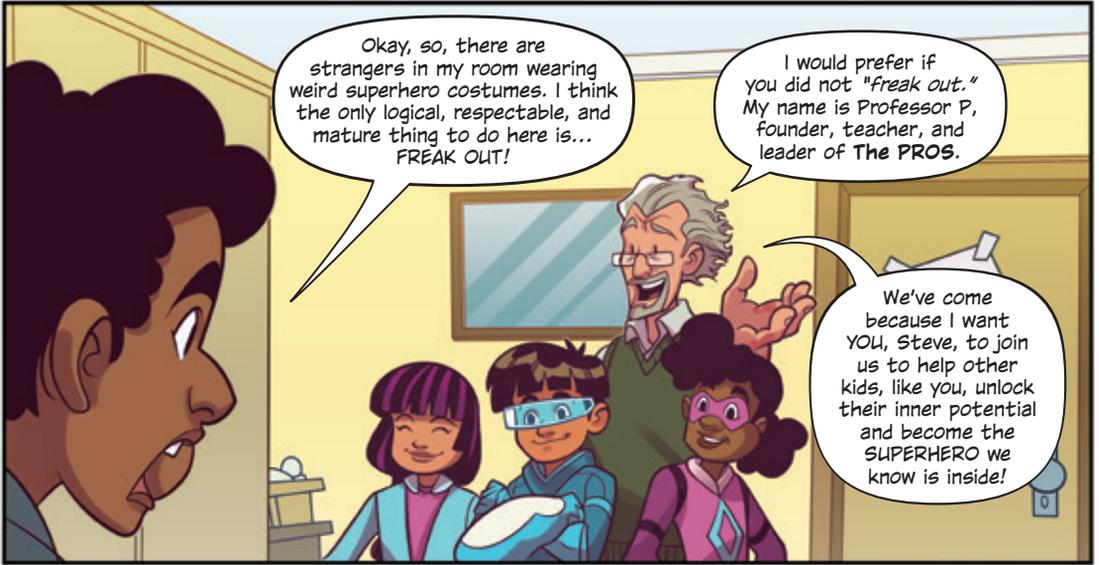
I know. It really stinks you have to miss the field trip. We can go as a family another time. Or, we can see a movie after you go to the doctor if you feel up to it.

I know she's trying to make me feel better, but I just really wish I could be with my friends...

Sure, sounds great, Mom...

All right, kids. Please help me clear the table and get dessert.





Okay, so, there are strangers in my room wearing weird superhero costumes. I think the only logical, respectable, and mature thing to do here is... **FREAK OUT!**

I would prefer if you did not "freak out." My name is Professor P, founder, teacher, and leader of **The PROS**.

We've come because I want **YOU**, Steve, to join us to help other kids, like you, unlock their inner potential and become the **SUPERHERO** we know is inside!

Who are you people? What do you mean, you want me to become a superhero?

Professor P, was I this shocked when you came to me?

Nah, I was there. You were cool, like me!

Come on, let's cut him some slack!

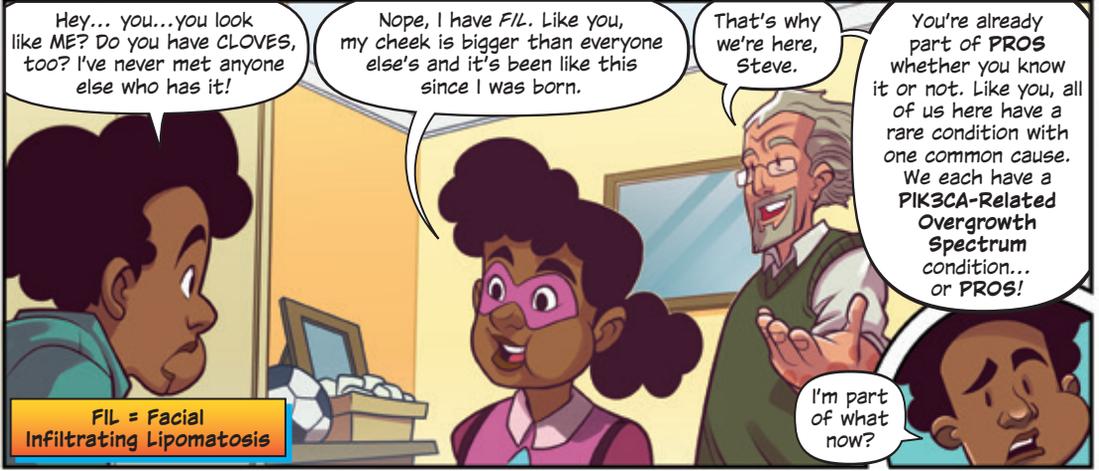


Hey... you...you look like **ME**? Do you have **CLOVES**, too? I've never met anyone else who has it!

Nope, I have **FIL**. Like you, my cheek is bigger than everyone else's and it's been like this since I was born.

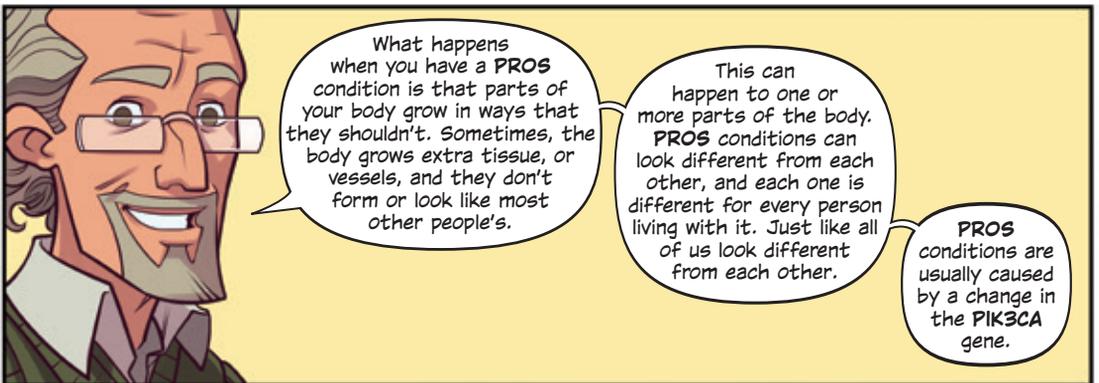
That's why we're here, Steve.

You're already part of **PROS** whether you know it or not. Like you, all of us here have a rare condition with one common cause. We each have a **PIK3CA-Related Overgrowth Spectrum** condition... or **PROS!**



**FIL = Facial Infiltrating Lipomatosis**

I'm part of what now?



What happens when you have a **PROS** condition is that parts of your body grow in ways that they shouldn't. Sometimes, the body grows extra tissue, or vessels, and they don't form or look like most other people's.

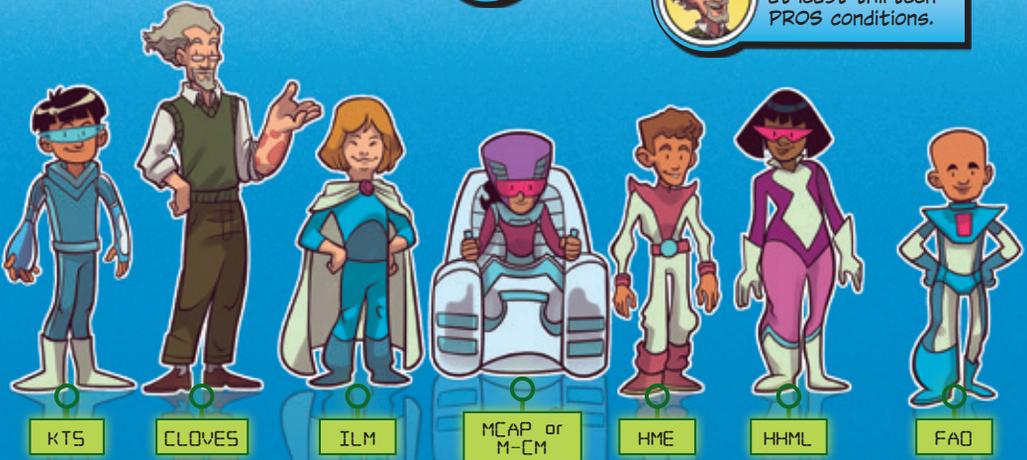
This can happen to one or more parts of the body. **PROS** conditions can look different from each other, and each one is different for every person living with it. Just like all of us look different from each other.

**PROS** conditions are usually caused by a change in the **PIK3CA** gene.

Now, there are only a few of us here today, but The PROS has kids of all ages, living with many different conditions.



In fact, there are at least thirteen PROS conditions.



That's right! I have FAVA, which means my veins don't work like everyone else's. I have a growth in my leg, which can really hurt. But it's different for everyone living with it.



And I have KTS. I have extra stuff on my arm and hand, so I wear this special sleeve to help. Also, my blood vessels gave me this birthmark that I'll have forever.



EN, BLK, or SK = Epidermal Nevus, Benign Lichenoid Keratosis, or Seborrheic Keratosis

FAVA = FibroAdipose Vascular Anomaly

KTS = Klippel-Trenaunay Syndrome

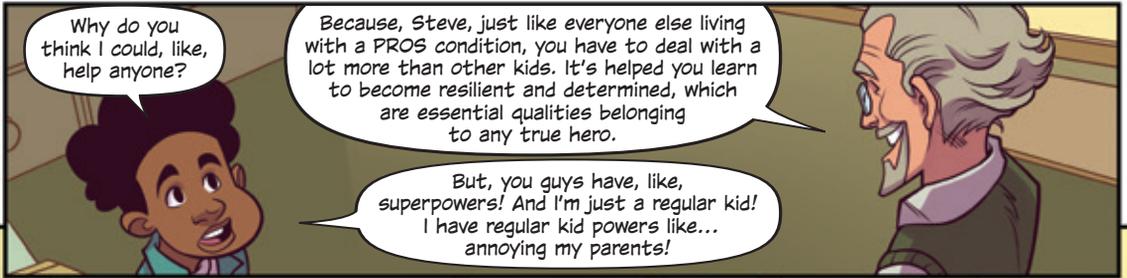
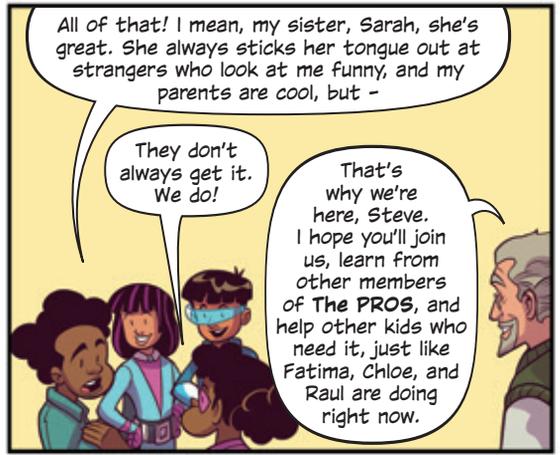
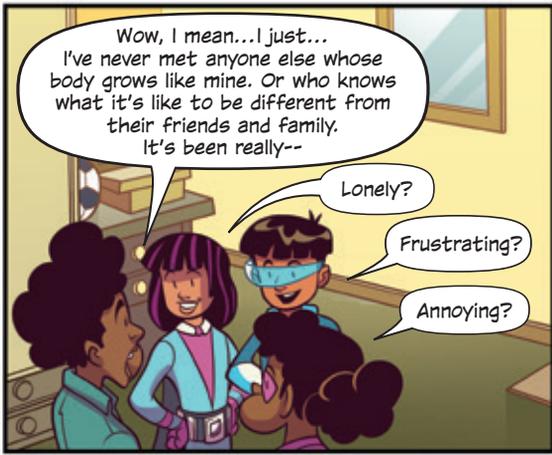
Check out pages 15 and 16 for full definitions and more information on PROS conditions.



That "stuff" is tissue!

Oh Professor P, you always have to throw out that medical lingo.

Don't mind him, Steve. Basically, while our bodies may be different, our conditions are caused by the same thing.



After a phone call with Steve's parents...

I can't believe my parents said, "YES"! They are, surprisingly, much cooler than I thought!

Well, remember, with the Ghost Train, we'll have you back in no time to do your homework, get to that doctor's appointment -

PROFESSOR P!

Er, I imagine, this is all quite "cool" as the kids say?

Yeah, normal went out the window when... well... when WE went out the window on a flying train!

Welcome to PROS Fortress! Once you become one of us, you'll be able to teleport here whenever you want. Though teleportation is shut off during school hours.



Yeah, thanks a lot, Professor P. Sometimes I want to just disappear when someone's being rude about how I look in class.



Ugh, I know. We had a new kid start last month, and he asked everyone but me what was up with my cheek and my foot. I finally told him, just ASK if you have questions. I don't mind talking about it.



I don't like talking about my leg. I talk about it with my mom and my doctor. I have to tell my teachers every year. I just tell people I was born different and leave it at that.

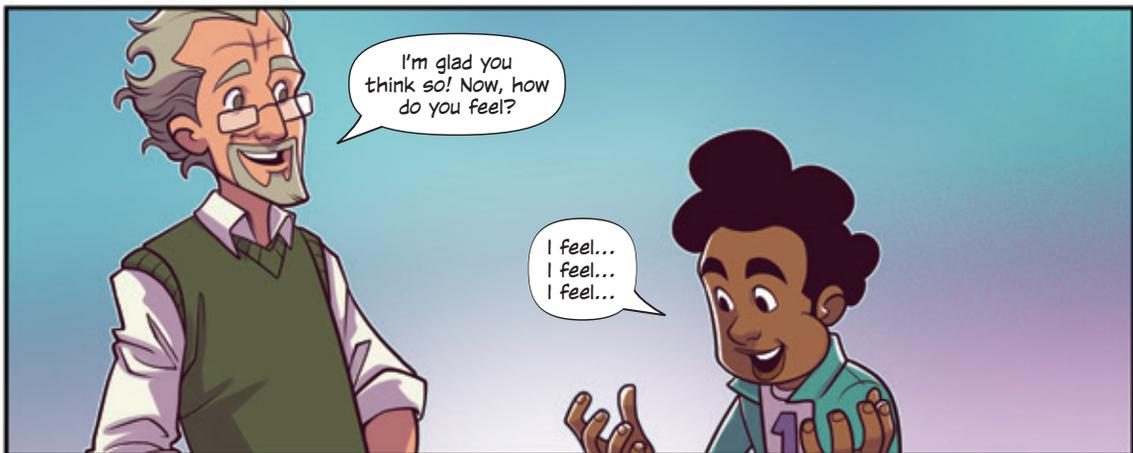


Well, Steve, here we are. These are the rocks that will give you superpowers.

Umm, yes, please! Superpowers, HERE I COME!

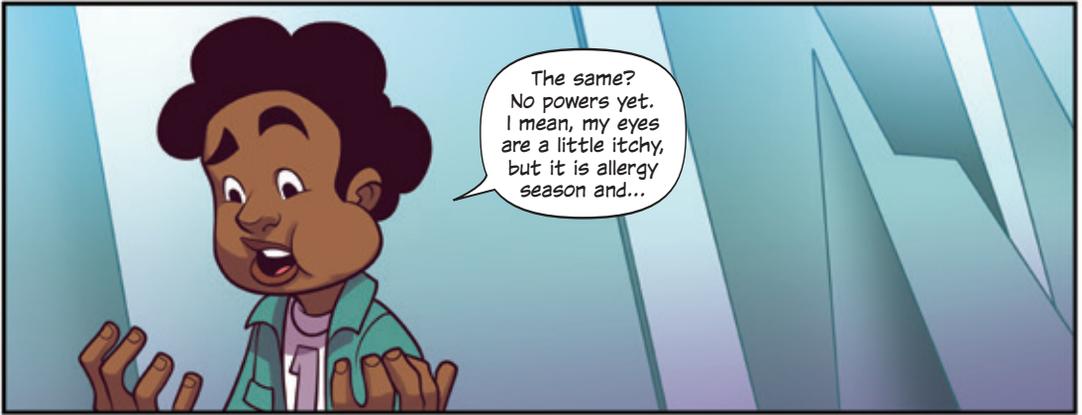


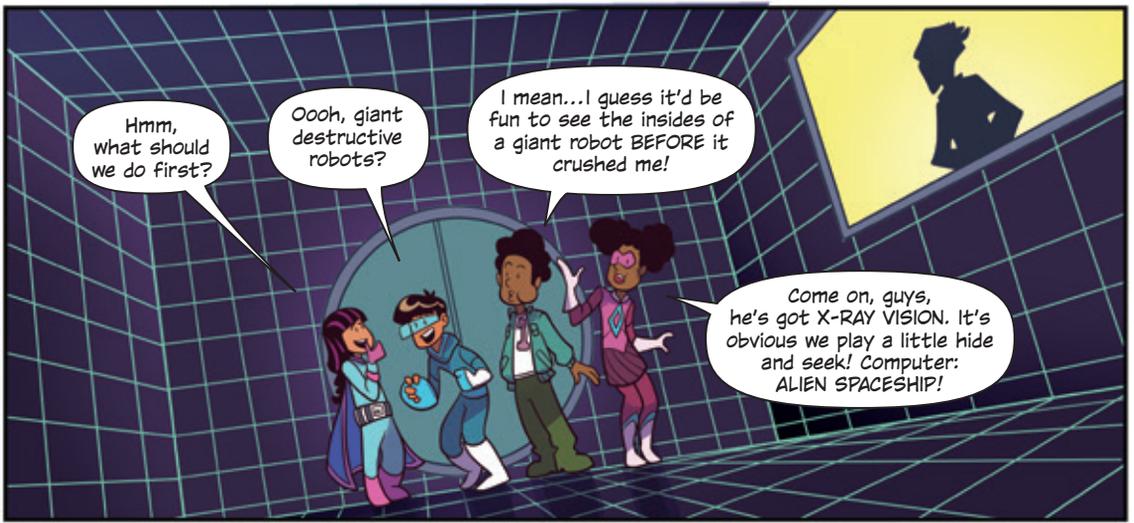
Whoa!  
This Place Is.  
AMAZING!



I'm glad you  
think so! Now, how  
do you feel?

I feel...  
I feel...  
I feel...



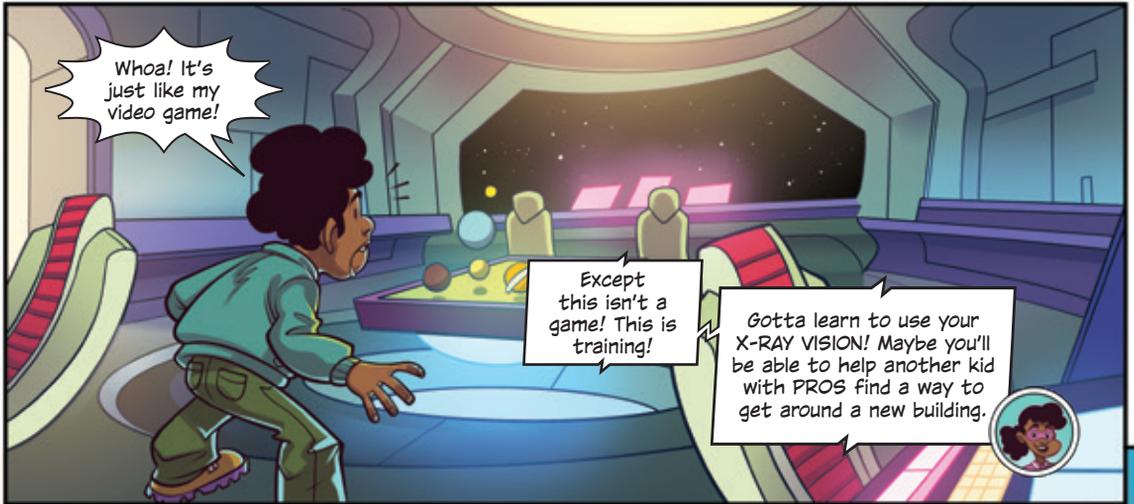


Hmm, what should we do first?

Oooh, giant destructive robots?

I mean...I guess it'd be fun to see the insides of a giant robot BEFORE it crushed me!

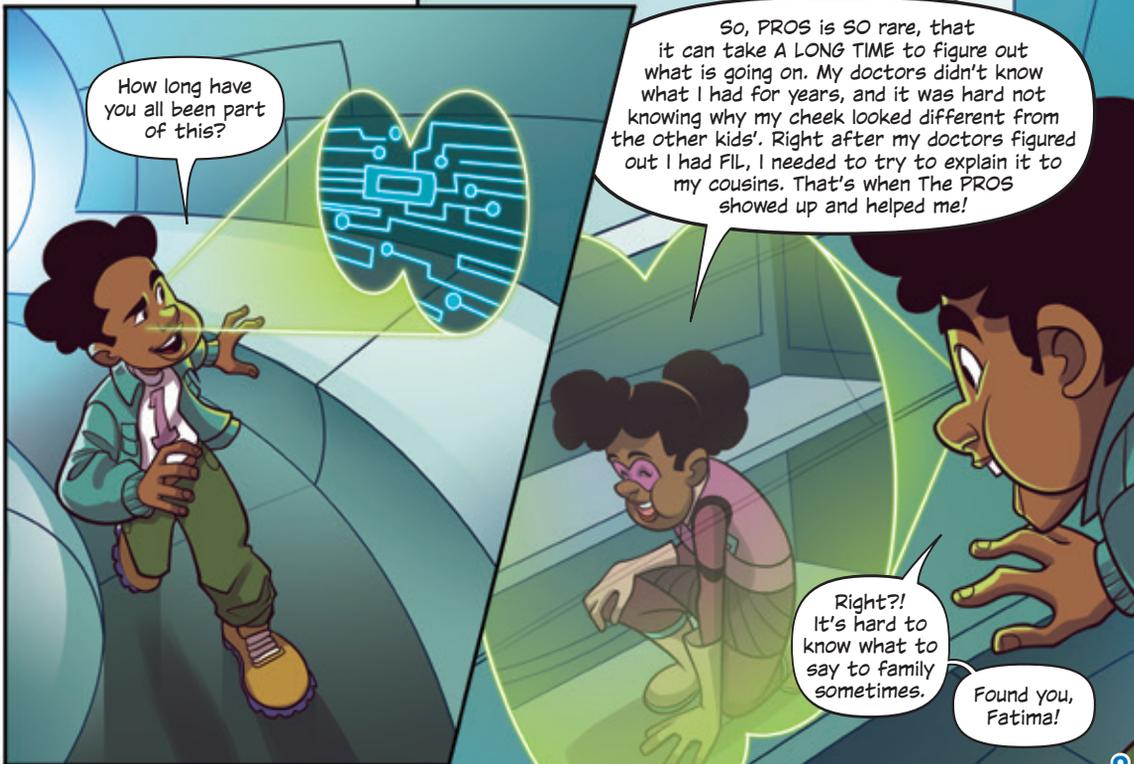
Come on, guys, he's got X-RAY VISION. It's obvious we play a little hide and seek! Computer: ALIEN SPACESHIP!



Whoa! It's just like my video game!

Except this isn't a game! This is training!

Gotta learn to use your X-RAY VISION! Maybe you'll be able to help another kid with PROS find a way to get around a new building.



How long have you all been part of this?

So, PROS is SO rare, that it can take A LONG TIME to figure out what is going on. My doctors didn't know what I had for years, and it was hard not knowing why my cheek looked different from the other kids'. Right after my doctors figured out I had FIL, I needed to try to explain it to my cousins. That's when The PROS showed up and helped me!

Right?! It's hard to know what to say to family sometimes.

Found you, Fatima!



Something else that is like, annoying, is that PROS is so rare. Not many doctors really know much about it. This can mean visits with LOTS of different doctors and getting around all those doctors' offices is the worst.

I already have trouble getting around my THREE-STORY school every day with all the stairs. I had to switch my classes around. So, adding more doctors' appointments is just BLEH!

Right?! It stinks. Chloe. I SEE YOU!



And, of course, lots of doctors' visits mean LOTS of tests, and LOTS of patience until you find the right team. Even after you find the right team, there is still a lifetime of more tests, and more things you miss out on.

I had to miss a video game tournament that I, like, worked really hard to get into because of going to the doctor's.

Dude, you're a gamer too? We've got to play together online or something! Oh, and, FOUND YA!

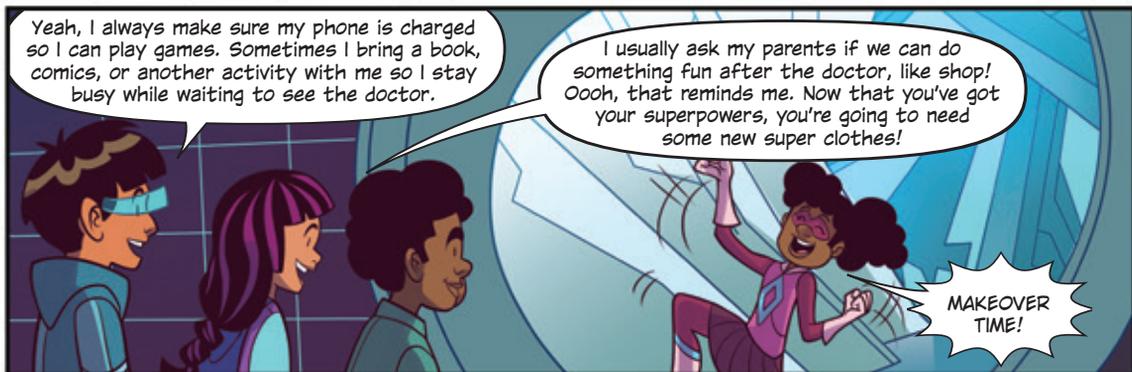


Man, it's so nice to finally talk to kids like me who GET IT! All the pain, all the confusion, all the weird looks people give you, and all the appointments and tests.

I have another checkup tomorrow. UGH!

They are SO annoying.

Right?! I have to go to the doctor who looks at my leg, my orthopedic whatever, all the time. Professor P is big on using real words and names. Anyway, people at school think I'm like, making up excuses for missing class.



A short time later!

These clothes are next level!

As the saying goes, "With great powers, comes great clothes!"

Ah, Steve, there you are. Have you met Jessica?

Jessica is another member of **The PROS** team! She has **MCAP**, or **M-CM**, which is **Megalencephaly-Capillary Malformation** and has differences in her head and brain and other parts of the body. She also uses a wheelchair to get around.

I can breathe fire, but my real superpower is playing air hockey. Wanna play a game?

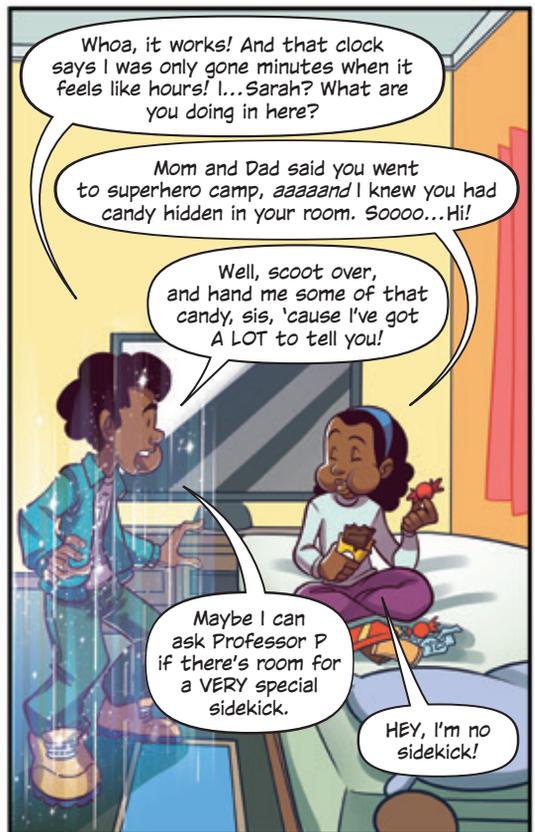
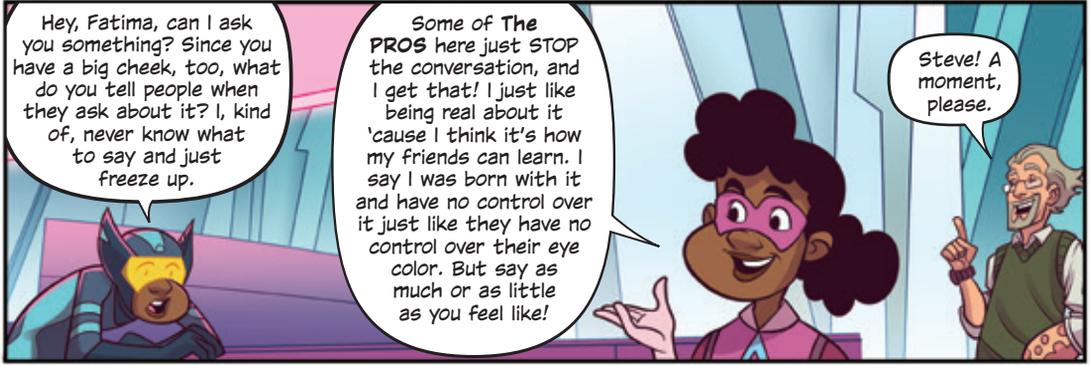
Professor P will call us if there's a kid with **PROS** who needs our help!

Heck yeah!

Aaaand, that's game!

Play again?

You beat me 8 times in a row! I think I'm good.





The end!

# GLOSSARY

## **BLOOD VESSELS**

Tiny vessels that carry blood in the body to everywhere it needs to go.

## **LYMPHATIC VESSELS**

Tiny vessels in the body that carry a clear, watery fluid (lymph) that helps the body fight infections.

## **OVERGROWTH**

Overgrowth means the body grows extra tissue. In PROS, this can happen on the outside and on the inside of the body.

## **PIK3CA GENE**

The PIK3CA gene gives orders the body follows to make one piece of a protein called PI3K. In PROS, the PIK3CA gene is changed in such a way that it gives orders to make a PI3K that sends too many signals to grow.

## **PROS CONDITIONS**

A group of conditions where one part—or more parts—of the body grows too much. PROS conditions are caused by a change in the PIK3CA gene. The letters in the word PROS stand for PIK3CA-Related Overgrowth Spectrum.

## **KTS (KLIPPEL-TRENAUNAY SYNDROME)**

Tiny blood vessels in the skin grow and form a large birthmark on the leg or other parts of the body. Other parts of the body, like the bone, skin, and lymphatic vessels, may grow extra tissue.

## **CLOVES SYNDROME (CONGENITAL LIPOMATOUS OVERGROWTH, VASCULAR MALFORMATIONS, EPIDERMAL NEVI, SCOLIOSIS/SKELETAL AND SPINAL)**

CLOVES syndrome affects many parts of the body. The torso, arms, legs, fingers, or toes may grow extra fatty tissue. The blood vessels and bones grow abnormally. The fingers or toes may grow very big, and the spine may curve too much to one side.

## **ILM (ISOLATED LYMPHATIC MALFORMATION)**

The face and neck, and sometimes other parts of the body, grow a soft, smooth lump of extra tissue filled with clear, watery fluid called lymph.

## **MCAP OR M-CM (MEGALENCEPHALY-CAPILLARY MALFORMATION)**

The body and head grow too big. The skin and blood vessels grow abnormally.

## **HME (HEMIMEGALENCEPHALY)/DMEG (DYSPLASTIC MEGALENCEPHALY)/FOCAL CORTICAL DYSPLASIA TYPE II**

One side—or both sides—of the brain grows too much.

# GLOSSARY

**HHML**  
(HEMIHYPERPLASIA-MULTIPLE  
LIPOMATOSIS)

One side of the body grows more than the other side.

**FIL**  
(FACIAL INFILTRATING  
LIPOMATOSIS)

One side of the face grows bigger than the other.

**FAVA**  
(FIBROADIPOSE  
VASCULAR ANOMALY)

A large part of a muscle in a limb (arm, leg, hand, foot) is taken over by tough, fatty tissue.

**MACRODACTYLY**

Fingers or toes grow too big.

**MUSCULAR HH**  
(HEMIHYPERPLASIA)

Arm or leg muscles on one side of the body grow too big.

**FAO**  
(FIBROADIPOSE  
HYPERPLASIA OR  
OVERGROWTH)

Fatty tissue overgrows in the arms or legs or another part of the body.

**CLAPO SYNDROME**  
(CAPILLARY MALFORMATION  
OF THE LOWER LIP, LYMPHATIC  
MALFORMATION OF THE FACE AND  
NECK, ASYMMETRY OF THE FACE  
AND LIMBS, AND PARTIAL OR  
GENERALIZED OVERGROWTH)

Extra blood vessels grow on the skin around the lips, or a soft smooth lump grows on the face or neck. One side of the face or body might grow more than the other side.

**EPIDERMAL NEVUS,  
BENIGN LICHENOID  
KERATOSIS, OR  
SEBORRHEIC KERATOSIS**

These conditions change the way parts of the skin look and feel. Extra skin grows in a line or a swirl pattern. Small, round red spots grow on the skin. Brown, black, or light tan bumps grow on the skin.

**SPECTRUM**

Spectrum means one person with a PROS condition can look very different, or have very different symptoms, from another person with the same, or a different, PROS condition. There can be a little or a lot of extra tissue on one or many parts of the body.

# Meet The PROS!

## **Content Advisors:**

Lauren Beauregard  
Christy Collins  
Kristen Davis  
Mellenee Finger  
Robynn Kuhns  
Lindsay Passodelis  
B Weintraub

## **Editor In Chief**

Columba Quigley, MD

## **Authors**

Kimberley Maxwell, PhD  
Shawn deLoache

## **Art Editor**

11x17 Studios

## **Art**

Israel Maia (Colors)  
Gabriela Cantagessi (Inks)  
Áthila Fabbio (Pencils)



*Jumo Health* and its logo, *Medikidz*, *In My Words*, and *In My Shoes* are registered trademarks of Jumo Health, Inc. All other trademarks are the property of their respective owners.

The health information contained herein is provided for educational purposes only and is not intended to replace discussions with your health care provider. All decisions regarding patient care must be made with a health care provider, considering the unique characteristics of the patient.

