

# TALKING ABOUT PROS WITH OTHERS

## LOOKING FOR TIPS TO:

- ▶ Explain your PIK3CA-Related Overgrowth Spectrum (PROS) condition to others?
- ▶ Discuss how it impacts your day-to-day activities?
- ▶ Tell someone you don't want to discuss your PROS condition?
- ▶ Tell someone you're happy to answer questions about PROS?
- ▶ Clarify a misunderstanding about PROS and PROS conditions?
- ▶ Ask for help or for something you need to manage your PROS condition?



## Explaining PROS



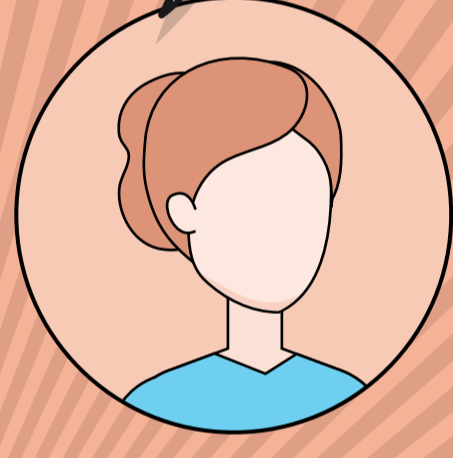
- I live with a rare condition that can cause overgrowth of tissue and abnormalities in blood and lymph vessels.
- It is part of a group of rare conditions known as PIK3CA-Related Overgrowth Spectrum, or "PROS" for short, caused by a specific gene mutation.
- I was born with it, but I didn't know I had it until later.
- There is no cure for PROS and I will live with it for the rest of my life, but I work closely with my doctors to address my symptoms.

- PROS conditions can look different from each other and may affect different parts of the body.
- Because of my PROS condition, I experience... *[share what you feel comfortable disclosing — eg, I need to use crutches, I have trouble walking for long periods, my legs sometimes hurt, my hand is bigger than the other].*
- Sometimes, I may need to miss school/work/social activities or go at a slower pace. I'll let you know when that is the case.
- I have to go for checkups more frequently to monitor my PROS condition.
- Living with a rare condition and managing the symptoms can be hard to deal with.
- There may be people who stare a little longer than normal if you look different to them. Sometimes, that might mean they are curious about you. In as few words as you'd like, you can tell them why you might look different if you are comfortable with doing so. Other times, their staring might hurt your feelings, and it's okay to say so or just walk away from them.

## Day-to-Day Impact



## If you don't feel like talking about it...



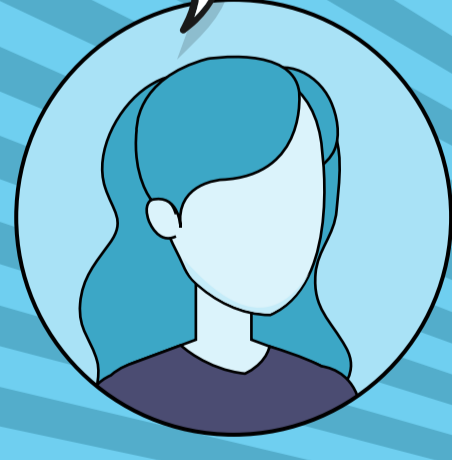
- I have something that is a PROS condition, called *[your condition]*. I don't feel like talking about it.
- Thanks for asking about it. I'm living with a medical condition that is one of the PROS conditions called *[your condition]*.
- I would prefer not to discuss *[note if there are particular aspects of PROS that you would prefer not to cover]*.
- There is more to me than my diagnosis. Let's talk about *[your hobbies, common interests, etc]* instead!
- I have a medical condition called *[condition]*. I am also a *[singer, chess player, magician, etc]*. I'd love to talk to you, and I would rather talk about *[singing, chess, magic, etc]*.

## Encourage Questions



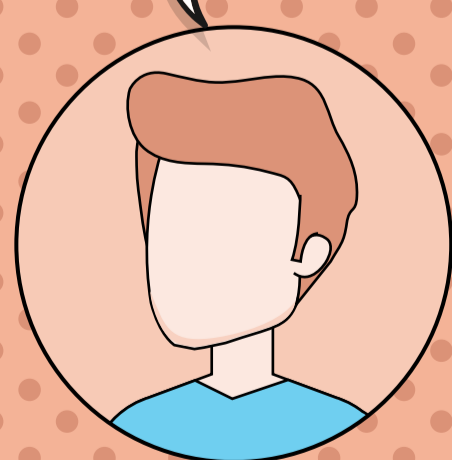
- I can tell you're curious. Do you have any questions about *[your condition]* or PROS?
- Thanks for asking about this. I'm happy to tell you more about PROS.
- PROS conditions impact everyone differently, so I can just tell you about my experiences.
- If you have questions *[consider specifying the areas you feel comfortable addressing]*, ask away. I have all the time in the world.

## Clarifying a Misunderstanding



- PROS conditions are rare and can take time to accurately diagnose.
- That's not quite right. I would be happy to direct you to some online resources to better explain.
- PROS conditions impact everyone differently, and my experience is unique to me.

## Asking for Help



- Thanks for inviting me to join. I may need to go at my own pace or have you help me.
- I have something called *[your condition]*, and sometimes I need help with *[share specifics about what you need]*.
- I would appreciate it if you *[specify what support you need]*.
- Can you please do *[share what you need]* for me? I am not able to because of *[your condition, symptoms]*. Thank you!



*This material is solely intended for educational purposes and does not depict the experiences of any specific patients. Any questions about proper care for PROS conditions should be directed to your health care provider.*