

PROS @ SCHOOL



Friends and teachers may ask you about living with PROS (also known as PIK3CA-Related Overgrowth Spectrum) or your condition. Keep in mind that they probably don't know anything about it yet. It can be hard to know what to say and how much to tell them.

Don't share if you don't want to. If you don't want to talk about PROS or your condition, you can say so!

If you do want to talk about PROS or your condition, consider these tips:



- **Be honest.** Talk about what you want, and don't answer every question if you don't want to answer.
- **Make it easy to understand.** Use words that are simple, and share just what they need to know. If you're confused about how to explain something, you can always ask your parent or guardian.
- **Take your time.** You don't have to explain everything about PROS or your condition all at once. Share more when you feel ready.
- **Think about why they are asking.** They are probably curious and want to understand PROS so they can get to know you better.
- **Share tips for asking questions.** If their questions hurt your feelings or made you feel uncomfortable, it's okay to say so.
- **Ask for help.** If you could use support from friends or teachers, let them know how they can help.

Check out these sample answers below. You can say them in your own words.

- **What is PROS/your condition?** It's something I was born with. It is rare. Parts of my body grow too much or are different from other people. *[If you want, you can share why you wear a sleeve, have trouble finding shoes, or use a crutch to walk.]*
- **What causes PROS/your condition?** I have a change in my PIK3CA (pronounced pick-three-C-A) gene. It's just something that I was born with.
- **When did PROS/your condition happen?** I was born with my condition, but it took some time to find out what it was.
- **How do you treat it?** I go to see doctors who understand PROS, and I have more doctors' appointments than other people. The doctors check on the parts of my body that are different.
- **Does it hurt? Why did you sit out of gym class?** It's different for everyone. For me, *[share what you want to about pain, sleeves, etc, or why you may need to skip things sometimes].*



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.