

PROS @ HOME



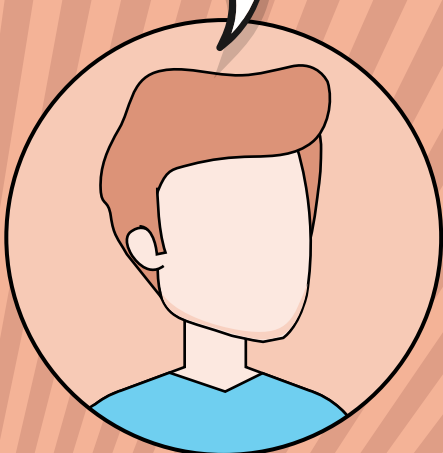
Below are tips for talking about PROS, PIK3CA-Related Overgrowth Spectrum, at home, as well as examples for how you can respond to questions in a way that may be easier for children to understand.

Explaining PROS and PROS Conditions



- PROS is a group of rare conditions that some people are born with. It means the body grows too much or differently than other people. PROS isn't something you have control over, just like people don't have control over how tall or short they are, or the color of their hair.
- There are many PROS conditions. Each one affects different parts of the body, and each person may have different experiences.
- PROS conditions are caused by changes in the PIK3CA gene (pronounced pick-three-C-A). Genes are a set of instructions about how you look and grow, and when PIK3CA changes, it can cause a PROS condition.
- It is necessary to see doctors who understand PROS conditions, and it may mean more visits to doctors than other people to check on the parts of the body that are different.

The Impact Of PROS



- Sometimes, because of the differences in the body, people with PROS conditions have trouble finding clothes and shoes that fit. When we find options that work, we stick with them! This also means that sometimes we get to buy custom clothes and shoes, while other kids don't!
- Because PROS conditions are rare, people—even strangers—may have questions. You don't have to answer if you don't want to, and you can share as little or as much as you want. You also may see people staring. Let me know if you ever feel uncomfortable, and we can deal with it together.
- Sometimes our plans may change because of doctors' visits or because you may not feel well, but we'll always make time for family activities.
- We want to talk about PROS conditions and support each other—honesty is the best policy! Whether you're feeling sick or sad or frustrated, please tell me and we can figure out what to do together to make you feel better.



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.