

PROS @ THE DOCTOR'S

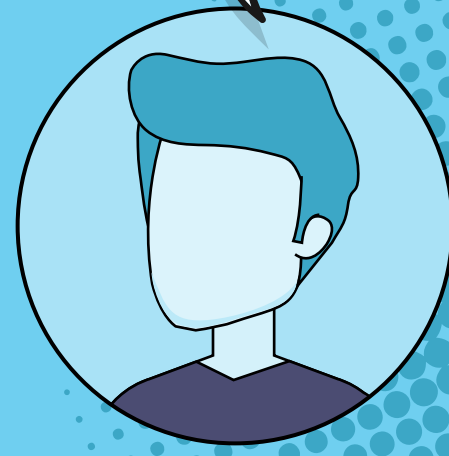


Talking to people about PROS, or PIK3CA-Related Overgrowth Spectrum, is never easy. Speaking to a doctor can prove even more challenging, especially if they aren't familiar with PROS conditions.

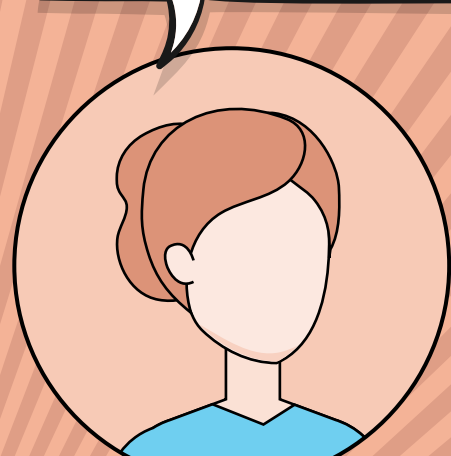
This guide includes tips and examples of how to talk to a new doctor about PROS (for yourself or your child) and how to prep for upcoming appointments.

Getting the Most From Your Appointment

- **Have a folder or app with important documents.** If there are previous test results, doctors' notes/referrals, health portals, or hospital visits that are key to explaining medical history, ensure you have these in an easy-to-carry folder or electronic health portal that you can hand over at the start of the appointment. It may also be helpful to provide the doctor with copies they can keep.
- **Make a list of questions.** Begin in the weeks leading up to your appointment and continue until the time you leave for your visit. See [Questions for the Doctor](#) (below) for suggestions. Bring a pen and paper so you can take notes as you ask questions.
- **Keep a symptom journal.** Track new and worsening symptoms to ensure you can communicate them to your doctor. Make sure you write down the dates you experienced symptoms.
- **Enlist your support system, if you can.** Bringing a friend or family member to your appointment can help.
- **Be honest.** Some symptoms and struggles may be difficult to discuss, but honesty is key to a better prognosis.
- **Take your time.** This is your chance to voice your concerns.



Explaining PROS Conditions



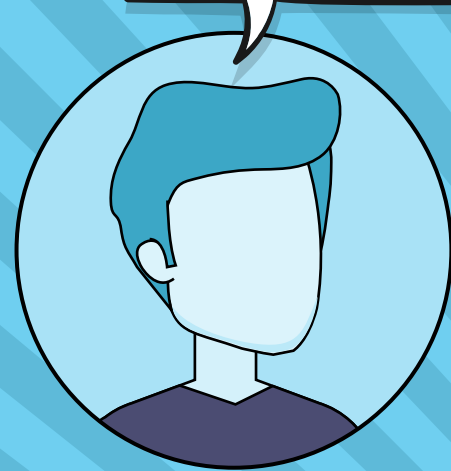
- My rare condition can cause overgrowth of tissue and abnormalities in blood vessels and lymphatic systems.
- There are many types of PROS conditions. Each one affects different parts of the body. My condition affects ____.
- I understand this is a rare condition and that many doctors are not familiar with it. It can take time to receive an accurate diagnosis and management plan.
- I work with a team of doctors, including _____, _____, _____.
- I have to go for checkups more frequently to monitor my PROS condition and adjust my care and management plan.
- These are the tests that I need to get regularly. The reason why is ____.

- **General experience:**
 - Because of my PROS condition, I experience....
 - I feel ____ physically and ____ emotionally.
 - Living with a rare condition and managing the symptoms can be challenging.
 - I enjoy doing many of the same things as other people, although I may do some of them a little differently.
 - My condition is affecting my life (school, work, social interactions) in the following ways...
- **Mobility:**
 - Walking and exercising can be difficult for me.
 - I have trouble doing certain activities, like _____, _____, _____.
- **Pain:**
 - I sometimes experience pain and discomfort.
 - Sometimes, I may need to skip activities or go at a slower pace because of the pain.
- **Emotional impact:**
 - Living with a rare condition can be...
 - It's hard to manage my PROS condition, and it impacts my emotions in the following ways...

Talking About PROS Symptoms or Concerns



Questions for the Doctor



- How will my PROS condition affect me/my child in the long term?
- Sometimes, I may need to miss school/activities or go at a slower pace. What is the best way to inform people about these restrictions? *Ask about physicians' notes for children.*
- Do you offer nighttime/weekend appointments, labs and MRI testing?
- Also, what day(s) do you hold your clinics each month?
- I sometimes experience pain. Are there ways to manage this? Are there physical therapists I could see?
- Will I need a wheelchair or tools to assist me with mobility?
- Will I need surgery?
- Will I need a helper or aide for activities?
- Will I require more frequent checkups to monitor my PROS condition and adjust my care and management plan?
- What type(s) of testing should I get each year?
- Are there any support and advocacy groups where I can connect with other patients and families?
- What are my management options? What is most appropriate for me?

MRI, magnetic resonance imaging.



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.