



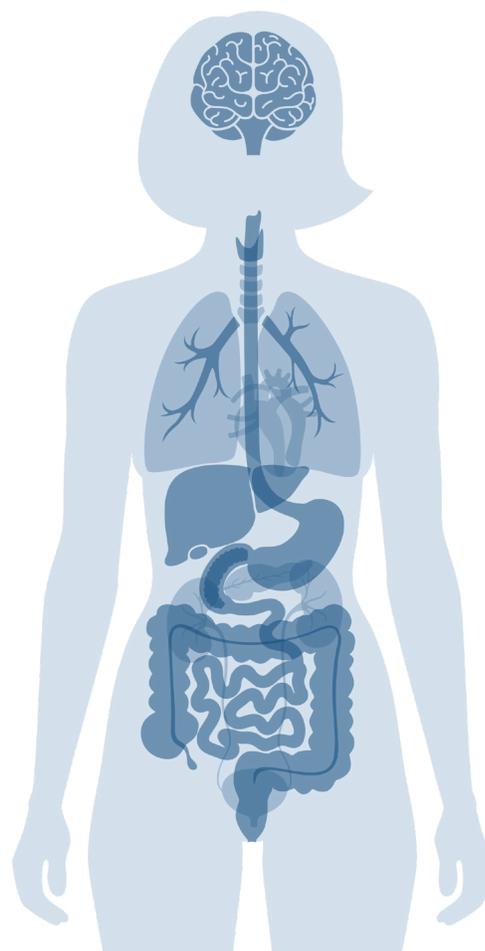
# BECOME YOUR OWN ADVOCATE

## LEARNING TO PARTNER WITH YOUR HEALTHCARE PROFESSIONALS

Listen to the podcast here: <https://allaboutapds.com/downloads-and-videos/>  
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### Understanding Activated PI3K Delta Syndrome (APDS)

- **Patients with APDS can develop a wide range of symptoms including<sup>1,2</sup>:**
  - *Upper airway tract complications*
    - » Repeated sinus and lung infections
    - » Pneumonia
    - » Damage to the lungs (Bronchiectasis)
  - *Chronic swollen lymph nodes*
    - » Bumps along the GI tract or lungs made of B and T cells (nodular lymphoid hyperplasia)
  - *Enlarged spleen and liver*
  - *Developmental delays*
  - *Autoimmune diseases that may affect many body parts including blood cells, joints, or the endocrine system*
  - *Gastrointestinal complications*
- **A wide range of symptoms means that patients with APDS may be cared for by healthcare providers across various specialties, such as:**
  - *Pulmonology*
  - *Allergy/Immunology*
  - *Hematology*
  - *Neurology*
  - *Gastroenterology*
- **Not all patients with APDS will experience the same signs and symptoms or severity. Your doctor is your best source of information about your condition**



## Building Your Treatment Team of Healthcare Professionals<sup>3</sup>

- Having specialists whom you can openly discuss your needs and goals is helpful and should be a long-term consideration
- Establishing a relationship with your trusted primary care physician (PCP) to include shared decision making and open dialogue is instrumental in building your team of specialists:
  - If you are not satisfied with the care and treatment you are receiving, it is important to find a PCP with whom you can relate to
- When you get a referral to see a specialist, things you may need to consider include:
  - Travel time to and from your specialist’s office
  - Your insurance coverage
  - Obtaining several physician names for each specialty referral
    - » Having multiple options may help you to find a specialist that best fits your needs
- Consider having both a local healthcare provider and team of specialists
- [www.AllAboutAPDS.com](http://www.AllAboutAPDS.com) provides a physician-finding tool to help identify several specialists who are closest to you



## Advocating For Your Best Possible Healthcare

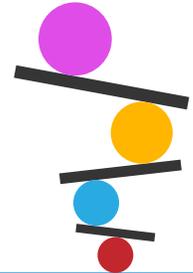
- Do your “homework”:
  - Follow-up with healthcare providers when needed
  - Research what you do not understand and make a list of questions for your providers
  - Learn to navigate your insurance process
  - Follow-up with insurance providers for authorization when needed
- Do everything YOU can do to help YOURSELF:
  - Even if you are feeling good, it is important to be consistent with your self-care
    - » Try not to miss appointments
    - » Continue your treatment regimen
    - » Continue caring for yourself (physically and mentally)





## How to Balance Managing Your Healthcare and Life

- Learn to balance your healthcare and your social life
- Prioritize yourself and your healthcare
- Acknowledge what you are capable of managing
  - For example, you may choose to turn down certain events or tasks to prioritize your health and well being



## How to Educate Yourself on Your Disease

- Search for reputable, trusted resources:
  - [www.primaryimmune.org](http://www.primaryimmune.org) provides educational videos and tools
  - [www.AllAboutAPDS.com](http://www.AllAboutAPDS.com) provides educational material on disease state awareness
- Ask your healthcare provider for their recommendations for resources and educational materials



## Support For Patients with APDS and PIs

- Finding support can help you navigate through your journey with APDS:
  - Meeting other patients with APDS who have experience navigating their disease, the healthcare system and insurance are excellent resources
- Immune Deficiency Foundation provides:  
<https://primaryimmune.org>
  - Patient advocacy support groups
  - Educational materials
  - Live and virtual seminars and workshops
- International Patient Organization for Primary Immunodeficiencies provides:  
<https://ipopi.org>
  - Advocacy and awareness to improve patient access to early diagnosis and patient-centered care
  - Support and guidance through their national member organization (NMO) in finding the best healthcare providers
  - Educational resources



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### REFERENCES

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2. Elkaim E, Neven B, Bruneau J. Clinical and immunologic phenotype associated with activated phosphoinositide 3-kinase delta syndrome 2: A cohort study. *J Allergy Clin Immunol.* 2016;138(1): 210-218 e219. doi:10.1016/j.jaci.2016.03.022.
3. Okun S, Schoenbaum S, Andrews D. Patients and health care teams forging effective partnerships. Discussion Paper, Institute of Medicine, Washington, DC. 2014. <http://www.iom.edu/patientsaspartners>