

## Externally-Led Patient Focused Drug Development

C-Path's Polycystic Kidney Disease Outcomes Consortium (PKDOC) and the PKD Foundation will be hosting an Externally-Led Patient Focused Drug Development (EL-PFDD) meeting for Autosomal Recessive Polycystic Kidney Disease (ARPKD) on Tuesday, August 29<sup>th</sup>. EL-PFDD meetings bring together patients and care partners, US Food and Drug Administration (FDA) representatives, pharmaceutical companies, physicians, and researchers who are experts in a particular disease. The goal of this public meeting is to hear directly from patients, their families, caregivers, and patient advocates about what it's like to live with ARPKD, so the FDA and pharmaceutical companies can better understand the patient experience to develop meaningful clinical trials and therapies.

Further details and registration can be found [here](#).

Are you ready to seize a unique opportunity to be recognized as a supporter for finding new treatments for ARPKD? We are seeking sponsorship to ensure that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation. The funds will be used to cover the cost of hosting the EL-PFDD meeting and developing a Voice of the Patient post-meeting report.

Information about sponsorships and associated benefits can be found [here](#).

A link to the recorded meeting can be found [here](#).

A link to the follow-up adjunct scientific workshop held on January 23, 2024, can be found [here](#).



The banner features a background image of people's hands raised in a gesture of support or agreement. On the left, there are two logos: the PKD Polycystic Kidney Disease Outcomes Consortium logo (a stylized blue and yellow shape) and the PKD Foundation logo (a circular pattern of colorful dots). The main text on the right reads "Externally-led Patient-Focused Drug Development Meeting for ARPKD" in large, bold, dark blue letters. Below this, in a light blue box, is the text "VIRTUAL MEETING FOR ARPKD PATIENTS AND THEIR FAMILIES", "August 29, 2023", and "10 a.m. – 3 p.m. ET". At the bottom, a note states: "\*This is an open public meeting and anyone interested in learning more about ARPKD and CHF are welcome to attend. This includes family members, friends, researchers, clinicians, industry, and anyone wanting to join."

**PKD**  
POLYCYSTIC KIDNEY DISEASE  
OUTCOMES CONSORTIUM  
CRITICAL PATH INSTITUTE

**PKD FOUNDATION**  
Polycystic Kidney Disease

**Externally-led  
Patient-Focused  
Drug Development  
Meeting for ARPKD**

**VIRTUAL MEETING FOR ARPKD PATIENTS AND THEIR FAMILIES**  
August 29, 2023  
10 a.m. – 3 p.m. ET

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