

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 29th. 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 a group of people holding hands. On the left, there are two logos: the PKD Polycystic Kidney Disease Outcomes Consortium logo (a stylized 'C' shape) and the PKD Foundation logo (a circular arrangement of colored dots). To the right of these logos, the text 'Externally-led Patient-Focused Drug Development Meeting for ARPKD' is written in large, bold, dark blue letters. Below this, in a light blue box, the text 'VIRTUAL MEETING FOR ARPKD PATIENTS AND THEIR FAMILIES' is written in bold, dark blue letters, followed by the date 'August 29, 2023' and the time '10 a.m. – 3 p.m. ET'. At the bottom, a note in italics 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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