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.