



ADPKD REGISTRY CONSENT FORM

TITLE: ADPKD Patient Registry

PROTOCOL NO.: None
WCG IRB Protocol #120190065

SPONSOR: PKD Foundation

INVESTIGATOR: Elise M. Hoover, MPH
The PKD Foundation
1001 E 101st Terrace, Suite 220
Kansas City, MO 64131

**STUDY-RELATED
PHONE NUMBER(S):** 816-264-8478
800-753-4673 (24 hours)
1.800.PKD.CURE (753.2873)
registry@pkdcure.org

Information about the ADPKD Patient Registry

You are being asked to be in a research Registry run by the PKD Foundation. The PKD Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for PKD to improve the lives of those it affects. Our vision is to #endPKD.

Before you agree to take part in the ADPKD Patient Registry, it is important that you understand what is involved, what information you may receive, and what will be done with the information you provide. Please read this form carefully. The Registry staff can provide answers about the ADPKD Patient Registry provide link to FAQs and contact information.

If you are the parent or legal guardian of a child who may take part in this Registry, your permission and the permission of your child will be needed. When “you” appears in this form, if applicable it may refer to you or your child.

For questions about the Registry Goals and details of the ADPKD Patient Registry, contact the Registry Lead at registry@pkdcure.org. For all other questions, please visit the [PKD Foundation website](#) or the [PKD Connect](#) webpage, or call the PKD Hope Line at 844.PKD.HOPE (844.753.4673). You should also discuss this Registry with anyone you choose in order to better understand this Registry and your options.

A copy of the information in this form will be available to you via your website account. Additional information about this Registry is available in the ADPKD Patient Registry FAQ.

What is the ADPKD Patient Registry?

A patient registry is a database that collects health information of people with a specific disease or condition. In addition, a Registry keeps information in one place making it easier for researchers to utilize medical information while still protecting the privacy of those who take part. The ADPKD Patient Registry will collect data most relevant to your ADPKD diagnosis, its major symptoms and management,