

# CHILDREN'S NATIONAL

Center for Translational Science  
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## CLINICAL RESEARCH STUDY

### FAQ SHEET for Physicians of Potential Participants

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<b>TITLE OF STUDY:</b>	<b>Core A: The Hepato-Renal Fibrocystic Diseases Translational Resource</b>
<b>PRINCIPAL INVESTIGATOR:</b>	<b>Lisa Guay-Woodford, MD</b>
<b>IRBEAR PROTOCOL:</b>	<b>Pro00003209</b>

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**INTRODUCTION:** We have established a NIDDK-funded, interdisciplinary center of excellence in PKD-related research, with specific emphasis on recessive Polycystic Kidney Disease. Among the five Cores, the UAB HRFDCC includes the Core A: “The Hepato-renal Fibrocystic Diseases Translational Resource”, (<http://www.arpkdstudies.uab.edu/>).

**PROJECT:** The objectives of Core A: “The Hepato-renal Fibrocystic Diseases Translational Resource” are:

**One:** To extend the observational study “Core A: The ARPKD Clinical and Genetic Resource” database adding to ARPKD other hepato-renal fibrocystic diseases like Joubert syndrome, Bardet Biedl syndrome, Meckel-Gruber syndrome, Congenital Hepatic Fibrosis (CHF), Caroli syndrome (CS), Polycystic Liver Disease, Oro-Facial-Digital syndrome, Nephronophthisis (NPHP), and Glomerulocystic Kidney Disease.

**Two:** To broaden the educational tools for physicians, families and patients regarding the hepato-renal fibrocystic diseases, particularly ARPKD.

Through mechanisms developed by our P30 Core Center, Core A will make these important resources available to the broader community of interested investigators and physicians/healthcare providers. To protect patient confidentiality, unique numerical identifiers will be used to enter and store all clinical information.

We have obtained authorization from the participant/parents to release their own/child’s medical data and we are requesting that the physician/hospital provide the clinical information. If for any reason you require a copy of the signed study consent, please contact Elena Gibson, the Clinical Research Coordinator.

For questions, please contact Elena Gibson, ([egibson@cnmc.org](mailto:egibson@cnmc.org)), phone: 202-476-2197.

**RISKS/CONFIDENTIALITY:** Researchers do not expect any risks to come to your patient's participation in this study. There is always a potential for a breach of confidentiality. Only the people working on the study will know your patient's name. Researchers will take the necessary steps to prevent this risk from happening by keeping the records of this study confidential.

**VOLUNTARY PARTICIPATION:** Your patient's decision to participate or not participate in this research will not affect your patient's current or future care at Children's National.

**QUESTIONS:** If you have any questions, please call the Principal Investigator, [Lisa Guay-Woodford, MD](#) at: 202-476-5000 or [Elena Gibson, the Clinical Research Coordinator](#) at 202-476-2197.