

UAB-CHOP Pediatric Cohort Clinical and Translational Core

UAB PKD RTCC Clinical and Translational Core ClinicalTrials.Gov Identifier NCT04338048
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ADPedKD-US Cohort: Longitudinal cohort study of patients (< 18 years of age) with ADPKD.
US node of ADPedKD international database.

Study Sample (as of 09/09/2024):

- N=51 participants enrolled
- Age (at enrollment): 0-18 years
- Age (current): 3-23 years
- Gender composition: 50% Female 50% Male
- Race composition: White 66.67%, Black 11.90%, Hispanic 11.90%, Asian 4.76%, and Other 4.76%

Biorepository:

- Urine
- Plasma
- Serum

Clinical Phenotyping 1. Clinical history:

- Age of diagnosis
- Age at death, cause
- Prenatal history, including gestational age at diagnosis, oligo-/an-hydramnios
- Neonatal history, including delivery, Apgar scores, respiratory support, complications
- History of hypertension, growth delay, urinary tract infections
- Renal replacement therapy
- Dialysis
- Transplantation

- Nutritional support
- Medications, including tolvaptan

2. Family History – including consanguinity; age of ESKD of affected family members; history of extra-renal complications, e.g. intra-cranial aneurysms and liver cystic disease.

3. Physical Exam:

- Blood pressure
- Height / weight
- Tanner stage

4. Clinical Laboratory Results

- Electrolytes and cystatin-C (estimated GFR from CKiD equation and/or Bedside Schwartz formula) LFTs, including GGT
- Cbc; CRP
- Serum lipid profile
- Urine protein/creatinine ratio; urine calcium to creatinine ratio

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5. Genetic testing

6. Imaging

- Ultrasound – kidney / liver
- MR — kidney / liver / brain
- MR elastography

7. Echocardiography:

- Left Ventricular Mass
- Left Ventricular Ejection fraction

8. Histopathology

- Kidney
- Liver

Please note: There may be additional costs for the materials and shipping associated with your requests. You will be contacted directly by the provider regarding these costs.