

Core A: Hepato-Renal Fibrocystic Diseases Translational Resource

Blood Sample Collection from Patients with ARPKD or other Hepato-Renal Fibrocystic Diseases and Their Parents

Blood samples should be collected for DNA preparation in the tubes provided

Supplies Provided:

Sites will be provided with a “kit” from this Study that includes the following:

- **PAXgene tubes with blank labels**
 - Standard tubes for collecting 8.5-ml of whole blood
 - Modified tubes for collecting 5-ml of whole blood
- **Patient/Parent Information Forms:**
 - In the kit, we will provide an information form that has been completed by the patients/parents from whom blood will be collected. This form will contain the Patient study ID#; the Mother study ID#; Father study ID#;
 - Make a copy of the form for your records.
 - Place the original form in the return shipment mailer with the blood samples (see shipping instructions).

Patient Study Identification Number:

- Sites must contact Elena Gibson, the Study Coordinator, to obtain Study ID# for the patient, the mother, and the father. These ID# should be used to label the tubes BEFORE blood is drawn. This will allow the samples to be provided to the study as de-identified specimens without patient identifiers.
- Contact Information:
 - Elena Gibson RN(German certified)
 - Core A Research Coordinator
 - Phone: 202-476-2197 (9AM-5PM Monday-Friday)
 - E-mail: egibson@childrensnational.org

Labeling of blood collection tubes (BEFORE blood is drawn):

- **Patient:**
 - Patient Study ID#
 - Date of specimen collection
- **Patient's Mother:**
 - Mother Study ID#
 - Date of specimen collection
- **Patient's Father:**
 - Father Study ID#
 - Date of specimen collection

Sample collection:

Blood collection and DNA extraction will be performed using the PAXgene system (Qiagen). Specifically, we will request:

- 8.5-ml whole blood from placenta of the affected child (if available)
- 5-ml whole blood from affected children \leq 2 year of age
- 8.5-ml whole blood from affected children $>$ 2 year of age and their adult parents

Shipping of Blood Samples:

- Blood samples should be shipped at ambient temperature the same day they are collected Monday through Thursday. In the case of a Friday or a day prior to a holiday, hold at ambient temperature until the next business day.
- Do NOT ship for delivery on a Saturday or on a holiday.
- **Please include the following items in your shipment:**
 1. A primary, secure receptacle (i.e. specimen canister or leakproof bag) with absorbent.
 2. A secondary overpack or FedEx clinical bag.
 3. An itemized specimen packing list which includes:
 - a. the Patient Study ID#; date of collection, and sample size (8.5-ml or 5.0-ml).
 - b. the Mother Study ID#; date of collection, and sample size (8.5-ml).
 - c. the FatherStudy ID#; date of collection, and sample size (8.5-ml).
 4. Completed airbill and UN3373 diamond affixed to the outside of the shipper.
- **Use Federal Express # 2530-0934-9 for shipping charges.**
- **Ship to:**
- ATTN: Elena Gibson, RN (German certified)
 - Core A Research Coordinator
 - 111 Michigan Ave NW
Main Building, Floor 3.5, Room 119
Washington, DC 20010
 - Phone #: 202-476-2197
- Provide e-mail notification ahead of shipment delivery to egibson@childrensnational.org

Questions:

General questions:

- Contact Elena Gibson, RN (German certified)
 - Core A Clinical Research Coordinator
 - E-mail: egibson@childrensnational.org
 - Phone: 202-476-2197