**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:**

• **Patient/Parent Information Forms:**

o 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#;

o Make a copy of the form for your records.

o Place the original form in the return shipment mailer with the blood samples (see

shipping instructions).

**Patient Study Identification Number:**

• Sites must contact Christine Tran, 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:

o Elena Gibson

o Core A Research Coordinator

o Phone: 202-476-6877 (9AM-5PM Monday-Friday)

* E-mail: [egibson@cnmc.org](mailto:egibson@cnmc.org)
* Jasmine Jaber
* Core A Research Coordinator
* Phone: 202-476-2838
* E-mail: jjaber@cnmc.org

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

• **Patient:**

o Patient Study ID#

o Date of specimen collection

• **Patient’s Mother:**

o Mother Study ID#

o Date of specimen collection

• **Patient’s Father:**

o Father Study ID#

o Date of specimen collection

**Sample collection**:

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

o 6-ml whole blood from placenta of the affected child (if available)

o 4-ml whole blood from affected children < 2 year of age

o 6-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 (6-ml or 4-ml). b. the Mother Study ID#; date of collection, and sample size (6-ml).

c. the FatherStudy ID#; date of collection, and sample size (6-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:**

o ATTN: Jasmine Jaber

o Core A Research Coordinator

o 111 Michigan Ave NW

Main Building, Floor 3, Suite M3245

Washington, DC 20010

o Phone #: 202-476-2838

• Provide e-mail notification ahead of shipment delivery to [jjaber@CNMC.org](mailto:jjaber@CNMC.org)

**Questions:**

**General questions:**

• Jasmine Jaber, Core A Clinical Research Coordinator

o E-mail: jjaber@CNMC.org

* Phone: 202-476-2838