



Dear Friends,

Dr. Lisa Guay-Woodford, a pediatric nephrologist, has established a Database at the University of Alabama at Birmingham entitled: **Core A: ARPKD Clinical and Genetic Resource**. This resource is funded in part by the PKD Foundation and is sponsored by the NIH. The goal is to increase enrollment by fifty (50) new participants by May 01, 2010 and continue enrollment in the future.

Dr Guay-Woodford was inspired by the wide range in symptoms and severity of ARPKD. The Core A resource was designed to compare the clinical and mutation data in people with ARPKD to identify new ways to improve diagnosis and discover more effective treatments.

The study does not require visits; it is for gathering data only.

It is easy to enroll and all patients/families affected by ARPKD are encouraged to participate.

Step 1: Visit our website <http://www.arpkdstudies.uab.edu>.

Step 2: Submit the physician contact information online.*

For those patients/families who have participated in the NHGRI study directed by Dr. Meral Gunay-Aygun, please proceed as follows:

- List Dr. Meral Gunay-Aygun as the contact physician
- Contact Dr. Gunay-Aygun and complete the NIH **Release of Information** form. Complete and return the Release form to NIH, requesting that these records be sent to Dr. Guay-Woodford at the following address:

Lisa M. Guay-Woodford, M.D.
University of Alabama at Birmingham
Kaul Building 740
720 South 20th Street
Birmingham, AL 35294-0024

Step 3: Print the consent, sign, and return the signed consent by mail.

Step 4: Once we receive the signed consent and patient information, Teresa will enroll that child in our Core A Database.

*Some participants may have submitted contact information and not yet signed consent. If you are unsure, please contact Teresa.

For more information please contact Teresa Chacana, Research Nurse Coordinator, at 205-934-7649 or tchacana@uab.edu.