

INSTRUCTIONS FOR DATA ENTRY:

You can access the Clinical Database at (<http://www.arpkdstudies.uab.edu/>).

- Go to the website and click on Physician Access under the ARPKD Clinical Database
- Here is your access information to logon.
 - User Name: XXXX
 - Password: YYYY
- You will be directed to the “Change your Password” screen: please change your password
- You will be directed to the “ARPKD Dash Board” screen: go to Data Form Menu (Data Forms)
- Enter your Physician identifier (XYXY) and click “Get Patients”
- Scroll down to “Patient Id” and click on the Patient unique Identifier number (YXYX)
- Data may be entered directly on the Primary Data Form (F01) or the Follow Up Form (F11) Both forms may be printed, completed manually, and data then entered to the web-pages

For questions, please contact Teresa Chacana, RN (tchacana@uab.edu) 205-934-7649.

Please note:

According to the HHS Office of Human Research Protections (OHRP) guidance, the release of identifiable patient information does not constitute engagement in research on the part of the person providing the information (<http://www.hhs.gov/ohrp/>). In addition, we believe that the HIPAA requirements for secure disclosure of information are satisfied because we have obtained authorization from the parents to release their child’s data and we are requesting that the physician provide de-identified information electronically.

If for any reason you require a copy of the consent or the HIPAA authorization to release the requested information, please contact Teresa Chacana, RN (tchacana@uab.edu).

Thank you for your assistance!