A small handbook for ARegPKD
Enter [www.aregpkd.org](http://www.aregpkd.org) and visit our website.
Enter Username and password - both will be sent to you after registration in an e-mail.
In order to register you need to visit the Registration form and fill in the form. We will send you a username and password as soon as possible.

Once you have registered please make sure that a positive votum of the corresponding ethics committee has been obtained and that your patient and/or a representative has received, understood and signed the patient information and informed consent form.
After logging in, you can either Add a new patient or work on registered patients.
When you Add a new patient, you are directed to the Basic data section, which you need to fill in only once. Basic data covers general information on your patient and on the ARPKD diagnosis.

Please note: You can only continue after entering the Date of informed consent! Questions marked with * are mandatory and will be READ ONLY after saving the initial visit. Please fill in with care. Mandatory questions exist in the Basic Information and Initial diagnosis subfolders.
For patients participating in the 4C-study: You can import data from the 4C-study. To do so please open your patient's file of the 4C-study. You will find an Export for ARegPKD-button for every visit (and basic data). Please save the Export file e.g. on your desktop.

You can now import the data into ARegPKD. To do so browse for the data file and press the Import button. This import is only possible before saving. If you imported data these will be automatically filled in matching fields.

Don`t forget to press Save after entering your data!
Please note: it is advised to import data from the 4C-study when you start entering a patient`s data. If you want to import data for upcoming visits, this is no problem: go to Add next follow-up visit and you will find the yellow field with Import button automatically.

If you want to import data for visits that you already have entered, please write us an email as this option is available only for admininstration staff!
Important: If you want to add information to the Basic Data section later on you can always enter these topics in order to edit them. For example: If your patient is receiving genetic testing you can enter the information in Genetics later on.
In your Patients registry you will be able to see whether a visit is needed. Please enter data at least once every year.

Click on Add initial visit in order to fill in the information of the visit. You can also fill in the Termination entry in case of death or loss of follow up or Transfer patient’s data to another center.
You start the *Initial visit* with this view. The values in the orange fields will be calculated automatically after you pressed saving.

**Please note:** At the end of *Patient`s status* you are asked, if biosamples for storage in the ARegPKD biobank have been taken at this visit. We will send you corresponding labels for every year. If you have not yet received corresponding labels, please inform us!
If your patient already has a documented Initial visit, you can progress with Add follow-up visit or Add next follow-up visit.

You also get an overview over all entered visits.
Whenever you have any questions regarding ARegPKD, please do not hesitate to contact us!

- Fill in the Contact form

- Send an e-mail to info@aregpkd.org, kathrin.burgmaier@uk-koeln.de or max.liebau@uk-koeln.de