

Dear friends,

we are glad to present the **ADPKiDs study** that has been established with the support from the ERA-EDTA Working Group on Inherited Kidney Diseases (WGIKD) and has been endorsed by the European Society of Pediatric Nephrology (ESPN).

This study has **two very simple goals**, namely to establish a European cohort of children with autosomal dominant polycystic kidney disease (ADPKD) and to assess the prevalence of (pre)-hypertension by Ambulatory Blood Pressure Monitoring (ABPM).

To participate, you only need to transmit **online anonymized ABPM files** (retrospective or prospective) together with **extremely limited clinical information** (~5 min). To be eligible, patients need to have at least one renal cyst and a positive family history of ADPKD or a proven PKD1/PKD2 mutation.

**Mandatory data collection are restricted to:**

1. age
2. gender
3. height and weight
4. serum creatinine
5. blood pressure medications

If possible, we would also like to receive an evaluation of the renal involvement (generally by renal ultrasound), which can be restricted to simple renal measurement data (especially renal length) and/or to the count of cysts >1cm per kidney expressed per class (none / 1-2 / 3-5 / 6-10 / 11-20 / >20).

**OPTIONAL ANCILLARY STUDY**

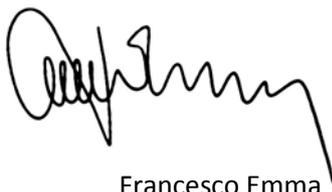
For those of you who are interested, the study also includes an optional part aiming at collecting  
- simple data on bone metabolism (serum Ca, P, PTH, FGF23 and urine Ca, creatinine and phosphate)  
- spontaneous urine output data (volume, creatinine, Na, proteins)

All data are anonymized. As you can see, the study is limited to the transmission of an ABPM profile per patient together with very limited clinical information; you will need to assess if your institution requires the approval from your ethical committee. If yes, attached please also find two examples of informed consent forms.

We are planning to collect data from more than 200 patients. All contributing physicians will be acknowledged in publications; we offer co-authorship to all partners who will contribute at least 8 patients with ABPM profiles to the analysis and will acknowledge all other contributors.

If you are interested, please contact us at the following e-mail address and we will provide you with a username and password: [adpkids@opbg.net](mailto:adpkids@opbg.net).

We are looking forward to collaborate with you

Handwritten signature of Francesco Emma in black ink.

Francesco Emma

Handwritten signature of Franz Schaefer in black ink.

Franz Schaefer