

ESPN research grant 2016 final report

Dr. Djalila Mekahli and Dr. Max Liebau (Inherited Renal Disorders WG)

ADPedKD: a European web-based database for longitudinal data registry of children with ADPKD

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the most common inherited kidney disease, with an estimated worldwide prevalence of 1 in 1000 live births and is the 4th common causes for renal replacement therapy worldwide. As it was regarded as an adult-onset disease for several decades, there is a lack of longitudinal data of large pediatric ADPKD cohorts. Nevertheless, evidence is growing that ADPKD begins in early childhood and children represent a specific target population for future treatment, allowing a better chance of preserving long term renal function. As adult ADPKD management has leapt up since the treatment by Tolvaptan has slow down the disease progression, it is necessary to better define the pediatric spectrum of the disease and to develop clear prognostic indicators of the disease progression in childhood.

For this purpose, a global ADPedKD project has been initiated by Djalila Mekahli and Max C. Liebau. This collaborative project is an international, multicenter, observational study, including both retrospective and prospective longitudinal data on childhood-diagnosed ADPKD. It is based on interoperable Web-based databases comprising 83 major pediatric nephrology centers throughout Africa, Asia, Australia, Europe, North America, South America and the United Kingdom. Africa, Asia and Europe are sharing one common database while Australia, United Kingdom and America have their separate source databases which are fully interoperable with the ADPedKD platform. The methodology of the ADPedKD initiative have been published in KI Reports where all the participants were listed as co-authors in the ADPedKD Consortium. [ADPedKD: A Global Online Platform on the Management of Children With ADPKD.](#) De Rechter S, et al. *Kidney Int Rep.* 2019 May 29;4(9):1271-1284

In the Web-based database, data encoding is subdivided into 3 sections: detailed basic data questionnaire (including genetics), visits (initial and follow-up) and study termination. Local investigators are able to access the ADPedKD website at any time for encoding and editing data. The web-site also give an access to all study-related documents including a handbook

on how to use the web-platform, patients information and informed consent forms available in **11 different languages**.

After signing the informed consent forms, each participating center are able to enter patient's data pseudonymously in the database accessible via <https://www.ADPedKd.org/>. All patients diagnosed with ADPKD before the age of 19 years are eligible for inclusion. Currently (18th September 2020), there are **726 patients enrolled** in the registry and **the sample size goal to begin first data analyses is 1000 patients**. These first analyses will focus on the incidence of presentations, comorbidities, genotype-phenotype correlation and potential predictors of renal function.

We received €10.000 from the ESPN in 2016. We used the grant for setting up the database, the website and the logo. We were also able to cover the publication fees of the KI reports manuscript.

If you would like to join the ADPedKD registry, don't hesitate to contact Dr. Dachy Angelique (angelique.dachy@uzleuven.be). Dr. Dachy starts a PhD in 2020 and will be available for study investigation and coordination as well as medical and ethical issues questions. We look forward to welcoming new members and we are confident that working together is the best way to reach a better understanding of the ADPKD pediatric perspective.

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