

ESPN 2014 Research Grant n5

European ARPKD registry

ARPKD is among the most severe disorders in pediatric nephrology. Important aspects of this disorder remains poorly understood, morbidity remains high and current treatment approaches are symptomatic and remain largely opinion-based

ARegPKD (www.aregpkd.org) is a multinational, mostly European, ARPKD registry study. In this project experienced and specialized clinical centers across Europe join forces in order to advance our understanding of ARPKD. European paediatric nephrology centers contribute to this initiative by introducing pseudonymized pro- and retrospective clinical patient data into our secure web-based database.

Currently 69 centers 20 countries are registered for ARegPKD, 14 centers more than in January 2015. While applications to local ethics committees are still ongoing in various places 166 patients have already been included, an increase of 62 patients since January 2015. Retrospective follow-up data exists for the majority of the patients for time frames of up to roughly 25 years.

As part of the newly established NEOCYST consortium on cystic kidney diseases of childhood ARegPKD will receive funding from the German Federal Ministry of Education and Research from February 2016 on. A manuscript on the establishment, the rationale and the objectives of ARPKD has been published at *BMC Nephrology*. Upcoming steps include first data evaluation and inclusion of more patients. The start-up funding granted by the ESPN allows to support centers with the coverage of local administrative costs etc. to expand this project. Additional European centers are invited to join.

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