ARegPKD (www.aregpkd.org) is a multinational surveillance study characterizing the longitudinal clinical course of patients suffering from autosomal recessive polycystic kidney disease. ARegPKD aims to provide observational evidence for unified clinical treatment concepts, to establish clinical or biochemical risk markers for disease progression and to lay the foundation for innovative translational research towards novel therapeutic targets and clinical trials for this severe disorder.

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By September 2020 more than 640 ARPKD patients have been included in ARegPKD with more than 3000 independent visits. Recruitment and data analysis are ongoing. First publications resulting from the database have identified risk markers for early dialysis dependency in ARPKD (Burgmaier et al., Journal of Pediatrics, 2018) and have described the clinical presentation of adult patients with ARPKD (Burgmaier et al., Scientific reports, 2019) as well as severe neurological outcomes after very early bilateral nephrectomies in patients with ARPKD (Burgmaier et al., Scientific reports, 2020).

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