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P406 -Autosomal dominant polycystic kidney disease (ADPKD)

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Our aims:
We are focusing on known priorities for research, such as hypertension in children, pain relief and improved understanding of natural history and progression (using data collected on RaDaR). ADPKD also affects the liver (polycystic liver disease) and we are keen to promote research in ameliorating the effects of liver as well as kidney cysts. In future years, research will be guided by the outputs of the ADPKD Priority Setting Partnership (PSP) being conducted in 2019 by the PKD Charity in association with the James Lind Alliance.
Who we are:
We are a multidisciplinary group dedicated to stimulating and nurturing clinical research into ADPKD in paediatric and adult populations. In addition to nephrology, experts from genetics and transplant are represented. There are four patient representative members on the CSG and we are a RaDaR Rare Disease group.