



INFORMED CONSENT

Dear parent,
as you know, your son/daughter has autosomal dominant polycystic kidney disease (ADPKD). Over the past decades, many progresses have been made in understanding the mechanisms that cause renal cysts to grow, allowing to develop new treatments, based on these findings. However, we only have limited information in children. Recent studies have shown that some children have high blood pressure, when measured with standard techniques, which, unfortunately, are not very reliable in pediatric patients. The best way to assess blood pressure in children is a 24h recording, also termed Ambulatory Blood Pressure Monitoring or "ABPM".

Main study

The aim of the ADPKiDs study is to assess the proportion of European children with ADPKD that have high blood pressure. We therefore ask your consent to transfer online the ABPM data of your child to the coordinating center of the study (Bambino Gesù Children's Hospital in Rome). In addition to the ABPM results, we will also transfer information on your child's age, gender, height, weight, serum creatinine and current medications (if any).

Optional data

Over the years, your doctor may have measured other data that could be useful in understanding other aspects of ADPKD. Specifically, recent studies suggest that some patients eliminate more phosphate than usual in their urines (which may impact bone mineralization), while other studies suggest that drinking more could be beneficial for subjects with ADPKD. If you agree, your physician will also send the following data, if they are available: serum calcium, phosphate, parathormone and FGF23 levels; 24h urine volume; urine concentration of creatinine, sodium, calcium, phosphate, proteins; spinal bone mineral density.

Additional information

Your child will not be submitted to any additional tests for the purpose of this study, nor will he/she receive any additional medication. There are no risks associated with this study. The main benefits for you and for your child will be to have contributed to medical knowledge, which may help improving treatment of ADPKD in the future.

All clinical data will be kept strictly confidential; data will be anonymized, meaning that it will not be possible for any investigator to trace back the identity of your child (your child's name will be replaced by a code).

Your participation is completely voluntary. No subjects will receive any type of incentives for participating in the study. You and your child have the right to decline participating to the study. Should you decide not to participate, this will not result in any loss of benefits or changes in medical attention. In addition, you may withdraw consent to the use of your child's data at anytime; these will be immediately destroyed by the coordinating center.

