Autosomal dominant polycystic kidney disease (ADPKD)

- ADPKD is a progressive and chronic genetic disease, primarily characterised by the development and enlargement of multiple fluid-filled cysts in the kidneys.\(^1,2\)

- ADPKD is the most common inherited kidney disease.\(^3\)
  - ADPKD is caused by faulty genes that can affect both sexes of all age, racial and ethnic groups.\(^3\)
  - ADPKD is thought to affect between 3-4 people per 10,000 – as many as 205,000 people in Europe.\(^4,5\)
  - ADPKD is a disease of genetic variability and therefore the disease course and progression can vary for each individual.
  - In certain cases, patients in early stage ADPKD often do not experience any symptoms and as a result are diagnosed late (30-55 years).\(^6-8\) By the time a decline in kidney function is identified, the destruction in kidney anatomy is already quite advanced.\(^9,10\)

The physical burden of ADPKD

- The formation and growth of kidney cysts leads to an increase in kidney size, or totally kidney volume (TKV), which is a continuous and quantifiable indication of disease progression.\(^1,10\)
  - ADPKD patients experience a variety of complications including hypertension, chronic and acute pain, repeated urinary tract infections (UTIs) and blood in the urine (haematuria).\(^1\)
  - Approximately half of patients reach end-stage renal disease (ESRD) and require renal replacement therapy (RRT) in the form of dialysis or a kidney transplant by age 54.\(^11,12\)
  - ADPKD is the fourth leading cause of ESRD and accounts for around 10% of patients with ESRD requiring RRT.\(^6\)

The emotional burden

- In addition to the physical symptoms of the disease, ADPKD causes a profound psychological and emotional burden for those living with the disease, their families and loved ones.\(^14-16\)
  - Patients with ADPKD report significantly impaired health-related quality of life issues due to pain, anxiety, depression and consequent difficulty with activities of daily living.\(^14-16\)
  - ADPKD patients are more likely to experience anxiety and depression compared to the general population.\(^17,18\)
  - The findings of the largest ever survey of people with ADPKD in Europe highlighted the negative impact the disease has on families (77% of respondents), relationships (41%), sexual relationships (42%), social lives (33%) and the decision to have children (35%).\(^19\)

The financial burden for society:

- ADPKD exacts a high financial and societal cost on healthcare systems.\(^20,21\) This is due to the increased risk of adverse outcomes such as cardiovascular disease events, hospitalisations, resource utilisation and mortality.\(^20\)
- Annual direct healthcare costs for ADPKD are estimated at €2 billion in the EU alone.\(^22\)
Autosomal dominant polycystic kidney disease (ADPKD)

References

8. Cornec-Le Gall et al. ERA-EDTA poster 2013 "Clinical factors predicting renal outcomes in ADPKD: results of the GENKYST registry"