



## **Manifiesto of the Alliance Against Autosomal Dominant Polycystic Kidney Disease**

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is a chronic, progressive and hereditary condition. It involves the formation of cysts in the kidneys, which affects other bodily organs too. In Spain, more than 20,000 people suffer from this disease and it is responsible for up to one in ten of all patients needing dialysis or transplantation.

However, ADPKD still fails to occupy an important position in awareness strategies on chronic conditions, not even in the area of kidney disease. Consequently, it remains today a disease that is unknown by the general public and even by the health community. This situation leads to a feeling of uncertainty and incomprehension in patients and their relatives.

For this reason, we at the **Alliance against Autosomal Dominant Polycystic Kidney Disease (ADPKD)** feel obliged to present this Manifiesto as a starting point in addressing this situation and moving towards a national focus coordinated by all interested parties that improves the health care received by patients. This Manifiesto may be seen as a call to national, regional and local public administrations, scientific societies, health administrators and boards, pharmaceutical companies, the media and the general public.

The **Alliance against Autosomal Dominant Polycystic Kidney Disease (ADPKD)** considers it necessary to:

- Increase social and health sensitivities to ADPKD.
- Draw attention to this chronic and incurable disease, which has a powerful physical, emotional and social-occupational impact on those affected.
- Promote specific and effective action policies that improve ADPKD care and the quality of life of those affected.
- Increase knowledge of the disease by the health professionals involved and the health authorities.
- Improve the integral health care of ADPKD in Spain. This requires a focus on patients and their perceptions.
- Provide health professionals with the tools necessary for an excellent level of clinical practice.
- Ensure fairness in access to this practice by all patients in Spain.
- Foster research into ADPKD.
- Increase information and care in the patient's emotional, social and work sphere.

**The member scientific societies and patients' associations of the Alliance against ADPKD are:**



Sociedad Española de  
Farmacia Hospitalaria

