



A Policy Call to Address

# Rare Kidney Disease in Health Care Plans

A panel of experts from the nephrology community, including patients, carers and health economists, has identified four categories of specific policy actions to address the challenges that hinder the provision of targeted care for rare kidney diseases.

For the scientific publication in *CJASN* [click here](#)

## Awareness and prioritisation

- Recommend early diagnosis in national plans
- Launch education campaigns targeted towards physicians and patients
- Raise awareness of chronic kidney disease and rare kidney diseases amongst policymakers and the general population
- Develop policy guidelines specific to rare kidney diseases

## Management

- Develop clinical guidelines specific to rare kidney diseases
- Improve access to innovative therapies
- Design and implement rare kidney diseases registries
- Conduct PROM\*-oriented studies
- Launch multi-disciplinary teams with a focus on rare kidney diseases

\*patient-reported outcome measures



## Diagnosis

- Introduce policies to promote genetic testing
- Implement urine screening programmes
- Advance research for diagnostic tools
- Advance genome and biomarker research

## Therapeutic innovation

- Allocate research & development funds to rare kidney diseases
- Generate evidence to expand understanding of rare kidney diseases
- Identify and validate surrogate endpoints
- Conduct large-scale multicentric studies
- Increase acceptance of alternative statistical methods