ERN on kidney diseases (ERKNet)

Rare and complex kidney diseases encompass a wide range of congenital, inherited, and acquired disorders. It is estimated that at least two million Europeans are affected by rare kidney diseases, with glomerulopathies and congenital renal malformations accounting for about one million cases each. In addition, inherited tubulopathies, tubulointerstitial diseases and thrombotic microangiopathies represent a number of rare and ultra-rare disorders of high clinical relevance.

State-of-the-art diagnostic tools can provide valuable information on disease prognosis and therapeutic options. However, access to testing is not universal. Due to delayed diagnosis and inadequate treatment, many rare kidney diseases unnecessarily progress to kidney failure.

ERKNet aims to enhance the management of patients with rare kidney diseases, especially new and complex cases, through online consultation services. The network's expert working groups establish consensus-based diagnostic algorithms for patients with suspected rare kidney diseases, including standard criteria for genetic testing in cases of suspected inherited kidney disease. In addition, the working groups define clinical pathways for therapeutic management after a thorough review of available treatments.

Since awareness and knowledge among healthcare professionals are essential for identifying and treating rare kidney diseases, ERKNet has introduced a three-year postgraduate curriculum based on clinical training, webinars and e-learning, which provides a state-of-the-art education on the entire spectrum of rare kidney diseases. Those who successfully complete the course will be recognised as 'European Rare Kidney Disease Specialists'.

ERKNet has established ERKReg, the European Rare Kidney Disease Registry. This online registry provides demographic information and facilitates collaborative clinical research by identifying cohorts of patients with rare kidney diseases across Europe. Moreover, the registry provides clinical performance statistics and benchmarking across the specialist centres, supporting harmonised and optimised care for rare kidney disorders in all ERKNet hospitals and clinics.

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