ERN on kidney diseases (ERKNet)

Rare and complex kidney diseases comprise a wide range of congenital, hereditary and acquired disorders. It is estimated that at least 2 million Europeans are affected by rare kidney diseases, with glomerulopathies and congenital kidney malformations each accounting for approximately 1 million cases. In addition, inherited tubulopathies, tubulointerstitial diseases and thrombotic microangiopathies represent a number of rare and ultra-rare diseases of high clinical relevance.

Online consultation services will improve management of new and complex cases.

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

This ERN will seek to improve standards of diagnosis and treatment across Europe. The network will establish a consensus on rational diagnostic algorithms for patients presenting with signs and symptoms of renal disease, including standard criteria for genetic testing in cases of suspected hereditary kidney disease. Working groups will then define clinical pathways for therapeutic management after thorough analysis of available treatments.

Online consultation services will improve management of new and complex cases. Access to a virtual consultation board will be complemented by administrative measures to facilitate patient travel to specialised centres where necessary, in line with the EU Cross-border Healthcare Directive and Social Security Regulation. A series of webinars will be developed for teaching and training health professionals.

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