From Care to Cure: an EU-wide Network Advancing Rare Kidney Disease Healthcare and Research

24 June | Online Webinar | Event Report

Summary

On 24 June 2026, the European Kidney Health Alliance (EKHA) and the European Reference Network for Rare Kidney Diseases (ERKNet) held a webinar bringing together clinicians, researchers, patient representatives and policy experts. Moderated by Prof. Djalila Mekahli, the event explored how European cooperation can improve diagnosis, care and research for people living with rare kidney diseases.

The presentations highlighted persistent inequalities in access to genetic testing, specialist care, essential therapies and innovative treatments. Building on EKHA's Call to Action, they identified priorities for translating European expertise into national practice: funded care pathways, stronger research and registries, meaningful patient involvement and more equitable treatment access.

Opening policy update

EU Safe Hearts Plan and cardiovascular health checks

EKHA welcomed the European Commission's Safe Hearts Plan as an important step towards strengthening cardiovascular–renal–metabolic prevention. However, the Plan lacks dedicated chronic kidney disease (CKD) targets and sufficient emphasis on systematic kidney screening, particularly albuminuria testing.

EKHA highlighted its involvement in the European Alliance for Cardiovascular Health (EACH), which has developed recommendations for integrated health checks incorporating kidney-related indicators, including albuminuria (uACR) and estimated glomerular filtration rate (eGFR). Continued advocacy is needed to ensure these measures are reflected in EU recommendations and implemented across Member States.

European Parliament Resolution on Kidney Health

EKHA provided an update on its efforts to secure a dedicated European Parliament Resolution on Kidney Health, an initiative launched during its World Kidney Day event in March 2026. The Alliance is engaging with Members of the European Parliament (MEPs) across political groups to build support for stronger EU action. Potential steps include a hearing within the Parliament's Committee on Public Health (SANT), parliamentary questions and an own-initiative report (INI). These initiatives aim to increase political awareness and establish kidney health as a key European public health priority, which would set the groundwork for a possible Resolution on Kidney Health.

Organ donation and transplantation

EKHA expressed concern that an updated EU Action Plan on Organ Donation and Transplantation was not included in the European Commission's 2026 Work Programme. In January 2026, EKHA joined the European Society for Organ Transplantation (ESOT) and more than 40 other organisations in calling for renewed European action through a letter to the Commission. Following the Commission's response, EKHA has continued engaging with national stakeholders and policymakers to strengthen coordination, reduce inequalities in access to transplantation and encourage renewed EU action.

EU rare disease policy developments

The presentation also reviewed the broader EU rare disease policy framework, including the 2009 Council Recommendation, European Reference Networks (ERNs), the European Rare Diseases Research Alliance (ERDERA) and the JARDIN Joint Action. While these initiatives have strengthened European cooperation, challenges remain regarding sustainable funding, coordination and integration into national healthcare systems.

Building on its Call to Action on Rare Kidney Diseases, EKHA reiterated four priorities: earlier diagnosis, improved care pathways, stronger research and evidence generation, and equitable access to innovative treatments.

Patient care

Patient advocates highlighted unequal access to transplantation, genetic testing, specialist services and essential medicines across Europe, alongside the social, emotional and financial pressures facing families. The Rare Kidney Disease Barometer and patient involvement in developing ADPKD care pathways illustrated the value of incorporating lived experience into research, healthcare planning and policymaking.

Early diagnosis and coordinated care

Presentations stressed the need for earlier diagnosis, especially for children with inherited kidney conditions, and more consistent access to genetic testing and expert care. The ADPKD pathway developed by ERKNet and implemented through the JARDIN Joint Action demonstrated how European guidelines can inform coordinated national care. Clear referrals, multidisciplinary teams and sustainable funding remain essential for effective implementation.

Education, research and registries

ERKNet's postgraduate curriculum, webinars and multilingual resources support the sharing of specialist expertise across countries. Speakers also highlighted gaps in paediatric evidence and uneven clinical trial activity, calling for stronger cross-border research and innovative study designs. The European Rare Kidney Disease Registry (ERKReg) supports research and quality improvement through shared patient data, including evidence on disease progression and treatment outcomes.

Access and equity in rare disease treatments

European marketing authorisation does not guarantee timely patient access: national assessment, pricing and reimbursement procedures can create significant differences between countries. Speakers highlighted the need for closer cooperation on health technology assessment, more transparent reimbursement decisions and stronger use of real-world evidence to help reduce inequalities in access to essential and innovative therapies.

Main policy takeaways

Discussions throughout the webinar highlighted several priorities for strengthening rare kidney disease healthcare and research across Europe.

1. Strengthen the integration of rare kidney diseases into EU and national health policies

Despite progress in European rare disease cooperation, implementation remains fragmented across Member States. Greater political coordination, sustainable funding and stronger integration of European Reference Networks into national healthcare systems are needed to ensure equitable access to specialised care.

2. Improve early diagnosis and access to specialised testing

Delayed diagnosis remains a major challenge, particularly for patients with rare and inherited kidney diseases. Greater access to genetic testing, specialist consultations and timely referral pathways is essential. Earlier diagnosis must also be accompanied by appropriate treatment and long-term follow-up to improve patient outcomes.

3. Strengthen research, clinical trials and evidence generation

Rare kidney disease research continues to face challenges linked to small patient populations, fragmented data and limited clinical trial opportunities. Greater European cooperation, innovative trial methodologies and investment in patient registries are essential to accelerate research. Particular attention should be given to improving paediatric participation and developing appropriate clinical endpoints.

4. Reduce inequalities in access to treatments

Significant disparities persist between Member States in the availability and reimbursement of essential and innovative treatments. Greater coordination in health technology assessment, improved transparency and the use of real-world evidence could help address uncertainties and facilitate more equitable access to therapies.

5. Strengthen healthcare professional education and patient involvement

Continued investment in specialist education, knowledge sharing and multidisciplinary training is needed to improve the management of rare kidney diseases. At the same time, patients and caregivers should be meaningfully involved in research, guideline development and healthcare planning, ensuring that policies reflect their clinical, psychological and practical needs.