

eUROGEN: SHARE. CARE. CURE.

ERN FOR URORECTOGENITAL DISEASES & CONDITIONS

What are ERNs?

- European Reference Networks are virtual networks of doctors and researchers with high expertise in rare or low-prevalence diseases and complex conditions.
- Approximately 6-8,000 rare diseases affect 30m EU citizens
- No country alone has the knowledge or capacity to provide access to diagnosis and high-quality treatment for all of these.
- In 2017, the European Commission launched 24 ERNs involving 900+ highly specialised healthcare teams, in 300+ hospitals across 26 EU countries.

What is eUROGEN?

- eUROGEN is the ERN for rare and complex urorectogenital diseases and conditions.
- Our network comprises 29 healthcare providers (as full members), 12 associated national centers and 4 national coordination hubs (as affiliated partners) across 19 countries.
- We are currently assessing the applications for 31 new healthcare providers to join our network as full members.
- The European Association of Urology and ARM-Net are Supporting Partners.

What is CPMS?

- The Clinical Patient Management System is a secure web platform
- Pseudonymised patient data is shared between healthcare providers/multidisciplinary teams, allowing faster diagnosis and treatment across national borders.
- Since CPMS went live in November 2017, eUROGEN experts have discussed the cases of 97 patients.

We believe wholeheartedly in the EC's mission statement for ERNs: "Share. Care. Cure."

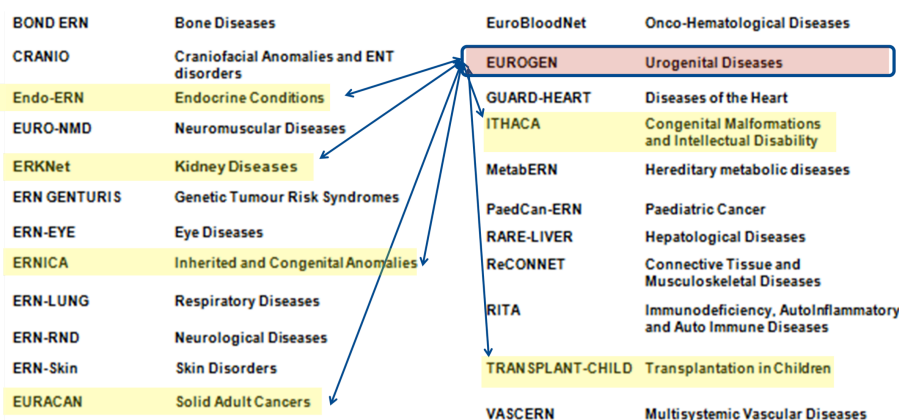


Fig 1. eUROGEN is connected to other ERNs by cross-ERN actions

Current activities within eUROGEN

- We work closely with other ERNs to facilitate the best treatment for patients with overlapping conditions (Fig 1).
- We are developing patient registries (Fig 2).
- We run regular education and training activities targeting patients and clinician, e.g. online webinars..
- We are developing guidelines and best practice documents that can be used by the wider community of clinicians dealing with these conditions.
- We are actively involved in cutting-edge research that can improve the understanding and treatment of these conditions.
- We are committed to transforming the care for rare and complex urorectogenital diseases & conditions by 2030.**

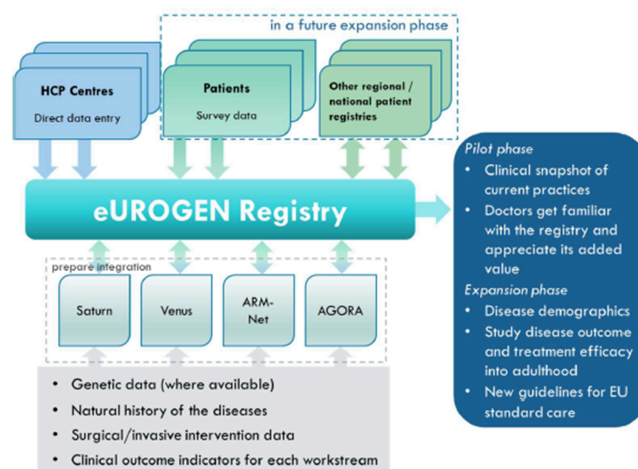


Fig 2. eUROGEN will develop registries for rare diseases

<http://eurogen-ern.eu/>