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.

Patients at the centre

- Patients and their representatives are at the heart of eUROGEN.
- To ensure that patient voices are continuously heard at all levels within our ERN, we work closely with European Patient Advocacy Groups (EPAGS), who bring together elected patient representatives and affiliated organizations.

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.**

http://eurogen-ern.eu/