eUROGEN

European Reference Network for Rare and Complex Urogenital Diseases and Conditions
eUROGEN - Mission

eUROGEN will deliver:

• Quicker specialist evaluation
• More equitable access to high quality
  • Diagnosis
  • Treatment
  • Follow-up

For patients with rare urogenital diseases and complex conditions who need highly specialised assessment and surgery.
eUROGEN - Vision

Knowledge, Costs, Training, Collaboration, Outcomes, Patients.
eUROGEN - Objectives

- **Improve care** for patients with rare, or low prevalence complex diseases or conditions
- **Concentrate expertise** where capacity and knowledge are rare
- **Provide access to** the most appropriate **diagnosis and treatment** of certain conditions
- **Allow expertise to travel** across borders - not patient
- **Act as focal point** for medical training and research
eUROGEN – Strategic Board

Strategic board:
Chair: Network Coordinator, EC, All Healthcare Provider, European Association of Urology, Patient advisory board

Advisory Board:
Nurses, Physiotherapists, Pathologists, Radiologists, Paediatric Psychologists, Epidemiologists, Geneticists, EAU young Academics, Guidelines, Research, EUMS/JCPU, EBCOG, EUROCAT

Patient advisory board:
(n=98 patient organisations on Orphanet database)

Operational board:
Chair: Coordinator, Work stream leads, EAU Guidelines, EC, Patient advisory board, training leads, research leads, clinical leads

Michelle Battye
EAU EU Policy Coordinator

Prof Christopher Chapple (UK)
Network Coordinator
Sheffield Teaching Hospitals
NHS Trust
Rare Congenital Uro-recto-genital Anomalies

- Complex genital reconstructions (DSDs)
- Bladder extrophy/epispadias
- Rare urological stone and kidney diseases
- Non-syndromic urogenital tract malformation of male & female
- Posterior urethral valve
- Posterior hypospadias
- Urorectal/anorectal malformations

Advisory board including ARM Network

Lead: Prof. Wout Feitz (NL) Radboud UMC Nijmegen
eUROGEN – Work Stream 2

**Functional urogenital conditions requiring highly specialised surgery**

- Complicated and complex pelvic floor disorders
- Rare diseases and conditions affecting the female urethra
- Urethral reconstruction in rare diseases and conditions
- Rare retroperitoneal diseases and conditions

**Advisory board**

Leader: Prof Margit Fisch (DE) University Hospital Hamburg
eUROGEN – Work Stream 3

Rare urogenital tumours

Penile cancer
Testicular cancer
Adrenal tumours
Abdomino pelvic sarcoma

Advisory board

Leader: Mr Vijay Sangar (UK) Christie NHS Foundation Trust
eUROGEN – Facilities & Support

- IT platform and toolbox
- Life long urological care and transition tools
- Services provided by ERN
- Clinical pathways and guidelines
- Funding and patient exchange support
- Research gap analysis and proposals
- Education & training and continuation of care

Network
Urogenital Diseases

European Reference Network
European Association of Urology
29 healthcare providers in 11 Member States

BE University Hospital Liège
BE University Hospital Ghent
BE University Hospital Leuven
DK Aarhus University Hospital
DK Copenhagen University Hospital Rigshospitalet
FR Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades
DE Charité Universitätsmedizin Berlin
DE Klinikum der Universität München
DE Klinikum Bremen-Mitte
DE Universitätsklinikum Leipzig
DE Universitätsklinikum Regensburg
DE Universitätsklinikum Hamburg-Eppendorf
IT AO Padua
IT Foundation polyclinic University A. Gemelli Rome
IT Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic Milan
IT Pediatric hospital Bambino Gesù Rome

LT Vilnius University Hospital Santariškių Klinikos
NL Erasmus MC: University Medical Center Rotterdam
NL Radboud University Medical Center Nijmegen
PL Medical University of Gdansk, Copernicus Medical Company LTD
PT Instituto Português de Oncologia do Porto Francisco Gentil, EPE
SE Karolinska University Hospital
SE Sahlgrenska University Hospital
UK Guy's and St Thomas' NHS Foundation Trust
UK King's College Hospital NHS Foundation Trust
UK Sheffield Teaching Hospitals NHS Foundation Trust
UK St George's University Hospitals NHS Foundation Trust
UK The Christie NHS Foundation Trust
UK University College London Hospitals NHS Foundation Trust
eUROGEN – Populate IT platform

Collaborative platform

- Available in March 2017
- List of rare urogenital disease areas and highly complex conditions covered
- Patients and clinicians know where to go to find information
- Quicker access to the expertise they need

Clinical collaboration platform

- Available in July 2017
- With the healthcare providers involved
- Patients can be enrolled starting July 2017
• ePAG (European Patients Advisory Group) for all ERNs
• Using multidisciplinary teams
• Increasing the number of patients being seen
• Leads to better outcomes
eUROGEN – Services to be provided

• Signposting information in an understandable way
• Virtual European MDT case discussions
• Second opinions by the leading experts in multiple HCPs
• Live streaming of:
  • rare urogenital procedures
  • highly complex cases
eUROGEN – Added value

• Data Collection
• Training of Health Care Professionals
• Virtual MDT expert advice
• Efficient use of Research Centres and Resources
• EAU Organisational Structure
Clear definition of roles and responsibilities
• Access and authorisations for use of IT platforms
• Involvement of patients
• Strategic Board meeting and kick off event
• Transparent reporting of activities and outcomes
eUROGEN – Interaction between ERNs

Care for patients with multi-organ diseases

Interactions between ePAGs
• Establishing **protocols** for interactions between ERNs
• Exchange of **best practice** between ERNs
• **Share experience** with IT platform and exchange of knowledge
• Patient approved **informed consent** forms
• **Ethical and legal guidance**
• Work to establish an authorisation & reimbursement mechanism for the provision of virtual cross-border clinical expert advice
• Goal of equity for all patients
• Provision of information to patients and clinicians on ERNs
eUROGEN – Share. Care. Cure

**EUROPEAN REFERENCE NETWORKS**
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.

ERNs are now a reality!

*Spread the message*

Annual EAU Congress
24-28 March London