

ERN for rare urogenital diseases & complex conditions:
Chair: Prof. Wout Feitz (Network Coordinator)
EC, all Healthcare Providers, Affiliated Partners, National Coordination Hubs, Supporting Partners, Advisory Board, EPAGs

Advisory Board:
Nurses, Physiotherapists, Pathologists, Radiologists, Paediatric Psychologists, Epidemiologists, Geneticists, EAU Young Academics, Guidelines, Research, EBPU, EBCOG, EUROCAT

Coordinating Team:
Network Coordinator: Wout Feitz
Operational manager: Michelle Battye
CPMS Implementation Lead: Chris Chapple
Lead WS 1: Wout Feitz
Lead WS 2: Margit Fisch
Lead WS 3: Vijay Sangar

European Patient Advisory Groups (EPAGs):
(n=98 patient organisations on Orphanet database)

Supporting Partners:
EAU, ARM-Net, ESSIC, ESPU, EUPSA

Operational Board:
Manager: Michelle Battye
Workstream Leads, EAU Guidelines, EC, EPAGs, clinical leads, research leads, education leads

Workstream 1:
Rare Congenital Uro-recto-genital anomalies

Workstream 2:
Functional urogenital conditions requiring highly specialised surgery

Workstream 3:
Rare urogenital tumours

Lead: Prof Wout Feitz
- Clinical: Andrzej Gołębiewski
- Research: Magdalena Fossum
- Education: Jorgen Thorup
- EPAG: Dalia Aminoff

Lead: Prof Margit Fisch
- Clinical: Dan Wood
- Research: John Heesakkers
- Education: Frank Van der Aa
- EPAG: Serena Bartezzati

Lead: Mr Vijay Sangar
- Clinical: Maarten Albersen
- Research: Asif Muneer
- Education: Mariangela Mancini
- EPAG: Richard Stamp

1.1 Complex genital reconstructions (DSDs)
DAC: Katja Wolffenbuttel
Vice-DAC: Tbd

1.2 Bladder exstrophy/epispadias
DAC: Tbd
Vice-DAC: Gundela Holmdahl

1.3 Rare urological stone & kidney diseases
DAC: Kay Thomas
Vice-DAC: Tbd

1.4 Non-syndromic urogenital tract malformation
DAC: Giovanni Mosiello
Vice-DAC: Kate Abrahamsson

1.5 Posterior urethral valve
DAC: Yazan Rawashdeh
Vice-DAC: Tbd

1.6 Posterior hypospadias
DAC: Magdalena Fossum
Vice-DAC: Tbd

1.7 Urorectal/anorectal malformations
DAC: Ivo de Blaauw
Vice-DAC: Tbd

2.1 Complicated & complex pelvic floor disorders
DAC: John Heesakkers
Vice-DAC: Tbd

2.2 Rare diseases & conditions affecting female urethra
DAC: Richard Inman
Vice-DAC: Tbd

2.3 Urethral reconstruction in rare diseases & conditions
DAC: Tbd
Vice-DAC: Tbd

2.4 Rare retroperitoneal diseases & conditions
DAC: Tbd
Vice-DAC: Tbd

2.5 Interstitial Cystitis
DAC: Mariangela Mancini
Vice-DAC: Tbd

2.6 Adult urogenital reconstructive surgery
DAC: Dan Wood
Vice-DAC: Tbd

2.7 Surgery for transgender patients
DAC: Silke Riechardt
Vice-DAC: Timo Ole Nieder

3.1 Penile cancer
DAC: Ben Ayres
Vice-DAC: Tbd

3.2 Testicular cancer
DAC: Christian Meyer
Vice-DAC: Tbd

3.3 Adrenal tumours
DAC: Hans Langenhuijsen
Vice-DAC: Tbd

3.4 Abdomino-pelvic sarcoma
DAC: Tbd
Vice-DAC: Tbd

3.5 Rare renal tumour surgery
DAC: Tbd
Vice-DAC: Tbd