



European Reference Network
for rare or low prevalence complex diseases

Network
Urogenital Diseases
(ERN eUROGEN)

ERN eUROGEN

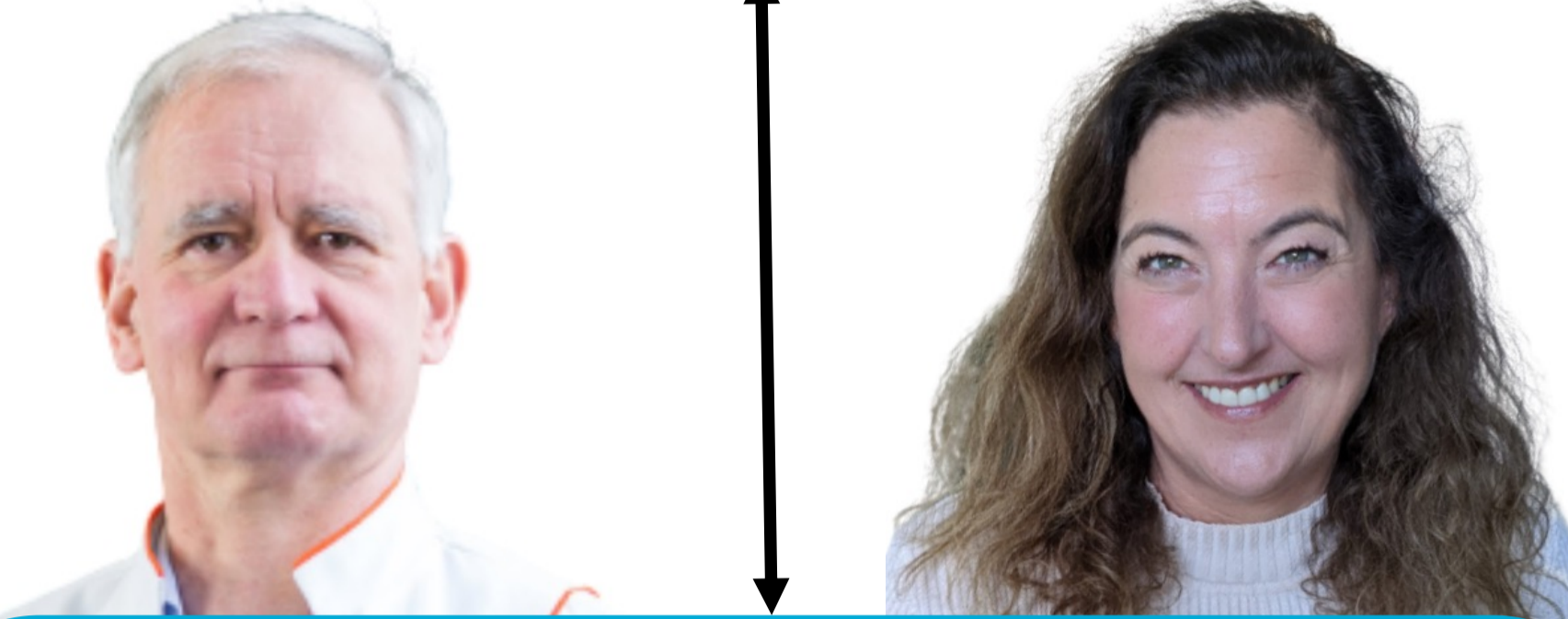
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European Commission

HEALTH

ERN for Rare Urogenital Diseases & Complex Conditions:
European Commission (DG SANTE)
Strategic Board: Network HCP Coordinator Representative,
Full Member & Affiliated Partner Healthcare Providers (HCPs),
ERN Patient Advocacy Group Chair (Dalia Aminoff)



Advisory Board:
International expert clinicians, nurses, physiotherapists, pathologists, radiologists, psychologists, epidemiologists, geneticists, EAU Young Academics, EAU Guidelines Office, EAU Research Foundation, EBPU, EBCOG, EUROCAT

Coordination Team:
Network HCP Coordinator Rep: Wout Feitz
Programme Manager: Michelle Battye
Workstream Leads,
Business Support Manager,
CPMS Management & Helpdesk Team,
Registry Management Team

European Patient Advocacy Group (ePAG):
ePAG Advocates (supported by EURORDIS)

Supporting Partners:
ARM-Net, EAU, ESPU, ESSIC, EUPSA,
individual experts, patient organisations,
individual patients & family members

Operational Board:
Coordination Team +
Clinical/Research/Education Leads, ePAG Chair

Workstream 1:
Rare Congenital
Uro-Recto-Genital Anomalies

Workstream 2:
Functional Urogenital Conditions Requiring
Highly Specialised Surgery

Workstream 3:
Rare
Urogenital Tumours



WS Lead: Prof Wout Feitz
- Clinical Lead: Andrzej Gołębiewski
- Research Lead: Magdalena Fossum
- Education Lead: Jorgen Thorup
- ePAG Advocates: Claire Harkin, Dalia Aminoff, & Kate Tyler



WS Lead: Prof Margit Fisch
- Clinical Lead: tbd
- Research Lead: John Heesakkers
- Education Lead: Frank Van der Aa
- ePAG Advocates: Anna De Santis, Kate Tyler, & Serena Bartezzati



WS Lead: Dr Hans Langenhuijsen
- Clinical Lead: Peter-Paul Willemse
- Research Lead: tbd
- Education Lead: Mariangela Mancini
- ePAG Advocates: John Osborne, Kenny Manzie, & Rob Cornes

1.1 Complex Genital Reconstructions (DSDs)
EA Coordinator: Katja Wolffenbuttel
Vice-EA Coordinator: Verena Ellerkamp

1.2 Bladder Exstrophy/Epispadias
EA Coordinator: Alaa El Ghoneimi
Vice-EA Coordinator: Gundela Holmdahl

1.3 Rare Urological Stone & Kidney Diseases
EA Coordinator: tbd
Vice-EA Coordinator: tbd

1.4 Non-Syndromic Urogenital Tract Malformation
EA Coordinator: Giovanni Mosiello
Vice-EA Coordinator: Kate Abrahamsson

1.5 Posterior Urethral Valve
EA Coordinator: Yazan Rawashdeh
Vice-EA Coordinator: Rafal Chrzan

1.6 Posterior Hypospadias
EA Coordinator: Magdalena Fossum
Vice-EA Coordinator: Alessandro Morlacco

1.7 Urorectal/Anorectal Malformations
EA Coordinator: Ivo de Blaauw
Vice-EA Coordinator: Martin Lacher

2.1 Complicated & Complex Pelvic Floor Disorders
EA Coordinator: John Heesakkers
Vice-EA Coordinator: Michel Wyndaele

2.2 Rare Diseases & Conditions Affecting the Female Urethra
EA Coordinator: tbd
Vice-EA Coordinator: tbd

2.3 Urethral Reconstruction in Rare Diseases & Conditions
EA Coordinator: Gunter de Win
Vice-EA Coordinator: tbd

2.4 Rare Retroperitoneal Diseases & Conditions
EA Coordinator: tbd
Vice-EA Coordinator: tbd

2.5 Interstitial Cystitis
EA Coordinator: Mariangela Mancini
Vice-EA Coordinator: Alessandro Giammò

2.6 Adult Urogenital Reconstructive Surgery
EA Coordinator: Laetitia de Kort
Vice-EA Coordinator: tbd

2.7 Surgery for Transgender Patients
EA Coordinator: Armin Soave
Vice-EA Coordinator: Timo Ole Nieder

3.1 Penile Cancer
EA Coordinator: Oscar Brouwer
Vice-EA Coordinator: Marco Falcone

3.2 Testicular Cancer
EA Coordinator: Yue Che
Vice-EA Coordinator: Tomas Buchler

3.3 Adrenal Tumours
EA Coordinator: Hans Langenhuijsen
Vice-EA Coordinator: Nikola Knežević

3.4 Abdomino-Pelvic Sarcoma
EA Coordinator: tbd
Vice-EA Coordinator: tbd

3.5 Rare Renal Tumour Surgery
EA Coordinator: tbd
Vice-EA Coordinator: tbd



European Association of Urology



European Paediatric Surgeons' Association