



**European Reference Network**  
for rare or low prevalence complex diseases

**Network**  
Urogenital Diseases  
(ERN eUROGEN)

# ERN eUROGEN

**Share. Care. Cure.**

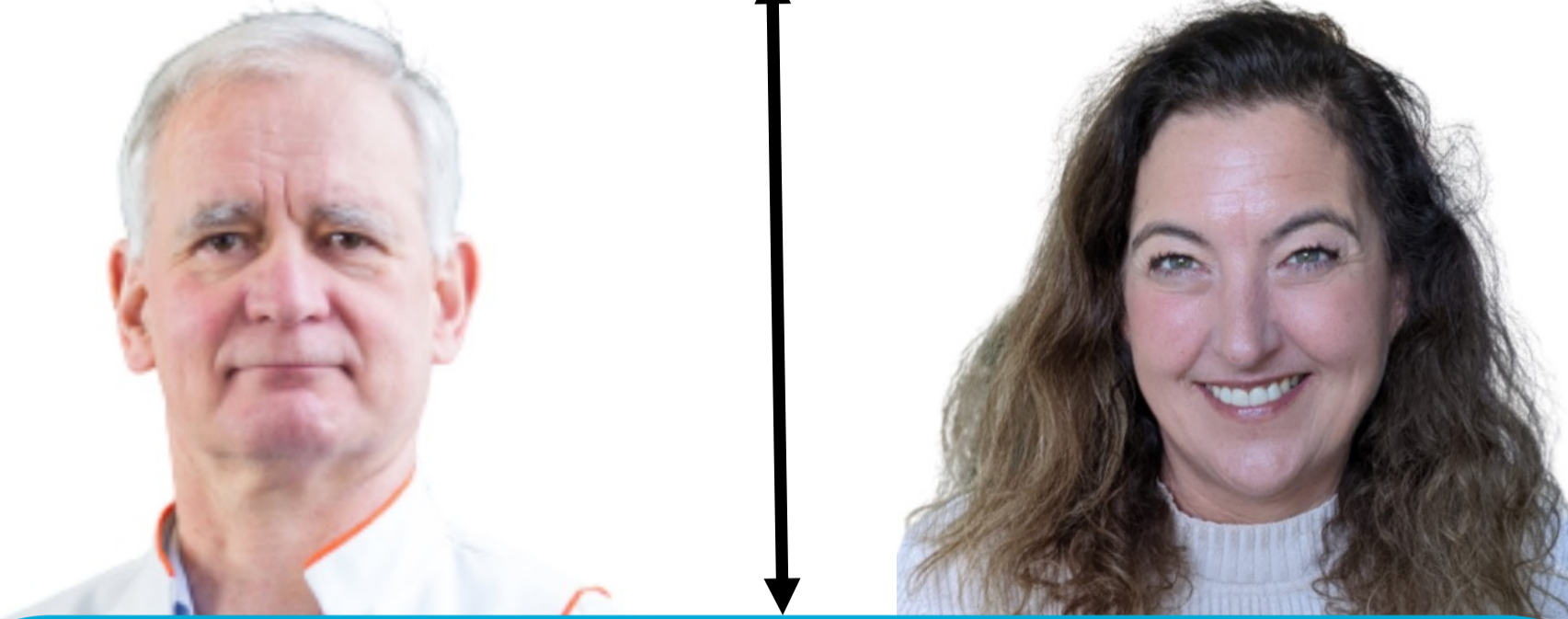


European Commission

**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: Michel Wyndaele
- Education Lead: Mariangela Mancini
- ePAG Advocates: John Osborne, Kenny Manzie, Rob Cornes, & Gemma Crane

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: Malte Vetterlein  
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: Victor Schüttfort  
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