

**ERN for Rare Uro-Recto-Genital Diseases & Complex Conditions:**  
European Commission (DG SANTE)  
**Strategic Board:** Coordinator,  
Full Member & Affiliated Partner Healthcare Providers (HCPs),  
ERN Patient Advocacy Group Chair



**Coordination Team:**  
*Coordinator: Peter Mulders*  
*Sub-Coordinator: Ivo de Blaauw*  
*Programme Manager: Michelle Battye*  
Business Support Manager,  
CPMS Management & Helpdesk Team,  
Registry Management Team

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

**Supporting Partners:**  
ARM-Net, EAU, ESPU, ESSIC, EUPSA,  
EURORDIS, ICS, individual experts

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

**Workstream 1:**  
Rare Congenital  
Uro-Recto-Genital Anomalies

**Workstream 2:**  
Functional Uro-Recto-Genital Conditions  
Requiring Highly Specialised Surgery

**Workstream 3:**  
Rare  
Uro-Recto-Genital Tumours



**WS Lead: Dr Giovanni Mosiello**  
- 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: Michel Wyndaele  
- Research Lead: John Heesakkers  
- Education Lead: Frank Van der Aa  
- ePAG Advocates: Anna De Santis, Kate Tyler,  
& Serena Bartezzati

**WS Lead: Prof Tahlita Zuiverloon**  
- Clinical Lead: Peter-Paul Willemse  
- Research Lead: tbd  
- 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: Anna Bujons Tur  
Vice-EA Coordinator: tbd

1.4 Non-Syndromic Uro-Recto-Genital 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 Uro-Recto-Genital 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: tbd  
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