

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: Kay Thomas

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