

# ERN eUROGEN Guidelines & Clinical Decisions

## Support Tools

### Factsheet (v. 16.06.2021)

The European Commission issued a call for tender in 2018 for an organisation or consortium to work with the ERNs to produce clinical guidelines to the same high standards and with methodological rigour. It was agreed by the Board of the Network at the ERN eUROGEN Strategic Board meeting in Noordwijk on 11- 12 June 2018 that, to avoid duplication of effort and resources, a logical approach would be for intensive work on guidelines to start only once the tender had been awarded. This has now happened, and the Spanish Consortium delivered the ERN methodology for developing clinical guidelines and Clinical Decision-Making Support Tools (CDSTs) on 28 January 2021.

During the monthly workstream and Disease Area Coordinators meetings, the network has reviewed the existing guidelines for the 16 disease areas covered by ERN eUROGEN to identify what currently exists and where there are gaps. The results of this work were discussed during the three-monthly meetings with the ePAGs and at the annual Strategic Board meeting in June 2018. A prioritisation exercise was carried out including the views of the ePAGs and two areas for new guidelines and five areas for the development of expert consensus recommendations were provisionally agreed upon. This work was presented in the report on guidelines (deliverable 4.1) which is saved [within the ERN eUROGEN section of the ECP](#) and published [on our website](#). This has been shared with the Spanish consortium.

The disease areas that were agreed upon for guidelines work in 2018, which will be reviewed by the ERN eUROGEN Expert Group on Guidelines during their first meeting to avoid duplication of work and align priorities, are:

- Full clinical guidelines in areas where none currently exist:
  - Anorectal malformations (ARMs)
  - Vesicovaginal fistulae
- Clinical Decision Support Tools (CDSTs) to elaborate more specifically on disease areas which are currently a part of the more comprehensive guideline:
  - Abdominopelvic Sarcomas
  - Melanoma effecting genitourinary tract
  - Cystinuria - collaboration with ERKNet
  - Bladder Exstrophy
  - Groin Dissection
  - Complex genital reconstructions for Congenital Adrenal Hyperplasia (CAH)

## JOINT WORKING WITH OTHER ERNS AND SUPPORTING PARTNERS

### ERN ITHACA – Joint working group on spina bifida and its urological aspects

- Paediatric Guidelines – Giovanni Mosiello and Kate Abrahamsson
- Transition Guidelines – Dan Wood
- Adult Guidelines – Andrea Manunta and Benoit Peyronnet

### ERN ERNICA

- Collaborative approach on GL for ARMAs
- Collaborative approach on GL for Hirschsprung Disease

### ERN ERKNet

- CDST on Cystinuria
- Consensus paper on fetal LUTO (prenatal and postnatal)

#### EAU Guideline Office and Pediatric Urology GL Group

- Collaborative approach on GLS / CDST for WS1

#### ESSIC

- Collaborative approach on GLS / CDST for Interstitial Cystitis

#### ESPU

- Collaborative approach on GLS / CDST for WS1

#### EUPSA

- Collaborative approach on GL for ARMs

#### EAU/AUA

- Penile cancer (work underway)

## EXPERT PANEL

- We have established an ERN eUROGEN Expert Panel on Guidelines
- All Supporting Partners were asked to appoint a representative to be part of the Expert Group
- Expert Panel to meet and appoint chair and co-chair; review prioritisation exercise and validate or modify; appoints disease specific guidelines subgroups (according to ERN methodology)

Members:

Name	Type of Member
Dalia Aminoff	EPAG Representative
Magdalena Fossum	HCP Representative & Disease Area Coordinator
Giovanni Mosiello	HCP Representative & Disease Area Coordinator
Ernest Leva	HCP Representative
Ana Frobe	AP Representative
Marijana Jazvic	AP Representative
Barbara Daniela Iacobelli	HCP Representative
Mariangela Mancini	HCP Representative & Disease Area Coordinator
Martin Lacher	HCP Representative
Jan-Hendrik Gosemann	HCP Representative
Karin Plass	Supporting Partner - EAU
Salvatore Cascio	Supporting Partner - EUPSA
Paola Midrio	Supporting Partner - EUPSA & ARMNet
Ramnath Subramaniam	Supporting Partner - ESPU
Aurore Bouty	Supporting Partner - ESPU
Mauro Cervigni	Supporting Partner - ESSIC
Wout Feitz	ERN / Ex Officio
Michelle Battye	ERN / Ex Officio
Jen Tidman	ERN / Ex Officio

## TRAINING

- We have found volunteers to follow the ERN guidelines training to start 14 April 2021. (1 advanced level, 5 intermediate).

## Volunteers:

Training Level	Name
Advanced	Magdalena Fossum
Basic-Intermediate	Jan-Hendrik Gosemann
Basic-Intermediate	Martin Lacher
Basic-Intermediate	Marc Miserez
Basic-Intermediate	Gundela Holmdahl
Basic-Intermediate	ARM-Net TBC
Basic-Intermediate	Tabea Schröder
Basic-Intermediate	Anne-Françoise Spinoit
Basic-Intermediate	Giovanni Mosiello
Basic-Intermediate	Rien Nijman
Basic-Intermediate	Andrzej Gołębiowski
Basic-Intermediate	Antonio Di Cesare
Basic-Intermediate	Ernesto Leva
Basic-Intermediate	Ana Bujons Tur
Basic-Intermediate	Martin Promm
Basic-Intermediate	Mariangela Mancini
Basic-Intermediate	Marten Albersen
Basic-Intermediate	Ana Frobe
Basic-Intermediate	Marijana Jazvic
Advanced	Alberto Breda
Basic-Intermediate	Marija Miletić
Basic-Intermediate	Valerie Flaum

## NEXT STEPS

- ERN eUROGEN has sent a request to the Spanish consortium in May 2021 indicating that we would like to be in the first group of 5 ERNs that begins to work actively first with the consortium
- Representative from Spanish consortium attended ERN eUROGEN Strategic Board meeting (4 June 2021) to present the timeline of the work and to answer questions from the network
- First meeting to be arranged and Chair and Co-chair elected
- Develop and execute a survey to members and supporting partners, who is active on which GLS
- Identify current gaps and support needed for the period 2021-2027



European  
Reference  
Networks

[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)



European  
Reference  
Network  
for rare or low prevalence  
complex diseases

Network  
Urogenital Diseases  
(ERN eUROGEN)

<http://eurogen-ern.eu/>

