 

**ERN eUROGEN Clinical Practice Guidelines**

**& Clinical Decision Support Tools**

**Factsheet (v.2022-09-08)**

ERN Guidelines Consortium

The European Commission issued a call for tender in 2018 for an organisation or consortium to work with the European Reference Networks (ERNs) to produce clinical guidelines to the same high standards and with methodological rigour. The tender was won by a Spanish consortium led by [Fundacion Progreso y Salud](https://www.juntadeandalucia.es/fundacionprogresoysalud/" \t "_blank) who delivered the [ERN methodological handbooks](https://eurogen-ern.eu/wp-content/uploads/2021/09/ERN-Guidelines-Methodological-Handbooks.zip) for developing Clinical Practice Guidelines (CPGs) and Clinical Decision Support Tools (CDSTs) on 28 January 2021.

ERN eUROGEN sent a request to the consortium in May 2021 indicating that we would like to be in the first group of ERNs to begin working with them. A representative from Spanish consortium attended the ERN eUROGEN annual Strategic Board Meeting (virtual) on 4 June 2021 to present a timeline of the work and to answer questions from the network.

ERN eUROGEN GUIDELINES Expert panel

In spring 2021, ERN eUROGEN established a Guidelines Expert Panel. All representatives from our Healthcare Providers (HCPs), Affiliated Partners (APs) (Associated National Centres and National Coordination Hubs) and European Patient Advocacy Groups (ePAGs) were invited to apply to join the panel. In addition, all Supporting Partners were asked to appoint a representative to be part of the panel. Interested applicants had to complete a Disclosure of Interest before joining.

The panel, led by a chair and co-chair, will review, validate, and modify the list of potential CPGs and CDSTs and appoint disease specific subgroups to work on the CPGs and CDSTs (according to the ERN methodology).

The current members of the ERN eUROGEN Guidelines Expert Panel are:

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| **Name** | **Type of Member** |
| Ana Fröbe | Former AP Representative |
| Barbara Daniela Iacobelli | HCP Representative |
| Dalia Aminoff | ePAG Representative |
| Ernesto Leva | HCP Representative |
| Giovanni Mosiello | HCP Representative & Disease Area Coordinator |
| Ivo de Blaauw | HCP Representative & Disease Area Coordinator |
| Jan-Hendrik Gösemann | HCP Representative |
| Karin Plass | Supporting Partner - EAU |
| Kate Tyler | ePAG Representative |
| Luke Harper | ESPU Representative |
| Magdalena Fossum | HCP Representative & Disease Area Coordinator |
| Mariangela Mancini | HCP Representative & Disease Area Coordinator |
| Marija Miletić | Former AP Representative |
| Martin Lacher | HCP Representative |
| Mauro Cervigni | Supporting Partner - ESSIC |
| Paola Midrio | Supporting Partner - EUPSA & ARMNet |
| Ramnath Subramaniam (Co-Chair) | Supporting Partner - ESPU |
| Salvatore Cascio | Supporting Partner - EUPSA |
| Serena Bartezzati | ePAG Representative |
| Wout Feitz (Chair) | ERN eUROGEN HCP Network Coordinator Representative |
| Yazan Rawashdeh | HCP Representative |

On 14 June 2022, Ramnath Subramaniam was appointed as Co-Chair of the panel. Wout Feitz remains Chair at present.

ERN GUIDELINES Training

The below ERN eUROGEN members volunteered to take part in ERN guidelines training provided by the consortium, which commenced 14 April 2021:

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| **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 Gołębiewski |
| 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 |

ERN eUROGEN Current Activities

Since 2018, during the monthly workstream management meetings, ERN eUROGEN has reviewed the expertise areas covered by the network, to identify what guidelines and tools currently exist and where there are gaps. The results of this work were discussed during the bi-monthly meetings with the ePAGs and at the annual Strategic Board Meeting in June 2018. An exercise was carried out to avoid duplication of work, align priorities and prioritise topics.

The list of topics was reviewed by the ERN eUROGEN Guidelines Expert Panel during their kick-off meeting on 7 September 2021, and it was decided to progress a **Clinical Practice Guideline (CPG) on anorectal malformation (ARM),** translating and endorsing an existing Dutch guideline. A subgroup was formed with Jan Gösemann and Martin Lacher as Chair and Co-Chair, and work started subsequently with the Spanish agency, IACS.

On 21 July 2022 the Consortium informed us that:

* IACS and ERN eUROGEN will collaborate for the 4th support round (6 months). Support will start on 27 October 2022 and finish on 27 April 2023.
* The support provided by IACS will be devoted to finishing the adoption/adaptation of the CPG on ARM.
* Experts/clinicians from ERN eUROGEN will be involved in this process and will be helped (when needed) by IACS’ methodologists.
* Progress meetings between ERN eUROGEN and IACS will be regularly organised by IACS.

At the ERN eUROGEN Guidelines Expert Panel kick-off meeting on 7 September 2021, it was also decided to progress a **Clinical Decision Support Tool (CDST) on posterior urethral valves (PUV).** A subgroup was formed with Magdalena Fossum and Yazan Rawashdeh as Chair and Co-Chair. Unfortunately, the Consortium and Agency have not been able to provide simultaneous support for this. In June 2022 it was noted that a French guideline is being developed, which we could potentially translate and endorse as a CPG, as per the CPG on ARM. The ERN eUROGEN Coordination Team are in discussion with the subgroup chairs about how to proceed.

ERN eUROGEN Future activities

Proposed topics for future CPGs and CDSTs are as follows:

* Clinical Practice Guidelines (CPGs) in areas where none currently exist:
  + Vesicovaginal fistulae (in collaboration with the EAU Female LUTS Guidelines Panel)
  + Congenital solitary functioning kidney (in collaboration with ERN ERKnet, ESPN, ESPU & EAU Guidelines Office)
* Clinical Decision Support Tools (CDSTs) to elaborate more specifically on disease areas which are currently a part of a more comprehensive guideline:
  + Abdominopelvic sarcomas
  + Melanoma affecting the genitourinary tract
  + Groin Dissection
  + Complex genital reconstructions for Congenital Adrenal Hyperplasia (CAH)
* A recommendation on best practice or a review from a group of experts
  + Non-syndromic urogenital tract malformation (EA 1.4), with experts e.g., Giovanni Mosiello, Kirsten Kluivers, Chiara Lucchetti, Linda Cardozo, Mariangela Mancini, Stefanie Märzheuser, etc.

Joint working with other ERNs, Supporting Partners, & Others

**ERN ITHACA**

* Joint working group on spina bifida and its urological aspects (with the EAU Guidelines Office and others)
* **CPG on Paediatric Spina Bifida** – Giovanni Mosiello & Kate Abrahamsson (Memorandum of Understanding in progress)
  + With funding from the EJP RD, GM arranged a Research Workshop on Spina Bifida in Rennes, FR where discussion on the guideline was progressed, and GM has been successful in his application to the EJP RD for a second workshop, hopefully to be held in October 2022.
* **CPG on Adult Spina** **Bifida** – Andrea Manunta & Benoit Peyronnet

**ERN ERNICA**

* Collaborative approach on **Anorectal Malformation**
* Collaborative approach on **Hirschsprung’s Disease**

**ERN ERKNet**

* A consensus paper on **cystinuria** has been published:
  + Servais A, Thomas K, Dello Strologo L, Sayer JA, Bekri S, Bertholet-Thomas A, Bultitude M, Capolongo G, Cerkauskiene R, Daudon M, Doizi S, Gillion V, Gràcia-Garcia S, Halbritter J, Heidet L, van den Heijkant M, Lemoine S, Knebelmann B, Emma F, Levtchenko E; Metabolic Nephropathy Workgroup of the European Reference Network for Rare Kidney Diseases (ERKNet) and eUROGEN. Cystinuria: clinical practice recommendation. Kidney Int. 2021 Jan;99(1):48-58. doi: [10.1016/j.kint.2020.06.035](https://doi.org/10.1016/j.kint.2020.06.035)
* A consensus paper on **foetal lower urinary tract obstruction** has been published:
  + Capone, V., Persico, N., Berrettini, A. *et al.* Definition, diagnosis and management of fetal lower urinary tract obstruction: consensus of the ERKNet CAKUT-Obstructive Uropathy Work Group. *Nat Rev Urol* **19,**295–303 (2022). doi: [10.1038/s41585-022-00563-8](https://doi.org/10.1038/s41585-022-00563-8)
* Collaborative approach on **CPG for congenital solitary functioning** kidney (Memorandum of Understanding in progress)
* A consensus paper on **urological and nephrological aspects of PUV** – once ERN eUROGEN CDST complete

**EAU Guidelines Office and Pediatric Urology Guidelines Panel**

* Collaborative approach on CPG / CDST for WS1

**EAU/CAU/GSRGT**

* Collaborative approach on CPG / CDST for WS3

**ESSIC**

* Collaborative approach on CPG / CDST for WS2

**ESPU**

* Collaborative approach on CPG / CDST for WS1

**EUPSA**

* Collaborative approach on CPG / CDST for WS1

**DGU**

* Collaborative approach on **CPG for Bladder Exstrophy**

Next steps

* ARM subgroup to progress endorsement of CPG
* PUV subgroup to progress development of CDST
* ERN eUROGEN Guidelines Expert Panel to:
  + develop and execute a survey to members and supporting partners on who Is active on which CPGs and CDSTs
  + progress joint working with other ERNs, Supporting Partners, and others
* ERN eUROGEN Guidelines Expert Panel to identify gaps and support needed for the remainder of the EU4Health Programme 2021-2027

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