

ERN on uro-recto-genital diseases and conditions (ERN eUROGEN)

Rare and complex uro-recto-genital conditions can require surgical correction, often during the neonatal period or in childhood. Urinary and faecal incontinence are a heavy burden on paediatric, adolescent and adult patients. Affected individuals require life-long care provided by multidisciplinary teams of experts who plan and perform surgery and provide post-operative care with additional support from physiotherapy and psychology teams when needed.

ERN eUROGEN provides independently evaluated best practice guidelines and improves the sharing of outcomes. For the first time, it aims to offer the capacity for tracking long-term outcomes for patients over a 15-20 year period through the ERN eUROGEN Registry.

The network collects data and materials where they are lacking; develops new clinical guidelines; builds evidence of best practice; identifies variations in current clinical practice; develops education and training programmes; sets the research agenda in collaboration with patient representatives; and shares knowledge through participation in virtual consultations on the CPMS and through multidisciplinary teams. New specialists for rare and complex uro-recto-genital diseases benefit from specific training and clinical exchange visits offered by the ERN eUROGEN exchange programme.

Ultimately, the network seeks to advance innovation in medicine and improve diagnostics and treatment for rare and complex uro-recto-genital patients through the 'Share. Care. Cure' strategy.

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