

ERN eUROGEN Global Collaboration Strategy

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European Reference Network
for rare or low prevalence complex diseases
Network Urogenital Diseases (ERN eUROGEN)

murdoch children's research institute

cureforu

- Collaboration -
- Knowledge Exchange -
- Registries -
- Research -

Radboudumc
university medical center

ARMnet

EAU
European Association of Urology

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1. INTRODUCTION

Health systems in the European Union aim to provide high-quality, cost-effective care. However, this is particularly difficult in the case of the rare or low-prevalence complex diseases that affect the daily lives of around 30 million EU citizens.

[European Reference Networks](#) (ERNs) are virtual networks involving healthcare providers (HCPs) across Europe. They aim to facilitate innovations for patients with rare diseases or complex conditions that require highly specialised treatment and concentrated new knowledge generation and resources. The ERNs are not a time-limited project. Instead, they are an EU initiative which is a new form of interaction based on [Directive 2011/24/EU](#) on the application of patients' rights in cross-border healthcare between healthcare providers and the Member States at a scale never attempted before, supported and funded by the EC, to improve care for patients with rare diseases and complex conditions.

24 European Reference Networks (ERNs) for rare or low prevalence or complex diseases were set up by the European Commission (EC) in 2017 and are now fully operational, creating an interconnected EU global network focusing on nearly all rare (> 7000), low prevalence and complex diseases, regardless of the age of the patients. ERN membership is based not only on state-of-the-art clinical expertise recognised by the health ministries of the Member States but also on the excellence of all stakeholders' research, education, and training activities. Links with patient organisations are today more robust than ever.

[Directive 2011/24/EU](#) establishes the legal base that ERNs should “**collaborate closely with other centres of expertise and networks at national and international level**” and on 19 May 2022, the EC announced the launch of work on a new [EU Global Health Strategy](#).

Therefore, as the ERNs come to the end of their first five years of operation, now is the time for the ERN eUROGEN [Strategic Board](#) to reflect on achievements and how the ERN could collaborate most effectively with other centres of expertise and networks at national, European and international levels.

2. EUROPEAN COLLABORATION: SUPPORTING PARTNERS

Since the beginning, ERN eUROGEN has aimed to collaborate as actively as possible with the major scientific societies related to the specific expertise areas covered by the network. One of the network's strengths is that it brings together paediatric and adult urologists and surgeons, facilitating highly specialised uro-recto-genital congenital, functional urogenital conditions, and

rare urology tumour care of patients from birth to end of life. The strategic objectives of the scientific societies align perfectly with those of ERN eUROGEN, with such organisations able to collaborate to focus on rare diseases and complex conditions.

Therefore, a clear framework for collaboration was developed early on in our operations to allow [Supporting Partner](#) organisations such as scientific societies as well as individual experts or patients to collaborate with the ERN clearly and transparently. Linking any patient representatives from these scientific societies and ERN eUROGEN is also beneficial. To date, Supporting Partner agreements have been signed with the following organisations:

- [European Association of Urology](#) (EAU)
- [European Society for Paediatric Urology](#) (ESPU)
- [Anorectal Malformations Network \(ARM Net\)](#)
- [International Society for the Study of Bladder Pain Syndrome](#) (ESSIC)
- [European Paediatric Surgeons' Association](#) (EUPSA)

One of ERN eUROGEN's objectives is to [disseminate](#) knowledge across the network and beyond through active cross-ERN and external [collaborations](#) and provide public and network information updates through the ERN eUROGEN [website](#), [e-newsletters](#), and [social media platforms](#), including our [YouTube channel](#). The scientific societies' added communication and dissemination capabilities are key, allowing us to spread the message about the specific services offered by the ERNs to healthcare professionals, patients, and the public in general.

The solid foundation of collaboration with the scientific societies has been strengthened during the last few years and will now be expanded internationally.

3. EUROPEAN & INTERNATIONAL POLICY DEVELOPMENTS

3.1. Rare 2030

[Rare 2030](#) was a two-year foresight study funded by the [European Commission](#) that gathered the input of over 250 experts from across the rare disease community (patients, practitioners, and key opinion leaders) to propose policy recommendations leading to improved policy and a better future for people living with a rare disease in Europe.

The study resulted in [eight overarching recommendations](#) to ensure that the future of the 30 million people living with a rare disease is not left to luck or chance. The eight final recommendations cover diagnosis, treatment, care, research, data, and European and national infrastructures and set out the roadmap for the next decade of rare disease policies.

ERN eUROGEN had three members in the expert group. They attended several virtual meetings of the Rare 2030 "Panel of Experts", along with many other stakeholders, to validate the trends and drivers that were identified, ranked, and prioritised throughout the year to define possible future trends important for rare diseases. They also contributed comments ensuring that highly specialised surgery was included in the recommendations, along with other important treatment options for patients with rare diseases and complex conditions.

3.2. RDI & WHO Collaborative Global Network

In December 2019, [Rare Diseases International](#) (RDI) signed a [Memorandum of Understanding](#) with the [World Health Organisation](#) (WHO).

In 2021, the [Collaborative Global Network](#) (CGN) Panel of Experts was set up and [Michelle Battye](#), ERN eUROGEN Programme Manager, was invited to contribute to this work. The panel aims to shape international policy on rare diseases, strengthen health systems to address rare diseases, advance Universal Health Coverage (UHC), and create global networks for patients with rare diseases and link them to existing structures in Europe, such as the ERNs.

Now in its third year, the collaboration focuses on developing a common [Operational Description for Rare Diseases](#) and laying the groundwork for the CGN and centres of excellence for rare diseases.

4. INTERNATIONAL COLLABORATION

Over the last few years, it has become clear that international organisations are becoming increasingly interested in the innovative ERN model of using [secure digital technologies](#) to connect clinical and patient experts on rare diseases and complex conditions with healthcare professionals and patients seeking advice or information.

This is one of the strengths of the ERN model, and the transparent funding from the [European Commission](#) means that the products developed by the ERNs (e.g., [clinical practice guidelines and clinical decision support tools](#), [publications](#), and protocols and documents related to [registry](#) development, such as [Joint Research Centre](#) (JRC) core datasets, informed consent, and data sharing agreements between healthcare providers, etc.) can be shared with other organisations as examples of good practice during collaborative exchanges. We believe that some “quick wins” are possible through collaborations around the development of the ERN eUROGEN [registry](#).

Some examples of our existing international collaborations are listed below.

4.1. South America and worldwide

Aims	Who is involved	Next steps
<ul style="list-style-type: none"> • To set up a new penile cancer registry for South America (higher incidence rate than the EU). • To share registry-related protocols to ensure new registries are interoperable at a technical level because the same core data points are used. • To exchange knowledge on specific data sets for inclusion related to penile cancer. • To increase research potential – more patients and comparability between regions. 	<p>Working Group (established September 2021):</p> <ul style="list-style-type: none"> • The ERN eUROGEN HCP Network Coordinator Representative and current ERN eUROGEN HCP Members (from Workstream 3 – Rare Urogenital Tumours, EA 3.1 Penile Cancer) and previous UK ERN eUROGEN HCP members, • European Association of Urology (EAU) Guidelines Office penile cancer representatives, • EAU Research Foundation (EAU RF) registry representatives, • Confederación Americana de Urología (CAU) penile cancer representatives, • Global Society of Rare Genitourinary Tumors (GSRGT) penile cancer representatives. 	<ul style="list-style-type: none"> • Appoint chair • Sign Memorandum of Understanding • Hold regular meetings • Knowledge exchange of expertise/information/protocols

4.2. Australia and New Zealand

Aims	Who is involved	Next steps
<ul style="list-style-type: none"> • To set up a new registry for ARMs for Australia and New Zealand. Isabel Hageman, ERN eUROGEN Registry Assistant, is a PhD candidate being supervised jointly by Prof Ivo de Blaauw (Radboudumc, NL), Sebastian King and Misel Trajanowska (MCRI, AU) and this is the aim of her research and thesis. • To share registry-related protocols to ensure new registries are interoperable at a technical level because the same core data points are used. • To exchange knowledge on specific data sets for inclusion related to ARMs. • To increase research potential – more patients and comparability between regions. 	<p>Memorandum of Understanding signed and in place (since April 2022)</p> <ul style="list-style-type: none"> • ERN eUROGEN • Radboudumc, Nijmegen • Murdoch Children’s Research Institute (MCRI), Melbourne 	<ul style="list-style-type: none"> • Hold regular meetings • Knowledge exchange of expertise/information/protocols

4.3. Developing World (Pakistan, Afghanistan, Ethiopia, Turkey, etc.)

Aims	Who is involved	Next steps
<ul style="list-style-type: none"> • To facilitate healthcare professionals from developed and developing countries to connect, 	<p>Memorandum of Understanding signed</p>	<ul style="list-style-type: none"> • Hold regular meetings

<p>collaborate and learn from each other through CureForU's digital collaboration portal and share knowledge of best practices gained from using the ERN Clinical Patient Management System (CPMS).</p> <ul style="list-style-type: none"> • To deliver faster specialist evaluation and more equitable access to high-quality diagnoses, treatment, and care for patients with rare urogenital diseases and complex conditions who need highly specialised assessment and surgery. • To cover a wide geographical area of European developed countries and developing countries (e.g., Pakistan, Afghanistan, Ethiopia, Turkey, etc.) and help those lacking technology or expertise by providing high-quality, highly specialised services through knowledge exchange. • To disseminate relevant knowledge and information and promote each other when appropriate. • To stimulate and contribute to research activities (where possible). • To develop, exchange, and disseminate clinical practice guidelines and clinical decision support tools and link and/or add data to patient registries when interoperable and feasible. • To train and educate urologists and surgeons, including through the CureForU mentorship programme and training courses, through the ERN Academy and ERN eUROGEN videos of highly specialised surgeries, and through the mobility of expertise (where possible). 	<p>and in place (since March 2022)</p> <ul style="list-style-type: none"> • ERN eUROGEN • CureForU 	<ul style="list-style-type: none"> • Knowledge exchange of expertise/information/protocols
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