

SUPPORTING PARTNER COLLABORATION AGREEMENT

Between the European Reference Network for rare urorectogenital diseases and complex conditions (ERN eUROGEN) and EURORDIS-Rare Diseases Europe

Governance

On 7 May 2024, EURORDIS-Rare Diseases Europe, hereinafter referred to as EURORDIS, agreed to sign a Supporting Partner Agreement with ERN eUROGEN to formalise the terms of collaboration between the two organisations.

An email was sent to the ERN eUROGEN Strategic Board asking them to vote on the inclusion of EURORDIS as a Supporting Partner. All respondents unanimously welcomed the input of EURORDIS-Rare Diseases Europe.

EURORDIS is therefore officially recognised by ERN eUROGEN as a Supporting Partner and ERN eUROGEN affirms its commitment to work in collaboration with EURORDIS and their representatives for the benefit of patients living with rare urorectogenital diseases and complex conditions, under the leadership of the Coordinator and Coordinating Healthcare Provider (HCP), which is Radboudumc, Nijmegen in The Netherlands.

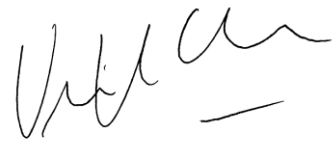
Terms of collaboration between ERN eUROGEN and EURORDIS-Rare Diseases Europe

- ERN eUROGEN and EURORDIS agree to work in collaboration, where possible, on areas of common strategic interest.
- In conveying their opinions and input ERN eUROGEN and EURORDIS will be respectful to the viewpoints and opinions of others and ensure criticism is constructive, to ensure that we can maintain the very high standards of professionalism that the ERN adheres to. An open and collaborative debate where all individuals can feel respected and valued is a core principle.
- EURORDIS accepts all the Articles, rights and obligations listed in the ERN eUROGEN Governance Document and ERN eUROGEN Conflict of Interests Policy.
- One representative of EURORDIS may attend the annual ERN eUROGEN Strategic Board meeting with no financial compensation by ERN eUROGEN and with no voting rights but an advisory status and informative role.
- EURORDIS will support the ERN eUROGEN Coordinating team and its European Patient Advocacy Group team to structure patient representation in the Network and implement an effective approach to patient partnership throughout ERN eUROGEN's core activity areas (health and social care, training and education, information and outreach, research and Network strategy and management). EURORDIS will also support the Network to embed the principles for a healthy partnership recognised in the [Patient Partnership Framework for the ERNs](#) in these activities: mutual respect, learning, transparency, complementarity, shared leadership, team work, professionalism, continuity and clarity of roles and responsibilities.

- EURORDIS will support ERN eUROGEN patient representatives, patient organisations and individual patients to partner effectively with clinicians by providing opportunities for peer learning and knowledge sharing on relevant topics and offering guidance on methodological approaches to partner in these areas and to bring the patient community needs and perspectives.
- EURORDIS and ERN eUROGEN will collaborate to raise awareness and address the impact that rare conditions have on Mental Health & Wellbeing, specifically hosting a minimum of one joint webinar, as well as designating 1 clinical and 1 patient representative involved in ERN eUROGEN to take part in EURORDIS Mental Health Partnership Network.
- EURORDIS will provide ERN eUROGEN access to online dashboards of Rare Barometer surveys, presenting the number of respondents and raw results for the list of urogenital diseases provided by ERN eUROGEN. ERN eUROGEN will be able to use its results from Rare Barometer surveys for publication, on the condition that they refer to Rare Barometer (mentioning the programme or adding the Rare Barometer logo and mentioning that Rare Barometer is a EURORDIS initiative).¹
- ERN eUROGEN will be invited to renew its Associate Partnership of the European Conference for Rare Diseases & Orphan Products (ECRD), the largest multi-stakeholder gathering in Europe for the rare disease community), organised every two years. In exchange for actively promoting the Call for Posters and registrations, ERN eUROGEN will be entitled to one complimentary registration (ERN Coordinator only) to attend the conference in person or online.
- ERN eUROGEN and EURORDIS will consider requests to disseminate relevant information from each other, through their communications channels via exchange between communications managers. The contact persons for EURORDIS and eUROGEN are referred to in Annex I.
- ERN eUROGEN and EURORDIS will meet at least once a year concerning collaboration, expectations, and future directions.
- This Agreement will have an initial duration of 3 years and will be renewed automatically for successive one (3) year terms unless either Party notifies the other in writing not less than thirty (30) days prior to the expiration of the current term, of its intention not to renew. Both the initial term and any renewal term are subject to earlier termination as otherwise provided for by this Agreement.
- If EURORDIS wishes to terminate their collaboration as a Supporting Partner, in case of a Conflict of Interest (COI), a difference in direction, or other reasons, they should write to the ERN Coordinator explaining the reasons for the termination. The ERN Coordination Team will review the termination and then a letter will be sent to EURORDIS-Rare Diseases Europe to end the collaboration.
- If ERN eUROGEN wishes to terminate the collaboration with EURORDIS-Rare Diseases Europe due to COI, difference in direction, or other reasons, after an additional consultation has been offered to exchange views, discuss the change in collaboration and future options, a letter will be sent by the ERN eUROGEN Coordination Team to end the termination.

¹ Rare Barometer is EURORDIS global survey initiative.

EURODIS-Rare Diseases Europe



Virginie Bros-Facer
Chief Executive Officer
Date: 14 May 2024

ERN eUROGEN



Prof. Wout Feitz.
ERN eUROGEN Coordinator
Date: 7 May 2024

Annex I

Contact details for Communications

For the purposes of discussing communications topics relevant to this Supporting Partner Agreement, ERN eUROGEN communication manager is Jen Tidman, ERN eUROGEN Business Support Manager: jentidman@radboudumc.nl

EURORDIS contact person will be Stanislav Ostapenko (stanislav.ostapenko@eurordis.org), EURORDIS Communications Director.