European Rare Diseases
Research Alliance

Networking Support Scheme

Small support scheme for networking initiatives to share knowledge on rare diseases and rare cancers

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ANNEX 2 of Call Text

January 2026

Submission on a continuous basis
Collection of applications every 6 months, starting from October 7, 2025.

Call text version of January 2026 has to be used for the round with collection date of April 7, 2026 (Round 2026A) and later.

For further information,
The application template, the Frequently Asked Questions (FAQ), and the link to the ERDERA electronic submission platform can be found at the ERDERA website.

For questions concerning content:
Read the Frequently Asked Questions (FAQ) on: ERDERA website
Or contact the Networking Support Scheme Secretariat:
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ANNEX 2: ELIGIBILITY OF PATIENT ADVOCACY ORGANIZATION (PAO)

The Patient Advocacy Organizations should fulfil the following criteria to be eligible to receive funding:

Legitimacy:

- Represent diseases that are in the scope of the call according to the information in 4.1 (eligibility and non-eligibility of diseases and topics).
- The organization should be formally established and registered as a not-for-profit organization for more than 1 year in one of the countries involved in ERDERA. See Annex 1 for the countries involved.

Mission/objectives:

- The organization shall have its mission/objectives clearly defined and should agree to have it/them published on ERDERA website.

Activities:

- The organization shall have, as part of its activities, a specific interest in rare diseases or rare cancers which should be documented (e.g., through a report published on the organization website).

Representation:

- The organization shall be representative of rare disease patients or rare cancer patients within
    - EU Member States
    - EU/EEA states
    - ERDERA partner countries next to EU Member States and EU/EEA states

  The list of countries is indicated in the table in Annex 1.

Structure:

- The organization should have governing bodies which include a majority of rare disease patients or their family members OR rare cancer patients or their family members.
- The organization's governing structure should Include a legal financial representative for signing a financial report.

Accountability:

- The organization should have proven activities such as rare disease patient support, rare cancer patient support, advocacy activities, and/or rare disease/rare cancer research.
- Statements and opinions of the organization should reflect the views and opinions of its members and adequate consultation procedures with those members should be in place. In particular, the organization should ensure that the appropriate flow of information is in place to allow dialogue both ways: from and towards its members.
- The organization can demonstrate that its account system is able to trace all costs related to the project and archive these costs for a duration of 5 years after the last payment received from the funder.

Transparency:

- The organization shall be financially independent, particularly from the pharmaceutical industry (max. 49 % of funding from several companies) and disclose to ERDERA its sources of funding both public and private by providing the name of the bodies and their individual financial contribution, both in absolute terms and in terms of the overall percentage of the organization budget. Any relationship with corporate sponsorship should be clear and transparent. This information shall be communicated to ERDERA on an annual basis.
- The organization shall publish on its website the articles of association, sources of funding, and information on their activities.