



European **Rare Diseases**
Research Alliance

Networking Support Scheme

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

Frequently Asked Questions (FAQ)

July 2025

For further information,

The call text, application template and the link to the ERDERA electronic submission platform can be found at the [ERDERA website](#).

For questions concerning content:

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GENERAL QUESTIONS

1. DOES YOUR NETWORKING EVENT FIT IN THE SCOPE OF THE CALL?

Yes, if your event addresses both aims of the NSS: it facilitates scientific knowledge exchange on rare diseases or rare cancers within a network of clinicians, researchers, research managers and/or patients and includes in the applying consortium at least one (or more) representative(s) from underrepresented country(ies) (listed in Annex 1 of the Call text).

The focus of the networking events should be on research results and their implications, as well as on innovative solutions. The results of these networking events may lead to future collaborative and novel research efforts.

Non-research-focused gatherings (e.g., family meetings) are not eligible.

2. SHOULD EACH APPLICATION BE FOR A SINGLE EVENT OR CAN IT BE FOR A SERIES OF EVENTS?

Funding is meant for a single event, not for a series of events. However, a single event may take place on consecutive days.

3. IS THERE AN OPTION FOR CO-FINANCING?

Yes, co-financing is possible. See also Question 34.

4. WHAT ARE THE PARAMETERS FOR INDUSTRY INVOLVEMENT?

Industry cannot be funded as applicant, but industry is allowed to join the Networking event with own budget and is allowed to cofund the event. However, the content of the event should be developed by the consortium that applies for funding at the Networking Support Scheme and independently of the industry.

5. WHEN ARE THE COLLECTION DATES AND WHEN CAN MY EVENT TAKE PLACE IF SELECTED?

The call is continuously open from May 2025 till April 2029, unless the entire budget is exhausted. Each 6 months, on specific dates in October and April, the applications are collected and competitively evaluated after the eligibility check of the applications. The eligibility and evaluation phase will take approximately 6 months. If the application is selected, then the event has to take place no later than 15 months after selection.

As an example: if the collection date of the applications is October 7, 2025, the selection process is finalized in April 2026, the Networking event has to take place no later than July 2027.

6 HOW LONG WILL THE EVALUATION PROCESS TAKE PLACE? WHEN WILL WE RECEIVE A DECISION FROM THE NETWORKING EVALUATION COMMITTEE?

Up to 6 months, but it depends on the selection of the Networking Evaluation Committee (NEC). The evaluation procedure may take one or two steps:

- (1) A scientific evaluation by the Networking Evaluation Committee (NEC).
 - a. The application is ranked on average below 12 points. In this case, the decision that the application is not selected will be sent about 4-5 months after the collection date, including the opinion and recommendations of the NEC.
 - b. The application is ranked on average with 12 points or higher, in this case the application will receive an ethics assessment.
- (2) Ethics assessment: The Ethics Advisory Group (EAG) assesses the ethics requirements using the completed self-assessment table. This will result in ethics recommendations. If the EAG decides that the ethics recommendations cannot be met, the application will not be funded.
- (3) The two-step procedure for applications that were selected by the NEC will take about 6 months, including informing the applicants of the outcomes of the evaluations.

7. IS THERE A MAXIMUM NUMBER OF APPLICATIONS THAT WILL BE FUNDED IN EACH ROUND?

Yes, for each round there is a target budget of € 375,000. Since each event will cost maximum € 30,000, the maximum number of applications that can be funded in a round is about 12-13.

8. DO YOU HAVE AN EXAMPLE OF A SELECTED APPLICATION?

Yes, you can find examples of selected Networking events by clicking on NSS on the [Dashboard](#) of the European Joint Programme on Rare Diseases in which a similar Networking Support Scheme was organized.

9. IF MY APPLICATION WAS NOT SELECTED IN THE PAST, CAN WE RESUBMIT THE APPLICATION?

Yes, you can reapply but only once. It is expected that you will take into consideration the recommendations of the Networking Evaluation Committee and explain what changes you made to the reapplication. See section 4.7 in the Call text.

10. CAN I APPLY FOR FUNDING OF A PUBLICATION/ AN ARTICLE OR APPLY FOR FUNDING FOR A PRESENTATION AT A CONGRESS?

No, the Networking Support Scheme funds the organization of a Networking event (workshop or conference), but not the publication of an article or a presentation at another congress than a Networking event.

11 WHAT KIND OF ORGANIZATIONS ARE LMT AND ZONMW, AND HOW DO THESE DIFFER FROM NSSS AND ERDERA?

LMT (Lietuvos mokslo taryba - Research Council of Lithuania) and ZonMw (The Netherlands Organisation for Health Research and Development) are national research funding organizations which are partners in European Rare Diseases Research Alliance (ERDERA) consortium. These organizations run jointly the Networking Support Scheme Secretariat (NSSS) which implements one of the ERDERA funding instruments - the Networking Support Scheme (NSS).

[ERDERA](#) is a programme cofunded by the European Commission and has the ambition to improve the health and wellbeing of the 30 million people in Europe who live with rare conditions, while making the EU the world leader in rare-disease science and innovation.

QUESTIONS ON ELIGIBILITY AND CONSORTIUM MEMBERS

12 SHOULD THE CONSORTIUM MEMBERS BE INDIVIDUALS OR ORGANIZATIONS?

Individuals are applying on behalf of their organization. Individuals without an organization cannot apply. Individuals from the same organization, having different experiences and/or separate roles in the organization of the Networking event may apply. Keep in mind that the consortium that applies should involve representatives from at least three different countries, including at least one from an underrepresented country. Annex 1 in the Call text lists the underrepresented countries.

13 IF MY ORGANIZATION IS A EUROPEAN ORGANIZATION, TO WHICH COUNTRY WILL IT BE ATTRIBUTED?

The country where the European organization is registered will be used as the country of the organization. Even though a European organization may comprise several organizations, you still need additional organizations from two other countries that are eligible for ERDERA, to have an eligible consortium that can apply.

14 IF MORE THAN ONE PERSON FROM THE SAME ORGANIZATION WOULD APPLY, WOULD THIS PERSON COUNT AS ANOTHER CO-APPLICANT?

It is possible to have two or more applicants from the same institute if you clearly indicate that they have different organizational roles e.g., one applicant is the local organizer and the other applicant participates in the scientific programme committee.

When you have more than 10 (co-)applicants in the application because two people from the same institute are applicants, you may choose to put the name/role of one of those people in the text of the application.

15 WHERE CAN I FIND THE ELIGIBLE COUNTRIES?

The countries that are eligible are mentioned in Annex 1 of the Call text and in Annex 1 of this Frequently Asked Questions (FAQ) document.

16 ARE PARTICIPANTS FROM AUSTRALIA, CANADA, UK, AND SWITZERLAND ELIGIBLE AS APPLICANT?

Participants from UK, Switzerland, Canada, or Australia are **not eligible as principal applicant** in the Networking Support Scheme (NSS) as the NSS is funded through EU (Horizon Europe) budget.

However, the organizations of **co-applicants** that are located in Australia, Canada, United Kingdom, and Switzerland are eligible to take part in the applying consortium as these four countries are taking part in ERDERA.

17 IS OUR PATIENT ADVOCACY ORGANIZATION (PAO) ELIGIBLE AS A PRINCIPAL APPLICANT?

Yes, if the applying organization is formally established and registered as a not-for-profit organization in one of the eligible countries (see Annex 1 in the Call text).

Please check Annex 2 of the Call text to see whether your Patient Advocacy Organization (PAO) is eligible.

When your PAO would like to be **principal applicant** then it has to upload the completed and signed Declaration of Honour to the ERDERA online submission platform.

It is possible that your organization is registered in an eligible country, but you cannot tick all four boxes in the Declaration of Honour. In that case your organization is not eligible as a principal applicant, but you may still apply as a **co-applicant** in the consortium. Another organization or institute should be the eligible principal applicant in this consortium.

18 HOW CAN I FIND A PAO FOR A SPECIFIC DISEASE?

For information about where to find patient partners and PAOs willing to be involved in Networking events, please see:

- Orphanet portal for rare diseases and drugs [patient organisation directory](#)
- Rare Diseases Europe ([EURORDIS](#))
- European Reference Networks ([ERNs](#))
- European Patient's Academy on Therapeutic Innovation ([EUPATI](#))
- [European Patients' Forum](#)
- [Research Patient Partnership resources](#) (CIHR-IG)

19 HOW CAN I FIND AN EXPERT IN AN UNDERREPRESENTED COUNTRY?

You may start using [Orphanet](#) that has several directories on expert centres, professionals, and institutions and on patient organizations. EURORDIS has a [list of member associations](#) in 75 countries.

You may look in the [Dashboard of funded rare diseases projects](#) in which names of members of selected research consortia or networking events are indicated.

You may also ask rare disease research funding organizations in underrepresented countries to help you. You can find the representatives of these funding organizations in the Guidelines of ERDERA Joint Transnational Calls on the [ERDERA website](#).

20 ARE APPLICANTS FROM PRIVATE HOSPITALS ELIGIBLE AS A PRINCIPAL APPLICANT?

Yes, applicants from private hospitals are allowed to apply as principal applicants.

21 IS A PHD CANDIDATE CONSIDERED TO BE AN EARLY CAREER RESEARCHER?

No, a PhD candidate (with or without a medical degree) is not considered to be an Early Career Researcher according to the definition in section 4.6.1 in the Call text.

If the person brings added value to the applying consortium, you can indicate in the application text or in his/her CV that this young person is at the start of his/her research career.

The Networking Support Scheme encourages PhD candidates and young researchers to join the consortium or to have a role in the event, e.g., presenting posters, helping the local organizers with the event, etc.

22 WHAT IS THE DEFINITION OF A RESEARCH MANAGER?

A research manager is eligible to apply for a networking event in the NSS if he/she is working at a university, other higher education institution, public research institute, or in the clinical/public health sector (hospitals/public health and/or other healthcare settings and health organizations) and is involved in organizing research, e.g., an ERN project manager.

23 CAN I STILL CHANGE APPLICANTS AFTER SUBMITTING MY APPLICATION?

The application cannot be altered after you have saved and submitted the application in the ERDERA online submission platform.

24 WHAT IS THE DEFINITION OF UNDIAGNOSED DISEASES IN THE NETWORKING SUPPORT SCHEME?

Cohorts of undiagnosed patients who are suspected of suffering from a rare disease/ rare cancer. Undiagnosed patients have symptoms or a set of symptoms that are seen in other rare diseases or rare cancers, have no diagnosis after a significant time period and have visited several kinds of medical specialists. These diseases may be unusual presentations of known rare diseases/rare cancers or a disease that is yet to be characterized.

ORPHAcode 616874: Rare disorder without a determined diagnosis after full investigation.

QUESTIONS FOR REGISTERING ON THE ERDERA ONLINE SUBMISSION PLATFORM AND COMPLETING RELEVANT INFORMATION ON THIS PLATFORM AND APPLICATION TEMPLATE

25 WHO IS THE RESPONSIBLE PERSON TO COMPLETE THE INFORMATION ON THE ERDERA ONLINE SUBMISSION PLATFORM AND IN THE APPLICATION TEMPLATE?

Only a principal applicant is the person who should register on the ERDERA online submission platform and has to complete the necessary information for the application on behalf of all applicants of the specific application and to upload all additional documents. The link to register is [ERDERA - European Rare Diseases Research Alliance](#).

After registration, you can choose in the dropdown list "Type of funding" the Networking Support Scheme (year. number).

More information on using the ERDERA NSS online submission platform is present in the document "Instructions for use of ERDERA NSS online submission platform" on the [ERDERA](#) website under "*Downloadable documents*".

26 WHAT HAS A CO-APPLICANT TO DO FOR THE APPLICATION?

As a co-applicant you should not register on the ERDERA online submission platform.

However, as co-applicant, you should support the principal applicant by e.g., giving information on his/her CV, discussing with the other consortium members the goals of the event, programme of the event, logistics, communication channels, role in the event itself. All this information is needed for the ERDERA online submission platform and application template that the principal applicant has to complete.

Co-applicants have to sign the signature page of the application (in addition to the Principal applicant).

27 IS THERE AN EXAMPLE OF THE INFORMATION THAT HAS TO BE PROVIDED IN THE ERDERA ONLINE SUBMISSION?

On the [ERDERA](#) website a document is available that provides information what kind of information is needed on the ERDERA online submission platform ("*Preview of the information that has to be completed on the ERDERA NSS submission platform*"). This document is not intended to be filled out, but only to show what kind of information has to be written on this platform.

Only proposals that have been entered electronically at the ERDERA online submission platform will be evaluated.

28 WHERE CAN I FIND THE APPLICATION TEMPLATE?

The application template is available on the [ERDERA](#) website. Members of the consortium can download it and work together to complete the application.

29 WHO SHOULD BE CONTACTED IN CASE OF TECHNICAL PROBLEMS OF THE ERDERA ONLINE SUBMISSION SYSTEM?

For any technical problems regarding the ERDERA electronic proposal submission, please send an email to MyScienceWork: E-mail: erdera@mysciencework.freshdesk.com

30 WHAT IS THE CONTEXT OF THE KEYWORDS AND WHY ARE TWO QUESTIONS ON KEYWORDS PRESENT?

The 3-7 keywords in one of the questions are meant for the Networking Support Scheme Secretariat (NSSS) to understand what you think are the most prominent issues/elements of the Networking event. The secretariat uses these keywords to find evaluators who can review the application. Therefore, the keywords should focus on the content of the Networking event.

The list of keywords in the second question is meant for monitoring by the European Commission. You will see that these keywords comprise a wide array of keywords; most of them will not be appropriate for your Networking event. Nevertheless, please try to find a few words that are useful to describe the goals of your Networking event.

31 WHAT SHOULD A CV OF A PAO REPRESENTATIVE CONTAIN?

The CV for a PAO representative is asked in relation to the networking event and the role in the consortium for the networking event. In this way evaluators can review whether the consortium has relevant expertise and that it is capable of organizing the event; you may think of expertise in the content of the topic of the networking event, organizational skills, role in PAO and role in the organization of this networking event (taking part in the scientific programme committee, taking part as local organizer, etc.), trainings from EURORDIS, etc. If a person e.g., has a financial job outside the PAO and will be the principal applicant who will deal with the budget – then it may be good to write down what kind of job this person is doing next to the role in the PAO. Furthermore, as PAO it is important to check the information whether the PAO is eligible (Annex 2 in the Call text) based what the PAO is doing.

32 CAN YOU CLARIFY WHAT IS EXPECTED IN A RISK MANAGEMENT PLAN IN CASE OBJECTIVES OF THE EVENT CANNOT BE MET?

The risk management plan should describe contingencies for the event, for example speakers pulling out, sponsors are withdrawing, the conference place is too small in relation to the number of participants that show interest, etc.

BUDGET RELATED QUESTIONS

33 WHERE CAN I FIND INFORMATION ON WHAT COSTS ARE ELIGIBLE AND HOW MUCH?

In Annex 3 of the Call text and of this FAQ document, issues are mentioned that are eligible for funding and the indicated costs.

34 IS IT ALLOWED TO FIND ADDITIONAL FUNDING/ IN CASH COFUNDING?

Yes, it is possible to find an additional budget (in cash co-funding) if the costs of your proposed event will be higher than the maximum €30,000 (including VAT) that you can request from the Networking Support Scheme. Examples for co-funding in cash are a registration fee of the participants, co-financing by the industry, own budget from the organization of an applicant, grant from a medical society, etc.

However, you are not allowed to make profit from the Networking event. In that case, the amount of the profit will be reduced from the requested budget of the Networking Support Scheme.

35 CAN THE FUNDING OF THE NETWORKING SUPPORT SCHEME COVER THE COST OF REGISTRATION TICKETS?

You do not have to ask for registration fee/tickets. If you do, the costs for registration fee/tickets have to be put under part B of the budget plan as “co-funding in cash” and will be subtracted from the total budget. The maximum budget that you can ask for in the Networking Support Scheme is € 30,000 including VAT.

36 WHERE CAN WE ADD COSTS THAT ARE NOT ELIGIBLE?

You can provide information on all expected costs related to the networking event in the application template. The costs that will be funded by other means can be put in part B of the budget plan and the requested budget from the Networking Support Scheme in part C. The maximum requested costs from the Networking Support Scheme is €30,000 (including VAT). Below the budget plan there is space to justify the requested costs from the Networking Support Scheme.

In the ERDERA online submission platform, you have to indicate the budget that you request from the Networking Support Scheme. In case your Networking event is more expensive than € 30,000 you can indicate the other costs that will be covered by other funding.

37 IF THE PRINCIPAL APPLICANT ORGANIZES THE EVENT ON THE PREMISES OF ITS OWN INSTITUTE, ARE THE COSTS FOR THE MEETING ROOM,

LUNCH, TECHNICAL ASSISTANCE INVOICED BY THE APPLICANTS' INSTITUTE ELIGIBLE COSTS?

The EU general principles on best value for money, competition, transparency, etc. have to be followed. If the usual practice of the principal applicant is to have an internal caterer, then he/she can stick to this and does not have to use an external provider, especially for the networking event. If the principal applicant has additional requirements in his/her own institution such as the necessity of having three quotes for any payments between € 0 to € 30,000, then the principal Applicant should always follow the internal rules of the institution and provide the quotes to the accountant of the institution. As the costs of the networking event have to be justified to ZonMw, the principal applicant has to follow both the usual accounting principles of its own institute and the obligations for ZonMw.

38 IS IT ALLOWED TO WAIVE THE REGISTRATION FEE/TICKET FOR A SUBGROUP OF PARTICIPANTS E.G., FROM UNDERREPRESENTED COUNTRIES OR PATIENT ADVOCACY ORGANISATIONS?

One of the aims of the Networking Support Scheme is to involve participants from usually underrepresented countries. Furthermore, the involvement of patient advocacy organizations is encouraged. Therefore, it fits within the ideas of the Networking Support Scheme to waive the registration fee for these subgroups, if you ask for registration fees.

39 IS IT POSSIBLE TO APPLY FOR TRAVEL, HOTEL AND CATERING COSTS FOR ATTENDEES FROM ANY ERDERA COUNTRY OR ONLY FROM UNDERREPRESENTED COUNTRIES?

You can apply for travel, hotel, and catering costs of any delegate (members of a PAO, clinicians, researchers, and research managers) from the ERDERA countries listed in Annex 1 of the Call text and of this FAQ document. An indication of the costs that can be funded in the Networking Support Scheme is mentioned in Annex 3 of the Call text.

40 IS IT ALLOWED TO FUND A PARTICIPANT AT A NETWORKING EVENT WHO COMES FROM A COUNTRY OUTSIDE OF THE ELIGIBLE COUNTRIES?

Annex 1 of the NSS Call text summarizes the eligible countries in which an institute or organization can apply for a networking event and in which a networking event can take place.

A participant outside these countries can attend the networking event, however he/she has to secure his/her own budget for travel and lodgings. In case this person is an invited speaker or chair, travel and lodgings may be paid through the budget of the Networking Support Scheme. See section 4.5 of the Call text.

41 ARE LOGISTIC / EVENT RELATED COSTS ELIGIBLE, SUCH AS TRANSFERS, DELEGATE PACKAGES, VIDEOS AND PHOTOGRAPHER SERVICE?

Travel costs to and from the airport, etc. are eligible costs. In the budget plan in the application template, you will see that “Materials e.g. Programme booklet” are eligible costs. When you indicate clearly in the application form the mentioned purpose for which you would like to use the photographer/videographer, the Networking Support Scheme might cover it.

42 WHAT IS MEANT BY MISCELLANEOUS BUDGET?

In the miscellaneous line, we mean additional costs (in euro) that are specific for the event, e.g. costs for visa for invited speakers, or costs for an item that is needed for the event and that has not been stated in the lines above in the budget plan.

43 WHAT ARE THE PAYMENT CONDITIONS FOR APPROVED PROJECTS?

Organizers will receive 50% prepayment after the letter containing the grant decision, obligations and applicable terms and conditions in relation to the execution of the proposed activities has been sent. If the principal applicant is a PAO, 80% prepayment is possible if required by the PAO. The final financial settlement by the NSSS/ZonMw takes place after receiving a copy of the report with outcomes of the networking event (PDF of the information on the online monitoring platform of ERDERA) and the financial report with relevant supporting documents (see “Specification of costs after the event”, section 4.2.1 of the call text – electronic invoices, tickets, etc.) within 3 months after the event has taken place.

44 WHICH PARTY WILL RECEIVE FUNDING FOR THE EVENT?

The institution/organization of the principal applicant will receive funding.

45 WHAT WILL HAPPEN IN CASE OF UNDERSPENDING OR OVERSPENDING OF THE GRANTED BUDGET?

In case of underspending on the granted budget, the actual costs will be reimbursed. These costs will be lower than the granted budget.

In case of overspending and the realized costs are higher than the granted budget, the overspending will not be reimbursed even if you justify it. NSSS/ZonMw will not reimburse a higher budget than the budget that was asked for in the application. The maximum budget that you can apply for is €30,000. – including VAT. Therefore, it is important to prepare a realistic budget plan.

ADDITIONAL DOCUMENTS

46 HOW MANY PAGES CAN WE USE FOR THE DRAFT PROGRAMME?

The draft programme should not exceed two pages.

47 SHOULD APPLICANTS SIGN THE SIGNATURE PAGE DIGITALLY OR ON PAPER?

Both ways of signing the signature form are eligible. Principal applicants and all co-applicants should sign the signature page.

48 SHOULD EACH PAO UPLOAD THE COMPLETED DECLARATION OF HONOUR (DOH)?

Only a PAO that is the principal applicant in the consortium has to complete the Declaration of Honour. Take care that all four boxes in the Declaration of Honour have to be ticked according to the state of the art of the PAO. If one of the boxes cannot be ticked, the PAO is not eligible for receiving funding. In that case the PAO can still be applicant but another eligible applicant in the consortium should become the principal applicant. If the Declaration of Honour of the PAO is not signed, the consortium is not eligible, and the application will not be sent to the Networking Evaluation Committee for review.

QUESTIONS ON ETHICS

49 WHERE CAN I FIND INFORMATION HOW TO COMPLETE THE ETHICS SELF-ASSESSMENT TABLE?

On the [ERDERA](#) website a tutorial video (3.10 minutes) is available that provides information on completing the self-assessment table. Please see this video before completing the ethics self-assessment table, a mandatory document that has to be uploaded on the ERDERA NSS online submission platform.

50 SHOULD I COMPLETE THE RED ROWS OF THE ETHICS SELF-ASSESSMENT TABLE?

No, you should complete only the green and blank rows in the table. The red rows are not applicable for the applications in the Networking Support Scheme.

51 SHOULD I SAY “YES” TO THE QUESTION “DOES IT INVOLVE PROCESSING OF GENETIC INFORMATION?” IF I DAILY WORK WITH GENETIC DATA BUT NO GENETIC DATA ARE DISCLOSED IN MY PRESENTATION?

The section on personal data refers only to the data processing activities performed for the purposes of the event. You should reply **“NO”** because genetic information should not be processed in the context of the networking event, but possibly only discussed anonymously.

52 WHAT DOES THE WORD ‘REFERENCE’ MEAN IN THE ETHICS SECTION?

The word “reference” in the ethics part means the place in the application template where the evaluators can find the information for that particular part.

6 ANNEXES TO THE CALL TEXT

ANNEX 1: ELIGIBILITY IN COUNTRIES PARTICIPATING IN ERDERA

Eligible countries. The organization **of the principal applicant** has to be located in the following eligible countries that participate in ERDERA:

COUNTRY	COUNTRY
Austria	Belgium
Bulgaria	Cyprus
Czechia	Denmark
Estonia	Finland
France	Germany
Georgia	Greece
Hungary	Iceland
Ireland	Israel
Italy	Latvia
Lithuania	Luxembourg
Morocco	Norway
Poland	Portugal
Romania	Serbia
Slovakia	Slovenia
Spain	Sweden
Türkiye	The Netherlands

The Networking event may take place in the countries listed in the table above.

List of eligible usually underrepresented countries (UCs): Bulgaria, Cyprus, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Latvia, Lithuania, Morocco, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, and Türkiye.

The organizations of co-applicants may be located in the countries listed in the table above **AND in Australia, Canada, United Kingdom, and Switzerland** which also take part in ERDERA.

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 1A 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 (see list of countries 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.
- Includes in its governing structure a legal financial representative for signing a financial report.

Accountability:

- With proven activities such as rare disease patient support/rare cancer patient support and/or 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.
- 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.

ANNEX 3: INFORMATION FOR BUDGET ESTIMATION OF NETWORKING EVENT

The principal applicant must justify the costs for the Networking event, ensuring they are reasonable and adhere to the rules of their institution (e.g., if institutional policies require obtaining three quotes for a service must be).

The Networking Support Scheme does not cover research costs or personnel costs related to preparing the networking event. However, technical support for hybrid events are eligible costs.

The table on the following page provides **indications** for eligible components for face to face or hybrid networking events.



Average costs for organization of meetings/workshops		Average costs in Euro (VAT included)	Remarks
Other Goods and services	Meeting room	700	Per day
	Lunch	35	Per person / day
	Dinner	45	Per person / workshop
	Coffee break	9	Per person / break
	Audio/video equipment for non-hybrid meetings (screen, video projector, etc.)	200	Per day
	Audio/video equipment (screen, video-projector, etc.) for hybrid meeting	600	Per day
Travel and accommodation	Travel in Europe	600	Round trip
	Travel Israel or Türkiye to Europe	1000	Round trip
	Traveling from US/CA to Europe	2000	Round trip
	Hotel with breakfast	120	Per person/night