

## **EJP RD**

### **European Joint Programme on Rare Diseases**

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Rare Disease European Joint Programme Cofund



Grant agreement number 825575

## **Del 7.2**

### **Call document for Networking Support Scheme**

**Organisation name of lead beneficiary for this deliverable:**

Partner 34 – ZonMw

**Due date of deliverable:** month 07

**Dissemination level:** Public

# Networking Support Scheme

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

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## Call text including guidelines for applicants

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Submission on a continuous basis

Collection of proposals: every three months,  
starting from March 3, 2020

The application template with the link to the electronic proposal submission system  
ProjectNet light can be found at the EJP RD website:

<http://www.ejprarediseases.org/index.php/networking-support/>

For questions on content:  
contact the Networking Support Scheme Secretariat  
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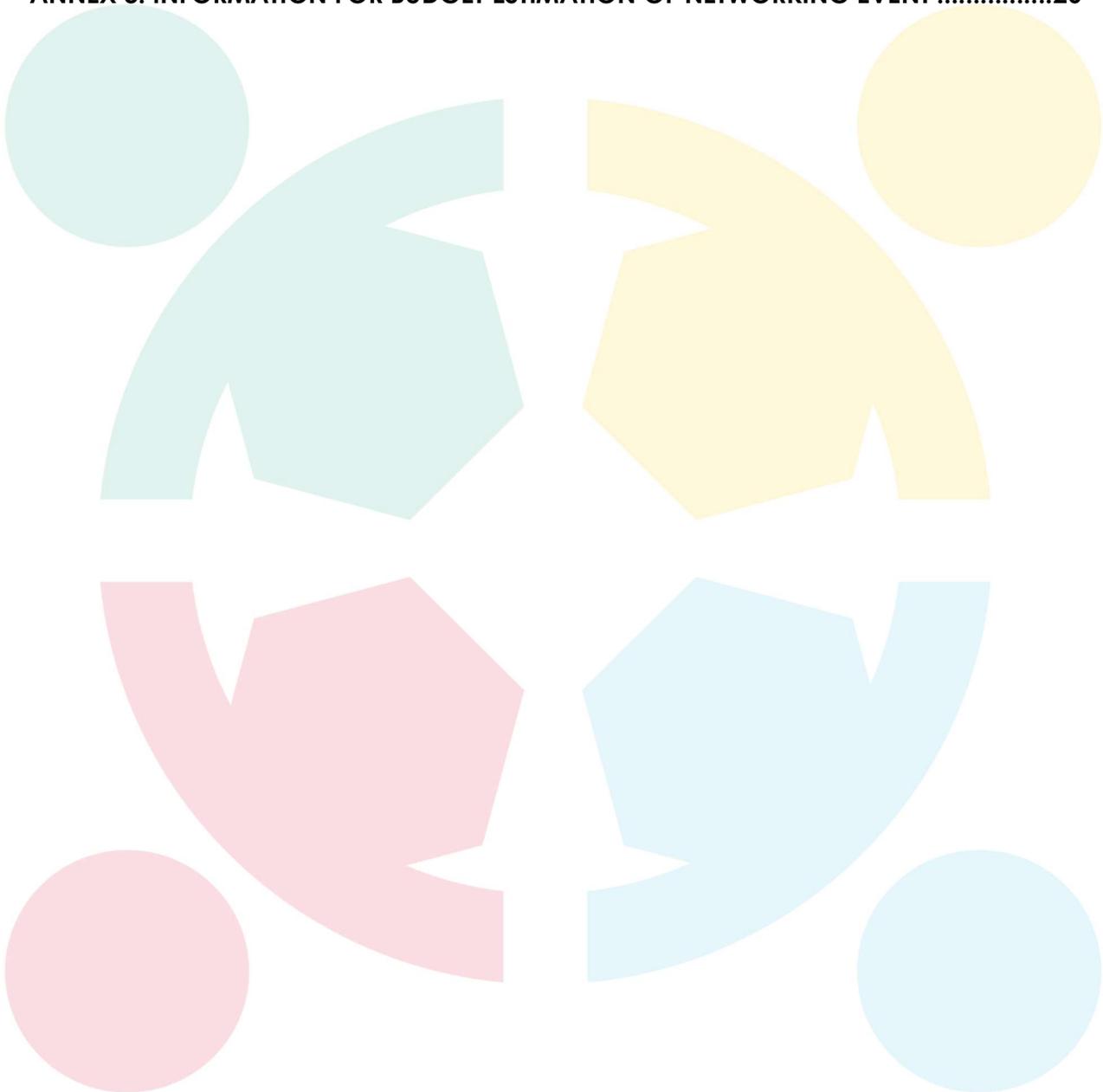


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## THE NETWORKING SUPPORT SCHEME IN SUMMARY

### AIM

The aim of the Networking Support Scheme in the European Joint Programme on Rare Diseases (EJP RD) is to encourage sharing of knowledge on rare diseases and rare cancers of health care professionals, researchers and patients. The Networking Support Scheme also aims to enable or increase the participation of usually underrepresented countries in Europe in new and in existing/expanding research networks on rare disease(s) or rare cancer(s). The scheme will provide financial support to applicants for fostering organization of workshops or conferences to support new research networks or strengthening existing research networks, to enable exchange of knowledge, paying attention to (the implications of) research results and innovative solutions and strengthening the collaborations between different stakeholders. The results of these networking events may lead to future collaborative research efforts.

### PRACTICAL INFORMATION

In this Networking Support Scheme applicants from all countries that are involved in the EJP RD (See Annex 1A for these countries) can apply for a budget of a maximum of 30,000 € per event to organise a **transnational** European/international event to share and disseminate knowledge on rare diseases. A specific application template has to be completed. The call will be open on a continuous basis from mid-December 2019. The applications will be collected every three months and the eligibility will be checked. The collection dates are indicated on the EJP RD website. Applications that pass the eligibility check will be evaluated in a competitive way by an independent Networking Evaluation Committee using defined evaluation criteria. The rules of the European Union's Horizon 2020 research and innovation programme will be applied.

### EARLY ASSESSMENT

After four rounds, there will be an assessment of this Networking Support Scheme (foreseen in the first semester of 2021) to analyse whether the scheme meets the expectations of the EJP RD and the rare diseases and rare cancers research community. To make sure the feedback of applicants is properly taken into account for the improvement of the scheme, applicants will be asked to complete a dedicated short survey.

## 1. MOTIVATION

There are at least 7000 distinct rare diseases, the great majority being of genetic origin. Although individually rare, taken together rare diseases affect at least 26-30 million people in Europe. Moreover, they represent a major issue in health care: a large number of these diseases have an early or very early onset and/or lead to a significant decrease of life expectancy. Moreover, most of them cause chronic illnesses with a large impact on quality of life and the health care system.

Therefore, research on rare diseases is needed to provide knowledge for prevention, diagnosis and better care of patients. Yet, research is hampered by lack of resources at several levels: (1) Few scientists work on any given specific disease, (2) There are few patients per disease and they are scattered over large geographic areas, causing difficulties to assemble the necessary cohorts, (3) Existing databases and bio-material collections are usually local, small, and not accessible or standardised, (4) The complex clinical phenotypes of these diseases require interdisciplinary cooperation to improve research and treatment.

The specificities of rare diseases - limited number of patients per disease, scarcity of relevant knowledge and expertise, and fragmentation of research - single them out as a distinctive domain of very high European added value. Rare diseases are a prime example of a research area that necessitates collaboration on a transnational scale.

In this context, the European Joint Programme on Rare Diseases (EJP RD) starts a new funding scheme to encourage networking to share new and existing knowledge on rare diseases and rare cancers: The Networking Support Scheme.

## 2. AIMS OF THE NETWORKING SUPPORT SCHEME

The main aim of the Networking Support Scheme is to encourage sharing of knowledge on rare diseases to support health care professionals, researchers and patients/patient advocacy organizations with a networking budget to organize themselves into transnational (clinical) research networks that focus on a (group of) rare disease(s), a (group of) rare cancer(s) or on cohorts of undiagnosed patients that are suspected of suffering from a rare disease/rare diseases. The Networking Support Scheme also aims to enable or increase the participation of usually underrepresented countries in Europe in new and in existing research networks on rare disease(s) or rare cancer(s).

The Networking Support Scheme will provide financial support to third parties for fostering organization of workshops or conferences to support new research networks or strengthening existing research networks to enable exchange and improvement of knowledge on rare disease(s) and rare cancer(s) and/or to encourage further innovation and research e.g. by preparing an application for another networking grant, training grant or research grant in an EC or other international programme.

The Networking Support Scheme will lead to an increased uptake of research results in the rare diseases community by paying attention to (the implications of) research results and innovative solutions and strengthening the collaborations between different stakeholders.

The necessary expertise and a clear added value in the transnational collaboration should be brought together from academia, clinical/public health sector and patients/patient advocacy organisations, and from private companies when relevant.

The aim of the Networking Support Scheme is in compliance with the vision and goals set by the International Rare Diseases Research Consortium (IRDiRC) which fosters international collaboration in rare diseases research, including rare cancers.

The IRDiRC vision is: Enable all people living with a rare disease to receive an accurate diagnosis, care, and available therapy within one year of coming to medical attention.

To work towards this vision, IRDiRC has set three goals for the next decade:

1. All patients coming to medical attention with a suspected rare disease will be diagnosed within one year if their disorder is known in the medical literature; all currently undiagnosable individuals will enter a globally coordinated diagnostic and research pipeline;
2. 1000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options;
3. Methodologies will be developed to assess the impact of diagnoses and therapies on rare disease patients.

For more information see IRDiRC website: <http://www.irdirc.org/>.

### 3. APPLICATION

#### 3.1. ELIGIBILITY AND NON-ELIGIBILITY OF DISEASES AND TOPICS

A. **The diseases are eligible** if the definitions mentioned below are applicable:

- A rare disease or group of rare diseases that affect not more than five in 10,000 persons in the European Community, EC associated states and Canada.
- A rare cancer with an incidence of less than 6 per 100,000 persons per year. For the list of rare cancers see: [http://www.ecpc.org/Documents/Projects/-RARECAREnet/RARECAREnet\\_list\\_of\\_rare\\_cancers.xlsx](http://www.ecpc.org/Documents/Projects/-RARECAREnet/RARECAREnet_list_of_rare_cancers.xlsx).
- Cohorts of undiagnosed patients that are suspected of suffering from a rare disease/ rare diseases.

B. **The topics are eligible** if new research networks or (strengthened) existing research networks exchange knowledge, paying attention to (the implications of) research results and innovative solutions.

C. The following rare diseases are **NOT eligible**:

Rare infectious diseases are excluded from applying in the Networking Support Scheme as this scheme focuses on rare diseases that are in the scope of the European Reference Networks ([https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)).

D. The following topics are **NOT eligible**:

Clinical Practice Guidelines (CPG) and other Clinical Decision Support Tools (CDSTs) that ERNs would like to develop, appraise and/or implement are not eligible topics in this Networking Support Scheme as the Directorate-General for Health and Food safety from the European Commission will provide other means for elaborating these topics (<https://etendering.ted.europa.eu/cft/cft-documents.html?cftId=3788>).

### 3.2. ELIGIBILITY OF APPLICANTS

Rare disease researchers and health care professionals working in universities, other higher education institutions, public research institutes<sup>1</sup>, or in the clinical/public health sector (hospitals/public health and/or other health care settings and health organisations) established in the countries involved in the EJP RD are eligible to apply. The countries are mentioned in Annex 1A.

Also, Patient Advocacy Organisations (PAOs) are eligible when they are a legal entity established in the countries involved in the EJP RD. In general, an eligible participating patient advocacy group is defined as a not-for-profit organisation organised under private law, which is, according to their articles of association (also: articles of incorporation and their by-laws) patient focused, where patients and/or carers and/or family members of patients represent a majority of members in governing bodies and are financially independent, particularly from the pharmaceutical industry (max. 49 % of funding from several companies). More information on eligibility of Patient Advocacy Organisations is mentioned in Annex 2.

Only transnational networks will be funded. The consortium submitting an application for a networking budget must involve a minimum of **three eligible applicants** (researchers and/or health care professionals and/or patient advocacy organisations) from at least **three different countries participating in the EJP RD at the time of the application (see Annex 1A)**. The maximum number of eligible applicants in an applying consortium is **10** applicants.

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<sup>1</sup> Funded by the government for at least 50%

One of the eligible applicants will be **the principal applicant**. The organisation of the principal applicant has to be a legal entity and established in one of the countries mentioned in **Annex 1, Table A**.

The roles of the principal applicant and co-applicants are described in section 3.5 and 3.6.

► An application will be eligible only if there are at least three eligible partners from three different eligible countries. If this condition is not fulfilled, **the entire proposal will be rejected without further review**.

- Applicants are encouraged to include researchers and/or health care professionals and/or patient advocacy organizations from EJP RD participating countries usually underrepresented in networks (Armenia, Bulgaria, Croatia, Czech Republic, Estonia, Georgia, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Serbia, Slovakia, Slovenia and Turkey) as (co) applicants.
- Networks are also encouraged to include Early Career Scientists in their network, e.g. as (co)organiser. For further information on the definition see 6.5.
- The inclusion of patient advocacy organizations (PAO) in the network is highly encouraged. If PAO involvement is not deemed appropriate within a specific network, this should be explained and justified.

Researchers and health care professionals working in institutes that are established in countries that are **not involved in the EJP RD** or patients/patient advocacy organisations that are established in countries that are **not involved in the EJP RD cannot be applicants** for the networking event. They can join the networking event as participant of the networking event, but will not be eligible to directly receive funds and will have to secure their own funding to be able to join the networking events.

### 3.3. ELIGIBILITY OF THE COUNTRY WHERE THE NETWORKING EVENT MAY TAKE PLACE

The networking event has to take place in one of the countries that are mentioned in Annex 1. A possibility to increase the participation of usually underrepresented countries in Europe may be to organise the networking event in one of those regions, if this would be an added value. The local organiser of the event should always be a part of the applying consortium.

### 3.4. OTHER ELIGIBILITY CRITERIA

#### 3.4.1. Time period between application and the networking event

The application of the networking event has to be sent **at least 6 months** before the event will take place. If this is not the case, the application will not be eligible and declined and will not be evaluated. The networking event has to be organised **at maximum 12 months after the application date**. If the networking event is organised

more than 1 year after this date, the networking budget will be revoked if no justification can be given for the delay in organizing the event.

### **3.4.2. Eligibility of expenditure, maximum budget per networking event and contracting party for the service provision agreement**

The maximum budget is € 30,000 for one event, inclusive of any VAT that is due. Each event needs a separate application.

The costs for a networking event have to be clearly specified in the application form. Only expenses for the organization of networking meetings, workshops or conferences are eligible, including travel and hotel costs. Information for budget estimation for a networking event is given in Annex 3. It is up to the applying consortium to decide whether interested potential participants may be funded by the budget for the networking event or they have to secure their own funding.

It is allowed to organise a satellite event back to back to e.g. an international symposium. In that case only the additional costs will be eligible (meeting room, audio-visual equipment, additional hotel night(s), travel costs of those participants that will come specifically to this satellite event, etc.).

The Networking Support Scheme does not support research costs or personnel costs for preparing the networking event and/or for being present at the networking event.

The principal applicant will be the only contact person for the Networking Support Scheme and the organisation of the principal applicant will receive the budget if the networking event is selected upon evaluation. The principal applicant is responsible for justification of the expenditure.

### **3.4.3. Length of the text in the application**

- ▶ Proposals exceeding the length limitations of any section will be discarded without further review.

## **3.5. ROLE OF THE PRINCIPAL APPLICANT**

The **principal applicant** is a **researcher**, or **health care professional working at an institute** established in a country that is mentioned in **Annex 1A** or **representative of a PAO** established in a country that is mentioned in **Annex 1A**. The principal applicant will represent the network externally and towards the Networking Support Scheme Secretariat at ZonMw, The Netherlands. The principal applicant is the only contact person on behalf of the consortium for ZonMw. The organisation of the principal applicant will receive the funding on behalf of the network and will be held accountable for the management of the expenses for the networking event.

The principal applicant has to communicate the information from the Networking Support Scheme Secretariat to the co-applicants. The principal applicant is also responsible for the reporting (financial report and report on outcomes of the networking event).

### 3.6. ROLE OF THE CO-APPLICANT

Each consortium that applies for a transnational networking event has to nominate next to the principal applicant **at least two** co-applicants from at least two different eligible countries and also different from the country where the principal applicant works. For eligible countries for co-applicants: see **Annex 1A**. The applying consortium may consist of **maximum 9 co-applicants** next to the principal applicant. The co-applicants will organise the networking event together with the principal applicant. The organisation of the principal applicant will receive the budget and will be responsible to distribute budget to the co-applicants and other participants if needed.

The applying consortium should consist of partners who will develop the scientific programme of the networking event, the logistic organiser(s)/local organiser(s) of the networking event and/or partners involved in communication and/or finances. The division of this work for organising the networking event is the responsibility of the co-applicants together with the principal applicant.

### 3.7. OTHER PARTICIPANTS

The applying consortium may consist of maximum 10 applicants (1 principal applicant and 9 co-applicants). The applying consortium is allowed to invite other participants to join the networking event. There is no limit to the number of participants, However the maximum budget that can be requested is € 30,000 for a networking event (see 3.8 Practical issues).

Researchers and health care professionals working in institutes that are established in **countries** that are **involved in the EJP RD**, and patient advocacy organisations that are established in **countries** that **are involved in the EJP RD** are eligible to receive funds for travel and hotel costs to be able to join the networking event.

Researchers and health care professionals working in institutes that are established in countries that are **NOT** involved in the EJP RD, and patient advocacy organisations that are established in countries that are **NOT** involved in the EJP RD will have to secure their own funding to be able to join the networking event.

### 3.8. PRACTICAL ISSUES

Information on eligible components of the organisation of the networking event and average costs that can be requested is indicated in two tables in Annex 3.

#### 3.8.1. Coverage of the costs

The maximum budget is € 30,000 for one networking event, inclusive of any VAT that is due.

The costs for the networking event have to be specified and justified in a detailed budget plan in the application template and after the event by sending all necessary information (including electronic invoices, tickets, etc.) to the Networking Support Scheme Secretariat so that the secretariat is able to check the incurred costs. In case

the costs cannot be justified there will be no reimbursement. Tables 1 and 2 in Annex 3 give information on the eligible items and estimated average costs.

Co-funding (e.g. by asking a registration fee or receiving a financial contribution of an industry partner) is allowed. However, making profit out of the event is not allowed. In case of co-funding by a private-for profit organisation the applicants of the Networking Support Scheme should take care that the content of the networking event is not influenced by this organisation.

### **3.8.2. How often can an applicant apply and how often can a network apply**

Applicants may apply for budget for a networking event more than once, but not in the same competitive selection round.

The same application that is not selected in a competitive round may apply only once again under the Networking Support Scheme of the EJP RD, taking into account the comments after evaluation of the first application. When the revised application is not selected in a second competitive round, it is not possible to apply with the same application for the third time.

Applicants can apply for funding for a follow-up networking event after being selected earlier. These networks must clearly demonstrate the success of the first selected networking event and have to indicate clearly why a follow-up event is needed. The applications for a follow-up event will compete on the same terms as applications for new networking events.

A network that has been selected before in the Networking Support Scheme can apply again for funding for a networking meeting with different objectives. These networks must clearly demonstrate the success of the earlier selected networking meeting. These applications will compete at the same terms as applications for other networking meetings.

### **3.8.3. Communication on selected networking event and dissemination of outcomes**

#### *3.8.3.1. Communication of selected networking event*

The title of the networking event, name of the principal applicant, city/country where the networking event is supposed to take place and the lay summary written by the applicants in the application template will be published on the website of the EJP RD immediately after the application is selected.

The selected networking event is considered to be open for participants coming from other organisations/other countries. The applicants may limit the number of participants in a networking event and decide if they have budget to invite and cover the costs for (some) participants from institutions/patient advocacy organisations in EJP RD involved countries (see Annex 1A) or that participants may come at their own expenses.

The organising consortium may widen its public by transforming the networking event into a webinar.

### 3.8.3.2. *Dissemination of outcomes of selected networking event*

The outcomes of the networking event should be publicly available. Exceptions on this general rule are possible, e.g. information for the preparation of a research application in a competitive Call, but should be justified by the principal applicant.

The principal applicant has to send a final report using a specific on-line reporting form within 2 months after the date of the event, including a public lay summary with a description on the content, the outcomes and the next steps. The public lay summary on the outcomes of the networking event will be published on the EJP RD website. Also, the general slides of the networking event have to be made publicly available on the EJP RD website - with the possibility of removal of unpublished data or ideas. It is expected that the applicants of the selected networking event will also report the outcomes e.g. via scientific articles, articles for the involved patient advocacy organisations and for the general public, newsletters, presentations at other meetings.

### 3.8.4. Some advice before submitting the proposal

- Read this call text several times, including the aim of the Networking Support Scheme and the evaluation criteria (see 5.1);
- Make sure that your proposal falls within the aims of the Networking Support Scheme;
- Make sure that your proposal fulfils the eligibility criteria of the Networking Support Scheme;
- Use the application template provided on the EJP RD website (<http://www.ejprarediseases.org/index.php/networking-support/>);
- Respect the length limitations of each section in the application template. Only the application template provided on the EJP RD web page will be accepted.

## 3.9. SUBMISSION OF PROPOSALS FOR A NETWORKING EVENT

### 3.9.1. Registration

Applying consortia who intend to submit a transnational proposal for a networking event should register at the ZonMw electronic application system ProjectNet. Instructions for registration and application on this system are published on the EJP RD website ([www.ejprarediseases.org](http://www.ejprarediseases.org)).

### 3.9.2. Proposal submission

There will be a **one-stage submission procedure for the applications**. An application template (in English) has to be completed by the applicants of a proposal for a networking event and must be submitted by the principal applicant to the Networking Support Scheme Secretariat (NSSS) using the electronic submission system ProjectNet

of ZonMw with the link: <http://projectnet.zonmw.nl/projectnet/servlet/projectnet?subsidyGuide&id=200003287>.

The application template (in English) can be submitted to the NSSS on a continuous basis. Every three months the applications will be collected and evaluated in a competitive way. A calendar of collection dates will be provided on the EJP RD website.

Please note that only the application template for the Networking Support Scheme provided on the EJP RD web page (<http://www.ejprarediseases.org/index.php/-networking-support/>) and/or on ProjectNet will be accepted. The proposal document must respect the format (DIN-A4, Century Gothic 11, single-spaced) and the length indicated. Proposals exceeding these limitations will be rejected. The proposal should include both the application text and the budget plan.

The following information has to be provided in the application template:

- The title of the networking event and information whether it is a new application;
- Public lay summary (max. 1600 characters including spaces). This summary will be published on the public part of the EJP RD website if the application is selected;
- The (group of) rare disease(s) or rare cancer(s) concerned;
- Keywords to describe the content of the networking event (3-7);
- Location (city, country) where the networking event will be organised;
- Proposed number of days, proposed date(s) of the networking event and number of expected participants per day;
- Description of the networking event e.g. objectives and background of the proposed networking event; description of the unmet medical and patient need that is addressed by the proposed networking event, added value of the transnational collaboration, choice of participants to be invited, description of involvement of industry (if applicable), proposed outcomes of the event and dissemination of the outcomes, risk management plan in case objectives of the event cannot be met, sustainability or extension of the research network after the networking event and/or use of the expected results for future work in the field.
- Information on the principal applicant, brief CV and description of his/her role in the networking event;
- Information on **at least two** and **maximum nine** co-applicants, brief CV for each co-applicant and description of their individual roles in the networking event;
- In principle the networking event should be open for other interested parties. The applicants may provide a URL for further information to be published online on the website of the EJP RD after the application is selected;

- Budget plan: expenses, co-funding in cash, requested budget from the Networking Support Scheme;
- Information of the bank account to which the budget will be transferred. This information will only be used, when the application is selected;
- Date and signature of the principal applicant (also on behalf of the co-applicants).

## 4. NETWORKING EVALUATION COMMITTEE

**The Networking Evaluation Committee (NEC)** is a panel of independent experts issued by funding agencies and EURORDIS and is responsible for the evaluation of the submitted applications. NEC members must sign a confidentiality agreement and a statement to confirm that they will use the ZonMw's Code for Dealing with Personal Interests, which has been in place from July 1, 2019. (Note: according to Dutch Law the names of the members of the NEC have to be published).

## 5. EVALUATION

### 5.1. EVALUATION CRITERIA

Proposals will be assessed according to specific evaluation criteria that are in line with Horizon 2020 rules (see below), using a common evaluation form. A scoring system from 0 to 5 will be used to evaluate the proposal's performance with respect to the different evaluation criteria.

#### Scoring system:

- 0: Failure.** The proposal fails to address the criterion in question or cannot be judged because of missing or incomplete information.
- 1: Poor.** The proposal shows serious weaknesses in relation to the criterion in question.
- 2: Fair.** The proposal generally addresses the criterion, but there are significant weaknesses that need corrections.
- 3: Good.** The proposal addresses the criterion in question well, but certain improvements are necessary.
- 4: Very good.** The proposal addresses the criterion very well, but small improvements are possible.
- 5: Excellent.** The proposal successfully addresses all aspects of the criterion in question.

**Evaluation Criteria:**

## 1. Excellence

- a. Clarity and pertinence of the objectives of the networking event;
- b. Justification of the networking event as the best approach to achieve the objectives;
- c. Soundness of the concept of the networking event;
- d. Innovative potential of the networking event;
- e. Feasibility of the networking event (adequate requested resources, time schedule);
- f. Competence and experience of the applicants in the field(s) of the rare disease(s) (previous work in the field, expertise) in relation to the objectives of the networking event.

## 2. Impact

- a. Potential of the expected results from the networking event for future clinical, public health and/or other socio-economic health relevant implications;
- b. Added value of transnational collaboration: gathering a critical mass of information, harmonization of data, sharing of specific knowledge, etc.;
- c. Effectiveness of the proposed networking event to exploit and disseminate the results of the event and to communicate the event;
- d. Active and meaningful engagement of knowledge-users as well as patient(s) or patients' advocacy organisation representatives(s) in the event;
- e. Active and meaningful engagement of Early Career Scientists in the event;
- f. Inclusion of participants from countries involved in the EJP RD that are usually underrepresented in networks;
- g. Involvement of industry (when relevant).

## 3. Quality and efficiency of the implementation

- a. Complementarity of the applicants in relation to the objectives of the networking event;
- b. Appropriateness of the management, including risk management and contingency plans;
- c. Budget and cost-benefit ratio of the event.

Evaluation scores will be awarded for the 3 main criteria, and not singularly for the different aspects listed below the criteria. Each criterion will be scored on a 5-point scale. The threshold for individual criteria will be 3. The overall threshold, applying to

the sum of the three individual scores, will be 12. The maximum score that can be reached from all three criteria together is 15 points.

## 5.2. PROCEDURE FOR EVALUATION OF PROPOSALS

### 5.2.1. Eligibility check

The Networking Support Scheme Secretariat will check all proposals to ensure that they meet the call's formal criteria (e.g. number of applicants, country of applicants; inclusion of all necessary information in English, page length of each section, time period between application and the networking event).

- ▶ Please note that proposals not meeting the formal criteria and requirements **will be declined without further review.**

### 5.2.2. Peer review of proposals

Proposals passing the eligibility check will be forwarded to the Networking Evaluation Committee (NEC) for a remote evaluation (see evaluation criteria in section 5.1). The members of the NEC will perform the assessment of the proposals and complete the evaluation forms with scores and comments for each criterion. A ranking list of the evaluated proposals will be prepared by the NSSS and sent to the NEC for final recommendations.

### 5.2.3. Ethical evaluation

Dependent on the topic of the networking events the proposals may also be remotely evaluated by an independent expert in ethics. The need for an ethical evaluation will be determined by the AREB, the Advisory Regulatory Ethics Board of the EJP RD. The expert in ethics will report on the feasibility of the networking event application to comply with the ethical requirements. If necessary, it will list those tasks that need to be done and documents that need to be submitted by the principal applicant of the evaluated application in order to receive the approval for funding from the ethical point of view. In case an ethical evaluation has taken place only those proposals approved by both, the scientific and ethical evaluations (complying with all central and regional/national ethical requirements), will be funded.

According to Horizon 2020 rules, an ethical evaluation is needed if personal data are processed in the context of research. Therefore, the principal applicant is responsible for following these rules. Personal data have to be processed properly (including contact details of participants of the networking event in registration forms). No personal data should be disseminated in the presentations shown in the networking event. Participants of the networking event have to be aware for which purpose their contact details are used and have to be informed upfront (e.g. by the text "Your contact details are solely processed for the purpose of this workshop and its proceedings"). If the contact details will be used for other purposes (eg. sending

newsletters, or sharing with others), the principal applicant needs the consent of the participants.

### **5.3. FUNDING DECISION**

Based on the ranking list established by the NEC and on available funding, the NSSS will decide which networks will be selected. The NSSS will also decide on the maximum budget for the specific networking event taking into account the recommendations of the NEC on the budget requested by the applicants.

If necessary, the NSSS will determine a priority order for proposals, which have been awarded the same score within a ranked list. The following criteria will be applied successively for every group of *ex aequo* proposals requiring prioritization, starting with the highest scored group, and continuing in descending order:

- Proposals with participation of underrepresented countries;
- Proposals that address diseases not otherwise covered by more highly ranked proposals.

The budget per calendar year will be about € 615,000. Twelve or thirteen competitive rounds for the Networking Support Scheme are envisioned with a total budget of 2M€.

The NSSS will communicate the final decision to the principal applicant together with the final short consensus summary feedback of the evaluation from the NEC.

## **6. FINANCIAL AND LEGAL ISSUES**

### **6.1. FUNDING CONTRACTS**

For this Networking Support Scheme, ZonMw will conclude a service provision agreement with the selected proposals based on the provisions of Chapter 7, Title 7, Section 7:7:1 article 400 of the Dutch Civil Code, with the principal applicant whose proposal has been accepted. This service provision agreement will contain the applicable terms and conditions in relation to the execution of the proposed activities, such as the ARVODI terms & Conditions 2018\_English (<https://www.pianoo.nl/en/legal-framework/general-government-terms-and-conditions/general-government-terms-and-conditions>).

For the purpose of this Service provision agreement, 'principal applicant' is the service provider ('opdrachtnemer') and ZonMw is the client ('opdrachtgever') as described in Chapter 7, Title 7, Section 7:7:1, article 400 of the Dutch Civil Code<sup>2</sup>.

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<sup>2</sup> [https://wetten.overheid.nl/BWBR0005290/2019-03-16#Boek7\\_Titeldeel7\\_Afdeling1\\_Artikel400](https://wetten.overheid.nl/BWBR0005290/2019-03-16#Boek7_Titeldeel7_Afdeling1_Artikel400)

The principal applicant is solely responsible towards ZonMw for fulfilling all its obligations resulting from the service provision agreement as concluded between ZonMw and the principal applicant.

- ▶ An example of the service provision agreement that has to be signed by the principal applicant upon selection of the proposal for a Networking event is available on the EJP RD website. A principal applicant may show this document to his/her legal officer before applying to be sure that it is possible to sign this document upon selection of the proposal.

The principal applicant of the selected network will be the contact person for the Network Support Scheme Secretariat. The Awards are always provided in the form of a guarantee budget up to a maximum amount. It is possible to receive up to 50% of the budget indicated in the service provision agreement before the networking event. In case a representative of a Patient Advocacy Organisation is the principal applicant it is possible to ask for a guarantee budget of 80% before the networking event. The final financial settlement by the Networking Support Scheme Secretariat takes place after receiving a copy of the report with outcomes of the networking event (pdf of the information on the online monitoring system of FNRS that will be sent automatically after completing this report) and the financial report with relevant supporting documents (electronic invoices, tickets, etc.) within 3 months after the event has taken place.

The principal applicant is accountable for the expenses of the networking event. The principal applicant may choose whether his/her organisation pays all activities for the networking event or send budget for hotel, travel and/or meeting costs to co-applicants. The costs have to be accounted for in the final financial report.

Changes to the composition of the applicants of the Networking Support Scheme or changes in requested budget cannot occur within the contract unless agreed by the NSSS. The principal applicant shall inform the NSSS of any minor or major change of the event that might affect the implementation of the project. In case of major changes, an independent expert can be consulted to help with the final decision.

## **6.2. OWNERSHIP OF INTELLECTUAL PROPERTY RIGHTS**

Results and new Intellectual Property Rights (IPR) resulting from networking events funded through the EJP RD Networking Support Scheme will be owned by the projects beneficiaries' organisations according to national/regional rules on IPR. If several participants have jointly carried out work generating new IPR, they shall agree amongst themselves (Consortium Agreement) as to the allocation of ownership of IPR, taking into account their contributions to the creation of those IPR as well as the relevant guidelines on IPR issues.

The results of the project and IPR created should be actively exploited and made available for use, whether for commercial gain or not, in order for public benefit to be obtained from the knowledge created.

The EJP RD shall have the right to use for their own purposes documents, information and results submitted by the principal applicants of the selected networking events, provided that the owner's rights are kept and taking care to specify their origin.

### **6.3. IRDIRC POLICIES AND GUIDELINES AND IRDIRC RECOGNIZED RESOURCES**

The applicants are expected to follow IRDiRC policies and guidelines. For more information see <http://www.irdirc.org/>.

Outcomes of a networking event may be considered for an application to become an IRDiRC Recognized Resource. IRDiRC Recognized Resources is a quality indicator, based on a specific set of criteria, that was created to highlight key resources which, if used more broadly, would accelerate the pace of translating discoveries into clinical applications. Any resource compliant with the criteria may apply for the label. For more information see <http://www.irdirc.org/research/irdirc-recognized-resources/>.

### **6.4. RESPECT FOR RELEVANT EUROPEAN AND INTERNATIONAL STANDARDS**

The submitted proposals must respect relevant European and international standards like:

- The General Data Protection Regulation (GDPR): the EC Regulation (EC 2016/679) on the protection of natural persons with regard to the processing of personal data and on the free movement of such data: <https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en>);
- European Research Council Guidelines on Implementation of Open Access to Scientific Publications and Research Data (referred to in [http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/open-access\\_en.htm](http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/open-access_en.htm));
- General ethical and legal requirements: Ethics is an integral part of research. Please be aware that regulations and ethical issues vary across different countries and should be considered from the outset. The EJP RD expects applications to fulfil ethical and legal requirements. Among other things, special attention will be paid to potential ethical issues (e.g. research on humans or animals; privacy of data and biomaterials; informed consent; etc.). Only projects that fulfil the legal and ethical international/EU and national and institutional standards will be funded. See also 5.2.3 Ethical evaluation.

### **6.5. DEFINITION OF EARLY CAREER SCIENTISTS**

Early Career Scientists are defined in analogy to the regulations of the European Research Council (ERC) criteria for starting grants. In short, this means having been awarded his/her first doctoral degree at least 2 and up to 7 years prior to the proposal

submission deadline. Extensions to this definition period are allowed in case of reasonably justified career breaks, which must be properly documented. Acceptable career breaks are leaves of absence for maternal or paternal breaks as well as long-term sick leave and compulsory military service.

For medical doctors (or applicants holding a degree in medicine), a medical doctor degree is not considered by itself as equivalent to a PhD award. To be considered an **Early Career Scientist**, medical doctors (or applicants holding a degree in medicine) need to provide the certificates of both a medical doctor degree and a PhD or proof of an appointment that requires doctoral equivalency (e.g. postdoctoral fellowship, professorship appointment). In these cases, the certified date of the medical doctor degree completion plus two years is the time reference for calculation of the definition time window (i.e. 4 - 9 years past the medical doctor degree). For medical doctors who have been awarded both an MD and a PhD, the date of the earliest degree that makes the applicant eligible takes precedence in the calculation of the eligibility time window (2 - 7 years after PhD or 4 - 9 years past the medical doctor). For clinical training, an extension will be given by the documented amount of clinical training actually received by the applicant after the award of the first eligible degree, and by up to 4 years maximum.

## 7. RESPONSIBILITIES, REPORTING REQUIREMENTS AND DISSEMINATION

The principal applicants of all funded networking events must submit a report on the outcomes of these networking events within two months after their selected event has taken place. The report format is customized using indicators and using a specific online reporting form. The public lay summary of the outcomes will be published on the EJP RD website.

All reports will be monitored and assessed by responsible agencies within the EJP RD and used for dissemination and communication purposes of the EJP RD.

This monitoring will be under the responsibility of CSO-MOH, Israel and FNRS, Belgium, which is responsible for the online monitoring system for the selected networking events. All reports must be in English and use a common electronic reporting form that will be provided. The principal applicant is responsible for delivery of the report (see 6.1).

Each applicant must ensure open access (free of charge, online access for any user) to all peer-reviewed scientific publications relating to its results according to EC regulations.

Applicants must ensure that all outcomes (publications, etc.) of networking events include a proper acknowledgement of EJP RD and the EC funding. This includes the display of the EJP RD logo when possible.

In addition, unless the EC requests or agrees otherwise or unless it is impossible, any dissemination of results (in any form, including electronic) must:

(a) display the EU emblem and

(b) include the following text:

“This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 825575”.

When displayed together with another logo, the EU emblem must have appropriate prominence.

For the purposes of the obligations under this Article, the beneficiary may use the EU emblem without first obtaining approval from the Agency. This does not, however, give it the right to exclusive use. Moreover, the beneficiary may not inappropriately use the EU emblem or any similar trademark or logo, either by registration or by any other means.

## 8. CONTACT AND FURTHER INFORMATION

The administrative management of the Networking Support Scheme will be ensured by the Networking Support Scheme Secretariat (NSSS) that is set up at ZonMw, The Netherlands. The NSSS will be responsible for collection of the applications at each deadline, supporting the Network Evaluation Committee (NEC) and communication with the principal applicants, including sending the budget for the events to the organisations of the selected principal applicants. The principal applicant will be the person contacted by the NSSS during the application and selection procedure, so he/she must forward the information to the other applicants.

Further information on the EJP RD, the Networking Support Scheme and the follow-up is available at the EJP RD website ([www.ejprarediseases.org](http://www.ejprarediseases.org)).

9. ANNEXES



**ANNEX 1: ELIGIBILITY IN COUNTRIES PARTICIPATING IN THE EJP RD**

**A. Principal applicant and co-applicants** are allowed to apply if their organisation is located in the following countries that participate in the EJP RD.

Armenia, Bulgaria, Croatia, Czech Republic, Estonia, Georgia, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Serbia, Slovakia, Slovenia and Turkey are seen as usually underrepresented countries.

COUNTRY	COUNTRY
Armenia	Austria
Belgium	Bulgaria
Croatia	Czech Republic
Denmark	Estonia
Finland	France
Germany	Georgia
Greece	Hungary
Ireland	Israel
Italy	Latvia
Lithuania	Luxembourg
Malta	Norway
Poland	Portugal
Romania	Serbia
Slovakia	Slovenia
Spain	Sweden
Switzerland	The Netherlands
Turkey	United Kingdom

**B. The networking event** may take place in the countries mentioned in the table above **AND in Canada** that also takes part in the EJP RD.

## ANNEX 2: ELIGIBILITY OF PATIENT ADVOCACY ORGANISATION (PAO)

The Patient Advocacy Organisations have to fulfil the following criteria:

- Legitimacy:
  - Represent diseases that are eligible according to the information in 3.1 (eligibility and non-eligibility of diseases and topics).
  - The organisation should be formally established and registered as a not-for-profit organisation in one of the countries involved in the EJP RD. See Annex 1A for the countries involved.
- Mission/objectives:
  - The organisation shall have its mission/objectives clearly defined and should agree to have it/them published on the EJP RD website.
- Activities:
  - The organisation 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 organisation website).
- Representation:
  - The organisation shall be representative of rare disease patients or rare cancer patients within a member state or throughout the EU/EEA.
- Structure:
  - The organisation should have governing bodies which includes a majority of rare disease patients or family members of rare disease patients OR rare cancer patients or family members of rare cancer patients.
  - Includes in its governing structure a designated representative legally authorised to sign a contract with ZonMw.
- 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 organisation should reflect the views and opinions of its members and adequate consultation procedures with those members should be in place. In particular, the organisation 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 organisation shall be financially independent, particularly from the pharmaceutical industry (max. 49 % of funding from several companies) and disclose to the EJP RD 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 overall percentage of the organisation budget. Any relationship with corporate sponsorship should be clear and transparent. This information shall be communicated to the EJP RD on an annual basis.
  - The organisation 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**

Table 1: Indication of eligible components and of average costs to be used for the budget estimation of the networking event

The Networking Support Scheme does not support research costs or personnel costs for preparing the networking event and/or for being present at the networking event.

AVERAGE MEETING COSTS	Average costs in Euro (VAT included)	Remarks
Meeting room + Audio/Video equipment (screen, video projector, microphones) and teleconference needs	900 €	Per day
Lunch	35 €	Per person/day
Networking dinner (the evening before a one-day event or on the evening of the first day of a two-day event). The costs of one dinner per networking event is allowed.	45 €	Per person
Coffee break	9 €	Per person/break

Table 2: Indication of average travel and hotel costs to be used for the budget estimation of the networking event

AVERAGE TRAVEL COSTS	Average costs in Euro (VAT included)	Remarks
Travel within Europe (round trip)	300 €	
Travel between Europe and European associated countries (e.g. Israel, Turkey) (round trip)	1,000 €	
Travel between Europe and Canada (round trip)	2,000 €	
Hotel with breakfast	120 €	Per person/night