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

March 2022

Submission on a continuous basis from July 1, 2022
Final collection dates in EJP RD:
September 1, 2022
December 1, 2022

Also, the application template, the Frequently Asked Questions (FAQ)
and 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 concerning content:
Read the Frequently Asked Questions (FAQ) on:
http://www.ejprarediseases.org/index.php/networking-support/
or contact the Networking Support Scheme Secretariat/ZonMw, The Netherlands:
Tel:+31 70 349 52 20
E-mail: NSSS@zonmw.nl

For questions concerning ProjectNet light after having read the instructions):
ProjectNet servicedesk
Tel:+31 70 349 51 78
E-mail: servicedesk@zonmw.nl

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The first 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 or rare cancers between health care professionals, researchers, and patients in new or expanding research networks by funding networking events.

The second aim of the Networking Support Scheme is to enable or increase the participation of usually underrepresented countries in Europe in new and in expanding research networks on rare diseases or rare cancers.

The focus of the workshops or conferences should be (the implications of) research results and innovative solutions. The results of these networking events may lead to future collaborative and novel 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 networking event to organise a **transnational** European/international event to share and disseminate knowledge on rare diseases.

From June 3, 2021, the applicants can choose between the format of a face-to-face meeting, a hybrid meeting or an online meeting. In a hybrid meeting, a group is present in one location and additional participants are present online.

A specific application template has to be completed. The call is open continuously again from July 1, 2022 till December 1, 2022. The applications are collected every three months and the eligibility is checked. The collection dates are indicated on the EJP RD website. Applications that pass the eligibility check are evaluated competitively by an independent Networking Evaluation Committee using defined evaluation criteria. The rules of the European Union's Horizon 2020 research and innovation programme are applied.

Selected networking events are published on the EJP RD website. These may be used as inspiration for building the applying consortium or defining topics for an application.

LIST OF ABBREVIATIONS

AREB	Advisory Regulatory Ethics Board of the EJP RD
EC	European Commission
ECS	Early Career Scientist
EJP RD	European Joint Programme on Rare Diseases
EU	European Union
GDPR	General Data Protection Regulation
IPR	Intellectual Property Rights
IRDiRC	International Rare Diseases Research Consortium
NSS	Networking Support Scheme
NSSS	Networking Support Scheme Secretariat (ZonMw)
PAO	Patient Advocay Organisation

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 in 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) started a new funding scheme at the end of 2019 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 Networking Support Scheme will provide financial support to third parties for fostering the organization of workshops or conferences.

The first aim of the Networking Support Scheme in the European Joint Programme on Rare Diseases (EJP RD) is to encourage sharing of knowledge between health care professionals, researchers, and patients/patient advocacy organisations (PAOs) in new or expanding 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(s).

The second aim of the Networking Support Scheme is to enable or increase the participation of usually underrepresented countries in Europe in new and in expanding research networks on rare diseases or rare cancers.

The focus of the workshops or conferences should be (the implications of) research results and innovative solutions. The results of these networking events may lead to future collaborative and novel research efforts and increased uptake of research results in the rare disease and rare cancer communities, strengthening the collaborations between different stakeholders.

The aims of the Networking Support Scheme are 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. Therefore, the content of (an application for) a Networking event should be in compliance with the vision and goals of IRDiRC.

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:

- 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;
- 1000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options;
- 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 FORMAT OF THE NETWORKING EVENT

From June 3, 2021, the applicants can choose between the format of:

- a face-to-face (in-person) meeting,
- a hybrid meeting. In a hybrid meeting, a group is present in one location and additional participants are present online,
- an online (virtual) meeting.

The choice of the format may depend on the aim of the networking event and the participants in the event. As the focus of the Networking Support Scheme is on collaboration and networking of the participants of the event, the applicants have to think of the networking possibilities, also in online or hybrid meetings. Online networking events should not be organised only with lectures or webinar but should also include interactive sessions. For tips and tricks on how to facilitate networking in online meetings and events, you may look for online tutorials, where many suggestions can be found – e.g. https://www.youtube.com/watch?v=ETUKZX3vie0 and https://www.youtube.com/watch?v=ypVQ-Laz17o.

Furthermore, you may look at this website or others for possibilities for collaboration software.

Moreover, there are professional virtual event organizers/planners to assist with organizing successful virtual events.

In the application template, you have to justify the chosen format and the required budget for all formats. All costs should be reasonable. See Annex 3 for suggested items and costs.

4   APPLICATION

4.1   ELIGIBILITY AND NON-ELIGIBILITY CRITERIA

The applications for the networking events should meet the first and/or second aim of the Networking Support Scheme. The focus of the workshops or conferences should be (the implications of) research results and innovative solutions. The results of these networking events may lead to future collaborative and novel research efforts and increased uptake of research results in the rare disease and rare cancer communities, strengthening the collaborations between different stakeholders.

A. **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://rarecarenet.istitutotumori.mi.it/rarecarenet/index.php/cancerlist

Cohorts of undiagnosed patients that are suspected of suffering from a rare disease/ rare diseases.

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).

B. **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.

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 if these can be elaborated and funded within the means of the Directorate-General for Health and Food safety from the European Commission (http://funcanis.es/european-reference-network-clinical-practice-guidelines-and-clinical-decision-support-tools/).

4.2 ELIGIBILITY OF APPLICANTS

Rare disease researchers and health care professionals working in universities, other higher education institutions, public research institutes[1], 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 pharma-ceutical industry (max. 49 % of funding from several companies). More information on the 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.

One of the eligible applicants will be **the principal applicant**. The organisations of the applicants have to be legal entities and established in countries mentioned in **Annex 1, Table A.**

The roles of the principal applicant and co-applicants are described in section 4.5 and 4.6.

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 PAOs 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.

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[1] Funded by the government for at least 50%

Networks are also encouraged to include Early Career Scientists (ECSs) in their network, e.g. as (co)organiser. For further information on the definition of an Early Career Scientist, see 4.8.

The inclusion of patient advocacy organizations (PAOs) in the network is highly encouraged. For more information on patient-centred care and strategies to involve patient representatives and PAOs in your research project, please consult the EJP RD Short Guide on patient partnerships in rare disease research projects. If PAO involvement is not deemed appropriate within a specific network, this should be explained and justified.

For information on where to find patient representatives and PAOs willing to be involved in research, please see:

- Orphanet portal for rare diseases and drugs patient organization directory
- Rare Diseases Europe (EURORDIS)
- European Reference Networks (ERNs)
- European Patient's Academy on Therapeutic Innovation (EUPATI)
- National patient alliance on rare diseases or (rare) cancers.

PAOs can be Principal applicant of an application. However, the topic of the networking event should be sharing of knowledge in connection with research results. PAOs may ask researchers or clinicians to be co-applicants in an application, dependent on what kind of knowledge will be shared. A family gathering without discussing research results is not eligible in this funding scheme.

Researchers and health care professionals working in institutes that are established in countries that are **not involved in the EJP RD** or PAOs that are established in countries that are **not involved in the EJP RD cannot be applicants** for the networking event. If they are an invited speaker, the costs for their travel and hotel may be paid through the networking budget. Otherwise, they will have to secure their own funding when they would like to participate in the networking events.

4.3   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 part of the applying consortium.

4.4 OTHER ELIGIBILITY CRITERIA

4.4.1 TIME PERIOD BETWEEN APPLICATION AND THE NETWORKING EVENT

The application for 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 a maximum of 12 months after the application date**. If the networking event is organised more than 12 months after this date, the networking budget will be revoked if no justification can be given for the delay in organizing the event.

4.4.2 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, and independent of the chosen format (face-to-face, online or hybrid). It is not possible to apply for a series of Networking events.

The costs for a networking event have to be clearly specified in the application form. Only expenses for the organization of networking meetings are eligible. 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. However, the satellite networking event should have a specific goal in relation to the Networking Support Scheme. Only the additional costs of the satellite meeting 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, additional technical support, etc.).

The Networking Support Scheme does not support research costs or personnel costs for preparing the networking event. Technical support for the online/hybrid event is eligible costs.

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 the justification of the expenditure.

4.4.3 LENGTH OF THE TEXT IN THE APPLICATION

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

4.5   ROLE OF THE PRINCIPAL APPLICANT

The **principal applicant** is an eligible **researcher, health care professional** or **representative of a PAO**. 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).

4.6   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 a **maximum of 9 co-applicants** next to the principal applicant (10 persons in total). The co-applicants will organise the networking event together with the principal applicant.

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.

4.7   OTHER PARTICIPANTS

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 4.9 Practical issues).

Researchers and health care professionals working in institutes that are established in **countries** that are **involved in the EJP RD**, and PAOs 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 PAOs 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, unless the applying consortium invites them as speakers.

4.8 DEFINITION OF EARLY CAREER SCIENTIST

Early Career Scientists are defined in analogy to the regulations of the European Research Council criteria for starting grants. In short, this means for **researchers** that they have 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 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.

4.9 PRACTICAL ISSUES

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

4.9.1 COVERAGE OF THE COSTS

The maximum budget is € 30,000 for one networking event, inclusive of any VAT that is due and independent of the chosen format.

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. The tables 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 a profit out of the event is not allowed. In the 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. The presence of a private-for-profit organisation cannot be funded by the Networking Support Scheme.

4.9.2   HOW OFTEN CAN AN APPLICANT APPLY AND HOW OFTEN CAN A NETWORK APPLY

Applicants may apply for a 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. This revised application will compete at the same terms as applications for other networking meetings in this second round. When the revised application is not selected in the 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.

4.9.3   COMMUNICATION ON SELECTED NETWORKING EVENT AND DISSEMINATION OF OUTCOMES

4.9.3.1 COMMUNICATION OF SELECTED NETWORKING EVENT

The title of the networking event, names of the applicants 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.

4.9.3.2 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 online reporting form within 2 months after the date of the event, including a public lay summary with a description of the content, the outcomes, and the next steps. The public lay summary of 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 the general public, newsletters, presentations at other meetings.

4.10 SUBMISSION OF PROPOSALS FOR A NETWORKING EVENT

4.10.1 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 6.1);
- 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.

4.10.2 REGISTRATION

Applying consortia who intend to submit a transnational proposal for a networking event should register at the ZonMw electronic application system ProjectNet as early as possible as it takes time to put the names of the applicants in the system and have it incorporated in this system. Instructions for registration and application on this system are published on the EJP RD website.

4.10.3 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 and must be submitted by the principal applicant 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 on a continuous basis from July 1, 2022 again. Every three months the applications will be collected and evaluated in a competitive way. A calendar of collection dates is provided on the EJP RD website.

Please note that only the application template for the Networking Support Scheme provided on the EJP RD website page 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 must be provided in the application template:

- The title of the networking event, information on what kind of application (new, resubmitted; satellite event, etc.) and the networking format that will be chosen.
- 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 public lay summary has to be copied on the ProjectNet online.
    o A useful lay summary describes the who, what, where, when, why and how of the networking event, the target group/medical domain and the proposed impact of the networking event.
    o Use short sentences – and write in plain English. Imagine you're talking to a distant family member who works in another field.
    o Ask a layperson to read the summary and revise if needed.
- 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 in case of face-to-face or hybrid meeting;
- 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 the 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, use of the expected results for future work in the field.

- (Draft) programme/agenda of the networking event which indicates the structure and further specifications of the networking event, like potential speakers.
- Explanation on the choice of format of the event (face-to-face, hybrid or online). Indication on how the organisation of the event will allow efficient networking of participants (organisation of the program, tools to be used, etc);
- How does this networking event make a difference for the research field? How does this event make a difference in comparison to previously organised meetings?
- 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, description of their individual roles in the networking event and brief CV for each co-applicant;
- 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, name, and signature of the principal applicant (also on behalf of the co-applicants).

5 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 June, 2020. (Note: according to Dutch Law the names of the members of the NEC may have to be published).

6   EVALUATION

6.1   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 (time schedule, adequate requested resources,);

f.   Competence and experience of the applicants in the field(s) of the rare disease(s)/rare cancer(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; How does this event make a difference in comparison to previously organised meetings or meetings of other networks for the rare disease(s)/rare cancer(s)?

b.   Added-value of transnational collaboration: gathering a critical mass of information, harmonization of data, sharing of specific knowledge, etc.;

c.   Inclusion of participants from countries involved in the EJP RD that are usually underrepresented in networks;

d.   Active and meaningful engagement of knowledge-users in the event;

e.   Active and meaningful engagement of Early Career Scientists in the event;

f.   Active and meaningful engagement of patient(s) or patients' advocacy organisation representatives(s) in the event;

g.   Involvement of industry (when relevant);

h.   Sustainability or extension of the research network after the networking event and effectiveness of the proposed networking event to exploit and disseminate the results of the event and to communicate the event.

3. Quality and efficiency of the implementation

a.   Complementarity of the applicants in relation to the objectives of the networking event;

b.   Soundness of the format (face-to-face, hybrid, or online networking event); Will the chosen format ensure enough collaboration/networking;

c.   Appropriateness of the management, including risk management and contingency plans;

d.   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.

6.2   PROCEDURE FOR EVALUATION OF PROPOSALS

6.2.1 ELIGIBILITY CHECK

The Networking Support Scheme Secretariat (NSSS) will check all proposals to ensure that they meet the call's formal criteria (e.g. the 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, whether the topic of the networking event is within the aims of the Networking Support Scheme). The NSSS communicates the result of the eligibility check by e-mail.

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

6.2.2 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 6.1). The members of the NEC will perform the assessment of the proposals and complete the evaluation forms with scores and comments for each criterion.

Each proposal is assessed by NEC members with a clinician or researcher background and with a PAO background. The evaluation reports for a specific proposal are discussed in a remote consensus meeting to come to a consensus for this proposal. The consensus assessments are discussed in a remote plenary meeting with NEC members and final recommendations are given. A ranking list of the evaluated proposals and the summary reports are validated by the NEC.

6.2.3 ETHICS ASSESSMENT

In the application template, a pre-filled H2020 self-assessment ethics template has to be completed by the applicants. Members of the AREB, the Advisory Regulatory Ethics Board of the EJP RD, assess this completed ethics template and will list those tasks that need to be done and documents that need to be submitted by the principal applicant in case that the application is selected. All required ethics documents have to be made available upon request.

According to Horizon 2020 rules, an ethical assessment 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 (e.g. sending newsletters, or sharing with others), the principal applicant needs the consent of the participants. Of additional relevance for the ethics, assessment is to know if patients are invited to join and if the meeting is held online or partially online.

6.3   FUNDING DECISION

Selected applications will be funded based on the ranking list established by the NEC, ethics assessment by the AREB and available funding in the Networking Support Scheme.

The NSSS will 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. Ten or eleven competitive rounds for the Networking Support Scheme are envisioned with a total budget of less than 2M€.

The final decision of the evaluation will be communicated to the principal applicant by e-mail from the NSSS. This decision will be accompanied by the final summary report of the scientific evaluation and - in case that the application is selected for funding - the report of the ethics assessment by the AREB.

6.4   REDRESS PROCEDURE

The principal applicant may submit a request for redress **within one month** of the notification of the eligibility result or the final decision of the evaluation procedure, if the principal applicant/applying consortium feel that there has been a shortcoming

in the way their proposal has been evaluated that may affect the final decision on whether to fund it or not or if they believe the result of the eligibility check is incorrect.

An internal review committee of the EJP RD will examine requests for redress. The committee's role is to ensure a coherent interpretation of such requests and equal treatment of applicants.

The request for redress must be:

- Related to the evaluation process, or eligibility check, as described in Section 6.2 of this Call Text.
- Performed through completing an online form on the EJP RD website, including a clear description of the grounds for the complaint. The link to the online form to submit the request is: https://forms.office.com/r/WP0tW0NCfs
- The completed online form must be sent to the EJP RD email address EJPRD-redress@ejprarediseases.org within one month from the receipt of the email of the NSSS.
- Sent by the principal applicant (the person who submitted the original application).

The internal committee will review the case and will recommend an appropriate course of action to the NSSS, responsible for handling the applications in the Networking Support Scheme. If there is clear evidence that a shortcoming could affect the eventual funding decision, it is possible that all or part of the proposal will be re-evaluated.

Please note:

- This procedure is concerned with the evaluation and/or eligibility checking process. The internal committee will not call into question the scientific or technical judgement of appropriately qualified experts.
- A re-evaluation will only be carried out if there is evidence of a shortcoming that affects the final decision on eligibility or the final decision whether to fund or not. This means, for example, that a problem relating to one evaluation criterion will not lead to a re-evaluation if a proposal has failed anyway on other criteria.
- The evaluation score following any re-evaluation will be regarded as definitive. It may be lower than the original score.

Only one request for redress per application will be considered by the internal committee. It is not possible to submit a new request for redress after the reception of the result of the previous demand. All requests for redress will be treated in confidence and have to be sent to the following e-mail address using the abovementioned online form: EJPRD-redress@ejprarediseases.org

If you have any question about the redress process, please contact
EJPRD-redress@ejprarediseases.org.

A reply will be sent within **one month of the deadline for redress requests**. If a definitive response cannot be given at that stage, this reply will indicate when a definitive response will be provided. The EJP RD will not engage in any further discussion about the evaluation of the application beyond the definitive response.

7   FINANCIAL AND LEGAL ISSUES

7.1   FUNDING CONTRACTS

For this Networking Support Scheme, ZonMw (the acting Networking Support Scheme Secretariat -NSSS) 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[1], 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.

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 NSSS. 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 PAO 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 NSSS 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

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[1]   https://wetten.overheid.nl/BWBR0005290/2019-03-16#Boek7_Titeldeel7_Afdeling1_Artikel400

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 the 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.

7.2   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 of to specify their origin.

7.3   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/.
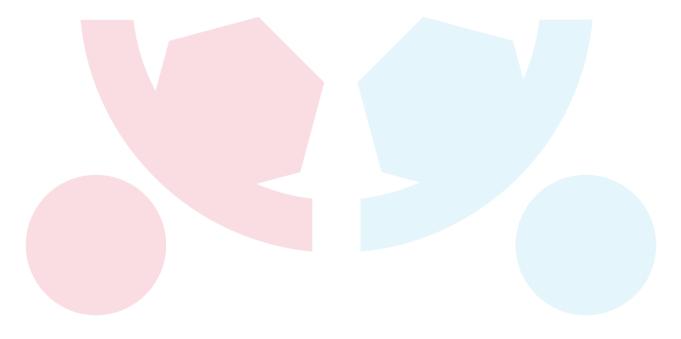
7.4 RESPECT FOR RELEVANT EUROPEAN AND INTERNATIONAL STANDARDS

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 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);

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 6.2.3 Ethical evaluation.

8   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 the delivery of the report (see 7.1).

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.

9 CONTACT AND FURTHER INFORMATION

The administrative management of the Networking Support Scheme will be ensured by the NSSS at ZonMw, The Netherlands. The NSSS will be responsible for the collection of the applications at each deadline, supporting the NEC and communicating 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](#).

10 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 include 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 the 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

The principal applicant has to justify the costs for the Networking meeting. The costs should be reasonable. The rules of the institution of the principal applicant have to be followed: e.g. in case three quotes have to be asked for according to the institutional rules, then these rules have to be followed.

The Networking Support Scheme does not support research costs or personnel costs for preparing the networking event. Technical support for the online/hybrid event is eligible costs.

Tables 1 and 2:   indications for costs of eligible components in face-to-face networking events and face-to-face part a hybrid meeting.

Table 3:   indications for eligible components for online networking events and the online part of a hybrid meeting

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Table 1: Indication of eligible components/average costs
to be used for the budget estimation of the face-to-face networking event or the face-to-face component of a hybrid 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 are 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

Table 3: Indication of eligible components to be used for the budget estimation of the online networking event

Online components
Meeting services (hosting, streaming etc.)
Additional networking services (breakout rooms, brainstorming tools, etc.)
Technical support and moderation
Translation services
Accessibility (disabilities)

Example of website with online networking tools.