

European Joint Programme on Rare Diseases (EJP RD)

ERN-RD training and support program

Research Training Workshop

Call Text

The call opens on 01. September 2022
The deadline for application is 01. October 2022

The links to the electronic application form, as well as this call document (pdf) can be found at the EJP RD website.

[Application Form](#)

1. MOTIVATION

An EJP RD survey investigating the needs of the European Reference Networks (ERN (ERN)¹ demonstrated that it is necessary to enlarge and intensify training opportunities in the field of **research** on rare diseases. Based on this result, the EJP RD WP 17 "ERN-RD training and support program" focus group proposed to deliver training programs based on two main components:

- **Research training workshops,**
- Research mobility fellowships

In the long term all training activities should be accredited.

2. AIM OF THE CALL

The aim of this call is to identify the most suitable topics for the organization of research training workshops targeted to the ERNs. Selected research training workshops will have to train ERN researchers and clinicians in ERN relevant innovative training themes. Training themes may include innovative research methodologies, diagnostic research methodologies, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc. Moreover, workshops will be aiming to provide a cross-ERN added value.

The successful applicant will receive the financial support to organize a 2 days workshop. The successful applicant will be supported by the WP17 coordination team (see contact details in part 8 of this document), specifically the call for workshop participants will be managed by the WP17 coordination team. The organization on-site will be responsibility of the selected organizer.

There should be no overlap of the workshops with other EJP RD training activities foreseen (for overview on this please visit: <https://www.ejprarediseases.org/index.php/training-and-empowerment/>).

The workshops will be open only to participants affiliated to ERN institutions. The costs of the organization may cover the following items:

- Meeting room(s)
- Catering (coffee breaks, lunch)
- Travel and accommodation of speakers
- Travel and accommodation of participants

EJP RD has established general guidelines for the costs of the organization of events that are provided in Annex 1. The applicants are strongly encouraged to apply these guidelines to the extent possible while planning the organization of their workshop(s).

3. EVALUATION COMMITTEE

¹ Further information: https://ec.europa.eu/health/ern_en

All proposals will be evaluated by the Scientific Evaluation Committee (SEC) composed of:

- WP 17 leader: Holm Graessner, University Tübingen (EKUT) and ERN-RND coordinator
- Three WP17 Task leaders:
 - Nicoline Hoogerbrugge, Radboud University Medical Center Nijmegen (RUMC) and ERN GENTURIS coordinator
 - Franz Schäfer, Heidelberg University Hospital (UKL-HD) and ERKNet coordinator
 - Alberto Pereira, Leiden University Medical Center (LUMC) / Amsterdam UMC (AMC) and Endo-ERN coordinator
- Five independent external scientific experts (not working within any of the 24 ERNs)
- One representative of the EJP RD coordination

All members of the SEC will sign the confidentiality agreement and disclose any Conflict of Interest. In case an application concerns an applicant or host (secondment) institution from one of the ERNs to which belong the four members of the WP17, they will not take part in the evaluation of this specific application and final funding decision.

4. APPLICATIONS

4.1 Eligibility criteria

The **applicant submitting workshop topics must be:**

- Affiliated to any EJP RD beneficiary institution (for the list of the EJP RD beneficiary organization please see the link: <http://www.ejprarediseases.org/index.php/about/members/#1551866330856-bccc35fe-1374>)

OR

- Affiliated to an ERN Full Member. The list of full ERN Members per country and per network can be found here: https://ec.europa.eu/health/ern_en

OR

- Affiliated to an ERN Affiliated² Partner institution at the time when the application is submitted, as well as during the period of the execution of the workshop.

4.2 Information to be submitted

Applications must be written in English and respect the format and the length indicated in the application form. Applications exceeding these limitations will be rejected without further review. Applicants must provide personal information and

² For definitions of Affiliated Partners see the Board Statement of 10 October 2017: https://ec.europa.eu/health/sites/health/files/ern/docs/boms_affiliated_partners_en.pdf

submit appropriate information about the topic and the workshop itself, as specified below.

PERSONAL INFORMATION

- a. Full name
- b. Affiliation and full address of the institution
- c. Specify to which ERN or EJP RD beneficiary you are affiliated:
 - a list of ERN members per network and per country can be found here: https://ec.europa.eu/health/ern_en:
 - Beneficiary of EJP RD
- d. Email address

WORKSHOP TOPIC (*max. 4000 characters*)

Excellence

- e. Title of the workshop
- f. Training objectives
- g. Innovative and ERN cross-cutting aspects
- h. Type of research covered by the proposed topic (basic, clinical, translational)
- i. Type and level of seniority of researchers to which the workshop is addressed

Impact

- j. Relevance of the topic for the ERN(s)
- k. How the topic will induce or enhance collaboration within and between ERNs?
- l. Benefits to the RD community expected from the workshop

Implementation

- m. Training methodology
- n. Organization of the workshop
 - Proposed whereabouts of the workshop
 - Approximate number of local speakers and external speakers

4.3 Timeline

The submission will be opened from 01. September until 01. October 2022.

To be able to align participant selection processes and workshop organization as well as to ensure a timely organization of the workshop, the selected workshops should be organized at earliest 5 months and at latest 10 months from receiving the official approval. Workshop organizers who have not submitted **all** necessary information to launch the opening of the workshop 5 months before the planned workshop date will not receive the approved funding. In addition, not respecting the 10 months deadline to conduct the workshop will lead to cancellation of the funding approval.

5. EVALUATION

5.1 Evaluation criteria

The topics will be selected based on the following criteria:

5.1.1 Excellence

- Addressing cross-cutting issues relevant for ERNs
- Multidisciplinary aspects
- Fostering ERN collaboration
- No overlap with other EJP RD training activities

5.1.2 Impact

- Relevance of the topic for the ERN(s)
- Will the topic induce or enhance collaboration within and between ERNs?
- Benefits to the RD community by the workshop

5.1.3 Implementation

- Appropriate training methodology
- Appropriate venue of workshop

Scoring system:

0: Failure: The proposal fails to address the criteria in question, or cannot be judged because of missing or incomplete information.

1: Poor: Low priority and relevance for any target group.

2: Fair: Moderate priority and relevance for a small target group.

3: Good: Moderate priority and relevance for a large ERN cross cutting target group. More information /certain improvements may be necessary

4: Very good: High priority and relevance for a small target group

5: Excellent: High priority and relevance for a large ERN cross cutting target group

5.2 Evaluation of proposals and funding decision

The process for evaluation of the submitted proposals will be organized in three steps:

- **Eligibility check:** the WP17 workshop coordination team from LUMC-Leiden and EKUT-Tübingen will check all proposals against eligibility rules as described above. Eligible proposals will be forwarded to the SEC. Applicants of non-eligible proposals will be notified and can resubmit an application on a next call if they fulfil then all eligibility criteria.
- **Individual (remote) evaluation by the SEC:** Each application will be evaluated remotely by 3 members of the SEC: one ERN representative and two external experts. Proposals will be assessed according to specific evaluation criteria that are in line with Horizon 2020 rules (see above), 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. Each criterion will be scored out of

5. The threshold for individual criteria will be 3. The maximum score that can be reached from all five criteria together is 15 points.

- **Consensus discussion and final funding decision:** The WP17 coordination team will prepare an evaluation summary report including evaluations of all Workshops proposals and preliminary ranking list based on the mean scores.

All 10 SEC members will meet (via a conference call) to discuss further and take the final decision.

The summary review report of the SEC recommendations and reasons for rejection of the application will be prepared by the SEC members involved in the individual evaluation and forwarded by email to declined applicants. The successful applicants will also receive respective notifications by email.

The representative of the EJP RD coordination will ensure that the whole implementation and evaluation process of the call is in line with the Horizon 2020 guidelines and respects transparency and equal opportunity rules.

- **Ethical evaluation**

Dependent on the topic of the workshop 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 workshop 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 workshop participants in registration forms). No personal data should be disseminated in the presentations shown in the workshop. Participants of the research training workshop 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.

6. FINANCIAL AND LEGAL ISSUES

6.1 Funding model

Around 7 workshops per year will be financed between 2020 and 2023 (thus a total of max 28 workshops are expected to be funded). A minimum of 15 participants from different Health Care Providers Members of the European Reference Networks have to receive full reimbursement of their costs (hotel, travel) by the approved funding.

The maximum budget assigned to a workshop is 25.000€. This should cover:

- venue hire, administrative costs, audio-visual and IT facilities essential for the workshop
- Travel and accommodation expenses for approximately 20 participants (indicative maximum costs per participant: 603€)
- Travel and accommodation expenses for invited speakers (indicative maximum costs per speaker: 603€)

If the workshop organizer is affiliated to an EJP RD beneficiary institution or linked third party, the budget of 25.000€ will be allocated within the EJP RD budget under WP17 workshop organization. This budget will come from the central WP17 coordination site: LUMC, the Netherlands. The organizer will be able to declare the actual costs of organization of the workshop through the EJP RD annual financial reporting (as with the other EJP RD costs). The eligibility rules are set in the EJP RD Grant agreement 825575. The reimbursement will be based on the actual costs declared in the reporting.

If the workshop organizer is affiliated to an institution which is not an EJP RD beneficiary all expenses will be paid by LUMC.

The workshop organizer should consider the EJP-RD general guidelines for the costs of the organization of events (Annex 1).

6.2 Research consortium agreement and ownership of intellectual property rights

Each Research Workshop will become an integral part of the EJP RD and thus EJP RD Grant Agreement and Framework Consortium Agreement will apply. Results and new Intellectual Property Rights (IPR) resulting from workshops funded through the EJP RD WP17 internal call for research workshops will be owned by the projects beneficiaries' organisations according to specific national/regional rules on IPR and as specified in the EJP RD Framework Consortium Agreement. If several participants have jointly carried out work generating new IPR, they shall agree amongst themselves (FCA sections 8.1 and 8.2: *As set forth under Article 26.2 of the Grant Agreement, the joint owners must agree in writing on the allocation and terms of exercise of their joint ownership in a separate agreement ("Joint Ownership Agreement") to ensure compliance with their obligations under this Framework 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 research workshops 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 (GA article 28.1: *Each beneficiary must — up to four years after the period set out in Article 3 — take measures aiming to ensure 'exploitation' of its results*).

The EJP RD shall have the right to use documents, information and results submitted by the workshop organisers and/or to use the information and results for their own purposes, provided that the owner's rights are kept and taking care to specify their origin (GA articles 31.2: *The beneficiaries must give each other access — on a royalty-free basis — to results needed for implementing their own tasks under the action, and 31.3: The beneficiaries must give each other — under fair and reasonable conditions (see Article 25.3) — access to results needed for exploiting their own results*).

6.3 IRDiRC policies and guidelines

The aim of the call 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.

The IRDiRC vision: 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.

In order to work towards this vision, IRDiRC has set three goals for the next decade:

Goal 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

Goal 2: 1000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options

Goal 3: Methodologies will be developed to assess the impact of diagnoses and therapies on rare disease patients.

The project partners are expected to follow IRDiRC policies and guidelines.

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

6.4 Respect of relevant European and international standards

The submitted proposals have to respect relevant European and international standards like:

- The new 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. This Regulation applies in all Member States from May 25, 2018 and thus also for the EJP RD Research fellowship granted projects (<https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en>).

- The EC Directive 2010/63/EU on the protection of animals used for scientific purposes (<http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32010L0063>)
- 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)
- To make research data findable, accessible, interoperable and re-usable (FAIR), a data management strategy is mandatory in the full proposal. For an example of questions for a data management strategy, see Annex 1 in http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf.
- A data management strategy/plan should include information on:
 - *the handling of research data during & after the end of the project;*
 - *what data will be collected, processed and/or generated and/or reused;*
 - *which methodology & standards will be applied;*
 - *whether data will be shared/made open access;*
 - *how data will be curated & preserved (including after the end of the project).*
- 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.

7. RESPONSIBILITIES, REPORTING REQUIREMENTS AND DISSEMINATION

SATISFACTION SURVEY

- The organizer must conduct a short satisfaction survey – which will be provided by WP17 - at the end of the workshop to inquire about the benefits of the training for the participants, learning skills/knowledge and collect other relevant information for the overall training. The results of the survey must be sent to the WP17 coordination team and will be used for continuous improvement of future workshops.

DISSEMINATION

- The organizer has to provide a workshop summary which will be used to announce the workshop through ERN/EJP RD Newsletters, Websites, Tweets, etc.
- The organizer should collect testimonials of participants of the workshop which will be used in different EJP RD communication campaigns.

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

- display the EU emblem
- display EJP RD logo
- ERN and/or institutional logo
- 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.

8. CONTACT AND FURTHER INFORMATION

The WP17 workshop coordination team is based at EKUT-Tübingen, Germany and LUMC-Leiden, the Netherlands.

- email: sanja.hermanns@ejprd-project.eu
- email: c.n.van_beuzekom@lumc.nl

Annex I

General guidelines for the indicative costs of the organization of events:

Total budget per workshop: € 25 000,00

Maximum number of participants: 20

Eligible costs for the organization of a 2 days workshop:

	≠Days	Unit costs	Cost per attendee
Travel	--	€350,00	€350,00
Hotel	1	€120,00	€120,00
Diner	1	€45,00	€45,00
Lunch	2	€35,00	€70,00
Coffee breaks	2	€9,00	€18,00
TOTAL	--	--	€603,00

If **external speakers** are envisaged, similar costs should be anticipated.