

# European Joint Programme on Rare Diseases (EJP RD)

## ERN-RD training and support program

### Research Training Workshop

#### Call Text

**The call opens on 31 August 2020**  
**The deadline for application is 12 October 2020**

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

Application form:

<https://forms.office.com/Pages/ResponsePage.aspx?id=AcQ6OB2ia0KAcI90w2twk8f8TO5199dFvKkSOEEBdRIUNFAyQTdOVE5ZTVZCNDdUVFITWDIJWlpHNS4u>

Call document:

<https://www.ejprarediseases.org/index.php/training-and-empowerment/ern-trainings/>

## 1. MOTIVATION

An EJP RD survey investigating the needs of the European Reference Networks (ERN (ERN)<sup>1</sup> 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

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<sup>1</sup> Further information: [https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)

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

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

- WP17 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) and Endo-ERN coordinator
- Three 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. The list of EJP RD beneficiary organizations can be found here: <https://www.ejprarediseases.org/index.php/about/members/>

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](https://ec.europa.eu/health/ern_en)

OR

- Affiliated to an ERN Affiliated<sup>2</sup> 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 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. Applicant affiliation to ERN full/affiliated partner or EJP RD beneficiary institution
- d. Email address

### WORKSHOP TOPIC (*max. 4000 characters for e-n*)

#### 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

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<sup>2</sup> 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](https://ec.europa.eu/health/sites/health/files/ern/docs/boms_affiliated_partners_en.pdf)

## 4.3 Timeline

The submission will be opened from 31 August 2020 until 12 October 2020.

There will be two calls per year (opening foreseen for 2021 in mid-January mid- June) to choose topics for funding of 6-7 workshops per year. To be able to align participant selection processes and workshop organisation as well as to ensure a timely organisation of the workshop, the selected workshops should be organized at earliest 4 months and at latest 9 months from receiving the official approval by the evaluation committee. **DUE TO THE COVID-19 OUTBREAK, AN EXCEPTIONAL EXTENSION FOR THE ORGANISATIONAL TIMEFRAME COMPARED TO THE CALL TEXT WILL BE ALLOWED. THIS MEANS THAT THE WORKSHOPS MAY BE ORGANISED BETWEEN 4 AND 18 MONTHS AFTER RECEIVING POSITIVE RESPONSE FROM THE COORDINATION OFFICE OR APPROVAL FOR FUNDING.**

## 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 8 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.

## 6. FINANCIAL AND LEGAL ISSUES

## 6.1 Funding model

A maximum of 7 workshops for 20 participants will be financed per year between 2020 and 2023 (thus a total of 28 workshops are expected to be funded):

The total budget foreseen for the workshop call is of 680.000 €. This budget will be managed by the two responsible institutions:

- Tübingen-EKUT, 340.000€
- Leiden-LUMC, 340.000 €

Funded applications will be divided into two equal groups and (by default) assigned to one of the managing institutions.

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 20 participants (maximum 603€ per participant)
- Travel and accommodation expenses for invited speakers (maximum 603€ per speaker)

All expenses will be paid by one of the two WP17 coordination sites (LUMC-Leiden or EKUT-Tübingen). Only actual costs occurred for the workshop organization will be eligible. The workshop organizer should consider the EJP-RD general guidelines for the costs of the organization of events (Annex 1).

The workshop organizer must ensure that the service providers (e.g. catering company) issue the invoice to EKUT-Tübingen or LUMC-Leiden, depending on whether EKUT-Tübingen or LUMC-Leiden is the responsible WP17 managing institution.

## 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](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](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@med.uni-tuebingen.de](mailto:sanja.hermanns@med.uni-tuebingen.de)
- email: [RareEndoERN@lumc.nl](mailto:RareEndoERN@lumc.nl)

## Annex I

### General guidelines for the costs of the organization of events

The maximum budget per workshop is € 25 000,00

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

The maximum cost per attendee is 603€. If **external speakers** are envisaged, similar costs should be anticipated (i.e. maximum expense of 603€ per speaker). The remaining amount should be used to cover venue hire, administrative costs, audio-visual and IT facilities essential for the workshop.