

## EJP RD

# European Joint Programme on Rare Diseases

H2020-SC1-2018-Single-Stage-RTD  
SC1-BHC-04-2018  
Rare Disease European Joint Programme Cofund



Grant agreement number 825575

## Del 17.3

# First Annual report on implementation of training programs

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

Partner 58 – EKUT

**Due date of deliverable:** month 13

**Dissemination level:**

PU

Definitions of the terms used / Task assignments:

**WP17 work package lead:** University Tübingen (EKUT) - Holm Graessner (coordinator of ERN-RND) and Sanja Hermanns (Scientific Project Manager)

**WP17 work package participants:**

- Leiden University Medical Center (LUMC) - Alberto Pereira (AP), coordinator of EndoERN and Charlotte van de Beuzekom (CvB), EndoERN project manager,
- Radboud University Medical center-Nijmegen (RUMC) - Nicoline Hoogerbrooge (NH), coordinator of ERN GENTURIS and Nicoline Geverink (NG), ERN GENTURIS project manager and
- University Hospital Heidelberg (UKL-HD) - Franz Schaeffer (FS), coordinator of ERKnet and Tanja Wlodkowski (TW), ERKnet project manager.

**WP17 Task 17.1 - Task lead:** UKL-HD - Franz Schaeffer and Tanja Wlodkowski (TW)

**Task 17.1 - Task participants:**

- LUMC (AP and CvB)
- RUMC (NH and NG)
- EKUT (HG and SH)

**WP17 Task 17.2 - Task lead:** LUMC - Alberto Pereira and Charlotte van de Beuzekom

**Task 17.2 - Task participants:**

- EKUT (HG and SH)
- RUMC (NH and NG)
- UKL-HD (FS and TW)

**WP17 Task 17.3 - Task lead:** EKUT - Holm Graessner and Sanja Hermanns

**Task 17.3 - Task participants:**

- LUMC (AP and CvB)
- RUMC (NH and NG)
- UKL-HD (FS and TW)

**WP17 Task 17.4 - Task lead:** EKUT - Holm Graessner and Sanja Hermanns

**Task 17.4 - Task participants:**

- LUMC (AP and CvB)
- RUMC (NH and NG)
- UKL-HD (FS and TW)

**WP17 coordination team lead:** Sanja Hermanns (EKUT)

**WP17 coordination team:** Sanja Hermanns (EKUT), Charlotte van de Beuzekom (LUMC), Tanja Wlodkowski (UKL-HD) and Noline Geverink (RUMC)

Research Mobility Fellowships-**Coordination Team (FCT):** Tanja Wlodkowski (UKL-HD) and Noline Geverink (RUMC)

Research Training **Workshop -Coordination Team (WCT):** Sanja Hermanns (EKUT) and Charlotte van de Beuzekom (LUMC)

**Focus group:** representatives of each of the 24 European Reference Networks (ERN)

The WP17 lead beneficiary - EKUT (ERN-RND) and the WP17 participants - LUMC (EndoERN), UKL-HD-ErkNET) and RUMC (ERN GENTURIS) have conducted a survey aiming to map the existing training programs in the ERNs and to assess the needs in terms of target groups, formats, contents (task 17.1). A focus group meeting in Leiden (26 June 2019) has followed in order to analyse the survey data and decide on measures (task 17.2). The following list enumerates the attendees of the focus group meeting in Leiden:

- Euro NMD, Teresinha Evangelista, Paris, France
- ERN-Skin, Maya El Hachem, Rome, Italy
- ERN-RND, Judit Molnar, Budapest, Hungary
- VASCERN, Raffaella GAETANO, Milan, Italy
- ERNICA, Roel Bakx, Amsterdam UMC, Netherlands
- ERN GENTURIS, Richarda de Voer, Nijmegen, Netherlands
- eUROGEN, Naside Mangir, Sheffield, UK
- ITHACA, Alessandra Renieri, Siena, Italy
- ERN CRANIO, Renee de Rooter, Rotterdam, Netherlands
- ERN-LUNG, Petra Pennekamp, University Hospital Muenster, Germany
- Endo-ERN, Vallo Tillmann, Tartu University Hospital, Estonia
- ERN-Lung, Jan Stolk; Leiden University Medical Center; Netherlands
- BOND, Neveen Hamdy, Leiden University, Netherlands

- ERKNET, Tanja Levart, Ljubljana, Slovenia
- ERKNET, Tory Kalman, Budapest, Hungary
- ERKNET, Aleksandra Zurowska, Gdansk, Poland
- ERN-RND, Holm Graessner, Tübingen, Germany
- Endo-ERN, Alberto Pereira, Leiden, Netherlands
- ERN GENTURIS, Nicoline Hoogerbrugge, Nijmegen, Netherlands
- ERKNET, Franz Schaefer, Heidelberg, Germany

Taking into consideration the survey results (see Deliverable 17.1), the WP17 participants have decided to develop and deliver tailored research training activities to support RD research, which is the result of the focus group meeting (see deliverable 17.2).

This ERN research training program will be based on two main components:

- research mobility fellowships and
- research training workshops.

In M7-M12, the participants have worked together on creating the documents for the two calls to be launched in year 2 for the above-mentioned training measures.

This included:

- defining the exact eligibility criteria for the applicants
- determining the contents of the application and required obligatory information
- composing the scientific evaluation committee,
- defining the exact evaluation criteria and process
- setting-up a funding model in line with local reimbursement rules
- allocating tasks to the different partners
- defining timelines and frequency of the call openings
- setting up the process of workshop organization

The call documents have been reviewed by the EJP RD coordination team and comments have been accordingly addressed. The call documents have been finalized in a meeting together with the EJP RD Coordination on December 13, 2019. The Call documents have been subsequently validated by the EJP RD coordination team and the EC (see Annex 1-4).

In addition, two templates to be submitted in the application for the research mobility fellowships have been created: Letter of acceptance from the host institution (Annex 2) and Letter of Support from the home institution (Annex 3).

Furthermore, a strategy on disseminating and announcing the calls through different communication channels has been developed. The calls should be disseminated through the EJP RD communication channels with the help of the EJP RD communication officer and further *via*:

- EC-ERN Secretariat and Communication office Isabel DEVE/Coline van HACKE
- ERN Project Managers (the PMs should then disseminate the information to their member-HCP (Health Care Providers) and Affiliated Partners)
- individual communication and dissemination channels of the 24 ERNs (website, newsletter, Twitter, Facebook, etc.)
- Medical faculties (office of doctoral affairs and medical graduate schools) of the ERN member university hospitals (in particular for the fellowships).
- Talks at conferences given by ERN coordinators (s. separate PowerPoint document)

The WP17 coordination team lead (Sanja Hermanns) has also rolled-out the use of the LimeSurvey tool and subsequently created the two online application forms.



## Annex 1

# European Joint Programme on Rare Diseases (EJP RD)

ERN rare diseases training and support  
program

Research Mobility Fellowship

### Call Text

**The call opens on 3. February 2020**

**The deadline for application is 16. March 2020**

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

<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 workshops,
- Research **mobility fellowships**

In the long term all training activities should be accredited.

## 2. AIM OF THE CALL

The call for **Research Mobility Fellowships** aims to financially support PhD students and medical doctors working in ERN-member institutions to undertake short scientific visits (secondments) fostering specialist research training outside their countries of residence and within one of the ERN host institutions.

Applicants who will receive fellowships for Research Mobility **should acquire at their host (secondment) institution new competences and knowledge related to their research on rare diseases and with benefit to their ERN.**

The research mobility fellowships are meant to **cover stays of 2 weeks up to 3 months.**

The exchange will be accomplished exclusively within member institutions of the same ERN or between member institutions of different ERNs.

## 3. EVALUATION COMMITTEE

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:

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

- Nicoline Hoogerbrugge, Radboud University Medical Center Nijmegen (RUMC) and ERN GENTURIS coordinator
- Franz Schaefer, 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

For the purpose of this call, two categories of applicants can apply:

- PhD students with a minimum of one year of research experience;
- Physicians having finished their first year of specialist training

Furthermore:

- The **applicant must be affiliated to an ERN full member** or to an ERN-Affiliated<sup>2</sup> Partner institution from one of the 24 ERNs at the time when the application is submitted, as well as during the proposed period of the training stay. 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)
- Both, the **home and host (secondment) institutions must be Full members or Affiliated Partners of an ERN** at the time when the application is submitted, as well as during the proposed period of the training stay;
- The training stay should last between 2 weeks and 3 months;
- The training must be completed within one year from the application approval.

### 4.2 Information to be submitted

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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)



The applications must be written in English and must be submitted using the online application form (<https://sondage.inserm.fr/index.php/883776/lang-en>). Applicants must provide personal information and submit a research project plan, information about their current work, and information about the home and the host (secondment) institution. Applications using a different format or exceeding the length limitations of any sections will be rejected without further review.

#### PERSONAL INFORMATION

- a. Full name
- b. Email address
- c. Position
  - PhD student
  - Physician

#### INFORMATION ABOUT THE APPLICANT'S HOME AND HOST (SECONDMENT) INSTITUTION

- d. Applicant's home institution
  - Name of the institution, department/unit and full postal address
  - Institution membership in the 24 European Reference Networks (dropdown menu- multiple selections possible)
  - Supervisor's full name and email address
  - Letter of support (to be uploaded in the submission system); the template is provided on the EJP RD website
- e. Applicant's host (secondment) institution
  - Name of the institution, department/unit and full postal address
  - Institution membership in the 24 European Reference Networks (dropdown menu- multiple selections possible)
  - Supervisor's full name and email address
  - Letter of support (to be uploaded in the submission system); the template is provided on the EJP RD website

#### RESEARCH PROJECT PLAN

- f. Project title
- g. Description of the project (*max. 2000 characters*)
  - Outline of the project stating a clear learning goal for the proposed training stay
  - Information about how the newly acquired skills and knowledge will be transferred back to the home institution
- h. Relevance of the proposed training stay to your ERN in terms of investigated disease (how the acquired knowledge will impact the RD domain of your ERN);
- i. Description of methods to be learned during the training stay (*max. 1000 characters*. Clearly describe the methods you will be trained in during your stay).

- j. Statement on motivation for intended training stay (max. 2000 characters). Brief description of the expected benefit from the fellowship program:
  - On the applicant's personal career
  - On the applicant's home institution
  - On the applicant's host institution (if applicable)
  - On the ERN(s) of which the applicant's home/host institution/s are part of
- k. Expected start date and duration of the planned stay
- l. Description of requested budget

#### INFORMATION ABOUT THE APPLICANT'S CURRENT WORK

- m. For PhD students:
  - Start date and (expected) completion year of PhD degree
  - Short description of your PhD project (max. 1000 characters) briefly summarizing main study area, aims of the project, key results obtained so far.
- n. For physicians:
  - CV (1 page, PDF format to be uploaded in the submission system);
  - Year of specialist training (e.g. postgraduate year 1 - PGY1)

### 4.3 Timeline

The submission will be opened from 3. February 2020 until 16. March 2020.

There will be two calls a year for research mobility fellowships (at the End of January and the end of June).

Note: Rejected applications can be resubmitted once. The comments from the evaluation committee should be addressed in the resubmitted application. One research mobility fellowship can be granted per fellow.

## 5. EVALUATION

### 5.1 Evaluation criteria

The fellows will be selected based on the following criteria:

**Excellence:**

- Quality of the proposed training/research plan;
- Applicant's skills and competences;

**Impact:**

- Impact on/added value of the training for the career prospects and knowledge of the applicant;
- Impact on/added value of the training and newly acquired knowledge/skills to the home and host institution (potential for exploitation of acquired knowledge/skills; establishment of new collaboration);
- Impact on/added value of the training and newly acquired knowledge/skills to the ERN as a whole;

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**Implementation:**

- Organization and proposed methodology of the training;
- Relevance of the resources and budget required;
- Relevance of the training timeline.

## 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 fellowship coordination team from UKL-Heidelberg and RUMC Nijmegen will check all proposals against the eligibility rules described above. Eligible proposals will be forwarded to the SEC. Non-eligible applicants 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 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. Evaluation scores will be awarded for the 3 main criteria (Excellence, Impact and Implementation), and not singularly for the different aspects listed below the criteria. Each criterion will be scored out of 5. 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.

- **Consensus discussion and final funding decision:** The WP17 fellowship coordination team will prepare the Evaluation Book including evaluations of all projects and preliminary ranking list based on the mean scores received by each proposal.

All 8 SEC members will meet (via a conference call) to discuss further and establish a ranking of the proposals recommended for funding.

The summary review report of the SEC recommendations and reasons for rejection of the application will be prepared by the WP17 fellowship coordination team and forwarded by email to declined applicants. The successful candidates will also receive respective notification 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.

#### 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

## 6. FINANCIAL AND LEGAL ISSUES

### 6.1 Funding model

The total budget foreseen for the fellowships call is of 600.000 €. This budget will be managed by the two responsible institutions:

- Heidelberg-UKL-HD, 300.000€
- Nijmegen-RUMC, 300.000 €.

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

**Travel up to 400€ for the entire fellowship and accommodation expenses up to 2000€ per month will be covered for a fellowship with a duration of up to 3 months. Please note that the costs covered by fellowship have to be financed in advance by the fellows and will be reimbursed against receipt up to a fixed limit.**

### Travel expenses

Fellows will be reimbursed for travel expenses from their place of origin to the host institute, and will receive reimbursement for one single return ticket up to a maximum amount of € 400. The travels must be organized on the basis of the most appropriate and cost-effective means of transport:

- If travelling by air, we will reimburse an economy class ticket only.
- The cost of travel by private car shall be reimbursed at the rate of 0.19 € per km. with a maximum of 1 return per week.

Travel expenses will only be reimbursed on presentation of supporting documents: tickets and/or invoices. These must show the class of travel used, the time of travel and the amount paid. Taxi fares and parking will not be reimbursed.

The supporting documents should be sent to: [genturis@radboudumc.nl](mailto:genturis@radboudumc.nl) / [fellowships@erknnet.org](mailto:fellowships@erknnet.org)

The supporting documents can be sent from the moment they are in the possession of the fellow. We strive to reimburse the costs within 2 weeks.

### Accommodation expenses

We will reimburse the fellow's accommodation expenses up to a maximum of € 100,- per night and € 2.000,- per month (maximum duration exchange is 3 months).

Accommodation expenses will be reimbursed only on presentation of supporting documents such as hotel invoices.

Other subsistence costs such as telephone costs, meals and local transport (bus, tram, metro, taxi, parking, motorway tolls, etc.) will not be reimbursed.

The supporting documents should be sent to: [genturis@radboudumc.nl](mailto:genturis@radboudumc.nl) or [fellowships@erknnet.org](mailto:fellowships@erknnet.org)

The supporting documents can be sent from the moment they are in the possession of the fellow. We strive to reimburse the costs within 2 weeks.

It is important to note that fellows will remain under the employment contract of their home institution; thus their home institution should continue to pay their salary, and all social security will apply during their stay.

## 6.2 Funding contracts

Each fellow will receive and sign a fellowship funding agreement provided by the managing institution. The agreement will specify the rules of reimbursement, timelines

and eligibility rules of the incurred costs. The funded fellows are responsible to provide the original invoices in order to be reimbursed. The managing institutions will be responsible to deliver financial report to the European Commission within regular (yearly) EJP RD reporting period.

### 6.3 Research consortium agreement and ownership of intellectual property rights

Although the primary goal of the training fellowships is not to deliver any specific research results, it is important to underline that each of the research training fellowships will become an integral part of the EJP RD and thus EJP RD Grant Agreement and Framework Consortium Agreement will apply.

Thus, results and new Intellectual Property Rights (IPR) (if any) resulting from projects funded through the EJP RD WP17 internal call for research fellowship will be owned by the host (secondment) organisations according to specific national/regional rules on IPR and as specified in the EJP RD Framework Consortium Agreement (FCA). 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 training fellowship 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 involved partners 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*).

### 6.4 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/> .

## 6.5 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 (if relevant for the project). 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

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

Successful fellows must ensure that all outcomes (publications, etc.) of the EJP RD research fellowships include a proper acknowledgement of EJP RD. This includes the display of the EJP RD logo when possible.

Beneficiaries must also include acknowledgement according to institutions rules, where applicable.

### REPORTING

The fellows must submit short summary on the research training project accomplished at the host (secondment) institution at the latest 3 months after its end to the Call Coordination at the following email address: [sanja.hermanns@med.uni-tuebingen.de](mailto:sanja.hermanns@med.uni-tuebingen.de)

### DISSEMINATION

- The fellow should present the research project at either an ERN Annual Meeting, EJP RD meeting, relevant national or local meetings or professional society meetings. If invited to an EJP RD conference, presentation of the research project there will be obligatory.
- The fellow has to provide a short text describing his/her research project for digital dissemination purposes (ERN/EJP RD Newsletters, Websites, Tweets) to the



EJP RD communication officer, Eleonora Passeri (email: [eleonora.passeri@ejprarediseases.org](mailto:eleonora.passeri@ejprarediseases.org))

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

- display the EU emblem
- applicable ERN 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.

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 appropriate the EU emblem or any similar trademark or logo, either by registration or by any other means.

#### SASTISFACTION SURVEY

The mobility fellows have to fill two online satisfaction surveys related to:

- the quality of the research training they received as well as
- the impact on their research activity following the training.

The call coordination team will provide them with the corresponding link.

## 8. CONTACT AND FURTHER INFORMATION

The WP17 fellowship coordination team is based at UKL-Heidelberg, Germany and RUMC-Nijmegen, the Netherlands. The submitted applications from fellows affiliated to member institutions of ERN-RND, ERN EURO-NMD, ERN EpiCARE, ERN EYE, ERN CRANIO, ERN ITHACA, ERKNet, ERN Rare-Liver, ERN TRANSPLANT-CHILD, ERN GUARD-HEART, ERN LUNG and ERN eUROGEN will be handled by UKL-Heidelberg.

- email: [fellowships@erknet.org](mailto:fellowships@erknet.org)

The submitted applications from fellows affiliated to member institutions of ERN GENTURIS, ERN EURACAN, ERN PaedCan, ERN ReCONNET, ERN EuroBloodNet, ERN RITA,

ERNICA, Endo-ERN, MetabERN, VASCERN, ERN SKIN and ERN BOND, will be handled by  
Radboud UMC, Nijmegen:

- email: [genturis@radboudumc.nl](mailto:genturis@radboudumc.nl)



## Annex 2

### Letter of Support by the Home Institution

Letter of Support for \_\_\_\_\_<sup>3</sup>

In my capacity as head of \_\_\_\_\_<sup>4</sup> at \_\_\_\_\_<sup>5</sup>, I fully support the candidate's application for a research mobility fellowship under WP 17 'ERN RD training and support program' of the EJP-RD Programme. He/She will travel to \_\_\_\_\_<sup>6</sup> to realize the Research Project \_\_\_\_\_ (proposal title).

I hereby confirm that I am familiar with the contents of the proposed Research Project Plan<sup>7</sup> and that they are in line with the position and work/research experience of the applicant. The planned research mobility is relevant in the context of the applicant's position at our institution and benefits the interests of our unit/department.

Following the completion of the research mobility, the candidate will resume his/her position at our institution.

Name: \_\_\_\_\_  
(BLOCK letters)

Date: \_\_\_\_\_  
Signature

Stamp (home institution/department):

<sup>3</sup> Name of the applicant

<sup>4</sup> Indicate the name of the unit/department you head; the applicant needs to hold a position at this unit/department

<sup>5</sup> Indicate the name of your institution

<sup>6</sup> Indicate the name of the host institution

<sup>7</sup> The Research Project Plan is a text which lists the research/teaching/training activities the staff applicant plans to carry out during the mobility period at the host institution. The Letter of Support (=this present document) must only be signed if the Research Project Plan has been provided by the applicant for your evaluation.

## Annex 3

### Letter of Acceptance by the Host Institution

Host Institution:

Faculty/Department:

Address:

Contact person:

Tel. Nr:

Email:

I herewith attest that our organisation agrees to host Mr./Ms. \_\_\_\_\_<sup>8</sup> as a visiting PhD student/medical resident \_\_\_\_\_<sup>9</sup> to carry out a research project \_\_\_\_\_ (*project title*) in the framework of the WP 17 'ERN RD training and support programme' of the EJP-RD Programme.

Period of stay: from \_\_\_\_\_ until \_\_\_\_\_

*(if not confirmed yet, please specify the length of stay)*

Date:

Name of Head of Department:

Signature:

Stamp (Department or Institute):

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<sup>8</sup> Name of the applicant

<sup>9</sup> Please specify: PhD or MD and year of PhD or specialist medical training

## Annex 4

# European Joint Programme on Rare Diseases (EJP RD)

ERN-RD training and support program

Research Training Workshop

### Call Text

**The call opens on 3. February 2020**

**The deadline for application is 2. March 2020**

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

<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>10</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 to ERNs only. The costs of the organization may cover the following items:

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

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<sup>10</sup> Further information: [https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)

- 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

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

OR

- Affiliated to an ERN Affiliated<sup>11</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

The applications must be submitted using the online application form (<https://sondage.inserm.fr/index.php/512337/lang-en>). 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

- o. Full name
- p. Affiliation and full address of the institution
- q. Institution affiliation to ERN or EJP RD beneficiary
- r. Email address

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

#### Excellence

- s. Title of the workshop
- t. Training objectives
- u. Innovative and ERN cross-cutting aspects
- v. Type of research covered by the proposed topic (basic, clinical, translational)
- w. Type and level of seniority of researchers to which the workshop is addressed

#### Impact

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

#### Implementation

- aa. Training methodology
- bb. Organization of the workshop
  - a. Proposed whereabouts of the workshop
  - b. Approximate number of local and external speakers

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<sup>11</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 3. February 2020 until 2. March 2020.

There will be two calls per year (opening foreseen at the End of January and end of June) to choose topics for funding in total 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.

## 5. EVALUATION

### 5.2 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 WP17 coordination team 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

6-7 workshops will be financed per year between 2020 and 2023 (thus a total of 24 to 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 650€ per participant)
- Travel and accommodation expenses for invited speakers (maximum 650€ 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.

### 6.3 Funding contracts

Each organizing institution will receive and sign a workshop funding agreement provided by the managing institutions (EKUT-Tübingen or LUMC-Leiden). The agreement will specify the rules of payment, timelines and eligibility rules of the incurred costs. 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.

Changes to the budget cannot occur within the funding agreement, unless there is a good justification.

### 6.4 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*).

## 6.5 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/>

## 6.6 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/FN/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.

- Sanja Hermanns, University Tübingen  
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