# **European Joint Programme on Rare Diseases (EJP RD)**

# **ERN Rare Disease Training and Support Program**

# **Research Mobility Fellowship**

# **Call Text**

The call opens March 15<sup>st</sup> 2021
The deadline for application is April 26<sup>th</sup> 2021

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-



# 1. MOTIVATION

An EJP RD survey investigating the needs of the European Reference Networks (ERN) 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

#### 2. AIM OF THE CALL

The call for Research Mobility **Fellowships** aims to support PhD students, Postdocs and medical doctors in training to undertake scientific visits **fostering specialist research training** outside their countries of residence.

The exchange can be carried out either:

- within the same ERN (Full Members and Affiliated Partners), OR
- between different ERNs (Full Members and Affiliated Partners), OR
- between ERN Full Members / Affiliated Partners and non-ERN institutions.

Either home or host (secondment) institution must be a Full Member or Affiliated Partner of an ERN at the time when the application is submitted, as well as during the proposed period of the training stay.

Successful applicants should acquire new competences and knowledge related to their research on rare diseases, with a defined research plan and demonstrable benefit to the ERN of the home and/or host institution.

Fellows should take into consideration several elements such as:

- Relevance and impact of the project, for the fellow, home and host institutions and the ERN as a whole
- Clear added value for the ERN(s)
- Quality of the research proposal
- Organization and proposed methodology of the training
- Relevance of timelines and of required resources and budget

The research mobility fellowships are meant to cover stays of **4 weeks to 6 months** duration.

# 3. EVALUATION COMMITTEE

All proposals will be evaluated by the Scientific Evaluation Committee (SEC) composed of three ERN representatives, three independent external scientific experts and one representative of the EJP RD coordination.



In addition, applications will be remotely evaluated by ethics expert members of the Advisory Regulatory Ethics Board (AREB) of the EJP RD, to verify the compliance with the applicable ethics requirements.

# 4. APPLICATIONS

# 4.1 Eligibility criteria

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

- PhD students with a minimum of one year of research experience at the time of submitting a proposal
- Postdocs/research fellows within five years after receiving PhD degree at the time of submitting the proposal
- Physicians with at least one year of rare disease specialist training and within five years of completion of clinical training at the time of submitting the proposal

#### Furthermore,

- Either home or host (secondment) institution must be a Full Member or Affiliated
  Partner of an ERN 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 <a href="here">here</a>.
- Both the home and host institutions must be located in EU countries and/or in countries in which EJP RD beneficiaries are located, which are: Austria, Armenia, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Georgia, Greece, Hungary, Ireland, Israel, Italy, Netherlands, Latvia, Lithuania, Luxembourg, Malta, Norway, Poland, Portugal, Romania, Serbia, Spain, Sweden, Slovakia, Slovenia, Switzerland, Turkey and UK.
- Duration of training stay is 4 weeks to 6 months
- Training must be completed within 18 months from the application approval
- Training is not allowed to start before the receipt of the official approval letter from the WP 17 coordination office.
- Residency of the applicant must be in a country involved in EJP RD (see above)

### 4.2 Information to be submitted

The applications must be written in English and must be submitted using the online application form. Applicants must provide personal information and submit a research project plan, information about their current work, information about the home and the host institution and about ethics aspects, as specified bellow. Applications using a different format or exceeding the length limitations of any sections will be rejected without further review.

The following information is requested in the online application form:



#### PERSONAL INFORMATION

- a. Full name
- b. Email address
- c. Position

# 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
  - ERN membership/partner status
  - Supervisor's full name, position and email address
  - <u>Supervisor's Letter of support in PDF format</u> (to be sent via mail)
- e. Applicant's host (secondment) institution
  - Name of the institution, department/unit and full postal address
  - ERN membership/partner status
  - Supervisor's full name, position and email address
  - <u>Supervisor's Letter of support in PDF format</u> (to be sent via mail)

#### **RESEARCH PROJECT PLAN**

- f. Project title
- g. Description of the project (max. 300 words)
  - Outline of the project stating a clear learning goal for the proposed training stay.
  - Research question aimed to be addressed during or following the fellowship stay using the knowledge and skills obtained during the exchange
  - Description how the newly acquired skills and knowledge will be transferred back to the home institution.
- h. Relevance of the proposed training stay to sending and/or receiving ERN
- i. Description of methods to be learned during the training stay (max. 300 words) Clearly describe the methods you will be trained in during your stay and clearly describe the timelines of your project (max. 300 words).
- j. Statement on motivation for intended training stay (max. 300 words). 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
- I. 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 PhD project (max. 300 words) briefly summarizing main study area, aims of the project, key results obtained so far.
- CV (1 page, PDF format, to be sent via mail)

#### n. For physicians:

- Start date and end date of specialist training
- CV (1 page, PDF format, to be sent via mail)

#### o. For Postdocs:

- Indication when the PhD degree was obtained
- Short description of research project (max. 300 words) briefly summarizing main study area, aims of the project, key results obtained so far.
- CV (1 page, PDF format, to be sent via mail)

#### **ETHICS CONSIDERATIONS**

- Does your fellowship involve: Use of human embryos and fetuses /humans/ vulnerable patients / children and minors / patients who are unable to give informed consent / use of invasive techniques / collection or use of human biological samples / processing of personal data / use of animals/ transfer of data or material to third countries/other ethics issues
- If you have answered yes to one or more of these questions, please, describe in more detail the ethical issues that have to be considered at the outset and how they will be dealt with (e.g. GDPR, informed consent procedures, ethical approval, policies etc.) (max. 300 words)
- Is there anything else you would like to mention with regard to ethical aspects?

#### 4.3 Timeline

This call will be open for submission from March 15th 2021 until April 26th 2021.

Note: Rejected applications can be resubmitted once. The comments from the evaluation committee should be addressed in the resubmitted application. Only 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

#### Implementation:

- Organization and proposed methodology of the training
- Relevance of the resources and budget required
- Appropriateness of the requested training duration

# 5.2 Evaluation of proposals and funding decision

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

- Eligibility check: the WP17 fellowship coordination team will check all proposals for compliance with the eligibility criteria described above. Eligible proposals will be forwarded to the SEC. Non-eligible applicants will be notified and if they applied for the first time they can resubmit an application on a next call if they fulfill all eligibility criteria by then.
- **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 in line with Horizon 2020 rules, 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.
- Ethics evaluation: Applications that have reached the scoring threshold will be forwarded to the EJP RD Advisory Regulatory Ethics Board (AREB) for review of potential ethical issues. AREB experts will assess the compliance of a given proposal with applicable ethical requirements. In case of ethics requirements to be fulfilled before the starting of the fellowship, the applicant will be contacted with further ethics related questions. Only after these are clarified and the ethics clearance is obtained the proposal will be considered as fundable. If no ethics related questions remain, the proposal is approved. Only those proposals that fulfil the regulatory and ethical international/EU and national and institutional requirements will be funded.



- Consensus discussion and final funding decision: All SEC members will meet for final review, discussion and ranking of the proposals, and select the proposals recommended for funding.
  - Summary review reports including SEC recommendations will be prepared by the WP17 Coordination Team, validated by the SEC members and forwarded to all applicants.
  - The WP17 Coordination Team will notify all applicants of the final funding decision only after ethics clearance is finalised.

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

Travel up to 400 € for the entire fellowship and accommodation expenses up to 2.000 € per month will be covered for a fellowship with a duration of up to 6 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 as set out below:

#### 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 can be sent from the moment they are in the possession of the fellow. We strive to reimburse the costs within 6 weeks.

#### <u>Accommodation expenses</u>

We will reimburse the fellow's accommodation expenses up to a maximum of  $100 \in per$  night and  $2.000 \in per$  month (maximum duration exchange is 6 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 can be sent from the moment they are in the possession of the fellow. We strive to reimburse the costs within 6 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 social security that 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 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 is to 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 <a href="http://www.irdirc.org/">http://www.irdirc.org/</a>.

# 6.5 Respect of relevant European and international standards

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

- The General Data Protection Regulation (GDPR): the European Regulation (EU)2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data: <a href="https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en">https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en</a>);
- The EC Directive 2010/63/EU on the protection of animals used for scientific purposes (<a href="http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32010L0063">http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32010L0063</a>);
- European Research Council Guidelines on Implementation of Open Access to



Scientific Publications and Research Data (<a href="https://ec.europa.eu/research/participants/data/ref/h2020/other/hi/oa-pilot/h2020-hi-erc-oa-guide\_en.pdf">https://ec.europa.eu/research/participants/data/ref/h2020/other/hi/oa-pilot/h2020-hi-erc-oa-guide\_en.pdf</a>);

- 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 <a href="http://ec.europa.eu/research/participants/data/ref/h2020/grants-manual/hi/oa">http://ec.europa.eu/research/participants/data/ref/h2020/grants-manual/hi/oa</a>
- 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. Ethics should be embedded in the research and considered from the outset, and although legal and regulatory considerations may vary across different countries, EJPRD will only fund proposals which comply with national and international ethical standards, rules and legislations.
- International Ethical Guidelines for Biomedical Research Involving Human Subjects CIOMS-WHO (2016);
- Oviedo Convention and its Additional Protocol on human rights and biomedicine, concerning biomedical research (2005);
- COUNCIL OF EUROPE COMMITTEE OF MINISTERS. Recommendation CM/Rec (2016)6 of the Committee of Ministers to member States on research on biological material of human origin (Adopted by the Committee of Ministers on 11 May 2016).

# 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 the 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 a 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.

#### **DISSEMINATION**

- The fellow should present the research project at either an ERN Annual Meeting, EJP RD meeting, and/or relevant national or international medical professional society meetings. If invited to an EJP RD conference, presentation of the research project will be mandatory.
- The fellow should 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.

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 are required to complete two online satisfaction surveys related to:

- the quality of the research training they received
- 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 Email: fellowships@erknet.org