



External Newsletter n°5: Special Edition. December 2019

Welcome to the EJP RD NEWSLETTER

Every month, latest news of the biggest European rare diseases initiative, bringing together funders, researchers, patients and clinicians!

EDITO

In this EJP RD newsletter special edition we would like to focus your attention on:

- Pre-announcement of the EJP RD Joint Transnational Call (JTC) 2020 fostering development of new therapies for rare diseases
- EJP RD Internal Call for proposals on Clinical Trials Methodology Demonstration Projects
- The announcement of list of granted projects of the EJP RD JTC2019
- Early bird registration for the joint RE(ACT) Congress & IRDiRC Conference that has been extended until Friday 20 December!

EJP RD JOINT TRANSNATIONAL CALL 2020 (JTC2020)

EJP RD Joint Translational Call JTC2020 pre-announcement



Link to the EJP RD website for more info:
<http://www.ejprardiseases.org/index.php/joint-transnational-calls/>

PRE-CLINICAL RESEARCH TO DEVELOP EFFECTIVE THERAPIES FOR RARE DISEASES

MAIN FEATURES:

- Involves 30 funding institutions from 22 countries
- Projects should include min. of 4 eligible partners from 4 different countries
- Academia, clinical/public health sector, SMEs & patients advocacy organisations are eligible (check national regulations)
- Max. duration of the projects in 36 months
- The inclusion of early career researchers is encouraged

Pre-proposal submission deadline

12th February 2020



The **Preliminary Announcement of the [EJP RD JTC2020](#)** is online!

Topic is: **PRE-CLINICAL RESEARCH TO DEVELOP EFFECTIVE THERAPIES FOR RARE DISEASES**. There will be a two-stage submission procedure for joint applications: pre-proposals and full proposals. The call is scheduled to open on **December 13, 2019** and the deadline for the submission of pre-proposal is **12 February, 2020**.

EJP RD INTERNAL CALL FOR PROPOSALS - CLINICAL TRIALS METHODOLOGY DEMONSTRATION PROJECTS

EJP RD INTERNAL CALL FOR PROPOSALS 2019



Link to the EJP RD website for more info:
<http://www.ejprareddiseases.org/index.php/joint-transnational-calls-2/>

CLINICAL TRIALS METHODOLOGY DEMONSTRATION PROJECTS



MAIN FEATURES:

- Aims to show the usability and capability of the innovative statistical methodologies for clinical trials in rare diseases
- Only teams from EJP RD beneficiary institutions are allowed
- Only existing data from clinical trials that were completed should be used
- Max. duration of the projects is 24 months

Official call opening: **1st February 2020**

The duration of the demonstration projects can be **up to 24 months**

The [Clinical Trials Methodology Demonstration Projects Call](#) is OPEN. The call fosters the usability and capability of the innovative statistical methodologies for clinical trials in rare diseases, which have not been demonstrated on existing data for specific rare disease clinical trials yet. Only teams from the EJP RD beneficiary institutions (including linked third parties) will be eligible. ERN member institutions and their Affiliated Partners are also eligible. Official call opening: **February 1, 2020.**

EJP RD JTC2019: FUNDED PROJECTS

EJP RD Joint Translational Call JTC2019: Funded Projects



Link to the EJP RD website for more info:
TO BE ADDED ONCE WE GO PUBLIC

Research projects to accelerate diagnosis and/or explore disease progression and mechanisms of rare diseases



MAIN FEATURES:

- 22 consortia with a foreseen budget of about 30,5 Mio € (6 Mio € of co-funding from the European Commission)
- 140 research teams
- 26 countries involved in the projects
- 17 patient advocacy organizations
- 10 projects out of the total 22 consortia have teams from at least one EU13 country

In December 2018 the EJP RD launched its first Joint Transnational Call (JTC2019) co-funded with the European Commission to fund multilateral **“Research projects to accelerate diagnosis and/or explore disease progression and mechanisms of rare diseases”**. The **aim** of the call was to enable scientists in different countries to build an effective collaboration on a common interdisciplinary research project based on complementarities and sharing of expertise, with a clear benefit for patients. Twenty three countries joined this call: Austria, Belgium, Canada (including Québec), Czech Republic, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Lithuania, Luxembourg, Poland, Portugal, Slovakia, Spain, Sweden, Switzerland, The Netherlands and Turkey.

The process included a two-step submission and evaluation procedure.

In the first step a total of 217 eligible pre-proposals were submitted. After careful examination by the Scientific Evaluation Committee (SEC), 52 pre-proposals were selected for full submission. Each of the full proposals was then evaluated by at least two additional external experts whose reviews were sent to project coordinators in order to give them the opportunity of studying the assessments and commenting on experts' arguments and evaluations. Both inputs were taken into account in a second SEC meeting.

Following the second SEC evaluation and ranking of the best projects, 22 consortia with a foreseen budget of about 30,5 Mio € were selected for funding, including almost 6 Mio € of co-funding from the European Commission. Selected projects can be seen [here](#).



**RE (ACT) CONGRESS
and IRDiRC CONFERENCE**
11-14 March 2020 Berlin

EARLY BIRD REGISTRATION has been extended until 20 December.

SUBMIT YOUR ABSTRACT!

Join a major event on rare diseases in 2020: The [RE\(ACT\) Congress and IRDiRC Conference 2020](#). When? **March 11-14 2020**. Where? **Berlin, Germany**.

Early bird registration has been extended until FRIDAY Dec 20!

Young and professional scientists, patients & patient representatives, as well as other rare diseases stakeholders are welcome to discuss latest cutting-edge research, innovation, and policy with the leaders in the rare disease fields. You can consult the [list of speakers](#).

The scientific program has been inspired by **IRDiRC principles** and achievements and by the **IRDiRC activities foreseen in 2020** and it encompasses topics like diagnosis & artificial intelligence, molecular etiology, innovative clinical trials, patient engagement and drugs for all. [Full program](#) is available. For abstract information and submission click [here](#).

This exceptional joint edition is being organized by the [Blackswan Foundation](#) and [IRDiRC](#) in collaboration with the [EJP RD](#) and in partnership with [EURORDIS](#) and the [Rare Diseases International](#) (RDI, global alliance of people living with rare disease).

To stay updated follow [RE\(ACT\)](#) and [IRDiRC](#) on twitter!

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EJP RD is coordinated by the National Institute for Health and Medical Research (INSERM)



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