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# What is new this month?

December 2020

## EJP RD HIGHLIGHTS

21 DECEMBER 2020

### **The Joint Transnational Call 2021 on Social Sciences and Humanities Research is now OPEN!**

EJP RD has launched the **JTC2021** which aims 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 future benefit for patients.

**Topic: Social sciences and Humanities**

**Research to improve health care implementation and everyday life of people living with a rare disease.**

Research proposals should cover at least one of the following areas

- Health & social care services research to improve patient and familial/household health outcomes
- Economic Impact of Rare diseases
- Psychological and Social Impact of Rare diseases
- Studies addressing the impact/burden of the delay in diagnosis and of the lack of therapeutic intervention.
- e-Health in rare diseases: Use of innovative technology systems for care practices in health and social services
- Development and enhancement of health outcomes research methods in rare diseases
- Effects of pandemic crisis and the global outbreak alert and response on the rare disease field, and the emergence of innovative care pathways in this regard.

Other research topics are possible as long as they focus on social science and humanities research and are not in the excluded topics list.



Partners belonging to one of the following categories may request funding under a joint research proposal (according to country/regional regulations): **academia** (research teams working in universities, other higher education institutions or research institutes), **clinical/public health sector** (research teams working in hospitals/public health and/or other health care settings and health organizations), **enterprises** (all sizes of private companies) when allowed by national/regional regulations, **patient advocacy organizations**.

**Our [matchmaking tool](#) will help you find your ideal project partner.**

The maximum duration of the project is three years.

**TIMELINE:**

- **16 February 2021:** Pre-proposal submission deadline
- **End of April 2021:** Invitation to full proposal
- **15 June 2021:** Full proposal submission deadline
- **30 July 2021:** Deadline for rebuttals
- **November 2021:** Notification of funding decision

**For more information, click below.**

[More information](#)

13-15 JANUARY 2021

## RE(ACT) Congress & IRDiRC Conference



Registrations for the **RE(ACT) Congress and IRDiRC Conference** joint online event funded by EJP RD are **still open**. The event will take place on **13-15 January 2021**. It aims to bring together **scientific leaders, patients, and policy makers** to advance research on rare diseases.

To obtain your discount register [here](#) before **31st of December**.

Note that **in compensation to attendees who registered before the announcement of the event being moved online, 3 free extra accesses will be granted** to them to invite guests.

The program is available [here](#).

[Registration](#)

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## EJP RD FUNDING OPPORTUNITIES

LAUNCHED ON 7 DECEMBER

### Internal Call for Innovation Project in Clinical Trials Methodology in Limited Populations

The Internal Call for Innovation Project in Clinical Trials Methodology in Limited Populations has

been launched on **December 7, 2020**. The call is open to **EJP RD beneficiaries and their linked third parties**.

The innovation methodologies topics particularly include (but are not limited to):

- **Development of a disease progression model from a natural history cohort or other observational studies.**
- **Development and validation of a disease specific clinically meaningful outcome with special interest in PCOMs, or composite endpoints.**
- **Development of a design and analysis procedure for a pharmacometric model and/or bridging study.**
- **Development of a randomization-based model as an alternative analysis strategy and explore the level of evidence.**

The call aims to **encourage collaborations among groups of experts** consisting of different stakeholders including methodological experts, clinicians, patients and industry (when relevant) who will jointly develop innovative ready-to-use methods to enhance RD clinical trial methodologies.

#### **TIMELINE**

- **25 January 2021:** A networking meeting will be held to consolidate the collaborative networks.
- **3 March 2021:** Foreseen call closing deadline

To get more information and to pre-identify if your institution is eligible **click below**.

[More information](#)

25th JANUARY 2021

## **Information/ Networking Event for the internal call for innovation projects in clinical trials methodologies in limited populations applicants**

In the context of the EJP RD internal call for innovation projects in clinical trials methodologies in limited populations, that opened on 7th of December 2020 and will close on 3rd of March 2021, an "Information/Networking Event" will be organized on the 25th of January 2021. The meeting will take place online from 15:00 to 18:30.

All interested applicants are invited to participate in this event. The objectives of the meeting are as follows:

- Presentation of the call modalities and objectives followed by Q&A session with participants
- Presentation of various perspectives of the remaining challenges that the present call will target (for example in relation to: use of registries, innovation in methodology space, PCOMs, pharmacogenetic biomarkers and pharmacokinetics development, the vision of regulators on future of RD clinical trials, model for innovating therapy in ultra RDs, ethical guidance)



**EJP RD  
OPEN  
FUNDING  
OPPORTUNITIES**

- Open session for participants to discuss the gaps that they would like to tackle and initiate partnerships among interested parties.

The [registration](#) to the meeting is mandatory and will close on the 18 of January 2021.

For more information you can visit our [website](#).

Registration



## EJP RD IN EVENTS

**EJP RD Coordinator Dr Daria Julkowska will be presenting EJP RD at the following virtual event:**

- 21st January 2021: **Virtual Webinar RDCA-DAP and EATRIS Present Rare Disease Drug Development**

**EJP RD has also been presented at the following annual meeting in December:**

- 12th December: **ITHACA Virtual Board Meeting**

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## OTHER NEWS FROM EJP RD

### 2 new open positions at the EJP RD Coordination Team

The EJP RD Coordination Unit is Hiring! We are searching for :

- A **Junior Project Manager** to participate at the coordination of The Training Activities and the Virtual Platform of Data, Resources and Tools. He/she will also be in charge of all MS Teams technical issues and demands, and will participate to the management of the EJP RD Helpdesk.

- An **IRDiRC Scientific Secretariat Coordinator** to ensure the management of the Scientific Secretariat of IRDiRC. He/she will supervise the scientific secretariat, ensure the connexion with EJP RD actions, and manage assigned activities and operations.

If you want to join us, [apply now!](#)

For more information, contact us at [coordination\(a\)ejprarediseases.org](mailto:coordination(a)ejprarediseases.org)

Apply

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## OTHER NEWS FROM PARTNERS

### The ERICA Project: joining forces to integrate research and innovation capacity across all 24 European Reference Networks

The **European Rare dIsease research Coordination and support Action** (ERICA) Project application under H2020 **has received a positive evaluation for funding (2.3 million euros for 29 partners)** to establish a structural framework in support of the research activities of the ERNs.

ERICA will strengthen research and innovation capacity by integration of ERN research activities, and outreach to European research infrastructures to synergistically increase impact and innovation. This will result in safe, accessible and efficient access of therapies for the benefit of patients with rare diseases.

More information

### Ring14 International: Call for research grant application 2021

Ring14 International has launched the 4th Call dedicated to developing research projects on the "Ring14" Syndrome and other diseases due to rearrangements of Chromosome 14 (Chromosome Ring 14) online. The Call for proposals intends to finance a researcher for a year with a salary of 50,000 euros. Funds should be available by the end of July 2021.

**Deadline for submitting applications is January 15, 2021.**

More information

### ADVANCE Online Course

The **European infrastructure for translational medicine (EATRIS)** has announced the launch of the ADVANCE Online Course on December 1st. ADVANCE is a 30-month EU training project, supported by Erasmus Plus with the objective to develop a 3-stage blended learning programme to **support early-career biomedical scientists in developing currently missing scientific knowledge, transversal skills and competences to meet the key challenge areas existing in the ATMP development cycle.**

The course is hosted by EATRIS consortium partner Elevate Health in their online learning environment. **To see more information and to register press the button below.**



## CAREERS

**Job opportunities** are available at EJP RD member institutions

- The EJP RD Coordination Team is looking for:
  - A **Junior Project Manager**
  - An **IRDiRC Scientific Secretariat Coordinator**
- The Fondation Maladies Rares is looking for their new **Research Administration Manager**
- The VASCERN coordination team is looking for their new **Project Manager**
- The Banque Nationale de Données Maladies Rares (national bank of rare diseases data) is looking for an **Interoperability Data Steward**
- ERN-EYE, Hôpitaux Universitaires de Strasbourg, France is looking for:
  - a **Medical Fellow**
  - a **Scientific Project Manager**
  - a **REDgistry Project Manager**
  - a **Medical Writer**



**EJP RD has received funding from the  
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