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WHAT IS NEW this month?



SHORT GUIDE ON PATIENT PARTNERSHIPS

AVAILABLE ON OUR WEBSITE

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EJP RD HIGHLIGHTS

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Joint Transnational Call 2021 on social sciences and Humanities Research: Preliminary Announcement



EJP RD is delighted to pre-announce 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.

There will be a two-stage submission procedure for joint applications: **pre-proposals (deadline : 16th February 2021)** and **full proposals (deadline : 15th June 2021)**. The call is scheduled to **open in early December 2020**. The maximum duration of the project is three years.

For more information, click below.

[More information](#)

RE(ACT) Congress & IRDiRC Conference

13-15 JANUARY 2021

EJP RD is glad to be a part of the organisation of the **RE(ACT) Congress**

and IRDiRC Conference joint online event that 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](#)

The European Commission jointly evaluates the Orphan and Paediatric Regulations



The **European Pharmaceutical Strategy** was recently released and it includes strengths and weaknesses of the legal instruments and the European Commission is preparing the review of the legislation on medicines for rare diseases and children: the Orphan and Paediatric Regulations.

EJP RD is going to prepare a position paper to highlight the point of view of researchers, clinicians and

patients and discuss how to address identified gaps and weaknesses in the rare diseases research.

Click the button below to see more information.

[More information](#)

EJP RD FUNDING OPPORTUNITIES

COLLECTION DATE : 1st DECEMBER

Networking Support Scheme (NSS) Call

COVID 19 OUTBREAK ADAPTATION: Exceptional extensions are provided. Events can be organised between 6 and 18 months after the application date. Online events are also possible.

The aim of the NSS call is to encourage the **sharing of knowledge** of health care professionals, researchers and patients on rare diseases and rare cancers, as well as

**EJP RD OPEN
FUNDING
OPPORTUNITIES**

to enable or increase the participation of usually underrepresented countries in Europe in new and in existing research networks.

Eligible applicants are **health care professionals, researchers and patient advocacy organizations** from the following countries involved in the EJP RD: Armenia, Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Georgia, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, Luxembourg, Malta, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, The Netherlands, Turkey, United Kingdom. There is no limit to the number of participants, however the maximum budget that can be requested is **€ 30,000 for a networking event**.

The next collection date is 1st DECEMBER at 14:00 (CET). To get more information and to apply, click below.

[More information](#)



EJP RD IN EVENTS

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30TH NOVEMBER 2020

EMA's Workshop on Support for Orphan Medicines Development

EJP RD will be present at the **European Medicines Agency's** Workshop on Support for Orphan Medicines Development. The goal of this event is to emphasise on an early medicine development and regulatory interactions. Dr Daria Julkowska will be presenting on current funding schemes.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

[Registration](#)

EJP RD WILL ALSO BE PRESENTED AT AN ANNUAL MEETING :

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



OTHER NEWS FROM PARTNERS

Upcoming ERN Webinars in November

10 November 2020, 3:00pm CET

- ERN-RND. "**Rehabilitation in ataxia: current evidence and practice**" by Ludger Schöls.

13th November, 2:00pm - 3:00pm CET

- ERN-RITA: "**Too much of a response: Hyperinflammation HLH and MAS and beyond**" by Fabrizio De Benedetti.

19 November 2020, 2:00pm CET

- EURO-NMD. "**Congenital Myasthenia Syndrome – an update**" by Sithara Ramdas.

24 November 2020, 3:00pm CET

ERN-RND. "**Development of Sara-home: a novel assessment tool for patients with ataxia**" by Gessica Vasco & Susanna Summa.

24th November, 5:00pm - 6:00pm CET

- Endo-ERN: "**Diagnosis and management of Silver–Russell Syndrome, a multidisciplinary care is necessary**" by Irene Netchine.

26 November 2020, 5:00pm - 6:00pm CET

- ERN-EpiCARE. "**Non-adherence to treatment in epilepsy**" by Oliver Henning.

The Economist Unit's report on the challenges for policy makers, patients and healthcare professionals in rare neurological diseases.

EJP RD member and Coordinator of the European Reference Network for Rare Neurological Diseases (ERN-RND) Holm Graessner was involved in the production of **The Economist Intelligence Unit's** report entitled "**Navigating rare neurological diseases: meeting the challenge for policy makers, patients and healthcare professionals**". The report addresses **policy challenges** facing rare diseases, particularly rare neurological diseases (RNDs).

The report is being discussed on this day November 10th in a virtual roundtable "**Individually rare, collectively common: Managing rare neurological diseases in a post-covid 19 world**" hosted by The Economist Events and Roche.

For more information on the key findings in the report click below.

[More information](#)

Survey on administration devices for children's care

The European Paediatric Translational Research Infrastructure (EPTRI) has launched the initiatives dedicated to **paediatric patients** and **families** in collaboration with **European Paediatric Formulation Initiative** (EuPFI) to deliver a short questionnaire in order to help finding ways of making children's care devices more user-friendly.

The survey is addressed to boys and girls between 10 to 18 years of age and their parents.

The participation is voluntary and there will be no need to share names or contact details. The answers will be kept confidential and will only be used for this study.

The questionnaire will take approximately 10-15 minutes to be completed and it is available in four languages:

- **Albanian:** [Paediatric Device Survey Albania](#)
- **Italian:** [Paediatric Device Survey Italy](#)
- **Spanish:** [Paediatric Device Survey Spain](#)
- **English:** [Paediatric Device Survey UK](#)

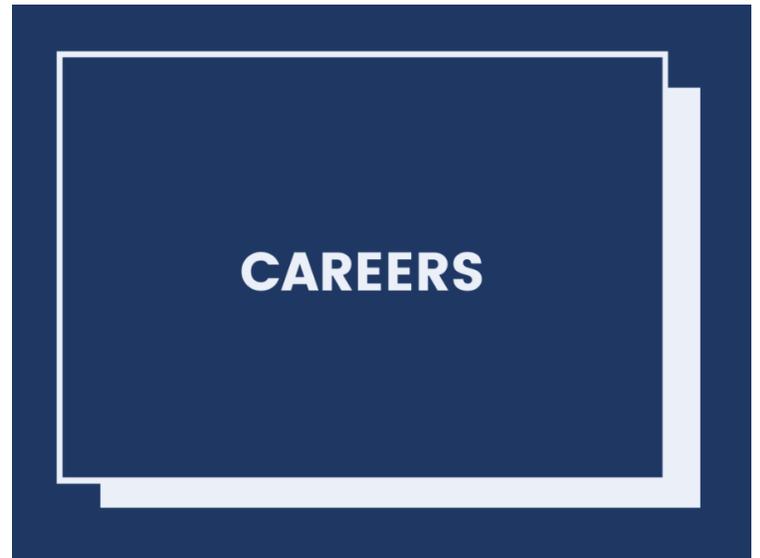
[More information](#)

CAREERS

Job opportunities are available at EJP RD member institutions

- EJP RD is looking for its **Ethics Advisor**
- The Banque Nationale de Données Maladies Rares 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**



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