

To consult the online version, [click here](#)



What is new this month?

February 2021

EJP RD HIGHLIGHTS

Information Webinar for the Joint Transnational Call 2021 interested applicants

FEBRUARY 2ND, 2021

The EJP RD is glad to invite you to the information webinar organised for potential applicants to the **Joint Transnational Call 2021 on "Social Sciences and Humanities Research to Improve Health Care Implementation and Everyday Life of People Living with a Rare Disease"**.

The webinar will take place **online on February 2nd, 2021 3:00pm – 4:30pm CET.**

All interested applicants are invited to register and participate to this event. **The registration to this event is mandatory and will close on January 29th, 2021.**

The objective of this information webinar is to give you details on the objectives, topics and administrative rules for this call for projects.

The general presentation will be followed by a Q&A session with the participants.

You can already submit your question in the registration form. To register click the button below.



[Registration](#)

EJP RD Policy Meeting

JANUARY 12th-13th, 2021

Last week, on the 12th and 13th of January, The European Joint Programme on Rare Diseases (EJP RD) held its first Policy Meeting



engaging EJP RD partners and numerous external stakeholders. The meeting was an occasion to update on the work done in EJP RD and to start the discussion on the future of EJPRD through the perspective of the forthcoming Rare Diseases Partnership under Horizon Europe (HE).

[Read More](#)

EURORDIS 10th Blackpearl Award & Rare2030 Final Conference

FEBRUARY 23-24th, 2021

Looking for exciting new events? Don't miss out and join EURORDIS LIVE at the **Rare2030 Final Conference** and the **10th annual Black Pearl Award, to which EJP RD is glad to be an official outreach partner.**

- Learn about the future of rare diseases at the **Rare2030 Final Conference**. You will have a unique opportunity to engage with some of Europe's most prominent policymakers, opinion leaders, and medical specialists, and lead the way for the future of our community. The event will be held virtually –and for **free – on 23 February 2021 at 13:30 – 18:30 CET.**
- In 2021 the **Black Pearl Award** marks its 10th anniversary, rewarding exceptional contributions to shaping the future of people living with a rare disease and building a better and more inclusive for everyone. Put on your dress, or suit, or even your pyjamas, and let's celebrate the Award together on **24 February 2021 at 17:00 CET.**



To register click the button below.

[Registration](#)

Rare Disease Day 2021

FEBRUARY 28th, 2021



RAREDISEASEDAY.ORG

As every year, February is rare disease month which ends on the 28th with Rare Disease Day. Multiple **events** will be held worldwide. EJP RD will contribute to Rare Disease Day. Stay tuned to see this year's video. Subscribe to our **Twitter** page.

[Website](#)

EJP RD FUNDING OPPORTUNITIES

Joint Transnational Call 2021 on Social Sciences and Humanities Research

OPEN SINCE DECEMBER 16th, 2020



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:

- **2 February 2021: Information Webinar**
- **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](#)

OPEN SINCE DECEMBER 7th, 2020

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 have been 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](#)



EJP RD IN EVENTS

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

- 27th January 2021: **The Festival of Genomics & Biodata**
- 26th February 2021: **Heritable Human Genome Editing: Rare Disease Week Discussion**

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 **Responsible for IRDiRC Scientific Secretariat** 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.
- 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.

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

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

[Apply](#)

OTHER NEWS

ERA-NET NEURON: Call for Proposals for Transnational Research Projects on Neurodevelopmental Disorders

If you are interested in how **neuroscientific research on neurodevelopmental disorders** and its translation into diagnostic and therapeutic outcomes is a **central pillar to promote healthy living** in Europe and worldwide, the **ERA-NET Neuron** Call for proposals for Transnational Research Projects on Neurodevelopmental Disorders was launched January 7th and will close March 9th 14:00 CET.

To address this topic, the 'Network of European Funding for Neuroscience Research' (NEURON) aims to coordinate research efforts and funding programmes across Europe and beyond to promote disease-related biomedical research on neurodevelopmental disorders.

[More Information](#)

A EURORDIS position paper: Key Principles for Newborn Screening

For the first time, **EURORDIS**, alongside its Council of National Alliances, Council of European Federations and its members, have set out **11 Key Principles to support a harmonised European approach to Newborn Screening**. The vast inequalities across Europe, coupled with technological and scientific advances highlight the urgent need to move forward from the status quo.

The principles make clear that Newborn Screening should be organised as a system with clearly defined roles and responsibilities, and governance and accountability structures that are transparent and robust. Appropriate psychological, social and economic support standards for families whose newborn is screened should also be in place. Healthcare professionals should receive thorough training, and there is a need for broader public awareness. As all future citizens should be screened, everybody needs to understand the why and how of screening. European wide standards should also be set to ensure every parent in Europe can expect the same timing, collection methods, follow-up and information when their baby is screened.

We are calling for **the creation of a European Union level expert working group to coordinate this action**, and for the **European Institutions to endorse such initiatives**. In addition, we call on the Steering Group on Health Promotion and Prevention (SGPP), the committee that advises the European Commission on public health actions, **to initiate a best practice collaboration with some Member States to pilot Newborn Screening programmes** based on these principles.

[Click the button below to read the full paper.](#)

Dravet Syndrome funding opportunity

Gruppo Famiglie Dravet ONLUS, Italy, in partnership with Apoyo Dravet, Dravet Syndrom e.V, Dravet Syndrome UK, Stichting Dravet Syndroom Nederland/Vlaanderen and Swiss Dravet Syndrome Association (SDSA), all European non profit organisations dedicated to Dravet Syndrome, will make available **funds for a two years research project aimed at understanding the pathogenesis of Dravet syndrome and at paving the way to new treatments** that will ultimately lead to better quality of life for people with DS. **The budget requested can be made up to 125,000 Euros.** International applicants are welcome

Full text of the Call and the submission guidelines are available [here](#).

Letters of intentions must be submitted on line [here](#) , not later than March 1, 2021

[More information](#)

CAREERS

Job opportunities are available at EJP RD member institutions

- The EJP RD Coordination Team is looking for:
 - An **IRDiRC Scientific Secretariat Coordinator**
 - A **Junior Project Manager**
- 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
European Union's Horizon 2020 research and innovation programme under GA N°825575**



To modify your preferences OR unsubscribe from this list [click here](#)