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Newsletter n° 11 - October 2020

Welcome to the EJP RD NEWSLETTER

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

EJP RD GENERAL ASSEMBLY AND CONSORTIUM MEETING

The EJP RD General Assembly (GA) and Consortium meeting was held online from 14 to 18 September 2020. It gathered more than **500 participants** with over 50 to 170 people per session. Multiple topics were approached **such as experimental data resources available in the EJP RD Virtual Platform, funding opportunities and trainings as well as dedicated support services for multinational clinical trials and research translation.**

The meeting achieved its goal of providing to all participants the opportunity to learn, share knowledge and network! Thanks to the lively discussions, new ideas and never-ending energy of rare diseases community, EJP RD is ready to dive into next phase and prepare for its third year of activities

SHORT GUIDE ON PATIENT PARTNERSHIPS



IN RARE DISEASE RESEARCH PROJECTS

We are proud to share a short guide on [Patient Partnerships](#) that was developed by EJP RD with the help of a working group led by [EURORDIS](#). The guide aims to encourage fruitful, sustainable and enduring partnerships between scientists and patient organisations in order to involve patients within the research. The guide is available [here](#).

EJP RD OPEN FUNDING OPPORTUNITIES

The [Research Training Workshops](#) call is OPEN until the 12th October

The goal of the [workshops](#) is to train researchers and clinicians affiliated to ERN in relevant topics on rare diseases research. Topics can be proposed by clinicians/investigators affiliated to ERN-institutions or EJP RD beneficiaries. To apply click [here](#).

The [European Research Network's Research Mobility Fellowships](#) call is now OPEN until 13 November 2020

The call for **Research Mobility Fellowships** aims to financially support PhD students and medical doctors in training affiliated to ERN Full Members or ERN Affiliated Partners to undertake short scientific visits (secondments) fostering specialist research training outside their countries of residence and within one of the ERN host institutions. To apply click [here](#).

EARLY ANNOUNCEMENT OF THE JOINT TRANSNATIONAL CALL 2021

The JTC 2021 will have for specific objective to promote multinational project on **Social sciences and Humanities (SSH) Research** to improve health care implementation and everyday life of people living with a rare disease.

Transnational research proposals must 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
- 1. **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.
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The call is scheduled to open in **December**, with a pre-proposal **submission deadline in February**.

More information [here](#).ed

EJP RD IN EVENTS

SAVE THE DATE

21st October

- If you are interested in **the impact of [European Open Science Cloud](#) and expected collaboration with rare diseases community** join us at **EOSC Symposium** where the coordinator of the EJP RD, Dr Daria Julkowska will participate in panel discussion of the **[“Widening to the public and private sectors”](#)** session. Registration are open until the 13th October [here](#).

- As one of the key stakeholders, EJP RD will be discussing with **[Beyond 1 Million Genomes](#)** project and other actors on how to set up a framework for successful

cooperation to support the creation of pan-European genome-based health data infrastructure. More information and registrations [here](#).

30th November

EJP RD will be present at EMA's [Workshop on Support for Orphan Medicines Development](#). The goal of this event is to emphasise on an early medicine development and regulatory interactions. Registration are open [here](#). Dr Daria Julkowska will be presenting on **current funding schemes**.

EJP RD will also be presented at **annual meetings** :

- 15th October : [ERN-EYE General Annual Meeting Virtual](#)
 - 22nd - 24th October : [VASCERN Days 2020](#)
 - 12th December : [ITHACA Virtual Board Meeting](#)
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OTHER NEWS FROM EJP RD PARTNERS

ERN WEBINARS



Upcoming [ERN webinars](#) in October

ERN-RND “**Diagnostic algorithm for childhood onset chorea**“ by Juan Dario Ortigoza-Escobar. 13 October 2020, 3 pm CET

ERN-RND “**Clinical practice recommendations for physical therapy for Huntington’s disease**“ by Bernhard Landwehrmeyer. 20 October 2020, 3 pm CET

EURO-NMD “**Personalized care for patients with ALS: ALS Home monitoring & coaching**“ by Anita Beelen. 22 October 2020, 2 pm CET

ERN-EpiCARE “**Sexuality and epilepsy**“ by Oliver Henning. 22 October 2020, 5pm CET

COVID-19 RELATED NEWS

Share4Rare's registry on COVID-19's impact on rare diseases' patients



A new **patient registry** will be created by [Share4Rare](#) to better understand how COVID-19 affects people with rare or undiagnosed diseases. Share4Rare will collect the information through a series of questionnaires addressed to patients living with a rare disease and who have tested positive for SARS-CoV-2 infection

For more information click [here](#).

OTHER RELATED INITIATIVES

ICCBH Virtual Forum – Bone Fragility Disorders in Children



18 - 20 November 2020

ICCBH organises a [virtual meeting](#) on bone fragility disorders on the 18-20 November 2020. The deadline for registration is **30 October 2020**.

EJP RD HELPDESK



The [EJP RD HelpDesk](#) is available for any inquires on EJP RD actions and services itself, including funding opportunities, clinical trials support office, FAIR-ification support for ERN registries, innovation mentoring support and follow up funding search for projects with high translational potential.

Hundreds of EJP RD experts are there to support RD community so do not hesitate to submit any question or request.

CAREERS

Opening positions are available at EJP RD **member institutions**.

ERN-EYE, Hôpitaux Universitaires de Strasbourg, France :

- **MEDICAL FELLOW**
 - **SCIENTIFIC PROJECT MANAGER**
 - **REDgistry PROJECT MANAGER**
 - **MEDICAL WRITER**
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