



External Newsletter n°5: January - February 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!

### EDITO

Welcome back to the first newsletter edition of the 2020! In this edition, we would like to focus your attention to the DNA Radio podcast where our Coordinator, Dr. Daria Julkowska talks about the EJP RD.

Moreover, do not miss numerous registrations to congresses, workshops and funding opportunities open by, or in partnership with EJP RD.

In addition, you will find a list of upcoming conferences, meetings, workshops, and summer schools across Europe as well as a list of several additional open calls on neuroscience, ethics, and personalized medicine. ERNs initiatives such as meetings and webinars are also reported.

Last but not least, the EJP RD has been mentioned together with IRDiRC on the "Orientation" official document prepared by the EU Commission to define key impact factors for the Horizon Europe program (2021 - 2024).

### Celebrating Rare Diseases Month! Podcast on EJP RD is now online on DNA Radio



DNA TODAY: A GENETICS PODCAST

**DR. DARIA JULKOWSKA**

Rare Disease Month



Dr. Daria Julkowska joined the [podcast show](#) on DNA Radio for Rare Disease Month to speak about rare diseases and present the EJP RD project. DNA Today podcast and radio show explores how genetics impacts our health and it

## RE(ACT) Congress 2020 and IRDiRC Conference, Berlin, Germany. 11 - 14 March 2020



This special [co-joint event](#) has been organized in collaboration with the EJP RD, and in partnership with Eurordis and Rare Disease International. Special rates are available! This transversal event will give you the opportunity to assist to the workshop on orphan drug development or learn about the latest innovations in RD diagnosis, therapies and societal inclusiveness. It will be a unique occasion to network and meet high-profile scientific leaders, experts as well as young scientists from a variety of breakthrough scientific fields and patients/patient advocacy organizations. Deadline for the abstract submission has been extended to 10 Feb.

## EJP RD OPEN CALLS

**EJP RD INTERNAL CALL FOR PROPOSALS**

**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

Official call opening: 1<sup>st</sup> February 2020  
The duration of the projects can be up to 2 years

### EJP RD internal call for proposals - Clinical Trials Methodology Demonstration Projects

The Clinical Trials Methodology Demonstration Projects Call is now open for submission of the 1-pager letters of interest. Deadline is 15 March 2020. It aims to show 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. Please note that this call is open for teams from institutions that are beneficiaries of the EJP RD project.

[More info](#)

**EJP RD - ERN INTERNAL TRAINING AND SUPPORT PROGRAM CALLS**

**RESEARCH MOBILITY FELLOWSHIP**

- Financially support research fellows to undertake short scientific visits (secondments) following specialist research training outside their countries of residence and within one of the ERN host institutions
- Assessment period: 12 months
- RD research with a minimum of one year of research experience
- Research fellow must have their first year of specialist training completed
- The research mobility fellowships cover costs of 2 weeks up to 3 months
- 2 calls per year: end of January and end of June

**RESEARCH TRAINING WORKSHOP**

- Identify the most suitable topics for the organization of research training workshops with a cross-ERN added value
- Training topics may include: research methodologies, programs, interdisciplinary treatment approaches (e.g. gene therapy, telemedicine)
- Workshop covers the organization of a 2 day workshop (e.g. including catering & travel and accommodation of students and participants)
- Applicants must be affiliated to an EJP RD beneficiary institution OR to an ERN Full Member OR ERN Affiliated Partner institution
- 2 calls per year: end of January and end of June

Registration opens on 3 February and closes on 16 March

### EJP RD European Reference Networks (ERNs) RD Training and Support Programs

The training programs are based on two main components: Research Mobility Fellowship (RMF) and Research Training Workshops (RTW). The RMF call is now open, deadline is 16 March. The aim is to financially support PhD students and medical doctors working in ERN-member institutions to undertake short scientific visits (secondments) up to 3 months fostering specialist research training outside their countries of residence and within one of the ERN host institutions. The RTW call is aimed at identifying the most suitable proposals for the organization of 2 days workshop targeted to the ERNs

needs. The costs of the workshops will be covered by the EJP RD. Only workshop proposers from ERN or EJP RD beneficiary institutions can apply. Selected RTW will have to train ERN researchers and clinicians. The workshops will be open to ERNs only. Deadline is 2 March 2020.

[More info](#)

## More EJP RD news

### Congrats to our coordinator Dr. Daria Julkowska for the EURORDIS Black Pearl 2020 - European Rare Disease Leadership Award.



Dr. Daria Julkowska won this [award](#) for her “*outstanding leadership and dedication shown to the rare disease community and the positive impact she has had on rare disease research and partnerships in Europe and beyond*”. Her commitment to rare disease community within E-Rare, IRDiRC, and most notably as coordinator of the EJP RD has been acknowledged.

## Related Meetings



**European Paediatric Translational Research Infrastructure (EPTRI) Open Meeting. 2 - 3 April 2020. Brussels, Belgium**

EPTRI is an EU funded project aimed to design the framework for a new infrastructure dedicated to paediatric research that will work to accelerate the paediatric drug development processes from medicines discovery, biomarkers identification, and preclinical research to developmental



**ELIXIR Bioinformatics Industry Forum. 28 April 2020. London, UK**

The ELIXIR Bioinformatics Industry Forum brings together technical specialists and academics to discuss visionary ideas, bottlenecks and solutions to some of the major challenges in the data driven life science sector. This year's speakers include a mix from



**2nd ERN-Transplant Child Workshop. 14 May 2020. Warsaw, Poland.**

The main aim of this workshop is to address training in the area of paediatric transplantation according to the holistic approach of the network and allows integrate educational activities in all type of transplant and a wide variety of professionals involved in all phases of the

pharmacology, age tailored formulations and medical devices. The final goal is to facilitate the translation of the acquired new knowledge and scientific innovation into paediatric clinical studies phases and medical use. [DJ1] This design phase of the EPTRI project is on its final rush and before entering in the preparatory phase, EPTRI would like to invite researchers, companies, agencies, patient groups, health care professionals, and all other interested parties to participate to the EPTRI Open meeting that will be held on 2 - 3 April 2020 in Brussels. The call for abstract to this meeting is open, deadline is 29 February 2020.

[More info](#)



### **ECRD, 15 - 16 May 2020. Stockholm, Sweden**

The EJP RD is a full partner of the ECRD event that is globally recognized as the largest, patient-led rare disease event in which collaborative dialogue, learning and conversation takes place, forming the groundwork to shape future rare disease policies. Early bird registration is open until 20 March 2020. Submissions for poster abstracts are now open until 10 February 2020.

[More info](#)

software providers, funders and academics such as Amazon Web Services, Google, the University of Oxford, and the Chan Zuckerberg Initiative. The event is a unique and interactive mix of high-level keynote presentations, roundtable sessions, panel discussions and five minute Flash Talks from start-ups and SMEs. The event is free to attend.

[More info](#)



### **European Conference on the Diffusion of Genomic Medicine: Health Economics & Policy, 28 - 29 May 2020. Dijon, France**

This conference aims to contribute to the development of research in genomic medicine concerning its evaluation, its dissemination, and the public policies accompanying this new type of medicine. Given this conference is part of the H2020 European project "Solve-RD: Solving the unsolved Rare Diseases", research focusing on rare diseases is one of the targets. Registration opens on 3 Feb 2020 and the Call for Abstract closes on 12 Feb 2020.

[More info](#)

transplant. This workshop provides skills to perform a common and transversal approach to all types of paediatric transplantation procedure. This edition will be focused on medical and nursing team involved in the follow-up of paediatric transplanted patients.

[More info](#)



### **3rd Neuromuscular Translation Summer School. 6 - 10 July 2020. Leiden, Netherland**

The EURO-NMD and TREAT-NMD building on the past two summer schools, organize this residential course that will furnish attendees such as researchers and clinicians with a well-rounded knowledge of the translational pathway. Attendees will also benefit from the very latest knowledge available in the neuromuscular community as this course is delivered by key stakeholder in the field. To ensure a high-quality learning environment class sizes are kept deliberately small. With this in mind, it is recommended applying promptly to ensure the maximum chance of

successfully securing a place at their next Summer School. Registration is now open.

[More info](#)

## Related News & Opportunities

The [H-Care pilot survey](#) is the initiative of EURORDIS Rare Barometer and 4 European Reference Networks. Its long term goal is to develop a centralised patient feedback mechanism across the 8000+ rare and complex diseases, and across all 24 ERNs. All patients with a rare or complex disease plus members of their families and their caregivers can participate in the survey. Patients living with a disease treated in one of the four European Reference Networks that initiated this pilot survey are specifically encouraged to participate: lung diseases; kidney diseases; urinal, colorectal and genital diseases; and genetic tumour risk syndromes. The survey will run until 29 February, 2020. For more info and H-Care [communication toolkit](#).



## Rare Diseases Related Calls

[ERAPerMed Call](#) on “Multidisciplinary Research Projects on Personalised Medicine – Pre-/Clinical research, Big Data and ICT, Implementation and User’s Perspective” is online, deadline for pre-proposal submission is 5 March 2020, 5 pm CET.



[ZNM - Zusammen Stark! e.V. - Research Grant Awards](#) designed to promote research in areas that will have the greatest potential to move towards treatments and cures for centronuclear myopathies are open. Deadline is 31 March 2020.



[ERA-Net Neuron Calls](#) Proposals for Transnational Research Projects are open. The 2020 “Sensory Disorders” closes on 10 March 2020, 2pm CET, while the 2020 “Neuroethics (ELSA)” on 28 April 2020, 2pm CET.





**JPND transnational call** on “Novel imaging and brain stimulation methods and technologies related to neurodegenerative diseases” is online. Deadline for the Pre-proposals is 3 March 2020 at 3pm CET, for full proposals is 30 June 2020 at 3pm CET.



## ERNs Related Info

A list of upcoming **webinars** organized by the following ERNs is available:

EURO-NMD, MetabERN, ERN-RND - ERN-EuroNMD - European Academy of Neurology (EAN), ERN-EpiCARE, ERKNet, EuroBloodNet.



More info on the **ERNs upcoming annual meetings and workshops** listed below can be found here:

1. 3rd Annual EpiCARE meeting. 14 - 15 February 2020. Lyon, France
2. 4th Annual Meeting of the European Reference Network for Rare Kidney Diseases. 13 - 14 May 2020. Heidelberg, Germany
  - 2nd ERN-TransplantChild workshop. 14 May 2020. Warsaw, Poland
  - 3rd Neuromuscular Translational Summer School 2020. 6 - 10 July 2020. Leiden, Netherlands

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



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