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Newsletter n°1 - April 2019

Welcome to the EJP RD NEWSLETTER

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

What is the EJP RD ?

The European Joint Programme on Rare Diseases (EJP RD) is a 5 years programme co-funded by the European Commission that brings over 130 institutions from 35 countries to **improve the integration, the efficacy, the production and the social impact of research on RD**. EJP RD fosters the development, demonstration and promotion of Europe/world-wide sharing of research and clinical data, resources and know-how. Furthermore, it will implement and expand an efficient model of financial support for all types of research on RD (fundamental, clinical, epidemiological, social, economic, health service) coupled with accelerated exploitation of research results for benefit of patients. Find out more about our actions [HERE](#).



On the 30th and 31st of January EJP RD held its operational Kick-Off meeting. It was the opportunity to talk about the project and our common goals. We also took some pictures, including one for the Rare Disease Day!

More EJP RD news:

EJP RD Trainings

Did you know that EJP RD plans to train over 1500 participants (researchers, patients and medical personnel) within at least 15 training courses? Our trainings for 2019 are online and you can check the training themes and whether they are up for registration.

[Read more >](#)

EJP RD & GA4GH

On February 4th, the EJP RD was named a 2019 GA4GH Driver Project and will contribute to the creation of frameworks and standards to enable the responsible, voluntary, and secure sharing of genomic and health-related data.

[Read more >](#)

RDD 2019

We've worked on the Rare Diseases campaign with @Mediaplanet featuring exclusive content from key figures advocating for the awareness of rare diseases. Read how the European Joint Programme on Rare Diseases can help turbo-charge the research for the benefits of patients.

[Read more >](#)

Job offers



The EJP RD is looking for its COMMUNICATION MANAGER! If you are passionate about communication, rare diseases are close to your heart and want to join our international team in Paris, [send us your application ASAP!](#)



The CRG has an open position for the role of FRONT-END DEVELOPER FOR THE RD-CONNECT GPAP in Barcelona, for a duration of 1 year. Want to apply? Follow [this link](#)



The Radboud University Medical Center is looking for Data Steward for Rare Diseases Project. Learn more and [send your application](#) before April, 9 2019!

Related Events

LAST DAYS TO REGISTER!

The RE(AC)T America congress is taking place in Toronto, Canada from May 8th to 11th 2019. Don't miss your chance and profit from exceptional code "HAPPYCRAZYRATE", [register now!](#)





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



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