



Newsletter n°2 - June 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!

### EDITO

The EJP RD coordination team wishes you all happy June. Summer is coming up but before the break we would like to share with you some of our latest news from the EJP RD side and from other "EJP RD friends". In this newsletter, scientific and advocacy topics are presented to provide you a broad spectrum of information on the rare diseases field. Relevant training courses organized by EJP RD members are listed as well as patient-centered projects both aimed at raising awareness of rare diseases.

Check out our EJP RD newsletter for details, additional info and links! Get involved and join our growing EJP RD community!



## Trainings open for registration!!!

EJP RD has two very interesting upcoming **training courses** for this fall, registrations are still open so it is time to join us!

- The "[International Summer School on Rare Disease Registries and FAIRification of Data](#)" will be held in Rome, Italy, on 23rd – 27th September, registration is open until June, 20th.

- The "[Quality assurance, variant interpretation and data management in the NGS diagnosis era](#)" will take place in Leuven, Belgium, on 23rd – 25th October, registration is open until July, 31st.

The training courses will be in English; registrations are free of charge, however participants are expected to arrange their own travel, accommodation and other expenses to attend the course. To ensure active participation and exchange with teaching staff and fellows, a maximum of 30 participants for the Summer School in Rome and 20 for that one in Leuven will be admitted; IMPORTANT: few travel fellowships are also available.

## More EJP RD news:

### Biobanking

"Organizing & maximizing rare disease biological sample data in biobanks" training took place on April 1-2 in Milan, Italy.

The participants highly appreciated the use of the problem-based learning methodology and enjoyed the courses.

[Read more >](#)

### Transparent evaluations of FAIRness

EJP RD partner, MD Wilkinson et al. published an article on transparent evaluations of FAIRness that is increasingly required by a wide range of stakeholders, from scientists to publishers, funding agencies and policy makers

[Read more >](#)

### EU-OPENSOURCE open calls

EU-OPENSOURCE-DRIVE is launching its first open calls for research proposals. Two Transnational Access Calls are currently opened:

- Chemoproteomics call
- Small molecule screening call

[Read more >](#)

## Related Events & Opportunities

### European Research and Innovation Days

It is the first annual policy event of the European Commission, bringing together stakeholders to meet and co-create the strategic priorities for the European Commission's investment in research and innovation. Don't wait and register!

[More information here](#)



The European Commission has launched the first **Horizon Impact Award**. This award recognises and celebrates outstanding projects that have used their results to provide value for society.

[More information here](#)



The call for **NOMINATIONS for the EURORDIS Black Pearl Awards 2020 is now open**. The Awards are presented to patient advocates, organisations, policy makers, scientists, companies and media for their major achievements and outstanding commitment to the rare disease cause.

[More information about the award and how to nominate your candidate here](#)



### Rare As One Project

Patient-led organizations are invited by the Chan Zuckerberg Initiative (CZI) to apply for a new two-year grant opportunity to support the development and launch of a research network for their rare disease area in partnership with clinicians and researchers.

[More information here.](#)



**A position paper** on: "Achieving Holistic Person-Centred Care to Leave no One Behind" was launched at the EURORDIS Membership Meeting in Bucharest. Read about the contribution to



improve the everyday life of people living with a rare disease and their families [here](#).

The **draft Strategic Research Agenda (SRA)** developed by the EU funded **TO-REACH Consortium** is now **available for consultation, wich will be open** until 28th June 2019. The SRA has the ambition to address the increasing challenges faced by health systems, directed to those research areas of major relevance in the coming years.

[More information here](#)



**The 7th European Conference on Health Law** entitled 'Innovation & Healthcare New challenges for Europe' will take place in September 25th - 27th, Toulouse, France  
[More information here](#)



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