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External Newsletter n° 8: April 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!

A WORD FROM THE COORDINATION

EJP RD members and partners are sharing the world concern on Covid-19 outbreak and its impact on our daily lives. We would like to thank all the clinicians, nurses, and healthcare professionals that are working hard to save lives and keep us safe. Our thought goes also to the Covid-19 patients and their families, to those who are still fighting and those who lost the battle. EJP RD is close to the rare disease community and it is committed to do its part to support and help patients, clinicians, and researchers during this hard time.

We would like to underline and send also a special thanks to all EJP RD partners that continue working and support activities of the EJP RD while at the same time being on the front-line helping patients admitted to the hospitals and providing support to rare diseases patients and families. Their outstanding commitment empowers us and keeps us believe that we should continue to support and reinforce our efforts for the benefit of rare diseases community.

We don't give up, we remain together and we will get through it stronger than before. Stay safe and thank you!

Edito

In this edition of April we would like to share with you the latest EJP RD initiatives (open calls and training workshops) and provide you highlights on relevant calls recently open by the EC as well as a prestigious prize for young researchers. In addition, we share with you some actions taken by several EU organizations and institutions to fight in a collaborative manner the effort toward the Covid-19 outbreak. A short reminder about the ECRD online conference that will take place on 14 - 15 May, save the date and register!

EJP RD HELPDESK

Don't forget the [EJP RD Helpdesk](#) is available for any inquiries and services provided by the EJP RD including Clinical Trials Support Office and Innovation Management Advice.



EJP RD TRAINING WORKSHOPS & CALLS

EJP RD TRAINING WORKSHOPS

Quality assurance, variant interpretation and data management in the NGS diagnostic era

Registration for [this course](#) is now open, deadline is 20 July. The course will take place in Istanbul, Turkey on 12-14 October. A mitigation plan due to Covid-19 is in place. The aim is to teach participants about the evaluation of the pathogenic nature and clinical significance of genetic variants, on the criteria that have to be set to the NGS analysis pipelines and on the use of international databases. The targeted audience is: Laboratory scientists (EBMG registered), junior scientists, clinical geneticists, other medical specialists in training, policy makers and assessors for laboratory accreditation, and patient representatives, with a basic knowledge in biology or medicine. To ensure active participation and exchange with teaching staff and fellow participants, a maximum of 35 participants will be admitted to the training course. There are #2 travel fellowships available, participants from EU-13 countries are encouraged to apply. The workshop and registration are free of charge.

Implementing Biomedical Research Projects: The Complete Workflow from Concept, ELSI and Privacy Considerations to High-Quality Biobanking

Registration for [this course](#) is now open, deadline has been extended to 27 April. The course will be online, 11-14 May from 2 pm - 5.30pm each day. This workshop is aimed at biomedical researchers, medical professionals, and biobank managers who want to organise biomedical research projects on human biological samples. In two modules there will be used several use-cases to address the key issues in biomedical research involving human subjects, human biological samples and associated medical data. Participants from EU-13 countries and patient representatives are encouraged to apply. The workshop and registration are free of charge.

EJP RD OPEN CALLS

EJP RD Rare Diseases Research (RDR) Challenges Call is open

This [innovative call](#) aims at solve specific research challenges in the

EJP RD Networking Support Scheme (NSS) Call is open

Collection date for evaluation of 2 June has been cancelled due to Covid-19

field of therapeutic development for rare diseases as well as at facilitate and fund collaborative projects between industry, academia, SMEs, and patient organizations. The total budget is 1.5 Mio €. The call is open to academia, clinical/public health sector, SMEs, and rare disease patient representatives from eligible countries involved in the EJP RD; deadline is 30 June at 2pm CEST. Industry partners have been involved in the identification of four challenges that are the topics of the call and that were validated by the EJP RD partners including patients. It is still possible to establish consortia via a B2B tool.

outbreak; next collection date is 1 September at 2 pm CEST. The [NSS call](#) aims to encourage sharing of knowledge on rare diseases and rare cancers of health care professionals, researchers and patients. The NSS also aims to enable or increase the participation of usually underrepresented countries in Europe in new and in existing research networks on rare disease(s) or rare cancer(s). Eligible applicants are health care professionals, researchers and patient advocacy organizations from the countries involved in the EJP RD.

OTHER RELATED INITIATIVES - CONFERENCES, CALLS & PRIZES

[European Conference on Rare Diseases & Orphan Products \(ECRD\)](#)

will now take place online allowing more people from the safety and comfort of their own home, connecting via an interactive online platform wherever they are in the world. Program at glance is available for consultation. The conference's full programme will continue to be updated as the content of each theme is being finalised and adapted to an online audience. Register at the new reduced rates. Please, register also for the free ECRD 2020 pre-conference WEBINAR that will take place on Thursday 23 April 1-2pm CEST. This webinar is an opportunity for you to hear the latest outcomes of the Rare2030 Foresight Study and understand how the study lays a foundation for policy discussions throughout each theme of the conference.

[Share4Rare webinars](#) done together with Melanoma Patient Network Europe, Newcastle University, and World Duchenne Organization:

- 'Online Advocacy – Social Media & Valuable Tools'. Wednesday 22 April – 7 pm CEST.
- 'State of the Art of Rare Disease Activities in Europe'. Wednesday 29 April – 7.30 pm CEST.

[H2020: MSCA IF & COFUND calls](#). The EU has recently opened #2 important calls:

- Individual Fellowships: MSCA-H2020-IF-2020. The goal is to enhance the creative and innovative potential of experienced researchers, wishing to diversify their individual competence in terms of skill acquisition through advanced training, international and intersectoral mobility. Deadline: 9 September 2020, 5pm Brussels time
- Co-funding of regional, national and international programmes: MSCA-H2020-COFUND-2020. The aim is to stimulate regional, national or international programmes to foster excellence in researchers' training, mobility and career development, spreading the best practices of the Marie Skłodowska-Curie actions. Deadline: 29 September 2020, 5pm Brussels time

[Science & SciLifeLab Prize for Young Scientists](#) – Open for Applications. The young scientists' prize award by SciLifeLab together with Science/AAAS – the Science & SciLifeLab Prize for Young Scientists is now open for applications. Four recent PhDs are selected as winners and will be published by Science, receive up to 30,000 USD and be invited to Sweden to receive their awards, present their research, and meet with leading scientists in their respective

COVID-19 RELATED NEWS

[Commission launches “COVID-19 Clinical Management Support System”](#). The aim is to support clinicians in hospitals that are currently facing the coronavirus emergency all over Europe. Based on the experience with the ERNs, the initiative will help to create rapid connections across Europe among the hospitals indicated by the Member States as reference centres for Covid-19. Clinicians can rely on a dedicated helpdesk managed by DG SANTE to set up web conferences and exchange with their peers in Europe on possible treatments, and on how to handle severe and complex cases. This synergy aims to speed up the adoption of specific treatment options and help reduce some of the uncertainties due to the unknown aspects of the virus.

[COVID-19 Public Health Emergency of International Concern \(PHEIC\)](#). Global research and innovation forum: towards a research roadmap. The World Health Organization (WHO) has developed and launched an official document to support [D] research to control the epidemic. Broad consensus has been reached on the need for research to focus on actions that can save lives now to ensure that those affected are promptly diagnosed and receive optimal care. At the same time, integrate innovation within each research thematic area as well as to support research priorities in a way that leads to the development of global research platform(s) for the next disease X epidemic is the priority. These actions will accelerate research, R&D for diagnostics, therapeutics and vaccines, and their timely access.

[EMA establishes task force to take quick and coordinated regulatory action related to Covid-19 medicines](#). As part of its health threat plan activated to fight Covid-19, the Agency has finalised and published the composition and objectives of its Covid-19 EMA pandemic Task Force (COVID-ETF) which assists Member States and the European Commission in dealing with development, authorisation and safety monitoring of therapeutics and vaccines intended for treatment or prevention of Covid-19. The main purpose of the COVID-ETF is to draw on the expertise of the European medicines regulatory network and ensure a fast and coordinated response to the Covid-19 pandemic. The task force is accountable to EMA's human medicines committee (CHMP) for all its activities. Strict rules are in place to assure the independence of all members.

[Implications of coronavirus disease \(Covid-19\) on methodological aspects of ongoing clinical trials](#). EMA has developed a guidance covering actions that sponsors of ongoing clinical trials affected by the Covid-19 pandemic should take to help ensure the integrity of their studies and interpretation of study results while safeguarding the safety of trial participants as a first priority. This complements the good clinical practice guidance on how sponsors should adjust the management of clinical trials and participants during the Covid-19 outbreak. EMA's Biostatistics Working Party encourages affected clinical trial sponsors to seek scientific advice on these matters; furthermore, EMA will be flexible and pragmatic during the assessment of affected clinical trial data submitted to the Agency as part of marketing authorisation applications. The guidance is under a four-week public consultation until 25 April 2020.

[Anti-Covid-19 drugs](#). There is no anti-Covid-19 drug globally accepted for treatment, but many drugs are under investigations. About 16 trials of antivirals are under development. An updated list is freely available.

[EATRIS Response to the Covid-19 pandemic](#). EATRIS (European Infrastructure and one of the EJP RD partners) mission is to accelerate the translation of promising scientific discoveries into benefits for patients. The

focus of its main activities is on bridging the innovation gap between the lab and the clinic as well as offer services and expertise to increase chances of research to successfully reach patients. The EATRIS infrastructure's resources are therefore highly relevant for the research community in the context of the Covid-19 pandemic, a complete list of expertise and services is available.

[INB/ELIXIR-ES nodes and TransBioNet members effort on Covid-19 research.](#) This is a collection of databases, public repositories, tools, scientific publications, consortia, and research projects of the INB/ELIXIR-ES nodes and TransBioNet members across Spain supporting global SARS-CoV-2 and Covid-19 research and knowledge. Information and links are available.

[ELIXIR support to Covid-19 research.](#) ELIXIR (European Infrastructure and one of the EJP RD partners) provides a range of services that can be used for studying the SARS-CoV-2 coronavirus and the Covid-19 disease. The webpage listed several topics and it is constantly updated.

[BBMRI-ERIC has released COVID-19 specific support.](#) BBMRI (European Infrastructure and one of the EJP RD partners) collected and organized information on the resources national nodes and individual biobanks to researchers working on COVID-19, including samples, facilities, labs, guidance etc. The info will be constantly updated. In addition, the BBMRI Directory with the new Covid-19 filter to find samples and datasets applicable to research on SARS-CoV-2 and Covid-19 is also enabled.

OTHER NEWS FROM THE EJP RD RELATED PARTNERS

[Building a data strategy for the European Reference Networks \(ERNs\)- A EURORDIS contribution.](#) EURORDIS has launched a new contribution on ERNs and health data to trigger a strategic discussion on health data and ERNs that will allow the Networks to have a long-term strategy that is aligned with their needs and ambition. The proposal aims to progress towards developing a comprehensive ERN data strategy that is structured around two distinct dimensions, the strategic thinking and the operational aspects. EURORDIS calls on the ERN Board of Member States, the eHealth Network, the European Commission and the Network Coordinators to consider the proposals set out in this paper and take concrete steps to orchestrate a structured multi-stakeholder dialogue on this topic.

[GA4GH Virtual Connect 2020 Meeting Report and Resources Now Available.](#) The GA4GH meeting was online due to the Covid-19 outbreak. The level of participation and engagement of participants coming from different geographical locations have motivated the organizers to develop resources and materials collected during the virtual meeting and make them available to everyone. Meeting Reports are available on the website or to be downloaded as pdf versions. EJP RD contributes to the GA4GH as one of its Driver Projects.

[ERNs & COVID-19.](#) List with all the resources, recommendations, guidelines, surveys, links, and any other informative materials developed or collected by the ERNs to provide support to clinicians and patients during the Covid-19 outbreak. The info provided by the ERNs is constantly updated.

ERNS RELATED INFO

Webinars & Meetings



**European
Reference
Networks**

[List of upcoming webinars](#) organized by the following ERNs: ERN-RND - ERN-EuroNMD - European Academy of Neurology (EAN), ERN-EpiCARE, ERKNet, EuroBloodNet, Transplant Child.

Information regarding updated ERNs annual meetings scheduled in 2020-2021 can be found [here](#).

CAREER

Two [opening positions](#) are available at EJP RD member institutions:

- HELPDESK ASSISTANT, Institution of Myology, France
- TECHNOLOGY TRANSFER ASSOCIATE, Fondazione Telethon, Italy

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



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