What's new?
February 2023

HIGHLIGHTS

3-min Satisfaction Survey for EJP RD services: **Deadline: February 10th, 2023**

The European Joint Programme on Rare Diseases (EJP RD) - Work Package 19 “Facilitating partnerships and accelerating translation for higher patient impact”, aims to support the RD community to translate high quality research more effectively into high impact interventions for the RD patient community. For that, WP19 offers three main services:

- **Mentoring for translational research** which aims to empower researchers to conduct rigorous translational research by providing active project mentoring and technical support.

- **Follow-on funding support** which aims to improve the uptake of successful research projects towards clinical implementation by identifying suitable funding opportunities and finding partners for the development of new treatments and diagnostics for rare diseases.

- **The Innovation Management Toolbox (IMT)** is an online virtual library which provides self-help resources openly accessible to the RD research community.

We would like to assess the added value of the above-mentioned services and your satisfaction if you have already used any of them. Your feedback is very valuable for further development of the services.

The survey will be open until **February 10th, 2023**.

Click here for the survey

Upcoming EJP RD - ERN Workshops

In the context of EJP RD's ERN Workshops, multiple face-to-face workshops are being organised:

1. **Psychological, molecular and administration aspects of Hereditary breast and ovarian cancer genetic population screening (HBOC GPS)**: 27-28 April 2023 (Riga, Latvia), registration deadline: **February 22nd, 2023**

   [more information]
2. **Rare Together**: 8-9 May 2023 (Nijmegen-Lent, The Netherlands), registration deadline: **February 15th, 2023**, [more information here](#)

3. **Genetics and Precision Medicine in Rare Diseases**: 18-19 May 2023 (Lisbon, Portugal), registration deadline: **March 23rd, 2023**, [more information here](#)

4. **Desmoid tumors (DTs) in patients with Familial Adenomatous Polyposis (FAP): an interdisciplinary approach**: 22-23 May 2023 (Milan Italy), registration deadline: **March 7th, 2023**, [more information here](#)

5. **The Blood-Brain Barrier: current research and novel therapeutic crossing approaches**: 8-9 June 2023, registration deadline: **February 24th, 2023**, [more information here](#)

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**Training on Strategies to Foster Solutions of Undiagnosed Rare Disease Cases:**

Registration open until **February 15th, 2023**

As part of the training activities proposed by EJP RD, a 3-day training course on “Training on strategies to foster solutions of undiagnosed rare disease cases” is being organised by Istituto Superiore di Sanità (ISS) in close collaboration with EJP RD partners. The training will be held in **Rome, Italy on 3-5 April 2023**.

The course is open to the international research community, to clinicians and to medical specialists who have experience and concrete interest in the diagnosis and research on rare diseases.

**Joint Transnational Call 2023**

**Pre-proposal submission deadline: February 15th, 2023**

The EJP RD Joint Transnational Call, a funding opportunity for research projects, has been launched on **December 12th, 2022**.

The aim of the funding opportunity is to enable scientists in different countries to build an effective collaboration on a common interdisciplinary research project based on complementarities and sharing of expertise, with expected impact to use the results in the future for benefit of patients.

**Topic: Natural History Studies addressing unmet needs in Rare Diseases**
SAVE THE DATE: RE(ACT) Congress & IRDiRC Conference

Register and join us!

The joint event “RE(ACT) Congress and IRDiRC Conference 2023” aims to bring together scientific leaders and experts and young scientists from various breakthrough scientific fields to present cutting-edge research, exchange ideas, and discuss rare diseases research policies. Patients and patient organizations committed to research will also be in attendance to share their experiences and perspectives.

This event represents an exciting program with outstanding speakers and an in-person event with multiple ways of networking!

We look forward to welcoming you to Berlin, Germany from March 15th - 18th, 2023.
Registration and programme

EJP RD Networking Symposium: Complex genetics of inherited arrhythmias
Register for the EJP RD Networking Symposium:
Complex genetics of inherited arrhythmias that will take place in Amsterdam on March 16th-17th, 2023. This symposium on inherited arrhythmias is funded by the EJP-RD Networking Support Scheme.

1st International CTNNB1 Syndrome Conference
A networking event, funded by EJP RD’s Networking Support Scheme, is being organised in Madrid, Spain on March 23rd-24th, 2023. This unprecedented event for the CTNNB1 community aims to bring together healthcare professionals, industry, families, and patient advocacy organizations working together to raise awareness, accelerate the development of effective treatments and improve the lives of those affected with CTNNB1 syndrome.
OTHER NEWS FROM PARTNERS

World Duchenne Organization’s FAIR Training Program
Register before February 20th, 2023
The World Duchenne Organization is pleased to announce that thanks to a collaborative initiative driven by their technical partners, FAIR Data Systems in Madrid, a FAIR Training Program will be available online to all those interested in understanding the value and future impact of the FAIR Guiding Principles.

ERICA WP4 Webinar: Essential requirements before thinking about a clinical trial
Register before February 26th, 2023
The European Rare Disease Research Coordination and Support Action consortium (ERICA) is organising the WP4 Clinical Trial Support webinar “Essential requirements before thinking about a clinical trial” in collaboration with EJP RD and ERN BOND. Registration is open here until February 26th, 2023.
#SeeRare – the global Rare Disease Day event

Rare Disease International (RDI) has opened the event platform for #SeeRare – the global Rare Disease Day event organized in partnership with the international Rare Disease Day campaign. #SeeRare will take place online on February 28th, 2023, at 14.00 CET | 08.00 EST.

The event aims to give greater visibility to rare disease groups around the world. Registration is open here.

Click below to learn how to be part of the event!

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NEWS FROM THE INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM (IRDiRC)

Call for Members: 2023 IRDiRC Task Forces

IRDiRC launches the Call for Members for the four new Task Forces of the 2023 Roadmap.

Check out the newly approved Task Forces:

1. **Funding Models to Support the Spectrum of Rare Disease Research and Development**
2. **Framework to assess impacts associated with diagnosis, treatment, support, and community integration**
3. **Functional Analysis**
4. **Preparing for genetic N-of-1 treatments of patients with ultra-rare mutations**

If you are interested in taking part in any of these activities please send a CV, bio sketch, and letter of motivation (one paragraph each) to the IRDiRC Scientific Secretariat (scisec-irdirc@ejprarediseases.org) with the email title "TF Member Application-IRDiRC-[TF..."
CAREERS

Job opportunities are available at EJP RD member institutions:

- EJP RD Coordination Team is looking for a Scientific Project Manager
- EURO-NMD is looking for a Senior Project Manager
- EURORDIS is looking for an Events and Nominations Intern,
  an Operations Junior Manager, 2 Research Executives and a Research
  Assistant

EJP RD has received funding from the
European Union’s Horizon 2020 research and innovation programme under GA N°825575

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