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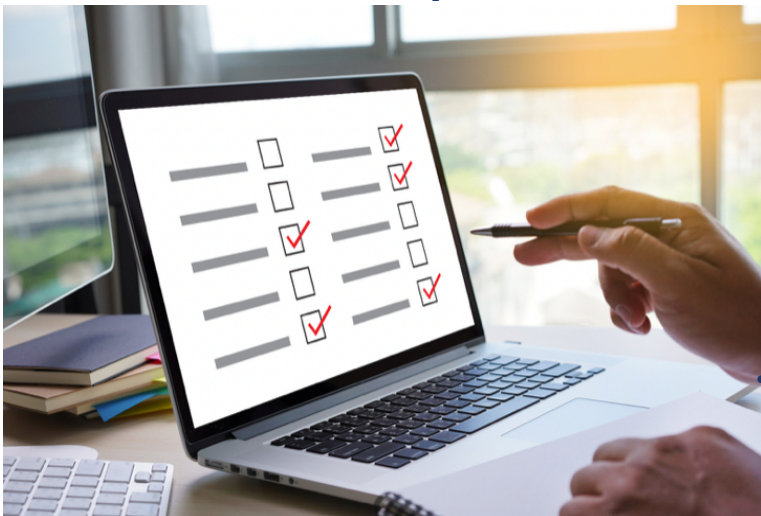


What's new?

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**

[here](#)

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](#)



All EJP RD upcoming events

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.

[Registration and more](#)

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

EUROPEAN JOINT PROGRAMME
RARE DISEASES

FUNDING OPPORTUNITY FOR
RESEARCH PROJECTS

**JOINT
TRANSNATIONAL
CALL 2023**

**TOPIC: NATURAL HISTORY STUDIES
ADDRESSING UNMET NEEDS IN RARE DISEASES**

12 DECEMBER 2022 - LAUNCH OF THE CALL
15 DECEMBER 2022 - INFORMATION WEBINAR FOR POTENTIAL APPLICANTS
15 FEBRUARY 2023 - PRE-PROPOSAL SUBMISSION DEADLINE

THE EUROPEAN JOINT PROGRAMME ON RARE DISEASES IS AN INITIATIVE THAT HAS RECEIVED FUNDING FROM THE EUROPEAN UNION'S HORIZON 2020 RESEARCH AND INNOVATION PROGRAMME UNDER GRANT AGREEMENT N°825575

[More information](#)

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**.

Complex genetics of inherited arrhythmias: moving from the research lab to the clinic



Registration and programme

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.



[Registration and programme](#)

OTHER NEWS FROM PARTNERS

World Duchenne Organization's FAIR Training Program

Register before February 20th, 2023

European Institute of Innovation and Technology

(EIT) Health's Catapult Videos On-Demand

platform has been launched!

The EIT Health Catapult programme showcases carefully selected ventures from all over Europe and actively looking for Seed and Series A investments.



[More information](#)

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.

[Registration, programme, and more information](#)

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**.

ERICA European Rare Disease Research Coordination and Support Action

WP4 Webinar

Essential requirements before thinking about a clinical trial

Viviana Giannuzzi
Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus

February 28th, 2023 12:00-13:00 CET

[More information](#)

#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!

[More information](#)



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:

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

New IRDiRC Task Forces

Framework to assess impacts associated with diagnosis, treatment, support, and community integration that can capture changes along the rare disease patient and family journey

Functional Analysis

Funding Models to Support the Spectrum of RD Research and Development

Preparing for Genetic N-of-1 Treatments of Patients with Ultra-Rare Mutations

Apply before 20 February 2023

IRDiRC

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

Name]" before **February 20th, 2023**.

[More information](#)

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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