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What's new?

September 2022

EJP RD HIGHLIGHTS

The Fourth EJP RD General Assembly and Consortium Meeting: **13-15 September 2022 - Live tweet from Porto, Portugal**



The **Fourth EJP RD General Assembly (GA) and Consortium meeting** will be taking place between **September 13 - 15, 2022**.

The GA meeting is the perfect occasion to **bring together all EJP RD members to have an open discussion on the work done so far and define the new**

road map for the next year(s).

Search for **#EJPRDGeneralAssembly2022** on Twitter and our Instagram story for updates!

Instagram

Twitter

ERN Research Training Workshops funding opportunity: **Now open until October 1st**

The **ERN Research Training**

Workshops funding

opportunity is now open for applications until **October 1st**. The goal of the workshops is to **train researchers and clinicians affiliated to ERN- Full Members or – Affiliated Partners in relevant topics on research in rare diseases**. Training themes may

include innovative research methodologies, diagnostic research topics, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc. Moreover, the workshops will be aiming to provide a cross-ERN added value.

The workshops will be delivered as two-day events. The costs for the workshop organization will be covered up to a limit of **€25,000** (venue, administrative, audio-visual and IT facilities essential for the workshop, catering, travel and accommodation expenses of workshops participants and invited speakers, if envisaged).

The workshops selected for funding will be attended only by individuals affiliated to ERN institutions. Participants will be selected by the coordinator of the ERN managing institution and the workshop organizer based on pre-defined criteria.

[More information](#)

“Bring Your Own Omics Data” Workshop pre registration:

Deadline: September 9th, 2022



The EJP RD “Bring Your Own Omics Data” Workshop pre-registration form is now open.

The 2-day workshop will take place on **November 17th and 18th 2022**, face to face in Nijmegen (Netherlands). Costs for travel and accommodation might be available for participants from ERNs and EJP RD beneficiaries.

The “Bring Your Own Omics Data” (BYOOD)

Workshop **aims to help with optimising and**

integrating your omics data, initiate network analysis, and continue collaborations with the data analysis team.

In order to prepare the workshop and adapt it to your needs, **please complete the pre-registration form by September, 9th 2022.**

<https://forms.office.com/pages/responsepage.aspx?>

[id=AcQ6OB2ia0KAcI90w2twkyfZuB17KINIoHk8NTaO83NUOTQ0VkJJEVkJySINMSks3REkwTjgyT001WC4u](https://forms.office.com/pages/responsepage.aspx?id=AcQ6OB2ia0KAcI90w2twkyfZuB17KINIoHk8NTaO83NUOTQ0VkJJEVkJySINMSks3REkwTjgyT001WC4u)

[More information](#)

Nominations for the Black Pearl Awards

Deadline: September 4th, 2022

Do you know the next Black Pearl Awardee?

There is someone you know who has **improved the lives of people living with a rare disease**. Their outstanding efforts as either an organisation, company, researcher, scientist, patient advocate, or policy maker have contributed to the betterment of the rare disease community. **Let's get their contribution noticed and give them the visibility their actions deserve!**

Nominate them today!

Deadline for nomination: September 4th, 2022



[More information](#)

ERN Research Mobility Fellowship: **Opening soon (3 October 2022)**

The last call for the Research Mobility Fellowships funding opportunity will open on October 3rd. The call aims to **support PhD students, postdocs and medical doctors in training to undertake scientific visits fostering specialist research training outside their countries of residence.**

Read statements from past fellows!

Open on October 3rd, 2022
until November 13th, 2022

The ERN

Research Mobility Fellowship funding opportunity

What can be funded?
Visits of junior clinical or lab researchers aimed to acquire scientific skills and advance rare disease research performed by the ERNs

Who can be funded?
PhD students, post-Docs and medical doctors from ERN Member/Affiliated Partner centers or other European research institutions

Where can you go?
- To another ERN Member/Affiliated Partner center
- To any research institution in Europe
Either home or host institution must be a Full Member or Affiliated Partner of an ERN

For how long can you go?
1 to 6 months



<https://www.ejprardiseases.org/ern-research-mobility-fellowship/>

The aim of the call is in compliance with the vision and goals set by the International Rare Diseases Research Consortium (IRDiRC), which fosters international collaboration in rare diseases research.





Past fellows

More information on the funding opportunity

UPCOMING ERN WORKSHOPS

Rhabdoid tumors in clinic and research: From basic biology to the patient bed

Registration deadline extended: September 15th, 2022

In the context of [EJP RD's ERN Workshops](#), a **face-to-face workshop** entitled "Rhabdoid tumors in clinic and research: From basic biology to the patient bed" aimed at **discussing the current clinical standard of treatment in rhabdoid tumors, as well as the controversies in the rhabdoid tumors regimen** is being organized by Dr. Pascal Johann of the [Universitätsklinikum Augsburg](#).

The **in-person event** will take place on **November 5th, 2022** in

Charenton-le-Pont, France.

The workshop is open by prior registration and selection to **both PhD or Master students from the life sciences and MD students or residents, although advanced-stage PIs or physicians with more extensive clinical experience are invited to join.** All participants must be affiliated to an ERN Full Member or affiliated Partner institution.

The training workshop is **free of charge.**

Registration is open and closes on **September 15th, 2022.**

Those selected to participate from among the applicants will be informed by October 1st, 2022, of their selection.

Registration & More information

EJP RD FUNDING OPPORTUNITIES**Networking Support Scheme (NSS) Funding Opportunity****OPEN CALL**

Next collection date: **December 1st, 2022**

2023.

The aim of the NSS call is **to encourage knowledge-sharing between health care professionals, researchers and patients** on rare diseases and rare cancers, as well as **to enable or increase the participation of usually underrepresented countries in Europe in new and existing research networks.** Eligible applicants are **health care professionals,**

The NSS has been expanded to include online and hybrid networking events that can now be funded in addition to face-to-face events. A hybrid networking event consists of a group of participants networking face-to-face at a specific location together with other participants networking online.

Your event should take place between February 15th, 2023, and September 1st,

researchers, and patient advocacy organisations from the following countries involved in the EJP RD: Armenia, Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Georgia, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, Luxembourg, Malta, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, the Netherlands, Turkey, United Kingdom. There is no limit on the number of participants per event; however, the maximum budget that can be requested is **€ 30,000 per networking event**.

The next collection date is December 1st, 2022, at 14:00 (CEST)

Selected past networking events are available [here](#) providing insights on using this funding opportunity.

To get more information and to apply, click below.

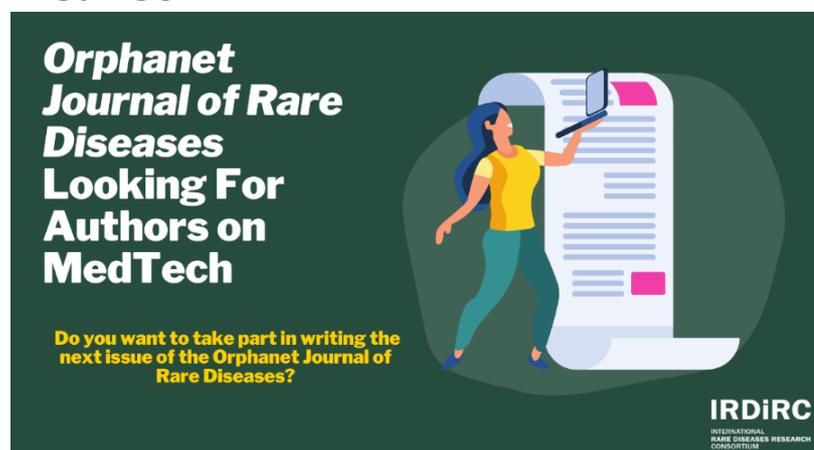
[More information](#)

[All EJP RD open funding opportunities here](#)



NEWS FROM THE INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM (IRDiRC)

Orphanet Journal of Rare Diseases series looking for authors on MedTech



As one of the outcomes of the **MedTech for Rare Diseases Working Group** led by IRDiRC members Anneliene Jonker and Marc Doms, the Orphanet Journal of Rare Diseases has decided to focus a thematic issue on the questions regarding the research and development of orphan devices and medical technologies that are being developed for Rare Diseases patients.

[More information](#)

CAREERS

[Job opportunities](#) are available at EJP RD member institutions:

- **EJP RD Coordination Team** is looking for a **Financial and Administrative Manager (bilingual French-English)**

- **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**
- **Izmir Biomedicine and Genome Center (IBG)** is looking for an **ERA Chair and Head of the Unit for Rare Diseases at IBG (project RareBoost #952346, H2020- WIDESPREAD-06-2020)**



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