

IRDIRC HIGHLIGHTS

New Task Forces & Working Groups

Enabling and Enhancing Telehealth for Rare Diseases Across the Globe

IRDIRC is currently assembling a team of experts to populate this Task Force and is specifically looking for members with expertise/experience in one or more of the following areas:

- Telehealth providers across a wide variety of specialties, disorders, and geographic locations
- Professional organizations that support career development for clinicians
- Primary and specialty care providers
- Policy makers
- Healthcare systems
- Healthcare insurance companies

Able to commit to monthly teleconferences, a yearly meeting, regular committee activities, and email correspondence

The deadline for application is 30 November. If you are interested in taking part in this activity, please send your CV, biosketch, and letter of motivation (one paragraph each) to the [Scientific Secretariat](#).



CALL FOR MEMBERS

Task Force on "Enabling & Enhancing Telehealth for Rare Diseases Across the Globe"

IRDIRC is currently recruiting experts for this Task Force and is specifically looking for telehealth providers, primary and specialty care providers, policy makers, healthcare systems, and healthcare insurance companies.

<https://irdirc.org>

[More Information](#)

Working Group Opening: MedTech for Rare Diseases



Do you want to explore the role and value of medical devices in rare diseases?

New IRDiRC Working Group

on MedTech for Rare Diseases

Apply before 14 December

IRDIRC
INTERNATIONAL
RARE DISEASES RESEARCH
CONSORTIUM

The [Therapies Scientific Committee \(TSC\)](#), the [Interdisciplinary Scientific Committee \(ISC\)](#) and the [University of Twente](#) are jointly establishing a Working Group to explore the role and value of medical devices in rare diseases. The Working Group aims to create a better understanding and enhanced awareness of device developer's needs, the standardized outcomes to define user needs for devices, and

to offer a groundwork for developing solutions to improve the (regulatory) landscape of MedTech use for rare disease patients.

Interested candidates can submit their application (CV, biosketch and letter of motivation, one paragraph each) to the [Scientific Secretariat](#) **before 14 December**.

[More Information](#)

1000 new rare diseases treatments by 2027, identifying and bringing forward strategic actions

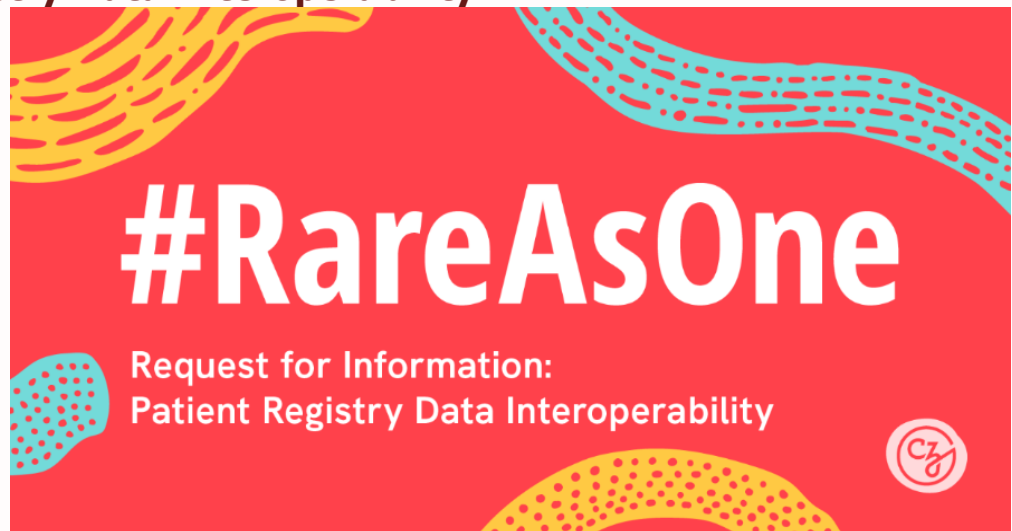
The *IRDiRC: 1000 new rare diseases treatments by 2027, identifying and bringing forward strategic actions* has been published in the Rare Disease and Orphan Drugs Journal. The manuscript describes **the recent key steps undertaken by the [IRDiRC Therapies Scientific Committee \(TSC\)](#) to support the future approval of 1000 new therapies for rare diseases.**

[Read the manuscript](#)

NEWS FROM IRDiRC MEMBERS

Chan Zuckerberg Initiative launches Request for Information (RFI) on Patient Registry Data Interoperability

[The Chan Zuckerberg Initiative \(CZI\)](#) has launched a Request for Information (RFI): Patient Registry Data Interoperability as part of the Rare As One project, aimed at mapping data interoperability challenges and support ideas that will



make it easier for patient communities to share data with researchers, and for researchers to fully leverage patient voices in research.

Application Deadline: November 30th

[More Information](#)

OTHER NEWS

European Joint Programme on Rare Diseases Joint Transnational Call 2022: Pre-announcement of the funding opportunity for research projects

THE
EUROPEAN JOINT PROGRAMME
ON RARE DISEASES
OPENS THE
JOINT TRANSNATIONAL CALL 2022
A FUNDING OPPORTUNITY FOR RESEARCH PROJECTS

Try our matchmaking tool to find your ideal project partner!

14 DECEMBER: Launch of the call
16 DECEMBER: Information webinar for potential applicants
16 FEBRUARY: Pre-proposal submission deadline

Topic: Development of new analytic tools and pathways to accelerate diagnosis and facilitate diagnostic monitoring of rare diseases

ejprarediseases.org

The European Joint Programme on Rare Diseases just pre-announced the Joint Transnational Call 2022, a funding opportunity for research projects on the development of new analytic tools and pathways to accelerate diagnosis and facilitate diagnostic monitoring of rare diseases.

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: Development of new analytic tools and pathways to accelerate diagnosis and facilitate diagnostic monitoring of rare diseases

The call will open on December 14th.

[More Information](#)

Leave No Patient Behind - A Global Black Bone Disease Registry by the AKU Society

The AKU Society just launched a crowdfunding campaign to raise funds for a global Black Bone Disease registry in order to gather information about AKU patients around the world in one single place.

This will allow the AKU Society to make the case for access to the life-changing drug Nitisinone in the many countries where it is not yet available. It will also help them prepare plans for gene therapy and other new treatment studies.

[More Information](#)
