ERN ReCONNET Newsletter

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RarERN Path:
a methodology by ERN ReCONNET

The RarERN Path methodology aims to create a single reference organisational model for patients' care pathways which, if applied in different contexts, helps to ensure an improved, cost-effective and patient-centred equal care to rare and complex diseases.

The development of the RarERN Path methodology involved different stakeholders: health economists, clinicians and researchers expert in rare and complex diseases, communication experts, experts in patients' involvement and narrative medicine and policy-makers.

Read more

ERICA

The European Rare Disease research Coordination and support Action (ERICA) received a positive evaluation for a Horizon 2020 grant. The ERICA Consortium (led by Alberto Pereira) consists of 29 partners: EJP RD, all 24 ERNs, EURORDIS, Orphanet, Mapi Research Trust and European Research Infrastructure for Translational Medicine.

More info

Assessment of ERN ReCONNET new applicants: next steps

After the final review by the Board of Network, the next step will be the Validation of the Application by the Independent Assessment Body.

Info on 2019 Call for membership

ERN ReCONNET webinars

New ERN ReCONNET webinars have been released and are available on our YouTube channel:
– Fransiska Malfait and Alberto Sulli, Skin manifestations in EDS: what are they and how to manage them

– Leema Robert and Fransiska Malfait, Cardiovascular aspects of EDS – Joint ERN ReCONNET and VASCERN webinar

Mature ERN system in 2030

Read the EURORDIS "Recommendations to achieve a mature European Referene Networks system in 2030"

Eurordis Photo Award 2021

Do you have a photo that shows what it's like to live with a rare disease? Submit to Eurordis Photo Award!

SAF España in EURORDIS

SAF España has been accepted as EURORDIS full member since the 13th of November 2020

EJP RD calls

JTC 2021

The 3rd EJP RD Joint Transnational Call for Rare Diseases Research Project (JTC 2021) focuses on "Social sciences and Humanities Research to improve health care implementation and everyday life of people living with a rare disease".

The call is open.

More info

NSS

The aim of the Networking Support Scheme (NSS) in the EJP RD is to encourage sharing of knowledge on rare diseases and rare cancers of health care professionals, researchers and patients.

The call is open on a continuous basis.

More info

Internal call

The Internal call for collaborative innovation projects to improve rare diseases clinical trials methodologies in limited populations is open to EJP RD beneficiaries and their linked third parties.

The call is open.

More info

COVID-19 dedicated section on ERN ReCONNET website

The ERN ReCONNET COVID-19 dedicated section is constantly being updated with all statements from organisations and entities related to ERN ReCONNET and people with connective tissue and musculoskeletal diseases.

Updates on COVID-19

COVID-19
Clinical Management Support System

The European Commission launched the COVID-19 Clinical Management Support System with the aim to support clinicians in hospitals that are currently facing the coronavirus emergency all over Europe.
Based on the experience with the European Reference Networks, the initiative helps 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.
For joining the system, you need to register here.

More info on COVID-19 CMSS

Clinical Patient Management System

The Clinical Patient Management System (CPMS) aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of Member States in Europe.
The CPMS is a secure Software as a Service (SaaS) that enables health professionals to enrol patients using comprehensive data models. Health professionals can use the CPMS to collaborate actively and share patient within and across ERNs.
For more information on how to access the CPMS and how to

request a virtual consultation, please contact us at:
helpdesk.reconnet@ao-pisa.toscana.it

More info

ERN ReCONNET IT Services

You can find all informations about the **ERN ReCONNET IT Services** on the ERN ReCONNET website, with additional **CPMS training videos**.

More info

Meetings and congresses

RE(ACT) congress and IRDiRC conference online

The 6th RE(ACT) Congress and the 4th IRDiRC Conference will be held online on 13-15 January 2021. It aims to bring together scientific leaders and experts and young scientists from a variety of breakthrough scientific fields to present cutting-edge research, exchange ideas, and discuss policies related to rare diseases research. Patients and patient organizations, who are committed to research, will also be in attendance to share their experiences and perspectives.

ERN ReCONNET plenary meeting

The next ERN ReCONNET plenary meeting has been postponed to 2021

On our website you will find all the news updated and much more about our network.

Website

SOCIAL MEDIA CHANNELS

ERN ReCONNET YouTube Channel and Twitter page

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ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are supported by the European Commission. For more information about the ERNs and the EU health strategy please visit ec.europa.eu/health/ern_en