ERN ReCONNET Newsletter

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ERN ReCONNET Scientific Congress & Plenary Meeting

The **First Scientific International Congress of the ERN ReCONNET** took place from *20th to 22nd April 2023* in Brussels, right after also the **ERN ReCONNET Plenary Meeting** was held from *22nd to 24th April.*

The Congress was a *unique opportunity* for all the ERN ReCONNET members to interact with the multiple stakeholders of the rare and complex connective tissue and musculoskeletal diseases community and to discuss innovative approaches while fostering collaborations across Europe. The brainstorm exercise spanned over several relevant key points, such as: *Epidemiology of rCTDs, ERN ReCONNET Points to Consider for treating ARDs patients with antiviral therapies and antibody products anti-SARS-CoV-2, Diagnosis and clinical management of rCTDs, Biobanking and registries, Quality of life of rCTDs, Organisational and economic aspects of rCTDs, Therapeutic management of rCTDs, Comorbidities, Innovative approach of clinical studies in rCTDs.*

Moreover, two special "*Meet the experts*" appointments on "*Pregnancy in rare and complex connective tissue diseases:*

patients and physicians point of view" with the *ePAG Silvia Aguilera* (Elche, Spain) and *Prof. Marta Mosca* as well as on "*Ehlers-Danlos syndromes*" with *ePAG Charissa Frank* (Beringen, Belgium) and *Dr. Fransiska Malfait* (Gent, Belgium) were held.

In addition, **ERN ReCONNET** was very proud to have received *82 scientific posters* from its scientists and researchers.

Regarding the **ERN ReCONNET Plenary Meeting**, the event took place in person after 3 years of pandemic and it was an amazing experience as we finally met in person the new members of **ERN ReCONNET** that joined in 2022 and we have also seen the amazing work that is being organzed by all the *Working Groups and Disease Groups*. The discussions held were very precious to reflect on the new governance and of course also to discuss the exciting proposals collected during the *Network Cafè*, which was a great success and that might be repeated also in our future meetings.

The *ERN ReCONNET Coordination Team* would like to thank you all for your participation to the **First ERN ReCONNET International Scientific Congress**; it has been amazing have you there and stay tuned for the announcement of the *2nd ERN ReCONNET International Scientific Congress*!

Results of the
ERN ReCONNET Evaluation

The **ERN ReCONNET Network evaluation** reported an *outstanding level of performance in accomplishing all the planned objective*. The Evaluation can be considered as a huge success with a *full 100% compliance with Network criteria.*

The Evaluators reported that **ERN ReCONNET** has developed an excellent level of maturity regarding its purpose,

governance, leadership, learning, and sustainability. According to the external evaluators, the approach adopted in the **Network** has been *fruitful*. It has *integrated all* the stakeholders, affiliated members, and ePAGs and could be seen as *an example for other Networks*.

The next steps of the evaluation foresee that the **Network** coordinators and ERN members can send their comments to the Evaluators on the draft evaluation reports and do to this, they have 2 months from the date of reception of the draft report. The FMs evaluated with "Needs improvement" have to develop and submit an improvement plan in the same 2 months period. After These 2 months, final reports will be elaborated by the Evaluators and will be sent to ERNs and to the European Commission.

The **new ERN ReCONNET Grant** will start on *1st September 2023* and it will have *7 beneficiaries and 8 Work Packages*. The grant proposal was submitted on 6th June and the evaluation report is expected by the end of July–August. The signature of the new Grant agreement and the related budget transfer from the European Commission is expected to take place in *February 2024*.

ERN ReCONNET at EULAR 2023

EULAR 2023 was a blast for the **ERN ReCONNET**, we had plenty of people (old and new friends) stopping by to say hi or asking questions or just curious about what **ERN ReCONNET** does at our booth. This year, the **ERN ReCONNET** *Young Working Group* promoted the allocation of *5 bursaries* for the participation of *3 young clinicians* and *2 ePAG Advocates* to the *2023 EULAR Congress*

A special thanks to our *bursary winners* that have helped us to spread even more the **ERN ReCONNET** *voice, mission, and vision.* Here are some **ERN ReCONNET video pills** (1-2 min

videos) done by Dr. Massimo Radin and Dr. Chiara Cardamone talking about what are their take home messages!

A new dedicated *playlist* on our **ERN ReCONNET YouTube Channel** was created to collect your voice and future pills from our network.

ERN ReCONNET
Strategic Meeting in Rome

A **Strategic Meeting** with all the Members of the *Steering Committee* to prepare together the next years of **ERN ReCONNET** actions and initiatives was held in *March 2023*. In a nutshell, the **ERN ReCONNET** Strategic Meeting aims at:

- Identifying and analyzing strengths, weaknesses, opportunities and threats of the **Network**
- Agree on the objectives and the strategy of the **Network** for the next 3 years, including the operational and financial plans
- Prepare for the coming **ERN ReCONNET** Grant proposal

The meeting agenda was very rich of relevant topics and the discussion was fruitful and reached a *common consensus* on how to achieve such goals by keep working all together.

New ERN ReCONNET
ePAG Advocates appointed

The **ERN ReCONNET ePAG community** is getting bigger and bigger, let's welcome our new members:
– **Camelia Bucsa** from Romania, representing the *Romanian Association of Relapsing Polychondritis Patients (ASPOR)*
– **Magdalena Ciupera** from Poland, representing the *Let's stick together Association (3majmy się Razem Association)*
– **Olga Drapalova** from Czech Republic, she will be representing the *Czech League against the Rheumatism (Revma Liga Ceská republika)*
– **Silke Schlüter** from Germany, representing the *German Society for Muscular Disorders (Deutsche Gesellschaft für Muskelkranke e.V.)*.
Thank you for joining us and we look forward to work with you!

ERN ReCONNET ePAGs

ERN Exchange Program

The **ERN Exchange Program**, launched by the *European Commission (EC)*, is meant to support the sharing of knowledge and stimulate collaboration among the Networks by organising exchange visits and it is fully supported by the funds of the EC.
In particular, **ERN ReCONNET** was allocated 45 "packages" (days of exchange – 1 package=5 days) and *launched 2 calls for interest*: After the first call, 3 exchanges were organised and the program was stopped due to the pandemic; a second call was launched in 2022 and a total of 43 Exchanges were organised out of the 52 received applications.
ERN ReCONNET is the second ERN in terms of number of

packages used.

The program was a great success in **ERN ReCONNET**, participants have particularly appreciated the opportunity of visiting other ERN centres. Interest on this exchange program was received also from outside the Network (non-ERN members). *The opportunity of organising a new Exchange Program will be discussed in the near future.*

ERN exchange program

The Scientific voice of ERN ReCONNET members

ERN ReCONNET new relevant publications (reviews, recommendation, and supplement) on several topics have been released and are available, free download.

Here is the list:

– **ERN ReCONNET points to consider for treating patients living with autoimmune rheumatic diseases with antiviral therapies and anti-SARS-CoV-2 antibody products.** *Talarico et al.*, 2023. Clin Exp Rheumatol.

– **The added value of a European Reference Network on rare and complex connective tissue and musculoskeletal diseases: insights after the first 5 years of the ERN ReCONNET.** *Talarico et al., 2022.* Clin Exp Rheumatol.

– **An overlook on the current registries for rare and complex connective tissue diseases and the future scenario of TogethERN ReCONNET.** *Bandeira et al.,* 2022. Sec. Rheumatology

– **Rare inside rare: rare aspects of rare and complex connective tissue and musculoskeletal diseases.** 2022. Clinical Experimental Rheumatology.

Get in touch with the *Coordination Team* if your **ERN ReCONNET** papers has been published.

ERN ReCONNET
Good Practice Initiative

A dedicated webinar was held on *June 12th* on the **ERN ReCONNET** *Good Practices sharing strategies*.

The agenda was rich of relevant presentations that triggered a stimulating brainstorm among all the participants. In details, the topics were the following:

– Organisation of inpatient care in a Reference Center for non-vascular Ehlers-Danlos syndromes

– Patient education program on connective tissue diseases

– Education and exercises for patients of the Myozitdy group

– Duesseldorf campaign against undiagnosed rheumatism D-KUR

– A step-wise approach in the organisation of care during transition from paediatric to adult age: reporting the protocol of a monocentric experience.

We thank all the speakers and the participants for the productive discussion and we look forward to work together on some new ideas.

ERN ReCONNET Upcoming meetings

ERN ReCONNET will be participating at the following upcoming events, will you be joining us? More info and details will be shared soon, so stay tuned!

– **Conference on Rare diseases and the European reference networks.** Bilbao (Spain). Oct 10–11 2023

– **American College of Rheumatology (ACR) Convergence 2023**, San Diego (US). Nov 10–15, 2023.

– **60° Congresso Nazionale Società Italiana di Reumatologia (SIR)**, Rimini (Italy). Nov 22–25, 2023

@ meetings!

ERN ReCONNET joins the Awareness Days of its rCTDs

ERN ReCONNET has a strong and unique connection with its *ePAG*, so to further show our support to their communities the *Coordination Team* has decided to start a new project where the **ERN ReCONNET** Network joins relevant *awareness days campaigns* on social media to celebrate our patient communities during the year.

In *June*, we joined the [Antiphospholipid Syndrome on the (9th)](#) and [World Scleroderma Awareness (29th) Days](#). Patients are patients 24/7 and we are in this together, so as

ERN ReCONNET, we are happy to show them our support and we hope that more and more ERN ReCONNET members will join us along the way.

On July 23rd, **ERN ReCONNET** will be joining the *Sjrogren awareness day*, so stay tuned and join us this campaing on our social media!

ERN ReCONNET webinars:
Past & New season

The next season of the **ERN ReCONNET** *Education and Traning Webinars* will start on *September 6th* with new exciting sessions for HCPs, patients, and general society.

We take this opportunity to thank all the speakers, moderators, participants, the *Education and Training Team* for the incredible work done for this 2022–2023 season.

We look forward for the new one!

And if you have missed some of our ERN ReCONNET webinars, check them out and don't forget to share them across your communities.

ERN ReCONNET webinars

ERN ReCONNET YouTube Channel:
Webinars, video pills,
and much more!

Recorded **ERN ReCONNET webinars** are available on our **ERN ReCONNET YouTube channel**. In particular, the following ERN ReCONNET webinars have been uploaded on our ERN ReCONNET YoutTube channel:

– _Good Practices sharing initiatives_
– _EULAR2023 Debrief – for people living with lupus_
– _Mixed Connective Tissue Disease: a 2023 update_
– _What is APS? How can I explain it to my family and friends?_
– _What are the pitfalls and red flags of RP to be considered by the GP/HCP?_

Don't forget to subscribe to our **ERN ReCONNET YouTube Channel** to stay up to date with the latest news.

ERN ReCONNET YouTube Channel

ERN ReCONNET @ EURORDIS Good practices

EURORDIS has been awarded a grant from Boston Scientific Foundation Europe to support a webinar series 'Building Good Practices' for European Patient Advocate Groups (ePAGs). The _ePAG webinar series_ comprised four quarterly online meetings, for which EURORDIS sourced topics and speakers from among the ePAG patient volunteers. The main goals are to:

– Inspire other ePAG advocates to replicate or adapt good practices to their own needs and context,
– Increase their representation of the rare disease patient community and in turn elevate the two-way communication between patients and theERNs
– Encourage ePAG advocates to deliver webinars which they have developed to guide others through their own experience, identifying success factors and lessons learned.

ERN ReCONNET has presented *many Good Practice* and the last one is related to the *Involvement of our ePAG Advocates in the recent ERN Evaluation*, in which ERN ReCONNET was presented by our **ePAG Charissa Frank.**

Available recording

New members at the
ERN ReCONNET Coordination Team

Dr. Eleonora Passeri

Hi, my name is Eleonora Passeri and I am your new Communication and Dissemination Manager. I am a neuroscientist by education and training: I earned a bachelor's in Biological Science, a master's in Molecular Biology, I got my PhD in Neuroscience at Tuebingen University as Marie Curie fellowship. I later moved to the US for my postdoctoral studies in neuro-immunology and psychiatry at McLean Hospital, Georgetown University, and Johns Hopkins Hospital. I decided to move my career into science communication almost 10 years ago, I am also a patient advocate for rare diseases and /or neurodevelopmental disorders. Currently, I am doing a Patient Advocacy Management Master (a part time program) at Cattolica

Dr. Maria Elena Manfredini

My name is Maria Elena Manfredini and I am your new Project Manager TogethERN ReCONNET, and I wanted to reach out to briefly introduce myself. I have an educational background as a sociologist earned in Rome and in Bielefeld. Later, I graduated with a postgraduate Master's Degree in European Studies from the College of Europe in Bruges. I switched careers over ten years ago, going from the social sciences to the field of medical research, and I spent that time managing Horizon – Marie Curie – Projects at the Medical University of Vienna.

I have lately developed an interest for Medical Humanities and have just finished my training to become a facilitator for Narrative Medicine.

University in Rome as full fellowship.

I had the pleasure to meet in person or virtually some of you and I look forward to meeting you all in the upcoming months.

I am really excited about this new journey, so feel free to get in touch with me with any ideas or questions.

I feel honoured to have joined the team because this project is a great opportunity to contribute to improve the lives of people with rare diseases and I am very excited to give my contribution.

Coordination Team

NEW ERN ReCONNET LinkedIn Official Page

Join the ERN ReCONNET
Professional Community on LinkedIn

In May, **ERN ReCONNET** has launched its *official LinkedIn page* as a new way to engage, interact, and communicate with our professional community and increase our audiences to other potentially interested and relevant stakeholders.

Help us to disseminate our work, actions, and initiatives, you can also add your **ERN ReCONNET** membership in your bio!

ERN ReCONNET LinkedIn Page

ERN ReCONNET
on Social Media

The **ERN ReCONNET** Coordination Team is working hard to increase the impact of our *Network* across new social media to spread and disseminate our actions, initiatives, projects, activities, ideas, and YOUR VOICE to new audiences and general society!

But, *we need your help and support*, so don't forget to subscribe to the **ERN ReCONNET** official *YouTube channel* and to follow us on the **ERN ReCONNET social media** (Twitter, LinkedIn, Facebook) by using the hashtag *#ERNReCONNET.*

Facebook   Twitter   Web   Linkedin   Youtube

ERN ReCONNET Coordination Team
wish you all a...

Condividi   Condividi   Condividi

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