



European
Reference
Network

ERN
ReCONNET

Programme

Prague
9-11 April
2025

ERN ReCONNET

2nd International Congress
on rare and low-prevalence
connective tissue and
musculoskeletal diseases

Welcome

On behalf of the Congress Committee, it is a great pleasure to invite you to take part to the 2nd ERN ReCONNET International Congress on rare and low-prevalence connective tissue diseases which will take place in Prague, Czech Republic, on April 9–11, 2025.

We are looking forward to welcoming you in Prague.

Knowledge, awareness and a patient-centred approach have been cornerstones of the activity of ERN ReCONNET, the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases, in its first five years of activity and the programme reflects the ERN mission, covering important topics in the diagnosis and management of rare and complex diseases such epidemiology, diagnosis and clinical management, biobanking and registries, quality.

The programme has been developed to integrate the perspective of the different stakeholders involved in rare diseases management. For this reason we expect that the congress will be of interest not only for specialists but also for people living with a rare disease, caregivers, clinicians, policy makers, industry, and will represent an opportunity for rare and complex connective tissue diseases community to meet, work together and find new inspirations for research, diagnosis and therapy.

We are excited about meeting you at this innovative conference that, we hope, will stimulate and foster collaborations all around Europe! Therefore, we warmly invite to present and share original and significant experience, research and innovation in the field of rare and complex connective tissue diseases.

We are looking forward to welcoming you in Prague.

Marta Mosca on behalf of the Congress Committee

Chairperson of the Congress

Marta Mosca, Italy

International Scientific Committee

Silvia Aguilera, Spain

Tobias Alexander, Germany

Janette Andersen, Belgium

Laurent Arnaud, France

Chiara Baldini, Italy

Jose Ballarin Castan, Spain

Stefano Bombardieri, Italy

Coralie Bouillot, France

Camelia Bucsa, Romania

Gerd R. Burmester, Germany

Sara Cannizzo, Italy

Patricia E. Carreira, Spain

Marco Castori, Italy

Benjamin Chaigne, France

Magdalena Ciupera, Poland

Eva Collado-Gonzalez, Spain

Alain Cornet, Belgium

Maurizio Cutolo, Italy

Emanuel Della Torre, Italy

Andrea Doria, Italy

Olga Drapalova, Czech Republic

Sue Farrington, UK

João Cabral da Fonseca, Portugal

Charissa Frank, Belgium

Ilaria Galetti, Italy

Andrea Gaglioti, Italy

Vera Marlene Guimarães, Portugal

Eric Hachulla, France

Frédéric Houssiau, Belgium

Luca Iaccarino, Italy

Maarteen Limper, The Netherlands

Ingrid Lundberg, Sweden

Franciska Malfait, Belgium

Diana Marinello, Italy

Lisa Matthews, UK

Marco Matucci Cerinic, Italy

Alain Meyer, France

Marta Mosca, Italy

Ulf Müller-Ladner, Germany

Gaetane Nocturne, France

Marzena Olesinska, Poland

Cristina Pamfil, Romania

Simona Rednic, Romania

Christophe Richez, France

Matthias Schneider, Germany

Silke Schlüter, Germany

Savino Sciascia, Italy

Vanessa Smith, Belgium

Alberto Sulli, Italy

Rosaria Talarico, Italy

Maria Tektonidou, Greece

Jacob van Laar, The Netherlands

Ana Vieira, Portugal

Madelon Vonk, The Netherlands



European
Reference
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ERN ReCONNET Coordination Team

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<https://reconnet.ern-net.eu>

Wednesday, April 9, 2025

Programme

14:30–14:45

Introduction and welcome

M. Mosca (Pisa, Italy)

14:45–15:25

CAR-T cell therapy: one size fits all?

14:45–15:05

Essential basics: How does CAR-T cell therapy work?

M. Becilli (Rome, Italy)

15:05–15:25

3 years of CAR-T cell therapy for autoimmune diseases: success and problems to solve

M. Hagen (Erlangen, Germany)

15:25–16:25

Updates in the management of anti-phospholipid syndrome

15:25–15:45

Living with APS difficulties and expectations. Quality of life in APS

S. Aguilera (Alicante, Spain)

15:45–16:05

Treatment of Catastrophic APS

R. Cervera (Barcelona, Spain)

16:05–16:25

Unmet needs and challenges in the treatment of APS

S. Sciascia (Turin, Italy)



16:25–17:15

Coffee Break and Poster tour

Programme

17:15-18:15

Sjogren

17:15-17:30

Patients' unmet needs

A. Vieira (Lisbon, Portugal)

17:30-17:45

Different perception of disease severity between patients and clinicians

C. Bouillot (Gland, Switzerland)

17:45-18:00

State of the art of biomarkers in SjD

C. Baldini (Pisa, Italy)

18:00-18:15


Lymphoma: adapting patients monitoring in clinical practice

G. Nocturne (Le Kremlin-Bicêtre, France)



Thursday, April 10, 2025

Programme

- 08:00–09:00 **How to self manage digital lesions: yes we do!**
Tips and Tricks in the management of digital ulcers
C. Campochiario (Milan, Italy)
- 09:00–10:00 **Polychondritis: where are we?**
- 09:00–09:20 **The burden of relapsing polychondritis in 2025**
C. Bucsa (Cluj-Napoca, Romania)
- 09:20–09:40 **Management of relapsing polychondritis in 2025**
S. Rednic (Cluj-Napoca, Romania)
- 09:40–10:00 **Quality of life in relapsing polychondritis. What we know and what can we do more?**
L. Arnaud (Strasbourg, France)
- 10:00–11:00 **How to suspect, diagnose and manage EDS**
- 10:00–10:20 **The clinical spectrum of EDS**
F. Malfait (Gent, Belgium)
- 10:20–10:40 **Microvascular involvement in ED hypermobile syndrome**
A. Sulli (Genoa, Italy)
- 10:40–11:00 **The cloud of unknowing: how to trace a novel framework for people with joint hypermobility**
M. Castori (Foggia, Italy)
-  11:00–11:45 **Coffee Break and Poster tour**

11:45-12:45

Difficulties in diagnosis and classification: from UCTD to MCTD

11:45-12:05

Doctor, can you ask me...? What MCTD and UCTD patients want to be asked

M. Ciupera (Warsaw, Poland), V. Guimarães (Lisbon, Portugal)

12:05-12:25

What is UCTD? Discuss definition of UCTD clinical picture and unmet needs

L. Iaccarino (Padua, Italy)

12:25-12:45

What is MCTD? Critical analysis of current classification criteria, clinical unmet needs

M. Olesinska (Warsaw, Poland)



12:45-14:00

Lunch

14:00-15:00

Living with a chronic disease: quality of life, self management

14:00-14:20

How to improve fatigue and quality of life in rare RMD patients: the example of IIM

H. Alexanderson (Stockholm, Sweden)

14:20-14:40

Pain: a common problem for our patients

M. Cutolo (Genoa, Italy)

14:40-15:00

Patient education: which role in clinical practice?

E. Hachulla (Lille, France)

15:00-16:00

What is new in IgG4-related diseases

15:00-15:20

Identification of Red Flags for diagnosis IgG4-related disease

E. Della Torre (Milan, Italy)

15:20-15:40

Emerging therapeutic options for IgG4-related disease

E. Culver (Oxford, UK)

15:40-16:00

Definition of PROMs in IgG4-related diseases

J. Ballarin (Barcelona, Spain)

16:00-16:45

Lecture: The importance of the ERN Registries: TogetHERN ReCONNET where are we?

M. Schneider (Düsseldorf, Germany), R. Talarico (Pisa, Italy)



16:45-17:15

Coffee Break

17:15-18:15

Systemic sclerosis

17:15-17:35

Unmet needs in 2025: news from the truth-tellers: the patient perspective

S. Farrington (London, UK)

17:35-17:55

**The experience of EUSTAR: what have we learned and how can we integrate with the ERN registry.
New opportunities**

M. Matucci Cerinic (Milan, Italy)

17:55-18:15

The (non) pharmacological management of systemic sclerosis: what is new in the horizon?

J. De Vries-Bouwstra (Leiden, The Netherlands)

18:15-18:45

Let's act together: please stand up!

Tips and tricks on how to function well

M. Koulopoulou (London, UK)

Friday, April 11, 2025

Programme

08:45-09:45

Inflammatory myopathies

08:45-09:05

Living with inflammatory myopathies: patient perspective and unmet needs

K. Cheng (Basel, Switzerland)

09:05-09:25

**The experience of Myonet registry: what have we learned and how can we integrate with the ERN registry.
New opportunities**

I. Lundberg (Stockholm, Sweden)

09:25-09:45

Unmet needs and challenges in the treatment of inflammatory myopathies

A. Meyer (Strasbourg, France)

09:45-10:45

SLE

09:45-10:05

Living with lupus survey

A. Cornet (Brussels, Belgium)

10:05-10:25

Rare in rare: how to manage rare manifestations of SLE

L. Arnaud (Strasbourg, France)

10:25-10:45

How the management of SLE has changed in the last decade


M. Mosca (Pisa, Italy)



10:45-11:45

Coffee Break and Poster tour

Programme

11:45-12:45	Pediatric rare diseases
11:45-12:00	From Childhood to Adulthood: Challenges of Connective Tissue Disorders Across Ages C. Ciurtin (London, UK)
12:00-12:15	When Should We Suspect Monogenic Causes in Juvenile Onset Connective Tissue Disorders? S. Kamphuis (Rotterdam, The Netherlands)
12:15-12:30	Predicting Outcomes in Juvenile Connective Tissue Disorders J. Anton Lopez (Barcelona, Spain)
12:30-12:45	Transition of patients with paediatric onset CTDs – which model of care should we follow? F. Oliveira Ramos (Lisbon, Portugal)
12:45-13:30	A glance to the future: from telemedicine to artificial intelligence a revolution in the management of rare diseases?
12:45-13:00	How to best use AI and big data in the management of rare diseases G. Burmester (Berlin, Germany)
13:00-13:15	No more dr GOOGLE: lupus 100 and lupus GPT Z. Karakikla-Mitsakou (Brussels, Belgium)
13:15-13:30	The patient perspective on telemedicine J. Andersen (Brussels, Belgium)
 13:30-14:30	Lunch
14:30	Departure

**Important dates**

Late registration deadline:
Onsite registration: From

March 25th 2025**March 26th 2025 and onsite****Abstract submission**

For each abstract, an author is expected to attend the congress and present the poster presentation. The presenting author of the accepted abstract must register by the registration deadline and attend the Congress. Abstract for which no author has registered to attend the Congress will not be included in the Congress Scientific Programme.

Posters

All posters must have maximum dimensions of 70cm x 100cm (vertical orientation). Poster boards will be set up in a dedicated area of the Congress venue and must remain up for the all length of the Congress, so that participants will be able to view them at their convenience. The presenter of each poster is kindly asked to remain close to the poster area.

**UEMS Accreditation**

The 2nd International Congress on rare and low-prevalence connective tissue and musculoskeletal diseases (ERNeReCONNET), PRAGUE, Czech Republic 09/04/2025 - 11/04/2025, has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) with 13.5 European CME credits (ECMEC®s). Each medical specialist should claim only those hours of credit that he/she actually spent in the educational activity.

General and Scientific Information

Through an agreement between the Union Européenne des Médecins Spécialistes and the American Medical Association, physicians may convert EACCME® credits to an equivalent number of AMA PRA Category 1 Credits™. Information on the process to convert EACCME® credit to AMA credit can be found at <https://edhub.ama-assn.org/pages/applications>. Live educational activities, occurring outside of Canada, recognised by the UEMS-EACCME® for ECMEC®s are deemed to be Accredited Group Learning Activities (Section 1) as defined by the Maintenance of Certification Program of the Royal College of Physicians and Surgeons of Canada.

CME Provider



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Organizing Secretariat



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Congress Venue

OREA Hotel Pyramida

Belohorska 24

Prague 6, 16900, Czech Republic

<https://www.orea.cz/en/hotel-pyramida>

How to reach the Congress Venue



From Václav Havel Airport Prague (13 km)

The Airport is only a 25-minute taxi ride away from the venue.

Otherwise, it's possible to:

- Take Bus 191 from the airport to Vypich (end station). At Vypich, transfer to Tram 22 heading towards Nádraží Hostivař. Get off at the Malovanka tram stop. The OREA Hotel Pyramida is a short 3-minute walk from the Malovanka tram stop (total expected time: 44 minutes)



From Prague Main Railway Station–Praha Hlavní Nádraží (7 km)

If you are going to depart from the central railway station, it's possible to:

- Take a Taxi (total expected time: 20 minutes)
- From the railway station, take Metro Line C (Red Line) towards Háje. Get off at the Muzeum stop (1 stop). At Muzeum, switch to Metro Line A (Green Line) towards Nemocnice Motol. Get off at the Malostranská stop (3 stops). Exit the metro station and transfer to Tram 22 heading towards Bílá Hora. Get off at the Malovanka tram stop. The OREA Hotel Pyramida is a short 2-minute walk from the Malovanka stop (total expected time: 30 minutes)

From Praguedowntown (6 km)

- Take a Taxi (total expected time: 15 minutes)
- From central areas like Wenceslas Square (Václavské náměstí) or Old Town (Staroměstská), locate the nearest tram stop. Take Tram 22 heading towards Bílá Hora. Get off at the Malovanka tram stop. The OREA Hotel Pyramida is a short 2-minute walk from the Malovanka tram stop (total expected time: 15-20 minutes)
- By Walking (if near Prague Castle): from Prague Castle or nearby areas, walk to the congress venue via Loretánská Street and continue along Belohorská Street. The OREA Hotel Pyramida will be on your left (total expected time: 25-30 minutes on foot)

Secretariat and Registration Desk

The on-site registration desks will be open during the following days:

- Wednesday April 9th 2025 12:30 – 18:30
- Thursday April 10th 2025 07:45 – 18:00
- Friday April 11th 2025 07:45 – 14:00

Admission

Participants are kindly requested to wear their badge during all congress activities. The badge will admit to the scientific sessions, exhibition area, coffee breaks and lunches.

Language

The official language is English. No simultaneous translation will be provided.

Attendance Certificates

You will be able to download and print your Certificate of Attendance upon completion of the online evaluation form you will receive by email at the end of the Congress.

Accommodation

A large number of rooms at preferential rates have been reserved at **Orea Pyramida Hotel Praha**, which is also the venue of the congress.

OREA Hotel Pyramida Praha is set within a 10-minute walk from Prague Castle. The city center is 15 minutes away by public transport and 15-minute drive from the airport.

Hotel reservation is possible during the registration process.

Visa Requirements

All non-Czechs nationals entering Czech Republic must provide valid travel documentation. Delegates who hold neither an EU passport nor a Schengen visa should check as soon as possible the Czech Republic Ministry of Foreign Affairs' website to see if they require a visa to enter the Czech Republic.

Visa regulations depend on your nationality and country of origin. For the most updated information regarding visa requirements, we do suggest you contact your local consulate for full and official instructions on the specific visa regulations and application procedures that apply to you.

If a visa is required, delegates should apply to the Czechs Diplomatic and Consular Representations in their country of residence with the documents outlined on the Ministry of Foreign Affairs' website. Invitation letters to the conference may be downloaded online at registration area of our website.

 Please Note: Visa applications may take several months. Please check this now.

Visa application fees vary. Please contact the embassy or consulate in order to enquire about costs.

Presentation of the requested documentation does not guarantee that the visa will be issued.

AIM Group will be glad to assist you if you need any other written invitation or other document to support your visa application at the following e-mail address: visa@aimgroup.eu

Invitation Letter

The Official Invitation letter to be included in your application to enter Czech Republic can be downloaded from the web site. If you did not submit your personal data yet, click on "First time user" and fill in the submission form.

Once you finish to fill in the personal data form, click on "Invitation Letter (VISA)" on the left side menu. If you already submitted your personal data, log in (using your User ID and Password) and click on "Edit your personal data" to insert the passport details, at the end click on "Invitation Letter (VISA)" from the left side menu.

The Invitation Letter will not be legally or financially binding on the Organizing Secretariat. Expenses related to the conference shall be borne by delegates themselves.

Registrations (All fees are 21% VAT included)

	within March 25 th 2025	from March 26 th 2025 and onsite
Delegate member ERN*	€ 250,00	
Delegate NON member ERN	€ 400,00	€ 450,00
Students/Trainees**	€ 200,00	€ 250,00
Healthcare professional***	€ 150,00	
Patients****	€ 50,00	

* In order to benefit from the special fee, a submission of your status confirmation must be uploaded online during the registration process (i.e. approval letter signed by the Head of Department or copy of your status ID).

** Nurses, physiotherapists, occupational therapists and other nearby allied health professionals. A letter of confirmation of your status from the Head of Unit or Institute must accompany and uploaded in the online registration.

*** Patients registering at this fee must upload a proof of their status declaration by a doctor or a proof of their membership of a Patient Association during the registration process. If no certificate is being uploaded, the registration process cannot be completed.

Online Services will close on: March 2025

During the registration process you will also have the opportunity to make a Hotel reservation

The delegate fee includes:

- Admission to the scientific sessions
- Congress bag holding all the meeting materials
- Certificate of attendance
- Access to the poster area
- Coffee breaks and lunches, according to the programme

Payment

All major credit cards are accepted (VISA, Mastercard/Eurocard, American Express).

If you decide to pay by bank transfer, please remind to clearly state the name(s) of the delegate(s) and of the event "ERN ReConnet 2025".

Registration will be considered confirmed when the payment is received. An invoice will follow.

Name Changes

After March 15th 2025 sponsors who wish to make name changes will be charged of an handling fee of € 50,00 (VAT 21% included) per name change. A new registration form for each replacement participant will be required before the name change can be processed. Individuals may make name changes only in exceptional cases.

Cancellation Policy

Notification of cancellation must be sent in writing to
AIM GROUP INTERNATIONAL (ern.reconnetcongress@aimgroup.eu).

Cancellations will be accepted until March 15th 2025 with a refund of all prepaid fees except for a 30% administration charge. No refunds will be made for cancellations received after this date.

Scientific Secretariat

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