

Formal invitation to the 2nd European Charcot-Marie-Tooth Specialists Conference Antwerp – Belgium, October 23-25, 2025

Dear Colleague,

On behalf and in the name of the European CMT Federation (ECMTF), the University of Antwerp (UAntwerp) and the European CMT Research Association (ECRA) I have the pleasure to formally invite you to the 2nd European Charcot-Marie-Tooth Specialists Conference to be held in Antwerp, Belgium, October 23-25, 2025.

As you can see from the **preliminary draft program** (annexed) we aim to bring together scientists, clinicians, and other health professionals specialized in inherited neuromuscular diseases (iNMD) and, in particular, in CMT on the one side, and representatives of patient organisations, pharmaceutical industries and health politics, on the other side, to join their efforts and give CMT research a strong new impetus. In accordance with the conditions set for EU funding and the terms of our proposal under the EU4Health program we focus not only on a discussion of most recent achievements and new ideas in CMT research, but we also wish, as a result of the conference, to present practical “deliveries” such as

- Recommendations for (new) clinical outcome measures,
- Guidelines for physiotherapy in neuromuscular diseases,
- A model interdisciplinary joint project, e.g. on diagnostics,
- An outline for a European/global data sharing framework
- An outline for an online training seminar on iNMD and, in particular, CMT.

1. Call for abstracts

We herewith warmly invite you to submit abstracts for presentations (10 min.) or posters (format A1), and for joint projects to be presented and discussed during the conference. Please use the official abstract-forms that will be available on the [Conference Website](#) by the end of June and submit your abstract electronically through this tool **not later than 1st August 2025**.

The ECRA Scientific Council will select the presentations, posters and projects for the conference, and inform you about the decisions taken by 15th August 2025.

Abstracts will be published on the Conference website and made available to all participants with the abstract-book distributed at the Conference. Abstracts for projects will not be published except in case the author(s) expressly so wish.

2. Final program and Registration for the Conference

The **final program** of the conference will be established on the basis of the abstracts submitted to us (supra 1.) and will be circulated among all pre-registered and other potential participants by August 20, 2025.

Formal registration for participating at the conference is open from 1st July 2025; we kindly ask you to use the electronic registration tool than available at the [Conference Website](#). You will find another tool for the payment of your registration fee at this same place.

The **registration fee** is €200,- for each participant, a reduced fee of €100,- applies to students and postdocs. Members of ECRA benefit of a rebate equal to their membership fee already paid for 2025.

Given the limited size of the available rooms, we are bound to limit the number of participants to a maximum of 180. Priority will be given to

1. Participants having submitted an abstract or project and were selected for presenting at the conference,
2. ECRA members and representatives of patient advocacy groups members of ECMTF,
3. interested scientists who have not submitted an abstract, or whose abstracts were not accepted (with a quota of 50% for “next generation” researchers: students and postdocs).

Registrations become valid only after confirmation and upon payment of the registration fee. There will be no refund of the registration fee after your registration is confirmed.

The **deadline for registration** is 15th September 2025. Please understand that we cannot accept any registration after this date, except for very extraordinary circumstances.

Note: We will take pictures and also provide for a live-stream and video-takes published on YouTube of selected sessions of the conference. With your registration we assume that you agree with your picture to be published through social media, journals etc., unless you have expressed your disagreement in a written note to the organisers.

3. Poster Contest

A **poster contest** is arranged for all posters presented at the conference, with the award for the best posters (selected by the ECRA Scientific Committee):

- €500,- for the first price
- €300,- for the second price
- €100,- for the third price

A special **poster award ceremony** is on the program for giving the winners an opportunity to present their work and be honoured by the president of the Scientific Committee.

4. Special arrangements and benefits

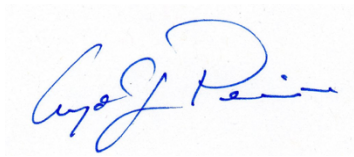
In case we obtain the funding for the conference requested under the EU4Health Program we can offer each active participant a lump sum of €200,- as a **refund for accommodation expenses**. Speakers, presenters, poster-

givers, project-teams selected, and members of the orga-team are considered “active” participants. This refund would be paid after the conference upon request and presentation of the hotel-receipt.

Under the same condition (written request and proving document) we offer “**young researcher fellowships**” of up to €250,- to cover travelling costs for students or postdocs selected and invited to give a talk, to present a poster or to participate at a joint project discussed at the conference.

We are thrilled to welcoming you this October 23-25 in Antwerp !

In the name also of Vincent Timmerman and Filippo Genovese
with all kind regards

A handwritten signature in blue ink, appearing to read 'Ingolf Pernice', is shown on a light-colored background.

Ingolf Pernice

Annexed: Preliminary draft program (annotated)



Preliminary Draft Program

2nd European CMT Specialist Conference

The European CMT Federation (ECMTF), the European CMT Research Association (ECRA) and the University of Antwerp (UAntwerp) plan the 2nd European CMT Specialist Conference to take place in Antwerp, Belgium from Thursday 23 to Saturday 25 October 2025.

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History in brief

The European Charcot-Marie-Tooth (CMT) Consortium was founded more than 30 years ago, when the major CMT neuropathy causing mutation, the CMT1A duplication on chromosome 17, was discovered. The CMT consortium was partly funded through an EU-BIOMED2 project which allowed it to bring together CMT researchers from Europe, the Middle East and North Africa. From 1991 to 2001, 5 conferences were held in Antwerp – Belgium (always in the Congres Hotel Ter Elst in Edegem). Afterwards, a conference was organized every two years, alternating with the North American CMT Consortium, allowing colleagues from different continents to attend. Both consortia grew into the International CMT Consortium. The number of participants steadily increased and reaching almost 200. During these conferences we strived to cover all aspects of CMT research; molecular genetics, neurobiology, clinical neurology, neurophysiology, neuropathology, cell and animal models and therapeutic approaches. All participants were eligible for oral or poster presentation, and priority was given to young researchers and physicians. The aim was to exchange new research results (before publication) and to strengthen collaboration between research groups. The scientific program (two and a half days) provided sufficient time for discussion after each presentation, extensive poster sessions and discussions during the breaks.

The 5th International CMT Congress of 2013 became a satellite meeting of the biennial meeting of the Peripheral Nerve Society (PNS in Saint-Malo, France). The dates of both meetings were aligned to allow participants to reduce their travel costs. Abstracts were published in The Journal of the Peripheral

Nervous System (JPNS is the official journal of the PNS). Because of organizational reasons, the next biennial International CMT consortia meetings were integrated as a special interest group, the CMTR (CMT and related neuropathies), within the Peripheral Nerve Society.

*Given the rapid developments in the CMT research field, the **2025 second European CMT Specialist Conference** in Antwerp will follow the needs formulated during the European CMT Federation's 1st European CMT Specialist Conference held in Paris in 2023, and by the recently created ECRA foundation. With the 2025 conference, we aim to boost structured interdisciplinary research cooperation, including patient advocacy groups and industry, and to organize networking towards EU funding opportunities through joint projects, rather than competing with the CMTR special interest group within the Peripheral Nerve Society, to where most participants adhere already.*

Summary (from the Grant Proposal to EU4H)

In response to the objectives set out in EU Regulation 2021/522 we propose a conference to boost biomedical research and to improve the efficiency of the European health care system(s) and address critical unmet needs in the field of inherited neuromuscular diseases (iNMDs). Building on the success of the EJPRD-funded 1st European CMT Specialists Conference 2023, we leverage the diverse group of Charcot-Marie-Tooth (CMT) diseases as a model to create an urgently needed forum for EU-wide coordination to confront key roadblocks shared across the iNMD field, and rare genetic diseases in general. Our non-profit, Union-wide conference will complement the existing portfolio of national and international conferences dedicated to specific scientific, medical or patient communities, by assembling key stakeholders across disciplines: scientists, clinicians and other health professionals together with representatives of European patient organizations, pharmaceutical industries and policymakers. Recent progress in diagnostics, therapies, and outcome assessment will be contextualized within the unique practical challenges relating to rare diseases: lack of knowledge and awareness, difficulty for patients to find a specialist within a reasonable distance, fragmentation and inaccessibility of relevant data for researchers, industry's reluctance to invest in research etc. We will disseminate information and foster education, develop new ideas for digital care, discuss models for data-sharing in line with GDPR and the EHDS, explore applications of AI in diagnostics and invite industry to participate in collaborative projects that will pave the way for new medicines. Targeted public outreach in the run-up to the conference, live streaming and social media activities during the conference and comprehensive Europe-wide reporting in the follow-up phase will put our proposals, guidelines and recommendations up for public debate. Sustainability and the further development of the outcomes will be ensured by the newly founded ECRA.

Draft Program

Thursday 23/10/25

13.30-14:45 ECRA Task force (provisional board, open ended) meets for organizational matters including action program (2025-2030)

This meeting aims at preparing the General Assembly. The agenda will be adopted and sent to all the members of ECRA together with the invitation to the GA latest August 15, 2025. Upon the basis of documents and drafts worked out by the ECRA task force beforehand, here we have to

- finalize the agenda of the GA to be adopted as first point of the GA;
- find candidates for the offices – president, vice-president, treasurer, secretary and other board-members;
- decide upon the establishment of committees (financial committee?)
- prepare the discussion of the action program of ECRA for the coming 5 years.

Coffee break

15:25-16:45 ECRA General Assembly

Election of the board members, including the president, vice-president, treasurer, secretary. Amendment of the Articles of Association (as requested by the tax authorities), Establishment of committees. Adoption of the first 5-years Action program. Intermediary (ENMC) Workshops / Webinars? Date for next GA / conference 2027 etc.

17:00-19.00 Opening ceremony and opening lectures (Vincent Timmerman / Ingolf Pernice, EU Commissioner, policy makers from all levels)

Vincent Timmerman is the host and will welcome the speakers of this ceremony (policy-makers) and all other the participants of the conference. This is for explaining the objectives of the conference and inviting the policy-makers to share their view on European health-policy priorities and expectations for this conference.

Ingolf Pernice will express our thanks, also to the sponsors, and give a short overview on the concept and the more technical/organization matters of the event.

Friday 24/10/2025

9.00 – 10:30 1st plenary oral presentations (intro talk with discussion 30 min, than 5x10 min oral presentations with discussion, 10 min buffer): Basic sciences and the many faces of CMT

Chair: Mary Reilly with Arabela Acalinei

Speaker: Tanya Stojkovic / Maike Dohrn

Objectives:

- Setting the stage – Understand better CMT with its many subtypes as one of the most frequent iNMDs and give an overview on new therapeutic approaches.
- Raise awareness, encourage commitment among the medical profession and the patients to partner,
- prepare material for integrating iNMDs and, in particular, CMT in medical training programs, and for specialized online seminars.

Tasks and deliverables:

- Present and explain recent achievements and new challenges in iNMD research – and the role of the patients in the research process –
- Discuss symptoms and methods of diagnosis, natural history, and socio-economic impact of various iNMDs –
- Prepare **recommendations** for integrating iNMDs into medical training programs and develop an outline for a new **online training program / seminar on iNMDs**.

10:30 – 11:00 Coffee Break

11:00 – 12:30 2nd plenary oral presentations (same form): Methods: diagnostics / genetics of CMT neuropathies

Chair: Francesc Palau with Tim Vangansewinkel

Speaker: Angelo Schenone / Jonathan Baets

Objectives:

- Assess perspectives and new approaches for rapid and reliable diagnosis iNMDs, also as an input for medical training program
- Increase engagement of pharmaceutical companies for research in diagnostics and drug development

Tasks and deliverables:

- Identify methods, e.g. genetic sequencing, histopathological studies, electrophysiological analysis, cell and tissue models, etc., to determine causes and diagnose of various inherited neuromuscular diseases
- Perspectives and conditions for the use of AI in diagnostics, the identification of biomarkers, the prediction of long-term disease progression, the accurate subtype classification, etc. (deliverable: report)
- Model and incentives for active cooperation of multiple research partners including patients and scientists from pharmaceutical industry, for developing new methods in diagnostics and therapy (deliverable: joint research project)

13:00 – 14:30 Light Lunch + Poster session 1

14:30 – 16:00 3rd plenary oral presentations (same form): genetic and other therapeutic approaches on CMT neuropathies

Chair: Angelo Schenone with Helena Pernice

Speaker: Kleopas Kleopa

Objectives:

- New therapeutic approaches and drug development for inherited neuromuscular diseases, and the specific roles of the patients (as partners) and of industrial partners in the R&D process
- Value patients' and physiotherapists' possible contribution to the R&D processes in iNMDs.

Tasks and deliverables:

- Review and evaluate current preclinical tools and strategies for the development of new therapeutic approaches – assess the possible value of a partnership with the pharmaceutical industry (deliverable: model joint project)
- Analyse physiotherapy and the role of patients in terms of active participation and outcome assessment, including avenues towards streamlined collection of data, anonymized in conformity with GDPR (deliverable: **guidelines for therapists and patients**)
- Assess perspectives and risks of genetic engineering methods – possible combination with current and new alternative therapeutic approaches – assess potentials raised by inclusion of patients as partners (deliverable: **critical report/overview**)

16:00 – 16:30 Coffee Break

16:30 – 18:00 Fishbowl „idea workshops“ – presentation, discussion and organizing joint projects and initiatives (15min p/p)

Chair: Vincent Timmerman with Ingolf Pernice

Objective:

- Interdisciplinary research groups with participation of industry-scientists present their joint project and receive constructive critique and valuable input from among the audience with a view to participate in the ECRA mentoring and support scheme for grant applications.

Task and deliverables:

- Confirm at least **two joint projects** to become the flagships of ECRA medium term support

19:00 – 22:00 “Gala”-Dinner Zaal HORTA („thematic” tables is an option)

Saturday 25/20/2025

08:30 – 10:00 4th plenary oral presentation (same form): Patient registers and data sharing in the European Health Data Space

Chair: Jonathan Baets with Filippo Genovese

Speaker: Wolfgang M. Pernice

Objectives:

- Progress towards an interoperable system of patient registries and health databases allowing the application of AI for diagnostics and therapy-options
- Ensure researchers’ free and easy access to health data relevant to their specific research projects on iNMDs

Task and deliverables:

- Identify key pain points in current data sharing practices and develop solutions for a framework GDPR and EHDS-compliant, pan-European interoperable **system of data sharing** as a basis for the application of AI in CMT diagnostics
- Elaborate a strategy for a European data sharing scheme for iNMDs (deliverable: outline)

10:00 – 10:30 Coffee Break

10:30 – 12:00 5th plenary oral presentation (same form): Clinical Outcome Measures / Clinical Trials of CMT neuropathies

Chair: Maike Dohrn with Alexandre Hoyau

Speaker: Davide Pareyson

Objectives:

- Understand the state of the art and offer new methods including the use of AI for reliable outcome assessment of possible benefits of therapies for iNMDs and CMT in particular
- Harmonization: Perspectives, benefits and risks of standardization of outcome assessment.

Tasks and deliverables:

- Assessment of current methods employed to measure efficacy and benefits of treatments, and approaches (deliverable: **Valuating reliable COA for therapies, research and drug development**)
- Identification of conditions for common global standards for clinical outcome measures (deliverable: **report**)
- New approaches, including AI, for assessing therapeutic intervention efficacy (**report**)

12:00 – 13:00 Light Lunch + Poster session 2

13:00 – 14:30 Open session (10 min talk, 20 min discussion): Physiotherapy / digital care / patients as partners

Chair: Maïke Dohrn

Speaker: Gita Ramdharry / Helena Pernice / Katherine Forsey

Objectives:

- Present and discuss some essential aspects of physiotherapy for patients with neuromuscular conditions and, in particular, CMT, including new developments
- Develop tools of telemedicine to boost effective cooperative treatment, research and development
- Mobilize and change the role of patients: Direct involvement and equitable inclusion of patients as active partners in clinical practice and throughout the entire research and development processes related to diagnostics and therapies

Tasks and deliverables:

- Conceptualizing “patients as partners”
- Strategy and **recommendations** for the active involvement and participation of patients in iNMD therapy and R&D processes (deliverable: **action plan**)
- Telemedicine in iNMD: Digital care and other aspects of telemedicine to provide for direct communication between patients and specialists - challenges and opportunities (deliverable: **telemedicine guidelines for a digital care strategy**)

14:30 – 15:00 Filippo Genovese: Posters Award ceremony – awards

Based upon the presentations at the poster sessions a jury (members of the ECRA scientific council) will select the winner(s) of the 2025 poster contest. **With a short laudatio pronounced by the president of the jury the award will be bestowed by the president of the ECMTF.**

15:00 – 16:00 Mary Reilly: Concluding Remarks – further work of ECRA

16:00 Good bye with small reception

(drafting groups for guidelines, strategies, recommendations etc. will meet in parallel to poster sessions, and as far as needed, also after the conclusion of the conference)
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