PRESS RELEASE:

Uniting for Health

We have the pleasure to announce the **2nd European Charcot-Marie-Tooth Specialists Conference**, Antwerp, Belgium, from October 23 to 25, 2025.

This conference is a common project of the European CMT Federation (ECMTF), the University of Antwerp as the host, and the European CMT Research Association (ECRA) that was created as a follow-up of the 1st European Charcot-Marie-Tooth Specialists Conference 2023 in Paris (Paris Conference) with the aim to stimulate cooperative research on CMT.

The draft program and detailed information on registration, the venue, accommodation and abstract submission can be found on the Conference-website:

https://www.uantwerpen.be/en/conferences/2nd-european-cmt-specialist-conference/.

The website will regularly be updated. Our ambition is to share, discuss and build upon achievements in science and discuss new projects in the field of inherited neuromuscular diseases, in particular CMT, but also to produce concrete deliverables. Members of the ECRA Scientific Council and other experts will chair and introduce each plenary session.

The final program and abstracts as well as recent **topical publications** related to the subject of each session will be published on the Conference website.

Select talks and presentations will be open to the public through a **life-stream. Video-takes and a photo-documentation** will be made available on our websites for those who wish to see them in the future.

For any further information not found on our conference-website please send an email to conference@ecra-np.org. We will try to answer instantly.

Filippo Genovese Vincent Timmerman Ingolf Pernice

Background Information

CMT, also known as HMSN, is a hereditary, slowly progressive peripheral neuromuscular disease that often manifests already in childhood. The common clinical features are progressive muscle wasting and weakness together with sensory loss starting in the feet and progressing more proximally including to the hands. Foot deformity is common. The gait becomes clumsy, and twisting an ankle and stumbling are typical even in children and adolescents. Muscle pain, fatigue and increasing loss of mobility are common – and over time, the need for walking aids, walkers, and sometimes wheelchairs follow. Many doctors are not familiar with the disease, its typical symptoms and neurological signs which can lead to a delay in diagnosis.There is still no effective therapy for CMT but there are many research efforts ongoing. However, obstacles to developing therapies include a lack of awareness of the disease, a lack of financial support, the low profitability prospects for industry and the unavailability of sufficient data for researchers. This is typical for the approximately 8000 other rare diseases.

Due to the relatively low number of patients with CMT, meaningful research requires cooperation across national borders. European-wide, even global networking and collaboration are imperative. Thus, cross-border research groups have been formed to enable projects and later publications on specific aspects. Among the EU-funded European Reference Networks (ERN) there is the network for neuromuscular diseases (EURO-NMD), to which CMT is assigned. The ERNs aim to bring together highly specialised hospitals and reference centres to provide experts with a forum for exchanging experiences and advice on diagnosis and the best available treatment. Specialists in CMT also meet at the annual conferences of the International Peripheral Nerve Society (PNS) in a specialised working group, the CMT and Related Neuropathies Consortium (CMTR), to discuss the latest research highlights. All of this facilitates the scientists to find collaborative partners for their research interests. Many important steps in research have already been made possible in this way. Yet, there is still no cure for any of the many variants of CMT.

The European patient advocacy groups, jointly organised in the ECMTF, have therefore taken a new initiative which has been well received by many people working in research and clinical practice, as well as in industry and politics. By institutionalising cooperation in the form of a European CMT Research Association (ECRA) the interests of researchers can be combined, and joint research projects can more easily be organised, mentored and supported. This includes assistance in applying for research funding, so that young talent can be integrated in the field of CMT and relevant companies will be engaged in the development of innovative therapies.

ECRA was founded in particular to provide a multi-stakeholder forum and support structure for developing interdisciplinary cooperation and joint projects in close partnership with patient organisations and industry. Accordingly, the goals of ECRA include:

- pooling the expertise of highly motivated researchers through forums and forms of structured interdisciplinary cooperation and promoting young scientists,
- mobilising ‘patients as partners’, from local support to active collaboration with researchers,

in order to

- put the care of those affected on a new footing

- ensure better access for researchers to patient data through an interoperable system of patient registries and data in the European Health Data Space (EHDS),
- strengthen research funding through close cooperation with industry.

The Antwerp Conference also offers ECRA an opportunity to celebrate its own inauguration, have its first General Meeting and start its operational work. One of its first tasks will be to ensure the implementation of the decisions taken at the Conference.
