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Medical training program CMT - recommendations and outline for online seminars

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CMT is a rare disease and often not or poorly treated in medical school training programs throughout Europe. Physicians and therapists - with the exception of a few specialists in each country - as well as the general public are rarely aware of the mere existence of CMT, let alone of the causes, the symptoms and approaches of treatment. Patients have often to wait many years until they get a diagnosis and appropriate treatment. Given this untenable situation and the high socio-economic costs of the disease, patient organizations have for many years organized “awareness campaigns” on CMT. Yet, further measures are needed to improve existing information deficits. The problem has been raised and discussed at the 2nd European CMT Specialists Conference, October 2025 in Antwerp.

Our following recommendations and an outline for CMT online seminars are based upon the materials and literature listed below.

Recommendations:

- A. Rare diseases, and inherited neuromuscular diseases (iNMD's) like CMT, in particular, should become part of the medical school training programs provided for students and in the continuing education of practicing doctors and other therapists.
- B. The general topics listed below should be dealt with in medical training programs, and a certain degree of knowledge on iNMD's and their symptoms should generally be required for health professionals.

- C. Existing online materials and information for healthcare professionals, such as listed below, are valuable sources for not only establishing specialized training programs in iNMD's but also for continuing education including online seminars.

Outline for CMT online seminars

Online seminars on CMT can become important tools for spreading information on CMT not only among healthcare professionals but also for patient organizations in their daily work and for the broader public, and for policy-makers. Many of the webinars listed below already provide an excellent introduction into the relevant aspects of CMT and other iNMD's, as well as information about new developments in CMT research and the development of the different therapeutical approaches. In parallel to the preparation of the Antwerp Conference, leading experts, members of ECRA, have written a highly topical overview of CMT and related neuropathies (Burns J et al 2026). Together with all the other articles listed, interested readers find here all the relevant information on CMT and the state of research in the field.

More than for teaching in medical schools, a didactical preparation of the materials is necessary for an online seminar. Graphical representations, images and short videos from clinical practice, showing typical deformities of the feet and hands of those affected, as well as movement patterns of the respective forms of CMT, are just as important materials as video-records of patients' reports about their experiences with the respective disease.

Online courses offer the special opportunity of including visual materials. They open up the possibility of documenting the practical course of a neurological examination of CMT patients, for example, or demonstrating important physiotherapy exercises, the correct use of aids, or even foot operations and their effects.

The General Topics listed below are a guideline also for the establishment of CMT online courses. Each of the listed paragraphs could become the subject of one or more sessions. A list of questions at the end of each session to be answered by the participants until the following session and shortly be discussed at its beginning, would significantly increase the learning effect.

General Topics

1. What is CMT (history, causes, symptoms, prevalence, different types and subtypes, typical natural history, pathomechanisms, socio-economic costs)
2. Diagnostics: Medical history of the patient, family history, neurological examination, nerve conduction studies, genetic testing including diagnostic techniques and interpretation of genetic results; ancillary investigations, differential diagnosis.
3. Approaches, progress and perspectives of research on pathomechanisms, preclinical models, development and testing of disease modifying therapies, including genetic therapy

4. General management and care, including symptomatic treatment, aids and orthotics, surgical treatment, rehabilitation therapy, psychological care, self-help groups.
5. Outcome measures, biomarkers, tools to monitor disease course and response to treatment (observational studies and interventional clinical trials)
6. CMT and health policies: Specific challenges for research and treatment of rare diseases, raising awareness, "patients as partners".

Sources / information for healthcare professionals and patients:

- European Reference Network (EURO-NMD ERN and ERN-RND) and European Academy of Neurology (EAN) Webinars series: : Peripheral Nerve Diseases - Charcot-Marie-Tooth Disease (CMT (January 2026)
EURO-NMD Webinar Series
<https://ern-euro-nmd.eu/event/cmt-episode-1-challenges-in-the-diagnosis-and-treatment-of-inherited-neuropathies/>
<https://ern-euro-nmd.eu/event/cmt-episode-2-progress-in-genetic-diagnosis-for-neuropathies/>
<https://ern-euro-nmd.eu/event/cmt-episode-3-bioarkers-and-outcome-measures-for-clinical-trial-readiness-in-charcot-marie-tooth-disease-cmt/>
<https://ern-euro-nmd.eu/event/cmt-episode-4-current-progress-in-charcot-marie-tooth-disease-cmt-treatments/>
- Webinar series (May-November 2025) organised by ECRA in preparation for the 2nd European CMT Specialist Conference in Antwerp (October 2025)
<https://ecmtf.org/events/second-european-charcot-marie-tooth-specialists-conference/#:~:text=Program%20and%20Information-,Webinar%20Series,-In%20preparation%20for>
- European Reference Network (ERN) and European Academy of Neurology (EAN) Webinars series on CMT (October 2023)
<https://ern-euro-nmd.eu/event/pathomechanisms-of-charcot-marie-tooth-disease/>
<https://ern-euro-nmd.eu/event/diagnosis-of-charcot-marie-tooth-disease/>
<https://ern-euro-nmd.eu/event/treatment-of-charcot-marie-tooth-disease/>
<https://ern-euro-nmd.eu/event/gene-therapy/>
- Charcot Marie Tooth Association (CMTA) webinar series
<https://cmtausa.org/webinar-recordings/>
- European CMT Federation (ECMF) webinar series 2024
https://www.youtube.com/playlist?list=PLwfAhL-RrrV73GsBYV2w4l9RA_32yMSOZF
- Muscular Dystrophy Association (MDA) Virtual learning (March 2024)
Virtual Learning: Updates in Research and Clinical Care for CMT

<https://www.mda.org/care/community-ed/mda-virtual-learning/2024/mda-virtual-learning-updates-in-research-and-clinical-care-for-cmt>

- Peripheral Nerve Society (PNS) / CMTR Consortium
CMTR patient resources <https://pnsociety.com/special-interest-groups/cmtr/cmtr-patient-resources/>

Publications:

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