



## Associazione Nazionale ACMT-RETE per la malattia di Charcot Marie Tooth

**ACMT-Rete** is an Italian National Non-Profit Organization of Social Utility for purposes of assistance and self-help among Charcot-Marie-Tooth patients and their families.

Too many people with CMT have not been diagnosed yet, and there are no cures. Those who suddenly found themselves hit by Charcot Marie Tooth are forced into a path full of uncertainties and suffering, even worsened by the precariousness of medical and scientific information, although CMT is one of the most common peripheral neuropathies in the world. Early diagnosis and preventive measures are the only weapons to fight against disease progression.

Since 2001, thanks to high-level professionals offering their support and collaboration and to our association, awareness on CMT has progressively grown and many ambitious research projects and treatment protocols are spreading, making us look at the future with a positive attitude.



### GOALS:

- Stimulate **research** in order to increase the skills and knowledge related to the treatment of CMT disease and similar syndromes;
- Encourage the creation of **centers of excellence** for the diagnosis and treatment which can work in partnership with one another;
- Promote the **meeting and exchange of information and experience** among people affected by Charcot Marie Tooth disease and their families through the media and moments of socialization;
- Be point of **information** concerning trusted medical centers and professionals, legal aspects regarding disabled people;
- Cooperate with other associations in order to improve the patients' **quality of life**;
- Provide **support** and up-to-date information through our portal, [www.acmt-rete.it](http://www.acmt-rete.it).

### AIMS:

- Promote research and training of specialized professionals in collaboration with physicians, institutions, associations and organizations;
- Encourage the creation of a network of physicians, researchers and other professionals orbiting around peripheral neuropathies;
- Facilitate and contribute to the realization of centers and specialist teams;
- Listen at the patients' needs and their families' and give them information;
- Mediate medical advice services provided by a team of selected specialists via the Internet in the "Medcenter" section of our website;
- Raise funds to finance the activities of the association and research, even with unconventional but brilliant initiatives like creating jewelry and accessories from our hated buttons.

### ON-GOING PROJECTS AND ACHIEVEMENTS:

- **"Reality-like" short movie** with a group of patients as actors and a set of interviews with a neurologist, a surgeon and a physiatrist describing to their colleagues and patients what the C.M.T. syndrome is and how it should be faced. The DVD has been distributed to all the diagnostic centers and health structures throughout Italy;
- An **advertisement** of our Association and CMT involving a famous Italian comic actor has been broadcasted over national television networks. A second ad with a well-known Italian singer has been filmed and will be soon broadcasted;
- **Training course meant for physical therapists** focused on the rehabilitation of CMT patients was held in five different locations spread all over the national territory;
- A **high-level Medical Congress** involving the best professionals orbiting around CMT is organized biennially;
- **Self-help meetings** involving all the association members who wish to participate take place every two years; moral support and advice are also provided on multimedia platforms (forums, Facebook, email) and over the phone by properly trained personnel;
- Organization of a meeting involving around 40 professionals among Italian neurologists, physiatrists and surgeons to reach a **consensus on a unique set of criteria and a common protocol for evaluating CMT patients**;
- Contribution to the creation of a **National registry of patients with CMT** which could be used for future clinical trials and research;
- Collaboration with **Telethon**, the biggest Italian association promoting and funding research in the field of neurological disorders;
- An innovative **post-surgery rehabilitation protocol**, which has been designed to get the most out of surgical interventions, is currently under evaluation;
- **Research Fellowships** in the field of CMT have been funded.

**We gratefully thank all our collaborators  
and supporters for giving us CMTERS hope for a better tomorrow.**

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