



Charcot-Marie-Tooth Awareness campaign during October Month

The European CMT Federation (or ECMTF) is launching its 4th campaign to raise awareness about the Charcot-Marie-Tooth group of diseases: the most common of rare diseases. It will run in October 2020 in 7 European countries, and it aims to make the general public and health professionals more aware of the pathologies and symptoms. This campaign aims to improve screening and limit diagnosis errors to get the best possible care as early as possible ...

A rare disease ... yet common

Charcot-Marie-Tooth disease (CMT), named after the three doctors who first described it, is a rare and little-known neuropathy.

The number of sufferers in Europe is estimated to be around 300,000 people, which makes CMT the most common of rare diseases!

CMT is a genetic disorder that affects the peripheral nerves linking the spinal cord to the muscles and the sensory organs, transmitting messages from the brain to the limbs. These signals involve motor abilities, affecting movement, and sensory faculties, affecting the sense of touch or feeling pain. The combination of these messages also helps in maintaining balance.

Charcot-Marie-Tooth disease affects 1 in 1,220 – 2,500 people

A disease which "is unknown and ignored"

The disease develops slowly and has many repercussions: progressive deformity of the feet and the hands (foot drop, claw toes, wasting muscles in the calves, forearms, and hands), problems with balance, sensitivity issues, tiredness, pains, cramps, etc. and the quality of life for Charcot-Marie-Tooth sufferers deteriorates.

CMT is often spoken of as an "invisible handicap" because the difficulties are usually not readily visible or underestimated. The number and the severity of the symptoms are also extremely varied from one patient to another. Understanding CMT is also made more difficult for family and friends, as well as for health professionals involved in the diagnosis.

A communication campaign to get the Charcot-Marie-Tooth disease known and recognised.

The 4th campaign by the European CMT Federation begins on the 1st of October in 7 European countries: United Kingdom, France, Belgium, the Netherlands, Italy, Spain, and Germany. There are two visuals, one for the general public and one aimed at health professionals who will back up the awareness campaign around Charcot Marie Tooth diseases. There will be a poster campaign in the London Tube and the Paris Metro, and displays on Milan's bus shelters. In each country, there will be a digital campaign aimed at doctors and podiatrists on LinkedIn and in the specialised press, which will last for about three months.

France and Italy will have the support of expert ambassadors: Professor Philippe Denormandie, Orthopedic surgeon at Raymond Poincaré Hospital, Garches, France and Dr. Francesco Ferraro, Head of Neuromotory Rehabilitation Facility, Bozzolo (MN), Italy.

CMT sufferers: expert patients

"We can rely on the patient's intelligence: sharing and listening better to know how they feel, to understand their suffering better. It's up to us to get closer to the patient, to make better decisions together, to help them,

guide them and offer suitable treatments."

"To influence outcomes and beat the disease, we must keep on asking questions, treat the symptoms and try to understand the causes"

P^r Philippe Denormandie, ambassador for the 4th European CMT Federation awareness campaign, Orthopedic surgeon at Raymond Poincaré Hospital, Garches, France.

Treatment of Charcot-Marie-Tooth: a Multidisciplinary Challenge

"It is necessary to overcome the concept that since there is not a causal cure yet, there are no solutions to CMT patients' problems: people have a potential which is sometimes unexpressed."

Dr. Francesco Ferraro, ambassador for the 4th European CMT Federation awareness campaign, Psychiatrist, Head of Neuromotory Rehabilitation Facility, Bozzolo (MN), Italy.



The European CMT Federation, the campaign organizer

The ECMTF is a consortium of 15 patients' associations (10 Full Members and 5 Associate Members) set up in August 2018, and represents about 1/3 of people suffering from Charcot-Marie-Tooth disease in Europe, about 100,000 patients. The ECMTF is member of EURORDIS, EFNA, and TREAT-NMD.

The main objectives for CMT Europe are:

- Making the general public throughout Europe more aware of CMT
- Promoting and supporting collaborative research.

More about CMT :

A family disease, a family of diseases

Charcot-Marie-Tooth disease is hereditary and rarely random. There are several kinds of pathology because several genes can be involved. CMT symptoms originate when a peripheral nerve is affected, and the speed of nerve impulses is slowed. The damage may affect both the axon, which transmits the nerve impulse, or the myelin sheath wrapped around it for protection or maybe both at the same time.

No cure, but research is making progress

There is no cure available for CMT. Patients can improve their quality of life by a multi-disciplinary approach: use of devices (orthotics, foot supports, etc.), physiotherapy and self-rehabilitation, adapted physical activity, psychological support, technical help, alternative medicines (acupuncture, sophrology ...), etc.

A drug developed by the Pharnext laboratory is currently being tested, and the phase 3 results show a positive effect for CMT1A, the most widespread form of the disease. This drug has shown significant improvement in patients. Pharnext has applied for marketing authorisation (MMA) in the United States and Europe.