WHAT IS CMT?

Charcot-Marie-Tooth (shar-ko~’ mä-re´ tooth)

CMT is the acronym for Charcot-Marie-Tooth disease, named after the three physicians who first described it: Drs. Jean-Martin Charcot and Pierre Marie (both from France) and Howard Henry Tooth (of the United Kingdom). It is estimated that CMT affects 3+ million people worldwide, regardless of gender, race, or ethnicity.

CMT is a group of like diseases caused by inherited genetic mutations. CMT damages the peripheral nerves outside of the brain and spinal cord.

The nervous system consists of the central nervous system and the peripheral nervous system. The central nervous system consists of the brain and spinal cord. The peripheral nervous system consists of all of the nerves that branch off the central nervous system and extend to the feet and hands. CMT is called a neuromuscular condition because it is the failure of the nerves that cause the malfunctioning of the muscles (unlike muscular dystrophy which affects the muscles themselves).

WHAT ARE THE SYMPTOMS OF CMT?

Muscle Pain    Hand Tremors    Cold Hands and feet    Drop Foot    Nerve Pain    Chronic Fatigue
Numbness    Curled Fingers    Muscle Atrophy    Curled Toes    High Arches (or Flat Feet)    Breathing Difficulties

First signs may include toe-walking, frequent tripping, ankle sprains, clumsiness, and “burning” or pins-and-needles sensations in the feet and/or hands.

Structural foot deformities such as high arches and hammertoes (curled toes) are common, but some people have flat feet and straight toes. Later in the disease process, contractures may develop in the fingers and hands.

Foot drop (inability to lift foot at ankle), poor balance, and problems walking may develop as muscles atrophy in the feet and legs, and some people may have hip dysplasia.
Difficulty with tasks involving manual dexterity, such as writing, grasping or picking up small objects or manipulating zippers and buttons can develop as atrophy in the hands sets in and progresses.

Abnormal sensation, loss of ability to feel light touch, the overall sense of touch, and the ability to perceive temperature change can become diminished, or even lost, in CMT. The loss of the ability to sense where one’s body is in space (proprioception) is also common, and many people experience musculoskeletal or neuropathic pain.

Poor tolerance for cool, cold and/or hot temperatures is typical. Many people have chronically cold hands and feet. Additional symptoms may include flexed fingers, contractures, tremor, knee and/or hip problems, muscle cramps, muscle spasms, thenar muscle atrophy (loss of muscle mass between the thumb and forefinger), loss of overall hand strength, absent or reduced reflexes, chronic fatigue, obstructive sleep apnea, poor circulation, scoliosis, kyphosis, hip dysplasia.

Rare symptoms include breathing difficulties caused by respiratory muscle weakness, swallowing or speaking difficulties, neurogenic bladder, hearing loss, optic neuropathy and vocal cord paralysis.

The psychological impact of having CMT can’t be ignored, leading to irritability, depression, anxiety, feelings of hopelessness and guilt.

IS THERE A TREATMENT FOR CMT?

Although there is no drug treatment for CMT, physical/occupational therapy and moderate activity (but not overexertion) can help maintain muscle strength, endurance and flexibility. Mechanical supports like AFOs (ankle-foot orthoses) and custom-made shoes can improve gait and balance. When medically indicated, orthopedic surgery can correct deformity and help maintain mobility and function. Occupational therapy and adaptive devices can help people perform activities of daily living. Download our Guide to Physical/Occupational Therapy at: cmtausa.org/living-with-cmt/find-resources

Exercises that do not put undue stress on the joints are strongly recommended:

Swimming • Walking with balance walking poles • Yoga • Pilates • Tai chi

ANY MEDICATIONS PEOPLE WITH CMT SHOULD AVOID?

YES! Some medications are potentially toxic to people with CMT. Vincristine has been proven hazardous and should be avoided by all CMT patients. Taxols also pose a high risk to people with CMT. The complete list of potentially neurotoxic medications can be viewed at www.cmtausa.org/medicationlist. Before taking any medication or changing medications, be sure your physician is fully aware of your medical condition, and discuss any possible side effects they may have on CMT.

Have a drug/medication question?
Visit cmtausa.org/medquest or email asktheexpert@cmtausa.org