



*"CMT runs through my veins ... so I have a passion for finding the best intervention for myself, my family members and my other patients."*

*—Branch Hunsaker, CPO,  
Clinic Manager at  
Hanger Clinic in Provo, Utah  
CMTA 2015 "I'm a Star" Winner*

### CMTA Clinical Centers of Excellence

One of the CMTA's primary missions is improving the quality of life for those with CMT and one way this is accomplished is by sponsoring patient-centric, multi-disciplinary CMT clinics, staffed by some of the highest quality CMT clinicians and researchers in the world. Through these CMTA-designated Centers of Excellence, children, adults and families affected by CMT can be assured of receiving comprehensive care by a team of CMT experts, including orthotists, some of whom are also Hanger clinicians.

## CMTA resources

#### CONTACT

[info@cmtausa.org](mailto:info@cmtausa.org)

#### CMTA WEBSITE

[www.cmtausa.org](http://www.cmtausa.org)

#### CMTA FACEBOOK PAGE

[www.CMTAssociation.com](http://www.CMTAssociation.com)

#### CMTA YOUTUBE CHANNEL

[www.youtube.com/user/CMTAssociation](http://www.youtube.com/user/CMTAssociation)

#### CONNECT WITH THE CMTA ON TWITTER

[twitter@cmtastar](https://twitter.com/cmtastar)



**Charcot-Marie-Tooth Association**

PO Box 105 • Glenolden, PA 19036

800-606-2682



# Diagnosing Charcot-Marie-Tooth:

## *How Not to Miss It*



# Charcot-Marie-Tooth is:

A progressive disorder of the peripheral nerves, causing people to lose normal use of their hands, arms, feet and legs. As the nerves die off, the muscles around them atrophy.

One of the most commonly inherited genetic disorders, affecting an estimated one in 2,500 people of all races and ethnic groups worldwide.



## Symptoms vary with each individual, but commonly include:

- Foot deformity (very high arched feet) and foot drop (inability to hold foot horizontal)
- “Slapping” gait (feet slap on the floor when walking because of foot drop)
- Loss of muscle in the lower legs, leading to skinny calves
- Numbness in the feet
- Difficulty with balance
- Similar symptoms in the arms and hands in later stages

## Delayed diagnosis of CMT is common:

- There are more than 80 CMT subtypes and the broad range of onset and severity may lead to misdiagnosis or missed diagnoses. Patients with mild cases may not realize they have the disease until they are middle-aged and develop a foot drop.
- According to Michael Shy, MD, a professor of neurology, pediatrics, and physiology at the University of Iowa’s Carver College of Medicine in Iowa City, the literature as to when to use orthotics or AFOs, or when to perform surgery, is very poor, and decisions are almost always based on the orthotist’s clinical judgment.
- Early diagnosis and intervention in people with Charcot-Marie-Tooth disease give clinicians and patients a valuable head start on keeping symptom progression in check.

## Common foot types seen in CMT:

- **Pes cavus:** The most typical type, a high-arched foot with a rigid “cave” under the instep. Calluses are common on the balls of the feet. Chronic ankle sprains and foot drop are common, as well. Hammer toes, claw toes and corns on the toes are typical. The muscles within the foot itself (intrinsic muscles) atrophy, and cause the toes to curl up. Treatment ranges from wearing insoles to surgery.
- **Paralytic Flatfoot:** A less-common foot type, which usually requires some type of fusion in the arch to stabilize the progressive breakdown.
- **Foot Drop:** Weakness in the muscles of the front of the calf cause foot drop; those with stronger muscles in the calf are better able to lift the front of the foot up. Bracing can be effective, and rocker bottom shoes and surgery to move stronger muscles to the top of the foot are all helpful.

## There is no cure for CMT and no drug treatment for it. Patients turn for relief to:

- Physical therapy, occupational therapy, and physical activity, which can help maintain muscle strength and improve independent functioning
- Orthopedic equipment (such as braces, inserts, or orthopedic shoes), which may make it easier to walk.
- Orthopedic surgery on the feet, which can maintain or even restore function to enable walking.

# CMTA

## Charcot-Marie-Tooth Association

- Is the leading source of information about CMT for more than 25,000 patients, families and clinicians.
- Offers a variety of educational materials and conferences, coordinates support and action groups in North America, and provides physician referrals and works closely with the clinical and research communities.
- Is the leading financial sponsor of drug discovery research within the CMT community, known as STAR (Strategy to Accelerate Research).
- Is the only CMT-specific patient advocacy organization in North America, strategically aligned with the National Institutes of Health Rare Disease Clinical Research Network.
- Currently has more than 80 branches that meet regularly, four to six times per year and typically have speakers at each meeting: [http://www.cmtausa.org/resource-directory/wpbdp\\_category/cmta-branches/#main](http://www.cmtausa.org/resource-directory/wpbdp_category/cmta-branches/#main)

In addition to the branch meetings, the CMTA regularly convenes other groups throughout the year, offering multiple opportunities to “get out the word” about your services:

- Patient/Family Conferences are full-day events, typically drawing some 200 people. We’ll be holding a Patient/Family Conference in State College, Pennsylvania, in June 2016.
- Mini-conferences are half-day events, typically drawing 100 people.