

What is Charcot-Marie-Tooth disease (CMT)?

Charcot-Marie Tooth disease (CMT), named for three doctors who described the condition in the late 1800's, is one of the most common inherited neurologic conditions. About one in 2,500 people have CMT. CMT typically first affects the lower legs and feet leading to weakness, numbness, and sometimes changes in the shape of the foot. As the condition progresses, weakness and numbness can also occur in the hands and forearms. CMT does not affect a person's intelligence and is usually not associated with a shortened life span.

Who is involved with the study?

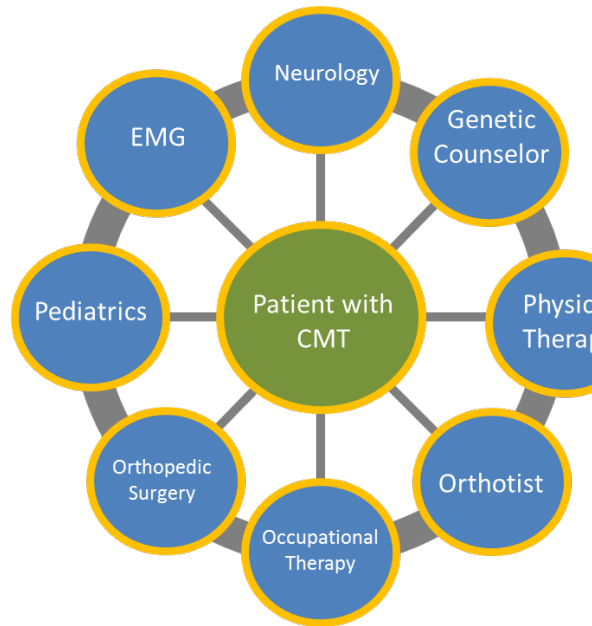
The CMT clinic is a multidisciplinary clinic, meaning that many different specialists are involved in our evaluation. This includes:

Clinic Director/Neurologist - Dr. Michael Shy
Electrophysiology – Leigha Rios
Genetic Counselor– Tiffany Grider
Genetic Counseling Assistant – Miranda Keith
Research Assistant – Amanda Dragon, Thomas Woodford
Pediatrics - Dr. Rosemary Shy
Physical Therapy – Mary Shepherd, Deb Parrott
Occupational Therapy – Rachel Rose
Orthotist – Tim Leist

Purpose of the clinic:

The CMT Clinic at the University of Iowa is interested in seeing people with all types of inherited neuropathies. In addition to providing quality clinical care, we are also involved with clinical research studies to better understand the progression and natural history of CMT and related conditions. Effective treatments or therapies for CMT will require understanding the timing and rate of progression of this condition in order to judge the effectiveness of medication.

We hope that these studies will form the basis for patient evaluation procedures in future clinical trials for the treatment of CMT.



The clinic has been in place since 1997 and patients from all over the United States and over 25 countries have been evaluated. We believe that our combination of clinical and basic research, as well as the multidisciplinary nature of our clinical approach enables us to be uniquely qualified to understand study and care for people with CMT.

Our interest in inherited neuropathies is not limited to either patient care or clinical research. The physicians involved all maintain basic science laboratories that are looking at developing approaches for the treatment of CMT. These studies are ongoing, although no cure is ready for use in patients at this time. Our laboratory investigations are funded by the National Institutes of Health, the Muscular Dystrophy Association, and the Charcot-Marie-Tooth Association.

What happens during an evaluation?

Evaluations typically take the entire day, ending around 4:30/5:00p.m. Those coming in from out of town should plan on arriving the day before their appointment. You will initially meet with the genetic counselor to talk about the study and the specific testing that will be performed and to answer any questions.

Genetic issues related to CMT and options for testing will also be discussed. A series of tests will be performed, including:

Hand function testing – various painless tests to evaluate hand strength and function.

Nerve conduction velocity testing – measures the speed at which impulses travel through nerves – some people find this uncomfortable.

Peds Score – in order to better understand the way CMT affects children, kids (21 and under) will do extra balance, strength, and hand dexterity tests.

Quality of Life (QoL) – you will be asked to fill out a brief questionnaire about your quality of life.

****Some patients may be asked to consider having a skin biopsy. If you qualify for this study, we will discuss this possibility with you in more detail. You always have the option to decline any of these procedures.**

You will also be evaluated by Dr. Shy who will go over your medical history and do a neurologic examination. Most people will also be evaluated by an orthotist who will address possible rehabilitation needs such as bracing and physical and occupational therapy.

Payment:

We will bill insurance for some parts of our evaluation (Including both Physical and Occupational Therapy). If you have an HMO, or we are out of network for your insurance company, and need a referral, it will be your responsibility to obtain it prior to your appointment. We will give you the appropriate information to obtain the referral when you schedule your appointment.

Helpful Tips for your appointment:

- The appointment will take the entire day. There will be a break for lunch. Please let us know ahead of time if you have time constraints.
- Bring any orthotics, braces or other devices that you use, even if you are not currently wearing them. It helps us to see what works for you and what does not.
- Bring a pair of shorts and comfortable shoes for your comfort during the appointment
- You may want to bring a book as there may be some down time during your appointment
- Please note that your appointment will take place in the Institute for Clinical and Translational Science (ICTS) Clinical Research Unit (CRU) at the University of Iowa, Boyd Tower near Elevator A.
- The closest parking ramp to the CRU is Parking Ramp 1

Get Involved!

Participate in developing research for CMT. Join the patient contact registry by visiting <https://www.rarediseasesnetwork.org/registry> and find out more about CMT.

For More Information about CMT:**The Charcot-Marie Tooth Association**

P.O. Box 105
Glenolden, PA 19036
Phone: 800-606-CMTA
www.cmtusa.org

Muscular Dystrophy Association

National Headquarters
161 N. Clark, Suite 3550
Chicago, Illinois 60601
(800) 572-1717
<https://www.mda.org/>

Hereditary Neuropathy Association

P.O. Box 287103
New York, NY 10128
Phone: 917-648-6971
www.hereditaryneuropathy.org

The Neuropathy Association

60 E. 42nd St. Suite 942
New York, NY 10165
Phone: 212-692-0662
www.neuropathy.org

University of Iowa CMT Clinic

Mailing Address: University of Iowa
Department of Neurology
2007 RCP
200 Hawkins Drive
Iowa City, IA 52242

Appointments: 319-384-6362
UICMTclinic@uiowa.edu



Charcot-Marie-Tooth Clinic

