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:

For More Information about CMT:

Inherited Neuropathies Consortium

www.rarediseasesnetwork.org/cms/inc

The Charcot-Marie Tooth Association

Tel: 800-606-CMTA

www.cmtusa.org

Muscular Dystrophy Association

Tel: 800-572-1717

www.mdausa.org

Hereditary Neuropathy Foundation

Tel: 855-HELPCMT (435-7268)

www.hnf-cure.org

The Foundation for Peripheral Neuropathy

Tel: 877-883-9942

www.foundationforpn.org

University of Iowa CMT Center of Excellence

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

Appointments:

Phone: 319-384-6362

UICMTClinic@uiowa.edu

Charcot Marie Tooth

Center of Excellence

UNIVERSITY OF IOWA HOSPITALS & CLINICS

University of Iowa Health Care

Part of the Inherited Neuropathies Consortium
www.rarediseasesnetwork.org/cms/inc

Tel: 319-384-6362

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, however it is important to remember that there are over 100 different genetic forms of CMT, so the symptoms can vary from person to person..

What would a clinic visit involve?

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

Clinic Director/Neurologist - Dr. Michael Shy, Dr. Laurie Gutmann

Electrophysiology - Dr. Andrea Swenson

Genetic Counselors– Shawna Feely, Tiffany Grider, and Janel Phetteplace

Research Assistant – Chelsea Bacon

Orthopedic surgery – Dr. John Femino

Pediatrics - Dr. Rosemary Shy

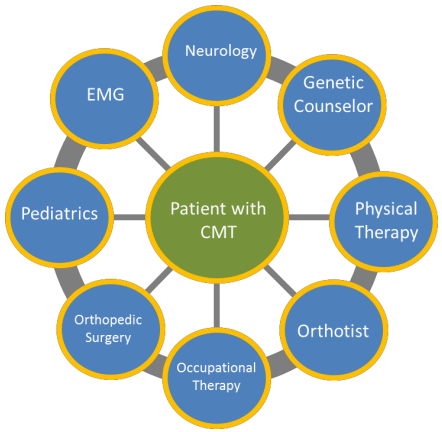
Physical Therapy – Mary Shepherd or Jen Fitzpatrick,

Occupational Therapy – Rachel Pins

Orthotist – Tim Leist

What is the 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 Unites 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 as current and future trials begin for use in patients with CMT. Our laboratory investigations are funded by the National Institutes of Health, the Muscular Dystrophy Association, and the Charcot- Marie-Tooth Association.

What happens during a CMT Clinic evaluation?

Evaluations typically take the entire day, ending around 4:30/5:00 p.m. Those coming in from out of town should plan on arriving the day before their appointment. You will initially meet with one of the team genetic counselors to talk about the clinic and studies available to you. After a series of testing based on that discussion, genetic issues related to CMT including genetic testing options will be discussed. The consent from provided reviews some of the testing that could be performed during the day. Depending on the person, this may include:

Neurological examination—physical exam by neurologist

Nerve Conduction Studies—measures nerve function

Hand Function Testing—measures hand strength/function

CMT Pediatric Score—For 21 and under to measure overall function

CMT Infant Score—For 5 and under to measure function

Quality of Life Questionnaires—asked about how symptoms affect your every day life

Physical Therapy/Occupational Therapy assessments

After the assessments, a detailed After Visit Summary (AVS) will be provided to you same day to review the recommendations from all of your providers and to review the genetic testing plan discussed with your genetic counselor. For follow up questions or concerns, you can contact the main clinic number or your genetic counselor directly.