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## **Position Guide**

### ***Chief Executive Officer***

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



**POSITION:** **Chief Executive Officer**

**REPORTS TO:** **Board of Directors**

**LOCATION:** **Flexible (United States)**

### **VISION**

A world without CMT.

### **MISSION**

*To support the development of new drugs to treat CMT, to improve the quality of life for people with CMT, and, ultimately, to find a cure.*

### **WHAT IS CMT?**

Charcot-Marie-Tooth Disease, or CMT, is a group of inherited disorders that affect the peripheral nerves, which are the nerves outside the brain and spinal cord. There are over 80 kinds of CMT, which are all caused by different types of gene mutations. More CMT-causing genes are being discovered every year. CMT is just one kind of neuropathy (also called peripheral neuropathy), meaning simply that the peripheral nerves are damaged. There are many other causes of polyneuropathy, including the most common cause—diabetes. CMT affects about 2.8 million people worldwide and 150,000 people in the U.S., of all races and ethnic groups.

Charcot-Marie-Tooth is named after the three physicians who were the first to describe it in 1886: Jean-Martin Charcot, Pierre Marie and Howard Henry Tooth. CMT is inherited. It is not contagious, nor is it caused by anything in the environment. For most types of CMT, a parent affected by the disease has a 50% chance of passing it on to his/her child.

With CMT, damaged nerve fibers result in neuropathy. The nerves in the legs and arms, which are the longest, are affected first. Nerve fibers that create movement and nerve fibers that transmit sensations are both affected. CMT causes weakness and numbness, usually starting in the feet. In the most common kinds of CMT, symptoms usually begin before the age of 20 years. Later, similar symptoms also may appear in the arms and hands. CMT does not affect brain function.

CMT usually gets worse, slowly, with age. The problems with weakness, numbness, difficulty with balance, and orthopedic problems can progress to the point of causing disability. Pain can be an issue, either as a direct result of the neuropathy (neuropathic pain) or as consequence of orthopedic problems. There are no known treatments that will stop or slow down the progression of CMT, but the CMTA is funding research to find these treatments.

## WHAT IS THE CMTA?

The Charcot-Marie-Tooth Association was founded in 1983 and incorporated in Pennsylvania as a 501(c)(3) federally recognized charity (it was originally founded as the National Foundation for Peroneal Muscular Atrophy). The original founder, Dr. Howard Shapiro, was himself, a patient with CMT.

From its inception, the CMTA has followed a twofold mission: supporting research on the causes and possible cures for CMT, and; focusing on patient education and support. From an organization of only a few hundred members, the association has grown to be known throughout the medical world, serving over 20,000 persons who make inquiries through the Internet, by phone calls and with letters asking for information and publications. Recently, the Strategy to Accelerate Research initiative or STAR (see below), adopted by the CMTA in 2008, has made a significant impact on the pace of CMT research by vastly increasing funding for CMT investigators across the country.

In its early years, the CMTA was helpful in accelerating a number of significant breakthroughs on the causes of CMT. These early discoveries paved the way for the development of diagnostic blood tests for several types of CMT thus providing the definitive answer for many on what type of CMT they have, and also providing their families with knowledge of the pattern of inheritance. To share this information with patients, the CMTA began publishing a newsletter in 1987. The *CMTA Report* is now published quarterly to provide patients with the knowledge and understanding to deal effectively with the disease.

Throughout the years, a major strength of the CMTA has been arranging conferences and bringing individuals and researchers involved with CMT together. For researchers, the CMTA established a North American CMT Consortium of clinicians and researchers with expertise in molecular biology, genetics, neurophysiology and clinical medicine. The CMTA was a founding sponsor and collaborator of the 1st International CMT Conference in 2003. The goal was to exchange new information and, equally important, to start new collaborations and strengthen existing networks between European and North American research groups. With lectures covering clinical, diagnostic, and basic research issues of CMT neuropathies, the International CMT Consortium meetings have been held regularly since then. The 6th International CMT Consortium took place in Quebec City, Quebec, Canada in 2015.

Patient-family conferences have also been a useful means of introducing patients to medical specialists in their area who treat CMT and are familiar with the disorder. Conferences have been held in Philadelphia, PA, Wilmington, DE, Detroit, MI, New Orleans, LA, Miami, FL, Dallas, TX, Akron, OH, and San Francisco and Los Angeles, CA. Supporting [CMTA branches](#) is another important way in which the Association serves its members. Branches are run by dedicated leaders who provide other CMT patients in their general area a means by which they can interact with others dealing with the same problems and listen to specialists who discuss topics such as surgeries, physical therapy, genetics, shoe fitting and bracing. Branches are currently located in 75 different areas of the country.

The CMTA has a 15 member [Board of Directors](#) who establish policy and procedures and spearhead fundraising activities such as golf tournaments and “swims for the cure.”

CMTA also has a [STAR Advisory Board](#) made up of clinicians, researchers, and drug development experts. Because patient advocacy is one of the CMTA's missions, an active [Advisory Board](#), comprised of CMT specialists, offer insights into some of the important, but not neurological issues facing people dealing with CMT. Our experts come from a wide variety of backgrounds and will be happy to assist CMTA members who have questions in areas in which they would be considered "experts." Lastly, the CMTA has a staff of 8, located in multiple locations around the U.S. and an operating budget of approximately \$4M, primarily dedicated to supporting research on causes of the disease and treatments.

### THE OPPORTUNITY

Eight years ago, in an effort to accelerate the pace of research underway and to encourage researchers and industry partners to seek a treatment for CMT, the Board of Directors approved the [STAR Initiative \(Strategy to Accelerate Research\)](#). STAR was created with one goal: to find treatments to slow, stop or reverse the progression of CMT.

Working with investigators and scientists chosen from an international body of the world's most accomplished medical pioneers, STAR is now leading critical CMT research. The STAR program's success is due to the willingness of scientists working in their areas of expertise to come together as a team to advance CMT research, sharing and communicating ideas, discoveries and findings. Scientists sharing their successes and failures, every month, is what sets the STAR program apart from any other CMT-related research effort.

STAR's collaborative research is done by university labs, large pharmaceutical companies and small research organizations working with the world's leading CMT experts to create groundbreaking, efficient results at each step of discovery. The opportunities associated with STAR, stem from the fact that the causes of CMT have been pinpointed, leading to the identification of more than 90 specific gene mutations. More importantly, the fact that these genetic mutations can be replicated in laboratory models opens an extraordinary window of opportunity to develop treatments and cures for CMT in the immediate and foreseeable future.

To further advance these efforts, the CMTA is working with the New York Stem Cell Foundation (NYSCF) to develop human cellular models of CMT. And, along with the Muscular Dystrophy Association, CMT United Kingdom, and TREAT NMD (the European Neuromuscular Network), CMTA is a partnering patient advocacy group within the Inherited Neuropathy Consortium (INC). The CMTA is well positioned to facilitate patient recruitment and involvement in cutting-edge research.

The CMTA has developed critical partnerships with industry leaders to advance its work and the STAR Initiative. Over the past several years, the CMTA has developed [Alliance Partners](#) in the pharmaceutical and therapeutic industry, including: Genzyme (A Sanofi Company), Addex Therapeutics; Affectis Pharmaceuticals; and Neusentis (A Pfizer Research Unit). The partnership with Genzyme, for example, has allowed high-throughput screening of close to 2 million compounds, a true breakthrough in the search for a treatment. In addition to the Alliance Partners, CMTA also has partnerships with PsychoGenics, HumanFirst Therapeutics, Horizon Discovery, Charles River, and the Jackson Laboratory.

The chances to identify a treatment for CMT 1A, the most common form of the disease, have never been greater than at this moment. The next CEO will have the opportunity to work with a motivated, professional and passionate Board, engaged industry partners, and researchers from across the globe to ensure the STAR Initiative reaches its goal of developing a first treatment for this disease. Working on a multifaceted approach of private and public resource generation and partnership with industry and academia, the CEO will drive the activities of CMTA to a new level of achievement in pursuit of its mission. Recognizing this critical moment, the CEO will have the opportunity to elevate the profile of CMTA into new markets and expand its stature through broader community engagement and support education and medical research.

### **POSITION SUMMARY**

The Chief Executive Officer is responsible for the overall leadership of the organization to ensure delivery of the highest quality activities while safeguarding its financial stability. As the leader of the organization, the CEO reports to the Board of Directors and is responsible for: executing the strategic plan to address the growing needs of CMTA and its constituents; actively engaging in sophisticated fundraising and development activities; developing and managing the organization's overall finances; managing and leading the staff and fostering an organizational climate to develop and build staff competencies; collaborating with other leaders and decision makers in the broader CMT community; providing the vision to address future challenges and opportunities; and representing the organization as its key spokesperson and fundraiser.

### **CANDIDATE PROFILE**

We seek an accomplished leader with demonstrated success in organizational leadership, strong development experience and solid business acumen gained from his or her professional career. The qualified candidate must demonstrate a commitment to and present evidence of strong results from best practice management, community engagement and enterprise development as distinguishing factors in their success. Proven leadership in bringing passion, vision, direction, business discipline, accountability and inspiration to an organization is required. This person must also have an understanding of and commitment to the distinctive goal of building a stronger organization to advance the mission of the CMTA.

The person we seek is a strategic thinker and problem-solver. Senior-level executive experience in addressing organizational opportunities and challenges that has been accomplished through strong analytical skills, good professional judgment and decisiveness is required. Knowledge and experience dealing with a variety of constituencies including members, academics, corporate industry partners, elected officials, donors, civic leaders and volunteer groups is extremely valuable. An understanding of the trends, opportunities and challenges inherent in the fields of medical research and drug development is preferred.

The ideal candidate will be able to demonstrate fundraising success through active engagement and solicitation of major individual donors, foundations and corporations. A career history as a dynamic communicator, written and oral, strong technology skills and proven capabilities to establish and maintain an active presence within a sophisticated philanthropic community are highly desirable. Working with board members in creating appropriate avenues for their participation in fundraising is highly preferred.

A passion for the advancement of disease specific research and support, at minimum, is required. Specific experience with CMT is ideal but not required. Intellectual curiosity to understand the specific issues, opportunities and concerns of the CMT community and the ability to translate that understanding into motivating action by various stakeholders is required.

The successful candidate must also be suited to be a confident public face of the organization, whose interpersonal skills demonstrate an ability to work in harmony at all levels (internally and externally), listen to and respect the viewpoints of others, and strive to share with others the credit and recognition of well-done jobs. Good facilitation and organizing skills are critical in working effectively with others in administrative and volunteer roles. Experience helping an organization build a broad audience through a strong social media presence is valued.

An undergraduate degree from a college or university is required; a graduate degree is preferred. Evidence of continuing education through conferences, seminars and workshops would be a plus.

To apply, please send a current resume and letter of introduction to Kittleman & Associates, LLC at [kittlemansearch.com/charcotmarietooth-association/](http://kittlemansearch.com/charcotmarietooth-association/)

For more information about CMTA, visit <http://cmtausa.org/>