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FOR IMMEDIATE RELEASE

**National Neuropathy Awareness Week, May 18<sup>th</sup>-May 24<sup>th</sup>**

**STRATEGY TO ACCELERATE RESEARCH (STAR™) FOR CHARCOT-MARIE-TOOTH DISORDER MAY HOLD PROMISE FOR MS, MD AND ALS**

CHESTER, PA – Despite its discovery over 100 years ago, most people have never heard of Charcot-Marie-Tooth (CMT) disorder, and yet it is the most commonly inherited peripheral neuropathy, estimated to affect one in every 2,500 people — 2.6 million worldwide. CMT is a progressive disorder that causes the nerve cells leading to the body’s extremities to slowly degenerate, resulting in the loss of normal use of feet/legs and hands/arms.

National Neuropathy Awareness Week, May 18<sup>th</sup>-May 24<sup>th</sup>, brings focus to the work of the Charcot-Marie-Tooth Association (CMTA) as it recently launched the Strategy to Accelerate Research (STAR™) to develop treatments —and eventually a cure—for CMT.

“STAR represents the unprecedented collaboration of CMT experts from across the globe,” said Patrick A. Livney, Chairman of the CMTA Board of Directors. “We are excited about a research process that stands to provide treatments for this disorder within three years and a cure within ten years. Moreover, the results may provide insight into similar neuromuscular disorders such as Multiple Sclerosis, Muscular Dystrophy and Amyotrophic Lateral Sclerosis.”

The STAR initiative is one of the CMTA’s most comprehensive research efforts. Since its inception in 1983, the CMTA has been dedicated to providing support, education and research funds for its patients and researchers. Its website, [www.charcot-marie-tooth.org](http://www.charcot-marie-tooth.org), logs thousands of visitors per year and serves as a central repository for reliable information on CMT. The CMTA is celebrating its 25<sup>th</sup> Anniversary this year.

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## **About CMT:**

CMT affects people of all ages, genders, races and ethnicities. It usually is not life-threatening and almost never affects intellectual functioning. The first signs may be frequent tripping or clumsiness, often accompanied by an abnormal burning sensation in the extremities. As the condition progresses, symptoms may include:

- Weakness in hands or ankles
- High arches
- Foot drop
- Hammertoes
- Muscle loss in the feet/legs, hands/arms
- Deformities
- Loss of motor nerve control

CMT is inherited in most instances. In dominant forms, if one parent has CMT their children have a 50/50 chance of developing the disorder. Less frequently, both parents carry a recessive CMT gene although they do not show signs of the disorder. In this instance, their children have a 25% chance of developing CMT. As with all genetic disorders, CMT can also appear as a mutation in people with no prior hereditary history.

At present there is no cure for CMT. Common treatments include physical therapy, occupational therapy, bracing, and custom orthoses. Orthopedic surgical options are also available, but patients should carefully weigh the potential benefits and risks when making this decision.

## **About the Charcot-Marie-Tooth Association (CMTA):**

The CMTA, headquartered in Chester, Pennsylvania, is a 501(C)(3) nonprofit organization founded in 1983. The CMTA's goals include providing patient support, public education, promotion of research, and ultimately the improved treatment and cure of CMT. The CMTA is offering a free membership in celebration of its 25<sup>th</sup> year anniversary. The resource list of medications that should be avoided by people with CMT can be found on their website. The organization is led by an executive director and governed by a voluntary Board of Directors (BOD), and an international Medical Advisory Board (MAB) comprised of over fifty clinical and research professionals in specialties such as neurology, genetics, orthopedic surgery, physiatry, physical therapy and podiatry. Their Scientific Advisory Board (SAB) is comprised of senior scientists with extensive research experience related to CMT. An External Advisory Board, made up of internationally recognized scientists, serves in an advisory capacity to the SAB. The CMTA has more than 15,000 patients and families, supportive friends, and medical professionals in its member database. For more information, visit [www.charcot-marie-tooth.org](http://www.charcot-marie-tooth.org).

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Editors Note: To schedule an interview with Patrick A. Livney, Chairman of the CMTA Board of Directors, a medical expert or a patient advocate, please contact Shannon Baker at 412.381-5400. Please visit the Media Room on the CMTA's website for images and graphics.