



CHARCOT-MARIE-TOOTH ASSOCIATION

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August 22, 2014

The Honorable Nikki R. Haley
Office of the Governor
1205 Pendleton Street
Columbia, South Carolina 29201

Dear Governor Haley:

On behalf of the Charcot-Marie-Tooth Association (CMTA), I am writing to request a Proclamation from your office declaring Charcot-Marie-Tooth Awareness Month, September 2014. This month has been designated by our association to focus national attention on increasing public awareness of this severe medical condition that affects approximately 145,000 Americans. CMT is the most commonly inherited peripheral neuropathy affecting 1 in 2,500 people worldwide.

There are now 4.77 million citizens in our beautiful state of South Carolina. Approximately 1908 of them have CMT.

Often not noticed at birth, there are many citizens who may be undiagnosed, misdiagnosed or unaware of the slow progression of this insidious and degenerative neuromuscular disorder. CMT often manifests itself during childhood; however, its progression may go unnoticed until later in life. Muscle atrophy in the extremities, coupled with ataxia, chronic pain, overwhelming fatigue and loss of sensation often perplex doctors and other medical professionals who remain undereducated about Charcot-Marie-Tooth Disease. Awareness Month is designed to explain the signs and symptoms of CMT to both the public and medical communities; to encourage people to seek medical assistance before deformities and nerve damage occur.

Genetic testing, although expensive, is often the best way to detect the presence of CMT. Early intervention in children is critical to good health and disease management. CMTA's STAR (Strategy to Accelerate Research) Initiative is dedicated to conducting research and developing treatments and, ultimately, the cure. Funding for this integral program is based on public donations and corporate alliances. The Charcot-Marie-Tooth Association is working nationally and internationally to expand public awareness this coming September and special events are being planned coast to coast and, in fact, worldwide.

A proclamation from the Governor's Office from the great State of South Carolina for Charcot-Marie-Tooth Awareness Month, September 2014, would be most powerful in directing focus on this devastating disorder. I am enclosing my name and number should you require additional information or to arrange for a formal presentation. Thank you in advance for issuing a Proclamation for Charcot-Marie-Tooth Awareness Month September 2014.

Respectfully,

Kenneth Stephen Rivers
CMTA Support and Action Group Facilitator
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OUR VISION: A world without CMT.

OUR MISSION: To generate the resources to find a cure, to create awareness and to improve the quality of life.

Charcot-Marie-Tooth disease is the most common inherited neuropathy.

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