September, 2020

Dr. Sanjay Gupta
49 Jesse Hill Jr Drive SE
Faculty Office Building Suite 337
Atlanta, GA 30303

Dear Dr. Gupta:

I write to urge you to inform your viewers about a rare neurological disease that some of them may have without even knowing it. Charcot-Marie-Tooth (CMT) disease is one of the most commonly inherited peripheral neuropathies, affecting an estimated one in 2,500 individuals, or 3 million souls worldwide and yet very few people have ever heard of it. Many people who have it are misdiagnosed or not diagnosed at all.

CMT is a progressive disorder of the long, or peripheral, nerves to the feet and hands. As the nerves die, the muscles around them atrophy, causing people to lose normal use of their extremities. More than 20 million people suffer from peripheral neuropathy and while it has other causes—like diabetes, physical injuries, and certain autoimmune diseases to name a few—it is a hallmark of CMT.

CMT symptoms vary, but in addition to neuropathy commonly include: loss of muscle in the lower legs, leading to very skinny calves; numbness in the feet; difficulty with balance; and a “slapping" gait. Severity and onset vary widely—children born with severe cases may never be able to walk while people with milder cases may not realize they have the disease until they are middle-aged and develop foot drop.

There is no drug treatment for CMT, but exercise and physical activity help people who have it maintain movement, strength and flexibility. With exercise, unaffected muscles can be strengthened to help do the work of those that have atrophied because of CMT. For some, surgery can provide relief, particularly children whose unbalanced muscles have not yet resulted in deformity.

While CMT is currently incurable, the Charcot-Marie-Tooth Association (www.cmtausa.org) is leading the search for treatments and a cure. In 2008, it implemented its Strategy to Accelerate Research, or STAR, bringing together top scientists, academics and industry partners to work together on a cure—and raising funds to fuel the research. The CMTA’s crack team of top scientists and industry partners worked on more than 50 research projects in 2019, encompassing everything from gene therapy to small molecule therapies to drugs that promote axon survival and preserve nerve function.

As a person who lives with CMT, I ask that you please speak out on this disease in September—CMT Awareness Month. Educating your viewers about CMT would be a valuable public service and could save some from a long road to diagnosis.

Very truly yours,