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**FOR IMMEDIATE RELEASE**

**Baltimore Native “Swims for a Cure” for Charcot-Marie-Tooth Disorder During Chesapeake Bay Challenge**

**-Raises Funds for Strategy to Accelerate Research (STAR™) Which May Offer New Therapies for Charcot-Marie-Tooth and Similar Disorders-**

**Baltimore, MD** – Undaunted, for the past six years Steve O'Donnell has been braving cold waters swimming in the Chesapeake Bay Challenge to raise research funds for a common, but the little known neuropathy that affects him called Charcot-Marie-Tooth (CMT) disorder. On June 8, O'Donnell, along with friends and family members, will continue the tradition and hope to raise even more money which will support new and ambitious research into CMT. Last year, O'Donnell's team raised over \$190,000 for the cause, \$500,000 in all since 2001.

O'Donnell's brother also has CMT, which is the most commonly inherited peripheral neuropathy, estimated to affect one in every 2,500 people, or 2.6-million people 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 the feet/legs and hands/arms.

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“My family and I have experienced first hand the suffering caused by CMT. As a member of the Board of Directors for the national Charcot-Marie-Tooth Association (CMTA), I have met many generations of people, young through old, with this debilitating condition. It is my hope that one day no family will have to deal with the fear of passing the disorder on to subsequent generations” said O’Donnell.

Thanks to a newly launched CMTA initiative, the Strategy to Accelerate Research (STAR™), therapies and perhaps a cure are on the horizon. Based on genetic advances, leading experts from across the globe believe that STAR may provide treatments and a cure for CMT, as well as related neuromuscular disorders.

To make a tax deductible donation to support research for Charcot-Marie-Tooth disorder, visit [www.CMTinfo.org](http://www.CMTinfo.org) or call the CMTA toll free at 1-800-606-2682.

### **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 cases. In dominant forms, one parent has CMT and 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 new mutation in people with no prior hereditary history.

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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 organization is led by an Executive Director and is governed by a voluntary Board of Directors (BOD). It also has 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. The CMTA 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: Steve O'Donnell is available for interviews. Please contact Shannon Baker at 412.381.5400 for scheduling assistance. You may also visit the Media Room at [www.CMTinfo.org](http://www.CMTinfo.org) for additional information.**