



**FOR IMMEDIATE RELEASE:**

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**CHARCOT-MARIE-TOOTH PHYSICIAN/PATIENT/FAMILY CONFERENCE  
SCHEDULED FOR SATURDAY, NOVEMBER 8, AT MITCHELL PARK COMMUNITY  
CENTER, PALO ALTO**

*--Educational Conference Covers the Management of CMT, the Latest Medical Advances and the  
Current Research to Treat and Eventually Cure the Most Commonly Inherited Neurological  
Disorder—*

Palo Alto, CA, October 14, 2008 – Patients with the peripheral neuropathy known as Charcot-Marie-Tooth disorder will be able to attend a Physician/Patient/Family Conference on Saturday, November 8, 2008, from 8:30 a.m. until 5:30 p.m. at the Mitchell Park Community Center in Palo Alto.

Charcot-Marie-Tooth disorder affects one in 2,500 people—2.6 million worldwide – and is the most commonly inherited peripheral neuropathy. 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 hands/arms and legs/feet. It may also lead to a loss of sensory functions and deformities. CMT strikes all ages, genders, races and ethnicities. People with CMT lose their ability to do daily activities that are often taken for granted.

The day-long conference will be held at:

**The Mitchell Park Community Center  
3800 Middlefield Road  
Palo Alto, CA  
Saturday, November 8, 2008  
8:30 a.m. – 5:30 p.m.**

Some of the nation's leading CMT medical researchers and clinicians, including Wayne State CMT Clinic Director Dr. Michael Shy, CMTA Board Chairman and President Patrick Livney, orthotist Sean McKale, genetic counselors Cathy Siskind and Shawna Feely, pediatrician Dr. Rosemary Shy as well as board and staff members of the CMTA will make presentations.

Attendees will learn about this often misdiagnosed disorder and have the opportunity to:

- Hear the latest advances in the diagnosis and treatment of CMT.
- Meet the expert medical staff from the Wayne State University CMT Clinic in Detroit, Michigan.
- Speak with experienced professionals from the CMTA and members of its Board of Directors.
- Become familiar with the Strategy to Accelerate Research or STAR™, the CMTA's ambitious research initiative that holds promise for effective therapies for some types of CMT within three to five years and a possible cure within 10 years.
- Exchange information with other CMT patients, friends and families.

Admission to the conference, which includes lunch and a snack, is \$15 for members of the CMTA and \$20 for nonmembers. Those interested in attending can register by calling 800-606-CMTA, ext. 103, by emailing: [conference@charcot-marie-tooth.org](mailto:conference@charcot-marie-tooth.org) or by going online at [www.cmtausa.org/paloalto](http://www.cmtausa.org/paloalto) by November 1, 2008.

Sponsored by the Charcot-Marie-Tooth Association, the conference is being organized by CMTA board member and support group leader Elizabeth Ouellette, whose 15-year-old son, Yohan, has CMT.

“This conference fulfills a dream and portends to be a special day for the CMT community throughout the West Coast region,” Ms. Ouellette said. “The CMTA and our growing support group network are committed to keeping those affected by the debilitating effects of this progressive disease current with education, medical treatments, and the latest status of the STAR™ initiative.”

#### **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 percent

chance of developing CMT. As with all genetic disorders, CMT can also appear as a new 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 orthotics. 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 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 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. 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).

Media note: To arrange an interview with Michael E. Shy, MD; Patrick A. Livney, the CMTA Chairman and President, or Board Member and Conference organizer Elizabeth Ouellette, please contact Shannon Baker at 412.381.5400 or by e-mail at [sbaker@gmdadv.com](mailto:sbaker@gmdadv.com). Visit the Media Room at [www.charcot-marie-tooth.org](http://www.charcot-marie-tooth.org) for electronic documents, bio-sketches, medical images, photographs and other pertinent information.