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## **CMTA Joins Forces with European CMT Federation To Collaborate on Research, Awareness**

### **FOR IMMEDIATE RELEASE**

**GLENOLDEN, PA, UNITED STATES, JUNE 1, 2023**—The Charcot-Marie-Tooth Association (CMTA) Board of Directors voted May 15 to formalize its relationship with the European CMT Federation (ECMTF). Previously a partner and collaborator, the CMTA is now a full-fledged member of the ECMTF, strengthening ties between the two organizations and furthering their common goals of supporting the CMT community and accelerating the search for a cure.

ICMT is a progressive disease of the peripheral nerves that causes one in 2,500 people to lose normal use of their feet, legs, arms and hands. As the nerves die, the muscles around them follow suit. Symptoms include foot deformity (very high arched feet) and foot drop (inability to hold foot horizontal); a slapping gait (feet slap on the floor when walking); loss of muscle in the lower legs, leading to skinny calves; numbness in the feet; and difficulty with balance. In rare cases, hearing, vision and breathing may also be affected.

The CMTA is the leading patient advocacy organization driving CMT research. Its mission is to develop treatments and a cure for the 3 million people worldwide who live with the disease, while improving the quality of life for patients and their families. The CMTA has invested \$23.5 million in the search for a cure and its Strategy to Accelerate Research (STAR) brings world-renowned CMT researchers together with pharmaceutical and biotechnology partners and patients to accelerate scientific breakthroughs. The CMTA also offers community services, including 70 local branches, educational materials and patient conferences.

The ECMTF is a nonprofit created to unite all the CMT advocacy groups across Europe to help raise awareness and promote better care for people with CMT, fund research and encourage the formation of new organizations in countries where there is no CMT advocacy group. It was formed in Italy in 2016 after a meeting of six European organizations and now brings together all the European CMT associations as well as those of Israel and China.

Further strengthening ties between the ECMTF and the CMTA, several CMTA representatives will speak or chair sessions at the ECMTF's inaugural European CMT Specialist's Conference in Paris on June 9 – 10. They include Katherine

Forsey, PhD, the CMTA's chief research officer, and several members of the CMTA's international STAR Advisory Board—Dr. Stephan Züchner (USA), Dr. Davide Pareyson (Italy), Dr. Mary Reilly (UK) and Dr. Kleopas Kleopa (Cyprus). The conference will aid global collaboration and best practices sharing on research, diagnosis, treatments, data management, registries and CMT community engagement.

Noting that the CMTA was a very early supporter and friend of the ECMTF, CMTA Board Chair Gilles Bouchard said, “We are delighted to formalize this relationship. With many potential therapies now in the pipeline, it is critical that CMT patients have a strong and unified voice all over the world.”

ECMTF President Daniel Tanesse said, “Thanks to the open-mindedness of our friend Gilles Bouchard and his team, we have maintained very cordial and fruitful relations with CMTA for a long time. The formalization of this cooperation by the membership of CMTA to ECMTF will only reinforce our common will to work for the good of people with CMT. It is a perfect example of the will expressed in our slogan: Together we are stronger!”

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