MdDS Foundation Honors World Rare Disease Day

It will soon be Rare Disease Day (February 28), a day when those with MdDS as well as many others worldwide will pause to acknowledge rare conditions (http://www.rarediseaseday.org/). On this day, hundreds of patient organizations from more than 60 countries and regions worldwide are planning awareness-raising activities converging around the slogan “Rare Disorders without Borders”. With all this attention and effort, there is hope. Hope that a cure will be found and relief provided to those affected by a rare condition.

Your help in increasing awareness and fund-raising for MdDS has made a huge difference. In brief:

• **AWARENESS.** Brochures provided by the Foundation (and carried by many volunteers) have been circulated far and wide to health care providers and those affected by MdDS. A decade ago, most doctors had never heard of MdDS. Today, more are aware although many remain uninformed. We must actively continue efforts to inform via brochures, the Internet, and social media in order to insure that those with MdDS do not endure a lengthy ordeal in health care systems in search of a diagnosis.

• **RESEARCH FUNDING.** During the past 5 years, the MdDS Balance Disorder Foundation has provided research funds to Drs. Yoon-Hee Cha (formerly at the University of California at Los Angeles and currently at the Laureate Institute for Brain Research) and Brian Clark (Ohio University). More recently, the NIH has provided funding for MdDS research by Drs. Cha and Mingjia Dai (Mount Sinai School of Medicine). Clinical and translational research is a slow process. However, thanks to dedicated investigators, advances in understanding the basis and treatment of MdDS are well underway.

• **BIOMEDICAL RESEARCH.** Many of you have been/continue to be participants in research studies conducted around the world. Surveys, imaging, laboratory experiments, and repetitive transcranial magnetic stimulation (rTMS) are now the norm. Only a few years ago there was none.

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• **BIOMEDICAL LITERATURE.** Numerous research studies by Drs. Cha and Clark have now moved into the published literature. These have begun to inform health care providers and researchers about MdDS. Publications include:


Dr. Clark’s research studies remain on-going. Dr. Cha has recently finished initial imaging and rTMS studies at UCLA (she will soon complete collection of data); by May, she will begin new rTMS studies at the Laureate Institute for Brain Research (LIBR). Indeed, grant funding provided by the Foundation was instrumental in the acquisition of TMS technologies at LIBR. We remain hopeful that targets in the brain and the duration of rTMS will be refined to provide sustained relief for those with MdDS. To achieve these goals, we must continue to generate funds to support research.

The above is intended to capture the message of Rare Disease Day for MdDS: with awareness and research, we will continue to demystify this syndrome.

Thanks to each of you for your part in all of the above. Raise your hand on Rare Disease Day and be counted!