

FOR IMMEDIATE RELEASE: September 2016
CONTACT: Pat Whitney patwhitney00@gmail.com

Misdiagnosed, Undiagnosed and Diagnosed:

Orthostatic Tremor Remains an Incurable Mystery

Having a rare disorder does not mean you have to face it alone. Find out how you can locate a support group, participate in clinical studies and support ongoing research. September is Orthostatic Tremor Awareness Month.

Before the internet, when you had symptoms clinicians couldn't diagnose, you might have sought a second or third opinion. And if none of those doctors had heard of your symptoms, you might have decided you were one in a million and would simply live with the situation, especially, if your symptoms were life-limiting, but not life-threatening.

So it is with Orthostatic Tremor (OT), or weight-bearing tremor, where when one stands up, the legs begin almost immediately to feel weak and unsteady. Walking at a brisk pace can alleviate the symptoms, especially early on, but as one progresses in age, walking becomes less and less easy and balance is profoundly affected, while standing unsupported is simply not possible.

People with OT can walk, but not stand – not an easy concept for others to grasp! It's like riding a bike – you can ride along at a certain pace, moving slowly means wobbling and standing still doesn't work at all.

First identified in 1984, OT is considered a rare neurological disorder and has been widely misdiagnosed and undiagnosed. In 2000, Gloria MacWright who was newly diagnosed created a website (orthostatictremor.org) and within two weeks received her first response from a fellow patient. Today that website has over a thousand responders worldwide, provides an ongoing series of personal case histories, is a repository of clinical papers and monographs and offers a Forum for shared information and dialogue among patients and families.

Beginning in 2008, people who made contact through the website have held support group meetings alternate years in different parts of the US to listen to clinicians speak about what is known about OT, to share personal coping strategies and to participate in clinical studies. Core organizers of the OT group have raised thousands of dollars for clinical studies conducted at the University of Nebraska Medical Center in Omaha under the leadership of Dr. Diego Torres-Russotto and through NORD (National Organization of Rare Disorders) grant awards to researchers in the US and France who are studying OT and possible treatments.

Twenty-four people with OT and their companions from five countries gathered this past spring to hear Dr. Joseph Jankovic, founder and director of the Parkinson's Disease Center and Movement Disorders Clinic at Baylor College of Medicine in Houston.

Without the OT website, none of this would be happening. “Being able to meet others who share this rare disability is so helpful,” said one participant at this year’s meeting in Houston. “Just knowing that we can fund research and help find some answers gives me hope,” commented another. “Being part of the ongoing clinical studies in Omaha makes me feel I’m doing something important and positive,” was another response. And, “I feel better just knowing I’m not the only one,” sums it up for most.

To learn more about OT, the group meetings, how to participate in the clinical studies and ways to support NORD grant awards for research or donate to the OT Foundation at the University of Omaha Medical Center, go to **OrthostaticTremor.org**.