

## It's Up to Us

As of the end of 2022, The OT community has now raised over \$175,000 toward Orthostatic Tremor research through our fundraising affiliations with NORD (National Organization of Rare Disorders) and the University of Nebraska Foundation (UNF).

Money donated to OT Research via UNF has supported the work of neurologist Diego Torres-Russotto, MD, who leads a team of clinicians at the University of Nebraska Medical Center in Omaha, where many of us have participated in three earlier clinical studies.

Our contributions to NORD fund OT Research selected from proposals reviewed by NORD's Medical Advisory Board. Currently, \$42,500 has been awarded by NORD to Dr. Robert Chen, MA, MBBChir, MSc of Krembil Brain Institute, University Health Network, Toronto, Canada, to study the use of low intensity focused ultrasound (FUS), to address the dysfunctional cerebellar activities in OT patients.

We are not seeking additional funding for the research at UNMC as previously donated funds are sufficient for completing and publishing the research led by Dr. Torres there.

When Dr. Torres begins his new research at Florida International University, a new support fund will be established there and an announcement made in this newsletter.

Support of NORD continues, visit this [LINK](#) and choose Primary Orthostatic Tremor from the Research Fund drop down menu or mail to NORD, 55 Kenosia Ave, Danbury, CT 06810, specifying Primary Orthostatic Tremor.

## Dr. Diego Torres to Complete His Work with Colleagues on Current UNMC Projects and to Continue Orthostatic Tremor Research at Florida International University



L to R: Diego Torres-Russotto, MD, FAAN, Professor, Vice-Chair for Education. Dept. of Neurological Sciences (UNMC); Amy Hellman, MD, FAAN, Associate Professor, Specialty: Movement Disorders; David E. Warren, PhD, Assistant Professor, Specialty: Research; Erin Cameron-Smith, MD, Assistant Professor, Dept. of Neurological Sciences.

*We continue to actively work on the analysis of the many data points that we have, and in publishing more of the results. In the interim, we have submitted three important OT papers. The plantar grasp sign, the curling of the toes that many patients experience, was found to be present in more than 80% of the patients, and the paper has been submitted for peer reviewing. I have had the privilege to collaborate with a team of experts from the Netherlands, led by Drs. Fleur Van Rootselaar and Swinnen to validate the first translation from English into a different language (Dutch) of the OT-10 Severity Scale. Lastly, the UNMC paper on functional MRI and Transcranial Magnetic Stimulation findings led by Dr. Warren has been submitted as well.*

*I would like to take this opportunity to give you a personal update. I have taken the position of Inaugural Neurology Chair at the Miami Neuroscience Institute / Baptist Health, associated with Florida International University. I will start there in March 2023, without any unexpected delays on the many OT research projects that I am leading. Moreover, I will continue to lead the work with my many collaborators at UNMC to complete the rest of the projects. Dr. Amy Hellman will take over as Interim Chief of the Movement Disorders Division. Dr. Erin Smith will become the Fellowship Director. Both have been working with me in OT projects for many years. We have been using the funds from the UNMC Foundation for OT in*  
Continued on page 2

## Gloria Nelson MacWright

### ***And Her Website That Has Brought Us Together*** ***[www.orthostatictremor.org](http://www.orthostatictremor.org)***

More than twenty years ago, when Gloria was first diagnosed with OT and neither she nor her doctor knew of another person who had this disorder, she was



encouraged to create a website and within two weeks of going live, she had her first respondent.

Having met on the website, ten of us with OT convened at the Mayo clinic in Rochester, MN, in 2008 with Dr. Matsumoto which turned out to be a learning experience for him and for us. A core group of us got to know one another and continued to meet every two years in Atlantic City, Houston, Sydney, Australia, and more recently in Omaha for clinical studies in 2012, 2014, and 2017, led by Dr. Torres, the last of which included 52 people with OT from around the world and 33 control companions!

**Dr. Torres** Continued from pg 1  
*a conservative fashion to pay for data analysis and paper submission costs. The analysis and publication of the rest of the projects will*

*deplete the moneys left within our OT Fund.*

*We are as committed to the OT community as always. We thank you for all the support.*

*Diego*

Diego R. Torres-Russotto, MD, FAAN (he/him/él)  
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Adjunct Professor of Kinematics at UNO  
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## **Dr. Robert Chen Continues Research on Orthostatic Tremor at University Health Network in Toronto**

Funded by a grant from NORD (National Organization of Rare Disorders based in Danbury, CT), Dr. Robert Chen, MA, MBBChir, MSc, is moving forward in his research on Orthostatic Tremor. The project was delayed during Covid 19, affecting the recruitment of volunteers who must be diagnosed with Primary Orthostatic Tremor by a movement disorders specialist and have no other major

neurological or psychiatric illness. The clinical studies will be conducted at the University Health Network, Toronto, Canada. Interested participants may contact [chenlabneuromod@uhn.ca](mailto:chenlabneuromod@uhn.ca), for more information. Dr. Chen has spent the last year testing his procedures for this clinical study and has submitted a request to NORD for a two-year *No Cost Extension* to make up for the unforeseen delays.

*Robert Chen, MA, MBBChir, MSc, FRCPC*  
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## **Orthostatic Tremor Featured in the New York Times Sunday Magazine** **Thanks to Ruth Hochheiser**

Persistence paid off when Ruth Hochheiser reached out to the Diagnosis column writer of the *New York Times* and pitched the coverage of Orthostatic Tremor that appeared in the August 21 edition of the Magazine Sec-

tion, this past summer. With over 800,000 Sunday paper subscribers and more than 6 million digital readers, this was major exposure for our rare disorder. Thank you, Ruth, for your journalistic coup!

