

# orthostatic tremor newsletter

# Together we can stand up to OT

June 2021 Issue 1

## It's Upto Us

Over the last dozen years, we—the OT community—have contributed over \$130,000 toward Orthostatic Tremor research through our fundraising with NORD (National Organization of Rare Disorders) and the University of Nebraska Foundation (UNF).

Money donated to OT Research via UNF supports the work of neurologist Diego Torres-Russotto, MD, who leads a team of clinicians at the University of Nebraska Medical Center in Omaha. Many of us have participated in three earlier clinical studies conducted by Dr. Torres and his team, and we are looking forward to hearing more about the next study.

Our contributions to NORD support 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.

**Please join us in donating** to Dr. Torres' ongoing OT Research at <https://nufoundation.org/fund/01130710/> or mail to UNF, PO Box 82555, Lincoln, NE 68501-2555 noting OT Research and Education Fund #01130710. Or to NORD, at <https://rarediseases.org/donate-to-nord-restricted/> and select Primary Orthostatic Tremor from the Research Fund dropdown menu or mail to NORD, 55 Kenosia Ave, Danbury, CT 06810, specifying the Primary Orthostatic Tremor Fund.

## Movement Disorders in Neurological Sciences Team at The University of Nebraska Medical Center



Top row- Dr. Danish Bhatti, MD, Dr. Diego Torres, MD - Chief Movement Disorders Division, Dr. Sarah Doss, MD, Dr. Kiel Woodward, MD, Dr. Amy Hellman, MD, Dr. Bertoni, MD, Julie Pavelka, MS, APRN-NP, Lori Schuetze-Education Coordinator, Dr. Erin Cameron-Smith, Cindy Penke, RN Case Manager, Dr. Miguel Situ, MD, Tova Safford-Administrative I, Dr. Deepmala Nandanwar, Alysa Nichols, RN. Not pictured Dr. Mara Seier, MD.

*We have had a very successful year taking into account all the difficulties caused by the pandemic and have published a number of papers from our OT work. The OT Ataxia Paper and the EEG Study were both accepted for publication in peer reviewed journals.*

*The publishing of the OT Scale was a major accomplishment. We are currently working on publishing the OT Forum Survey of patients with OT, and the translation of the OT Scale into Dutch and many other projects.*

*What we would like to focus on for the future is to understand the genetics of OT. To this end, we would*

*need to develop a biobank and purchase state-of-the-art EMG (electromyography) equipment to be able to measure tremor in the best possible way, and which will cost \$100,000.00.*

*We are also planning on having an update during OT month (September) via a Webinar, so that everyone interested can attend online. We will reach out to the community with sign ups and updates as we get closer to the September date.*

—Dr. Diego Torres, MD, Chief, Movement Disorders Division, The University of Nebraska Medical Center

# thank you!

## Dr. Robert Chen and His Research Team at Krembil Brain Institute, University Health Network, Toronto

L to R: Dr. Robert Chen, MA, MBBChir, MSc; Dr. Jean-Francois Nankoo (Post-doctoral Fellow); and Dr. Talyta Grippe (Research Fellow)



*Dr. Chen and his team, who have been delayed by Covid-19 restrictions, are beginning to recruit for their investigation of the use of low intensity focused ultrasound (FUS), a novel non-invasive brain stimulation technique, to normalize the dysfunctional cerebellar activities in OT patients, as this newsletter is published.*

## Thank you, Gloria Nelson MacWright

Twenty years ago, when Gloria was first diagnosed with OT and neither



she nor her doctor knew of another person with this disorder, she was encouraged to

create a website and within two weeks of going live, Gloria received the first of what now numbers over 2500 global responses.

Having met on the website, ten of us with OT convened in 2008 at the Mayo clinic in Rochester, MN, 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!

## My Story: Patricia Ryan

Hixson, TN My journey with OT began in the summer of 2004 when I was 64 years old and preparing for our 40<sup>th</sup> wedding anniversary. Our whole family was gathering in Florida where we went every year. We wanted to renew our wedding vows and this would be the perfect time as our family would all be there from Iowa, Massachusetts and Tennessee, our home state.



As I would practice what I was going to say on that day I noticed my legs were trembling whenever I was standing. I attributed it to excitement and nerves. But, when that day finally arrived and we were all standing on the balcony of our condo overlooking the ocean I could hardly stand still. Again I thought it was because I was a little bit nervous.

When we got home from Florida I started researching “shaky legs” and tremors of the legs and ended up on the Orthostatic Tremor website. I read Gloria’s story and knew immediately that I was experiencing OT, identifying with everything Gloria said.

My Primary Care Physician was not familiar with OT, but listened to my research and prescribed clonazepam and gabapentin. I am still taking those two medications today and they have been a big help in diminishing my OT symptoms.

I was not officially diagnosed until 2014 when I attended an OT meeting in Omaha, Nebraska. Dr. Torres did the diagnosis with his iPhone strapped to my leg.

My tremors have progressed slowly through the 17 years. I have

balance problems and prefer going barefoot and when I do wear shoes they must not have any “bounce” to them. I have difficulty walking in the dark, up and down stairs, and sometimes I am not able to walk and carry anything. I also find I walk better in my own home than in unfamiliar places. I am thankful I have no pain and that I sleep very well.

I have learned to adapt to my tremors and do what I can and leave

## I read Gloria’s story and knew immediately I was experiencing OT

what I can’t. I have good days and bad days. I am grateful my children are grown and self-sufficient and I have a wonderful husband who helps me more than he will ever know. He keeps an eye on me and is always there with a strong arm if I need it.

Five years ago we moved to a one-level townhome which we love and this has been a great help to me not to have any stairs.

I do cook and often sit on a stool at the stove. I don’t use anything else to assist me at this time. Every morning before getting out of bed I spend 15 minutes stretching. I try to walk as much as I can and have done chair exercises.

The best advice I can give is to stay positive and not focus on the disease. Wake up each morning and be thankful for another day and keep your faith in the Lord.

# A Challenge Gift Can Make All the Difference

Two years ago, in support of Dr. Torres's OT Research at the University of Nebraska Medical Center, a family from our OT community generously offered to make a gift to match all other donations for the next year, up to a total of \$10,000. The response to this extremely thoughtful gift was a substantial increase in donations for that year.

Anyone interested in making a challenge gift of any amount is encouraged to be in touch with Edwin Lyons to establish the challenge process which will then be presented to the OT community through this newsletter and posted on the OT website, [www.orthostatictremor.org](http://www.orthostatictremor.org).

Contact: Edwin Lyons, Director of Development, Nebraska Medicine, University of Nebraska Medical Center, University of Nebraska Foundation, 2285 South 67th Street, Suite 200, Omaha, NE 68106, or 492-504-3339 or [edwin.lyons@unfoundation.org](mailto:edwin.lyons@unfoundation.org).

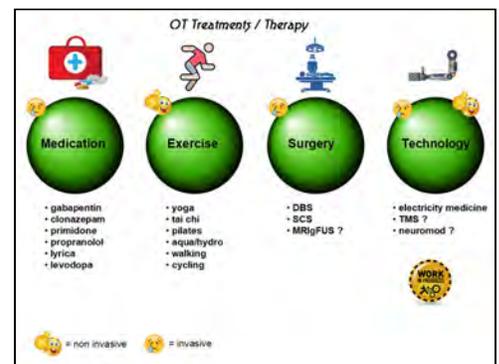
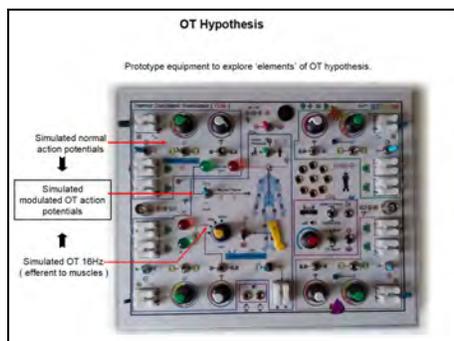
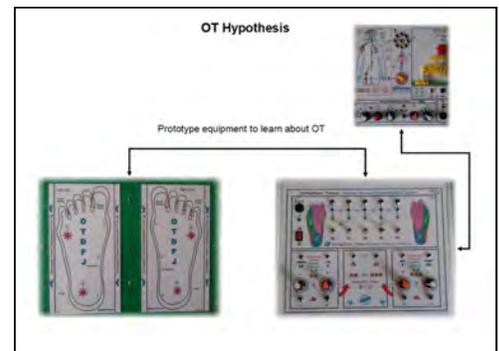
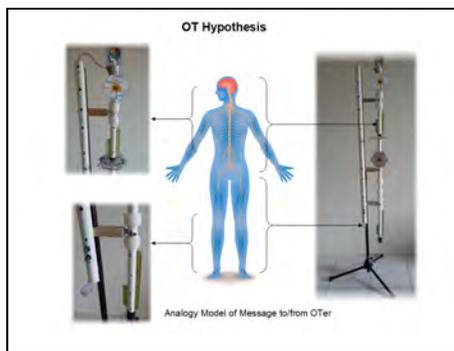
## Analysis of Orthostatic Tremor in Australia

This past year, Soon Lye Chan, in Australia, learned of Orthostatic Tremor online and got in touch with Peggy Whitta who set up a series of Zoom meetings between Soon Lye and a few OT patients who have attended the OT clinical studies in Omaha. Soon Lye, a former Program Manager with Robert BOSCH, LLC, an engineering company, has spent four decades volunteering to create adaptive equipment to assist people with disabilities. He was intrigued with OT and immediately set out to learn all he could from us, and to apply a systems approach to understanding it. He continues to study and analyze OT and looks forward to conducting in-person studies when Covid restrictions permit. The following graphics were created by Soon Lye Chan and are used with permission.

The volunteer work underway, is to firstly, try to understand and explore the potential 'mechanism(s)' for OT. To do so, requires custom test & simulation equipment to be designed and built. ( see attached images ). Then , postulate ideas on how to substantiate elements of the hypothesis and hopefully , to propose and build concept solutions for testing. The intent is to try to reduce the impact of OT - not to cure the condition. E.g. perhaps attempt to attenuate the amplitude of the OT modulated " messages".



First proto " OT Reliever "



**In September 2021,**  
**Dr. Diego Torres will conduct**  
**a webinar open to anyone**  
**interested in learning more**  
**about OT. Watch for an email**  
**announcement to register for**  
**this free webinar or check at**  
**[www.orthostatictremor.org](http://www.orthostatictremor.org)**