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DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

Dysautonomia International Announces Research Grants

East Moriches, New York: Dysautonomia International has awarded its first four research grants to support research on Postural Orthostatic Tachycardia Syndrome (POTS).

"These grants are an important first step in Dysautonomia International's mission to increase the pace of POTS research," said Ellen Kessler, CPA, Treasurer and co-founder of Dysautonomia International, "we look forward to supporting research on other autonomic disorders as our organization continues to grow." Lauren E. Stiles, Esq, President and co-founder of Dysautonomia International, notes, "not only will these grants fund much needed POTS research, some will include training for students and young researchers, to help attract new talent to the field of autonomic disorders research. With the number of people being diagnosed with POTS increasing, we need more experts in this field."

These four awards will support a variety of research projects - evaluating the effectiveness of a non-pharmacological treatment for POTS related tachycardia; evaluating the effectiveness of a pharmacological treatment for the "brain fog" experienced by many POTS patients; examining the relationship between autoimmunity and POTS; and a study seeking to understand the role of nitric oxide, a potent vasodilator, in the brain of POTS patients.

After a competitive grant application process the Board of Directors has funded projects proposed by the following researchers:

Svetlana Blitshteyn, MD, Clinical Assistant Professor in the Department of Neurology at the University at Buffalo School of Medicine and Director of the Dysautonomia Clinic in Williamsville, NY. Dr. Blitshteyn will study autoimmune serum markers in POTS patients and the rate of autoimmune co-morbidities seen in POTS patients. Dr. Blitshteyn notes, "[i]n the past several years, there have been several studies suggesting that POTS may have an autoimmune etiology. Anecdotally, some patients with POTS and co-morbid autoimmune conditions have benefited from the use of a short course of steroids, Plaquenil, IVIG or plasmapheresis. Before clinical trials of these therapies in patients with POTS can be considered, a better understanding of the relationship between POTS and autoimmunity is needed. We hope that this study will shed further light on the relationship between POTS and autoimmunity."

Kamal R. Chémali, MD, Associate Professor of Medicine in the Department of Neurology at Eastern Virginia Medical School and the Director of the Neuromuscular and Autonomic Neurology Program at Sentara Hospital in Norfolk, VA. Dr. Chemali will study the use of music therapy in POTS patients who continue to be symptomatic despite maximized standard treatment. Music therapy has been used as an add-on therapy in other neurological conditions, such as Parkinson's and Traumatic Brain Injury, to help improve functionality and reduce some symptoms. There is prior research documenting that music can be used to "entrain" the heart rhythm, either slowing it down or speeding it up based on the tempo of the music. Dr. Chemali will investigate whether this entrainment can be used to help POTS patients reduce

their symptomatic tachycardia.

Satish R. Raj, MD, MSCI, Associate Professor in Medicine and Pharmacology at Vanderbilt University's Autonomic Dysfunction Center in Nashville, TN. Dr. Raj's grant will assist with an investigation of a drug with the potential to combat the cognitive impairment experienced by many POTS patients. Dr. Raj notes, "Many patients with POTS complain about cognitive impairment (sometimes called "brain fog"). For many patients, this is the most troubling part of their disorder. It can limit their ability to continue to work. Following Vanderbilt's work showing some objective problems on cognitive testing in POTS patients we are beginning to study treatments that may improve this debilitating problem."

Julian Stewart, MD, PhD and **Andrew T. Del Pozzi, PhD** will study cerebral blood flow in response to nitric oxide in POTS patients. Nitric oxide is a very important neurotransmitter that plays a role in regulating the tone of blood vessels. Prior research has shown that POTS patients have a decreased response to nitric oxide in their peripheral blood vessels. This study will evaluate whether the decreased nitric oxide response is also occurring in the brains of POTS patients. Dr. Stewart is a Professor of Pediatrics, Physiology and Medicine and Director of the Center for Hypotension at New York Medical College. Dr. Del Pozzi is a post-doctoral trainee working in Dr. Stewart's autonomic lab at New York Medical College.

About Dysautonomia and POTS

Dysautonomia is a group of medical conditions resulting from a malfunction of the autonomic nervous system. The autonomic nervous system controls essential bodily functions, such as heart rate, blood pressure, digestion, and temperature control.

POTS is a form of dysautonomia characterized by an excessive increase in heart rate that occurs with standing that is relieved by laying down. POTS symptoms can also include lightheadedness, chest pains, shortness of breath, fainting, unstable blood pressure, migraines, sensitivity to temperature changes, and problems with gastrointestinal motility. An estimated 25% of POTS patients are so disabled they cannot work or attend school. Approximately 80% of POTS patients are female, most between the ages of 13 and 50.

About Dysautonomia International

Dysautonomia International is an all-volunteer 501(c)(3) non-profit organization headquartered in New York. The organization was founded in 2012 by a group of patients and parent/caregivers impacted by autonomic disorders. The organization has grown into a global movement with offices in several states and volunteers across the world. Dysautonomia International's Medical Advisory Board is comprised of many of the world's leading physicians and researchers who study and treat autonomic disorders. Dysautonomia International raises funds for research, educates medical professionals and the public, and provides patients and their families useful tools and resources to help cope with the daily struggles of living with an autonomic disorder.

For more information about dysautonomia and POTS visit www.dysautonomiainternational.org.

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