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ResearchMatch launches registry for Postural Orthostatic Tachycardia Syndrome.



ResearchMatch Connects Postural Orthostatic Tachycardia Syndrome Study Volunteers with Researchers

Nashville, TN – September 16, 2013 -- [ResearchMatch](#) (RM), the country's first nationwide, non-profit, volunteer, research recruitment platform for all health conditions, is launching a research registry for Postural Orthostatic Tachycardia Syndrome (POTS) patients in collaboration with [Dysautonomia International](#), an non-profit patient advocacy group dedicated to identifying the causes and cures for all forms of dysautonomia, including POTS.

RM has a simple goal – to bring together two groups of people who are searching for each other: people who are trying to find research studies, and researchers who are looking for people to participate in their studies. It is a free, secure online registry that has been developed by major academic institutions across the country to engage others in today's ethical, expedited research. RM's innovative collaboration with Dysautonomia International provides a voice for POTS patients in the research process.

Standing up is something most of us do every day. Imagine if this simple act was a challenge. POTS patients experience excessive heart rate increases upon standing, and this is often accompanied by many other symptoms such as chest pain, shortness of breath, lightheadedness, gastrointestinal problems and cognitive impairment. The disability seen in POTS has been compared to what is seen in Congestive Heart Failure and Chronic Obstructive Pulmonary Disease, yet the majority of POTS patients are young women. It is estimated that 1 out of every 100 teens develop POTS before adulthood, and about 80% of patients are female. Boys and adult men and women can develop POTS as well.

Dr. Satish R. Raj, Associate Professor of Medicine and Pharmacology, and preeminent POTS researcher at the [Autonomic Dysfunction Center at Vanderbilt University](#), notes, "Clinical research is going to be the vehicle for

advancing our understanding of POTS, and for the development of more effective therapies. ResearchMatch will allow for POTS researchers to more easily find those POTS patients interested in participating in research studies. I hope that ResearchMatch will catalyze our research.”

“Dysautonomia International is eager to team up with ResearchMatch to enroll as many POTS patients as possible in the ResearchMatch database. We're working with patients and researchers to do all that we can to support research, so that we can figure out what causes POTS, how to effectively treat it, and hopefully someday how to cure or prevent it,” said Lauren Stiles, Esq., President of Dysautonomia International.

All volunteers who register with RM indicating Postural Orthostatic Tachycardia Syndrome (POTS) as one of their conditions will be prompted to answer additional questions about their condition to enhance the precision and prescreening process for matching volunteers with research teams studying POTS. To register, please visit www.researchmatch.org.

About ResearchMatch

[ResearchMatch](#) is a national partnership created as a centralized, web-based recruitment registry, connecting individuals who are interested in participating in research with researchers nationwide. The site is funded in part by [the National Institutes of Health \(NIH\) and Clinical and Translational Science Award \(CTSA\)](#) program grants. The CTSA program is led by the NIH's [National Center for Advancing Translational Science \(NCATS\)](#). The content of this website is solely the responsibility of ResearchMatch and Vanderbilt University and does not necessarily represent the official views of the NIH.

About Dysautonomia International

[Dysautonomia International](#) is a 501(c)(3) non-profit founded in 2012 by patients, caregivers, physicians and researchers. Their mission is to identify the causes and cures for all forms of dysautonomia and to enhance the quality-of-life of people currently living with these illnesses. They do this by raising funds for research, promoting awareness of dysautonomia within the medical profession and the general public, and providing patients and families with useful tools, resources and information regarding dysautonomia.

About The Vanderbilt Autonomic Dysfunction Center

[The Vanderbilt Autonomic Dysfunction Center](#) was established in 1978 as the first international center for patient care, research, and training focusing exclusively on disorders of the autonomic nervous system. Its creation brought together in one site a cadre of physicians, scientists and nurses who could foster a balanced scientific approach to elucidation of the etiology and optimal therapy of these disorders. Autonomic disorders cause loss of regulation of the heart, blood vessels, stomach, bowel and bladder. Affected patients may have palpitations or lose consciousness, and some have a rapidly fatal course. We hope to join with patient support groups to harness the knowledge and energies of physicians and investigators in the major centers where these patients are cared for, so that they can discover ways to treat and to cure these diseases. The greater the collaboration between doctors and patients, the more we can learn about these disorders. This important first step is necessary if we are ever to find genuinely effective and curative treatments.

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