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Contact: Lauren Stiles, Esq.

E-mail: info@dysautonomiainternational.org**Patients Fund Their Own Research When Federal Funding Falls Through**

FREDERICK, MARYLAND (July 2, 2014) – 15 year-old Sabrina Riordan of Frederick, Maryland has been dreaming about medical research. That's because Sabrina lives with a debilitating medical condition with no cure and no FDA approved treatments, POTS (postural orthostatic tachycardia syndrome). POTS is estimated to impact over one million Americans, more than double the number of people that are diagnosed with multiple sclerosis, yet unlike multiple sclerosis, there are no pharmaceutical companies lining up to develop new drugs, there is very little federal research funding, and there are very few POTS specialty centers. "Many doctors don't even know it exists," says Sabrina.

In 2012, patients, families and concerned physicians banded together to form Dysautonomia International, a non-profit that raises money for research on different forms of dysautonomia, including POTS. "While POTS is a well documented medical condition, researchers are still trying to figure out what causes the widespread symptoms seen in POTS, which includes severe lightheadedness, chest pain, gastrointestinal disturbances and more," says Lauren Stiles, Esq., President & Co-Founder of Dysautonomia International. "More research is desperately needed, but federal funding is sparse."

With Dysautonomia International leading the way, patients are playing an increasing role in POTS research. After the National Institutes of Health denied funding for a promising POTS research study, Dysautonomia International reached out to the patient community to fund the project. Over the course of two months, patients donated more than \$50,000 to fund the study, which will look for antibodies that may be responsible for the cardiovascular symptoms seen in POTS. If the study reveals that a large percentage of POTS patients have these antibodies, as preliminary studies have found, this might lead to a whole new way of treating POTS.

To save money and speed up the pace of research, [Dysautonomia International](http://dysautonomiainternational.org) invited researchers from Vanderbilt University to collect blood samples needed for the research project during the organization's [annual conference](http://dysautonomiainternational.org), held in D.C. from July 11th-14th. The research project will be led by noted POTS expert, Dr. Satish R. Raj, Associate Professor of Medicine and Pharmacology at the Vanderbilt University Autonomic Dysfunction Center. Dr. Raj explains, "[t]his conference is the largest gathering of POTS patients in the world, so it's a great place to conduct research. We hope that this research will advance our scientific understanding of POTS."

When asked if she would be participating in the study occurring at the conference, Sabrina says, "[o]f course! I'm ready to roll up my sleeve to help find a cure for POTS!"

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