



Standing Up to POTS is a 501(c)(3) not-for-profit organization whose mission is to help patients with postural orthostatic tachycardia syndrome (POTS) live their best lives. We do this in three main ways:

- Research to help improve quality of life for people with POTS
- Advocate to increase awareness in the general public and medical community
- Support families currently struggling with POTS

Although POTS is not visible or typically life-threatening, it causes an enormous emotional, physical, and financial burden to patients and their families. The burden is made worse by the lack of understanding and public awareness, combined with some of the unique features of POTS, such as inability to be upright, frequent fainting episodes, adrenaline rushes, severe brain fog, pain, and the unpredictable flares of these symptoms. The physical disability, cognitive impairment, pain, and disruption to schooling/career/life plans leaves these patients with myriad challenges to everyday living. Standing Up to POTS works to address these challenges.

“Standing Up to POTS has improved my life: First, they provide great practical information that you can’t find anywhere else. Second, they make me feel less alone, because of the kind people in the support group. Third, they make me feel understood, which I value after decades of feeling like I’d never fit in anywhere again. Knowing that this organization is working on my behalf makes me more optimistic about living with POTS.” Jill B., POTS sufferer

Select Research Publications in Scientific Journal supported by Standing Up to POTS:

Pederson, Cathy L., and Jill Blettner Brook. 2017. "Health-Related Quality of Life and Suicide Risk in Postural Tachycardia Syndrome." *Clinical Autonomic Research*. 27(2): 75-81.

Pederson, Cathy L., and Jill Blettner Brook. 2017. "Sleep Disturbance Linked to Suicidal Ideation in Postural Orthostatic Tachycardia Syndrome." *Science and Nature of Sleep*. 9: 109-115.

Select Advocacy Articles in Professional Journals and Online

Pederson, Cathy L., Kathleen Gorman Ezell, and Greta Hochstetler Mayer. 2017. "Invisible Illness Increases Risk of Suicidal Ideation: The Role of Social Workers in Preventing Suicide." *Health & Social Work*. doi.org/10.1093/hsw/hlx029.

Pederson, Cathy L. and Greta Hochstetler Mayer. 2016. "The Tangible Effects of Invisible Illness: Counselors who understand the role of chronic illness in depression, anxiety and suicide can provide a safe places for clients to be heard, validated, and comforted." *Counseling Today*. 58(11): 56-59.

Nakagawa, Lindsay J. "Why We Need to Stop Comparing All Illnesses to Cancer." *The Mighty*, January 30, 2017

Pederson, Cathy L. "10 Ways to Support Your Chronically Ill Friend." *The Mighty*, October 20, 2016

“Words of Hope: A 13-year-old member writes about her illness to inspire others.” *Thrivent Magazine*. December, 2015, p. 5.



Website: www.StandingUptoPOTS.org
Email: info@standinguptopots.org



Support provided for those with POTS

- Website. Over 40 pages filled with practical tips to improve understanding of POTS and quality of life for those suffering from it, at www.StandingUptoPOTS.org. We have had visitors from more than 150 countries!
- Facebook page. With more than 3,500 likes, this venue is used to share new research findings, tips for improving quality of life, and memes to raise awareness about POTS.
- Support Group. More than 1,000 patients, family members, and friends of those with POTS join together to generate and receive support each other.
- Teens Only Support Group. More than 260 teens who can share their triumphs and frustrations related to living with the symptoms and isolation experienced during their formative teenage years with others who “get it.”

Our Founder

Standing Up to POTS was founded in 2014 by Dr. Cathy Pederson, Professor of Biology at Wittenberg University. She holds a Ph.D. in Physiology and Neurobiology from Rutgers, and has directed an active research program for more than two decades. As a mother of a child with POTS, Dr. Pederson brings both passion and scientific understanding of the autonomic nervous system and POTS to our organization.

Your Donation Matters!

Your donation will make a difference. In the United States, there are more people suffering from POTS than multiple sclerosis, Parkinson’s Disease, and amyotrophic lateral sclerosis combined, but POTS has just a fraction of the research funding. The Standing Up to POTS Research Fund currently funds \$10,000 POTS related research grants related to improving quality of life for people with POTS now. We also run advocacy campaigns to improve awareness in the healthcare community and general public.

- \$100 = 45 copies of “My Life with POTS” books for donation to healthcare practitioners
- \$150 = Platform for an online survey about quality of life issues for people with POTS
- \$300 = Ergonomic High Performance Pippetor for molecular medical research
- \$500 = Diagnostic testing for one patient to better understand underlying causes of POTS

