

Standing Up to POTS is a 501(c)(3) not-for-profit organization whose mission is to improve the quality of life for people with POTS through research, advocacy, and support. 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.

- Research
 - Standing Up to POTS has **awarded \$41,250 in grants** to research teams in the U.S., Canada, and Germany.
 - Our board members have published seven of our own quality of life research papers in 2017 and 2018 alone.
- Advocacy to increase awareness in the general public and medical community
 - Our website features over 40 pages filled with practical tips to improve understanding of POTS and quality of life for those currently suffering. We have had visitors from more than 150 countries!
 - Through social media, Standing Up to POTS shares new research findings, nutrition tips, information about disability and the law, a counseling corner, and more to support our POTS community.
- Support families currently struggling with POTS
 - Online, we have approximately 2,000 patients, family members, and friends of those with POTS join together to generate and receive support each other in our two online support groups.
 - Locally, we are developing a network of regional support groups where members can meet face-to-face to talk about issues surrounding life with chronic illness.

“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



Jill B. before treatment (A) and after treatment (B)



POTS families at 4th Annual Standing Up to POTS 5K
October 2017

Select Research Publications by Standing Up to POTS Board Members (*):

Pederson, Cathy L. *, and Jeffrey B. Brookings. 2018. "Suicide Risk Linked with Perceived Burdensomeness in Postural Tachycardia Syndrome." *Journal of Health Science & Education*. 2(1): 128.

Weinstock, Leonard B., Jill Blettner Brook*, Trisha L. Myers, and Brent Goodman. 2018. "Successful Treatment of Postural Orthostatic Tachycardia and Mast Cell Activation Syndromes Using Naltrexone, Immunoglobulin and Antibiotic Treatment." *BMJ Case Reports*. doi:10.1136/bcr-2017-221405

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 by our Board Members (*):

Pederson, Cathy L. *, Kathleen Gorman-Ezell*, and Greta Hochstetler Mayer. 2018. "Assessing Depression in Those who are Chronically Ill." *Counseling Today*. 60(9): 38-43

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.

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

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.

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 Pippettor for molecular medical research
- \$500 = Diagnostic testing for one patient to better understand underlying causes of POTS



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