

# DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

Post Office Box 596  
East Moriches, NY 11940

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[info@dysautonomiainternational.org](mailto:info@dysautonomiainternational.org)  
[www.dysautonomiainternational.org](http://www.dysautonomiainternational.org)

December 2022

Hon. Representative Katherine Clark  
US House of Representatives  
Washington, DC 20515

Dear Representative Clark:

We are writing to you as your constituents on an important matter.

The National Institute of Health (NIH) received over \$45 billion from Congress this year for medical research. Yet less than \$2 million a year (or 0.004%) is directed toward funding research on a chronic condition called postural orthostatic tachycardia syndrome (POTS) that more than 3 million other Americans suffer from, including many here in Massachusetts.

POTS is one of the most common autonomic nervous system disorders. POTS can cause lightheadedness, fainting, tachycardia, chest pains, shortness of breath, GI upset, shaking, exercise intolerance, temperature sensitivity and more. While POTS predominantly impacts young women who look healthy on the outside, researchers compare the disability seen in POTS to the disability seen in conditions like COPD and congestive heart failure.

For many patients, waking up every morning with an overwhelming combination of symptoms that prevent you going to school or work is commonplace. The simplest of tasks, including getting out of bed and dressing for the day are unachievable, and the quality of life significantly declines. POTS typically takes years to diagnose due to a lack of awareness in the medical community.

As POTS patients, caregivers, and advocates on behalf of people with POTS, we are asking for your help. According to a recent report issued by the leading POTS experts from around the world, including several Harvard experts here in Massachusetts, the scientific community needs \$10 million dedicated for POTS to accelerate diagnosis and potential treatment options for patients. And, despite repeated directives from Congress in the annual appropriations bills, the NIH has yet to increase funding for POTS. Therefore, I request that you include the following funding and language in the end of year funding bill currently being negotiated.

Postural Orthostatic Tachycardia Syndrome [POTS] – POTS is one of the most common forms of dysautonomia, estimated to impact 1 to 3 million Americans prior to the COVID-19 pandemic. Recent research suggests that 67% of individuals – an estimated 38 million Americans – experiencing post-acute sequelae of SARS-COV-2 [PASC] are developing moderate to severe dysautonomia, most commonly presenting as POTS. Due to the sudden increase in the patient population affected by this debilitating disorder, Congress includes an increase of \$10,000,000 for NIH to support new research on POTS, to address the gaps in current knowledge identified during the NIH's July 2019 workshop, Postural Orthostatic Tachycardia Syndrome (POTS): State of the Science, Clinical Care, and Research. We strongly encourage the NIH to establish a multi-institute Notice of Special Interest to spur additional needed research addressing the identified gaps in knowledge.

Thank you for your time and consideration.

Sincerely,

Dear Representative Clark, We met at the Malden Thanksgiving Project at the YMCA this year by the United Way. I suffer from dysautonomia and more research into POTS and other autonomic disorders would greatly help my outlook in life. As there is little funding and research into POTS, it is extremely frustrating that there are very few answers and solutions to treating POTS. I am constantly facing an uphill battle and since it's an invisible illness, many people do not understand what I am going through. Your support to the POTS community with more funding would be exceptionally beneficial for all POTS sufferers. It would truly be a game-changer. Thank you so much for your time and consideration. I greatly appreciate it!

Bruno Artacho  
88 Bay Dr  
Sudbury MA 01776-1957

As a husband of a POTS patient, I know how badly POTS research is needed. The majority of doctors don't know how to explain my wife's health issues and the ones that understand the diagnosis don't have the tools for treatment. It's taken 4 plus years of her researching and experimenting on her own to learn how to combat the illness to feel like she is finally in a place where there is a little bit of hope. My hope for others is they don't have to experience the same disbelief, the fear of not knowing what's wrong, and do not have to struggle for years for answers. I hope for a healthcare system that is able to treat patients effectively.

Netia McCray  
8 Crestview Drive  
Malden MA 2148

As someone who has experienced newly onset POTS after her COVID infection in March 2020, I have been unable to be the STEM educator that I once was nor the community member I was. Unfortunately, I am not alone and I realize the impact of on our community when we need each other the most. I've spent over 6 figures in order to find an explanation for my sudden decrease in quality of life and my new reality. We ask that you consider the number of MA residents, myself included, who suffer from this condition and need support from MGH, Tufts, Beth Israel, and more to diagnose and help treat this condition. We want to return to normal, but it seems normal is no longer an option until we begin to take POTS as a serious medical condition.

Christy Hart  
91 Woburn St  
Lexington MA 02420-2223

Dear Representative Clark, This funding would be important to my family as my young 8 year-old cousin suffers from POTS and it is a devastating condition that affects the whole family, and her ability to function. I hope you will include the funding and the above language in the end of year funding bill. Thank you for your service and consideration.

Deanne Dworski-Riggs  
53 Magoun St # 1  
Cambridge MA 02140-1616

Dear Representative Clark, We just got reassigned to your district and are looking forward to working with you. Sadly, after getting COVID two years ago I got POTS. It's effected my ability to sit, stand, sleep, eat and spend time with friends and family. I still can only work part time. Like many chronic illnesses that effect mainly women it has been understudied. Many healthcare providers don't even know about POTS nevermind having treatments for everyone. I sincerely hope you support this issue and would welcome the opportunity to discuss it further. Deanne Dworski-Riggs 860-655-1880

Susan Sparks  
123 S Shaker Rd  
Harvard MA 1451

Diagnosis and treatment is very difficult and expensive. I have had to go outside of doctors who take insurance to make any progress. Still searching for that elusive approach that will work.

Carrie Richards  
244 Park St Apt A20  
North Attleboro MA 02760-1262

I am a Healthcare worker, Radiologic Technologist, who contracted COVID from a patient at the Boston hospital where I worked in March of 2020. I have since been diagnosed with POTS & other health issues due to Long COVID. I was healthy prior to contracting COVID. Having been diagnosed with POTS and other conditions, it is not easy to work as I did prior. I was fired from the hospital where I contracted COVID the first time. This was due to my previous employer's unwillingness to understand and accommodate me due to my Acute COVID illness and the issues I faced after developing Long COVID. I can't express how unfair this has been. We need help and funding to get back our health. Our world's have been turned upside down in every way imaginable. Researching POTS and it's connection to Long COVID is essential. This is currently effecting millions suffering around the world & the economy.

Carina Wallack  
127 Putnam St  
Watertown MA 02472-1981

I am a POTS patient and I live in Watertown. I've experienced POTS symptoms for as long as I can remember due to a genetic disorder called Ehlers Danlos Syndrome (EDS). I wasn't diagnosed with POTS until I was 26 years old. POTS symptoms including dizziness, nausea, fatigue, and migraines impact my life everyday. We need more specialists, more research, more treatment options, and earlier diagnosis for all patients. Thank you for support of this crucial issue that impacts my life every day.

Tiffany Anderson  
37 Lyman Ave  
Medford MA 02155-4316

I am a resident of Medford and have suffered from POTS for six years. I am disabled due to POTS and comorbid conditions. Please support this much needed funding for research, especially as Long Covid has unfortunately resulted in many more people suffering like me. We desperately need our lives back!

Vivek Mukhatyar  
109 Pine St  
Woburn MA 01801-3373

I am the husband of someone who suffers from dysautonomia and the POTS. Research will be extremely valuable to improve the lives of so many people who suffer from this extremely debilitating condition. This is a small contribution can have a big impact.

Robyn King  
93 Northridge Rd  
Ipswich MA 01938-1456

I keep hearing of more people, especially young women, being affected by this disabling condition. Please increase the funding for POTS research.

Jim Coady  
14 Bradford Rd  
Natick MA 01760-1238

I urge you to support and help patients by funding further research and physician education.

Amy Piselli  
41 Silver lane  
Holliston MA 1746

I was diagnosed with POTS in 2008 and was treated horribly by medical staff who weren't familiar with the disorder and who didn't believe me. I was debilitated for 2-3 years and unable to work or care for my children. My 2 nieces currently have POTS post-COVID infection and are not able to continue their college education full time. Please fight for more funding to help everyone who is currently suffering. Thank you.

Rebecca Freed  
53 4th St  
Medford MA 02155-5001

I've been disabled by POTS for 20 years. I really need treatments developed so that I can go back to work and contribute to society!

Dr. Megan McCoy  
Concord MA 1742

It is imperative we find answers to this disorder that is taking so many people out of the work force and to train doctors to recognize and treat. We need multi-disciplinarian centers for patients to receive appropriate care. This work will not only help patients with Long Covid but others with post viral chronic illnesses that have gone untreated and unrecognized even before Covid hit so many. I urge you to support and help patients by further research and physician education.

Stephanie East  
Gloucester MA 1930

It took 5 years to finally be diagnosed due to the fact it is not known or even understood in the medical community. During that time period were many scary ER visits, doctor,Äôs appointments, and second opinions. I believe more funding is desperately needed to support the research and also more education is definitely needed for this invisible disease. Thank you

Jacqueline Rutter  
47 Northridge Rd  
Ipswich MA 01938-1454

Millions of Americans, mostly young women like my daughter, have had their lives derailed by POTS. Many patients are unable to attend school or work, and struggle with basic activities-of-daily-living. POTS is a poorly-understood, disabling, complex chronic illness with no FDA-approved treatments. Please support this funding request so this largely-neglected patient population will have hope for a brighter future. My family and many others here in Massachusetts would be very grateful.

Sarah Hamilton  
Florence MA 1062

My life was radically changed when I developed POTS after a COVID infection nearly three years ago. Please help us to learn more about this problem so that I and many like me might return more fully to our lives.

Meghan Pauly  
50 Hinckley Rd  
Milton MA 02186-1634

My name is Meghan. I am an undergraduate student studying neuroscience and aspiring to go to medical school to become a pediatrician. While working as an EMT during the pandemic, I contracted Covid and was subsequently diagnosed with POTS. Everyday is a struggle dealing with my symptoms and fainting episodes. Constantly trying new combinations of medications and lifestyle changes is not an efficient or healthy way to manage a chronic illness. Please consider increasing funding for POTS research to find ways for millions of young women like me to manage this chronic condition so we can lead lives full of empathy, learning, and achievement.

Steve Sloan  
178 Goden St.  
Belmont MA 2478

My wife suffers from both dysautonomia and a related connective tissue disorder known as hypermobile Ehlers-Danlos Syndrome, which is also neglected and needs research funding.

Elisabeth Keller  
16 Prentiss St  
Cambridge MA 02140-2212

Our daughter was diagnosed at MGH with POTS 3 years ago. Her life was derailed. The medical system is not equipped to receive and support the growing number of patients with this disorder. Your support for increased funding is greatly needed.

Elizabeth Raycroft  
32 Appomattox Rd  
Ipswich MA 01938-2844  
Please fund POTS research!

Ariel Macey  
15 Powers Rd  
Mendon MA 01756-1045  
Please help so many that are suffering and disabled. We need more funding to research how to serve this community better! Your advocacy is paramount. Thank you.

William Simon  
84 Line St Apt 2  
Somerville MA 02143-4484  
Please please please support more spending on research into POTS.

Annie Peters  
396 S Main St  
Brookline MA 2445  
Please support additional POTS funding. We want to work and live our lives. Thanks.

Heather Finlay-Morreale, MD  
64 Gates Rd  
Shrewsbury MA 01545-2329

Please support more funding for POTS research. PreCOVID it was already a major problem disabling many, myself included. Now with so many LongCOVID cases involving POTS it is an issue affecting work force size and mass-scale disability. It is still a little understood disease and even with today's best treatments, which aren't much, many remain unable to function. More funding could accelerate better treatments.

Krista Ripley  
Melrose MA 2176

Please support POTS research so no one else has go 8+ years without a proper diagnosis and treatment. There are so many others like me on this petition and around the country.

Leah Spada  
124 Linden St  
Attleboro MA 02703-4828

Please support this in support of my amazing sister!!

Andrew Gully  
47 Northridge Rd  
Ipswich MA 01938-1454

POTS disproportionately impacts women. In fact, 90 percent of the patients nationwide are females, with symptoms starting in middle and high school years, college and beyond. Studies now show Long COVID is dramatically growing this population, which historically has had a difficult time being taken seriously because POTS is not well understood and women's health concerns are often dismissed. Massachusetts, with its excellent colleges and universities, has a large and envious population of promising young women. POTS, however, is robbing a large number of them of their expected futures as engaged, energetic and productive residents. I know what that means. My daughter has had POTS for 15 years. The quality of her life has eroded to the point she has been unable to work for three years. The only hope for her, and little girls coming behind her, is research into the causes and possible treatments for POTS. Please support this request.

Susan Gordon-Schiowitz  
25 Hereford Rd  
Marblehead MA 01945-1814

Thank you for your support on this issue. I was diagnosed with POTS after having COVID at the start of the Pandemic. As a clinical social worker, I have had the opportunity to providing support and counseling to people and families living with the impact of chronic illnesses throughout my career since the 1990s. Since my own parent has had dysautonomia for over 30 yrs (only recently diagnosed), I understand both personally and professionally what it means to live in this situation, not getting answers, and watching someone suffer. Now, becoming a patient myself has really opened my eyes even more to the grueling and lonely nature of having a chronic, and so far, incurable condition which has drastically interfered with quality of life for myself and my household. I'd be happy to share my story with you. Thank you for your help!

Kevin Convey  
643 Ash St  
Brockton MA 02301-5754

The daughter of one of my best friends is beset by this condition -- and it is heartbreaking. Please do what you can to help her and millions of others who suffer.

Jojo Emerson  
6E Gregory Island Rd  
South Hamilton MA 01982-2620

We hope your advocacy for an increase of research funding for POTS can help the patients, families, and caregivers in your constituency find a cure!

Jake M.  
Boston MA 02114  
More money for POTS!

Stephen & Deb Rutter  
33 Summer St  
Andover MA 01810-3626

Kathleen Kiley  
20 Fuller St Apt 2  
Gloucester MA 01930-3912

Lindsay Spada  
7 Livermore St  
Worcester MA 01606-1154

Susan Russell  
24 High St  
Ipswich MA 01938-1946

Jessica Horwitz  
7 Henry St  
Winchester MA 01890-3608

Mitesh Mehta  
16 Blueberry Hill Ln  
Melrose MA 02176-6400

George Diep  
53 Magoun St  
Cambridge MA 02140-1616

Jessica Smolow  
55 Milton St  
Arlington MA 02474-8705

Annie Bonsey  
16 Prentiss St  
Cambridge MA 02140-2212

Emily Conrad  
127 Putnam St  
Watertown MA 02472-1981

Catherine Cuddy  
34 Little Tree Ln  
Framingham MA 01701-4774

Clare McNamara  
62 Marlboro Rd  
Woburn MA 01801-3440

Lillian Mela  
10 Cherry St  
Lexington MA 02421-4121

Diana Agori  
Cambridge MA 02138

Erin Rowland  
178 Goden St  
Belmont MA 02478-2951

Katie Pellecchia  
87 Homer St  
East Boston MA 02128-1531

Alyssa Boffoli  
6 Hadley Pl Apt 1  
Medford MA 02155-3931

Christina Christoforo  
78 Clark Rd  
Ipswich MA 01938-2811

Luke Hanley  
12 Braemore Rd  
Medford MA 02155-6579

Brian Mitterko  
7 Livermore St  
Worcester MA 01606-1154

Dan Bryant  
2 Birchmeadow Rd  
Amesbury MA 01913-5503

Jacklyn Rouse  
18 P Tree Ln  
Kingston MA 02364-1882

Anastasia Vekiarides  
463 Weld Street  
MA 02132

Frank Rose  
778 Bay St  
Taunton MA 02780-1311

Shivangi Mehta  
16 Blueberry Hill Ln  
Melrose MA 02176-6400

Kelly Lynn  
133 Seaport Blvd  
Boston MA 02210-2659

Ann Carlson  
5 Tiger Row  
Georgetown MA 01833-1247

Elizabeth Doherty  
130 Cambridgepark Dr Unit 433  
Cambridge MA 02140-2567

Joyce Gully  
23 Navasota Ave  
Worcester MA 01602-1116

Geraldine Costello  
6 Sawyer St  
Wareham MA 02571-2004

James Bush  
Cottage Street  
Hingham MA 02043

Mary Beth Emerson  
305 Mayflower St  
Duxbury MA 02332-4306

Lisa Parker  
6104 Thompson Farm  
Bedford MA 01730-1497

Mark Weiner  
3 Carriage Dr  
Lexington MA 02420-1120

Laura Mandelberg  
46 Teel St # 1  
Arlington MA 02474-5536

Jay Feinstein  
127 Nichols Ave  
Watertown MA 02472-4129

Joshua Driesman  
127 Nichols Ave  
Watertown MA 02472-4129

Julia Goldberg  
8 Saint Paul St  
Cambridge MA 02139

Michele Champion  
46 Northridge Rd  
Ipswich MA 01938-1439

Jonelle Lonergan  
37 Curve Rd  
Stoneham MA 02180-3904

Tishi Shah  
15 Blueberry Hill Ln  
Melrose MA 02176-6400

Kathleen Convey  
643 Ash St  
Brockton MA 02301-5754

Stanley Selkow  
27 Catherine Rose Rd  
Harwich MA 02645-1043

Wendy Giunta  
7 Westover Dr  
Lynnfield MA 01940-1834

Jeffrey Kerner  
36 Tobey Rd  
Belmont MA 02478-4259

Marian Silk  
55 Florence Rd  
Lowell MA 01851-3501

Ben Dorn  
53 4th St  
Medford MA 02155-5001

Christine Adams  
78 Outlook Dr  
Lexington MA 02421-6927

Lisa Tanzer  
25 Northern Ave  
Boston MA 02210-1815

Terrence Costello  
42 Lowell St  
Malden MA 02148-7752

Karen Lekstrom  
80 Ripley Ave  
Marlborough MA 01752-1967

Christine Doherty  
13 Purchase St  
Newburyport MA 01950-3041

Leah Williams  
30 Mount Pleasant St.  
Cambridge MA 2140

Sophie Gordon  
61 Prince St  
Brookline MA 02445-7836

Scott Pettingell  
12 Dotty Ann Dr  
Framingham MA 01701-7600

Tina Ripley  
Melrose MA 02176

Andrea Young  
87 Foundry Rd  
Sharon MA 02067-2879

Sarah Jagdmann  
540 Revere Beach Blvd Unit 530  
Revere MA 02151

Martha Woodward  
5 Hitchin Post Rd  
Chelmsford MA 01824-1919

Ryan Keenan  
47 Northridge Rd  
Ipswich MA 01938-1454

Jacquelyn Booth  
11 Snake Brook Rd  
Wayland MA 01778-5013

Stephanie Bryant  
2 Birchmeadow Rd  
Amesbury MA 01913-5503

Jared Ahern  
Stoneham MA 02180

Audrey and Neil OConnor  
26 Stillman St Apt 6-4  
Boston MA 02113-1695

Liz Duffy  
17 Viking Ln  
Sandwich MA 02563-2664

Leslie Brunetta  
29 Roberts Rd  
Cambridge MA 02138-3226

Brian Flood  
410 Boston Post Rd  
Sudbury MA 01776-3058

Dylan Gully  
6E Gregory Island Rd  
South Hamilton MA 01982-2620

Mary Artacho  
88 Bay Dr  
Sudbury MA 01776-1957

Lori Bouchard  
202 Moulton St  
South Hamilton MA 01982-1226

Josephine Lavoie  
303 Lees River Ave  
SOMERSET MA 02725

Mary Pritchard  
399 River Rd  
Andover MA 01810-4276



Dara Casey  
64 Holt Rd  
Andover MA 01810-4122

Deborah Selkow  
27 Catherine Rose Rd  
Harwich MA 02645-1043

Ilene Weiner  
3 Carriage Dr  
Lexington MA 02420-1120

Gary Young  
87 Foundry Rd  
Sharon MA 02067-2879

Lindsay Horowitz  
2 Westgate Rd  
Framingham MA 01701-8836

Samantha Young  
87 Foundry Rd  
Sharon MA 02067-2879

Cindy Moy  
Arlington MA 02476

Ronald Boudreau  
65 Bridge St  
Medfield MA 02149

Marisa Vest  
Boston MA 02111

Carla Cornejo  
Roslindale MA 02131

Carol Ryan  
38 Appomattox Road Ipswich  
Ipswich MA 01938

Gerri Wright  
103 Burlingame Rd  
Charlton MA 01507-5203

Aiko Callahan  
7 Brownlea Rd  
Framingham MA 01701-4213

Ann Fay  
5 Goulding St E  
Sherborn MA 01770-1632

Maia Selkow  
Harwich MA 02645

Caroline Becker  
24 Concord Ave  
Cambridge MA 02138-2370

Caroline DeLuca  
349 Crescent St  
Waltham MA 02135

Stephanie Lampila  
608 Boston Post Rd E Apt 24  
Marlborough MA 01752-3743

Leah Rogoff  
Boston MA 02114

Nancy McGurl  
33 Pope Rd  
Acton MA 01720-5623

Eric Shaw  
43 Fayette St Apt 1  
Cambridge MA 02143

Ian Garvie  
40 Howard Ct Unit 4  
Woburn MA 01801-5805

Dawn Correale  
12 Cricklewood Ln  
Melrose MA 02176-4219

Geetika Gupta  
109 Pine St  
Woburn MA 01801-3373

Irene Li  
Brighton MA 2135  
Alex Caulfield  
Somerville MA 02143

Jacob Marsh  
Brookline MA 02446

Ben Levine  
25 Hereford Rd  
Marblehead 01945

Joan Best  
Ipswich MA 01938

Annie Fortnow  
Watertown MA 02472

Jeff Clouter  
3 Drury Ln  
Natick MA 01760-1201

Spandan Shah  
Melrose MA 02176