DYSAUTONOMIA INTERNATIONAL
AWARENESS ADVOCACY ADVANCEMENT

Post Office Box 596
East Moriches, NY 11940

info@dysautonomiainternational.org
www.dysautonomiainternational.org

October 27, 2023

The Honorable Bill Cassidy
Ranking Member
Senate Health, Education, Labor and Pensions Committee

Re: Recommendations to Improve the National Institutes of Health

Dear Senator Cassidy:

On behalf of Dysautonomia International, thank you for the opportunity to provide comments on how the National Institutes of Health (NIH) can improve its processes to better support lifesaving biomedical research.

Dysautonomia International is a U.S. based non-profit organization dedicated to raising awareness, promoting research, and providing support for over 70 million individuals living with dysautonomia worldwide. Dysautonomia is an umbrella term used to describe various medical conditions that cause a malfunction of the autonomic nervous system, which is responsible for regulating automatic bodily functions such as heart rate, blood pressure, digestion, sweating, pupil function, bladder function, and temperature control. Problems with the autonomic nerves can lead to widespread, often debilitating symptoms, making daily life challenging for those affected. Despite its impact, dysautonomia is frequently misunderstood and often goes undiagnosed. Unfortunately, most forms of dysautonomia have no FDA approved treatment options, leaving patients and their families without hope for a better future.

For the past six years, our organization has worked with Congressional champions to include language in each end-of-year federal funding bill encouraging the NIH to increase research on a common form of dysautonomia called postural orthostatic tachycardia syndrome (POTS). POTS was estimated to impact three million Americans pre-pandemic, and it most often develops after an infection. Unfortunately, millions of Americans have developed new onset cases of POTS after a COVID-19 infection. A recent Stanford study found that 67% of Long COVID patients are developing moderate to severe dysautonomia, most commonly presenting as POTS.[1] Additionally, Walter Reed National Military Medical Center physicians note that half of their Long COVID patients are meeting the criteria for POTS.[2] To date, NIH POTS research funding has remained stagnant at approximately $2 million per year – less than 20 cents per

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[1] https://www.frontiersin.org/articles/10.3389/fneur.2022.1012668/full

[2] https://walterreed.tricare.mil/News-Gallery/Articles/Article/3558601/walter-reed-partners-with-uniformed-services-university-to-treat-long-haul-covid

patient annually – whereas other neurological diseases that cause similar disability and impact fewer Americans, such as Parkinson's and multiple sclerosis, receive over $100 per patient annually. Dysautonomia International is deeply concerned that the NIH has ignored congressional directives to increase its investment in POTS research, which has contributed to a lack of treatment options for patients

Our organization has tried to work with the NIH in earnest to increase the pace and quality of POTS research in the U.S. As part of that work, we have asked the NIH how many POTS grant applications the NIH has received, and how many NIH has received and not funded in recent years. This would help us better understand whether POTS applications are being turned down and why, or if not enough POTS applications are being submitted in the first place. If the former, we would be able to assist the research community in drafting better grant applications to successfully advance science for the benefit of patients. If the latter, we would be able to refocus efforts on stimulating the research field by encouraging early-researchers to join the POTS field. To date, NIH leadership has refused to provide this information. In that same vein, we are concerned that the NIH has repeatedly provided inaccurate public reporting regarding POTS research funding. Many NIH reports claim that the agency is funding more POTS research than it actually is. For example, the NIH's online annual categorical spending report for FY2020 claims that a $593,377 Parkinson's disease imaging study occurring at NIH is a POTS study.[3] This study has nothing to do with POTS, as confirmed by the NIH researchers involved. Our organization, and a group of 30 leading POTS experts from our nation's finest medical institutions, have written to the NIH asking for corrections to these public reports, but our pleas have been disregarded.[4]

Financial conflicts of interest (COI) amongst individuals responsible for NIH decision making is another concern. In serving on several committees as part of the NIH's RECOVER study, a $1.15 billion federal effort to understand Long COVID, we have noticed that some of the RECOVER decision makers, researchers appointed by NIH to serve on various decision-making committees, had clear financial conflicts of interest. Current NIH COI requirements should have prohibited these individuals from voting on research involving companies they had ownership or other financial relationships with. This is a basic tenet of research ethics, and ethics becomes even more important when studies are being paid for by taxpayer dollars. We raised these ethics concerns with RECOVER leadership at New York University, the Duke Clinical Trials Research Institute, and with NIH leadership. To our knowledge, nothing has been done to investigate these conflicts or address them.

Finally, we are concerned about the peer-review process at NIH. POTS and other forms of dysautonomia are not well-known to most clinicians and researchers, even those with prestigious academic pedigrees. POTS patients take an average of over four years to get properly diagnosed, and the average patient has to see seven doctors before they are diagnosed. After diagnosis, 75% of POTS patients encounter a clinician who is unaware of POTS thus lacking the knowledge on how to treat it. It is our experience that the same knowledge gap on POTS exists within NIH staff and on the peer-review panels. NIH is sending applications for POTS to peer-review panels that have no expertise in the disease area they are making decisions on,

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[3] National Institutes of Health, Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), FY2020; NINDS Project Number 1ZIANS003033-14, Mechanisms of Catecholaminergic Neurodegeneration. See https://report.nih.gov/funding/categorical-spending#.

[4] See page 4 of the March 4, 2020 Letter to NIH Director Francis Collins (Attachment A)

resulting in lower scores for POTS applications that would likely score well if they were for a more well-known disease. This inevitably influences what researchers choose to focus on, especially when they rely on federal dollars to launch or sustain their medical research careers. In fact, we have had several POTS researchers indicate to us that their university department chairs told them not to focus on POTS research, because they will never get funded by NIH.

While we are supportive of the overall mission of the NIH and understand it has a difficult mission to fulfill, we are concerned that lack of accountability is a consistent pattern. We do not want our comments to be used to reduce NIH funding or turn NIH decision making on research grants over to elected officials, but we do want NIH to feel a sense of responsibility and accountability to the American taxpayer, and to operate with the idea that transparency is better than secrecy when it comes to public funding of medical research.

Our recommendations to address the concerns raised above are as follows:

1. Require Accurate Information to be Included in NIH Spending Reports

To ensure accuracy in the information NIH shares with Congress and the public on its spending decisions, we recommend requiring NIH to update its online Estimates of Funding for Various Research, Condition and Disease Categories (RCDC) to ensure that information on POTS spending is accurate. See Attachment A for examples of erroneously classified studies.

2. Require Transparency in NIH Grant Application Decision-Making

To enhance transparency and public trust in the grant decision making process, we recommend that the NIH be required to publicly report the following:

2a. The number of all research applications received annually and the total dollar amount of grant applications received for each disease area annually, tracked by the categories in the NIH's existing Research, Condition and Disease Categorization Process reports.

2b. The number of all research applications sent through the peer-review process within NIH, and the total dollar amount of grant applications sent through the peer-review process within NIH, tracked by the categories in the NIH's existing Research, Condition and Disease Categorization Process reports.

2c. The number of all research applications received that were not sent to the peer-review process and the total dollar amount of grant applications that were not sent through the peer-review process, tracked by the categories in the NIH's existing Research, Condition and Disease Categorization Process reports.

2d. A report summarizing this information should be available online for public review and updated annually. It should follow the format of the existing RCDC report, or be a supplement to that report.

3. Implement and Enforce Uniform Conflict Disclosure Policies Across NIH

To reduce conflicts of interest amongst individuals entrusted to make decisions and recommendations to NIH, to strengthen public trust in the NIH, and to streamline the conflicts disclosure process at NIH:

3a. All NIH grant applicants, collaborators, consultants, contractors, subcontractors, advisors, committee or panel members, employees, and anyone with the ability to influence decision making on the use of NIH funding, research priorities, or study design, should be required to submit a uniform conflicts of interest disclosure form.

3b. For practicality, we would recommend an online form.

3c. These conflict disclosure forms should be maintained in a publicly accessible online database.

3d. All members of NIH decision making and advisory committees, such as the RECOVER committees, peer-review panels, and other decision-making bodies, should have real time access to the disclosures of their decision-making peers prior to any vote of the committee member.

3e. NIH should establish a uniform policy for individuals with conflicts to recuse themselves from any decision-making action which is relevant to their conflict of interest.

3f. NIH should establish a uniform process for researchers, study participants, committee members, advisory board, NIH staff, or members of the public, to raise conflict of interest concerns, and a process for NIH to investigate and respond to those concerns in a timely manner.

4. Invite Knowledgeable Researchers, Clinicians and Patient Advocates to Review Rare or Underserved Disease Applications

To improve the quality of the funding decisions made by NIH and enhance public trust in the NIH:

4a. Congress should encourage and empower NIH to utilize peer-reviewers who have actual research and/or research expertise, or lived experience, in the disease area they are making grant funding decisions on. While we did emphasize the need for improved conflict disclosure policies above, we also believe that NIH's conflict policies as applied to the peer-review process may be overly strict, resulting in many highly qualified peer-reviewers being eliminated from the pool of potential reviewers even when their conflict is not relevant to the research proposals they are being asked to review.

4b. At a minimum, NIH peer-review panels should be required to have three experts in a disease area prior to scoring and grant funding decisions on applications for rare and underserved disease areas.
4c. NIH should implement a program to provide science-savvy patient experts opportunities to review grant applications and provide input on the NIH decision making process, particularly in rare or underserved diseases where it may be harder to find clinical and research experts. There are many patients advocates who know just as much about their disease as the leading researchers in their field, and patient engagement in medical research design, implementation, grant decision-making, and pre-publication peer-review is already happening outside of NIH.

4c. Rare diseases are already defined by federal law as diseases that impact fewer than 200,000 Americans. Underserved disease areas are non-rare conditions that can be objectively identified as “underserved” by the following criteria:

- No FDA approved treatment for the condition, and one of the following:
    - Less than $50M in NIH research funding allocated to study the condition in the prior fiscal year; or
    - Fewer than 20 grants funded by NIH to study the condition in the prior fiscal year.

Dysautonomia International appreciates your consideration of these recommendations. As you develop legislative proposals to improve upon the mission of the NIH, we encourage you to seek continuous input from the patient community, especially those with underserved diseases like POTS and other forms of dysautonomia. If you have any additional questions, please contact me at 631-202-1720 or lstiles@dysautonomiainternational.org.

Respectfully submitted,

L Stiles

Lauren Stiles, JD
President, Dysautonomia International

Enc.

DYSAUTONOMIA INTERNATIONAL
AWARENESS ADVOCACY ADVANCEMENT

ATTACHMENT A

Post Office Box 596
East Moriches, NY 11940

info@dysautonomiainternational.org
www.dysautonomiainternational.org

March 4, 2020

Francis Collins, MD, PhD
Director, National Institutes of Health
Building 1
9000 Rockville Pike
Bethesda, MD 20892

Re: NIH Report on Postural Orthostatic Tachycardia Syndrome (POTS)

Dear Dr. Collins,

The undersigned researchers and clinicians write to you to express concerns regarding the recent NIH report, "Postural Orthostatic Tachycardia Syndrome (POTS): State of the Science, Clinical Care, and Research" which you submitted to the House and Senate Appropriations Committees on January 31, 2020. We have concerns regarding the process NIH implemented to create the report. Additionally, there are several factual errors in the report, and the report fails to provide the information requested by Congress, which we consider essential to moving this field of research forward.

Concerns About The Process NIH Used to Create the Report

As you know, in the report accompanying the fiscal year (FY) 2019 appropriations for the Department of Health and Human Services, the Senate Committee on Appropriations stated, in pertinent part:

> *The Committee encourages NHLBI and NINDS to jointly host a symposium with participants from NIAID, NIDDK, NICHD and leading external researchers and stakeholders to examine the current state of POTS research. The Committee directs the NIH to provide a report to the House and Senate Committees on Appropriations 9 months after enactment of this act* ***that reflects participants' findings*** *on: (1) the current state of POTS research; (2) priority areas of focus for future POTS research through 2025; (3) a summary of ongoing or upcoming efforts by NIH to advance the scientific understanding of POTS; and (4) an estimate of the level of funding that would be needed annually to achieve objectives (2) and (3).* (Senate Reports 115-289, page 92) (emphasis added)

On July 29, 2019, 29 POTS experts from around the world gathered at the NIH offices in Bethesda, MD for the first-ever NIH research meeting on POTS. The group was eager to begin a conversation with NIH on the critical unmet needs in our field and exciting opportunities for new research that would allow us to deliver more effective treatments for millions of Americans living with POTS.

Unfortunately, the resulting NIH report does not reflect the findings of the meeting participants as directed by Congress. The report was written by NIH staff who, respectfully, have little to no expertise in POTS.

The meeting chairs, Satish Raj, MD, MSCI and Steven Vernino, MD, PhD, were the only meeting participants allowed to see a draft of the report prepared by NIH staff. A majority of the substantive edits provided by the meeting chairs were disregarded by NIH staff and not incorporated into the final report. No response was ever provided by NIH staff to the edits the meeting chairs requested, nor did the meeting chairs see a final copy of the report before it was submitted to Congress. The first time the meeting chairs saw the final report was February 11, 2020, eleven days after the final report was submitted to Congress.

None of the other POTS expert meeting participants were given an opportunity to review or comment on the draft report, despite the fact that their names appear on it. Other POTS expert meeting participants requested the opportunity to review and comment on the draft, but their requests were denied by NIH staff.

A fair and transparent process aimed at meeting the Congressional directive to provide a report that included the participants' findings would have allowed all of the POTS experts invited to the meeting adequate time to review and comment upon the report. If NIH staff disagreed with the POTS expert participants' findings, NIH staff could have noted this in the report or in an accompanying letter. Instead, the perspectives of the POTS experts who lent their time and talents to the NIH for the purposes of this meeting were largely ignored.

The Report Contains Several Factual Errors

The report contains several factual errors that should be corrected by the NIH in an amended report. The patient community, the academic community, and the media is likely to cite this report in the future; therefore, NIH has an obligation to ensure that the report is factually accurate.

First, the report asserts that NIH is funding over $9.35M in POTS or related research. This is a grossly inflated number. Of the 14 studies included on the list prepared by NIH staff, only four of them are POTS or POTS related research studies, and one additional grant has a small portion of its funding related to POTS. In total, NIH is currently funding less than $2M in grants related to POTS (see attached spreadsheet). NIH staff ignored edits on the draft report from both meeting chairs seeking to correct this misinformation. This is discussed further below.

Second, the report implies there is serious disagreement amongst experts on the POTS diagnostic criteria, relabeling internationally accepted consensus criteria as "key features" rather than diagnostic criteria. There is no serious disagreement amongst a majority of experts on the POTS diagnostic criteria. The NIH minimized the significance of internationally accepted consensus criteria and ignored edits on the draft report from the meeting chairs seeking to correct this misinformation.

Third, the report falsely claims that chronic fatigue syndrome is the most common co-morbidity in POTS. This was not presented by any expert during the NIH meeting, nor does this appear anywhere in the POTS literature. NIH provides two citations to support this claim. Citation 7 is a 2000 study from Mayo Clinic that does not make any assessment or assertion regarding the percentage of POTS patients who have co-morbid chronic fatigue syndrome. Citation 8 confirms that migraine, irritable bowel syndrome and Ehlers-Danlos syndrome are more common co-morbidities in POTS than chronic fatigue syndrome. Throughout the literature and in clinical practices that serve a large POTS population, it is clear that small fiber neuropathy, migraine, autoimmunity, neurocardiogenic syncope and Ehlers-Danlos syndrome are all equally or more common than chronic fatigue syndrome in the POTS population. NIH staff ignored comments from the meeting chairs regarding the NIH's over-emphasis of the relevance of chronic fatigue syndrome in the report.

Fourth, the report states that half of individuals diagnosed with POTS are children and adolescents. This was not asserted by any expert during the meeting, nor is this supported by the published data on POTS. About half of POTS patients develop POTS symptoms in adolescence, and half develop POTS symptoms in adulthood.[1] A majority of adolescent onset patients have not fully recovered by the time they reach adulthood,[2] therefore a majority of individuals living with POTS are adults.

Fifth, the report claims "NIH investigators also have reported POTS in families who carry genetic mutations that cause increased production of alpha-tryptase." NIH investigators did not report a genetic mutation. They reported on a few families who had duplicate copies of the alpha-tryptase gene, which is known to occur in about 5% of the general population.

Sixth, the report claims that "[p]hysicians also recommend that patients with POTS regularly check and track their blood pressure and pulse." This was not stated by any of the experts during the meeting, and it is contrary to the advice that is given by most POTS experts to their patients. Regular monitoring of blood pressure and pulse is only recommended by clinicians to POTS patients in limited circumstances, such as when starting a new medication, or when beginning a new exercise regimen.

Seventh, the report states that structural studies of the autonomic nerves would be invasive and "unlikely to benefit patients." The assertion that neuropathology studies are unlikely to benefit patients was never made during the expert meeting. In many autonomic labs, it is routine clinical practice to perform skin punch biopsies to screen for small fiber neuropathy in POTS patients. This benefits patients, because it can confirm the presence of small fiber neuropathy, providing validation for the patient, and leading to identification of a treatable underlying cause in some cases.

The Report Fails To Provide the Information Requested by Congress

Congress directed NIH to prepare a report that reflected the meeting participants' findings on four objectives:
(1) the current state of POTS research;
(2) priority areas of focus for future POTS research through 2025;
(3) a summary of ongoing or upcoming efforts by NIH to advance the scientific understanding of POTS; and
(4) an estimate of the level of funding that would be needed annually to achieve objectives (2) and (3).

Objective 1

The report barely achieves objective 1. There has been 25 years of research progress in understanding POTS, but the report only includes a three-page summary. Outdated studies are cited throughout the report. A majority of the study findings POTS experts presented during the meeting were not mentioned or cited in the report.

Objective 2

The report broadly describes eight priority areas for future research. This is the one part of the report that seems to have met the objective.

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[1] Shaw, BH, Stiles, LE, Bourne, K, Green, EA, Shibao, CA, Okamoto, LE, Garland, EM, Gamboa, A, Diedrich, A, Raj, V, Sheldon, RS, Biaggioni, I, Robertson, D, Raj, SR. The face of postural tachycardia syndrome – insights from a large cross-sectional online community-based survey. *J Intern Med* 2019; 286: 438– 448.

[2] Bhatia R, Kizilbash SJ, Ahrens SP, Killian KM, Kimmes SA, Knoebel EE, Muppa P, Weaver AL, Fischer PR. Outcomes of Adolescent-Onset Postural Orthostatic Tachycardia Syndrome. *J Pediatr*. 2016;173:149–153.

Objective 3

As noted above, the report grossly exaggerates NIH's ongoing efforts to advance the scientific understanding of POTS by including millions of dollars in research funding that has nothing to do with POTS in the report.

NIH staff completely disregarded edits requested by the meeting chairs, who advised NIH staff that most of the funding on the list was not related to POTS whatsoever.

The items in **bold** in this table were presented in the NIH report as part of "Table 1 - Active NIH Funding for Projects on POTS and Related Research" (NIH POTS Report, page 15). The items in *red italics* are the actual numbers, as determined by the meeting chairs and other POTS experts who carefully reviewed each project NIH included in the report.

Table 1. Active NIH Funding for Projects on POTS and Related Research

NIH ICO	**Number of projects claimed to be POTS related by NIH**	*Number of POTS related projects determined by POTS experts*	**Active POTS Related Funding Claimed by NIH**	*Active POTS Related Funding determined by POTS experts*
NHGRI	**1**	*1*	**$166,235**	*$166,235*
NHLBI	**5**	*3*	**$2,270,230**	*$1,588,514*
NIDCD	**1**	*NONE*	**$511,179**	*NONE*
NICHD	**1**	*NONE*	**$400,541**	*NONE*
NINDS	**4**	*NONE*	**$4,783,993**	*NONE*
Office of the Director	**2**	*NONE*	**$1,226,406**	*NONE*
Totals	**14**	*4*	**$9,358,584**	*$1,754,749*

Detailed comments on the relevance or non-relevance of each study listed by NIH can be found on the attached spreadsheet.

For example, NIH claimed an NINDS intramural study, Biomarkers of Catecholaminergic Degeneration, is a POTS related study. However, the study is about neurodegenerative disorders like Parkinson's and multiple system atrophy, diseases that occur in the elderly that have nothing to do with POTS. The meeting chairs pointed out this error to NIH staff, but their requested edits were ignored.

In addition to exaggerating the amount of funds NIH is spending on POTS or POTS related research, the report offers no information on upcoming efforts by NIH to advance the scientific understanding of POTS between 2020 and 2025. In fact, all of the POTS related grants cited by NIH expire by 2023.

Objective 4

The report completely fails to address objective 4. No estimate of the level of funding needed to achieve objectives 2 and 3 is provided.

While the report was supposed to reflect the participants' findings on the amount of funding needed to achieve the research objectives, NIH staff told the POTS expert speakers prior to the meeting that they were not allowed to recommend or even mention dollar amounts needed to fund the research priorities identified. There was no time on the agenda developed by NIH staff allocated to discussing what POTS research NIH was already funding, or the funding needed to achieve the priority areas identified by the meeting participants.

The report states “NIH is committed to sustained funding in order to advance research on POTS.” Again, this is not what Congress asked the NIH to report on. Congress asked NIH to report **the participants’ findings** regarding the top research priorities until 2025, and how much it would cost to fund those priorities. Moreover, sustained funding of $2M per year is insufficient to properly study even one of the eight priority areas mentioned in the report.

Conclusion

We urge the NIH to prepare a revised report with input from the meeting chairs and other POTS experts that offers Congress more accurate information on POTS, an accurate assessment of NIH’s active POTS research funding, specific priority areas for future research, and the funding necessary to achieve those objectives by 2025.

Sincerely,

Satish Raj, MD, MSCI, FACC
NIH POTS Meeting Co-Chair
President, American Autonomic Society
Professor of Cardiac Sciences
University of Calgary

Steven Vernino, MD, PhD
NIH POTS Meeting Co-Chair
President Elect, American Autonomic Society
Distinguished Teaching Professor & Vice Chair
Department of Neurology & Neurotherapeutics
University of Texas Southwestern

Hasan Abdallah, MD, FAAP, FACC, FSCAI
Medical Director
The Children’s Heart Institute

Amy C. Arnold, PhD
Assistant Professor
Department of Neural & Behavioral Sciences
Penn State College of Medicine
Adjunct Assistant Professor
Division of Clinical Pharmacology
& Autonomic Dysfunction Center
Vanderbilt University Medical Center

Jonas Axelsson, MD, PhD
Associate Professor
Department of Clinical Immunology
Medical Director, Center for Apheresis and Stem Cell Handling
Karolinska University Hospital
Clinical Research Center
Lund University

Roy L. Freeman, MD
Professor of Neurology
Director, Center for Autonomic and Peripheral Nerve Disorders
Harvard Medical School

Brent Goodman, MD
Assistant Professor of Neurology
Director, Autonomic Laboratory
Mayo Clinic

Blair P. Grubb, MD
Distinguished University Professor of Medicine and Pediatrics
Director, Clinical Cardiac Electrophysiology
Director, Clinical Autonomic Disorders Center
University of Toledo Medical Center

Mitchell Miglis, MD
Clinical Assistant Professor
Neurology and Neurological Sciences, Autonomic Division
Psychiatry and Behavioral Sciences, Sleep Medicine Division
Stanford University

Amanda J. Miller, PhD
Postdoctoral Fellow
Department of Neural and Behavioral Sciences
Pennsylvania State University College of Medicine

Jeffrey P. Moak, MD
Director, Electrophysiology and Pacing
Department of Cardiology
Children’s National Health System

Italo O. Biaggioni, MD
Professor of Medicine and Pharmacology
David Robertson, MD Professorship in Autonomic Disorders
Director, Vanderbilt Autonomic Dysfunction Center
Vanderbilt University Medical Center

Jeffrey Boris, MD
Pediatric Cardiologist

Kamal R. Chémali, MD
Associate Professor of Neurology
Eastern Virginia Medical School
Medical Director, Sentara Autonomic and Neuromuscular Center
Sentara Healthcare

Tae Chung, MD
Assistant Professor of PM&R and Neurology
Director, Johns Hopkins POTS Clinic Program
Johns Hopkins University

Melissa M. Cortez, DO
Assistant Professor of Neurology
Director, Autonomic Laboratory
University of Utah

André Diedrich, MD, PhD
Research Professor of Medicine and Biomedical Engineering
Vanderbilt Autonomic Dysfunction Center
Vanderbilt University Medical Center

Taylor Doherty, MD, FAAAAI
Associate Professor
Section Chief, Allergy and Immunology
Department of Medicine
University of California, San Diego
Staff Physician, Allergy and Immunology
VA San Diego Health System

Artur Fedorowski MD, PhD, FESC
Associate Professor
Dept. of Clinical Sciences
Lund University
Senior Consultant, Syncope Unit
Dept. of Cardiology
Skåne University Hospital

Laura A. Pace, MD, PhD
Assistant Professor
Department of Internal Medicine, Division of Gastroenterology
Director, Neurogastroenterology Clinic
Co-Director, Multidisciplinary Ehlers-Danlos Syndromes Clinic
University of Utah Adult Co-Lead, NIH Undiagnosed Diseases Network
Center for Genomic Medicine, University of Utah

Peter C. Rowe, MD
Professor
Department of Pediatrics
Sunshine Natural Wellbeing Foundation Professor of Chronic Fatigue and Related Disorders
Johns Hopkins University School of Medicine

Robert S. Sheldon, MD, PhD
Professor of Cardiac Sciences, Medicine and Medical Genetics
Libin Cardiovascular Institute of Alberta
University of Calgary

Cyndya Shibao, MD, MSCI, FAHA, FAAS
Associate Professor
Department of Medicine
Division of Clinical Pharmacology
Vanderbilt Autonomic Dysfunction Center
Vanderbilt University Medical Center

Julian Stewart, MD, PhD
Professor of Pediatrics, Physiology and Medicine
Director, Center for Hypotension
New York Medical College

Lauren Stiles, JD
President, Dysautonomia International
Research Assistant Professor of Neurology
Stony Brook University School of Medicine

David M. Systrom, MD
Assistant Professor
Pulmonary & Critical Care Medicine
Director, Advanced Cardiopulmonary Exercise Testing Program
Harvard Medical School

cc: Hon. Senator Roy Blunt
Hon. Senator Patty Murray
Hon. Representative Rosa DeLauro
Hon. Representative Tom Cole
Members of the Senate Appropriations Committee, Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Members of the House Appropriations Committee, Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Enc.

NIH Claimed POTS Funding vs Actual POTS Funding

March 4, 2020

Institute	Grant Number	Study Title and Citation in NIH Report	NIH Reporter Database Link	NIH Claimed POTS Related Research Funding	*Actual NIH POTS Related Research Funding*	***POTS Expert Determination: Is this a POTS or POTS Related Study?***	***POTS Expert Notes***
NHGRI	K08 HG008986-03	Individual Genomic Analyses to Discover the Molecular Basis and Mechanisms Contributing to Adult-Onset Disease 49	https://projectreporter.nih.gov/project_info_description.cfm?aid=9625792&icde=0	$166,235	*$166,235*	***POTS Related***	*This study is primarily focused on Ehlers-Danlos syndrome. Project ends Jan 2022.*
NHLBI	R01 HL128393-03	Autoimmune Basis for Postural Tachycardia Syndrome 34	Citation #34 links to a journal article on NET deficiency published in 2000, but here's the Reporter database link for the autoimmune POTS study: https://projectreporter.nih.gov/project_info_description.cfm?aid=9609479&icde=48577747	$587,364	*$587,364*	***POTS***	*This is a POTS study. Project ends Dec 2020.*
NHLBI	R00 HL122507-05	Autonomic: Angiotensin-(1-7) Interactions in Hypertension 55	https://projectreporter.nih.gov/project_info_description.cfm?aid=9482743	$244,491		***NOT POTS***	*Principal Investigator Dr. Amy Arnold confirms that this study is not related to POTS research. Study population is autonomic failure and rats with metabolic syndrome.*
NHLBI	R56 HL142583-01	Autonomic Determinants of Postural Tachycardia Syndrome 42	Citation #42 links to journal article on POTS published in 2012, but here's the Reporter database link for the Autonomic Determinants study: https://projectreporter.nih.gov/project_info_description.cfm?aid=9740250&icde=48577789&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&	$390,661	*$390,661*	***POTS***	*This is a POTS study. Project ends Aug 2023*
NHLBI	R01 HL134674-03	Cardiovagal Baroreflex Deficits Impair Neurovascular Coupling and Cognition in Postural Tachycardia Syndrome 30	Citation #30 links to 2014 journal article on POTS from David Kem's lab, but here's the link to the Cardiovagal Baroreflex study: https://projectreporter.nih.gov/project_info_description.cfm?aid=9695261&icde=48577797&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=	$610,489	*$610,489*	***POTS***	*This is a POTS study. Project ends May 2021*
NHLBI	R15 HL147286-01	Identification of Central Neural Pathways Responsible for FGF21-induced Changes in Sympathetic Metabolic and Cardiovascular Activity 61	https://projectreporter.nih.gov/project_info_description.cfm?aid=9731974	$437,225		***NOT POTS***	*This is about exploring mechanisms of metabolic syndrome that regulate blood pressure, and it has nothing to do with POTS.*
NICHD/OD	R01 HD072208-05	Pediatric CFS in a Community-Based Sample 58	https://projectreporter.nih.gov/project_info_description.cfm?aid=9315183	$400,541		***NOT POTS***	*This study is screening a pediatric population for chronic fatigue syndrome, and then screening CFS patients for orthostatic intolerance. There is no mention of the POTS criteria being applied. The PI has never published on POTS before.*
NIDCD	R01 DC008846-11	Chemical Anatomy and Synaptology of Vestibulo-Sympathetic Pathways 56	https://projectreporter.nih.gov/project_info_description.cfm?aid=9679488	$511,179		***NOT POTS***	*This study is exploring vestibular pathways that regulate blood pressure, claimed relevance to "neurogenic orthostatic hypotention and intolerance." There is no evidence linking POTS to vestibular BP regulation problems. PI has never published on POTS.*
NINDS	U54 NS065736-10	Autonomic Rare Diseases Clinical Research Consortium 62	https://projectreporter.nih.gov/project_info_description.cfm?aid=9564196	$1,250,001		***Most of this is NOT POTS***	*This is the Autonomic Disorders Consortium grant for research on rare autonomic disorders like MSA, PAF and AAG. POTS is not a rare autonomic disorder. A small amount of the total may have been spent to support Dr. Diedrich's vagus nerve stimulation study in POTS. Grant expires June 2020 and the Autonomic Disorders Consortium was not renewed by NIH.*
NINDS	ZIA NS003034-12	Biomarkers of Catecholaminergic Neurodegeneration 31	Citation 31 links to a 2000 paper on ganglionopathy, but here is the link to the Reporter databse entry for the Biomarkers study: https://projectreporter.nih.gov/project_info_description.cfm?aid=10018406&icde=48577672&ddparam=&ddvalue=&ddsub=&cr=2&csb=default&cs=ASC&pball=	$1,495,263		***NOT POTS***	*This is an intramural grant to study Parkinsons/MSA. PI confirmed that this study has nothing to do with POTS.*
NINDS	U54 NS105541-03	Cornell ME/CFS Collaborative Research Center 63	https://projectreporter.nih.gov/project_info_description.cfm?aid=9774340	$1,849,848		***NOT POTS***	*This is an ME/CFS study that has no mention of POTS in the study description on the Reporter database. PI has never published on POTS. Cornell doesn't even see POTS patients. They refer to Columbia.*
NINDS	K23 NS109274-01A1	Mechanisms and Clinical Impact of Myocardial Injury Following Traumatic Brain Injury 64	https://projectreporter.nih.gov/project_info_description.cfm?aid=9816144	$188,881		***NOT POTS***	*This is a study about hypotension and cardiac injury in severe TBI. Severe TBI is not associated with POTS. Hypotension and myocardial injury are not associated with POTS. PI has never published on POTS.*
OD	OT2 OD026580-01S1	Development of the Predictive NeuroCardiovascular Simulator 57	https://projectreporter.nih.gov/project_info_description.cfm?aid=10092300&icde=48958541&ddparam=&ddvalue=&ddsub=&cr=1&csb=default&cs=ASC&pball=	$691,875		***NOT POTS***	*This is a study about mapping pathways of autonomic cariovascular control with the goal of treating arrythmias. POTS is not an arrythmia. POTS is not mentioned in the NIH Reporter abstrract. The PI has never published on POTS.*
OD	OT2 OD023867-01S4	Mapping the Linkage between Auricular Vagus Nerve Receptors and Cardiovagal Modulation 65	https://projectreporter.nih.gov/project_info_description.cfm?aid=9981061	$534,531		***NOT POTS***	*This is mapping of the auricular branch of the vagus branch, which has nothing to do with POTS. PI has never published on POTS.*
				$9,358,584 NIH Claimed POTS Related Research Funding	***$1,754,749 Actual NIH POTS Related Research Funding***		

Attachment A