



AWARENESS



ADVOCACY



ADVANCEMENT

May 8, 2023

Lawrence A. Tabak, DDS, PhD  
Director, National Institutes of Health  
9000 Rockville Pike  
Bethesda, MD 20892

Re: NIH Investment in POTS Research

Dear Dr. Tabak,

The undersigned clinicians and researchers write to you seeking your support for an increase in investment in postural orthostatic tachycardia syndrome (POTS) research by the National Institutes of Health (NIH). We support Dysautonomia International's recent request for a \$50 million increase in NIH POTS research investment in FY2024.

As you may know, in 2018 Congress asked the NIH to hold a POTS expert consensus meeting to identify the top research priorities needed to advance clinical care for millions of Americans living with POTS, and to identify how much funding would be needed to pursue the identified research priorities. As a result, NIH invited many of the undersigned POTS researchers and clinicians to attend the NIH POTS Experts Consensus Meeting, held July 29, 2019 at the NIH campus in Bethesda, MD. Following that meeting, the 30 POTS experts who attended the NIH meeting published two reports documenting their findings from the meeting. Part 1 focused on the state of the science and clinical care, and Part 2 focused on priorities for POTS care and research. Both reports are attached hereto for your reference. The experts noted that an increase in NIH funding of \$10M per year for the next five years would be needed to address the research priorities outlined in the consensus documents. Unfortunately, it does not appear that NIH has increased its POTS research investment since 2019.

The need for NIH to invest more in POTS research is even greater now than it was in 2019, as the POTS population has significantly grown during the COVID-19 pandemic. POTS is one of the many manifestations of autonomic dysfunction that can occur in individuals suffering from post-acute sequelae of SARS-CoV-2 (PASC, often referred to as Long COVID).

The POTS research field is ripe for new investment, with several lines of research that offer great hope for new therapeutic approaches, opportunities to refine the use of existing treatment approaches, and new diagnostic approaches. But we need a greater investment in POTS research to stimulate the field and bring these possibilities to fruition.

We encourage the NIH to issue a funded multi-institute Request for Applications (RFA), with \$50M allocated to funding high-quality POTS research proposals. We encourage the NIH to include a broad range of NIH grant mechanisms in the RFA, from early career development grants, to traditional R01 grants, to larger programmatic grants.

Recognizing that many clinicians and researchers do not receive sufficient training in autonomic disorders and as a result, do not have substantive clinical or research experience in POTS, we also encourage the NIH to create a special interest panel to review POTS grant applications, consisting of experienced POTS researchers and clinicians who can fairly and accurately judge the scientific merit of POTS proposals received by NIH.

In conclusion, we hope that NIH will prioritize POTS research in FY2024 and beyond, so that we can deliver more effective treatments to this large and growing underserved patient community.

Respectfully submitted,

**Steven Vernino, MD, PhD**

Professor and Academic Vice-Chair  
Dr. Bob and Jean Smith Foundation  
Distinguished  
Chair in Neuromuscular Disease Research  
Department of Neurology & Neurotherapeutics  
UT Southwestern Medical Center

**Roy Freeman, MD**

Professor of Neurology  
Director, Center for Autonomic and Peripheral  
Nerve Disorders  
Harvard Medical School

**Tae Chung, MD**

Assistant Professor of PM&R and Neurology  
Johns Hopkins University School of Medicine

**Italo Biaggioni, MD**

Professor of Medicine and Pharmacology  
Director, Vanderbilt Autonomic Dysfunction  
Center  
Vanderbilt University Medical Center

**Mitchell Miglis, MD, FAAN**

Clinical Associate Professor  
Neurology & Neurological Sciences, Autonomic  
Division  
Psychiatry & Behavioral Sciences, Sleep  
Medicine Division  
Co-Director, Post-Acute COVID Syndrome  
Clinic  
Stanford University

**Mohammed T. Numan, MD**

Professor, Pediatric Cardiology  
Director, Pediatric Cardiac Electrophysiology  
The University of Texas Health Science Center  
at Houston

**Julian Stewart, MD, PhD**

Professor of Pediatrics, Physiology &  
Medicine  
Director, Center for Hypotension  
New York Medical College

**Peter Novak, MD, PhD**

Associate Professor of Neurology  
Brigham and Women's Hospital  
Harvard Medical School

**Malcolm V. Brock, MD**

EF Gordon Professor of Surgery  
Johns Hopkins University School of  
Medicine

**Glen Cook, MD**

Director, Autonomic Clinic  
Walter Reed National Military Medical  
Center  
Assistant Professor, Department of  
Neurology  
Uniformed Services University F. Edward  
Hebert School of Medicine

**Blair Grubb, MD**

Distinguished University Professor of  
Medicine and Pediatrics  
Division of Cardiology, Department of  
Medicine  
College of Medicine and Life Sciences  
The University of Toledo Medical Center

**Hasan Abdallah, MD, FAAP, FACC,  
FSCAI**

Medical Director, Children's Heart Institute  
Director of Regional Cardiac Services,  
Blalock Taussig Thomas Heart Center  
Johns Hopkins Medicine

**Melissa Cortez, DO**

Associate Professor of Neurology  
Director, Autonomic Laboratory  
University of Utah

**Satish Raj, MD, MSCI**

Professor of Cardiovascular Medicine  
University of Calgary

**Mark Gudesblatt, MD**

South Shore Neurologic Associates  
New York University

**Jeff Boris, MD**

Pediatric Cardiologist  
Jeffrey Boris, MD, LLC

**Taylor Doherty, MD, FAAAAI**

Professor of Medicine  
Interim Co-Chief, Division of Rheumatology,  
Allergy and Immunology  
Department of Medicine  
University of California, San Diego  
Staff Physician, Allergy and Immunology  
VA San Diego Health System

**Paola Sandroni, MD, PhD**

Professor of Neurology  
Mayo Clinic

**Svetlana Blitshteyn, MD**

Director & Founder, Dysautonomia Clinic  
Clinical Associate Professor of Neurology  
University at Buffalo Jacobs School of  
Medicine & Biomedical Sciences

**Alexis Cutchins, MD**

Assistant Professor of Medicine  
Division of Cardiology  
Medical director of the EUHM Echo lab  
Emory Women's Heart Center

**Sarah Diekman, MD**

Instructor, University of North Carolina  
Director, Diekman Dysautonomia, LLC

**Cyndya A. Shibao, MD, MSCI, FAHA, FAAS**

Associate Professor of Medicine  
Vanderbilt Autonomic Dysfunction Center  
Vanderbilt University Medical Center

**Amanda Miller, PhD**

Post-Doctoral Fellow  
Penn State Hershey Medical Center

**Nicholas Wiessner Larsen, MD**

Clinical Assistant Professor, Neurology &  
Neurological Sciences  
Stanford University

**Andrew A. White, MD FAAAAI FAAAAI**

Clinical Professor of Medicine  
Division of Allergy, Asthma and  
Immunology  
Scripps Clinic

**Todd Levine, MD**

Medical Director Neurology  
Honor Health

**Brittany Adler, MD**

Assistant Professor of Medicine  
Division of Rheumatology  
Johns Hopkins University School of  
Medicine

**William Frye, PhD, BCB, ABPP**

Pediatric Psychologist  
Johns Hopkins All Children's Hospital

**David Saperstein, MD**

Director, Center for Complex Neurology,  
EDS & POTS  
Associate Clinical Professor of Neurology  
University of Arizona College of Medicine

**Laura Pace, MD, PhD**

Founder & CEO  
Metrodora Institute

**Alan Pocink, MD**

Athena Health

**Kara J. Wada, MD**

Clinical Assistant Professor  
Associate Allergy/Immunology Fellowship  
Program Director  
The Ohio State University Wexner Medical  
Center

**Pam R. Taub, MD, FACC, FASPC**  
Director of Step Family Foundation  
Cardiovascular Rehabilitation and Wellness  
Center  
Professor of Medicine  
UC San Diego Health System

**Kamal R. Chemali, MD**  
Associate Professor of Neurology  
Case Western Reserve University School of  
Medicine  
Director, Autonomic Program and Laboratories  
Medical Director, Center for Music and  
Medicine  
University Hospitals Cleveland Medical Center

**Andre Diedrich, MD, PhD**  
Res. Professor of Medicine &  
Biomedical Engineering  
Autonomic Dysfunction Center  
Department of Medicine  
Division of Clinical Pharmacology  
Vanderbilt University Medical Center

**Luis Oakamoto, MD**  
Research Associate Professor of Medicine  
Division of Clinical Pharmacology  
Autonomic Dysfunction Center  
Vanderbilt University Medical Center

**Anne Louise Oaklander, MD, PhD**  
Associate Professor Neurology  
Massachusetts General Hospital, Harvard  
Medical School

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

**Brent Goodman, MD**  
Assistant Professor of Neurology  
Director, Autonomic Laboratory  
Interim Chair, Division of Neuromuscular  
Medicine, Department of Neurology  
Director, Autonomic Laboratory  
Mayo Clinic

**Alissa Zingman, MD, MPH**  
CEO, PRISM Spine & Joint

**Nathaniel M. Robbins, MD**  
Assistant Professor  
Department of Neurology  
Dartmouth Geisel School of Medicine

cc: Tara A. Schwetz, PhD  
Acting Principal Deputy Director  
National Institutes of Health