

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

November 25, 2014

David Robertson, M.D.
Elton Yates Professor of Medicine,
Pharmacology & Neurology
Director, Clinical Research Center
Vanderbilt University School of Medicine
AA3228 Medical Center North
1161 21st Avenue South
Nashville, TN 37232-2195

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67 Woodlawn Avenue
East Moriches, NY 11940

Washington, D.C. Regional Office
6151 Executive Boulevard
Rockville, MD 20852-3901

Re: Support for the Autonomic Disorders Consortium Renewal Application

Dear Dr. Robertson,

Dysautonomia International, a 501(c)(3) organization, was founded in 2012 to help identify causes and cures for disorders of the autonomic nervous system and to enhance the quality-of-life of individuals living with these illnesses.

Through our outreach efforts we have connected with tens of thousands of individuals suffering with autonomic disorders. Dysautonomia International is raising funds for research, providing free educational programming to medical professionals, empowering patients and caregivers by providing access to accurate information and useful resources, and working to increase public awareness of these often misdiagnosed conditions.

We are writing to express our support for continued funding of the Rare Disease Clinical Research Network Autonomic Disorders Consortium (the "Consortium").

The research conducted by Consortium members has the potential to benefit millions of Americans and millions more around the world. This research is desperately needed. Autonomic disorders often result in severe deterioration of an individual's quality-of-life, and some can even be fatal. Further research is needed to understand how and why these conditions develop, what occurs once the condition develops, how to best treat these conditions and, hopefully, how to cure and prevent these conditions. There is currently no cure for any of disorders the Consortium studies. Treatments available at this time do not provide symptomatic relief for a substantial percentage of patients. This is why it is imperative that the Consortium continue to receive full funding.

While individual autonomic disorders are rare, cumulatively they impact millions of Americans. Unfortunately these conditions are not well understood by the medical community at-large and there are few physicians specializing in diagnosing and treating autonomic disorders. As patients, we know first-hand this often results in long delays in diagnosis. Patients often endure misdiagnoses, inappropriate treatment, and exorbitant medical expenses as they are shuffled from one specialist to another. Needless pain and suffering is caused due to improper treatment. This patient community is grossly underserved by the shortage of physicians practicing in this area and by the lack of knowledge and effective treatments. The Consortium is uniquely positioned to address these issues as it provides the rare opportunity for training of specialists in autonomic disorders.

While there is no concrete data on the economic impact of these disorders, without a doubt it is large and at a minimum includes increased health care costs, lost productivity and wages, and an increased burden on government assistance programs. An investment in research on autonomic disorders, even in this time of fiscal restraint, makes good economic sense. Not only will the research funded by the Consortium save the federal government and millions of American families significant money in wasted health care expenses, it will also provide those families hope for a better future.

If Consortium funding is continued, researchers will be able to continue working together on projects of utmost importance to the patient community. Dysautonomia International is currently working with a Consortium member to develop the largest cohort POTS study ever conducted. This is laying groundwork for the first long term prospective study of a large group of POTS patients. This long term study is urgently needed to elucidate the causes and triggers of cycles of symptom improvement and decline that has been documented in many POTS patients. This study will also track co-morbidities, family history, economic impacts, and the diagnosis process patients had experienced. In order for this study to succeed, large numbers of patients must be enrolled. The Consortium, which fosters collaborative research among the major autonomic research centers, will be essential to this project.

Dysautonomia International stands ready to help if the Consortium funding is continued. We are positioned to assist with patient recruitment; dissemination of educational information to patients, the public and medical professionals; directing traffic to the Consortium website through our established networks; and providing patient perspectives in study design. Our organization has already been recruiting patients to enroll in the Autonomic Disorders Consortium Research Registry and we have been keeping the patient community informed of research opportunities.

We are also prepared to assist with research funding. Since our launch in the fall of 2012 we have funded \$66,000 in research grants. We just received our first large gift of \$200,000 for research and we expect to continue expanding our fundraising capacity in the months and years ahead. Our grants can be used to supplement Consortium funded projects as well as to provide seed funding to assist early career investigators.

On behalf of the Board of Directors of Dysautonomia International, and the patients and families that we serve, we offer our unequivocal support for full funding of the Autonomic Disorders Consortium.

Sincerely,



Lauren E. Stiles, Esq.