

August 11, 2017

Hon. Mayor Fred Eisenberger
Hamilton City Hall
2nd floor - 71 Main Street West
Hamilton, Ontario L8P 4Y5

Re: Dysautonomia Awareness Month
Proclamation Request

Dear Mayor Fred,

I am seeking your assistance in raising awareness of an important public health matter. October is “Dysautonomia Awareness Month” around the world. We're asking the City of Hamilton to help us raise awareness by issuing a Proclamation declaring October to be Dysautonomia Awareness Month in Hamilton Ontario.

Dysautonomia (pronounced “dis – oughta – know' – me – uh”) is an umbrella term used to describe several different neurological conditions caused by a malfunction of the autonomic nervous system. The autonomic nervous system controls all of the involuntary bodily functions that we normally take for granted – regulation of our blood pressure, heart rate, respiratory rate, digestion, kidney function, temperature control, pupil constriction and dilation, etc. When the autonomic nerves are damaged, it can cause very serious problems in one or more of these systems.

In 2014, my oldest of three daughters, Julianna, now almost 18, was diagnosed with a form of Dysautonomia known as Postural Orthostatic Tachycardia Syndrome (POTS). While many people have never heard of it, POTS is not rare. Mayo Clinic researchers estimate that POTS impacts 1 out of 100 teens, and a total of 1-3 million Americans including adult onset patients, and millions more around the globe, making POTS more common than well-known conditions like multiple sclerosis and Parkinson's disease. The majority of people living with POTS are young women between ages 12 and 40, although older adults and males can be impacted too. POTS symptoms include tachycardia upon standing, blood pooling in the extremities, blood pressure dysregulation, fainting, dilated pupils which cause a sensitivity to light and frequent migraines, chest pains, shortness of breath, gastrointestinal motility problems, peripheral neuropathy, and many other symptoms. Autonomic disorders cause so many symptoms, because the autonomic nervous system controls so many different bodily functions. Experts compare the disability seen in POTS to what is seen in COPD and congestive heart failure. 25% of people living with POTS cannot work or attend school, resulting in a substantial economic and social impact to families and our country as a whole.

Raising awareness about Dysautonomia will help other patients get diagnosed in a timelier manner, as many Dysautonomia patients suffer undiagnosed or misdiagnosed for many years due to a lack of public and physician awareness about Dysautonomia. With your help, we can change that in Hamilton Ontario!

I have attached a sample proclamation and some information about Dysautonomia for your consideration. The proclamation was drafted by Dysautonomia International, a 501(c)(3) non-profit that is dedicated to improving the lives of individuals living with Dysautonomia through research, education, advocacy and awareness. If you are interested, you can learn more about POTS and other forms of Dysautonomia on their website, www.dysautonomiainternational.org.

Please let me know if our city council office is able to help us raise awareness of Dysautonomia by issuing the attached proclamation declaring October to be Dysautonomia Awareness Month in Hamilton Ontario. Ideally, we would like to obtain the proclamation in early October, as we are planning a fundraising event at Upper Gage Garage, on the east mountain, on Wednesday October 11 (tentative date) complete with food trucks, with local press coverage as well about Dysautonomia Awareness Month after the proclamation is issued. It would be wonderful to light up City Hall **Turquoise** (the official colour) as well and have a gathering there to mark the event.

If there is any other information you need, or if you have any questions, please feel free to contact me.

Respectfully,

April Almeida

E-mail: aprilalmeida@gmail.com

Web: www.dysautonomiainternational.org

Facebook: www.facebook.com/dysautonomiainternational

Twitter: @Dysautonomia

A PROCLAMATION FOR DYSAUTONOMIA AWARENESS MONTH

WHEREAS, Dysautonomia is a group of medical conditions that result in a malfunction of the autonomic nervous system, which is responsible for “automatic” bodily functions such as respiration, heart rate, blood pressure, digestion, temperature control and more;

WHEREAS, some forms of Dysautonomia are considered rare diseases, such as Multiple System Atrophy and Pure Autonomic Failure, while other forms of Dysautonomia are common, impacting millions of people in the US and around the world, such as Diabetic Autonomic Neuropathy, Neurocardiogenic Syncope and Postural Orthostatic Tachycardia Syndrome;

WHEREAS, Dysautonomia impacts people of any age, gender, race or background, including many individuals living in The Greater Hamilton area;

WHEREAS, some forms of Dysautonomia can be very disabling and this disability can result in social isolation, stress on the families of those impacted, and financial hardship;

WHEREAS, some forms of Dysautonomia can result in death, causing tremendous pain and suffering for those impacted and their loved ones;

WHEREAS, increased awareness about Dysautonomia will help patients get diagnosed and treated earlier, save lives, and foster support for individuals and families coping with Dysautonomia in our community;

WHEREAS, Dysautonomia International, a 501(c)(3) non-profit organization that advocates on behalf of patients living with Dysautonomia, encourages communities to celebrate Dysautonomia Awareness Month each October around the world;

WHEREAS, we seek to recognize the contributions of the professional medical community, patients and family members who are working to educate our citizenry about Dysautonomia in The Greater Hamilton area.

**NOW, THEREFORE, I, _____,
_____ of _____, do hereby proclaim
the month of October as,**

DYSAUTONOMIA AWARENESS MONTH

Throughout _____