

August 17, 2012

Governor of Massachusetts
Attn: Governor Patrick
Office of the Governor, Room 360
Boston, MA 02133

Re: Request for a proclamation recognizing the month of August as Digestive Motility Awareness Month in the State of Massachusetts be approved starting in 2013.

Dear Governor Patrick,

I would like to introduce you to G-PACT (Gastroparesis Patient Association for Cures and Treatments) which is a 501(c)3 non-profit organization which was founded on August 23, 2001. Most of the personnel suffer from Gastroparesis (GP) and/or Chronic Intestinal Pseudo-Obstruction (CIP) personally, *as I myself do.*

I have included a flier available from G-PACT that is available both online and by mail to the public that outlines in brief layman terms the description, medical information and impacts of Gastroparesis and Chronic Intestinal Pseudo-Obstruction, two of the primary and most medically compromising digestive motility disorders. I have also included a few pages directly from the online website which provides more information about the services that G-PACT provides to the public and medical community.

Treatment options continue to be limited due to lack of both research and awareness. These limited treatment options are often temporary and to date there is still no cure for GP or CIP. Medical options available include drugs aimed at reducing symptoms, but not treating the underlying cause. Drugs that have shown to be overwhelmingly safe and effective in the majority of those who take them have either been pulled from the market or not approved for use in the USA.

Many Gastroenterologists prefer the results of Domperidone, one of the more successful motility medications available which can only be obtained from other countries. Domperidone has been studied for years in the US and despite its proven and documented safety record. The lack of *acknowledging the quantity of established diagnosed patients with GP, the medical community and patient demand* has allowed for this continued none justification by the FDA to approve and distribute Domperidone within the US.

This is a prime example of the underwhelming lack of scientific research, public and medical community awareness. To date no one is aware of changes scheduled to approve this medication in the United States of America.

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This disease can progress through the digestive tract leading to, in extreme cases, the need for organ transplants. While the minimal amount of medications, medically assisted interventions and transplant can add additional years to a patient's life but does not remove this disease nor necessarily increase their overall quality of life. As you can already begin to see the lack of awareness can and has resulted in the deterioration of many patients due to long-term suffering and misdiagnosis, medical and social misunderstanding.

Patients with Gastroparesis and/or Chronic Intestinal Pseudo-Obstruction suffer from debilitating effects of chronic nausea, vomiting, abdominal pain, malnutrition, dehydration, and weight loss, because these conditions prevent food from moving through the digestive tract. Those with GP and/or CIP that become unable to maintain adequate nutrition and hydration must rely on tube feedings directly in to the intestines or IV nutrition (TPN) in order to sustain life. Complications of IV nutrition included sepsis (infection of the blood stream), loss of venous access, blood clots, liver failure and death. Tube feedings may result in bowel obstructions and infections. These are rarely an option in those with Chronic Intestinal Pseudo-Obstruction (CIP) and often not effective in Gastroparesis (GP).

These patients represent the 5 million people in the United States, men and women, including children, who suffer from GP and/or CIP, which is 2% of the American population suffering from a disorder that is neglectfully under researched and lacks broad medical and public awareness. Social life for these patients is often limited given that our present social dynamics in the US revolve around food and beverages which leaves the untreated, undiagnosed and none-medically managed individual isolated and given poor nutrition, home-bound.

I hope that the plight and importance of Digestive Motility Disorders and the significance of Gastroparesis is not lost its impact over the years. Many residents are living America. Please help me in raising awareness of these conditions, raising awareness to the need of both medical and scientific research along with the raised awareness of the community and a shined light on those suffering alone and many medically under-treated. Again, I ask with the request of issuing a proclamation recognizing the month of August as Digestive Motility Awareness Month In the State of Massachusetts with the sincerest hopes that it can be established as an 'annual month of awareness' moving forward.

I think you would agree that it is amazing to see what is provided to the community by G-PACT considering it is run by a president and volunteers all diagnosed with various forms of a Digestive Motility Disorders. Just think what G-PACT and other small organizations could do within each state and the increases in the overall Quality of Life for those with Gastroparesis (GP) and/or Chronic Intestinal Pseudo-Obstruction (CIP) or any of the numerous Digestive Tract Paralysis' (DTP) if increased awareness, research and funding could be raised. With your approval to proclaim August as Digestive Motility Awareness Month in the State of Massachusetts, we could create that opportunity for patients, citizens, professionals, organizations, scientists, researchers, medical and

pharmaceutical companies, to focus their energies and time on one thing; the much needed research and spot lighted awareness of saving the lives of a significant growing population with motility disorders.

I would like to thank you in advance for your time and serious consideration of this request for a proclamation that is annually recognized for the month of August. Please do not hesitate to contact me directly at 425-449-6279 first or G-PACT Public Relations at 1-888-874-7228 ext 82 (888-URG-PACT) for additional information.

Sincerely,



Taunna Lee Jarvimaki

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Enclosures: (3 total)

G-PACT Flyer (1)

Brief outline of community services provided by G-PACT (2)