

G-PACT. ORG
MEMBER

"DIGESTIVE MOTILITY AWARENESS" MONTH
AUGUST 2013



G-PACT - Massachusetts

Sat, Jun 8, 2013 at 7:02 PM

Here is the letter plus my information (please forgive me, I'm a rather private person! But I find this to be important enough for it :))

Hello. My name is [redacted] and I am a member of G-PACT from Boston, Massachusetts. I hope to send support to your cause from my state in the form of a brief version of my story -

I have always had trouble eating, and have been slender all my life. However, in 2008 I was in hospital for severe pain and nausea. I couldn't eat and was exhausted. I lived on Ensure. Eventually I began to eat a little bit more, but still suffered nausea, fatigue, and occasionally fainting spells. In 2011 I was ecstatic to be accepted into nursing school. However, when the clinical rotations began I found that because I couldn't eat a lot (due to abdominal pain and constant nausea) I would faint while trying to tend to patients. Despite my love of medicine and my desire to continue my education, I had to quit nursing school. I was put in the hospital and eventually tried for a brief time on a nasojejun tube to force some weight on my exhausted body. By this point (June 2012, almost my 23rd birthday) I could barely get up from my bed without fainting. Two months earlier I had been diagnosed with postural orthostatic tachycardia syndrome, to go along with my gastroparesis. I stand tall at 5'8" but weighed 99lbs. All the doctors had to say to me: anorexia nervosa. I was furious. I was in such pain, so weak all the time, and my education that I valued so much was at a stand-still. Finally, Dr. Derek Frederickson from Norwood Hospital realized that I had a true problem. He listened to the stories of all the failed medications, tried some new ones, and finally decided upon surgery to at least relieve some symptoms. On 8 April 2013 I had a total colectomy with ileorectal anastomosis. I have gained 8 pounds since then but still suffer horrible postprandial pain and nausea. Today, after much thought and experience, I have made the decision to pursue an education in pharmacology. I hope that someday the pain/problems that has interrupted so much of my life can be cured with a simple pill.

Thank you so much for your time and consideration,

PS - Taunna, if you wish to contact me, my mobile phone number is (774)-266-4854. (Also, it's proof of residency ;)) I can't thank you enough for the opportunity to participate in this project.

Additional information -

Mailing [redacted]
[redacted]
[redacted]
[redacted]

2430242

July 20, 2013

Massachusetts Governor Deval Patrick
State House
Office of the Governor
Boston MA 02133

Re: Request for a proclamation recognizing August 2013 as "Digestive Motility Awareness"

Dear Governor Patrick,

My hope is to provide you with enough supporting information that you will have no hesitation in approving a proclamation designating August as Digestive Motility Awareness Month in the State of Massachusetts. It is the hopes of G-PACT and I to someday have this become an annual awareness event across the United States. For now we do a fair amount of letter campaigning and depend on the gracious help from our volunteers and the efforts of individual to raise awareness throughout the year. We hope that you will join us in our efforts by acknowledging the residents of Massachusetts living with Gastroparesis and/or Chronic Intestinal Pseudo-Obstruction by proclaiming August 2013 as Digestive Motility Awareness month.

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, volunteers and board of directors, suffer from Gastroparesis (GP) and/or Chronic Intestinal Pseudo-Obstruction (CIP), as I myself do. G-PACT makes available both online and by mail to the public that outlines in brief layman terms the description, medical information and impacts of Gastroparesis (GP) and Chronic Intestinal Pseudo-Obstruction (CIP), two of the primary and most medically compromising digestive motility disorders. <http://www.g-pact.org>

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.

Most 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 USA.

Proclamation Request Form

Request being made by Taunna Jarvimaki, G-PACT Volunteer Facilitator
G-PACT: Gastroparesis Patient Association for Cures and Treatments, Inc.

Please mail completed Proclamation to:

Taunna Jarvimaki
G-PACT Volunteer Facilitator
17837 First Ave S, #517
Normandy Park, WA 98148
Contact number: (425) 449-6279
Contact email address: thepoetsmuse@gmail.com

Proclamation Name: **“Digestive Motility Awareness Month”**

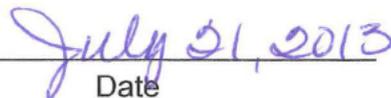
Requested for the full month of August 2013

- Suggested language has been attached but in no way is required.
- Attached is an official letter of request along with additional supporting documents.

Please reference <http://www.g-pact.org> for more information about G-PACT and viewable media kit. G-PACT is volunteer supported and though we are a US based and licensed 501(c)(3) non-profit organization, we do provide limited services to individuals throughout the world including Wales, Italy, Australia, New Zealand, Germany, the UK, Canada, Norway, Spain, Switzerland, New Zealand, among others.

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<http://www.g-pact.org>


Signature


Date

Proposed Proclamation Verbiage for State of ()

Proclamation

WHEREAS, digestive diseases, in general, rank first among illnesses for total economic burden making up about 15 percent of all direct health care costs; and

WHEREAS, 20 to 30 percent of the North American population experience bothersome upper or lower digestive tract motility disturbances on a chronic basis; and

WHEREAS, occurring in any region of the digestive tract, this family of digestive motility diseases, disorders may produce chronic motor and sensory disturbances characterized by weakened, spastic, or failed propulsion (motility) food through the digestive system; and

WHEREAS, patients, who may appear well, but are nevertheless suffering, struggle against the lack of support from those who do not understand the debilitating nature of their digestive symptoms; and

WHEREAS, G-PACT (Gastroparesis Patient Association for Cures and Treatments, Inc.) are committed to educating the healthcare community, patients and the general public regarding the serious natures of digestive motility diseases/disorders such as, but not limited to, Gastroparesis and Chronic Intestinal Pseudo-Obstruction, by providing patient advocacy programs, multiple support programs with a dedicated and continued focus on raising awareness on the need for further research, early detection and symptom management for those afflicted with a digestive or gastrointestinal motility disorder.

NOW, THEREFORE, I, () Governor of the State of (), do hereby proclaim August 2013 as

“Digestive Motility Awareness Month”

in () State, and I urge all citizens to join me in this special observance.

tlj, 6/12/20123 G-PACT

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Jarvinmaki, T.L.