



THE PACT

Winter 2010

The Perfect Valentine

~Erika Mott

I was recently hospitalized for a week from complications relating to my motility impairment, and found myself struck with the inevitable ennui that anyone that has ever been immobilized in a hospital bed can attest to. As an NPO patient (Nothing by mouth, or ‘*Nil per os*’ in Latin), I repeatedly scowled at the myriad of chocolate-related Valentine’s Day advertisements on the television. Not too long thereafter, my husband returned to the hospital from his job with his characteristically heartwarming smile and a get-well balloon.

Throughout my entire stay Andrew had, without complaint, spent the nights curled up in a sleeping bag in the corner of the room where he would not be in the way of the staff that frequented my bedside. I stared at him briefly as he slept and realized with a very powerful sense of gratitude that the perfect Valentine’s Day gift is not about chocolate. Nor is it about cards, stuffed animals, champagne, or candlelight dinners. It is, at the very core, about love. Love comes in many forms. Whether it be friends, family, or our partners: the unsurpassable feeling of caring and devotion towards those close to us is something we can always seek solace in during challenging times. For me, the best medicine I received in the hospital was not through my IV. Instead, it was the comfort in knowing that my Valentine was there for me, unconditionally. And that is a gift that should be celebrated far more often than one rosy-hued day in mid-winter.

Press Release from Tranzyme Pharma

Tranzyme Pharma released the name of their prokinetic drug candidate in a press release on January 27th. “Ulimorelin”, a gherlin-targeting intravenously administered medicine, has shown promise in treating motility impairment throughout its phase two trials. Compared to patients taking placebos, patients taking this Ulimorelin (formerly referred to as TZP-101) demonstrated an improvement in gastric emptying as well as a significant reduction in the classic symptoms of Gastroparesis: nausea, vomiting, and loss of appetite.

For more information regarding Tranzyme Pharma and their developments, go to www.g-pact.org/research.html.

Spotlight Patient: Christine Gould

Hi, my name is Christine Gould, and I am 28 years old. I have been a registered nurse in the state of Maine for 9 years, and am currently employed as a Director of Clinical Services at a National Homecare Agency. It is the best job I could have ever been blessed with: I have worked there for nearly two years, and have given as much love and dedication to my clients as anyone in my position can, since I know from experience what it is like to be ill.

I never imagined in my life that I would one day be in the hands of a doctor or nurse managing such a trying disease. In January 2005 I had begun vomiting off and on without any rhyme or reason. I avoided things if that seemed to trigger nausea, but couldn't understand what was causing the symptoms. My Gastroenterologist and I were established already because I have IBS also, and he immediately wanted to see if there was anything wrong with my stomach. After performing an EGD, he unfortunately found that I had Gastroparesis. He gave me a prescription for Reglan, and sent me on my way. Unfortunately, I was unable to tolerate even low doses of the drug due to the fatigue it was causing. I even drifted off one day while driving, hitting a curb as I did so.

I was switched to Domperidone, and when its effectiveness waned after 18 months of use, a new physician recommended Erythromycin. (Another failure due to its side effects.) Originally uncomfortable with the thought of Botox therapy, it became my next option after a second attempt at using Domperidone failed to provide lasting relief. The Botox did seem to help a little bit, but not enough to merit the expense. The doctors suggested having a Gastric Neurostimulator placed and I did so in April of 2009.

I did have a very hard time with nausea after the surgery. After the anesthesia cleared, I was able to start taking things to drink and eat. I did not have any long term problems from the surgery. I did have a new symptom arise: debilitating pain. About nine months after my pacemaker was placed, the doctor suggested shutting it off. I agreed, and since then I have struggled with a loss of appetite. My pain has improved, likely due to a mostly liquid diet, but still, everyday is a struggle. Despite crippling fatigue, I still work over forty hours per week, but I essentially have a desk job. I do patient visits once in a while, but I really can't run all over the place anymore as it can be exhausting. I always feel like I am not getting enough nutrition. Though I weigh myself regularly so I don't get out of touch with the weight loss, I have still lost a total of eighty pounds to date due to nausea, lack of appetite, fullness, and generalized wasting.

After being in contact with others on a support group, I had a great thought: I have always liked helping others. All I kept on thinking was that there had to be a way to raise awareness and support those who, like me, suffer from Gastroparesis. I thought back a video that I had been shown in elementary school. The video, which made me cry, was about this new disease that people were catching and dying from called AIDS/HIV. To raise awareness and find treatment options, the people showcased in the video made a quilt. It was absolutely huge to my recollection: big enough to fill a gym! They explained that each square in the quilt honored someone affected by this devastating disease. I have a close friend who is doing special things to help raise awareness for HIV/AIDS now, and he is my inspiration.

In honor of my friend, I would like to help raise awareness of Gastroparesis and Chronic Intestinal Pseudo-obstruction by honoring their "quilt" and making the most gigantic GP/CIP quilt that you can imagine! If you or someone you know has GP or CIP and has interest in participating in this project, please e-mail me at: ChristineG529@gmail.com. I will be in touch with you with the details of: The Quilt Project.

In my young career of 9 years, I will tell you what I share with others, when their health is ripped away:

“They can take everything away from you, but they cannot take your HOPE. Hold that HOPE close to your heart.”

~Christine Gould, Maine

2010 Digestive Disease National Coalition (DDNC)

~Carissa Haston

G-PACT has been so busy that things have been sneaking up on us! This is a good thing, but it means we are later than last year in sending out some important information!

On March 7-8, G-PACT will once again participate in the Digestive Diseases National Coalition (DDNC). This event takes place in Washington, DC at the Phoenix Park Hotel. As members, G-PACT has the opportunity to attend the annual board meeting and represent gastric motility disorders and our organization on Sunday morning.

The event starts at 1 PM on Sunday afternoon. The first day involves a conference which brings in a number of physicians, government officials, and others to speak on various conditions. DDNC officials present the agenda that they have for the event and the goals they are trying to accomplish in the upcoming year. The conference ends at 5 PM, followed by a reception in the hotel where the event is held.

Monday is a full day starting at 8 AM with breakfast in the hotel, also provided by the DDNC. After that, each person is grouped together based on state(s) and given a list of senators and representatives we will be visiting. The morning includes visits to three senators. It is followed by a luncheon at noon in which Senator Bob Casey from PA will be honored this year. At 1:30 the luncheon concludes and visits to three different representatives begin. There is a debriefing at 4 PM.

G-PACT has the opportunity this year to specifically meet with an aid of Senator John McCain, or perhaps even McCain himself. McCain recently denounced the importance of researching gastric motility disorders. After a conversation with a McCain aid recently about this, G-PACT has begun to change their minds and they have agreed to meet with us at the DDNC so that we can further educate them on the devastating impact of these conditions on the lives of patients and the need for more research. We have already changed the minds of members of the FDA and blown them away by sharing our stories, and this is an incredible opportunity to impact a very influential Senator as well. Only G-PACT board members will be involved in this part, but ALL patients, caregivers, family, and friends are welcome to attend the DDNC and go around with others from your state(s) and share your stories, our goals and reasons for being there, and what the needs of gastric motility patients are!

The more people we have, the greater impact we make! Last year we were highly represented and that made quite an impression on the DDNC. We need as many people from as many different states as possible so we are widely represented. We are particularly looking for people from PA this year since Bob Casey is this year's honoree, but everyone is invited! We have people flying in all the way from Washington State!

For those of you on home infusion or who are concerned about making the days physically, Dr. Kevin Olden, a physician with whom we work closely, is providing us with an infusion nurse to be available to help in case anyone has a physical problem while there. G-PACT will also work on accommodations in traveling from building to building as much as possible for those who have difficulty with a lot of walking or are in wheelchairs.

Please go to the DDNC website at www.ddnc.org for more information and to register for the event. After registering, please be sure to e-mail us at contact@g-pact.org to let us know you are coming so we can plan efficiently and ensure that we have enough materials with us to distribute. Please remember to list G-PACT as the organization you are representing. We will provide all groups with copies of our educational materials to leave with each senator and representative and will meet together on Sunday or Monday morning to discuss our agenda and what we want to express with each government official.

G-PACT can't express how exciting and rewarding this event is. If you have never done any lobbying before, you are in for an awesome experience and have an opportunity to make an impact on making further advancements towards better treatment options or a cure for Gastroparesis and intestinal pseudo-obstruction! What we found to be very exciting last year is that others in our group who were representing other conditions were so enthralled with the stories from members of G-PACT that in the end they spent more time talking about our needs when meeting with representatives than their own needs! What a way to make an impact!

Facebook "Status Update"

G-PACT's presence and popularity on Facebook continues to grow with more applications and resources added monthly. There are now state-specific G-PACT pages in order for members to stay updated on local events and resources.

Furthermore, the **Gastroparesis and Pseudo-Obstruction Awareness Gifts** application was added to Facebook: a lighthearted and fun way to generate awareness among friends. Gifts such as 'hospital discharge papers' and 'chicken broth' go a long way in both generating smiles as well as awareness for Gastroparesis and Pseudo-Obstruction. Add the application to your account at http://apps.facebook.com/gastroparesi-fejigc/?link=dashboard&_fb_q=1

Congratulations To Our New VP!

Recently, our very own Michael Smith was promoted to Vice President. Deservedly so, as Mike has proven unparalleled dedication and compassion to G-PACT's cause throughout the two years he has been involved with the organization. We are endlessly grateful to have Michael fighting for us, and for so passionately dedicating himself to bettering the lives of those living with Gastroparesis and Chronic Intestinal Pseudo-Obstruction.

McCain's Opposition to Funding Motility Research

In recent months, Senator John McCain has issued several comments regarding his opposition to 665,000 dollars being directed towards Motility research. For the millions of people whose day-to-day lives are severely impacted by the challenges of GI motility disorders, these comments are both uncouth, and uncalled for. G-PACT Vice President Michael Smith writes:

"...After suffering from paralysis of the digestive tract for 22 years and working for a cure over this time, I can't help to think that Senator McCain simply did not take the time to do his homework on this issue. Unfortunately, the need for government research funding for motility research for an amount that the Yankees would normally spend on a utility infielder has been caused by a complete market failure with regard to the US medical research industry's ability to navigate the shoals of Washington towards a solution for digestive tract paralysis."

As the article indicates, McCain's remarks dealt a disastrous blow to the rapport that has slowly been building between motility research advocates and a federal Government that has come to understand that there are millions of patients in the United States debilitated by a poorly understood condition. Michael Smith's full article can be found at:

<http://seriousmedicinestrategy.blogspot.com/2010/02/g-pact-vs-john-mccain.html>.

G-PACT is also sponsoring a petition to correct McCain's remarks which we strongly urge everyone to sign and share with their peers. The petition, which seeks to help the Senator gain a better appreciation of what it is to live with debilitating Gastrointestinal Dysmotility, can be found at

<http://www.ipetitions.com/petition/gastricmotilityresearch/>

G-PACT Cookbook Recipes Needed

Looking for new diet ideas? Looking for things that might work for your sluggish tummy? G-PACT is working on putting together a cookbook for GP/CIP patients.

In order for this to be successful, we need to collect recipes from patients. These recipes should follow the low fat/low fiber guidelines. We will have dietitians review each recipe before it is included in the book.

This effort will only be as good as the contributions we receive, so please help us out! Send your recipes to cookbook@g-pact.org. Please list ingredients and directions to complete the recipe. Also include your name as you want it to be printed in the book.

We will accept recipes until April 1st.

Recipe Corner

We all know too well the ramifications of living day to day on a low motility diet heavily comprised of liquids and pureed foods. Struck with the culinary boredom of surviving on applesauce and smoothies, I began to play around in my kitchen. Cooking is a hobby/obsession of mine but I often find myself unable to taste my own creations. Being creative with soft and liquid foods not only allows me to rekindle a passion, but it also allows me to continue to enjoy what I eat despite my illness! This recipe is fantastic any time of year, but especially during these cold winter months when winter squash takes the spotlight as the season's hot vegetable.

Butternut Squash Puree with Honey Sage Butter

http://www.food52.com/recipes/1115_butternut_squash_puree_with_honey_sage_butter

Nothing says autumn like this fragrant, beautiful puree.

Serves 8

- 1 butternut squash, peeled, seeded and cubed into 1" pieces
 - 2 tablespoons extra virgin olive oil
 - 1 teaspoon salt
 - 1/2 cup heavy cream
 - 1 cup whole milk
 - 2 tablespoons butter
 - 16 fresh sage leaves*
 - 1 teaspoon honey
1. Preheat oven to 400 degrees.
 2. On a large cooking sheet, combine butternut squash, oil and salt.
 3. Roast the butternut squash for 20 minutes, stirring once halfway through. Remove from oven.
 4. Push the squash pieces through a ricer into a large bowl. Stir in milk and cream and set aside.
 5. In a shallow pan on the stovetop, melt the butter over medium heat. Once it starts foaming, skim the foam.
 6. *Raise heat to medium high then drop the sage leaves in in batches, submerging them in the butter for 5-10 seconds until they become crisp, but before they turn brown. Remove them one by one as they finish and set aside. Repeat with all remaining sage leaves.
 7. Once you've fried all the sage leaves, remove pan from heat. Stir in the honey and then pour the butter mixture over the squash. Top with the fried sage leaves and serve.

**Note: This recipe may not be well suited for everyone. You are your best judge for what can or cannot be tolerated. Be sure to modify recipe as needed to best suit your needs. For example, I discarded the sage leaves after they had become fragrant in the melting butter. Sage is a fibrous leaf and thus not easily tolerated by many.*