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**Perez, Thomas**

Michelle

**From:****Sent:** Thursday, April 04, 2002 12:01 PM**To:** pereztc@cder.fda.gov; lotronex@yahoogroups.com**Subject:** (no subject)

Tom Perez, (Please read this and let anyone see it at the April 23rd meeting)

I am going to send you my story about how IBS and Lotronex had changed my life, but first I need to let you know how strongly I feel about getting back this medicine. Imagine you are all ready to go out, but can't leave the house. Imagine you are gonna get married, but need to take so much medicine to drug you up so you do not have a diarrhea attack. Imagine your nephew wants to leave for his championship baseball game, but you are late. Imagine your father in law dies and you drive alone in the car to his funeral, because you are scared to have a diarrhea attack in the car, on the street, at the game or at the funeral. Imagine your grandma asks you to drive her to the doctor, but you just had three attacks and are scared to leave the house. These have all happened to me and many more embarrassing things.

I have been through a lot and the only thing that has ever helped was Lotronex. It should be my decision to take Lotronex. My life is meaningless this way. I let everyone down including my child, husband, family and friends. I am so depressed. Everywhere I go I am looking for a bathroom. It is not right. When I was on Lotronex I was able to go to the park, games, movies, dinner and I did not even care where the bathroom was, little did I know it would all be taken away. Please please please for, if not for us then our families give us back Lotronex. Here is my sad story.....

Hello to All...

I am a 31 year old female from NJ. I have had IBS for 12 years. When I was 19, I was in the car with a boyfriend and had to use the bathroom...IMMEDIATELY. I didn't think I could make it. After that episode and many more, I have been scared to leave the house. Of course I have to leave, but I am always looking for the bathroom. I have canceled many engagements with friends and family, because I was scared of needing a bathroom. My family did not look at this as a real problem and didn't understand. Actually they still don't 100% yet. My family tells me if I have to go just go, they do not understand that it is painful and embarrassing. I will not go in a car with anyone except my husband, just in case I need to use the rest room. My bathroom episode does not come and go quickly... I have cramping and I am in pain for hours before and after each episode. How can I ask a couple on our way to dinner if they can wait 2 hours while I have a diarrhea attack? Well, I don't ask anyone for anything. Most of the time I don't even leave the house. Many vacations, dinners, concerts, day trips and movies have been cut very short or I just don't go.

I had many many many tests done about 3, 5 and 10 years ago and was told it is IBS and that it was all in my head. They gave me many prescriptions (depression and anti spasmodic meds), but nothing. So, I began to think it was in my head too. I am also lactose intolerant and don't like red meat, so as you can see eating is a chore too! I about 20 lb. over weight, because all I eat is bagels and bread (high carbs). They bind me and that's what I need. I have bought cases of Immodium over the years, but after 3 days of Lotronex I have not bought any since. I have been asked to be in about 10 weddings and would worry until they were finally over (what if I needed a bathroom during the ceremony), including my own, in case I got sick and ruined someone's wedding, I have many more horror stories. I do not remember most of my wedding because I took something to relax me, so I did not think of my stomach problems.

We have gone on many vacations most with my husband annoyed because I would not do anything without a bathroom in site. Most people take for granted a bathroom, but to me it is my savior and at many times my only hope. I promised my husband that when we got home from vacation I would go to the doctor for my problem and so I did. Lotronex was just released and the doctor said "Michele this is your answer." I could not drive the car fast enough. After 3 days!!! I was sooooo much better. Now, I used the bathroom once or twice a month instead of 5 or 6 times a day. I was going daily and I was normal.

I needed to get better for my son. He is 17 months now and my unborn child (4 months pregnant). I didn't want him to miss out cause mommy doesn't like to go out of the house. I could not do that to him too!!! I live close to NYC and took day trips with my son and husband, I was a person again. I felt great. I went for dinner, movies, central park etc....and yes I still looked for a bathroom, but I didn't need it. YEAH!!!!

Then D day came and my husband called and said "that Lotronex was recalled and the insurance would not cover it, but I could buy it" of course...I did. It was very expensive, but worth every dime. You can't put a price on a new life....Now, I have been without for one full year and its gotten bad. Before I got pregnant my doctor prescribed a medication that I took many years ago called LIBRAX CAPS along with PAXil, it was OK, but I

mean nothing like before with LOTRONEX.

Hey not to get all feministic here, but if this drug was for men too do you think it would have been recalled? Men have always made decisions and they effect women.

The first time I took LOTRONEX I needed one a day for about a week, after that I took 2.

So, anyway I am ready to make a difference. I called and E-mailed everyone I could. I am sending this letter out to about 100 people to get our stories out. I actually can almost cry when I know there are other people like me out there. I feel better reading letters, knowing we can make a difference. I am usually the quiet type, but when it comes to getting back my life I have a big mouth. I have lost way to many years already for this.

I was hospitalized a few times too and had many unpleasant procedures. Another nice person wrote to me and said that they work for GLAXO and want the drug back, but they feel it is never gonna happen. What can I do???? What can we do??? How do people change things that are wrong?? I am a teacher, but now a stay at home Mom and want to give my child his mother back.

I am sorry this is so long, but how can I put 12 years in one letter. I tried, but if you do not want to read this then just delete it. I see so many other stories that really touch my heart. Let's make a difference. Good luck and I hope we can do this.

Please lets get Lotronex back!!!!