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Perez, Thomas

From: MARILYN SCHOFIELD
Sent: Wednesday, April 10, 2002 3:47 PM
To: lotronex action.group; Perezt@cder.fda.gov
Cc: Tocataryan@aol.com
Subject: Re: [LAG] Please bring back LOTRONEX!

Dear Leslie - We've all been there, unfortunately! I am a church organist, among other things. In the summer the minister and I don't wear robes, as the service is more casual. One Sunday I had a bad attack on the way to the church, and by the time I got there, I was a mess. I shot into the bathroom, leaving a trail. I normally carry a change of clothes in the car, but these had been used and I had forgotten to replace them, so had nothing to change to. My friend ran up and got my robe, church started 10 minutes late when I walked to the organ in my robe and a blouse underneath! That was it! My good friend mopped the bathroom and hall, then made the 40 minute round trip home to bring me some clean clothes. Of course, the whole service I was panicked that I would have another episode in plain view of the congregation!

It sure isn't ever fun to have these attacks in public, which is why so many of us stay home.
Marilyn

----- Original Message -----

From:
Sent: Monday, April 08, 2002 10:53 PM
To: Perezt@cder.fda.gov
Cc:
Subject: [LAG] Please bring back LOTRONEX!

This is my story which may be graphic at times, but the disease, IBS, is a horror. I am a single parent with 2 teenage daughters. I am the Department Chairperson for the ELL/Foreign Language Dept. in a high school on Long Island. I am also the Summer School Principal. These advancements in my career were made possible when I was taking Lotronex and feeling the best I have ever felt in my LIFE!

Let me relate a recent episode that I had without Lotronex.

We had an altercation between some students at the high school and all administrators and supervisors were given areas to patrol with their walkie-talkies. I was assigned to the Main Entrance Area. There I was in a nice business suit, stockings and heels when all of a sudden I had an attack of Diarrhea out of nowhere. Let me just say that my problem with D is also frequency and urgency. I started to run to the nurse's office which was the nearest bathroom, but it was too late. Here comes the disgusting reality of this disease. I reached the bathroom and took my clothes off and everything fell out on the floor, the toilet everywhere. I was in the bathroom for 45 minutes cleaning myself and the floor. I had to clean and throw away my underwear and stockings and exit the bathroom as the professional I'm supposed to be. I had to fight the tears, the depression, and the thoughts of suicide if this is how I have to live. Is this living? Could you live like this everyday not knowing when or where it is going to happen? I don't think so. Luckily I live close to my job so I was able to go home change and return as if it was a normal day. I should add these episodes are painful too and it absolutely destroys my skin, having to use Vaseline or Desitin as if I were changing a baby. It is gross. I can go on with episodes on the highway, in a restaurant, at a movie, at a football game, at the airport. I don't think people realize how debilitating this disease is, and quite frankly, you're very lucky not to experience this. It is imperative that we be allowed to take the only drug that deals directly with IBS and be monitored by our doctors. People should know that if the drug is making them constipated, they should stop taking the drug. It's common sense to me. These are the drugs I have to take everyday without the Lotronex and I STILL HAVE DIARRHEA, FREQUENCY, URGENCY, AND SIDE EFFECTS FROM THESE DRUGS.

They are:

Colazal 9 pills per day
Pentasa 4 pills per day
Flagyl 1 pill per day
Belladonna Tincture 8 drops 3 times per day
Elavil 1 pill

Purinthal (6MP) 1 per day

Imodium AD as needed 2-6 pills per day

Do you think that all these drugs are a healthy alternative to Lotronex? I doubt it. Please help us.

Thank you for your time,

Leslie