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Personal Statement of Julia Alberino

You're going to hear from a lot of IBS patients today, and I have already submitted a letter containing my story so I will keep my remarks brief. I'm here today at my own expense, to speak on my own behalf. I am a member of both the IBS Self Help Group and the Lotronex Action Group, but I am not here ot represent either. Our spokespersons will do that admirably, I'm sure. I have had IBS for more than thirty years, and although I have tried valiantly not to have IBS control my life, the fact is that it has and does. Every time I cancel a business meeting or a pleasure trip because I'm too sick to attend, IBS is controlling my life. When I had to give up a job I loved in favor of one without a long commute, IBS was controlling my life. When I have to cancel any plans at the last minute, IBS is in control. Maybe you can't imagine that a non-life threatening illness can completely take over a person's life, but for much of the past thirty years, IBS has had a devastating effect on my life. I am an intensely private person, so embarrassing accidents in public can send me into hiding for weeks. I remember with particular horror one accident that happened on the lunch break at a professional conference. The conference was in my home city, but I wasn't close to home. I had no hotel room to run up to in order to change and no change of clothes with me. As I struggled to clean myself up in a public bathroom, all I could think was "What do I do now?" I had to discard my ruined underwear and panty hose, but luckily not much had gotten on my skirt. I ran to a nearby drug store to buy new undies and hose, and then back to the public rest room to put them on, then breathlessly back to the conference room. It was the first, but no the last public embarrassment. Those have happened twice more. I'm more mature now, and maybe I handle them better. I've learned to always have a change of clothes close at hand.

I'm more honest in telling others about my IBS and the ways it can affect me without warning than I used to be. My friends have learned not to count on me for meals out, movies or plays. I'll go when I can, but that's not as often as they or I would like.

In the thirty years of suffering, there were 22 wonderful months. Those were the months when I was on Lotronex. I almost forgot I had IBS. I could meet all my work responsibilities and take on hew ones, have a social life, eat a balanced diet and best of all there was no pain and no daily diarrhea to dominate my life. During that time, I was able to start graduate school (I have since had to drop out; it's all I can do to make it through the work day with the return of my IBS). I knew that there were problems with Lotronex; my physician had been candid about the possibility of ischemic colitis and severe constipation. She explained to me that for that reason, we would have to stay in close touch while I was taking Lotronex and that if I had any problem at all, I was to stop the Lotronex and call her immediately. On the third day I was on Lotronex, I did have constipation, for the first time in my life. Following my doctor's advice I skipped that day's dose and things returned to normal. Normal was a real treat for me, after thirty years of diarrhea. The night I came home from class and saw on the internet that Lotronex had been withdrawn, I was beside myself. By that time I'd had eight months of living like a normal person, and I wasn't ready to give that up. I quickly obtained as much Lotronex as I could lay my hand son and cut my dose to one pill a day to stretch the supply. Amazingly, I got as good results on the one pill as I'd gotten with two. Later on, as my supply dwindled, I cut to ½ pill a day. The results at that dosage weren't quite as good, but for the most part, the diarrhea stayed controlled, with just a few episodes a week. It wasn't as good as on the full dose of Lotronex, but it was infinitely better than the pre-Lotronex days. I think the point I'm trying to make here is that there is no "one size fits all dosage," and one of the ways to manage the risk might be to determine each person's individual dose. Of course, that means that doctor and patient both have to take some responsibility and they have to maintain an open line of communication. I believe that's doable. Doctor-patient communication is critical to managing any chronic illness, and that's what I consider IBS to be.

The other point I'd like to make before I close is that PATIENTS have to take some responsibility for knowing their own bodies. I read somewhere that some of the patients who got constipated on Lotronex waited four days or more to contact their physicians. What were they waiting for? Hadn't they been listening when their doctors explained the possible adverse effects of Lotronex? I'm giving the doctors the benefit of the doubt here in assuming they were responsible enough to read the Lotronex prescribing information and share it candidly with their patients.

My experience has been that used correctly and conscientiously, Lotronex is a safe and effective drug. I believe the committee can come up with a risk management program that will work, and I hope that the risk management will also involve stringent reporting requirements on patient experience, so that additional information on Lotronex's safety, efficacy and long term effects can be compiled.

Thank you giving me the opportunity to speak here today.