



Adventures

ALS Adventures is a periodic account of life's experiences by a person living with the disease.
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Although it has not been a month since I last sent you a monthly ALS update, I thought it might be fun to tell you about our trip to Washington DC, especially since we were there when that small plane invaded the no-fly zone over the Capital. (The TV News reported it pretty accurately.)

You may recall that Susan and I decided to attend the ALS Association's National Advocacy Day in Washington DC. About 750 people attended and many are struggling with various stages of ALS, and many of them were in wheelchairs. All had anxious loved ones caring for them and hoping that this effort would be productive. Our quest was to be part of the team that approached members of congress to request their support for proposed ALS related legislation.

The first day events started out pretty much uneventful, until I asked why we were scheduled to see our House Representatives and not our Senators. In so many words, I was told that the "big guys" at National would see the Senators. Did I hear that right? Now let me get this straight, we flew all the way to Washington DC to "get involved" but we

weren't needed? No, that's not it, we're needed to go see the gazillion Representatives, because they represent small districts in the state and there's just too many of them for the "big guys" to go see. But the Senators, there's only two of them. Now that's where the power is! Moreover, the "professionals" should go see the Senators!

I immediately got a gut wrenching burning pain in my stomach. (No, it's not that acid reflux thing.) Now we're fired up! I said I'm calling our Senators and we'll go see them all by ourselves. As Susan quickly pointed out, I got fired up, SHE had to make the phone calls! (You know, they might not be able to understand my "garbled" speech.)

Day two. We're on the hill. ("On the hill", that's what those of us who are politically connected call visiting the Senate and House offices.) Anyway, rather than attending the training class "Visit your Congressional Leaders 101", Susan and I are on the hill because we have appointments with both Senators Barbara Boxer and Diane Feinstein. Well, maybe not the Senators in person, we actually had appointments with their Legislative Aids. (We quickly learned that you must be REALLY important in order to meet face to face with a senator. We also learned that even the big guys would most likely meet with Legislative Aids. What, even the big guys will meet with the Legislative Aids? Did I miss something?)

Day three. Susan and I catch up with our "team". We're once

again on the hill, but this time we're there to meet with our Representatives. Our team leader, (he's never been to DC before), had organized our team so that inside a 15 minute allotted time slot, each of us would make a carefully choreographed presentation. Guess what. He did good. We were organized, each of us knew what to say, we stayed on target, and we delivered our message. And guess what again. It's also not unusual to meet with Legislative Aids when visiting the House too. We visited six Representative's offices. Two of those, we met with the Representative himself. I think most importantly, our presentations seemed well received by whomever we were speaking with. It seemed to be worth the effort. (However, I guess we'll have to wait to see what the actual end results are.)

Oh yeah. Day three is when that small plane entered the no-fly zone. We had already visited three representative offices, and we were in one of the federal buildings having lunch. Here's the setting. There must have been 300 of us. We were on the fifth floor. The room was crowded and the elevators were packed bringing up even more. At least a dozen folks were in wheel chairs. It was hot and sticky outside, and we all had walked what seemed like miles that morning, so some of us were pretty tired.

Then it happened. A security guard entered the room blowing his whistle. Huh? What's he saying? Evacuate the building? We couldn't believe it. What was this, a fire drill to see how long it would take to evacuate such a