



Adventures

ALS Adventures is a periodic account of life's experiences by a person living with the disease.
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This past month has been interesting, as we have been to Vegas for a two-week stint at the CONEXPO trade show, and we have gone back to UCLA for my clinical trial visit and another time for my regular quarterly check up.

Here's the latest.

After returning home from our Darth Vader sledding adventure on the UP we packed up the motor home (AKA "The Box") and headed to Las Vegas.

The first week was set-up and the second week was the actual trade show. During set-up, we stayed in the box at a nearby RV park and we moved to the convention hotel when the show began.

Set up went smooth, well almost. Our equipment arrived damaged and needed a paint job. High winds blew down our booth (the booth was outside). Gale force winds also foiled my best laid plans for a 15 foot banner intended to gently wave in the breeze (A few trips to the hardware store for bigger pipe and a late night rush assembly job solved that). We had to pay off (under the table) a forklift driver to move our equipment (Mike Butler had to fork out those bucks).

In addition, our next-door booth neighbor filed a claim for the paint overspray damage to their equipment from getting our equipment repainted. Hmm, think we should participate again three years from now???

The show went well, kind of. Although we thought our 15 x 40 booth

was big, compared to others around us we were small. So small in fact, that we were somewhat hidden. The real challenge for me was to keep talking. Butler said not to worry, HE WOULD DO ALL THE TALKING. Yeah okay, but I couldn't keep quiet. Chatting with old friends and talking to potential customers with my slurred (one too many scotch and sodas) voice was my biggest concern. Everyone was kind and understanding. Even those who did not know me were patient and willing to go slow.

With Susan's "I can interpret anything he says" attitude, and with a bottle of water in one hand and with her tugging on the other hand reminding me that it's time to go rest, we got through it all just fine.

After returning home, it was time to head to UCLA for the monthly clinical trial evaluation and check up.

This was a routine visit where they checked muscle strength and lung capacity. I'm happy to report that there is no discernable motor muscle deterioration and my lung capacity is still near 100 percent. They noted my speech has diminished some since the last visit, but that wasn't news. So, we have another two visits before they issue the clinical trial pills.

The most interesting visit was yesterday's quarterly check up. We're so impressed with the level of care and the team of doctors and specialist at UCLA. This is not just one doctor visit, it's six! And, every one of them treats me like I'm their most important patient. In addition, they even have someone there who is worried about how Susan is handling it all.

The speech therapist was troubled that my new "type & talk" machine has not yet arrived. She said she would get into that.

The swallowing specialist is concerned about some of my eating problems. She said I'm eating the right stuff (that's a first!) but I need to try some new techniques for getting the food past my tongue. (She wouldn't buy into my suggested "drinking

diet".) She said I have to learn to overcome the loss in tongue dexterity. Apparently the same tongue muscles used to form words are used to "launch" food down your throat. Hmm, I never thought of eating as the process of launching food down your throat. That's kind of an interesting mental picture!

One doc was most interested in how my tongue looked. She is considering entering my tongue into a study. (Just what I've always wanted, to have a picture of my tongue on the cover of the American Medical Association's monthly magazine.)

We discussed some new signs, muscle twitching in my legs. Although that's not good, it is expected. They offered some exercise suggestions and said it's just another reminder of what we are really dealing with.

Another doc thinks I might qualify for a contraption that can be fitted in the roof of my mouth to enhance my speaking ability. Now that gets my attention. So we have an appointment toward the end of this month to see a dental-ALS specialist for a work-up. We'll see, and we're hopeful.

BUT CHECK THIS OUT. Yesterday's examination revealed something else, a simple way to improve my enunciation right now. ALS affects the air flow that comes out when I speak. If I hold my nose, the air is redirected and somehow causes my words to be more discernable. I LIKE IT! Any time someone approaches and wants to talk, all I have to do is hold my nose. The communication is instant. I don't even have to try to speak!

So I'm sitting here holding my nose, trying to decide what I want to do for a little excitement. Shall we scoot off to St Ignace for a few days? Should we jump in the box and head out to some exotic location? Maybe we ought to go sit on the beach and enjoy the sunset. Then there's that work thing. Decisions, decisions.