



## Adventures

*ALS Adventures, is a periodic account of life's experiences by a person living with the disease. Written by: Mike Justice, PALS-People with ALS. Contact Mike: mikej@justiceassociates.com*

### Headed Home---July 11, 2005

The month of June this year was pretty special on the UP. The weather was perfect. The skies were blue with puffy white clouds; the water on Lake Huron was calm and the locals were jabbering about fishing. Our remodel project was plodding along slowly, but looking good, and it's almost time for my monthly clinical trial check-up so we needed to come home.

Heading back to CA, due to a goofy airline schedule, we decided to take a rental car 100 miles to our "second choice" airport. We rented a Subaru. You know, one of those little not-enough-room-for-my-long-legs subcompact jobs.

Wouldn't you know, we encountered a roadwork detour about three miles from the airport. And as usual, we're running a little late. There's no time! Our flight leaves in 30 minutes! We've got to turn in the rental car ... check in ... and clear airport security!

Hey, calm down I'm thinking. It's a construction zone. I work in the industry. I'm a consultant, right? I'm comfortable here. I recognize the equipment. We'll just slowly maneuver our way right through the roadwork! "I can BS my way past anyone," I mumbled. Susan frantically reminded me that I can't talk, and SHE's the one who'll have to explain! "Never mind," I mumbled again. "Just talk about diesel emissions, or black smoke or something." And besides, I continued "everyone knows that all you have to do is 'look' like you know what you're doing!" (Yeah right, while driving a subcompact Subaru ... with two toy poodles sitting in our laps ... in the heart of red neck country!)

Anyway, we zigzag past the barricade and speed up to a slow moving Caterpillar scraper. Carefully working our way around the scraper, we encountered a big hulking excavator sitting broadside in the road. Look, there's room to squeeze past on that soft shoulder ... if we don't get stuck! We did (get past) and then came face-to-face with a huge end loader equipped with "Log Grabber Jaws" on the bucket. The operator, a devious guy, decided to play with us a little. As we approached, he opened up the jaws threatening to grab our little Subaru. Susan screeched that it's going to get us! And for a brief moment, I bought in. I gunned it right past the "Jaws of Death"!

We could then see in the distance, the barricade on the other end. Whew! We made it! We took one look and realized, we're not out of this yet! The airport entrance was only 100 yards ahead, but our access was totally blocked with a solid barricade made up of 24-inch diameter concrete culvert pipes positioned end-to-end across the road. (We're on the inside looking out!)

There's no time to turn back! Susan exclaimed, "we're going to miss our flight!" I mumbled something about the little Subaru having a bumper. A plastic bumper, right? But it must be designed to bump! So I gunned it again! We hit one of those concrete pipes and guess what, it's round ... it rolled! Ah-ha! A couple more bumps and we have an opening! Alas! We've made it! Looking over our shoulders, those construction guys, they just shook their heads and laughed.

We caught that flight. (Think Hertz will notice the bumper?)

The clinical trial is progressing just fine. A couple of weeks ago, the day that I increased the dosage to eight "horse pills" per day, I got sick. For two days, I had flu-like symptoms, but clearly not the flu. Proof that I've got the real thing and not a placebo? Maybe. But then maybe it WAS some kind of flu. We don't know, and the ALS doc was non-committal. (Seven more months of eight pills each day.)

One thing I've become acutely aware of with ALS, is my propensity for physical work has greatly diminished. Or maybe it's called "getting old". I don't know. Anyway, it's a strange feeling. I can now become very tired, feeling exhausted, all of a sudden. (The ALS docs tell us that's not uncommon.) Fortunately, a brief rest period quickly restores the energy. So working on projects at our place Up North has taken on a more or less, casual pace.

It was during one of those brief respites, about dusk, that Susan and I headed out to the deck to sit a spell on our old-timey porch swing, intending to while away few moments ... just-a-swing-n. About the time our butts hit the swing, we realized that as we came out the door, a bat flew into the house. Our immediate priority ... that bat!

We both grabbed a broom. (You know, bats and brooms kind of go together.) We created quite a scene. It had a creepy tiny little bat face ... that terrifying look of a vampire! I knew any moment it would attack my neck, and suck out all my blood! It dove at Susan as she swung the broom wildly. She squealed like a schoolgirl. I laughed at her; it dove at me! Susan laughed at me. (I squealed like a schoolgirl!) We survived; the bat did too.

The ALS dentist made the tongue longer on my palatal lift. (I heard that some of you tried the upside down spoon in the mouth, pushed against the lolygozel experiment, which I suggested last month. If you didn't try it, there's still time. Just don't forget to stand over the toilet!)

Nevertheless, the palatal lift extension clearly improves the enunciation. That's good! But it has an uncanny tendency to initiate the gag response. That's not so good. And it's big. So I have this huge contraction in my mouth that helps my speech to be a little understandable, if I don't throw up! Ummm, I guess I've got more of that ... getting-use-to-it stuff.

Oh yeah, one more thing. We bought a boat. Used, (looks new) bow rider, it's a small one, only 18 ft, with a 135 HP inboard engine. Perfect for zipping over to Mackinac Island for dinner. (About 3 miles.)

Interesting. When we went to the marina to launch, we inquired about places to dock on the island. Now get this, "pinkies up" ... we're told that they don't allow the riff-raff to dock on the island. We're supposed to take the ferry if we want to visit the island. Whoa! Wrong message! (Don't you just hate that kind of stuff.) I've decided ... life's too short not to take few chances. (This coming from a true Boy Scout who prior to ALS, considered living on the edge to mean ... not wearing my seatbelt for three blocks.) So now, we're headed straight for the island, all 135 horses roaring! (Can't you picture the ROARING.)

When we arrived at the island marina, we sized up the situation. Let's see. Lots of big private boats. A ferry dock. No public dock. But there are some open docks with large NO PARKING signs. (No Parking? What, do they think we're driving a car?) One of those No Parking spots will work just fine. Remember my previous comment ... "just 'look' like you know what you're doing." We promptly tied off, climbed onto the dock, and boldly strolled off to have dinner. (We did have a cocky little smirk on our faces.)

We'll be here in CA for a few more days then back Up North, until time to head to South Carolina for a high school reunion in early August. Then it's more doctor appointments, a cruise to Alaska, 2 weddings and a baby and a trip to NY. The rest of the year will be way too busy to fool with ALS. I think I'll just skip it for a while.