



# Adventures

*ALS Adventures is a periodic account of life's experiences by a person living with the disease.*  
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April has been a jam-packed month with planning and excitement about two weddings and a baby. All this has kept me somewhat distracted from the ALS thing. But truth is, it's still here, and we continue to try to accept the subtle changes that always seem present. My voice really has become problematic.

However, on a positive note, my "type and talk" computer finally arrived. This one is a lot better than the loaner that I had a couple of months ago. The voice quality is better and it has some pretty clever features. For example, the recordings I made of my own voice a couple of months ago can be loaded and called up with a couple of key strokes. It also plugs into my computer so files can be transferred, saved and manipulated. The only problem is the monotone voice quality. It asks a question, makes a statement, and yells for help, all with the same level of expression. Hmmmm, Susan says it sounds just like me!

You may recall last month, I mentioned the possibility of me getting a dental device that might improve my speech. We finally got in to see the ALS dental doc. She made an interesting comment about my lolygozle. (Some demented people call that little thing that hangs down in the back of your throat a uvula. The rest of us normal folks call it a lolygozle.) Anyway, she said that my lolygozle does not move when I say aah. Try it, go look in the mirror and say aah. Your lolygozle moves a lot. She said something called a "palatal lift" might improve my speech because holding my nose helps with the enunciation and, my soft pallet

does not move. (The soft palate is the thing the lolygozle hangs from.)

Okay, after we said sure let's give it a try; she said she needed to take an impression of my mouth. Ever had that done? First she stuffs this tray full of plaster in my mouth and as I'm choking to death, she says RELAX. Yeah right, relax! I go back for my first fitting in a couple of weeks.

I also went in for my monthly check-up, as part of the clinical trial program. The doc there concluded that all my motor muscles still appear strong and my lung capacity is still good. That's really great news! I get the pill next month, or the placebo. We're anxious for that to begin. The placebo or the real thing, ether way, it's what hope is made of.

I have found one good thing about having ALS. I have several female docs. They all are "lookers". Go figure, did someone decide that since having ALS is a bumpy ride, it would be nice if the doctors were good looking? Susan had previously pretended not to notice the pretty doctors as they examine me each month. This time she's over in the corner making provocative faces as my doc is checking to see how strong I am. And believe me, there's some kind of a "man thing" that makes you want to be strong during these examinations.

Susan and I are headed to Washington DC next Sunday to participate in an ALS Advocacy event. One of our client's father died of ALS a few years ago. Our client heard of my diagnosis and called to encourage us to go to DC and participate. He was instrumental in getting the Advocacy thing started. He said that fundraisers are good and important, but the real money is in Washington. So Susan and I, along with several others from California, will be visiting our congressmen pushing for more research money. Someone thinks it will help get the message across if people are heard who actually have the disease. We'll see. Politics has

not ever been our strong suit. We're consultants, we deal with rules and regulations and facts and figures and sometimes we sell "big ole hulking" mining equipment. You know, we have a little red on our necks. Can we make an impression on a bunch of politicians? I just don't know!

One more fun thing; every year in April the classic car show comes to Seal Beach. Every year we walk through the show and Susan listens to me scheme about owning my very own classic. No, we didn't buy a classic. However, we did convince our friends to sell us their 1993, Fortieth Anniversary, Corvette. It's white (soon to be red), Fast-back with a removable glass top, less than 35,000 original miles, with a "go fast" 300 HP engine. We reasoned that our friends were not driving the car, and everyone knows it's not good to leave a car garaged all the time. So hey, maybe we ought to help. Anyway, we now own it. We don't need it. And we don't need the speeding tickets it is sure to draw. Susan ordered those vanity license plates for our new toy. TOY4MNS (Toy for Mike & Susan, get it?) I guess we may look like a couple of old geezers when we remove the top and tool down all three blocks of Seal Beach's Main Street. But at this stage, WHO CARES! And I've had no problem convincing Susan to go topless!!

Not long ago one of my docs said we should plan our life in 3-month increments. Reassess how things are going and then plan for three more months. We're counting on this ALS progression to be SLOW. I figure we have at least another 7 years to own that Corvette before it can be considered a classic. So we have decided to plan our life in 7-year increments. Seven years from now, I want to enter that Vette in the Seal Beach Classic car show. That'll show 'em!