

## Meds & Machines March 8, 2006

I don't mean to start out on a sad note, but I'm feeling a little blue. It's our clinical trial. We started 13 months ago, and can you believe it, it's over. We had our last visit a couple of days ago. It was sad to bid farewell to the monthly visits with the clinic's staff. Susan and I looked at each other and said, "Is that it? It's over?" No one cares any longer about our daily routine. They don't care if I took all my meds. They don't care if I can't reach the back of my head with my left hand. Yeah, of course friends and family still care, even the clinic's staff, they still care, but you know ... it's over.

I probably don't qualify for another clinical trial ... have lost too much lung capacity. Do I think it helped being in the clinical trial? Well, yes, it was the basis for lots of "hope," and that was priceless. We think I had the real drug, not the placebo, but my gut says the real drug had no impact. The ALS doc says "maybe." "You're still walking, and perhaps you wouldn't be." Hmmm ... perhaps.

What's next? Life, that's what's next. It goes on and we want to milk it for all that's left. And the good news ... we'll have more time to do other stuff.

Last month's ride in the ambulance stimulated interest from some of my regular docs. Doctors don't like it when you go to the hospital unless they prescribe it. They get all beside themselves and want to fix something.

So what do you think ... they prescribe more meds and more machines. Now it's not like I don't already take too many meds, and our bedroom is starting to look more like an ER than a bedroom.

For a disease that has no known cause and no known cure, why do I take so many meds? And remember that only one med is thought to help prolong life ... maybe.

So what are all the others???

The others are intended to improve the quality of life. You know, relieve the symptoms. Saliva, choking, blah, blah, blah. And I'll continue to take the clinical trial drug. But add them up ... there's 24 pills each day. No wonder we have to take a cuckoo pill.

That's right, they figure with all this ALS B.S. and all those stupid pills, it might make you feel a little sad, (you think?) so they add one psycho pill to the mix. Susan takes 'em too. We call it the cuckoo pill.

We dump them all down the feeding tube, so who cares!

But that brings up a good point. How the hell can people take drugs, you know, the illegal stuff? I mean I hate pills, I hate shots ... and although I'm not swallowing these, I'm always looking for a reason to not take something.

I don't get it ... there must be a bunch of people out there that like to take pills. Think they grew up liking pills? Is that the difference between people who take drugs and those who don't?

Hmmm ... Mamas, teach your babies to hate taking their medicine. I know, when they are sick that might be tough, but think about it ... teach them to hate medicine ... one short generation ... we could win the whole war on drugs thing!

The ambulance ride caused another machine to enter our world. Our newest machine is a "cough assist." Now this thing is somewhat intimidating. I mean, first off it's kind of big. It overwhelms my night stand. It's an arm load for Susan to carry and nowadays, it's more than I can lift. But its size is only one thing. Turn it on and it makes you step back ... way back. It makes a tremendous suck and blow noise.

And I'm supposed to do what with this thing? Put that mask thing over my mouth and nose? Yeah right! "SEND IT BACK!"

Susan urged me to try it out before I actually need it. The technician guy said it won't hurt. "Good ... let him try it!"

Okay, okay. "Give me that mask." The technician said hold it tight or it will

blow off my face. What? It might blow my face off? "SEND IT BACK!" Don't be silly. "It won't blow your face off ... It will blow off your face." Huh?

So he turned it on. I watched it cycle through sucking and blowing. He said, "It's going to pause, that's when you slam it on your face." What? Slam it on my face? "SEND IT BACK!"

It paused. Both hands, I slammed it over my nose and mouth. All of a sudden it's blowing my lungs full. Eyeballs bulge ... chest heaves, as it swells up, then instantly it starts sucking. My eyes suck back in my head ... my chest caves in ... my guts surge up near my throat. All that air it blew in, it sucked out ... plus some. My vocal cords start to flutter as the air is being pulled from my lungs. (Sounds strange.) And this thing is supposed to do what?



**In the pulmonary doc's office, that's D'Neene. She's a lover. And she makes sure my breathing's at its best**

The weirdest contraption yet, is intended to help me hold up my head. I got fitted for it a couple of weeks ago. I DON'T LIKE IT!

First it has a metal/foam/plastic vest to strap on. Reminds me of a gladiator's vest with a coat of arms in the center. I DON'T LIKE IT!

Then I clip on a padded shelf where my chin is supposed to rest. Next, two rods extend up past my ears and hold a back-of-the-head rest. Add a couple of straps and I'm trapped in it. (Can't move the head though!) It's supposed to take the load off my neck. I STILL DON'T LIKE IT!

Hmmm. All this is supposed to improve the quality of life ... Hmmm.

I've been surprised how much response to this newsletter has been about Blacky. Blacky the cat. Blacky is no longer a kitten. He's not yet fully a cat either. I think that makes him an obnoxious teenager.

Ahhh, you say. Don't be mean. I'm not. He is. He's an adolescent. He decided a couple of days ago to climb Susan's back. Tiny sharp claws and all, dug right in. I didn't know what hit her. There we were dealing with my feeding tube when WHAM! Susan falls over backward ... screaming!

There is one good thing. He's building up his frequent flyer miles. Every night, several times a night, Susan flings him out of the bed for doing something obnoxious. I look up and there he goes again, flying across the room. That's good though. When we start traveling again, he'll get to fly free.

Dealing with our pets always has a certain level of humility built in. I'm sure everyone has their favorite story. But this next tale is ... funny ... sort of.

You see, friends John and Melissa, they are grandparents, and they have adopted their grandson, which now makes them, um ... parents ... I think. Anyway, Melissa passed on this story in a response to one of the ALS newsletters. Check it out.

*...picture early Christmas morning, I in my flannel, John in his jammies, and GAGE is leaping for JOY because SANTA has brought him a HAMSTER ... complete with a tri-level condo and an executive level exercise ball.*

*Of course Crumbles (yes he had been named in under 30 seconds, because SANTA only left crumbs on the cookie plate), had to come out immediately. I ever so carefully try and GRAB him. But he bites me hard enough to draw copious amounts of blood! Nevertheless, I get him in his little BALL, and I go into the kitchen to get a band aid and a cup of coffee (doing some mumbling to myself about what was MRS CLAUS thinking when she thought up this one!)*

*Then John and GAGE enter the family room to check out the Christmas Stockings.....we all return to the TREE and what to our horror do we see, but SADIE the dog, our beloved DOXIE, standing over one DEAD hamster.*

*Yep you get it, Crumbles had ... EXPIRED. John is looking at me, I am looking at him, he yells, "HE'S DEAD!" And Gage begins to cry hysterically ... ALL DAY LONG...no other present would do....it was a very long, long day.*

*But ... 9:00 AM the next morning we were all at PETCO ... we now have BLINKY firmly housed in the condo ... what a DRAMA!!*

See what fun our pets make for us.

This month saw one other adventure. Remember our graphic designer son, Jason? He had the art exhibit in New York. Well he now has a solo exhibit at the Presidio's Thoreau Galleries in San Francisco. It's a big deal so we decided to drive up for the opening festivities.

That is, Susan drove, I rode. But it was the motor home she was driving, not a car. (We call it our "Box")

The box had not been driven in a year. It needed the cobwebs brushed off and a few minor repairs completed before we could hit the road. One of those chores involved moving the living room recliner. It's held to the floor with two long screws. I've moved it myself several times and it's pretty easy. But this time it would be Susan's job. I can't lift or do the work with my weak arms. She would have to do it all.

The power screwdriver had that chair loose in minutes. Putting it back ... that was the challenge.

Susan's on all fours, one screw in place, the other is being stubborn. She couldn't get it lined up with the hole. I figured I could do more than supervise, I could help! I could not lift it but I could throw my weight into it so it was tipped up. So far, so good.

Susan said, "Move it to the right." I leaned into it and she screamed as it pinned her against the desk. A frantic move on my part landed the chair on my toe. She said, "Hold it right there!" What? It's on my toe! I can't say those words though. I just squirmed and pushed. She hollered again, "Don't move! It's lined up!" But it's still on my toe! She's running that power screw driver ... she doesn't know the chair's on my toe. She's driving that thing home. It's still on my toe! Damn ... not being able to speak sure can have its down side!

We've had the motor home for several years and Susan is a veteran at driving it. But driving is one thing. Hitching up the toad (our tow vehicle) and dealing with the outside connections of such unmentionables as the "poop chute," those were chores that I have traditionally handled.

This outing, Susan did it all. It was sort of a test. That is, are we done with the motor home and may as well sell it, or can Susan really handle everything so we can make one more cross country trip?

Round trip, 6 days, 1000 miles. Didn't hurt anybody or anything. Proof that we're ready to head for the right coast, maybe to return to the left coast next fall? We'll see.



**Driving's one thing, says Susan ... hooking up the "poop chute," that's the man's job!**

Readers who want to learn more about ALS can log onto the ALS Association's web site ... [www.alsa.org](http://www.alsa.org).