



## Adventures

*ALS Adventures is a periodic account of life's experiences by a person living with the disease.*  
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### I Got the Pill June 7, 2005

Finally, I'm through the "evaluation" phase and it's time to start the clinical trial. You may recall that I signed up about 3 months ago to participate in a Double Blind Clinical Trial of Minocycline. (Double blind means neither the doc or the patient knows if you're getting the real thing or a placebo.) Minocycline is a drug that has proven effective in laboratory research, slowing the progression of ALS in several studies of mice afflicted with the disease. The doc told me she had a bottle of blue pills, and that I should start immediately with the recommended dosage.

Call me strange, but my mind went to the word "blue". I thought I've seen those ads. Guys who take that little blue pill report, how should I say this, "having lots of fun". Oops! Wrong shade of blue. These things are BIG, UGLY, capsules! Think about it, I'm already having trouble swallowing and they issue me a bottle of pills that would choke a horse! Nevertheless, I'm in this for the hope, and possible good it might do. I'll get them down somehow.

Minocycline is an antibiotic used with minimal side effects for over 30 years treating conditions like

acne. About 7 years ago (medical research is a slow process) a very smart Dr demonstrated that minocycline has the ability to "protect" neurons. Subsequent animal studies have indicated a favorable impact on a variety of neurological diseases including multiple sclerosis, Parkinson's, Huntington's and ALS. Interesting, they are not using minocycline as an antibiotic. They have found that minocycline has a unique characteristic of being able to somehow create a protective shield around a motor neuron. That shield appears to repel the substance in an ALS patient that is thought to attack and kill motor neurons. Dead motor neurons, not a good thing, it equates to paralysis and loss of all muscle control.

Although there have been other studies of other medications on mice, none have proven-out in humans. However, there are many reasons that researchers feel this one might be different. All mice with ALS die prematurely. I'm particularly impressed by the report that the little mice taking minocycline, (tiny little blue capsules?) experienced extended survival of more than twice the life expectancy of the ones not taking the drug. More than TWICE the life expectancy! That has a much better ring to it than the other drug I'm taking, (Rilutek) which is thought to extend live by only a few months. Let's see now, the normal life expectancy for an ALS patient is 3 to 5 years. Is there a chance minocycline might double that? Seems worth the hassle of a clinical trial to me! All in all, I'm pretty excited about starting the pill. I think I feel bet-

ter already! And I just checked the mirror, NO ACNE!

I'm often asked if minocycline works, will my speech return. The simple answer is no. But think of it this way. Let's say you have a couple of lively dogs. You learn of a new dog food that will assure a long healthy life for the pups. You race out and buy some and on your return home you find one of your beloved pets, dead. (It's only a story, don't be sad!) Anyway, you feed the remaining dog the food and it prospers well. But, no matter how much you give to the dead dog, you stuff some in its little dead mouth, even if you pour that food all over the it, it's still dead. The motor neurons in my throat are kind of like that dead dog. They're dead, and all the drugs in the world won't bring them back to life. Interesting mental picture, that dead dog covered in dog food, huh.

The other doc I saw just today is the ALS dentist. She's the one fitting me for the palatal lift. A device that "might" help me with enunciation. Here's the deal. I got a "learner" device about 3 weeks ago. It was not intended to help me speak better. I'm supposed to learn to keep the darn thing in my mouth without gagging or throwing up. It's been quite an experience. The thing looks a little like a dental bridge. It's shaped like an upside down spoon with little wires designed to grip my upper teeth which hold it in place and pushes up on my soft pallet. It has an extension that resembles the tongue in your tennis shoes. With each visit, the ALS dentist will make that tongue longer so that one day it will push

on my lolygozle (you know, the uvula) and in theory I should see an improvement in my enunciation.

Fortunately, you'll be happy to hear that you can experience for yourself what this thing feels like. Here's what you do, you can try this at home. Take a teaspoon. Turn it upside down, so the rounded side is up. (In your minds eye think about how that spoon might fit in the roof of your mouth.) Now, place the spoon inside your mouth up against the roof and slowly push it back until it touches your lolygozle. Next while holding the spoon in place, count to ten out loud. Got it? Pretty simple huh. Uh-oh, I forgot to tell you to stand over the toilet during this experiment, just so you have a handy place to deposit your stomach contents once the spoon hits your lolygozle. It will bring a whole new meaning to that old saying, "gag me with a spoon".

Nevertheless, the ALS dentist added about 3/8 of an inch to the palatal lift tongue today. And frankly, I think I can already discern a very small enunciation improvement. I am encouraged by that! Moreover, I think I'll hang in there, gagging and all.

On a final note, Susan and I have just returned from a couple of weeks at our place "up north". (Up north, our hide-away place in the Upper Peninsula on Lake Huron in Michigan) We are in the throws of a remodeling project by remote control, so we needed to go back there and check out the progress.

While there, I decided to orchestrate moving in the new refrigerator. This is one of those BIG built-in jobs that weighs no less than a zillion pounds. With me and four big guys we started the trek from the garage to its intended spot in the new kitchen. Here's the scene. We have it through the door, lying on its side. One guy is hollering he is "loosing it"! Another one is fussing about not hitting the wall (that he just painted). And a third guy says, "Wait, lets think about this". And I'm barking instructions. Well kind of. (Remember, I don't speak too good anymore.) So in all the commotion no one can hear me! I started beating on the side of the frig to get their attention. Susan, she could not stand to watch anymore. She went to the deck where she could throw-up. And that guy who was hollering that he was losing it, if you could have only seen the way he looked at me!

Bottom line: the new kitchen is looking "rustically elegant", the natural slate on the floors looks really special, and the new stairs, they look awesome! Check out the attached pic. That's the view from our front deck. There is something very special about being "up north".

What's next? Now that the Dr appointments are done for the month, we'll take care of a few business things and probably head back up north. We will be there for 2-3 weeks before we return to California for next month's Dr visits. It's a cycle we're trying to get used to.

In the meantime, we're on-line no matter where we are, and would love to hear from you. (As you might guess, e-mail works better than phone calls these days.)

