

Page One: Life

Yes, it's been a while! I appreciate that several have commented that it's been a while since the last update... it tells me that you read them and pray for us!

Spring was busy with that trip to Cleveland with SEMA friends, followed by more testing at Washington University near Easter. While we do not see the direct results of those annual checkups and scans, we DO have "quality time" with a great neurologist who can answer my questions in a general way. So, I learn a lot about the disease and diagnosis, but not a lot more about Susan specifically. It's up to me to piece it together.



A highlight this Spring was the addition of a new porch/entryway on the house! Son-in-law Christopher used this project to launch his renovation business, and it turned out great!

Spring has merged into summer with the corresponding heat and humidity... and another round of those routine checkups that are now a part of our lives! Three appointments this past week! We've enjoyed all the grandkids' birthday events, and I was privileged to speak at a conference or two as well.

But the major activities have involved Veteran work right at home. To strengthen individual Veteran groups and create some dynamic support among them, I've launched the Veterans Coalition of Lawrence County and Southwest Missouri. That's a mouthful, but we call it



VCLC for short. With their willing cooperation, the Veterans' groups (like the VFW, the American Legion, etc.) are now working together and making improvements to our existing building in town. We've incorporated as a nonprofit and painted the interior of the main room to rent out for community and family activities.

To summarize "Life"... it continues at a slow but steady pace. One activity a day is enough. And sustaining the house and routines of family, doctor, cooking, laundry, and daily variety is plenty-nuff!

Page Two: Susan

I've learned a principle that has never been said plainly but seems to hold true as I compare what the docs say with what the family support groups say. Simply put, "If it's fast, it's fast; if it's slow, it's slow." We are in the slow category.

As other FTD family members share their stories, several who were diagnosed about the same time we were diagnosed have already said goodbye to their loved ones. Yet, all the

doctors have told me, “It’s progressing.” One added the word “slowly” to his visit notes, and that was the clue. It IS a progressive condition, and the good news is that even though it is progressing, **it is slow**. When the “average” is 6-8 years, “by definition” some cases will be less than that and some cases much longer than that. I don’t think there is a “better.” For us, it is slow progression. So, we maximize the “joy-moments” each day.

Susan is a mixture of things retained and things lost. To ask a direct question will likely have a response fade away and you’ll get no answer. But we will be driving down the road and suddenly she’ll say, “Look at those pretty flowers!” or “There are some horses!” Spontaneity has replaced a lot of deliberate conversation. And there is always a tune in her head, too. She has always enjoyed music, so we listen to favorite CD’s or the radio. But the “internal radio” is always “on,” as reflected by her contended humming and tapping her hand or foot to the beat. Music, beauty, animals, and art are healthy things these days.



*Susan with her sister,
Linda, at Baby Maverick's
birthday party yesterday!*

Page Three: Gary

Many times, I stared at the keyboard knowing I should update you, but the responses varied from “I’m dealing with other things” to “I just don’t have the words right now.” How to explain the subtle changes? How to describe the routines of doing all the household tasks and setting the schedule... like there is a schedule to set! Laundry is NOT an interesting topic!

My pendulum has swung between “I’ve got this!” to “I’m clueless!” I’ve worked hard to keep “enough” in my world to keep me engaged and contributing to worthy causes, but it’s a delicate balance as Susan is brought along to every meeting or Zoom call.

I’m so blessed that she is willing to roll with “whatever” the daily schedule brings us, since so many with FTD are not! But it is getting harder to travel—near or far. And her anxiety increases when there are new surroundings. One day can be a breeze; the next an insurmountable challenge. And there’s no pattern that explains why... so trips and changes are rare and scheduled with care.

I understand “you need to take care of yourself to take care of her.” And overall, I think we’re on target with this (but not a bullseye!). Doing good; not perfect. Thanks to family and friends who are there for us in many ways-- really appreciate each of you!

Page Four: The Lessons Learned

Every day matters. Make the most of each one-- for you and for those you love!

Gary