

# ***Upward Bound Ministries Newsletter***

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## **Test Results**

Hello again, upward Bounders! This month's letter is really late (seems to be a habit lately!) but I was waiting for test results before I wrote you. It took longer than expected. As you recall, my neurologist set me up at the Psychology Clinic at Shands Hospital in Gainesville to undergo extensive cognitive testing as a result of my neurological issues I have been battling since late February. That was the most intense day of my life! The testing lasted from 9am until 7:30pm, with only a lunch break. It was nothing painful, just one test after another that challenged my thought process and cognitive skills. I was given every test you can imagine. Some I did good at, and others I completely messed up. Each test was designed to give analysis on different parts of the brain to see if they were functioning correctly. They started off relatively easy then progressed to be very difficult each time. Very tiring and very stressful. I thought my head was going to explode! Needless to say, I exhibited just about every symptom from minor to major in front of my doctor that day. The next day was even worse, as I went to my speech therapist here in Tampa and completely lost it, as I had a major episode that lasted 15 minutes. When those kinds of episodes happen, they are so intense that it looks like I am one crazy person! I really thought after those two days I would end up being locked up! Haha!

Well, here it is in a nutshell, although it's way more complicated than this. The doctors there are not that convinced I am dealing with PTSD. They are sure, however, that I have developed a neurological Tic Disorder called *Tourettism*. That's basically the same thing as *Tourettes Syndrome*, only it's not inherited. The test results indicated the parts of the brain which were affected had to do specifically with motor and speech impulses. Their observation of my behavior was that my symptoms resembled *Tourettes*, where my body jerks and has sudden spasms, ranging from minor to major. Also the stuttering and repeating of words and phrases are indications of impaired speech also associated with *Tourettes*. The main thing they noticed was the constant loud noises I would make in my breathing patterns, especially when stressed. That is what *Tourettes* patients do – utter noises and have spasms. Long story short, I have no ability to control my motor and speech impulses. I am usually fine when I am by myself and do not have to talk to anybody. But any time I try to talk to an individual either live or on the phone, the symptoms kick in. When I am in situations that are in close quarters outside the home, they get worse. That is also common with *Tourettes* victims. The only symptom that I do not show that is common in some *Tourettes* patients is occasional uttering of swear words. That's an uncontrollable impulse some of them have, and boy am I glad I don't have that one! Can you just imagine me trying to minister to kids in that condition? Haha! (*Not that I don't feel like swearing every now and then with all of this! Haha! But thank God I don't.*) I think I have mentioned before that when I practice singing at home or in the car, none of these symptoms show up. The whole thing is still really bizarre.

## **No Easy Explanation**

Where this whole thing becomes even more complicated is trying to figure out why I am having these symptoms. *Tourettism* can be caused by severe head trauma, but the results of my MRI taken here in Tampa does not indicate that my existing brain trauma is that severe. I only show minor signs of

trauma on the scans. The doctors do not think what they see is enough to be causing what I have. Even though my cognitive skills such as memory loss and concentration problems, etc. can easily be related to the head trauma, the *Tourettes* symptoms are very confusing to them.

Here's where it gets even a little more crazy. *Tourettism* can also be caused by adverse side effects from certain antipsychotic drugs. Sure enough, the first or second full day I was in ICU in Oklahoma, I developed a bad case of hiccups that would not go away. They were persistent and often in nature. Of course they caused a lot of pain to my broken ribs at the time, so I remember begging them all day to do something. They tried a lot of things, none of which worked. Finally, some time either just before or during wrist surgery, I was given a certain antipsychotic drug to stop those hiccups, which eventually worked. But that certain drug just happens to be on the list of possible contributors to *Tourettism* as a result of adverse side effects.

The other confusing thing to the doctors is the timing of when these symptoms began – 3 months after the accident. Of the thousands of automobile accident trauma cases they have either seen or worked, my case is very rare. They really have no other cases similar to mine to compare to.

## Prognosis

Right now they cannot guarantee me what kind of results will come from this. It may or may not be permanent. Some of that may depend on further findings related to the actual cause. In about another two weeks, they are scheduled to have a gathering of many experts to specifically discuss my case. My doctor at Shands told me they would likely end up writing an article on my case for publication because it is so rare. (Oh boy, I will be famous for all the wrong reasons! Ha!)

My neurologist is also setting me up with another specialist at Shands Hospital who deals specifically with Tic Disorders and in particular *Tourettes*. Most of my treatment will be psychological in nature, teaching me how to cope and handle what I have so that I can function in public. Otherwise, we don't know about what medicines, if any, they will give me. I am finding that people with full blown *Tourettes* don't normally recover – they just learn to cope with it. I think for me it will likely depend on if it's just head trauma. In that case, maybe time will heal it. But if the drug was involved, we don't know if we can undo the damage. It's not necessarily the amount of the drug that concerns them, and they know it's not in my system now. It's the timing as to which it was given to me, immediately after a severe head trauma case. Lots of other things were going on in the brain at that time, and more research has to be done.

## So What Now?

Seems to be the question of the day! I'm always asking that. OK, what now? More waiting, more testing, more working with new doctors – it all gets old. I just want to be out there doing what God has called me to do. But it looks as if this thing can drag out at least through the summer. If at some point, however, they can get me where I can function and not have bad episodes under stressful situations, I still plan to at least try to do my concerts again this fall. Even if it means I have to live with this condition. To me it will be all the more powerful to let people see me struggle to talk but sing flawlessly! (Well, at least on key most of the time! Haha!)

## Financial Status

Many of you have been asking how we are holding up financially. Thanks to the donations of many of our friends, children's ministries, churches, and children's groups who have taken up love offerings,

we have been able to sustain ourselves through this ordeal without going broke! My summer income will be sorely missed, as that is my bread and butter that usually helps me in the slower winter months. But God has been faithful to provide and there is no reason to believe He won't continue to fulfill His promise to supply all our needs according to His riches in glory. (Phil 4:19) We have been using those donations, along with Tammy's salary, to pay our bills and just live. We have tried to nickel and dime all the hospitals and doctors in Oklahoma and in Tampa. They are enormous to say the least. Some of them work with us. Others turn us over to collection agencies. It's no fun, and frankly some of it is cruel. I am sure many of you have had to deal with the same things in your lives at one time or another.

But the bottom line is that we're still making it, and we thank God for his provision every step of the way. We still have enough in donations to get us by for two more months. Between now and then, anything can happen. Who knows, maybe God will even allow me to get back on the road!

We just want to again thank each of you who have given on our behalf and all of you who have been praying for us. What would we have done without such wonderful friends? I am beyond blessed to be surrounded by such incredible people!

## Why, Lord?

Do you ever find yourself asking that question? I do. As much as I try to stay strong in the midst of all this, I have to admit I am just as human as everybody else and sometimes I really get down. I go through periods of sadness and numbness, just like you probably do. The latest episode came just a few days ago when we had to put our dog Lucy down. It was the hardest thing I have ever had to endure since my Dad's death a few years ago. Mainly because Lucy was my little girl – she wouldn't leave my side through this whole episode from the day I got back from Oklahoma. When Tammy was gone to work, Lucy was there to brighten my day. It's almost as if she was God's little angel assigned to me to get me through the tough times when I was by myself. Then, all of a sudden, she's gone. Just like my spring tours. Just like my summer. It feels like like the rug has been pulled right out from under me.....again. It hurt. It hurt bad. I asked the Lord "Why? It's not like I need any more grief in my life right now!". Do you ever feel that way? If so, join the club. Grief and uncertainty is common to us all. Even to Jesus. Remember on the cross, even Jesus asked "Why have You forsaken me?"

I have been reading a book by James Dobson called ***"When God Doesn't Make Sense"***. I strongly recommend it for any of you who are going through difficult times that just do not seem to make any sense. Some of you may know God is near as I do - but even so, like me, you are confused and seem to have no answers to your situation. Others of you may feel like God is a million miles away from you. As Dobson wrote in his book, *"Having a steadfast faith in God does not guarantee a happy, carefree life"*. We all go through seasons of pain, disappointment or confusion. *(The key word there is "seasons". Remember, it's only for a season!)* That's why the Bible tells us not to "lean on our own understanding" during those times, but "in all of our ways to acknowledge Him and He will make our paths straight." Again, to quote James Dobson, *"With God, even when nothing seems to be happening, something is happening. The Lord is at work in His own unique way even when our prayers seem to echo back from an empty universe."* 1 Peter 3:12 says that "The eyes of the Lord are on the righteous and His ears are attentive to their prayer." Psalm 34:17 says "The righteous cry out, and the Lord hears them; he delivers them from all their troubles."

I think it's safe to say that His purposes and plans are very different than ours and His timing is rarely our timing. Sometimes it may even seem like He is a little late in giving us what we pray for in times of struggle. All I can say is that at times I struggle with the same emotions anybody else would. Sometimes when it rains, it pours. Mark Twain said *"Life is just one darn thing after another!"*

Sometimes it seems as if there is no end in sight. Many times things don't move as fast as I would like them to. And for those of you who know me, you know that's a real Achilles Heel with me! Simply put, there is no stability or predictability in this imperfect world that we live in.

## Keep the Faith!

But even in these lowest of times, I somehow sooner or later always end up going back to the fact that God did not take me Home when He easily could have on November 15th. So deep down I know He has a plan, even if my feelings fluctuate. Just because it's not working out the way I had envisioned or in the timely manner I wanted doesn't mean He's not working. I can only remind myself and encourage you to hold strong to your faith. Faith is what honors God. These are opportunities, as hard as they are, for our faith to grow. Someone once said, "Faith is holding on to uncertainties with passionate conviction". I once read that faith does not always instantly deliver you, but it always carries you through. How true! And isn't it more than just a coincidence that in the tough times, God develops our character? I don't always want to hear that, but I know it's true. I don't always enjoy the pain of a workout, but I like the results. Spiritual muscles, like physical muscles, grow through the pain of resistance, usually over a period of time.

Some day all our difficulties in this life will all make sense. Whether we get the answer here or whether we'll have all of eternity to talk about it, it will all come together. The light bulb will come on sooner or later – in God's time. I have a feeling we will all look back at some point and say, "Oh, so that's what You were doing all along! That makes total sense! Wow, Lord, You are awesome and Your plans are so perfect! You knew what You were doing all along!"

But for now, in the midst of whatever it is you may go through before then, - present, past or future, hold on to your faith with the tenacity of a lion! Believe even when God doesn't make sense! We can be assured from God's character and through the scripture He left us to live by that we are in the palm of His hands and that His timing is perfect. He knows what He is doing. Dobson said, "He intervenes at just the right moment for our ultimate good." What we will face or are facing may *not be currently good*, but with the right attitude *He'll use it for our good*. So when you find your attitude slipping as I do at times, hold on tight to your faith! It's not a mind game, it's our foundation that holds us up and keeps us from falling.

Until next time, take care and be blessed,  
and make it your mission every day to ***Be a blessing to someone else!***

**Cya here, there, or in the air!**  
**We're Upward Bound!**  
***Uncle Charlie***