

Living with a Brain Tumor: Patient and Caregiver Panel

- Dr. Jeffrey Wefel, PhD, ABPP, The University of Texas MD Anderson Cancer Center
- Steven and Jordan Rhoads
- Robert and Melanie Johnson
- Timothy and Valerie Hoehnke

Ms. Spawn: I'm going to welcome back Dr. Jeffrey Wefel. Where's Dr. Wefel? There he is.

[Applause.]

And he's going to introduce our panel.

Dr. Wefel: Okay, thank you. Good morning, everybody. Nice to see you again. We have a full room here, folks. Okay? We have a bunch of -- yesterday, you heard from a bunch of experts in the health care field, but today we're going to hear from another form of experts, right? Your peers. I'm very happy to be a part of this and so I want to welcome each of the couples here up on stage. Steven and Jordan Rhoades, could you please come and join us? All the way from Texas.

[Applause.]

I believe there's some cards, we have some assigned seating. Yeah. Robert and Melanie Johnson.

[Applause.]

And Timothy and Valerie Hoehnke.

[Applause.]

All right, perfect. Now each panelist is going to share a brief introduction about their story as they're navigating through the process of living with a brain tumor or caring for the loved one who has a brain tumor. We're then going to open it up to the floor as you heard from Nadia and really solicit any questions that you have, or if you'd like to be responsive and share some of your experience as well that would be wonderful.

When we get to that portion, I've designed a few carrier phrases that maybe would help you to think about how you might organize a question. Feel free to use those carrier phrases or discard them entirely and put it in your own words, okay?

I think, just like yesterday, it might be helpful when you ask your question if you could stand up and announce your name and then share your question or ideas with the rest of us, okay? Without further ado, let's go ahead and get started. Maybe we'll just move from right to left. Timothy, we'll start with you.

Mr. Hoehnke: Okay, sounds good. My journey with cancer and brain tumors starts back in 2006. In 2006 before my senior year of high school, I was diagnosed with Leukemia. ALL leukemia.

Spent two and a half years doing chemo and high dose of standards and Mountain Dew bags of chemo -- yeah, that's what I called them. My big thing that I did, I continued school. I graduated in 2007 which was supposed to be my graduation year. I continued to go to college, right away. I'm a stubborn guy. I wanted to keep going, so I kept going. I took two years of college tuition as a Make A Wish. So I was determined to beat it when I was 16 and I've been to Disney so I got lucky with that aspect. So I could have done a lot of other trips but I wanted to go to college and I knew college was expensive. I threw the idea that maybe I could take some tuition. A grant in an aspect and they granted it.

So that's what I did. I had a few years to go to college, a little bit of a break. Then 2013 happened. In 2013, the fall of 2013, I had a Gran Mall. Just out of the blue, on a Thursday night. I was going to play softball. I was in [inaudible 00:12:17] and I collapsed. No signs or symptoms leading up to it, but I collapsed. When I woke up, I was in the ambulance and they were telling me I had a Gran Mall seizure.

I'm denying everything. "No, I didn't. No, I didn't. No, I didn't." Got to the hospital, they did some scans and they said I had a tumor. I was still in denial at this point. When I was told I had a tumor and then -- this was a Thursday night -- when we talked to all the doctors and the surgeon, I was told I was having surgery that Monday, that following Monday. It was a quick turn around. There was no looking back now.

I had to stop college and have surgery on a whole new aspect of life that I had no clue about. It's what happens a lot, to all of us. We get handed the book and we're supposed to adapt to it right away. We have no time to really do research.

I had my surgery, I found out I had two tumors. An astrocytoma and an oligodendroglioma -- so many syllables. We got most of it out but it was spiderwebbed into my brain. You can only cut so far before you start cutting actual brain. We took out as much as we could; I did radiation therapy the whole summer. Monday through Friday for eight weeks. And then, like I said, I'm stubborn -- determined. The following -- next fall I went back to school. I took the summer to heal and whatever, that aspect. But I went back to school because I wanted to graduate. I was determined but it was too much.

So I stopped, took a semester off and I had a five-year gap of just rebuilding my life and human in all aspects -- mentally and physically. But then, five years came. With five years it came and it became stronger. It was the night of my graduation and I got a call early morning from my doctor saying she needed to see me the next day.

This was something I was like, "Oh no." When the doctor calls you, this is serious, you know? It's not one of her nurses or someone who calls. I got that call and I said okay. I had to see her the next day and I was just thinking, the tumor's growing back. That's all I was thinking. I didn't tell my parents about it because the 10-year journey of already having cancer and everything and then finally graduating -- this was a win for all of us. Not just me, but for all of us. I didn't say a word. I had my brother drop me off the next morning; I was alone.

My doctor, the first thing she said was "Why are you alone!" Oh, jeez. Well then. Good morning to you too. I could see on her face this was serious, but I was still under the impression the most it could be is tumor grown. But she showed me the MRI. She turned the computer and she showed me. I could instantly see it. Little bit of like an egg, a bird egg. It was a brand-new tumor, right next to where my old tumor was but it was brand new. White as can be and I was devastated. I just graduated with an occupational therapy degree and I was getting ready to take the boards exam.

I call it real life. I was ready for a career, start paying my loan back. I was ready. I was so happy I graduated, like okay let's do all this. Then to get hit with such a blow and not even like weeks later or a couple days later. Right after walking across the stage was just a punch in the gut.

I had to call my parents, have everybody come. Again, this happened on a Wednesday and then then that following Monday was the surgery. There was no way -- I asked my surgeon, "Can you give me a month? Just to study, take my boards exam, all this information is still in my head." It was a no go. No go, no go, surgery is immediate and we all know that pathology takes a little bit of time after surgery.

When the results came back, we were told it was a GBM. At this time we don't exactly know what a GBM is but through discussion and everything. We're told this is severe, this is a Grade 4. Oh my gosh. You start thinking about quality of life. The big aspect of quality of life. Especially since it's been 12 years at time just battling. A roller coaster, it takes me up, down, up, down. Just the shock of everything I've been through and I'm hit again when life is literally going to start for me. Adulthood, I guess you could say.

Like I said, now -- now after wearing a device, it's called the Optune by Novacure and after the resection of it I did radiation and chemo. Then I wear this to help slow down the growth of the GBM and I've adapted to life with it. I've been wearing it for a little over a year -- we'll call it a year and now -- my saying is I flipped the script. The whole 13 years is -- I've been living with cancer. It's been like, it sounds bad, right? You're living with cancer. Cancer is your main thing.

I switched it. I am -- cancer is living with me. I'm going about doing everything.

[Applause.]

Rock climbing, you name it. I take this thing for a ride. Let me introduce you to someone. Let's meet Tina. Tina is my device, my Optune. Tina's great, right. She comes with me everywhere, batteries and everything. This device makes it so I can do everything. I can thrive. Thriving while surviving. You don't just get the title of a survivor. I'm thriving.

[Applause.]

Let's see this. Can you hear this thing? This is the most annoying thing in the world.

[Laughter.]

You tune out your significant other sometimes? Selective hearing? I think that happens a lot with this thing. But when that thing beeps; oh my god it's annoying. And she turns into Felicia.

[Laughter.]

I think most of us are adults. "God dammit, Felicia." And it's so frustrating and there's a lot of times it's not beeping from the battery or something. It's, I'll leave it on the couch and I'll get up without it and it'll yank me back. And then I'm "Felicia!" and like I named it. I gave it the two names. It's something that's stuck with me but at the same time it's funny. It's funny to laugh with it. I know what it's doing, I know it's doing well but then I can joke with it. Joke about it and laugh and then know that everything is okay.

You know, I'm going to have it for a while but at the same time, it's a nuisance sometimes. It might hook in the door and I'm just "Felicia!" Sometimes I'll unplug for a little bit and I'll say, "Bye, Felicia." And I'll leave it on the bed. That's a little bit about me.

[Applause.]

This is my caregiver, my mother of 30 years. No, that's how old I am -- not. Valerie Hoehnke.

[Applause.]

Mrs. Hoehnke: I always say I'm a mother first; we're all mothers of our children. But this caregiver role started back in 2006. Just to give you a little bit of a background about me, I do have rheumatoid arthritis, so I had already been in this medical field for a long time. I've had it since I was nine years old, so I knew how to talk to doctors, I knew insurance problems, I knew all of that stuff. I had lived it.

But I hadn't lived cancer, I hadn't lived that world. When my 16-year-old, who was running cross-country, was on the swim team, was a pitcher and a catcher in high school, was doing great in high school, all the sudden he's in the hospital and they're telling me he's got Leukemia.

What do you do? You're in shock. You, you wonder what does this mean? Where is he going? What is he going to do? You start mourning that child that you had and you're waiting to find out what that child is going to be like, and then you deal with all the side effects and all the damage. Survivorship comes with a lot of damage and a lot of hurt to his quality of life.

I remember getting a phone call -- we kept saying his hips hurt, his hips hurt, his hips are stiff. I get a phone call; he's got avascular necrosis; his hips are dead. I said, "He's a runner. What do you mean his hips are dead?" So it was one battle after another and as a mother and caregiver I had to tell him the news. Then we go to the doctor appointment and then they tell him.

It was really hard and we got through that and as a caregiver, when you're done with all the treatments and everything, you're like, "Okay. Now what?" All of that stress and activity is gone? He's going about his life and I'm like, "Okay. I work and I do this and I do that." But that other part that was all consuming is gone, because the treatment's gone, everything's done. He beat leukemia, everything's done.

There was this void in my life. Okay, I'm not a caregiver anymore. I found a way -- I found my life again and I did what everybody does. I go back to work, enjoy myself, enjoy him and my other son and go on vacations. We do everything we want to do.

Then I get a phone call. He's out playing baseball so I don't know who it was, it was my neighbor who was studying to be a nurse. She goes, "Val, Tim's having a Gran Mal seizure." I said, "What? He's playing baseball."

"No, I'm there. He's having a seizure. What do you want us to do?"

I'm like, "Did you call 911?" yeah, they did. There happened to be an EMT there. We met him at the hospital -- they ambulanced him to the hospital. But it was the local, small hospital and here it was nine o'clock at night. They had no body to do an MRI there, nobody to do a CAT scan there. So we had to wait around for somebody to come from home to do the scan.

When they did the scan they said, "Well, we see a mass." So they called Frader Hospital and I ended up walk -- driving him to Frader at midnight. Walking into the 5th floor neuro with him -- walking, at night -- and admitting him. Hm?

Mr. Hoehnke: We both walked.

Mrs. Hoehnke: Yes.

Mr. Hoehnke: You're like my patient is walking in.

Mrs. Hoehnke: It's a teaching hospital -- has any of you ever been in teaching hospitals? Yeah. Mm-hm. Yeah. So the next morning these wonderful neurology students come in at six a.m. I'm already back, you know, I went home, slept three hours and came back. Because I wanted to hear everything that's going on and I know doctors come in early. So I'm already there.

They look at Tim and go, "Well you're having surgery Monday." We didn't even know what this was yet. Nobody had even talked to us yet. I have a resident telling me he's having surgery on Monday. I go, "Oh really?" Tim's like, "No I'm not."

Three hours later we finally meet our neuro-oncologist and five hours we meet the surgeon. So we had tons of questions for them.

Like he said, he went through surgery. After surgery he had a few complications; his scar was bleeding and they're stapling him in front of me. I'm like, "Oh." I actually had to leave. My husband finally came and I said, "I can't do this anymore." And I left. I just couldn't watch this anymore. Blood was gushing, nobody was listening to us.

They didn't want to take the pack off, they finally took the packing off. Oh, it was just one of those things.

The next day -- so he had surgery on Monday, Wednesday at 6 p.m. they say to me, "You're being discharged. Tim's being discharged."

I said, "He is?" I have no clothes because there's not a closet. There's nothing, it's all in my car or at home. Yeah, he can walk -- his pain wasn't under control but he can walk, he can go home. I said, "I don't have any clothes for him." Well, he can go in the hospital clothes. What? I said, no.

Then one of the residents has the gall to say to me, "You know, this isn't a hospital."

Mr. Hoehnke: Hotel.

Mrs. Hoehnke: Oh, hotel. This isn't a hotel. I'm like, "How dare you?" We had been through enough hospitals to know it's not a hotel. They discharged him; we took him out in hospital stuff. At 10 o'clock that night we're trying to get his prescriptions. We're trying to do everything we can.

He was back in the hospital on Saturday, he had had a seizure. Nothing had been managed correctly. Boy, when I saw his surgeon in two weeks, I gave him an earful. I said, "Residents are wonderful but you better be teaching them bedside manner. And you better be teaching them what they're supposed to do and know because I'm all for teaching the next generation but not at the expense of my son."

We had a really bad experience. Okay, he goes through all of that and the radiation. It took me longer to drive there, park than the radiation took. It took us half an hour to drive there, park, get up there, register. He goes in for 15 minutes, boom, we're doing the same thing back. And it was every day like that.

You think, oh that's only an hour out of your day. It's stressful. It's hard. You know he's being strapped down with this cage on his head and you're watching all the other patients and families in the waiting room and you're just thinking, "Ugh, this is my life. This is what I'm going to have the rest --"

We did that. He didn't have to go through chemo that time and he did his six-month checkups. We always had scan anxiety.

Mr. Hoehnke: Scanxiety.

Mrs. Hoehnke: Scanxiety. He'd always say to me, "Why are you getting so worked up?" Honey. Ugh. You never know, you know?

Mr. Hoehnke: It was big because the doctor let us know it's not a matter of if it comes back, it was when it comes back.

Mrs. Hoehnke: I always joked with him I said, "It can't come back until I'm dead and gone. I'm gone." You know, it's got to come back later. When in 2018 after graduation -- and I knew something was up. Tim wasn't himself that night, but I was so excited to see him cross the stage and accomplish a goal he wanted to accomplish.

I was taking pictures and doing all of that. Then that morning he calls me. I happened to be at home because I was having arthritis problems so I wasn't at work. I screamed. That's the first time I think I ever screamed. I looked to the sky, I screamed, I cried, I swore, I couldn't breathe. He's saying, "Can you come to the hospital?"

Here we go again. It's an awful, awful feeling and it's good to have that good team with you, because that team really does help. We were lucky enough to have our same team. We had the same neuro-oncologist, we had the same surgeon, we had the same radiologist. When he was irradiated back in 2013, they said you can only irradiate the brain once. I'm like, okay, now what can they do? He's got a glioblastoma, what are we going to do?

They said there's new technology. I love it when years go by and there's new technology. We had the phase radiation where it was in phases. I think that's what it's called. But he had to lay on that table for 45 minutes each time. That's a long time. How many songs?

Mr. Hoehnke: I think it was like 11 songs. I was always counting, "I got two more songs and I'm done."

Mrs. Hoehnke: Then you're supposed to take the TMZ with the radiation. His platelets couldn't handle it because of all the chemo he's had over the years. So his platelets would just dive, he couldn't take the TMZ. He did the radiation, then he had a month off.

Six weeks from surgery to start radiation and in my head, that tumor's growing. I'm calling the doctor, "Why aren't we doing anything?" and you know, stressed out. He said, "It'll be fine, it'll be fine."

After the radiation we had to wait that month and I'm thinking, "It's growing, it's growing." They said no, the radiation is still working. We got through it. He's still on -- he's got one more five-day TMZ to do and then after that we pray.

All right, that's my story.

Mr. Johnson: All right, good morning. I'm Bob Johnson. Bear with me, I speak three languages. Two of which are gibberish and nonsense and then the third one is English. Buckle up and get ready for that. I refer to myself as the lucky of the unlucky.

2003 I had a pituitary tumor. It was enough to drive me and got this terrible, painful head pain. I don't like the term headaches because headaches you can take an Advil or a Tylenol and you can move on. This was not anywhere close to that. In fact my doctor thought I was going to need morphine when he admitted me.

It was large enough that it was basically pressing on my optic nerve and blessedly wasn't affecting any -- it was [inaudible 00:32:32] so it wasn't affecting my pituitary functions. I had it removed, after I had it removed, I became -- what do you call it. I had to have all my hormones replaced. All except for one, came really close though about 2005.

Anyway, basically I had growth hormone, testosterone, my thyroid and diabetic inceptus is what I was diagnosed with at that point. Six months later after surgery I had the luck of also having a stroke with seizures. The seizures lasted about three months after the stroke. They subsided about December. From September and finally in December they subsided.

It was about a good ten years after that, I was trying to balance all my hormone replacements. It seemed like every time I would go in; they would get worse. It seemed like really my pituitary was giving out and was quitting on me there.

I came really close to also [inaudible 00:33:43] adrenaline. I'm on my last concentration core. At the time we were considering putting me on some Cortisone and all that for my adrenaline issues.

Then all the sudden everything just started turning around. It was quite amazing. Every visit everything was just getting better. Within three to four years ago I finally plateaued where I'm only on thyroid and diabetes insipidus at this point. Even my thyroid has gotten better and we've decreased doses on that as well.

I have a lot of cognitive issues at times. I used to work in computers. I was a programmer, managed a help desk and networking and all that. I basically had to quit doing that. I can't see things through. It's really hard for me to link thoughts together. Things just lag for a term; things just drop off.

There's days when I can't even read a menu when I go into restaurants. The head pain has gotten better. I did end up having to have a nerve stimulator input in my head to decrease the nerve pains that I do have. I had that done 2005, 2007, 2009, 2011. It's an ongoing thing.

I think I'm doing much better without it now. The head pain has also got very much better in more recent years. I deal with a lot of fatigue along with everything else. I've basically been transforming. I took a little bit of time off, I found myself. I've been working at hospitals, now I work in physical therapy. Just as an aide, but I find it rewarding to help other people. Work with people, move them on forward.

I can sympathize with people as they're going through their things. Many times I'm working with stroke patients, so I've been there. My left side was affected, it's gotten so much better. Once again, I'm blessed with getting better all the time.

A little bit about myself because I've also -- I've taken on -- I like to run. I like to run a lot of 5ks, 10ks, half marathons. Half marathons are pretty hard on me with my diabetic insipidus. I'm always on the edge of being dehydrated or over-hydrated. I'm always trying to balance that out which is really hard on a half marathon.

Everybody asks me, when you running a full marathon? When I concur my first half marathons. I also do a lot of obstacle course racing. I get out there and like to do Tough Mudders and Spartans and stuff like that.

I've always been a real active person, so when I got this diagnosis it kind of hit me pretty hard. I also play guitar. All the music which I had to kind of dumb down a little bit, because, once again, I can't really follow sheet music or any of that. I lose my place really easily. It's just a non-stop of just trying to keep things easier.

I try to maintain a life where I have structure. I always put everything in the same places, I walk around with notebooks as much as possible. I try to organize my thoughts. Otherwise, I just kind of really enjoy life.

When I did get my diagnosis, my son was three years old. That was pretty heartbreaking at that time. To sit there and look at my son playing on the floor of a hospital and realizing that, what I'm going through, I didn't really know what the outcome was going to be.

Basically, through everything I went through, I just basically diverted a lot of my energy toward making sure that he had a really good childhood. Prepping him for life and moving forward. I'm going to turn it over to you now.

[Applause.]

Mrs. Johnson: As a caregiver, probably the one thing at the time he was diagnosed -- it was brought up yesterday that they're stubborn. Timothy even mentioned he's stubborn. I had to pretty much force him to go to his primary care doctor.

He's like, "No, no. I'm okay." I'm like, "You're sitting downstairs in the basement, no lights, no." You kind of have to step up and kind of force them. You can't be afraid to do that. Little did I know when we went to the primary care doctor, her answer was high blood pressure runs in the family; this is related to that.

I said, he's in severe pain, this has never happened to him. It's definitely not his norm. At the time, we were on HMO insurance so in order to go anywhere else we needed a referral. We did -- I ended up pretty much fighting to see a neurologist. That same day we actually went to the neurologist who did the MRI. Right?

Mr. Johnson: Yep.

Mrs. Johnson: We were home a half hour and then we got the phone call that he needs to go to the hospital, there is something on his brain, but it should be treatable by just a pill. Everything just starts going through my head.

First of all, we have -- like he said -- our three-year-old sitting here. I'm like, how do I get to a hospital? This sounds more severe.

As a caregiver don't be fearful to ask for help. We were very blessed; his parents lived ten minutes away. I called them, his dad said, "You stay right there. We're going to come pick you guys up and we're taking you. I don't want you driving. We will take care of our son's family, and Andrew, we will take care of Andrew."

We get to the hospital and when the neurologist comes in, you're told you're going to have surgery. I was like, "What?". As a caregiver it's very emotional. I found myself looking back going, "What did we do to deserve this?" You can't do that.

So we did, he had the surgery. I found myself not taking care of myself. As a matter of fact, he was lying in ICU; you still had the synodrain in you. He's yelling at me, "Will you go downstairs to the cafeteria? You have not [eaten] in 24 hours." I'd like to point out that it's imperative that we take care of ourselves.

You know, I was lucky enough where he was kind of also able to keep track of me. Like I said, our son was three years old. Our son did so many trips. I remember one time where he was -- he mentioned having the nerve stimulator and having it be replaced so many times. I was sitting in the living room, playing with my son and the doctor comes out and tells me that he almost passed.

Just all these emotions you deal with. Again, I was just "What did we do to deserve this?" Don't be afraid to talk to people, don't be afraid to ask for help. I'm blessed where I work, they actually support the American Brain Tumor Association. They're a monthly charity. I meant Vincent there and I don't really -- you know, they have talked about the care mentors.

I am actually one of those, and I've actually found out that being a mentor helped me deal with. You know, he still has his bad days. I walked in the house and he's downstairs and you know that the head pain is real bad and the first thing that comes to my mind is, is something coming back? That's always the first thought.

I have a very active job where I need to go out, I need to travel. It's helped me; okay, I can talk. Don't worry, he's having a bad day. You know, it's just going to -- life has to go on. Adapt to the life. You know, like he'll say, "Did where put keys?" about -- his term is --

Mr. Johnson: New normal.

Mrs. Johnson: And it's true, we do the half marathons together. He pushes me, we do the Mud Runs together. You know, at the time -- our son is our only son obviously -- going through everything we were like we've had our family, that's it. He's away at college now.

The best advice that I can give is just make sure that you take care of yourself. Don't look back and think what have we done, why is this happening to me? My joke at work is -- and everybody laughs at me -- because they can tell if he's having a bad day. I come in and I'm quiet and it's just another bump in the road. We'll get over that bump and we need to enjoy life.

[Applause.]

Mr. Rhodes: All right, good morning. How's everybody doing? My name's Steven. I'm a brain tumor survivor as well. These guys both have great stories, but you're going to hear a wildly different version, I think, from me.

I want to thank you, ABTA, for having us up here. This is a great forum. I'm really appreciative of just having the comradery amongst the tumor survivors and caregivers. I think it's a great avenue with which to communicate. I'll tell you a little bit about myself now.

I would consider myself a very normal person. The tumor didn't make me special; I still don't think it makes me special. For whatever reason, I tend to trivialize things.

When I woke up on July 11th, 2017, I had just dropped my wife off at the airport to go do a conference. I had gone to the gym, run four miles, worked out for an hour. Went in for an MRI on my neck thinking, you know, just some tingling of the finger and no problem. Three MRIs later they tell me I've got a brain tumor.

It kind of changes your life. It's kind of crazy just the cadence of which that happens. I think anybody in this room will feel the exact same way that I do on that front. It's just crazy.

I probably should tell you what kind of tumor I had if we're doing that. Benign, fortunately, intraventricular meningioma, eight centimeters. Rather large. We, fortunately, didn't have to go have a surgery in two days like both these gentlemen did. We had a month, they told us, to wait. We went and saw six doctors in two weeks. Which is just a ton of visits. My wife and I both work; she's a consultant, I work -- worked in finance at the time. So you have a life outside of the tumor too, that you've got to take care of.

I worked every day up until the day I had surgery, as did she. And you fit in doctor's visits as you can. It's just a -- it's a lot to have to deal with at one point and time. It's just a lot going on. Trying to read some notes here, sorry.

The biggest thing, I think to tell somebody is, when you're dealing with the tumor, it's just always important to kind of put things in perspective. Not that you can necessarily have fun with the tumor, but you can certainly have fun with the process. That's something that we kept in our lives all the time that we were dealing with this. To this day, we just have fun with things.

I remember very early on, they put me on a giant dose of steroids because the tumor was so large. Dexamethasone makes you feel terrible at some instances. I felt terrible, my stomach turned, I couldn't sleep, didn't want to eat and I stopped sweating. Which we're in Texas -- that's not a good thing in July. Outside became very hard to deal with on a daily basis. Even just getting in the car and heating up the car. The small things that you just don't think of that impacts you.

One of the times we were just having a week and Jordan, my wife, said "Let's go do something fun." I was like, okay, great. Let's do something fun. We go bowling. Bowling is just something we've done from time to time through college. We've been together for just about 12 years now. I look at her to confirm. We get in there, pay, shoes on, ready to go, she looks at me and goes "Just because you have a tumor, I'm not going to take it easy on you." I was like, "All right, let's do this." She did beat me, unfortunately.

Let's talk a little bit about surgery now. When I -- when we did the process of vetting doctors we went through -- we stayed in Texas primarily. I know there's a lot of great doctors in some other states but, Texas has an awesome medical system between Houston and Dallas. We ultimately chose to leave the town which we lived in, Dallas, and go down to Houston for a surgery. Everyone asked, well why did you do that? Why didn't you stay home?

When we picked a doctor, we had a choice. Which was a great thing, not everybody has that option. The guy we went and saw down there, I don't know what it was that stood out or how I picked but it was probably just a gut feel thing.

My father-in-law has told me for years -- I'm an economist by trade, I work in finance and data is a very big part of my life on a daily basis -- always tells me, think with your gut more. You need to think with your gut more. That's how he's done business for years and this was one of those times where I listened to him and said, "I'm going to think with my gut." What differentiated the guy we went with versus everybody else? All the surgeons, the ones in this room, the ones outside this room, everyone is very well qualified. You're all brilliant people. Far beyond more brilliant than I am and this surgeon had a couple residents in there.

We talked a lot about patient care, bedside manner, he was pointing things out about me, about my condition, etcetera. Talking about how he would go in to get the tumor. He mentioned it was very large so it was just a complex surgery, we're talking 12 hours. At the end of it he looked at me just very simply said, "I've got this." or "We've got this." And that was my decision, it was that simple.

Just somebody else having confidence in you. Not that I thought I wasn't going to make it or wasn't going to make it through or something would go wrong but hearing somebody else say that -- the guy that's operating on you mind you -- it's a gut feeling. That was my gut feel. That's all I need to feel. I walked out of the room, looked at her and said, "All right. Houston." It was that simple.

He level set all the expectations I had of him too, because of where it was at -- it was in a ventricle -- I had a tube for a while. They pulled that very quickly, thank goodness. I didn't have to have a shunt for (inaudible 00:50:16). Sat on the midline so there was a nerve involved, he wanted to make sure we didn't impact my left-hand side, left arm, left foot. There was also a blood vessel running through that it was touching against and they wanted to make sure that that wouldn't be impacted too, so I didn't stroke or seize or anything. Obviously, you guys all deal with this, you know what I'm saying here.

I think the thing that I didn't realize through this whole process and maybe that nobody told me, was that I expected to wake up and be just perfectly fine and normal. While my experience -- they told me I'd be in the hospital 10 days, I was in there seven. I still have things that just get to me and especially right after the fact. You just have to be patient with the process and patient with healing. It's just not something that happens overnight and I'm typically one that moves fast, I talk fast. I get things done fast.

I've had to, especially a couple years ago, I had to kind of take a step back and say, "You need to let your body heal." My doctor was smart enough to know that I worked that way, much the same that he did. He saw a lot of himself in me. He took my driver's license away and told me you're not driving for three months. Because he knew I'd be in the office in the two weeks, trying to do work. He also knew I was going to try and be in the gym or working out or running or something. Just to move, to act, to be me.

The things that I've learned is that you have to one; be patient with yourself. Two; recognize that there is a new normal like Rob did say. Up to my tumor diagnosis, I really had nothing wrong with me. I had some minor headaches. I had a little tingling in a finger and a few good doctors made great calls by doing MRIs at the right time and found this thing. We operated, got it out, and I'm sitting here today just fine.

I still have things that make me a little different than I was before. I'm hypersensitive to light, I'm hypersensitive to sound. At work, I have two dimmed down lights over top of me. I've had to dim my monitor to the smallest brightness that it possibly is. While I feel very normal on a daily basis, headaches are terrible. The thing that nobody tells you is when they cut on your brain, yeah there's no nerve endings in the brain, but all that skin around -- cartilage, tissue that builds up there. It hurts. Flat out, cold is terrible.

I mean, it's just one of those things that you deal with but be patient. That's my message; just be patient with yourself, be patient with the process. Time takes care of a lot of things. I'm also adjusting to the new normal and I don't mind it, it's okay.

[Applause.]

Mrs. Rhodes: Hey everybody, my name is Jordan. As Stephen mentioned, I am Stephen's wife. Two years ago in July, as he mentioned, he had dropped me off at the airport. We live in Dallas; I was in Orlando and I knew that he was going to speak with the neurosurgeon because what Stephen did not mention about his story is, he originally went in to see an orthopedic surgeon about his shoulder pain.

That surgeon did an MRI of his neck and noticed some swelling at the base of his skull and indicated he may have had something called a Chiari malformation. He had a follow up appointment with a neurosurgeon. They did a full MRI of his head just to check, was what the neurosurgeon said. Let's just check it out, yeah, we see the swelling but let's go ahead and do a full scan.

I knew while I was at work that day, I was with (inaudible 00:54:33) so I was working at a bank. I was anticipating the call to let us know that yes, he had this Chiari malformation, he may have to have a surgery or a procedure. At about, I think it was one o'clock that afternoon, I got a phone call from him.

The first words out of his mouth were, "I have a mass in my brain." It hits you, at the time we'd been married almost five years. He's my college sweetheart. This man that I love so much, you hear "I have a mass in my brain.". You know, I'm at work. I'm in front of clients so I'm choking back tears. I walk into the director of the bank, into the office, his office and I just have a full breakdown in front of him.

I'm not one to cry very often. I grew up looking at a very well put together Southern woman who just does not like to show a lot of emotions. That's typically how I carry myself. I'm standing in his office in front of him and two of my other clients just having a breakdown. The only words I could choke out were "my husband has a mass in his brain".

Thankfully my clients were wonderful, gave me a big hug. The director drove me back to the hotel and said we're going to get you on a flight today. As I'm continuing to cry in his car, he's trying to

console me, get my bag put together. He looks at me and says, "Are you going to be okay going to the airport by yourself?" I said, "Yeah, I'm going to be fine." I kind of sucked it back up and thought okay, let's do this.

I was fortunately able to get on a flight that night. I believe in signs, honestly. I'm a person of faith and I just believe in that and I've believed in that through our entire journey. When I got to the airport, you know, somebody booked the flight so quickly I was in a row like B6 and in the middle seat. When I got there, I got upgraded to first class and I thought, well I didn't put in an upgrade. That's weird.

I walked over to -- I fly American and I usually fly a lot for work. At the time I was gone Sunday through Friday every week. So I was travelling quite a bit. I went to the admiral's club and walked in and I do not have an Admiral's club membership. I just asked if I could buy a day pass for today, because I wanted a quiet space. I wanted a space where I wasn't around -- Orlando, if any of you have been there, I mean it's crazy.

I love children, but those children. They're just running around and smacking heads all the time and I was continuing my breakdown. I wanted to honestly go sit in the conference room, or in a quiet space. I walked in and I don't know if the lady behind the counter had seen that I had been crying for an hour or what, but she looked at me and she said, "You know what, just come on in. Don't worry, don't pay for it." So that was sign number two and I thought what is going on? People are showing me some mercy today.

Then I walked up to get a glass of wine and I was going to purchase a glass of wine because there's the free wine and then there's the wine that you pay 15 dollars a glass for. I thought, ugh, I'm going to get a glass of wine to clam my nerves. When I went to the bartender to pay, "It's on me."

I thought three times in the course of an hour, people are showing me mercy and I'm like, it sounds crazy but I thought we're going to be okay. We're going to be okay. It was just a few instances of kindness from strangers that helped me think we're going to get through this. We're going to be all right.

Thankfully I went home. The following day we went into the neurosurgeon's office and he honestly just kind of flipped on his screen and showed us. It took my breath away because you see this brain scan and all of a sudden, this white that was the size of a naval orange. I looked at him and I said, "That can't be it." And he said, "That's why we called you in here today."

I cried again and stopped and grabbed my pen and paper and started writing furiously, every single word that came out of his mouth because we were shocked. His dad was with us at that appointment because his mom and his sister were overseas. It was July -- his mom and his sister had kind of taken a girl's vacation to Europe.

It was just his dad and I with him. Every single appointment that we went to I kind of joked and said, "I'm your personal brain tumor secretary now." I wrote down every single thing I heard and from that point forward, I cried in that first office and then I almost regret that I didn't show more emotion

through the process. Because my brain flipped into, I need to be the strong one. I need to be the pillar for him.

Internally, my mind was saying constantly because we'd been together for so long and we did not have a family at this point. I started thinking, you know, I didn't want to let myself go down that rabbit hole of we had this construct of a life built. He's my sweetheart, we're going to be together for 60 years. We're going to have this big family and a bunch of children. I was thinking what if that doesn't happen? I didn't want to let that show because I always wanted to be strong. I always wanted to be that woman who stands by her husband and is the strength for him whenever he's down, because he's always been that for me.

I didn't talk about a lot of those internal feelings for fear of freaking him out or getting him upset. As he said, we had a few weeks thankfully. We were extremely blessed that we had a few weeks to go and talk to different surgeons. I know that not everyone is afforded that opportunity so I'm really thankful we were able to do that.

On surgery day, I feel like it looked almost like a scene from a movie, because we had 20 people in the waiting room. He's got a very large family; we've got lots of friends. It was just so much flurry of activity in the waiting room, waiting for him. They would call over the intercom and say, "Jordan Rhoades please come to the front counter." The whole family would just stop and look at me. What's going on?

His mother, she was just in shambles the whole time. I can understand that now, we now have a daughter who's nine months old and I can understand now. Why she was completely in shambles. She would run behind me, hold my hand basically and talk. They were calling me from the OR to just update me.

"Yes, we're in at this point." I'd say, "Okay, that's fine. How is he? Is he doing okay?" After his 12-hour marathon they weren't telling us anything, and I'm a little pushy. A little bit. The surgeon, he had already come out and told us "We're good, they're going to stitch him back up. We're going to move him into the neuro ICU." I was just like; I want back there. Saw that they had just put him in his room. The nurses were all around him, getting all the machines hooked up and everything.

When I rounded the corner and I saw him, he looked up and said "Hey, sweetheart." I didn't expect that he would be awake or that he would recognize me or know that I was coming around the corner, but in that moment, I was just like I can't believe this. I'm so excited and I went and ran and grabbed his mom and said, "Come back, come see him. He's great. He lifted his hand and waved at me. Everything is going so well." It was just pure excitement that everything was going to be okay in that moment.

That evening, I stayed with him in the room in one of those plastic recliners, ya'll know what I'm talking about. Plastic recliner, I asked for a pillow and the pillow was like a tissue. Asked for a blanket and the blanket was not good, I would have been better with a towel, honestly.

I stayed with him that evening and he had an art-line. Every time he would move a little bit just blaring sound, constantly. He was so uncomfortable so he kept asking me like, "Honey, can you please put a pillow under my arm. Can you please help me?" He was so nice the whole time. Just asking me can you please, can you please?

Finally he said, "Babe, what time is it?" and I said "It's 3:30 in the morning, sweetheart." He goes, "Honey, you need to go to bed. You need to go to sleep." I went, "I know, I know. Sweetheart, so do you." He kept apologizing to me because I had to take him a little container to use the restroom in. He kept apologizing and I'm thinking, you just had brain surgery. I'm here to do whatever you need; it does not matter.

It just -- throughout the whole experience, it made me realize that number one as a caregiver it's okay to feel all of the emotions. For me, it hit me like a mac truck honestly. He was 28 years old when he was diagnosed and like he mentioned, very active. We're both very active together. I didn't want to allow myself to feel what I was really feeling at the time. It's okay.

I would echo what Melanie said, you have to be patient with yourself. We had a great road to recovery and he's doing really well today. There are times when he's still a little off. Brain surgery impacts you in a big way; brain tumors impact you in a big way, but I'm very thankful for this community and thankful for the opportunity for us to be here. Thank you.

[Applause.]

Dr. Wefel: Thank you all for sharing so candidly those stories. This is now our opportunity to open it up to everyone on the floor. To remind you, again, if you have a question please raise your hand. ABTA staff will be coming around. If you prefer to write them down on cards you can do that. There should be some cards on the tables and then we can bring those up.

If we could advance one more, I promised some carrier phrases. I was thinking, you know, sometimes it's hard to structure a question I might have and this might be some carrier phrases that could then fit you, that you could use.

We hope to find information and advice about how you handled such and such. Do you have any experience or advice about this? You can use it, of course format questions in your own way as well. In case you need some help, this is a way to structure that.

Anybody have any questions? Do we see any hands? There we go, there's one over here.

Q: Hi, I'm Sydney. Timothy, I'm about to graduate from high school but how did you manage graduating high school with your situation?

Mr. Hoehnke: With leukemia and my school situation, I took a full course load my first three years there. I was able to take that pace. I would take certain classes on Monday, Wednesday and

Friday and then I would take my afternoon classes on Tuesday and Thursday. They would also give me the course load of worksheets and stuff to take home. They would just say give it to me when you can.

I was fortunate in that way, where the teachers were really understanding. They also gave me the option to graduate a year later and take a year off. Like I said, I'm stubborn and I really wanted to graduate with my friends. At the time, I didn't know that they were going vanish, you could say, later on. At the time, I really wanted to stick to something that was there. Solid, solid state, a solid mass that I was going to be surrounded with.

There were a lot of times that I literally just got to school and I'd call my parents and say, "I'm not feeling good." And have to go home, but the school was super understanding. I was able to do it by half days.

Q: Thank you.

Mrs. H: He was so stubborn that some days -- he wouldn't take a school bus. They offered him a school bus, but you know, a senior taking a school bus is not cool. One time he was driving my Jeep and he comes home and there's crap all over the side of the Jeep. He's throwing up outside the Jeep while he's driving. So yeah, he's stubborn.

Mr. H: I mean, it was blue Gatorade. The car was blue, so. Thank you.

Dr. Wefel: There's a question over here.

Q: Hi, my name is Mary. Whoever gets this question -- I'm not sure. The question is now that you're in a new normal and during while you were working with all the appointments and side effects and trauma, emotional trauma or every bad report or whatever, what about your friendships? Your relationships and your social life and like now you're suddenly in this other category of person that maybe they don't know how to deal with.

What advice do you have for -- how do you clue in your friends to deal with you now that you're different? How do you maintain relationships and how do you still have friends and a social life?

Mr. Johnson: Okay, I'll take this one. Basically, I let me close friends know everything so they understand what I'm going through. After that, I actually make fun of myself. For example, when I raise money for the ABTA it's always under the term fatheads. Because I have a little more fat in my head than the rest of you. When they filled the void in, they filled a little bit of fat in there so I don't have any leakage.

I let all my friends know and basically, we kept on doing the things we did before. Yeah, I do tap out. I'm tired -- the running joke at work is, is when it's lunch time you can find me -- I'll be sleeping in my car. I am like the master of napping.

A2: I'd like to add a little bit to that if that's okay. Your true friends show up when you need them, obviously. When you just tell people on the street, some people react very poorly. Some people react very well. They want to be there for you, they want to be involved.

When we went through my surgery, we had like a room of 20. My best friend and his wife came down and supported. Her entire family came, my entire family came. The ones that are your true friends always show up. That group is solid, you should have a good core.

Friends are friends. Friends are like family for us and they show up for you.

Mrs. Rhodes: I think a lot of times, we have a very high expectation. At least I do and he does, for recovery. Like Stephen mentioned in his story, he didn't realize how long some of the effects would last. He's still feeling a lot of the effects from his surgery, even though his surgery was two years ago.

For instance, he carries ear plugs with him because even if we are at church or if we go to a concert or if a movie is too loud, he has to put the ear plugs in. He'll kind of joke about it and say, "God, I just can't handle it anymore."

Mr. Rhodes: Getting old.

Mrs. Rhodes: There's a lot of times where he's wearing sunglasses inside because some of the lights are just too, too bright. We just try to be candid with people and say, "No big deal. He had a brain tumor, it's fine."

The more that we try to be as open as possible with people -- some people will get kind of put off and freak out. But that's just our new normal. That's what he carries with him and we just kind of mention it.

Mr. Hoehnke: I guess for me, it's a lot of people -- the fact that they understand. They don't understand and so they think about it and they don't know what to say. They don't know how to react. It's not that they're bad friends, they just -- because of that fact they kind of walk away or go away from it.

You got a lot of them that are still there, especially in the beginning, when it's very apparent. You're struggling and everything. They start to fade away when everything looks great, because -- especially if you're not speaking about everything you're feeling and everything, they think you're doing well.

What I find, is I have to keep reaching out still. I have to put in that little bit more effort so that they know I'm still needing those friends. I'm still your friend, I'm just different. Little bit different. I still would like to hang out or I'd still like to do things with them.

Q: Maybe I'll add a question on top of this to the caregivers. Frequently we hear that caregivers have a great burden, there's this emerging concept that we're appreciating more and more. Because we're asking more and more about caregiver burn out. I think one of the things that we talk about with

caregivers is having networks of care support. Maybe you're not trying to do all of it yourself, all the time. How do you go about establishing that? What have you found successful ways to navigate that? Is that part of what you do?

Mrs. Hoehnke: At first, I would say no to all the help that people were offering. A lot of people would say what can I do? That put more stress on me because I had to figure out what to tell them to do for me. I don't know. I started going to a care giver support group and somebody in that group said take all the help that is offered. Don't say no.

Whether you think you need it or not, take the help. I started saying yeah, but I can't tell you what to do for me. Just, yeah, I'll take the help. A friend of mine started a meal train, so then that worked. Another person came over and cleaned my house; wonderful. Just little things like that.

Mrs. Johnson: I'm kind of like Jordan. I kind of hold things in and I probably still do. I'll go to work and I'll be really quiet. People have just kind of learned to realize Melonie's just not her normal self. Everybody else that knows me, I'm loud and jokey.

I think my friends and coworkers have realized Melonie's not her normal self, so they'll initiate. They will ask, "Hey, are you okay?" they don't hesitate. Is Bob okay today? They'll ask me. That's kind of helped me learn this new norm. Just recently -- I'm the type where if we're invited somewhere and he's having a bad day -- no, we're not going to go. We were just recently invited to a barbeque. I offered to bring the alcohol from our local brewery.

We get in the car and he's like, I just can't do it. My head -- I'm not feeling myself. I'm like, okay, fine, we're going to go home. I literally did but then he said you have 30 cans of beer, what are we going to do with it?

So I did, I packed up. Kind of getting used to this and this is probably the first time I have ever done that. I'm going to go; I'm going to stay a little bit and it was actually a coworker that was having the barbeque. She kind of knew as soon as I came in, "Hey, how's Bob?" I explained.

She's like okay, just stay as long as you want. We want you to try to enjoy yourself. You kind of do need -- I use my friends as a push. You need to listen to them, to help you speak how you're feeling. Like Jordan said, you can't hold it all in, because it gets to you.

Mrs. Rhodes: For me, since I recently had a baby. We have a nine-month-old daughter and that was a humbling experience. I had a C-section so I had to rely on other people for help. When he had surgery and I was taking care of him, I was doing everything.

I mean, I was like burning the midnight oil taking care of him, taking care of our house, cleaning. We didn't have a baby at that point. Something that I learned from a friend of mine, she told me before I had the baby, allow everyone to come in and help. I know you don't want to, but allow them to come in.

One of the tips that she gave me was to write out a list of all the things that need to be done and just put it up on the refrigerator. When people come in and they say what can I do, there's a list on the fridge.

There's a list of things; maybe the dishwasher needs to be done, maybe the dog needs to go to the groomer, you know. There's a whole list of things that can get done this week. When you're done please check it off.

That was a great help, because I mean, when we had the baby, we had a ton of people coming in and they always wanted to do something. It was helpful to just say go check the list.

Dr. Wefel: Other questions?

Q: Valerie, you already talked a bit about this. I address this to any of the care givers. Can you say any particular strategies you've been able to use to deal with the medical system when it's not responding appropriately?

Mrs. Hoehnke: I guess I always prepare for our appointments. Like you were his scribe, I'm Tim's scribe. As soon as there's bad news, his brain just shuts down. I'm the one writing and scribing. I always write questions before I go in. The doctor jokes, I don't see a notepad today. Because I've always got questions ready.

We always talk about what do we want to ask and things like that. Recently, his insurance decided he wasn't going to have them anymore because of his disability and Social Security had been goofed up. So I had this weighing on my shoulders. Okay, now who do I go to for this? Where do I go?

In my caregiver support group, a social worker came and started talking about different insurances you can apply for and different things you can do and I'm like, how come nobody told me this?

In my phone I'm writing down all this stuff that I want to do and the next day I called and talked to the social worker. Got an appointment and he and I solved like four crises. His school loans, his insurance. What was the other stuff? There were quite a few things that we were having problems with and we were able to solve it all just through the social worker at the hospital.

I think one of the things doctors should do is not make that an option. The social worker. The social worker should be something you have to do. Whether you think you do or not, you should have to. Because they've got a wealth of information.

Other than that, I'll call and if I get the wrong person, I'll ask who should I be talking to about this? I'll call again. I'm one of those -- I'm hounding people all the time to get the answer. Try to do it as nicely as possible. He uses Mi Chart a lot. Do you know what Mi Chart is? Okay. He uses that a lot to get questions answered. Does that help you?

Mrs. Rhodes: I'll also say you are your best advocate. You've got a team of doctors or medical professionals who are helping, but I fully believe I'm my best advocate. I do the same. I would come prepared with lots of questions and still do when we have scans. Lots of questions of what the roadmap for the future looks like. That's always a personal belief.

Q: Hi, my question is more directed towards Timothy and Valerie. I am a mother -- my daughter does not like the word caregiver. She has labeled me a helicopter mom and I'm proud of the title, because whether she's three years old or if she's 30 years old with brain cancer, she's still my daughter. She is still my reason to get up every day, to put one foot in front of the other.

She's also a very strong, independent, educated, young woman who doesn't want a helicopter mom. She doesn't want a caregiver to go with her to every appointment. My question for Timothy is, how do you accept losing a little bit of your independence and relying more on a parent as being a young man.

And Valerie, how to no longer become a helicopter mom?

Mr. Hoehnke: I like the secret face. I look at her, shut up. Just, no more. Or I'll look like uh-huh and she'll jump in. Honestly, my room in the house or whatever that I'll run away to I guess in that aspect; I'll unleash and relax. Our secret code is a typical question. So what is the plan today or something? She won't answer or something. Mom! What is the plan? And she'll yell back and then we'll -- that's how we unload stress is by yelling at each other. At the end of the day; why were we yelling? I don't know, because you were yelling. We know we don't mean to yell, but it's our way of unloading stress without being mean about it.

She's my punching bag if I really want to say it.

Mrs. Hoehnke: It took a lot of years to get to the point where Tim and I are now. He sent me an article once about letting young adults do what young adults need to do. That article was really an eye opener. I do want to take care of my baby and I do want to do everything for him.

I've learned to wait for him to say, yeah, I need your help. Yeah, I want you there. What are we asking today? What are we doing today? Those are really important questions. When he was on the steroids, we had roid rage -- oh my. Oh my.

Mr. Hoehnke: When she would use the microwave instead of the oven or something -- oh boy, watch out.

Mrs. Hoehnke: That is one hard thing to live through. You know it's not your son, you know it's not your person, it's the steroids. Boy, does it hurt and it hurts hard. One day, we had a long conversation -- argument; "You hurt me when you said this. You hurt me when you said that." And I would say, "But I heard this and this is what you were doing." He'd say no, I didn't say that.

Mr. Hoehnke: We realized we were both confused on what was said.

Mrs. Hoehnke: We both had our -- we left that conversation still mad at each other and still upset, but we aired it all out. He'd love to be totally independent and I'd love for him to be totally independent and on his own, but he recognizes that yeah, I need somebody there to write the notes for me. I'm going to shut down as soon as somebody says it's bad or we need to go to clinical trial, which they told us in June.

Then in July they told us no, it's stable. The whole month of June was gone. As soon as I get bad news, I'm like -- okay.

Mr. Hoehnke: One big thing is we both write down the questions before an appointment or something. Or we talk about the questions, because sometimes I get blindsided. We used to get blindsided by each other asking a question. I didn't know about that question.

Because we want to both be prepared for -- so that's why I give the looks.

Q: I also have a list when we go to the doctor. So, helicopter mom has a list of what she is not allowed to ask.

Mr. Hoehnke: Yeah, pretty much. Exactly.

Mrs. Hoehnke: I'll want to ask this and he'll say, "No, we don't need to ask that."

Mr. Hoehnke: It's normally like, if I bring it up, then we can talk about it.

Mrs. Hoehnke: Sometimes I can convince to let me talk. It's a dance. I have to recognize that he is an adult. He understands that I just can't.

Dr. Wefel: This brings us to the conclusion of this panel. I want to thank you all again so very much for sharing with us, and to all of you for participating as well. Give you one last round of applause before we break.