

## BrainLine Talks With Susannah and Jason Ferguson

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Video Link: <http://www.brainline.org/content/multimedia.php?id=814>

### Supporting Intimate Relationships

**Susannah Ferguson:** We'd been dating six months when Jason's TBI happened. And then now it's been five and a half years that we've been together. We got married a year and a half after the accident. And I'll let you tell how it occurred.

**Jason Ferguson:** Or how we've been. Okay.

**Susannah Ferguson:** No.

**Jason Ferguson:** I was a sound engineer though before the accident. And, um, I went to one of the places that I had the account for to do sound. I had either been wake boarding or down at the beach to do one of the concerts.

**Susannah Ferguson:** You're not telling that.

**Jason Ferguson:** Oh, okay.

**Susannah Ferguson:** How the accident happened.

**Jason Ferguson:** Oh, the accident happened. That day I had ... I went out, being sneaky I thought, went and had a class and everything on diamonds and looking at engagement rings and everything. Because I couldn't afford the Tiffany of diamonds and stuff. But she saw this and only Tiffany's will do. So I went out looking.

**Susannah Ferguson:** That was always the joke.

**Jason Ferguson:** And then that night we were supposed to go look at Christmas trees which wouldn't have mattered anyway. Because little did we know, I wouldn't have been around to see it, awake. That night I went to one of the establishments where I was working or had the account to work at. And I was there until quite late in the morning, early morning hours, to about 4:30, 5:00 o'clock with the managers and some cops and they were still there. Well, and I don't remember any of that.

But supposedly, looking at the truck and what happened is I was going the highway ... going down the highway close to where the opposite of where I was living at a high rate of speed. They estimate to 90, 110 miles an hour. I throw some barrels on the feeder road on the onramp to the feeder road on the highway. Well, it clipped a three-quarter ton large truck. And it clipped it. And it went up like this. And I came out the side window. The truck ended up way over here. And I ended up in the stop sign they estimate about 200 feet down the road.

No one stopped or anything like that. I couldn't have ... I wasn't wearing my seatbelt at the time. Somebody can say, oh, you shouldn't drink hard liquor and all that stuff. But everything came together. So that was what happened. That was one of the hardest part about the recovery of everything. I mean, hey. I messed up. I had this accident. I did this to myself. But thank God, I didn't kill anybody else or hurt anybody else like that. But the truck was basically the cab was flattened down and half the front end was missing.

**Susannah Ferguson:** And then as heart breaking as ... the morning of his accident, I had gotten a page like at 5:00 o'clock, 4:30, 5:00 o'clock in the morning. And I didn't recognize the number. And so I didn't call them back. I went to work as a regular day. And then somewhere around, I don't know, 9:00 or 10:00 o'clock in the morning, I got a call transferred into where I was at in the hospital. And it was his sister telling me that he had been in this horrible accident. I went over, rushed to the hospital. Everything was told to me what had happened. And I looked at the page that I had received early in the morning and it was the emergency room at that hospital. Because they had found my number. And so they were trying to page me to be the contact person of him. And I hadn't returned the call. And then he was in a coma from December 17th through the beginning of January. He had opened his eyes for the first time on New Year's Day.

**Jason Ferguson:** On New Year's Eve though is when I kind of peeked my eyes opened at you though.

**Susannah Ferguson:** Mm-hmm.

**Jason Ferguson:** And one thing about it to say the only thing I remember from the whole coma and everything is I saw the golden city which I interpreted to be heaven. I can still remember that like it happened five minutes ago. And the story ... even through the post-traumatic amnesia where I thought that I was a racecar driver or the movie star with these people, that's never, ever faltered or changed. And I was standing ... I still remember, I was standing in front of a calm flowing river. And it wasn't real wide.

But there was highway with grass on each side. And to my direct left hand side, there's a small arched bridge across the way with a wall that went as far as you could see both ways. And behind that wall was the golden city. Behind me was dark woods. But the next thing I know appeared the four horsemen come riding out of an opening in the wall. And I mainly remember the first one because the horse and buggy was about ... it seemed like it was about that big. I had to look up to it. And I just remember that first one because he turned around and pointed for me to go in.

I was walking. I started, you know, it was beautiful and light wind. So I started across the bridge. Well, I got about halfway across the bridge. And I hear Suzanna in the background come running. And she's running and saying, no. It's not your time to go. You can't go in the room. Build a bridge and she embraced me. And then I go. And we walk back across the bridge. And I didn't die.

**Victoria McDonough:** Do you remember walking up? Just briefly just tell me maybe that scenario, how long you were in the hospital. You mentioned you were in a wheelchair and you were told you wouldn't walk again. If you can just tell us briefly about that period before when you got home and then we'll talk about the relationship.

**Jason Ferguson:** I went to the rehab hospital after. I was in ... they probably ... after I was still in a coma. Because when you open your eyes, oh, he's out of a coma. But I was probably still in there for another week or two. Or that's how long I stayed at the hospital.

**Susannah Ferguson:** You were at the ... he was at the trauma center for about a month. And then from there, he went to the rehab hospital. And he was there for about two weeks, two and a half weeks. And when they discharged him from the rehab hospital, he was still using the wheelchair. He was able to walk. But he didn't have strength. And the main thing that I remember about his activity in the wheelchair is that he had such a hard time. He had no strength in his upper body whatsoever or no trunk strength. So he's in the wheelchair, but he's falling forward. Because he can't hold himself up. And so that was the huge thing with walking was that he didn't have any strength. He had lost approximately seventy-five pounds from the time of admission to the time of discharge home. So, um, within a month and a half, he

lost all that weight.

**Victoria McDonough:** How about talking and cognitive memory? Tell me the scenario with that.

**Susannah Ferguson:** Very, very slurred. As far as his speech, his speech was very slow. Purposeful, but very, very slow. He was still in what they call the post-traumatic amnesia. He couldn't remember from ten minutes ago. It was sort of our inside joke kind of thing. He couldn't remember what he had for lunch today. But he could tell me what he had yesterday. And then the next day, he couldn't remember what he had today. But he could then remember what he had the day before which he couldn't remember. So that was one of the things. And at that point, they said he would need 24 hour supervision forever.

**Jason Ferguson:** But we got married approximately a year and a half after my accident which is very uncommon as well. Because most people just leave anyway. They don't want to take that vow of, well, I want to be married to you. But I don't want to marry the injury. But the thing that helps us the most, and sometimes we still have trouble, but that's with every couple. That's life ... is communication. We communicate. She lets me talk to her. But something that may embarrass me or really get me down, it may not be much of anything. But it's really got me down. I can't figure it out. So to know that it's okay to still have these feelings and have these thoughts and everything like that. I'm able to express myself. And then when we got married, I said, yeah. We've been through the hard part. Everything else is gravy. But that's lumpy gravy. It will be forever. It's still worth it.

**Susannah Ferguson:** I think as far as our relationship, it's commitment. Commitment to one another. And not just saying that you're committed, but really truly in your gut being committed no matter what. And that is what keeps us together.

**Susannah Ferguson:** No, we're not saying.

**Victoria McDonough:** Relatively speaking.

**Susannah Ferguson:** We walk. We walk.

**Jason Ferguson:** Yeah, so much tragedy to help us to make it through is the walking. Not only does it help with the exercise to lose the weight because Lord knows I need to. It happens to just see everything, get the fresh air, clear things out. For her escape from me ...

**Susannah Ferguson:** I go to work.

**Jason Ferguson:** She takes a long hot shower. And she goes to work and takes a hot, you know, when she gets home takes a bubble bath. For me, I play dominoes on the computer. You know, like I play some dominoes, that helps wind me down. I don't know what it is, but that helps wind me down. And then I write ...

**Susannah Ferguson:** And then one of the other things that I want to say is that if we didn't have faith in God and we didn't have our religious beliefs, then we would never have made it. And that has been a huge thing that has kept us not only together, but kept us going for the long haul. And right after his accident, one of the things that I used to feel and say was that this can't be it. This just can't be it. God didn't bring us together for this to just be all that there is. There's got to be more. There's got to be more. And that became our little slogan is that there's more for us to do, more for him to do. That God didn't save him. I mean, he didn't recover from this. Or he didn't live through this injury to go back and doing live music and working in bars. You know, God has more for him to do and more for us to do. And here he is.

**Jason Ferguson:** What I said about my previous life, it doesn't matter now. It really ... that was the old Jason as I like to say. As many people with TBI do say is that was the old life. Because I don't really associate with the crowd of people that I did, you know, the fast. I worked in the music industry. So people weren't there just to be my friend. Oh, we didn't come to see just Jason. They wanted to get into see the show. They wanted to do stuff with that, the drinking, the drugs, sex, drugs and rock and roll, everything you hear about. And all that stuff you hear about happening on the road, it does. I don't want to be a part of that now. I had one band that said when you get better, you're going to come work for us. I said, no, I'm not. I said, God didn't keep me here to work in bars every night.

She actually ... and (inaudible) ... started out she was a psychologist. And then after the year, I started out being on the advisory committee, just giving my feedback for the projects and everything. Because one thing I've learned through working this is that whenever a doctor or somebody or just a layman tells us, oh, I know how you feel. I know what you mean. Well, no, you don't. Until somebody like myself or somebody else who has it, you want to talk to me, somebody goes, you know, they had a traumatic brain injury, they know it better. I mean, they know how it happened.

So one of the projects I worked on the most is the social re-integration project. Where peers with brain injury help other peers with brain injury re-integrate back into society. Because that's the hardest part of the whole injury. Okay. You lived. You made it back here. You can talk. Now what? You've got to sit inside all the time? No, you get out and be a part of society. That's living.

**Susannah Ferguson:** And so with him working there at the brain injury research center, it has really given to me, my opinion, is that it's really given brain injury survivors a voice. Jason is their voice in the research community, in the medical community, to speak out and say, no. You don't really know. I do know. Because I have lived it. And so he offers invaluable advice and recommendations of how better to treat survivors.

**Jason Ferguson:** I take care of our son Belson. I've been able to write from home some and kind of do speaking engagements with my wife. But it is something that one the doctors, pretty much everybody ever ... what I've seen is people with traumatic brain injury are kind of shunted to the side. People don't think we can take care of ourselves, much less take care of another life and successfully raise a child or have children or be loved. I see so many men that I've met at the various councils when you go in the home or put in homes because their family doesn't know how to react or put up with them as they say.

**Susannah Ferguson:** Yes and no. My family and friends did not understand my decision to be committed to Jason and go ahead and marry Jason. They thought I deserved more than to be a caretaker of someone with a traumatic brain injury. But whenever I made my decision and my decision was final, they stood beside me. So they were supportive after they understood that this was the decision and this was the commitment. Since that decision, no one has second guessed my judgment and Jason's judgment for Jason to be the primary caregiver while I'm at work. In fact, everyone has applauded his abilities. Because he does such a wonderful job. And in my opinion, it's such an honor. Not many men get to be that active in their children's life. And I think that it's such an honor that Jason is going to be able to mold our child.

**Jason Ferguson:** So many times I hear, oh, so you're Mr. Mom. No, I'm still dad.

**Jason Ferguson:** It's great.

**Susannah Ferguson:** The day that he was born, that was wow.

**Jason Ferguson:** Yeah, that was.

**Susannah Ferguson:** I mean, he's only five months. He's five months today.

**Jason Ferguson:** Today's his fifth month. Whatever, the greatest ... when there's two forces are winning. When we saw ... when I saw her walking, when they opened the door, I'd never seen the wedding dress or anything. They opened the door. Everything that happened for the past year and a half went running through my head. And that bullshit where I hadn't been able to cry before, came out. And I was just balling. And she was so beautiful. And I just ... all the wonderful memories and the hard part for, you know, hard times and the wonderful all just going through my head. And I'm so thankful to be there. And then the most recent one five months ago was being there with my wife and being in the room and watching our son be born and be a part of everything. And still be able to be a part of everything.

**Victoria McDonough:** How about you, Suzanna?

**Susannah Ferguson:** Oh, it's the same days. It's the same days. To me, it's just so awesome. But it's an everyday thing too. I mean, when I come home from work and to see how happy the baby is and to see how happy dad is. And, you know, where most men ... and I know I'm generalizing ... but, you know, most men can't handle the stress of baby. And Jason is just calm and cool the whole time and knows exactly the right thing to do and say. It's very comforting.

I mean, like with every marriage there are frustrations. So I don't know if there's a day or time I wouldn't want to repeat. Only because each thing I've learned from. I wouldn't, you know, a lot of people the first answer would say I wouldn't want to repeat the day that his accident happened and go back and take that away. But in our situation, his accident has made us better people. And I wouldn't trade things from happening the way they did at all. I'm glad ... and it's sort of odd to say that ... I'm glad that this accident happened. That it has made us better people for it.

**Jason Ferguson:** I'm so thankful for all of the experiences I'm able to be able to do. To be able to experience it. To be able to express how I feel about him. And nobody likes to hurt or go through bad times of life. But I'm getting the experience of getting to do it.

You know, like each other, love each other. And always tell the caregiver to listen. Just listen. That's the best part of it. Suzanne's there for me. And she'd say little things. I mean, just the little things to others were so big. Just give you a boost of self-esteem and let them know that, hey. I am somebody that's worthy of love. Case in point. When people would disregard me or not want to listen to me or they're actually being mean to me, she would be right there to stand up and get bowed up and move them for me.

**Victoria McDonough:** What would you tell people?

**Susannah Ferguson:** I would tell a couple that if they want the relationship to survive that they have to make it the most important thing in their life. Right underneath God. That they have to make that most important. That the couples that we have been friends with, most of the couples that we have been friend with that we've met through the brain injury circuit, the couples that have failed are ones that started having outside relationships that they put higher priority than the marriage or than the relationship with the survivor and the caregiver. That that is just key to destruction. I mean, it really is. It's the downfall. And you've got a friendship, whether it's a platonic friendship or not, if that becomes more important than spending time with their ... with your survivor or caregiver, whichever one has the outside relationship. And that is the downfall.

One of the things I would tell another couple or another survivor is to make sure that you get lined up with health care professionals that really know about brain injury. Not just know of a thing called brain

injury, but really know about brain injury. And that might mean that you're not seeing a regular primary care physician. Or it might not mean you're seeing a regular internal medicine. That you might need to see someone who works in physical medicine rehabilitation. Make sure that you're keyed up with someone that understands what's going on.

Because so many times I think that the health care community gives the survivor and the caregiver poor advice of how to handle things. And then that can also lead to the destruction of situations. One of the ladies outside after the talk was asking me questions about fatigue. That she was having problems with her husband and fatigue. And I told her the best thing is just let him have his fatigue. Let him have his sleep. That he needs it. And she said that she'd been pushing him to stay awake. And her physician has been pushing him to stay awake. So it's not as if you can just avoid the symptoms. The symptoms are there because of a reason.

**Jason Ferguson:** We have found other families who have been through this to give us a heads up what to expect. We didn't know anything. Susie just said, okay. This is the way we do it.

**Susannah Ferguson:** From the time of his release from the rehab hospital, he was not with any kind of physical therapy, any kind of rehab period for another year, a little over a year. And so we were sort of doing this on our own. Just sort of, okay. This might work. He had problem with fine motor skills. He couldn't pinch things. I bought him a light bright. Here. Start doing ...

**Jason Ferguson:** I got pretty pictures. I felt ...

**Susannah Ferguson:** It made him feel happy that he was making a pretty picture for me. And instead of me being the adult, oh, that's childish, I let myself be the child and get excited over pretty light bright pictures. And it made him feel like he was doing something nice for me. And so it's the littlest things. But just to keep trying was the biggest piece of advice that I would say to anyone that has ever had a brain injury is that ...

**Jason Ferguson:** Keep on living. Keep on living.

**Susannah Ferguson:** Life is not over. You're still an important person in society. Just because you've had a brain injury doesn't change that.

**Susannah Ferguson:** And the light bright was the one that we did. We talked about it and the squeeze ball, those little gel stress balls.

**Victoria McDonough:** Can you explain that as if we hadn't heard that?

**Susannah Ferguson:** The stress ball we would use, of course, to build up strength in the hands. But then also as an anxiety reliever. So whenever he would get in large crowds, he would become very anxious having to deal with other people, talk to other people. He would become very anxious. And some of his outburst of emotions were avoided. Because he was able to squeeze the stress ball and calm himself down. And then one of the biggest things that is important is for us to get to know each other well enough to where I can give him cues that aren't embarrassing, to give him non-verbal cues of, okay. You need to go on. Because so many times, he'll get into conversations with people and just go off in left field about who knows what? They're not paying attention. They're wanting to leave. HE's not realizing what the situation is.

**Jason Ferguson:** Reading body language.

**Victoria McDonough:** Do you have a symbol?



**Jason Ferguson:** Well, she cups some eyes.

**Susannah Ferguson:** I cup my eyes.

**Jason Ferguson:** She does. May say something.

**Susannah Ferguson:** But just several little things. I might just put my hand on his back. And that gives him the key of, okay. I need to wrap it up. And other things so many times people just make comments. And they have good intentions. But he would take things to heart. He would run into someone. Okay, I'll give you a call tomorrow. Or I'll give you a call sometime. Or in a couple of days. That was always it. I'll give you a call in a couple of days.

**Jason Ferguson:** I would wait right there by the phone.

**Susannah Ferguson:** He would wait right by the phone anticipating their phone call.

**Jason Ferguson:** They said they were going to call.

**Susannah Ferguson:** But the phone call would never come. And so it's heartbreaking for me to see that happening. And so instead of letting it go, we would sit and talk hours on end about this is life. It's bizarre what people say. But it isn't really what they mean. And it's not any slight against you. It's just say, you know, talk.

**Jason Ferguson:** And as far as one of the greatest things that helped me the most was the squeeze ball and the light bright, but also writing. Because I still write to this day. I wrote that poem just for today and I love it. Oh, you wrote that? I look back, I've written well over 300 different poems. I say, oh, I wrote that?

**Susannah Ferguson:** He'll write a poem about everything. He'll write a poem whenever he's having to ride the bus, sitting at the bus stop writing a poem about people that he encountered.

**Jason Ferguson:** The Social Security office, people cheating the system.

**Susannah Ferguson:** But it helped to work on [sneezes]

**Jason Ferguson:** Bless you.

**Susannah Ferguson:** ... his writing skills, but also to help his thought process of trying to work through what's really going on and getting it out. Because that was a huge problem. And that he wasn't able to articulate what he wanted and what he was thinking. And so, therefore because he couldn't articulate, people would assume he isn't thinking anything. And I think that's a very common misconception is that people think that ... outsiders think that survivors of a brain injury don't really have anything going on when in fact they do. They just can't get it out.

**Jason Ferguson:** Stages or spurts it seemed like. And I know that is I know other things (inaudible). But it was like at the time I would just get embarrassed. Or case in point the other night, we were at a restaurant and I started stuttering. I got embarrassed. The waiter didn't do anything. He didn't say anything. I started getting a little bit teary eyed. Because I'd get embarrassed. As soon as he took when we walked over to the ...

**Susannah Ferguson:** We were with some friends. And I said, okay. Come on, let's go to the bathroom.

And we get up and walk to the bathroom. And we have a little one-on-one pow wow away from everyone and saying ...

**Jason Ferguson:** She's not beating me up or anything. But, you know, she's just telling me

**Susannah Ferguson:** Say it's okay. It's okay. You're doing great.

**Jason Ferguson:** But for months things have gotten a lot easier, a lot easier. Especially one thing that Susie told me that I think that really helped me in my whole recovery of dealing with other people is that you can't control other people. You can only control yourself. When I realized that, it was such a weight off my shoulders. Because I can only control my, okay, I have to be the better person. Or I have to be the person to say, okay. I do what I say I want to do. Not worry about them because I can't control them.

**Susannah Ferguson:** And you can't control their reaction of how things are.

**Jason Ferguson:** Yeah.

**Susannah Ferguson:** And the other big thing I know we talked about earlier was with emotions. That even if it might be trivial, that that might be the way he feels. So, um, like the waiter example, if he gets upset because he can't speak correctly to the waiter, well, I can blow it off and say, oh. It's just the waiter. Who cares? But he cares. Jason cares that he can't speak understandably to the waiter. And so that's why it's important. It doesn't matter that ... the waiter is trivial. But Jason's feeling of worth of whether or not he can communicate effectively is important. And so that's why we focus and we'll talk about whatever situation it is to make sure that he realizes it's okay.