

## **Interview 1: Transcript**

### **Question: And what have you been up to since Shake It Up?**

Answer: I've been tied in with different organizations in Rhode Island with disabled sports and stuff like that. In the winter it's tough to get outside so there really wasn't much to do. But recently I was in a group meeting and we were talking about some of the activities we'll do this summer.

### **What are you all planning?**

I could see some more handcycling. We're really interested in the SCUBA diving that's coming up. As for the kayaking, when the weather warms up. Every time I get in the kayak they flip you over (laughs).

### **Have you been active in any of the physical or recreational activities you did with Shake It Up, handcycling...?**

Yeah, some handcycling and stuff, with some of the same people we dealt with in Shake. I stay involved with the local spinal chord injury people here.

### **In addition to all of the recreational stuff, we did some of those morning workshops like nutrition, how to talk to health professionals, how to take care of your skin and your body. Have you used any of that information?**

Actually when I go to the support groups I speak about things now instead of just listening. The funny thing is they give me the bowel and bladder program all the time. It's because of my humor, they know that I automatically start off like, "well, we're going to talk about the bowel and bladder program. I know it's a shitty subject, but we're going to do it," just to break the ice, I think they throw it my way.

### **Do you use any of the information personally?**

Well, as I'm told from other spinal chord injuries, I'm pretty much more stable than some of the people that've been doing this for years. Just keep on doing it. Don't change anything. But it goes with my environment and attitude.

### **Have you stayed in touch with anybody that you met at Shake It Up? Any of the other participants?**

As for participants from Shake It Up, I run into them at different support groups and stuff. The PARI living center is right around the corner, so I run into people who are involved with it. [Names withheld]. I run into people a lot from Shake A Leg, which is kind of involved both ways. Me personally, people know who I am and I keep in touch.

### **So is it good for you to meet people through Shake It Up?**

Oh, yeah. I think the more spinal chord injuries I meet the more we benefit from each other. Able bodies tell us, “do this, do that” but at the same time they’re not in the same situation as us. They try. You and Lisa, you know.

**Yeah, I try, but I know I certainly don’t understand it altogether.**

Being a little more boisterous helps the situation.

### **What benefits did you get being a partner in Shake It Up?**

I think the first general thing you benefit from is knowing that there are so many more people out there like you and to see the different dramatic things, not that I like to drop names, but there was one gentleman and the kite pulled him out of his wheelchair (laughs). You don’t catch that if you don’t have a spinal chord injury. I run into him every so often. He’s a challenge to talk to, but you got to love him because you see him all the different times.

What’s hard to explain is how I run into all these people in these bizarre situations, in a mall or I’ll be anywhere. You never know where I’m going to be. The minute I learned to get on public buses and stuff like that – I do not like to be home. Just because I’m a quadriplegic doesn’t mean I can’t be out in public.

### **What else, just in general, do you want to say about Shake It Up or your participation in it?**

Being that it’s an organization started as more of a research project, they took it way beyond where I thought it was going to go. It really did connect a lot of us together. So I hope that Brown and PARI and all the other organizations keep stuff going like that. I think I would have found a lot of the resources myself anyway, but a lot of the people I see out there had no idea of the services that are out there. The most dramatic thing about spinal chord injuries is they either go my way where you go out and do everything or they lock themselves in their houses and hide. The worst thing they can do is do that. You may as well just dig a hole and climb in it if you’re going to do that. We’re regular people. We’re just in wheelchairs, know what I mean? It’s tough. But the things you learn being in this chair ... it’s phenomenal.

I make a joke out of everything, but there you go through Shake A Leg and Shake It Up and they tell us about eating right, this, that and the other thing, But when you’re in a wheelchair and you want that high-priced cereal that’s way up at the top, and I’m wheeling down and all I see is free toys, sugar, sugar, free toys. I’ve got to stop and go to the courtesy booth to get someone to help me get the high box of cereal. They send me Chuckie, who’s the nicest gentleman in the local superstore, he’s a Down’s kid, about this high (motions about four feet high), so he doesn’t do any better than me in a wheelchair. He can’t get to the good cereal either.

**So, so much for eating well.**

No, what you do is wait, staring at the good cereal until someone comes down the corridor and you say, "can you get me that basic one, or that fruit and fiber one up there?"

---