# Transcription of Interview with Monica, her Mom and Laura Bundesen

Laura: What do you know about your brain, what happened to your brain and how it was treated?

Monica: I had brain surgery, like - the right hemisphere got taken out because I had really bad, bad seizures and I couldn’t even function correctly because it would damage my right side of my brain. Not good.

Laura: But it took the seizures away when you had the right hemisphere removed? But you don’t remember that surgery.

Monica: Right.

Laura: So, do you have any feelings about how this has affected your life?

Monica: Sometimes different people would stare at me and lots of times they would ask different questions, and to be honest with you, I don’t like it. And lots of times I would tell them,” I’m a normal person and you just don’t even know that I had brain surgery.”

Laura: Do you explain to people that you had brain surgery?

Monica: Sometimes yes and sometimes no, but I have to do it under privacy reasons. And I’m in a self-advocacy class, so, the reason why I said for privacy reasons is that lots of times I have to keep it as a secret. A lot of times, so, that’s why I always do it differently.

Mom: Why do you have to keep it a secret?

Monica: For privacy reasons Mom, That’s why I’ve been learning about that in my self-advocacy class, Mom. That’s why.

Mom: So that means you don’t necessarily tell people private things about yourself.

Monica: Right.

Mom: What kind of questions do people ask you? Is it because of your arm do you think? Do people ask you about your arm?

Monica: Yes.

Laura: So, what have you learned to do that you’re very proud of?

Monica: I have a favorite hobby that I used to do – it’s called fused beads magnets. And what they are is you put each bead on a form and make a design with it and when you’re all done filling it out you iron it with a special paper and it melts together and makes a nice design.

Laura: And, what would you like to learn how to do?

Monica: Usually, helping other people out. But, if it’s with brain surgery or if somebody can’t speak then, I can talk for them.

Laura: Interesting – so how do you know what they want to say if they can’t speak?

Monica: Usually, they use a communication device like a *** and, I have two friends that use one. And the other one is named Bob, who uses a communication device as well. One of my friends is blind in both eyes and she's paralyzed and she has seizures too as well, and she can't walk. So, that's why I talk for them a lot.

Laura: So how does the communication device work?

Monica: They use these handles with their heads. Sometimes on their legs. Like for "yes" or for "no". Or if someone is like upset and can give you a big stare and they will start crying. So, I always cheer up people.

Laura: Well, you seem very cheerful to me. So, they must be very happy to have you around. Are you in any kind of support group for people who have had brain injuries? Have you ever met somebody else who has had a hemisphere removed from their brain?

Monica: No.

Laura: So you're very unique. Do you know if it's a very common operation?

Mom: It is not unusual. So, you know when you go to any of the big cities and the neurosurgeons certainly have done these kinds of things. They're now not removing the hemispheres any longer - they are just simply disconnecting it. The reason that they removed her hemisphere is because that's why she was having the seizures because there was so much damage on that hemisphere. And, when it's connected to the other hemisphere it like transfers to the other hemisphere. So, what they used to do is surgery to disconnect and remove it. Now they are leaving the hemisphere there. I think what they found was that by taking it out the spinal fluid got off kilter. So, for example, she has to have a shunt that regulates the fluid around her brain. Because suddenly you don't have that volume there any longer. So they've improved on this technique. We've met a woman whose daughter had that surgery but we never met the daughter. Remember Misty? Her daughter had that surgery. But, Monica is doing a lot of public speaking now.

Laura: Oh – tell me about that?

Monica: I'm in a self-advocacy class trying to do a project on the roads right now and one of the roads I'm working on is Union Street – There are too many potholes ok? But the week before somebody almost approached me and said that somebody went over on a bad pothole on Union Street and I went over to the Town Hall and made sure that they knew what was going on.

Mom: Writing letters to a lot of the state representatives as far as things that are important to them so learning how to do some advocacy at the local level or the state level. Monica went to Boston with people who are involved in the adult family foster care and she did a speech there. (Some discussion here about how many people were there. 2000?) All the same, she's able to get up and read a written speech in front of a lot of people. And she's also been in a lot of plays so she is really trying to hone her skills in so far as being able to advocate for the disability community.

Laura: So, Monica what message would you like people to get?

Monica: If someone is looking at a person that has a disability, I'm just going to let them know, " If you're going to be staring at someone that has a left side that can't work, then you need to think – before you judge anybody…..anybody." Ok, if somebody is staring or misjudging other people, I would say to them, "You're so darn wrong – You're so darn wrong." What they are doing is the wrong thing to do on their part.

Laura: If people are curious about your disability are you comfortable with people asking about it or do you prefer them not to?

Monica: No, for privacy reasons.

Laura: So, the main message is not to judge people who are different then you are?

Monica: Yes.

Laura: So, what else would you like me to know about being you?

Monica: If somebody is going to misjudging or mistreating someone with a disability, I would tell them, "Don't misjudge. Don't be rude. You have to be nice. You have to be kind." Like my friend Susan – she is blind in both eyes from birth, OK.. and lots of people have been misjudging her too. I mean that is so wrong. There is bullying, there is misjudgment, everything, and that is so wrong. I would just say "Bye…bye…"

Laura: So how do you keep your spirits up? How do you stay so happy?

Monica: I do my Build-a-Bears a lot. And, I see a therapist as well.

Laura: It sounds like you keep pretty busy. You've have a lot going on in your life

Monica: Yes.

Mom: Monica meditates.

Laura: Oh, you do? That's great.

Mom: On Tuesday, she goes over to Springfield College and they have a program where they tailor what a person would like to learn. So, mostly she's been doing reading. When Monica got out of High School when she was 22, she could barely read. So, they really taught her how to read.

Laura: Do you like to read?

Monica: Usually yes and usually no. But, lots of times if I am reading my phone or the iPad mini, I just do it that way and I do my healing frequency.

Mom: Technology is really a very, very useful tool for young adults who have some other limitations so we think of the voice activated kind of stuff. She has learned a lot with her technology. It has made a lot of things very accessible, and like a lot of young people you ask her a question and her first thought is "Oh, let me find out"

Laura: Google!

Monica: Yes.

Mom: She really knows how all of those things work. She’s good with all the voice activated stuff. So, Monica, you don’t remember any about living in Miami?

Monica: No.

Mom:  So Monica had her surgery when she was 10 turning 11, right. So it was 17-18 years since she had the surgery. So, it seems like any experience she had prior to the surgery she doesn’t seem to have any memories of.  But, It was a long road back. She was in a wheelchair. She couldn’t walk after the surgery. She couldn’t see. Her face was all blown up. (Monica demonstrates) Her eyes were swollen shut and then she had to go to a rehab facility. She was at Children’s Hospital for the surgery and then we went to Franciscan Children’s Hospital, which is a rehab facility in Brighton, and then she was there for several inpatients, and then she had outpatient therapies. She started off every day where she was an outpatient. She had speech therapy, occupational therapy, physical therapy to get back the functionality she had lost and so it was a big deal. But, it really paid off. Not everybody who has this kind of surgery gets this kind of result. She was very fortunate.  But, Monica was born with brain damage. It’s not that the hemisphere was removed because it had grown normally. The reason she had the seizures was because in utero it had not developed properly. So when they did the surgery it was like an atrophy. So, it was much smaller. The surgery took about 13 hours. The brain surgeon said that when he was doing the surgery it was more like something like hardened gum and it should have been more like jello. So, it gives you an idea of the very difference – of what the matter really was. So, it was no surprise that she had these intractable seizures. She was on all these different medications that never did anything for her because that whole hemisphere was so damaged.

Laura: So it sounds like her quality of life really improved after the surgery

Monica: Yes.

Mom: Hugely.

Laura: and after the rehab.

Mom: She was very irritable as you can sort of imagine because she had all of this abnormal electrical activity going on all of the time. She did have like 10 seizures a day and some of her seizures would last 15 minutes. So, she couldn’t really do anything. I would’ve never let her go over to someone else’s house or certainly go in a pool or anything like that, because I had to watch her all the time. Even going up stairs because you never knew when one of the seizures was going to hit.

Laura: So it sounds like the surgery was really a blessing in you being able to live a very active and a happy life.

Monica: Yes a happy, happy, happy, life!