



Interviewee: **Sarah Heinzl**

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Interviewers: **Athena Aardweg, Judy Barricella**  
**& Tony Buba**

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Voices of Our Region  
Sara Heinzl  
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Sara: O.k., my name is Sara Heinzl, I live in Pittsburgh. My family is big; I have two brothers, one younger, one older; I have two half-sisters, both older. My two sisters have one kid each. One is a boy, one is a girl. I live with my mom and my two brothers. I think that's it. I go to Brashear High School. Four years ago, I was diagnosed with a rare but uncommon, but not rare disease called acute transverse myelitis, and basically that's a disease that one in a million people get so I'm excited to say I'm one in a million.

Interviewer: You are.

Sara: Haha. But it's actually were your myelinal sheath, which is kind of like saran wrap around your spinal cord. When you get sick, the virus, if it travels to your spinal cord, it bounces off because of the myelin sheath that protects it. They said it probably was a viral infection that went to my spinal cord, made it swell, made it infected and so it cut off the brain signals from my brain to my legs.

Interviewer: That was four years ago, you were 14.

Sara: Yes. Actually, June thirtieth. I was outside on my deck and I was having so much back pain and leg pain. It was like shooting pains and then it was just uncomfortable and so I called my mom and I was like "I don't know what to do," and she was like "just take some Tylenol, go lay inside". So as I was traveling into the house I collapsed completely. Like I started wobbling and I, like my legs, I didn't feel like they were underneath me anymore, and they just gave out. And so my brother-in-law said that maybe it was just a like a Charlie horse or just some kind of leg pain. So he carried me into the couch and I laid there for maybe 15-20 minutes and the pain was even worse. I was in so much pain. My legs started going from – like my torso area down, after an hour maybe I couldn't feel my toes any more. So they rushed me to the hospital, and went through so many MRI's and CAT scans and brain scans to see what was wrong and then the deciding factor was a spinal tap. Um, I was in the hospital for a week. They put me on an IV of steroids. I went to Children's Institute. So I was there for three months, two months.

Interviewer: Were you?

Sara: Yeah, I was there for a good bit. They had me in outpatient therapy for maybe a year or so, maybe a year and a half. I went to the doctor's. And like I remember that day perfectly, it was horrible. And they were like, "Walking isn't really a realistic goal anymore." Now I don't have to have any expectations and it was kind of like you know I'd feel normal again if I walked. But I mean, that's the mental state that I had, and then once he told me that I was kind of like, "You know what? I'm as normal as I'm going to get, so you know I can just deal with it or I can cry about it."

Interviewer: But you went back to school? I mean you went to high school.

Sara: Oh yes, I was in high school.

Interviewer: In your wheelchair.

Sara: Mhmm.

Interviewer: And the high school was accessible?

Sara: Um, barely. No – yea it is, it is. We've had some problems with fire drills and things before, but we got that, we got it all figured out. I had to get a jitney key, I wasn't allowed to get my own key so I had to get someone to give me their key like not even supposed to and I had to go get a copy made and oh, I mean they don't want kids on the elevators, but... And then of course I've been left up on the third floor a few times, in a fire drill. But they got it figured out that like they'd have the football team carry me down so I was not complaining after that! I would have a study hall the last period of every day and, which kind of put me back a little bit in my schooling, I had to take an extra year of Spanish 'cause there's requirements that you have to fill that I wasn't able to fill because of my therapy. And then three days a week I had to travel from here to the Institute. One day it was like an hour earlier so I had to miss my last period or second to last period class.

Interviewer: So your family, your brothers, how do they treat you?

Sara: Ha ha ha. We act like we hate each other and we're always screaming at each other but it's like my brothers have so much respect for me and I have respect for them and how they live and how they feel and the same with them. My brother wrote on his MySpace, like you have columns where you write your favorite books, your favorite movies, and then you have like your heroes, and he was talking about how when you think of a hero you think of like someone who's in a cape and big muscles but I was actually his hero. So.

Interviewer: Who's your hero?

Sara: I don't know if I consider people heroes. I consider them people I look up to, and that's my whole family. That's John Sikora. That's all of the women on my basketball team and people I look up to even including people who have been in wheelchairs for long times and you know are going through what I'm going through, or have gone through what I've gone through. So I mean anybody who has to live with a disability is considered a hero or someone to be looked up to in some way.

Interviewer: Are you driving?

Sara: I don't have my license 'cause it's actually really, really difficult right now to get it. But I do have my permit and I do drive some.

Interviewer: So where are you learning to drive?

Sara: Well I did take lessons at the UPMC, very expensive lessons.

Interviewer: Really?

Sara: Yeah but I graduated in like two lessons so. I'm not that bad of a driver, I don't watch my speed. So.

Sara: My mom has a car and we have removable hand controls.

Interviewer: That's nice.

Sara: And actually, actually they are considered to be less dependable because you screw them on. But they're so nice. I mean I can take them out of my mom's car and put them in any car, exactly. They were \$300 so they're actually my friend's so I'm borrowing them right now, but I mean I don't even think I'd really get permanent ones 'cause like these are just so easy to use. Like, it's no big deal.

Interviewer: So do you think this happening to you was the most difficult thing in your whole life?

Sara: Yeah, probably. I wouldn't consider it a burden though. You know, it's a new step. Not literally, of course, but it's a new step. So I don't sweat the small stuff even though this is kind of big, but...

Interviewer: How do you have this wonderful attitude? You're so young.

Sara: Ha ha ha It's probably because of sports. And because when I was an able body I used to play so many sports. I was going out for track. I ran every day. I was really in shape. I played soccer, I played volleyball. I love sports and thanks to my coach, I'm not a disabled athlete. I became an athlete that's disabled. I love basketball. My physical therapist brought my attention to a flyer that was for wheelchair basketball and I remember coming home and telling my mom, like, "Mom, if I don't like this, do I really have to do it?" She's like, "No Sara, just go to the first practice, just try a few sports." "I really don't want to," and so. I actually ended up loving it and it's a big stress reliever. It helps me keep in shape. I did water-skiing and I loved it. It was so much fun. It was just like I was up on the water and it's like you know what, you can't tell that I'm in a wheelchair you just think I'm you know like one of those kind of things, and then I tried wheelchair basketball and I loved it even more because I met so many people with conditions like mine and new conditions.

Interviewer: You got a scholarship to...?

Sara: Yes. I got a scholarship. An \$8,000 scholarship to go play for the University of Illinois.

Interviewer: To play wheelchair basketball?

Sara: Yes.

Interviewer: For a girls' team?

Sara: Yes. I was actually getting another \$10,000 if I signed my first year.

Interviewer: You'll be in Illinois?

Sara: No, not my first year. I'm going to Edinboro. Starting in the fall.

Interviewer: Oh, this September.

Sara: Yes.

Interviewer: Oh, so you're going to Edinboro for a year.

Sara: Yes and then.

Interviewer: Then transfer.

Sara: Mmmmm. Going through high school nowadays in a wheelchair like being disabled, it's just like. I mean you're always labeled. All of the stereotypes. I mean, a – you know, she can't walk. Like I can stand up. I can put pressure on my legs. Things like that, like ooh. "She was in a car accident." If you don't know my disability usually they say I was in a car accident.

Interviewer: What else?

Sara: Everything. Being accepted. Everyone's always like well there's a speed limit in here. And running over toes. You know. There was a girl who wanted to fight me a few years ago. Yeah, because she made a comment about me running over her toes. She'd made a big deal about it. Like she'd jump up on a wall – make a huge scene. And so one day I was like "Ahhh, if you're going to say I run over your toes why don't you come here and let me put your foot under my wheel?" She didn't like that too much. I just started screaming and ooh never got in a fight though. Thank goodness.

Interviewer: What about the guys at school? Are they?

Sara: Like a lot of guys they don't think that I can do the things that I can do like I mean like going out to restaurants would be a little bit harder. Guys don't want to make that

extra step to actually get to know me. But the girls are even worse. I ran for Homecoming Queen this year and a girl made a comment. She made a comment about how I shouldn't be allowed to run and how because I used my disability to get people to vote for me. Because I had the handicap symbol on it and it says "Roll with the queen. Vote Sara." And like I had so many cute posters and things like that and didn't like it, said I was using my disability to get votes and saying like that I shouldn't be allowed to run. You know because the queen has to walk down the Red Carpet, not roll. Like just little petty things that just seemed so stupid. So.

Interviewer: What do you want to do when you get out of school?

Sara: I want to actually work with HOPE Network and work with disabled children. Children that. I mean show them my situation and teach them that you know it's ok to be different and actually no one's really normal. Show kids especially that there are other options than you know coming home and playing on the computer. 'Cause I know that's all I did my first year in a wheelchair. I came home and I played Sims. I still do that, but you know I'm more physically active. It makes me a lot better person. It makes me a happier person so. I just want to show kids that there are sports. On Saturdays, one Saturday a month I help out with a wheelchair basketball clinic. It's a disabled, for children. And I just love it! I love teaching kids. I'm not the best basketball player in the world, not yet at least. But it's like I love getting that feeling of "yeah, I taught them what I know!" And now they get to go home and they get to practice and they become a better person or they become better at whatever they want to do and I love to share my experience with people, I have no problem telling people my story or anything. My aunt is like sometimes she gets made fun of and thinks she's my chauffeur, but she drives me anywhere I need to go. She's driven me to every therapy session, you know picked me up from school. She was there for me every day for my physical therapy. Every physical therapy session she was there. And she's taken me to basketball every Wednesday for the last three years and then my mom would pick me up and my mom would take me to all of the other events, you know, like the Variety events and then sometimes water-skiing.

Interviewer: Any questions, Athena?

Interviewer 2: No, as long as you ask about advice or words to live by.

Sara: Gandhi "Be the change you want to see in the world."