

About Health TV with Jeanne Blake
Travis Roy Update
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JEANNE BLAKE: Welcome to *About Health TV*, I'm Jeanne Blake. Every year about 11,000 people suffer a spinal cord injury. Our guest today has been with us before on *About Health TV*, he's Travis Roy and he was injured 11 seconds after he took the ice at Boston University in his first college hockey game that was about 10 years ago. His book about his life with spinal cord injury "*Eleven Seconds, the Story of Tragedy, Courage and Triumph*," continues to sell, it's been updated eight years after it was published and it was six years ago that he first joined us here on *About Health TV*. Travis welcome back, we've got a lot of catching up to do don't we?

TRAVIS ROY: Thanks, it's my pleasure. I had a great time last time. It's nice to be on a show where you can really go beyond the headlines and really dig into what really matters and what's important.

JEANNE BLAKE: You had a real impact on all of us and it's really great to see you looking so well.

TRAVIS ROY: Thank you!

JEANNE BLAKE: And your spirits seem to be good and I'm glad and I know that you're doing so much good out there in the world. I'm following through friends and through the newspaper.

TRAVIS ROY: I'm really trying. Doing my best. You know, I've always had great support from all around the streets of Boston to a great family and good friends. Of course, I have great insurance through the NCAA that over the last ten years I've really seen how big of a difference that's made to keep the relationships and everything else in place and the way they were before my accident.

JEANNE BLAKE: Before we went on the air we were talking about that. You and I know some people in common that have suffered spinal cord injuries since you were last here and it isn't always the way that you have it. Insurance is differed person to person.

TRAVIS ROY: My situation is incredibly unique. I'm less than the one percent that have the insurance that cover. I have 24-hour home care, I've got most of my the wheelchair, my van, voice activated computer, there's basically been insurance here and there to pay for that. I just don't know how the people that do it that don't have the right insurance because as I say, it puts burdens on everybody. It puts burdens on the parents, the loved ones, and then it changes the dynamic of the family and the friendships. Really our country isn't set up to care for people with significant disabilities like quadriplegia and, fortunately, I was saying there's really two ways to go about this: that we put all our money into caring for people with disabilities or we put all the money into research. Or we kind of do a little bit of both which is what we do and I think that's probably the right cause but at the same time, I think we've dropped the ball or haven't had the funny notion of that.

JEANNE BLAKE: We've had Chaz Southard and his dad on this program and their situation is different and they don't have the insurance and I think that in that program they talked about the strain and you've spent time with Chaz and his family.

TRAVIS ROY: Right, yes. And I just, those are the people that I have the utmost respect for and just absolute respect for them to continue to move forward for them to try to make the best. When you've got to worry about just dealing with the health of this disability. There are urinary tract infections, very common. You never know, I happened to be at the doctor's the other day and wasn't feeling right. Can you tell me what you think, where does it hurt? Well, you have no idea, you know it's such a guessing game and it's very frustrating. But it's, just dealing with the physical aspect, much less the financial aspect and then most people end up living in their family's homes or they get pushed out to nursing homes and that's just not a great quality life. As you know, I'm 30 years old. I couldn't imagine living with my parents with no foreseeable change. And, fortunately again, I'm unique, I have the insurance and I'm very grateful and that's why I try to come and do shows and, I know people are probably sick of seeing me in the media but at the same time, I think, I just want to keep the awareness going. When I talk with people with spinal cord injuries and they say I appreciate that you continue to create the awareness and that's really the reason I do this. I'd be happy to not be behind or in

front of a camera again but it's important and we've made progress and we're getting there but, at the same time, we've still got a long ways to go.

JEANNE BLAKE: When you were here you were still a student at Boston University.

TRAVIS ROY: Yes.

JEANNE BLAKE: And you are living independently now in Boston with a 24-hour aide, and it does allow you to do the work that you do and tell us just a little bit more about that. You travel nationally to speak?

TRAVIS ROY: I travel occasionally nationally. I try to keep in the Northeast, the east coast. I do some motivational speaking. I've done work probably for four or five years in just looking for places to speak and just in the last, a little bit of media again around my 10-year anniversary. I'm finally in a position where I'm ready to speak to most any group. I have the confidence. I've learned my material and that's been a lot of fun and I think anybody just wants to find something that they're good at, something that gives them some enjoyments and fulfillment, but at the same time, I can earn a living, which is huge. You know, I've always had pride but it really helps when you make it on your own.

JEANNE BLAKE: Absolutely.

TRAVIS ROY: Which is so big.

JEANNE BLAKE: Dear friends of mine, Frank Dalaklis and his wife Elaine, have gone through a terrible tragedy. Frank was in a car crash and was left quadriplegic and they've spoken Travis about your visits to him both at Mass General and at the spinal cord, at Spaulding and how much that has meant to them. Both, I think, on a level of giving them some hope because you do so beautifully because you're so motivated to do well and so you can get around, you can have a life. But also you've helped the family learn so much about what to expect.

TRAVIS ROY: It's, well there is just, I didn't know a thing about paralysis before my accident. My parents didn't know anything about paralysis and it's a life-long course trying to

figure what it is and how to deal with it and make the best of it. Over time, as you mentioned, it's been 10 years since my accident and the thing that in looking back that surprises me the most and just shocked is how far I've come since that first year. That first year was just a nightmare for everybody and so many issues and accidents and embarrassing scenes and just tears and if I can go in and speak with a family just share some of them. I don't want to give them all, there's so overwhelmed enough, but just to give them maybe a few shortcuts or a few "here's what you can expect" it does make all the difference in trying to do it in a way where it works because to be honest with you there were people that came into my room after my accident and I just wasn't ready to hear it to be quite honest with you. They're in a very difficult situation. There's really three levels of paralysis: ven-dependent quadriplegic.

JEANNE BLAKE: Right. People who can't breath on their own.

TRAVIS ROY: People that can't breathe on their own. Is the worst. And, unfortunately, Frank is dealing with that.

JEANNE BLAKE: Actually, do you know what? He's off the ventilator for 20 hours a day or something.

TRAVIS ROY: Is he really?

JEANNE BLAKE: He's just amazing. For the viewers who don't know, this is a phenomenal family. His progress, he's a 72-year old man so I'm not surprised because the whole family's, they are so close and they are all working together and he's worked really hard to get off that ventilator.

TRAVIS ROY: That's terrific.

JEANNE BLAKE: And he's even shocked the doctors and I think that the support including yours has really had a tremendous impact on his willingness to fight and he's just, he's a fighter anyway, they've got a great spirit.

TRAVIS ROY: He is a fighter.

JEANNE BLAKE: Travis, in your book, as we mentioned earlier, it's "Eleven Seconds" – you now have added a new chapter and it's been reprinted.

TRAVIS ROY: Sure.

JEANNE BLAKE: And, by the way, if you go to the bookstore to get this book don't look for the updated version

TRAVIS ROY: The updated version.

JEANNE BLAKE: On the cover because the publisher didn't put it there, so buy it anyway and look through the back and you'll find the newest chapter but, what did you add? Because I think that, I hope that you added this information for families on what to expect.

TRAVIS ROY: Well, I didn't add too much there. I think that originally a lot of that was there. Again, it was my first year after my accident that I wrote it but I think I talked a lot about those headaches and maybe not, maybe I should have added a few more of the solutions but I talked a lot about. It had been eight years since I had written the book so a lot of people were sort of curious, what happened with the girlfriend? Of course, that was a popular question. I kind of talked briefly about that, and my family, where my dad was at? Where my mom's at? Effie, my dog at the time, which kind of she runs through the book and she passed away recently, and just kind of telling people what happened over the last eight years. From graduating from college and living in Boston and I talked a little bit about my faith. Honestly, I wasn't the most religious person didn't have the most faith, but over time that's kind of built up a little bit and the prayers, the letters and everybody would tell me they prayed for me and early after my accident I didn't give it a whole lot of weight. But as I get older and mature and think more about it, my life, as they say, I can't believe how far I've come and I give a lot of weight now to those prayers. I feel like they were answered many times over.

JEANNE BLAKE: Can you explain that? Because I know that some people who are, as a medical reporter I come in contact with a lot of people who experience tragedy or illness and I think that they go through a period of time where they say well, where is God? How could this happen? And I don't believe.

TRAVIS ROY: Absolutely.

JEANNE BLAKE: I think that they'd want to hear how you came to a place where you're still dependent on the chair but your faith is strong.

TRAVIS ROY: I think for me it was black and white. It was if they are praying for me, then I will walk again. Everything will be all better. I'll be able to walk or improvement or something will change. The truth was I had no change after my accident but the one thing that I never thought about was the strength to overcome and the strength to move on each day and I feel that those prayers gave me the strength to move forward and to move on and that's how I look at it now and that's why I'm grateful for the people that have supported me over the years and the prayers. That's the change that I've made in my thought process and it's made things a little easier. It kind of gives you an idea that you've got somebody you're working with through this. You are not alone and that things are going to be alright. Maybe not ever easy, but hopefully I'll continue to have the strength to keep going on.

JEANNE BLAKE: It sort of shifts the glass from being completely empty to half full.

TRAVIS ROY: Sure, and I talk now that I've got a pretty full glass at this point, I'm not even worried about half-full or half empty.

JEANNE BLAKE: That's good Travis. You've taken your energy and several years, I think, was it just a year after your accident that you started the Travis Roy Foundation?

TRAVIS ROY: We did, it was about a year after, a little more than a year after my accident we started the Travis Roy Foundation. I think there was a little confusion early on whether this was going towards me or something and not at all. We, the money raised goes towards spinal cord research. I'm still very hopeful for a cure. The other half of the money raised goes toward individual grants. We talked about individuals that don't have the insurance and trying to get the right

JEANNE BLAKE: Right, can you give us an example of some of the people that you've been able to help?

TRAVIS ROY: Absolutely. We had a trustee meeting this past Friday and we had about \$50,000 to give out. Not a lot of money, but a good little chunk and we gave grants I think to twelve or thirteen different people around the country. Some Massachusetts residents and those grants consisted of wheelchairs, consisted of lifts to lift you out of your wheelchair to get to the bed. I spoke with somebody recently where he was the same age as me, a little younger, had a motorcycle accident and his father is his primary caregiver, and he was concerned because his father was getting old and they had a lift that you have to roll it across the bedroom to get from the chair to the bed and he was concerned that his dad wasn't going to be able to do it as he got older and he asked me if they could have a new track lift that wouldn't require any real rolling or pushing or lifting and so that's one that's on tap. If we had a little bit more money that one's next. But he just got on the list.

JEANNE BLAKE: It's so satisfying for you to be able to do that.

TRAVIS ROY: It's really amazing. I love meeting the people. Sometimes I don't get to meet all of the people that we give grants to, as I said, are around the country and certainly some around Boston but it's made a big difference. The demand is just huge and we can't meet it and sometimes I get frustrated with that and we're always looking for new ways to raise some money.

JEANNE BLAKE: This is a good time to give your, I guess you can go to your website right?

TRAVIS ROY: Sure, the TravisRoyFoundation.org it's a great website. Not only is it some of the different fundraisers going on, but it's a great educational resource.

JEANNE BLAKE: I spent a lot of time on there in anticipation of talking with you and I actually thought well I guess Travis doesn't have to write another book because I was, and that's something I want to ask if you are planning to do that. I think after knowing what you've been able to do for the Dalaklis family and for Chaz, you are a real resource and I think that from the way I've had it described to me that on a national level you're recognized as being a tremendous resource for people and I wonder if there. I was glad to see so much on your website almost about what to expect so that people can go there who've experienced the injury.

TRAVIS ROY: Yes.

JEANNE BLAKE: But I also wondered if you aren't thinking about putting that into another book.

TRAVIS ROY: There's different avenues there. As you've said there's a lot of data on there and I'd love to take credit for it but we've got a great person that does that, Janice Folly. And she, from clinic trials, what's going on in clinical trials to research the literature to spinal cord rehabilitation centers. As far as writing another book, I, as I say, I'm hopeful that there will be a cure of some sort. I'm not going to playing hockey again, running or jumping. I'd love to have my independence back. I'd love to, if I need a wheelchair, or at least maybe I can get myself out of it and get into bed or get to the shower that would be a, I'm hoping that I can walk but I don't want to get too optimistic. And I think, I'm hopeful that that day will come and then maybe will be ready to write another book but with the first book I had no idea how long that experience was going to go and in looking back, it turned out to be a great experience.

JEANNE BLAKE: You've reached a lot of people with that book.

TRAVIS ROY: A lot of women, a lot of men, a lot of children and it's with the update I think it still seems to do well and I'm still, I feel like it has great importance.

JEANNE BLAKE: Travis, back to your desire and hope that you will walk again, there is so much debate around stem cell treatment.

TRAVIS ROY: Sure.

JEANNE BLAKE: And work and research. It must be frustrating to you in many ways that we're not moving ahead as quickly as we could.

TRAVIS ROY: It's very frustrating. In the stem cell, of course you've got to mention the embryonic stem cell research. There's lots of different kinds of stem cells and my real feeling all along has been I just want to give the scientists/researchers all the tools and let them go down the road and if one of them works great, and if one of them doesn't, embryonic stem cells don't work, fine, we'll go in the next direction but, let's give them what they feel has the most hope.

Then, of course, the politics, it's just incredibly frustrating and what we've lost over the last six years, The democrats, republicans, it's just extremely frustrating that we're so polarized at this point and I just keep praying for some great leader that is going to come walk right down the middle and bring us all together and I think this country's prime for that person because I don't think either of us are real happy whether you're a republican with your own party or democrat with that party. But it is frustrating and the research that gets done in this country, the big research it's government funded.

JEANNE BLAKE: There is, in other countries, there is research that gives you this hope and it's real.

TRAVIS ROY: It's amazing in the US and don't get me wrong, there's a lot going on in this country but it's all mostly privately funded and there is some going on but there still be one arm tied behind their back. But yes, I mean, Israel, a lot of research there trying to, in Israel a lot of the suicide bombings leads to a lot of spinal cord injuries. Shrapnel – we've got a lot of soldiers coming back from the war that are paralyzed that, as I say, this country isn't ready to be dealing with.

JEANNE BLAKE: And I think that we don't know a lot about that. We don't hear a lot about that.

TRAVIS ROY: No, not at all. But fortunately, yes, the rest of the world and many countries are working on research and I've been rather disappointed over the last ten years that more progress hasn't been made. I'm very hopeful of starting to see some things that as disappointed as I was in the previous ten, I think maybe I'm going to be surprised at how far we've come in the next ten. With that said, once they find that cure, it's still a long ways before it gets to mainstream and to myself and Frank and everybody else but it's great to have hope.

JEANNE BLAKE: It is great to have hope.

TRAVIS ROY: There's not doubt about that.

JEANNE BLAKE: As you move around the city and the country through your work and through your life, this is sort of shifting gears, I'm wondering how far you think we've come as a country in terms of people acknowledging and how people view people with disabilities?

TRAVIS ROY: I think we've come a long way. I think we have a younger generation that is great. Kids, people my age, and I think really open to it. I mean, I remember being in grade school and high school and seeing kids in special ed mixed in with the public high school and maybe not the same classrooms but in the same school and I think we're getting there but at the same time there are certainly times where there's certainly room for improvement.

JEANNE BLAKE: Can you share an example of a time that you maybe weren't treated as you would have been were you walking down the street?

TRAVIS ROY: I think sometimes there's people that see you coming or sometimes I can't hit buttons to elevators and sometimes people see me kind of struggling with it trying to knock that button and you can see people kind of notice and they don't know. Some will come right over and can I help you out, others are just hoping, you can just see it and they're praying don't ask me to help you.

JEANNE BLAKE: You're kidding me. I mean I don't understand that. What do you think that is?

TRAVIS ROY: It's just a lack of knowledge, a lack of ignorance that I don't think it's, I think there's more of a fear of doing something wrong.

JEANNE BLAKE: Okay.

TRAVIS ROY: Than it is anything else and definitely I think there's some people out there that still that are not sure. Everybody should be out there in a wheelchair and associated

JEANNE BLAKE: Do you ever speak up? Have you ever

TRAVIS ROY: That's one of the things I learned my first year back in BU was, didn't go very well. It wasn't good and it was primarily because I didn't know A) who I was in a wheelchair and how to react and interact and I mainly kept my head down. But the second year I knew I had to do better and kept my head up. I looked people in the eyes, I smiled, I said hello and once I did that it was amazing that it broke the glass. It kind of gave people a comfort to be able to say that's just a person and it opens up for a question especially you say, hello, how are you?

JEANNE BLAKE: So I think that you're right, it's people just don't know how.

TRAVIS ROY: It's unfortunately the onness is I feel is almost more on the people with the disabilities to reach out to people that aren't familiar. And then you just, and sometimes I understand and sometimes I see people with a disability and I'm not quite sure what the disability is or what their constraints are and, and then at the same time I know of a few people that get very frustrated when somebody says can I help you out? Or can I push you up the hill, so you're always going to get some different answers but I've always been trying to open the door, leave my door open to people that ask questions and help out.

JEANNE BLAKE: Before we go, we've just got two minutes left, I want to end on a note of revisiting how people can support your foundation because of the good work that you are doing.

TRAVIS ROY: Thank you.

JEANNE BLAKE: Do you have events coming up?

TRAVIS ROY: We don't right now, nothing in Boston. We have a great event up in Vermont, a wiffle ball tournament. Ricky Craven NASCAR race car driver just did a snowmobile ride up in Maine. But please keep updated with our website again, TravisRoyFoundation.org and we'll certainly let you know of some upcoming events. We do have some plans hopefully coming up in the next year, different events around Boston.

JEANNE BLAKE: But I also think this program airs in other parts of the country and if people wanted to support spinal cord injury they could do it through your foundation?

TRAVIS ROY: Absolutely.

JEANNE BLAKE: And they can do something independent. If children wanted to have a car wash in Debuke, they could do that right?

TRAVIS ROY: Sure, and that's really all we ask. Raising money is not easy and many times it's not a lot of fun but if you come up with a unique idea, you know a car wash is great in the spring. And as I say the wiffle ball tournament. We're always looking for new ideas, and especially volunteers that can implement the ideas and make things happen.

JEANNE BLAKE: You'd think it would also be a great way for young people to continue to be educated about people with disabilities and it's important I think to remind folks again that this is not money that goes to you but it goes to help support people who otherwise will continue to meet even greater obstacles than they already face.

TRAVIS ROY: Absolutely. I mean just giving a voice activating computer to somebody. We all know how much we rely on those computers beyond the internet and they go to take classes on the internet, they can be entertained. There's so many things they can do and just something as simple as that \$1500 computer with the software really opens up, opens up a life and the other thing is you can make on-line donations.

JEANNE BLAKE: That's right.

TRAVIS ROY: Right at the website as well so I really appreciate you taking the time and letting people know about the Foundation and the book and whatever else and just helping to create more awareness out there. That's, as I say, why I continue to do it and I appreciate you giving me an opportunity.

JEANNE BLAKE: Well you do it well.

TRAVIS ROY: Thank you.

JEANNE BLAKE: You're a young man with tremendous grace and it's a pleasure to have you here and to know you Travis.

TRAVIS ROY: Thank you.

JEANNE BLAKE: I wish you all the best. And we want to thank you for joining us on *About Health TV*. I'm Jeanne Blake. Remember it's www.TravisRoyFoundation.org. I'll see you next time.