Allen Rucker, Author ‘The Best Seat in the House’
2008 Rare Neuroimmunologic Disorders Symposium

Transcription from presentation available at https://youtu.be/bA01NEfdu5A

[00:02] Okay, we are so very lucky to have the last person we are going to have up here to speak, I met him in March and he truly is one of the funniest people to sit and talk to, if you haven’t gotten a chance to know him you've got to sit next to him and also read his book. Allen Rucker is an author and he wrote a book about life with Transverse Myelitis called “The Best Seat in the House.” It’s amazingly funny it’s candid it’s wonderful. He has written articles for New Mobility Magazine and I know other books that he’s written too. We are all lucky and blessed to have him here: Allen Rucker.

[01:03] Wheelchairs, you can’t have more than one wheelchair on a stage, it’s a law. Hi, Hi, Hi. It’s great to be here. Sandy, I think you actually thanked everyone in the room and I probably everyone in the room deserved to be thanked. It was really an honor when Sandy called me up and said would you speak before this group and I said ya sure and I thought about it for two minutes and I go “wait a minute, this is a room full of experts these people actually know what I am talking about this won’t be good I can’t do my normal B.S. that I do with virtually every group that I talk to because they never heard of Transverse Myelitis they think you get it from monkeys in the Amazon or something, no really, you can say anything but I am dealing with two experts here tonight one is the expert of one of these people who have one of these neuro immunologic diseases because your story is probably as interesting and gripping and dramatic as mine. And the other of course is the medical experts who we all came to hear because they are in some way improving our lives. So I guess I really have to cut the B.S. and only tell you the truth, so it’s going to be embarrassing for me and my wife before the nights over.

[02:25] The first thing I want to tell you is for the sake of honesty is I don’t know what to call myself, maybe you can help me out this week. Most people outside of this community would call me a victim, a TM victim, “Oh he got this weird disease and now he’s a victim. I don’t think of myself as a victim, I never used the word victim and so I can’t call myself that. Then I thought, “Maybe I am a TM survivor.” But then I thought, “The cancer people kind of own that and you have to borrow that word from them and then I am not a survivor most of us survive. And I am not a TM lover and not a TM user and I am not a TM participant, I didn’t ask to join this thing, I am serious, I don’t know, I am a person who has TM but that doesn’t have any ring to it it’s kind of boring. So anyway, I am still working on that so tonight I figured there is a good term for all of us who have one of these diseases, I like to call us the “Chosen Ones.” You think that’s good? Sandy is that OK? We will borrow it from the Jewish tradition and we will give it back when we are done with it. So walk around and say, “Are you a Chosen One and say, “yes I am. So good it sounds a little like scientology but you will get used to it, we are the “Chosen Ones.” And I was chosen as one of the chosen ones and I know a lot of you have seen my book or some of you have read it. I was chosen as one of the chosen one in 1996 and just like Sandy says it just came out of the sky which it happens to a lot of you. The name of the book is: “The Best Seat in the House, How I Woke Up One Tuesday and Was Paralyzed for Life.” And that’s exactly what happened, it didn’t take very long. But what is interesting is the point in my life that this occurred. This occurred at what I like to call a perfect storm of bad circumstances to get a disease in. It was the middle Nineties my so-called career in Hollywood was going sideways if not sliding off the map. We had a mortgage the size of Montana we owed everyone in the world and my mother-in-law lived with us. Is that not you know, and so to top the whole thing off I wake up one day and I am paralyzed for the rest of my life. I didn’t really need this and
in retrospect, I saw the paralysis or the TM as a kind of wakeup call, you know, to kind of get my life together. Of course, I didn’t need this wakeup call a really intense religious conversion would have been great, were like Oral Roberts I feel the right hand of God or maybe a D.U.I. a couple of nights in the drunk, in the drunk tank, but not to have to wake up on a Tuesday and wobble around my room for an hour and a half like a drunken sailor and then I am paralyzed for the rest of my life. I don’t know if anyone is in charge of all this but if they are they should chill out because this is overkill OK. All they needed to do was hit me on the back of the head with a hammer real hard and I would have paid attention. But this is what happened and this is was my wakeup call and this was a wakeup call for me, I know different people have different experiences that occur in different points in their lives, this is just the point in life that it occurred for me.

Because what happened is I immediately came up with the analogy I was reborn not in the religious sense which would have been a lot easier but to become almost literally be reborn to kind of start over again. I was totally helpless, I couldn’t do the things I thought that I had pretty well mastered by the age of three years old, I couldn’t go to the bathroom, I couldn’t sit up, I couldn’t roll over in bed, I couldn’t do anything, I was truly, truly helpless, it was a state of infancy is what it was. And as I began, and of course you know, you have a survival instinct you begin to master these things and what I realized, this is lesson number one that I can impart to you is that feeling psychologically helpless and feeling physically helpless are two really different things I really did feel psychologically helpless to guide my life in some kind of rewarding way when I was struck with Transverse Myelitis and when I became actually helpless truly helpless is what happens is that as you begin to master the smallest things like, sitting up on the side of the bed was a great victory for me, being able to transfer into a chair was a great victory for me, being able to transfer into a car without falling on the ground, being able to sit without tipping over backwards and ending up like some upside down turtle at a party. It was all a victory for me and there is something going on and maybe doctor Kaplan or someone else could see there is something going on neurologically when you begin to master the smallest things you begin to have a sense of mastery that could lead and in my case to a certain extent lead to things that I thought before that I thought physiologically I couldn’t master. In other words, you develop a kind of sense of mastery about your life. So in that sense it was really kind of valuable I figured in the first couple of weeks if I could get through this, if I could go from laying down to sitting up maybe I could do some other things in my life that I thought I didn’t have control over but I probably do have control over. So my image was like being reborn or at least re-growing up I like to say.

My wife’s image was moving to a new country and it was really like that too just like being transferred to a new country, when I finally left the hospital and had to go out into the real world where no one is paralyzed or very few people are paralyzed or actually a lot of people are paralyzed you just don’t see them they are kind of invisible. But to go out into a normal social world all of a sudden, I had to you know I wasn’t an infant anymore I was in the fifth grade I didn’t know what quite to say at the party to the pretty girl you know. I was like a teenager I was self-conscious and nervous and had a chip on my shoulder all those kinds of things teenagers have. And it was like a foreigner going to another land and learn another language, the language I had to learn was a visual language a social language.

Because the world treats you differently as everyone in this room knows and I don’t know why it is and you guys have to know I have traveled around the world and our friend from Sri Lanka can probably tell us this and other people for the disabled America is Valhalla, America is so far ahead of any
other culture besides maybe Canada, and yet people in America feel weird around the disabled. Part of it is deeply rooted in people’s fear of illness and impairment almost primitive and part of it is social awkwardness. So I had to learn again how to move around and so going to a party for instance was a big deal because you didn’t quite nowhere to sit or stand so to speak and you were always in anyone’s way and invariably what would happen is you would go and your hostess is very nice and every one’s very nice really, really nice and your hostess would go, “He’s a nice place for you.” And they place you over by a potted plant in the corner so you wouldn’t be running over people’s toes, right and you would be sitting way over there and the bar would be way over there and you know there was no way for you to get to that bar and you’d just sit there and someone would come by and you’d go, “Hi, come over here.” You are like a little kid that no one can see because every one’s talking and there all standing and they can’t see you at the party. And the person who invariably shows up is the person who wants to talk to you about disease and death, because they know you must know about this, right, look you are in a wheelchair you will know about my mother pesky diverticulitis or something like that. “You know all about cancer you know all about cancer well no. But you are in a wheelchair so you end up with the hypochondriac in the room and that’s who you get to talk to the whole evening. And you just want to hang out with people and you don’t want to be defined by your disease and you’re invariably are defined by your disease and you have to leave early you have to say “You know I have to go home I am very tired, which of course you are not, you just want to get to the bar again so you end up going home three or four hours early. And it’s true I am not making this stuff up and it’s true you have to be a little more assertive and say you know and you could say, “Maybe I could park right by the door where I could see people and not by the potted plant, that kind of thing. What you really realize and again I am sure I am talking to the choirs I am preaching to the choirs here but you know bear with me is that in America anyway people don’t discriminate against you people don’t look down upon you people don’t think that by-in-large not everyone don’t think because you are in a wheelchair you are mentally retarded, that’s not a hundred percent I’ll tell you a story in a minute, but by-in-large people think you are OK they just want to be really nice to you. And they are so nice to you that there’re really irritating. They are irritatingly nice. They are patronizingly nice, they go out of their way to be nice. You get into a car, I drive so I take my wheelchair apart and I almost never, I go to the grocery store and I get out of the wheelchair I go in and buy my groceries and I come back four people want to help me back into the car and I don’t want to be rude and say, “How do you think I got out of the car? I can do this myself I don’t really need your help. It’s a kind of confusing thing because they are just being nice but part of that being nice is they are trying to say you are special, I see you are in a wheelchair, I feel badly for you, I pity you, there’s all kinds of emotions being transferred there under that cover of niceness.

[13:09] My favorite too nice story which is in the book, but it’s my absolutely favorite story it occurred about nine months after I became paralyzed. I tried to go back to work as fast as I could because work was my salvation and I actually went back to early and I got sick and I got a pulmonary embolism, I was working about nine or ten months afterwards and I went to Las Vegas to work with a group called Penn and Teller these magicians these kind of weird magicians, very weird. So, I was writing in on a show for them and I was staying at the MGM Grand hotel. Now Las Vegas if you haven’t been there is the most friendly handicapped place on the face of the earth. It’s great, it is absolutely great. They figured out something that the rest of the world hadn’t figured out which is guess what people in wheelchairs have money too and their perfectly happy to throw it away just like the next idiot and especially if they are a little old in a wheelchair and their sick of giving money to their grandkids and they just want to go to Vegas and blow it all. Well come on in because we have slot machines down on your level, we have
black jack tables, this is absolutely true, go there they have black jack tables on your level you never have trouble they have an elevator and lift and probably a guy to push you, the whole thing is geared to old people because they really, they figured out that people in wheelchairs really like to part with their money because they want to feel normal and lose a fortune just like the next idiot, right? So it’s a great place to be paralyzed you hang out and you can do anything, anything.

[14:54] So one morning I was at the MGM Grand so I decided to wheel down the street and go to the local Starbuck’s, it’s a cool thing to do so I am wheeling down the street going to the Starbuck’s and there is a really long line at the Starbuck’s on the strip Las Vegas boulevard in Las Vegas and it was just people normally lined up for some Sunday morning Starbuck’s plus no one had told me this there was a huge rock concert then night before so there was many kind of drug addled zombie kids wandering around the streets of Las Vegas, right? Many of them hadn’t been a sleep for days and they been listening to music and their eyes are kind of big and they look like zombie’s. so they were part of the crowd and I am sitting there in a wheelchair and all of a sudden I feel some one grabs my chair and starts shoving me to the front of the line and this guy, and I didn’t know who it was, and this guys, and literally people are falling out of the way right, this guy is shoving me to the line and I don’t know what’s going on and about half way up he stops and makes this announcement, and he turns to everyone and he says: “Do you know what this guy did for us in Vietnam? He took a bullet in the back for us in Vietnam and by God I am going to buy him a cup of coffee. And everybody kind of just backed off you know and they were a little scared of him an I was scared of him and everybody was scared of him and the guy was going to buy me a cup of coffee and I realized at that moment I realized that if I let this guy buy me a cup of coffee he was going to come home and live with me. He was going to take over my life, hey man I’ll just stay in your place I don’t have a place to stay I’ll just stay with you and if people give you a hassle I’ll give them. So, I didn’t have the heart to tell him I was of the Vietnam generation and I did look like I was kind of dressed in V.A. clothing and I had all the look of someone but I had but I could break his heart and tell him I hadn’t been anywhere near Vietnam, I was actually opposed to the war in Vietnam, I didn’t want to go anywhere near it. But I realized I could let him buy me a cup of coffee. So, I had to go into my Vietnam Vet pattern: “Listen, Man, I know where you are coming from Man, I don’t let anyone buy me a coffee Man, you know what I am saying Man, he went ya sure and he wandered away. Anyway, but that’s what to kind is. When people assume thing that really aren’t true and it happens all the time.

[17:27] There is another story I like to tell, I was doing a radio show a national public radio show and a guy called in and he was in a wheelchair and he could get, he lived in Long Island and he could get bounce down the stairs to the subway get on a train and go in to Manhattan and come home and bounce back up. I can’t bounce down any stairs myself, I don’t know maybe some of you can I can’t I avoid stairs and you don’t want to go into the elevators in the New York subway let me tell you people live in those elevators, right. And any way this guy had the ability to do that, he was an amazing guy. So one day he is at the top of the stairs and you can see how these guys do this he’s kind of balancing himself an bouncing down a step at a time, he’s down two steps down with about nine steps to go and someone grabs his wheelchair and says: “Let me help you.” By the time the guy grabbed the wheelchair their both tumbling down the stairs, the wheelchair was tumbling down the stairs and they got to the bottom of the stairs and the guy was on top of the guy and the guy wasn’t hurt it was just like “I needed your help” and the guy looks at him and he says: “Boy I bet your glad I came along aren’t you.” So be careful, you temporarily ambulatory people out there don’t be so nice we don’t need you to be so nice.
Anyway during this whole process of learning how to behave I am learning how to define myself which goes back to my original comment about not thinking of myself as a victim, I realized that people were applying words to me all the time that weren’t true, that in fact were detrimental, one of them is victim, I am not a victim, I mean I was victimized by this the same way someone who lives in an Air Stream trailer in the middle of Kansas is victimized by a tornado and 12 years later they wouldn’t define their life by it. They wouldn’t say I am a lifelong victim because I got hit by that tornado. I am not a lifelong victim because I got hit by this, I really don’t like that term because it’s a term of pity or tragedy and I don’t think what happened to me is either pitiful or tragic. On the other hand, and I hate to be the one to tell you this I am not a hero. People would invariably call me a hero simply because I survived something that lots of people, tens of thousands of people from LA to Sri Lanka survive or get through every day. They think you are a hero because you are not a junkie or you are not someone who is hidden in a closet and can’t come out and it’s just an over statement it’s like words in this culture get used all time, everyone a hero, right? You go on the Doctor Phil show and you get through a whole hour and they think you are a hero. You are not a hero, a hero is a person who someone who risks his life for someone else’s life and I didn’t risk my life for anyone else’s life and the thing about calling yourself a hero is it’s a bad message that you sent to yourself because it’s kind of magical thinking you think, if you really think you are a hero you think heroic things are going to happen to you, magical thing are going to happen to you and you are setting yourself up for disappointment because it’s not that way you’re not a hero. But the third thing learned is that, this is going to be weird to say I am not paralyzed, I know I am, I am not crazy I didn’t have to much wine to drink no one tried to pour wine down my throat. I am not paralyzed in the sense that I do not define myself when I wake up in the morning is “Allen paralyzed Rucker” or “Allen TM lover Rucker,” or whatever. It’s really not part of my personal definition. Maybe this is because I got it at 51 and already had a well-developed or shaky ego at the time but the point is it’s just not I truly don’t go to sleep thinking I am paralyzed and I don’t wake up in the morning thinking I am paralyzed I wake up in the morning like most people worried about paying bills or getting something done or getting yelled at by a member of the family or something like that.

So, if you take that word out you take that definition out of your vocabulary it’s a really valuable thing to do, it’s just a mind game that you play sometimes we think that there are all these words that, in California the state government has a list of words that you are not supposed to use around the disabled. Now a real freedom thinking friends of mine think that’s ridiculous, if I want to call a guy a spaz I’ll call him a spaz, right? They don’t understand that it is kind of prim and proper it really is to call someone a victim or call them spastic or to call him impaired or crippled, I call myself crippled all the time that because I am crippled, I can do that. But those words do have meaning they do have potency and other people will take, if you say those words about yourself then other people will define you like that, part of it is just a word game.

One of the things that I really learned since I wrote the book I was still even after I wrote the book even after I went through this whole experience of first eight or nine years of this. I still didn’t want to hand out with other people disabled people, it was a little weird, you know, I didn’t want to be part of their club, I didn’t want to feel it somehow made this impression of making me feel bad about myself looking around because I know people I have this website I get letters from people who have been paralyzed been impaired for decades and still don’t want to be around other disabled people it makes them feel weird. I was kind of forced into to it I had to talk to Sandy Segal although he not impaired, well not the same kind of impairment, I got sucked into the TMA association, I got sucked into a group at the
writers guild, I belong to the Writers Guild called Writers with Disabilities and I started hanging around because of these activities kind of forced to hang around with other people with disabilities and I went through a shift I was still growing up I not only didn’t mind being around these people after a while I preferred to be around these people I liked these people these people were just like me these people had the same black humor that I did you know they could see it they could see beyond it the fact is they never looked at my chair they never thought of me as paralyzed or impaired in any way they knew where I was coming from. In fact, my very favorite line came from a woman who was part of this Writers Guild Group and she has some kind of, I don’t know a chronic rheumatoid disorder where she couldn’t walk from the very beginning of her life her joints just didn’t work so she walks kind of a crutches. I have a lot to do with the “diversity community” you all didn’t know that you belong to the “diversity community” and in places like LA there are arguing about who belongs to the “diversity community” does a neat nick a person who is to neat are they a part of the “diversity community”, someone who drives to fast in other words it’s a foggy hazy thing about where do you go so we are having one of these discussions and this girl Carol who is pretty impaired we were having a discussion one day on who’s disabled and who isn’t disabled and we were carry one and finally she raised her hand and made this kind of radical announcement she says, “A disabled person is someone who has to put their underwear on with a stick.” And we all went, “Of course that’s it that is the definition.” To her that was the definition of a disabled person. And we said so anyone who comes in are they disabled, well do they have to put their underwear on with a stick well let’s get them out of here. It’s one of the best lines I have ever heard.

I also, what happens is when I became to like to enjoy hanging out with other disabled people I realized that my disability was a window into worlds that I would have never had access before and the main window that I have been working on for the past year are returning disabled Iraq and Afghan vets. I was invited to go to, this was Dr. Kaplan and I was talking about this earlier, this is kind of a stealth war we are fighting twin stealth wars there are people out there fighting and dying and injured and a lot of us don’t see them at the mall and don’t know anybody it’s not my cousin I don’t have any in-laws etc. It’s kind of out there because it’s a volunteer army and I realized that I had a true interest in knowing these guys and also, I had a kind of entry card I could walk in the room, my wife and I went to, to spend a day at Walter Reed and we and the way it’s broken up there are three major injuries in these wars and I could go into a whole explanation of that. The main injury is traumatic brain injury it’s by far the number of greatest number of physical injuries the second one is amputation so this is all because of IED’s these bomb’s that blow up and actually there are relatively few spinal cord injuries but in there are a lot of mental problems, but anyway so we go to this we go to Walter Reed we spend a day there and I am handing my book out and my editors there and we don’t quite know and we just want to hang out with these guys. And you walk into a room and let me tell you it’s a truly memorial experience to walk into a room where you see 25 or 30 young men under twenty five years old missing one leg, two legs, a leg and an arm, two legs and having a brain injury etc. it is frightening and it is the face of war and it is the first time a saw the face of these wars and I walked in but I could communicate with them in a also most easy fashion because I was in a wheelchair all of a sudden I had a bond with people I didn’t have a bond with culture, you know most of them came from small towns barely had a high school education very young they weren’t anything like me but we had a bond and I realized that these guys had great stories to tell and they would tell jokes just like this one.
The very first guy we met when we went in he only had one leg and he said it’s pretty good you know my success with chicks has gone up like ten percent because they think in cool that I have this fake leg, plus I can go into a bar, this is the first thing out of the guys mouth, I can go into a bar and bet any one that I can put one foot on the ground and one foot on the ceiling and drink and drink a beer. And he said invariably, invariably someone says, “I don’t believe that, let’s see you do that.” So, he unscrews in one leg puts it on the ceiling and drinks a beer and says, “Give me a hundred dollars.” This is the first thing out of the guy’s mouth. It was just great you know. And now I am doing someone mentioned I am doing a piece on disabled manly Iraq vets two years after for this magazine New Mobility so I am calling these guys up every day and I am talking to them. So like Carol you know the girl with the holding your underwear on with stick, they had the same kind of humor the same kind distance they made me feel more relaxed about myself but also soldiers have something that I have learned that I have learned from these guys someone said something that I don’t think I had the more I see them the more I admire them they have a kind of stoicism they have a belief that they are more ready to except their fate and go on then the rest of us are.

For instance, the guy that’s probably going to be on the cover of the magazine is a C-3 quadriplegic with one leg missing. He got shot, I don’t know why the leg is missing, he got shot by a sniper almost everyone there is IED but this guy got shot by a sniper in the thing and he said he said, “You know I don’t feel bad about this in the next building that they went into I watched six guys get blown to bits by an IED, I watched six guys die arms and legs and heads flying off, I am lucky I am here in Denver I got my wife I can function were going to have kid I am working at this I am working that and for me this is just the “new normal”. And I love that phrase that’s actually the name of the article “The New Normal” because this guy, this is a twenty-two year old kid that should be angry with the government for sending him there and should be angry for having the bad luck for sending him there is should be angry, he barley has a high school education his future has been totally compromised and he didn’t feel that way at all and I am really impressed with that I am really impressed with these kids not in a super patriotic way but in a human way these guys are gusty, these guys are tough and I admire them and I feel like I prophet from being around them.

They have actually have a stoicism and attitude of tough mindedness as you probably know it an ancient philosophy going back a couple of thousand years just dealing with life and the principle is, I am no doctor I am no philosopher I just play one at these meetings the major principle of the stoic attitude is that all of us waist to much of our time worrying about things we have no control over. I had no control over this I spent years worrying over this until I realized I don’t have any control over this. What I do have control over is what goes on here, (he points to his head) is in our minds we have control over our thoughts and if you work at controlling your thoughts, if you don’t call yourself a victim in your private moments I am not talking about your in public I am not talking about when you are home and you are in your bed and you start to feel sorry for yourself and you think you are a victim and you stop yourself and you say, “No I am not a victim, I am carrying on here.” Those kinds of thoughts make a huge difference in your life. There is a say that one of the stoic’s Marcus Aurelius, it’s one of my favorite sayings, I love the stoic’s because they talk in aphorisms and I can actually remember the aphorisms because they are little sayings and one of his is “forget the judgment forget the I am hurt and soon you will forget the hurt itself.” It’s easy for him to say he probably didn’t have Transverse Myelitis, right? And he wasn’t talking about physical hurt he was talking about emotional hurt, if you keep defining yourself as I am hurt and you are really exacerbating the actual hurt that you feel. That’s easy to say these things
and is easy to preach this kind of stoic attitude, though mindedness. And it’s easy to talk about but it is not that easy to do. But in my own life what I found is I felt that when I wrote the book that that was it that everything I knew was in that book and as I just told you with these solders and with these other disabled people I’ve learned a lot more and I continue to learn more and I continue to change and I will leave you with one little example of that. Only a few weeks ago I woke up from a dream and realized for the first time I was in a wheelchair in a dream. For the entire 12 years I have been paralyzed I have never been in a wheelchair in a dream I have always been you know cool walking around you know you are making this stuff up why would you want to be in a wheelchair? Right? You want to be dancing like Baryshnikov you want to be whole. But I realized I had this very weird dream where, every weird dream where they had built, the Canadians will like this they built a hiking path an accessible hiking path across Canada from Vancouver to Nova Scotia and I for some reason wanted to go on a hike across that hiking path, my wife stayed at home she didn’t want to go for obvious reasons to here I am I am hiking across Canada and I am rolling in my wheelchair and some of the times someone is helping me up a hill and some of the times I am some old guys on my lap and I am helping him you know and it’s just what it is and I realize that was a real break though, that I now except the fact at least in my dream life that being in a wheelchair is normal and is just as normal as someone who is not in a wheelchair or to use the guys term which I will continue to use it is for me the new normal. That’s it.