



Hi, it's Larry and you're listening to *Disability Nation*, an audio magazine by and for people with disabilities.

As always, welcome to the show and I hope things are going great for you and that life is treating you well.

If you were presented with the opportunity to have your disability cured, or at least some of the effects of it alleviated, would you do it? That was the question posed to my guest this week on *Disability Nation*. His name is Michael May and we'll talk with him about a procedure that he had done that restored some of his vision and his experience since then. It's a pretty interesting discussion, so we'll get to that shortly.

Also on the show this week we'll have some coverage of a hearing that took place recently in the House of Representatives with the House Subcommittee on Telecommunications and the Internet.

If you wish to contact *Disability Nation*, you can reach me in a couple of ways. You can go to the website; it's www.disabilitynation.net. You can send e-mail to contact@disabilitynation.net. Or you can phone (480) 302-9300; that's the *Disability Nation* phone portal provided by PhonePortals.com. Again, (480) 302-9300. By calling that number you can leave voice mail and listen to episodes of the show.

Thanks again for listening and I hope you enjoy the show.

Larry Wanger: Well, my guest this week on *Disability Nation* is Michael May. Mike is the President of Sendero Group, which is a company that produces GPS products that work with other technology for blind and visually impaired people. About two, three months ago I read an article in the newspaper that talked about Mike and a procedure that he had which restored some of his eyesight, and it mentioned a book called *Crashing Through*. So I took the time to read that, found it very interesting, and thought I'd try to talk with Mike about his experience and about the book. So I'm pleased to welcome Michael May to the show.

Mike, to get started why don't you take just a couple seconds for folks who don't know you to just introduce yourself a little bit and

talk about who you are, what you do professionally, and whatever else you care to share with us.

Michael May: Sure. I'm Mike May. I'm President and CEO of Sendero Group which makes GPS software and systems for the blind and visually impaired, and we distribute several other products as well.

I was blinded at age 3 from a chemical explosion and was totally blind until age 46 at which time I had a rather unexpected opportunity to have some low vision and have a stem cell and cornea transplant which resulted in some vision. So I've had a whole new pioneering experience learning to deal with vision, which fits right in with my lifestyle, my career, which has been to be involved in startup companies and learning how to do new sports and that sort of thing.

Larry Wanger: Many listeners will be familiar with the book *Crashing Through*, but for those who aren't can you take just a couple of minutes to kind of give an overview or a summary of the book and what it's about?

Michael May: *Crashing Through* is by Robert Kurson. It is not a biography; it is really a -- he would call it a profile, I suppose. He did another book called *Shadow Divers* about a German U-boat discovered off the coast of New Jersey and the quest of these two divers to discover its origins and its history; another true story.

And so he interviewed me over the course of almost three years in a very, very meticulous manner and got every little detail of my life. And then, being a storyteller, he wove that together in a fashion that he thought would be interesting and compelling to his readers. So he considers it more of an adventure story and not really any kind of a biography, or for that matter even a profile. He wanted it to be, as it says in the -- *Crashing Through: A Story of Risk, Adventure, and the Man who Dared to See*.

Larry Wanger: And the name of the book, *Crashing Through*, is kind of a deliberate name and it's talked about a bit in the book. Can you say a bit about that?

Michael May: Well, *Crashing Through* was not my favorite title, nor Robert's for that matter; but Random House picked it and it's grown on me over time. Some of these things are just chosen for marketing reasons. It's one component of the way that I operate which is sometimes you just have to bulldoze ahead and plow through things in order to make it happen.

But I think of my way of operating as being more of what is also talked about in the book is there is always a way. And so when you come up against a wall, you could crash through it but you could also climb over it or go around it or use some ingenuity to figure out what is the best way to circumvent this obstacle? So the book's really about adventures and obstacles in the way that I have gone about in my life of dealing with those different things.

Larry Wanger: And obviously a major focus of the book -- not the only focus, but a major focus of it -- is the actual procedure that you had, what you call in the book "new vision." And can you explain a bit -- I know you mentioned it earlier, but can you explain a bit about the procedure that you had and what it involved?

Michael May: The procedure I had was to replace the scar tissue that was covering my eye that was blinding me with new tissue. So it was a two-step operation. First, they took stem cell tissue from a donor eye and replaced the scar tissue on my eye with this fresh tissue. They let it grow in over the course of three or four months. And when that was healthy, then they could do a cornea transplant, which of course is a much more standard operation. But the cornea would not be successful and be implanted in my eye if there wasn't good tissue on the surface for it to implant into. And that two-step procedure then resulted in some low vision.

The doctors set the expectation very low. They didn't know if I'd get vision; if so, how much, how long would it last? And there was many, many questions that gave me a lot of pause when I was considering whether I should even have the operation or not.

There was also considerations of increased risk of cancer because of the immune suppressant drugs and all of the hassle and expense that goes along with dealing with the medical components of having an eye operation like this.

And then there was all the psychological issues of I've spent my life learning that I didn't need to have sight in order to do things and be successful and have a rich life, and all of a sudden I'm going back on that philosophy. How does that impact me psychologically? What's the blind community and other disabled people going to think about me turning against our inner community?

Larry Wanger: You've kind of just alluded to my next question here. You wrestled with a lot of issues -- and it's a major focus of the book -- before agreeing to proceed with this and can you talk a little bit more about the decision making process and -- I mean, that's a real interesting part of the book. How did you weigh out the pros and

cons and decide to go ahead with this, given what you knew about the side effects and risks and yet the possibilities?

Michael May: Well, you have this funny dichotomy because at first glance one would say a blind person is offered to have vision and this is Biblical -- Biblical proportions. And everybody would say, "Of course. Why wouldn't a blind person want to have vision if they were presented with the opportunity?"

But on the other hand, you look at those documented cases of vision restoration after long-term blindness over the last hundreds of years. And there's only been 20 cases of documented -- not that it hasn't happened more than that, but only 20 documented cases -- and you find out that it wasn't easy. People were very depressed because they didn't get as much vision as they thought. People committed suicide, all sorts of horrible things. And there were very few success stories, if any, out of those 20 cases.

And so you've got to look at history and a track record like that and say, "Well, why would I be different?" And that's what I had to explore and talk to my friends about. And there's not really any therapists or anybody you can discuss this with; it's more a matter of using common sense and looking within oneself to figure out what is my life make-up like compared to these other folks that didn't have successes?

Larry Wanger: One of the most interesting parts of the book for me was not necessarily the procedure and how all that went necessarily, but was more the discussion about seeing and how sighted people see versus -- someone with good vision or perfect vision would see versus what you're seeing, and the discussion about what the eye sees and how the brain processes it and that kind of thing. Kind of describe, if you could, what you see and how you see, because there's definitely -- it sounded like some real differences and something's happening there.

Michael May: Well, this was an incredible education that I got because I never thought of vision as anything more than perfect vision, low vision, and no vision. It was just almost black and white. And as I discovered, that is not at all true.

First of all, vision -- we often use the word and people come up to a blind person and they'll say, "Did you see that movie? Oh, I'm so sorry. I didn't mean to use the word 'see.'" But really the word "see" is most appropriate because when you see a movie you're seeing it with a number of senses. It's more figurative than it is literal. You may not have seen the movie, but you heard it. You were there with

other people; you have a sense of it. And so it's really this sense of the world as opposed to actually what you perceive with your eyeballs that composes this concept of seeing. And a number of vision scientists, Dr. Richard Gregory in England the most notable, have talked about this concept of this holistic approach to seeing. That's one thing that I had to figure out as I went forward.

As it turns out, when a sighted person -- when somebody has full vision and they perceive an object, let's say you see a person out of the corner of your eye. Your picture of that person is the whole person, if you recognize them, because you've seen them before and you have, let's say, an image in your database. And that image is triggered by the little clue that you got out of the corner of your eye of that person. So you think that you're seeing the whole person. You see their face, their body, their shape, everything. But in fact, all you really saw was their profile, part of them. So these clues are really used as triggers for the whole database.

Well, what does that mean to somebody who is acquiring vision and hasn't had it for 43 years? That means that I have to build up my database of people and stuff. I had no database. It was just a tactile and other sensory database but not a visual database. And when you start breaking the world into one image at a time, there's just trillions of images and it's quite an overwhelming task to develop this database in order to see.

So, for example, when I see an object in front of me I have to sit there and analyze it and figure it out and really cogitate. What is this? Is it a motorcycle or is it a person? And when I first got vision I had no database and that was much harder to figure out than it is now, eight years later, when I've seen just a portion of these trillions of images, but at least more than I had when I started. So now I'm starting to operate more like a normal seeing person would in the respect that I see a clue, it triggers an image because I've seen the thing before, and that helps me visualize the object much more easily and quicker than I used to. In the beginning it might have taken me, let's say, 10 seconds to perceive motorcycle or person; and now that same process might take me a second or two.

Larry Wanger: And so you're eight years out from the procedure. Has your vision remained pretty much the same? And I guess the follow-up question with that is, because of all the drugs that you had to take to prevent rejection of the cornea and the cells and that kind of thing, has your health still been good?

Michael May: My visual acuity is about the same as when I started out. It hasn't gotten any better; it hasn't gotten any worse. But I see much better

and that's because of the reasons that I just explained. My visual library is building up, my database is building up; that's one thing. And then the other thing is that I'm also integrating the information better than I used to.

So at the beginning I used to be able to look at something and I would just see it, but I wasn't really listening or thinking about it in another fashion. And now what I do is I figure out what's better for me in this situation? Vision, audio, a combination of both? And so that integration factor is something that I really didn't start utilizing effectively until probably a year after the initial operation and then it happened more and more over time.

So three or four years out, I was seeing better because I would shut the vision off when I didn't need it, de-tune it if it was interfering, or use it exclusively if it was the only thing that I could use. Let's say I'm looking out a window and I see something that goes by and I can't hear it. It's in a hotel room and I can't open the window and listen, but I can see it. I need to figure out, is that a bird? Is it a plane? Is it -- whatever.

Larry Wanger: As you look back to before you had the procedure -- and I know you talk a lot about some of the issues that you considered and thought process, but probably you had some hopes and maybe some expectations perhaps for the future. How does that look when you look back at it? I mean, is this kind of everything you thought it would be? Has it kind of really through a curve for you? What do you think there?

Michael May: Well, the reason I decided to go ahead with this was because by definition Mike May is a pioneer. I've always had a lot of curiosity and had to fulfill that curiosity and I decided when I looked at all the different medical reasons for not having it, etc., that those things were outweighed by my curiosity and by the fact that I had to be who I am. And therefore, eight years out I say, "Yeah, I'm glad I did this." It's been fascinating. I would have kicked myself indefinitely if I hadn't checked it out, no matter the ramifications.

I could still lose some vision. I could still have some cancerous issues. I have had one basal cell carcinoma. Did that come from too much sun as a kid or did it come from the immune suppressant drugs? Who knows? It doesn't really matter. But I did the right thing so that I can continue to be who I am and have an interesting life.

Larry Wanger: Technology and medical research and those kinds of things have and will continue to bring about opportunities for people with

disabilities in this area. And this may be a difficult question, but I wonder what advise or thought process would you suggest to someone who -- be it this type of procedure or something else -- but what thought process would you suggest to a person who's thinking about a procedure that might reduce the impact of their disability or give them greater independence that they don't have now?

Michael May: Well, I think people should make sure they're moving on two tracks and not on one. So when somebody's newly disabled, they're obviously thinking about the medical issues and not thinking about the coping issues and "how do I work around this?" And "how do I get the tools and techniques and technology to deal with this disability?"

My recommendation is do everything you can to learn the adaptive tools and techniques because even if you have some medical procedure that helps, it's probably not going to reverse your issue 100 percent. Now, that's not always the case, but certainly when it comes to blindness or long-term blindness, as I have experienced, once you have vision it's only a certain amount of vision. It's not allowing me to read a book or drive a car. The lights don't just come on 100 percent.

Therefore, the fact that I have alternative tools and techniques means that I can use the vision that I got for my benefit. It helps in certain convenience ways and it helps in certain entertainment ways. But if I had to depend -- if I waited around for this operation and had no real reading and computer skills, I would really be probably one of those 20 people that were depressed and had an awful time with the experience because the vision that I got would not be good enough to read or to drive. And in fact, I have alternative techniques for doing those things, for getting around and for reading; I don't really need the vision for it.

I think the same thing is going to apply for people in most situations where a medical solution comes about. They just don't want to focus 100 percent of their energy on that. Maybe focus five percent of it. Keep aware of what's out there, what medical advancements are happening, but don't be preoccupied with it.

For links and more information about topics featured on today's show, to get a transcript, or to download any other episode, be sure to visit the Disability Nation website at www.disabilitynation.net.

On Thursday, May 1st, a hearing concerning draft legislation entitled the "Twenty-First Century Communications and Video Accessibility Act" was held before the House

Committee on Telecommunications and the Internet. This proposed legislation will greatly enhance accessibility for deaf and hard of hearing folks, and people with other disabilities, to various forms of technology including the television, Internet, and others. I wanted to share with you some testimony shared at the hearing by Sergeant Major Jesse Acosta who is blind and represented the American Council of the Blind. His testimony is pretty powerful and helps to really illustrate to Congress and to others why changes in technology and accessibility requirements are needed. I provided links and other information at the *Disability Nation* website so you can learn more about this proposed legislation and those who support it.

Edward Markey: A final witness is Sergeant Major Jesse Acosta who has served in the United States Army since 1976. Sergeant Major is not in uniform today because he is not here in his official capacity, nor is he testifying on behalf of the United States Armed Services. If he were in uniform, among the many accommodations he has earned you would see the Purple Heart, the Bronze Star, the Meritorious Service medal. Sergeant Major Acosta has served in Iraq since 2006 where he was injured in a mortar attack. His most severe injury was the loss of his right eye and the loss of vision in his left eye. Sergeant Major Acosta, you represent brave men and women from across the country who have returned from Iraq with disabilities. We appreciate your service and we look forward to your testimony.

Jesse Acosta: Good morning Chairman Markey, ranking member Stearns, and members of the subcommittee. My name is Jesse Acosta. I'm a Sergeant Major in the United States Army and I'm currently still active at this point in time.

As you heard, I came back from the war in Iraq completely blind and I'm here to testify on my experiences on the outside and to represent American Council of the Blind. Let me start with this.

Prior to being shipped over seas I was a user of the Sprint wireless system cell phone. I wanted to continue to use the same provider when I came home with my injuries and as I went to a Sprint store and asked, "What do you have for me that would be blind-friendly?" so I can use and navigate that was accessible to me; a young lady came to me with a cell phone and said, "Sir, right here on the number 5 key you'll find a little nub on it. You will be able to navigate. Above the five is a 2. On the right is a 6. On the left is a 4. On the bottom is the 8."

I stood there quietly. "So what about the rest?" Well, it wasn't user-friendly to me. The accessibility wasn't there.

And by this, what I'm saying is that here in the United States, the richest nation in the world, we have the technology to give us

accessibility; whether it be for satellite receivers, cable receivers, and televisions. Just by pressing a button on a remote control will give us that accessibility as far as a screen reader. Do we have that? No.

I own a 1984 Chrysler LeBaron. You can sit behind the wheel on that vehicle, install or place the key in the ignition, and if you do nothing it will tell you, "Keys left in ignition." Once you start the vehicle, as the vehicle is warming up, if the fluids are low it will tell you so. If the system is not charging, it will tell you so. This vehicle is a 1984, almost 30 years old, and it just has a little chip that will describe what's wrong for the vehicle. I believe it was user-friendly to the females. I have no idea, but still, how can a vehicle talk to me and still we have components on the outside -- as I mentioned -- that cannot describe what's happening to us?

My favorite programs -- *CSI: Miami*, *CSI: New York*, and also *CSI: Las Vegas*. Of the three, only one has descriptive audio in it; that's *CSI: Las Vegas*. So what about the other two? I'm stuck on one? No, it's not acceptable.

You know, I love watching these programs, but when there's something of essence in the program that's not being described, I have to sit quietly and wait and see what is going to be said, or yell for my family members or my wife, Connie, "What are they displaying on TV?" It's vital to the movie. But what if it was something -- a scroll going by?

I live in California. Over there we shake, rattle, and roll. We also have mudslides. But if it was a screen going on the TV set, "Brace yourself. We're going to have an after-effect. We just had a 6.0 in central California." Am I going to be able to read that? No. What if my family members are out shopping; there's nobody there? I won't know a thing. It's very important.

What brings back to memory also is my child, Brittany. I remember we used to buy her electronic books. It was a standard book, but to the left side of that book you can press a button and it would read you page by page as it went on. It would read to you and describe what was going on. Simple little things like that. A book that cost \$1.50 and we can't implement this law of accessibility? It's not acceptable.

I urge you members -- Chairman Markey, Ranking Member Stearns -- pass this law. Make it a law. Let's not wait for it to happen. Let's not leave it to the market. And with that, that concludes my testimony.

Major Acosta was then asked by one of the representatives on the panel at the hearing about his experience when disaster strikes and what he observes or the information he's able to get from television and other sources.

Jesse Acosta: With these laws that have been passed, it's done tremendous for some of us who are disabled, although I've been educated for the past two years. For my first 48 years, I was blind; and now that I have lost my sight, guess what? I see 20/20, clearly what's going on around our nation here when we -- I say "we" -- the blind community has been left out.

To answer your question as to what happens in case of a disaster, that's my answer ma'am. There's nothing I can see on TV or get to a button to tell me what is going on.

Congress member: Well, let me anticipate how you're feeling when we heard how bad the fire season is going to be this year in Southern California from the heavy --

Jesse Acosta: It could be bad, ma'am.

Congress member: It must make you a little edgy to anticipate how you're going to behave when the evacuation plan is scrolled across the television and everybody is dashing around getting ready to evacuate and you're kind of confused.

Jesse Acosta: Yes, ma'am. Well, I stand a better chance swimming out in the ocean and people yelling "there's a shark" than to get the information from the TV or the radio. So, ma'am --

Congress member: You really drive it home.

Jesse Acosta: -- it's going to be tough.

Congress member: It's going to be tough.

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