

Episode 17 - The Importance of Sharing Your Story with Rob Roozeboom

Mike Hoenig:

Well, Hey, everybody, this is Mike Hoenig with the University of Iowa Center for Disabilities and Development, welcoming you to another episode of Disability Exchange. Disability Exchange is a podcast dedicated to elevating and centering the voices of people with disabilities and their families by giving them the opportunity to share their own stories. We are supported through funds from the University of Iowa Center for Excellence in Developmental Disabilities, and we have a great partnership with the Midwest[ern] Public Health Training Center, which is a part of the University of Iowa College of Public Health. We are very excited about our guest that's going to be joining us for the podcast today, but before we introduce him, I'd like to turn things over to my illustrious co-host, Judy. Judy, go ahead and introduce yourself.

Judy Warth:

I am Judy Warth, I'm here at the university's Center for Excellence in Developmental Disabilities as well. I am very excited about our guests today because I have the good fortune of being able to sit on Iowa Governor's Developmental Disability Planning Council with Rob. And the perspectives and the stories that he brings, his intelligence and business savvy are just wonderful to have as we are talking about issues of disability. Rob, we'd like to welcome you. Rob Roozeboom, Roozeboom-

Rob Roozeboom:

Roozeboom.

Mike Hoenig:

Roozeboom.

Judy Warth:

... Roozeboom from Sheldon, Iowa is here to join us today. Rob, you want to tell us a little bit about yourself?

Rob Roozeboom:

Sure. Yeah. Rob Roozeboom, actually, Iowan native. I was born in Des Moines. I was raised on a farm until I was nine years old in Pella, Iowa. Then my dad changed careers when he was about I think 35, 36. Left the farm, became a pastor, a minister, went to seminary, had a couple churches. And so at nine years old, I stopped being a farm kid and started being a city kid, which was a whole different ball game. And we left Iowa, spent time in Michigan, where my dad went to school. First church was in Minnesota, then moved back to Iowa halfway through my junior year with my parents. Then when I graduated, I

went on to Phoenix, Arizona. By the time I got back a year and a half later, my parents left and went to Knoxville, Iowa on a new church start.

And so I've spent time in different states, but the disability and why disability is so close to my heart is there's three in our family. And when I was that kid growing up a farm, I really didn't realize I was different, but I have an older sister and a younger brother. My older sister walked on her toes, and actually, the University of Iowa is the place we went. They were concerned on why she walked on her toes. Went to the University of Iowa to get checked out and found out that my sister was diagnosed with a disease called muscular dystrophy. At that time they were looking at a form called Becker.

It was years later that we learned it's actually limb girdle. And so my sister had it, which means my brother and I now need to be tested. I was tested, also diagnosed with limb girdle, muscular dystrophy. And then my brother, no. No symptoms, no anything. He grew up with two siblings quote unquote having a disability where he did not. And so that's kind of the background of our story. Started as a farm kid, became a city kid. Really didn't notice a whole lot of a difference until about sixth grade. That's when I started realizing, "Okay, things are different for me."

Mike Hoenig:

That's quite a story. Well, I'm a little bit of a kindred spirit here. I went to a college in Pella at Central. So, I got to have that experience being in that rural, I'm pretty familiar with it. And so refresh us on the timeline a little bit. Your dad had a career change and you moved to Michigan. How old were you then?

Rob Roozeboom:

I was nine when he left the farm. And when he graduated from seminary, I was now 12, and so left Michigan, moved to Minnesota.

Mike Hoenig:

So your muscular dystrophy diagnosis was going on and your sister's kind of right in the middle of all this moving. Did that create a lot of stress? Were you the type of person and family that just kind of rolled with it? I mean, I guess you probably don't exactly roll with it because it is life changing, but talk to us a little bit about how that impacted you and your family as you were going through so many other changes as well?

Rob Roozeboom:

Yeah, absolutely. So, when I left the farm at nine, this sounds crazy, when I left the farm, I'm a kid, what do I know? But that's all I knew. I would wake up every morning, look out the window and see what my dad was wearing. And I dressed exactly the same. It was everything I loved, everything I knew. I had so much fun being out there where we were harvesting crops or we were working with animals, just loved it. So at nine, when he sat us down, I learned something. I learned that the things that I love get taken,

because that's what I knew and that wasn't going to be there anymore. So the stress of moving, is there a little bit of excitement in moving? Yeah, there is, but there's also this scariness of everything I've ever known as a child, a nine-year-old child is now gone.

I can vividly remember seeing the moving truck show up and people loading. And now as a nine-year-old kid, it feels like you're moving forever away. Michigan's a journey from Iowa. And all of a sudden from being out on the farm and being with your dad every day, he's in school, you're in a city, the culture is different, the school is different. And all of a sudden ... You've been told, because you were diagnosed at five with this disease called muscular dystrophy, but you don't understand it. You don't understand really what the diagnosis is all about or what it's going to do to you. And so not only are you a different kid in a different city, you've never actually lived in a city before, but you end up in a different culture because where we went to school, what was different?

I mean, we had many, many multiple ethnic backgrounds, which was a great learning experience, but it was different from what I was used to and what I grew up with. And then you grow up ... This is during the Michael Jordan era. And I always grew up with the belief that you can be cut and still become the greatest, you can be cut from your basketball team, but the harder you work, the harder you try, the better you become. What I didn't understand was I can't beat this disease on my own and I also didn't know that it would progress the way that it would. So, all of a sudden, you're a kid in a new school running PE classes and you're like, "Why should we be able to beat that kid? Why didn't I run faster than that kid?"

And so you have your own internalization of what's happening that I didn't even see it so much in my sister. I was so busy focused on me, which is extremely selfish, but trying to fit in, trying to make friends, trying to be the kid that's not noticed because he's different. And so not only is that happening, but my dad's going to school. I mean, to be honest, it wasn't the nicest neighborhood we lived in. It's the first time I've ever got jumped and mugged. I mean, I'm only a 10 year old kid and I'm experiencing all of this. And so you're processing all of that. And then it was a couple years later, I asked my mom, "How did they deal with it?" That was the question. How do we process this change? And my parents, I used to get frustrated and I asked them, "Why do we never talk about it as a family?"

We didn't talk about it. We didn't talk about muscular dystrophy, we didn't really talk about being different. And I said, "Why do we never talk about it?" And my parents are baby boomers. They grew up in the era of this. They said, "If we didn't talk about it didn't exist." And I said, "That's a load of crap." I said, "I had to deal with it day in, day out. Just because we swept it under the rug, doesn't mean there's no dust underneath the rug." So when you have this mentality of, if we don't talk about it, doesn't exist, you as a child have to figure out, how do I process this? How do I deal with this? Because this is a reality.

I've heard doctors say that it's going to go this way or that way. But I don't believe them, but yet, why am I not measuring up to everybody else? So, you asked me about the stress level. My stress was through the roof, left what I loved, what I knew, what I was comfortable with, I'm in a new school with new individuals and I'm not measuring up to the rest of them. And it was a rough neighborhood. So three years of, "Well, this is interesting, good call dad. Way to change careers." So I would say for me personally, it was extremely stressful.

Judy Warth:

Yeah. That sounds like it. In the event, we have a listener who perhaps doesn't understand what muscular dystrophy is, would you mind giving them the cliff notes version?

Rob Roozeboom:

Sure, absolutely. So, muscular dystrophy really ... I hate to use the word became famous, but it's what Jerry Lewis, for 50 years, it was called the Jerry Lewis National Day Telethon or whatever. My wife and I have actually been on it in 2001, 2002, met Jerry Lewis. So why did they host this? Because individuals diagnosed with muscular dystrophy, and there are 43 different type or umbrellas. ALS, which is Luke Garrett's Disease, falls under muscular dystrophy even though it's not necessarily muscular dystrophy. So you can have respiratory issues and obviously muscular dystrophy means muscles. They atrophy, they go away, so they progress. It's a progressive. Currently, my form is incurable. There's not a pill out there, there's not a regimen, there's not a treatment that you can take. So, as you get older, I'll use limb girdle, as an example, it's very similar to the way it sounds.

It's your girdle area and your limbs, so you lose your shoulder muscle, you lose your biceps, you lose your thighs, you lose your core to where maybe you could walk as a child, you could run as a child, you could play sports as a child, and as you grow up, it affects everybody differently. They told me, "Rob, you will be in a wheelchair full time at 30 years old." But I didn't believe them at nine, 10, 11, 12 years old. I didn't even believe them when I was 30, because I still wasn't in a wheelchair full time. You see me today at 45, I'm still not in it full, full time. But the reality's there, this progressive wasting diseases, my shoulders are not what they were, my back is not, my thighs aren't. Your muscles just deteriorate over time, and that's what muscular dystrophy is like. And if you have a respiratory, say SMA or something, it can kill you. Our form should not shorten our life expectancy, but there are forms that definitely bring in a challenge.

Mike Hoenig:

Boy, there's so many places we could go from there, but I'm going to throw you one that you may not be expecting. For your listeners out there, before I came to work at the UCEDD, at the Center for Disabilities and Development, I worked for Center for Independent Living, which is a nonprofit advocacy organization, and that was actually quite a number of years ago now, back in the early '90s. But right about that time, there was a group that had come together, and actually, I don't know when it started, but it was called Jerry's Orphans, and they were people who felt like that.

And some of them ... most of them actually, had been on the Jerry Lewis telethon and ended up feeling like, "Well," he was really trying to almost put a charity model out there and they were out to show what their capabilities were and that this was demeaning in some way. I'm curious if you ever have heard of that group and what your thoughts were. I mean, it sounds like you were on the show as well, on the telethon. What are your thoughts on that?

Rob Roozeboom:

That's a great question, because you often wonder, when you show somebody's story, you really don't want to demean them, but at the same time you want to give individuals the reality of the situation. My initial thought, I have not heard of Jerry's Orphan's, I've heard of Jerry's Kids, and obviously I became one of those as an adult. What was my first take? The Muscular Dystrophy Association. Until I met the president and vice president and Jerry Lewis, I thought to myself, "Why do we raise all this money? Over a billion dollars has been given and we still don't have a cure. Where's this going? I mean, what are we doing with all these resources?"

Now, I get the opportunity to fly to LA, meet them personally and share our story. It was the most humbling, unique, amazing experience I've ever had. And because of the way I was treated and the way that I saw them work, really to find a cure for muscular dystrophy and the way they treat individuals that fight a muscular dystrophy or just have adversity in their life is some of the reasons why we do what we do today through our organization, through a major live event and how we try to take care of people.

I learned meeting them that I never had to question where those dollars were going. When I sat down with the president vice president at the Muscular Dystrophy Association and I heard Jerry talk, I never questioned again how deeply they wanted to find a cure, how deeply they cared, how deeply they were motivated to eradicate muscular dystrophy, to not have parents lose children anymore at early ages, to not have individuals fight this horrible debilitating disease. So to me, it wasn't demoralizing or charity, I hate the word charity, but at the same time to get people involved, you do have to pull on some heartstrings. You've got to people how real this is. This is our reality? Are there things we can do? Sure, there's things we can do. But there's also things we need help with. And if this is a way that we can get there faster, let's go. I still dream of the day of a cure.

Judy Warth:

I'm going to drag you down just a second longer, and then I'm going to let you shine. Because as I've been reading your bio, I mean, you have taken your life and made it magical in many, many ways, but this road has not been easy. I remember reading about some issues with depression, substance abuse, many of the things that are caused by our lives, and I would imagine, imagine enhanced by a disability that just isn't fair. Do you mind sharing a little bit about that with us?

Rob Roozeboom:

Yeah. When I told you my dad left farming, he became a pastor. So you're going to get a little bit of my faith here. Obviously, if you grow up the pastor's kid, there's two ways, you can either embrace it or you can run away from it. I ran away from it for a long time, Judy, because of kind of what you said, you used a word in that statement that I don't wrestle with as much today, but fairness. Life's not fair. I try to teach my kids that. Figure out life is not fair, and you can get to being happy a lot quicker. It's not level.

The playing field is not level, it never will be level, and there are just certain things that are never going to be fair. No matter how hard we try, we make mistakes, we call it imperfect people.

And so you can't always level a playing for field. And I became very angry about that. And then I was also taught that I was created and that there was a God that loved me. That did not sit very well with me, because I was like, "Are you kidding me? Is this for my punishment? Did I do something wrong? Is this for his enjoyment or entertainment to watch me suffer and get angry and then to have a younger brother not have it." And all of a sudden you love farming and you become a town kid. And again, I grew up in the Michael Jordan era, which is sports is king. I mean, I grew up in the high school days of if you don't play sports, you're nothing, you're nobody, you don't exist. And so to watch my brother rise, he became a starting football player, that was my dream after farming.

It was to be the high school inside linebacker, starting football. I'd run a tunnel, it's Friday night, I'd put the helmet on and run through the tunnel and all the cheerleaders are going, "Rob! Rob! Rob!" as I run by. And I was like, "This is it." Now my brother got that. My brother got to start basketball. That was my other dream. I'd come running on a court, pretend I could dunk it, even though I'm 5'8". And then it was one thing after the other. And I watched him play and I watched him set some records, whether it was the assist record or it was this. Then I watched him leave football to run across country, which back then I didn't even think it was a sport. That was extremely hard. I'm like serious, "You blessed this kid and he's leaving football to run. Just run."

My son now runs cross country. He was a four time state qualifier, and I absolutely love cross country. But back then I was like, "Dude, you're an idiot, man. Play football. That's all that matters." So I grew up with this constant just anger, just absolute anger. And I told you a little bit about the faith part. When I was taught I was created, I had to wrestle with this. I've never asked to be here, I never asked to be made to be put on earth. None of that. I never asked to be here, and yet I'm here and I got to deal with this. That has been extremely challenging for me to walk through and to accept and to understand. And so when you add that to watching your brother do almost everything you want to do to not talking about it, oh yeah, it was painful. It was extremely painful.

And that's where I lost sports as a 15 year old kid. I played basketball, football, baseball. Now I was never a starter. I pitched one time in sixth grade because I thought I was a real rockstar. The only strike I got is the kid ducked because the ball was coming at his head and it hit the bat. But my brother was an amazing pitcher and here I am trying to pitch. So I played sports all the way through my freshman year. I collapsed twice in football, my legs gave out. Collapsed twice in basketball, my legs gave out. And then in baseball, I was up the bat and a kid that went to our church who threw like a crazy man, hit me in the leg. I had the seams marked into my shin.

Mike Hoenig:

Oh my!

Rob Roozeboom:

That's why I got hit. And not because I got hurt, but that was the end of it. After baseball season, I have never played organized sports again. So when I started this, I said, "I learned that the things I love get

taken from me. First, it was the farm, now it's sports." And so I'm being raised in a Christian home with my dad preaching and sharing, and I am so confused because I'm like, "Why are the things that I love being taken from me? I don't understand this." That put me on a course of, I don't care, I don't give a fly and flip about anything. You can't kick me out of sports because I can't play anymore. So I really started to have this rebellious anger that got me in trouble, because you couldn't take anything away from me anymore.

It seemed like everything was taken. So if I didn't want to go to class, I didn't go to class. If I wanted to party, I party. And then it goes back to being a teenager, because most of this I'm walking through as a teenager. I just want to fit in. So, if kids are asking me in a hallway, "Why do you walk that way? Why did your brother play sports and you don't play? Why did he set the assist record?" I'll do whatever it to fit in. I wasn't strong enough as an individual to be like, "This is who I am, accept me or don't accept me." No, I was a crowd follower. I just wanted to be accepted and loved.

When I found it through abusive behavior, that's how I did it. And other times it wasn't just because of the abuse of behavior, it was because I was angry. And so I rebelled and I did things that I knew I shouldn't do. And so that's who I am when you ... I mean, I'll be as Frank as I can be with you, the first time I ever attempted suicide, I was in eighth grade. I just didn't want to be here anymore. I was done. I was so angry. I hurt so bad inside that I used to punch walls at night just to let the anger come out. It was a depressing dark time back then. It was tough. It was really tough.

Judy Warth:

I really appreciate you sharing that, Rob, because so many people don't factor in all of the mental health things that come into play with each consecutive loss, the loss that we experience just as human beings. But then you factor in the issues of your disability. But as I said, I was going to turn the corner with you because something changed, something changed. When was that magic moment?

Rob Roozeboom:

So again, I can't shy away from faith because it's all part of the journey.

Mike Hoenig:

Sure.

Rob Roozeboom:

But it was when my wife came into my life. So I met this beautiful girl in high school. I'll never forget it. I remember her walking into the library one day in these Daisy Duke shorts, and I'm like, "Yeah, that's the one. Right there, that's the one." I love her personality's kind of bubbly. She had blonde hair back then. I always had a thing for blondes. Now we've been married 24 years and she dyes her hair or whatever, it's a little darker now. I'm like, "When I married you are blonde. What happened? Come on." But yeah, we

did not date in high school. It wasn't until I was living in Phoenix. And again, I was on a soul-searching journey. I was trying to figure out why I was put on this earth.

And so I had a lot of conversations with the big man upstairs, call him God, we had lots of conversations. I'm a faith guy and the Bible has been a part of our life for a long time. And I used to think, "In the Old Testament people got burning bushes and stuff, why can't I get something like that? A big neon sign. This why you're hear." So when I was in Arizona, I used to look up in the sky and see where the jets crossed paths and it made an X and I figured, "Hey, X marks the spot. This is where I'm supposed to be. I'm supposed to be in Phoenix." Well, God has found a way of showing me differently, and this girl that I always wanted back in high school, we ended up crossing paths.

Again, it was out of a tough time, I was in Arizona. I kind of left out rebellion because I was worried if I didn't leave, I'd be in jail or I'd be dead because I was still rebelling pretty rough back then. And I went to Phoenix. I had to come back because somebody very close to my parents died and I decided, "You know what? It's time to start rebuilding a relationship with my parents before it's too late." So to speak, so I came back. It was actually a faith weekend and Sharla the girl I always wanted date was there and ended up driving to ... a long story. I won't go into it, but anyway, our paths crossed, that's a whole nother story. It's crazy. It's a miraculous story. Because we hadn't talked in a year. I lived 1,300 miles away.

I was dating another girl at the time that I flew back to Iowa with from Arizona, and I end up going back to the airport with my parents driving Sharla, the girl I always wanted to date on one side and the girl I am dating on the other side, and it was crazy. Needless to say, Sharla was going to Haiti on a mission trip. I called her shortly after she had gotten back, I was in Arizona, she was in Iowa. And I decided, "You know what? I'm 1,300 miles away, I'm going to tell you how I feel, because if you say no, I'll stay in Arizona. It's 1,300 miles away. I probably won't run into you." Well, four hours into my courage on that phone call, I said, "Hey, this is how I feel." And she goes, "Me too." I said, "Great. I'll see you in a month."

I moved home, that was in March, we were engaged in June, we were married in November and that changed my world. My wife has taught me what love looks like. We call it servant love, no strings attached. When I married her, I got obviously an extended family. She's got two 11 year old sisters, they are twin, they're the mouthiest women you'll ever meet. In a good way, in a good way. And then she has her older brother. The first time I met the twins, one of them looked at me and said, "You have MD? So what? Get over it." That was my pep talk. I'm like, "What am I getting into?" They're like, "If you want to jump out of an airplane, if you want to drive a tractor, drive a semi, we'll do it. You want go boating, you want to ride a jet ski, we'll figure it out.

And they have been so right. It's been unbelievable. And when you get around that, when you have a callous heart, the way I call it, my heart was so hard at that time, it was so hurt, it was broken. But when you get around individuals that are like, "We'll make some things possible, we won't take no for an answer, and we will love you unconditionally," those scales start to fall. And the one thing, watching that, because as I said, my wife and I have been married 24 years now. To see that love model day in and day out, changed my world. The best story that I can give you is we are in Minneapolis, I get to travel for what I do.

Back then I would wheel my wheelchair to the door of the men's room, she would stand me up and then I would walk into the men's room and go to the bathroom, or she'd hold the door, I'd wheel my wheelchair into the bathroom, and then my wheelchair would lift me up to where I could stand on my

own, use urinal and come out. This particular time, she had held the door, I wheeled in my wheelchair, I was putting it up so I could climb out of it myself, get to the bathroom, and a guy walked in behind me and he goes, "Do you mind if I ask?" At first, he said, "Do you need help?" I'm like, "No buddy, I'm good. I can do this my own." Then he goes, "Do you mind if I ask?" I said, "What?" He goes, "What was the accident?" I said, "No, no." He asked if he could help.

He went to the bathroom, obviously beat me out. And by the time I did my thing, put the chair down, got back in the chair, washed my hands, he was long out of the bathroom. He stopped my wife on the outside and he goes, "Is that your husband in there?" And when I share the story, I usually go, "No." She was like, "No, that's not my husband." But no she's said, "Yeah, that's my husband." She goes, "Why?" He goes, "Well, do you mind if I ask what the accident was?" And he goes, "I'm a pharmacist, I'm just curious." And she goes, "There was no accident." And the stranger goes, "So you knew." She goes, "Yeah, he has muscular dystrophy. I knew." And this stranger looks at my wife in this restaurant in Minneapolis and goes, "You married him anyway. What? Why would you marry him if you knew this was the progress."

And then this stranger looked at my wife, because my wife goes, "Yeah, I married him anyway." And that stranger looked at my wife and goes, "Now that's love." And he walked away. That's what has changed me. That, and having faith and seeing the beautiful things in the world, understanding there is adversity, there are challenges. I some days have way more questions than I have answers, but I have found a hope that I hold onto. I believe in a better tomorrow. I believe that there is a purpose for why I'm on this earth. I believe what my wife models to me, I want to model to other people, I want to model it to our kids. It's going from darkness, depression, substance abuse, wanting to die, to "Okay, this sucks. I'm not going to lie, there are days it sucks. It's challenging. It's painful. But it's 59 degrees sunny, no wind, Northwest Iowa, I got a beautiful wife, I got three great kids, I love what I do. Man, I really like life."

Judy Warth:

And you got a haircut?

Mike Hoenig:

And it shows.

Rob Roozeboom:

And I got a haircut!

Mike Hoenig:

You're so much more. I mean, you've taken us on a journey of your disability, but you are so much more than that disability. Would you mind sharing with our listeners all the things that Rob does in this world?

Rob Roozeboom:

Sure. I mentioned earlier that I was on the National Telethon back in 2001, 2002. I remember when I got that phone call because I was going to school. I was going to college because when I asked my soon to be father-in-law if I can marry his daughter, he's like, "That's fine, but you're going to college because you're never going to work with your hands, you're going to have to get a four year degree," or whatever. I hated school. I was like, "Do I have to? I want to marry her, so I got four year school. Go into school, I think I'm going to be a teacher, and I'm like, "No, not going to be a teacher. "Well, what can I ... Maybe I'll be ... Well, what can I get done the soonest was really what I asked my advisor." And they're like, "Business." I'm like, "Great, sign me up. Put me in business school, maybe I'll go into banking or whatever."

So I'm in school, all of a sudden, that faith thing kicks in. I had to go to some Bible classes at this particular school and all of a sudden, I've grown up with my dad being a pastor, but the Bible became so real to me. I'm just like, "You want to talk about some crazy stuff? Pick that book up. You'll find all kinds of stuff in there." And so I'm like, "Wow, I wonder what that would be like to share that." And all of a sudden I've gone from brokenness and heartache to wanting to take my life to now embracing life. And I heard, and you can argue this or not, but I heard, going to tell your story. I'm like, "No, I'm not going to go tell kids I screwed up. I'm not going to go tell kids I want to take my life. I'm not going to go tell people that." Go tell your stuff. No. Argue for about two years on it. End up graduating college started an organization called Rise Ministries when I was 25 years old, 2001.

And it's sharing the story, the story of brokenness, the story of confusion, the story of heartache, the story of hurt, the story of being compared and less than, and so we start sharing that story. Then I get the opportunity to go on the National Telethon, and share it with 63 million viewers. I told you it was the most crazy experience I've ever had, and it was, it was crazy. And then we start sharing at youth groups and then we start sharing at some conferences and then it's like, "Well, I'm not going to make it just being a speaker, we need to build an entire ministry around this." So we do, we start building a ministry, we do a little radio program, that's 60 seconds food for thought that ends up going ... I think when it was all said and done maybe 300 stations around the country, something like that for teenagers.

And then we did some other stuff. We started a magazine for teens and then we realized teens don't really read magazines, so we stopped doing that. We kept speaking. And then in 2005, somebody came to me and said, "Hey, you ever thought about doing a Christian music festival?" "No. No. Why would I do that? There's one 60 miles down the road. I don't even know what that looks like." And so we started looking at that and that was the opportunity to be like, "Okay, are we going to do that? Are we not going to do that?" And so we did start a festival back in 2005, a Christian music festival, and that has grown into almost 18,000 people over two days in our small little community of northwest Iowa. We now do a podcast called Enjoying the Journey where I get to interview some amazing guests.

I still get the opportunity to travel and speak. Last week I was in Kentucky and Nashville. I get to sit on the DD Council. I've sat on other boards. I sit on the Christian Festival Association board, where there are 32 other festivals from across the country. We get together once a year in Nashville. I get the opportunity to own a couple businesses with partnerships. So I still have my fingers in business. When I said earlier, the things that I love were kind of taken from me, yes, they were, but they've come back around. And so I now get to dabble just a little bit in agriculture. So, where we host our festival, there's 66 acres to take care of. We were just blessed enough to build a permanent stage. It's over a half million dollar stage that we were able to do during COVID.

I mean, last year, right before Easter, I got a call and said, "Hey, we're going to move this building offsite, Rob, would you have any use to have this building on the RiseFest grounds? And by the way, you have a week to decide and you got to have it moved in two months." Oh, fantastic. Well, anyway, we ended up dissecting that into three separate buildings. We get to partner with other organizations, it's just an incredible journey or ride, whatever word you want to use to describe it. Our son who is 19, just joined the national guard, got back in December and has come on board with us as our church and partner relations guy. So, I'm working with him day in and day out.

And then he gets to ... He doesn't always like so much, but he gets to be my arms and legs and travel with me. And he's like, "Dad, I thought I loved traveling, but I don't like it as much as I used to." I'm like, "Well, shut up, get in the car. We got to go." And so it is an incredible time right now. I've been able to do this now for 21 years, that's kind of a daily basis of what's going on with myself and Rise. And we have a team. We have a team of ... there's about eight or 11 of us, we just had our meeting last night. And there's about 41 of us that put on a festival that will host hopefully 18 to 20,000 people in a couple months.

Mike Hoenig:

I was just going to say that we'll have to connect offsite after the podcast, because I have some thoughts about accessibility of missions and festivals and that kind of thing for those of us who have other disabilities. So, that'll be a fun conversation to have. We do really need to begin wrapping up. And I'm stealing Judy's thunder. Unbelievable. But one of the questions that Judy likes to ask and what we all do is, and you've got a long life ahead of you, so this may sound a little premature. But if you could pick one thing right now that you could see as a legacy that you would like to leave behind, what would that be?

Rob Roozeboom:

Oh, that's a fantastic question. I wish I could articulate that question.

Mike Hoenig:

Maybe you have already in many respects in terms of your faith and the importance of love, but are there other? Is there something else?

Judy Warth:

When we look back on Rob's life, what will we say?

Rob Roozeboom:

I hope that you will say he never quit, he wanted to make this world a better place. Will I ever be Martin Luther King Jr. kind of guy? I would love to say yes, I would love to say that we put our efforts together to make this world a better place, that we continued on, that the things that were so much bigger than us, that were so important to accomplish, we gave it our best effort. I really want people to look back and be like, "Yeah, he walked through some hard things, but he had a hope and a faith that I want know about. What was it that he held on? What was that? Why did he talk about his faith so much? Why did he in a better? Why did he care for the way that he cared? Or why did he get involved where he got involved? Just that kind of stuff.

When I take my last breath, I just hope it made a difference, honestly. That's what it comes down to. And right now, not only is it faith in telling people about hope, that is huge to me. I mean, that's what I do on a daily basis. But the other side of that is what we're doing right now, this podcast, this idea of disabilities, this idea of realizing where we're failing and how we can do it better. How can we make life better for individuals such as myself that have a disability where we're falling short, whether that's helping stay employed, it's caregivers, it's education, that's really what I want to be a part of.

Judy Warth:

Hey, Rob, your legacy comes straight from when Harry met Sally. Mike, I'll take some of what he's having. Okay?

Mike Hoenig:

Well, you're living out your legacy, which is really awesome. And it's just been a real pleasure to be able to spend some time. We could spend a whole other hour, but we're being given the signal, the old clock on the wall or whatever you want to say.

Rob Roozeboom:

Yeah. Understand.

Mike Hoenig:

So, I just want to thank you so much for you to take your time out of your day to share so much of yourself with us. And I'd also like to thank our listeners for joining us and invite you to stay tuned for another podcast soon. And Judy, I'd like to turn it over to you for any final thoughts.

Judy Warth:

Rob, I mentioned when we started that my office was about 92 degrees. I got goosebumps, so thank you. I love that you talked about the intersectionality of faith and disability, and really, you talked about life. So, this ended up being just-

Mike Hoenig:

Absolutely.

Judy Warth:

... raising life that happens to include disability, which we all will experience. So, we cannot thank you enough for sharing your intimate story with us and this bit of yourself.

Rob Roozeboom:

Sure.

Judy Warth:

So, Mike, bring us home.

Mike Hoenig:

Well, this has been another Disability Exchange Podcast. We thank you, as I said, our listeners, special thanks to Rob and for our friends at the Midwest Public Health Training Center for making this a reality and making us look good. Once again, I want say goodbye for now, and please join us again soon for another episode of Disability Exchange.

Caitlin Owens:

Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for Disabilities and Development at the University of Iowa. Special thanks to Kyle Delveau for the music contribution.