

## Episode 20 - Some Silver Linings with Greg Fier

Mike Hoenig:

Well, hey everybody, it's Mike Hoenig from the University of Iowa, Center for Excellence in Developmental Disabilities or Iowa UCEDD. Welcome to another exciting addition of Disability Exchange. Disability Exchange has a purpose to elevate and center the voices of people with disabilities. And we do that by just providing a venue for people to share their stories. We are delighted to have a partnership with the Midwest[ern] Public Health Training Center. They do our production, all the behind-the-scenes editing and keeping us generally on track.

And I truly mean it when I say we have an exciting episode today and will be introducing our exciting guest here very shortly, but first I would like to turn it over to my illustrious... See, I said that twice in a row now, partner in crime, Judy Warth.

Judy Warth:

What happened to charming and everything else?

Mike Hoenig:

Oh, I'll do that next.

Judy Warth:

Okay, okay.

Mike Hoenig:

Yeah.

Judy Warth:

I'm Judy Warth, and I'm here at Iowa's University Center for Excellence in Developmental Disabilities with Mike, and excited for our discussion today. One of the fun things about doing this is, we get to meet people whose maybe our paths haven't crossed in the world until this moment.

And today, Greg Fier, not fire, Greg Fier is our guest. And I was introduced to him through a bio that talked about all of his work in the disability world, which is quite profound and significant. But as I did my research, I met a musician as well, and I love bringing out the multifaceted nature of the people who we see because sometimes in our world we go, "Oh, this is a disability advocate." I know that Greg is a grandfather, a musician, an artist, and a great spokesperson. So welcome, Greg, we're glad you're here, I'm excited to be able to talk with you today.

Greg Fier:

We appreciate the kind words there, and I am excited to be here and was very honored to be asked.

Mike Hoenig:

I was so glad when you responded. So for those of you out there in podcast land, I had the pleasure of meeting Greg, I think for the first time through an organization called IDAAN. IDAAN is one of those long acronyms, which stands for Iowa Disability and Aging Advocacy Network. Through IDAAN, I met Greg, and Greg is much more involved with it than I am, so you can certainly talk a lot more eloquently than I can.

But the reason I got involved is that we were looking at really trying to figure out how to really step up self-advocacy in Iowa, because for many years we had little individual things going on, but we didn't have really a lot of state-level opportunities. We had just gotten involved in a regional group with the states of Nebraska, Missouri, and Kansas, as well as Iowa.

We were trying to figure out, "Okay, what do we need to do in Iowa?" And I just remember coming to that first IDAAN meeting. I think we were maybe even on Zoom or something for that, and there was Greg. I'd never met you before either, but I just was so impressed that you were there and you were talking about your own personal experiences. So we've partnered on some IDAAN work, and then I believe you got involved and were participant in our self-advocates our SOAR conference, seeking opportunities for an advocacy revolution, and just recently hopped on a follow-up brainstorming Zoom meeting.

So Greg, I'd just like to begin here with you telling us a little bit about how you got started with advocacy.

Greg Fier:

Okay. Well, thanks again, Michael and Judy. I am really happy to be here to talk and I don't consider myself an outstanding advocate. I started looking across my little history that I sent you all too and I said, "Well, I have a number of things out there, but I still am learning and trying and riding coattails of people like Jen Wolf, and like I still feel almost like a newbie on this kind of thing.

But what got me into it, well, first was becoming disabled. 1995 I was diagnosed with multiple sclerosis. For folks who aren't aware of what that is, multiple sclerosis is a very unpredictable disease of the central nervous system that disrupts the signals through the brain and then from the brain to the body and back.

The immune system attacks the central nervous system in the brain and causes scars or lesions on the myelin sheath, which I know we all remember from first grade, is that the coating that covers our wire-like nerve endings, little holes are put in there.

It's so unpredictable because these lesions pop up in many different places in the brain or in the spine and disrupt the signals. So symptoms could be from numbness and tingling in body parts, to cognition

problems, to really severe fatigue and pain and blindness, and then of course, paralysis, which was personally what happened to me.

I was then diagnosed in '95, and it was nearly seven years before I was hit again with another symptom. At first, I was diagnosed with what was called relapsing and remitting MS. And that is the time where, as the name applies, is the symptoms come on for a while, and then they recede, although never completely. But then over the years, the symptoms flare up or exacerbate, and then they go back down. There are three forms of MS, but the other one is primary progressive where someone gets it and it just slowly continues to get worse and worse.

And then the third kind is called secondary progressive. And that's what I've been diagnosed now since 2006. Secondary progressive is someone who starts with relapsing-remitting and then changes to primary progressive. There are big distinctions between these three, but again, the disease can do a lot of things to a lot of people.

For me, it put me in a wheelchair and I'm at a point now where, pretty much the only thing that I can move are what's above my shoulders, and I am very grateful for that. I've got some control of my mental functions anyway. So when I got in the wheelchair, of course your social life is severely inhibited by that. So I found myself being at home a lot, and learned how to use a computer hands-free. There's software out there for voice recognition, hands-free mouse, which allowed me to run my computer.

I was just kind of fishing around one day and... I'm sorry, I have to back up. In about 2013, I was approached by a lady here in town, Tami Leavens. I'm in Clinton, Iowa. And she said, "I'm thinking of starting an MS support group. Would you be interested in that?" And to be polite, I said, sure, because you know, the thought of support groups was just, I think a lot of people just think, that's not for me, you know, I don't want to go and sit in on a bunch of sob stories, but about a year later, she came to me and said, "Hey, we're starting this thing. Here's when our meeting is". And the support group that we have is affiliated with the National MS Society. Specifically, it's the Upper Midwest Chapter that we were connected with.

But the more I got involved with them, I met a man named Dan, gosh, here I'm not gonna remember his name. He's an advocate out of Minneapolis with the society. And he invited me to come out to Des Moines for the state action day, which I didn't know what the heck that was at all.

But basically the MS Society will have two or three issues, two or three bits of legislation that would help people living with Ms. And they go there and, you know, help to persuade legislators to vote that way. That was kind of interesting that what they did then was set up a Chinese food line that they brought Hy-Vee in and we'd sit there and there'd be this, you know, long buffet about all this food and we'd invite the legislators and their staff to come through and have a free lunch. And everyone shows up and there's a big, long line.

And we use that opportunity to grab elbows while people are waiting and, you know, make our pitch. So that the first one I was brought out to though, I think they were just saying, why don't you guys just sit in the dining room there with those guys? And I think maybe they're just, I hate to say poster child, but you know, that kind of thing. Yeah. Well, we're, you know, just there for visual effect. And we got there and another gal, Steffany Stern with the MS Society came up and chatted with me. And I got talking with her. She said, "oh, you need to be out in all". Because apparently the gift of gab is something that I was

cursed with sometimes. But yeah, so she brought me out there and one of the first people I met was Timi Brown-Powers representative from Waterloo, I believe, and Rita Hart and got talking with them.

And yeah, I was just kind of hooked on that after that. I realized that these legislators are people and yeah, there's no reason at all why someone like anyone can't pick up a telephone and give these people a call because they are working for us. And yeah, it just sparked a thing in me. And then, online I somehow, and I don't even know, Michael, how I was on that call with IDAAN. And looking back on that the timeline is still messing me up because I remember very clearly Dawn asking me what I thought of advocacy work. And I said, I don't even know what the word advocacy means. I said, you know, can we try a different word maybe to help people, you know, convince him to come in and do it.

And John said, "well, what, whatever word would, would you like?" And I couldn't think of anything of course, but that just kind of got me, it really peaked my interest. And I was given a lot of opportunities to meet with legislators through the MS Society in 2018, 2019, I was invited to go to Washington, DC for the Public Policy Conference. And yeah, here again, just make connections with people. And I wish I had more energy that I could utilize some of the connections I've made, but that was a long rambling story of how I got into this.

Mike Hoenig:

It's a great story.

Judy Warth:

Excellent. Impressive. What parts of it do you like the best? I mean, you've been rubbing elbows with a lot of people.

Greg Fier:

Yeah. Oh gosh. You know, one of the most memorable ones, Representative Norlin Mommsen and I had met Norlin because in 2015, our support group was putting on a walk, a fundraising walk, we call it the MS-issippi Walk and Roll. And it was a combination of a 3k, 5k walk and then we'd have a band concert. There's a beautiful band show here in Clinton on the river. And I have to step back a little bit again here.

One of the things, when I met Rita Hart that day, Tammy was out there with us. And Tammy had told Rita how I write and record music in a studio. And Rita came up to me and she said, "I understand you record music?. And I said, yes. She said "I sing". And I said, Really? So, whatever it was, maybe 45 days after that, Rita was in my home and I had her behind a microphone.

But the reason I got into that tangential story is that for the Walk and Roll, we asked Rita to come and sing the national Anthem. And I thought, well, you know, we don't want this to be a political organization or a political event. So we thought, well, let's invite all the legislators around. And one of them was Norlin Mommsen. And Norlin and I just got along very well. We were trying to run a little radio spot where we wanted to say, "take a rock and stroll at the walk and roll. And Norlin was trying to

say that in the microphone for me, he had one heck of a time. I was so tempted to put all of those bloopers on the radio for him, but I didn't want to embarrass the guy.

But anyway, so getting back to one of the most memorable events, and that is on maybe the second state action day that I was out in Des Moines, Norlin came up and asked me if I'd like to go down in the well there at the house and take pictures.

And as it turns out, there's no way to get a power chair in the well, and the next year when I came...well, that first year he told me that he was running all over the capital building, looking for some way to get there. There's a one step to get into the well down low there, one step. And he was trying to think, getting a ramp somewhere. He even started looking out windows to see if there were any pickups in the parking lot that might have plywood in the back of them, that he could make a ramp out of. But he couldn't do it.

And the next year when we got out there, I wasn't there 10 minutes and he come running up to me, big grin on his face. He said "you want to take pictures of the well today?" And he figured it out. And he had found that there was indeed a ramp made to go into that stuff, but it was sitting in a closet up on the third floor somewhere.

So he had to put up a sign saying, if you need a ramp, it is right behind you in this area. And yeah, we got in there to take pictures to the well, and had a chance to chat with Linda Upmeyer, the then Speaker of the House. Didn't get far with her, but I least had a chance to ask for a couple of things.

And then to top it off, Norlin on his, I don't know if it's weekly, but his post on Facebook, he wrote a really nice story about that. Saying how he had a chance to live in the shoes of someone that's disabled. And for someone who is... Norlin is a Republican and a lot of times that might be someone who is at odds with the kinds of legislations that we'd like to see as disabled or elderly folks.

But here, this is someone that we connected with. And I really think that because of that connection, if some legislation came along and the wind was blowing that way, that this might be a Republican who is going to be a little more open minded about that kind of thing.

So it gave me again, a real sense of connection and realizing that there are ways that we can break through this divide that we have in the country right now. So many things have happened since then, that kind of rob us of that feeling, I guess. But we like to just keep thinking that there's commonality somewhere in everyone's thoughts, that we can somehow agree that taking care of the elderly and disabled people is a priority that should be taken very seriously. We're hoping that we can get Iowa to lead the country.

Mike Hoenig:

I think one of the things you really hit on, I guess maybe I'm too much of an optimist, but I'd like to think that we still have common ground. We just need people to realize that.

Across parties, across many, many demographics, but one thing that I really picked up on, well, you said is the importance of building relationships. And I mean, I haven't worked with you all that frequently, but I can tell that that's something that's super important to you and I noticed that right before the

podcast, it didn't take long for you and Judy to really strike up a connection. And you are both definitely people that are excellent at developing and connecting. And so of course that was going to happen, but that is such an important piece within the legislative or policy process. And it seems like you're a natural at that.

Greg Fier:

Well, I guess I'm comfortable doing it and I've always been that way. I grew up in a town of 400, my folks ran the little grocery store there. So I grew up saying, "Hey, good day!", "thanks", as I'm bagging groceries. And yes, I've always found it pretty easy to talk with folks. But you're absolutely right, Mike, that is the key in this.

We're talking about self-advocacy, this is the kind of thing that I really want to promote to people and encourage people to find ways to meet their legislators. When they are at the town halls or the coffees, when your legislators are in town, get on down there and strike a conversation with them, it's amazing how much impact one person can have on the whole state, just by having that one conversation with someone.

Judy Warth:

And you know, Greg, I read a little bit about the Finch Fund. Can you tell us a little bit about that?

Greg Fier:

Oh, absolutely. Thanks for asking Judy. Yeah. The Finch Fund is the shortened name for the Bob Finch Memorial Fund.

Judy Warth:

Oh.

Greg Fier:

Yeah. This is assorted and long tail, but I really need to tell the whole thing. Back in 2011. And of course I'm already in my wheelchair there, but I was at a Halloween party, a very good friend of mine, who's always helped me out. But he was outdoors and boy, there were a good 60 or 70 people there I'd say. And a number of us were standing around the fire pit. And I was talking about how my equipment and the software, let me run the computer. And a friend of mine was standing behind me listening. I didn't realize he was there, but a fellow musician. And he said, "can you do Facebook and emails with that?" I said, sure. He said, we got to get one of those for Bob.

And I said, Bob who? And he said, Bob Finch. Well, that ball just kind of started rolling. So another friend Dave Layton here in town went to introduce me to Bob and Bob was in a nursing home in town. And he had been put there at age 56 because his functionality was just that low and he didn't have the resources to be able to stay at home. He said that he couldn't change the channel on his TV, stuck on lifetime, on like the horror, but no one should have to live that way. And just running lights and things. Well, I had the relationship with the head of the occupational therapy department at the St. Ambrose in Davenport. And he had come up with a way to take old power computers and he'd put his own processor in there.

He would take that and then monitor someone's house and using a sip and pump switch, which if anyone out there is not familiar with that, it's just a straw that you blow in or suck on. And it acts as a switch and on the monitor was the power to your TV and channel up and down, and volume up and down, or turn the lights up and down. And so I told Bob I was going to get him in touch with Jon Turnquist, his name was.

And then Dave and I, as we were leaving, got talking, you know, it'd be great if we could get him a laptop and some of this software and things that I use to control computer. And I thought, well, maybe we could just do a little fundraiser sometime and see if we could get some money raised up.

So he and I both just wrote things up and sent out emails to friends. And before I know it, we needed 1400, before he knew it. We had \$2,200. Wow. Yeah. So we bought this stuff up and we got the laptop to him only to find out that there is no wifi available at the nursing home, that little detail we forgot to clear up beforehand. So we paid for a little dish to be put in on the roof. And I said, he could use the computer as turns out, bob's last attempt to use computers he was using, Windows 95. And we were already at like seven, I think. And so, as it turns out, he really didn't have the basic knowledge of how to run a computer for this equipment to really help him. I mean, we learned lessons going through this, so you can't just hand someone something like that.

You really have to take into account the training to use equipment like that. But, but one thing Bob could do was get Pandora and he just loved to listen to music. Obviously he was just as happy as he could be with it. We had a little extra money and we left it in a bank account that Dave and I started, we called it The Bat Fund, Bob's assisted technology. And the money was in there. And about nine months later, a friend of mine came and said that her husband's aunt had MS and was about to go into a nursing home. And so we raised a little money. We got her a laptop and one of these hands-free mouse contraptions. And then we were contacted by Dave's ex-wife who works for Jackson County. And she knew of a gal who is a senior in high school who had some type of bone cancer and had to have her leg removed.

She had a half semester of school left, but they didn't have wifi at their home where they lived. So we put some money to do that. And you know, we just, or a couple times Dave and I looked at each other go, "we're doing good things here". It felt so good. And then here on the end of 2017, Bob passed away and he wanted his money to be left to the Multiple Sclerosis Foundation. The Multiple Sclerosis Foundation is now fit in Florida that actually people can apply for grants to purchase equipment. It was just after one of our Walk and Rolls, we had about \$13,000. We were going to send off to the MS Society and we thought, wouldn't it be nice to take some money and put it to the Foundation in Bob's name about \$2,000. So I got online one night with them and tried to make the deposit. And it wouldn't process. I tried it twice.

The next morning, I called Bob's sister and told her what had happened. I said, we're trying to put money in there. And she said, well, actually, no, he wanted the money to stay with the local MS people. She said, some people put together a walk and he said, there was a picture of him with some lady in the paper. I think maybe she's the one who ran the walk. And I said, well, actually, Kathy, that's us. That's our support group. And I think the picture that you're talking about is one he had with Rita Hart that was in the paper, it was a state Senator. And she said, oh, she said, wait, are you the ones who got Bob the laptop? And I said, yes, Dave and I did that.

She said, oh. she just forward thank yous to us on that. And then something just struck me then. When you would do fundraising for sponsors, for the walk, telling people that all the money was going to the Upper Midwest Chapter of the national MS society, we'd have a few folks say, well, it's too bad it couldn't stay local, but okay, I will sponsor.

We'd hear that enough. And something just hit me when talking with Bob's sister and Dave, that why don't we take this \$2000 that we were going to send to the MS foundation and start our own official fundraising nonprofit organization and the money was going to be raised to help a Clinton area MS victims. They say, people living with MS, that some don't like the word victims.

But anyway, to help them maintain their independence and quality of life. So since then we've raised somewhere in the neighborhood of \$70,000. And we have done almost \$50,000, well right now we're on our second bath remodel, putting in a walk in shower, we bought a couple of bands, a couple of power chairs, and yeah, it's just a really, really wonderful thing. So...

Mike Hoenig:

There's a reason you were not allowed to submit that contribution to the national, if that had gone through, this may have never happened. So, that's pretty amazing.

Greg Fier:

Yeah, exactly. Exactly. Somebody was - yeah, it just really clicked.

Judy Warth:

If somebody's listening, and they want to be part of contributing, what's the best way to reach out to you?

Greg Fier:

You can look for me, Greg Fier, or go to [thefinchfund.com](http://thefinchfund.com) and get right on there. You can click to donate. I'm not always great at keeping that thing up to date. In fact, I haven't written down the purchases and jobs that we did in 2021 yet, but it does have information about where and how to donate.



Mike Hoenig:

I think I may have actually met Bob many years ago. There used to be, and I'm sure it probably doesn't meet anymore, but there was an organization that was called something like the Clinton Mission for people with disabilities or something like that. There was a state office. And then there were chapters around the state. And I remember visiting that chapter several times. So and I want to say that Bob might have been a member of that, but many, many years ago.

Greg Fier:

Yeah. He was a musician and actually played, I actually played with Dave and with JC Monroe, who was the fellow at the Halloween party. He said, we got to get something for Bob, but they all played together back in the seventies. And as I understand it, Bob, as he started getting ill, was living in Iowa City and was the organizer of concerts down there in the..

Mike Hoenig:

Oh, maybe that's where

Greg Fier:

These outdoor ones yeah. Was like Wild Bob's Show or something like that. And so I understand that he was a motorcycle enthusiast and when he couldn't sit on that motorcycle and ride, someone made for him a motorcycle side car that he could drive up into, on his power chair and drive that motorcycle down the highway. That's something I would've loved to have seen, but yeah.

Mike Hoenig:

Technology at its best.

Greg Fier:

Isn't that something?

Judy Warth:

You know, Greg, I listened to you and I have multiple things in my head. One, you're a connector. You seem to be able to connect with people, find them and bring people together, as well as instill your story and your passion in them. You're a community builder. You get people, all these people talking, which is

pretty amazing, which makes you an amazing change maker. But like I said, when I started, I know you're a lot more than that. I understand, you're a grandfather. I know you got a dog. What else?

Greg Fier:

Yeah.

Judy Warth:

What else enriches your life?

Greg Fier:

First of all, thank you for those nice words and yeah too, as you were saying, Mike. Yeah, I think Judy and I made a connection right away, soon as I saw that beautiful head of hair and a big smile on her face, I thought, yeah, we just connected and...

Mike Hoenig:

Yep.

Greg Fier:

But yeah, what connects me? Yeah. Well, like you say, the grandkids and they do a lot of things on computer. But yeah, the music thing is probably the most enriching thing. I've not been able to do it as much as I would prefer the last few years, but I started playing in bands around the area, guitar when I was 18 years old and just really loved it. I had one band that we were together for 16 years. We were opening for some pretty big acts and we weren't great, but we were pretty good.

And I identified myself as that. I'm a guitar player and a singer. And, and when MS came along and took all that from me, it was really something that, it robbed me of my identity. And it wasn't until a buddy of mine, in fact, it was JC who I referred to before, showed me that this recording software, put on computer and another buddy of mine who was a tremendous guitar player, Ken Clark, would come and spend time with me and developed into a songwriter and recording artist. And I just learned by trial and error, there are days I'd go back from that computer. You know, someone would get me out of bed, into my wheelchair and I'd go roll in closet of mine there, the Power Church Studios and edit songs left and right. You know, I would have a recording of a song and have someone like Dave come in, who is an amazing saxophone player and I'd just have him just jam with the music.

And when I was done, he'd say, "Hey, let me do that again". So I'd have a whole nother track of him doing that. And then I would just go through and pick out the gems and plug those into the song or if there's one certain riff that I really liked, I would play it and the song in regular intervals, so it becomes

part of the theme of the song. And it really got to be where it was almost like painting. I remember telling my neurologist, I'm never done with one of these songs. And she said, well,[inaudible 00:35:21] has been known to make thousands of changes to his paintings.

Judy Warth:

Well, you know, I listened to your song, Silver Linings, and it totally captured me because it's really a powerful song. And in it you talk about the silver linings. And we like to kind of ask our guests, your life got changed, your world got all uprooted, but what would you say is the silver lining of your experience with MS and where life has led you?

Greg Fier:

Great question. That song deals with, the fact that they say "every cloud has a silver lining", but I've been looking and looking and can't see the silver and this cloud that's over my head. but it's about the passage of time. Time will heal these things and looking across my song list, there are just song ever song.

I talk about the passage of time and how it feels things. And in the same way that silver lining is the question is the same way on my Silver Lining, I think is that, yeah, I'm feeling like I'm making some changes in people's lives. Really gives a person a sense of purpose at the same time. There's always still that hunger for more. I'm never completely happy. I suffer with depression still on a daily basis, but you know, I don't know, maybe that's what's needed to motivate us to fight back and make the change so.

Mike Hoenig:

Well, I really believe that you have found the silver lining and just the way that as you said, that you've helped so many other people and that that is obviously one of your passions in life to connect and to really be there, whether through the Finch Foundation, through the fundraiser, through, I know we didn't even have a chance to get into upgrade Medicaid, although we have had the pleasure of talking with Jen. So we did cover that. We really do need to wrap up. And so we would very, very much like to thank you, Greg, for taking time out of your day, to spend with us and to share your really terrific story and how you are making a difference. And even though you may not see yourself as a leader or spokesperson, it's pretty clear to me that you have worked into that role. So Judy, any final thoughts before we close down?

Judy Warth:

None. Not at all, but I think the silver lining will, as you said, in your song, you will continue to reveal itself.

Greg Fier:

Yes.

Mike Hoenig:

Yes.

So again, thank you, Greg. Thank you, listeners. Thanks to our friends at Midwest[ern] Public Health Training Center and thanks to the dog for their contributions as well. So, we've really appreciate everyone's time. We look forward to welcoming you back next time to another episode of Disability Exchange. Bye everyone.

Caitlin Owens:

Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Venter 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.