

KENTON HALL LONG HAUL PAUL ASHLEY FIOLEK HUMOR — SQUEAKY WHEEL CROSSWORD EVENTS/CONF

ABILITY

Disney's Firebuds
+ Disability inclusion

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The Movie & the NFTs

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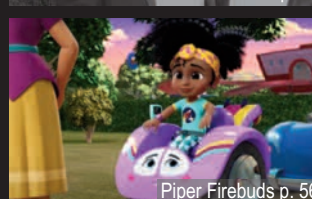
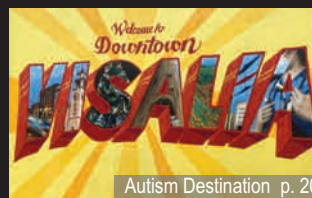
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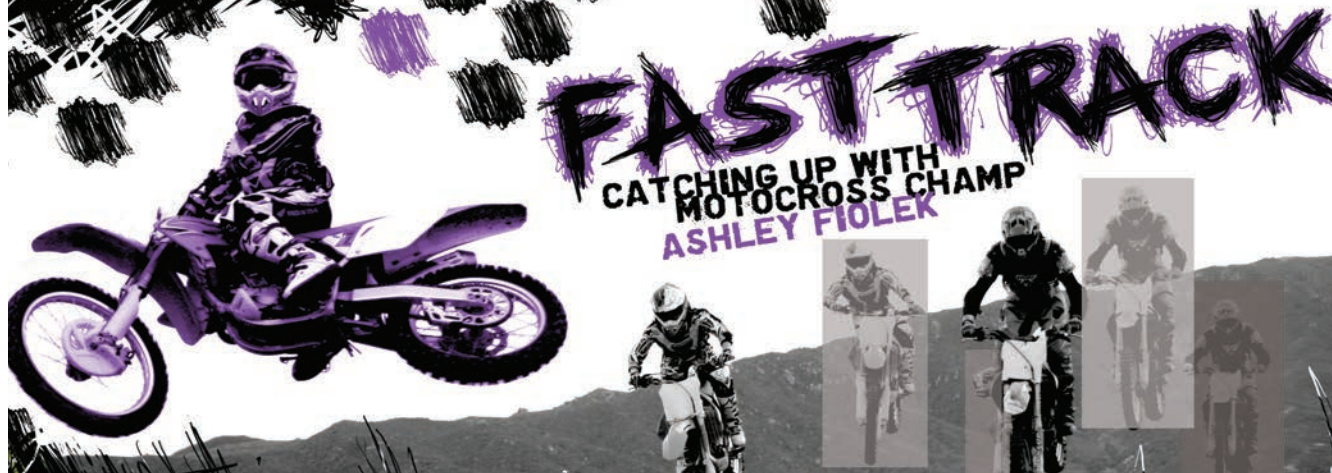
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I'm out traveling again! I left snowy, cold Utah to get in some riding and race practicing so I can be ready to enter some qualifiers to try out for the Loretta Lynn Nationals. Bambi, Lindsey and I packed up and started heading South for warmer weather and no snow!

So one of the main reasons that we headed south was to once again race the RedBull/Dade City 'Day in the Dirt'. I love this race it is so much fun and I always have a great time. The plan was to meet my parents and my brother and his girl friend over in Dade City and then hang out there for the weekend. We stopped at my brothers house near Pensacola Florida for the night and then the 4 of us headed out. My mom and dad were coming from Saint Augustine but they were bringing our motorhome.

Last year was cold and raining and we were parked way in the back. We wanted to be better prepared this year. We also had Bambi and my brother's dog, Havoc, staying with us so we wanted more room. We didn't let Red-Bull know about the motorhome until too late so they told us, unfortunately, we would not have hookups. We



were just happy to be able to bring it. My mom and dad arrived first with the motorhome and there was confusion as to where they should go. Nothing out of the ordinary for race day and my parents took it in stride. They finally got one of the Red-Bull staff and a guy on a 4 wheeler to get them to the right spot. Imagine their surprise where they were told to park right behind the starting line and they had electric and water! Whoo hoo we were all so happy, part of the track actually ran right behind our motorhome it was a lovely spot and we were parked right by some RedBull athletes.

Thursday was just spent setting up and getting my Yamaha ready for practice on Friday morning. After the work was done we all went to the local Dade City brewery which was a lot of fun. We got to bed early because we had to be ready for an 8am practice. My dad and I were once again doing the parent/child race so we rode in different practices based on our ages. It was a beautiful day and we had a great time. We were ready for the races on Saturday.

I rode a 2 stroke race first before mine and my dad's race. It was a lot of fun! 'Day in the Dirt' is fun because there is no pressure and everyone is just there to have a good time! I had a short break and then it was time to ride with my dad. We shared my Yamaha and every lap we had to come into the pits and switch riders. It was intense, it was about an hour and a half race. but we did it! So much fun. Saturday night I joined some of the RedBull athletes and signed autographs. That's what is so nice about this race, there are such good fans and everyone is there to have a good time.

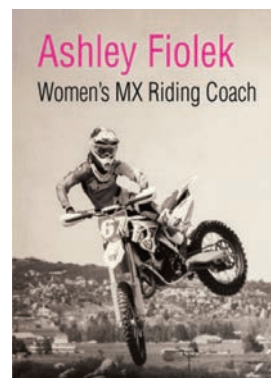
On Sunday I had another long race with a partner this time my friend Lindsay from VA had come to race with me as a team. This



time we each had our own bikes but we had to again come in every lap and switch. My dad was our mechanic, so much fun, it was hot but beautiful weather. I did an iron man race at the end of the day that was almost 2 hours. Whew..... I can't wait for next year but I definitely need to rest up.

We left Dade and headed to my mom and dad's house to stay for the week. We had a good time visiting and hanging out especially on Saint Patrick's day. After our visit there we left and we are slowly making our way back to Utah. We have been stopping along the way to ride at different tracks and are having a great time. Maybe you will see my riding around your local track, come say hi if you do.

■ ABILITY



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5 Ways to Clarify You're (Badass) Disabled and Not (Inspirational) Disabled

Everyone knows about the two types of disabled people. The traditional type is sad and inspirational, like the tiny boy with crutches who begs Ebenezer Scrooge for tidbits of hard bread with cold porridge. The new type of disabled is totally different and very cool, like the hot people with mobility aids from the woke TV commercials.

If you've found yourself caught between these two worlds, here are five easy ways to make it clear to those around you that you're the fresh, badass, better kind of disabled.

1. Curse excessively

While traditional disabled people say things like "please sir" and "ouch" and "for just one dollar a week you can support people like me," badass disabled people say things like "fuck yeah" and "check out this cripple-dump-truck ass."

2. Disregard your safety by doing risky things for fun

It's tempting to stay in bed all day knitting and counting your pills, but it's also important as a badass disabled person to do extreme things with an element of danger. Try bungee jumping, tongue-kissing strangers or crowd surfing in your wheelchair at a punk rock concert. This subtle disregard for safety lets the ableds know you have something in common with them and can be trusted.

3. Dress like it's 2047

It's not enough to dress like an average 2023 person. Trash all your blue jeans, raggedy flannels and anything beige. Instead you should wear neon colors, sport grungy tattoos and get a radical new haircut. Make it clear that you belong in a cyberpunk video game and not in your grandma's nursing home.

4. Avoid looking directly into the camera

When a camera is around, you probably feel an innate urge to stare straight into its cold lens and thank the generous viewers at home for their donations. If you find yourself in this position, you should look away from the camera, become elusive and make it chase you around town like a disabled version of Animal Planet's "Finding Bigfoot."

5. Be proud of your disability

This one is tricky and might have some people questioning your sanity, but that's OK. In fact, sanity is for the ableds and the traditional, boring type of disabled people. Make it clear that you have no shame or embarrassment, and communicate that your disability actually makes you superior. This badassery flips the narrative and proves once and for all that you are the good, new kind of disabled. ■ **ABILITY**

by Steven Verdile

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HELP IS NOT A FOUR LETTER WORD

Helping friends and family is part of everyday life. Helping neighbors in our local communities or people on the other side of the world is what makes most humans, well, humane. Whenever I help out a friend or neighbor it makes me feel all warm and fuzzy inside. I believe sharing my story of living with Multiple Sclerosis as I cross the country is helping others with chronic illness get through their life as well. Being able to help others brings me joy and makes everything I am sacrificing worthwhile.

Asking for help isn't quite as simple. When many of us need help, it's often hard to ask for it, because it can make us feel inadequate or make us feel like we have somehow failed. When someone offers to help me, I am usually quick to decline without really giving thought to the mutual benefits of accepting the assistance. It usually isn't until later that I realize I could have really used the help and I was a stubborn idiot for turning down such a gracious and sincere offer.

I must be getting wiser with age, because twice over the last couple of months, I found myself both asking for, and needing help from strangers. Both times, I was GLAD I did!

The first example was on a cold November morning. I was a couple hundred miles into a 1200 mile ride home from a motorcycle rally. I stopped at a gas station to swap gloves as the temperature was finally above freezing. I carefully placed my favorite and most expensive pair of gloves on top of the duffle bag strapped to my passenger seat as I removed the second pair of gloves from my saddlebag. I got gas and drove off forgetting to pack the first pair of gloves away. About 15 minutes later I had a sinking gut feeling that I forgot to do something at the last stop. Reaching back behind me I felt around and sure enough, I found a single glove. I pulled over to search the back of the bike, hoping it had lodged itself somewhere, but Lefty was nowhere to be found.

I looked at the GPS and realized I had ridden at least ten miles. Backtracking, then looking for the glove on the side of the freeway was going to add an hour or two to what was already an 18 hour day. I decided losing the glove was the consequence of being sloppy. As the gloves were expensive, I decided I would not be replacing them and I would have to just live with my mistake. Over the next 800 miles however, I felt remorse and regret that I had not retraced my ride to look for the lost, all-time favorite glove. It also dawned on me that losing one glove wasn't just a \$150 screw-up, it was really a \$300 mistake as I couldn't replace just the one glove! I then convinced myself I deserved to have winter gloves that fit properly and decided I would order another pair when I got home. After all, I do ride a motorcycle for a living so it was a write-off and having great handmade gloves



that fit- well, like a glove, was important. The day after I got home I went online to order a new pair and found the small glove company had gone out of business! I scoured Ebay and Craigslist for used replacements as well, but found nothing. I carried the right glove around the house like a security blanket, wondering what I was going to do with it.

Half jokingly, I decided to post my sad story of losing my favorite glove on Facebook. I asked for help locating my best friend 'Lefty'. I posted the route I took and a ten mile stretch of interstate between Alabama and Georgia where I thought it might have fallen off the bike. The post got some great sympathetic comments as well as a mix of stories of favorite gloves lost!

Less than an hour after my post, a gentleman I never met, posted that he found my glove on the side of the road in perfect condition and would put in the mail that evening! Someone actually left work early and rode to the exact area and searched along the highway for a small black lump to help a complete stranger! Many other riders had posted that they were on their way to the area to help as well!

My second need for help was in March, as I was heading down to Bike Week in Daytona. Because of the amount of miles I ride, I have an auxiliary fuel tank on the bike. I also pay close attention to my fuel consumption, balancing my speed and distance to minimize stops

each day. I constantly do the arithmetic in my head to know what I am averaging for fuel mileage. One thing I never do is push my bike in the red because, I don't like to, push my bike!

Not sure why it happened. I regularly get over 40 miles after hitting the blinking low fuel light. I used my GPS to locate my 6th gas stop of the day at a Love's truck stop 30 miles away. I went 29 miles before running out of gas! Despite it being 85 degrees in Georgia, I was still wearing my thermals and heated gear from the chilly start in New Jersey that morning. Overheated, I couldn't even remember the name of my towing service. I needed help. I watched hundreds of trailers hauling bikes to Daytona pass by me, but no one stopped. Dozens of bikes wizzed right past me without even looking at me on the side the freeway. My tow service app showed a 2 hour wait for gas to be delivered. I contemplated pushing my bike the mile or so to the station, knowing I would be beyond exhausted and would be risking getting rundown in the breakdown lane the entire slow walk. I accepted that I was in for a long wait as the temperature continued to rise. As I was starting to remove my boots and riding pants to get out of my long johns, a white Volkswagen pulled in behind my Yamaha and the driver quickly got out and asked me if I needed help.

"I ride motorbikes as well, and have run out of gas plenty myself. Can I go get you some gas?"



My brain screamed, “Hell, YES”, but my idiot mouth said, “Thanks for stopping, but I have my tow service coming with fuel in a couple hours.”

“That’s ridiculous. I’ll be right back with some gas.”

Ten minutes later, my new friend returned as promised with two gallons of fuel in a brand new fuel jug he had to buy and refused to take a penny from me. We chatted briefly while I repeatedly begged him to take my money, but he refused, leaving with a handshake and one of my Chasing the Cure calendars.

“I’m really glad I was able to help you. You would do the same for me, right? Please just pass it on. Help someone else.”

As I travel the country, I have benefitted from the generosity of strangers just like these examples many, many times. In fact, reading through some of my older stories, I found most of my greatest adventures involve breaking down, bad weather or failing to reach some destination. I also realize that most of these situations would have been very different if not for the help of others.

Asking for help is not a sign of weakness, it is a sign of strength. It takes strength to recognize and accept we can’t do everything ourselves or that we are overwhelmed and need some support. Family, friends and coworkers are all eager to help us, we just need to

accept it or ask for it.

Living with a chronic illness presents many unforeseen circumstances that simply require help from others. It may be physical help with chores or moving furniture. It might be financial help navigating medical expenses brought on by an unpredictable disease. It may be as simple as a ride to the pharmacy, or help watching the kids because our fatigue has worn us to the bone. Whether it be a gallon of gas or help finding a favorite glove, it is important for us all to remember that HELP is not a four letter word and we shouldn’t be afraid to ask for it.

■ **ABILITY**



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kenton HALL

Living with Bipolar and its Influence on His Art

Kenton Hall is a singer/songwriter, filmmaker, author, and proud dad of twin daughters, and he has just released his double album “Idiopath” and “Omniopath,” featuring 33 1/3 tracks. Hall also has bipolar disorder, diagnosed after he ran away from his abusive parents from Canada to the UK as a teenager. For World Bipolar Day on March 30, *ABILITY Magazine*’s journalist Karina Sturm speaks with Kenton Hall about growing up with bipolar disorder, running away from the cult he grew up in, his latest musical projects, and how his identities influence his art.

[CN: Brief mention of suicide]

Karina Sturm: Hi Kenton! Thanks so much for taking the time to talk to me today. I know you have had quite a rough start to your life! Do you want to tell me a bit about your teens and how you ended up running away from Canada to the UK?

Kenton Hall: I was raised by British parents in Canada, but they were members of a very strict religious cult. I always tried to escape because being a bisexual, atheist, bipolar teenager in a group of religious people didn’t sit awfully well with either of us. (Laughs). Since I had British citizenship, I came to the UK when I was 19, intending to just get away for six months, but, well, I’m still here. I got distracted by life somewhere along the way. I packed the night before and moved to a different country, which may have had something to do with the lack of impulse control when you have bipolar disorder. I wasn’t medicated back then. This is one of a handful of times in my life where being bipolar did me a favor - there aren’t many - by giving me the ability to take this massive leap of faith and make a decision that had no reasonableness or thought given to it, but was essential to me getting where I needed to be.

Sturm: You were found to have bipolar disorder at age

16, right? It must have been tough to navigate this new diagnosis without a support system at such a young age.

Hall: Yeah, it was. We suspected something was going on with me because I had been quite erratic in my emotional pitch from early childhood on. Then, there was a suicide attempt at age 16, where the possibility of bipolar was raised. Still, my parents not being particularly helpful - that’s maybe the understatement of the year - they hesitated to diagnose me since I was still an adolescent. They wanted to wait until I was an adult and did not offer me any medication. I remember a social worker sitting at the end of my bed saying, “Do you think this might have something to do with your parents’ religion and the conflict there?” And I responded, “Yes, I do, but I don’t know what you want me to do about it because I can’t just leave and live on the street. ‘Cause, for starters, I’m a writer. I have no real-world skills.” (Laughs). “So if I leave home at this point, I will die.” I struggled for another three years before I fled to another country, hoping to start anew. My daughters are going to be 21 this year, and when I look back on my own life, and I think about them at age 19, I wouldn’t put them in charge of a pair of roller skates, let alone move to another country and start with no support system whatsoever. (Laughs). They agree. They told me, “You were insane, Dad.” I said, “Yes, literally, legally, and with medical certificates to prove it.” (Laughs).

Sturm: How did you manage to get through your daily life alone in a new country at age 19 while at the same time managing your bipolar disorder?

Hall: I was a British citizen, but I couldn’t claim any unemployment, so while I was looking for work, I was on income support which, back then, was £38 a week. I was paying £50 a week in rent, so I was already starting at a minus £12 deficit. I used to busk in the street to make up the rest of the bills and try to survive. Then, I



Kenton Hall & The Necessary Measures



Idiopath

did the most sensible thing that any musician living alone does: I got myself a girlfriend. (Laughs).

When you've been living with bipolar disorder for a long time, you don't consider yourself to be different; you are not aware that your mood swings are an aberration compared to anybody else. It's always been the case for me that the mania could be very useful up to a point. When it starts, you feel great and energetic, and you feel like you can do incredible things. You are able to make decisions and imaginative leaps quickly. But at a certain point, it becomes painful, and if it doesn't stop, psychosis is waiting for you at the end of the tunnel. The following depression would be crippling, sometimes so crippling you would switch off altogether. I was constantly pinging back and forth between these highs and lows. When I was young and resilient, the highs were so high, and during the phases in between, I would simply wait to get back to the high. It was like being a drug addict who walked through the molasses of depression with the hope of a rush coming. I remember, many years later, when I finally found a treatment that worked, I realized that I'd been in pain 24 hours a day every single day of my life.

However, my memories of life before treatment are a bit muddled and not necessarily in order, but I got lucky in one specific way, which is the driving force for a lot of my work: When I started looking at bipolar disorder

from the outside while I was writing my book *Bisection*, I went on a lot of forums, and I realized that a lot of people with bipolar disorder don't have the language to articulate what they're experiencing. They don't have any outlet for their feelings, which I find heartbreaking. I could articulate what was happening to me even when it was extreme. It's how I'm wired. Language never entirely goes away. And that's why I feel a responsibility because if I can talk about it, I should talk about it! Many people fear the consequences of how they'll be viewed and judged because of it. However, I've reached an age where I do not care what anybody thinks of me. I still have a thousand regrets from earlier years; the choices I've made, things I've done under the influence of mania in particular, or the things I failed to do under the influence of depression. But there's no changing that. What I can do is ease the journey for somebody else. They see some-

thing I've written or hear what I've played, and maybe they feel that life is doable with bipolar disorder. It's not always fun, but it's possible.

Sturm: Are you using your music as an outlet to cope with all your feelings?

Hall: Actually, I have to be careful with music because it affects me emotionally in a way that no other art form I'm involved with does. I live in a leveled place most of the time now, thanks to heavy doses of pharmaceutical substances, but music cracks through that. When I was not well, I avoided music altogether simply because it was too much. My bipolar disorder is a different type of inspiration. I am much more capable at capturing my emotional journey in music than I am in prose. With prose and film, I'm better at capturing what I see in the world and other people's emotional journeys. Whereas in music, I'm able to access my emotions. I started listening to and analyzing music at a young age, and my first thought was, "I need to do this!" Same with writing. I didn't want to just consume it; I wanted to create it.

Sturm: Is there any art form you aren't good at?

Hall: Yes, painting and drawing. My stick figures get sued by other stick figures for pretending to be stick figures. (Laughs). But music, writing, and acting are all

different threads of trying to put my emotions in order.

Sturm: Tell me a bit about your new albums: *Omnipath* and *Idiopath*.

Hall: I have been away from writing music for ten years and had a lot of emotions I hadn't put in order. I shoved them to the back of my mind while concentrating on getting well. I also had teenage children who needed a different focus from me. Many of the big dramatic emotions I had been coping with up to that point usually would have been parceled into songs over the ten years; they'd gathered up and needed addressing. Suddenly, it felt like music was the best way of doing that. That's how it ended up being a 33-track album.

Sturm: Yeah, I was wondering about that. That's a lot of new songs!

Hall: This is what happened: One of my old bandmates moved back to the city where I'm living. He threatened me to start recording again. At first, I told him I didn't want to. However, I had a dozen songs in a bottom drawer from when I stopped making music professionally, so a bit later, I said, "Okay, we'll do those." But as soon as I started recording, I started writing again. Before I knew it, I had these songs that were all part of the same statement. No one could tell me I couldn't do a triple album because it was my record company. Then it becomes a press hook. Since "man releases album" isn't the most exciting headline in the world, "crazy man releases crazily long album" sounds slightly more interesting.

Sturm: What kind of art did you do during those ten years before you started recording music again? I assume you couldn't ignore all your creativity?

Hall: I was writing, but I was writing in other forms. I wrote and directed a movie, *A Dozen Summers*. I wrote a play and lots of scripts and stories. I mainly was filming and acting. I pivoted into a different part of my creativity. People used to ask me, "Oh, so you act, and you write, and you direct, and you make music?" And I always respond, "Yes, I tried to pick as many insecure careers as I could so that I could be broke and a bit nervous all the time instead. I'd like to be insecure across the entire arts; that would be great!" (Laughs). I could have been a writer and director while also being an accountant, but that's not who I am. I didn't have a fallback position. All of my fallback positions were equally insecure as my go-to ones.

Sturm: So you've always been a writer, a musician, and a filmmaker at the same time?

Hall: I think of myself as a writer first, and then all the others spring from that. I don't make any difference in my head between writing a script and writing a song. It's different muscles and different outcomes, but it's all

storytelling. Maybe I should call myself a storyteller if that didn't sound horribly wanky. People will fight you in the street if you tell them you are a storyteller. And they will be correct. But that's it. I'm interested in people's stories. I know how chaotic it is inside here [pointing towards his forehead]. And I remain fascinated with what's happening inside the people I'm speaking to. I know that whatever conversation we're having, you also think 1,001 things, and I want to know all about them. So that becomes the genesis of wanting to tell stories because you hope, mainly if you've been through some of the struggles with mental illness, it builds your empathy. Because if you're self-aware in a good way, you realize that all that pain and everything you kept to yourself, other people are probably doing the same thing in their own way, which means that you have to be a lot more careful about how you speak to them. You have to be more considerate of other people's feelings because you can't judge anything on the surface. You can't judge people purely on what they say. You can't even judge people purely on what they do. In your younger years, you react to what's on the surface, and I learned a lot about people that I probably would have hated if I judged them on the first impression. But when you take the time to understand how complicated a human being is, you sometimes find real and more substantial connections.

Sturm: Does this mean your new album contains songs covering your experiences of those ten years you weren't songwriting?

Hall: This is purely coincidental, but the songs I'd written when I was last writing songs ten years ago came at the beginning of a new relationship. So some of those songs are about a new person coming into your life and the trauma around that. And then, ten years later, I was processing the end of that same relationship. I managed to get that whole story from my perspective on the album. I'm also talking about some other things I've struggled with or thought about, so it is a pretty good snapshot of me over the ten years with that relationship at the center. It's about new beginnings and losses, but also all the challenges I've wrestled with, including getting well, in the middle of that. It's nice to have a romantic relationship in there, because that's what most people understand. Additionally, I feel a lot, and I didn't get a chance to speak out about many of those feelings. Being a musician, that's when you get the opportunity to say it. So it's a very long love letter with tangents.

Sturm: Isn't a love song a must-have on any album?

Hall: You definitely get told that, but I think they always mean a "sappy ballad." There are ballads on this record, but I don't tend toward the sappy. It is a heartache record in a lot of ways, not just from the romantic perspective, but a heartache in terms of processing the world and seeing how much pain is in it. My songs are the empathetic response to it. The album also features



songs about toxic masculinity. I've realized it is easy to become toxic if you're not vigilant, even for a nice guy. So this album is about maturing to a certain extent. How you view your relationships with other people changes massively over a period of ten years, particularly if you're drawn to self-analysis, as I am. I have to be because I must ensure my emotions aren't pinging off in a dangerous direction. One of the hardest things when living with bipolar disorder is that when you approach psychosis, you don't know if any of what you think is true. For instance, I might suddenly believe I am a talented musician. But how am I supposed to judge whether I'm meant to be doing this or if I'm kidding myself when the first thing my brain might do is tell me that I'm better than I am or that it's all going to work out? It might be lying to me like a son of a b*tch. So I am constantly walking this fine line and asking myself: Am I making rational decisions? Am I making decisions influenced by the chemicals of my brain being mixed up by a cowboy? I've replaced the constant pain and reactionary way of living with a very vigilant process of questioning my decisions. And at times, you are desperate to make an impulsive decision while also dealing with the impatience and rejection that are part of the business. You are putting your face in the chainsaw a little bit because the people most capable of doing the job, meaning the people that are emotionally open, emotion-

ally aware, and able to write and to create, are at the same time the people that are hurt most by the brutal industry surrounding it. The level of rejection and apathy in the music and film business is extreme. Anytime you put something out in the world, you're not dealing with people saying, "This is terrible." You're mostly experiencing them asking, "So?" This apathy is the hardest because that's where you're constantly banging your head against a wall, trying to get through. Rationally, if you're competent at what you do, your audience is out there somewhere. It's not everyone; it will never be everyone. You have to find the people that will respond to what you do, but you don't know where they are. They're hiding amongst 8 billion human beings. And in reality, you need about 3,000 of them to keep your living going. And how do you get to them through all these gatekeepers, which either costs time or money or judging on their taste? You have to get through this wall of people in front of them saying, "It's not my thing. I like techno." Okay, but I don't need to talk to you. I have a techno friend. You talk to him. You introduce me to your singer-songwriter-liking friend, and we'll all balance this out. Dealing with that when you're also trying to be a grown-up and cannot go too far down the rabbit hole because you don't always come out is a big part of the job. You must arm yourself against it and be patient, but simultaneously, you cannot miss out on

those leaps you must make. It's a minefield, but you know, it's my minefield.

Sturm: How are you coping with the rejection and lack of empathy so that it doesn't harm your mental health?

Hall: It's a process. There are days when I feel it nudges me toward a darker way of thinking or feeling either desperate or despondent. But I know where my anchor points are. My kids are grown up, but they're still my go-to to shake myself loose of the beginnings of something. It's easy to go to them and just let them ramble at me about their lives, and suddenly my problems don't seem so terrible because I've got to focus. You can always find some dad thing to do or to fix. So generally, finding somebody else to help is my coping strategy. Going and finding another artist struggling with the industry - it's so much easier to deal with from the outside - and giving them a pep talk sometimes is the pep talk that I need. And it's easier to give it to somebody else. One of the reasons why we did the covers version of the album - other than it was at 4 am when I thought, "Yes, let's get 36 other artists to cover the songs as well because I haven't got enough to do." - was that it made the whole experience less insular for me because I was able to speak with other artists, and also being able to hear the songs reinterpreted meant I wasn't quite so judgmental regarding myself. I could listen to my songs as compositions because it wasn't my voice or playing. It meant during the whole process, I could celebrate other artists who had done these remarkable jobs. And that has kept some of the worst at bay.

Sturm: Tell me a little about how your other identities, for instance, identifying as bisexual, influenced this album.

Hall: I don't often talk about my sexuality because I don't want to be jumping on anyone's coattails. I am more like 70/30 or 80/20, and I don't know if that's bisexual enough. When the children were small, we talked about diversity with them and tried to bring them up to be quite open. Later, I would hear them say to one of their friends, "My dad's half gay." (Laughing). And I said, "Well, it's 70/30." (Laughing). They didn't have a problem with it because children don't until they're told. After growing up in an incredibly restrictive environment where everything was sinful and bad, and then coming out, it took me a long time to work out how I felt about anything. But once I did, I stopped caring about what anybody thought. I'm fortunate enough that I have a job where, the vast majority of the time, I don't run into an extraordinary amount of prejudice about my mental health. When you're in a group of artists, and you say, "Oh, by the way, I live with bipolar disorder," they tend to go, "Okay, yeah, I'm schizophrenic, and he's got anxiety, and she's depressed, and they're dealing with their own thing." Only when you walk into the regular world, where people are uneducated about it, you will get any kickback. For instance, I took a job



with a charity a few years ago, trying to get finances in order and doing communication. So I was writing and making little films for them. I remember having to tell the manager that I was bipolar. It was so weird because it had been so long since I'd seen that fear. This wasn't a bad person. This was a supportive person who wanted to do the right thing, but the immediate reaction was, "Oh, what the hell do I do?" And that reminded me of what it's like for other people living with things that the rest of the world doesn't understand. I have worked hard to get in a position where if anyone has issues with my mental health or sexuality, I can simply say, "So, I've lost all respect for you now, but never mind, just jog on." Most people don't get that luxury. They have to live in the world and be around people that don't necessarily understand them or have any desire to understand them. And that's another reason I feel responsible for talking about mental health. You have to be a positive force in the universe.

Sturm: I couldn't agree more. Thanks for speaking so openly about your mental health! I genuinely appreciate your advocacy and learned a lot from you today. I hope your album is going to be super successful. Take care and talk to you soon!

Hall: Thank you for having me. Take care. Bye. ■ **ABILITY**

kentonhall.wordpress.com

Welcome to Downtown



Autism Certified Destination

In downtown Visalia, California, next to the local post office, stands a lone sequoia tree, named The Legacy Tree. It is a very tall baby tree, if you will, planted nearly 100 years ago. Surrounding the tree, is a wide, extended, circular mulch and rock area, which indicates the projected growth of the circumference of the tree once it reaches maturity. Sequoia trees are considered the largest living trees on earth and can live to be 3,000 years old. They are known for their massive trunks which can reach 36 feet in diameter. As of 2015, the Legacy Tree in downtown Visalia had a diameter of 41 inches. It still has a ways to go before reaching maturity.

I found my visit to the city of Visalia, which has recently earned the title of the first “Autism Certified Destina-

tion” in California, and is also known as the “Gateway to Sequoia and Kings Canyon National parks,” to be both encouraging and heart-warming, as well as cause for reflection.

On one hand, I met extraordinary individuals and teams, doing everything in their power to do better for the community, dedicating time, energy, and money, for trainings for themselves and their employees. Braving new territory (new to them) has expanded their understandings of inclusivity, and has even prompted critical reflection of who else has been included, and who has not. Ultimately, everyone I spoke to expressed the joy of connecting with autistic people and their families, but also in connecting with inclusive goals for their business

own



and community. This desire to “do the right thing,” appears to be making a difference for community members, at least for those whose mindsets are being transformed. And it is Visalia’s hope that this Autism Certified Destination status will draw more families and individuals to experience the rich beauty and history of the city and its natural and cultural resources, without stressful attitudinal barriers and other access barriers that often prevent people from traveling.

On the other hand, upon interviewing a diverse array of autistic individuals and families, there were mixed responses to the concept of autism certification, and even to the writing of this article by me, a non-autistic individual. Before getting to these considerations for

reflection, let’s look at how this autism certification endeavor began and the growth that has been made.

When asked about the origins of this autism certification endeavor, Suzanne Bianco, Visit Visalia’s tourism marketing director, stated that an employee had mentioned to their board that travel options for families of children with autism were limited due to inflexibility and lack of compassion in many travel destinations. With that information, Visit Visalia’s board began to explore possibilities for eliminating barriers and creating a more inclusive and welcoming community for neurodivergent guests visiting Visalia. Their search led them to the International Board of Credentialing and Continuing Education Standards (IBCCES).



According to their website, IBCCES provides trainings and certifications in autism and neurodiversity for a variety of industries including healthcare, education, workplace, public safety & community, and travel & entertainment. Of the 19 board members of IBCCES listed on their website, 2 of them identify as autistic self-advocates. Mesa, Arizona is the first Autism Certified City in the United States (not to be confused with an Autism Certified Destination). Marc Garcia, the president and CEO of Visit Mesa, Mesa's destination marketing organization, is also on the board of directors of IBCCES. Under Garcia's leadership, Mesa, Arizona aims to become the nation's most accessible city. Visit Visalia received encouragement from Visit Mesa and IBCCES, and from there they devised a plan.

Over the past couple years, Visit Visalia has been reaching out to local businesses and incentivizing them to get training to make them "Certified Autism Centers," also a certification category offered by IBCCES. Businesses had to commit to the initial financial investment, but then received reimbursement from Visit Visalia once certified. Now that 42% of Visalia's key hotels, and 15 family-friendly attractions are Certified Autism Centers, under the criteria set by IBCCES, Visalia qualifies to be a Certified Autism Destination. At Visit Visalia's office in downtown Visalia, guests can drop by for a free "sensory backpack" if traveling with someone who is autistic, and if noise canceling headphones are needed, they can be borrowed as well. Sensory backpacks are also available at each of the Certified Autism Centers.

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sible to a blind visitor, they would provide a guided tour and describe the artwork and read the labels to the guest. This accommodation will be listed on the website. They have a ramp that leads to their art classroom where Arts Visalia offers art classes. They recently hired an American Sign Language interpreter as they have 2 deaf individuals who signed up for classes. Goans stated that the main takeaway they got from the certification experience is “to address the needs of the individual, not the diagnosis. Let the individual tell you what they need.”

Due to weather-related closures of Sequoia and Kings Canyon National Parks, I was unable to visit. However, their National Park Service website hosts a page about



Imagine U Children's Museum

their accessibility features. The page menu includes links to information for deaf, blind, and mobility access, as well as their policy related to service animals. Most notably, they have a new accessibility film series to give disabled visitors previews of what they can expect when visiting the parks.

As a sibling advocate and inclusion advocate, I appreciate the time, energy, honest self-reflection, and active changes they are making to be more inclusive. Most of the individuals I met have no personal connection to autism, but are driven by a desire to empower others through access to a part of their world. They are clearly passionate about sharing that world with others, and are willing to learn how to do so.

As an autism sibling growing up, my family never went on a vacation. Not once. In fact, the only place we went for fun was a drive-in movie theater (my siblings and I comfortably contained in the back of our old station wagon), or on afternoon drives to rural parts of our county (same station wagon), where my brother could run free and safe, and without risk of judgment or stares from others. (See my article entitled, “Almost Heaven” in *AwareNow Magazine*.) After visiting Visalia, I wondered if my parents would have considered a family vacation had there been an Autism Certified Destination. So I called and asked my 80-year-old father. With-



Visalia Adventure Park

out hesitation, he said, “Well yeah, of course.” I asked him why. “Because people would be understanding.” He isn’t alone.

Jose and Francine Moreno of Fresno, California, recently took their family, including their 2 young autistic sons, on a road trip to Visalia for that exact same reason. They wanted a place where people would understand and accommodate their sons’ needs and welcome their family. They were not disappointed.

I asked several other parents and autistic individuals for their feedback as well. Responses were unique, raw, nuanced, informative, and thought-provoking.



Tulare County Museum of Farm Labor and Agriculture

Dianne Olayvar, mother of an autistic child said, “In short — YES!! I am now inclined to visit Visalia knowing this info! We love to travel but due to my son’s needs it can be scary and challenging. It is very nice to hear that a region is educating themselves to be better inclusive, flexible, and accommodating to the needs of autistic families. Our kids work so hard to be a part of this world and unfortunately, there are too many people who don’t take the time and energy to welcome them back. Autism families can be very busy – from meetings to doctor appointments to multiple therapies in a week – not to mention the time it takes to support our loved ones through whatever they need additional help with

(communication, behavior, etc.)—that a vacation away from the comfort of our homes can feel daunting. We don't want to go somewhere and have to deal with the looks and sighs of the public or have to explain our loved ones. I think the more a place is educated and can support us, the more we can relax, 'vacation,' and make memories with our families."

Maria Nagy, mother of an autistic young man, responded, "Actually, it IS on my radar. We bought a camping van and I thought OKAY, that's a good starting point! And, I truly would like to see my city of Coronado get



on this! No excuses! Also, the autism certification for Sesame Place, or the Kulture City signage and supports at zoos, it's creating awareness, conversations and planning that can reach across disabilities when executed, and may move into a constant planning mindset."

Kavita Sreedhar, mother of an autistic individual, responded, "I would absolutely want to travel to Visalia because I know that my kiddo wouldn't feel judged there. Unlike some of the popular destinations like Disney and Universal who do not take into account developmental disabilities and sensory triggers for autistic individuals, and provide lip service or token support by providing a DAS (disability access service) return time pass which does nothing to improve their experience (5 rides in 7 hours in 90 degree heat and loud non-sensory-friendly spaces throughout made the 'Happiest Place on Earth' the most traumatic one for my kiddo last year). So this comes as welcome news!"

Judy Mark, co-founder and president of Disability Voices United, and mother of an autistic man, said, "I'm always for communities and businesses being welcoming and getting training. But we need to dig a little deeper. Has the school district been providing educational services that are needed, particularly to the children of the thousands of farm workers that live there? Have local businesses and citizens been politically supportive of fully funding the IDEA (Individuals with Disabilities Act). The Speaker of the US House of Representatives,



Republican, Kevin McCarthy, is from that area. Have the businesses given jobs to people with autism? This is where the rubber hits the road.

Shubha Bala, disability justice activist and parent of an autistic preschooler responded, "As a parent to a kid who is autistic and it is a visible disability for them, I recently went to a town where a store had some autism sticker in their window. And I was really close to finally bringing my son into a store! We've never done that before—in part because of the pandemic. But I thought maaaaaybe they won't stare at us, judge us, or yell at us, if he does grab things and do other things that basically any toddler would do, but it can be especially hard for us.

Also, I wondered, will they have awareness around his AAC (Augmentative and Alternative Communication), his unique way of communicating multimodally, and will they have more patience and openness to different communication?

For my son, how he is perceived can be compounded by racism – explicit or subconscious. So as he gets bigger and older, will people at least have an awareness of how him being autistic can impact what he says and how he moves? I'm not saying it would suddenly get rid of racism but is it one more inching towards him being able to be safer?

On the other hand, autism awareness means so many different things to so many different people. I have been wary about places that cater to autistic people. So often I've experienced people putting him into a box of 'this is how autistic people are'. Not every autistic person responds to social stories and a sensory corner. At least my kid doesn't. But I find that that is so often what it means. Or someone may think, I've gotten this training, so now I know how to interact with your son. What I actually want is a place that's been trained in disability justice and how to not be ableist. This means approaching ALL people as individuals with unique needs and ways of being. Not putting my son into an autistic box and missing him for who he is."



Otto Lana, who identifies as ‘a scholar and a baller who just happens to be an autistic self-advocate’ responded, “I think it is great they want to be more inclusive as a city. But I am cynical and think it is a cheap marketing ploy and a money grab from the certification board. With the CDC stating 1 in 36 people are diagnosed with autism, I am afraid they view us as a huge demographic of often desperate people looking for their tribe.”

Lana, continues, “I am cynical because I personally find it offensive that museums claim they are sensory friendly which really means they open early on a random Saturday once a month to accommodate the needs of ‘whoever’. Separate is not equal. I am bitter and triggered by this distinction. I was forcibly removed from an AMC theater when I was young because I had trouble sitting in my seat while watching Toy Story 3. After contacting the management of AMC, they said they were within their rights to ask me to leave and not refund my ticket because they offer ‘monthly autism-friendly screenings of movies’. When we explained that the (other) theater was not accessible and not near my home, my comments were disregarded. Also ‘autism friendly’ can often mean childlike or infantile. I have my hair cut by a guy with face tattoos, not a kids cut type of place. A real manly barber shop with hot rod magazines and beer in the fridge next to a strip club. The barber is the most patient and kind man you will ever meet. He does not have video games or Disney films playing on big screens. He does however have great skill and an attitude for inclusion.”

“I have never been to Visalia but did look up the city based on this new distinction. I have to say I was slightly horrified by the idea of the lanyard/bracelet with the yellow sunflower (Hidden Disabilities Sunflower Program listed on the website for Visit Visalia). If you have sensory issues you are not going to wear a yellow sunflower. And why do you need this labeling anyways? Shouldn’t the locals just help anyone and everyone with kindness and good customer service? I think a certification for Universal Design would be so much better, a certification that a city goes above and beyond handicapped bathrooms and curb cuts. Those are my

thoughts, but again, I want to preface that I have not been to Visalia so this is without actually seeing this inclusive action in practice.” states Lana.

Bella Santoyo, autistic self-advocate replied, “I wouldn’t be more likely to visit Visalia simply because, for me, traveling is easy. I do think many families may like knowing that they are visiting an ‘autism certified’ destination as it may give them peace of mind knowing that their child will be welcomed. I know several people for whom going away is hard such that they rarely travel. I do think disability awareness is important and I prefer that universal accommodations be made available to all who need it.”

Jillian Parramore, Disability Rights California board member and Autistic Self-Advocacy Network member, said, “First of all, *ABILITY Magazine* and Visit Visalia should have had someone on the autism spectrum visiting Visalia and writing this article, or you should have included your brother. Why were we overlooked? The city’s efforts seem to be more geared toward caregivers and parents than anyone on the spectrum who is looking for a vacation to go on.” Jillian also brought up other access needs sometimes related to autism such as economic feasibility, transportation, and dietary considerations. Jillian concludes, “I challenge people to do better.”

I think that’s one thing everyone can agree on. Doing better. There is as much diversity of opinions about autism awareness, autism certification, and what that means, as there is diversity in people’s personal experiences and individual needs. But Visalia’s citizens and businesses are wanting better. Families are wanting better. Individuals are wanting better. So how can we work together to determine what “better” looks like? What are the areas of growth we should focus on?

Visalia, beautiful, pure, and meaningful as it is, has a ways to go before its trunk fills up that prepared space surrounding it. It takes time to grow a mature sequoia, as well as a mature, universally accessible community. Planting a seed is just the beginning.

I say, go visit that Legacy Tree, The Sequoia and Kings Canyon National Parks, the museums, farms, fun parks, restaurants, and other attractions. Learn the history and culture. Get to know some extraordinary, inclusive, and growth-mindset people. And introduce yourself. Autistic or not. ■ **ABILITY**

To learn why I did not bring my brother on this trip, read *ABILITY Magazine*’s article on ‘Durable Accommodations’

artsvisalia.org
tularecountymuseum.org
adventurepark.com
visitvisalia.com

by Diana Pastora Carson, M.Ed.
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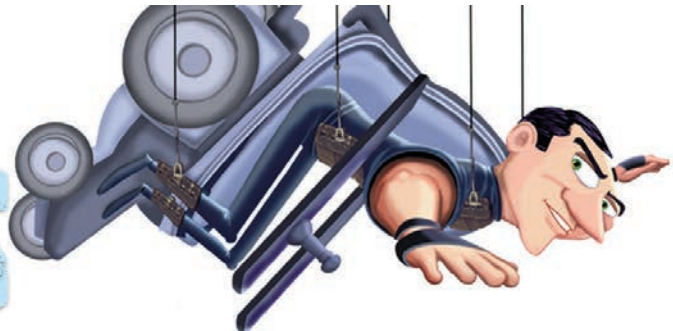
STAND ALONE



FRANCHISE



MEET THE SUPERCRIPS



Want to see a disabled character on the big screen played by a genuinely disabled actor? Want to get into NFTs? SupercripNFT is helping audiences do both by crowdfunding an original film from the filmmakers behind “Bottleshock”, “Shoot ‘Em Up” and the newly released “Coffee Wars” with gameable NFTs and a new blockchain currency. *ABILITY Magazine*’s George Kaplan and Chet Cooper chatted with the team behind “Supercrip”: actor Tobias Forrest, filmmakers Randall Miller and Michael Davis and “MacNerd” Steven McKeon.

George Kaplan: Can you tell us more about “Supercrip” and how everybody was attracted to the project?

Tobias Forrest: I had just moved out to LA. I had no intentions on becoming an actor or anything like that, but someone had told me about a Christopher Reeve acting scholarship that was through the Media Access awards. I had just gotten my master’s in psychology. I had to portray an old man with Alzheimer’s for my class, and everyone said, “You should be an actor.” And I said, “What? Uh, OK.” But this opportunity landed in my lap. I went to the audition. I did the old man with Alzheimer’s. I won the audition and I got a lot of money and I decided, “Well, let me try acting.” And at the same time, Randy was doing a movie and he said, “Toby, jump in as an extra on my movie.” It was really like my first job.

Randall Miller: The movie was called “Nobel Son,” with Alan Rickman and Mary Steenburgen and a number of other actors.

Forrest: Which also gave me the incredible experience of me being with Alan Rickman and hanging out with him one-on-one for an hour just talking about acting and theater and what a profound experience to be an extra talking to this huge star on this film set. And then fast-forward, years later Randy’s doing another movie called “Coffee Wars,” which is about to come out, you’ll hear more about that in a moment, and he said, “Toby, why don’t we throw you in this role as the head judge? The wheelchair doesn’t matter, it’s not part of the character, just like in the other movie, you just happen to be a guy in a wheelchair sitting at a table.” And now I just have more lines. (laughter)

Miller: Well, it’s more than that. He’s a pivotal character in the piece. He’s the nemesis for the lead character.

Michael Davis: The movie is about, in real life they have barista competitions, like the Olympics of coffee-making.

Miller: That’s true. This happens every year.

Davis: The story is like a “Pitch Perfect” but with coffee. It’s about a barista trying to save her vegan coffee shop, she needs to win the barista competition, but they don’t want her to use her vegan milk. She has to use real milk, and she won’t. And so it has this very green thing. But anyway, Toby plays this judge who’s had this big run-in with her in the past, so he’s kind of the antagonist of the story. They have this great scene where they haven’t seen each other for years, where she had flipped out on him, and now he sees her, but he raises up his

wheelchair so he goes nose-to-nose, eye-to-eye with her.

Forrest: He gets some leverage!

Miller: I have to say, the funny thing about it, we're starting to do the PR and press and stuff, and I was talking to the press people, and I said, "You know, we really should do something with Toby's character, with Tobias, he's a great speaker and a PWD and he can really speak to all of that." And the PR people were like, "Well, I don't know if that's right," and I'm like, "What do you mean?" "Well, he's not really disabled, is he?" And I'm like, "What are you talking about? He is!" He was so convincing that they didn't believe that he wasn't a disabled character who was actually disabled.

Miller: And that's the issue that we're addressing with "Supercrip", in a way, that people—for years, the lead characters in a lot of movies would be someone who was an actor playing a disabled character in order to show what great acting talent they had.

Davis: It's like Daniel Day-Lewis in "My Left Foot." He is not disabled, but he has to go for the role that'll give him the Oscar because he gets to play a disabled person.

Miller: So Toby and I, we know each other, and one day Toby drove out to our house in his van, and I was shocked, because I didn't know that he could drive and he recently got a van, and we started spinning on this idea of, "What if Toby was an Uber driver who picks up a famous actor and through the course of the story, the two of them might find out that they're going after the same role."

Davis: It's a funny buddy comedy.

Miller: Yeah. So that was the beginning of the idea of the movie "Supercrip," which addresses the idea of a disability, of people being portrayed correctly in movies. And then about a year or two later, after we did the "Coffee Wars" movie and we continued to work on "Supercrip," Michael and I got together, we know each other from years ago film school. He's amazing, a filmmaker and also an illustrator, and we started coming up with the idea of how to create this artwork that would flip the whole thing on its head, which is what the "Supercrip" NFTs do.

Davis: If you think about it, you have all these abled actors playing disabled people. We decided to parody it by taking a disabled actor, Toby, playing all these super-abled people to make the point. What if we flipped it around and only people like Toby go to play Superman? And then the Supercrip campaign is going to raise money to start the process of getting the Supercrip movie made, which is promoting this, but also it'll give a portion of the proceeds to different disabled organizations and also give away scholarships for disabled actors to

maybe make their short film portfolio piece or acting classes and all that kind of stuff.

Forrest: Which I think is cool, because it aligns with what ABILITY Corps is doing, what abilityJOBS and abilityEntertainment are so focused on, "Let's get people opportunities to be employed and to do the thing they want to do, to live their passion." That's the problem right now, the disparity, that performers with disabilities will only be considered for a job where the character has a disability. They'll never be thrown in as just the uncle, the father, the doctor unless it says "with a disability," "in a wheelchair," "blind," whatever it might be. And if it's a major role, that'll go to a major named actor because they want to sell the movie and to be able to get the funding for the movie. We want to eliminate that factor and say, "We can take a great named actor and put him or her in this other great role and we can filter the movie with other great actors and also other performers with disabilities in roles that aren't disabled, that are characters with disability." And then we have the opportunity. It's great that it aligns with what you guys are doing.

Miller: The essence of the movie is the idea that in part of the movie Toby's with a group of people who always get put up with roles, but essentially in the end, a major able-bodied actor will get that role. The crux of this movie, which is the real essence of this movie, is, what if a character like Toby goes up for the role against a famous actor who's trying to prove his chops, trying to play the disabled character? If you really make that conflict strong and honest and tell both sides of it, you can see that this is something that really shouldn't happen. In this day and age, it shouldn't happen. You should have authenticity across the board.

Davis: You probably can show the star actor, you can see how selfish he is about wanting to get this role and his fame and the money and all that kind of stuff, and he's willing to do anything. He kind of wants the Toby character, he wants the shadow, the Toby character, to learn how to act like a disabled person, so he's extra-friendly to the Toby character. He uses him.

Chet Cooper: Is it completely written already?

Miller: Yeah, yeah.

Davis: It's a great script. It's a really fun script.

Forrest: It's not a far cry from my real life, if you know what I'm saying, in the sense of struggling artist.

Davis: It's basically a buddy comedy. It's sort of like a Butch and Sundance, although a slight focus is on the Toby character and his challenges. But basically you have Toby, who really wants to launch his career as an actor, and he's struggling, and then there's this big superstar, and he wants to be known as a real actor, not



Michael Davis and Randall Miller working on artwork for Supercrip

just an action guy.

Miller: He's had a problem where he's done something horrible and he needs to be reinvigorated.

Davis: Now he needs to rebuild his career, so he figures if he plays this great, gigantic disability part that's destined for an Oscar nomination, he can make his career great. In the meantime, if Toby, who's more able to play this authentically, can get the part, he can really make his career. These two guys don't know that they're up for the same part, so the superstar is kind of using Toby, watching him. "How do I make my performance work? I'm going to watch Toby."

Forrest: It's a character study, yeah.

Miller: It's funny, but it also has something important at the bottom of it, which is also what the NFT thing is. It's like, there's something funny about it, there's something colorful and funny about it, but there's a real essence to it. I think that if you make it entertaining and inviting and it's a fun movie, people will gravitate towards it. They don't feel like they're being force-fed some sort of concept. They think it's part of what they want to learn about and they enjoy the experience, and then they go, "Yeah, sure, it should be that way." And then things start to change. That's my thinking, at least.

Kaplan: You told us more about the plot. How did you land on NFTs to fund the film and the charitable aspect as well?

Steven McKeon: That's probably due to me. I haven't done much talking here. I'm a technical nerd, I guess you would put it, not to go for the nerd stuff here. I've been in IT and software for 25 years. I've run multiple software development companies. We make blockchain products. I've been in this space for nine years. I have a quarter million followers on Twitter, I'm well-known in this space, and I really like what this technology is. Recently in the news you hear all these different things, but the technology itself is sound. There are just always actors who try to take advantage of others, and it happens occasionally. The technology is revolutionary, and it will change the world. I just like building in this space.

Randall got introduced to me by a marketing company months ago. They didn't really take good care of him. He ran into a development team that took advantage of him. I said, "Listen, I'll take good care of you." I cleaned it up. I tried to make sure I was taking good care of him as a friend. He's a really likable guy, and I like what the cause is. My mom's also disabled. The books would also say I'm partially disabled, too, because I have ADHD, I've been clinically diagnosed with that, and I'm a little bit on the spectrum. But I think I've made it further than other people would in this position. I'm always trying to help people who have been marginalized a little bit by our society. It's really important to me. I think it's trying to put a bright light on an area that a lot of people don't want to talk about, but sometimes you have to have that uncomfortable conversation to make change.



Lames Bond



Aqua Sushi Roll

Facilitating the technical aspects of it was challenging. I don't know how much you know about NFTs or what that even stands for: nonfungible token. It's an entity on the blockchain. There are some technical challenges. This isn't just one picture. These are animated pictures. We had to generate and create our own code to make all this work in a fashion that'll still be efficient enough to look good on your web page or your phone, but it'll still be high enough quality for the movie buffs here who want 4K videos for everything.

Davis: I gave him the original artwork in 4K.

McKeon: Oh, I love the quality, it's just nobody can download it. (laughter)

Davis: When you get the Lames Bond in his wheelchair, it's not just an image, you get the machine guns firing out that Aston Martin, he's got a smoke screen, so all these tokens are animated.

McKeon: They're like little mini-movies.

Davis: They're not just images.

McKeon: There was no software out there that would generate them the way we needed it for this, so we had to make it ourselves. It's a unique way of generating these things. It's a unique art. There's nothing out in the NFT space that's even remotely close to what this is. I think it's also a hybrid between creatives and technical people for the first time. This is another medium to get stuff out there to help support the movie and the cause. That's how I see the ecosystem. We're also creating a token besides the NFT collection. A token is financial. It's actually like bitcoin and you can trade it. So we're already in the process of creating that.

Miller: And the idea on that is, we'll create a portion of that that as people buy and sell the token, there's a bit of

money that's then used not only for this film but for future films that have people in front of and behind the scenes.

McKeon: We take 5% of any transaction that ever happens. If you buy, sell, or trade this token, it's goes into this wallet. We'll be using that as a reserve for causes. Besides the selling of the NFTs, we're also creating a money system to support the NFTs and also there will be a game that you can race in, kind of like a Supercip derby.

Kaplan: I'm curious about this video game, this racing derby.

Davis: It's a side-scrolling Mario Kart.

McKeon: Exactly, that's the best way to put it. You are good at pitching, Mike. It's a two-dimensional thing. They tried to make this three-dimensional, but I think the way he did it is better. They're racing across each other with little things, you'll have to jump over rocks and like that, and they can fall. We basically want to gamify the experience of using NFTs in a game that they can earn some tokens from. And just by having that going on, we're automatically helping the cause.

Davis: When people buy these NFTs, they're buying first of the artwork, but then the artwork is sort of a membership or gives you access to other things. One of the things would be the game. They call it a utility. You're not just buying the artwork, the token gives you benefits. And Randy and I originally got into NFTs because we had seen that there was this animated series called "Stoner Cats" that Mila Kunis and Ashton Kutcher crowdfunded by selling NFT tokens of their stoned druggie cats that are the funny characters, and they raised the money to make this animated series without having to run around and raise financing. They raised it through basically selling these tokens. Their utility was,

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which is sort of a weird game, why would Andy Warhol blow up and be worth a million dollars, when it's just a weird Marilyn Monroe. People buy fine art because it can go up in value. Well, with these NFTs, the ones that were the most valuable were the ones that were rare that only had certain details. A lot of times when they had these campaigns for the artwork, these people who were art investors would try to buy gigantic swaths of them because they were hoping to get the one that was super-valuable that they could later resell. That's where the tradition of, when you generate these NFTs, that you randomize them. It's sort of like a gumball machine where you open it and you don't know if you'll get a green one or a yellow one coming out. it's kind of like, it's the luck of the draw.

Miller: And that's how people buy them, too. You can't buy a particular one. When you buy it, you don't know which one you'll get. We don't know which one you'll get.

Davis: You might get a high-powered one or a medium-powered one.

Kaplan: Oh, so it's randomized?

Miller: They're all completely randomized.

Cooper: You get to choose if it's Lames Bond or not?

Miller: No, you don't. All randomized. I can explain the rarity, too. In addition, to add to the rarity of it, there are three levels: super-powered, where there are five characters, and then —

Davis: And how many of the super-powered ones?

Miller: Ninety-nine for each one of them. So that's 5 x 99, 495 of those. And then there's — what's it called?

Davis: Hero? I don't know.

Miller: There are three different levels, super-powered, franchise, and — I can't remember the names. The second level has 200 of each one of them.

Davis: So less rare.

Miller: And there are seven of those. And then the last level, there are 300 of each of those and there's 12 characters. You can see that there are some that are the most rare and some that are less rare. But that doesn't mean that you could get one of the other ones that's in the 300 grouping that might have a higher power rating that makes it even more rare than the other ones. It's just that there's less likelihood that you'll get the most rare one.

Davis: And the one reason why it's good to randomize is, like I said, it's like a fine art market. A lot of people collect the artwork, but then they resell them if they think they go up in value. Not that it's a good thing. We want people to buy it for the utility and support the cause, but some people are like house flippers. They take the NFT artwork and they flip it. And oftentimes the creators buy their own NFTs to support their own project. They own their own NFTs, but they don't want word out there that the owners are secretly getting the super-rare ones because they'll be more valuable.

Davis: If Randy and I were to buy tokens, we don't know whether we'll get a rare one or a medium-rare one. We don't control it. It's all randomized. that's what makes it fair. It prevents people from putting something out on the market and then holding the super-rare ones for themselves.

Miller: I said to Mac, how do we do the same thing, and I don't mean to use this term, because I don't know whether the term is used, the money token thing. How do we do the same random thing, where we can't con-



Tobias Forrest and friend

trol it? He said that the way to do that is, there's a contract. We don't own any of the actual tokens. We have to buy tokens just like anybody else would buy them. The only thing, the thing that goes back to "Supercrip" the movie and all these ideas to help all these different charities is this five percent, and the five percent, over time, if it's successful, can be a significant amount of money, because every time someone trades, it's 5% that goes back.

Cooper: That's what I wanted to get at. Don't you want people to keep flipping them?

Davis: Yeah.

Miller: Yeah, they do naturally. Like when you look at the most famous one, the Bored Ape Yacht Club (BAYC). The flipping of it is where the people who had the original idea, that's where the money goes to. It's a little piece, like five percent.

Cooper: But once you've made that five percent, that's it, unless they flip. So it seems like you should try to figure out a way to incentivize or at least say, "Here's how it works. Flip it to your friend. Have your friend flip it to somebody else." (laughs)

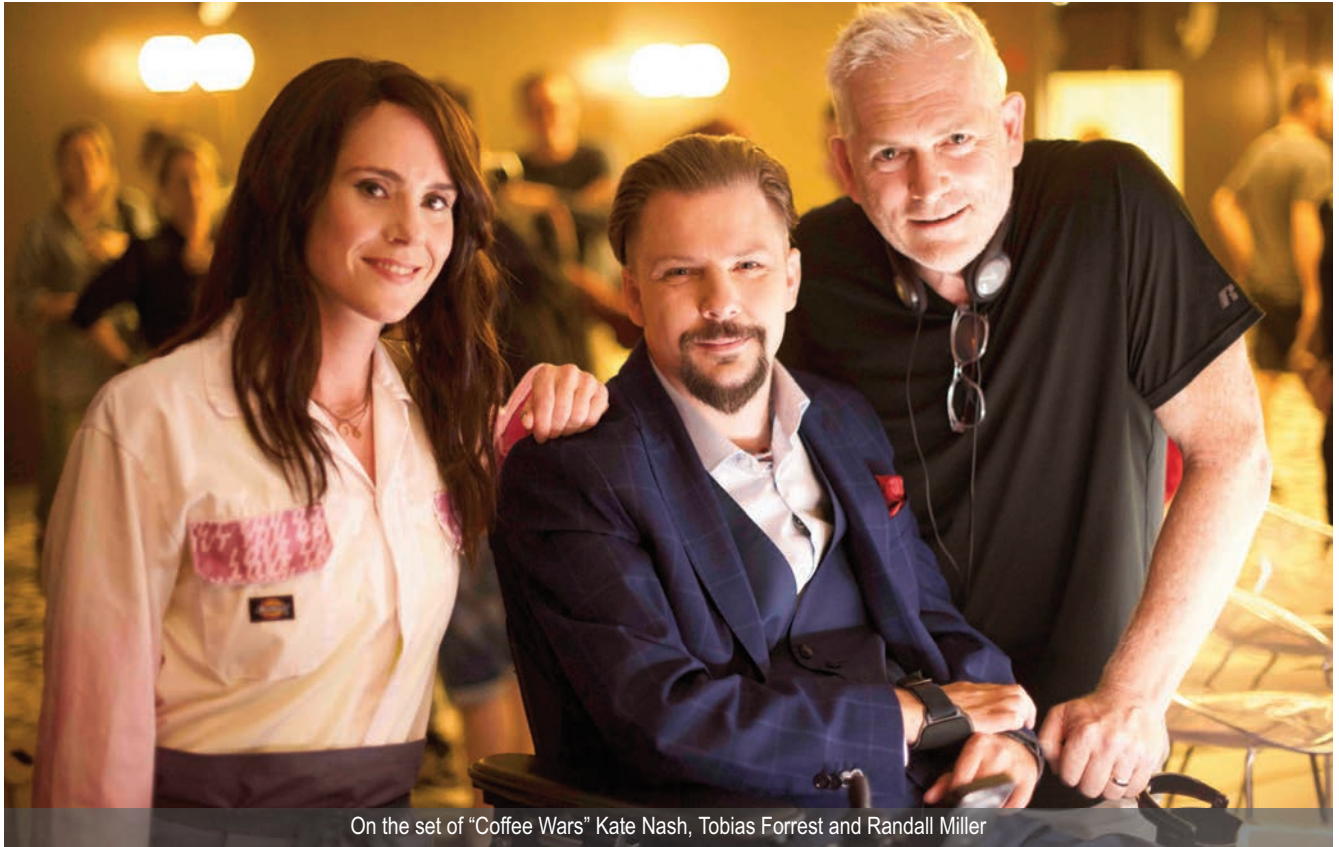
Miller: No, no. In the beginning, when we sell these NFTs, about 80%, 7% is going to fund the "Supercrip" movie. That's what's happening.

Cooper: Oh, after the fact.

Davis: But that's a higher percentage of the original sales are also going to charities and scholarships, and later on, once that's given out, then we continue to fund those scholarships through this 5%. But just to give you a background, have you guys ever heard of this NFT artist Beeple? He's the biggest guy in the world, like Sotheby's. One of his pieces of artwork sold for, like, sixty million dollars. The great thing about NFT artwork, unlike if you were in fine arts like Jackson Pollock, once he sells his painting, let's say the first time he sells it for ten thousand dollars, that's all he makes. But now MOMA buys it for twenty million, and he doesn't get a piece of that.

In the NFT world, they build in a small percentage of every sale. Every time Beeple's thing sells at Sotheby's for sixty million, he gets a piece of that, a small piece of that, but it's really significant. So over the lifetime of the artwork, when it's traded, the artist always get a little commission on each sale. I really like how that democratizes and helps the artist participate in the growth of his artwork's popularity.

Forrest: The point being that we want to be able to correct that wrong, we all see it, and in any other industry it would have been addressed by now. How come the person at the front desk can't be someone with a disability? How come the CEO can't be someone with a disability? So we're—you know the percentages, I'm sure, Chet, that 20% of the population has a disability and less than 1% of characters with disabilities are performers with disabilities. It's a really disappointing and disparaging number, and we want to correct that number.



On the set of "Coffee Wars" Kate Nash, Tobias Forrest and Randall Miller

Cooper: You guys have put together, the NFTs, the gaming, the power, and the movie. There's a lot of moving parts, pun intended. Do you have an NFT with any coffee?

Miller: (laughter) No. If you look at these various characters, you can see them around me, they're all the most famous—I won't use their names, but they're the most famous movies' most famous characters. The idea is that if you just step back and say that your regular audience goes to see Marvel, to see Disney, to see these gigantic movies. If they actually looked at those movies and thought for a moment, even for a moment, even in a comedy moment, they thought, "What if this guy or woman who's the lead character were a disabled person or had been a disabled person ten or twenty years ago in this movie, this series I'm watching?" Probably their point of view would be shifted. Just like the way I remember distinctly the moment that African American characters became much more—there would be an African American lead, an Asian lead, and you would just assume that that's the way the world is, which you're supposed to assume in real life, if you're a normal person.

Miller: But they haven't done that with disabled characters yet. My thinking is, if I can shake that up, there's no reason why Toby shouldn't be—and I'm not trying to disparage Peter Dinklage or anything like that, but no reason someone like Toby can't be what Peter Dinklage is now. He's a movie star. They put movies around him. Something was just announced on IMDB about a mov-

ing that he's doing with somebody else that has nothing to do with the fact that he's a little person at all. He's this famous actor now. It feels like we should have people in wheelchairs, just like we have other things, Marlee Matlin is now a movie star, there should be a person in a wheelchair who's a bona fide movie star. That should exist.

Davis: Yeah, many, many of them.

Forrest: I think Michael's right, we need a lot.

Miller: That's how we came to this idea. How do we put this out in a way that'll make people think about it differently?

Cooper: What did you say, Toby?

Forrest: I said Michael's right. How many white Chrises are there on "The Avengers"? It just seems crazy.

Davis: But it also can just be normal, why can't we have a "Harry Met Sally" where one of the characters is PWD? We love Billy Kristol because he's funny and we have empathy for him. That part doesn't rely on him being able to walk around. All the charm in that movie is his personality and his force of character. Why can't we have more disabled actors who are so charming or funny or great playing that part and having a great romantic comedy, and then they become a star? ■ **ABILITY**



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Col NEEDHAM

Founder of IMDb—A Movie Lovers Hollywood Story

British software engineer Colin Needham's fascination with movies began at the tender age of 5 when he won a coloring contest to see a movie in a theater. His passion with films lead him to start a diary to keep track of movies he watched and catalogue all of the details connected to its production.

The diaries morphed into a printed resource book. In the early '90s the database was available on the web called IMDb, acronym for Internet Movie Database. Amazon acquired IMDb in 1998, and has grown to become the world's most popular source for movie, TV and celebrity information.

As a subsidiary of Amazon, IMDb is based in Seattle, but Col Needham's office remains in Bristol, England, where he founded the business. From Amazon's office Col met remotely with *ABILITY Magazine's* Chet Cooper to discuss IMDb and to share his enthusiastic support of the Easterseals Disability Film Challenge.

Chet Cooper: Do you typically go to Amazon's London office?

Colin Needham: No. I have mostly been working from home for the last three years. But I'm in London today for a dinner this evening. I'm basically borrowing room in another person's office. (laughter) I do have an office in Bristol, in the southwest of England. I am reminded that it was literally three years ago this week that the

UK pandemic lockdown began. And as we all were, having to adjust to working from home, I got a lovely invite from Nic Novicki and Easterseals, to be a juror on the Disability Film Challenge.

I think the Film Challenge had already chosen Documentary as the theme for 2020. So, the first set of films was all documentaries. So many of the filmmakers made the very smart pivot to make a documentary about lockdown and the pandemic. There we all were, in our isolation, and I found myself on the jury of the Film Challenge. It was a breath of fresh air to watch the stories that had been told and to admire the creativity that had gone into each one.

Cooper: So much talent.

Needham: Yes! And all of this was in a matter of weeks. I'm trying to remember the exact timing, but I do remember it being early in the lockdown period. And despite the situation, people had come up with amazing stories to tell from a documentary perspective. It was one of my escapes out into the real world from my location all alone with my family in Bristol in the UK. It felt like this kind of global film competition with such amazing stories to tell—I was thinking, "Oh, wow, this is such an important thing and it's so great to get these stories out there." That first year being on the jury, then the following year I was invited back. And I was like, "Oh, I would so love to be on your jury again." And now it's



Col's first and second computers. 1990 Diary of movie notes.

reached the point where—I don't know if I'm should say this, but I'd be disappointed (laughs) not to be asked. (laughs)

Cooper: (laughs) I'm sure you'll be asked.

Needham: It's such a good competition. I'm one of these people—oh, I'm sorry, I should let you ask some questions! Do you want me to continue down this thread? Is this OK?

Cooper: Yes, please keep going!

Needham: (laughs) OK. My all-time favorite movie quote is from the 1991 movie, "Grand Canyon" directed by Lawrence Kasdan. Steve Martin's character says, "All of life's riddles are answered in the movies." The way that quote speaks to me is through seeing a film, a feature, a short, a documentary, it can take the audience member, like me on a journey to another time period, another culture, another language, another person's experience. I'm not for one second saying that watching a film about something is the equivalent of somebody else's experience, but it at least lets you look inside their world.

That's one of the things that drives me about film and inspires me in terms of IMDb and the way it can help a storyteller reach their audience somewhere in the world via some technology (laughs). And even if the opportunity is to watch something only via a phone, the more people can hear and see stories from other people's perspectives, the more understanding there will be between people. I'm a great believer in the more movies you see, the better the world gets. But I genuinely believe that.

So, to participate in the Disability Film Challenge is such a great honor from that perspective and gives me the chance to hear stories from people throughout the disability community. That's why I found it great. So

sorry! Now you can ask me a question! (laughter)

Cooper: Staying on the theme of what Nic has developed, have you also heard of the Focus on Ability Short Film Festival out of Australia?

Needham: I have not heard about them. [quickly looking for somewhere to note that down]

Cooper: You could go to *ABILITY Magazine* and read our interview with Jess Orcsik about the making of Focus on Ability. She's from a legendary acting family in Australia. They helped create it, the festival reaches millions in multiple countries.

Needham: Wow!

Cooper: I wanted to dig a little bit into your younger years, you've always had a love for film, and you started this when you were 14?

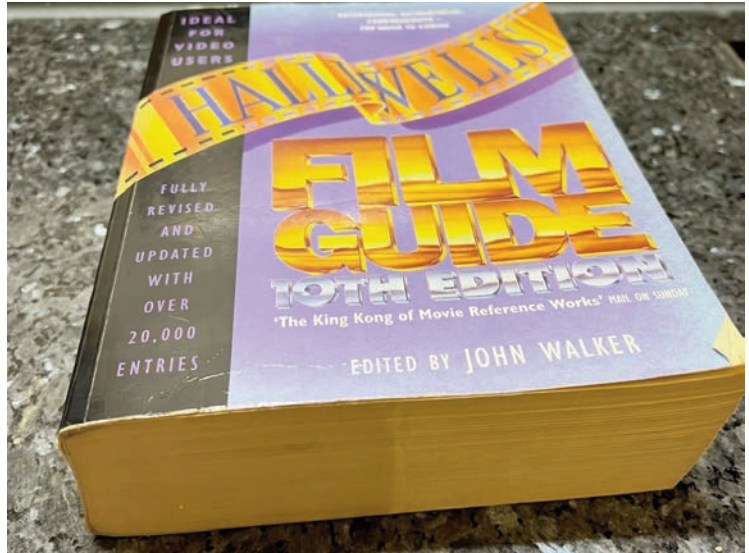
Needham: Yes! (laughs) Yeah! I could talk for hours, so I'll keep it kind of focused and short and to the point. Essentially, I've been obsessed with film since I saw my first movie in a theater when I was five years old. I'd won a coloring competition in the local newspaper, and the prize was two tickets to go see a movie. I went along and I fell in love with film. From that point on, all I wanted to do was to see more movies.

Cooper: What was the movie?

Needham: The movie was a re-release of "Snow White and the Seven Dwarfs."

Cooper: You were five years old?

Needham: Yeah. there's a little funny twist to this story, so I might as well tell you now. I was staying with my grandmother and she said, "Hey, would you like to enter



Years of diaries and print addition that became IMDb

a coloring competition.” I don’t even know if five-year-old me understood what that was, but the local newspaper printed a scene from “Snow White and the Seven Dwarfs” with no colors. I did my best to color between the lines, and I won! It’s so funny, my mother keeps everything. I’m just looking something up on my phone to show you. [showed picture of letter]

Cooper: That is wonderful.

Needham: The funny thing is, she didn’t keep what I colored, but she kept the letter from the newspaper telling me I had won. And this is the thing that began my passion for film, my hobby, my role, my career, everything I did all began with this coloring competition.

Now, 15 years ago, I was talking to my grandmother about the coloring competition, and I said, “You know, IMDb, it’s all because of the coloring competition.” And she looked at me and she said, “Ooohh!” And I’m like, “What do you mean?” And she says, “I’ve got a terrible confession to make.” And I’m like, “What? What?” And she said—

Cooper: (trying not to laugh)

Needham: You can see what’s coming, can’t you? She said, “After you went to bed that night, I couldn’t help but go over all of the bits that you missed and all of the colors that you got wrong and everything.” And I’m like, “Oh, my goodness! Everything I do is all based on a fraudulent coloring competition entry?” (laughter) “Oh, no!” What do you do under these circumstances? But there you go.

Cooper: I think you need to give everything back, shut down the company—

(laughter)

Needham: Anyway, back to the brief plot, I’m the right age for “Star Wars,” the first “Star Wars” movie, for the birth of the home computer revolution in the UK and the home video revolution in the UK. Those two things were both happening at the end of the ’70s and the early ’80s. So, I found myself in 1981 being in the position where I was seeing so many movies on VHS tapes that I could no longer keep track of what I’d seen and what I hadn’t seen. I got a paper diary, and I would write down what movies I saw on what day. But I’m also interested in who wrote them, who directed them, who was in them. So, I went to my very small home computer and created a database. I used to rewind the VHS tapes and type in the credits, just for my own use. That’s the birth of IMDb, my teenage film diary.

I got online in 1985. I met like-minded people on the Internet in the late ’80s, and then in October 1990 launched the very first downloadable IMDb software and data before the Web existed.

Cooper: In 1990, sure, early.

Needham: Yeah, so early.

Cooper: That was barely the World Wide Web. That was pure Internet.

Needham: Pure Internet, before the Web existed. It was just a group of volunteers like me, passionate about movies, wanting to share their love of movies with people around the world. We would never meet. We would never even do a video call because video calls didn’t exist. It was all done by email. It shows you—a lot of the time people can have a negative view of technology, but it allowed a group of people to collaborate on this all without ever meeting, from different places throughout the world, different first languages, but we all spoke English, and we were able to work on this.



Col Needham, Olivia Munn and Kevin Smith at IMDb San Diego Comic-Con 2018

So, we launched a website in 1993, and we were one of the first 100 websites to launch. Again, it was all volunteer, and it was just on a college Web server. It grew so big by 1995 that we couldn't really do it as a hobby anymore. We had to choose between closing it down or seeing if we could incorporate as a business and work on it maybe in a professional capacity.

This was in the very early days. We didn't know if it would work. We bought our first server on a credit card. I sold our first piece of advertising two weeks later and was able to pay off the credit card. By the summer of 1996 I had enough confidence that I could quit my day job and become our first full-time employee. And then as the business grew, we would convert our different volunteer shareholders into full-time employees as we could afford to pay them.

That ran very, very nicely for the next two years, and in December of '97, I got an email from somebody working for Jeff Bezos at Amazon. It said Jeff would be over in the UK and would like to come and discuss some business ideas. We went along. Jeff explained how Amazon was going from selling books to music to movies, and what would we think about a potential acquisition? It sounded like such a good partnership. There we were and over the course of just a day we decided thinking, "We should go for that." So, we became Amazon's first-ever acquisition in April of 1998.

We've been part of Amazon ever since, and during that time IMDb has grown from strength to strength. We have 200 million customers who visit IMDb across the Web, across apps every month. We offer IMDb Pro for

people within the film industry as a subscription service. It's just a joy to be in this role doing this for all these years—that's how we got here.

Cooper: Amazon's grown a little bit since you met with Bezos?

Needham: Yes, they have! (laughs) Just a little bit. And it's been a great partnership. IMDb's developed things independently, but during that time we also do things together. IMDb helps power the FIRE-TV experience, so you look up a movie or a show on it you'll find IMDb ratings and trivia, cast and crew. We also have a feature called X-Ray, so if you're watching a movie on your FIRE-TV and you press the Pause button, up will pop the head shots of the people in the current scene. All of that is powered with IMDb information. If you ask Alexa an entertainment-related question, there's a good chance she will answer using IMDb information. We've kind of stayed true to our mission, which is basically to power the creation, the discovery, and the enjoyment of entertainment everywhere. But everywhere keeps getting bigger! (laughs)

Cooper: (laughs) Do you travel much? You have a global industry now. You could be anywhere and do business, really.

Needham: And again, that's the power of technology. I used to travel a lot more prior to the pandemic, but these days, one of the beauties of the world is that we have the magic of Zoom. Virtual film festivals mean people can attend things without needing to be physically there. So, I don't travel as much as I used to, but I do still



Karen & Col Needham and Jeff Bezos

travel. We were in Sundance earlier in the year.

If you think about these things from an accessibility perspective, the ability to attend a film festival without necessarily needing to travel to the physical location is a good thing. It's only a good thing. Who knows where things are going with VR goggles, they may eliminate some of those final boundaries, and that may mean you can actually have that experience.

I remember back to 2020 the Disability Film Challenge awards were all done on Zoom! (laughs) All of the jury coordination, the evening itself, everything. And then we were able to go live via Zoom to different locations. It allowed us to go wherever people were. I'm very passionate about entertainment, and I'm also very passionate about how technology can help the world. (laughs)

Cooper: I one hundred-percent agree. I think COVID has moved us forward. It's now set in our psyche, we understand that we have the capability to connect in this way now. Also, websites are becoming more accessible. At ABILITY Corps, we've built websites, the technology is evolving to be fully accessible with screen readers, navigation standards, Alt text, etc., it's opening up the world.

Needham: Yeah!

Cooper: Have you come out yet to LA for the Film Challenge?

Needham: In the last three years, I've only been in LA once. (laughs)

Cooper: Maybe next year you'll come out.

Needham: Yeah! Although now, it's one of those things where you don't know—because I've done it so long virtually, I wonder whether I would betray something by doing it in real life.

It's been so fun to work with Easterseals. IMDb Pro helps our professional customers get discovered by helping them promote themselves to the industry. We were looking for ways we could be more inclusive and accessible. So Easterseals is a great partner to work with from that perspective.

We began this journey asking how IMDb can help people get discovered? How can we help the industry professional make more inclusive, authentic and equitable hiring decisions? Particularly for on-screen talent. Those questions led us to the last piece of the puzzle, which was essentially granting people with disabilities access to IMDb Pro for free and allowing customers to claim their page. We worked again with Easterseals to make sure our customers are comfortable, and give the opportunity to identify as part of the disability community. IMDb also provide tools that allow people making hiring decisions to discover those people.

Each person decides how much information they want to share. And also, just in the interests of full transparency, this access for PWD is kind of like a free tier of IMDb Pro. IMDb Pro still exists as a subscription service, and obviously you get more with a paid subscription, but we are providing free access to people to claim their page and be able to describe themselves so



Col and Karen Needham

they can be authentically hired. It's one step along the road of many steps that we're happy to be taking.

Cooper: Interesting. We too were early adopters of the web. *ABILITY Magazine* got online in late 1993, and in 1995 we launched abilityJOBS.com, the first job board for job seekers with disabilities. Amazon is one of our Leading A-D-A members.

Needham: Oh, great!

Cooper: In addition, we support abilityEntertainment (abilityE.org). [I can show you on my screen]

Needham: Yes, I'm seeing it on my own laptop.

Cooper: There are thousands of performers with disabilities. It's searchable by very specific disabilities. For example, Netflix asked us to find a young person with a South Asian accent with a disability, and Disney TV Animation asked us to find a voice over actor who is an authentic wheelchair user. Many roles have been filled thanks to our talent search capabilities.

Needham: Wow!

Cooper: abilityE is nonprofit and free to talent.

Needham: I like that, the more people working on disability inclusion, the better for everyone.

Since Col Needham was so excited to be a judge in past Easter Seals Disability Film Challenges, ABILITY minds wanted to know if Needham would return. Cooper contacted the Film Challenge's organizer (and friend of ABILITY), Nic Novicki, for a comment.

Novicki: It's truly an honor to work with IMDb. It's a site that I've used throughout my career as an actor, as a producer and, ultimately, to find talent. They've really



helped us make the Film Challenge possible, grow and become more exciting. The fact that Col Needham, the CEO of IMDb, is a judge is truly an honor. He's been a judge since 2020. And every year, it's just so incredible to be able to get the input and the ability to have someone of his stature in the entertainment industry and the business world reviewing these films.

Cooper: I think I know this answer. Will you invite Col back?

Novicki: (laughs) I will definitely invite Col back this year and as many years as he wants to judge.

Cooper: (laughs) He'll be happy with that.

Novicki: Yeah. I've become friends with him through the Challenge and events. It's great to be around him and learn from him.

Cooper: You should do some stand-up in England and go visit him in Bristol.

Novicki: (laughs) I know! I've done stand-up in England. I did tours for the troops over there. It's funny because his wife was saying—I sat at the table with him and his wife. I met his wife a couple of times. She's so nice, too. Basically, she was like, "Yeah, come stay with us!" They have a screening room. It was awesome.

Cooper: They both seem like jolly people.

Novicki: Yeah.

Cooper: Lots of smiles.

Novicki: Hopefully, I'll see you at our awards ceremony again at Sony. ■ **ABILITY**

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MELISSA MANCHESTER

A career spanning over 40 years, singer-songwriter, actress, recording artist, Grammy award-winning Melissa Manchester has multiple albums and counting. Manchester has had her songs recorded by Barbra Streisand, Roberta Flack, Kenny Loggins, to name a few. She is a wonderfully energetic artist with roots firmly planted in music and a talented family encompassing all avenues of art. Manchester had a unique experience growing up with a musician father in the Metropolitan Opera and a mother in the fashion industry. Her love for music grew and developed as she continued exploring a beautifully colorful life in New York. From an early age she began her career singing jingles for commercials, a road that took her alongside musicians like Barry Manilow "we were all musicians, but we were all making a living singing jingles" says Manchester. She also created a group called the Harlettes singing backup for Bette Midler. A career sprinkled with creative endeavors, Grammy win and Academy award nominations, Manchester shared her journey with *ABILITY* as well as her experiences with the lack of accessibility for performers in theatre.





Chet Cooper: Where did you start your music career?

Melissa Manchester: I was raised in New York, in the Bronx and Manhattan. I come from a very creative family. My father was a musician in the Metropolitan Opera Orchestra, and my mother was a pioneer in the fashion industry. So my sister and I were raised in a very festive version of normal in really the perfect place. The Bronx was like out of a black-and-white movie. And then when we moved down to Manhattan, it was very exciting. When I became a teenager, I went to the High School of Performing Arts in the middle of the theater

district. I started to become a jingle singer when I was 15. My brother-in-law worked at one of the jingle houses, and he knew that I sang, and he hired me, and I started to become a jingle singer. And that's where I met Barry Manilow and Patty Austin and Nicky Ashford and Valerie Simpson. We were all musicians, but we were all making a living singing jingles.

Cooper: You were all jingling together!

Manchester: (laughs) Yeah! Some were more established than others, but Barry was the new music director

for the up-and-coming Bette Midler, and I was playing in clubs in colleges all over the New Jersey/New York/Connecticut tri-state area. I made demos and was summarily rejected by record companies for about seven years. I was the founding member of the Harlettes, Bette Midler's background group. I worked in street theater. I was a go-for on the first season of "Sesame Street" at the Children's Television Network, because everything was just down the street from where I lived. It was a very vibrant place to live. Lincoln Center was new. Theater was exploding. It was just great.

Cooper: What about your sister? Does she sing?

Manchester: She did, but she is an executive producer over at E-Entertainment News. She's the recipient of five daytime Emmys.

Cooper: Very talented family!

Manchester: Yes! They're all on her piano. They look beautiful.

Cooper: What was your first big break?

Manchester: I think my first big break probably was being signed to Bell Records. I had been, as I said, trying to get a record deal with about seven years, and then I auditioned for the president of Bell Records, which in the day was a singles label. I auditioned for the president of the company, the late Larry Uttal, and I sang many of my songs for a room full of guys in white rolled-up shirts, not a woman to be seen.

When it was over, as I was walking out, and I was tired that day, he said, "How important is this to you?" I said, "Listen, I'm doing this with you or without you. Good-bye and thank you." And the next day I had a record contract. So I was there for a couple of years, made two albums, and then that company was absorbed in Arista Records, whose president was Clive Davis. And then I had my first hit single on that album, my third album, called "Midnight Blue." That sequence of events, there's never one thing that happens, but that sequence of events really opened up an audience base. Because I'd been playing for college audiences for several years, but that successful single was a huge vehicle to expand audiences and sizes of arenas and stuff.

Cooper: I've seen pictures of you with a lot of different people. Like Lily Tomlin, what was the connection there?

Manchester: She came with Dolly Parton to see me at a concert at Universal Amphitheater many years ago. She's spectacular.

Cooper: What about Dolly?

Manchester: That was the first time I had met her back-

stage, I had met her at a party afterwards, but most recently Dolly and I sang a duet version recording of "Midnight Blue," which will be coming out on my 25th album later this year called "Review."

Cooper: Very nice! Did we just get a scoop?

Manchester: (laughs) I don't know. This is my 25th album in celebration of my 50th year of my career. Dolly and I will be singing a duet of "Midnight Blue" and Kenny Loggins and I will be at long last recording our song "Whenever I Call You Friend."

Cooper: Very nice. Were you about to cast the person who used the wheelchair who had polio in your play, were you able to cast a person with a disability?

Manchester: At the time, in the early '90s, we tried, we scoured to nation to find a person who was actually in a chair who could sing and act. And a) we couldn't, and b) the theater that we were in, it was an off-Broadway theater, had not put in ramps.

Cooper: Oh, wow!

Manchester: This was before ADA, so that was very difficult. But when we do it again, we're definitely going to have—we already know the actor we're going to use.

Cooper: That's great. Were you able to find him easily this time?

Manchester: He posts himself on YouTube performing, and I thought, "Him! Let's use him!" Long before there was social media, it was tricky to reach out to people. But we tried.

Cooper: It's really great to hear that. Before we end I'll share my screen to show you abilityE.org. There are thousands of performs with different types of disabilities.

Manchester: That's great!

Cooper: Netflix came to us looking for help, that's how it all started.

Manchester: That's fantastic! Years ago, I was affiliated with the Access Theater up in Santa Barbara. They were created by Rod Latham. I got to know them because I had been part of a television special that was saluting—not Special Olympics, but Special Entertainment, I believe it was, also Eunice Shriver.

Cooper: Maybe Best Buddies?

Manchester: No. I know Best Buddies. Anyway, the Access Theater based in Santa Barbara no longer is but it was completely people—playwrights, actors, ballerinas, everybody with a challenge and everybody magnif-



icent. And again, Rod Latham, a native of Santa Barbara, created the Access Theater. And I had done several benefits for them, too.

Cooper: I love that!

Manchester: And I think you can find this on YouTube, when I did a remake of Burt Bacharach's "Walk On By," Dionne Warwick's "Walk On By," the powers that be, record company management, blahblahblah, they all wanted me to do—I slowed the song down, I always knew that there was a dramatic intention that needed to be mind, so when it was time to do a video, they all said, "So boy meets girl, boy loses girl, girl loses boy, blahblahblah." I said, "No. We're going to do a homeless woman who has to drop her kids off at a shelter because she can no longer take care of them." And then went, "What?"

And we did. And we used actors, child actors from the Access Theater, to be part of it. If you can find it on YouTube, it's there, you'll see all of the kids. It's beautiful.

Cooper: Hopefully when we find it, we'll link it to the article, too, so more people can see that.

Manchester: Yeah, please do.

Cooper: I love it when I don't know what's going to happen, like showing you this and this other great story comes up.

Manchester: You wouldn't know this, but my mother was in the 1950s the first vice president of the Bronx chapter of Cerebral Palsy.

Cooper: Is that the same as a New York CP?

Manchester: Now it is probably, but in those days, each borough had their own.

Cooper: That became the largest of all the affiliates of CP. Wow! So growing up you saw some of the work they were doing. I don't know if you read the article with Marsha, but the interviewers were David Zimmerman, who works with Performing Arts Studio West similar to Access Theater in Santa Barbara, and Geri Jewell. Geri's been a rock star for CP.

Manchester: My sister is good friends with Geri. She loves her.

Cooper: Oh, nice! I did a couple of last-minute emails to see if Geri wanted to be on this zoom, the other person was Max Gail. Do you remember him?

Manchester: Yes!

Cooper: He was going to be on and surprise you. I'm sure he says hi.

Manchester: (laughs) Nice!

Lia Martirosyan: Can I interject?

Cooper: No, we're talking.

(laughter)

Martirosyan: I've been listening and it's been great. I'd like to explore your involvement at USC. Are you still a professor there?

Manchester: No. I was adjunct there for four or five years, and I just got too busy, I could not commit any more. But it was fantastic while I was there. I'm still friends with some of my former students, which is lovely.

Martirosyan: How did you get into that?

Manchester: Part of it beats me!

(laughter)

The vice-dean of the music department reached out to me one day years ago and said, "Would you like to take over this class for the composer Jason Robert Brown?" He's very well known in the theater world. He had a commitment in New York and could no longer do this. So I said, "Well, sure. I've never thought of being a teacher, but..." I took over this very interesting class called "Theater Writing for Pop Students," which should be taught in every music college everywhere. And then they had such a good time with me, I guess, that they kept inviting me back. I was working with young singer-songwriters. It was great. It was a grant experience.

The thing about teaching is, it teaches you how much you know. When a kid asks you a question and you actually know the answer. The other thing is that you realize that no matter how much a kid says they have lived, there's just empty space sometimes. (laughter) So the main thing about teaching is that you're helping them to learn how to think. That's all. You come from your own experience. You're helping them learn how to think. It was very touching.

Martirosyan: That's beautiful. How about these lovely awards you've won and been nominated for. How does that make you feel in terms of where you are in your

career and your passion?

Manchester: Well, I mean, it makes me feel good.

(laughter)

As a Grammy winner, I'm part of a very small club, for which I'm very grateful, because I was recognized by my peers. Being nominated, honestly, is a great achievement in and of itself. And you do this not knowing what the outcome will be. I recently heard a wonderful writer say, "Forget about following your passion. Most people don't know what their passion is. Start with your curiosity. What are you curious about? The curiosity can turn into a passion." And I think that is genius advice.

A handful of us knew what we wanted to do since we were five. I had no plan B. I was going to do this somehow. But most people don't. But they are curious about things, and if teachers could help them just foster and encourage curiosity, the curiosity in and of itself can ignite into a passion.

Martirosyan: I love that. I'm curious about whether or not you're being recognized for the songs you've written as opposed to singing songs that have already been written. Does it have a different flavor for you?

Manchester: There's a subtle nuance of gravitas when you're singing a song that you've written, because you were in the room when it was written, and you know what sparked the idea, and usually the collaboration. However, that said, a great song is a great song, and to be gifted with a great song that endures and is embraced by millions of people you'll never meet as if it's their own is a unique way to spend one's life. And the deeper I get into my career, the more treasure I find that, because it's rare, it's really rare.

So you were trained operatically, classically?

Martirosyan: Yes, I was.

Manchester: I was raised around the opera, because my father played in the orchestra of the Metropolitan Opera. I was raised in the wings of hearing spectacular singers, and of course every Saturday we listened to Live from the Met on the radio, which I still do.

Martirosyan: What a beautiful experience for you!

Manchester: Yes, it was unique. When my parents during the week couldn't find a babysitter and my father was at rehearsal, he would bring me down to the Met as a little girl, and he would put me (laughs) in the wings standing next to great big guy who pulled the curtains, and he would say, "Stay!" and he would go into the orchestra to play. It was just spectacular. Seeing theatrical lights, hearing the swish of taffeta gowns.

Lessons to Be Learned



Martirosyan: My goodness.

Manchester: Dress rehearsals come by you rapidly, and hearing unbelievable stars vocalizing and then going onstage. It was just thrilling, really.

Martirosyan: That didn't pull you to want to be in the operatic genre?

Manchester: No. I know for truth, and I'm sure you know, that the commitment to being an opera singer is like being a monk. You must learn the repertoire, you must live in the country that the repertoire is based on, anyway, that's what I know from colleagues. They've lived in Germany and France and wherever to get the language under their belt. But we had lots of opera singers and musicians and ballerinas at our house.

Martirosyan: Oh, that's beautiful!

Manchester: It was fantastic, yeah.

Cooper: I know she would never say it, so I'll share that Lia and I have traveled around the world maybe a couple times. Different countries we're in, whether it's Italy, even China, they think she's local when she starts singing. She has this way of doing this with her voice that makes it seem local, native. It's incredible.

Manchester: How beautiful!

Cooper: I never thought of the difference between standing and singing and an effect that your body has—

Manchester: I will tell you that the first concert that I did when I returned to the stage after having my ankle surgery and I was still not walking, so I had to be hoisted onto the stage, but by that time I was able to use the one-legged scooter. I had a dear friend who decorated my wheelchair and my scooter. I was in sparkles and tinsel and it was all very festive and the audience had a great time.

But just the strength it took to sing again, because I had been on my back and in a chair for over a month by that

time, and it was an outdoor concert, I think it was in July or August, it was hot. I felt like I would pass out, because I was sitting, of course. To have that kind of breadth, lung capacity, where you're not standing and being able to straight up and down breathe wide, but to have to sit and breathe wide, it is a very different experience. My hat goes off to those who have the sing in a chair, because it's a monumental challenge. I mean, if you don't know any different, you don't know any different. But it's remarkable.

Martirosyan: Did you feel an urge to get up at any moment?

Manchester: I couldn't. I physically couldn't. I could not stand on that ankle. I was not out of bandages yet. I was either—I don't know if you heard, but I had had all of my appliances decorated by friends. I had tinsel and sparkles and glitter and all kinds of fun stuff for the audience to look at. I had a scooter and I had—did I have a walker? I had a walker, but I was still only hopping. And I had my wheelchair, and I was lifted onto the stage by two big guys because I just wasn't walking. So I would go from the piano stool, and they'd say, "What do you want?" and I'd either have the scooter or the chair. The fortitude it took for me on that hot summer night to find a way to manage singing, because I sing big, was really new for me.

Martirosyan: Just being able to experience something from that perspective.

Manchester: Exactly.

Cooper: How do you know Marsha Malamet?

Manchester: We started songwriting and recording around the same time in New York. She was one of a pack of us who were trying to get our foot in the door, and I remember I really got to know her music listening to her "Coney Island" album, her first album. I thought it was so wonderful and thoughtful and original and her voice was so interesting and she used it in such an interesting way. And then I got to meet her. So we've been traveling in similar circles for a very long time.

Cooper: Do you stay in touch?

Manchester: Not too much. I would see her at parties and we did try to write a song once and it didn't come to fruition. But then I sang at a benefit for her at Catalina's a few years ago. I was very pleased to have the opportunity to sing "Lessons To Be Learned," her very beautiful song.

Cooper: How was she doing at the time with her Parkinson?

Manchester: At the benefit she was quite challenged, in a wheelchair, but she had asked me specifically to sing two songs, and that was lovely. She was brought up on

stage and we all kissed her and loved on her.

In the benefit, she had asked me to sing "When Paris Was a Woman," which is a song that I wrote about Gertrude Stein and Alice B. Toklas, and the other song she asked me to sing was, "Through the Eyes of Love."

Cooper: How did it come about, "The Lessons To Be Learned" was that chosen?

Manchester: That was sent to me with a presentation of what this project was about and it resonates with the themes of things I've written about over the years. Within context, it's always everything. I think it's a fitting and touching tribute for Marsha to sing this song. And I'll be singing it in one of my upcoming shows.

Cooper: I heard you had used a wheelchair for a while?

Manchester: Yes. A while ago. It was just a fluke accident and I broke my ankle. I had to have it repaired through surgery. It's a complicated recuperation, much more than a knee replacement, which I have also experienced, because you can't put weight on it for a very long time. You can be in a walker. A scooter was pointless. So I was in a chair. I was in a rehab facility for a while until the pain started to subside, and it did pretty quickly, and then I came home.

What I really noticed while I was in my chair was that the energy it takes when you're encountering people, because you are looking at them usually around the waist, and to keep looking up is a lot of energy. Interestingly enough, I've written a musical called "I Sent a Letter to My Love" where the main male character is in a chair because he has polio. So it was interesting to finally have that experience myself. When I was finally allowed to come home, I remember the first day I was home, you're maneuvering and I was banging into every corner of every wall, and I was getting hungry for an egg salad sandwich. It took me an hour and a half to make that sandwich, because I had to be very careful of the boiling water. I had to figure out how to get the egg out of the boiling water safely, because I was at the height of the oven.

I just kept rolling back and forth three feet in either direction to finally manage to make the sandwich. It was eye-opening, of course. It was an interesting moment.

Cooper: There are so many people I've talked to over the years who have used a chair for a short period of time, and their experience and change of attitude of what accessibility really means in all aspects, from the work environment to the home environment to travel in general.

Manchester: Yes. It's very interesting, since I was in a chair for quite a long time, because with a broken ankle, you simply cannot put weight on that in any way, shape,





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or form before the doctor says you can. It was so much easier to just shut down when people were interacting with you or trying to because of the energy it took to sit in a chair. Your diaphragm is squished, so your lung capacity is squished. It's compromised. It was a lot.

Cooper: Did you see any shift in attitude of the way people spoke to you?

Manchester: I think so. There's no way to deny that there's that nuanced—either people will talk a little louder (laughs) or articulate a little more (laughs). Personally, it was just more exhausting to get around. I had very kind people helping me out. I would be put in that motorized scooter in the grocery store. But it was still a lot, because it just took—I was not used to—as a race, we don't realize how much energy it takes just to live. When we are compromised in any way, we really don't realize what we take for granted and how to live with intention is much more fruitful as a way to live because it could be gone.

Cooper: There is also an unconscious bias that seems to permeate our society. The nonprofit ABILITY Corps that we support created abilityEntertainment. It connects talent with disabilities and the entertainment industry.

Manchester: Sure. I look forward to scouring your website to look for singing actors who are chair- or crutch-abled.

Cooper: There are thousands of talented people.

Martirosyan: Do you have a project coming up?

Manchester: Yes. I wrote a musical in the '90s called "I Sent a Letter To My Love," where the lead male character had polio. He was left with a chair, and it's part of the plot line. We had tried and tried and tried to find a wheelchair actor who could sing my music, and a) it was very difficult to locate a company that was ability-centric, and/or the theater, this was before the ADA, there were no ramps. It was all of that, and I thought, "Man, I'm going to let this pass in this moment, because I've got to get this show up." It ran off-Broadway for a while, and then it had another production outside of Boston.

There's talk about doing it again, which would be lovely, and I said, "This is not even a discussion." And everybody agreed. I was saying that there is a wonderful young actor who is just extraordinary. He's been on YouTube and you can see him perform. I forget his name right now. He's in a chair. He can walk with crutches, but he's in a chair and he can sing his face off. Hopefully when we get a production—we will access your website. ■ **ABILITY**

melissamanchester.com





Disney Junior shines spotlight on Disability Inclusion

Disney TV Animation and Disney Junior are leaning in on disability inclusion with the animated series, “Firebuds.” The hit show is geared toward children ages 2-7 and is set in a fantasy town where young children of first responders have vehicle friends who talk. Together, the friends help people in the community with problems, big or small.

“Firebuds” weaves disability and health topics into many of its storylines, and characters with disabilities are featured in several episodes. Disney’s commitment to disability inclusion is also evident in the casting of actors with disabilities to voice select “Firebuds” characters.

ABILITY Magazine caught up with Sammi Haney who voices “Piper” and Henry Shipp, the voice of “Castor” on “Firebuds.” In separate conversations, Sammi and Henry each shared their experiences on “Firebuds,” and what they hope young viewers will learn from the show.

First up, is our conversation with Sammi Haney, a young actress from San Antonio, Texas. Sammi was born with Osteogenesis Imperfecta Type III (Brittle Bone Disease) and is a wheelchair user.

Jennifer Goga: Hi Sammi! Thanks for taking the time to talk with me today. How are you doing?

Sammi Haney: Hello! I’m doing great.

Goga: Sammi, would you tell me a little bit about yourself?

Sammi: OK. My name is Sammi Haney and I live in San Antonio, Texas. I do the voice of ‘Piper’ on the Disney show, “Firebuds.” I also acted on “Raising Dion,” a TV show for Netflix.

Goga: How did you get involved in acting?

Sammi: My mom saw a Facebook post about a casting call for “Raising Dion.” She thought it sounded like me, so we tried it.

Goga: Did your mom just have a feeling you’d be good at it?



Sammi: I guess the casting call description kind of sounded like me, so we decided to try it out. And I got the part.

Goga: OK. Tell me a little bit about the “Raising Dion” experience. You played the role of Esperanza, a good friend of the main character, Dion, right?

Sammi: Mm-hmm.

It was really fun. I made a lot of friends there. I got to do a lot of stuff, see a lot of pretty cool things.

Matt Haney (Sammi’s father): Sammi, do you want to tell Jennifer about the fun you had at the Emmys?

Sammi: Oh, yeah. I got nominated for an Emmy for “Raising Dion,” and it was super fun. I got to meet a bunch of people. I met the girls from the “The Babysitters Club.” That was pretty awesome, because I’m a big fan of that show. I also met—a comedy guy? Dad, who was the guy we met?

Matt: The guy who did Snuffaluffagus? Oh, you mean the host, Jack McBrayer? He’s a comedian. He has his own TV show, too.

Sammi: Yeah, we got to meet Jack McBrayer and also the guy who voices Snuffaluffagus.

Matt: Sammi was nominated for a Children’s and Family Emmy for her role in season two of “Raising Dion.”

Goga: Was it a big fancy awards show-type thing?

Sammi: Yeah, it was fancy. They had all kinds of food and stuff.

Goga: It was in LA, at the Wilshire Ebell Theater, I think. Is that right?

Sammi: Yes, I think that’s it. I’m not good at names.

Goga: Did you get to dress up and everything for the awards show, too?

Sammi: Definitely!

Goga: Sammi, what was it like working on the “Firebuds” show?

Sammi: It was really fun. I got to go to go to a local studio and do it.

So, I didn’t even have to leave San Antonio.

Goga: That was convenient.

Sammi: Yes. I’d go into a soundproof booth, and I had headphones that I put on, and there’s a mic and a table with the script on it. Then I say my lines different times in different ways so they can get a really good one. There’s a control thing where there’s a bunch of buttons, and a person controls the buttons and stuff. I don’t know how to explain it. (laughs)

Goga: You’re doing a very good job of explaining it. I can imagine. Was your mom or dad with you? Were you by yourself with your big headphones on sitting in the booth?

Sammi: It was kind of like two rooms conjoined. My mom and dad and the audio guy were in one room, and I was in the other room with just a door. When I open the door, I can go into the sound booth and out of the sound booth and into the room where my parents are.

Goga: Can you tell me a little bit about your character on the show?

Sammi: My character “Piper” is a talking wheelchair. The wheelchair user character is “Jazzy.” We’re the friends of Bo, the main character. Bo’s vehicle friend is a fire truck, and there are some other kids with different first aid vehicles—

Matt: First responders?

Sammi: —first responder vehicles. We go on adventures and do different stuff.

Goga: You’ve already been in a few episodes, right?

Sammi: Mm-hmm.

Goga: Can you tell me maybe one of the stories you were in, what was happening?

Sammi: There’s an episode called “Big Tread.” It’s about a camping trip and one of the kids tells a scary story and my character “Piper” gets scared and runs off. And then “Jazzy” goes after me and we kind of get lost. Then the other kids come after us, but we’re on this bridge and I’m too scared to get off the bridge because I think it is breaking. So, the other kids have to save me.

Goga: Oh, that sounds like a good story. What do you want little kids who are watching to learn from the episodes you’ve been in?

Sammi: I hope they learn about inclusivity and that people with disabilities aren’t really that different from

people without disabilities.

Goga: That's a great lesson.

Sammi: And I hope they learn that you should not treat people with disabilities differently and stuff. Also, if a person with a disability is watching the show, I hope they can relate and see that there are other people with disabilities on shows.

Goga: Good point. Have you gotten to meet the actress who plays "Jazzy?"

Sammi: I know her a little bit.

Matt: When "Raising Dion" season one came out, Lolo Spencer, who plays Jazzy on "Firebuds," posted a maybe 10-minute video celebrating Esperanza's character and the show as a whole. She was pumping Sammi up and congratulating her on how much she loved her role.

Goga: Oh, that's great.

Matt: So, we started following Lolo on social media, so that's how we know her. We enjoy her posts and like to see what she's doing. Lolo will comment on Sammi's posts and whatnot. They haven't met in person, but they've met on social media. And that happened before either of them was cast for "Firebuds." So, it was really cool that Sammi and Lolo were put together on the "Firebuds" show.

Sammi: Yes, that was neat.

Goga: What a nice coincidence

Matt: Yes, totally.

Goga: This might be a question for your dad, Sammi. Matt, how did you find out about abilityEntertainment? I know Sammi has had a profile on the abilityE platform for a few years now. And, in the early stages of production that's how Disney found Sammi for an audition.

Matt: I don't remember exactly how we came across the abilityE website, but I do remember that right away we thought, "Sammi needs to get a profile on there, definitely." We immediately saw the value in it.

Goga: And Sammi's abilityE profile paid off for the "Firebuds" role. I'm not sure if you're aware that Disney casting reached out to abilityE for help finding a young actress who uses a wheelchair to audition. Disney asked if we could provide them with abilityE members who met the profile for the character they were casting, and Sammi's was one of the profiles that we did provide to them.

Matt: Oh, cool.

Goga: So, our abilityE team was thrilled to play a small part in the Disney casting process. But Sammi obviously did all the rest with her sassy, fun personality and acting skills, right? You're the one who landed the role.

Sammi: Thank you!

Goga: And there are more episodes to come on "Firebuds." . Who knows? Maybe there will be even more roles. Sammi, do you want to continue acting?

Sammi: Yes, I do!

Goga: Do you have anything else in the pipeline that you can talk about?

Sammi: Not acting, but I do have a book coming out—

Goga: Oh, wow!

Sammi: —called "Savvy Sammi." It's about me—it's sort of like a series of books, and it includes different people with disabilities as superheroes. And I'm one of them. I'm a superhero, and I have to—well, I'm not going to go too far into it, because I want people to actually read the book. (laughter)

Matt: Yeah, in her book Sammi has to save a bunch of animals. The title is "Savvy Sammi," and it's available to buy on Amazon.

Goga: What do you see yourself doing when you get older, Sammi? Do you want to continue acting, or is there something else you'd like to try?

Sammi: I think I'll go into animal care and stuff like that when I'm older.

Goga: I want to ask your dad, or you can answer, too, Sammi. I wanted to hear about the DisabilityShirts.com project you have. How did that come about?

Matt: When Sammi got the "Esperanza" role, it kind of inspired me a little bit. When she was born, I wanted to start a t-shirt line building awareness around disability, but I thought it'd be too hard to do, and that the learning curve would be too much for me. I know how to do graphic design for print, but I didn't know anything about building a website.

But after I saw Sammi jump in and do acting, I thought, "Well, if she can jump in and be on a Netflix show, then I should just jump in and start this disability shirts thing I've always wanted to do but never did." So, I just started making designs and showing them to Sammi, and she'd be like, "No, I don't like that one, we're not using that one." And I'd be like, "OK, OK." She was kind of the one who decided whether the idea was good and whether it looked like something she would wear.

Sammi: And I helped with the sayings.

Matt: Yes, I would just brainstorm ideas with Sammi and my wife. Sammi always has the final approval. Sammi helped me realize that sometimes you have to jump in with both feet and see if it works and not be afraid to fail.

Goga: And how is that going?

Matt: It's not really something that we make money on. The profit margins are so small, t. But it's just something we're doing for the sake of trying to be more of an advocate and give people stuff they can wear to raise awareness.

We do get pretty consistent orders, and we have repeat customers, who come back again and again. But it's not like it's a booming business. It's a slow thing. We try to add some new designs and keep it fresh. It's been a good experience, just getting feedback from people on the shirts is a really positive thing.

Goga: You have some cool designs, like "Diversity is Fire." Sammi, good job on your creative input.

Sammi: It's mostly Dad who comes up with it, I just get the final say.

Goga: Well thanks to both of you for all that you're doing to raise awareness and advocate for people with disabilities.

###

ABILITY Magazine also spoke with Henry and his father Jeremy Shipp about their involvement with "Firebuds." Henry was born with a cleft lip and palate and has had four surgeries to date. Jeremy, a Disney Junior writer, drew inspiration from his son for the "Cleft Hood" episode. It features a vehicle character named "Castor" who is reluctant about surgery, preferring instead to go to a fair with his friends. Henry voices "Castor" in the show, which includes lively songs that entertain while teaching a valuable lesson.

Jennifer Goga: Hi Henry and Jeremy, it's good to talk to both of you. You're in California, right?

Henry Shipp: Yes, we're in Burbank.



Goga: Jeremy, can you give me some background on "Firebuds" and the "Cleft Hood" episode with Henry?

Jeremy Shipp: Well, I am a writer on "Firebuds." On the show, we seek inspiration everywhere. We are frequently looking for the vehicle equivalent of an issue that kids and people deal with in their everyday lives. And my son Henry's good attitude, his good cheer have been an inspiration for a while. So, I pitched an idea about a car with a cleft hood. I was encouraged by my story editor at the time, and creator, Craig Gerber, instantly said yes to the episode.

We worked for a while on the episode, and when it came time to cast the young vehicle named Castor, who has the cleft hood, I suggested Henry. I know he's a good actor, but he also has a good sound to his voice. He's worked hard in speech therapy to be able to form certain sounds at the front of his mouth, and I wanted an actor who had that cleft experience to voice the role of Castor.

Goga: Absolutely. It's so valuable to cast people who are authentic in their role—they have lived the experience of the character.

Jeremy: We're a bit removed, we writers, from the casting process. For my part, I asked Henry, "Would you be



willing to audition?" And he said yes, so we worked on our audition and we sent it in and waited for a while, and he got the part.

Goga: Were you nervous for the audition, Henry?

Henry: I was a little bit nervous. I hadn't done anything like this before.

Goga: Was it fun?

Henry: It was pretty fun. Everyone was really, really nice. I only had to take a few takes per line.

Jeremy: We worked hard on it. We read through the lines beforehand. They remarked that they were impressed. He came in with a take for each line, an approach. He didn't do a cold read.

Goga: Nice. Henry did you physically go into a studio?

Henry: Yep.

Jeremy: It was the highlight of my career sitting in that booth with Henry as he did his lines..

Goga: Henry, do your friends know that you're a star?

Henry: (Shrugs and looks at his dad)

Jeremy: He's been pretty good keeping the secret, because we weren't allowed to talk about this yet, but now we can talk about it.

Henry: We can?

Jeremy: (laughs) Yeah, absolutely.

Goga: (laughs) You look happy you can finally tell your friends, Henry. Do you think you would like to do something like this again?

Henry: Well, (pause) yes, but my voice has been changing, so I don't know if I'll get the part of Castor again.

Goga: Well, there are other roles out there. Do you feel people treat you differently because of your cleft?

Henry: Not at all.

Goga: What message do you want kids watching this episode to get?

Henry: I really want them to feel like they're not alone.

Jeremy: One of the things that I am proud of Henry for,



and proud of the kids around here is that the existence of Henry's cleft was always taken in stride. We talk about it all the time, no problem. And his friends also take it in stride.

He's got a small scar here (pointing to Henry's lip), and a little bit of a fistula on the roof of his mouth still that we will probably have worked on down the line. But Henry takes everything in stride.

I think the germ of the idea for the "Cleft Hood" episode was, when Henry was younger and he had some surgeries. I think he understood, at some level, that surgery would be helpful to him, but he didn't really want to go. (laughs) That's where the idea for the story came from.

Goga: Henry, how many surgeries have you had?

Henry: Four.

Jeremy: Two of them before he was one.

Goga: So maybe you don't remember those early ones?

Henry: No.

Jeremy: That's a great point. I don't think he remembers them, but I suspect that it's in there. You weren't able to

form memories at that age, but I suspect that in your head there is a kind of subconscious memory of being taken away from us and brought in to the doctor's to be operated on. I think that may still be swirling around in there. That's what I believe.

Goga: Did you at least get a lot of ice cream, Henry?

Henry: Yes. That was all I ate for, like, ten days.

Goga: So there's an upside there. And you look great!

Jeremy: (laughs) He looks fantastic, I think!

Henry: Thank you!

Goga: Jeremy, you've been in the business writing for a while.

Jeremy: That's right. I've been working full-time as a writer for about 13 years. I started at Nickelodeon. My first staff job was on "Teenage Mutant Ninja Turtles." I've been bouncing around from show to show. I did an ABC sitcom. I worked on "Dinotrux" at Netflix, wrote on "Rapunzel's Tangled Adventure" at Disney, that was my first experience at Disney. I worked in development, and here I am on "Firebuds."

Goga: At *ABILITY Magazine*, as you can imagine, we

love to highlight stories like this one, how you and Henry are bringing a story like “Cleft Hood” to kids everywhere.

Jeremy: Yes, it's so important that kids can see themselves on screen. I really wanted the episode to be about empathy, not just the cleft condition.

Goga: It's wonderful that Disney understands the importance of stories like this and also that they believe in authentic representation. It's so nice to hear Henry, who's personally experienced a cleft, voicing the character. I understand there are other episodes coming up that will feature characters with disabilities.

Jeremy: Yes, “Jazzy” and her wheelchair “Piper” is one of the stories coming up. She has spina bifida. She's got some wonderful episodes coming up. We really do try to look for all areas that we can shine a light on. Inclusion and diversity are very important in the writers' room. We talk about our personal experiences, about what's happening in the world and is there a version that would resonate with our age range?

Goga: That's so great to hear.

Jeremy: We try to introduce topics digestible for the preschool audience. That's all very important for us. Even specifically with a cleft hood, my wife, Henry and I were talking moments ago about how often, and this is not unique to me, I'm not the first to say this, how often villains have scars or facial differences. That's just kind of like a quick design trope to suggest that a character is mean or something like that.

Goga: You're right.

Jeremy: That doesn't always have to be the case. So often, storytellers use a scar to illustrate a dark backstory. But that's not the only way to do it. I think it's a lot more brave to show our protagonist with a facial difference. Henry's scar, as hard to see as it is, even still, does not connote villainy at all!

Goga: (laughs) It definitely does not.

Jeremy: He's had a unique experience, and he's a wonderful kid.

Goga: I can see that's true. I understand you and your wife Elizabeth, are involved in the Smile Train non-profit, right?

Jeremy: We have raised money for Smile Train and Henry has raised money for them too. Just last year he sold some baked cookies. I believe he raised, I think—

Henry: Over \$300?

Jeremy: I think it was closer to \$600. I know you were

able to pay the cost of one surgery for a child. Henry set up a little stand out there to sell stuff, and the proceeds went straight to Smile Train.

Goga: Oh, nice. So, Smile Train provides financial support for parents and kids who are going through cleft surgeries.

Jeremy: Yes.

Goga: That's great. Will you watch the episode that's coming up together?

Henry: Yes, definitely! We're probably going to have a big party.

Goga: A watch party?

Jeremy: I'm hearing about this for the first time right now, but I guess we'd better do it. (laughs)

Goga: (laughs) I think you'd better, especially now that Henry is allowed to talk about his role on the show..

Jeremy: That's right! He does appreciate the chance to talk about it, to talk about Henry, to talk about his experiences.

Goga: Are you aware of the abilityEntertainment platform, called abilityE.

Jeremy: That was just brought to my attention, and I think it's fantastic.

Goga: You know, you can post Henry's profile on it if he wanted.

Jeremy: You know what? We may very well do that.

And we're now adding behind-the-scenes people. We're trying to get directors, set decorators, writers, etc. Of course it might mean more competition for you, Jeremy, but—

Jeremy: (laughs) I completely understand and encourage this! What a wonderful thing this is!

Goga: Yes, we're really proud of it. This is how Disney Animation found the voice over actor for Piper. We think it could become an important tool to help get more people with disabilities working in the entertainment industry. Henry's experience is a great example of how important it is to have authentic representation.

Jeremy: It is wonderful and thank you so much for sharing your screen so I can see this. Immediately after this I'll show this to my wife. ■ ABILITY

disneyplus.com

Ashir Wilson — Finding better ways to do things in Pakistan and beyond

I'd never met Ashir Wilson before this interview, but I knew who he was, for we run in the same circles. Below, we discuss his pioneering work as a blind experimentation associate at UNDP Pakistan and his philosophy of disability, development sector work and education. It was a pleasure to finally meet Ashir, whose talent and ambition are matched only by his off-the-wall humor and infectious good cheer. He's the sort of person whom you really have to meet—though hopefully, this interview does him justice, too.

Itto Outini: Good morning, Ashir.

Ashir Wilson: Itto, no! It's goodnight! It's 12:00 a.m. here.

Itto: [laughter] Sorry, I forgot! I'm so glad we finally have this chance to meet and talk. Can we start by sharing a bit more about yourself?

Ashir: Let's see...I have two siblings, and all of us were born blind. My eldest sister first attended school, and then I followed. For me, there were many challenges, but I had support from friends and family the whole way, and after navigating them, things started going well.

Itto: What sorts of challenges? How did you overcome them?

Ashir: I started at a school for the blind, but unfortunately, in my country of Pakistan, we have the preschools for persons with disabilities, but the resources aren't there for good education. I reached 10th standard before having any exposure to English. If you

want to be competitive, you have to go to the school for non-disabled people.

When I arrived at the mainstream school, I had to start by learning languages. Communication. I had that by 12th standard. Then I decided to pursue my education further, but when I was seeking admission to college, first they said, "Okay. You're a brilliant student. We've seen your grades. But how do you compete in the classroom with sighted people? I'm sorry, but we can't let you in."

Itto: That's not fun.

Ashir: No. But I didn't give up. I reached up to the higher authorities. I wrote letters and emails. They asked me to come for another interview. After one or two interviews, they said, "Okay, now. You're right. Welcome." That's how I got in.

Itto: And what was life like at the university?

Ashir: Pakistan, you know, it's in South Asia, and South Asia's not a region where you have things like, for example, digital libraries, digital dictation, assistive technologies. Not at the public universities. Now it's getting better, but not at the time. The books were all hard copies. I had problems with the librarian in my department, which was international relations. The librarian said, "We can't give you a library card. All these books are useless to you." Fortunately, I had friends and people from my classes who were willing to help me. Later, I talked to my teachers, and they started recording their lectures. Somehow, I completed my degree.



Itto: What did you take away from those experiences, besides your degree?

Ashir: It changed my perspective. Usually, people with disabilities stay by themselves. We focus on our own issues. But public university taught me it's not just about persons with disabilities. We're all in trouble, us young people in Pakistan. 65 percent of us are young, but we don't have the capacity at public universities, so not enough of us are getting education. We can't keep up with the global standards. As a person with a disabil-

ity, I need inclusion, but I need to be included in a system that's working, not failing and broken. When I understood this, I broadened my scope. I started working on capacity-building for young people in Pakistan.

Itto: What does capacity-building mean?

Ashir: Capacity-building means training for people, building communication skills, teaching technology. I don't yet have an organization, but I want to start one. The problem is, it takes lots of time, lots of money. You have to give 20, 30 hours a week, and you're not getting

paid. You need other people to help you, but how do you pay them?

Itto: Are you partnering with any organizations?

Ashir: Not this year. I've mostly been working with UNDP. But before, I was volunteering with an organization based in Turkey. They started a program called Model Organization of Islamic Cooperation (MOIC), which is based on the Model United Nations. The idea was to take young people from different Muslim countries, which might not have good resources, good education, and connect them with each other, connect them with resources, then train them as policy leaders.

Itto: Interesting. How does this work?

Ashir: They started by building clubs at universities. Club members plan activities, have lectures on different topics, do simulations on various issues. Then they draft policy recommendation papers. If the papers are good, MOIC helps polish their recommendations and takes them to conferences. We had a conference here in Pakistan in 2018. I was on the organizing committee. But then this Covid happened, and it slowed things down. But they're still working. They've already launched in many Muslim countries.

Itto: What other projects are you working on, besides that organization?

Ashir: Just some small things with friends. As I said, we don't have funding. But, for example, I did a podcast series with an academic in the US who has her own organization, Critical Connections. Also, I worked on a webinar series that's against religious extremism, covering topics like faith and harmony, how to moderate your religious sentiments, those sorts of things.

Itto: Do you consider yourself an activist?

Ashir: I don't call myself activist because I don't go on TV or anything like that, but I love talking with people. In my personal life, I discuss these things with people, and I think it helps them learn.

Itto: What about UNDP? How did you end up with the United Nations?

Ashir: I first applied for something called social inclusion officer, which is a volunteer position. I didn't get selected. After that, my profile was on the roster and big people were seeing my name and knowing about my passion to join the UN. They were tagging me for this and that, ads for different positions. In the beginning, I didn't apply for things because it was all so new. Sometimes, I couldn't even understand the job descriptions. Itto: You worried you might not have the right skills?

Ashir: Exactly. How would I know which skills are right

when I don't even know what this position is?

Itto: How did you overcome your fear?

Ashir: Five people from my circle tagged me for this accelerator lab position, so I thought, "Okay, why not apply?"

Itto: What do you do now with UNDP?

Ashir: I'm an experimentation associate with the accelerator lab. Our job is finding better way to do things. For example, our country office is working on plastic waste management. So, let's suppose we used to say, "We must increase the infrastructure." Now the Accelerator Lab comes along and says, "It's not just about the physical infrastructure, it's also about the behavioral infrastructure." It's never simply one thing or the other. It's many things contributing to the problem. We look at different parts, and then we intervene and close all the loopholes.

I'm lucky to have a very supportive supervisor. He never holds me back from doing anything. I do everything: daily operations, financial transactions, lab reports, organizing events online, in person...each and every little thing, I do. My supervisor even took me on a field assignment. Five days in the field, doing plastic waste experimentation, and I didn't have an assistant, only my supervisor. He would help when I asked for assistance, and when he wasn't around, I would ask local people. I would say, like, for example, "Oh, God, I can't see, and I need to go to use the restroom! Can you kindly take me to the restroom?" They would take me, and I would talk with them and hear their stories.

Itto: And that tells you more about the place where you're working.

Ashir: Exactly. That's a connection with the local community.

Itto: Since you've worked for other organizations, how would you compare them to UNDP?

Ashir: I've been fortunate. I worked for a local policy think tank, and the team was so supportive. But it's also me. I have very good communication skills. I want to do resource mobilization, which means building partnerships and connections. In my experience, most organizations want people with communication skills. Of course, communication goes both ways. Sometimes, people at the organizations will ask me, for example, "If I use the word 'disability,' is it fine? Is it okay? I hope you're not offended. If I'm using the word 'blind,' is it fine? I hope you're not offended. If you're offended, I am really, really sorry!" There's no need for all this. I'm an adult with an education. It's my job to say, "Be comfortable. Ask about my disability as you'd ask my name, my father's profession, my mother's profession."



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Itto: What do you think can be done to encourage that kind of open communication?

Ashir: We need to make people more confident. For example, sometimes if a person has a disability, they don't want to go alone to a restaurant, but we should encourage them. When people interact with the outside world, it helps them. We should also have organizations that teach communication skills.

Branching out a bit more, I'm in favor of legislative quotas. We have this already for minorities, for women, so why not for person with disabilities? It's already there in some places. For example, Uganda. Uganda has quotas for persons with disabilities in their legislative assemblies. If we have persons with disabilities in the legislative assembly, I think it will show the world that we can communicate, we can debate, we can handle complex problems--all of that will be happening publicly.

There should also be scholarships for persons with disabilities so we can go to university and build up our communication skills. Also, maybe we could have an investment platform.

Itto: What are investment platforms?

Ashir: It's where you gather a bunch of investors on one

platform, and you share some big projects that people are working on, and they choose where to put their money. So, I'm thinking, maybe you can have a system where investors fund a scholarship for persons with disabilities to get an education, and when they're done, they go to work for the investor for three, four, five years.

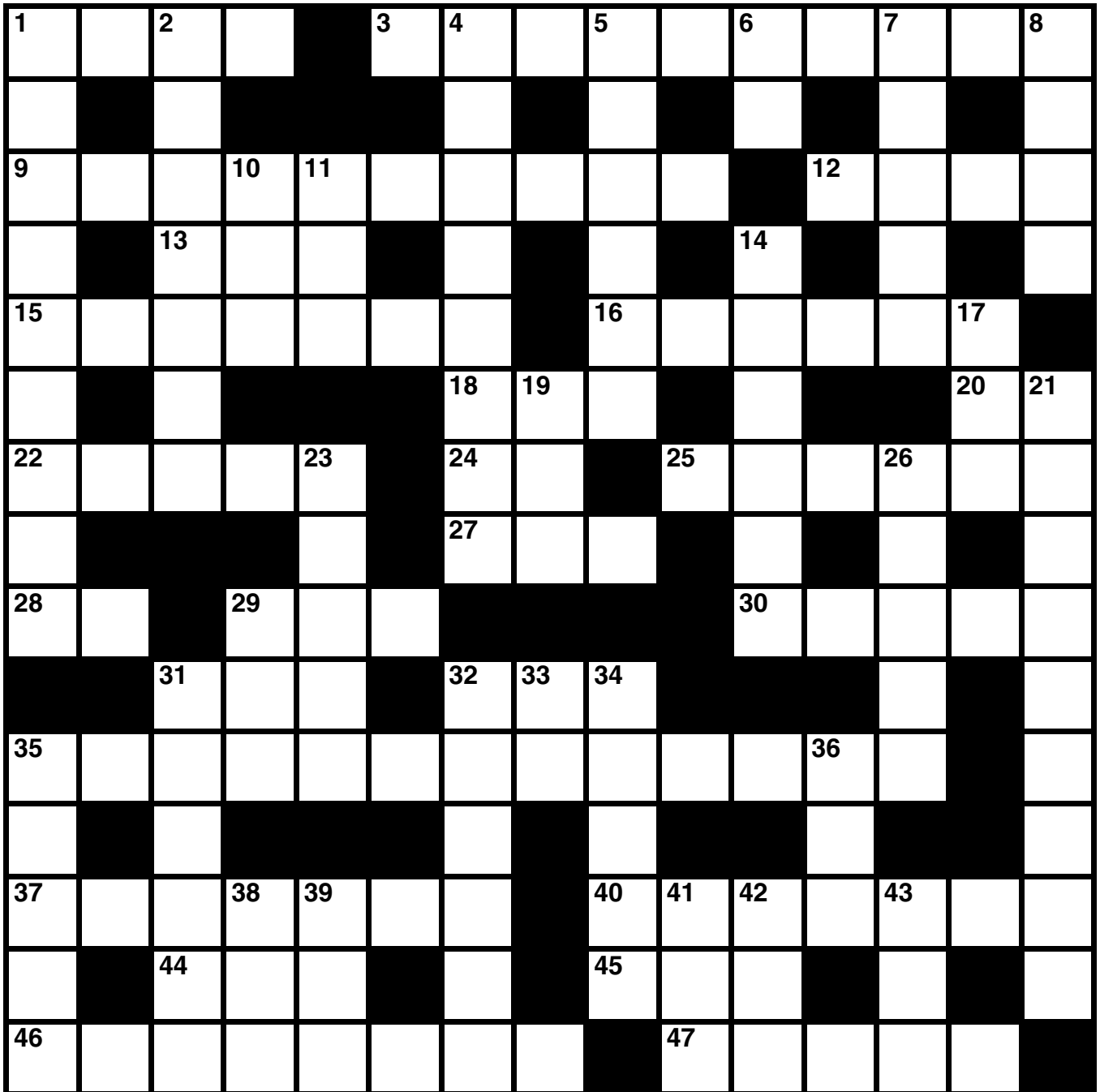
Itto: I like that. What would you like people to take away from this interview?

Ashir: I have three things. One is to please start looking at disability issues from a technical point of view, a viewpoint of problem-solving, not only with empathy. Second, stop thinking about persons with disabilities as if we're all the same, with all the same needs and the same limitations and aspirations. We're all different, and we all need different things. Third, I want to build connections. I want to get my projects going. So, if you're reading this and you have some interest in collaborating or investing or something, please just contact me!

■ **ABILITY**

by Itto Outini

ABILITY'S



Crossword Puzzle



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A C R O S S

1. Christopher Reeve role (first name)
3. Late El Paso philanthropist who was the backbone of the Dustball Rally, 2 words
9. Company providing modular access mats for people with disabilities, 2 words
12. Elderly
13. "A Chorus Line" tune
15. Most courageous
16. American actress and comedian who advocates for people with disabilities, _____ Potter
18. "Brokeback Mountain" director Ang
20. Peach state, abbr.
22. Sanctuary
24. Electric vehicle, for short
25. The S in ISA (the design for wheelchair access)
27. Morning rose moisture
28. Bismarck locale, abbr.
29. Lunch sandwich, for short
30. Tranquility
31. Vocal support
32. Short sleep
35. "Grey's Anatomy" star who is an advocate for people suffering from cyclic vomiting syndrome, 2 words
37. Selma's state
40. Heartfelt
44. Hellos
45. BBQ serving
46. UK airport going the extra mile for people with disabilities
47. _____ Elizabeth Jordan: actress with cerebral palsy who advocates for Divas with Disabilities and Women of Color Unite

D O W N

1. "Disabled and cute" lady, 2 words
2. _____ Noblitt: American teen actor, dynamic wheelchair dancer, and differently abled advocate for people with cerebral palsy, epilepsy and hearing disabilities
4. Deserving
5. Empower
6. Working
7. Bird that is an American symbol
8. Team
10. Last page of a book
11. Understand
14. Hearten and keep afloat, 2 words
17. Doctors Without Borders, e.g.
19. Time just before an event
21. Lessen, as pain
23. Healthy green mix
26. Very intelligent person
29. "Fight for Your Mind" _____ Harper who supports Little Kids Rock
31. Ashley Fiolek's new sponsor
32. New Mexico Native Americans
33. _____, shucks!
34. English writer, activist and TV presenter who formed a foundation to help burn victims, Katie _____
35. Trainer
36. Oprah's network
38. Small, as a part
39. Finely pulverized lava
41. Pitch in
42. Baseball stat, abbr.
43. A very long time

answers on page 70

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- Pi in Eye

FOR PATIENTS

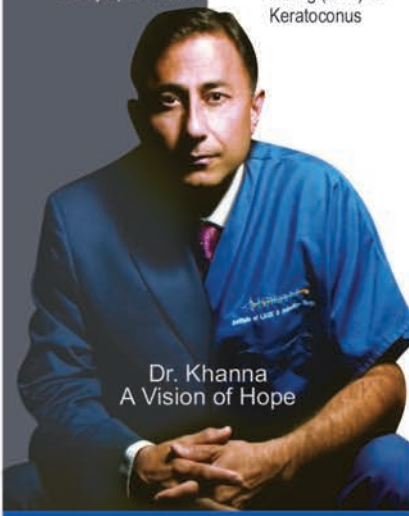
ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

OTHER THAN

LASIK

- Pterygium
- Intacs & Cross-linking (CXL) for Keratoconus



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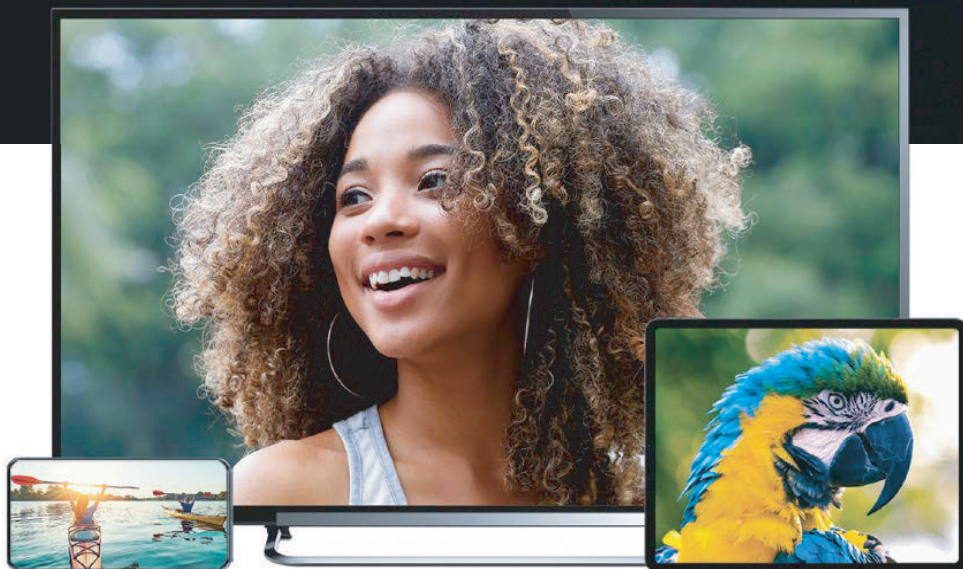
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