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ABILITY

IRONMAN
Athletic Champions

LACHI
Music for the Soul

US HEALTHCARE
Challenges and Chances

MS ON HOLD
Long Haul Paul

Lu Feng Receives China's First Multichannel Cochlea



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ADVERTISING
For advertising information e-mail advertising@abilitymagazine.com 949.854.8700

DISTRIBUTION
Faxon-RoweCom Library Services
Ebsco - Library Services
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CORPORATE SHIPPING
ABILITY Magazine
8941 Atlanta Ave.
Huntington Beach, CA 92646
Tel 949.854.8700

ABILITY Magazine is published bimonthly by CR Cooper
8941 Atlanta Ave. HB, CA 92646 (ISSN 1062-5321) All Rights Reserved
Membership: $29.70 per 1 year (6 issues)
Send address changes to *ABILITY Magazine*, Attention: Subscriptions Manager
PO Box 10878, Costa Mesa, CA 92627; Katherine Maher Issue Oct/Nov 2020

Published in USA

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The views expressed in this issue may not be those of *ABILITY Magazine*

Library of Congress
Washington D.C. ISSN 1062-5321

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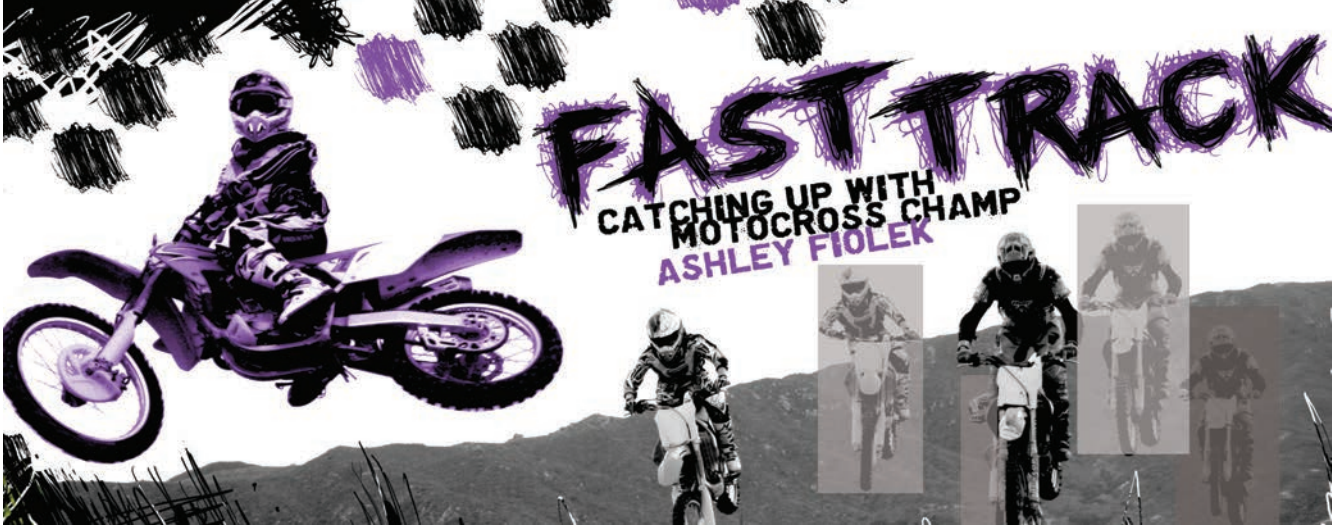
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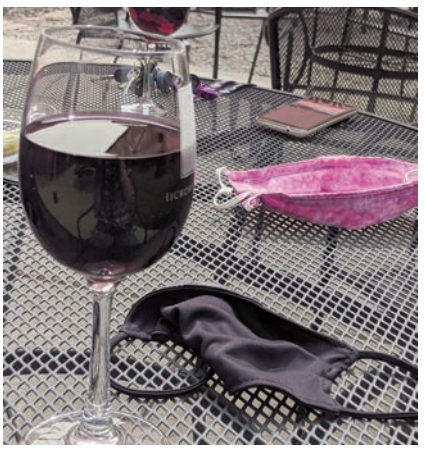
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I've been traveling the East coast for my AFMX schools which has been the highlight of my summer and fall :) It has been exciting and fun with my mom and Lindsey. The weather has been off and on with raining and very cold weather but we've been lucky with the classes to have beautiful days. All of the students have been really fun to work with and am very impressed with them. I have seen a lot of improvement from the start of the classes to the end.

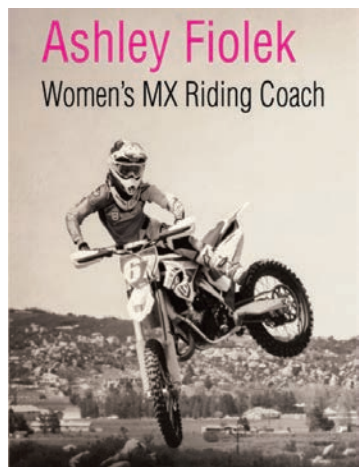


I love to travel and hit a bunch of new different tracks. I brought my dog Bambi with us on this trip so it's a bit tight in my trailer, but it has been working. So far Twisted MX is my favorite track (loamy and sand track) also it's in Michigan and that' s where I'm from so it was nice to be able to go there and visit my family as well. My family came over to our campground on Sunday and we all had BBQ together and watched football. We are staying in Michigan for a week so it's nice to be able to hit all of my favorite restaurants and local places that I miss and don' t get to see all of the time.



In Illinois we hit a bunch of wineries and it was really fun. Hickory Winery was my favorite one. We were able to sit out by the vineyards too. It's a very beautiful place. We have had some adventures my mom is obsessed with our new ice maker and makes tons of ice every day (do you think she is bored?) She also got smacked in the tooth/lip with our pop up screened in tent and she thought she lost a tooth. It was funny, but I felt bad for her. I wish I had caught in on video. I know, worst daughter ever! We have been gone for over a month now but we still have one more class then headed back home to sunny Florida. Have a great Fall everyone do something different.

■ ABILITY



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Almost every day,

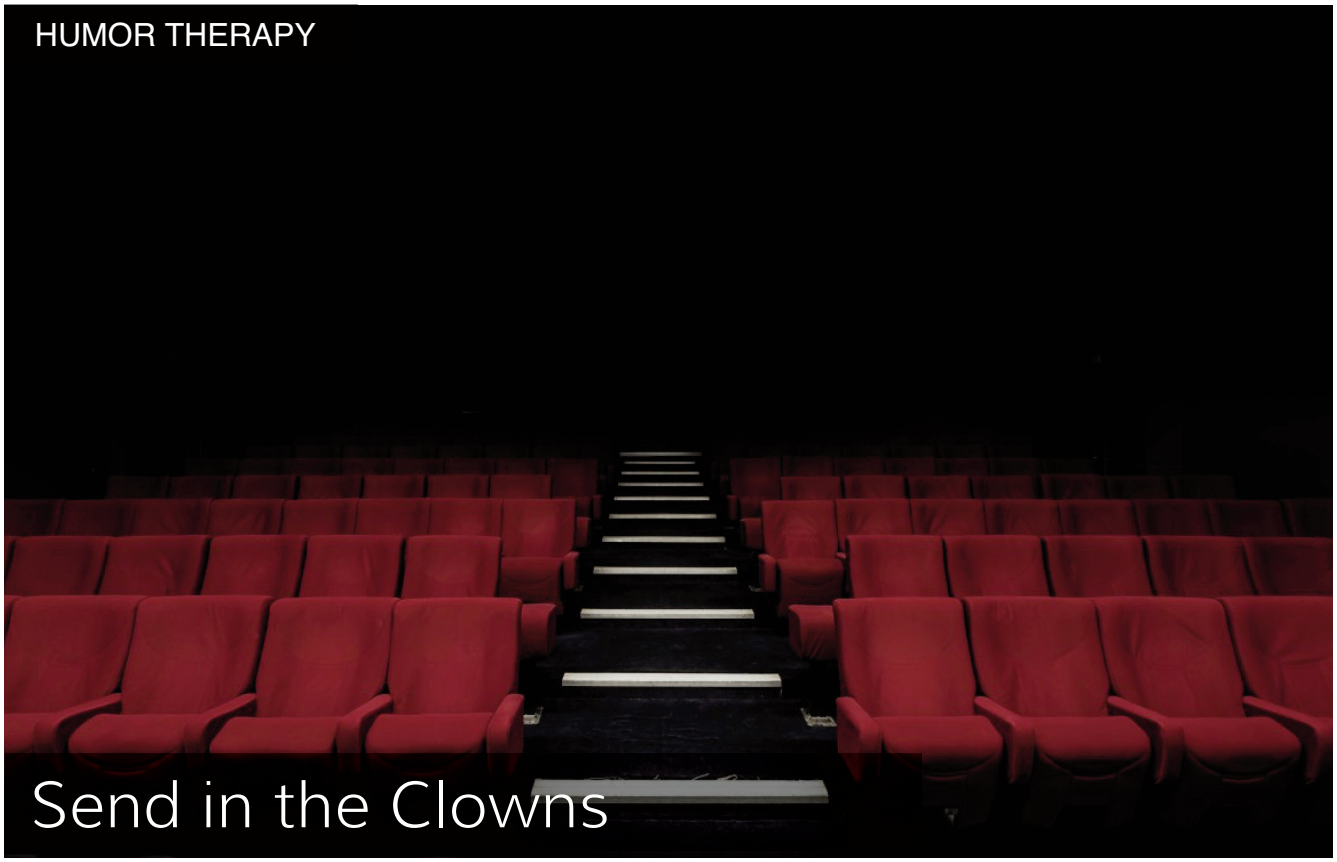
NAMI—the National Alliance on Mental Illness—adds something new to its Web site. Whether it's the latest on science and research, opportunities for education and support, resources for recovery, or tools for advocacy, I turn to NAMI.org to keep me informed, inspired and involved.

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Send in the Clowns

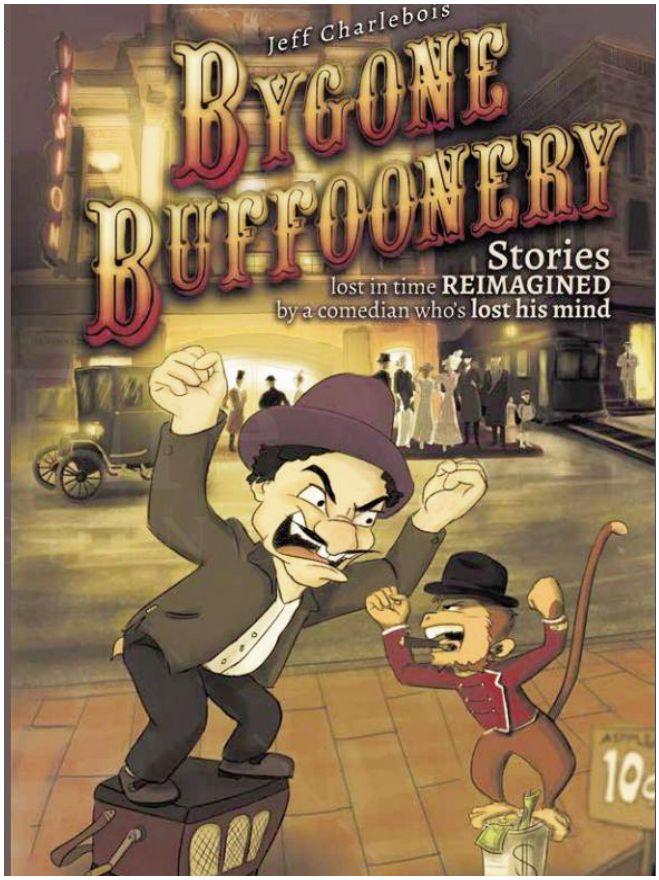
The virus shutdown has taken its toll on industries that one may have never imagined. Yes, we know about the restaurants, hotels, gyms, salons, and most office jobs. But, what about the comedians? The backbone of this great country. Since the plague began, nobody's been able to laugh because our beloved comics have had nowhere to perform. This has left society miserable and searching for the laughs.

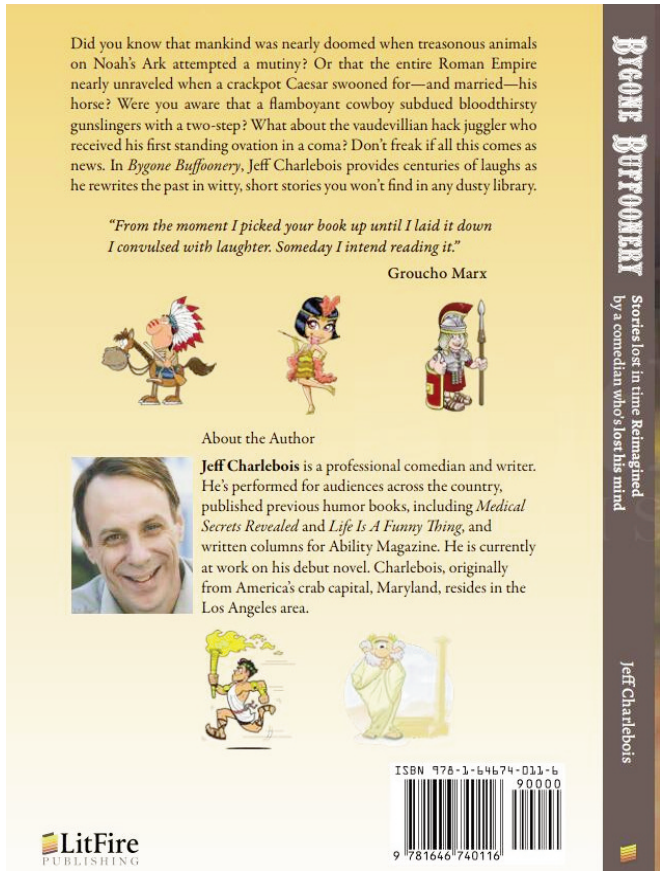
As a fellow comedian myself, I miss the limelight, being on stage, where all the focus is on me, where it should be. It's the only time I get any attention in this life. It's the only occupation where you welcome people laughing at you. I take that back, there's clowns and mimes, but they're a dying breed. And how much can you take of a mime? Five minutes tops. It's like, "Okay, I'm not getting it. Are you trapped in a box, a trunk, an aquarium? Say something, dammit!" Getting on that stage is like heroine to comedians. A room full of laughter brings about an unexplainable high. And, when you get on a roll, it's a rush better than any needle in a vain. Now, without any stage time, comedians all over the country are going into withdrawal, jonesing for a laugh. The sad thing is there's no rehab centers set up to handle these shaking, sweating comics.

It's not just the comedians, it also hits the people who frequent comedy clubs. They need those laughs at the end of a long week of kissing up to the boss and dealing with irate customers on the phone who want their money back for the crap you sold them. The chuckle venue is where they go to escape life, even though it costs a mortgage payment for drinks. They can also take out their frustrations by heckling and belittling some green comic. Does life getting any better than destroying someone's dreams? I think not.

Without an audience I am left with telling friends new jokes that have popped up in mind that I feel must somehow get out in the world. The only problem with that is my friends never laugh at my jokes. The standard response is usually, "I hope you're not going to use that on stage." If I had always listened to them, I would've never had an act. So, now I'm left slipping out jokes to strangers I meet in grocery stores. "The prices are great in this store. Gatorade's only a quarter and you only have to buy forty of them to get that price. I knew I should've brought the eighteen-wheeler with me." The problem with this is, everybody's wearing masks, so I have no idea if they're at least smiling, which is usually a sign that they enjoyed the joke. Yeah, I see their eyes crinkle a little, but does that mean they liked it or are they saying "buzz off, creep? I'm not a good crinkled-eye reader, yet.

Topical humor is now obsolete. It's not even worth using any brain power to come up with some twist on Kayne West running for president. By the time clubs open again people will have forgotten the rapper threw his hat into the ring. Many have already forgotten. It's not even worth writing any Covid 19 jokes, even though I just did the other day. I might as well share it with you because it will soon obsolete and I'll have nothing. "The other day I was in a store and a lady came up to me and





said, 'You should be wearing a mask. I responded, 'Lady, I'm not afraid of no virus.' She fired back, 'I'm not talking about the virus. You just need to wear a mask.' I snapped back, 'Well you're no Halle Berry either.'" That felt good to get that out. I'm just going to believe you're laughing. When this nightmare is over the last thing people will want to hear about is the virus that wreaked so much havoc in everyone's lives. That Wuhan chapter will want to be forgotten. After waiting so long to get on a stage that last thing you want is to bring that virus up only to be pelted with vegetables and booed. Personally, I live for the day when I don't hear the word "virus" six hundred times a day. And I long for the day when we can move on and get the important news like why Leonardo DiCaprio is no longer on Facebook or why the Khardasian are cancelling their award-winning show. Look at me, I just slipped in some topical humor. You better be smiling under that mask.

Many comics are trying to get their fix on social media which was usually used for promoting their shows. The attention-starved comedian needs to know they are still loved so they throw out silly pictures with silly jokes desperately hoping for comments that lets them know they still got it. For instance, they post a photo with them walking their dog in their Bermuda shorts with a caption that reads, "Wouldn't it be great if we could go to the bathroom anywhere too?" Okay, it's not comedy gold, but a few "likes" and comments like "OMG, you're soooo funny" is enough to get them through the day and stem off the suicidal thoughts. Many comedians have stopped playing music and replaced it with a laugh track. It's just something to keep their blood flowing until the clubs and cruise ships re-open.

As you can see this crazy virus is hard on all of us, but I think we can all agree that the comedians have taken the brunt of the shutdown. Can they ever recover? It's hard to say. Many will probably never get their timing back and fall by the waist-side, never to dot the stage again. Yes, this may be a good thing, but it's the few funny ones we need to be concerned about. We need the comedians. Without them, our existence is empty. Who will open our eyes to the absurdity of this world, keep the politicians in check, and put a smile on our face after a long week of struggling through life's relentless troubles that beat all of us down? Maybe, in hindsight, we should've offered the comic carte blanche with Covid 19. We need you so much we're willing to keep the clubs open because without you our lives our meaningless and, without the laughs, we're nothing.

Where are the clowns? Send in the clowns. Well, maybe, next year. ■ ABILITY

Jeff Charlebois

wheelfunnystuff.com





中国第一例多导人工耳蜗植入者

Lu Feng, First Person with Multichannel Cochlea in China

On the day I met Lu Feng, he had just rushed back to Beijing from his hometown in Wuxi. He was dragging his suitcase. He wore a black T-shirt with relaxed shorts and canvas sandals, a set of casual clothes. He was nothing like I had expected. Later, I would learn that he had gained more than ten kilograms since the beginning of the epidemic. Lu Feng, 56 years old this year, has unkempt and tousled hair, and his hairline is still strong. With black-rimmed glasses on the bridge of his nose, he looks a bit like Japanese writer Kensaburo Oe.

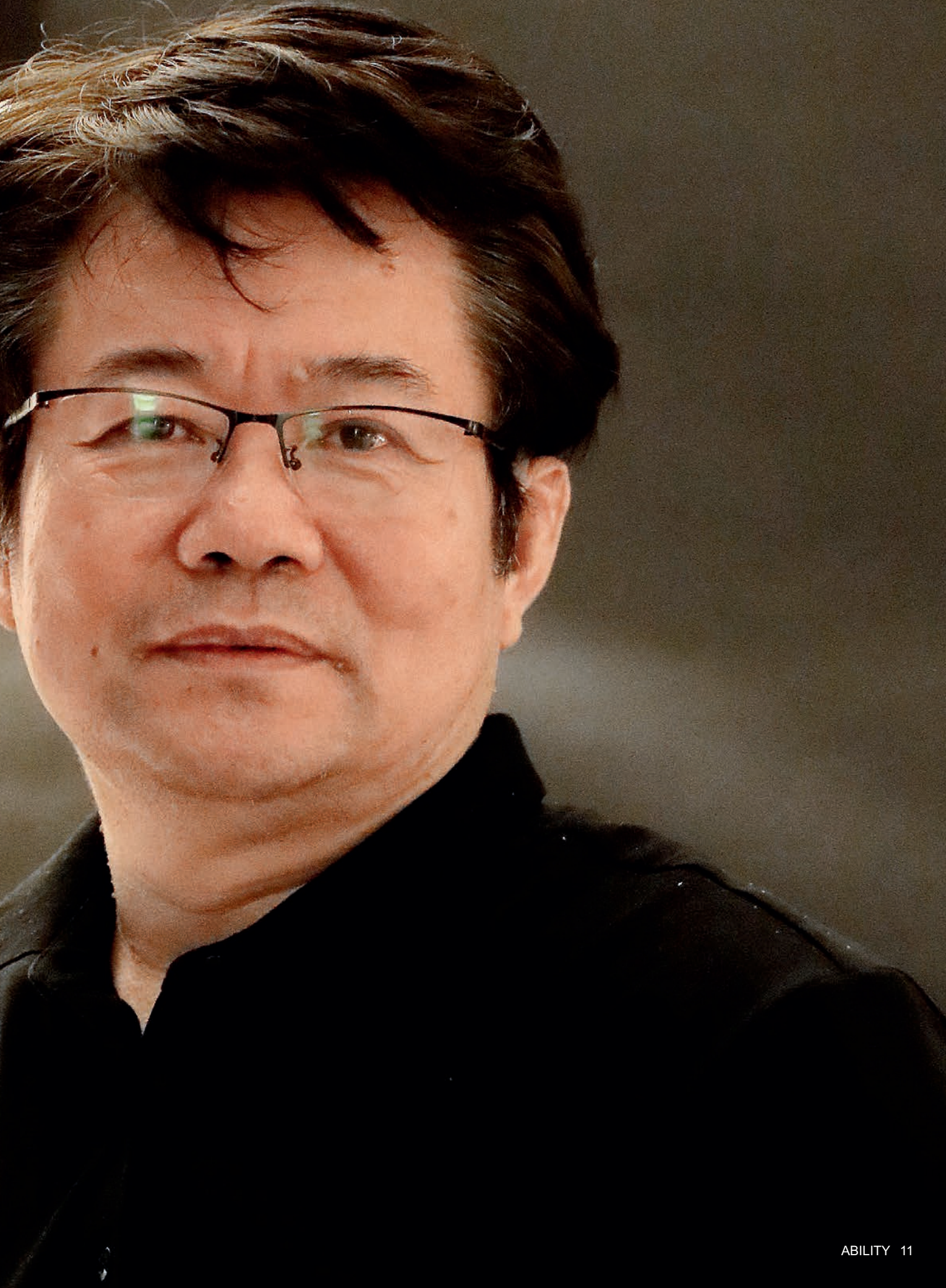
At dinner, the lights in the restaurant were dim, and there was noise everywhere. He took off two electronic gadgets from the collar of his shirt and put them on the table with a "Pada" sound. He explained, "Both are cochlear implants. The round one is used for speaking, and the long one is used for making phone calls." After asking, I found out that each unit price is around 10,000 yuan.

In the 25 years after he received the cochlear implant surgery in Beijing in 1995, Lu Feng spent a lot of time there. What has not changed is that his Mandarin still has a distinct Jiangsu and Zhejiang accent. "Beijing is too fast, and I still like the south". Holding a glass of beer, Lu Feng opened the conversation.

Hitting the upper limit of medical technology

Lu Feng likes sports, especially badminton in recent years. He has played 100 courts across the country, and his calf is covered with strong muscle bumps. When he was young, Lu Feng preferred playing soccer. The last time he played was in 1985, when he was 21 years old. It was an amateur game and Lu Feng accidentally injured the meniscus of his right leg. He originally thought the injury was just an episode in his life, but he didn't expect it to bring about a drastic change.

Before the injury, he worked as a video reporter for Jiangsu TV Station. After taking the TOEFL test, he received admission notices from two American univer-





sities. In order not to affect his study abroad, he decided to undergo meniscus removal surgery in China. The surgery was very successful. However, a wound infection occurred after the operation, and the doctor used a large amount of neomycin to wash the wound. The neomycin, which should have entered the upper end and exited from the lower end of the drainage tube, was accidentally blocked at the lower end, but the doctor did not find out in time, which led to blood poisoning. During the hospitalization, Lu Feng's hearing declined rapidly. The doctor suggested, "Go home and rest, and you'll be fine." This eventually triggered drug-induced neurological deafness. The 140-kg young man had only 90 kg left when he was discharged.

The hospital knew that it was at fault, and promised to pay him 3000 yuan, "equivalent to 300,000 yuan now", said Lu Feng. But he has not yet taken it because he "cannot let it go." The most anxious were Lu Feng's parents. Her sister also gave up the opportunity to study abroad. They first believed that there must be special medicines abroad. But their hope was shattered when the doctors in Europe said, "It's time to give up. This disease can't be cured".

One winter when he was seeing a doctor in Hangzhou, his father rented a house next to the hospital. One day his father came back and found that he didn't bring his keys. In the house, Lu Feng was engrossed by a novel. His father saw him through the crack in the door and kept knocking on the door and the window, but Lu Feng sat motionless and didn't respond. His father could not bear the matter and collapsed outside. They continued their journey of seeking medical advice until they met Professor Deng Yuancheng, the founder of the country's hearing rehabilitation, who wrote, "Don't seek medical help again. Go home and wait for the advancement of science and technology." The family had not accepted the situation, but there was nothing that could be done. In the face of the limits of medical technology, money is useless.

It wasn't until 10 years later that a phone call from Beijing provided Lu Feng's family with ripples of hope in the still water.

Back to the world of sound

Lu Feng once said that he must thank Mr. Deng Pufang for where he is today. In June 1993, the then Australian Prime Minister Keating visited China and met with Deng Pufang, then chairman of the China Disabled Persons' Federation. Mr. Keating hoped to cooperate with the Chinese government to use Australia's latest technological achievements in cochlear implants to help Chinese hearing-impaired patients rebuild their hearing. In

May 1995, Deng Pufang was invited to visit Australia and he visited the Cochlear Implant Company headquartered in Sydney. It was also this friendly visit that laid the prospect of arranging Chinese patients to undergo surgery in the future.

In the year when Lu Feng was deaf, Cochlear's 22-channel cochlear implant was approved for clinical use. In the following ten years, there had been tens of thousands of successful cases internationally. The operation in China would be the first attempt of a cochlear implant outside of a western language environment. They needed a patient who understood English and had acquired hearing loss. Lu Feng became the lucky one.

From the results, Lu Feng was lucky, but at the time it meant additional risks. The operation itself was also a medical experiment. Lu Feng, who rushed to Beijing after receiving a call from Professor Deng Yuancheng, wrote something similar to a suicide note the day before the operation. He was sure in his heart. "Maybe it will succeed tomorrow, or it may not. You see this thing I wrote and know it is my own choice and has nothing to do with you (parents, sister)."

On May 4, 1995, the Youth Day, Lu Feng underwent a cochlear implant for his right ear at Peking Union Medical College Hospital. Two doctors, Professor Perlman from Australia and Professor Cao Keli from Union Hospital, worked in the operating room for nearly nine hours, which was longer than the previous surgeries. Later, it was learned that Asians have different skulls from Europeans.

One month after the operation, Lu Feng, who returned to the hospital, turned on his cochlear device while a group of media personnel watched him. He heard a lot of sounds instantly, but didn't know where these sounds came from or what they meant. He was extremely depressed, as if he had entered a strange society. The person from the surgery team wrote to him, "That's because you haven't heard for 10 years. Go back and try to communicate in a quiet environment."

After coming out of the hospital, Lu Feng, a little depressed, walked slowly along the street with his sister, passing Chang'an Avenue, and walking to Wangfujing. The two bought a newspaper on the road and entered the Quanjude Roast Duck Restaurant. In the box, his sister picked up the newspaper, covered her face and called him: Lu Feng. Lu Feng could not see or know where the sound was coming from. Hearing these two words, he felt they were very familiar words. She called again: Lu Feng. Lu Feng asked, "Is someone calling my name?" His sister remained motionless, still holding the newspaper. Lu Feng gently pushed aside the newspaper in front of her sister and saw her tears streaming down. The two talked until 3 o'clock in the morning that day.

Three days later, Lu Feng was able to communicate on a one-on-one basis in a quiet environment. After another three months, Lu Feng's hearing in his right ear basically returned to normal. In 2016, Professor Cao Keli from Peking Union Medical College Hospital, together with Professor Liu Yuhe from Peking University First Hospital, implanted his other ear with the contralateral cochlear. Lu Feng and Professor Cao became friends for life after two operations.

The promotion of cochlear implants has a long way to go

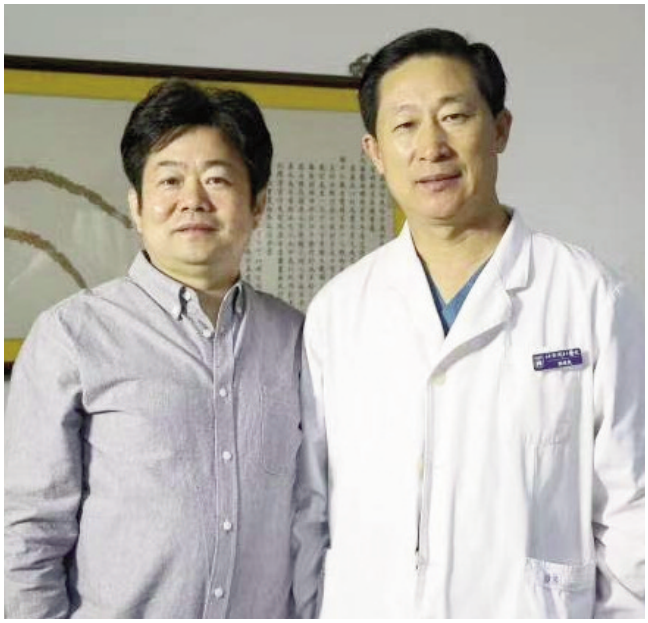
Lu Feng often returns to his hometown in Wuxi is to visit relatives as well. His parents are both older generations of educators, and both are 89 years old this year. His mother suffered a car accident a few years ago and had a partial amputation of one leg, and her hearing loss was severe. She wanted to know many things but couldn't hear clearly, and as a result had a knot in her heart. It took a lot of time to explain many things to her every time Lu Feng went home. Lu Feng suddenly had the opportunity to feel empathy. "I was young when I was deaf. I didn't think so much. I only slowly understood the mood of my parents back then. It is very complicated." He bought a hearing aid for his mother, but the effect was not satisfactory. It remains one of his sore spots.

Many people know that Lu Feng was the first person in China to receive a cochlear implant, but they don't know that a second person entered the operating room the day after Lu Feng's surgery. "He is a professor at Tsinghua University and one of the heroes of China's first-generation atomic bombs."

In 2007, Lu Feng resigned from the Australian Cochlear Company to start an Internet company. He knew that "people with poor hearing may not have poor intelligence." Among the more than 20 employees recruited, 4 were hearing impaired, and 3 of them have received cochlear implants. "People with the same experience are particularly comfortable in social relations, so they can help each other." Now Lu Feng is also the director of the Cochlear Implant Committee of the Chinese Association of the Deaf. He speaks from his own experience and actively promotes the significance of cochlear implants to the society.

As the person who has worn cochlear implants for the longest time in China, Lu Feng already considers cochlear implants an ordinary electronic product. "There are still many people who are afraid of cochlear implants. The best publicity is to make people realize that this thing is very common. It's the same as wearing glasses." Lu Feng said that an operation now only takes 40 minutes and the wound is much smaller. "Have you seen the pictures of my operation? That wound is very scary."

The bigger obstacle comes from the economic side. In



the past 27 years, Lu Feng's cochlear implants have undergone five external upgrades. From listening to music to making calls, from wired to wireless, the external device is getting smaller and smaller, and the equipment is becoming more and more intelligent, but the cost of updating so far is more than 1 million yuan.

Lu Feng said that, according to the association's statistics, starting with him, only 90,000 people in the country have received cochlear implants in 25 years. The current population of hearing impaired in the country is 28 million, and 7.5 million are suitable for surgery. Cochlear implants are still far from popularization. "2019 is the year with the fastest growth in the number of cochlear implant operations, with a figure of around 10,000. Among them, there are about 6,000 national projects."

Surgery is only the first pass

Since serving in the Chinese Association for the Deaf, Lu Feng has learned even more untold stories about cochlear implants. For example, operations require experienced doctors to perform. At present, about 200 hospitals across the country have the ability to perform operations, but the standards vary. "Each patient's physique is different, so various things often happen during surgery. This is how it is if you don't do well." Lu Feng squeezed his face in the middle with both hands, "Facial paralysis." These patients were eventually transferred to hospitals in major cities such as Beijing and Shanghai to receive "secondary operations."

There are also problems with the patients themselves. There was a hearing-impaired child who underwent surgery in Hong Kong for the first time. One year later, the surgical wound burst and the skull could be seen. "Then he was hurried to Shanghai to take it out, and went to another hospital in Beijing to receive the implantation operation but it failed. I found Professor Cao Keli and he put back the cochlear device." Lu Feng made a grimace, "Don't you think it is scary? Later I found that this child's body is rejecting foreign objects."

According to Lu Feng, at present, the country's efforts to help hearing-impaired patients are focused on young people, and remedial measures for middle-aged and elderly hearing-impaired persons have always been lacking. Only a few provinces' disability federations have provided subsidies for cochlear implants and replacement devices for this population. "Parents of deaf children are suffering, and adult hearing-impaired patients themselves suffer more." In recent years, Lu Feng has encountered 3 suicide cases caused by poor surgical results. "There was an entrepreneur who spent 300,000 yuan on a cochlear implant, and the result was unsatisfactory. He became depressed and committed suicide 20 days after the operation."

As a result, Lu Feng proposed a new topic: postoperative psychological intervention, including intervention for parents of deaf children. "We have seen mom and dad give birth to a child looking happy. What should we do if the child is deaf? Falling from heaven to underground, the whole family is in chaos." Therefore, one of Lu Feng's projects in recent years has been to promote psychological counseling training within the China Association for the Deaf.

"Now there are three imported brands and two domestically-produced brands in the cochlear implant market, and another French cochlear implant brand will soon enter the Chinese market. The gap between Chinese and foreign products is reflected in the technology. But the cochlear implant is essentially a monopoly industry, so foreign products can be sold so expensively." According to Lu Feng, "Cochlear implants should not become a luxury. I hope that one day it can be a Sino-foreign joint venture, like a car, which will greatly reduce the financial pressure on patients."

The latest product line of the brand he is wearing does not match the internal device in the earliest right ear, so he has no chance to update it. "In the past 20 years, the basic functions of the cochlear implant have not changed. It is nothing but more peripheral functions." He hopes that the cochlear will evolve to be smarter in the future, is usable on boot, and adapts to body tissue.

Lu Feng finished his last sip of beer, "At that time, I must take the original one out and replace it with a new one," then he laughed. ■ ABILITY

writer/ photographer Bai Fan

This story is part of a series of articles published as an exclusive editorial exchange between *China Press for People with Disabilities & Spring Breeze* and *ABILITY Magazine*


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MISSION ON HOLD, OR.....HOLD MY MISSION

Most of my speaking events for MS audiences have been cancelled this year due to the pandemic. Likewise, most of the motorcycle events have also been cancelled or postponed until next year. I don't have to point out, without events to travel to, I am grounded. Three quarters of the year have passed and I am down at least 30,000 miles from where I was this time last year.

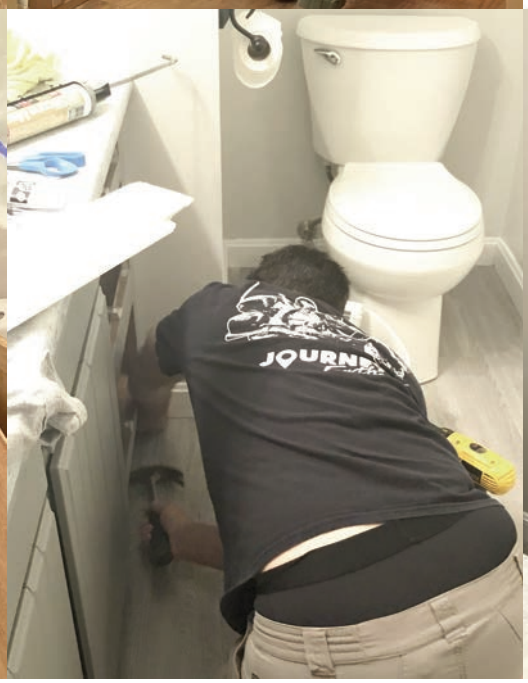
For the last eight years I have had people tell me how dangerous traveling by motorcycle is and I should be very careful as my luck will run out someday. Traveling is also expensive; gas, food, lodging, tires, oil and gear that wears out each year adds up quickly.

Being on the road was way more risky and expensive than staying home.








Or so I thought.

Since the country shut down trying to slow down the spread of Covid, I've been to the emergency room twice. My kidney dropped a 10mm stone that only a laser and a front end loader could remove, and some mild chest pains got me to the front of the line for an overnight stay and a heart catheterization procedure looking for yet another clogged artery. They didn't find any this time, the cholesterol meds seemed to be working.

Next week I am getting a corneal transplant in my left eye to fix some scarring that has been blurring my vision since last year. I am looking forward to being able to see again out of both eyes! The following week, I am finally getting around to scheduling my nerve relocation surgery to take care of something they call cubital tunnel syndrome. My funny bone nerve sticks out and causes quite a bit of discomfort and tingling in my hands. I have not been able to rest my elbow on anything without a shock running up my arm for almost a decade. I just never had a six week period where I could stay home for the recovery, until now. Thanks Covid-19.

Thankfully my wife has good health insurance through her employer. I reached our $4000 deductible in record time and I am scheduling these non-emergency surgeries now because I have the down time and for the rest of the year, my medical bills are free!

Not to be outdone by the healthcare system, I also decided while I was grounded to do some work around the house. Fix some rotted windowsills, re-stain the decks, cut down a few dead trees and split some wood for the upcoming winter. I may not have earned any money this year, but I have stayed busy working every single day.



My wife talked about freshening up the main bathroom. Maybe some new fixtures and paint the aging oak vanity. I decided to help her with trying to remove the tub enclosure drain that was leaking and rusty. The grout in the floor tiles needed redoing and a few tiles could stand to be replaced. I thought I would surprise her with a few extra updates when she got out of work.

It was a simple, one day job.

Trying to remove the 40 year old tub drain created a little problem that morphed into a full fledge floor to ceiling remodel! The fiberglass tub enclosure cracked, the plumbing broke off inside the walls, the floor tile disintegrated and the vanity blew apart when I tried to carefully remove it. The doors, trim and just about every single nail in the room ended up becoming a problem that needed to be addressed. On the fourth day, I actually went to Home Depot 7 separate times!

I spent ten days total, from seven in the morning until nine or ten each night, ripping out the entire bathroom and repairing or replacing everything. Thanks to watching my Dad growing up and a little bit of YouTube, I was able to install a whole new tub and shower enclosure, relocate and replace all the plumbing and drains, redo the electrical and vent, sheetrock the walls and replace the flooring, toilet and sink. I rebuild the frame for the vanity and refinished the top in epoxy. I even cut the once bare mirror and made a custom frame for it. The trim was all replaced, doors painted and all the hardware and fixtures replaced.

So, yes, 2020 was the year I was stuck mostly at home, unable to ride for MS or share my story with other patients as I did in years past.

However, in no way shape for form has it been easier, healthier, safer or less expensive!

I need to ride! ■ ABILITY

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Challenges and Chances:

Navigating the US Healthcare System with a Chronic Condition

ABILITY Magazine speaks with four chronically ill people about their experiences navigating the system, the advocates supporting them to get the care that they need and deserve, and with experts who explain what we could do better in the United States.

Do I have cancer? This thought had been on my mind for months. I could have received answers immediately, but my insurance kept denying the MRI necessary to rule out cancer. I am just one of many people fighting for their rights within the US healthcare system every single day.

Karina, 34, San Francisco

When I went for my latest doctor's appointment with a gastroenterologist, I didn't quite expect the consequences our 60-minute-talk would have on my life, or that I would spend the upcoming weeks on the phone, arguing with my insurance. I thought I was simply seeing a doctor who would help me manage my gastrointestinal symptoms that have been worsening since I was a child. Instead, our appointment turned out to become my biggest nightmare. I started by talking about my folder full of chronic health conditions, which are almost all related to a rare, genetic connective tissue disorder called Ehlers-Danlos syndrome (EDS). I was diagnosed with EDS in 2014, and over the following few years, I added a new condition to the list almost every month. Over the course of our conversation, the specialist became aware of a mutation in my genes that causes a condition which is associated with a significantly higher risk of developing pancreatic cancer - one of the deadliest cancers.

After speaking to a pancreatic cancer expert, my doctor decided - carefully considering all my preexisting conditions, allergies and risk factors - to order a cancer screening via MRI. For two days, I was in shock. Then I learned that my insurance denied the test. The following weeks, I spent on the phone with my insurance, legal representation, patient advocacy organizations, and my doctors. I had to cancel my MRI appointment three times and live with the constant fear of having cancer at age 34. A routine test could have confirmed or ruled out issues with my pancreas, but since all expensive imaging needs prior authorization from my insurance, (and more often than not, they deny those referrals), I had to fight an insurance company that receives a large sum of money to fulfill my medical needs. Instead of the MRI, they wanted me to have cheaper diagnostic



Arghavan Salles, MD, PhD


Karina

tests, which would have required several doctor's office visits in times of rising numbers of COVID cases in my state. Some of these tests weren't indicated for the suspected condition; others, I couldn't have due to my complex medical history. Many attempts to explain my situation failed. For several weeks, I lay awake at night unable to get c-word out of my head. Then I'd wake up and summon what little energy I had contacting researchers and fighting my insurance.

I filed an expedited appeal, which got denied as well. Then, my doctor called my insurance for a peer-to-peer review, which, again, led to another denial. Meanwhile, I tried to find out whether I could pay the MRI out-of-pocket, as I have done many times with other treatments or appointments in the past. The test was estimated to be around 4000 Dollars, already including a 60 percent discount for self-pay patients. Under no circumstances could I afford this. I didn't have a choice. I had to continue fighting and waiting.*

Prior authorization and other barriers

Caitlin Donovan and her team at The Patient Advocate Foundation (PAF) help chronically ill people to access the care they need. "The PAF provides free case management and assistance programs for anyone with a diagnosed chronic condition. So today, anyone with diabetes, lupus, AIDS, or even COVID can get our help. Additionally, the National Patient Advocate Foundation advocates for patients and teaches them to advocate for themselves," Caitlin, senior director of both organizations, says. Since its founding in 1996, the PAF has supported over 1.3 million people in the US with a staff of more than 200. Their biggest problem are the growing population of underinsured people, who, in theory, have insurance coverage, but in practice, it often doesn't cover anything. "We help these people with anything from having trouble getting into a clinical trial, their insurance not covering enough, to them having gotten a huge medical bill. One of the biggest issues people call us for is transportation-related. The average amount our organization gets asked for is 22 dollars per way for gas. And that's a very striking way of showing where the barriers are in this country because that's less than a movie night," Caitlin explains.

Caitlin, who calls herself "a bit of a nerd," initially worked for a congressman and later for a lobbyist. As a liberal catholic, she met a nun, who argued that in order to be morally sound, a country needs to provide healthcare for all people. "I thought 'I am going to work for her,' and I did," Caitlin says. She quit her job and worked for liberal nuns who were medical feminists. After, she was determined to continue helping people and decided to stay in the healthcare sector, bringing her to the PAF. "We all have an obligation to help one another, and the healthcare system in this country is the source of one of the greatest injustices and moral crises. It just keeps multiplying in so many different areas. It affects people's housing, jobs, and nutrition. It affects everything," she says.

In 2019, the organization worked with 23,702 patients that needed personal assistance, of which a quarter reported to be disabled. According to Caitlin, every case manager makes an average of 22 phone calls to solve one single case. These managers are professionals - mostly people with a nursing or social work background. "If it takes them so many phone calls, it seems impossible for the average person to navigate the system effectively and efficiently," Caitlin adds.

Often, these cases revolve around issues of obtaining care, for example, getting the authorization for a diagnostic test, like in my case. I am in no way a rarity - to the contrary. According to a survey by the American Medical Association (AMA), in 2019, 86 percent of physicians in the US reported that the burden associated with prior authorization requests has increased over the last five years, and the whole process "often or always" led to delayed care for half of those patients. In a quarter of these cases, it has tremendous consequences for the patient. They might suffer serious adverse events. "Prior authorization was put in place to protect insurances from the enormous price problem we have in this country. But the problem is this works against the patients, who cannot get the care they need. We need to stop practices like that and rework the system to favor patients," she says. One piece of advice the professional advocate gives to the people the PAF supports is that dealing with your insurance is a contract negotiation and should not be approached emotionally. "It's deeply personal, but it is a contract, and therefore you need to use their language to support your case."

While my battle with insurance lingered on, I began to investigate how other people with disabilities or chronic conditions were being impacted by barriers to their healthcare; and many stories were much worse than my own.

Steve, 31, Minnesota

Steve was 12 years old when he developed severe diarrhea. When his mom brought him to his pediatrician, they ran dozens of tests and found out his liver enzymes were dangerously elevated. He was later diagnosed with primary sclerosing cholangitis (PSC), a chronic and progressive condition affecting the bile ducts of the liver. On top of it, he showed symptoms of ulcerative colitis, an inflammation of the large intestines. Only two years later, Steve's liver was too damaged to function properly. While his friends enjoyed their first year in High School, Steve needed a liver transplant, or else he was going to die. "My disease progressed really quickly. I spent about six months on the transplant waiting list, and I was listed for both, pediatric and adult, as well as for half and whole liver. I was on the top of every list possible due to the severity of my condition," Steve remembers. He received the life-saving organ on Christmas Eve 2003. However, he had no idea how serious his condition was until media picked up his story and used the headline: 'Local boy went from near death to prosperous life.' "I remember making a joke about that, and my parents where like, 'Well….' I totally get that because as a parent, how do you explain to your 13-year-old that things aren't looking good for him?" Steve says. The following years after his transplantation, Steve lived a life between medical appointments, school and later university. He studied college administration and became 'a professional sick person,' as he calls himself - until he developed complications of his PSC again. "With the liver disease I have, what can happen is that the bile ducts are getting inflamed and bile doesn't flow through the body. Then that infection spreads, causing sepsis. If it happens once, it's okay, but in my case, it kept happening over and over again. And I was hospitalized several times," Steve explains.

His liver enzymes continuously rose to the point that he had to be re-listed for another liver transplant, and that's when things got complicated. "It was one of those situations where you know you go through something big, and usually, you would say to your insurance company, 'Hey, heads up, this is happening.' I was still on my parents' insurance, so I don't know if I have a distorted view of it, but to me, it sounded like they just said, 'Nope.' And I responded, 'What do you mean, no? I need this to live.' And they were just like, 'No, we don't do second liver transplants,'" Steve recalls. As a consequence of the denial, Steve's mother wrote a heartfelt letter, making a case why her son deserves a second transplant. The letter states: "A liver transplant is the only known cure for PSC and the doctors see no other option to provide Steven with a chance to have a normal life expectancy. If there was another option, we would certainly consider anything." According to Steve's mother, the insurance policy would have covered a second kidney or bone marrow transplantation, but only one liver. She continued to talk about Steve's warm and caring personality and attached photos of him, as well as letters from his doctors, professors, and everyone that could possibly make a case for her son Steve. Meanwhile, his condition worsened, and he had to undergo a painful procedure called biliary drainage, where a tube is put in the main bile duct. "It would come out of my abdomen and drain into a bag that was strapped to my leg. I had that in for two separate 1.5-year episodes. It was a nightmare because I was going to college and then grad school, and every four or five weeks, I would have to go back into the hospital," Steve says.

While juggling university, chronic health issues, constant hospital visits, and painful treatments, at the same time, Steve and his family had to fight his insurance and fear for his life. "For a while it was both, arguing that I deserved a second transplant as a human, which is pretty sick in general, and then also convincing them that monetarily it makes way more sense to have this one surgery and not have to pay for all the other treatments. It's disgusting that we even had to make the first case, let alone the capitalistic case afterwards," Steve explains. For people outside the US, it is hard to imagine that a 23-year-old could be denied a life-saving surgery, but in the US, that's not uncommon. "I thought I just have to deal with it until my life ends - until I die from it. In my brain, I conceptualized this almost like an endurance race that certainly had an end to it," Steve states.

He did not die. Steve received his second liver in 2014 after his mother switched jobs, which came with a new insurance, and they covered the expenses. Today, Steve is 31 years old and an advocate for other chronically ill people. "Why is anybody not deserving of healthcare in general? That's something I really struggle with. I don't understand how anyone can be okay with the fact that insurance companies are making money of such a vulnerable population," Steve emphasizes.

Limited access to healthcare

Despite living in a developed country with some of the top medical experts worldwide, many Americans die from a lack of access to proper healthcare because they cannot afford health insurance. According to a study by Families USA, a non-profit organization advocating for healthcare for all, more than 26,000 people in the US died during 2006 from a lack of health insurance. Being uninsured has been associated with a higher risk of death since the 80s, and even in 2018, nine percent of Americans still did not have health insurance, depending on the state they lived in. "At that time - before the 'Affordable Care Act (ACA)' - people did not have as much access to Medicaid as they do now," Cheryl Fish-Parcham, Director of Access Initiatives at Families USA, says. "They also didn't have access to private insurance coverage on the individual market that had decent benefits or was affordable. So there were many people who were uninsured and could not get care. Unfortunately, that's again the case now. We are


Steve

living through a pandemic that has caused many people to lose their jobs and with it their health insurance." The organization has just released another report on what they call 'the greatest public health crisis of the century:' the COVID-19 pandemic. Their study showed that 5.4 million people in the US lost their insurance due to unemployment since the start of the pandemic. "These people are not getting preventive care. They don't have access to care until it becomes such an emergency, so there is not an easy intervention anymore. Generally, federal law requires that hospitals provide stabilizing care if the absence of immediate medical care would lead to permanent damage, but that's a really high bar to pass. So you end up with people who have cancer, but it's not life-threatening yet, or other serious conditions where they should have care but they are not getting it," Cheryl explains. 20 percent of all adults in each one of eight states are uninsured right now. At the forefront are Texas and Florida, which both have seen one of the highest increases of daily new COVID cases and total case counts during this pandemic. Those numbers would be much worse if the ACA were to be removed. "Under the ACA, 20 million people gained coverage that didn't have it before. Without the ACA, they would lose their insurance again, because Medicaid expansions in many states and the right to buy individual insurance with premium tax credits would end, as well as insurers could deny you based on whether you have preexisting conditions or not. Simply a lot of services would go away," Cheryl states. Families USA follows policy development and talks about what consumers need in federal and state policy. They advocate for Americans to get the best possible healthcare protection. "We don't have a public coverage system that's universal, nor do we have a public health system that's universal. So people here are struggling with high prices and are not guaranteed any type of coverage that helps them afford their care," Cheryl adds. Right now, her organization tries to preserve the bits they have gained: coverage for 20 million people. "We don't want that to go away, and then we want those protections to be built out, so that more people can gain coverage. And additionally, we need an equitable healthcare system that doesn't discriminate against people based on disability, gender or race."
Amy, a 45-year old woman from California, experienced this discrimination firsthand.

Amy, 45, California

August 11, 2019: a day Amy will never forget. All of a sudden, she developed severe weakness in her legs, making it hard for her to walk properly. Additionally, she lost control over her bladder and was in excruciating pain. As a veterinarian, she immediately suspected cauda equina syndrome, a neurological complication due to a herniated disc in her lumbar spine, which is considered an acute emergency that requires immediate treatment. Her father drove her to the closest emergency room. Barely able to stand on her feet, Amy needed the support of two people to manage the long walk into the hospital. Once the doctor arrived, she confronted him with her suspicion of having cauda equina syndrome and requested an MRI, but was met with disbelief. The physician brushed her off and told her that she just had an exacerbation of her chronic back pain. "And then he wrote up this whole thing about that I had anxiety, which I hadn't found out until I requested my medical record," Amy says. She was discharged without any diagnostic testing.

On August 13, she had an MRI, which Amy initiated and paid for herself. The MRI confirmed cauda equine syndrome. Amy was right. Over the following days, she sent many e-mails to her doctors to get a referral to a neurosurgeon, but none was able to see her. "My neurologic symptoms are continuing to worsen. When I presented to the ER, I had difficulty initiating urination. That symptom has worsened, and I have loss of urge to urinate. I also have not had a bowel movement in several days," she wrote on August 15. "Then, on the 16th, my symptoms got significantly worse. I couldn't feel my feet because they were so numb. I had this ice-cold sensation of my legs. I got really worried," Amy says. She went back to the ER and was immediately admitted to the hospital. Emergency surgery followed on August 17, a whole week after the onset of her neurological symptoms. "By the day I had surgery, it would take me half an hour to urinate. I had lost the sensory urge to urinate. It's been ten months since I had surgery, and I still have difficulty urinating; I still have a weakness to my limbs and difficulty walking. I am 50 percent better than before, but I am still worse than the

day I presented to the ER," Amy explains. "I could have been normal if I would have had surgery within 24 hours. And it's so sad how much the system is broken. Not only do you have the injustice of being denied the emergency care that you needed, but then you have these permanent symptoms you have to live with for the rest of your life," she adds.

Gender bias in medicine

In Amy's case, typical gender stereotypes might have played a role. Gender bias in medicine is a known phenomenon and often affects women. Studies have found that women stating health issues are generally taken less seriously than men, and often their physical symptoms are brushed off as being 'all in their heads.' "It's well documented that when women experience pain, they are more likely to be labeled as having a psychiatric cause for the pain. Even the word hysterical is very much tied to sexism, and it's only used for women," Arghavan Salles, MD and PhD at Stanford, says. Salles is a surgeon, but additionally researches gender bias in medicine, as well as develops programs related to diversity and inclusion. Salles, like many female surgeons, has personal experience with gender bias in medicine. "When I was a mid-level resident, a female surgeon was concerned about a patient who was not doing well. She wasn't screaming or anything; she was rightfully concerned. A male surgeon said, 'You don't have to get hysterical over it.' The same guy also said to me when I was a second-year resident, 'I don't know why we bother to train women to become surgeons because they just want to go off to have babies.'" Those comments did not have any consequences, according to Salles. On top of this, she noticed differences how female doctors are treated compared to their male colleagues in terms of their attitude. "Male doctors are usually talented or skilled, but for women, words like pleasant or unpleasant were used - not smart, or she did the right thing." When those biases are experienced as a patient, the consequences can be detrimental. One study found that women who present to the ER with abdominal pain are less likely to receive pain medication than men. Even worse, women with acute coronary syndrome - all conditions that lead to reduced blood flow in the heart - experienced large delays in access to proper care compared to men. This got more prevalent when those women were young and lived with preexisting conditions such as anxiety. "I think it's important to know that this is not intentional. Most people are not consciously telling themselves that the woman patient is making things up. It's part of the biases we take in from the world around us, which makes it harder to fight because if people don't even know they are doing this, the behavior is harder to change," Salles explains.

Based on a literature review by Swedish researchers, the 'typical' man is usually presented as being stoic, tolerating and denying pain, whereas women are seen as sensitive to pain, hysterical, emotional, complaining, and, again, as if the pain is all in their head. Women also get prescribed more antidepressants. And these stereotypes can affect our performance and how we view ourselves. This phenomenon is called stereotype threat. "If you are a woman doing a math test and somebody asks your gender before the test that reminds you that women aren't supposed to be good at math. And that simple reminder seems to be enough to worsen people's performance. You are thinking about this stereotype that exists and how you are going to disprove it, and just having those thoughts on a subconscious level might take away from your working memory capacity and thereby lowering your actual performance," Dr. Salles says. She explains further that it's not only men who are biased. Any person is influenced by the people around them, the news sources they consume, shows they watch, and many other things. "We all have developed ways of taking in the massive amounts of information around us very quickly, putting people into categories to make sense of the world. That is how it happens."

Nevertheless, how can we change this, so female patients are treated as equals? "I think that we have a lot of different challenges. It's important not to focus only on implicit bias. It's definitely part of the problem, but there is still explicit bias, there is still actual sexism, there is racism. People are ableist. People still express consciously in addition to implicit bias," Dr. Salles states. The researcher thinks it's important to build more systems that bypass biases, much like a blind audition at an orchestra.

"Everybody wants to say that implicit bias training is the solution. And I am not here to say it's bad, but we don't have strong data supporting behavior change after implicit bias training. Sometimes people walk out of the training and feel even more empowered to be biased because they get the message that everyone is biased and so it's okay. People want a quick solution, like with anything in life. Your sink is clogged, you want to have it fixed now. You don't want to work on a clogged sink for the next six months. Unfortunately, in the realm of biases - explicit or implicit - there is no quick fix. It's constant vigilance at any level. That's the only way we get around it," she adds.

Barby, 47, Arizona

Barby is an advocate for people with chronic illnesses and lives with several herself: endometriosis, reflex sympathetic dystrophy, dystonia, and she is a breast cancer survivor. As a self-proclaimed 'cheerleader of hope,' she is dedicated to helping other people navigate the healthcare system. "I had to learn the hard way, and I wanted to be the light for someone else who struggles," Barby says. As a strong voice in her community, she advocated for more transparency of healthcare pricing in the state of Arizona, which led to law HB2045 being put into place requiring hospitals and healthcare providers to reveal the prices for medical


Barby

tests and treatments before the procedure. In theory, this sounds beneficial for all patients, but according to Barby, a part of this legislature was misinterpreted: the co-insurance payment. “Prior to this law, we saw lots of denied prior authorizations. That’s one way insurances would delay care so the patient would give up. Now, with this transparency law, it’s the providers who are blocking access to care. Because what we are seeing now is that the provider will say, ‘You need this procedure or medication, and you have to pay the 20 percent you are responsible for - the co-insurance - before we give you the care.’ In the past, they would give you the procedure you needed and then send you a bill that you could pay over time. Now, they say you have to pay the whole amount up front,” Barby explains. She has been experiencing the consequences of this interpretation firsthand for more than two years.

Barby needs bladder surgery to treat incontinence, which has significantly altered her quality of life. “They said the surgery costs 30,000, so I owe 6000. Until I pay that, they won’t give me the surgery. You suffer - and in my case, pee your pants. It’s really a tough situation to be in. You can’t get the care you need. And you don’t have a choice. So people are giving up; people are at the end of their ropes,” Barby says. It already took her 18 months just to be able to pay the co-insurance for the diagnostic test needed before the surgery, and since then, she has tried everything to save the money for the actual operation - so far unsuccessfully. “As a patient, I had to realize that I am not going to be able to improve this area of my life until years down the line because I do not have the ability. And I have seen a deterioration in my health overall because of this,” Barby states.

As a chronically ill person, the implemented law combined with the already substantial burden of the prior authorization process makes Barby worry about her future life. “When I had pneumonia, my doctor said, ‘Before you come to my office, I want you to stop at the imaging center and get an x-ray.’ So I went up to the counter, and the lady said it is 36 dollars I need to pay before the x-ray. I literally had pneumonia and trouble breathing and did not know what was wrong, and they had to charge me upfront. What if this was life-threatening, and I just cannot come up with the money?” she explains.

Healthcare costs and systems

Despite having a decent insurance plan, many people can barely afford their co-insurance. Paying 20 percent of a test or treatment that costs several thousand dollars can lead to a life full of medical debt, not even considering people who are uninsured and have to pay the whole amount out-of-pocket, causing bankruptcy. In 2007, one study found that the cause for more than 60 percent of bankruptcies in the US was medical debt. Continuously, studies have shown the US has by far the most expensive healthcare in the world. A liver transplant, for example, as Steve needed twice in the past, costs 62 percent more compared to other developed countries. A report by the International Federation of Health Plans (IFHP) found that medical costs - whether for surgery, medication, imaging, or hospital stays - are almost always the highest in the US. An MRI, for instance, costs an average of 1430 Dollars in the US, while it is only 190 Dollars in Holland.

“It’s often said things are just more expensive in America. But actually, that’s not true. It is more likely that there is less competition in the system in America. Certainly, there is no competition in free health services, like in the UK and New Zealand,” Christopher Watney, CEO of the IFHP, says. The IFHP is an industry body that represents health insurance companies around the world and helps them to create networks. Together, they work on the big issues that affect all health insurance businesses around the world, largely driven by challenges in delivering healthcare.

According to Watney, a contributing factor to the high healthcare prices in the US is an inefficient regulation due to the system being so fragmented and large. In New Zealand, for example, drug prices are regulated by a government entity called PHARMAC. “PHARMAC is given the amount of money the government wants to spend on drugs; they are the only organization

pharmaceutical companies can negotiate with, and they are extremely good at negotiating," Watney explains. Such an entity does not exist in the US. Adalimumab (Humira), a medication commonly used to treat autoimmune conditions such as rheumatoid arthritis or Crohn's disease, costs 4480 Dollars in the US, while affected people can get it for 740 Dollars in South Africa, or 1570 Dollars in Germany.

"And then there is a huge amount of administrative waste in the US, because of all the different systems which require a variety of people to manage those without standardized health records. If I can't find the results for the MRI scan, I am not going digging for them. Let's just do another one, right? This happens all the time to the point where up to a third of all healthcare costs in America - and to be fair, in most parts of the world - are wasted," Watney states. "Fundamentally, America is the land of the free market. And when it comes to healthcare, that's the same philosophy. However, there is no real good reason for America having such disproportionally high healthcare costs. You can explain it, but it is very hard to justify." Prices for the same procedure can vary widely, depending on the hospital and state, and without any regulation, every institution can decide how much they charge. While the average cost of an MRI in US is 1430, mine, which was performed at one of the elite hospitals in the US was priced at 14,000 dollars. "It really comes down to what the market will bear. You price up to the point when the supply doesn't meet the demand anymore. In America, particularly in terms of health, there are many things that are world-leading. If you can afford it, you can get some of the best care in the world," Watney says.

The world roughly has four different healthcare systems. In the UK, for instance, the Beveridge Model is applied. Here, the government and ultimately taxation pays for all healthcare-related costs. Another well-functioning system is the Bismarck Model countries like Germany adapted. The Bismarck Model depends on a universal multi-payer system, meaning employers and employees pay into funds that finance insurances. The National Health Insurance Model combines both of these. And then there is the Out-of-Pocket Model, which is less of a health system and more of not having established care in the country. It means everyone pays all expenses themselves, which, unfortunately, counts for many Americans that lost their jobs and, therefore, their insurance during COVID times.

The US, in fact, has all four health systems, according to Watney. And there really isn't a perfect one, but a few countries seem to do better than others. "Cuba has a really interesting health system. They do two things really well: education and healthcare. It's a good example of matching costs to needs because all of the healthcare staff is employed by the government. Some European models are quite good, too, like the German or the UK model. Ultimately, it comes down to efficiency when these systems are judged, but what I am proposing is that health systems should actually be judged by their outcomes, not by how efficiently the money is spent," Watney says. What he is referring to is a system that switches its focus to the patient's well-being. "It means we don't pay the surgeons for the number of knees they can replace. We pay them on the basis of the mobility of their patient. Usually, the surgeon's incentive is to cut people open and replace hips and knees. But what if we paid them anyway even if you don't need to get your knees replaced?" Watney explains. An outcome-based system would reward the surgeon for the amount of people that are walking well - not for how many knees he or she replaced. "This system could make a big difference to delivered healthcare in the US and reduce the cost of healthcare overall."

The US healthcare system is quite broken in many areas. However, most of the people I interviewed got the care they needed - sooner or later - but not without a long and straining fight. In my case, after four weeks of daily calls, taking every legal route possible, an independent reviewer assigned by the *California Department of Insurances* decided to overturn my insurance's decision. As a governmental entity, the *Department of Insurances* has the last word, which forced my insurance to authorize the MRI without further delays. I won. However, the process put an immense strain on my mental health. I had the MRI on July 16, seven weeks after my doctor ordered it. Fortunately, it came back negative; no cancer. Steve got his second liver, but only because his family was fortunate that their new insurance covered the expenses. If they didn't have this option, he would likely not be here today. Amy got her surgery; however, too late. She has to live with a permanent disability. And Barby's fight continues. Unless she can pay her co-insurance in total before surgery, she won't get the treatment she needs.

Even though, we have seen positive developments in the US healthcare system with the ACA, for example, it's still a long way to go until we meet the needs of most Americans. Specifically people with chronic illnesses and disabilities need better and faster access to healthcare without discrimination. We can only hope that the hard work of organizations such as the *PAF* or *Families USA*, and researchers like Dr. Arghavan Salles pays out at some point and improves conditions for all Americans. Until then, we have to keep fighting for the most important part of our existence: our health; and the care that we need to continue living the best way we can. ■ ABILITY

by Karina Ulrike Sturm

**The insurance company did not respond to several interview requests.*





LACHI

Little seems to hold back Lachi, a prolific New York City-based recording artist, songwriter, and diversity inclusion advocate. Interviewed by *ABILITY* ten years ago, she has since expanded her music repertoire, recording a wide variety of music, influenced by multiple genres, and reflective of her many passions. She has released songs with SONY and Warner Music, collaborating with and supported by some of the biggest names in the dance music industry. Her latest singles are "Fool Me," with Lush Records, and "Genius" by LSD.

The daughter of Nigerian immigrants, she was born in Maryland with a congenital visual impairment. Music became a natural outlet for her. She has since synthesized, if you will, her considerable musical talent with advocacy work, performing at disability pride events and focusing on "disability visability" on national diversity and inclusion panels. ABILITY's Laura Wheeler caught up with the busy artist to discuss her latest creative endeavors, upbringing, and advocacy work.

Wheeler: Lachi,does it have a significance or a meaning?

Lachi: I go by Lachi. I try as much as I can to not go by my government name, however, the Barbra Streisand effect continues to haunt me. That is my middle name. My middle name is Ulachi. It means ring of God. Not sure I live up to that.

Wheeler: What language is it from?



Lachi: It's from Igbo.

Wheeler: Oh, my gosh! Nigeria, Igbo!

Lachi: Yes. My parents are Nigerian. They came to America in the late '70s. I grew up in a combination of west Philadelphia, upstate New York, and North Carolina. I was born in Baltimore. I eventually made my way back here to New York City. I chose the name Lachi because growing up I went by my regular name, and I was very shy and quiet and had a lot of trouble making friends. I was sort of awkward. I was stuck in the middle; it's not that I am totally blind. I am sort of blind. A lot of people look at me like, "Does she need help? Is she not smart?" As opposed to, "Oh, she must be visually impaired."

When I went to college and moved to New York, I decided to change my name to Lachi and decided to change my whole persona and start to turn into the person I am now, who is a complete 180 degrees 4from the young girl I once was. Totally loud, totally obnoxious. You can find me down the street, laughing and screaming very loud. I'm the type of person people switch tables for because I'm just so loud. (laughs) Right! I love to tell jokes and tell stories. I just wasn't that before. It's about leaving the nest, too, a change of scenery, realizing that you can reinvent yourself.

Wheeler: When did you start getting into music?

Lachi: I was always into music, ever since I was very young. The story is, and I don't know how true this is, honestly, I think my mom made this up, but the story is that she bought a keyboard for my older sister, who is several years older than I am. I think I was about three or four, and my sister threw it in the garbage because she didn't like music. She wanted to dance. So I picked it out of the garbage and started learning how to use it and playing it. That's the story. Don't know if that's true, because I don't remember it. But I've been playing the keys and writing songs since I could write and talk and read and whatnot.

I would get all of my stuffed animals, put them in a big group, and I would make them sing. They weren't very good— (laughs) —the alto section was always flat (laughter), but they were very disciplined. When I told them to be quiet, they were.

I was shy, didn't have a lot of friends, so I spent a lot of my time in a corner, writing, reading, creating music, creating poetry. The real creative side of myself was highly nurtured while I was growing up, while other people were outside playing soccer or doing whatever they do.

Wheeler: Who do you work with?

Lachi: For my music, I am currently signed to a management agency called Big Management. I've been with them for about four years. It was really great when we first started. However, the manager I worked closely with at that agency passed away from COVID-19 in April. It was really rough because we were very close. He was the one person at that agency getting me a lot of stuff. Now, I'm just kind of flailing about, trying to figure out what I'll do next.

Then, in terms of organizations, I've been tangentially working with, I have done some stuff with Respectability.org. I joined their speakers bureau. I've been doing some speaking gigs through them. I've also been working with an organization called Divas with Disabilities. They haven't done much, but I love their concept, dealing with women of color who have disabilities and trying to raise them up in the media. I have also been working very closely with different disability pride festival companies that put on disability pride events in these cities and states—namely New Jersey, New York, and Pennsylvania—sort of northeast, where I'm from.

I could go on forever. I'm working a lot with inclusion branding in terms of fashion design. If I have a show, I'll try to wear garments by a disability-inclusive brand at my shows.

Wheeler: That's a great idea!

Lachi: Yeah. That's been really fun. So many others I can't think of right now. There's another one called Eye Inspire. They are relatively new, but I love the woman who's running it. She's a DJ friend of mine. They are trying to teach young kids who are visually impaired or have sight loss or are blind about music and empowering themselves. Things of that nature. That's also based in Europe.

Laurel Wheeler: Where in Europe?

Lachi: It's in the UK.

Wheeler: So, music became an outlet for you early on?

Lachi: It definitely became a way for me to express my emotions, especially since I was so quiet. I would write songs about the things I felt and the things I saw and the way I would watch other people react to things and internalize it and write songs about other people's experiences. It was definitely a way for me to express myself, because I was unable to express myself verbally and in other ways.

Wheeler: Do you play anything besides the keyboard?

Lachi: I noodle on the guitar, but I also get my nails done, so— (laughs)

Wheeler: Yeah, that's not easy when you've got nails.

Lachi: Right. That's pretty much it. I own a ukulele. But for whatever reason, I'm so used to the way a guitar goes that I can't transfer it over as well as I'd like. But keyboard is my main instrument, as well as my vocal cords.

Wheeler: I was reading your website and listening to your music, I know you said you listened to a lot of Beatles and Radiohead and others. I hear a lot of different multicultural influences in your music, which is really cool in my opinion. I even found where you had done a recording with an Israeli and a Moroccan musician.

Lachi: Oh, yes! (laughs)

Wheeler: Tell me about some of the different influences on your music and how they came about.

Lachi: Like you mentioned, I have a very eclectic sense of music, especially when it comes to influences. Growing up and going to college, it was a lot of Beatles, Radiohead, Alicia Keyes, and Lauren Hill. It was very eclectic. But my mother, in her secret scheme to try to turn me into a virtuoso pianist, she got me Beethoven, Mozart, Chopin. That got filtered in. One of my biggest influences in terms of songwriting is definitely Thea. I was a fan of hers for a long time, and finally the world started realizing it as well.

You know, when my mother first came to America in the late '70s and early '80s, she came as a professor to work at different universities, and she would literally just play nonstop all of the music that all of her other professor friends would say, "You need to hear this!" So we would listen to things like Dolly Parton, because we lived in the whitest parts of upstate New York. Or what's the name of that guy, "You've gotta know when to hold 'em!" (Kenny Rogers) We would listen to him, all sorts of country. But at the same time, we would also listen to hip-hop. I listened to a lot of Biggie. My brothers were into Tupac. We listened to so much. And then my brother was in a band, and he would shove Smashing Pumpkins for whatever reason down our throats.

And as well, being Nigerian, we always had to listen to Nigerian music, all the time. Because whenever there are family gatherings or reunions, they'd whip it out. And my mom would whip it out early in the morning when she was cooking breakfast.

Wheeler: Who were some of the Nigerian musicians you all listened to the most?

Lachi: From back in growing-up times, I can't pinpoint names, but she did listen to a lot of church music, the gospel-y type of "praise music," I think is what you call it. I could sing them for you, but I couldn't name names.



Today I am definitely into a lot of the more hip sort of modern music, I guess you could call it—pop and rap from Nigeria, especially since a lot of Nigerians are hooking up with Western musicians to make some great music.

Wheeler: There have been a lot of cool collaborations.

Lachi: There's been a lot of great collaborations. Falz did a "This Is Nigeria" sort of a rendition of "This Is America." There's so much good stuff. Jay-Z went over there and did a bunch of songs. DJ Khaled has done a bunch of collaborations. They're recognizing that Nigeria is a force for music.

Wheeler: Growing up, you got into music. Did you always know that's what you wanted to do for a profession?

Lachi: I always really loved music. When I was young, I had told myself, not only do I want to be a musician, but I also want to be a writer. I want to be a musician with a big fancy manager. I want to be a writer with a big fancy agent. And I want to dabble in acting. That was my dream.

But my parents told me, "Hey, listen, you've got to have a backup plan." And being a child with a disability, they were harping on, "Let's walk the straight and narrow and make sure that you're able to get a job out here in this crazy world." And it's not like I was coddled. They saw my potential. I was really great with math. They were like, "Look, you're really good. We just want to make sure you get paid and we don't have to take care of you forever." (laughs)

Because my parents were more of that immigrant mindset, it was beat into me more in that way as opposed to the disability way. It was a lot more like, "Hey, you're an immigrant. Make sure you make it, because that's why we came here." (laughs) The age-old adage of Asian or African parents pushing for their kids to be doctors and lawyers and whatever. I was good at math, so my dad, who was also—he had gotten his master's in accounting—pushed for me to be an accountant, too. I kind of majored in economics and management while I was in school.

Wheeler: Was that at the University of North Carolina (UNC)?

Lachi: Yes. I opened up a lot and found music as a huge outlet. I joined the glee club.

Wheeler: And you founded a group, didn't you?

Lachi: Yes. While I was there, I opened up when I went—I studied abroad for a semester in the UK.

Wheeler: Where?

Lachi: At Canterbury. That was really interesting. And I opened up there a lot, because Europe was so different.

Wheeler: Europe is so different, and it's so disability-friendly, isn't it?

Lachi: You know what? The thing about it was that it was not a thing. Nobody cared.

Wheeler: Exactly. That's been my experience, too. No

one cares. It's refreshing.

Lachi: Yes. But it's kind of a two-way street. Sometimes you kind of want people to care a little bit.

Wheeler: That's true.

Lachi: The benefits of people not caring definitely outweigh people being overly sensitive. When I came back, a friend of mine was like, "Hey, let's start a group on campus, anything. I don't care what it is." I was like, "I would love to start a music group." We formed the UNC Cadence. There were a few iterations before we got to that name. They're still alive today, which I'm very proud of. After I left the nest, I guess, they're still clucking. I'm very excited about that. But then I moved to New York. As I got more and more popular at UNC, people were like, "What are you doing here?" (laughs) I started playing around town at UNC. I would host things called "piano nights," where people would come and yell and request songs for me to play and it would get very rowdy and very crowded. Eventually people started hiring me to play actual shows.

So I went to my counselor and I was like, "Hey, I was just thinking, I want to move to New York. What do you think?" He was like, "Yeah, go!" He was kind of an outthere, different kind of guy. (laughs) "Yeah, go. Whatever. If that's what you want to do, go do it!" So I did. I went to NYU. I loved everything about New York from the second I set foot. First of all, I went with nothing but the money for the bus ticket. (laughs) And whatever I was wearing at the time. I went to New York and I was immediately in love, from the transportation being so ridiculously easy— I moved up from North Carolina, where transportation is really slow, everyone is really slow, and everyone knows everyone. It was great to be in a sea of random people running around who don't care about anything. That was really, really great. And obviously, it was the music capital of the world, really. I started seeing so many opportunities. They say if you can make it in New York, you can make it anywhere. It's difficult to make friends or break in or make anything happen. But I knew that once I got a foothold somewhere, I could be good. I could feel that in the bones of the city.

Wheeler: What's your favorite borough in New York?

Lachi: Everyone's going to hate this answer, but it's Manhattan. Just because I live here.

Wheeler: I've been in New York a couple of times. Nothing wrong with Manhattan.

Lachi: Nothing wrong with Manhattan, no! I've lived in several different areas in Manhattan, in East Harlem, which was really great. And I also lived on the Lower East Side, near NYU. I lived in kind of like Greenwich Village, near NYU. Eh, it was OK. Very college-y, people barfing at, like, 2 a.m.

And then I lived in Hell's Kitchen, which was very rowdy and very fun, clubs in walking distance. And I lived there during a really good time in my life, right after I graduated. I was young and hip and everybody was obnoxious. It was great. And now I live in—what is this place? In Lenox Hill. It's quieter, older people. I'm kind of young for this place, but I like that it's quiet here. If I want to go clubbing or dancing or to a show or something, I can go and then I can come back and sleep it off.

Wheeler: Probably a little more peaceful than Hell's Kitchen.

Lachi: Yes, thank you! A place called Hell's Kitchen? Oh, come on!

Wheeler: I was just curious, because everyone I've ever met from New York has their favorite spots. I feel like, in a way, the whole city has a lot of personality, but I always feel like I learn something about someone's personality based on where their favorite spots are.

Lachi: That's true. I have lived in Queens and in Brooklyn, done short stints there. Like, when I first moved to New York, I moved to Queens, near Steinway. I don't know if you know where that is. The boroughs, as you know, have numbers. They all have their own different weird number system. I was in Queens on 42nd and Broadway. If you know New York, you know that 42nd and Broadway is smack dab in the center of Manhattan. It's Times Square. It's everything. But I was living on 42nd and Broadway in Queens. But I was going around telling all my friends that I lived on 42nd and Broadway! (laughs) "How did you afford that?" I'm like, "I don't know, it's a good price. What are you talking about?" And then they'd come and visit and be like, "This is Queens." "Yeah, sorry. I forgot to tell you." (laughs)

Wheeler: I know that along with singing you also do acting. How did you break into that?

Lachi: I do—part of it is, as a singer in the first place, you're already sort of acting, you know, music videos and things like that. So I decided, "You know what? I've got such a great speaking voice that I should really look into doing voiceover work." It's not a fun or specific or interesting story. I put a voiceover reel together. I shopped my voiceover reel, and I started booking voiceover gigs. A lot of my voice acting work is a little more corporate. A lot of it is narrative, accompanying in-house commercials and things like that. But the work is so consistent, I can't call it a side hustle anymore. I would absolutely love to break into animation, for sure. That just hasn't happened yet. But that is definitely one of my goals when it comes to voice acting.
In terms of speaking or being on a panel, which is



another huge thing I do, ever since I started going gung-ho about being open about my disability and being a proponent and advocate for it, the speaking side of things started flowing in. I'm so ensconced in the music industry right now, and I'm seeing how empty it is of people with disabilities and how it's not purposeful, they just have no idea that there's such an open void, that everyone is going, "Hey, Lachi, you're the only person I know with a disability. Can you tell us more about your experience?" That's my other thing that I do as opposed to just doing music.

Wheeler: It sounds like you just take advantage of the opportunities in front of you..

Lachi: I do. And I try to make some appear out of thin air. I'll be talking to someone and they'll say something along the lines of, "I had this idea, but XYZ." And I'll go, "Hey, you know what you should do?" And then it turns into something. It's just kind of a "yes/and" sort of lifestyle, which I sometimes regret but can't help.

Wheeler: What kinds of advocacy have you done? What kinds of spheres of influence have you been able to advocate in?

Lachi: You're absolutely right. I do focus a lot on disability advocacy, but with a focus on representation and more visibility in entertainment and media. I generalize that. I try to steer away from specifically Hollywood and try to keep it either entertainment in general or music-specific. One of my favorite things to do is to guest-speak or moderate a panel in front of mainstream audiences that would otherwise not be familiar with that sphere. For example, on September 14, I moderated a panel for an organization called Women in Music. It's a relatively well-known international organization filled with major label executives, award-winning artists, and things like that. They help each other. It's a nonprofit, so they all help each other, keep each other educated and informed, allow each other to rise up in the industry. It's a very powerful network.

They had a diversity discussion a few weeks back, and I came up to them and said, "Your diversity discussion did not include disability. It seemed highly favored towards gender and things of that nature, sexuality, race, religion. As all of these panels do." I don't want to put them on the spot. I do this at pretty much every diversity panel I attend. I notice that they don't have disability in it. Women in Music took that extra step, so I'm very excited and honored. They said, "Hey, you know what? We want to have a disability-specific panel and we would like for you to moderate it." I was excited about that. It was a very high-visibility spot for women in music who have a disability.

Wheeler: Is it something that will be online and people can watch? How would someone go about seeing it?

Lachi: I know that it is online for people to watch. I know that it will be online live, and as soon as I get to link to pre-attend, I can forward that to you. I have to double-check to make sure it will be available after.

Wheeler: I would love for you to check on that.

Lachi: That would be great. That's not the only panel I'm doing. I'm doing several literally next week on the same topic. The only reason I mentioned Women in Music is because they're sort of a major organization. But that's pretty much what I do: attend different diversity panels and make sure disability is included when it comes to music and entertainment.

Wheeler: What have I not touched on that you would want readers to know about?

Lachi: I work in electronic dance music specifically as a vocalist. Anyone who read my previous article will know that I started out in the alternative pop arena. It wasn't really me or who I was. I ended up ditching the band situation and went sort of urban, I guess, because people were like, "Oh, you're Black, you're more like Alicia Keyes or Beyoncé. You should do that." So I started doing more urban stuff, and that wasn't really me either. So I was like, "Where can I find a place where I can just be myself and just write songs and hopefully people will like it?" It turned out that the dance scene was a really great place for that. That's why it worked out that the management agency that I worked with was with dance.

Another great thing about it is, it's not so visual in the sense that it's very remote. A lot of times a producer will make a track in his studio and then a singer will do her top line or her vocals in her studio, and they'll just switch things off, which happens a lot. It's been pretty useful for me, because when COVID hit, my life didn't change much.

Wheeler: And you just put out an album, didn't you?

Lachi: I just put out a single the other day called "Fool Me," with Lush Records, a very fun little ditty. Not all of my songs are about empowerment, but they are definitely all about being a badass and being very confident. (laughs)

And another thing I wanted to talk about that's probably most important is the fact that I will be putting out a song called "Genius" by LSD. It's already a song by Labrinth, Thea, and Diplo. I arranged an a cappella version of it. I have a bunch of singers from a group called Metzo performing my arrangement of "Genius" by LSD. They did a really great job of it. The song is a mash-up with Beethoven's Fifth Symphony. It's like a nod to Thea and Beethoven, two huge influences in my life. That song will be coming out September 15. I appear as a featured artist in there somewhere.

Wheeler: Where will it be at?

Lachi: It'll just be released online, so you'd be able to find it on Spotify and SoundCloud, Apple, Amazon. It's very important to me.

Wheeler: What do you see yourself doing in the next year, the next couple of years?

Lachi: I have really taken a shine to advocacy, whether it be music advocacy, advocating for artists in general, for women in music, for people with disabilities in music or in entertainment in general, or just advocating for people with disabilities, period. I will always be a musician at heart, and I will always continue to excel in my music career. I hope to continue to work with bigger and bigger names and put out bigger and bigger albums. But in terms of specifics, just about a month ago, I got a really amazing opportunity to meet with Senator Schumer's office, to meet with Congresswoman Maloney's office, to advocate for artists, to try to talk about passing some of these legislative acts that are specific to musicians. This opportunity right now to speak to Women in Music about women with disabilities in music, it's so where the flow state is, how you get into that flow state when you're doing something you just know God wants you to do? (laughs)

Advocacy is where my calling is. And, of course, music is my bread and butter, the fuel for everything I do. I would always love to excel in music. But advocating has been my calling, and I will continue to grow and rise in that aspect as well. And like I said to Chet earlier, "Hello? I want to do more acting." I want to do more of my fun voice acting and things like that.

Wheeler: You want to get into animation, too?

Lachi: I want to get into animation, and I also wouldn't mind honestly doing whatever. At the end of the day, I am a huge personality with a lot to say and I'm very talented, not to toot my own horn. (laughs) It's kind of like, recognize that I'm a great force for good when it comes to showcasing disability talent.

Wheeler: Before I let you go, I'll just rapid-fire some random questions.

Lachi: Yeah, sure.

Wheeler: Favorite vacation spot?

Lachi: St. Petersburg, Russia.

Wheeler: Have you been to the church with the golden dome?



Lachi: Yes, yes.

Wheeler: When I was there, I got to go inside that church, and they gave me a tactile tour. I got to touch all the 3D models.

Lachi: Oh, nice!

Wheeler: I can't believe you said St. Petersburg, Russia.

Lachi: It's my favorite place ever. I globe-trot. I've been everywhere. I never like to go anywhere twice.

Wheeler: Favorite memory?

Lachi: Oh, wow! Yikes! I did a song with Markus Schulz. He's kind of a big DJ. We were all on a cruise ship and he was playing a DJ set and he randomly started playing the song we did, and he was like, "Lachi, come up!" So I came up and we were just singing the song in front of this huge crowd on a cruise ship with a really cool Manhattan backdrop. It was super highbrow and it was a lot of fun. It's a recent memory.

Wheeler: What are your hobbies?

Lachi: Apart from doing and singing music, which I do professionally, I would consider arranging a cappella a hobby of mine, even though I do it professionally. I also do it all the time for no money, because I love it. I love to write, so I write novels as a hobby. I also love to story. I know it's kind of corny, but I have a very active story following, so I love to do stupid things, like, I'll ask a question, like, "What did you do yesterday?" And people will say the most ridiculous answers, like "Ate a donut." So I'll share it and I'll have a picture of someone eating a donut and a song about donuts and I'll have that go for, like, 50 stories with everyone's answers. I've built this story following for my stupid Instagram stories. It's just something I like to do.

Wheeler: What's your favorite snack food?

Lachi: I like to eat almonds. I know that sounds corny, but I like to eat almonds with melty cheese. And I wish I knew the name of the cheese right now…

Wheeler: Are you a morning person or a night owl?

Lachi: Both. I don't sleep. I wake up at, like, 6:30 a.m. and I go to sleep at, like, 2:00 a.m. I'm pretty sure that's not good.

Wheeler: I would assume you're a heavy coffee drinker, then? What's your favorite coffee?
Lachi: I have Caribou, because I have a K-cup thing. I



used to really like Orens. I used to drink Orens coffee all the time, and my partner worked for Orens, and then he got fired, so I stopped drinking Orens! (laughs)

Wheeler: What are three things that you would say are on the bucket list of your life that you have yet to accomplish?. For me, I want to go skydiving and/or drive a Formula One car.

Lachi: (laughs) Yes! I would love to win a Grammy. That's one. Number two, I don't know. I would love to—(pause) I've always wanted to do something stupid like swim across the Niagara. You know? They'd be like, "Blind woman swims and dives across the Niagara." I'd be like, "That was me! I did that! I dived!" (laughs)

On my bucket-bucket list? I want to be a DJ. I want to DJ at clubs and parties and just go around and be like, "Hey, I'm a Black girl! No, I'm a Black DJ! No, I'm a girl DJ! Oh, no, wait, I'm a blind DJ." And people would be like, "Look, you're just a DJ." I would love to be a DJ. It doesn't fit anywhere in my whole life.

Wheeler: Hey, maybe it will some day. You never know. Who are some of the most interesting people you've had a chance to record with?

Lachi: I have a song with Snoop Dogg. I have that song with Markus Schulz that I mentioned, which was was also heavily supported by Armin van Buuren, who is also a big DJ in trance. He aired it, he played it, he remixed it, and all that kind of stuff, which is another big name. There are so many others. I've opened for Patti LaBelle, Quest, Love of the Roots. I feel like I've left somebody out.

I have one last thing I want to make sure I do say. As you know, I'm not afraid to plug myself, but I do have one other song that will be coming out and it's called "Duality." It's a song I wrote about the fact that we're all in cognitive dissonance. I was raised white but I am Black. I kind of have dude-like tendencies, but I'm a chick, stuff like that. And I was raised not disabled, but I'm obviously disabled. So I wrote a song called "Duality." My manager was obsessed with it. He was like, "This is the best song you ever wrote in your whole life! Everyone's going to love it! We have to put it out!" We started to make the moves to put it out, and he was in love with it, in love with it, in love with it—and then he passed away. This song is coming out September 25th and it's dedicated to him. ■ ABILITY

lachimusic.com



Carlos Moleda, ex-Navy SEAL, now retired paratriathlete.



IRONMAN

Successes, failures, inclusion and accessibility

The IRONMAN triathlons are among the most physically and mentally demanding endurance challenges on the planet. Athletes from every corner of the world compete: many fail, others succeed. ABILITY Magazine spoke with Tricia Downing, Roderick Sewell, Minda Dentler and Carlos Moleda about their athletic achievements as paratriathletes. Additionally, Bob Babbitt, founder of the Challenged Athletes Foundation (CAF), talks about accessibility in sports and the many ways his organization supports athletes with disabilities across the world, and Beth Atnip, vice president of global operations at the IRONMAN, shares how her company tries to make their races inclusive, diverse and accessible.

The first IRONMAN triathlon took place in 1978, but it wasn't until 1994 that the first athlete with a disability - Jon Franks, a paraplegic athlete from California - participated in one of the hardest triathlons in the world. He used a handcycle for the biking part of the race and a racing wheelchair for the marathon portion. Even though he didn't finish the race, he kicked off a whole new era. Just three years later, John Maclean from Australia managed to finish the IRONMAN World Championship as the first athlete with a disability. And from then on, paratriathletes from all over the world began competing in the IRONMAN.

Carlos Moleda

Carlos Moleda grew up in Brazil and started his career as a professional skateboarder. When he was 16 years old, he visited the US for the first time to take part in a skateboard competition. "I went home to Brazil and told my mom, 'When I turn 18, I want to live the US life: surfing and skateboarding'," Carlos says. And he did come back to the US, just not as pro-skater: in his mid-20s, he joined the Navy. "I wanted to be a deep-sea diver. That's when I found out more about the SEALs," Carlos says. He took the test and failed. "I couldn't swim. Imagine, I wanted to be a SEAL, and I didn't know how to swim," Carlos laughs. But he didn't give up. He took the test again, this time completing it within the allotted time, and was one of eleven people out of 120 who finished the SEALs training.



Carlos finished his first IRONMAN in 1998

On a mission in Panama a few years later, Carlos found himself in the center of an ambush. He was shot in the back and leg and was immediately paralyzed in his lower body. "In the beginning, you think this is temporary. In my mind, it was like in a few months, I will go back to work. And then when you realize this is for the long-term, you really reassess your life. You go through adjustments; some will take a life long to fully understand," Carlos says. At the time, he had few future prospects and didn't even consider sports an option. But this quickly changed. When Carlos moved on to rehab, his physical therapist signed him up for a wheelchair race. "She was



With a specifically designed handcycle, Carlos climbed the Kilimanjaro

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Roderick Sewell, first bilateral above-knee blade runner to complete the IRONMAN World Championship in Kona

like: 'Hey, I already signed you up for a 100-meter track race at the VA games," Carlos explains. From that moment on, sports became Carlos's life. By 1992, after only two years of recovery, Carlos was already a professional racer. "It just came naturally," he says.

Wheelchair racing was only the beginning. In 1998, Carlos didn't only finish his first IRONMAN, but he did so by breaking John Maclean's record by a full hour. "It wasn't intentional. I just wanted to survive. I really had no expectations," Carlos states. However, Carlos's time at the IRONMAN is mostly remembered for his battle with his competitor and close friend David Bailey, an American motocross legend. For three consecutive years, the two athletes competed with each other at the IRONMAN. In 1998 and 1999, Carlos won. Then came 2000. "I was completely overconfident like, 'I am going to kick his ass,'" Carlos states, but things didn't go exactly as planned. Carlos passed David on his handcycle shortly after they exited the water. "David thought it was a moped passing him because I was so fast," Carlos remembers. However, David soon caught up with Carlos. Then he was hit with bad luck: a flat tire. Intent on a fair race, Carlos waited for him at the transition to the marathon section. They were neck and neck through the final leg of the race. "People thought we were killing each other out there," Carlos states. In the end, David passed Carlos and won the race. "I call that the best race I ever lost because it was completely fair; we pushed each other to the brink of collapse, and the best man won." In total, Carlos finished all six IRONMANs he competed in. He was only able to do so by dedicating all of his time and energy into training.

According to Carlos, the marathon and the swimming portion mostly depend on the proper technique, whereas the bike section is about endurance. Prior to all IRONMANs, he worked out twice a day and rode 200 miles on his bike during the weekends. "All the things that apply to an able-bodied athlete apply to us too, but we have to take additional things into consideration, like body temperature or the loss of feeling in the limbs. We can break legs getting in and out of the chair; if our bodies get too hot, they can't cool off because of the spinal cord injury; our heart rate is higher from the start," he says.

Carlos retired from his racing career in 2015 at the age of 53, but sport is still a big part of his life, and he is always seeking a new challenge. In 2016, climbed Mount Kilimanjaro with his wife and son. With a specifically designed handcycle and some Navy friends, he made it up to Uhuru Peak, Kilimanjaro's summit. In an article about this adventure, his son calls Carlos "an artery of drive and ambition." When asked how he pushes his body to such extents, Carlos replies, "I don't think, 'Oh man, I really want to do that.' I think in terms of, 'How can I do that? Let's figure it out." Besides finding out where his boundaries are, because "that's where life happens," Carlos trains a team of female handcyclists and is an ambassador for the CAF, an organization supporting athletes with disabilities.

Supporting athletes with disabilities: The Challenged Athlete Foundation

Historically, athletes with disabilities never received the same public attention as their non-disabled counterparts, largely due to a lack of accurate media representation. However, this has shifted slowly, which has been reflected in the number of athletes with disabilities com-



peting in a variety of sports. The Challenged Athletes Foundation supports many of them. "We have been around for 27 years, have sent out over 30,000 grants and raised over 123 million dollars to help support athletes in 103 different sports in all 50 states and Puerto Rico," Bob Babbitt, co-founder of CAF, says. CAF has also supported people in 73 different countries. Everything started with Jim MacLaren. Jim was an athlete who lost a leg in a motorcycle accident and made history at the IRONMAN Hawaii by finishing the race in 10 hours and 42 minutes. A few years later, he had another accident and became a quadriplegic. Bob Babbitt and a few friends organized a fundraiser to buy an adaptive van for Jim, so he could still be independent, and CAF was born. "Sport is a huge part of our identity, of who we are. So it became our goal that if someone needed a piece of equipment, training, or travel, CAF would be there to help," Bob says.

"We are breaking down barriers every day." Before 1994, there were no divisions for people with disabilities at the IRONMAN. "For a number of years, they were hesitant," Bob says. But then Franks, Maclean, Moleda, and many after showed them that athletes with disabilities can indeed compete at the IRONMAN, just like anyone else. "The public's opinion went from, 'We don't think they can finish it' to 'These guys are racing,'" Bob says.

Participating in sports as a person with a disability often depends on being able to afford the necessary adaptive equipment, which is exactly what CAF is focusing on. "Before CAF, if you had a small child who is an amputee and needs prosthetics, doctors would say, 'You need to wait until the kid stops growing.' But then he or she is going to be slower than their friends, and their self-esteem and comfort level disappears," Bob says. CAF supports children of all ages and isn't solely focused on sports. "Back in the day, if you met somebody my age who is an amputee, they covered up their prosthetic leg. It was something they were ashamed of. If you talk to our kids now, it makes them feel different in a good way," Bob explains. They regain self-esteem and feel more content in their skin if they have access to the same activities as anyone else. "That's the power of sports," Bob adds.

One of the children CAF supported from a very young age is professional paraswimmer and handcyclists Roderick Sewell.

Roderick Sewell

Roderick grew up in San Diego, California, and was born without tibias, leading to amputations of both of his legs above his knees. When Roderick was 2 years old, his mom taught insurance coverage for his prosthetics, but she was turned down. She had to quit her job to get the costs covered, which allowed Roderick to learn how to walk. "I have been walking since, but it put us in a tough living situation where we were homeless for a few years," Roderick explains. When he was 8 years old, CAF became aware of Roderick and introduced him to Rudy Garcia-Tolson, the first other double-above-knee amputee he had ever met. Rudy soon became his role model and best friend and showed Roderick what was possible in terms of sports. Today, the two athletes share an apartment in New York and compete at every opportunity they get. "Once I met Rudy, it was like an eye-opener. I didn't know what I was capable of," Roderick remembers.



: Trish using her handcycle to compete at one of six IRONMANs

From that moment on, he naturally gravitated towards sports - besides swimming, because Roderick was afraid of water. “He was scared to death of swimming. Seriously, he was terrified to take a shower,” Bob Babbitt told me beforehand. However, Roderick overcame his fear, learned to swim, and has now been training for Paralympic swimming for 12 years. CAF sponsored Roderick’s first running blades when he was 10 years old, and since then, the triathlete has been unstoppable. In April 2019, Roderick participated in his first half-IRONMAN in Oceanside. “I ran my first half-marathon



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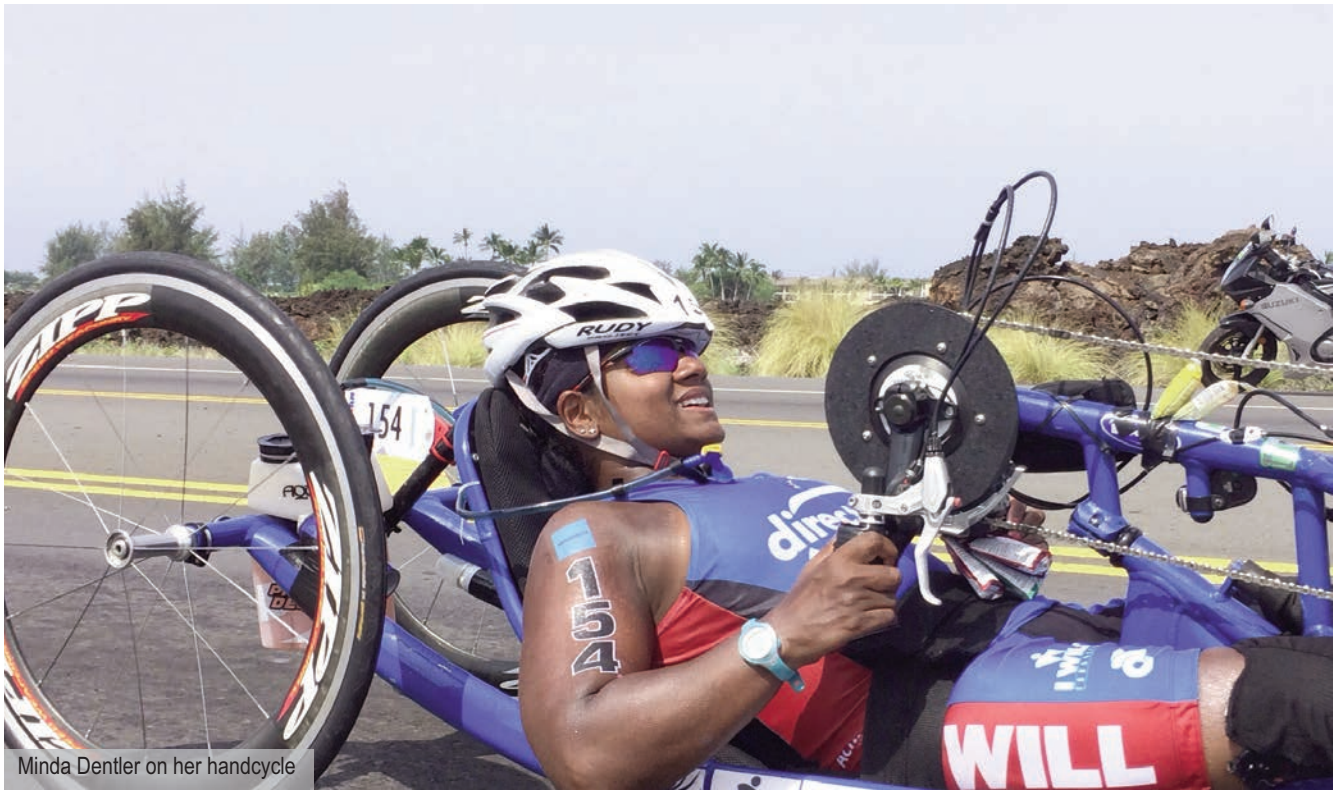
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Minda Dentler on her handcycle

at 1 hour and 39 minutes. Bob and Rudy were shocked. That moment, I felt like I could do an IRONMAN," Roderick remembers. But he didn't have a bike. CAF stepped in again and gave him his first handcycle, while his friend Rudy, who had finished an IRONMAN before, helped him prepare for the triathlon.

Then came race day: October 12, 2019; the IRONMAN World Championship in Kona. As a professional swimmer, Roderick easily managed the swim portion. "I came out an hour and nine minutes, which Rudy still makes fun of me for because it is kind of slow, according to him," Roderick chuckles. He transitioned to the bike portion of the triathlon and managed to finish it in 8 hours and 51 minutes. "That was the part we were focused on because that's what Rudy struggled with in the past. Between the bike and the run, the bike was the hardest part," Roderick explains. Then came the marathon part - Roderick's first full marathon. Exhausted from handcycling, he was fueled by the thought of everyone who supported him and the understanding that this event was bigger than just him. With only 6 miles left, Roderick stopped running and started walking. "I just remember freaking out and was like, 'Where is the cross-line?' Everybody keeps saying it's close, but I felt like it gets just further away," he says. Two miles later, he ran again and crossed the finishing line at 16 hours and 26 minutes as the first bilateral above-knee blade runner to complete the IRONMAN World Championship. "It's midnight, and I am dead tired, angry, hungry, nasty, and sweaty. I just wanted to go home. When I came in to the finish line, I didn't even stop or take it in. And I definitely tripped over the line. I am ready to go to bed. But the second I crossed, I see my mom in tears, Rudy is there, and they are so proud. Bob is there too, like a typical uncle. And I realized, it was a big night for a lot of people," Roderick says.

Some athletes cry when they finish an IRONMAN; others break down. Roderick celebrated in a different fashion. "Rudy gave me a water bottle full of beer. From start to finish, he knew exactly what I wanted."
Right now, Roderick's main focus is on his next Paralympics, especially on handcycling. "Swimming is secondary. Swimming definitely got me here, and it was why I did so well in Kona, but I am getting older, and I feel it," says the 28-year-old. "I tell people, I am sure Kona took a few years of my life. That's the beauty of IRONMAN. You are racing people of all ages and abilities, and it doesn't matter who you are. It's always going to be hard. And that's the metaphor of life."

The IRONMAN divisions and rules

For the most part, athletes with disabilities follow the same rules as non-disabled athletes at the IRONMAN. However, in 1997, two divisions were explicitly designed to create inclusivity at their races: the physically challenged (PC) open division and the handcycle (HC) division. The PC open division applies to all athletes with a disability "that substantially limits one or more major life activities," as stated by the IRONMAN rule book. Visually impaired triathletes also belong to this category. "Visually impaired athletes have certain standards to follow. For instance, one is that you have to be with a guide during the race. You have to be tethered to the guide during the swim. You have to ride a tandem for the bike portion. And you have to have a lead for the

run," Beth Atnip, vice president of global operations at the IRONMAN, says.

Beth Atnip has worked with IRONMAN in some capacity since 2007. As an athlete herself, she has organized small local triathlons before following her dream of working for IRONMAN. In 2012, she started as director of athletes services for North America, then switched to director of global operations. Today, she is vice president, handling safety, rules, customer service, and works with the HC and PC divisions. She has also created the rules for what she calls the Special Teams, which is a two-people team starting together at the competition, consisting of a non-disabled athlete and a disabled athlete "who is incapable of propelling themselves on the course using their own muscle power in any or all of the disciplines." One of the most popular teams in this category is 'Team Hoyt:' father Dick with son Rick, who lives with cerebral palsy. Together they took part in six IRONMAN races. And that's not an easy undertaking because for the swimming part, Dick pulls Rick behind him in an inflatable boat connected via a bungee rope; they use a uniquely designed bike with a front seat for Rick for the biking part and a special racing chair that Dick pushes during the marathon.

Most IRONMAN rules are created to keep the athletes safe. The Special Teams, for instance, will be accompanied by a safety guide during the swim. "The disabled athlete in the boat can't be seen by the able-bodied athlete because they are down in the water. And so we have to have a safety person in case the disabled athlete has a medical emergency during the swim," Beth explains. All other IRONMAN rules are mostly in line with the International Triathlon Union's (ITU) guidelines. The most apparent difference between athletes with disabilities versus non-disabled ones lies in the equipment they use. For example, handcycles are required to fit specific measurements in terms of length and wheel size, as do racing wheelchairs. Other rules regarding equipment apply to all athletes. For instance, the usage of flotation devices and snorkels are prohibited during the swim.

However, the rules aren't all set in stone. It's a case-by-case decision, especially when it comes to the Special Teams. "We do take requests if they have certain adaptive equipment. Many of the Special Teams spend a lot of money on custom-built equipment. And we do review our rules every year," Beth says.

Nevertheless, all athletes have to meet specified time cut-offs for the single divisions. At the IRONMAN World Championship in Kona, athletes need to finish the 2.4-mile swim in 2 hours and 20 minutes; the combined swim and 112-mile bike course in 10 hours and 30 minutes, and the entire race including the 26.2 miles marathon in 17 hours.

The swim and bike cut-off can be especially challenging for female handcyclists, says Tricia Downing, a world-class athlete.

Tricia Downing

Tricia, or Trish, was born an athlete. She started her career at the age of 4, swimming during the summer, gymnastics during the winter. At age 7, she competed in swimming; when she was 10, she participated in gymnastics competitions. She did so until she experienced a knee injury in high school and had to give up gymnastics - the first time Trish had to reinvent her athlete self. Every time an injury would get in the way of her sports career, she immediately found another activity she was good at. "This really has been the theme of my sporting career. Every sport has sort of ended before I was ready for it to end. But I carried that confidence of knowing I could make my body move in whatever ways somebody could teach me in order to do a new sport," Trish says. Trish's life has always centered around sports. Besides being an athlete, she studied sport management, during which she began competing in cycling. Besides taking part in races herself, she was also a tandem pilot for a visually impaired cyclist. "My cycling coach at the beginning of my career was a tandem pilot at the 1996 Atlanta games, and he introduced me to a camp at the Olympic training center in Colorado Springs. He found out that they were in need of a tandem pilot and called me up and said, 'I really think you should do this,'" Trish says. And she did. "I was so in awe with the people that I met there. They were fun and interesting. They all had disabilities and different life experiences than I had had. It was a group of people I fit in with really well. I enjoyed being a tandem pilot, and I learned a lot," Trish says.

During a training ride in September 2000, a car hit Trish, leaving her paralyzed from her chest down. Her physical limitations, however, didn't diminish her competitive spirit. Six months after her injury, she was already participating in her first half-marathon - the only difference: now, she was a wheelchair-racer. She already understood the sport from her time working with disabled athletes. "The camp back then showed me that my life after the accident wasn't over and that there is just a whole bunch of different options now. I feel really fortunate that I had that experience because it helped me get through my accident, as opposed to some people that are still emotionally processing. It was still mentally and emotionally difficult, but at least I had something as a go-to," she says. Since then, she has been part of more than 100 races.

With her history of swimming, biking, and racing professionally, the next logical step was doing triathlons. From 2004 to 2010, Trish continuously trained for IRONMANs. "You are going to get up, ride your bike, come home, eat, and go to bed, and that's it. It takes a lot of time and patience and building endurance," Trish explains. Overall, she did six IRONMANs and finished

two of those, and she was the first female paraplegic completing an IRONMAN triathlon.

While doing triathlons, Trish was recruited by the US rowing team. Following her life's motto, "suck it up," she pushed herself hard for her new passion and severely injured her back and hip, requiring four surgeries. "I am just the kind of person who tries not to complain, and 'suck it up' is the thing that always goes through my mind. Sometimes, that has served me well, and sometimes, it has not served me well," Trish admits. Until today, she has had more than 20 surgeries. "I have had a lot of health issues and things that needed to be addressed because of my spinal cord injury. So I have had to fight that over the past 20 years." It's a delicate balance to be an athlete with Trish's disability. Nevertheless, she has reinventing herself whenever she had to. When her rowing career abruptly ended, she got into professional shooting and is now working towards the Paralympics. The only group of sports Trish hasn't explored are ball sports. She feels like her hand-eye-coordination required with ball sports is not that great. "Also, I have an internal scaring from playing dodge ball in gym class where I got slammed in the side of my face in elementary school," Trish laughs.

These days, Trish is mainly focusing on her shooting career. She only wants to take part in triathlons for fun in the future. Specifically, the IRONMAN has become a challenging subject for Trish. As a paraplegic wheelchair athlete, she was facing unique challenges throughout her races, which made her think rather critical about accessibility at the IRONMAN. "Female athletes like me are using only their arms. And that's what you have to train for. You change up the muscles that you use and the way that you use them, but there is only so much going on above your waist. That's one of the real disadvantages of being a female. It makes it difficult to see that men have the ability to bulk up a lot more and be a lot stronger, whereas the women just struggle," Trish says. The athlete tried to advocate for a change of the cut-off times, specifically for female handcyclicsts at the IRONMAN, but without success. She didn't feel heard at all. "What happens at the IRONMAN when you are abled-bodied is that the bike portion is short and your run takes up all the time. But when you are in a wheelchair, your bike lag is what takes up all the time, because as soon as we get into the racing chair, we can do the marathon in 2 hours, which is at least twice or even three times as fast as the able-bodied runners," Trish explains. The problem she is referring to is the combined cut-off for the swim and bike portion, which, in her opinion, isn't accommodating for athletes like her. "When you are female and on a handcycle - if you don't have the most perfect day where everything lines up - you never will make that time cut. There is no taking any of it into account," Trish criticizes. On top of it, she feels that there is a different standard for wheelchair athletes overall. "We are supposed to be this super gimp, to be amazing, to be inspirational. If you can't be the best, you don't count, which is a really damaging way to operating sports. If you are able-bodied, you have the privilege of being average or even below average, but in disabled sports, you don't have that privilege."

Accessibility at the IRONMAN

Beth Atnip explains that her staff is providing as much accessibility as safely possible. "We work with people with all kinds of conditions, for example, neurological problems, that don't fit into any category. There is a definition for each division, but we try to be as accommodating as we can."

Nevertheless, some races are not inclusive for athletes with disabilities because they cannot be accessed either with handcycles or racing chairs. "This is normally due to either safety requirements from local authorities or there is some aspect that's not safe for handcycle athletes because on the bike they have a much lower profile. It just depends on the race. But where we can, we try to accommodate all categories," Beth says. One IRONMAN race has stairs in the transition area, making it hard for athletes with disabilities to switch from the bike to the racing chair. Technically, the rules only allow two people as 'handlers' for the athlete. "When we have circumstances like that, we work to accommodate the athletes and not let something like that prohibit someone from participating. So we would provide additional handlers. But if we accommodate one person, we make this accommodation for other people as well," Beth states. She thinks about accessibility 24/7. "From my perspective, it is just as important as any other component. When we bring new races online, we always try to work with the team and make sure to accommodate as many as possible. It's part of our vetting process."

And some athletes, specifically those belonging to the Special Teams, are also included in the development of new rules. "The Special Teams safety rules and guidelines are designed with some better known Special Teams that did multiple races. And then we take feedback from other races and review those rules annually," Beth explains.

Minda Dentler

Minda, a handcyclist from New York, has had mostly positive experiences regarding accessibility and accommodation for athletes with disabilities at the IRONMAN. "Usually, race directors and other athletes are supportive of athletes with disabilities like me," Minda says. And Minda takes an exceptional place in the IRONMAN history because she was the first woman using a handcycle and racing chair to finish the World Championship in Kona in 2013. However, she wasn't always a fan of sports. It took her until adulthood to find her love for racing.

Minda was born in Bombay, India, and contracted polio



at six months old, which paralyzed her from her hips down. Her birth mother left her in an orphanage, where she was later adopted by an American family. After moving to the US, Minda was finally able to access medical treatment for her condition, enabling her to walk with braces and crutches. "Because I contracted polio as a baby, I don't have any memories of living without polio. My legs are paralyzed, so I have had to learn to navigate the world as a person with a physical disability, and it impacts how I get to places and how I perform everyday tasks," Minda says.

Minda first got in touch with sports when she was 28 years old. A racing club for people with disabilities taught her how to ride a handcycle, and two years later, she competed at the NYC triathlon. "I signed up for swimming lessons and won a grant from CAF to buy my first racing wheelchair. I learned how to swim and run and completed the NYC triathlon," Minda says. Crossing her first finish line motivated her to go further. She joined a triathlon club, hired a coach, and began to train for the IRONMAN.

Her first attempt at the World Championship in Kona, however, failed. "I was prepared for the distance, but I wasn't fully prepared for the conditions: the heat, humidity and crosswinds, so I got pulled off the course at mile 60 on the bike for being too slow," Minda states. Ambitiously, she tried again a year later, and after a 5-year-journey of continuous training, she crossed the finishing line of the IRONMAN World Championship. "It was a realization of a dream and the culmination of all the hard work and dedication that I had put in over the years," Minda shares. What she likes most about triathlons is that she is competing side-by-side with non-disabled athletes. "I also believe athletes with disabilities bring a positive aspect to the race experience for all competitors," she says. Her ultimate future goal is to travel the world competing in triathlons.

Besides being an athlete, Minda works full-time and has a 5-year-old daughter. Additionally, as a polio survivor, she writes articles and speaks publicly about the importance of vaccination. "I find when people hear a personal story, it takes it from being a debate to a more informed decision." One highlight of her advocacy work was her travel to India for a national immunization drive. "It was personally rewarding to help administer the polio vaccine in the country that I contracted polio." By now, Minda has completed four IRONMAN distance triathlons, has vaccinated 23 children in India, and spoke in front of a 22,000 people audience.

Undoubtedly, Carlos, Roderick, Tricia, and Minda are all extraordinary athletes - regardless of their disability. They share the same traits as all professional athletes: determination, motivation, discipline, competitiveness, and never-ending ambition to win or at least finish whatever race they start. Their disability doesn't make them more or less inspirational than other athletes; their athletic achievements do. "What people should know about disabled athletes is: they are just athletes. They are the same. They have the same goals, the same hopes and dreams, and they just want to have a chance," Bob Babbitt ends.

■ ABILITY

by Karina Ulrike Sturm

ironman.com



Carlos Moleda, ex-Navy SEAL, now retired paratriathlete.



IPEDIA

CEO Katherine Maher

When you find out Wikipedia is the most visited website in the world, it just makes sense. It's where curious minds land and often your first search result when "Googling" an unfamiliar topic.

In the age of fast, safe-at-a-distance communication, *ABILITY Magazine*'s inquiring mind, Chet Cooper, needed some answers and Zoomed with Katherine Maher, CEO and Executive Director of Wikimedia Foundation, the supporting organization behind Wikipedia. What's behind that curtain? Where does Wikipedia get all its information? Katherine Maher dispels the darkness of our minds and enlightens us about the inner workings of Wikipedia and her goals for the organization.

Cooper: Will you share some background on Wikipedia and the Wikimedia Foundation, so readers have a better understanding of the history.

Maher: Sure. Wikipedia was founded in 2001 by Jimmy Wales–who is our founder–with the idea that the world would be better off if there was a free encyclopedia on the Internet. At the time, if you think of 2001 on the Web, it was a very different place. While you could get a lot of information, there was still a ton that wasn't accessible, available. Jimmy saw the future of the Internet as being something that would be a place that we would spend a lot of time and utilize for information-seeking, and he felt like an encyclopedia would be a core element of that, a core building block.

So, he created Wikipedia. As you know, it's a community-created encyclopedia. All the content is built



by volunteers. And very quickly, from 2001 to 2003, was the initial rapid expansion to other languages, globally. Because as it turns out, it's not just a good idea in English; it's a good idea everywhere in the world. And then through today it's grown tremendously. You could talk about different phases of Wikipedia. Up until 2006, it was a little bit more of the Wild West, and then it grew up a little bit in 2006 and is now a much more mature product with a much higher focus on quality today. It's widely read. It's amazing to me–who did not have Wikipedia as a student–to see how much it is an essential piece of the way young people, who come online and have never known a world without it, expect it to be there and seek information from it.

Now, our focus as the Wikimedia Foundation is what does the next generation look like for Wikipedia? What does it mean to be the best version of the encyclopedia that we can be, but also to be the best version of the encyclopedia for the greatest number of people? I think the promise of Wikipedia was not just that it was free–which was different than historic encyclopedias, which were very expensive–But now, we're also looking at how we make sure the knowledge that Wikipedia contains reflects the things that people seek and want to know and that they can participate in it, they can contribute to it, learn from it, regardless of where they come from or what their background is. It's a much more inclusive understanding of what knowledge can and should be.

Cooper: How do you monitor, filter, incorporate the information, the content to be sure it is what an encyclopedia used to be in dealing with—checking the facts? How do you deal with that?

Maher: The community volunteers are the ones who do it, and they are remarkably good at it. The way that the Wikimedia Foundation works is we host the website and we take care of the infrastructure to make Wikipedia works. And we support these global volunteer communities, who are the ones who create the content, set the editorial policies and write the articles. Some of the core principles of Wikipedia are that every single article has to have citations, at the bottom, back to the original source of information from which that article was created. The idea here is that all information on Wikipedia has to be verifiable in some way.

For us, that means that because we're not creating the original knowledge, we're not the researchers, the academics, the journalists. We have a commitment to readers, that they should be able to know where the information comes from and to research it themselves. It has proven to be a really effective way of ensuring the overall quality of Wikipedia because it means that in general, the information doesn't stay on Wikipedia unless it can be referenced back to a reliable source. We call it the "verifiability principle." That is the core of how Wikipedia works. Information comes from somewhere. It is integrated into a Wikipedia article. And you always

have the ability to check where that information came from, including when that information changes and the ability to change the article to reflect what has changed in the world around us.

Cooper: That's where the fact-based issues have to be looked at. The source? Anybody can build a website these days and put up information. And what you just said, put something into a Wikipedia page and link it back as a reference. How do you monitor that? How do you monitor with the mass numbers of volunteers you have doing the work, that you couldn't get bad players as volunteers?

Maher: Such a great question! The sources that belong—that are accepted on Wikipedia have to have—they are required to be what we consider a "reliable source." This is a policy definition that our community has come up with–a content policy. A reliable source must be a source that's respected or known in its field. It has to have its own editorial policies. For example, you wouldn't be able to just put up a blog and cite information back to that blog. You could have a blog, but it would have to be a specialized blog that is reputable in the field. Maybe it talks about user-centric design, for example. It would need to be notable in its own right. It would need to have its own editorial processes to be recognized for its reliability. That's how you end up with Wikipedia articles cited back to sources like the BBC and The Lancet, academic journals, and not my personal blog or my Twitter feed, heaven forbid! That is the differentiation, the emphasis on reliable sources–sources with their own editorial processes, editorial review, peer review, that are reputable in their field.

The reason it's both as specific and as vague as that is because, of course, the types of sources that you would look at to cover the coronavirus pandemic would include sources like breaking news events, like government reports on economic trends, medical journals like The New England Journal of Medicine and all of these different sectoral areas will have very different sources for that information. So, you need to be flexible enough to be able to say, "What's the impact of COVID on the arts?" and also "What's the impact of COVID on the vascular system?" These are very different sources that we'll be pulling that information from.

Cooper: To stay on COVID for a second–which is such an interesting topic because you have coming out of the White House oftentimes a different version than what might be coming out of the CDC or other health experts, WHO–How do you carve out that strange scenario that's happening right now with different sound bites that may or may not be true because of political issues?

Maher: This is really where the community is so spectacular. The volunteer editor community is responsible for doing this work. They hold—first, to answer your question from a while ago, they hold themselves to account for quality of contribution. For example, you might have a thousand editors working on one of the main COVID articles, and those editors have—(For) every contribution they make, there's a record of what their contribution is, which means that their peers editors can see if somebody is contributing constructively, productively, or in a way that would be damaging to the encyclopedia and its quality. And they use that peer accountability to ensure that contributions are high-quality. And when somebody, for example—and now I'll get back to the COVID question, if somebody were to introduce misinformation or unverifiable or unsupported assertions, the community can say, "Hey, editor 'ABC', we've noticed that you introduced this. Perhaps you made a mistake here. Perhaps this was unintentional." And if the editor was like, "Oh, you're right, it was a mistake," there's no problem. They can keep editing. If it turns out that editor has the particular point of view they're trying to push, a political point of view, a set of perspectives, and a form of bias, and they continue to come back and continue to try to introduce inaccurate or misleading or biased information, the rest of the editors can prevent them from editing that page or can block them from contributing to Wikipedia for a day or a week or longer. That's that form of self-regulation that helps the community stay accountable to itself.

On the question of COVID, what's really interesting to me is that this is probably one of the biggest challenges we've ever seen when it comes to breaking news with Wikipedia. We know more now than we did six months ago, but we knew nothing about the virus when it first emerged. It was a novel virus. So, there are all sorts of competing information from various different sources. You mentioned the CDC, but of course, there's every national health institute on the planet and then contradictory information within the U.S., between clinicians and practitioners—all the sorts of challenges. What the community members do is that they will only put information that has been substantiated from multiple sources if it is controversial in some sort of way. If it is a new interpretation–Let's say, that the virus is airborne or aerosolized, and we don't have any—and we sort of know that now. But, at the time, that was unsupported or uncertain. It was new information. The community would write something along the lines of, "Reports from the CDC, the NHS, the Korean Center for Disease Control indicate that coronavirus SARS COV2 is aerosolized."-And I'm making this up because I'm trying to use an example of how they would do it.–"However, more evidence is needed," or something to that effect.

Similarly, on [the issue of] should people wear masks or not, they might say, "Research in Germany indicates that mask-wearing compliance is correlated with a lower transmission. Current scientific communications say that mask-wearing is recommended." But they wouldn't take a side on one issue or another. They wouldn't come in and say, "Donald Trump says X,



Boris Johnson says Y, Antony Fauci says Z," and try to determine what's right. They would describe the conversation as it's happening and root it in the evidence-based publication that has occurred within the medical space.

Cooper: What I was hearing was something that was kind of different in my mind of what Wikipedia is–What I know of Wikipedia, in that I always thought it was materials put together by anyone who could post on there, but it sounded as though you're describing it more as editors and journalists putting the pieces together from information that comes in. I know you're calling them volunteers, but it's almost sounding like they're acting as journalists as well.

Maher: I think they would differentiate themselves and say they're not journalists because they don't do source information-gathering. What they do is tertiary source information, which means they do more of a desk review of materials that are available, whereas most journalists–The differentiation is that the field of journalism requires engaging with primary sources. Wikipedians engage with secondary sources, and journalists engage with primary sources. Like, you're talking to me as a primary source. A Wikipedian would read the article in ABILITY Magazine and say, "Ah, OK, this is written by a journalist. This is now a secondary source," and they would use it to write Wikipedia.

Where that comes into practice is, for example, we have numerous Wikipedians who are medical doctors. None of them would ever consider writing an article based on what they have experienced in their own medical practice the way a journalist might. In fact, a great article just came out in the Washington Post or GQ. I know the journalist–and it's not her outlet–where she wrote about having COVID and the implications of her personal experience and used that as a way of going out and exploring COVID in society. A Wikipedian would never do that. They would only start with what's been published by other reliable sources. I think what you just brought up, Wikipedians may have a specialization in a certain area But they don't view themselves as experts on any particular topic. And instead. they look at what many experts say and then work to synthesize that information.

Cooper: Do you know the amount of time that a typical volunteer puts in?

Maher: Oh, my gosh! So many hours! (laughs) It depends. We have about a quarter of a million editors a month who edit Wikipedia. About 75,000 of those–it changes month to month–are editors who edit five times or more in a month. If you're one of those 75,000, you're probably spending a few hours at least in a month editing Wikipedia. If you are one of the other 180,000, you are probably spending very little time at all. You might read an article and correct a grammatical error or make a sentence flow more smoothly or something like that, and maybe you spend 30 minutes on it. But to write an article from soup to nuts or to maintain the quality of an article that's already in existence can require quite a bit of time, because you're doing research into secondary sources, you're learning about a topic, and you're going really

deep in a way that for people who do it is extraordinarily satisfying. It's a project you do, like sewing a new piece of clothing or finishing a book or preparing a meal. It's a project that people engage with with tangible production at the end. But then there are lots of people who do much lighter-weight forms of engagement with Wikipedia as well.

Cooper: The volunteers have diverse backgrounds.

Maher: Oh, yeah, totally. We have people who are experts in their field, but even they edit with the understanding that they're one of many experts in their field. We also have 13-year-old high school students and retirees. We have grandparents, school teachers, electrical engineers, farmers—oh, my gosh, the range of individuals who contribute to Wikipedia is stunning when you get global. A man reached out to me on Twitter today who is an arborist. He works with trees, and he writes Wikipedia articles and has been on a quest to identify all the indigenous trees of the UK.

Cooper: Right. I heard he's branching out.

Maher: (laughs) Yes. It's just fascinating the range of people and interests that show up on the projects themselves.

Cooper: And did you respond to him?

Maher: I haven't yet. He pinged me after my calls had started for the day. But he invited me, if I'm ever in London or in the UK, to go on—it was like a tree journey. It was really sweet.

Cooper: And you're based in San Francisco?

Maher: I am, yes, although I'm from the East Coast originally. I came out here to work for Wikipedia.

Cooper: And your background?

Maher: I'm from the East Coast. I was raised in Connecticut. I studied in the Middle East, Middle Eastern and Islamic Studies. I thought I was going to be an academic. Instead, I worked primarily for human rights and international development organizations. I was very passionate about technology, a big nerd as a kid. I loved the computer. The Internet was new at the time, it was very exciting. My career was around merging these two passions of technology and human potential, human rights, access to dignity, access to opportunity, and how technology could enable that. So, when I was at UNICEF, we did work on access to health through mobile phones. And now I'm at Wikipedia working on access to information online.

Cooper: Where in the Middle East were you?

Maher: I spent two years living in Cairo and then was in—spent quite a bit of time in Lebanon, Syria, and Tunisia. Those are the three countries I probably spent the most time in other than in Egypt.

Cooper: So, you really have a different view when you look at what's happened after the Arab Spring and Syria and all that compared to when you were there.

Maher: (sighs) Oh, yeah. Certainly. I moved to the Middle East in 2002 as a student. And then I worked in the region with UNICEF. But in 2011 I spent quite a bit of time there in the aftermath of the revolutions doing research on the ground with human rights activists and independent journalists communities on their hopes and aspirations for a democratic transitions in Tunisia and Egypt. I was not able to go back to Syria at that point because it was too dangerous. But I'm certainly still in touch with a lot of folks from across the region.

Cooper: It's just amazing how most of the people in the U.S. are pretty much clueless on what's still going on in these regions.

Maher: There's a lot of really good people trying to live lives of dignity and opportunity in the world, and the Middle East is full of them as well. I wish that we met their needs and aspirations better in the U.S.

Cooper: Did you go to the World Wide Web conference in San Francisco?

Maher: I went to the one the year prior in Lyon, I think, and spoke at it. But it's a great conference, fascinating.

Cooper: We've been working with Web-for-All, but missed Lyon. That must have been a great experience. When you think about the WWW, it really wasn't that long ago since Sir Tim Berners-Lee was at CERN. Do you know Vint Cerf?

Maher: Of course!

Cooper: He's now on our advisory board.

Maher: Oh, fantastic!

Cooper: I've known him for about 25 years.

Maher: He's wonderful! I've had the chance to interact with him on a number of occasions. Fun story: Before COVID I used to go to a seminar on the future of the Internet with some of the people who were responsible for building it every fall. Vint used to take such great pleasure in going around with a towel draped over his arm and serving everyone wine. Being served wine by the father of the Internet was the weirdest experience! (laughs)

Cooper: (laughs)



Maher: It's like, "Shouldn't we be doing that for you, sir?" (laughter) And he always wears a three-piece suit. (laughs)

Cooper: We were both speakers at the National Press Club before COVID about the benefits of employment of people with disabilities and some of the work—the reason I was speaking is because we built the first job board for people with disabilities.

Maher: No kidding!

Cooper: It's abilityJOBS.com and it's been online since 1995.

Maher: Oh, my gosh, that's remarkable!

Cooper: More recently we built the first accessible online career fair. You've been to career fairs?

Maher: Of course, yeah.

Cooper: If you ever do any recruitment outreach to people with disabilities—

Maher: Oh, we would love to, Chet. It's one of the things that is a big part of our values, particularly since we're a totally remote organization, and for people with mobility challenges, we would love to be able to recruit more from your community.

Cooper: Our success is both with the large number of job seekers, but our growing number of recruiters —we have Google, Wells Fargo, CBRE, IRS, NSA, Facebook, National Institutes of Health; it's a who's who list. I'll quickly tell you what we do. It's face-to-face video event. Not all career sites are like that, a lot of them are just chat-based, where you text it in.

If we were there right now, there'd be a queue. Let's say you're the recruiter, I'm the job seeker. You'd see me. If I happened to be deaf, a third video appears and a sign language interpreter communicates between us. It's built with accessibility in it's DNA allowing screen readers for people that are blind, real time speech to text for people needing extra understanding for communication and internal video messaging for any candidate that didn't get a chance to meet a recruiter.

Maher: That's phenomenal. We'll definitely follow up. I would love to find a way to do this. One of the things that is so important to us as an organization–Our mission, as you know, we're the website–The website is great, and it's really useful to so many people. It's used by hundreds of millions of people around the world. It is already fantastic. But it could be so much better. And that's my passion. It's around all of the ways in which the full diversity of lived experiences on the planet, from ability and disability, place of origin, cultural identity, religious identity, ethnic or racial identity, indigenous culture are not yet really well represented. A huge part of the way that we better serve those communities is by having an organization that is more reflective of the diversity of the world. Just recruiting and enabling staff of all backgrounds. I would love to follow up with you on that.

Cooper: Let's do that. I would love to figure out a way

also to make it easier for people—I've heard so many stories of problems they've had with putting their own content on Wikipedia. They can't figure out how to do it when they feel like they have the facts, and then the model is as you described it, it has to be coming from another source. The idea that the editors, the volunteers, look at it as, "This sounds like it's marketing." Have you heard about that issue?

Maher: It's a real challenge. I think there are two general categories that falls into. One is when people try to write an article about themselves. That happens all the time, for very understandable reasons. I just had a nice young man, a social media influencer, reach out to me this weekend asking for help with that. Writing an article about yourself is considered a violation of our policies. It violates our conflict of interest policies. We like to say it's very hard to be neutral about yourself, so it's better if other people do that for you. Conflict of interest means you can't write about your employer, about yourself, your spouse or partner, things like that. That's the first category, and it's such a common one. Very often, once people understand why that policy exists, it becomes easier to have a conversation about what another form of contribution looks like.

The other one, which is very frequent, is that someone writes about something they're really passionate about or love–Let's say, their hometown, their favorite car manufacturer, their favorite video game–And they do so in a way that's so enthusiastic that it comes across like marketing. I think we do not do a good enough job, if I'm being very honest, of educating people when they first sign up to contribute about what the policies are around tone, neutrality, verification, conflict of interest, etc. One of the things people experience is that they might get frustrated because they put in a lot of good effort and don't feel appreciated for that effort. So, [what] we're working on right now is trying to find better ways to get what we think of as "onboarding people" into the process so that they learn those guide lines up front, as opposed to after they've already made a contribution, and they're feeling demotivated or dispirited.

Cooper: Are there tutorials out there that talk about those two areas?

Maher: There are a few, but I think the bigger issue is that because Wikipedia is so widely known, the tutorials that you would access maybe are harder to come by or find relative to the ease of just clicking "edit." It's much better known than the learning resources that we have for how to learn the project. What we're trying to do, what my hope is, what we're working on is how we can make that learning part of the editing process itself so you don't have to read or participate in a separate tutorial. But when you go to "Edit Wikipedia," it's sort of like signing up for any—it's very common these days to sign up for products and platforms and services, where you sign up and they ask, "Do you want to fill out your bio? Have you considered what your passion areas are? What your interests are?" And communicating that. Or signing up for channels or topics. We could do a much better job of onboarding people so we could say, "Hey, have you learned about the conflict of interest policy yet?" for example.

Cooper: If somebody's flagged as a conflict of interest, at this point, do they get some notice of what your rules are and how to deal with it to get possible information that they would like to see on Wikipedia done in a way that fits your framework?

Maher: The answer is yes, except of course this is both a good thing and a bad thing about the way that we work. The good thing is that we are so community-driven and historically, always have been. The bad thing is that oftentimes people get that notification from a community volunteer, and sometimes that person is trained on how to support and educate and sometimes that person is not. Sometimes people get a very supportive experience and correction and mentoring, and sometimes people get their wrist slapped. That is the outgrowth of being an organic community-driven grassroots organization in the sense that we have far fewer resources, and the community has always led the way, which has been wonderful. It's made Wikipedia exist. We view it as a strength and an asset.

But what we now, at our size and scale, need to do as an institution is to put in more supportive tools, training for editors, and training for newbies so that everyone has a more positive experience. When we were a tiny website, this was less of an issue. Now that we're so well established and popular and widely utilized, it's a responsibility on our side.

Cooper: That's great to hear. I was thinking about languages, have you heard of Amara?

Maher: I don't think so.

Cooper: Amara.org. It's crowdsourcing for closed captioning. We use it for our videos not just to ensure they are accessible to deaf and hard of hearing viewers, but they are captioned in multiple languages. We have over 2,000 volunteers working with us captioning in their native tongue.

Maher: That's really cool. This is something we were just talking about the other day. Wikipedia is the most famous of our projects, but Wikimedia Commons is where all of our media comes from, images and videos. We have been talking about how we really want to improve the quality of video on Wikipedia because so many people these days learn through video. It's a huge part of YouTube, if you are a non-native language speaker, to be able to watch a video helps with comprehension and also language acquisition and skill acquisition. One of the things we've been talking about is 'what can we do to support better video?"

One of the really exciting things for us has been—our community is phenomenal at translation. We've been talking about closed captioning and captioning of videos as a great jumping-off point for our volunteers, given how many of them are multilingual and how well established the multilingual capacity for translation among articles is for Wikipedia. I'll definitely look into that, thank you.

Cooper: It's used by TED Talks, Scientific American, Udacity, Net in Nederlands and many others. I will connect you with them.

Maher: That's great, thank you!

Cooper: I know you have to go is there anything that you'd like to talk about before we end?

Maher: What I would want your readers to know is that Wikipedia is a work in progress, but it's also a work that we make together. So, all the best things in the world, in my view, are the institutions that we steward as communities, but also the institutions that we have a hand in building, that reflect our aspirations as humans–whether that's at the level of local governance or whether it's in the sense of community centers. The things that we love and cherish are the things that represent our humanity. And Wikipedia, for me, really is that because it represents what we do together as people.

There are certainly issues. We've talked about some of them. I wish it were easier to contribute. There are ways in which it is not fully reflective of the world as a whole. A lot of work to be done. And yet also, Wikipedia is a reflection of this tremendous thing that people can do when they collaborate with no exterior, no ulterior motive or external reward promised. As a nonprofit, it's a complete gift that people give their time to build this work for people they'll never meet. For me, it's a tremendous gift of human generosity. Wikipedia runs on the generosity of volunteers. I would want people to know that. This is a truly human project, which means that it both has its foibles and is flawed, but it is also aspirational and beautiful and collaborative. It's a thing that we do together.

If people are interested in participating, we often say there are many ways to contribute. You can be a donor, that's probably the way most people interact with Wikipedia. You can be an editor, which is its own form of contribution. But I also think you can just be an engaged citizen and contribute to Wikipedia. The very nature of seeking information validates how important knowledge is to the world. Every time you read an article on our site, you're saying, "I value knowledge." When you say that, it's a reminder to institutions like ours and others that knowledge needs to be protected and defended. You're showing up on behalf of knowledge by the act of seeking it. For me, truly, in this world today, that act of seeking knowledge, of seeking understanding, and what that might lead to in terms of cooperation, collaboration, and dialogue, that's the basis for how we solve the greatest challenges of our time, from climate change to social and political division. We start by showing up and working together and by seeking to understand.

I hope that that's the thing people would hear, that this is a thing that we do together. That means there's a chance for you to be involved in it, no matter who you are, no matter what your background is. There's a chance for you to build the way that the world understands itself. That is profound. Nothing like that has ever existed in the history of humanity. That's my pitch! That's what I want people to know.

Cooper: That was beautiful! It did bring me to another thought about the digital divide and how we can deal with that. You're hearing more and more because of the distant learning with schools and children in certain areas in the U.S., but what about the digital divide globally. Since you are a hundred percent digital, is there anything tangible you could share about what you're trying to do in dealing with that?

Maher: Absolutely. You're completely right about the digital divide, and you just hit on one of my passion areas from my time at UNICEF. As you may know, it's not even as pure as a digital divide, because it's not just that half the population has Internet and half doesn't. It's also who has access to the Internet. it's highly gendered, for example. Most women in the world do not have access to the same degree of digital connectivity as men, heads of household, patriarchal structures, things like this. That goes on all the way through any form of invisible, whether it's minority or marginalized community. You have less access.

From our perspective, the digital divide is one of these issues, content divide, what we call "knowledge equity" is one of our big focuses, "knowledge gap" is another one. Within the digital divide in particular, though, especially since it tends to disproportionately affect learners, because even those who may have access to technology in a household tend to be the adults, tend to be primary breadwinner, things like that. So schoolchildren are often the ones who are most excluded from participation as we look globally. What we have done with our community, it's been a community-led initiative from day one, was from the very early days of Wikipedia to look at what Offline Wikipedia looks like.

Offline Wikipedia is an imperfect response to the digital divide, because it doesn't address questions, say, of literacy. But it does start to get into questions of connectivity and electricity. From the very early days, the community was focused on an offline version of Wikipedia which had no images, really low memory requirements, things like that. And now more in these current days, we support an organization financially and through some



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product work as well called Kiwix. They create a productized version of Offline Wikipedia for distribution globally, along with other learning resources. It's all packaged together into an offline resource. That and an initiative from some of our—we have other initiatives around our editing communities around Offline Medical Wikipedia, which is a really popular app for doctors and other medical professionals who need access to basic medical information. Wikipedia's medical articles are rigorously edited by our editing community, and that includes in multiple languages, as well as some efforts with a project called WikiFundi, a project from our African Wikipedia community, to engage people in offline editing, so that people don't have to have access to the Internet in order to be able to contribute their knowledge.

There's a range of different projects. Kiwix is certainly the biggest, and I know we can send over a little bit more about that. And if you were interested in talking to the folks behind that, they're wonderful. They're based out of Switzerland but have a pretty global footprint at this point. It doesn't address, as we said, literacy, indigenous languages, a number of these other issues, but it does start to address that distribution. And the crazy thing about it, something I love, is that we know that Wikipedia is one of the most popular websites in the world. We have about a billion visitors a month. We have no idea how widely used Kiwix is. We'll never know. We know we distribute it. We know it goes like hotcakes whenever they produce it. The team will show up with physical items to distribute in communities. It's also a digital version. You can download it, copy it infinitely. That's another aspect of us being freely licensed. It means that not only do we not know how far and wide Kiwix is distributed, because we have no licensing requirements around our IP, there's no way for us to track it, and that's completely fine. That's part of our mission. That's a huge part of why we are freely licensed. So we do the work. We support it with grant-making with the expectation and knowledge that it goes off and does good in the world, without having an understanding of just how large that global footprint is.

We know it's big, based on some data, but we'll never know. And I think that's kind of beautiful on some level.

Cooper: How is it distributed? If you're talking about a digital divide and you have a download, you can't download if you don't have—you're not printing?!
Maher: (laughs) No, we don't print Wikipedia. That would be enormous. We did a project to figure out how big it would be, and they found that English Wikipedia alone was something like 6,000 volumes. It's huge. Bigger than many small community libraries. So no, it is entirely a digital package. It is distributed in one of two ways. One is that you can download, and it's very small. The total size of a Wikipedia when stripped of images in particular is tiny, because it's all text-based. The bandwidth requirements are incredibly low. I don't know the exact number because it changes as Wikipedia keeps growing, but it's it in the MB size, not the KB size, if that makes any sense.



And if you include the images it's still relatively small, because we can do all sorts of fun things with compression to get that down. We're able to offer that as a download package. Many people in countries with inconsistent access to electricity and network bandwidth use things like trickle downloads. That allows you to be able to sync up whenever you're on and then go offline when you're not. That's a feature even in our apps for people who are in inconsistent connectivity environments. You can set it so that Wikipedia updates when you are offline.

The other one is physical distribution. It's really easy to copy these flash drives. You just stick them into the appropriate device drive, make a copy, and move it around. In my old world, we would call this a "sneaker net." You literally create something by sneakers.

Cooper: (laughs)

Maher: So we know that's how versions of Wikipedia get distributed in Cuba. There are other interesting issues with people trying to distribute it in areas with internet restrictions. The physical distribution on flash drives and copying tends to be the best way. As I said, because there are no IP restrictions, we don't have any digital copyright around restrictions. You can copy them endlessly and give them out however you would like. That tends to be the way that those get distributed. People will literally carry copies of them to conferences, and we'll be like, "Hey, are you going back to Ghana? All right, here's a box of them." And the community members will take them back and work within their own community networks to distribute them.

I'm so sorry. I do have to go. But I would love to continue the conversation. I've really enjoyed it. It's been fun to talk to someone who has such a historical and deep sense of what the work is.

Cooper: We will re-connect with you, both on the employment side, but also just some other ideas that might be very interesting for—not that you need additional projects.

Maher: (laughs) I love it. Let's do it. ■ ABILITY

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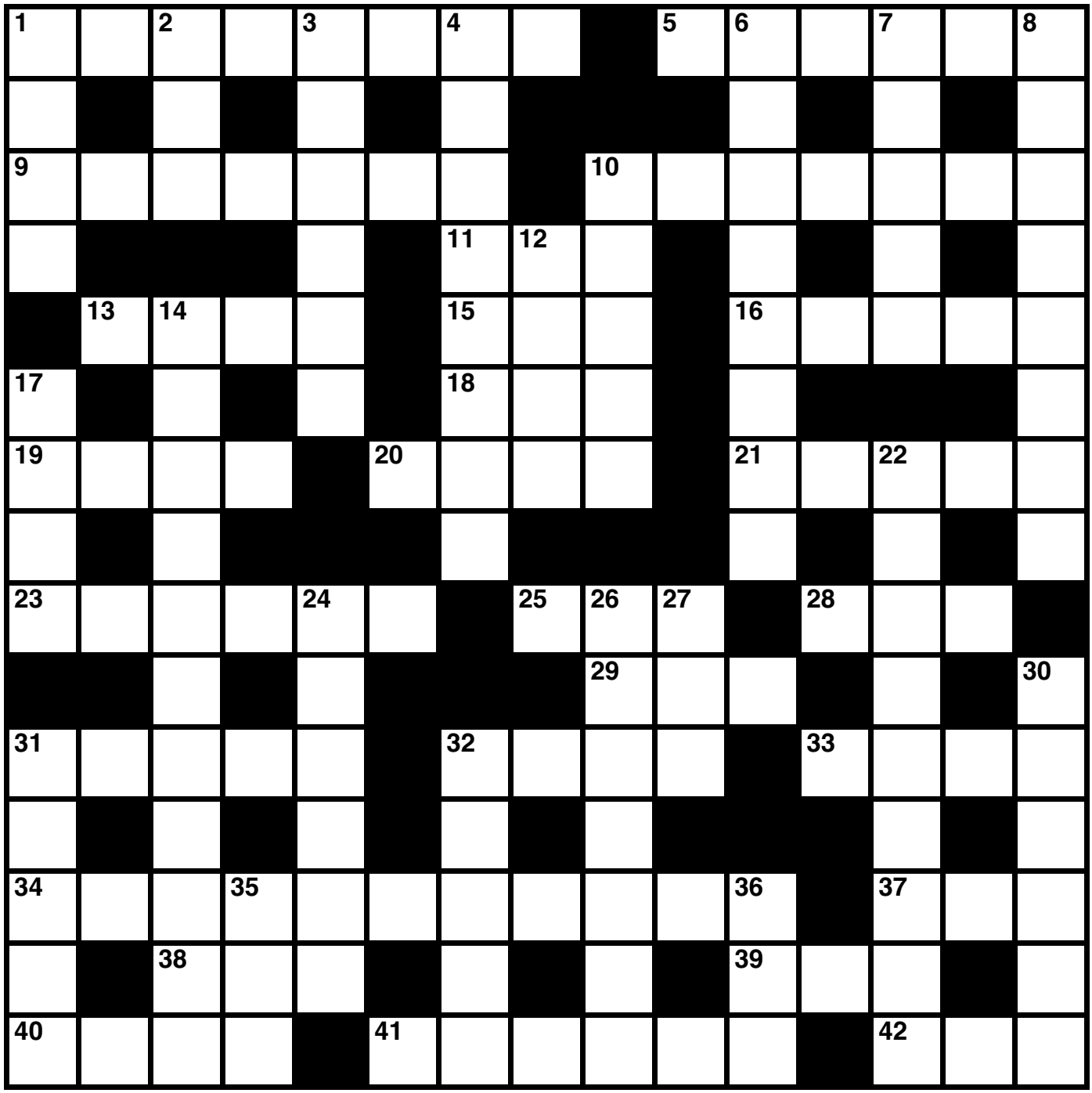
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Crossword Puzzle

ACROSS

1. Chinese lady who is blind and dedicated and running a business where she practices massage for blind people, 2 words
5. A wheelchair image is one on disabled signs
9. Get better
10. Lady devoted torights of people with disabilities Judy _____
11. Bill featuring Washington
13. Outer layer
15. "Welcome to Hawaii" gift
16. California border lake
18. Young chap
19. Exotic juice berry
20. "Facts of Life" star who fights cerebral palsy, ____ Jewell
21. Nicole Kidman's character's lover in "Cold Mountain"
23. Fall
25. Take advantage of
28. Celebrity who has Parkinson's, Michael J. ____
29. Mature gracefully
31. Path
32. Rock star whose ONE campaign has taken action to prevent poverty and disease in Africa
33. Rare disease that can lead to intellectual disabilities, epilepsy, hypotonia and feeding difficulties
34. Non-profit dedicated of people with disabilities, 2 words
37. How-to container
38. Mr. Potato Head attachment
39. Time just before
40. Beach castle material
41. Inherent
42. Color in a Crayola eight-pack

DOWN

1. Paralympian with the most medals, Trisha ____
2. California University
3. Come up with a new product
4. Laid out, as a carpet
6. Sound of Music song "Climb Every _____"
7. Dog park need
8. Actor who starred in "Joan of Arcadia" and has been a strong supported of Easter Seals, Joe _____
10. Fictional Alpine miss
12. Close
14. Disability rights acitivist from Germany, Raul _____
17. "___ Was a Rollin' Stone"
22. 1979 Bond movie
24. Outstanding athletic events paralympian from the UK, Stephen _____
26. "Black Magic Woman" band
27. "I" problem
30. One way to stand
31. Adolescents
32. Protected prairie animal
35. Itty bit
36. Date

answers on page 66

Crossword Puzzle



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