

ABILITY



MANDY HARVEY

Archie
COMICS
Nancy Silberkleit

+

China's Chen Yanping
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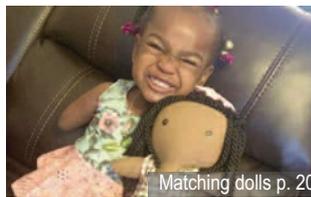
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The Arc
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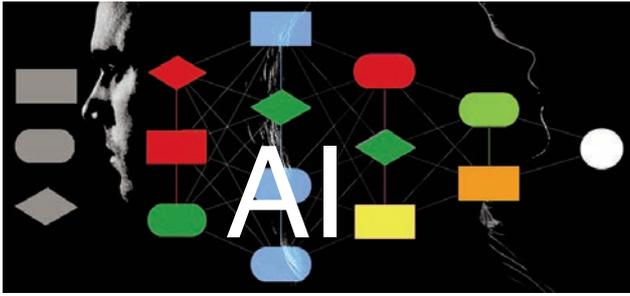
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People with disabilities face significant disadvantages in the workforce. According to the U.S. Equal Employment Opportunity Commission (EEOC), of all the employment discrimination cases filed in 2019, the most common claims involved disability-based discrimination (33.4%), closely followed by race and gender based discrimination. Today, a new form of employment discrimination causes concern: Artificial Intelligence (“AI”) bias.

What is Artificial Intelligence?

Artificial intelligence is a branch of computer science that develops computers and machines to imitate intelligent human behavior. General examples of AI in our daily lives might include “Siri” or “Alexa.” AI is also integrated into assistive technologies such as Seeing AI, AVA, Voiceitt, and smart wheelchairs, just to name a few.

How is Artificial Intelligence Used in Hiring and How Does it Impact People with Disabilities?

AI is also widely used in hiring and recruiting for jobs. According to Glassdoor, AI hiring tools are widely used across different industries, from “Allstate to Hilton to Five Guys Burgers.” A common example of AI can be found on LinkedIn, a website that connects job seekers with employers and recruiters. To employees, LinkedIn’s AI suggests a job they may be interested in based on their profile and job experience and suggests connections to potential employers as well. Other examples of AI hiring tools include text searching technology that screens high volumes of job applications, facial analysis technology that scans facial expressions and body language of applicants during video interviews, and voice scanning technology that evaluates a job applicant’s speech, tone, and word choices.

However, despite its convenience, AI is also capable of being biased based on race, gender, and disability status, and can be used in ways that exacerbate systemic employment discrimination. For instance, researchers have found that assessing facial movement and voice in applications may “massively discriminate against many people with disabilities that significantly affect facial expression and voice: disabilities such as deafness, blindness, speech disorders, and surviving a stroke.” Also, online personality tests and web-based neuroscience games used in AI hiring tools may screen out people with mental illnesses.

Generally, AI hiring tools are programmed to identify an employer’s preferred traits based on the employer’s existing pool of employees. That means, if disabled people are not represented in the employer’s current pool of employees, then the AI hiring tool may learn to screen out job candidates with a disability. Essentially, AI would treat “underrepresented traits as undesired traits.” As a result, “people with disabilities—like other marginalized groups—risk being excluded,” says Alexandra Givens, president and CEO of the Center for Democracy & Technology. To overcome bias, AI hiring tools need to be trained with more diverse data that includes employees with disabilities. Currently, disabled people are underrepresented in the workforce, and unsurprisingly, technology emulates this phenomenon. “If an algorithm’s training data lacks diversity, it can entrench existing patterns of exclusion in deeply harmful ways,” Givens wrote in an article for Slate.

Seeking Solutions through Legal Advocacy

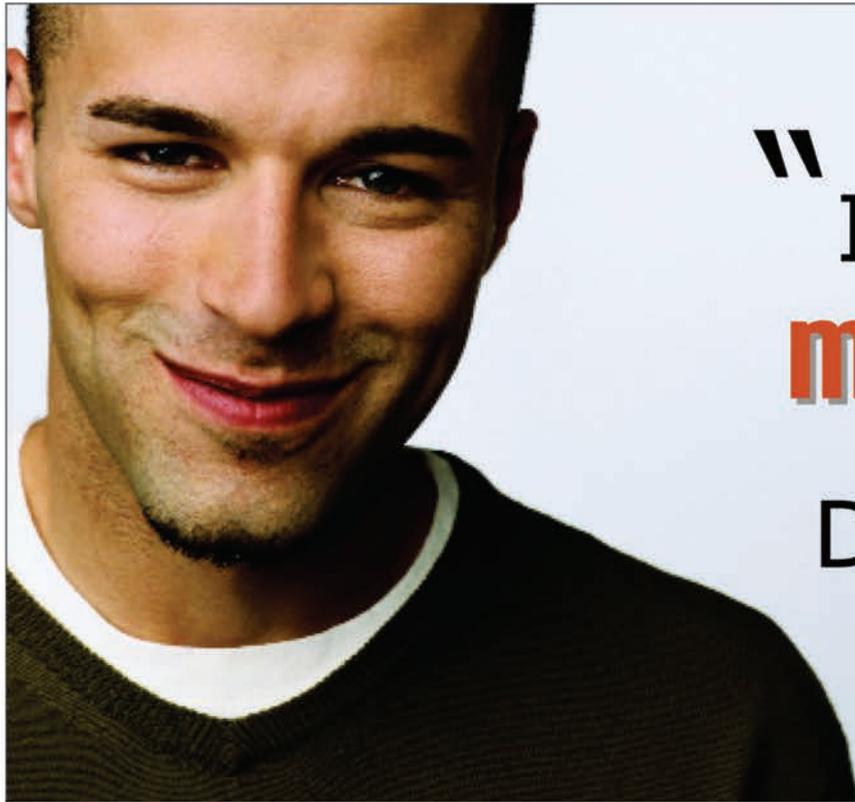
The ADA limits an employer’s ability to make disability related inquiries at the recruiting stage. AI hiring tools that enable employers to gain information regarding an applicant’s disability and screen out qualified candidates would face liability under the ADA as well as state and local human rights laws. According to Bloomberg, the U.S. Equal Employment Opportunity Commission is already investigating at least two potential claims and lawsuits involving an AI tool’s discriminatory decisions in hiring, promotion, and other workplace decisions.

State and local governments are proposing and enacting laws that regulate the use of AI hiring tools and scrutinize any discriminatory effects such tools may cause. Illinois has pioneered the AI Video Interview Act which requires employers to notify, explain and obtain consent from job applicants about its use of AI hiring tools. New York City is reviewing a proposed bill that would require sellers of the AI hiring tools to undergo an annual “bias audit.” While we await lawmakers to enact laws to promote AI accountability, advocates will seek action in courts to tackle discrimination arising from AI hiring tools. ■ ABILITY

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The Election...

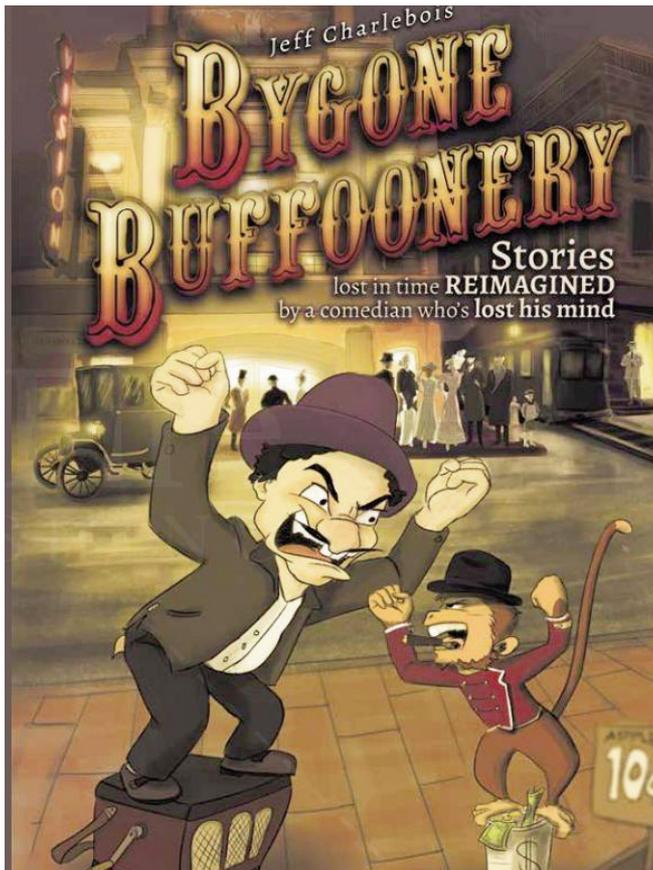
The Most Wonderful Time of the Year

Well, the insane 2020 election is behind us...finally. It seemed like it might go on to 2024. I would've died a thousand deaths. One can only take so much of a bad thing. Some consider it a done deal while others are clinging to a miracle. So now, half the country is elated, and the other half is severely depressed and suicidal. Besides the Civil War our country has never been so divided, except for the Coke vs Pepsi battle in the 1980s. Personally, I'd like to see the Democrats live on one side of the country and the Republicans on the other side. They can shoot rockets and lob missiles over the Mississippi River at each other.

One thing both sides can agree on is, thank God, the political commercials are over. We're tired of candidates telling us how noble they are. Boring us with promises that will never be kept. We just want to get back to those funny Progressive commercials with Flo and Jamie. My

cell phone was going crazy every five minutes with texts rolling in begging for campaign donations. If I give them some money, I couldn't pay my cell bill and they'd shut off my phone. Then who would you send your annoying money-groveling texts to.

There's a lot of claims of election fraud. Voting machines were suspect. Ballots coming in late. Dead people casting votes. To me that seems racist. Dead people are a significant portion of our population, although not very productive but, heck, either am I. These corpses have as much of a right to vote as anyone else. I'd even go so far as to say their probably smarter than the average voter. I saw a testimony of a woman who found out that her service dog had voted. She has no idea how. The mutt was by her side for the whole election day and swears he never ran off at any time. What baffles her is she has no clue who he voted for. Some candidate was able to corner the canine vote. The choice for president usually boils down to more government or less. I'm not a big government man. I'm



not even a big man. Hell, sometimes I think I'm not even a man. I've had girls ask me if I'm a man or a mouse? I always choose mouse. It's made my life simpler. A mouse doesn't have to be responsible and pay bills or get in some fight for sticking up for his girlfriend's honor. They get in beefs with guys in bars, and it's never the little dudes, calling them names and starting a fiery hoopla that always ends with "yeah, well, my boyfriend's gonna kick your ass." Then she looks at me and says, "Well, are you gonna do something? Are you a man or a mouse?" My answer is always the same, "squeak, squeak."

Now getting back to government, if this was a business it would be out of business. They're very inefficient. Anybody ever been to a DMV? If our government were a regular private business, they'd be bankrupt. Oh, that's right, they are, but only by 21 trillion. They need to cut down on the daily Starbucks and start chipping away at their debt. I'll bet my life no debt collectors blow up their phones.

It boggles my mind how people would want the government involved in its everyday life. Men can't even take simple orders from their wives. "Honey, I said get me a bottle of olive oil not Jim Beam." Some time ago the mayor of New York released a decree that stated you couldn't buy a soda over sixteen ounces. Who the hell is this guy to tell me I can't get fat or get diabetes?

Maybe a little flab makes my face look fuller and helps

Did you know that mankind was nearly doomed when treasonous animals on Noah's Ark attempted a mutiny? Or that the entire Roman Empire nearly unraveled when a crackpot Caesar swooned for—and married—his horse? Were you aware that a flamboyant cowboy subdued bloodthirsty gunslingers with a two-step? What about the vaudevillian hack juggler who received his first standing ovation in a coma? Don't freak if all this comes as news. In *Bygone Buffoonery*, Jeff Charlebois provides centuries of laughs as he rewrites the past in witty, short stories you won't find in any dusty library.

"From the moment I picked your book up until I laid it down I convulsed with laughter. Someday I intend reading it."

Groucho Marx



About the Author



Jeff Charlebois is a professional comedian and writer. He's performed for audiences across the country, published previous humor books, including *Medical Secrets Revealed* and *Life Is A Funny Thing*, and written columns for Ability Magazine. He is currently at work on his debut novel. Charlebois, originally from America's crab capital, Maryland, resides in the Los Angeles area.



LitFire PUBLISHING

BYGONE BUFFOONERY

Stories lost in time Reimagined by a comedian who's lost his mind

Jeff Charlebois

me get those elusive dates. Maybe one of my goals in life was to get diabetes. Don't rain on my parade. This is almost a free country, pal. Also, if I want to keep my dry cleaners' business open during Covid that's my prerogative. Our ancestors put the beatdown on the British for freedom and the pursuit of happiness. Nobody says you must come into my dry cleaners and chance catching the virus, but at least you have the choice. However, with the lockdown, you have no choice but to wear a food-stained shirt now. Just like the diabetes maybe I want the virus. I've always like to experience new things.

I was hoping Kayne would pull out this election even though I couldn't name one song of his. I'm more of a Helen Ready man, well, mouse. With this election debacle over I guess we can now get back to our lives and start enjoying the virus. It was ugly this time around because so much appeared to be a stake. After watching all the insane riots, looting, and ripping down our statues, it made me long for the America I once knew. I guess we'll see if we can find it again or if it's gone forever. ■ ABILITY

Jeff Charlebois

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陈艳萍 戏是生命里的那束光

Chen Yanping — Blind Opera Performer

Soon after losing her vision, Chen Yanping cut all connections to the outside world. It was the constant visits by Yu Jing and her friends that helped her re-find the value and meaning of her existence. But what truly brought them so tightly close, besides their time-tested friendship, is the passion of life they all shared - Yue Opera.

Chen Yanping

Chen Yanping was born in Zhou Shan, Zhejiang Province in June, 1979. In 2008 she founded and headed the Zhoushan Youth Yue Ju Opera Ensemble, and she served as the vice Chairwoman of Zhoushan Association of the Blind, and a visiting professor at Zhejiang Ocean University. In 2017 she signed in the 9th National Art Show of the Disabled and won the first prize in the opera genre. In 2020 she was presented the honor of being named the Second Zhejiang's Most Beautiful Disabled Individual.

Ever since the beginning of 2020, Chen Yanping has seen a sudden decrease in the opportunity to have her stage performance. As a Yue opera actress, she and her Zhoushan Youth Yue Opera Ensemble bore the brunt of the undesirable effects caused by the coronavirus pandemic: no place for rehearsals, shows were canceled, which imposed tremendous pressure on the traditional folk-art ensemble to survive.

Fortunately, the pandemic was slowly under control in southern China, and everything started to get back on the right track again. Zhoushan in early fall saw persistent raining days and the roads were often muddy, but as long as she could put on shows Yanping remained hopeful at heart.

Bringing to life an unofficial Yue opera ensemble

It was September 19, in a lodging house in Zhoushan. The rain outside the window was picking up steam. The balcony door was half open, allowing raindrops to blow





inside, only to disappear soon after they landed on the grey carpet.

Inside, Chen Yanping, frowning, held a phone playing an opera tune on its speaker in her left hand; her right hand rested on the shoulder of a young man wearing black clothes. He was not tall, looking stout and chubby, and in contrast Yanping had a slender, nicely stacked figure. She happened to have donned a white shirt, and the young man was in black and looked short and plump, which created a striking contrast in the standing mirror on the floor.

The phone was playing a cucurbit flute tune. The young man was playing the cucurbit flute, trying to catch up with the tune from the phone's speaker. Yanping kept tapping on his shoulder to help him keep up with the rhythm. She learned playing the cucurbit flute from her father, and she'd been trying hard to improve the young man's flute-playing skills. Both Yanping and the young man, Xiao Xu, are blind, and Xu works at the massage parlor owned by Yanping. This afternoon would mark Xu's debut performance as an actor from the Yue opera ensemble. The house where they had their practice is actually Yanping's home, which she had barely lived much after she purchased it. Looking to train disabled opera lovers who were willing to learn and practise, she renovated the house and repurposed it as a training cen-

ter for the art lovers. There was a room dedicated to storing the troupe's costumes and props. Having no place of her own to live in, Yanping had to turn to Yu Jing for lodging and food.

Yu Jing is able-bodied, and she has been Yanping's best friend ever since they came to know each other through learning the opera. They have been a pillar of support for each other. "We have different personalities, but we share the same values; and we really speak the same language," Yanping said. "After I lost my vision, I had little problem with singing, but I had to learn the actions of the opera by touching and following Yu Jing's body movements." When Yanping gave her debut performance several years ago and positively impressed the audience with her fluent skills at the municipal level art show of the disabled, few believed that she was actually blind. Jing was only too aware of the blood, sweat and tears behind her every movement. Throughout the performance, Jing was weeping in tears while Chen Yanping was performing on the stage.

In 2008, Yanping and Jing co-founded Zhoushan Youth Yue Opera Ensemble, headed by Yanping. They soon attracted the attention of legions of Yue opera fans, and as of today the ensemble has grown into a 20-performer troupe. Members of the ensemble came from all walks of life. Yanping owns her massage parlor, and Jing is a

department manager at a bank. The ensemble now gives as many Yue opera shows as 100 a year, and has so far held over 800 shows as part of the government agenda for public cultural benefits. Their performing arenas run the gamut from government agencies of all levels in Zhoushan, the army, schools, to nursing homes. Few unofficial troupes in Zhoushan have ever accomplished that.

Rising above the crucible of life

Yue opera, also known as Women's Opera, is performed by all-female performers. Its tunes are softer and gentler than those of Peking Opera, and oftentimes the characters are talented scholars and elegant ladies. Featuring plots full of twists and turns, Yue opera has long been cherished by the audience around the Zhejiang Province. Yanping was brought up by her grandparents, who happened to be fans of the opera, and since her childhood Yanping has been no stranger to opera theaters and stages. While her parents watched from the audience seats, she would often play at the theater gate with half an ear on what was singing on the stage, naturally learning to hum and sing a few tunes. At 16 she went to study Chinese medicine at Hangzhou Medical School, and her performance at the Cultural Festival on Campus was effusively approved of and praised by the local opera critics. Greatly encouraged, Yanping decided to take the plunge and apply herself further to the learning of Yue opera.

Her vision had become a persistent problem since she was in her 20s. At first her vision became blurry, and before long she couldn't travel without help, despite her efforts. It was diagnosed as Retinitis Pigmentosa. "Doctors claim it's something that comes with birth. It may start to flare up when I'm in my youth, or it may be as late as I'm middle-aged," says Yanping, who was nearly blind when she reached 26.

By that time Yanping had returned to Zhoushan to work, but not for long. Soon she lost her job because of her deteriorating vision. One day when she was idling around a local park, she came across a group of senior citizens singing Yue opera for personal enjoyment. Yanping kept turning up, and soon made acquaintance with the opera fans. Realizing that the young lady shared their passion in the opera, the group members one day encouraged her to join them and belt out a tune or two. She didn't chicken out. "You have great potential. What do you say if we recommend to you a professional mentor?" They suggested. And as it happened, Yanping was then recruited into the Zhoushan Folk Art Troupe, where she came to befriend Jing and other like-minded people.

Since the ensemble was set up in 2008, things hadn't been easy. Everything being an uncharted territory, they had to grope along, starting with recruitment of new members. They had little income, no place for

rehearsals, and the duo had to come up with everything out of their own pocket. To date they have invested about 800,000 yuan on costumes, props, transportation, and audio equipment. "For the first 6 years we were almost like entertaining ourselves," to quote Yanping and Jing. In order to survive, the ensemble had to work hard and play smart. They would take over shows in seasons that were considered either too hot or too cold for their "professional" counterpart troupes; they would agree to put on shows on many far-flung islands where transpiration was barely manageable. In some extreme cases they even agreed to perform for free.

It was an afternoon, and the show was held in a remote nursing home surrounded by scenic beauty. While the stage was being set up, Jing was doing makeup on Yanping by the window near the rear end of the meeting hall where the opera was to be conducted. Wearing a red vest printed with the name of their ensemble, Yanping trusted the handling of her face's makeup to her partner Jing, while in the meantime previewing with headphones the opera tunes she was to sing. Jing had just recently been out of the surgery of thyroidectomy and was not in the condition for stage performance, so she would act as the emcee of the show.

There were four performances in the show. Xiao Xu took the lead with his cucurbit flute performance, followed by 3 acts of Yue opera. Yanping was the third to come on the stage, after the Romance of the West Chamber. Right after Xu's performance she was arranged to change into costumes in a room next to the meeting hall. It was a common-or-garden nursing home room, so small it could barely accommodate Yanping and her colleagues with any spare space to stand.

Upon changing into her costumes Yanping was escorted to the edge of the stage. She turned to the stage where actions were on but, not being able to see, she lowered her head towards the ground. It was her turn now. Jing announced to the audience, "here I'm presenting our next piece, Blaming Sons, an act from the classic Yue opera the Story of Li Wa." The Story of Li Wa was adapted from the Extensive Gleanings of the Taiping Era, which tells the romantic story of Li Wa, a girl from a very poor family, who was later sold to the bawdy house to practice prostitution, and who happened upon a young man from Xing Yang, a customer of hers. Affections grew as they spent much time together, and after numbers of trials and tribulations they finally managed to live together as a couple. Yanping played Xing Yang the gentleman. Gone was the offstage Yanping who needed help even walking around, but on stage we witnessed a handsome young man, with impeccable singing and easy, accurate bodily performance.

There was an act worth noting here. Being chastised by his father, the young man plopped down on the ground, heavily and backwards. It was an act that once really sent Yanping suffering in agony. One time they had a



show in a village where conditions were really less than ideal: right below the thin felt laid the uneven concrete floor. Unknowingly, Yanping performed the act and had the vertebrae on her lower part the spine land smack-dab on a bump on the floor, immediately causing fracture to her vertebrae. She burst into tears in great pain.

Yet when the show came to this act, Yanping didn't hesitate a second. She raised her head, fell backwards, plopped down on the ground, all in one breath. The meeting hall had a few moments of dead silence before everybody suddenly exploded into a standing ovation.

After the show, Jing's mother emerged at the corridors to the meeting hall, ready to pack things up. She murmured with a heavy accent while looking at the piles of costumes and props. Only one comment was comprehended, though, that "I'm their best support staffer." Since the establishment of the ensemble in 2008, seeing that Jing might lose money on this, her mother had been against their ambitious project. But it didn't take long for her to realize that it was true love for the art on her daughter's side and she finally came to terms with it. Having noticed that the troupe had inadequate supporting crew, she volunteered to help out and soon became a staunch supporting member of the crew, further deepening

the bond with her daughter.

Giving everyone a stage to perform what they love

One and a half months after she had her vertebrae fractured, Yanping was back to take the ensemble to Dongyang to perform. She had to fix herself to stretchers in a van, and after that on a wheelchair. It was a harrowing and bumpy journey, but her heart was full of joy. A turning point for the troupe came in 2011 when, in three years they had won great numbers of hardcore fans, they were offered an opportunity to perform in the Zhoushan Grand Theater. "The tickets were complimentary, but they were so sought-after and so hard to come by, the theater's security guards came to conflict with the fans who couldn't get a ticket but were eager to get in," said Jing. The 700-seat theater had never seen a full turnout of the audience for any Yue opera shows, but their ensemble made it.

Two years ago, the Zhoushan Youth Yue Opera Ensemble, along with a group of 9 other private organizations, applied with the local Civil Affairs Administration for free offices and communal meeting rooms and was granted on application. Now they officially had their own space for everyday teaching and rehearsals. In a

few days there would be a folk-art competition among Zhoushan's unofficial folk-art troupes, and Yanping's troupe decided on releasing a show entitled Five Daughters Offering Felicitations. Like the plot featured in the movie *New Year's Visits*, this show tells a story of five daughters of a man and their husbands, when offering their congratulations on the father's birthday party, knowingly and conspiratorially angled for fame and fortune. Yanping played one of the sons-in-law. In rehearsals, She and her partners spotted many imperfections and they kept at it until it was all sorted out. Jing offered her opinions and instructions quite a lot.

Every day after rehearsal, Yanping returns to her massage parlor, which is under the charge of her brother. Her brother is also blind, but unlike his sister, he's more of a traditional type, content enough with his ordinary job as a massage therapist. He's very much influenced by their parents; even to this day, they still don't fully approve of their daughter's ambition in Yue opera and her operation of an ensemble. "They think it's too much hard work performing on stage. Whenever I'm on stage they worry a lot. For example, the show *Meeting in Pavilion* includes an act of dropping a fan on the floor, which is totally necessary, but my mother will be worried sick, thinking if it's her daughter's fault, or if my blindness causes many bloopers," says Yanping. Her purchasing a department but repurposing it for other uses certainly hasn't helped much to put things right between them.

Whenever Yanping spots musical talent in her disabled employees, she's willing, able and ready to give them a helping hand and improve their performing skills. Xiao Xu is one of the lucky ones who have then had opportunities to display their talents in folk-art shows. The employer-employee relationship has then grown into a unique friendship, teeming with rapport and affections. There are times when Yanping receives phone calls from them, requesting her immediate presence at the store. Concerned, Yanping rushes to the store, only to find that they have just missed her.

From self-entertaining to leaving behind a legacy

Yue Opera on Campus is a project that = Yanping and her crew members have long been promoting. The ensemble has once taught students at a little-known school for children of migrant workers to play the opera and had them attend folk art competitions from county to municipal to provincial levels, and won prizes at each level. "The Yue opera program really enhanced the school's image. The school teachers informed us on the phone that because of the well-performed program, the county leaders are going to visit them," said Yanping. The school will continue to keep the opera program as a prime course, and has invited Yanping and her crew members as instructors. She continued, "We have now had some impact on various kinds of schools in Zhoushan. Our opera program has been incorporated

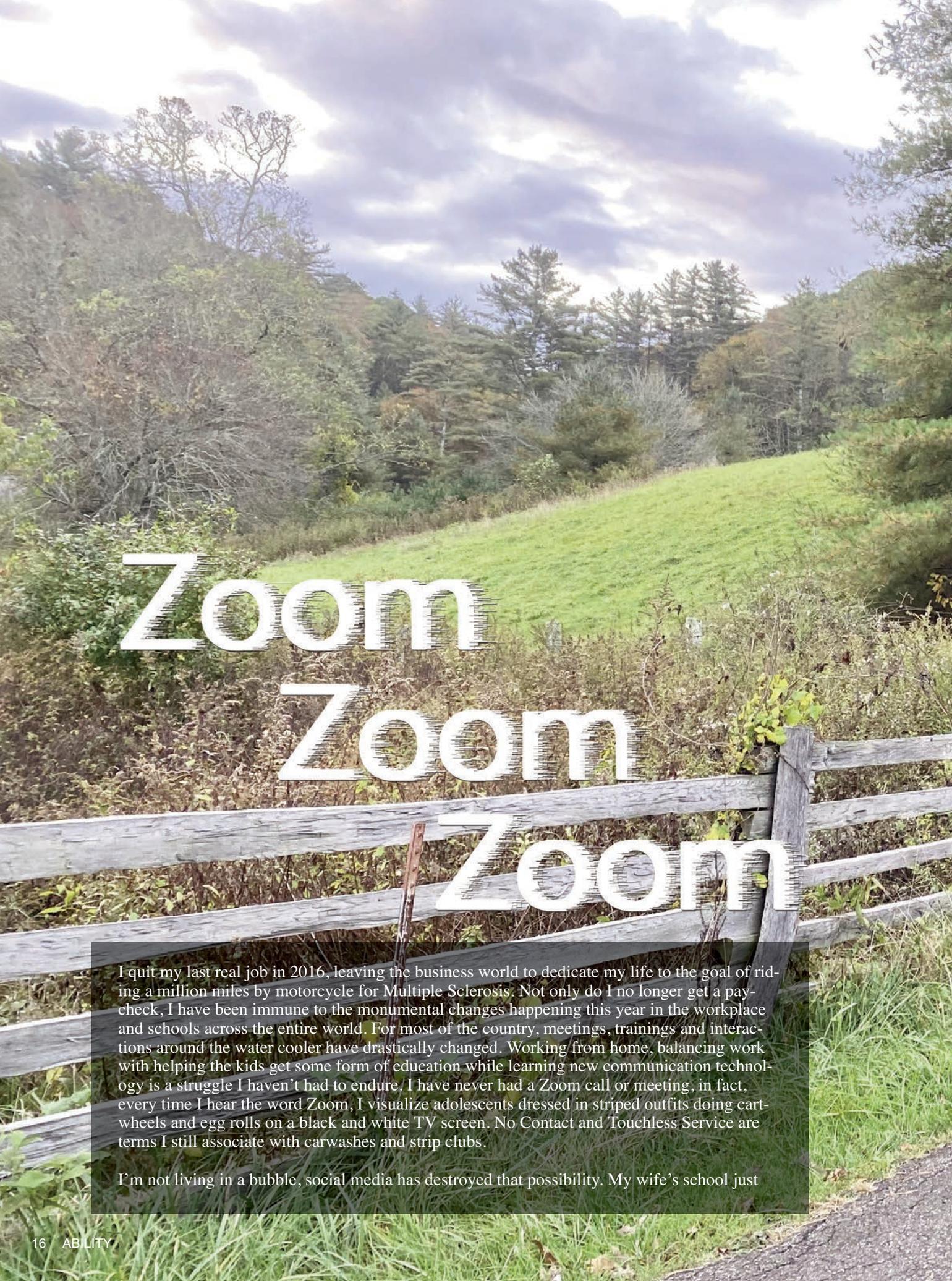
into the curriculum of Zhoushan Ocean University, and we have connected and coordinated with ten more schools now, from primary to senior high schools, where we'll give lectures and training classes." During the classes, the exquisite Yue opera costumes, the bewildering classics of Liang Shanbo and Zhu Yingtai and the *Dream of the Red Chamber* really had a chance to impress the students. More often than not, after the class parents would come to request to have more systematic studies of the opera for their children. From the parents' point of view, learning the folk art such as Yue opera is a great opportunity to expose their children to music, folk dancing, painting and various musical instruments. Besides, these skills are now mastered by only a select few of their peers, it will certainly give the children an advantage. In the summer of 2020, Yanping's ensemble organized their first Yue opera summer camp, yet another small but steady step to further popularising the art.

Over the years, Yanping has not only gone extra miles operating the ensemble, she has also been highly self-disciplined and aiming high for herself. In 2017, she signed up for the National Art Show of the Disabled as the very only Yue opera actress, and she was trained by seven professional instructors. "I got up at 7, started practicing at 7:30, all the way until 9 pm. I lost lots of weight, right from 55 kg to about 40 kg," she said. She had to change four or five costumes every day. Among the instructors some taught singing, some were experts in bodily techniques, and others specialized in musical instruments. "My hard work didn't go unrewarded - in the finals I won the national first prize," said Yanping, with pride in her voice.

Two years ago Yanping visited the Great Wall in Beijing. Although she nearly had to scramble up the Great Wall on all fours, she felt excited: "now I'm a True Man as once defined by our Chairman Mao!" Not until she returned from her trip to Beijing did Yanping decide to refurbish her house into an art training center. Never being the type to be satisfied with the status quo, she hopes to inspire as many disabled people to blend into society and commune with art as possible: "For those disabled people who have never stepped out of their homes, society isn't as they had imagined. For those who are brave enough to open the window and venture out, the sky is the limit!" ■ ABILITY



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*



Zoom Zoom Zoom

I quit my last real job in 2016, leaving the business world to dedicate my life to the goal of riding a million miles by motorcycle for Multiple Sclerosis. Not only do I no longer get a paycheck, I have been immune to the monumental changes happening this year in the workplace and schools across the entire world. For most of the country, meetings, trainings and interactions around the water cooler have drastically changed. Working from home, balancing work with helping the kids get some form of education while learning new communication technology is a struggle I haven't had to endure. I have never had a Zoom call or meeting, in fact, every time I hear the word Zoom, I visualize adolescents dressed in striped outfits doing cartwheels and egg rolls on a black and white TV screen. No Contact and Touchless Service are terms I still associate with carwashes and strip clubs.

I'm not living in a bubble, social media has destroyed that possibility. My wife's school just





went to full remote learning and not only do I see the stress it brings her, I see the enormous disruption this pandemic is causing across our state, the country and the globe. I guess not having a real job is sort of a blessing because I am not part of an office team or have people I work with on any level. I wasn't forced to make major adjustments to every day interactions with coworkers or clients and remembering to pull up my neckerchief going into gas stations was the extent of changes to my workday routine.

I am however affected by the virus in my personal life, being disconnected from those I love. It has been months since we have seen our granddaughter, my mom or my brothers and sisters. Yesterday, my son who lives alone, 100 miles away in the neighboring state informed me he cannot come for Thanksgiving this year as he would be violating his companies travel rules. He would have to self isolate for two weeks after his visit. He would also be violating travel restrictions in his state as well. Disappointed and a bit angry at the lack of uniform rules and regulations and the continued hypocrisy from our leaders, I suggested our family could get together the day after Thanksgiving legally, perhaps exchanging turkey sandwiches while standing for hours in the mile long line of bargain hunters waiting for Best Buy to open it's doors at the crack of dawn. After all, neither state has outlawed the annual Black Friday shopping stampede at the Mall, just the nontaxable Thanksgiving dinner with your family.
Ugh.

2020's pandemic has me spending more time at home, working on new fundraising ideas, trying to grow my online audiences and recovering from my eye and arm surgeries.

My major motorcycle events and presentations have not been replaced with some form of online conference or virtual reality convention, they have just cancelled all of them. I had only one speaking event for MS patients early this year and so I was excited to get a call inviting me to speak at the annual MS Views and News Symposium in Florida.

Although my eye was tender and light sensitive from my recent cornea transplant, I tossed a pirate patch over it for protection and let my good eye guide my Yamaha Tenere 700 from my home in New Hampshire to Orlando Florida. I took the long way down with a detour to get some great photos on the Blue Ridge Parkway in North Carolina. The 1300 mile ride on the new bike certainly improved my well being. After all, Motomedicine is an important part of my disease therapy!

Perhaps it was my subconscious that silenced the word virtual or maybe I just didn't care. I needed the miles and time back on the road. Although I certainly realized the audience would be tuning in to the live event from the safety of their own living rooms, it wasn't until I arrive at the studio that I learned the presenters were not actually attending the event in person, they were all broadcasting remotely as well. I had emailed the pro-



ducer, letting him know about what time I was arriving, but apparently he played along, thinking I was joking!

I may have been squinting and sweating from the lights, but I delivered my inspirational presentation live to a few hundred MS patients tuning in to hear the latest information on how to better live with their disease symptoms and progression. The event was a few hours long and I was not only happy to be part of it, but also proud, knowing money I raise helps fund educational events like it across the country. Since I began my quest 8 years and 450,000 miles ago, with the help of followers and friends across the country, I have raised a quarter of a million dollars for MS!

Upon arriving home, I was having some minor health issues and called my primary care doctor's office for an appointment. When the receptionist heard I had just returned from an out of state trip, she said I would first need to have a Covid test right away. She gave me a bunch of information on how to order a test online, how to fill out the questionnaire, where to send it, and more. I stopped writing down instructions when she further explained I would be receiving an email and a link to have my appointment with the doctor.

I put the pen down and interrupted her, "Excuse me. This appointment is not an actual office visit?"

"No," She replied. "It's called Telemedicine."

Perplexed as to why a covid test would be needed before Face-Timing my doctor, my only response was,

"Um. I'm sorry, but I am absolutely and completely confused."

"Don't worry," She added, "You will do fine. It's just like using Zoom." ■ ABILITY

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A Doll Like Me

Podcast Link

Children with disabilities don't often see themselves represented—and if they do, it's commonly an inaccurate or even harmful portrayal, as the movie *The Witches* has shown in recent weeks. Amy seeks to change this through her work at 'A Doll Like Me.' She creates dolls that resemble their owners: children with a variety of disabilities so that every child feels seen. *ABILITY Magazine's* Karina Sturm spoke with Amy about her motivation behind her non-profit and asked Mallory and daughter Alsae what their doll and disability representation means to them.

"Every kid should see themselves on the store shelves." That's the short answer to what motivated Amy Jandrievits to set up her non-profit A Doll Like Me. Amy is a 47-year-old mother of three who was a social worker at a pediatric oncology unit. "I think you always use whatever your experience is to shape who you are and what you do. Being a social worker at that time, I realized, kids of color and kids with any type of difference, whether it is a hand difference, wearing a hearing aid, or they are going through chemotherapy, are wildly under-represented in the toy market," Amy explains.

Two decades ago, Amy organized a Christmas donation program for the hospital she worked in. "There was this little girl, an African-American child, who had just gone through chemo and lost all of her hair. It felt so wrong to say, 'Here is this blonde princess for you for Christmas.' It was not a good fit, but at that time, nothing else existed."

Indeed, throughout my whole childhood in Germany in the 90s, it was a spectacle if a doll did have anything but a white skin tone; all of our dolls were white, had blue eyes and blonde hair. I remember in kindergarten, we had this little corner area featuring a kitchen and tiny beds for our dolls. One day, a new doll was introduced: It had brown eyes and darker skin compared to the other toys. All the children, including me, were staring at this beautiful toy. None of us had ever seen one like this.

Since then, we certainly have made tiny steps towards a more inclusive toy market. However, there is much room for improvement, especially when it comes to representing children with disabilities. We have definitely made strides. For American Girl, for example, it's been a pretty big step this year to release a doll with a hearing aid. I am glad they did that. But it's really not that big a deal. Right? People have had hearing aids in some capacity for many years," Amy states. Forty-eight million people in the US live with some degree of hearing loss, and in total, 3.9 percent of US families had a child

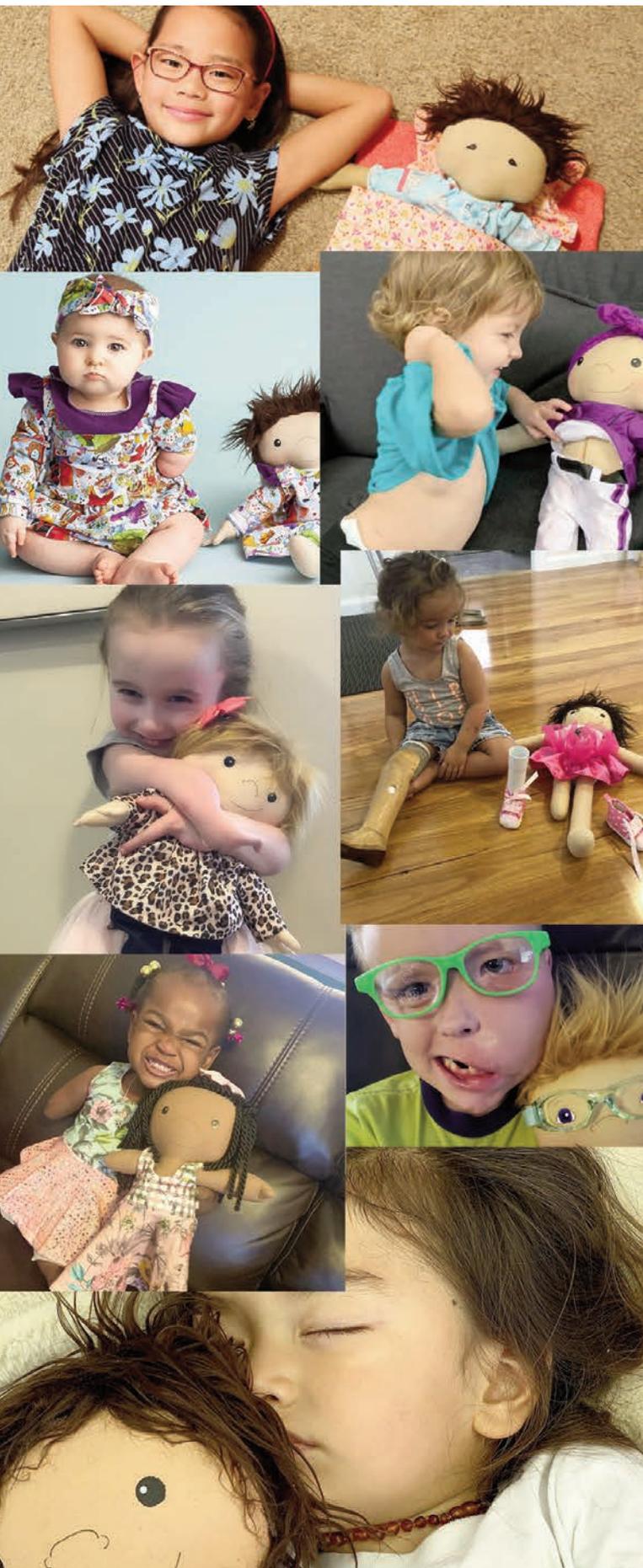
with a disability, whether they use prosthetics, a wheelchair, or have visible or invisible disabilities. They are a large minority.

Amy feels that every child has the right to receive a doll that represents themselves—no matter their ethnicity, ability or social status. Six years ago, Amy would sew Raggedy Ann dolls for fun in her spare time, until fate stepped in. "Somebody saw one of my dolls—they did not have any type of a difference—and said, 'Gosh, she looks just like my child,' who had had an amputation. So this person asked me if I could create a doll with an amputated leg." Amy did, and it was just the beginning. Photos of the doll she made were shared widely, and two months later, she had 200 more requests for dolls with limb differences in her inbox.

Amy has produced dolls with a variety of disabilities and chronic health conditions. "People are hungry for representation, and we all would go to the ends of the earth for someone we love," she says. One of her favorite dolls, she created for a girl from Syria who flew to Turkey after her family's house was bombed during war. She was severely burned on one side of her body, with her hair not growing back on half of her head. "Just from a skill level, it was very difficult, but even more so emotionally. We have become so callous and turned a blind eye to what happens in other countries. We often act like, 'If it does not affect me, it is not a big deal.' This doll put a face to what a Syrian refugee looks like."

Alsae's favorite subjects are writing, reading and math. From her dining table, which her family has not been able to use for dinner, she sends out dolls to children all around the globe. A few years ago, Alsae, a cheerful 7-year-old girl with long blonde hair that flows down her back, received a special gift. Alsae, not pronounced like Princess Elsa in *Frozen*—even though Alsae does look a bit like her—lives with a genetic condition called Microgastria limb reduction defect, with fewer than 60 cases reported around the world. "Lots of the symptoms Alsae has, doctors have never seen before," Alsae's mom, Mallory, says. "There is a whole spectrum of what parts of her body could be affected by her condition. She basically doesn't have a spleen; her kidneys are affected; she has severe scoliosis, and just had back surgery; she has neck anomalies and has been in halo traction for four and a half months when she was one, and again when she was five for four weeks. And it also affects her limbs and her arms," Mallory explains.

When I ask Mallory how Alsae's disability changes her



daily life, she says that it does and it does not. Since Alsae was born with limb differences, she has always figured out a way to make things work. Alsae loves to draw, and “she has the best fine motor skills I’ve ever seen,” Mallory says. “But that being said, she also struggles to button her pants, for example. Her spinal problems affect her greatly because she is not able to do certain things that other kids can do.”

When I meet Alsae, I quickly realize what her mom meant when she said she truly lights up a room. She confidently sits down in front of her mom’s laptop. I can only see her hairline—the chair is too small. “I am tall, and I am smart,” Alsae says. I laugh. She props up on a pillow and shows me her most beaming smile. We start talking, and Alsae tells me her favorite subjects are writing, reading and math. Math, in particular, she likes because she gets to incorporate her passion, drawing, using a different colored marker every day. “I never draw the same thing,” she says. During one of her hospital stays, she met a little girl that could only speak Spanish. Now, Alsae is determined to learn Spanish so that she can speak with her. She can already count to 29 in Spanish, as she demonstrated for me.

Alsae has to spend a lot of time in hospitals overall due to her chronic illness. One year, when she had to spend Christmas in a sterile hospital room, Mallory tried to find the perfect gift for her daughter and found A Doll Like Me. Back then, Alsae was only one year old and didn’t fully understand how unique her doll was. The beautiful toy mirrors her in the smallest of details. It even has two scars on the head in the same spot where Alsae had her halo traction.

Two years ago, Amy changed the doll to look more like grown-up Alsae. When I ask Alsae to tell me a bit about her doll, the first thing she says is, “She looks just like me!” and points towards the doll’s hands. “I think it’s incredibly important to have a doll that is uniquely beautiful like she is,” Mallory says. The doll’s name is Alsae, the 7-year-old explains, and she likes to draw and all the other things Alsae enjoys. In general, the representation of children with disabilities like Alsae’s in media or really anywhere is lacking. “In today’s day and age, we are so concerned about making sure we are representing a lot of different groups in minorities, and there is not only one person with a disability in the world; there are a lot of people in wheelchairs, with limb differences, and many other differences. I don’t think we do a good job representing them,” Mallory emphasizes.

Recently, Alsae’s limb difference was portrayed on TV—just not the way Mallory and the whole disability community had hoped for. In the newly released film *Witches*, actress Anne Hathaway plays the Grand High Witch, a character portrayed as scary by her three-fingered hand. “At first, I thought, ‘This cannot be it. The witch must turn good in the end. There needs to be some

reason why they did this.’ I started researching and just got hotter and hotter inside. How could this have gone through so many people, and nobody noticed that this is problematic?” Mallory says. Mallory does everything to let Alsae know that she can do anything she sets her mind to and that nothing will hold her back. “But this film really hit us hard because they added on this feature just to make the character appear scarier.”

According to a statement by Warner Bros., Hathaway’s role was supposed to have ‘cat-like claws,’ but their adaption wasn’t quite reflecting that and led to severe criticism from people with disabilities, especially people with limb differences. Using the hashtag #NotAWitch, many disabled people aired out their anger and made their voices heard.

Mallory spoke out as well. “I’m afraid of what a movie like this will do to young, impressionable minds. I’m afraid my beautiful child will be called a witch. This is not empowering to those born different, it is cruel. It is not okay to mark it up as scary, and correlate it with an evil character,” she wrote in a Facebook post.

As a consequence of the harsh criticism, Anne Hathaway apologized using a video of the Lucky Fin Project, an organization focused on raising awareness for people living with limb differences, and stating, “Let me begin by saying I do my best to be sensitive to the feelings and experiences of others not out of some scrambling PC fear, but because not hurting others seems like a basic level of decency we should all be striving for. As someone who really believes in inclusivity and really, really detests cruelty, I owe you all an apology for the pain caused. I am sorry. I did not connect limb difference with the GHW when the look of the character was brought to me; if I had, I assure you this never would have happened.” Mallory is glad Anne Hathaway and Warner Bros. acknowledged their mistake and apologized for it. However, it doesn’t mean much to her without consequential actions. “I know they did not cause this harm intentionally, but it is something that led to so much pain. Let’s say you are beating someone up, and you are like, ‘Oh, sorry,’ but you keep hitting the person—they are still airing the film—so in my head, they are still throwing punches. From a parent standpoint, I thought, ‘Cool, you apologized. Now what?’” Negative representation like this doesn’t only cause harm to children with disabilities now; it might influence generations after, which makes Amy’s work even more critical.

Amy doesn’t like to call her non-profit a business or even work. “It is a mission,” she says. At the beginning, she made a doll at a time, charging a fee that barely covered her expenses. A bit later, smaller donations enabled her to offer the dolls to families without a cost. From the very start, she didn’t want the families ordering the dolls to pay for them, and she never said no if someone wasn’t able to cover the costs for the material. “I would

just eat it. Not making a doll for someone who cannot pay for it is not in line with who I am,” she says. Then, two years ago, GoFundMe chose Amy as their Hero, which led to some media interest and the opportunity to convert A Doll Like Me to a non-profit organization. Since that day, Amy was able to provide all dolls to their little owners without a charge. “There is always this very brief pause in our interactions when I say, ‘You don’t have to pay because somebody already did.’ For some of these kids, their life is scrutiny. They are constantly judged or asked what is wrong with them. And this random act of kindness validates their beauty,” Amy explains.

Her non-profit is not a factory either. She sets her intention on each child and their doll—she finishes one doll before moving on to the next one. “It is like a prayer shawl. You think about the person you are making the doll for as you’re working. Some people pray for the person; however, I am thinking about things like: Is this doll going to sleep in their bed? Is it going to be in the hospital?” To Amy, they are not just dolls; they are a representation of a person, which makes her ‘business’ so unique.

Amy has big plans for her future. She hopes that on a bigger scale, advocacy will get us closer to inclusion. “I also feel like my kids should never watch TV without stuffing a doll,” Amy laughs. Additionally, she just wants to keep sewing on her messy dining room table, she says. “I crave being down there because I love doing it. It does not get old. Sometimes, people do not quite realize what an impact you can have on somebody.” And on the financial side, she hopes her business will be self-sufficient so that she can always guarantee the families that their dolls are already paid for.

“We really have to look at how we rectify that mixed message: You are beautiful. You are perfect just the way you are, but... you’re never going to see yourself. This is why I make these dolls. And the most powerful part about them is that for the first time in these kids’ lives, they’re seeing themselves!” Besides having a major impact on each little person’s life, Amy’s dolls also reflect the bigger picture: Representation does matter, and there is still a lot of work that needs to be done. But with people like Amy, we will get there, a doll at a time.

Representation matters! ■ ABILITY

You can support Amy and A Doll Like Me via Facebook
<https://www.facebook.com/nannysbabiestoodollslikeme>

or

GoFundMe

<https://www.gofundme.com/f/zu4kf2-a-doll-like-me>

by Karina Ulrike Sturm



mandy HARVEY

Perfect Pitch

All Mandy Harvey ever wanted was to be a singer. But that dream was nearly eclipsed by Ehlers-Danlos syndrome (EDS), a connective tissue disorder that left her profoundly deaf, unable to hear a sound. At the time, Harvey, a Colorado State University freshman, was studying vocal music education, and training for the career she'd always dreamed of. A gifted musician with perfect pitch, she tried hearing aids, which didn't help much, and the 19-year old was dropped from the music program. But with her father's encouragement and the use of visual tuners to help her find the correct pitch, Harvey found her way back to music. She sang jazz in local clubs, wrote songs, and was an audience favorite on "America's Got Talent" (season 12) in 2017, where her angelic, lucid tones won over Simon Cowell. She's

four albums and released multiple singles. When not engaged in music making, Harvey is an ambassador for nonprofit organizations No Barriers and Invisible Disability. She is also an author, having co-wrote *Sensing the Rhythm: Finding My Voice in a World Without Sound*, and more recently a children's book. Ability caught up with the Florida-based musician on Google Meet, which provides real-time speech to text captioning, to discuss her children's books, her music journey and the challenges along the way.

Chet Cooper: Can you first talk a little about your children's books with *Keepsake Tales*?

Mandy Harvey: Our goal was to write a book that's



about overcoming obstacles and challenges as a team, so you'll have multiple kids working together utilizing their unique skill sets and their differences that help them to succeed, because they're all different. The cool part about the book is parents can send in, on a secured level, a couple of very specific pictures, and then their child can be put into the book. No matter what your difference or different ability, you could see yourself being the hero of your own story, which I think is quite beautiful.

I think we're showing only five percent, or something like that, of children in books who have any kind of difference or disability. When you think about how much of the world is made up of people who are unique, it just doesn't make any sense. It is such a profound change that happens in your head when you see people who are like you accomplishing goals and dreams. It changes how you approach things, and it gives you the confidence to try.

Cooper: Is it a digital book?

Harvey: It's printed. I'm not sure if you'll be able to see this. I don't know if you can see me.

Cooper: I can see the book.

Harvey: This is a little girl named Heather, and she was born with one arm. You upload the pictures digitally and then you get a hard copy print, Her image is put into the story, so she gets to be on the adventure as she is. There are certain aspects and elements that are "forever," like the other people in her little journey. One of the other main characters is a boy who uses a wheelchair. You don't get to dictate, I guess, the other kids in the story. But the main person is you.

Cooper: To clarify, the picture that was sent to you was of that little girl?

Harvey: Yes. Her mom wanted this book to have her in it, so in every book, the name changes. So this one's called Heather Climbing in the Jungle, but it could be Charlie or Mandy. It's whoever the child is. And other their features, like their shirts and pants, are already programmed in, and then we utilize technology and artists to add them in. Most of the pictures we take—two or three shots—are of their face, and then we utilize those images and put them into the story.

Cooper: I'm sorry, I feel like I'm ignorant, asking dumb questions, but she is an amputee.

Harvey: She was born without an arm.

Cooper: So she was born with limb loss. What happens with another type of disability?

Harvey: We change it for every kid. Even if it's not a disability and it's just—

Cooper: —hidden?

Harvey: Another kid with a different race or background. We've had other children with Down syndrome, so they can see themselves being in a story. We change the images in each book, and we change aspects of the book to fit the characteristics of whoever the kid is.

Cooper: That is very customized. I had no idea. When you first mentioned it, I was picturing incorporating an image of the face into certain pages. But you're putting a lot of effort into each of these.

Harvey: What happens if you have another child who has a prosthetic? Just because their face is their face, it doesn't mean they can't see that that kid doesn't have a prosthetic. They can see all of themselves.

Cooper: That is really great. You're doing one-offs?

Harvey: The story's the same. This one's Ely. He gets to see himself on the same adventure. The adventure stays the same. Most of the dialogue stays the same, except their names are used, and pronouns are however their pronouns are selected. If they're "they" and "them," it's "they" and "them." If it's "he" and "she," it's customizable in that manner as well. And then you have differences. You can tell, in these two books, because the kids are kind of similar in stature. You'll see that their bodies look the same basically—the same pants, the same shirt. But the unique features of who they are is who they are. Whereas if the child is a different body shape or in a wheelchair or something else, then we customize the image so that it matches them.

Cooper: Very nice.

Harvey: Yeah. It's important. I don't know why we have this running desire to make everybody look "normal," when there really is not a thing of what is normal.

Cooper: Right. Are you aware of what we're doing in the entertainment industry, our group?

Harvey: Yes, I'm very aware. I've gone to a couple of different programs and awards and galas and stuff like that where we're trying to incorporate people who have disabilities that we're portraying in film to be the actors who are utilized in those roles instead of having just a bunch of, you know—"normally abled"? I don't know what the right word is, "average"—?

Cooper: (laughs)

Harvey: —people playing a unique difference. There are a lot of different people out there who are fully capable and brilliant. They just don't get the opportunity because they don't look like one specific person. But that's true with skin colors, accents and backgrounds. We have such a weird time with saying, "No, no, no, our audience is only going to watch this." I feel like we've moved beyond that, and the people who are deciding what we get to see aren't plugged in the way they need to be.

Cooper: Yes. We are working with most of the major studios right now with our abilityE.com. There are champions within those studios, but it's a hard industry to keep on track. Even though you have champions, there are so many layers in casting, plus the writers, and the old mindsets that exist.

Harvey: I think it's difficult because there are people who are afraid to do something different because it's unknown, and then once they open that door and jump in, they realize there wasn't really anything to be afraid of to begin with. But it's not just the people you see. It's every aspect of everything. We have 25 percent of the world who have a difference or a disability. We allow them such a small percentage of life, whether that's a job, such as the people who are running for coffee or one of the people who hold one of the boom mics—stuff like that. It's not just the people in front of the camera. It's all of the other people who make entertainment successful. We don't think about those roles.

You have all of these different programs about celebrating disability awareness month and stuff like that, and all of the people on the board and all of the people who are in these concerts and all of the people who are doing all the work are not differently abled. Why? We're everywhere. It's not scary, it's just new. Once we break that barrier down, it won't be a problem anymore.

Cooper: You're describing "Nothing about us without us." The work that we're doing, to let you know, is both in front and behind the camera. Everything you say is exactly in line with our thoughts. You lost your hearing when you were 18?

Harvey: Yeah, in 2006.

Cooper: Had you ever thought about disability issues before that?

Harvey: You know, I did. I've been hard of hearing my whole life and having to deal with all of those barriers like struggling to communicate and ear infections and surgeries and having to try different FM receivers and things like that. It's always been something that's been on the top of my mind. However, you get tastes of it that are undeniable. I remember the first time, when I was 17, and I had just had my first knee surgery. Right off the bat, early in my senior year, I dislocated my knee. I



missed the entire year, mostly just having a lot of surgeries. But there was an incident where I was in a wheelchair, and my family was going around and we were doing basic errands and shopping. We stopped at Kohl's, and the doors opened at you, and then there are two buttons you have to push. They don't just open both doors at the same time. They open one door and then you have to go in, and there's another button to push and that door opens.

I ended up getting stuck inside this matrix of problems, because the first door I got through fine, but to hit the other button, I had to move my chair close to the button, and then hitting that button, the door opened out into me to the point where I couldn't get out.

Cooper: Did you ever get out?

Harvey: (laughs) I was just stuck until somebody came and rescued me. And I thought, "This would have been a really obvious thing to fix, if they had had one person test it out with a wheelchair."

Cooper: Yes.

Harvey: But they don't take that simple step because, you know, they're just like, "Oh, we need a door button. Just stick it over there. It'll be less noticeable." I don't even know why they chose to put it there, but it was very obvious in that moment how little I think about the necessary steps of everything, and it became so obvious that I couldn't ignore it and I saw it everywhere.

Cooper: I have a story. I went with a friend who uses a wheelchair to a casting audition in a very old building

with a very, very small elevator. It could only fit her and me. In her chair she could not reach the buttons. If I hadn't been there, she couldn't have gotten to the floor that she needed to go to. It was an audition for an actor who uses a wheelchair.

Harvey: Yeah.

Cooper: Hopefully "universal design" is being taught in all architectural schools.

Harvey: Yeah, and unfortunately, it's difficult to go backwards. There are a lot of buildings that are grandfathered in, and until they decide to remodel, they don't have to deal with those problems, so they just ignore them until they can't, instead of doing the right thing and fixing them.

Cooper: Yes. Let's take the rest of this time to talk about your music career.

Harvey: (laughs) Sure. I started when I first lost my hearing as a way to get back to music, sticking with what I knew and what I loved, which was jazz, and then performing jazz, which is a joy. There will always be a huge part of my life that's connected with jazz. I was constantly faced with the questions of, what's the worst that can happen? I never wanted to be a performer. The idea of standing in front of people was absolutely nauseating. After I lost my hearing, which was my biggest year growing up, it was like, "What's the worst that can happen by singing in front of people?" I couldn't think of anything. It's not like they'll explode. The worst that could happen is, they don't like it. Who cares? It won't kill me.

I started asking better questions, instead of “What’s the worst that can happen?,” which is constantly focusing on the negative, but rather, “What’s the best that can happen?” By putting in all of this work to be frustrated, to sometimes want to punch a wall because I’ve spent the last 10 hours working on a song and went to sleep and woke up and can’t remember it, and there’s nothing I can do to recall that information other than to sit down at a piano and redo all of the things I just did. Why can’t it be easy? What’s the best that can happen by finding a way? It turns out that the best that can happen is that it encourages people to put in their own work and chase their own dreams and to open the door for a lot of conversation questions that people have been too afraid to ask or just not really cared to ask before.

That eventually led me to a conversation with a friend of mine named Erik Weihenmayer—he’s the first blind man to climb Mount Everest. He’s an amazing human being. He asked me why I was not writing my own music, which is another step of crazy. And I said, “It’s terrifying.” He said, “What’s the worst that can happen?” And I couldn’t think of anything. I tried to think about what’s the best that can happen? Maybe I’ll get to express myself and put words to all of these emotions I’ve been struggling to process and deal with. But even better, maybe it’ll give words to someone else who’s going through the same thing and give them an opportunity to know that they’re not doing it by themselves.

So I wrote a song called “Try.” I had this crazy opportunity to perform and audition for “America’s Got Talent” with this song. I look back on it and I’m not even sure why I was brave enough to do something that crazy. I just wanted to encourage one person, and if I could encourage one person to get up off the floor or start one conversation or change one person’s perspective of what a disability looks like, to say that we’re not broken pieces of rubble that you need to shove under a rug somewhere, but that we’re vibrant, intelligent, passionate, dream-filled people, it would be completely worth whatever happened. It became kind of a snowball effect from there of doubling down.

Now, I just released my fourth album, *Nice To Meet You*, which is all original music. I’m writing my next album, which is unbelievably so much fun! To be able to express myself in this way and to have other people attach to that music and start pushing for their own dreams and their own goals, it’s quite amazing. To think that it all started with a person who gave up on themselves and was a failure at seemingly everything. It’s a beautiful turnaround.

Cooper: Because you did try.

Harvey: (laughs) I did. And I failed a lot. I think that’s the beautiful part about it. It’s not just try and then if you put in the work and the effort, then all of your dreams will come true. That’s not true. That’s not the

point. The point is to say that it really doesn’t matter what the outcome will be. If you sit on the floor and you refuse to try, you’ve already failed. What’s the worst that can happen? It’s not like you can fail more. You already are at your lowest if you refuse to get up and try, and you are shutting the door to the possibility of difference—some change, some hope, some positivity, just something.

Cooper: So, it’s a combination of the journey and hopefully helping others at the same time?

Harvey: Yeah. I think if I were just stuck in my own head for this long, I would have lost my mind a long time ago. It’s not in my mental prowess to just focus on myself all the time. It’s very difficult for me to care about myself that much. (laughs) And that’s been true my whole life. I think it’s just the type of brain I am. I don’t know. Or some weird people-pleasing problem that I have. But it seems to be a problem that people enjoy. (laughs) I want to keep at it, then.

Cooper: If you know Jungian theory or Myers-Brigg, you’re described as a “feeler.”

Harvey: Yeah.

Cooper: Speaking about that journey, how did you meet Erik Weihenmayer? He loves journeys.

Harvey: Yeah, he’s amazing at journeys. I was singing at Jay’s Bistro in Fort Collins, Colorado, and a couple of members of the No Barriers team were there, and they asked me to come and speak to their staff before one of their yearly summits. I went and sang a cappella because I didn’t have a ukulele. I didn’t know how to play ukulele at that time. I just told my story, and I was so very angry and so very bitter, but I was making my way and trying to figure out life and learning to love who I was more so than I’ve ever really liked myself (laughs) in the past. And that’s where I met Erik and the whole No Barriers team, and they eventually asked me to sing and talk a little bit at the summit. I’ve been connected with them ever since. I think that was in—gosh, I want to say 2009.

Cooper: You can say 2009.

Harvey: (laughs) I think it was. I don’t want to be wrong, but it’s pretty close to being right around there.

Cooper: When you sing a cappella, what do you sing when you do that? Do you go back to your jazz roots?

Harvey: Nowadays, I’m a lot more adventurous, but I sang either “What a Wonderful World” or “Over the Rainbow.” I can’t remember which one I sang at that particular one. But I also do believe I did “Smile.” It was my song when I was at CSU [Colorado State University]. It’ll be forever a song that impacts my life, and



to me, as much as “Try” has impacted my life and other people’s lives, “Smile” was the song that kind of started everything for me. It was during the time when I was losing my hearing, and I thought that my memory of music was going to disappear and if I was going to forget every song I had ever heard, I was going to forget every song but one. I spent numerous hours and an unbelievable amount of time singing “Smile.” I’m not even sure why I picked it. I think it was just the first one that came to my mind when I made the decision to hurry up and pick a song before it was too late. I’d sing it every day, all day long, just so I could hold on to something.

Cooper: I am sorry. I have not heard you sing it today yet. (laughs)

Harvey: No? I love that song! It’s amazing. Do you want me to sing it now?

Cooper: I would love to hear it, yes.

Harvey: Sure. [sings the song]

*Smile tho’ your heart is aching
Smile even tho’ it’s breaking
When there are clouds in the sky*

*You’ll get by
If you smile
Thru’ your fear and sorrow
Smile and maybe tomorrow
You’ll see the sun come shining thru’ for you*

*Light up your face with gladness
Hide ev’ry trace of sadness
Altho’ a tear may be ever so near
That’s the time you must keep on trying
Smile, what’s the use of crying?
You’ll see that life is still worthwhile
If you just smile*

Cooper: There’s a background of an audience here that’s clapping, they’re on their feet— (laughs) That was really wonderful. Thank you for that.

Harvey: Thanks. I think I want to get the word “smile” tattooed on my foot.

Cooper: On your foot?

Harvey: So I can look down, because I always perform barefoot anyway. Some days it’s really difficult to stand up in front of an audience and to smile and to sing songs that I can’t hear for the benefit of them, because I don’t get to fully enjoy it. It’s very ghost-like to sing something that you can hear. I enjoy the team aspect of it in the vibrations, but sometimes you get wrapped up in the negatives, and it’s nice to have a reminder to say to yourself, “This is a huge journey that you’re on. You should be thankful.”

Cooper: I don’t do tattoos, but I could find somebody for you.

Harvey: (laughs) I’m not a huge tattoo person, either, but it seemed like a good idea. If I was going to have a tattoo on my foot, I would just make it that.

Cooper: That’s funny.

Harvey: I’m doing a lot of research on the cochlear implant right now. I’ve been kind of tossing the idea around of potentially getting one. I wasn’t a candidate for a long time, but it turns out that after all of the MRIs and tests that I am a candidate for one. So I’ve been doing research to see how it works for people, which kinds they bought and how that goes.

Cooper: I’ll connect you with ABILITY’s Marge Plasmier. She’s the one who got the cochlear implant. She could share her insights on how it’s worked for her.

Harvey: I would love to talk to her. It’s a daunting thing for many different reasons. You only get to pick that once. There are different companies.

Cooper: Same with tattoos. You had some problems

with you speaking at some point from certain people within the deaf community?

Harvey: I think everybody has the right to have their own opinion, and they've got reasons for it. I think with anything, you'll find people who are very supportive of what you do, people who don't care what you do because they're focused on their own thing, and then people who are not going to care for what you do. I think that as frustrating and terrifying as it is to have people hate what you do, I understand, vaguely, the reasons why and the problems and the discrimination and the fear of everything associated with being a part of that community, especially from the past. In our US history, if you had a disability, you were just taken from your family and shoved into institutions. Or people would refuse to allow you to have children because they didn't want you to spread your "disease" to further generations. There are so many different reasons why people legitimately get protective and fearful of things they have a history with. So I can't be mad with them for having an opinion. I can just choose to ignore them or take a piece of what they're trying to say and learn something about their perspective, whether or not I agree with it.

Cooper: I met Heather Whitestone. Do you know who she is?

Harvey: I don't off the top of my mind.

Cooper: She was Miss America in the mid-90s.

Harvey: Oh, yes.

Cooper: I met her when she first won, and from different travels throughout the year we would run into each other. By the end of her year, she had been beaten up so much by certain people who didn't want her to speak in public. She started out feeling like an angel and ended up so hardened, it was very discerning to see how she had to change to deal with what she wanted to do, and that was to communicate. She had the ability to speak, so why not speak? She had to harden herself to overcome the frustrations. And this was before social media. It was tough. I always felt sad for her situation.

Harvey: Yeah. It's difficult. You would hope that with as much as we talk about tolerance and accepting other people regardless of their lifestyle choices or whoever they are, you would like to think that that's true across the board, but there are always going to be people who care, and there will always be people who don't. She has to make a decision, as tough as it is, to say, "This is who I am, and I don't care what you think. This is how I'm going to communicate. This is how I communicate. I will try my best to be loving and respectful of you and hope that you can be loving and respectful of me. But in the end, it will not change who I am."

Cooper: That's really nice.

Harvey: It's a difficult choice, especially when people are hating on you and you don't want people hating on you. If I allowed myself to really dive into all of the random bullies who are out there who send me crappy messages all the time, I would be a nightmare of a mess. I just refuse to read them. What's the point? They don't know me at all.

Cooper: Are you talking about my emails to you?

Harvey: (laughs) Yeah! If you could just, like, shut up for a while? (laughs) No, I'm just kidding. No!

Cooper: That's funny. There are a lot of bullies out there, and they have a voice with social media, which is another topic.

Harvey: Truly, and this is my opinion, but I really do believe this: anything they say is far more of a reflection of them and the things that they're dealing with in their life than it has anything to do with me. Some people have so much anger and hate in themselves or at themselves that they have to spill it onto other people just to make them feel better. And in a weird way, if I can make them feel better by having them vomit bull crap onto my page, you go for it. I'm just going to delete it. Maybe it'll make you feel better. But I'm still succeeding in my job of encouraging people! (laughs)

Cooper: So you have a folder you've created called Bull Crap Vomit?

Harvey: (laughs) No, I don't keep it. I just delete. It's the same if I do a Facebook premiere or something like that. There are always a couple of people who are on guard, who are watching the comments, and if there's anything not appropriate in there, it could be something like, "Oh, I don't like that she's doing this," or "Oh, she's—," with all these curse words and whatnot, and it's like, I'm a family-friendly kind of person. I'll just delete it. I won't even read it. It won't change what I do tomorrow, unfortunately.

Cooper: You said "family-friendly." Do you have a family? Are you married? Children? I don't know anything about your background.

Harvey: I don't have any children yet. It would be a joy to eventually have kids. It's something I'm looking forward to. I am in a relationship with a gentleman. He's French, which is one of the big reasons why I'm interested in getting a cochlear implant, because I would like to learn French. He's learning how to communicate best with me, and sign language will always be my preferred language, so he's learning to sign for me, and I would like to learn French for him.

Cooper: Would you learn French sign language?



Harvey: I would like to do both. I can order for myself and I can understand the signs. I can read a lot more than I can say anything out loud, because pronouncing something I've never heard is a bit ridiculous, but I'm trying to learn phonetically. I used to sign in French when I was in high school, so I've got some idea about certain shapes and vowels. But his mom took a night class in French sign language. She didn't know it was different from American sign language. I started learning some French sign language just so she wouldn't know that she doesn't communicate with me still.

Cooper: That is so nice of you!

Harvey: Well, I feel bad. She went through the trouble of doing something extraordinarily nice for me, and the least I can do is repay the favor.

Cooper: Most people who are not within the deaf community do not know that there are different sign languages for different languages.

Harvey: Most people don't realize that 80 percent of families with a person who's deaf don't learn sign language. The fact that I have people in my life who are supportive of me and want to communicate on my level and are learning how to do so is rare, and it's a blessing.

I wish it weren't rare. They're different. Even sign language has accents, so you can tell a person who's from New York versus someone from California. They sign a little bit different.

Cooper: They use the middle finger more often?

Harvey: (laughs) The New Yorkers, they sign so fast, it's amazing! (laughs) It's like what you would think of a New Yorker. They don't have time to slow down for you. You'd better hurry and catch up. Whereas in other places, it's a little more fluid, a little more Zen.

Cooper: I didn't know that. I attended a Deaf cruise several years ago, on Royal Caribbean, with over 3,000 people who were deaf. Had you heard about that?

Harvey: Yeah, I've heard of that.

Cooper: What was interesting is I don't sign, so I was the odd person amongst thousands of people. And when they tried to communicate with other people from other countries, they would get in a circle and figure out how to communicate. It was so wonderful and interesting to watch. Everyone had such a great time. C.J. Jones was there. Do you know him?

Harvey: Of course. I love that man! He's so sweet. I was in Italy once—before COVID—and I was walking out of a store and I saw a couple of people signing. I was with my cousin and she smacked me on the arm and pointed them out. (laughs) Then looked at me like, "What is she looking at?" and I started signing to them and they lit up. And then we came over. They were from Italy, and we saw a couple of other people who were signing in this same square. One of them was from Brazil, and someone else was from a different country. We all sat down on the sidewalk and figured out how to introduce ourselves, because this person knew a little bit of this and that person knew a little bit of this. It was easy enough to explain the alphabet and have them stop on the right letter, even though they didn't know the alphabet the same way I did. It was a fun thing where you had at least four different languages of sign, everyone sitting down and trying to figure out how to say, "Hey, how are you? My name is—" We laughed so hard. It was a beautiful, random moment that I will never forget.

Cooper: I can imagine. That's partly what I was experiencing, except I was the fly on the wall. I couldn't be part of it all—I laughed, because I could tell everyone else was having such a wonderful time. Did you go to Rome?

Harvey: I have been to Rome. I went to Rome the last time in January of 2018. It was breathtaking. We went to Rome, and then we took the superfast train to Florence and spent a day there, and then back to Rome. I will never forget my trip to Rome.

Cooper: The last time I went to Rome, I interviewed a person name Roberto Wirth. Have you heard that name?

Harvey: I recognize the name, but I'm not sure why, I'll be honest.

Cooper: He owns one of the nicest hotels in Rome call the Hotel Hassler. He is deaf and he reads lips in five languages.

Harvey: That's crazy!

Cooper: (laughs) He's an interesting person and really fun to be with.

Harvey: Next time I'm in Rome, it would be nice to wave at him from a distance? "What's up?"

Cooper: You should go in and meet him.

Harvey: Oh, you know, people are busy. You don't want to interrupt his life. But it would be nice to meet him.

Cooper: He would love to meet you. It's a hotel where kings and queens and celebrities stay. It's on the top of the Spanish Steps. It's got an incredible view of the Seven Hills of Rome. You should just visit it, if nothing else.

Harvey: Oh, gosh, yes! I love visiting—I love buildings and architecture and history and art, so any time I'm in places like Rome, my brain just kind of explodes. It's a beautiful time.

Cooper: This is one of the architectural gems of Rome. Almost every picture you see of the Spanish Steps, you'll see a piece of the hotel above it. You've probably seen it, just didn't know what it was.

Harvey: Oh, I'm sure I've seen it.

Cooper: Do you know Gallaudet University?

Harvey: Of course.

Cooper: Do you know that we run the only online career fair that includes American sign language?

Harvey: I did not! That's amazing! That is also slightly sad.

Cooper: It is sad. The technology is so difficult. What they typically do is say that they are accommodating, that's a little bit of what we're doing now. It's chat based. But for what you and I are doing, this is not a job interview. When you're doing job interviews, you should have a sign language interpreter. That's our belief. We built the career fair a couple years ago, and it's been growing and growing. We have clients ranging from Google, Facebook, and different departments of

government to Wells Fargo and hundreds of other companies we're working with now.

The newest thing we're doing is allowing other entities to use the platform, with our help, and Gallaudet University is the first one to do this. This Friday, they are holding their first job fair and internship online system, and we're working with them. The deaf part we've done, that's fairly easy for us. But now we've been working with them for almost a month to incorporate students who are deaf-blind. Very difficult. It's never been done before, to have an online career fair that can accommodate a student who is deaf-blind. We'll see what happens after Friday, it if works. We've been testing and testing and working with them. It's a milestone, if everything can work out.

Harvey: I'm sending you all my hopes and love. I truly hope that it's a smash.

Cooper: We do, too. Either way, we will learn. We've been learning and growing and building. Every time we've been meeting, we've been having two and three meetings a week with them. We will be doing more with them next year as well. It will get better. And then we have our own ABILITY Job Fair December 3rd, which is, of course, the International Day of Disabilities, which the UN promoted. And we had one October 1st, which, as you know, is the National Disability Awareness month.

Harvey: Yeah.

Cooper: You didn't know about the ABILITY Job Fair?

Harvey: I've known of pieces and parts, but I haven't been so ingrained in it. I know of it because of Wells Fargo, because it's connected with No Barriers, so I had a conversation with one of the people from Wells Fargo about the ABILITY Job Fair.

Cooper: Oh, I thought maybe you knew of us because of Disability IN.

Harvey: Well, that is—they're all connected. When you have a conversation with one, you have a conversation with them all. Like the Disability:IN is connected with Wells Fargo and is connected with No Barriers. And No Barriers and Disability:IN. I was connected with both for this last event that I did for Disability Awareness month. I wouldn't say I know a lot about it, because I'm not really looking for a job. I just know of it. I didn't know too much about the innards of what-all you guys are doing there.

Cooper: To let you know, we built the first online job board as well. In 1995 we built ABILITYJobs.com.

Harvey: Amazing!



that one leg is tucked underneath the one that's dangling down. The one that's dangling down is pushing against the log that I'm sitting on with every fiber of my being so that I could hold myself forward and up, because there's nothing for me to lean back on. If I had let myself relax a little bit, I would have fallen backwards.

Cooper: I do not like heights, and when I saw you up there, I felt your anxiety. I thought, "Wow!" (laughs)

Harvey: (laughs) We did it intentionally because I'm afraid of heights. It was for those people who know me, and it was a nod to me pursuing facing fear in general.

Cooper: Nice!

Harvey: But I was up there far longer than I wanted to be, I'll tell you that right now! (laughs)

Cooper: I guess my biggest fear at one point was public speaking. I thought—

Harvey: That's like the number one or number three, it's always in the top three. People would rather die.

Cooper: That's helped hundreds of thousands of job seekers find employment. We've worked with over 5,000 companies to connect job seekers and recruiters.

Harvey: Do you work with Bristol Meyers Squibb?

Cooper: They've been a client. There are certain companies that are with us constantly, who are very active, forward-thinking and really want to find—not just doing the right thing—but find good talent, so they work with us in meaningful ways, rather than just checking the box.

Harvey: That's one of the reasons why I like Voya so much.

Cooper: We have not done much with Voya. I know they've been a client. I saw that you are working with them. I have a question about the video you've produced. How did you get up in that tree?

Harvey: (laughs) Funny story! There's no back to that tree where I'm leaning, so I'm not a superfan of heights. I'm a little afraid of heights. They had this rickety old wooden ladder and they leaned it up and I walked up and I sat down in this tree, and then they had to take the ladder away, which is a fantastic feeling. You'll notice

Cooper: I thought, "I'm going to just go on stage and get a ladder and climb up on the ladder and do some public speaking." (laughs)

Harvey: (laughs) Knock 'em both down in one swoop?

Cooper: (laughs)

Harvey: I'm scared of sharks.

Cooper: How are you going to get the shark on stage?

Harvey: (laughs) I've dabbled with an idea of going into a shark tank.

Cooper: TV show?

Harvey: (laughs) Maybe. No, like a real one. Both would be scary. I would have to invent something first. But a real shark tank. I can't even think about doing it. It makes me want to throw up.

Cooper: I surf, and I've had sharks—one in particular come underneath me, it was twice my size. I just kept

my hands and feet still and said, “OK, now it’s time to go in.” (laughs)

Harvey: Nope! Nope! No! I lived in Florida; I’m a Florida baby. My entire family is from here. I don’t get in the water. I sit up-beach and cannot—I have panic attacks. I have to hold somebody’s hand to get into the water. And I live here. I get nervous inside a swimming pool, especially if you can’t see the bottom. Sometimes if I’m in a bathtub and the water shakes for no reason, I’ll get out.

Cooper: There could be a shark in that bathtub! (laughs)

Harvey: (laughs) You never know. You just can’t. Bubble baths are a panic. You can’t see anything anymore. Maybe eels will come up through the pipe? I don’t know, but bad things will happen, I can tell you that for sure.

Cooper: (laughs) That is very funny.

Harvey: You think it’s a joke, but it’s the reality of the situation. (laughs) If I’m in there long enough, I get nervous. “All right, I’m out.” I can’t do it. I cannot do it. I love sitting in a bath, especially with having EDS, my knees enjoy it. But the thought about just going swimming in the ocean or learning how to surf—nope. Maybe one day, I would love to believe that I can conquer that fear as well, but it’ll take some effort, that is for sure.

Cooper: If you ever come to California, I will try to take you to a place that has very calm, slow-moving waves, and there are enough people in the water that the odds are they’ll eat somebody else, not you.

Harvey: (laughs) I’m game, however, I would say that if the odds are in anybody’s favor of something going wrong, it’ll be me. My dad always joked that if there was one person who got attacked by a shark on a mountain top, inside of a kiddie pool, it would be me.

Cooper: (laughs) Ouch!

Harvey: I have the worst luck ever. (laughs)

Cooper: Think about it. There was a song I heard recently, what was it called? “Try”?

Harvey: (laughs loudly) Someone should write that song! “Try, try some more!”

Cooper: And I think afterwards they might actually “Smile!”

Harvey: (laughs) Yeah, right before they die because a shark bit ‘em! You can try, but it doesn’t mean you’ll succeed.

Cooper: Try, try again.

Harvey: Yup, yup. (laughs)

Cooper: Is your latest music called “This Time”?

Harvey: Right. It’s about getting up off the floor and working as a community to move forward. “I’m movin’ on, so get out of my way.” It was also kind of a nod to all of those people who were constantly in the back of my mind who were telling me, “There’s no way you can be a musician because you can’t hear. There’s no way you can be a good musician because you can’t hear. You’ll never be successful. You’re wasting your time.” I learned a long time ago that if you let those people dictate who you are, you’re allowing them to put you in a very small box with limited possibilities. The only person who really knows what you’re capable of is you. “Get out of my way, ‘cause I’m movin’ forward.” But I didn’t say anything about “Get out of the way because I’m swimming forward.”

Cooper: (laughs) “There’s a shark behind me! Get out of the way!” How have you been holding up with COVID?

Harvey: COVID has been weird. I think it’s weird for everybody. I’ve never felt so disconnected in my life. It’s going back to square one. When I first lost my hearing in 2006-07, we didn’t have all this technology. We had flip phones. People were just getting into the idea of texting. If you wanted to have somebody call your insurance company, you really couldn’t do anything because if you called through a system, they would hang up on you, because it wasn’t patient confidentiality. There were all these different barriers. And now, being in a time where technology is rampant, yay! However, in public, when you have your communication completely shut off because everything is masked up, I feel so disconnected. I feel like it’s back to 2006. I feel like people just assume I’m a rude person who ignores everybody all the time, because they don’t even know that they’re talking to me. People give you instructions and you don’t know that they’re acknowledging you.

I’m not trying to be frustrating. I’m just trying to get by. Having EDS is difficult during COVID, because when I’m stressed is when my body shuts down and I have flares. The one thing you don’t want to feel is a lot of the same symptoms as COVID, when all of the news is telling you that if you get COVID you’re not going to make it. I’m having flares and similar problems, but I don’t have COVID. I don’t know. I had to take a break from focusing on the news and everything for a hot minute just so I could mend my body. I’ve been slowly trying to find ways to communicate better and to not be so disheartened by the whole thing. It’s difficult, though. ■ ABILITY

Podcast Link

IAN HARDING

'Pretty Little Liars', lupus and Germany Teil eins (Part 1)

Ian Harding is an actor, teen choice award winner, author, and passionate bird lover. Besides being known for playing Ezra Fitz, 'America's most beloved pedophile,' as he describes his role in the US show *Pretty Little Liars*, the 34-year-old is a passionate advocate for people with lupus, an empathic son to a mother with the chronic condition, and an ally to people with disabilities around the globe. In the first part of this interview, *ABILITY*'s Karina Sturm speaks with Ian about his childhood in Germany, his acting career and his work for the Lupus Foundation of America.

"How are your pain levels today?" is the first question Ian asked me during our conversation a week ago. "I am having a really tough day pain-wise," I respond. "Oh, I am sorry to hear that. May I ask why that is?" he says. Before I realize it, I hear myself talking about my period and how it influences my condition, and we have a good laugh about his vast knowledge of menstruation cycles and the related challenges. Ian isn't quite like his colleagues – I learn this early on.

A few days later, Ian takes 90 minutes out of his Saturday while moving houses to chat with me. He is relaxing on his couch in dark grey PJs with unkempt hair, which I appreciate as I am dressed in my pandemic attire: dressy blouse on top, sweatpants on the bottom. As a journalist, I should be leading this interview, but before I can ask my first question, I find myself being interviewed by Ian.

"Ein großes Bier bitte:" Remembering Ian's childhood in Germany.

Ian Harding: I love interviewing people because I don't actually want to drone on and on about myself. I would rather hear what you have to say, but that may not be the purpose of this article.

Karina Sturm: I mean, it's fun—(chuckles)—but let's dive into that first question for you now? You were born in Germany, which, as a German native, is of course something I am interested in. Can you tell me a little bit





Ian is a passionate bird watcher

about how long you lived there and when you came to the US?

Ian: I feel like whenever I meet somebody from Germany, and that fact comes out, I can see a bit of joy in their eyes. And then I'd tell them that I left when I was about three years old, and I could barely string a sentence together in German, and they would get very sad. You can even see this when I go through customs in Germany. I'll go up to the German customs officer, and he or she will look at me and see that my place of birth is Heidelberg, Germany. They would just spout off this slew of questions in German. I would tell them, "Oh, I'm so sorry. I was born in Heidelberg because my parents were in the military, and we were stationed there for three years." I only remember glimpses of it. I've been back to Heidelberg since, and it's very strange seeing the buildings and recognizing them, or being able to go down the street, saying something like, "We're going to turn here, and there's a grocery store." It's funny that this place feels somewhat familiar and yet so foreign at the same time.

Karina: Can you still speak some German? Do you remember a specific phrase?

Ian: One mistake I always make when Germans ask me, "Sprechen Sie Deutsch?" (Do you speak German?) I go, "Ein bisschen." (A bit). Then they respond, "Oh, awesome." And boom. They say a long sentence. I'm like, "Oh, sorry. That's all I know." I think I can get around in German cities, though. I also appreciate that in the German culture, if somebody who is not German can speak German, there's an excitement from the Germans because they know it's a very hard language. And the fact that you would learn it is really amazing to them. So I wish I spoke it a little bit better, but here in Los Angeles aren't too many opportunities to do so.

Karina: You should at least know how to order a beer, or how to say, "I love you" in German, so that you can impress your wife.

Ian: Ich möchte ein großes Bier bitte. (Can I have a large beer, please?)

Karina: You mean a Maß beer? (A 'Maß' is 1 Liter of beer traditionally served at German celebrations like the Oktoberfest.)

Ian: Ein Schwarzbier, Hefeweizen, Weißbier, Weiß mit Schuss, Schnapps. Also, I try to eat as little meat as possible - I am not entirely vegetarian; I can't even say that anymore - except when I go to Germany.

Karina: Oh yes, that's very hard in Germany.

Ian: Especially because I love the fried Schweinehaxe (roasted ham hock; a traditional German dish). It's delicious. Or the blood sausage. So I know how to ask for food items or where the train station and the airport are. But if you want to start talking about German literature, I'm pretty useless.

Karina: So you came to the US when you were a kid. When did you realize you wanted to become an actor?

Ian: I think I was always kind of performing, but growing up, every other month, I wanted to be something else. I wanted to have many different careers, and I would imagine stories about living that specific life. I feel like that's probably when my acting career started, because you are imagining yourself in a different role and empathize with someone else's life. At one point, I was obsessed with the idea of becoming a Navy SEAL. And given how much of a softy I am, I don't think that would have panned out. But I liked the idea of playing a Navy SEAL. It wasn't until I got to high school that I started doing plays. And I only began playing because I wasn't as athletic as the other guys that played soccer, which was my sport, and because I went to an all-boys school and the young women from surrounding schools would come to our plays. I felt like that's a great way to meet ladies. At some point, this became my afterthought, and I just wanted to do plays. Then I got a university degree and kind of found myself in Los Angeles. And here we are, talking about my career.

Karina: I just started watching *Pretty Little Liars* yesterday. How did you get that role?

Ian: I was very sort of lucky; not sort of, I was extremely lucky. It was the first audition for a lead in a TV show that I went to in Los Angeles. And my manager, who I still work with to this day, said, "Look, this is all just about getting practice. You know this already, but it's kind of a stretch for you, and it's your first pilot audition. Just go in, have fun, and learn how to audition." And because I didn't have the pressure of needing to get the job, I went in and just messed around. And they were like, "Yeah, this is great." So I kept auditioning because they kept calling me back, and then I met Lucy who's the lead of the show, and we hit it off, and the next thing you know, they are telling me I got this part. My manager is still very pragmatic, even to this day. He said, "Have fun with the pilot. Just because you do this

doesn't mean it'll get picked up." That's something I only learned recently, years later, after so many pilots have not been picked up. Then it went to series, and all of a sudden, it became a thing.

I remember being in this area in Los Angeles right by the Grove, which is a famous shopping mall. I was going to get dinner to bring back to my apartment. All of a sudden, I hear screaming. Then I realized that the screaming was actually because I was there. And I thought, "Oh shit, it's real now." That's how it started, and, boom, seven years go by.

Karina: How did you feel about being recognized in public all of a sudden, and people screaming because of you?

Ian: It was a lot, but I was really grateful. I was what I would call 'fame-adjacent.' Many other people on my show were more in the spotlight. There are some perks of fame that I enjoy, but I'm a bad celebrity because I cannot keep stoking the fire of my own image, but maybe that's what is required to be a big film or TV star. So when it first started happening, it was kind of cool. But I was never at that level where I was being hounded by the paparazzi.

This one time - I was outside of an event - when a paparazzi started taking photos of me, I actually asked him, "Is it a slow night or something like that? Why are you wasting your time on me?" He responded, "No, man. But is another famous person coming out with you right now?" And I said, "No." So we started talking. He had stopped taking photos by this point. Then he said, "Good night." This was the friendliest paparazzi I've ever met. But that's only happened three times in my career, which has been a joy.

Karina: Is there any role you would never play, for example, going fully nude, playing a super bad guy or a jellyfish (again), because that sounded a bit traumatic. (Ian talks about playing a jellyfish in his memoir *Odd Birds*.)

Ian: Ha, nice. Playing a jellyfish in college was so lovely. It was for this one specific project that was supposed to get you out of your comfort zone. And it did, because as an actor, I constantly needed to be doing something, and I couldn't just be still. So I had a teacher that told me I was going to be a jellyfish, and I had to float in an imaginary sea for hours on end. But is there any role I would never play? I would like to not do the same roles again and again and again. I think I don't want to repeat certain patterns. But no, otherwise, I'm really open to anything.

What role would you like to play?

Karina: Me? I'm not sure what kind of role I could play. I'm not a good actor. You know I am very 'German:'



direct and straight into your face. I am bad at lying, and I'm not sure if I could pretend I'm someone else.

Ian: I would say that those things would probably make you a fantastic actor because ideally, you're not lying. You are actually experiencing whatever is happening. That's quite tough when you're doing a scene where your whole family is dead, and you have this fake plastic ball sitting in your arms, and you have to make this real. But I think you'd be great. I'm also that jerk that tells everybody they should be an actor because I love it so much.

Karina: I think I enjoy being behind the camera a lot more. I want to be the person that puts other people in the spotlight. I don't like being the center of attention, and I would not deal well with paparazzi or press.

Ian: I love the work itself, but I don't think I'm the brightest person out there because I enjoy performing, but I don't actually like everything else that comes with it, like the need to constantly put yourself out there on social media. I still get weird looks if I'm at a party and someone says, "Oh, we're going to take a photo." And

I'm like, "Yeah, I don't really want to take any photos." Then they are telling me that I am on camera for a living. I know, but I never really watched what I do. It's fun to be in front of a camera, but I never want to see the end product. But what was your question?

Karina (laughs): Have you actually never watched one single episode of *Pretty Little Liars* then?

Ian: I think I got to season two or three, but after a while, I realized that I couldn't do this because I became so aware of my performance, and it got very shallow and looks-oriented. So I stopped watching it because it felt unhealthy.

Karina: You basically became a very popular person overnight, right? I saw a photo on Instagram which you took with a disposable camera because you couldn't afford a phone, and this was right at the beginning of filming *Pretty Little Liars*. How did it feel going from not being able to afford a phone to becoming a teen star overnight?

Ian: Yeah, it was very quick. I still haven't been able to



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Ian grew up with a mom who lives with lupus. He raises funds for the Lupus Foundation of America.

wrap my mind around it because what I'm experiencing as an actor now is what most actors experience right upfront, which is that you are auditioning, auditioning, and auditioning, but nothing is happening. And then boom, something happens. And you're like, "Oh yes, here we go." But then that thing dies, or the movie never sees the light of day, or it doesn't get distribution, or you are cut from it, which has happened a bunch. And after a while, you start thinking, "Do I just suck?"

I didn't know how to process becoming popular other than by being a little bit more withdrawn in public because it's a very weird thing if people recognize you, but at the same time, you feel bad for feeling bad about it because you're so lucky.

I think that's one of the reasons that I - especially at the beginning of my career - threw myself into trying to do

something for the Lupus Foundation because the world I was living in felt so ridiculous to me. I would get paid for showing up for a day of work while I would think of my mom, somebody who has a chronic illness but was also a captain in the US Navy. And she didn't make nearly as much as I did. And I felt like I have to do some good. That's how I dealt with it. It was just absurd. I cared about different things than the people around me, whose dress wasn't ready for the premiere, or their BMW was scratched. I thought this was just gross. I needed to do something worthwhile.

"I wasn't living like a monk, but I needed to do something:" Becoming a spokesperson for the Lupus Foundation.

Karina: You just made the transition to your advocacy for me, which would have been my next question. Do

you think that growing up with your mom, someone with a chronic illness, changed your perspective on life since you just mentioned the people around you were worried about their dresses, and your main concern was doing something useful with your money and your fame.

Ian: Don't get me wrong. If you look back at my Instagram through those years, I was also traveling a bunch. That was my splurge. I didn't want to get things; I wanted experiences. So by no means was I living like a monk. I wasn't living in a hut, driving a used bicycle while giving all my money to charity. But yes, I had a different perspective growing up because my mom - even though I didn't know the full extent of her battle with lupus - would say, "I'm very sorry. I have to lay down now," when she was extremely fatigued. But she still managed to raise two kids.

There was always the thought in the back of my mind that today might not be a good day for her because of this thing that I couldn't see. It wasn't like she was coughing up blood or something like that.

And we had some tough days where I would be really mad that my mom wouldn't come to my soccer game. It was not like I was going to play anyways because I sucked, but it wasn't until I got older that I recognized all the things that she had accomplished in spite of this disease and realized how dangerous it actually was. When I was older, she told me that when she was diagnosed, the doctor said she should make sure to have a will and that everything is handled because the average life expectancy at that point, from the time of diagnosis, was about eight years. She was around 40. So essentially, they told her that she was lucky if she saw 50. I can't even begin to imagine. And then you've got two young children. She's now - I don't want to say - way past 50; a decade or so. I just complimented her on one side and backhanded her on the other. (Laughs). So I'd always thought, "How do you redirect your luck in some way?" I thought I could just use my stupid fame to generate money for organizations that I believe in. Did I answer your question from an hour and a half ago?

Karina: (Laughs). Yes, you did! Do you still remember a memory related to when you realized your mom was kind of different from other moms?

Ian: I noticed little things when growing up. For instance, she was always covered head to toe because she was photo-sensitive to the sun, and she would always wear these huge hats because she would have a flare or a reaction if she was exposed to too much sunlight. And then there was one moment where the gravity of her diagnosis finally hit me. I was in college, and I had been given this rubber bracelet that had a lupus emblem on it. My friend from college said, "Do you know somebody with lupus?" And I said, "Yeah, my mom has it. Do you know somebody with lupus?" He responded, "I did." Past tense. His mother had had

lupus, and she died. Back then, I didn't know people could die from it. So that was one of those moments where suddenly everything fell into place.

Karina: Could you talk a little about the unique role you have as someone who advocates for lupus, but also

Ian: It's a strange role to have because sometimes there are people that actually have the chronic illness themselves but don't want to be an advocate or the face for it, especially if they're in the public eye. I know several actors who have lupus, some of whom are open about it, but some of whom are not, for reasons like if they want to be in a movie, it might be hard to get them insured for the role because they're 'sick.' And sometimes, they just don't want to be seen as a sick person, because, you know, "you need to be strong; you aren't allowed to show any weakness." And that puts people who actually have the disease in a very tricky situation.

So it's different coming from me, somebody who does not have the disease, but who knows firsthand that lupus is terrible because I've experienced the effects of having a mother who, despite her best efforts, could only be present in my life so much. She was constantly around and a fantastic mother, but she missed out on certain things because she was having a lupus flare, or we couldn't play outside because she wasn't able to move her hands.

The general public feels a bit icky and unsure about chronic illness because people don't want to see themselves in that role. What I've experienced, especially when it comes to any sort of charity work, is that people love supporting things that are 'simpler,' but when we are talking about chronic illness, there's a weird disconnect. People don't understand lupus the way they understand cancer, for example. Everybody knows breast cancer because it could kill you. Yes, lupus can kill you too, but mainly, especially these days, it's a quality of life issue. Especially in America, there is this idea of, "Well, if it's not going to kill you, and you are 'just' in pain a lot, suck it up." Obviously, I don't believe that, but I think that's the mentality.

So I think having me, somebody who is - for lack of a better phrase - neuro-typical and able-bodied in the sort of shitty way that we think about this phrase, say, "Lupus is bad and does need attention," helps to get the message through. ■ ABILITY

by Karina Ulrike Sturm

twitter.com/ianmharding
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Read more about Ian in Part 2:
In conversation with Ian Harding about ableism, disability language, future film projects and most kept secrets.

Podcast Link



Volker Eckl WIKIPEDIA

The Wikimedia Foundation is continually improving the user experience ensuring digital accessibility for people with disabilities. Leading the charge is Volker Eckl who started as a German Wikipedia contributor in 2004 joining the Wikimedia Foundation in 2015. Throughout his career, he has been building user interfaces to empower people to be more creative and productive by listening to the users.

ABILITY's Laurel Wheeler speaks with Volker about his work and shares her experience as a blind user navigating Wikipedia.

Laurel Wheeler: What is your role at Wikipedia?

Volker Eckl: I'm a lead user experience engineer. I have been spearheading the design system and developed the user interface library at the Wikimedia Foundation for the last couple of years. Mostly from the departments' side, we've been working together first in the design department, which I'm part of, also in the product department, where we focus mostly on building, improving, and maintaining the features of Wikimedia sites to come up with guidelines, technical help tools, and spreading the knowledge about what it means to have accessible products, have accessible apps, and disburse this information not only for our own use, but also in an exchange with our very active volunteer community, trying to improve lives of people who have certain impairments.

Wheeler: That's wonderful. How did you get into accessibility?

Eckl: I think I would have to start very far back when I learned to work with the Web. The reason I fell in love with the Web was connecting different ideas in the most open and easily accessible way. I've studied information design and later philosophy. My philosophy professor, who introduced me to Wikipedia, and I was like, "Wow! This is exactly what I would love to build, the project I would love to have!" Part of my getting introduced to the Web was a very great German resource that very quickly showed that one of the beauties of the open Web is that it's not limited to a certain way of looking at it. It should work in all kinds of devices. It should be available for all kinds of people. This has driven me for a long time in my career, this idea of providing an as open as possible Web.

Wheeler: That's awesome! You said "products." What are the products that Wikipedia has?

Eckl: That's a very good question. People always are astonished to hear that there's more than one thing. In digital accessibility development, we are separating parts of the website into so-called products. The most important one probably for people who are not too much aware of the insides of Wikipedia, we have several projects, like Wikimedia Commons, but for Wikipedia, we have an editing interface and a readers interface, which is somewhat separated. On the editor's side, the most prominent one would be VisualEditor. Nowadays all the editors can edit the articles that you're looking at.

Wheeler: You're calling them "products." They're not for sale? They're products within your arsenal of things—

Eckl: Right. Yes. Thanks for the clarification. That's an internal way of looking at software products. They are absolutely not for sale. They are free for you to use or to come and help us with development and contribute to it on the code side.

Wheeler: I know you have some very active volunteers, do you know if any volunteers might be using screen readers in their volunteer work?

Eckl: Yes, absolutely. There is now a very new affiliate group that has been very active with several of the volunteers who are screen reader users. It's called WikiBlind. It's an international user group of Wikipedia and Wikimedia projects users. They have been in the past not only helping me, they have been establishing guidelines on the content side and helping each other to make lives better in the reading capabilities of Wikipedia and in part also the editing interface of Wikipedia.

Wheeler: I'll have to look that up. I would like to get involved. One of the other many hats I wear is that I do Web accessibility for a university.

Eckl: Excellent.

Wheeler: I won't be doing it anymore because I'm about to move out of the country, but I would love to stay involved in Web accessibility somehow.



Eckl: Oh, wow! A lot of changes at the same time.

Wheeler: I got accepted to the University of Helsinki, and so I'm in the process—

Eckl: When are you moving?

Wheeler: As soon as my residence card shows up, which should be in one to two weeks, then I'm allowed to buy a flight. I've spent all day today using Wikipedia. I've been looking at the tram lines, an article about that, and different information about Helsinki. I have often used, Wikitravel?

Eckl: There are a few things here. All the work that I've been focusing on has been dispersed across a variety of Wikimedia movement project. Let me just make sure that we are thinking about the same thing, because Wikitravel is not Wikimedia.

Wheeler: Oh, interesting. Even though it has “wiki” in front of it?

Eckl: Yes. That doesn't mean a lot, because the Wikimedia Foundation comes out of the idea of the “wiki,” which was the software. The software then was used for a lot of different projects. There's a huge variety of wiki-called websites out there in the world that are not affiliated with the Wikimedia movement.

Eckl: I'm sometimes finding myself in cabs and trying to defend myself that the donation that has been given to

us is going to Wikileaks. (laughter) That's not affiliated with the Wikimedia Foundation.

Wheeler: Wikipedia and all of the different Wikimedia, the different websites they are part of, is that I can navigate by heading, by link, by anything to find any information I'm wanting.

Wheeler: So I'm able to use this to quickly look for the information I want to know to help me have an idea of what areas of the city to find housing in, for example. That's just one real-life way that I've managed to use this.

Eckl: I'm very happy to see you navigating those tables. You're probably as quickly as I am navigating those tables sometimes. I'm very impressed by the way you're finding your way through.

Wheeler: One of the cool things I enjoy about different Wikimedia, Wikipedia, and the different Wiki sites is that whenever I pull this up on my iPad, I love that it's slightly different. A lot of times all the headings are collapsed and I can simply go by heading and click on the one I want to expand and read the section I want to read, which in a mobile version makes it way easier to navigate because you don't have to scroll through everything. I always thought that was really interesting, how they present a little bit differently layout-wise. It's really cool.

Eckl: There's an important thing I need to clarify in the

very beginning of our interview. The Wikimedia Foundation cares mostly about the interface, not about the contents. So the contents come from volunteers. Although we have guidelines and the volunteers, we're standing on the shoulders of giants. The volunteers came very early on in their work on coming up with Wikipedia articles, things like accessibility guidelines. Those guidelines are not everywhere implemented, and not every article has seen a person with a screen reader coming across and then either taking it into their own hands and improving it or flagging it with other contributors here. This is something that needs more knowledge-sharing about making an interface more accessible.

Wheeler: I love how Wikipedia and Wikimedia's framework is set up as multilingual. I work with many languages every day, and if I have the automatic language detection setting turned on my computer and I'm reading an article that has English and Finnish, or English and Russian in it, it's set up such that it will automatically tell my screen reader which language to read correctly for me. That's something I really, really like.

Eckl: I highly appreciate hearing that. One of the things that also makes contributors understand very early on that what they are writing it not only for them and their friends, it's for the world, is that our projects have been set up multilingual from the very beginning. One of the things that we want to be smart about, because we are sharing knowledge, so we should be smart, is that people with impairments make up such a big number of humans that we would be not self-fulfilling, not reasonable to neglect their needs because if you trust the World Health Organization numbers, they would make up the fifth biggest language group. If we care about multilingualism, then something like disabilities could be seen as a similar group and a similar approach. That is important for us.

Wheeler: That's cool! I've always noticed that Wikimedia, Wikipedia, Wiki projects always do a really good job of describing photos. There were photos on that page, and there was enough text surrounding the photo that I knew what was happening. How do you guys make sure to accomplish that, where people do a really good job at making photos and visual content either straight-up accessible by alt-texting properly, or by adding enough surrounding content so that a blind user what know what's going on. How do you guys accomplish that? It's pretty incredible. I have not seen too many inaccessible images on any kind of a Wiki website.

Eckl: Interesting. I have seen some. In the big picture, this comes back again to the openness of the project and the motivation of people. They really want to share their knowledge. They really want to get into this project. There are guidelines for volunteers on how to describe pictures, and you seem to be lucky to have seen mostly articles where people were following those guidelines

and trying to provide a descriptive, not too long, not too short, image subtext.

Wheeler: That's really cool that you guys have an emphasis on that. I've always noticed that it's not perfect, but overwhelmingly I've noticed that I've never had a large problem with Wikipedia or Wikimedia images. I always thought that that was really cool.

In the future, what do you guys want to continue to advance accessibility?

Eckl: First and foremost, we have come up with some quite important milestones in the last couple of years. I just want to say them in the right order. From an interface perspective, we have some limitations in what we can care about. We can mostly care about physical and visual impairments. We can in some ways care about neurological impairments. But all the others, like cognitive, auditory, and speech are not necessarily the ones that are within easy reach for us now. But I don't want to say not completely. It's just from a technical limitations point of view. As a nonprofit organization, from a limited resourcing point of view. We have to refer to other devices, other software to help those people access our sites. And whenever we hear that there's still a limitation, whenever we hear about hurdles, how we can address those hurdles and possibly circumvent them.

The part that we've been focusing on most recently is, we're to come up with technical guidelines. I've already mentioned those. with tools for our product teams, how to make their products—I'm staying with this term—more accessible. A very simple example is if we find in the design team an accessible color palette and brought this within less than a few months to all our—accessible in the sense of high contrast—to all of our products.

There is an accessibility statement that we would like to see applied to all the projects that we are conforming to with content accessibility guidelines 2.1aa level. That's one thing that is very important for me. It's basically the industry standard, but we are looking from problem to problem if we can expand and extend and make our interfaces more inclusive and more accessible. This shouldn't be a stopgap, it's just a thing that as a product team we've agreed on to have as a requirement for new products to roll out, and like I said in the beginning, maintaining and improving our existing products.

Wheeler: That's great. One thing I thought of as well. I know that you have a lot of volunteers who help with these projects and you also have employees who work and oversee and work on these projects. What percentage, if any, of employees have disabilities?

Eckl: I'm not in HR. I know currently, we are expanding in our hiring to diversify our employment range of people when we're setting out to share knowledge for every human being. That's something that has been in

discussions. I'm too involved with on a day-to-day basis. I would have to refer for further details to other parts of the organization. But it doesn't help if just like the prototypical young San Francisco designer with perfect eyesight and perfect computer equipment is going to define interfaces. That is very clear. If we want to reach a diverse group of people, we have to work with them very closely. One of the things that we did was engaging the American Foundation for the Blind to work with us on new product releases.

Wheeler: It's cool that you work with the AFB.

Eckl: And I don't want to forget about the Wikimedia Foundation has taken the torch from the incredible user community, where we have user groups like WikiBlind.

Wheeler: What is the number of employees involved?

Eckl: We have just about 400 staff at the Wikimedia Foundation. That includes contractors around the world as well. And there are more than 250,000 editors around the world on Wikipedia and class to 300,000 across all the Wikimedia projects, including things like the photo repository with things like Media Commons or Wikidata or some of the other projects that are a little less well-known.

Wheeler: How does someone qualify to be a volunteer?

Eckl: You're qualified.

Wheeler: (laughs)

Eckl: We are open to everyone. There are clearly some guidelines and maybe some community processes that you'll have to get into and familiarize yourself with, but that is the beauty and one of the core powers of our approach. It is open and is meant to be open to everyone to contribute.

Wheeler: If there's a problem with a particular volunteer not doing the right thing, who monitors the volunteers? Who monitors the volunteers who monitor the volunteers?

Eckl: (laughs) There are different levels of social processes and in some ways also, for example, something very particularly successful is an artificial-intelligence bank, flagging certain changes in Wikipedia articles and Wikimedia contributions. There's another filtering flagging possible malicious contributions that then goes to more advanced user hands that have been positive in the community for a long time. That is a very short summary with big gaps.

Wheeler: What kinds of international resources does Wikimedia have to help gather the input of users with disabilities who don't speak English.

Eckl: This is a great question. I have to say that most of the environment that we're focusing in the product design on the disability side is making—getting—lowering the technical barriers, and the multilingual part comes from a separate project that is completely agnostic of the accessibility technical issues in the interface, so we are making sure that when this is an accessible interface, it also works in different languages for screen readers that have a different language set.

I know specifically of one that we've been exchanging in a South American user group that has been involved with blind users. And there are some spread out where people come back and say, "This is a user who wants to be active and is blind. We want to differ the technical issues to you guys while we are working on the content side with them."

Wheeler: Perfect. So Commons that you mentioned, that's a Wikipedia product?

Eckl: That's right. In the volunteer communities often find themselves separated by languages, so you have an English community, you have a German community, and so on, there are meetings and discussions and they're ongoing. There's very little that hasn't been reevaluated or won't be reevaluated. That's also one of the things of an open movement like the Wikimedia Foundation. There's nothing set in stone, although there are some guiding principles, like the neutral point of view, that seems to stay with us till the end of time, similar to that this is free and open for everyone to alter and contribute to, an encyclopedia in the case of Wikipedia. Those seem to be two rules that will probably not be disputed.

Wheeler: Is there anything else you want people to know?

Eckl: I think that for us it's incredibly important to emphasize this openness and to make sure to spread the word that we care about people with disabilities as we care about other people. To get the word out, if you run into trouble, 'this might be the organization and the website', where you see feedback. We're collecting those inputs. We're serious about lowering the hurdles, and that you love and you want to be part of in one way or another. ■ ABILITY

WikiBlind User Group:
https://meta.wikimedia.org/wiki/WikiBlind_User_Group

Wikipedia Manual of Style - Images
https://en.wikipedia.org/wiki/Wikipedia:Manual_of_Style/Images

Wikimedia Design Style Guide https://design.wikimedia.org/style-guide/design-principles_accessibility.html

Wikimedia Foundation statement of accessibility <https://wikimediafoundation.org/accessibility-statement/>

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Archie COMICS

Co-CEO Nancy Silberkleit

Archie Comics is one of the most enduring brands in the history of comics. Created in 1941, their lovable cast of wholesome characters — Archie Andrews, Betty Cooper, Veronica Lodge, and the rest of the Archie gang — captivated generations of readers, who devoured every word of their teenage predicaments. According to the company's website, they've sold more than two billion comics and are published in a dozen foreign languages and distributed worldwide. They're also the first mainstream comic book line to make its content available digitally.

Over the years, the Archie storyline has adapted, to stay in step with the times, introducing more diversity and contemporary themes. Recently, *ABILITY* met via Zoom with Nancy Silberkleit, of Archie Comic Publications. She is the widow of Michael Silberkleit, the son of Louis Silberkleit, one of the company's founders. Silberkleit spoke about her background in education, her role in the company, and her push to introduce more diverse characters and storylines.

ABILITY: Can you give us your history with Archie Comics?

Silberkleit: “Zam Wham Wow to *ABILITY Magazine*.” The iconic brand is going on its 80th year. But my true background, my true platform, is education. I graduated from Boston College in 1976. My family was not encouraging me to go on to college. I kind of propelled myself because that's what I wanted, that's what I believed in for myself. I believe going for that higher degree after college really served me well for what would happen to me at age 54.

I was a schoolteacher in a public school. Archie Comics has always been a family business, for 80 years—the Goldwater's and the Silberkleit's. My husband's dear partner, Richard Goldwater, passed away about 12 years ago, and, then seven months after that, shockingly, my husband passed away. It was absolutely shocking, something that just doesn't happen, but it happened, and Archie Comics was running rudderless. I was left to oversee the 50 percent of the other half. It was something I was not ever spoken to about in terms of what to do. So, I felt, at the time, I was at a loss. There was a force that did want my 50 percent, but I just didn't want





to sell. I would think about what it would be like on a yacht, like Veronica Lodge in the panels of the comic books, but I was kind of like this itch. I just couldn't get an answer for why I would not take the money.

It was only about maybe two years ago that the light bulb went on. Do teachers go into their careers thinking about getting rich? No, not at all. So, I think that is why I would not take the money. The blood that runs through my veins is about education and propelling knowledge. There was nothing else they could do but to ask me to come in as a co-CEO. I didn't even realize what the responsibilities of those words were until I looked them up. But for some reason, I stepped out of the classroom and into the Archie boardroom. I am the first female to ever walk through their doors. I do not hold an MBA. I do encourage the many young people—and anybody!—to always go for other degrees.

It's really your weapon. I feel very qualified in business because, as I said, I was kind of scared, holding on to Betty Cooper for dear life, but as I look back, I was overqualified for the job, because my job as a teacher is to get information into individual minds. And what better platform is *ABILITY Magazine* to know that there are so many different minds out there. So think about the job a teacher has in the classroom. At that moment, I was the art teacher. I saw 300 students during the week. So it was my job to be skilled in communicating information to individual minds in a way they could grasp what I was pitching. Because when you're standing up there in the classroom, not everyone is going to be able to grasp what you are doing.

I've had children who were blind, who were deaf. You have to be very resourceful. But as a businessperson and as the co-CEO at Archie Comics, it's my job to connect the brand to the people, and also to advance the brand. Isn't that what a teacher does every single day? So, I look back and I was overqualified for the job. That's my background. When I came in, there have been some stories that I carried with me from the classroom into publishing, and one was Scarlet. I can talk more about how Scarlet was created.

ABILITY: What grades were you teaching?

Silberkleit: I taught kindergarten through twelfth during my entire teaching

career, but the bulk of it was K-5 and then we went to K-4. But I have taught high school and middle school. And now, as a CEO, I get the opportunity to go to many universities around our globe and speak to them and also speak to business classes.

ABILITY: What are the demographics for Archie?

Silberkleit: It's global, ageless and genderless. It's for everyone. Archie Comics started out in 1941 with the idea that the company wanted to get something out there in comic book format for the eight-year-old girl. Because the comic book industry was very male-dominated, and there was nothing there for that young girl. So the company came up with the concept of having that all-American boy who's behind me who can't decide between two young ladies who are very different. You have Veronica Lodge, who I said has the Reed CIA in her. She has a lot of confidence, intelligence, and allure. And then you have Betty Cooper, who can do everything. She's very skilled in baking a cake, being attuned to kindness, and being there for others. So two very different people. That was the platform. And Archie Comics has a formula, which I'll get into in a minute.

But it ended up, when Archie Comics was launched, it appealed to everyone. The targeted person was the eight-year-old girl, but it morphed to include people who were finding maybe isolation, loneliness. They would carry these comic books in their pockets. There were always those young themes that reflected who they were. They had a bond. We have lots of fans who sub-

scribe to Archie Comics today who are reaching their eighties. So from the eight-year-old to the eighties, wherever I go, I don't know who to say is more popular. When I landed in India, I was like a superstar. When I go to the Philippines, I'm a superstar. Canada, a superstar. Burbank, California, a superstar.

Archie is everywhere, and it's known by such a diverse group of people. Since we were talking about disabilities, I've met so many Archie fans who are deaf. Also, I happen to have one of my stories in Braille. I wish I could do all our stories in Braille. But I was meeting people who were blind who were huge fans. David Patterson, who was the governor of New York at one time, he was a huge fan. I said, "Hey, David, how did you read?" Because he has some sight, but it's very difficult. His parents would buy those books and a friend of his would read them to him on the beach. Isn't that heartwarming? He always looked forward to that time. And he knows our characters very well. And our stories are so impactful. I find that they stay with you for a lifetime. And you carry them with you.

And, also, for the English language learner, they always say the Archie Comics taught them English. They also taught them slang. They didn't know what the word "jalopy" was, and they were curious. I never met my father-in-law, Louis Silberkleit. I never met John Goldwater, Sr., and I'd love to have them here at the table with us to thank them, because they gave not just to the US, but they gave the globe a treasure of literacy.

ABILITY: Where are you headquartered?

Silberkleit: We're in Pelham, New York. And I think there's Pelham, Alabama, and I'm sure there's a few more Pelhams, but we're in Pelham, New York. It's 45 minutes north of New York City.

ABILITY: Did you go to Comic Con in San Diego?

Silberkleit: Yes. That is an amazing event. All of them are amazing. I'm trying to think of another one out in California. Is it Emerald Comics? They're all very unique. In San Diego they go all out, and so does New York. They're spectacular. Each is very individual and special, just like people!

ABILITY: How did the character of Scarlet come about.

Silberkleit: First, I would like to say, as a comic book publisher, I want to share our dedication to equity and inclusion. There are a few words that sit on my shoulder. One is "engage." How do you engage people in conversation? And, of course, "empathy," the importance to practice empathy and understand its meaning versus "sympathy." Society, I'd say, needs to understand its difference in order to make the change. We need to teach that to people who come into this world. Each person is unique. Everyone is different. I'm sure you would

agree with that. Empathy, and I'm sure you know this, is a term we use for the ability to understand other people's feelings as if we were having them ourselves. Sympathy, I don't know if you can put this in your magazine, but to remind people, sympathy refers to the ability to take part in someone else's feelings, mostly by feeling sorrowful about misfortune. We want to teach empathy.

So Scarlet was created because I wanted to provide a platform that could view autism for its strengths and to communicate that autistic minds understand everything going on and want to be a part of things. I was brought over to speak in Athens, Greece, and they were housing me in a hotel store. It's called COCO-MAT. They are on top of understanding disabilities in the workforce. As I said, autistic minds understand everything going on and want to be a part of things. There's one gentleman, I hate to say he's autistic. He's a wonderful person in the store. I'd say, "Good morning!" to him every morning, and he never said anything back. That's his self, his style, the way he comes across. And then one day, as I was leaving, he just automatically said, "Hi." It was a delayed reaction to my every morning saying, "Hello."

I feel that autistic people are very much aware of what's going on, even if they're not engaged. And isolation is one of the worst things people can experience, period. People need to learn how to embrace and engage with different communication styles, as I just expressed. People also need to learn how to see people in deeper, more meaningful ways. Scarlet is the character who's autistic in the Archie Comics cast of characters. Scarlet is compassionate and inquisitive. She is of Filipina and Irish descent. She is gifted and interested in architecture as well as building ideas.

Here is one story with Scarlet called "Straw Thinking." Scarlet is not defined exclusively by her autism, nor should anyone be defined by a disability, but rather by their individual and unique ability. I love the title, and I apologize for saying "abilities," but ability. Scarlet is a whole person, and she teaches her friend how to befriend people with diverse lenses and approaches. And she's not intended to represent all autistic youth but having a representation of an autistic teen is important to raising awareness, enhancing empathy, emboldening education and giving that inspiration of courage to speak up, providing we don't assume or listen to rumors, that we get good information from reliable people. That was my feeling, and the importance of putting Scarlet out there.

ABILITY: Are you pulling in people who have autism to help you with the drafting of these stories?

Silberkleit: Yes, absolutely. Autistic and neurodivergent people shared feedback regarding how best to represent this biracial, autistic female character. I'm looking at some names here. Jason Phillip Harris, you should look

him up, he works with GLAAD (Gay and Lesbian Alliance Against Defamation). He empowers adults with disabilities. Jason Phillip Harris was very good support for me. Boston Children's Hospital had given me the names of some doctors who were very much connected. I've worked with the autistic people, and the message that kept coming back to me was, "You know what? My autistic teens are telling me that they want friends. They desire friends." This was in the very beginning of the idea that I wanted to do this and the importance of friends.

And then Diane Wiener, she's a research professor at a university, and Ray Felix, who did our very first story, "Kindness Works." His daughter is autistic. I am not an expert in this field of disabilities or autism. What I discuss does not provide medical advice; it's not a substitute for professional medical advice or diagnosis or treatment. It's the next part of why I started Scarlet that I'll share with you. It was from my experiences, but I knew I could not put Scarlet out unless I had a solid background of professionals who have worked in this field.

ABILITY: There's a wide diversity on the spectrum. What's the most surprising thing that you've encountered?

Silberkleit: I love the term "neurodiverse." We have gender diversity, we have all diversities, so why not neurodiverse? I love that. I think it's a cool name. But other people want to be defined as autistic. I'm never sure if I'm OK saying—I always say, "Autism is a part of Scarlet. There's so much more about her."

I keep my ears open, but I don't know exactly what is the right way to go. I thought we were all "person first." I thought that was the path we were going down. Now I'm hearing that it's changing to "disability first."

ABILITY: Can you talk more about the creation of Scarlet?

Silberkleit: I wanted to provide a platform that could view autism for its strength and its communication. It's not just that I'm a comic book publisher, and I know this is a powerful literary genre to get information across. But as I was a teacher, we did provide special instruction for those with autism. They came into the school, into that program, with diapers on, and they stayed with us for years.

There were a few students who would actively try to be inclusive, because the children had their room, but they would be mainstreamed into the music room and into other events. But then there were many who were not inclusive. And I felt that my autistic students were very much aware of this separation, but I feel they deeply desired to be a part of the group, of the school. But their verbal skills were not there. As I said, they came to us in

diapers and stuck with us for many, many years.

Then one of the students from the program, who had advanced verbally, came up to me in the class one day and said, "I think they are being mean. I think they are not being nice." I remember his words in my head. "I think they're not being nice." And that day has never, ever left me. The words stuck my heart. "I think they're not being nice." With that, I wanted to do something to get that message out as a comic book publisher and empower children and try to give out information. That child was able to communicate his feelings. He knew who to come to. He was advocating for himself. I was proud that he could articulate that, but not everyone can. I feel people understand what's going on. You may see that someone doesn't understand what's going on and you isolate them, and you ignore them.

That's another thing that gave life to Scarlet. I wanted to use that moment to identify her as autistic, but her stories show her desires, talents, interests, interactions, and self-advocacy. That's how Scarlet came about, and I'm very glad that I was able to have the resources to get other people involved. There's one panel, I don't know if told you, but the stories are only available to me. They are not available—I'll show you—in digest forms like this. They're not in single issues. The only way the Scarlet stories can be read is by contacting me.

This project was not about money but about messaging and awareness and empathy and engagement. How do I know if I put in one of Scarlet's stories that you read it? There are many stories in the digest, and that's where Scarlet's stories would have been found. People can get the story as a digital PDF by contacting me at Nancy.ArchieComics@gmail.com. Scarlet's stories are to seek out other ambassadors around the globe to highlight that autism is just one part of Scarlet. There's so much more about her as a whole person. She wants to teach comic book fans and Archie fans all about being an ambassador.

ABILITY: Is Scarlet embedded as a character within the framework of the comics.

Silberkleit: She's in the stories with our other characters. Her stories are created around the Riverdale cast, the Archie Comics cast. She's part of Riverdale High. Her stories right now are digital because she wants to have a platform and make sure you read her stories and hear her message. That's how they are available digitally. They're \$1.99 on PayPal. That's the platform that gets me to talk to people, so I get to speak to a lot of people about Scarlet. If they were just in the digest, as an Archie story with Scarlet in it, I wouldn't have the opportunity to be interviewed by **ABILITY** Magazine, or get to meet your fans.

ABILITY: At any point, are you looking to integrate her into the digest?

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Silberkleit: She's integrated into the stories. The one that just came out that I love is "Across the Pond with Love." It's a play on the royal Archie being born. At some point, I'm sure she's going to have a special book called Scarlet. There's no reason she can't be in the digest, but I want to make it clear that her stories, just like in her, have a very strong emphasis on being kind and inclusive. I do not get to have a conversation with people about these stories that they're reading in the digest. It's a story that could be in the digest, but I want to make sure I have an opportunity to spread Scarlet's message.

ABILITY: How many comic books does Archie Comics put out?

Silberkleit: We have so many I can't keep up with them. We print digitally and in the books, so we have Betty and Me, Jughead and Pals—there are so many titles. I don't have the number, because it does change.

ABILITY: Do any of the other characters in the comics have disabilities?

Silberkleit: Yes. We just launched a story—"Betty and Veronica Jumbo Comic"—and it's the first story in library 288. It recently came out in a digest that has a fall picture on it. We have Scarlet, and then we have Moose, who's dyslexic. But the one I'm thinking of is Harper Lodge, who's a fashion maven and also uses a wheelchair. Harper Lodge is Veronica's cousin. She's based on a real person named Jewel Kats, a Toronto-based author who was a huge Archie fan. She used a wheelchair. That story is in the digest, and it's the first story. I don't think it's come out in print yet. It's a digest that can be read at a library for free on the Hoopla platform. And when you read the first story, it will have Harper Lodge, who uses a wheelchair.

ABILITY: You sell subscriptions to individuals. Do you also include selling to schools?

Silberkleit: There's a program of comic book fairs that I started a long time ago, and I just packed up a box that went to Michigan. The comic books go into the schools, but this time, because of our situation, it was just a flyer, and the schools are able to pick out what books they like and then they send it back to me and I send it out. And I kind of like it this way, because when the books are at the schools, the kids are picking them up and they get bent and some of them get lost in reading them. This way was very easy. I think it was two weeks they had, and I just shipped a box to Michigan. Our outlet is digital, and it's direct from the company or it's at your bookstores in Abu Dhabi or the Philippines. I've been to the United Arab Emirates and to Dubai, and their bookstores are fabulous.

Our books are in bookstores around the world, but you can order directly from Archie and our comic bookstores. I'm trying to instill in people to contact their comic bookstores and find out about becoming a collector. It could be a lucrative investment. Decades later you could have a comic book that's worth a lot. But it's also fun collecting and organizing; it's beneficial to take care of something. Our comic books are available on many platforms. And for free in your library through sites that have Hoopla.

ABILITY: And you print them all in the US? Or different places, for shipping reasons?

Silberkleit: Different places. I don't oversee that aspect, so I can't truthfully answer that question.

ABILITY: So, you're co-running the organization. What's your part and what's the other person's part?

Silberkleit: My part is in education, and my partner is responsible for TV, movies and films.

We have picked up a lot of new fans who are reading our classics. Some of the young people who became big fans of the hit TV show Riverdale didn't know about the classic Archie. So they are exploring that. And also, I have heard many wonderful stories. There's one story from a 75-year-old grandma who said, "I've got to tell you this! I knew my grandchildren would be watching something called Riverdale and I looked into it and I wasn't so sure if it was MY Riverdale. And when I went down to watch it, I love it!" So 75-year-old people are becoming big fans of Riverdale, which is very different. It's very dark. But I had mentioned earlier when we first started speaking that Archie Comics, when it started out, it was with the idea of giving something to the eight-year-old female.

But there was a formula, which was to take a bunch of teenage students, put them in Riverdale High, create a little bit of chaos, and let them figure it out without any adult intervention. And that's the storyline of our talented writers and artists. The formula is, reflect the decade. Reflect what's coming on. Make it relevant. We don't want to keep seeing Betty and Veronica in poodle skirts. That formula will reflect what's going on in society, and that's exactly what the TV show Riverdale is about. It's doing exactly what those slapstick stories in Archie do. It gives us a little laugh. It reflects what's going on in society. What's happening in Riverdale is reflecting society. It's very dark. And the writers are taking that darkness. But it's the same formula.

ABILITY: And you're not going to stay away from the darkness?

Silberkleit: We have put out some Riverdale stories in digests, so it does pick up the darkness. We have readers who love the stories. But I would say it's around the 15-year-old and up who is attracted to that.

ABILITY: Since COVID is limiting your travel, what makes up your days now?

Silberkleit: I am so busy! The Diana Awards has me speaking in Athens again. I'm doing it through Zoom. I'm supposed to be leaving for Crete pretty soon. My talk is on a Zoom at the end of the month. I've been busy with these talks. I was on one for a Vermont library. That you can look up. I had my interpreter. It's Winhall public library. I did a talk a few days ago, and I just got a message that they put it up on one of their local TV shows.

ABILITY: Are you looking for any other ideas related to disability?

Silberkleit: I feel that with disability employment, there's real talent out there that's being overlooked, and it would be great if I did a story on that. There are a few stories I'm thinking about for Scarlet to get the message out there. But it won't happen for a bit. I launched

the story "Across the Pond" right around when COVID happened and not many of them have sold. I'm working on that.

ABILITY: We have been leaders in employment of people with disabilities, building the first job board on the web and an online career fair for job seekers with disabilities. I'm sure we can help with your story.

Silberkleit: That's a very good point. I don't know what story I'm doing. There's a whole spectrum of stories. I don't know which will be the next. I was thinking about one where maybe dating would be a part of it.

I'm not an expert in the field of disabilities or autism. I try to be relevant, but I realize the power that graphic literacy holds, because it's those visuals that spark you to expand the story. When you expand the story, you're incorporating your personal values, and it seems that the bits of information I do want you to get, you internalize it and you're more apt to hold onto it.

ABILITY: You have Archie memorabilia?

Silberkleit: I enjoy collecting Archie memorabilia. I have a collection that travels around, and it travels around the world with me, it did to Athens. It's displayed for free. It's again, how do we engage one in reading? I always feel like if I have these things that you notice, that someone may become a little bit more curious and say, "Oh, they represent some literacy that's entertaining." Maybe they'll pick up one of our Archie Comic books. I try to find different ways to tap into highlighting reading material and hoping someone will get hooked into the love of reading. That's what this is about. It's a magazine that did a story on me in 2014. When I came into Archie Comics, I had read no comic books. I had no love of reading. That goes back to how reading was presented to me. I was left back, no one explored my learning style. They couldn't figure out how to tap into helping me to read.

I finally learned to read, and I went to college, but I had no love for reading. So when I became the co-CEO of Archie Comics, I had stacks of comic books, and I had to read them. I quickly found that I couldn't put them down. I fell in love with reading. And then I wanted more to read. You would find me going to the library, going to bookstores, opening those pages and reading a book. Right now, I'm reading a book on the suffrage of women. Reading was something I did not do for entertainment. But, as I said, I have this traveling free exhibit of Archie stuff, no comic books, just to get people interested. "What's that? Where did it come from?" And maybe they would be curious to click on Archie.com and read the books. ■ ABILITY

archiecomics.com

What is the impact of visual social media on the integration of people with disabilities to our societies?

As a person without a disability, it is often difficult to understand the daily inconveniences faced by people with disabilities. I'm not proud to say that my understanding of accessibility started and ended with ramps in buildings and buttons to open automatic doors. It wasn't until very recently that I learned what exactly accessibility encompassed. In our new digital media focused society, accessibility online has become an issue disability advocates are constantly fighting for. Whether it's an application that allows websites to be read out to blind individuals or dyslexia-friendly word-formatting, the issues of individuals with a disability have taken a back seat in the online community. The vast majority of people without disability, myself included, take for granted the fact that the world, both online and physical, was made for them. They are the blueprint. This in essence, is the digital divide, that is invisible yet extremely penetrant.

The use of visual social media by disability advocates has forced us to look at our unconscious bias face-on and deal with its repercussions. Social media have the special ability to spotlight the hurts and grievances of individuals with disabilities and give them the visibility that they previously lacked. The once silenced story of their lack of equal opportunities has been given a chance to emerge and make an impact through movements on social media. Not only that, but social media has allowed individuals with a disability to reconstruct the long-standing views that disability is equatable to inadequacy.

People may sneer and joke about "influencer" culture, but there is no denying that it has had a tremendous impact on the evolution of disability advocacy. Tess Daly, for example, is an incredible makeup artist and fashion blogger based in Sheffield, England, but what makes her even more accomplished is her use of social media to bring awareness to disabilities. Tess was born with spinal muscular atrophy type 2 and has spent her life in a wheelchair. Despite her physical disability, Tess has used her story and skills to show the world that her disability isn't a hindrance to her dreams. She currently boasts over 200,000 followers on her Instagram. Tess's story is just one of the many examples of how social media has impacted the nature of advocacy. Platforms like Instagram and Twitter have allowed for the voices of actual disabled individuals to be heard and shared.

One of my favorite influencers that I watch on YouTube is Molly Burke. Molly Burke is a wonderful ball of sunshine that has been proving to her audience that despite being blind she can do anything a seeing person can do. Her channel includes challenges of her painting, doing her makeup and performing stunts with other YouTubers. Most of the time her comments are



filled with people in awe of the fact that she is so "normal". But that's exactly what Molly is fighting against. She is using her platform to show that normalcy is a concept biased against disabled people. Molly being blind and doing seemingly "normal" things shouldn't be shocking, but because we as a society have been conditioned into thinking that disabled people are more or less helpless, it shocks us. Digital media has the power to change the fabric of society. People like Molly and Tess are helping revise centuries-long misconceptions about what disability looks like.

I truly hope that we, the younger generation, can use our own platforms to advocate for the unheard, the silenced and historically marginalized.

by Kasturi Sarkar

I truly hope that we, the younger generation, can use our own platforms to advocate for the unheard, the silenced and historically marginalized.

Within the realm of visual social media, an individual, regardless of the limit in one's ability, is allowed the right of authentic self-representation. Media is adapting beyond textual and visual uses, which means the media sphere is ever-evolving to meet individual needs. In a way, we're seeing media that can genuinely account for the many aspects of people's identities, which are also ever-evolving in a similar sense. In our current year of 2020 alone, the amount of media outlets disposable on a global scale is immense, with numerous user personalization capabilities. This increase of capabilities is inclusive to those with disabilities rather than exclusive, as most of society might believe. Technological advances have allowed for progress in increasing access to social media to a wide variety of individuals with disabilities. For example, websites such as Usabilitygeek.com and Inclusivecitymaker.com offer a list of resources for individuals with a wide range of disabilities.

Visual social media plays the paradigm of both regarding how in its capabilities, seen within apps such as Instagram and Twitter, to name a few, have allowed the public to represent their respective social groups and their vices/ opinions fairly. Meaning that the power to change definitions within one's visual media use actively helps reflect and create concepts of belonging and potentially helps connect and create social groups via the internet. This sense of belonging and community within visual media is how the integration of changing the societal view on concepts of disability begins.

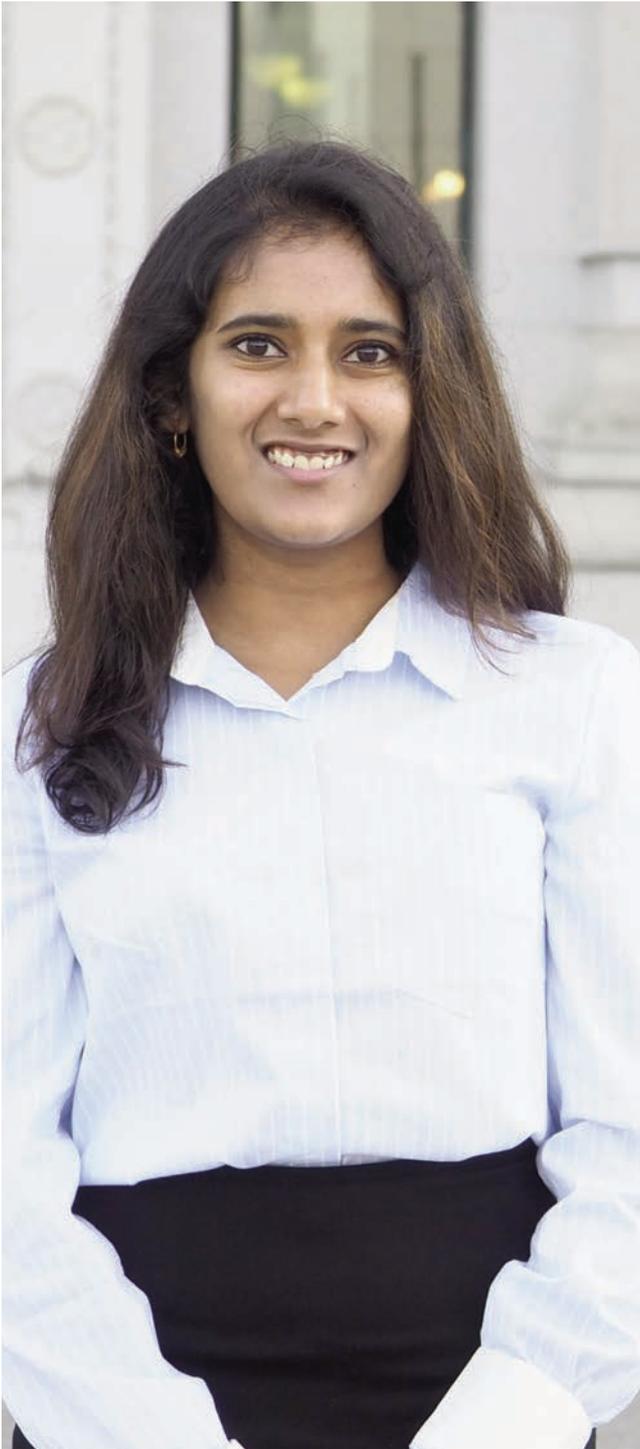
However, this understanding of media leads to another aspect of encompassed duties, assisting in coping. A majority of visual and verbal coping techniques that are usually present in media is through humor. The use of humor as a coping mechanism has been of use for centuries, and in a way, helping us as human beings to frame and make light of a situation based on how we perceive what is happening around us and create a sense of belonging. This factor of belonging is essential when we consider how media plays in the lives of those with physical or mental disabilities in particular. Coping through humor can become an important tool for building confidence, and confidence in the community of those with disabilities potentially increases the volume of visual media as a significant benefit to those looking for ways of manifesting the thoughts, values, and ideas to those close and the general public at times.

Stigma is an ugly but common factor that this world has seen based on bias and misunderstanding. Visual social media opens the door to change these definitions for oneself and for anyone to take those first few steps to



create a better space of representation through the lens of the individual experiencing the quoted disability. Through media, we see a normalization of acceptance and a gateway that can integrate critical aspects within many lives, including those with disabilities, to display and foster self-interpretation methods. These practices within personal digital media concepts create a digital space that is primarily safe of unsolicited bias for many as long as digital space and media remain accessible to the public.

by Spenser Stagers-Elmore



Visual social media has allowed users around the world to interact with individuals of different cultures and backgrounds while shedding light on their struggles. Those without disabilities often have the preconceived notion that those with disabilities often struggle to become independent and successful. However, people with disabilities now have powerful platforms to reshape this ableist narrative by sharing their stories and struggles. For example, YouTube is a powerful platform that allows people with disabilities to talk about their experiences. These platforms allow people with disabilities to

form a community where they can feel supported by others who share similar experiences. Additionally, social media helps make people with disabilities become more prominent figures. Many people with disabilities have become influencers such as Jillian Mercado. She is not only an activist but also a model who features her wheelchair prominently in photoshoots. She also raises awareness about the discrimination of people with disabilities. Another popular disabled influencer is Kaitlyn Dobrow. She is a disability rights activist and a make-up artist with a significant following on Instagram. She describes her life as a quadruple amputee while showcasing her skills as an artist. The success stories of people like Jillian Mercado and Kaitlyn Dobrow help disrupt the ableist narrative while providing role models to those struggling to come to terms with their disabilities.

Social media can also shed light on unique experiences that abled people do not experience. For example, YouTube influencers Squirmly and Grubs highlight the lifestyle of a couple in which one person is disabled and one person is abled. This YouTube channel initially just started as a way of sharing a unique lifestyle but quickly gained momentum. Now these influencers run a non-profit organization that helps provide helpful technology to those with muscular dystrophy. These types of YouTube channels showcase unique stories that help abled people better understand disabled people and engage in discussions about how society often discriminates against those with disabilities.

Social media also allows users to reach thousands of people enabling those with disabilities to spread their message to a much larger audience and engage in meaningful discussions through features such as commenting. For example, the hashtag features on social media platforms like Instagram and Twitter help users to build communities and connect with other individuals to deconstruct the ableist narrative. Hashtags like disabled and disabilities are most commonly used to spread awareness. For example, activist Annie Segarra highlights stories of individuals with varying disabilities as well as struggles that abled people might not even think about. She uses both Twitter and YouTube to share this message and engage in discussion. Social media also enables people with disabilities to support each other online such as Alice Wong, the founder of the Disabled Visibility Project (DVP). She compiles the stories of people with disabilities and moderates Facebook groups that discuss issues related to disabilities. Social media allows those with disabilities to support each other online to portray the realities of being disabled on their own terms. Therefore, social media empowers those with disabilities to find a supportive community and share their stories to combat discrimination and the perpetuated ableist narrative. ■ ABILITY

by Arushi Sahay

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*In pain
In trouble
In doubt
all three and sadness.*

*She sings
She laughs
She writes
with joy and gladness.*

*Unaware
of the empty stares,
headed in her direction.*

*Too young to have gathered
life tools,
for protection.*

*No matter the earth shattering
circumstances,
emotional human dances.*

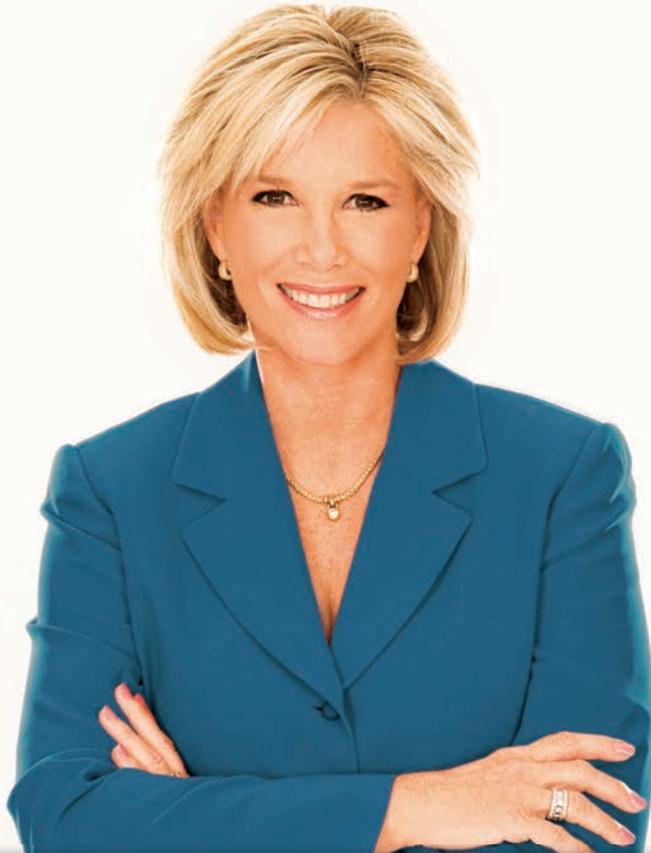
*Obligated to life,
laughs and takes her chances.*

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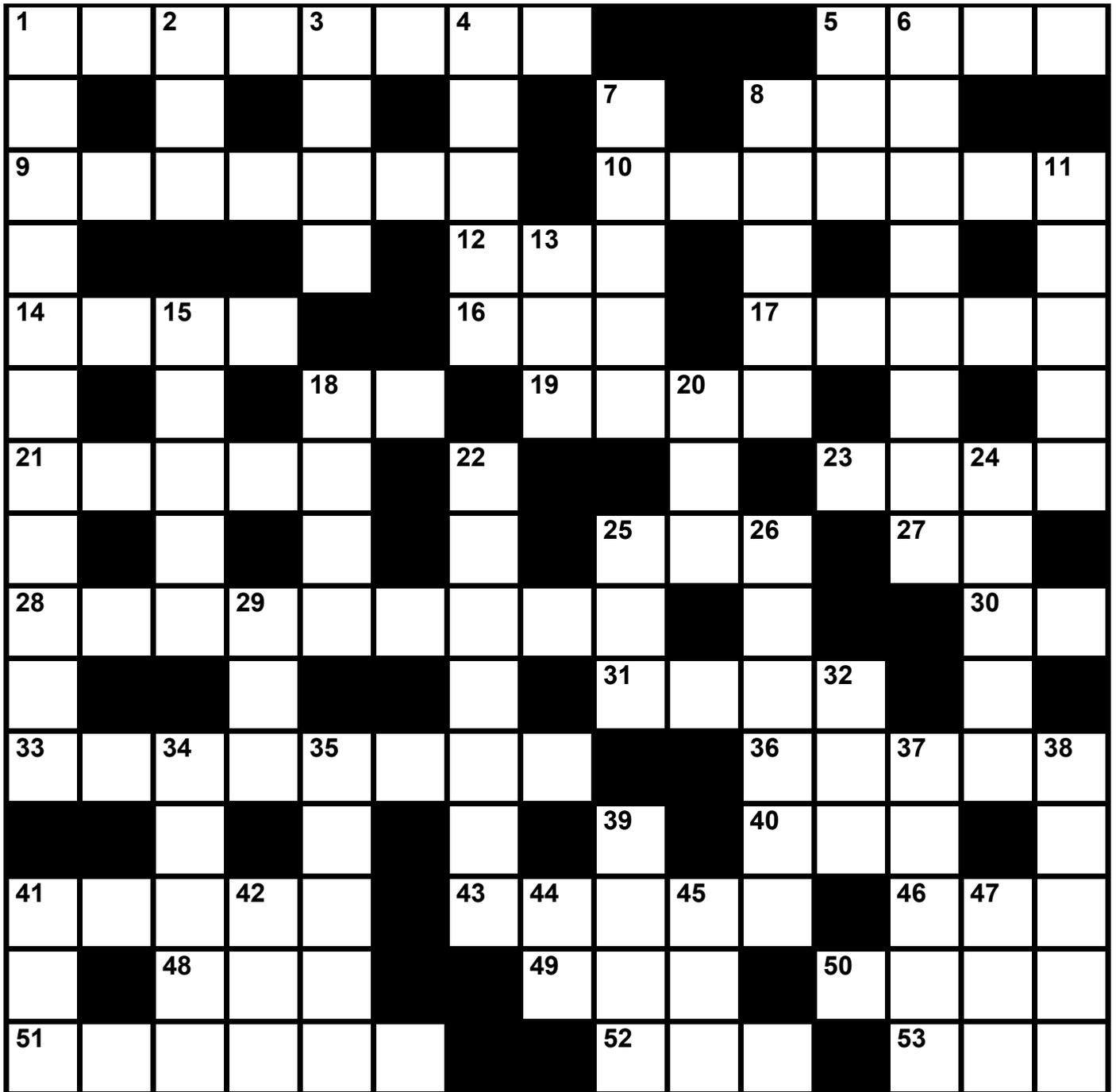


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ABILITY'S



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A C R O S S

1. Popular Chinese vlogger who is a wheelchair user and has polio, and films her life and work, 2 words
5. Abu Dhabi locale
8. BBQ residue
9. He lost both his hands in WWII but went on to win an Oscar as an actor, Harold ____
10. "Law and Order" groupings to identify a suspect, 2 words
12. "___ God" teen internet exclamation
14. Actress who starred in "My Gimp Life" ___ Sherer
16. ___ Novicki: actor and stand-up comedian and screenwriter who supports Easter Seals
17. "Sesame Street" regular
18. Senior, for short
19. Boxing round ending sound
21. "Famous Potatoes" state
23. Truck part
25. Def Jam genre
27. Des Moines region, abbr.
28. Community created online encyclopedia
30. Raleigh's state, abbr.
31. New Orleans music
33. California National Park that's both beautiful and accessible
36. Muslim woman comedian with cerebral palsy who helps disabled children in Palestine, Maysoun ____
40. It comes before beauty
41. NY based Nigerian singer works with Divas with Disabilities
43. Down Syndrome actor and singer who played "Corky" Thatcher on "Life Goes On", ___ Burke
46. Road covering
48. Relative
49. The in German
50. Tampa or Tacoma
51. Droopy-eared hound
52. See 11 down
53. Mule of song

D O W N

1. A&E reality show where the performing characters are young adults with Down Syndrome, abbr. - 3 words
2. Location device
3. Colors
4. Hose material
5. Ending for enzymes
6. The home of the International Art Education Center for the Disabled
7. ____ in Wonderland
8. "Push Girls" star who was paralyzed from the waist down but continued her career, Auti ____
11. Actor and comedian, born with muscular dystrophy, who played in the Hulu series "Ramy", goes with 52 across
13. Abbreviation for a popular Will Smith movie
15. Taken __ (surprised)
18. "Chicken ___ For the Soul"
20. "Glee" actress ___ Michele
22. Photographic, as memory
24. Hawaiian island
25. "The Big Bang Theory" character
26. Italian food staples
29. What a joke may break
32. Veer back in the other direction
34. They often get lost in the laundry
35. Augusta's state
37. Legendary Himalayan creatures
38. Actor who played Patton Plame in "NCIS: New Orleans" and started a foundation to raise awareness of spinal cord injury: ___ Mitchell
39. "Fifty First Dates" star, Barrymore
41. Friendly and patient dog breed
42. Half of a matched set

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45-65

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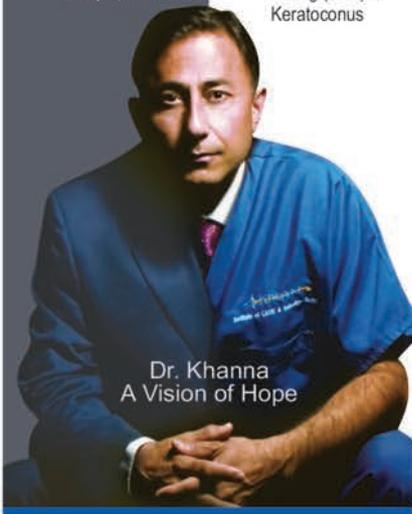
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- Pi in Eye
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- Pterygium
- Intacs & Cross-linking (CXL) for Keratoconus



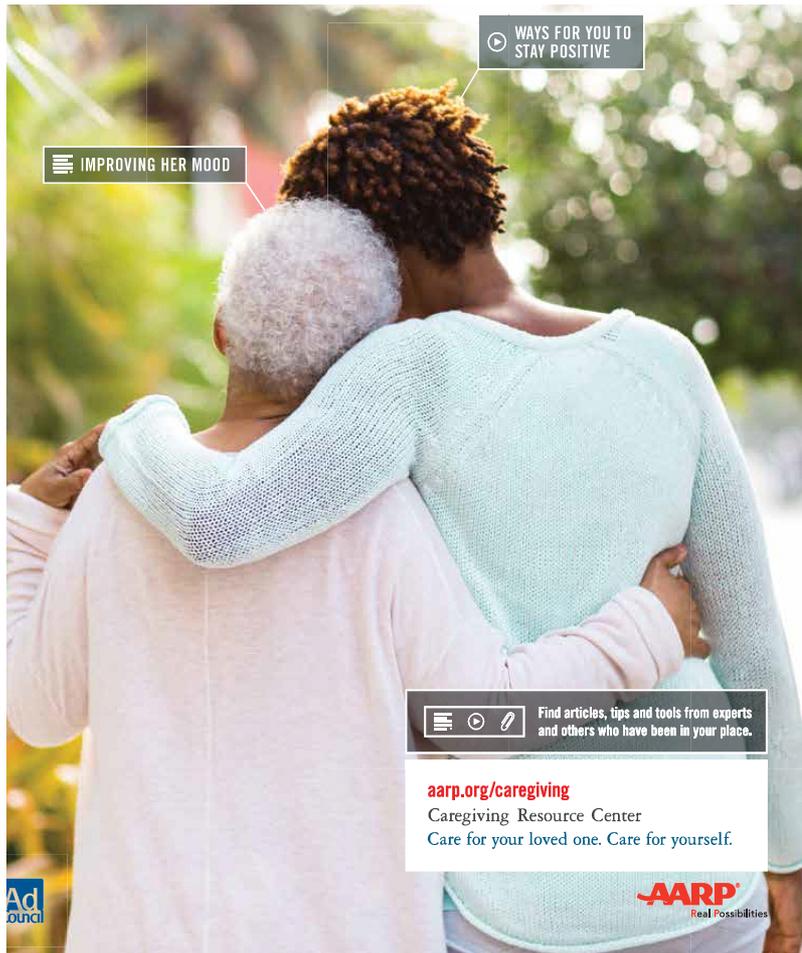
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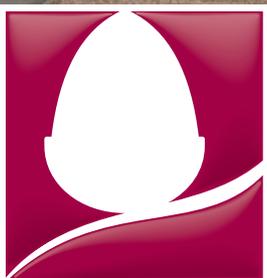
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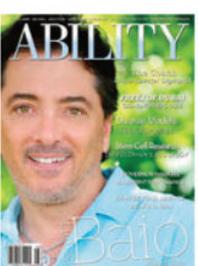
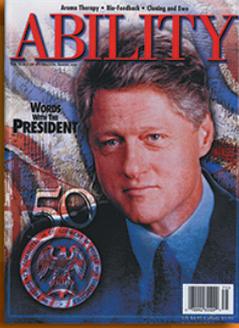


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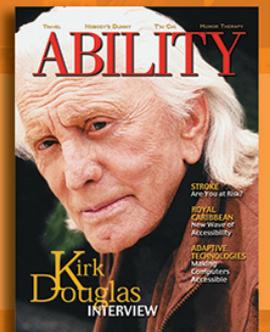
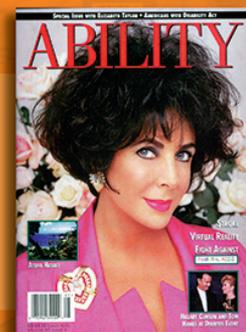
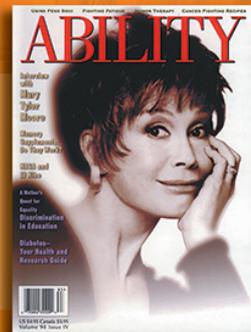
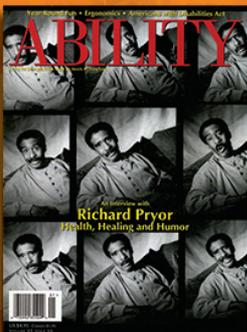
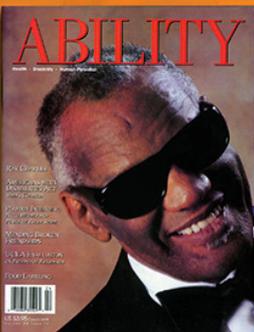
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