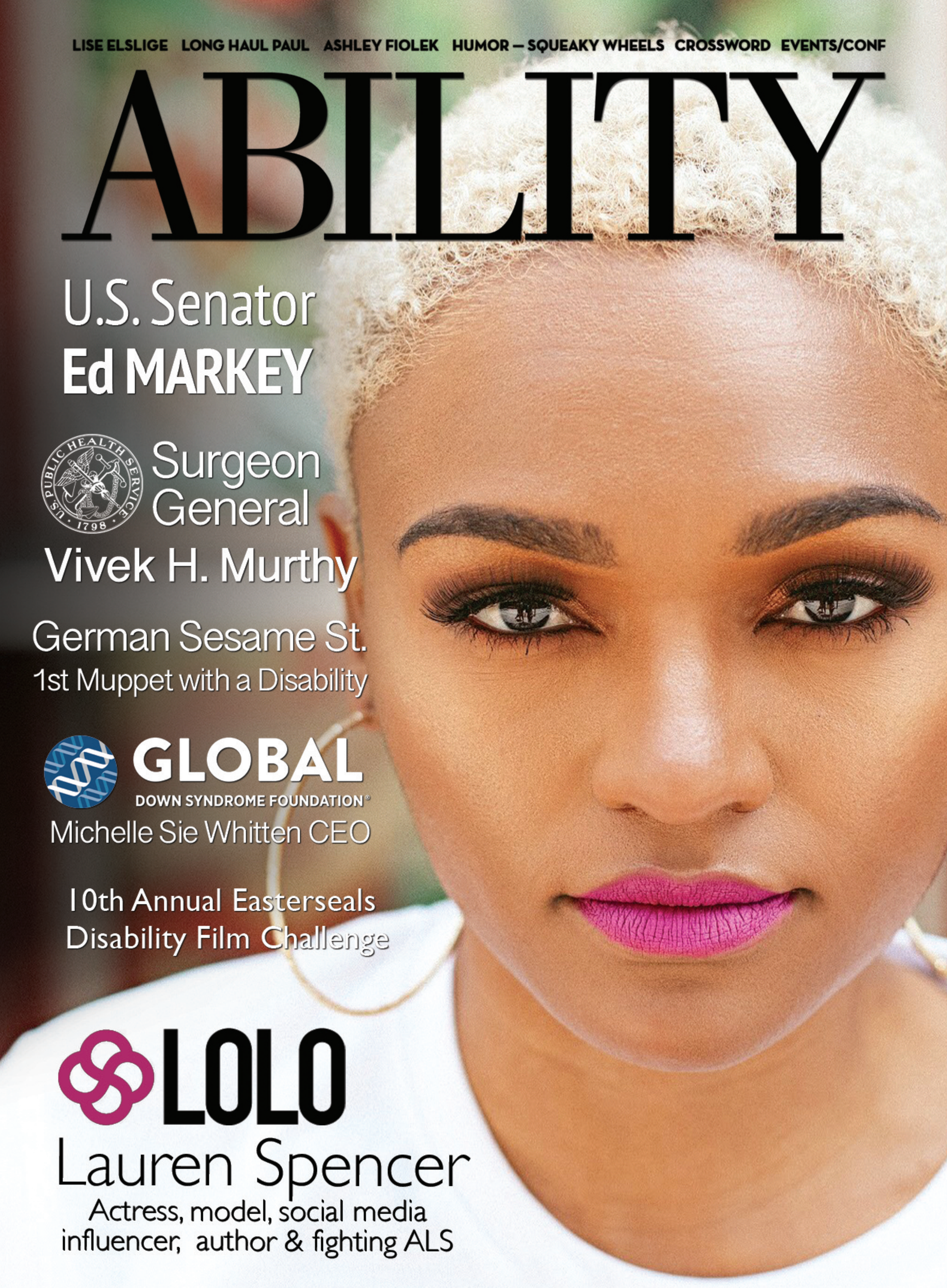
LISE ELSLIGE LONG HAUL PAUL ASHLEY FIOLEK HUMOR — SQUEAKY WHEELS CROSSWORD EVENTS/CONF

ABILITY



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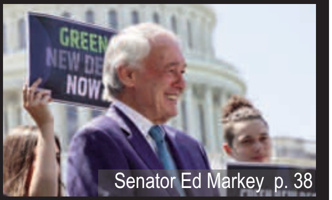
Sesame Street p. 32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Managing Editor
Gillian Friedman, MD

Managing Health Editor
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Humor Writers
Jeff Charlebois
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Editors
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Health Editor
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Regina Hall
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Itto Outini
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Bob Williams (Interactive Puzzle)

Multi-Media
Karina Ulrike Sturm

Graphic Art / Illustration
Scott Johnson
Melissa Murphy (Medical Illustration)

Photography
Jeff Vespa
Paul Pelland
Nancy Villere

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Sandy Grabowski

Translator
Jing Hu
Emily Deng

Marketing/Promotions
Social Media
Jennifer Goga
Lia Martirosyan
Tamay Shannon

AbilityJobs.com
Lori Daly
Vicky Dupree
George Kaplan
Marge Plasmier
Casey Mims
Denise Miller

Editorial
editorial@abilitymagazine.com

Publisher / Editor-in-Chief
Chet Cooper

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

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Ashley and Chet riding at Lake Elsinore MX park

ABILITY's Chet Cooper, a pseudo-motocross rider, caught up with Ashley and her father while the two were in California in 2009. A fierce competitor on the track, her persona off the trac—replete with an infectious smile and a lot of laughter—is equally engaging. Through her father, who served as her interpreter, Ashley talked about the pros and cons of being a young rider and deaf athlete, about her education, and about whom she really wants to beat on the track!

By the age of 17, Ashley had already won 13 Amateur Youth Championships, been featured in Rolling Stone and the New York Times, and was the 2004 America Motorcycle Association (AMA) Youth Motocrosser of the Year. Impressing even industry veterans, Ashley raised her own bar when she won the overall title at the Women's Motocross Association Championship in her rookie year. She also became the first deaf person to win an American Motocross Association National Championship.

Nicknamed Rude Pea—"because I never ride like a sweet pea"—Ashley is bringing women's motocross racing out of the shadows of a traditionally male-dominated sport. As the first woman ever to grace the cover of the industry's popular *TransWorld Motocross* magazine.

Chet Cooper: How does being deaf affect the sport for you?

Ashley Fiolek: I don't think that because I'm deaf I only have disadvantages. There are certainly advantages, too. If people are behind me, it doesn't bother me. There's no pressure from hearing their bikes, although I can see their shadows. The disadvantage is having to hold my line. I don't want to switch lines abruptly because I'll take somebody out. It all evens out.

Cooper: As you travel from country to country, what challenges do you face trying to communicate with people who sign in different languages?

Fiolek: When I first went to Europe, people didn't approach me. They waved and stuff, but they were a little shy. They didn't know how to communicate with me.

Cooper: A lot of people assume that sign language is a universal language, and they aren't aware that it is as varied as spoken languages. Have you experienced different sign languages in the countries you visited?

Fiolek: When I travel, sometimes I meet deaf people and they try to talk to me. They don't understand me and I don't understand them. But it's really cool that they have a different language.

Cooper: If you went to college, what would your major be?

Fiolek: I write a monthly column for *TransWorld Motocross* magazine. I enjoy writing, taking pictures, doing videos. That's probably what I would study.

Cooper: Did *TransWorld Motocross* come to you or did you approach them about writing a column?

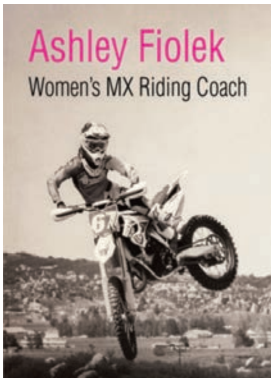
Fiolek: I'm good friends with Donn Maeda, the editor. He came to my house and interviewed me many years ago; we became very good friends. Over time he started an Internet column called "Ashley's Sidekick." That was years ago. After a while, he asked me to write in the magazine.

Cooper: I've read your columns, and you're a great writer. We'd love for you to contribute to this magazine!

Fiolek: That would be very cool. I would be very excited to be a part of that, for sure.

As they say, the rest is herstory.

■ ABILITY



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the SQUEAKY WHEEL

How to Say 'I Swear I'm Actually Disabled and Legit Need Accommodations' with Just Your Eyes

Everyone knows that workplaces are legally mandated to provide reasonable accommodations to those who need them.

But asking for accommodations is just SO humiliating, and nobody wants to be embarrassed when they're starting a new job! Lucky for you, we have the perfect tips and tricks to get you everything you need without ever needing to beg for that dirty little A-word.

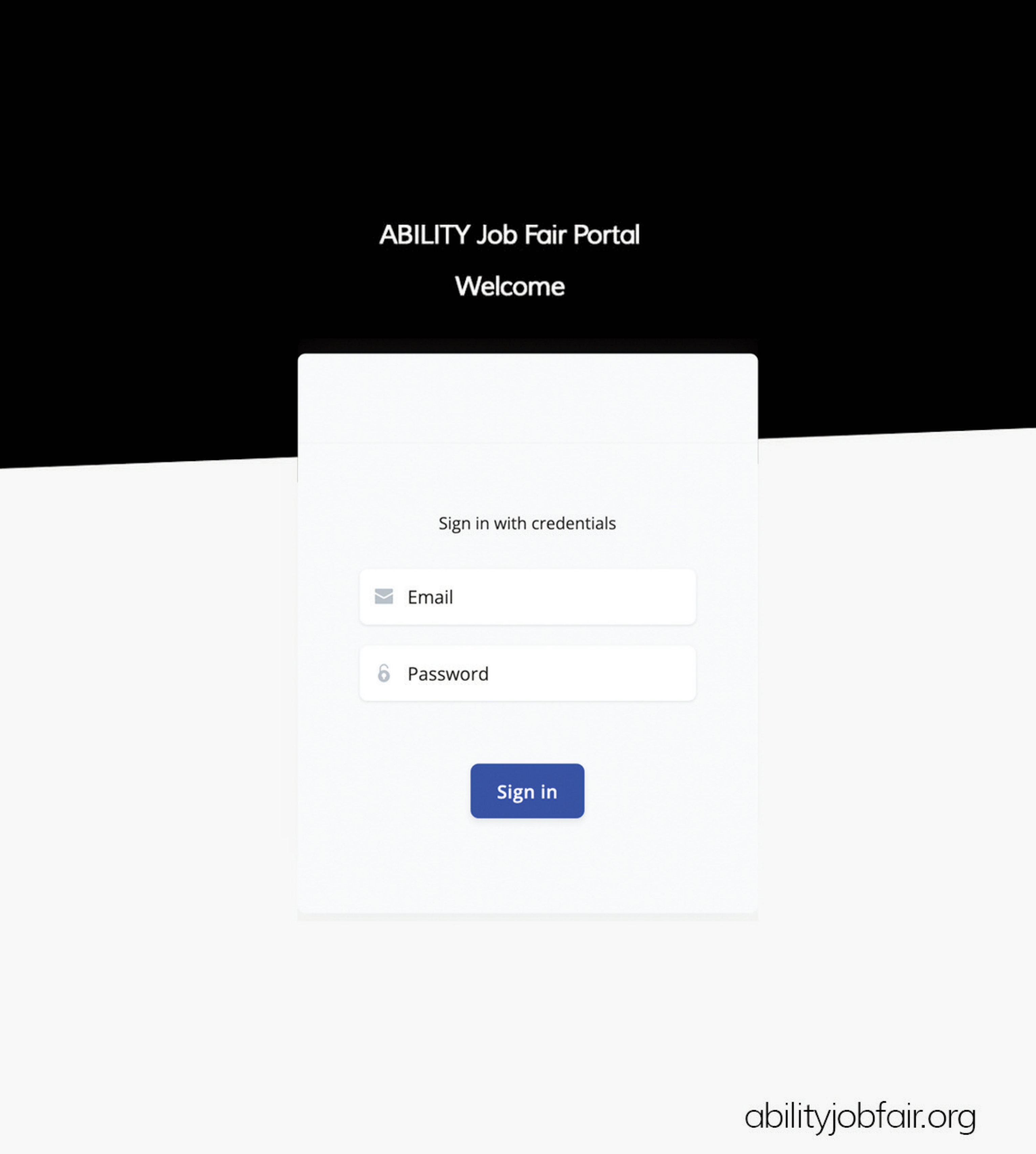
First, use your eyes. Well, just one of them. If your employer asks if you're disabled and need accommodations, say no, obviously, but wink. Aggressively. In corporate culture (and in 1960s cartoons), winking signals that you mean the opposite of what you're saying.

If that doesn't work, keep the conversation alive by "accidentally" leaving behind some cute little clues. Pretend to forget your Adderall prescription in the conference room so you just HAVE to ask a coworker to go grab it for you. If they happen to read it and realize your diagnosis, oopsie!

If your employer is still oblivious after all the winking and misplaced items, you can always try asking for accommodations "for a friend." This is totally normal, and the HR team definitely will believe you if you just say your friend works in a different office and that's why no one has ever seen them before. ■ ABILITY

by Steven Verdile

the-squeaky-wheel.com



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Maintenance by Long Haul Paul

I travelled 13,000 miles over the last three weeks, sharing my story at two different motorcycle events. After checking out my high mileage Tenere 700 at the Yamaha display, I get asked many questions about reliability and my maintenance schedule. There are different types of maintenance schedules, there is preventative maintenance, there is following the factory recommended maintenance, there is maintenance that you do because you have to, and then there are repairs; some expected and some. not so expected.

Looking at my motorcycle, one would bet it had never been washed, never mind serviced!
It ain't pretty, but it is rock solid and dependable, it has to be, as I trust t to take me across the entire country multiple times a month all summer long! (For the record, I did wash it with soap twice this year already.)

Because of the miles I ride every year, following the factory schedule would be overkill and very costly, but I do take care to listen to the bike and fix whatever needs fixing. I do everything myself; from accessorizing to repairs and maintenance. I know my bike and all it's parts almost as well as the engineers who built it. I really have no choice, because if something were to break while I'm traveling, those engineers or factory trained mechanics won't be there with me when I need to get back on the road!

Because the bike is ridden daily by one rider, I can tell when something is worn or in need of attention. While the factory recommends changing the spark plugs every 8,000 miles which is every two or three years for the average rider, I have found them to be within specs even after three times that, and now only change them about


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every 25,000 miles, or twice a year. The tires, brakes and chain all let me know when they need to be changed without even looking at them. The oil and filter get changed almost every time I get back home, which could be anywhere from six to ten thousand miles. I don't worry about oil much, as I do use synthetic and it gets replaced almost every month. I know where all the electrical plugs are located in the wiring harness and which ones will need to be cleaned after a winter of salt coats the connectors. I can tell when the bearings are getting worn by how they spin on the axles because I change my tires about every 5 weeks.

Much like a motorcycle, our bodies need more than just food for fuel and air to operate. Learning to listen to our body's subtle warnings and cry for service is important as we add miles and years to our intricate human machines. Knowing when something is not working as it should and addressing the issue before it gets worse is extremely important. Listening and looking for signs that something isn't quite right is a skill we can master over the years that no doctor's visit could match. Fixing an issue before it gets worse or falls off is just as important when it pertains to our bodies. Unlike a motorcycle, we only get one!

When you live with a chronic illness or disease, it is easy for health care providers to dismiss those new aches and pains as just another symptom or progression of the illness, but sometimes it is just our bodies calling for a bit more maintenance. A good diet and exercise tune-up can sometimes do wonders, and has nothing to do with our disease!

Just because my motorcycle looks like it's neglected and beat to hell, doesn't mean it is. My bike is a well oiled machine and quite possibly the most reliable bike I have ever owned.

Just like my Yamaha, time and circumstance will transform our body's appearance but keeping up on that maintenance will help keep us rolling down the road for many years to come!

■ ABILITY

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Allen Rucker and Debra Calla with their *Lights! Camera! Access!* awards *photo by Chet Cooper*

EXPLORING THE JOURNEY AND FUTURE OF INCLUSION IN ENTERTAINMENT

In 2011, the Media Access Awards made a triumphant return after a three-year hiatus. Deborah Calla, Chair of the Diversity Committee of the Producers Guild of America at the time and writer, producer Allen Rucker, played pivotal roles in reviving this once prestigious black tie event that recognizes successful disability inclusion in media.

In a recent interview with *ABILITY Magazine*, (a former winner of a Media Access Award), Calla shared insights into the background and growth of Media Access Awards (MAA), and the challenges faced by the entertainment industry, including the impact of AI and the ongoing writers' strike. Join us as we delve into Calla's experience and her vision for a more inclusive future with the ongoing impact of MAA.

Origins and Growth

Calla explained that the idea to revive the MAA stemmed from a conversation among the chairs of the Directors Guild, the Writers Guild, SAG-AFTRA and the Producers Guild at a 2010 event celebrating international

Kurt Yaager, Daryl "Chill" Mitchelll and Katherine Beattie *photo by Chet Cooper*

Tobias Forrest, Joe Mantegna, Debra Calla, guest and Allen Rucker

Debra Calla, Ben Lewin, Allen Rucker, David Shore, and guest at the MAA

“The status of the Media Access Awards, which was an organization started by Fern Field and Norman Lear in the late ’70s, came up during our conversation. After losing funding, the event had gone dark. For three years nothing had happened with it, and it seemed like people had just moved on,” Deborah Calla recalled.

That conversation sparked interest in MAA again, and a decision was made to resurrect the event.

“On the day of that first event back, I realized that these awards were something extremely important, and I just knew I needed to devote my time to it,” Calla explained,

During a conversation with writer, producer and disability advocate Allen Rucker, the two recognized their shared commitment to the mission of Media Access Awards. They agreed to work together to ensure ongoing growth and success for the important event.

Under their leadership, the event returned as an annual event for the past 13+ years. A subsequent partnership with Easterseals provided the support necessary for growth of the platform.

“Easter Seals saw Media Access Awards as a way to expand into media representation, and we saw partnering up with Easterseals as a good way to have greater support for the ambitions we had for the event. So, it was a win-win,” Calla said.

Now in its sixth year, the collaboration between MAA and Easterseals has helped the event grow each year, increasing awareness and promoting inclusive representation in media.

Pandemic Pivot

As with so many things, the COVID-19 pandemic brought unprecedented challenges, forcing MAA to shift from live events to streaming them online. For thosee past three years, the Extra TV platform served as the streaming platform for the Media Access Awards.

“We went from doing a huge live event at a hotel ballroom to streaming it online. It was definitely a change,” Calla said.

But Calla expressed appreciation for all those who worked hard to continue the mission of MAA during a very difficult time.

The Writers’ Strike and the Impact of AI

Discussing the ongoing writers’ strike, Calla acknowledged the cascading impact of the work stoppages, affecting not only writers but also actors, directors, and other industry professionals. Despite the challenges, she remains optimistic that such actions are necessary to safeguard the future of the industry.“We are seeing a huge change in the usage of AI in entertainment, and that needs to be addressed. A work stoppage is the only way that you can seriously bring people to the table,” Calla said.

Calla expressed both curiosity and concern about AI. While she acknowledged AI’s impressive capabilities in content creation, she added, “AI was fed data, and data comes from human work. It’s good stuff, but it’s based on original ideas of others’ hard labor, human experience, and that comes from human beings, not from AI.”

Calla believes it is crucial to address the usage of AI in the industry and protect the rights of those who contribute their creative labor.

Looking Ahead

The future looks bright for Media Access Awards. Its next event is slated for this Fall. There are discussions underway to potentially expand the MAA reach even further with a new broadcast and streaming partner. Calla explained that those negotiations are ongoing and will likely impact the exact date for the next Media Access Awards event.

The leadership of Deborah Calla and Allen Rucker leadership at MAA has had an impact on promoting disability inclusion and creating a more representative landscape in media. Despite the current challenges faced by the industry, Calla’s optimism and determination are evident as she enthusiastically talked about the history and future for Media Access Awards. ■ ABILITY

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U.S. Surgeon General Vice Admiral Vivek H Murthy

Feeling lonely? You're not alone. According to US Surgeon General Vivek Murthy (our country's 19th and 21st Surgeon General, serving under both the Obama and Biden administrations), even before the onset of the COVID-19 pandemic, about half of US adults reported significant experiences of loneliness – including Murthy himself at various points in his life. In his recent Surgeon General's Advisory on Our Epidemic of Loneliness and Isolation, as well as his captivating new book Together: The Healing Power of Human Connection in a Sometimes Lonely World, and his wellness-centered podcast House Calls, Murthy makes the case for viewing loneliness as a significant public health issue. Loneliness affects not only our emotional health, says Murthy, but also physical health, increasing the risk of heart disease, stroke, and premature death, as well as depression, anxiety, and dementia. Loneliness significantly drives up health care costs and other economic costs. Fortunately, Murthy also outlines many things we can do – as individuals, community organizations, workplaces, health systems, and governments – to facilitate improved social connection and lessen what he describes as our epidemic of loneliness.

Born in Northern England to a family of Indian descent, Murthy emigrated with his family in early childhood first to Canada and then to Miami when he was 3 years old. Valedictorian of his high school class, Murthy went on to attend college at Harvard University, graduating magna cum laude with a Bachelor of Arts (BA) in biochemical sciences. He earned a Doctor of Medicine (MD) degree from Yale School of Medicine and a Master's of Business Administration (MBA) from Yale School of Management, then completed residency training in internal medicine at the prestigious Brigham and Women's Hospital and Harvard Medical School.

Public service was an early focus for Murthy, even before he was clear about his future path in life. As a college freshman in 1995, Murthy co-founded VISIONS Worldwide, a nonprofit organization focused on HIV/AIDS education in the US and India. Two years later, he co-founded the Swasthya Community Health Partnership, which trained women to work as community health workers and educators in rural India. In 2008 – just around the end of his residency training—Murthy founded Doctors for America, now a nonprofit organization of more than 27,000 physician and medical students advocating for improving affordable healthcare access. Prior to his first term as US Surgeon General, Murthy served during Obama's first presidential term on the Presidential Advisory Council


MURTHY
U.S. PUBLIC HEALTH SERVICE

on Prevention, Health Promotion, and Integrative and Public Health, advising on strategies and partnerships to advance the nation's health through prevention measures. In November 2013, Murthy was nominated by President Obama to assume the post of US Surgeon General, the nation's top doctor and operational head of the US Public Health Service. Murthy's nomination received the public support of more than 100 US medical and public health organizations, and the endorsement of two prior surgeons general.

Murthy recently sat down with *ABILITY Magazine*'s Chet Cooper and Gillian Friedman, MD, to discuss his route to discovering the scope and significance of loneliness, as well as how we can combat it.

Chet Cooper: Did you always know you wanted to be a doctor?

Surgeon General Vivek H. Murthy: My parents are doctors and had a private practice. As a kid I would spend a lot of time there, greeting patients as they came, sorting papers, cleaning the office. I really fell in love with what they were doing, which was building beautiful relationships with patients. And even though I was too young to understand the science of what was happening, I did understand the humanity that the patients were experiencing, and that my parents also benefitted from the beautiful connections they were creating. So that inspired me to go into medicine.

But then there was a phase for about five or six years where I went in a different direction. I got really interested in history and in English literature and economics. I was thinking maybe I would do something in one of those three fields. It was my work in HIV when I was in college—my sister and I built a nonprofit organization that focused on HIV education in India at the time and later in the US—that brought me back to health and to medicine, because I realized how much I really did want to be a part of improving people's health and learning about their lives in the process.

Cooper: What does your sister do? Is she also a doctor?

Murthy: She is, yes. She's a family medicine doctor in Miami. In fact, she and my dad practice together. He also does family medicine. Some years ago they wanted me to move to Miami and to practice with them so we could be a family family practice, you know? I actually applied for a medical license in Florida and I was thinking about it seriously. It was right around that time that the White House called me and asked me if I wanted to be considered for the position of Surgeon General, and I ended up going down a very different path. Had it not been for this job, I could be in Miami right now practicing medicine with my dad and sister.

Cooper: So the Zoom background would be different from what I'm seeing now, more of a palm tree setting?

Murthy: (laughs) That's right! I'd be on the beach, perhaps.

Cooper: I would love to continue this—you're very personable—but I'll let Gillian, Dr. Friedman, ask some questions. There's a connection between the two of you that she'll talk about in a second.

Dr. Gillian Friedman: I was an English and economics major who always thought as a kid that I would go to medical school, but then I also got sidelined for a while. Similar a little bit in that respect. I'm interested in the fact that you're a Surgeon General with a podcast.

Murthy: (laughs)

Friedman: Which is really good, the House Calls podcast. That's unusual for somebody in sitting office of any kind. And the podcast is about wellness, not about medicine per se. I'm curious, how did that come about for you? How did you choose that platform?

Murthy: I spend much of my job talking, but what I really like doing is listening. It's something I did a lot as a doctor, spending time with patients and listening to their stories. Not only was it helpful for me in figuring out how to diagnose and treat them, but I also felt as though I learned a lot just by listening to people's life experiences. The podcast was an opportunity for me to do some listening and to try to bring out some of the wisdom in lessons that other people had gathered through their life experience and to share that with folks across the country. That was why we started the podcast.

A lot of our podcast sessions focus on the broader topic of well-being and how we can create that, whether it's through our relationship with technology, renegotiating that, or whether it's how we refocus our lives on relationships, how we deal with conflict, how we manage anxiety in our lives. The conversations go in many different directions, but they're all centered around how to create a life that is filled with good health, happiness and fulfillment in a world where sometimes that can be really difficult, where we're pulled in so many different directions, where the pace of life is so incredibly fast, and where there's so much pressure also to focus on a particular definition of success: how much fame do you have, how much money do you have, how much power do you have, how fancy is your job. These are the things we tend to associate with success.

Over the years when I've sat with patients toward the end of their lives and talked to them in those final days about what truly made their lives meaningful, they would talk about their relationships, the people they loved, the people they wished they had shared more time with, the people who loved them. They didn't talk about how much money they had, how big their office was, how fancy their job was, how long their curriculum vitae was. It struck me that we don't have to wait until the end of our lives to understand what truly makes us happy. We can recognize and start living a life that's consistent with that right now. That's what the conversations are often about, trying to understand what can really drive health, happiness and fulfillment in our lives and how we can work together to make a better reality.

Because this work is hard to do on our own. But if we know that there are others out there who are trying to walk down a similar path, who are trying to define success through their relationships and their contribution to the world, as opposed to through how many followers they have on social media or how much money they have in their bank account, that makes it a little easier to walk that path.

Friedman: How did you start focusing on loneliness. I just want to highlight the significance of a Surgeon General putting out an advisory about loneliness as a public health epidemic. We think of the word epidemic as meaning really widespread, something we want everybody to be aware of. How did you hit upon that?

Murthy: It certainly wasn't in the original plan, I'll tell you that. When I first started as Surgeon General, I had a bunch of other public health issues I wanted to work on, and I did work on many of them: the opioid epidemic, the e-cigarette crisis we had among youth, and many other issues that came up along the way, like Zika and Ebola and then of course COVID-19. But one of the things I realized in having conversations with people around our country is that people were actually struggling with loneliness. It kept coming up in conversation after conversation, often in subtle ways, with people telling me how invisible they felt or how they felt that they were carrying so many burdens in their lives and had to carry them alone.

I was talking to college students on campuses who were saying, "Yeah, I'm surrounded by thousands of other students, but there's no one with whom I can really be myself, who gets me. I feel really alone." Hearing that again and again made me realize that there was something happening here. It reminded me of the many conversations I'd had with patients over the years where I'd realized that they may have come in for pneumonia or a blood clot, but they were actually struggling with loneliness in the background. It reminded me of my own experiences struggling with loneliness as a kid and being too ashamed to talk about it. That shame is really important to recognize, because it's what keeps loneliness in the shadows. It's why one in two adults in America report measurable levels of loneliness. But we wouldn't know it because to all the outside world it looks like people are getting together all the time, that they're surrounded by lots of people, that they're laughing and having a wonderful time, because that's what people post on social media. That's the exterior face we put on for the rest of the world. Yet inside, there are a lot of people who are struggling.

So I decided to put that advisory forward, a Surgeon General's advisory for the first time on loneliness and

isolation, because I wanted to pull this issue out from the shadows. I wanted people to know they weren't alone if they were struggling, and I also wanted them to know that this really is a public health issue. Because when people struggle with being socially disconnected, it raises their risk of depression, anxiety, and suicide and also increases the risk of heart disease and stroke and dementia and premature death. When you have a risk factor that's impacting so many people, it's time for us to address it as a public health issue.

Friedman: That was one of the things I was struck by in reading your advisory—the stakes of addressing it. I'm a psychiatrist by training, so certainly I'm aware of how clinical depression can affect health. But you're talked about something broader than that. It might raise the risk of depression, for instance, but it can affect people even if they are not meeting criteria for a diagnoseable mental health condition.

Murthy: That's exactly right. It's a risk factor that impacts so much of our lives, not even just our health. It turns out that when we are struggling with being socially disconnected, it impacts how we perform our work. We're less creative, less engaged, less tied to our work, and that impacts our productivity in profound ways. It also impacts how our kids perform in school, and our level of civic engagement. It creates what I believe is a sense of division and polarization that's been growing over the years. Whether you care about health, or creating a community that is more unified, or having better productivity and better results in workplaces and schools, it turns out that building a more connected life helps in all those areas.

That's why I see our connection with one another as part of what fuels us as human beings. It's foundational to our lives, and building a more connected life in a more connected world strengthens that foundation. Everything we build on top of that, whether individual pursuits or the organizations that society depends on, becomes healthier and stronger.

Friedman: I was additionally struck that the statistic that you referred to – that one in two people are affected by loneliness – is a pre-pandemic figure. Also, the word epidemic – beyond meaning widespread – implies a condition different from previous eras, from a different cultural situation. Do you have any thoughts about how we got to this epidemic of loneliness?

Murthy: I'm really glad you raised that. The pandemic poured fuel on the fire of loneliness, but the fire was burning long before. In fact, we've seen for probably a half century or more declining participation in so many of the organizations that used to bring us together, like religious organizations, recreational leagues, other service-based and community organizations. But we've also had other changes in the last couple of decades. The introduction of all kinds of technology into our lives has been a boon in many ways. It's made us more efficient in some ways. It's given us opportunities to get groceries and packages and goods delivered to our houses, to come to us without our even having to leave our homes. But therein comes also the potential downside, which is that our opportunities to interact with one another have also declined.

Sometimes we don't think about that incidental interaction we have with somebody at the post office or the grocery store or waiting in line for coffee at the coffee shop. We don't always think of those as important or consequential. But it turns out they really are. One of the experiences highlighting this was COVID – that first year of COVID, in particular, where people really pulled back from their interactions with one another. I remember talking to so many people on the phone who would say, "You know, I just miss sitting in a coffee shop and being around other people. I miss walking in the mall and seeing other people out there. I miss just seeing other people, whether I know them or not."

As human beings, our need for connection is profound. We need the intimate connections, connections with spouses and best friends with whom we can get support. We need friends in our lives, people we can have birthday parties with, go on vacation with, take in a movie or a game with. But we also need a broader sense of community where we feel we belong. It could be people we work with, people we volunteer with in our community, our neighbors. These different levels of connection are important. I think of them as intimate connections, relational connections, and collective connections. And the reason that's important to know is that if you are, let's say, in a really fulfilling marriage but you don't have friendships and you don't have those collective community connections, you may feel lonely. And if you don't know that there are these different types of connections that we need in our lives and you're that person's spouse, you might think, "Gosh, this is my fault. If they're lonely, it's probably because our relationship isn't fulfilling."

However, that may not be the case at all. In fact, I say this as somebody who experienced loneliness at a time when I was in a very fulfilling relationship – and continue to be – with my wife, Alice. But the problem, which she herself in fact diagnosed, was that I wasn't spending time with my friends. I had lost touch with so many friends. And once I rebuilt that, gosh, I felt so much better, so much less lonely. But it wasn't about my relationship with my wife.

Friedman: I want to make sure I turn back to Chet and let him ask some questions. Thank you.

Murthy: That was great.

Cooper: Thank you, Gillian. I think the most important question is, how do you say to people, "I'm a General and a Vice Admiral"?

Murthy: (laughs) I keep it easy and simple. I just tell people, "Call me Vivek," that makes it really easy. That's what my friends call me. Otherwise people do get confused on what to call me. And technically I'm referred to as a Vice Admiral by rank, even though my title is that of Surgeon General. Sometimes that can get confusing.

Cooper: How do you choose who to be on your podcasts?

Murthy: That's a good question. It comes in different ways. Sometimes I'll read an article or a book that somebody wrote and it'll inspire me. Sometimes my team will have ideas about who we should talk to. I have an endless list of people with whom I want to have conversations. I'm just hungry to learn more about different pathways for creating well-being. The truth is, I'm a student of this as well. Like all of us, I've picked up a lot of lessons along the way, but I've got a lot more to learn. To me, one of the most important things we can do is to have conversations about these topics, recognizing that we all have different lives, but every now and then, something you hear about how somebody navigated a particular hardship in their life or a tool that they have or a life hack, if you will, that helps them manage some sort of challenge, sometimes that can help you. Not just help you in giving you a tool, but sometimes hearing these conversations can remind us that these issues are priorities, that as much as our lives in society are centered around work and traditional achievement, there are other things that may contribute as much if not more to our happiness and well-being.

So being a part of these conversations can sometimes draw in me and I hope our listeners that it's okay to prioritize your relationships, to prioritize physical activity, because that impacts your physical and your mental well-being. It's okay to think about how to carve out time for yourself, because we all need some time to ourselves to be able to let ourselves settle and ground ourselves, to let that noise settle around us that sometimes distracts us and prevents us from figuring out what really matters to us in our lives. I want people to feel that

they have permission to make those things priorities. I think that's what creates the foundation for health and well-being – when we've got healthy time with ourselves, we're building healthy relationships with others, and we have the permission to focus on things like exercise, diet, and other types of activities and practices that sustain us.

Cooper: Gillian has done so much in the mental health space, not just because of her career as a psychiatrist, but as a volunteer. Her efforts dealing with issues around suicide in the military, her nonprofit support, for example with ABILITY Corps and Habitat for Humanity. We build houses for families of low income with disabilities, and we access volunteers with disabilities to build the homes.

Murthy: Oh!

Cooper: There are so many great stories of people who had life-changing experiences volunteering and building someone a home.

Murthy: Just hearing a little bit about what you're doing, especially for the disability community, I so appreciate that. It's actually very relevant to what we were just talking about. One of the areas that we call out in our advisory on loneliness and isolation is that some populations are affected more than others. We want people to be cognizant of that. For example, many people are surprised to know that young people struggle with the highest rates of loneliness. They may be surprised to know that when you are dealing with severe illness, or if you're differently abled, or if you struggle with other challenges – such as past trauma, for example – that can all impact your ability to see other people, whether it's to physically get out and interact with other people or whether it's your psychological comfort and willingness to do so.

If we recognize just how important and consequential loneliness is, my hope is that as a society we can also recognize who is at greatest risk and take extra steps and efforts to make sure that people feel included. We can do this partly through simple things like checking on one another. When you know that it might be hard for somebody to go out and see others, when you know that they're struggling at home, whether with their own illness or taking care of a relative who may be struggling with an illness, it's important to check on them and to recognize that what we see on the outside, the brave face that everyone always tries to put on, doesn't always reflect the reality of what they're experiencing inside.

Sometimes it's just a simple call to someone who might be struggling or having a tough time. It can be a lifeline for them and can help them during incredibly difficult moments. The bottom line is, however you look at it, we all need each other. We're better off when we're connected in healthy relationships. My hope is that if we understand that, we can create the kind of society where everyone is included and no one is left out. Right now, there are too many people who are feeling left out, whether it's on the basis of their health and abilities, their race and ethnicity, their beliefs, whatever it might be. People for one reason or another are feeling that they don't belong and don't have a chance to be a part of a real community, and that hurts all of us. That's one of the key messages from our advisory: we should all be vested in how connected we are as a community, and when we talk about community, inclusion is a key component – that everyone is a part of that community.

And it starts locally. This feels like a big problem – one in two adults struggling perhaps with loneliness, that can seem overwhelming – but it starts locally. My hope is that people will think about the folks around them in their neighborhood, at work, their family and friends, and recognize that when we want to address loneliness, sometimes it's just reaching out to someone for 15 minutes a day to check on them and see how they're doing. That can make a difference. It's also making sure that when we are reaching out to people, we're giving them our full attention, that we're not distracted by technology when we're having dinner with a friend or when we're talking to a loved one or we're saying hello to a work colleague.

And just finding ways to serve others. Gosh, that's one of the most powerful antidotes to loneliness. Counterintuitive, perhaps, but it turns out that when we help other people, we forge a connection with them, and we also remind ourselves that we have value to bring to the world. That's something we can forget easily when we struggle with loneliness. We can start to feel we're not worthy of connection, that we're not likable or lovable in some way. And service reminds us that's not the case.

Friedman: Do you see that in the reverse also, that when you invite others to help, it has that benefit for them?

Murthy: That's absolutely right, and I'm so glad you said that. It can be really hard to ask for help. But asking for help is not just about you getting help – the person helping benefits, too. I'll tell you one small story that illustrates this, although I'm not recommending people do this. When I was working on a big writing project some time ago, I would spend time at a grocery store, in the cafeteria area. I would just be working and writing all the time. I was on my computer. I was there alone. But sometimes I wanted to go and get something to eat, go to the rest room, take a two-minute walk, just to get some fresh air. But what was I going to do with my computer? It was sitting there, with all my wires, bags, everything. I got to know over time some of the people who were sitting around me because there were some regulars, and I would just ask them, "Can you just watch my stuff for a couple minutes?" I was asking them for help. And while it seemed like that was really small, I'll tell you, it felt really good to be able to ask someone for help and to have someone step up and say, "Yeah, sure, I'll do that for you." They didn't know me and I didn't know them, but we were having this really human reassuring moment where we both stepped up to be there for one another. And that always felt good to me, to ask for help.

I know it can be hard sometimes to ask for help. We live in a culture where we're told, "Hey, you should be independent," and that means you shouldn't need anyone. But that's not consistent with being human, because as human beings we all need each other. We'll have moments where we need help and when we have a chance to help other people. So just remember, when you're asking for help, you're not just helping you. You're giving someone else an opportunity to do something that will help them, too.

Cooper: I had mentioned earlier that Gillian had a connection with you that she didn't know about.

Friedman: Oh! Doctors for America. I had no idea you founded Doctors for America.

Murthy: Oh, my gosh!

Friedman: I've been active with them.

Murthy: Wow! What a wonderful throwback! I love it. (laughs)

Friedman: I wasn't founding nonprofits in my undergraduate years and early medical school – I was just trying to get through my schooling. (laughs)

Murthy: (laughs)

Friedman: But thank you for doing that!

Murthy: I'm so glad that we did this. It was really good to talk to both of you. I so appreciate the work you're doing in the world.

Cooper: I'll start listening to your podcast.

Friedman: Thank you. It's so nice to meet you.

Murthy: It was for me, too. Take care. I'm glad we did this. ■ ABILITY

hhs.gov/surgeongeneral

10th Easterseals Disability Film Challenge Awards

Reaching a major milestone, the Easterseals Disability Film Challenge celebrated ten years of challenging and highlighting disabled filmmaking talent. With over 600 films since its inception, the awards were held at the Cary Grant Theater at Sony Studios drawing celebrities like Jameela Jamil and Peter Farrelly. *ABILITY Magazine*'s George Kaplan interviewed some of the nominees and presenters in attendance on the orange carpet.

This year's overarching theme, romance and passion for filmmaking, was definitely in the air. Seeing the disabled filmmaking community in full force and networking, it was hard not to feel inspired. Among the presenters were "Russian Doll" and the soon-to-be-released "Across the Spider-Verse" actor, Danielle Perez, Stephanie Nogueras of "Killing It" and actor and fashion designer, Natalie Trevonne.

Best Actor Winner, Layne Apffel, from “Rain in My Head” along with actor Sophia Morales and writer Chrissy Marshall

Mark Whitley, Guest, Beatriz Mallory, Nancy Weintraub, Mark Bertrand, Nic Novicki and Maria Serrao

"I owe a huge debt to the Disability Film Challenge." said Perez. "Nic [Novicki] creating this space where people can be seen, I can be seen. I can have community, I can connect with producers and writers and other actors. This community is so important to my success and to all of our success. As we become more successful, we're then able to say, 'Oh, I want to bring them along. I want to give a role to them. I want to give them an opportunity.' We all get to rise together. That's what's really important."

Trevonne added "The way I've seen it evolve is that so many more people are seeing themselves represented and wanting to get involved. Every year, the number of films just increased and increased. And you can tell that the excitement of wanting to be a part of the entertainment industry and really see ourselves is growing. And that's what I love most about it."

On the films themselves, Nogueras said "I'm hoping that when other people view these films, they'll see that there are stories that they weren't aware of. It'll open their minds, open their soul. They'll start to get curious and get to know these people who just happen to have a disability, and that's all. They'll become more comfortable and familiar, more welcoming, and provide more opportunities, at least I'm hoping so."

Sweeping three major categories, "Rain in my Head" took home Best Director for Chrissy Marshall, Best Actor for Layne Appfel and Best Film.

"This is my second year doing Easterseals Disability Film Challenge." said Marshall. "I always loved coming here and meeting all the other disabled creatives. I was really fortunate to meet a woman named Marie [Alyse Rodriguez], and she has her own film production company. And she introduced me to the lovely faces of [cinematographer Camilo Godoy and assistant director Sebastian Gonzalez] here, who helped me bring the whole project together. And then I've worked with [actor] Sophia Morales before, so I already knew that she's an amazing talent that I wanted in all my films, honestly. And same goes for Layne. They're both so incredibly talented, and I've seen them work in a bunch of different mediums, and they nail it every time.


Stephanie Noguer and Lolo Spencer give the Best Actor Award to Layne Apffel for "Rain in My Head"

The main point of our film is deafness is not a monolith. And people who grow up with different experiences and different accessibility needs have different access to sign language and language in general. And also as a queer woman myself, I really wanted to dip my toes into getting some queer representation as well."

In addition, the films "Smash or Pass", "Unlucky in Love" and "Leap of Love" won Best Editing, Best Writing and Best Awareness Campaign respectively.

"We're in such an exciting space right now. The world is finally taking note that there is a lot of talent, a lot of humor, and a lot of very unique perspectives within the disabled community." mused director and actor of "Leap of Love", Madison McLaughlin. "I think that people being able to create their own content, especially on TikTok and YouTube, has been really cool to see. Studios are starting to take note. So, I would love to see more content creators that are disabled, more actors, more people behind the camera that are disabled, get these really big, incredible deals with these huge studios because I think it's about time that representation is here."

McLaughlin continued, "Our film is a satire comedy. It really was born because my sisters and my best friend and I are all obsessed with reality dating shows, and we're all really frustrated at the lack of representation there. And so, we decided what would a reality dating show look like with disabled people. But if the producers were just maybe well-intentioned but definitely not well educated. And so that's how the satire scene was born."

The film challenge not only showcases talent, winners walk away with some amazing prizes: mentorship sessions with entertainment executives and talent, $2000 grants furnished by NBCUniversal, Dell computers, a one-year subscription to Adobe Creative Cloud and IMDb Pro, and screenings at Academy Award-qualifying festivals.

"It's really all about changing the way people see disability and television and film is what that's about." said president and CEO of Easterseals Southern California, Mark Whitley. "When you consider the power of television and film, I think the film challenge has helped to leverage and to put people with disabilities out front. And so many people have been involved in the film challenge and then also went on to get jobs in front of and behind the camera."

After seeing the awarded films at the night's festivities, the future of disabled talent looks bright. And with the involvement of major studios sponsoring each award, it looks like they're finally catching on. ■ ABILITY

disabilityfilmchallenge.com


SESAMSTRASSE
ROLL/CARD
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SCENE
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TAKE
1
FPS
DIRECTOR: Dennis Jacobsen
CAMERA: Robert Naczynsky
DATE: 18.03 2023
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Meet Elin, The German Sesame Street's First Muppet with a Disability

A muppet with a disability moves into the German Sesame Street: Elin. Elin uses a wheelchair to get around, but her disability is only a tiny portion of her identity. Elin is a young girl who likes tinkering with tech, talks a bit much, and sometimes mixes up words. She is now a permanent and regularly appearing character in "der Sesamstraße" on the German TV channel Norddeutscher Rundfunk (NDR).

Same Street Around The Globe

Who hasn't at least once heard of the Sesame Street? Who doesn't know the cult characters, Ernie and Bert? People of all ages can relate to the colorful, quirky, and fun muppets that live on the most famous street around the globe, Sesame Street. The show combines live-action, animation, and puppetry to educate children in basic academic and life skills, for instance, literacy, problem-solving, and socialization. It is probably the only street known across the whole globe and one of a few shows that managed to survive over decades. Thirty countries co-produce their own version of Sesame Street, all with a slight change in muppets and the stories they tell, which are adapted to the cultural background of the country. For example, Sesame Street in India is called Galli Galli Sim Sim.

The German Sesame Street

And it all started in the US! The first episode of Sesame Street was aired in 1969, and since then,

Ernie and Bert; Image by NDR/Sesame Workshop

PBS has produced 53 seasons! Behind all Sesame Streets across the globe stands a non-profit organization that ties them all together: The Sesame Workshop, a US non-profit supporting children in 150 countries across the globe. Without them, the German Sesamstraße would not exist. Some of the most popular characters are Elmo, a red muppet monster, Big Bird, a pompous yellow bird, and the Cookie Monster, a prominent and fluffy blue muppet. Germany's Sesamstraße features most of the characters from the US original, with some additional ones, for example, Samson, a huge, brown bear-like character, and, of course, the most recent development Elin, a girl who uses a wheelchair.

The most significant difference between Sesame Street in the US and Germany is that they target different age groups. "Our American colleagues start at around two years of age, while our narratives in Germany require the children to be around four to five years old. Additionally, in the US, they use more didactic elements than we do in Germany," Dirk Junk, Sesame Street Producer, explains. Each episode of Sesame Street is complexly crafted to convey a core message to the audience. The producers pick one specific topic, which will then be split up into several segments consisting of puppetry and documentary clips, all to educate children in a fun and exciting way. That's Junk's job. He develops the content for the episodes. A dream job? He laughs. "Yes, it is so much fun! Even though I haven't planned to become part of the Sesamstraße, I am really happy here."

Building a Role Model

On April 12, 2022, producer Junk received an e-mail from Equal Opportunities Officer at the NDR René Schaar, who asked Junk how he felt about diversifying their muppets. One day later, during a conference with editor Holger Hermesmeyer, Schaar brought up Ameera, a green muppet that is a part of the Sesame Street of North Africa and the Middle East. "Ameera loves math and sciences and plays basketball but also uses a wheelchair. And we needed a character like that in Germany, too." Schaar stepped out of his usual role at the NDR, where he is responsible for the diversity and equality of the channels' employees, but not the content of the TV program. "I didn't really have the capacity to develop a new character for the Sesamstraße, but since this was so close to my heart, I just did and still continue doing it on top of my regular job," Schaar, who lives with a limb difference himself, says. After Schaar discussed his ideas internally with the team at NDR, they reached out to the Sesame Workshop. Together, they brought the new character Elin, a girl with a disability, to life. One year after Schaar's initial input, the muppet was finalized and ready to be played.

Ernie and Bert; Image by NDR/Sesame Workshop

First Disabled Muppet

Elin will be a permanent character in the German show. She isn't only occurring once for the annual celebration of the international day of People with Disabilities but will be included in all activities at the Sesamstraße. "And there is no particular focus on her disability. You can see that she has one, but it is not constantly discussed in the show," Schaar says. Elin's disability is a part of who she is but not the center of attention, even though some episodes try to naturally bring in topics such as accessibility. For instance, in one episode, Elin and her friends are building soap boxes, but there is no hill around, so they discuss they might need a motor or won't be able to compete. Elin says she'd prefer a chain drive like those on bikes to protect the environment. Her friends agree. However, they all stare at Elin, questioning how she would ride a bike since she cannot paddle with her legs. Finally, they realize even though Elin cannot ride a regular bike, she can certainly use a hand bike. Her disability is casually mentioned in that context, but then everyone moves on to build their soapboxes for the competition, and Elin gets one with a hand drive. "It was long overdue that a disabled character moves into the German Sesamstraße because the show might be the very first time children come in contact with the topic of disability, and then we want to present it in a potential-oriented, positive but non-inspirational, solution-oriented, pragmatic and unemotional way," Schaar states. "We need to break the taboos around disability and show that living with a disability isn't sad or unfortunate; it can be cool!"

Who Is Elin?

Elin is Elmo's best friend. She loves technology and everything that has to do with science, technology, engineering, and math (STEM). She's a bit cheeky and sometimes thinks too fast, so she cannot find the right words. "Elin loves to tinker, which is unfortunate for her parents because once she lost one wheel of her wheelchair. But she promised to never do that again," Schaar laughs. Additionally, Elin has Turkish roots. Her grandparents immigrated to Germany from Turkey. "This opens up other options for us to discuss different areas of diversity in the future," he adds. The NDR finished filming its 50th season at the end of March 2023. Elin makes her first appearance with Krümelmonster (Cookie Monster) in a game show episode called Prima Klima, which addresses environmental issues and protection.

Nothing About Us, Without Us

Schaar brings in his personal experience to ensure Elin accurately represents people with disabilities. "Every

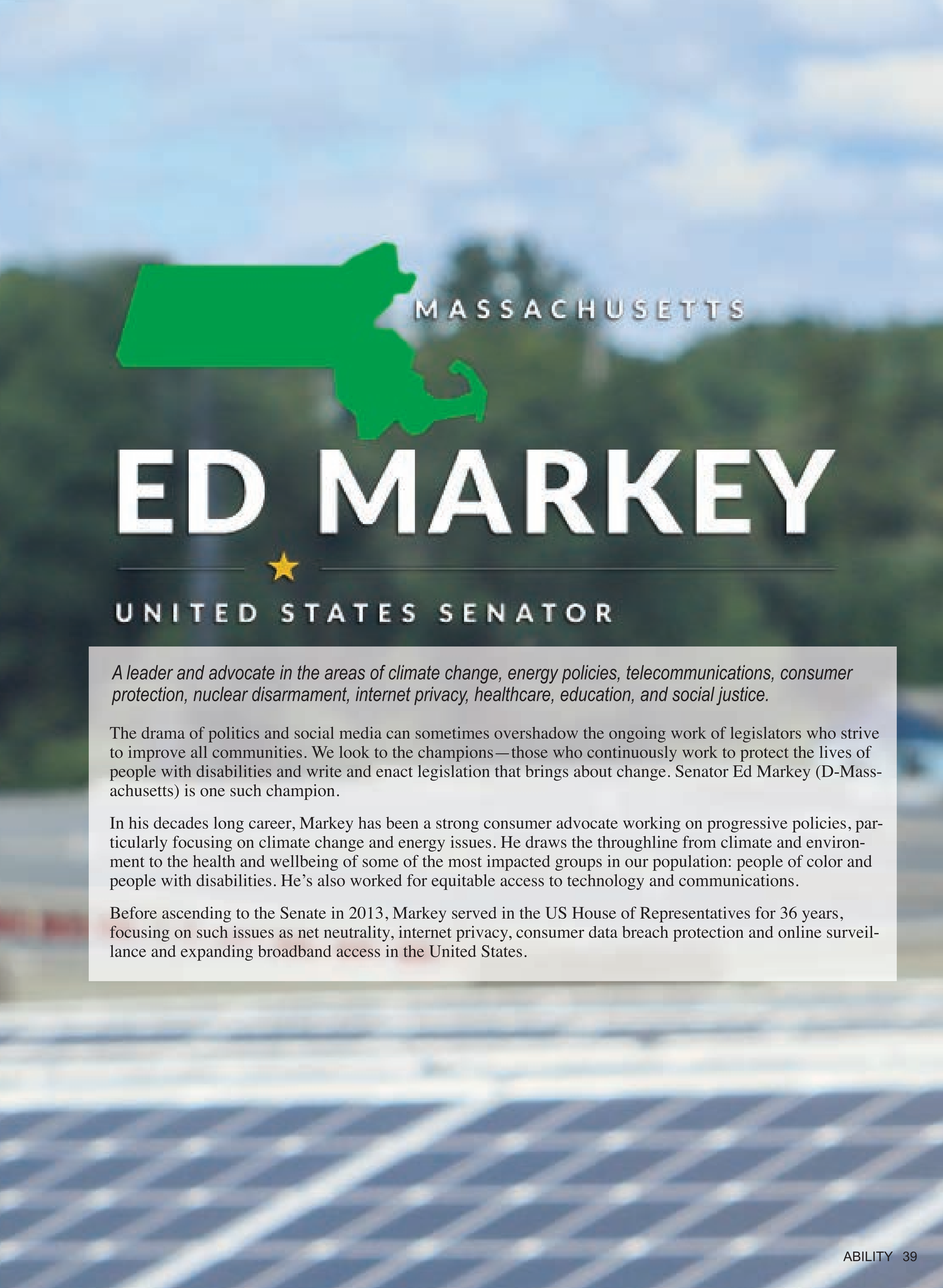
time someone says to me, 'Oh, René, I really couldn't live your life. It must be so hard,' I just want to show them what I do every day and be like, 'I don't know. It's actually quite nice to be me,'" Schaar laughs. In order to ensure Elin depicts people with disabilities well, he interviewed other disabled people from within the community. He shaped Elin to be the character on TV he always wanted to see when he grew up. And Schaar continues to involve the disability community in his work. When they told him the muppet's size didn't match up with the proportions of the wheelchair, the team of the Sesamstraße reworked the wheelchair to make it look more accurate. "To be fair, it's also a matter of functionality because the puppeteer has to sit between the wheels to direct Elin's movements and expressions," Schaar gives behind-the-scenes insight. Once the first episode was written, Schaar received the script and, again, re-connected with activists all over Germany to ask them whether the storyline was plausible and authentic.

Diversity & Inclusion

Sesame Street has been widely praised for how efficiently it is preparing young children for school and promoting diversity and inclusivity. "All Sesame Streets around the globe share that they are normalizing differences. However, the Americans began a lot earlier to highlight people from varying marginalized communities," Schaar says. It's not new that they talk about topics around LGBTQIA+, and immigration has always been at the core of the TV show with muppets in different colors and sizes. And with characters such as Elin, finally, they are ensuring children with disabilities will feel seen and represented as well. "Elin is an extraordinary muppet we'd love to move into other Sesame Streets as well," Junk shares. And we agree! With 20 percent of the world's population identifying as disabled, Elin is more important than ever. "We want children to not only have a good time watching the Sesamstraße, but we also want them to understand that the world is colorful and diverse and to feel empowered by every one of our episodes," Junk ends. ■ ABILITY

by Karina Ulrike Sturm

sesameworkshop.org



MASSACHUSETTS

ED MARKEY

UNITED STATES SENATOR

A leader and advocate in the areas of climate change, energy policies, telecommunications, consumer protection, nuclear disarmament, internet privacy, healthcare, education, and social justice.

The drama of politics and social media can sometimes overshadow the ongoing work of legislators who strive to improve all communities. We look to the champions—those who continuously work to protect the lives of people with disabilities and write and enact legislation that brings about change. Senator Ed Markey (D-Massachusetts) is one such champion.

In his decades long career, Markey has been a strong consumer advocate working on progressive policies, particularly focusing on climate change and energy issues. He draws the throughline from climate and environment to the health and wellbeing of some of the most impacted groups in our population: people of color and people with disabilities. He's also worked for equitable access to technology and communications.

Before ascending to the Senate in 2013, Markey served in the US House of Representatives for 36 years, focusing on such issues as net neutrality, internet privacy, consumer data breach protection and online surveillance and expanding broadband access in the United States.

As a senator, Markey has served on various committees, including the Committee on Commerce, Science, and Transportation; the Committee on Foreign Relations; and the Committee on Environment and Public Works. He has been a vocal and active member of these committees, working on legislation and conducting oversight on a wide range of issues within their jurisdictions.

ABILITY's Chet Cooper spoke with Sen. Markey about the numerous policies and legislation he has worked on over the years, as well as the significance of the legislation regarding people with disabilities.

Chet Cooper: Was there a moment you became aware of disability issues?

Senator Ed Markey: Growing up in Massachusetts everyone knew of Perkins School for the Blind. But when I was a member of the House of Representatives, Perkins was in my district. I learned from its students, educators, administrators—and from communities across my district—of the importance of prioritizing justice and accessibility at the heart of lawmaking. Disability justice is health justice. It’s racial justice. It's economic justice. The work of centers like Perkins is a living reminder that we have more to do to uphold the rights of people with disabilities.

At the turn of the century, I wrote the defining telecommunications laws on the books. I knew then that, to build a future connected by the internet, we could not leave people with disabilities unplugged from the conversation. Everyone deserves the opportunity to participate fully in the economic, social, cultural, and political life of this country. I continue to be inspired by the stories I hear from constituents and their families. Their futures have been made brighter by the tireless work of accessibility and disability justice advocates. I know the work is not yet finished, but the progress we have made encourages me in the essential fight for disability justice for all.

Cooper: Can you briefly describe 'The Protecting Moms and Babies Against Climate Change Act'?

Markey: Climate change is a threat to everyone’s health, including pregnant people and babies. No expecting parent should have to worry about their health in pregnancy. We know that extreme heat and pollution, made worse by the climate crisis, pose a threat to maternal and infant health. Hotter heatwaves and worsened wildfires are linked to eclampsia, miscarriage, preterm births, and lower birthweights. If we fail to address these risks, health outcomes will only worsen. Climate justice means healthy pregnancies and healthy children. The Protecting Moms and Babies Against Climate Change Act will ensure the federal government better supports community-based efforts that promote maternal and infant wellbeing, especially in communities of color where families are bearing the brunt of the climate crisis. Health professional schools will have the resources and funding necessary to protect vulnerable mothers and uphold quality maternal care.

Cooper: Does this connect with the Green New Deal for Health?

Markey: Everyone deserves access to quality health care and to be protected from the climate crisis. Nine in ten Americans live in a county impacted by a climate disaster in the past decade. Nearly one in three Americans today lack access to primary health care. COVID-19 taught us that our health system is not ready for climate emergencies. We have an obligation to both protect communities from climate disaster and to expand health care access. We need a Green New Deal for Health.

The Green New Deal for Health is our roadmap to build a more just and equitable health care system—one that puts the wellbeing of our workers, patients, and planet first. We can build a health care system that protects people AND the planet. We have to decarbonize the health care sector in this country, which accounts for more than eight percent of our greenhouse gas emissions, and we need to provide Medicare reimbursement to help people with disabilities install lifesaving, resilient home infrastructure to protect their health in extreme weather and blackouts. We know that a green health care system is a resilient health care system that protects and ensures access to care.

Better access to care means people are more resilient to an intensifying climate crisis, and when a crisis hits – like a pandemic or storm – they will have somewhere to go. We have to fight to keep hospitals in underserved communities from closing their doors. The Green New

Deal for Health would invest $130 billion over 5 years in community health centers and create accountability for health systems that close or reduce their services.

Cooper: How will the 'Community Mental Wellness and Resilience Act' benefit people?

Markey: Climate disasters are displacing families and upending peoples' lives all across our country. We know that hurricanes and wildfires leave more than a path of destruction in their wake. They leave frontline and environmental justice communities behind with the anxiety and stress of having to recover from disaster—deaths to mourn, injuries to treat, homes to rebuild, bills to pay. The mental health crisis in our country is rooted in systemic issues. From gun violence to climate change to an epidemic of loneliness, we need to understand the mental health crisis is a public health crisis. The Community Mental Wellness and Resilience Act would empower community led efforts to address mental health at a community-wide scale, rebuilding strong, connected communities that are more resilient to the challenges of today.

Mental health resources today are failing to reach these communities, especially for rural communities and Black, Brown, and indigenous communities, who are already often left behind by the health care system. That's why my colleagues and I have introduced the Community Mental Wellness and Resilience Act. Our legislation would establish a first-of-its-kind federal program to expand access to community-based mental wellness and resilience programs that address climate anxiety and toxic stresses. These services are the least that frontline communities deserve.

Cooper: You and Representative Alexandria Ocasio-Cortez introduced the 'Civilian Climate Corps for Jobs and Justice Act', can you give us more detail?

Markey: Last Congress, Congresswoman Ocasio-Cortez and I proposed a Civilian Climate Corps—building upon the New Deal-era Civilian Conservation Corps—to provide more than a million people with the opportunity to join the fight against the climate crisis. The Civilian Climate Corps would guarantee members a living wage and good benefits so they can act as climate champions in their communities, promoting climate resilience and laying the groundwork for a brighter, more livable future with justice at the center of its mission. This work will be made stronger by the more than 100 state and local service corps across the country who are already leading climate and conservation efforts.

Cooper: Did you expect Jessica Rosenworcel of the FCC to make her proposed video conferencing accessibility rules supporting your CVAA?

Markey: I am proud to work with our partners on the Federal Communications Commission and applaud Chairwoman Rosenworcel's leadership on these issues. I look forward to working with the FCC on these proposals to ensure people with disabilities have full access to video conferencing platforms and other important services.

A lot has changed since I wrote the nation's governing telecommunications laws years ago. Congress has an obligation to build upon those laws and ensure that accessibility and disability justice are never an afterthought. People with disabilities deserve equal access to the tools and technologies that define life in the 21st century – and that includes video conferencing. Since the COVID-19 pandemic hit, video conferencing has become increasingly essential for work, education, and healthcare, but many video conferencing services fall short for people with disabilities, leaving them disconnected. That is why Congresswoman Anna Eshoo and I introduced the 21st Century Communications and Video Accessibility Act, legislation that will build on the CVAA and promote increased access in existing and emerging technologies. Our legislation would also require video conferencing platforms to incorporate built-in accessibility features, such as automatic captioning features, interpreters, and other assistive technologies.

Senator Markey's "Greatest Hits" in Disability Policy and Legislation

Sen. Markey has led efforts in Congress to ensure that people with disabilities can fully access communications services and participate in the social, economic, recreational, and educational benefits of technology, social media, and telecommunications.

In 1982, Sen. Markey, then a member of the House of Representatives, worked to pass the Telecommunications Act for the Disabled to require essential telephones – defined by the Federal Communications Commission (FCC) as workplace telephones used by persons with hearing aids, emergency phones, and coin-operated phones – to be hearing aid compatible.

In 1988, he worked to pass the Hearing Aid Compatibility Act, which required most telephones manufactured or imported into the U.S. to be compatible for use with hearing aids. That same year, Senator Markey also worked to pass the Telecommunications Accessibility Enhancement Act, which required the government to ensure that communications with and within Federal agencies were accessible to people with hearing and speech disabilities.

In 1990, Congress passed the landmark Americans with Disabilities Act (ADA), which includes provisions Senator Markey fought to secure – including language to establish the nationwide telecommunications relay service program, through which communications assistants or other technologies are authorized to facilitate telephone calls for persons who are deaf, hard of hearing, or have speech disabilities. Later that year, Senator Markey passed the Television Decoder Circuitry Act to require TV makers to ensure that new TVs with screens larger

than 13 inches had the functionality to provide closed captioning.

In 1996, Senator Markey passed his landmark Telecommunications Act, sweeping legislation to usher in the next phase of the communications industry, which requires telecommunications services and equipment to be accessible to and usable by people with disabilities.

In 2010, Senator Markey's landmark accessibility legislation, the 21st Century Communications and Video Accessibility Act (CVAA), was signed into law by President Obama. The CVAA updated existing communications laws to ensure greater access to modern communications services for people with disabilities by strengthening requirements for closed captioning for streamed video, expanding existing rules regarding described programming, and requiring the FCC to improve access to broadcasted emergency information beyond on-screen text alerts.

In 2022, Senator Markey introduced his Communications, Video, and Technology Accessibility Act (CVTA) to build upon the success of the CVAA while addressing the pressing accessibility concerns of emerging and modern technologies, including livestreaming, virtual and augmented reality. The CVTA would also expand settings for closed captions and audio descriptions across all video programming devices, including televisions, smart phones, laptops, and tablets.

Markey has been a leading voice in calling attention to the ongoing impact of Long COVID and its chronic symptoms.

In March of 2022, Senator Markey and his colleagues Senators Duckworth and Kaine re-introduced their CARE for Long COVID Act to boost research efforts and expand treatment.

Also in March 2022, Senators Markey, Duckworth and Kaine called on the Social Security Administration to improve, formalize, and communicate guidance on the consideration of disability applications for individuals with Long COVID. While SSA had issued some guidance, this required a positive COVID-19 test or diagnosis with limited exceptions which may have inappropriately limited access to disability benefits for Long COVID patients. The Senators urged the SSA to revise these requirements to improve access to benefits and in recognition of testing unavailability at various points during the public health emergency.

In May 2022, Senators Markey, Duckworth, and Kaine urged the Department of Health and Human Services and the Centers for Disease Control and Prevention to better prioritize the needs of those at highest risk of severe illness and death from COVID-19 – seniors, people with disabilities, and the immunocompromised – in

their response to the public health emergency. The Senators requested that the Administration consult these communities, publicly report data on hospital-acquired COVID-19 infections and deaths, clarify mask mandates still applied in health care facilities, and explore options to make high-quality masks available to high-risk groups.

Also in May 2022, Senators Markey, Duckworth, Kaine, Smith, King and Whitehouse led their Senate colleagues in a letter to the Senate LLHS Appropriations Subcommittee urging the inclusion of $125 million to address Long COVID.

Markey has been a leader on the issue of medical leaves of absence in higher education, calling attention to practices which limit disabled students' access to higher education. In November 2022, Senator Markey wrote to the Department of Education and Department of Justice urging them to issue guidance on involuntary medical leaves of absences (involuntary MLOAs). Colleges and Universities utilize involuntary MLOAs to require students to leave their studies and campus life. It exposes them to undue financial, medical, and emotional burdens which make it harder for them to return to and complete their education.

Markey has worked to prevent discrimination of people with disabilities and their participation in jury service.

In March of 2023, Senator Markey and Congresswoman Katie Porter (CA-45) introduced their Disability and Age in Jury Service Nondiscrimination Act, an expanded version of their Disabled Jurors Nondiscrimination Act, to prohibit excluding a person from federal jury service on account of disability status or age. While Massachusetts and 26 other states currently prohibit excluding or disqualifying people from state jury service on account of a disability. Massachusetts and ten other states have prohibitions on age discrimination for state jury service.

Federal law does not yet prohibit the dismissal of potential jurors on the basis of disability or age.

In February of 2023, Senator Markey called on Twitter's new owner, Elon Musk, to reinstate the company's Accessibility Team and support the implementation of accessibility features on the platform. Under his ownership, Twitter notably removed automated closed captioning on Twitter Spaces, an audio -only livestreaming service. In his letter to Musk, Senator Markey wrote "Twitter has a responsibility to ensure that its platform is open and accessible to disabled users," and underscored the need for the company to ensure users with disabilities can fully participate on its platform. ■ ABILITY

markey.senate.gov

LOLO

Disability Lifestyle Influencer Lauren "Lolo" Spencer

Disability advocate Lauren “Lolo” Spencer gained popularity as a YouTube personality on her “Sitting Pretty” channel. Through the lens of disability, Lauren explores universal topics that include dating, sex, relationships, travel and employment. Lauren shares how she lives an active life with Amyotrophic Lateral Sclerosis (ALS) as an actress, model, social media influencer and author of a new book.

Lauren leveraged her YouTube success and began modeling for Tommy Hilfiger Adaptive and Adidas. Then the door to acting opened, and she landed the role of Jocelyn on the HBO Max series, “The Sex Lives of College Girls,” and she also voices the character of “Jazzy” on the hit Disney Junior series, Firebuds. But, Lauren is not content with all of that. So, she continues to offer candid advice and guidance for reaching lifestyle goals with “Sitting Pretty,” Instagram, her website LiveSolo and book, Access Your Drive and Enjoy the Ride: A Guide to Achieving Your Dreams from a Person with a Disability (Life Fulfilling Tools for Disabled People),

ABILITY Magazine’s Jennifer Goga had a conversation with Lauren via Zoom.

Lauren “Lolo” Spencer: Hello there!

Jennifer Goga: Hi, Lolo!

Spencer: Hi! How are you?

Goga: Good! I’m so excited to meet you.

Spencer: Yes! This is exciting!

Goga: You are a busy gal!

Spencer: (laughs) Tell me about it!

Goga: I was just checking out your Instagram and your website. I am impressed with everything you’re doing.

Spencer: Oh, thank you so much!

Goga: You are representing inclusion so well.

Spencer: Thank you so much. It's always great to be reminded that the work that I'm doing is going well. (laughs)

Goga: Yes, definitely. Tell me a little bit about yourself. I know things started to happen with your YouTube channel, "Sitting Pretty," is that right?

Spencer: Yeah, yeah. I started my YouTube channel "Sitting Pretty" back in 2015. I wanted to create a channel that highlighted disability lifestyle. I wanted to pick those topics that are universal to everybody but then just put my spin on it, adding my perspective as a person with a disability.

In everything I've done, I try to talk about universal topics, whether it's dating, sex, and relationships, travel or employment. I have even covered the benefits of being a wheelchair user and having a disability. But, I also share my insecurities around having a disability.

I wanted to create a space for disabled people that demonstrated the lifestyle we want to live is possible. And I hope to help people who are non-disabled to understand that we are all connected, we are all human, and that interacting with disabled people doesn't have to be intimidating or scary. And I talk about some of the things people probably should not say to people with a disability

Goga: That's fantastic. So, what was the chronology with you getting into modeling and acting?

Spencer: It all kind of happened simultaneously. I started my YouTube channel, and as a result of its popularity, I got an opportunity to model for the first time with Tommy Hilfiger Adaptive. And then, as I started exploring modeling, that's when the opportunity to act popped up. It all kind of happened as "Sitting Pretty" was growing.

Goga: Can you share how you landed the role on "The Sex Lives of College Girls?"

Spencer: I was already connected to my agency at the time "Sex Lives" popped up. The way I got offered to audition for the role was the traditional way: studios, productions, hit up agencies looking for particular talent. And then your agent submits you for it. That's what happened. It was during quarantine, so all the auditions were self-tapes first. Call-backs were done on Zoom.

Goga: How do you like being able to do the remote auditioning?

Spencer: For me, I enjoy it because I don't have to worry about transportation. (laughs) And making sure I'm getting to an audition on time or that I'm not waiting for 45 minutes for a car to pick me up after an audition that might take all of three minutes. So for me, it's way more convenient. I enjoy the self-tape process. And because I get to do it inside of my home, it's a more comfortable environment. Sometimes it could be a little intimidating to be in a room full of people who are literally judging you (laughs) to see if you fit a role or not, you know?

Goga: I can only imagine.

Spencer: And you don't know what they're looking for and you don't know if your performance is good enough, because it may be dope, but you might not have the quote-unquote "right look." So being able to audition from home alleviates some of that anxiety and makes the whole process a lot more enjoyable.

Goga: That's great. What's your experience been with the actual taping of "The Sex Lives of College Girls?" It's done in LA, right?

Spencer: When we shoot "Sex Lives," the majority of it is done here in LA. But we do have some scenes that are shot outside of the LA area, because technically Essex College, the fictitious school where the show takes place is on the East Coast. It's supposed to be in Vermont, so when we need to do our exterior shots, we travel to a location to match that vibe.

Goga: What's your experience been with the studio's accessiblity?

Spencer: From my personal experience, so far, so good. They've been really great since the beginning. Everyone is very, very aware and mindful of making sure that I can get to the stages, to get to and from the lot, making sure food-wise that I get the meals that I want to eat. In everything they're very, very mindful of all of my needs, making it convenient. Hair and makeup come to my dressing room, when traditionally the actors go to the hair and makeup trailer. They make sure the dressing room I have is big enough and accessible and comfortable and warm when I show up in the mornings. (laughs) That's very important!

Goga: That's great. Your character Jocelyn, would you say that she's like you?

Spencer: Yeah. There are definitely some similarities between Jocelyn and me, but more so the younger version of myself and Jocelyn are very similar in many ways. Now, being in my mid-30s, I'm not as rambunctious. These days, I don't need to be at every party that exists and entertain every boy who comes my way. I'm definitely past that stage of my life! (laughs) But the younger version of me and Jocelyn are similar in many ways.

Goga: That's neat. Transitioning to your book, there's so much to cover, I'm hoping I can get it all in. I don't know how you have time to sleep.

Spencer on the set of *The Sex Lives of College Girls*

Spencer: Listen, I don't know how I do it either, but I'm here and I'm excited.

Goga: I saw video clips on your Instagram about how they approached you and said, "If you ever have an idea for a book—" and you were like, "Yeah, as a matter of fact I do." How long did it take you to write the book, and are you happy with the way it turned out?

Spencer: It took me about two years to write the book. It was one of the most challenging things I've ever done. It was a long process to remember certain experiences in my life and turn those experiences into a tangible lesson for readers to be able to take and apply to their own lives.

It was a challenge, but it was worth it. I'm very pleased with the way it turned out. But it can be nerve-wracking ex, because people now have access to my life in a more intimate way. But I'm excited that it's here, and I hope it's helping readers in the way I intended.

Goga: Oh, good. Did they have someone who helped you write it? Or did you have the writing skills and you dove right in?

Spencer: I dove right in. I got no help.

Goga: That's impressive.

Spencer: Yeah. It was literally all me. The only kind of help was when I had to remember some of my earlier experiences, asking my mom, "Do you remember what happened?" Other than that, every single word on every single page is from my own brain. (laughs)

Goga: That's great! What was your goal for the book?

Spencer: I wanted to do it because throughout my career, as I was building my social media content, everyone kept asking me, "How do you do it? How did you create this for your life? What are you doing different from what everyone else is doing?" It was almost as if people were searching for some secret code of life that I found and that nobody else could access. Everyone wanted to know what the secret sauce was.

Goga: (laughs)

Spencer: At first I found it hard to easily translate how I was able to build my career in the way that I did. I don't know, it just seemed simple to me. But, I realized I had to dig deeper and share more about the moments in my life that contributed to my success today. So that was the purpose of the book, to give more insight and explain that, "Hey, I didn't find a magic lamp in some bushes and just rub it!" It was just one experience after another. Every decision I made led to the next pivotal point in my life that led to the next one. So, that was my intention for writing the book.

Goga: I understand.

Spencer: I hoped to provide information and tangible takeaways at the end of each chapter that people can apply to their own lives as well.

Goga: That's great. So your website Live Solo how did you come up with that? When did that start and what was your goal with it?

Spencer: Live Solo was an idea I started brainstorming during quarantine. Similar to the thought process behind the book, I realized people wanted answers on what I was doing differently than everyone else. There was a lot of interest in my fashion, the traveling, the experiences, the parties, the networking that I was doing. People were interested in my hair, my nails, how I was living independently in my own apartment. And dating was such a big, big, big topic of interest.

I thought, how do I share this part of my life and make it again something tangible for people to access. I wanted to create something that was bigger than just my life and my own experiences, because I know that this community isn't only me, and I'm not the only one living the life I'm living at the scale I'm living it. There are people with disabilities who are dating and live on their own and are fly and fashionable. So I wanted to tap into the community.

Goga: And you have a lot of information on the website. I saw that you have guest bloggers who contribute different points of view from varying disability experiences.

Spencer: I wanted to create something that was bigger than me and my own experiences and something that is helpful for the overall disabled community and those who want to support us. That's where Live Solo came up from. We're continuing to build a community for young adults with disabilities who are seeking independence and self-empowerment. Live Solo is a place online where you can tap into and learn more about disability lifestyle. There are resources for wheelchairs and devices and all of the medical stuff. But there isn't enough stuff out there to teach us how to date, how to dress, how to do our hair, all of these different things. And Live Solo is also a place to learn about each other's disabilities from a humanity perspective. That's what it's all about. We're continuing to grow it.

Goga: What a great resource. A lot of this resonates with me being legally blind. You offered some content and insights about how non-disabled people interact with people with disabilities. In my case, I use a white mobility cane to navigate in public spaces, and a lot of people do not know what the cane is all about, so I get a lot of different reactions.

Spencer: Yeah!

Goga: And even those who do know what the cane is for often think that I'm faking, because I do have some limited vision. People come up and say, "Hey, you're not blind!?" I like the way you address situations like mine and talk candidly about the right way to interact with people with disabilities. It's not that hard. We're all people. I'm happy to tell people about my condition, why I'm blind, how I do things, but sometimes it's difficult because they don't quite know how to approach me.

Spencer: Exactly! And that's what I think is important about Live Solo. The writers we have on our blog are not only just wheelchair users. It's people with varying disabilities, because we want everyone to be involved. That way if someone's on the site and they're learning tips on how to travel, and then the next blog that pops up might offer information about using a mobility cane as a blind person. I am so happy that Live Solo helps a broad range of people learn and understand many different perspectives. Even I am learning. I've read every blog that's up there, and I'm learning about other people's disabilities, about severe food allergies, OCD, ADHD, etc. It's fascinating to learn how people have been able to navigate based on their particular disabilities.

It's really a dope world to be a part of! (laughs)

Goga: For sure, there are so many great people doing great things these days. At ABILITY Magazine, we've been in the disability advocacy space for more than 30 years. And from that, we have created the only fully accessible virtual career fair for people with disabilities. It's a face-to-face platform where recruiters can meet one on one with job candidates. It's compatible with screen readers and we also offer live ASL interpreters if someone is hard of hearing or deaf. It's something we are so excited about. You have the ear of young people, and I would love for you to tell them that it's out there, among other things. There are so many great resources.

abilityEntertainment is our newest project. It's part of a whole suite of services we provide for actors and performers and writers and producers who have a disability. We are helping them get access to the entertainment industry. I wasn't sure if you had a chance to look at the site?

Spencer: I did! I did have a few moments to be able to quickly scroll through and see what you guys were

doing. It definitely looked really, really dope. It looks like an amazing resource. I think there's definitely some synergy between Live Solo and abilityE to maybe do a future collaboration and figure out how we can work together to make something happen. I'm definitely open to something like that.

Goga: That'd be great. We have the same goals of giving people information and access to various resources.

Spencer: Yeah, absolutely!

Goga: That's great. And that's how Sammi Haney was discovered for the voice role of "Piper" in "Firebuds."

Spencer: Oh, really?

Goga: Yeah. I know you voice the character of "Jazzy" on the show, and Sammi voices your character's talking wheelchair, "Piper," right? Sammi's parents put her profile on the abilityE website. Disney contacted us during COVID looking for a young actress who used a wheelchair. Our abilityE team was able to provide Disney with several actresses who met their casting profile. Sammi was one of them, and of course she did the rest with her audition. But Disney found Sammi through abilityE.

Spencer: I love that! I love Sammi, too. I haven't gotten a chance to meet her in person, but I've been following her career ever since she was on "Raising Dion," and we follow each other on social media.

Goga: I guess that makes sense you two have not met in person. Since voiceover work is done individually—you're not in the same room or anything.

Spencer: Oh, no, we're definitely not! (laughs)

Goga: Sammi said she wants to meet you in person. But it's cool you two can connect on social media at least.

Spencer: Yeah, she's a sweetheart. She's so cute. I just love her

Goga: Well, it sure was fun talking to you, Lolo!

Spencer: Oh, you made it easy with great questions!

Goga: Thank you so much for making time for me and all the best to you. Hopefully we'll come up with a way abilityE and Live Solo can work together to help even more people.

Spencer: I would love that. ■ ABILITY

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GLOBAL

DOWN SYNDROME FOUNDATION®

Michelle Sie Whitten, Co-founder, President, and CEO of Global Down syndrome Foundation (GLOBAL) is a friendly and intelligent force. Inspired by her daughter Sophia, who was born with Down syndrome, GLOBAL has had the same mission since its conception. They focus on spreading awareness that people with Down syndrome are important members of society and that they have been deprived of fundamental human rights and civil rights, such as medical care and research. Michelle, a longtime friend of ABILITY, had a chat with Chet Cooper and Lia Martirosyan on the latest with GLOBAL, including how GLOBAL's hard work and persistence lead to exciting new research as well as publishing the peer-reviewed paper: "Medical Care Guidelines for Adults with Down syndrome."

Lia Martirosyan: We haven't chatted since 2011, any updates, any news?

Michelle Sie Whitten: (laughs) Oh, my gosh. The great thing about GLOBAL is that we have never changed the mission in our work – to dramatically improve the lives of people with Down syndrome through research, medical care, education & advocacy. I think a lot of times nonprofits kind of start here and reinvent themselves and reinvent themselves and that is challenging. Fortunately, we've been steady, and that allows us to build a foundation, compound growth and see the fruits of that labor over a long period of time. One of the main things—if you remember, Lia and Chet—is that we had identified from the National Institutes of Health, from the executive director himself—at the time it was Elias Zerhouni—that Down syndrome was the least-funded genetic condition by the NIH. Around the time Sophia was born, the funding for Down syndrome research was about $18 million versus close to $200 million in that same year for autism.

Back then the numbers the NIH funded per disease or condition were not public. So, Dr. Elias had his people pull all those numbers, and he, himself, was very surprised. And he said, "If you do one thing, create an institute that does research in medical care for Down syndrome. Autism has it, Fragile X has it, you don't have it." He was so knowledgeable and inspiring so that's part of why we did what we did. We created GLOBAL and we created an Affiliate model, thinking that GLOBAL can't do everything. So, (we have) the Crnic Institute at the Anschutz Medical Campus to do basic and clinical research including Alzheimer's research, the Sie Center for Down syndrome at Children's Hospital Colorado (a top 10 hospital) providing the best pediatric care, and since 2011, we have an adult clinic at Denver Health. So, that's new, but that was always in the plan. The only accidental thing we did was we created the Alzheimer and Cognition Center affiliate, which is half under Crnic and half under the Neurology department at the University of Colorado School of Medicine on the Anschutz Medical Campus because of the unfortunate very close tie between Down syndrome and Alzheimer.

Martirosyan: So, you've had this affiliate model, which is very unique, where it's GLOBAL and four other affiliates?

Whitten: GLOBAL's daunting task is to do the government advocacy and the development fundraising and the outreach for not only GLOBAL but for all of our Affiliates. That's what we've been doing.

Fast forward, and the big thing that happened between 2011 and now was in October of 2017, when we had a seminal first-ever congressional hearing on Down syndrome research. It's really rewarding work, because what we see that other people perhaps don't get to see, is a government that is bipartisan. When the Republicans and the Democrats come together about NIH funding or Down syndrome research and medical care funding, they are actually in agreement and very respectful and working together. We like to think that people with Down syndrome bring out the best in us and that they bring people together. In today's world, that seems like a unicorn, so we've felt very privileged over the years to see that over and over again. At this hearing, we had at the time Chairman Tom Cole and Ranking Member Rosa DeLauro, Republican and Democrat, very respectful of each other and coming to mutual understanding even though they have very differing views.

During the hearing in 2017, everybody on the House Labor HHS Sub Appropriation Committee that oversees the NIH budget was shocked at the lack of funding for Down syndrome research. Afterwards, they moved quickly forward in requesting NIH to create a trans-NIH program, called INCLUDE, to fund additional Down syndrome research. INCLUDE is made up of 18 different NIH Institutes (for example the National Institute of Aging, the National Institute of Heart, Lung Blood, and the National Institute for Child Health and Human Development (NICHD).

We still have the primary funding through NICHD, but now we have INCLUDE which makes sense because one of the things that we brought to light is that people with Down syndrome have a radically different disease spectrum, where they're highly predisposed to certain diseases, like Alzheimer's and autoimmune diseases, and then they're highly protected in things like solid tumor cancers, or certain kinds of heart attack or stroke.

So many other areas are affected too. For example, we know in people with Down syndrome hearing and speech is affected, so it makes sense that the National Institute of Deafness and Other Communications Disorders supports INCLUDE. We worked so hard over the last 14 plus years to lobby and advocate for increased federal funding for Down syndrome research and medical care and we are very grateful to have succeeded.

We have come such a long way! we were at about $27 million before the hearing and as of fiscal year 2023 we are at $130 million.

Cooper: Nice.

Whitten: Each year it's has grown. It was $60 million, $90 million, then about $10 to $15 million a year after that. If you remember, in 2011 I talked about how when something gets defunded at NIH, scientists don't go into that field because they know there's no funding. So, back then we were deprived, that there was a serious dearth of Down syndrome researchers. People interested in intellectual disabilities went into autism or Fragile X where there was funding.

Today we're seeing a renaissance of Down syndrome research and medical care because of the funding we've advocated for. And that feels great. An important note is our community now better understands that research and medical care go hand in hand. Without the research, we can't have the guidelines. Without the guidelines, we can't have evidence-based practice that provides better healthcare.

2017 DC Hearing Michelle Sie Whitten, Dr. Joaquin Espinosa and Frank Stephens

That has been a huge win for our communities towards our two goals of elongating life and improving health outcomes.

I think I should mention some of our other Congressional Champions in addition to Representatives Rosa DeLauro and Tom Cole. There's Cathy McMorris Rodgers, whose son Cole, happens to have Down syndrome, and she has been on this journey with us from beginning. This year our AcceptAbility Gala honored Congressman Pete Stauber, whose son Isaac has Down syndrome, and Democratic Whip Katherine Clark with GLOBAL's highest honor, the Quincy Jones Exceptional Advocacy Award. Every year we honor one republican and one democrat. And we are creating two new awards, Chet and Lia—

Cooper: That's the name of the awards, Chet and Lia?

(Laughter)

Whitten: No, no. One is the Tom Cole GLOBAL Advancement Award, and one is the Rosa DeLauro GLOBAL Advancement Award. That is to acknowledge these two Congressional Champions in particular, are responsible for establishment of the INCLUDE Down syndrome research funding program at NIH and the increase in that funding.

This is very much congressional effort. While we have wonderful champions at NIH, and I do think there's been a sea change where they're embracing the INCLUDE program, it is still congressional directive and each year we are in DC advocating with our amazing self-advocates and families for appropriated funds. It's hard work but it's the key to elongating life and improving health outcomes for our loved ones with Down syndrome.

We also have our own Senator Hickenlooper now, he used to be our governor and mayor. He is a huge advocate along with Senators Michael Bennet and Chris Van Hollen. And then on the other side of the aisle, we have Senator Steve Daines and Senator Jerry Moran.

We also have amazing artists perform at our AcceptAbility Gala each year. This year we had GRAMMY© nominated, multi-platinum singer-songwriter Gavin DeGraw and he was beyond spectacular! At one point he got down from the stage into the audience and asked a self-advocate, Eric, what his favorite song was. And to everyone's surprise he got a 2nd microphone and sang "With a Little Help from My Friends" by the Beatles with Eric and it sounded great because he somehow worked his magic!

We also had one of our favorite football players with us, 3x Superbowl Champion, former Washington Commander and Denver Bronco, Mark Schlereth.

Abby Ashbrook is our 2023 AcceptAbility Gala Ambassador. And of course she rocked it on stage and on the step and repeat. She has a remarkable family so we are super lucky to have them as part of the GLOBAL family.

Cooper: That was a lot of information. You did a really good job. (laughs) That's a lot of material. I think you could go on to what the research is about.

Whitten: A big part of the GLOBAL strategy was created by my dad and our dear family friend Quincy Jones. Their plan, to make a measurable, significant impact, not just for Sophia, my daughter, my dad's granddaughter, and the apple of Quincy's eye, but everyone with Down syndrome. Because they're very strategic thinkers, their idea was if we could increase that NIH funding, we in the meantime would work very hard to rebuild the pipeline for Down syndrome research with philanthropic dollars to reestablish the pipeline. And then if we were successful—of course my father (John Sie) and Quincy would say "WHEN" we're successful – then our scientists would be in good position to get NIH grants because they were already doing the work and would have data and information that they could bring to the table.

Of course, me and my amazing hardworking staff were the ones on the front line, and there were times where we had our doubts. In the end it took almost 10 years to reach that goal.

So in the end the strategy worked! The Crnic Institute for Down Syndrome, and if you remember at the time, it was Tom Blumenthal, who's a brilliant, beautiful man, our first executive director, who then recruited one of the most brilliant, internationally renowned cancer specialists, Dr. Joaquín Espinosa, who has been our fearless director since 2017.

Dr. Espinosa was initially interested in why people with Down syndrome are protected from solid tumors and so predisposed to blood cancers. One of the important studies that came out of Crnic recently was on blood cancers showing the predisposition to acute lymphocytic leukemia (ALL) and acute myeloid leukemia (AML) compared to people without Down syndrome. The study provide insights into the cause of this and potential differentiated treatment. Here's the study publication from 3/2021 & excerpt.

Children with Down syndrome are 20-times more likely to develop acute lymphocytic leukemia (ALL) and 150-times more likely to develop acute myeloid leukemia (AML) compared to their typical peers. According to a new study by researchers at the Linda Crnic Institute for Down Syndrome, the reason could be that children with Down syndrome are more likely to present with clonal hematopoiesis (CH), a process in which a blood stem cell acquires a genetic mutation that promotes replication.

Cooper: One hundred and fifty times more?

Whitten: Yeah, a crazy number.

So, the cancer relationship is what got Dr. Espinosa involved. But then he couldn't help but see the whole systems biology black box, and he was like, "Wow, why haven't we done this or this or that?"

He was coming from the cancer field where anybody could look up anything about the different cancers because the field was well-funded and very sophisticated. The Cancer Institute at NIH had mandated that information be shared almost immediately from scientists they fund, de-identified of course, to accelerate science and provide a foundation for new scientists entering the field.

He was coming from an overpowered sector of science to a very underpowered, minimal sector of science. Ever since then he's been applying his cancer standards. The exciting news is that he had the Crnic Institute join forces with CHOP and Sage Bionetworks and they received the large NIH Down Syndrome National Data Coordinating Center grant so now the Down syndrome field is providing all this great de-identified data in real time which provides us scale and a pipeline of information for new scientists.

When we started GLOBAL there was one clinical trial where a drug was being tested to benefit people with Down syndrome. Today, with NIH INCLUDE funding, there are approximately 11 and we are proud to have grants for 4 of those at the Crnic Institute.
Crnic Immune Monitoring Station, Scientists & Self-Advocates Connor, Alan & YaridaCrnic Immune Monitoring Station, Scientists & Self-Advocates Connor, Alan & Yarida

Cooper: What was the first clinical trial for, and what are the others?

Whitten: There were three key things that that helped our lobbying and advocacy to establish INCLUDE and increase Down syndrome research from $27 million in 2016 to $130 million in 2023. First, Dr. Espinosa and his team made a huge scientific breakthrough in 2016 whereby we are now able to categorize Down syndrome as an immune system disorder.

Second, because of our stellar GLOBAL DC Team (Erin Book Mullen, Laura Simmons, Kevin Brennan and others at W&J and Bluebird Strategies) we were allowed to testify before Congress about the discriminatory lack of funding for Down syndrome research.

2022 AAG Senator John Hickenlooper, Delegate Eleanor Holmes Norton, Frank Stephens and Michelle

Third, we had a secret weapon – Frank Stephens! Frank is a GLOBAL board member, a GLOBAL Ambassador and a GLOBAL Quincy Jones Exceptional Advocacy Awardee. He is also an actor and renowned public speaker who happens to have Down syndrome. It was important to us that Congress hear directly from someone with Down syndrome.

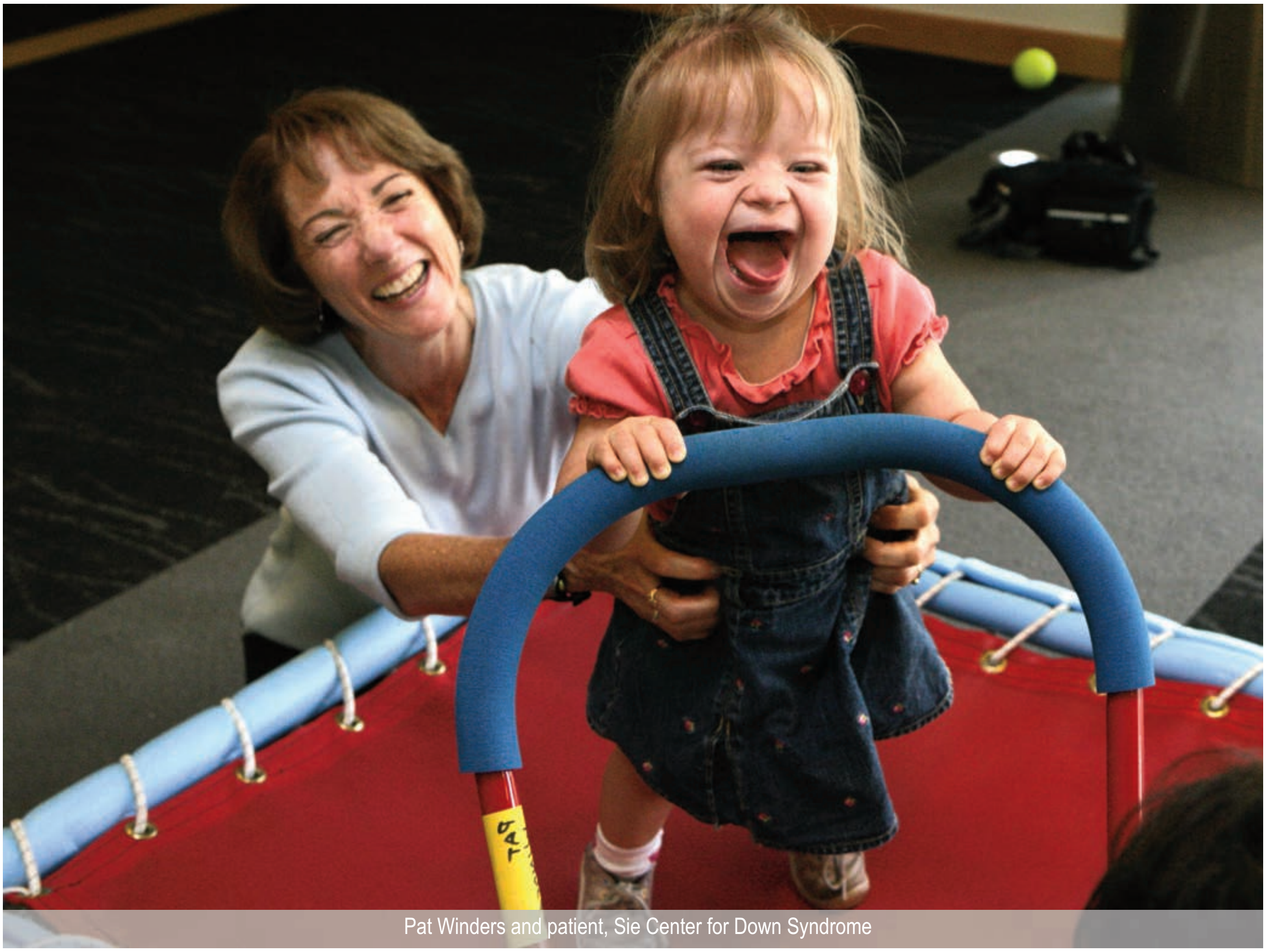
During his five-minute testimony to congress, he received a standing ovation (apparently that's never happened before). The ovation was driven by his famous words, "If you take one thing away, understand this: I'm a man with Down syndrome, and my life is worth living."

That evening, his testimony went viral to a million views. And today it is over 200 million!

Cooper: Oh, my gosh!

Whitten: The other thing we were bringing to the table was Dr. Espinosa, who testified and was able to say that in 2016, Crnic, obviously with GLOBAL support, made one of the biggest breakthroughs in Down syndrome research in the last 20 years. And that is, through our finding, we are able to categorize Down syndrome as an immune system disorder. The finding in 2016, and this was crazy, we had gotten blood draws through the Crnic Institute Human Trisome Project. Basically, Joaquín's vision was, you get data. Why don't we have data on these people? We don't have natural history. We had little pieces here and there. It was underfunded. It wasn't the scientists' fault. The medical people were trying to do things, but when you're getting $14 million, $16 million from NIH a year, what can you really do?

We raised money and there were two things we did which I think were really important. This is where the donor-return on investment is really great. We were able to look at the blood samples of 200+ people with Down syndrome. On just that number alone, the discovery that we made was the major immune system pathway in our body–which you probably heard about during COVID, that creates the cytokine storm–is called the interferon pathway. In people who are typical, like you and me, it turns on when we fight virus and infection, and when it's done it turns off. Our discovery was that the interferon pathway is lit up and on 24/7 from birth to death in people with Down syndrome. It doesn't turn off. It's constantly taxing the immune system, which could help explain why there are no solid tumors, why as they get older faster, why



Pat Winders and patient, Sie Center for Down Syndrome

there are all sorts of immune conditions, and cognition deficit. There are immune cells in our brain as well.

This also means that inflammation is a huge issue in our children and adults. That was our big discovery. What we didn't realize as we were making that discovery–but we realized quite quickly–is that there is an FDA-approved drug for rheumatoid arthritis that brings down interferon. So, we got the first clinical trial from NIH to test a class of drugs called JAK inhibitors that normalize interferon in people with Down syndrome. We were first testing people with skin immune conditions that are very visible: alopecia areata and psoriatic arthritis. A lot of people with Down syndrome have those. And the more terrible suppurativa boils. We were testing for a safety trial over a year period, just to see if it was safe.

Sixteen people, even after they left the safety trial—Now we're recruiting more people—the results are astounding. The majority of people in that trial, their primary physicians or doctors have continued them on a JAK inhibitor post-trial.

Cooper: Was this a blind study? A tolerance study?

Whitten: Unfortunately there's this thing called Down syndrome Regression, where someone with Down syndrome (and this includes someone who may have many motor and communication challenges to someone who is living and traveling independently) suddenly regresses to the point where it is difficult for them to feed or dress themselves.

You can imagine how devastating that is to families. There has been no rhyme or reason. We're just getting an understanding of what it is. We tried the JAK inhibitor on two patients in Colorado with regression and we were happy to see that it seem to reverse the regression. One of the patients has not relapsed for over a year.

Dr. Espinosa joined forces with Dr. Jonathan Santora at Children's Hospital Los Angeles and now we have another clinical grant to test the JAK inhibitor in people with Down syndrome regression disorder.

So, the science is truly remarkable. One of the things I like to highlight is that since we advocated for and NIH launched the INCLUDE Down syndrome research funding project, we not only have $130 million in FY2023 but now there are 16 institutes at NIH funding Down syndrome research versus one or two and many had never funded Down syndrome research before.

By the way, this is what INCLUDE stands for: INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome.

Cooper: This is really great. This is a little bit of a complicated math and research concept, but if you can go into those results of psoriasis, all the things that you just showed, if you could find the data of how much the medical costs of those people are occurring, you could do an analysis to see how much money would be saved by increasing your research and funds.

Whitten: Exactly. Boats are rising, not just ours. We do hope that all the scientists receiving INCLUDE Down syndrome research funding appreciate the decade-long work that went into getting those funds and the annual advocacy and lobbying work that goes into maintaining and increasing those funds.

At the end of the day we just want parity or our fair share. And with all the Congressional approvals of large increases in NIH funding that should be more than possible. Autism has been over $200 million a year for nearly two decades. Our ultimate goal is to get Down syndrome research to a steady state of over $200 million.

One challenge we had is that while Down syndrome is the leading cause of developmental delay in the US and the world, the numbers are relatively small. As of 2023, the most recent statistics would put the number at well over 400,000 people with Down syndrome in the U.S.

To address that, my father coined the phrase "therapeutic leverage." The idea being studying people with Down syndrome can also benefit hundreds of millions of people without Down syndrome.

To be clear, elongating life and improving health outcomes for people with Down syndrome is THE goal but if we can also improve the health of others we are more likely to capture the attention of Congress, NIH and others.

And this makes sense because people with Down syndrome are highly predisposed to Alzheimer's, all manner of autoimmunity, and blood cancer and highly protected from solid tumor cancer and certain types of heart attack and stroke. If you take the top five of these diseases, that represents about 60% of American deaths from those diseases. I think there's a there, and that's why this is working.

In the five years, our Crnic Institute has received 67 NIH awards and published 180 publications.

And we're not just looking at Alzheimer's, cancer and autoimmunity. We're looking at Down syndrome and autism, Down syndrome and mood dysregulation, anxiety, executive function, we're coming at cognition from many, many different directions. I'm really proud of that.

On the Alzheimer side, just like we have the brilliant Dr. Joaquín, we have the brilliant Dr. Huntington Potter. Another thing: we put in $1 million and Alzheimer Association put in $1 million for his Leukine trial because NIH doesn't tend to invest in exploratory work. And the results of that are also amazing. It's the first phase two trial of any Alzheimer treatment that improves memory plus all three biomarkers. It's early days, we've only had 60 people in the study and now we have to go to hundreds and more and more. But as part of that funding, we got the $7.5 million NIH grant to complete that trial network for Leukine in people without Down syndrome.

Just recently we were so pleased to receive another 5 year clinical trial grant from NIH to look at Leukine in young adults with Down syndrome and see how it affects cognition even before they get Alzheimer. If you remember, Chet, one of the markers for Alzheimer's in typical people is having three copies of the Amyloid Precursor Protein (APP) gene instead of two. That protein is on chromosome 21 so everyone with Down syndrome is born with three copies of APP and it is estimated that somewhere between 60-70% of people with Down syndrome will develop Alzheimer's dementia.

So we are HIGHLY motivated to cure Alzheimer's and we are deeply grateful to the National Institutes of Aging at NIH who are so caring, forward thinking, and have invested a lot in our Down syndrome population.

A great way anyone can help with our work is to give blood. It is easy to do and in fact our big discovery that Down syndrome can be categorized as an immune system disorder came from only 200+ participants who gave blood!

Another important topic is the seeming disparity of lifespan for African Americans with Down syndrome. As you know, Chet, we lost our beloved Ambassador DeOndra Dixon (Jamie's sister) in 2020, and that was beyond tragic. I can't tell you what a loss we feel every day without DeOndra.

Her whole family was part of our GLOBAL tribe and she was our energy and life-blood at every fashion show. We are still not recovered. We will make sure she is always loved and never forgotten. As you know her family, Mr. Dixon, her big brother Jamie Foxx, sister Deirdra, and Kim supported DeOndra growing up to become perhaps the most well-spoken, included, loving, and engaging person we had the privilege to travel with. And their support of GLOBAL along with Quincy was really what started us.

So we really do need to address this disparity of lifespan where a couple of research papers put the lifespan

Crnic Immune Monitoring Station, Scientists & Self-Advocates Connor, Alan & Yarida

of an African American or a Black person with Down syndrome at 36 versus 60 for a Caucasian, and we really want NIH and others to focus on that.
BBBY Fashion Show 2018 Paula WilcoxBBBY Fashion Show 2018 Paula Wilcox

But here's the problem. If NIH goes and says, "We're going to do an RFP (request for proposal), and we're going to do a clinical trial and enroll black people," we have an interesting history with enrolling black people and people with intellectual disabilities in research and for very good reason. Don't get me started with Willowbrook!

Cooper: Right.

Whitten: The assumption today would be that they would not show up. We need to think out of the box and help them think out of the box too, to say, "OK, the investment into this population may look different. It may go to a lot of outreach and education and medical care as part of the whole research plan."

And you build and earn trust through that piece. Part of the whole plan is you give them resources that they need, you give them education that they need where they see good results. You give them medical care that they need and they see good results. You ask them to participate in research, and they're just much more likely to do it. That's our thinking on it and not just for our loved ones with Down syndrome who are black but frankly all people who are differently-abled.

It's a little bit premature. We are still working on it. I think next year we're hoping to have a hearing in Washington DC about this important issue.

In medical care, since 2011 we've more than doubled the number of pediatric patients that we're seeing from 33 states and 10 countries. I think the last time we talked it was around 1,000, now it's over 2,200 patients! It's amazing what we're able to do. We have a prenatal and newborn pamphlet that we created. That's doing really well for pregnant women or newborn families. And then we've published probably the most definitive publication or study on behavior in children with Down syndrome by Dr. Lina Patel. She's also published, I think, the best book on potty training in people with Down. It's those important successes that we're getting on the medical side of things.

We also launched, since 2011, a pilot adult clinic at Denver Health, which is our safety net hospital here in town. At least as important, perhaps ever more important since we last talked, it took us over five years, a lot of money, and more blood, sweat, and tears than I wish to remember, but we published the first-ever medical care guidelines for adults with Down syndrome. If you remember, in the 1980s, the average lifespan was 28, and that's probably why our research was housed almost exclusively at the National Institute of Child Health and Human Development. Also, as you know, people with intellectual disabilities tend to fall off the map after high school anyway, socially, every which way, and medically as well. And our children's hospitals are infinitely more accessible than our adult ones.

With the authors being made up of the medical care directors of every major adult center for Down syndrome in the U.S., we were able to use GRADE and PICOT framework, which is very complicated and arduous. It was very difficult because we're trying to create best practices. What it revealed was what we already knew, that there's no research for the best practices. And we were relying a lot on the 20-plus experience of each of the authors to inform the guideline. We went through 11,000-plus publications as part of the review process, looking at our inclusion and exclusion criteria for nine medical areas. Usually, a guideline is about a single disease like Alzheimer's or diabetes. We're trying to do a whole human. It seems impossible. How do you do a whole human?

Our senior director of research and medical care, Bryn Gelaro LSW, is leading this impactful initiative. We picked nine medical areas, and we did inclusion/exclusion criteria on research studies for all the major medical directors of the centers together. We came up with a really strong guideline, so strong that it was published in JAMA. We are now confident that any medical professional can now find these guidelines and because they are published in JAMA we believe nearly everyone will also feel confident and comfortable following them even if they have only one patient with Down syndrome.

Cooper: It's peer-reviewed.

Whitten: Exactly. This is a problem. We did ask a lot of people to write the guidelines. We were like, "We'll give you money," but nobody wanted to do it because it was so difficult. So now we're on this treadmill, Chet, and we can't get off. We don't want to wait another 20 years before the next one. Things are changing so quickly because of our great work in research and medical care. We also cannot not add new topic areas such as solid tumor cancers, leukemia, sleep apnea, eye vision and physical therapy unless we continue to invest and work hard. We have to add new areas! And then we have to go back and update the nine areas we already completed and so on.

What we've promised the community is if they could invest in us over a five-year period we will update the adult guideline every sixth year. Usually, a small community like ours plans and fund-raises year-to-year. We need to break that cycle. If we want resources that require multiple years, let's do multiple years together. Let's invest and have impact together. Eventually, I would like to see some sort of endowment for that so that it is truly sustainable—because it's hard. If we promise these for generations to come, how many six year intervals do any of us have? It has to transcend us as individuals, and I suppose endowment is the best way to do that.

But this has been game-changing. People are taking it to their medical appointments. We have a family-friendly version–because it is quite complicated–that people love. And of course, all of it is downloadable free on our website. We just did a Spanish and Japanese version. By the end of the year, we'll have six more different languages that can be downloaded.

We're really proud of all that. The other thing that happens is that we've got a grant to do a deep dive on eye and vision issues in people with Down syndrome. One of the wonderful, intended consequences of having 2,200 patients at the Sie Center for Down Syndrome at Children's Hospital Colorado is that the ophthalmology department now has over 500 kids with Down syndrome! There, the irrepressible and brilliant Dr. Emily McCourt discovered that keratoconus, which can lead to complete loss of vision, is something that is way up in kids and adults with Down syndrome. And her findings have helped rewrite the eye care section of the American Academy of Pediatrics guidelines for children and adolescents with Down syndrome. With the cross-linking, we can stop keratoconus in its tracks. We can't reverse it, but we can stop it.

GLOBAL had underwritten the cross-linking machine, a Pentacam®, all this great equipment for the eye so that the medical professionals at the Sie Center and

Michelle Sie Whitten and Sophia Women's day 2020

Children's Hospital Colorado can really make a life-changing difference. Their first 18 patients who they used the cross-linking on had already lost vision in one eye–and that's why they were the first in line. We were so surprised to learn that of those first 18 patients, NINE had had Down syndrome.

As you can see, we're really proud of our work. The other thing we do have now is the prenatal and newborn pamphlet in Spanish and Icelandic, but we're on the precipice of having that in six different languages by the end of June or early July. We're excited about that.

We also now have an education center downstairs and plans for in 2024 or 2025 a coffee shop that hires people with Down syndrome in our building. We are doing a hotel employment training program with three hotels that are within a six-block radius of us. And then of course we have our award-winning magazine, Down Syndrome World™ which we love, and our quarterly webinars that are now on average attracting 400 people for each quarterly webinar. We're very excited that we have co-invested in Regis University–although we're tied with another Catholic university–to do a post-secondary program certificate for students with intellectual and developmental disabilities.

And because it's Jesuit, the head of all the Jesuit universities is very excited, and we already have Creighton, Gonzaga, and Loyola saying that they want to adopt a similar program to the Regis program that we just launched.

Cooper: How's Quincy, by the way? I haven't heard from him for a long time.

Whitten: He and my father are no spring chickens! But they are doing amazing well. They totally have their cognition and continue to have the best ideas and wisdom. Their ideas and how they approach problems strategically or what they advise is still pretty amazing and spot-on. I'm forever grateful that I've had the luck of having many different mentors. My first mentor was Peter Barton in the cable industry. But we've just had a lot of people from different walks of life support GLOBAL, and again, personally, for me to have been mentored by many different people in the cable industry, including Sharon Magness Blake and Laura Barton and then my mentors at NIH – Dr. Hodes, Dr. Tabak, Dr. Gibbons and Dr. Bianchi. I feel very lucky.

Martirosyan: What are your thoughts about the Barbie doll?

Whitten: The fact that Mattel is wanting to be inclusive, worked with a Down syndrome organization and created an inclusive doll is a huge step in the right direction. identity. However, I think it should be said, that there are many other dolls , even a baby dolls, with Down syndrome that have been available prior to this Barbie doll. I do think we should acknowledge those dolls and companies that have made a mark in terms of aware-

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ness and inclusion too. That's the first thing. The second thing is to acknowledge that Mattel is a big company that has worldwide distribution is amazing! This is huge and I hope they can come out with additional Barbie dolls with Down syndrome of different races, hair color, shapes and sizes.

OTHER BABY DOLLS WITH DOWN SYNDROME:
Miniland-Asian-Syndrome
Miniland-Baby-CAUCASIAN-Syndrome
Down-syndrome-reborn-doll-noah
Baby-boy-asian-with-down-syndrome

Cooper: The fashion show, I think I've attended a couple of them, how is that progressing, moving forward? Do you see any results from any of that of some of the people involved getting modeling gigs or acting gigs? Is there any connection to that? Once it's done, does everybody go home and is happy about it?

Whitten: We have a lot of diversity within our models. Choosing the models is very difficult because on the one hand, people are auditioning based on their ability to walk the runway. On the other hand, we do want to be mindful of gender parity, age diversity, ethnic and racial diversity and we are part of a larger disability community so how is that reflected? There's a lot that goes into choosing the models.

What we're having more and more of are people who are already starting to be models or actors or wanting to be famous social media influencers auditioning. Traditionally our models would have just been any wonderful kid or adult who was attracted to this opportunity, not necessarily somebody who wants to be or is already a professional model.

Now we have this interesting mix of people who look at this as career building to put this on their resume, and others who just want the experience and as a result we hear their confidence improves tremendously.

Cooper: Nice. Anything else you'd like to add? You haven't said much. (laughs)

Whitten: (laughs) When you've been over 10 years, come on! It's been a long time!

Cooper: It's a very impressive amount of work.

Whitten: Thank you. ■ ABILITY

globaldownsyndrome.org

A Loving Tribute to
DeOndra Dixon
9/6/1984 - 10/19/2020

Talented, intelligent, feisty, beautiful, kind, loving, caring, a pure and giving heart. A beacon of hope and a bright light in this sometimes dark world, our DeOndra will be sorely missed but never forgotten.

My Journey with Covid and MS

My journey through my disability has been a long one although an interesting and enriching one also. I have suffered from MS and mental health problems for most of my adult life but recently an interesting twist was added to my experience. I also suffered from Covid.

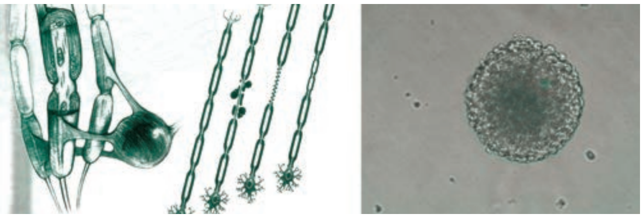
I've had what you'd call an interesting life. Not only have I had to deal with the stigma related to mental health for quite a long time, I also had to suffer from a physical disability along with it, multiple sclerosis. Nice combination. I'm by nature a happy person so I've dealt with both very well. Practicing Buddhism has helped as well. I've also had an active life despite my disability. I worked as a journalist for a while and managed a Community Access Center in Moncton. I taught Microsoft courses for the government. After that I volunteered: as a media relations officer for a local mental health organization during their yearly fundraiser and as a recreation's person at the Georges Dumont Hospital with elderly people. Now at the age of 56 I'm pretty much retired. But I've had a happy life until my experience with covid.

It all started nearly 30 years ago when I was 28 and was adoring my job as a communication officer for the department of health for the N.B. government. It was my dream job. But I had to leave it suddenly when I went into a chronic depression which I've suffered since then. I am treated now however and don't feel depressed most of the time. I do suffer from anxiety however. A few years after that, in my early thirties, when I had moved from Fredericton to Moncton to live with my parents I found out I have multiple sclerosis on top of that. The fact is that there are approximately 100 000 Canadians who suffer from MS and one out eight Canadians who suffer from depression. I am one of those myself.

The fact is that I am a happy person nevertheless. First of all, I am completely mobile and am happy for that, I don't have a physical disability yet. I'm on meds that control my MS. I also practice Buddhism. I also have a good psychiatrist and a neurologist. I feel blessed most of the time.

I was the happiest person until mid February 2022 when I caught covid. I have a poor immune system in the first place because of my ms. I was terrified for the first time in my life when the test turned out positive for covid. I was scared to death for a few days. You see, I've been living in a senior's home for the last five years because I am fully subsidised by the government here. All the residents including myself were fully vaccinated. I saw a lot of people around me catch covid and it was a milder case than mine. Staff members here and residents.No deaths.

The first thing I did when I found out I had covid was call my mother. She's my support system in general and told her: "Maman, I have covid." She couldn't believe it and was scared too. We were right in the middle of a wave in the news of people in senior's homes dying from covid. I then contacted my neurologist and he told me that there were special pills for people with a poor immune system who had covid and I had to contact my family doctor. I called her and she put me on a puffer and Nasonex. I was congested both in my lungs and my nose and had a terrible soar throat that kept me awake at night. I felt terrible. It didn't feel like a slight flu. She told me if I got worse not to call again but to go directly to the hospital. Luckily for me, after four days I was feeling better and started healing after that. Boy was it frightening though. I had felt really sick.

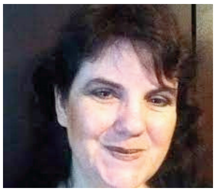


The funny thing about it is that it changed my life for the better. I almost felt like I had had a near death experience. I am so thankful for everything on life right now, starting with my family and friends, who had supported me so much. My brother who works as a scientist in San Diego California called me every day. Buddhists believe in compassion and loving kindness more than anything in life. Now I will be able to practice these principles for the rest of my life without the fear of death. My family call me their covid hero. We've been on lockdown in this residence almost all the time since Christmas. We can't leave the residence at all because there are still cases in the residence.

You might be wondering what I do with my time when I'm on lockdown. I meditate a lot and have come to be reflective of life. I know this will end eventually. I try to practice compassion and loving kindness to the residents around me. It's not easy because I'm fed up being locked in myself. But I try my best. As for my mental health problems. I'm on good meds. I'm not depressed at all although I suffer from anxiety. Not much I can do about it. I just learn to live with it. I know it will diminish when there is less covid around us.

I'm still happy and functioning well despite my illness-mostly because I refuse to give up and have a great support from the medical community, my family and friends. ■ ABILITY

by Lise Elsliger



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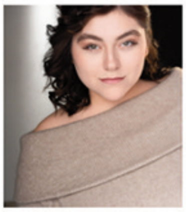

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Crossword Puzzle

Crossword Puzzle

ACROSS

1. "Midnight Blue" singer, Melissa
6. Scottish island in the theme tune for "Outlander"
10. Feature film that is designed to raise awareness about the lack of Hollywood roles for actors and actresses with disabilities
12. "If I Ruled the World" rapper
13. Medical show
14. Fun winter weapon
17. Dedicate, as time
19. Not for love __ money
20. Retailer offering accessible mobile phones with a Family Mobile Unlimited Plan
21. Young loves
22. Early afternoon hour
23. It makes the heart grow fonder, according to a saying
26. City which is known as the first "Autism certified Destination" in California
27. ''Brokeback Mountain'' director
28. Company well known for appliances
29. Freddy Krueger's street
30. Quadriplegic who stars in 10 across, Tobias ____
33. Fired up
35. Sleeping spot
36. Arts degree, abbr.
38. Useful carrier for a person traveling with someone with autism, _____ backpack
40. Actress who was the first woman with Down Syndrome to walk the red carpet at New York Fashion Week, Jamie _____
43. Not applicable, for short
45. Exist
46. Blind Pakistani who is pioneering "Capacity building" - Ashir _____
47. Captivates

DOWN

1. NBA star, ____ Malone
2. Take a quick sleep
3. Really crazy
4. Formal greeting
5. Sports award show
7. Songwriter who recently released his double album, "Diopath" and Omniopath"- 2 words
8. _____ Disability Film Challenge
9. Disney show for kids which includes characters with disabilities
11. Big coffee pot
15. "Wise" bird
16. Starbucks order
18. Foot extension
20. Giant sea mammal
21. Magazine front page
24. Southern beauty
25. Innovative
28. "Children of a Lesser ___" -Marlee Matlin starred
30. "30 Rock" star Tina
31. Fall back
32. British actress with Down's Syndrome who played Lady Pamela Holland in "Upstairs Downstairs"- ____ Gordy
34. __ Eliot, poet
35. It's included in whole wheat
37. Wilson of ''Wedding Crashers''
38. Put on a patch
39. Lennon's love
41. Major period of time
42. Nurses. abbr.
44. Popular

answers on page 68

Crossword Puzzle

ANSWERS

1 M	A	2 N	C	3 H	E	4 S	T	5 E	R	■	6 S	7 K	Y	8 E
O	■	A	■	A	■	I	■	S	■	9 F	■	E	■	A
10 S	11 U	P	E	R	C	R	I	P	■	I	■	12 N	A	S
13 E	R	■	■	E	■	■	■	Y	■	R	■	T	■	T
14 S	N	15 O	W	B	A	16 L	L	■	17 D	E	V	O	18 T	E
■	■	W	■	R	■	A	■	■	■	B	■	19 N	O	R
20 W	A	L	M	A	R	T	■	21 C	R	U	S	H	E	S
H	■	■	■	I	■	22 T	W	O	■	D	■	A	■	E
23 A	24 B	25 S	E	N	C	E	■	26 V	I	S	A	L	I	A
27 L	E	E	■	E	■	■	28 G	E	■	■	■	L	■	L
29 E	L	M	■	D	■	30 F	O	R	31 E	32 S	T	■	■	S
■	33 L	I	34 T	■	35 B	E	D	■	36 B	A	■	37 O	■	■
38 S	E	N	S	39 O	R	Y	■	■	40 B	R	41 E	W	E	42 R
E	■	A	■	43 N	A	■	■	44 I	■	45 A	R	E	■	N
46 W	I	L	S	O	N	■	47 E	N	C	H	A	N	T	S


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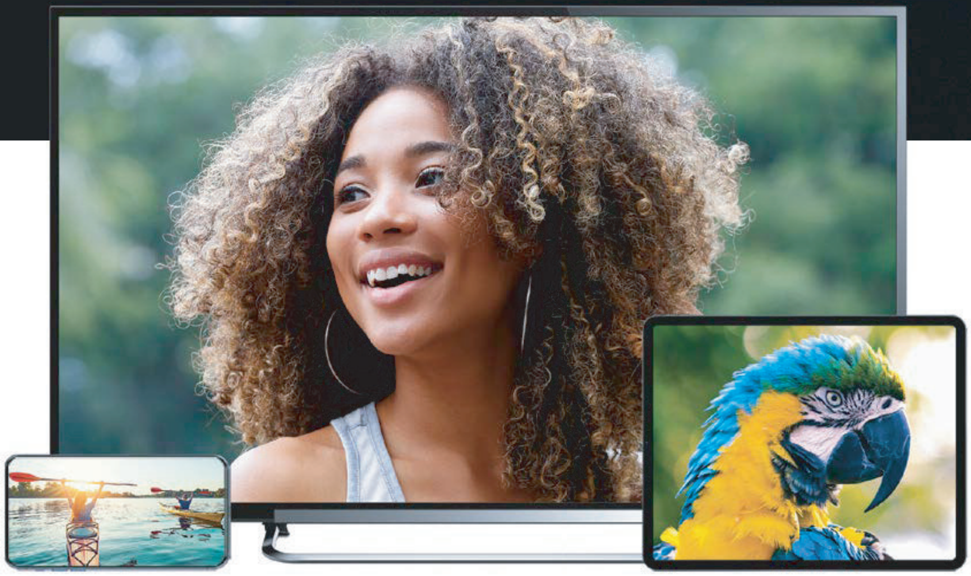

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