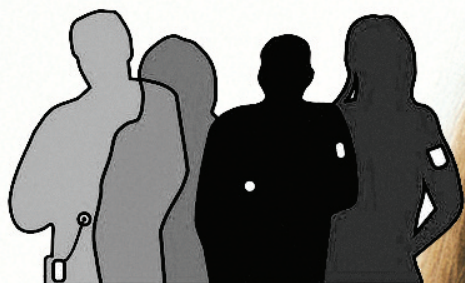


ABILITY



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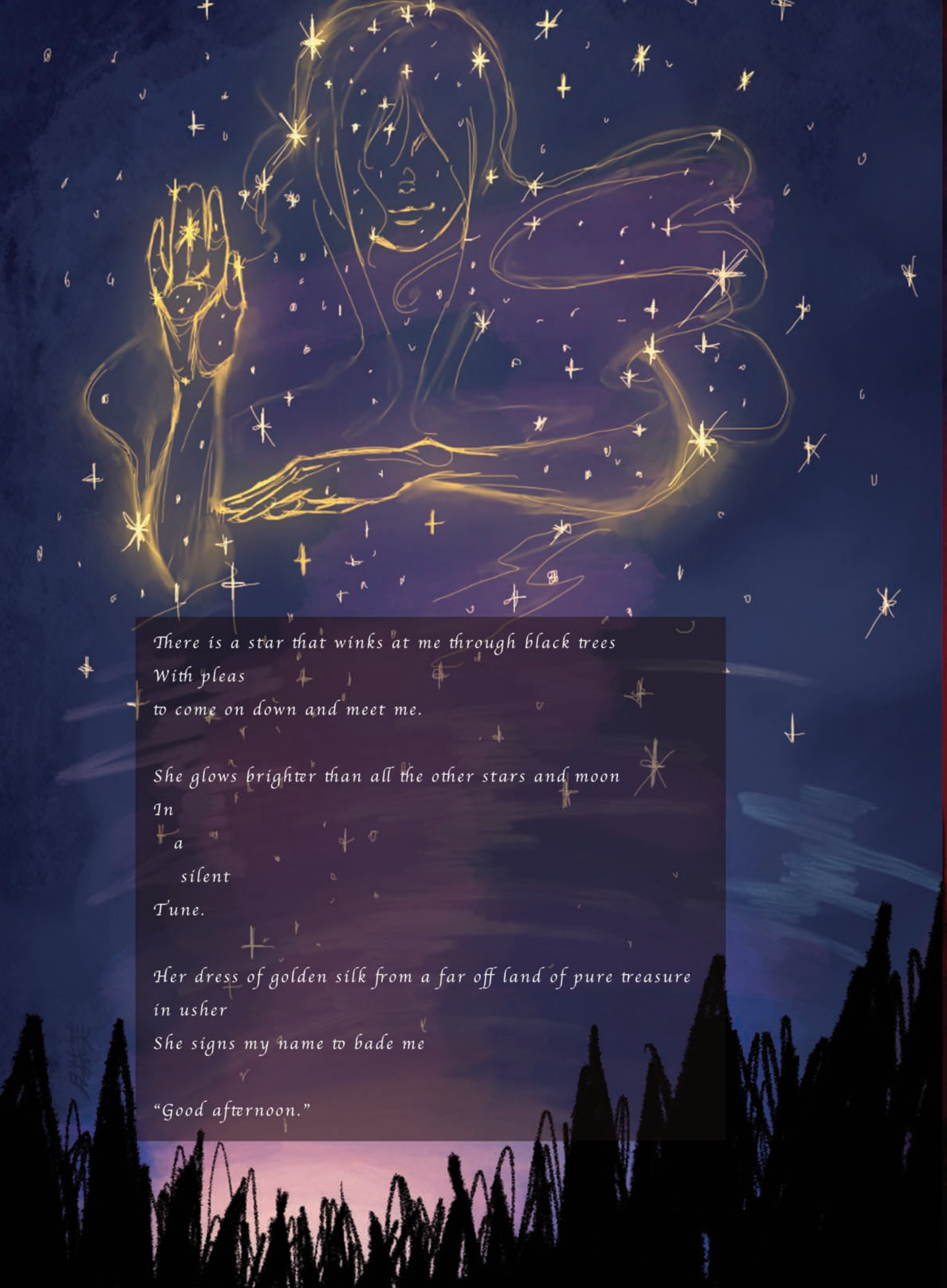
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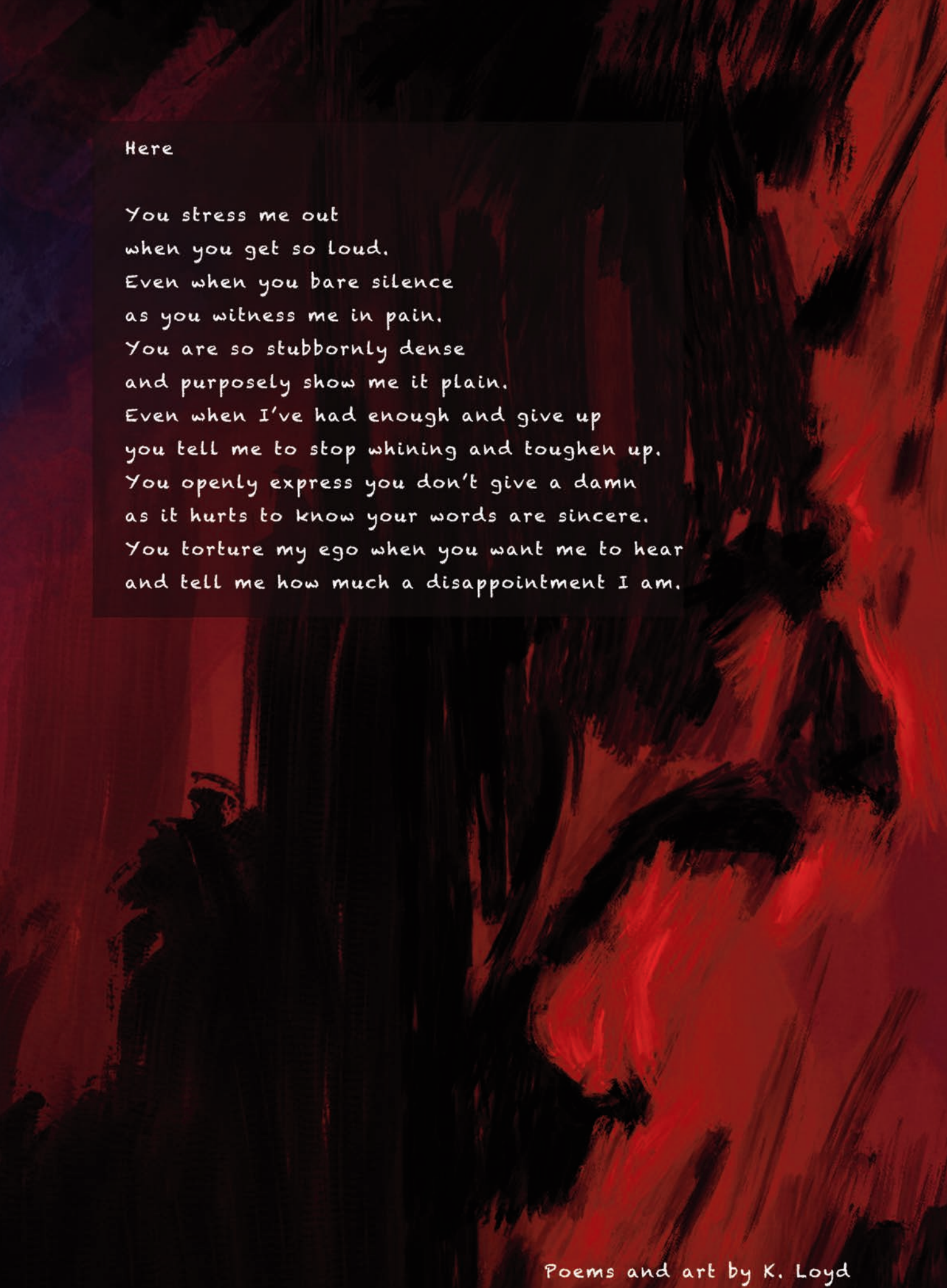
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The background of the entire page is a dark, deep blue night sky. It is filled with numerous small, white, four-pointed stars. A large, intricate constellation is drawn with thin, golden-yellow lines. This constellation forms a figure that appears to be a woman with long, flowing hair. Her right arm is raised, with the hand open and fingers spread. Her left arm is extended downwards. The figure's face is also composed of these golden lines, showing a gentle smile. The overall effect is that of a celestial being or a constellation personified.

*There is a star that winks at me through black trees
With pleas
to come on down and meet me.*

*She glows brighter than all the other stars and moon
In
a
silent
Tune.*

*Her dress of golden silk from a far off land of pure treasure
in usher
She signs my name to bade me
"Good afternoon."*



Here

You stress me out
when you get so loud.
Even when you bare silence
as you witness me in pain.
You are so stubbornly dense
and purposely show me it plain.
Even when I've had enough and give up
you tell me to stop whining and toughen up.
You openly express you don't give a damn
as it hurts to know your words are sincere.
You torture my ego when you want me to hear
and tell me how much a disappointment I am.



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and the R-Word All on the Upswing



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Typically, when disabled people imagine the future, they imagine flying wheelchairs, full inclusion in education and an end to the subminimum wage. They never thought about society going backward, as we have unfortunately started to see.

With the help of Robert F. Kennedy Jr., the Secretary of Health and Human Services who is notorious for his anti-vaccine stance, polio, which had been nearly eradicated thanks to a decades-long global vaccination campaign, is “ready to party like it’s 1949!” As it tweeted recently, polio is very excited by the thought of less federal funding for childhood vaccines as well as the end of school vaccine mandates.

Tooth decay is also set to surge in the coming years, and the bacteria responsible gave a high five to polio when they met at the Conference of Unpleasant Things. Tooth decay’s comeback will be facilitated by the belief, increasingly common in the US, that fluoridation is part of a government plot to lower people’s IQs. (In fact, the government’s laissez-faire attitude toward COVID is the main pillar of the current plot to lower people’s IQs.) Anyone who has seen British television, which features people from places where they do not flouridate the water supply, can attest to the fact that Americans, who generally do have fluoridated water, benefit greatly from it.

The third nasty thing linked to a regression in American

society is the fact that people are using the R-word more. Numerous news outlets reported that former Vice President Harris was called this word by Trump in meetings, and teachers have reported that it’s being used frequently in classrooms again for the first time in years. The R-word, when reached for comment, was absolutely ecstatic. “The ’90s are in! When you wear your JNCO jeans and flannel shirts, you should use me to remind others that people with disabilities are stupid, and that’s hilarious!”

People with disabilities, when reached for comment, were too busy gathering sticks and matches in preparation for the coming dark ages to find any of the above hilarious.

■ ABILITY

by Kate

Founder Steven Verdile

the-squeaky-wheel.com





A scenic mountain landscape with a blue lake and a motorcycle in the foreground. The motorcycle is a Yamaha Tenere 700, with a silver fuel tank and black bodywork. It is parked on a gravel path. The background features a large, blue lake surrounded by green hills and mountains under a clear sky.

It's FARKLE Season

In the world of long distance motorcycle riding, we often use the acronym FARKLE.

When we get a new motorcycle that we plan to ride for tens of thousands of miles each year, we customize it by adding parts and accessories to help us travel long days comfortably and safely. The first few months of ownership are spent getting to know the new bike and sorting out where and what FARKLES we want to install. Unlike pinstripes, loud exhausts or fancy chrome engine parts that some riders add to personalize their rides, FARKLES are actually Functional Accessories. Really Kool and Likely Expensive.

After logging my current 2021 Yamaha Tenere 700 for over 200,000 miles all across the country and Canada over the last few years, Yamaha just decided to give me a brand new one. I think they were tired of seeing me show up at national events with my dirty, ridden hard and put away wet, motorcycle.

The 2025 Yamaha Tenere 700 has some significant changes and to be honest, my



bike is starting to get a bit ragged around the edges! Not that I wouldn't trust it to go anywhere on the continent at a moments notice, just that as the highest mileage Tenere 700 in the world, it is showing lots of wear and tear and smells like a pair of dirty socks!

The 2025 model has better lighting, drive by wire and

traction control. The suspension has been improved as has the switchgear on the handle bars. A new dashboard, fuel tank, seat and drive modes for the engine. The bike is also much cleaner than mine, so how could I refuse a replacement?

I now have over a half a million miles on Yamaha Tenere's. My original CureChaser motorcycle is on permanent display at Barber Motorsports Museum in Birmingham Alabama. The next two bikes I rode as part of my million mile quest for Multiple Sclerosis; CureChaser II and III were raffled off completely accessorized, as I rode them, raising \$35,000 to benefit a MS Charity. My current Tenere, CureChaser IV will soon be raffled off as well, fully farkled.

While waiting for the new bike to be delivered, I started to make a list of the FARKLES I wanted to install once it arrived. Unlike starting from scratch with a whole new model, I had a pretty good idea of what items from the old bike worked for me and so I started ordering parts. Lots of parts!

It's hard to travel as much as I do without hard luggage. Saddlebags that are sturdy and lock hold all of my gear and tools. A tank bag is easily accessible and holds glasses and gloves and anything else I may need handy while riding. A better more comfortable seat, taller windscreen to hold back the buffeting on the freeway





Sage Creek Basin, Badlands NP 8/8/24

June 2025 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28						
August 2025 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28						
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Parent's Day						



Desert Center, California 11/2/23

July 2025 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28						
September 2025 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28						
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24	25	26	27	28	29	30
31						

and high power driving lights to help me through those long dark nights. I will need to add an auxiliary fuel tank so I don't have to stop 10 times each day for gas. I also add power ports to plug in my heated gear for the winter and installing heated handgrips are a no brainer.

I will add an insulated bladder to hold water, a thermos to hold other drinks and a radar detector to keep me honest. Crash bars protect the engine and plastic panels from drops and off road adventure mishaps, and an automatic chain oiler will help extend the life of my chain and sprockets.

With my memory issues and brain fog caused by the demyelination in my brain from MS, I can't go anywhere without a GPS. Two, in fact, a stand alone unit and my cellphone will be mounted and powered on the dash to help minimize those pesky wrong turns!

As my list grows, so does the realization that customizing my present from Yamaha is going to cost me about five thousand dollars! Another aspect of preparing a machine to ride a few hundred thousand miles is making calls to my trusty sponsors to see what products they are willing to donate to the cause. If nothing else, my million mile quest is a great way to test equipment and gear! ■ **ABILITY**





As the Americans with Disabilities Act was signed into law 1990, civil rights lawyer Eve Hill was just beginning her legal career. What followed was a decades-long commitment to advancing the rights of people with disabilities through litigation, public service, education and policy work. With experience spanning the Department of Justice as Deputy Assistant Attorney General of the U.S., local government, nonprofit advocacy, and now private practice, Hill is one of the nation's leading civil rights lawyers, known especially for her work with disability and LGBTQ+ justice.

ABILITY Magazine's Jennifer Woodall met Hill in a virtual interview to discuss two major legal battles that expose systemic failures in federal institutions. One lawsuit focuses on the Department of Veterans Affairs (VA) and its misuse of land in Los Angeles, originally intended to support unhoused veterans with disabilities. The other takes aim at the Maryland prison system's treatment of transgender women with gender dysphoria, raising serious concerns about access to medical care, housing placement, and constitutional rights behind bars. These cases highlight the deeply entrenched barriers disabled people face, particularly when compounded by homelessness, incarceration, and discrimination and the critical role that legal advocacy continues to play in challenging those systems.

Jennifer Woodall: I'd like to talk about the recent lawsuit against the Department of Veteran Affairs. Can you tell me how you first came to work on the lawsuit?

Eve Hill: Sure. Public Council, a nonprofit in Los Angeles, reached out to me. They had a few years ago, 2011 or so, filed a case against the VA for failing to use the property that had been donated to house veterans. Veterans in LA were still unhoused at a really disproportionate rate in comparison to





the rest of the country, and they had all this land available. Public Council had settled that case but had gotten a non-enforceable agreement. So, the VA had not followed through on its commitments under the settlement agreement. They wanted to sue (the VA) again and came to me because I have expertise in both suing the federal government and in the Rehabilitation Act and other disability rights laws. So, I signed on to be their disability rights lawyer

Woodall: Can you tell me the type of work that goes into preparing for a lawsuit like this?

Hill: Well, it's a lot. It's like a duck. All the work is happening under the surface before you see anything actually happen on the surface. We did a lot of work talking to homeless people, homeless veterans and homeless advocates about what was going on and really just made sure that there were issues that crossed the whole group—the things that were keeping them from getting housing, and that those housing lacks were interfering with their ability to get VA health services that they are entitled to.

We interviewed a lot of people, came up with our class representatives, came up with our class definition, researched the entire history of the property that the VA had been donated and did thorough research on the law that would apply to it. A lot of the work goes in at the

front end before we even file a case. And then we file the case.

Woodall: Can you give me a little bit of a breakdown on the ruling of that and how that went?

Hill: We had a trial that went for about a month in Los Angeles before Judge Carter. At the end of that, Judge Carter made a really in-depth, detailed ruling. He ruled that the VA had violated the Rehabilitation Act by discriminating against homeless veterans with disabilities, both because their failure to provide permanent supportive housing on the VA campus prevented veterans with disabilities from accessing the medical care that was provided on the campus that they're entitled to and because the failure to provide that housing on the campus or near the campus led to more institutionalization of homeless veterans with disabilities—because they would end up in mental hospitals, in jails, in homeless shelters and so forth, all of which are institutional as opposed to permanent supportive housing, which is community-based. So that was part of the decision.

The other decision was that what's called the AMI (Area Median Income) calculation, where they decide whether a person has low enough income to qualify for permanent support of housing. That income calculation took into account the VA disability benefits that people received. If you had a higher disability benefit, meaning

you were more disabled, you weren't going to be eligible for the housing that the VA provided. That was another aspect of disability discrimination.

Then the court held that these land use agreements that the VA had entered into with entities like UCLA, the Brentwood School, Bridgeland Oil and Safety Park violated two things. The Administrative Procedure Act because they were in violation of law. And then they also violated their fiduciary duties to the class. Because the property had been given to them in trust and the West Los Angeles Leasing Act had incorporated that trust, the VA was under an obligation to comply with the terms of the trust and had fiduciary duties to the beneficiaries of the trust, which were the homeless veterans with disabilities.

So, (the judge) found that those land use agreements violated the deed, the West Los Angeles Leasing Act, and the fiduciary duty under the deed, and so that those leases had to be avoided. So, he ordered, very specifically, the placement of 700 temporary supportive housing units on the campus within 12 to 18 months. He ordered the VA to come up with a plan to provide 1,800 permanent supportive housing units. The plan had to be within six months, and the completion of the permanent supportive housing units had to be within six years. He required the VA to begin construction on a town center to make sure that this was really community within 18 months.

Then he addressed the root causes of the VA's problems with housing veterans with disabilities, which included that they were not making enough referrals to the public housing authorities who then placed the people in permanent support of housing. So, he required the VA to increase its staffing there to ensure they made 25 referrals a week. He required them to staff up their voucher program to reduce attrition.

Part of what permanent support of housing does is provide supports around you so you don't do things like miss the rent or not show up at the unit and so forth, so he required them to increase their staffing to reduce the attrition numbers by 50%. He required them to increase outreach so they could be finding homeless veterans with disabilities and get them into the program. And then banned them from entering into any new land use agreements that didn't primarily or principally benefit veterans.

Woodall: On a ruling like that, where there's a time period to get a certain task done, who is the one that follows up to make sure that that actually happens?

Hill: The court appointed a monitor to work with the parties to make sure that they were on track and were doing the right things to get those things done.

Woodall: What do you think is the most difficult part

about building a case and lawsuit like this?

Hill: There are a couple of difficult parts. One, it's always difficult to get a class certified. And then other difficult parts were basically the intransigence of the VA and the fact that their housing voucher program is run by both the VA and the Department of Housing and Urban Development. So, we had to include the Department of Housing and Urban Development. And the fact that people with disabilities who are homeless are not just all located in one place. You can't find them. You have to do outreach. You have to do referrals. You have to really have a robust program to help them. Then the constant barriers to staffing up a program to make sure that it's adequately resourced to do the work that it needs to do. Those are the hardest things.

The hard things about doing a case are just the hard things about doing a case. It's hard to wrangle plaintiffs who are unhoused. They don't have stable housing, and it's often difficult to get in contact with them. Then the federal defendants brought a lot of motions, tried to get the case kicked out. So, we had to deal with all those things.

Woodall: If there are other disabled veterans across the country that might be experiencing something similar, do you have any recommendations on where they can start to try and advocate for themselves?

Hill: Well, they can start with their local fair housing organizations. Those are great places to go.— We had really great veteran advocates in LA.— So, they can start with their veterans advocacy groups and reach out to their protection and advocacy organizations, the disability rights organizations, all of whom could take these things on, and bring the issues to the attention of the VA because the VA is not necessarily paying clear attention to what's happening.

This was a really groundbreaking case. It shouldn't have been, but it was a really groundbreaking case to hold the federal government responsible for its obligations. It's hard to sue the federal government. They have a lot of lawyers. We don't have a lot of lawyers, but this was an egregious case where they had the land to do the right thing, and they are continuing to refuse to do the right thing. In fact, now they have appealed to the Ninth Circuit, and the Ninth Circuit has stayed implementation of the judge's order. So, nothing is happening right now, which is a real tragedy. Also, as the fires take place in Los Angeles, it's destroying more and more housing, and the problems are only getting worse.

Woodall: How do you deal with that pause in momentum? Is it just a waiting game?

Hill: Largely a waiting game. Our public interest organization clients and co-council, the inner city law center and public council continue to have to really work to try



and get our plaintiffs into housing themselves and keep them in housing. While you deal with the systemic issue, the individual issues are continuing. And you have to deal with those, too. It's really difficult, especially for them, our local partners, to keep doing the work, not let morale fall, and make sure that our individual plaintiffs get what they need, and that our class gets what they need. It's very difficult right now because they're not doing what was required by the district court.

Woodall: I'd like to shift the conversation to the lawsuits related to trans people. The first one I came across that you worked on was with Chelsea Gilliam. Can you give me a rundown of what those lawsuits entailed?

Hill: I'm not the only one doing these lawsuits, and so I can't really talk to what the others are doing. But in my case in Maryland, we sued the Maryland Department of Corrections for a couple of things, like failing to accommodate people with gender dysphoria, which in the Fourth Circuit is recognized as a disability qualifying under the ADA. So, they're failing to provide continued hormone replacement, hormone treatment, and other forms of gender-affirming care, like facial hair removal and female clothing and so forth and their housing of transgender women in men's facilities, often segregated in solitary confinement, basically.

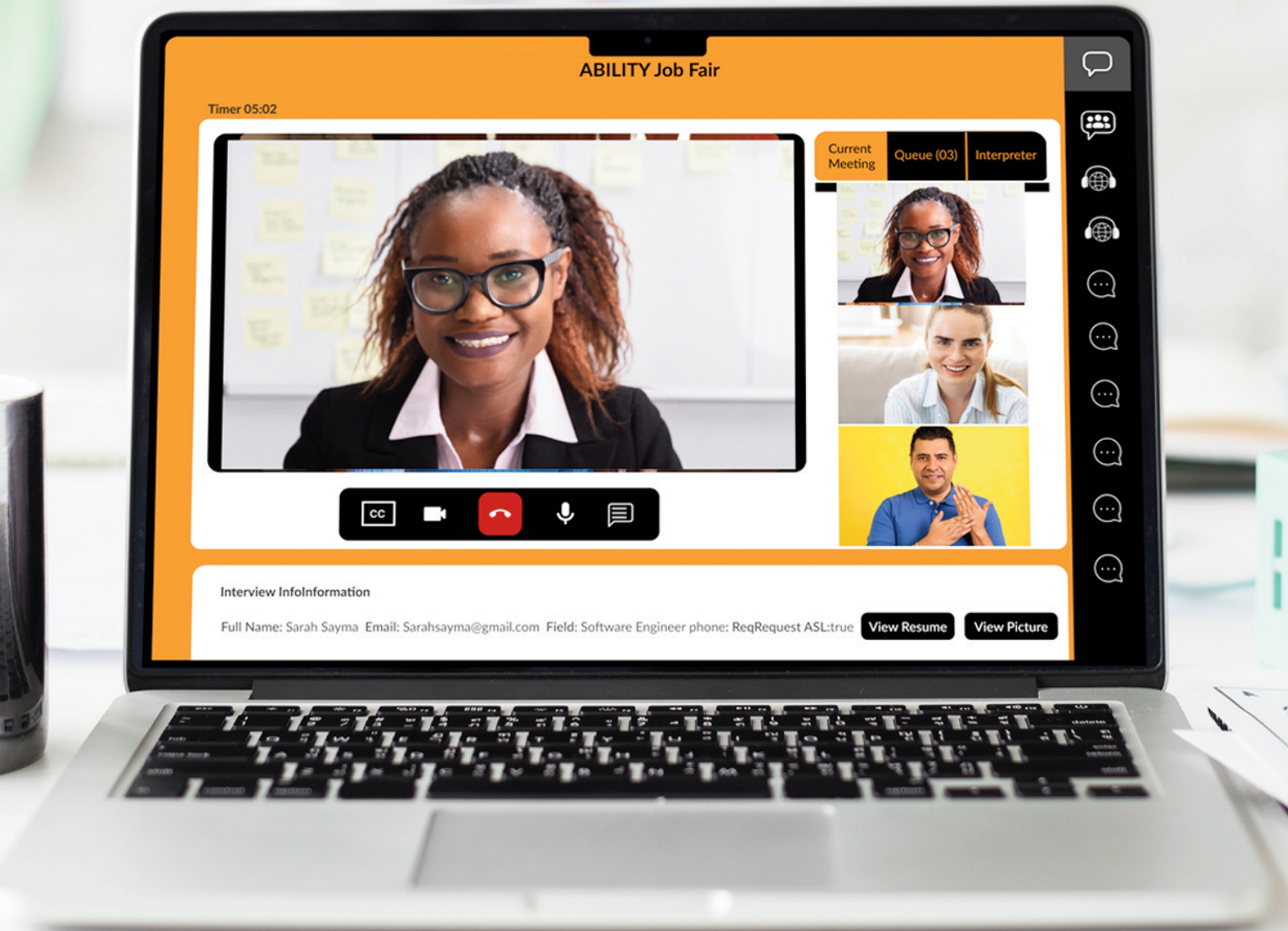
This, we allege, violates the Americans with Disabilities Act, which requires accommodations for people with disabilities, including gender dysphoria, and requires you to follow their treatment recommendations to the extent those necessitate reasonable accommodations. We also allege that it violates the Eighth Amendment, which is cruel and unusual punishment. So, they're subjecting these women to sexual harassment, sexual assault—just constant torture at the hands of other inmates and guards on the basis of their sex.

That's cruel and unusual, and we also think it's a violation of the sex discrimination prohibitions of the Constitution. So, the 14th Amendment is at play here as well. They're denying them jobs. They're often keeping them in segregated settings. Solitary confinement is cruel and unusual, especially when it's not for any legitimate purpose, and it only had the purpose of allegedly protecting them. That's not the best way to protect transgender women. You protect transgender women by protecting them in general population, and, really, by protecting them in general population with women because they are in fact women. So, those are the allegations there.

We have now survived a motion to dismiss, so our case is going to go into the discovery phase. In fact, two of my clients are out of prison now, so that's good. One of them is still in prison and still housed at a men's



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facility and still denied access to jobs. Her hormones have gotten better because we sought a preliminary injunction requiring them to make sure that her hormones were consistently provided, and it varies week to week, but mostly doing that.

Woodall: You say discovery phase. Can you tell me what that means?

Hill: The discovery phase means we get to ask the Department of Corrections all kinds of questions and take deposition interviews of the people who know what happened and what's happening and who are in charge. So, we are just starting that process now. That's a big issue in our case because, often, we have no transparency into who did what and when and why and who was in charge and who made the decisions. That was the one problem in the judge's motion to dismiss order. He dismissed a bunch of our named defendants because we couldn't say, "This person did this action." Say they were supervisors of the actions that happened. So, discovery will be really important for us to find out who did what, and then we can rename the people, the specific people who took the actions.

Woodall: Have you found any roadblocks specifically related to lack of knowledge about the trans space and a disability component like gender dysphoria?

Hill: Well, yes. The roadblocks are attitudinal, really. This assumption that transgender people don't have disabilities. Now, not all transgender people do have gender dysphoria, but a lot of them do have gender dysphoria. And gender dysphoria is a real medical issue and a real disability. So, not having people understand, particularly the people in leadership. Not having them understand that these are protected characteristics is really difficult, and not having them understand that this is a disability is really difficult. But the bigger issue is the flat-out animus against transgender people. The attitude of prison officials and prison staff is appalling. They are in a different century and they are outright opposed to accommodating transgender women in any way. They want them to disappear, but that's not possible.

Woodall: So, given the current administration's stance on topics like this, does your strategy on how you approach and present these cases change?

Hill: We have yet to see. Our cases are in court, so we have to count on the courts not being affected by the executive branch's anti-trans rhetoric and actions. We are hopeful that the judges will remain neutral and not be impacted by this set of actions on the federal level. One thing that does change is we used to have the Department of Justice's support for cases on behalf of transgender inmates and others.



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We obviously will not have that support in the future. In fact, one of the executive orders on transgender issues calls on the Department of Justice to amend the ADA and amend the Prison Rape Elimination Act to take transgender people out of the protections of those statutes. Now, the agencies themselves can't amend the ADA or the Prison Rape Elimination Act, they have to go to Congress to do that. So, we also are hopeful that Congress will not share in the administration's really appalling negative approach to transgender people.

These executive orders don't quite do this yet, but there's a possibility that they will revoke federal funding from prisons that do comply with the constitution and laws, and that would be horrendous. That will make it harder for prisons to actually comply with their laws. Or if the executive orders order the Bureau of Prisons to stop accommodating transgender people, we believe that's a violation of the Constitution and federal law as well, but we will actually have to fight the federal government to make clear in the courts that the law requires accommodation and requires protection and not cruel and unusual punishment of transgender people.

Woodall: Can you tell me about the Judge David L. Bazelon Center for Mental Health Law where you serve as a board member?

Hill: Yes, the Bazelon Center for Mental Health Law is now 50 years old and has been advocating for people with mental health conditions for all that time. They are really smart and really brave and really amazing advocates for people with mental health disabilities. They do a lot of systemic policy and individual work on behalf of folks with mental illness, including criminal justice reform issues. So, making sure that the police are not the ones who show up guns drawn in response to a mental health crisis, where the proper response is mental health services, and trying to make sure that people with disabilities aren't incarcerated when what they need is treatment—Incarceration isn't the only place to get treatment.— so making access to crisis care more available. They work on all those issues across the country.

They're also working a lot in the education space, both in terms of the fact that in K-12 education students with mental illness are disproportionately subject to punishment, discipline, and exclusion from school, and disproportionately recommend it into the justice system. Being kicked out, the school to prison pipeline, is a big issue. Then in higher education, making sure that people with mental health disabilities have the ability to get treatment. Often the college-based health clinics and mental health clinics have a problematic lack of privacy protections. The fact that you're getting a service at the mental health clinic can be reported to the school who can then take action



Eve Hill and Chelsea Gilliam. Lawsuit: Trans woman sexually abused, harassed in men's jail 2023

under the code of conduct or treating you as a direct threat and kick you out of school. This is a huge problem.

Woodall: Is that not a FERPA (Family Educational Rights and Privacy Act) violation?

Hill: No. We contend this, but those clinics argue that they are in fact part of the school, and FERPA doesn't prevent you from revealing that information within the school. So, people with mental health conditions in college and universities are being subjected to really draconian applications of the code of conduct when it's not applied to other people and are then being subjected to forced leaves of absence. Or when they take a leave of absence voluntarily, not being allowed back or losing their health coverage and losing their housing and losing the one thing that was stable for them. So, really, they're using mental health as a cudgel against students in ways that are not fair and that are illegal.

Woodall: How do you go about researching to see if your institution is one that's following that?

Hill: Find out what privacy protections they offer, whether those privacy protections include keeping information private from the institution. Some students don't know what privacy protections they're getting, they assume their information is private, but it's not necessarily.

Woodall: Is there anything else that you would like to talk about that we haven't covered yet?

Hill: Well, the new DEI executive order is not targeting

accessibility, but it is targeting disability inclusion. And we don't know yet how much it will target disability affirmative action. The executive orders are focusing on the fact that race and gender-based affirmative action is subject to some constitutional challenges. I don't believe those constitutional challenges are strong or right, but nonetheless, they believe that.

Disability affirmative action, because it's subject only to rational basis constitutional review, is not subject to those constitutional challenges. There is nothing that prohibits disability affirmative action, and disability affirmative action is required by the various sections of the Rehabilitation Act for the federal government and for federal contractors. So, we don't know yet how or whether those anti-DEI efforts will be applied to DEIA efforts, whether they'll be applied to accessibility efforts in the government, and whether they'll be applied to affirmative action disability programs within and outside the government. Those are extremely concerning.

People with disabilities are disproportionately unemployed due to discrimination and to the failures and lack of efforts to recruit them. So, at the very least, we don't know if they'll go after those programs or they'll just not implement and enforce them anymore. Either way, that puts a tremendous burden on advocates and individuals to try and enforce those laws without much transparency into what the federal government and federal contractors are doing in regard to hiring and employing people with disabilities. That really worries me.

■ ABILITY

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Trailblazing Accessible Events at Salesforce

You might recognize Salesforce from its iconic ads featuring Matthew McConaughey, that humorously show how disastrous customer experiences can be when businesses don't use the platform. Salesforce is not only one of the largest tech companies in the US, but it's also known for its strong commitment to "trailblazers", a term used to refer to customers, employees and partners.

One standout trailblazer is Amy Wood. Combining her passion for event planning with her desire to accommodate accessibility needs, Wood has helped transform the event experience for thousands of trailblazers. From transportation and food to wayfinding and event sessions, her work has enhanced all aspects of major B2B events like Dreamforce, which can be the size of a small city.

ABILITY Magazine's Marge Plasmier and Chet Cooper sat down with Wood, who is deaf, to discuss how her role at Salesforce has broadened her perspective on accessibility beyond her own disability. Wood also describes many of the accommodations adopted for trailblazers, overcoming challenges and the playbooks she developed that are used throughout the company.

Plasmier: What brought you to Salesforce initially?

Wood: I lived in Indianapolis at the time, and this was probably back in 2016. I was working in Indianapolis at a different company, and there were several laws that were passed that were dangerous to the LGBT community and also people with disabilities. The CEO of Salesforce Marc Benioff, spoke out against these laws that went into effect, and he said, "If you leave these laws in effect, I am going to remove the company. I'm going to remove all of the employees and pay for them to move to another state where they won't be in a harmful area."

That's how I first became aware of Salesforce and how Marc Benioff prioritizes the safety and comfort of his employees. Especially as a deaf person, that really resonated with me. I kept my eye on the job openings, and in 2019, I found a job that I really wanted to apply for. I applied for it and got the job, which was the event supervisor in Indianapolis. Previously, I worked in marketing for an insurance and financial services company. So, it was really great to get back to my roots in event planning.

Plasmier: What did you notice about Salesforce that started this process of making changes?

Wood: I noticed that Salesforce was really — There are five values that they work



Matthew McConaughey and Woody Harrelson in a Salesforce commercial.

through, that [Salesforce] lives by, which are trust, innovation, customer success, sustainability and equality. I really admired that. It's like customer success and trust were the two biggest things, and that's how we operate on our day-to-day work.

In my work, I was organizing events and welcoming customers to the tower. I would work with a Salesforce employee welcoming customers. I noticed that there was no way for customers to request an accommodation, whether they had a dietary restriction, or whether they needed captioning, or whether they needed a sign language interpreter. So, I started working locally with the event host. And I would say, "Okay, do any of your customers have dietary restrictions or peanut allergies?" —That's really a big one, or gluten-free. So that's very important. —Or do they need a sign language interpreter? And so, locally, in Indianapolis, I was able to make that change.

Most of my team was based in New York City, so we were spread out all over. We have someone in San Francisco, in Atlanta, Indianapolis, Chicago. So, I tried to work with the New York City team to implement these changes at a higher level and say, going forward, all event supervisors need to ask what accommodations are available.

Then in 2020, we went into the pandemic, and that is when we pivoted 100% to virtual events. So, the need for regulatory restrictions wasn't as important, but I noticed that there were a lot of meetings in a virtual event that didn't have captioning or sign language interpreters. At this time, I didn't really know much about screen readers or keyboard navigation, so that was really fun to learn about.

In fact, my boss got upset with me because I was not engaging in some of the events that were being put on our team or this headquarters. I told her, "I'm having a

really difficult time. There's no captioning available." And so, my boss said, "Well, we'll get you a sign language interpreter." I don't know sign language. I think that was a really great opportunity for me to educate people on the stereotypes of disability and how disability is a spectrum. I said, "Well, I don't know sign language, but I would love to see if we can schedule a human captioner." She said, "Fine, do whatever you need to do."

I actually took it upon myself to create a playbook on virtual event accessibility. When I tell you, my eyes were opened. I had no idea. I thought I was going to be automatically an expert because I'm deaf. But I started just looking online, how to make virtual events accessible for people with vision disabilities, if you're blind or low vision, for people who are deaf or hard of hearing, but then also people with mobility disabilities. I never imagined that someone with a mobility disability would need virtual event accessibility. You need keyboard navigation. Or if someone can't use a mouse, how are we going to create that platform or use a platform that they can navigate? Then I also learned about diversity and how that can be impacted by virtual events, scheduling breaks and publishing the agenda ahead of time and creating an agenda using simplified language so that it's not overwhelming.

So, I created that playbook and I shared it with my boss. She really liked it. Even though we were still in the pandemic and we weren't having in-person events, I created an in-person event playbook as well. Then I wanted to get feedback on this. I reached out to the Office of Accessibility, and I presented it to who is my boss now. He said, "This is really great" Later, my boss now, said, "In the spring, we're going to be hiring for accessible events. I would love for you to apply for this". And so, I was just very happy about that. I got the job and I loved it. It was exciting.

Plasmier: In your office of accessibility or accessible events, are you the only person in there? Do you have a team around you?

Wood: I have one person that reports to me. Her name is Joanna, and she is helping me with events more now. Now that I've been in this job for almost four years, the responsibility that I have has grown so much. I'll use Dreamforce as an example. Dreamforce is 40 to 100,000 people in one event every September. I am part of the core planning team. Every event has area leads, food and beverage, keynote, security, regulations and all of that, and then I am accessibility. I'm part of the early planning process, and I share guidance and best practices. I review plans, and sometimes I'll even do site visits and get feedback on removing barriers. So, anytime somebody registers for Dreamforce or any of our events, they can request an accommodation on the registration form. I need a sign language interpreter, I need a sighted escort, I need celiac meals for gluten free. There's a whole range of accommodations, so I own that. I will communicate that out to the appropriate team and then confirm with the person that requested that accommodation. Then on site, I own the disability help desk.

The most exciting part is we have a physical desk at Dreamforce where people can visit, and it could be a meeting point for their sign language interpreter. They can come and say, "I need an accessible shuttle. Where can I find that information?" Or they can even just come and vent like, "Hey, I had a really rough experience getting in here, and they need to talk to me about that." I'm sure you know how events can be frustrating for people sometimes. We have world tours all over the world. We have Trailblazer DX. We have Connections. Just so many events, probably 30 to 50 events every year. And so that's what I do for all of those events. And that's what Joanna helps me with.

Plasmier: That's a great overview. What challenges have you faced throughout this process?

Wood: I would say there're two. The two most common challenges are lack of awareness and lack of budgeting. And lack of awareness where people will say, "Well, the venue is wheelchair accessible. That should be good enough." Or they will say, "If we have deaf people or people with hearing loss, we'll create a section for the sign language interpreter, and we'll have them sit there." I think there's a lack of awareness of the spectrum of disabilities that we have. Not everybody knows sign language.

I think, really, just trying to change the mindset of those leads and say, "This is why we need to accommodate." First of all, accessibility is not a one-size-fits-all solution. This is why we need to have all these accessibility features to meet the needs of those people with disabilities. I think sometimes you get a little bit of resistance with that. Then sometimes you get people who are just

like, "Oh, wow, you really opened my eyes to a broader spectrum of disabilities."

Then budgeting part comes in today. As you can imagine, if I say, "We need to incorporate human captioners in the broadcast", they will say, "Who's going to pay for that?"

I always say, "You are."

Plasmier: Exactly.

Wood: Sometimes it's okay. They can go back to their leadership and say that we need X amount of dollars for this accessibility feature. Sometimes they'll get that. Then sometimes they'll come back to me and say, "instead of using a human captioner, can we use AI captions?" I would tell them, "That's your choice. If you're willing to experience the embarrassment of some really poor captioning, maybe mistakes, then go for it. But you're going to have to be prepared for the feedback. And you're also going to have to be aware of the poor quality that AI captions can deliver." I think those are the two biggest challenges that I have, is the lack lack of awareness and lack of budgeting.

Plasmier: What other types of budget issues have you faced. What have people balked at most or thought was just unnecessary?

Wood: That's a good question. I would say, four years ago, my first year, we had human captives on the keynote stage, and it was great. We got tremendous feedback on that. People really liked it, and it was very visible as well. And when we said, now, we would like to incorporate a captioning in all 45 of our breakout rooms, I think that was probably a bit of a—The leadership was saying, Why? The cost of that was about \$95,000. I can understand \$95,000. So, this is where we have to, again, the educational part of it comes into play.

First of all, I always say 80 % of people that use captions aren't even deaf or hard of hearing. If someone is from another country and English isn't their first language, captions are tremendously beneficial. If someone has ADHD and missed something that was said, that's really helpful. Or maybe someone dialing in from a noisy location and watching the video on their phone or their personal device. That captioning is going to be really helpful. We want the attendees to have takeaways from all of these breakout sessions.

We want them to feel like they were able to understand and retain all of that information. I think that would probably be the biggest expense that we really had to do a lot of convincing on and working with them and negotiate a little bit. We negotiated that we would use AI captions in the breakout sessions. We use Wordly. Have you heard of Wordly before?



ASL interpreter Jewel Jaurgui interpreting the main keynote

Plasmier: Yes.

Wood: And what was really the tipping point, the convincing point for Wordly was that it translates into, I think, 50 languages. So, you can open up the event app and have it translated into Chinese or Japanese, and that would be really beneficial for a lot of people.

And then I would say the other thing that took a lot of convincing for a couple of years wasn't price-wise, it was space-wise for a quiet zone. We needed quiet zones desperately. If you can imagine a huge conference, lots of people, lots of noise, it can be really overwhelming for people who are neurodiverse or people who are not neurotypical. And for three years, I was asking for a quiet zone, and I was never able to get ahead of space planning in time because rooms are very limited, space is very limited. And it makes sense that they want to maximize every square foot of that conference. Right.

Plasmier: Beyond your experience with events. Have you seen any type of transformation because of the work that you're doing with events? Has that transferred to the buildings? I know you're remote, but is there a counterpart like you for the buildings or for the different satellite offices around the world?

Wood: Absolutely, yes. And yes, we have seen a transformation in the last few years. My counterpart on the real estate design team is extremely passionate about accessibility and following best practices and going

above and beyond. As a matter of fact, our Chicago Tower was just built a few years ago, and it is incredibly accessible. So, if you're ever in Chicago, let me know. I'd love to take you on a tour. And a few things that stand out to me is it's wheelchair accessible for every square inch. There are some buildings that might make it difficult to navigate if it's a really narrow hallway or if the push button to open the door is blocked by a plant or something like that.

So, Elaine, my counterpart on the real estate team, has made a point to design new offices that go above and beyond. And so, a few things that stand out to me is there's different areas that have different degrees of lighting. Some people need brighter light, some people need dimmer light. So there are different areas that you can go to. There are also designated quiet zones. You can work in a quiet area or a working library. And then there's also desks that are adjustable height, which is really great. People can stand or they can sit or they can adjust if they have a wheelchair that's a certain height. So really phenomenal. And then there're also areas that are designed with muted colors as well. I had no idea that colors could really impact somebody's experience in that environment. We have brightly colored areas, but we also have areas that are more beige and muted colors so that it will be more suitable to someone's preferences.

Plasmier: That's great. Chet, do you have any questions while you're listening in?

Cooper: Salesforce is pretty much B2B, right? Can you tell the general public what Salesforce does?

Wood: Yeah, absolutely. This is a great way to put me on your spot. Salesforce is a software—Salesforce US is a customer relationship management tool. Basically, that's a software that a business can use, and it will give you a 360 view of your customer interaction and data. I'm going to back up a little bit, and I'm going to use the Marriott as an example. The Marriott Hotel is one of our biggest customers. So, on the front end, we have the public-facing website. You, as a customer, can say, I'm going to be in Texas on these days. What is the availability? And it will show you all of the options in that area. There might be three or four Marriotts in that specific area. And then on the back end, it will tell the company we have these people coming in on this reservation, and it will track all of that. And so, it's going to track all the revenue and the data around all of the customers around the world. Then also, it can do really exciting things like keep your date of birth in the system so that it'll automatically send you Marketing emails for your birthday and tell you, "Hey, we have sales in this area."

Are you planning to travel? Here are some coupons for this. That's a very, very basic, watered-down version of my explanation of what Salesforce does. But it's a customer relationship management software, and it's used all over the globe. It really helps provide dashboards as well so that you can look at every single area. You can break it all of your dashboards of what your regions to focus on or your specific customer. It really helps you make business decisions and Marketing decisions based on those dashboards. Does that help?

Cooper: We've had a relationship with Marriott that goes back decades, specifically with Richard Marriott. So, we've stayed at many properties. If I go to Marriott.com, is Salesforce running that? Or is it a piece of Marriott.com, that when you click on something like scheduling or booking or something, then it goes to Salesforce back-end?

Wood: No, it is all Marriott. We use Marriott as an example—The Salesforce architect will build that platform into the Marriott website. If you click on a scheduling page or other pages, it will still remain on Marriott; and all of that information will stay with Marriott. It does not come to us. But the Salesforce architect is the one that's going to build it according to the wishes that you have. Every business is different, so it's going to build it differently for what they need for their customer interface, the forward-facing public websites.

Cooper: You were talking about these global events that you have with these breakout sessions, lots of breakout sessions. What are in the sessions? I know it's B2B, but can you give some examples of who's

giving the session? These are outside vendors of Salesforce or inhouse?

Wood: It's a little bit of both. We have internal employees that may host an event, or we may partner with the customer that wants to host a breakout session. Mostly, the breakout sessions are about maximizing how you use Salesforce. There are so many different pages and ways to look at Salesforce and how you use it. Again, like you say, it's B2B, so there's a lot of B2B breakout sessions. Knowing how to maximize the product will allow you to build your websites, allow you to build your Marketing campaigns in a way that's really effective for you. I think that's what the breakout sessions are centered around, is maximizing how you're using the Salesforce product. So that you get a better return, ROI, which is the return on investment.

Cooper: But you've been doing this year after year, so things must be changing constantly for you to have content that's relevant to your audience.

Wood: Very much so. In fact, we are more focused now on AI. AI is taking over the world, artificial intelligence. We just released something called Agentforce last year. I need to study up better on Agent force. But what Agentforce does is if you go in and you type of question, How can I use this dashboard? Agentforce will generate a response for you. It has actually answered 83% of the questions that come into the Salesforce website. The customers say, I just answered my question. Thank you. Then that allows our real-life agents to focus on the questions that weren't answered by Agentforce. Yes, to your question, the content is changing. It is always evolving to make sure that we are staying on top of trends making sure that we're looking at what customers need from us the most and building sessions around that.

Cooper: The venues, I would assume, are changing on a regular basis. That's why you have to keep updating with your team, whether you're building offices. It's a moving target with venues, it seems. Am I correct with that?

Wood: Yes and no. Dreamforce, for example, is always in San Francisco at the Moscone Center. And that's in the heart of Dreamforce. Even though it's always in the same place, the plans, the floor layout and the floor plans are constantly evolving. And so we always have to make sure that we're on top of those things to make sure that accessibility is top of mind.

And one example I'll share is that they decided to change the flow of traffic on one of our streets, and they put a concrete barrier right on the curb cut. That's why I usually get there about four or five days before the event, and I do a walkthrough of the entire campus and try to look for things like that. And that was a simple fix. We called a bulldozer, and they moved about 10



Amy Wood showing a customer how to use a motorized scooter

inches to the left so that the curb cut was not blocked, and they could still have that flow of traffic change. And this last year, we actually expanded two streets. So, we needed to make sure that we were taking into consideration reviewing all of the expanded area that we had, and also communicating out to the San Francisco residents this street is closed and this is going to be the detour. That was an especially sensitive point for people that had disabilities. If they had to take a longer route to go around, how are we going to mitigate that for them?

Cooper: Within a venue, how do you work with people who are blind in terms of the navigation within a building. Do you use beacons that have been placed to identify where they are to map the internal building, are you aware of what I'm talking about?

Wood: The three things that come to mind for people who are blind or have low vision. Number one, we do

offer sighted escorts at the disability help desk. So, if someone says, "I am blind", or have low vision, we will have a sighted escort available for them during conference hours to help them navigate the entire campus, which has been growing in popularity. For the last three years that I've been doing it, we've had about 12 to 18 sighted escorts requested each year, and every sighted escort just loves it.

Then we also have MazeMaps. MazeMaps is an interactive mapping wayfinding tool that was built with the blind community in mind. MazeMaps is just like Google Maps, where you punch in a point of interest, and it will generate a step-by-step instruction on how to get there from where you are. So, it's not like you're just looking at a map and saying, Okay, I'm here, and I got to figure out how to get two blocks away. It's going to generate the step-by-step directions for you.



Dr. Victor Pineda speaking with Lucia Rios

Also, it has text-to-speech option. So, someone who's blind or has no vision, they can read it, they can have it read aloud and follow that map generated by MazeMaps. Then also, we have a partnership with Aira. It is very similar to Be My Eyes, where anybody can connect to a live agent, and a live agent would describe their surroundings to them. It can help them navigate down the street to a restaurant. They can show the camera to a menu or to an agenda, and the Aira agent will read aloud or describe their surroundings to them. So, we've got three layers of navigation assistance in our events, and we offer this at all of our events.

Plasmier: And about MazeMaps, is that within the building or just external.

Wood: MazeMaps is for the whole campus. So, for Dreamforce, for example, I think we had eight different buildings across 80 acres of property. The entire 80 acres is built into Maze maps, in all the different levels of each building. I think there're four levels. So, all of that is included in Maze maps.

Plasmier: So, you can take a person from one building, navigate outside of the building to the next building into the next location inside the building.

Wood: Correct. It is pretty comprehensive. And I thought it was really impressive just because I have a hard time reading maps and trying to figure out where I'm located and then how to get to a place that's four blocks away. So, it's really great that it updates in real-time, and it determines where you're located and then

generates that step-by-step map to get to where you need to be.

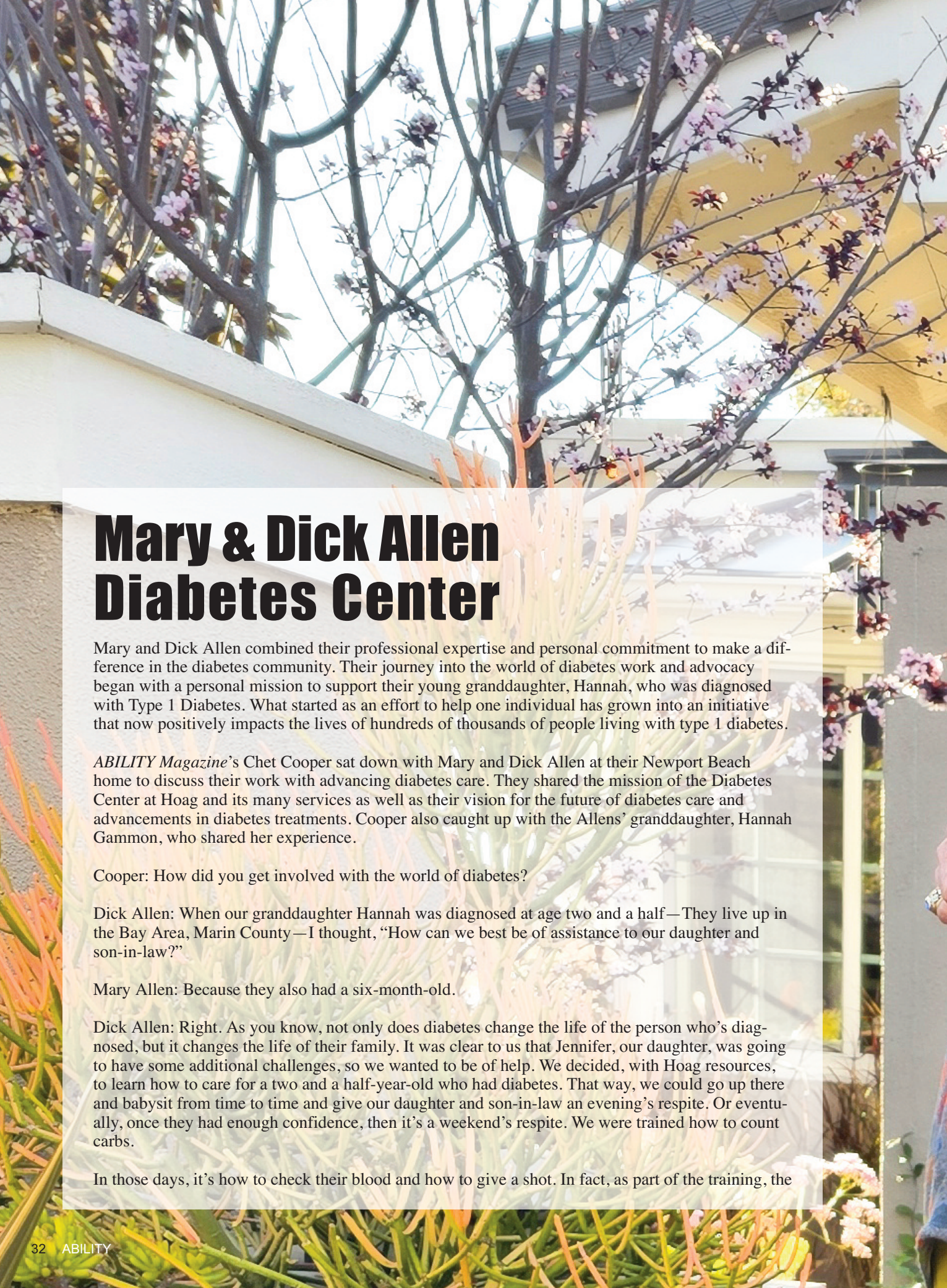
Plasmier: Sounds like you have a supportive CEO in Marc Benioff.

Wood: Yes, he is a good guy, and I think that he is also committed, being part of the CEOs that signed a commitment to accessibility. This is through the DisabilityIn program. Are you familiar with DisabilityIn?

Cooper: Yes. We're very aware. We were working with the President's Committee on Employment of People with Disabilities, which eventually was closed and became the Business Leadership Network, which morphed into DisabilityIn. We hope that all of the companies signing up with them eventually will be create real change within their organizations, real hiring, and showing a significant difference in employment rates of people with disabilities.

Plasmier: It's interesting to see Benioff's mix of innovation and social awareness.

Wood: He's very socially aware. And in fact, with the whole DEI program being cut across the country, he said we are not worried about our roles or worried about targeting, because we have the Office of Accessibility, but we also have the Office of Equality. We are accessibility and compliance, but also influencing. It's just really good that he doubled down on that commitment to be cognizant of ADA. ■ **ABILITY**



Mary & Dick Allen Diabetes Center

Mary and Dick Allen combined their professional expertise and personal commitment to make a difference in the diabetes community. Their journey into the world of diabetes work and advocacy began with a personal mission to support their young granddaughter, Hannah, who was diagnosed with Type 1 Diabetes. What started as an effort to help one individual has grown into an initiative that now positively impacts the lives of hundreds of thousands of people living with type 1 diabetes.

ABILITY Magazine's Chet Cooper sat down with Mary and Dick Allen at their Newport Beach home to discuss their work with advancing diabetes care. They shared the mission of the Diabetes Center at Hoag and its many services as well as their vision for the future of diabetes care and advancements in diabetes treatments. Cooper also caught up with the Allens' granddaughter, Hannah Gammon, who shared her experience.

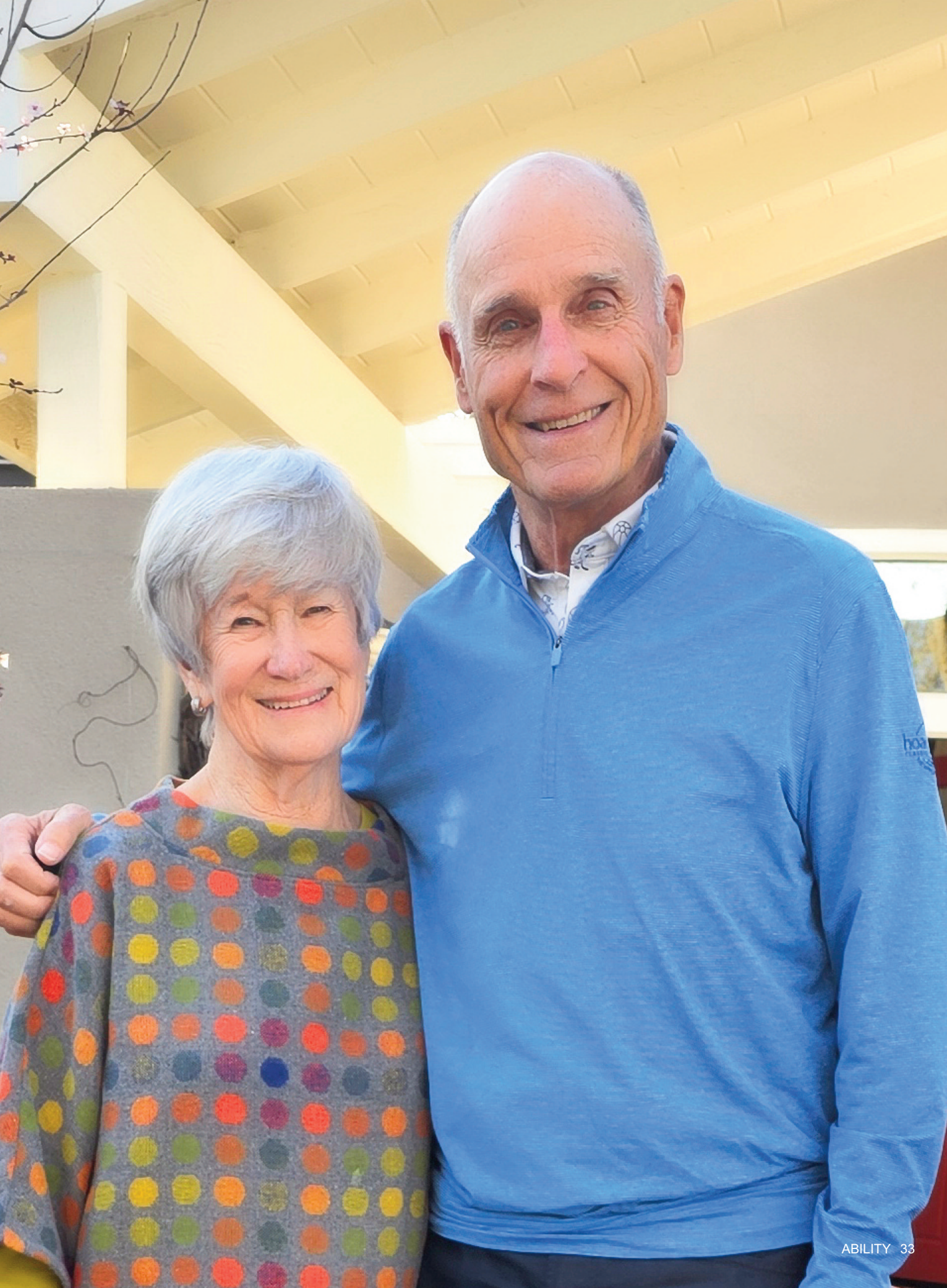
Cooper: How did you get involved with the world of diabetes?

Dick Allen: When our granddaughter Hannah was diagnosed at age two and a half—They live up in the Bay Area, Marin County—I thought, “How can we best be of assistance to our daughter and son-in-law?”

Mary Allen: Because they also had a six-month-old.

Dick Allen: Right. As you know, not only does diabetes change the life of the person who's diagnosed, but it changes the life of their family. It was clear to us that Jennifer, our daughter, was going to have some additional challenges, so we wanted to be of help. We decided, with Hoag resources, to learn how to care for a two and a half-year-old who had diabetes. That way, we could go up there and babysit from time to time and give our daughter and son-in-law an evening's respite. Or eventually, once they had enough confidence, then it's a weekend's respite. We were trained how to count carbs.

In those days, it's how to check their blood and how to give a shot. In fact, as part of the training, the





nurse insisted that we give ourselves a shot, not of insulin, but a shot. Anyway, the bottom line is we learned how to do it. We would go up there and care for Hannah. Mary always counted the carbs. I checked her blood sugar. Probably, I would say 8, 9, 10 times a day.

Mary Allen: You're good at that. (To Cooper) Did you ever have to do that with those little strips?

Cooper: It's so frustrating, yes.

Dick Allen: Well, that's what we did. Then I would give her shots three, four times a day as needed. So, all of that worked reasonably well. Then when Hannah turned eight or nine years old, her mother wanted her to go on a pump because it would give better control and make life easier for Hannah and easier for Jennifer.

So, I decided I needed to learn how to run a pump so that we could continue to go up and babysit. Kris Iyer, who was the head endocrinologist at the time at Hoag, who has type 1 diabetes, as it turned out. At that time, I was the chairman of the board of Hoag, so we had a relationship. Kris said, "Hey, Dick, I'll have the nurse for the pump company come in and train you how to use the pump, but only on the condition you agree to wear it." I said, fine. I went in and had a couple hours of instructions from the nurse, how to do it, yada, yada.

Finally, she said, "Are you ready to insert the cannula?"

I said, "Yeah." She continued to give me some instructions. And after maybe 30 seconds, I said, "I better sit down." And then another 30 seconds, I said, "I better lie down." I was having a vasovagal reaction. Where a sudden drop in blood pressure leading to fainting. Anyway, the bottom line on that is I learned how to run and manage the pump.

Cooper: Do you think that was happening like people get dizzy because of the sight of blood?

Dick Allen: Some people have a reaction when they just get a shot.

Cooper: It's a psychological reaction.

Dick Allen: Bingo. It's just I had the reaction to it. Then I wore the pump for three days. For the weekend, pumping saline, and obviously, it wasn't pumping insulin. But that process enabled me to learn how to manage the pump, how to manipulate the pump. That's what happened. And we would continue to go up and babysit.

Cooper: What were you using?

Dick Allen: It was Medtronic. In those days, this was back in probably 2005. Our daughter looked on the internet to see what's the most popular pump, and she picked a Medtronic. It was the latest model that existed at the time. So, that's what I and Hannah wore. But

every time we would go up there, it was almost a relearning process because it was not intuitive, it was not terribly user friendly. And, as I tell people, it was almost trial and error.

If you're injecting insulin, you don't want to be doing it on a trial and error basis. But that experience convinced me that, boy, there ought to be something better, easier to use. A better user interface, all those kinds of things. At about that point in time—This is now early 2007—Through a mutual friend, I happened to be introduced to a couple of engineers who were developing a new technology for an insulin pump. I met with them at Starbucks, had a cup of coffee and I liked what they were doing. It was the conceptual stage almost. But what they had in mind was a process that would be simpler, easier to use, a better user interface, smaller, just a whole number of benefits that would make it better for the patient. I spent a lot of time with them.

I would meet them two, three times a week and we'd strategize. The engineers would come up with some new ideas. Eventually, when they got the plan where they needed some money, I raised money from some friends, some former venture capital people. We put money in the company and recruited a CEO who had been on the board of Dexcom, and he was available.

Cooper: They're competing with Dexcom?

Dick Allen: No, Dexcom is the CGM (Continuous Glucose Monitoring). We were developing another pump.

Cooper: Competing against Tandem?

Mary Allen: No, it is Tandem.

Cooper: Oh, it is Tandem.

Mary Allen: It is Tandem. So, competing with Insulet and Medtronic.

Dick Allen: T-slim and the newest pump is much smaller called Mobi. I'll show you what it looks like.

Cooper: I'm still learning about the world of diabetes care, but I've heard of Mobi. I didn't know it was a Tandem pump.

Dick Allen: Right. It's the same company. As I said, I had met these engineers. They had an idea for a new technology, and Tandem ended up developing it. But the bottom line is we raised money. I recruited the CEO for Tandem. Then he moved the company from Laguna Niguel down to San Diego and made the company what it is, changed the name from what it had been with these two engineers to the name of Tandem. So, that became Tandem.

Cooper: Wow, I wasn't aware. I was only aware of the

Mary and Dick Allen Diabetes Center at Hoag. You have a great history both in your family and business. Leaving the Mary & Dick Allen Diabetes Center a rainbow appeared

Dick Allen: The whole notion with Tandem was we wanted it to be a better user interface, easier to use and more intuitive. I'll just give you one example. With the Medtronic pump, if you need to enter in your carbs or if you did this and you wanted to enter in your blood sugar, you'd have to get on their pump and you would scroll. So, you push a little button and you scroll, scroll, scroll...

Cooper: I think the T-slim user interface on the app is really good.

Dick Allen: What you're using is what came out of this original coffee I had with the guys that were developing a new technology.

Cooper: That's a small world.

Dick Allen: Yeah, it's a small world. That's our history. Well, then our experience with people who had type 1 diabetes, — You might want to tell that piece of it, Mary. What caused us to get involved in the diabetes center?

Mary Allen: Actually, Dick was the chairman of the board of JDRF (Juvenile Diabetes Research Foundation).

Cooper: I interviewed Mary Tyler Moore who as you know was their spokesperson.

Mary Allen: Oh, really! She always seemed like a neat lady. I hope that was true.

Dick Allen: Her husband was on the board of JDRF with me at the same time. I never got a chance to meet her.

Mary Allen: They've changed their name now to Breakthrough T1D. One thing that we heard about was the little test strips.

Once, when we were visiting our daughter—They were still pricking Hannah's fingers and toes and wherever—and there were test strips everywhere. There'd be some on the floor. There'd be some on the changing table. Finally, one day I said, "Jennifer, what do these test strips cost?"—Because they're testing her like 10 or 12 times a day—And she said, "I think they're about 90 cents a test strip." Let's round it up to a dollar just for easier math. If they're using anywhere from 10 a day, think about the people who don't have good insurance. When we were back here, we heard that there are kids who will cut their test strip in half.

Cooper: Clever on their part.



Cooking class at the Mary and Dick Allen Diabetes Center

Mary Allen: Yeah, exactly. To save money, but it doesn't give them an accurate reading. So, that's what gave birth to the diabetes center. One of the things we felt so strongly about was that when you walk in, the first question is not "what is your insurance?" The question would be "What can we do to help?" Yeah, nobody's going to be turned away.

Dick Allen: Yeah, that's how we got started. Hoag was very willing, obviously, to work with us to set up this diabetes center. And so, with the help of a lot of people in the community and the help of Dr. Kris Iyer and administration, the center became a reality.

Cooper: I felt like it was unique. Am I right about that?

Mary Allen: I would say for the most part. There are a few other centers around. There's a Barbara Davis Center in Denver. So, there are others.

Dick Allen: Thinking about your question of "Is it unique"? We think there are some unique features to it. I'll just give you a couple of examples. People with type 1 diabetes or type 2 diabetes, adults and pediatrics, we have services for all those people. Services for women who have gestational diabetes.

Cooper: What is that?

Dick Allen: In some cases, unfortunately, too many cases, women who are pregnant—They don't have diabetes but when they become pregnant, they develop type 2 diabetes. They call it gestational diabetes.

They're diabetic while they're pregnant. Once they give birth, the diabetes goes away.

I think the statistics are that 50% of those ladies will eventually develop type 2 diabetes. But while they're pregnant, you want to make sure their blood sugar is in their complete control. Do you know the name Ueberroth? Probably you do.

Cooper: He headed up the Olympic Games in LA and it made money, finally.

Mary Allen: Yeah, exactly.

Dick Allen: Ueberroth family made a significant contribution to the Diabetes Center to focus on gestational diabetes, women with diabetes. You know the Iacocca family?

Mary Iacocca had type 1 diabetes. And so, Lee Iacocca had set up a foundation to support research for type 1 diabetes. Their first non-research grant was to our diabetes center to focus on type 1 diabetes and innovation in type 1 diabetes care. So, they've endowed that particular program. Gavin Herbert's daughter has endowed a program called the Herbert Program for Young Adults. And it is a—What's the best way to describe that?

Mary Allen: Well, it's the young adults, and it's ages 18 to late '30s. And surveying that age group, they don't want a support group. They don't want anything called a support group. So, what they do is the first Friday of the month, they all meet. Oh, maybe be it a restaurant or

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Dick, Hannah and Mary

bowling or something so that they can all become friends.

Cooper: It's a mixer.

Mary Allen: It's like a mixer. Exactly. Yeah.

Dick Allen: It's funded by the diabetes center. Yeah.

Mary Allen: In a sense, it probably does become a support group, but they didn't want it to be called that. So, yeah, there's a lot of neat stuff going on there.

Dick Allen: I suspect some of that is unique. We have, as you know, we have a CHOC (Children's Hospital of Orange County) Center in the diabetes center, so we make sure the pediatric patients are cared for. There are some unique aspects to it. Through Dr. Ahn, we participate in a lot of clinical trials. You won't find many, maybe any non-academic centers, that are involved in clinical trials. Hoag, in general, has more clinical trials. I don't know the number, but I'm going to say 250 clinical trials in all of it, in cancer, across the board that people don't know about.

Cooper: And you brought CHOC in?

Mary Allen: Yes. Because of what we were hearing from parents of young kids, it'd be like an all day thing to go to CHOC because you end up sitting waiting. And they've got to take the child out of school. So, we worked with CHOC to open up this small office here. And I've had parents say they get in and out within an hour or so. And the good news is most of the kids only have to see their pediatric endocrinologist every three months or something like that.

Dick Allen: So, it's not like they're there all the time. There's a second center in Irvine right now. We have the one in Newport that you went to. There's one in Irvine.

But the truth is the treatment modalities for type 1 diabetes today, compared to when Hannah was diagnosed, are just like night and day. If you go back 20 years before Hannah was diagnosed, it's like night and day again.

Cooper: Weren't people dying?

Dick Allen: Type 1 was discovered by two scientists up

in Canada in 1922. Before that, people died. We had a breakfast last Saturday at the Diabetes Center for moms and dads and the little kids to come in with their teddy bear, Rufus, that they get when they're diagnosed. Somebody said something about, "Well, is it just recently that adults are being diagnosed with type 1?" And I said, "I don't think so." I said, "Probably what happened, years ago, they were misdiagnosed." Every doctor thinks they have type 2, and they either figured it out or they died back then because you didn't hear about it. That's why Juvenile Diabetes wanted to change the name because it's not just juveniles anymore.

Mary Allen: I was just going to say, when Hannah was first diagnosed at age two and a half, our heart just went out to their parents. And thank God, both of them, both our daughter and son-in-law, who we love to pieces, were on the same page. They both were willing to jump in. Because not all couples, that doesn't always work out like that. It just broke our heart that they had to deal with all this. And yet now, all these years later, and I hear about kids, let's say age 12 to 16 that get it. It's a much different story. They hate it.

Dick Allen: Because they know life without it.

Cooper: I get it.

One thing we were talking about was what type of dogs. I usually see that it's either labradors or retrievers. And the one girl said, "those are the dogs willing to learn. The golden retrievers, they're just born to do anything you want. They just love you. Labradors love the treats". She said, "They don't ever use the really smart dogs, like German shepherds because they have too much of mind of their own. They can be trained, but then they'll reach a point where they'll say, 'yeah, I'm done with this'."

Cooper: How was your granddaughter diagnosed?

Mary Allen: Hannah was two, two and a half. It was Christmas, and they were down here. They just kept thinking that she had strep throat and she was on antibiotics. And at one point, Jennifer, her mom, took Hannah's shirt off—and Hannah was always not chunky but just nice little body—I could see her ribs and I thought, "Oh." Then she kept saying, "my eyes." She and I would sit because she didn't feel well. And I would read to her, and she'd say, "my eyes," which meant nothing to us.

The center also has an education series, the one that you came to. Three months before, Dave Mina, the Health & Wellness Program Coordinator put on one for diabetes dogs—I always say the diabetes dogs, which makes it sound like the dogs have diabetes, but it's the alert dogs—There were three different people there that brought in their dogs, two independent women, and then the other one was a 16-year-old with her mom and dad.

Coincidentally, they were all black labradors. Their dogs alert them to their numbers, whether they're high or low, which I think is amazing that a dog can sense that.

After Hannah was diagnosed and she was in the hospital for three days, their pediatrician, who Jennifer really liked, came up and he really apologized because all it would have taken was to check her blood sugar. I don't know why pediatricians don't do that to little kids.

Cooper: Isn't that part of a standard lab, checking glucose?

Mary Allen: It's such a simple test.

Cooper: What do you think the reason would be? Is there a cost element for that test?

Mary Allen: That's a good question.

Dick Allen: It costs a little bit.

Mary Allen: What would it cost? If you're running a blood panel? I don't know.

Cooper: Are there stats on how many young kids have type 1 diabetes?

Dick Allen: I don't know the answer.

Mary Allen: I bet they have that somewhere. That's a good question.

Cooper: I would be curious to see if there can't be a push to make it routine to check glucose.

Mary Allen: I agree with you.

Dick Allen: Get on that.

Cooper: I think the three of us need to get on that.

Dick Allen: Nowadays, if you diagnose somebody with type 1 diabetes in the very early stages of having the autoantibodies, you can take a new drug that would prolong the insulin.

Mary Allen: What they call the honeymoon. There's still enough insulin in your body to get you through for a while.

Dick Allen: Maybe it can prolong it for maybe two years. I think the point is research is ongoing, and every day, they're coming up with some new understanding of the disease and a new understanding of what they could do to intervene. When you're first diagnosed, you were told five years.

Mary Allen: Five years. Everybody quotes that. Oh,



Cooking class at the Mary and Dick Allen Diabetes Center

remember how we were told five years? It was just at an outreach meeting.

Cooper: Five years for what?

Mary Allen: There'd be a cure. Whenever people were diagnosed, they would say, Well, in five years. I was at this meeting last week through Juvenile Diabetes, and they were all—Most of them at this meeting do have type 1—They were laughing about it. “Oh, yeah. I remember when I was diagnosed, five years, and that was 15 years ago”. But there has never been a cure for any autoimmune disease yet.

Cooper: I didn't know that.

Mary Allen: I didn't know that until not all that long ago. Isn't that interesting?

Dick Allen: The immune system is pretty complicated. The scientists are doing more and more work to try to understand how they could intervene to stop the process.

Cooking class at the MDADC

Mary Allen: One of the points of when they're trying to raise money for the diabetes part of it is they are hoping if they can find a cure, then maybe that would go across the board for other autoimmune diseases, whether it's stem cell or whatever it's going to be.

Cooper: What do you think about stem cell therapy?

Dick Allen: Various companies are doing work. One method involves taking stem cells, a type of cell that can develop into other cell types and turning them into the different cells found in the pancreas in clusters called islets. These islets include the beta cells, which make insulin.

Cooper: And the beauty of that it's not considered foreign.

Dick Allen: That's exactly right. So, when you get (cells) back into you, you don't need immunosuppressive drugs. And there was a recent study done where they take cadaveric cells. Then they narrow it down to the pancreatic islet cells and they manipulate them in some way, and then give them to patients with type 1 diabetes. The way they've manipulated them is such that you do not need to take immune-suppressant drugs. The point is, they're trying from a variety of different angles how to solve the problem, and eventually they'll get there.

You said something earlier that resonates with me. And I rephrase it a bit when I talk to new people joining Tandem Diabetes Group, new employees. And the speech is like this. I said, I want you to do well. But doing well is not enough because I want you to do good. And the opportunity at Tandem, since you're in the healthcare field, you're lucky because you can do well, but simultaneously you're doing good. We serve over 450,000 people, and you make life better for them. How nice is that?

Hannah Shares Her Experience via Video Chat

Cooper: Hi. You know I spoke with your grandparents.

Hannah Gammon: Yes.

Cooper: So, they have insight of things that you might not remember. I'd like to ask you a little bit about your first memories of knowing or realizing that you had type 1 diabetes.

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Hannah: I was diagnosed when I was two and a half, so I don't quite remember the beginning of it. I'm trying to think. Probably, when I was in elementary school is maybe when I kind of started to actually realize it because I was on my own, and there was actually someone else in my class who had type 1 as well. So, we would go to the nurse together and check our blood sugar during lunch. It was kind of normalized a little bit. I guess maybe that was kind of my first memories of it. And that's when I got on my first insulin pump too. So, that also kind of shifted things as well.

Cooper: What age do you think that was?

Hannah: I think around eight, maybe in third grade.

Cooper: Did your classmate also get a pump?

Hannah: No, he was on shots for a while. I think, maybe recently. He just got onto maybe the Omnipod pump, I'm not sure. But he was on shots for quite some time.

Cooper: Oh, just recently. And you've stayed in contact with him all these years?

Hannah: Not really. I've kind of seen him around. My mom and his mom have been friends for a while.

Cooper: What was your experience with other students and their understanding of your pump?

Hannah: I don't think anyone really asked about it too much, maybe here and there. I was always able to kind of take care of it myself and kind of handle it and keep it under wraps. Again, not on purpose, but just always able to just handle it. I don't remember feeling any dif-

ferent or anything like that.

Cooper: What did you do during lunch?

Hannah: I remember at least in elementary school, going with the other kid in my class, we would just go to the nurse and check our blood sugar together. So, it was kind of nice to do it with someone.

Cooper: And when you got the pump, did you let the pump do the analysis or did you still check your blood?

Hannah: I think for a little bit. I was on the Medtronic pump and still checking it. When I was in high school is when technology got a lot better. So, that's when having the pump kind of did everything. I was wearing the continuous glucose monitor.

Cooper: Have you tried different pumps?

Hannah: I started on the Medtronic and then I switched to the Tandem pump, and I've been on that one ever since.

Cooper: Is that the T-Slim?

Hannah: Yes.

Cooper: How are you managing your diabetes? Are you keeping a pretty good range?

Hannah: Yeah, but diabetes is very unpredictable. I mean I have an idea of how many carbs I'm going to eat for this one meal, but you know things differ throughout the day so much. If you're stressed and your blood sugar goes up, it's so unpredictable. Obviously, I try to stay in a good range, but it's unpredictable. So, things happen and then you just deal with it.

T-slim pump, Mobi pump - size relevant to a quarter, Mobi & Dexcom sensor

Cooper: When did you find out your grandfather tested the pump himself?

Hannah: I kind of feel like I've just always known. I know recently he tried out the Mobi, so I talked to him a little bit about that.

Cooper: Oh, he tried the Mobi as well. I didn't know. Have you tried the Mobi?

Hannah: Yeah, I'm actually trying it right now. I actually work remotely for Tandem, so I was able to get on it.

Cooper: And you find a big difference in the way you go about your day?

Hannah: I was always used to having my phone around, and so the Mobi wasn't a huge difference for

me personally. It's a fairly easy transition.

Cooper: I was thinking more about lifestyle in the sense of how you could actually tape the Mobi to your arm, for example.

Hannah: I tried that, I didn't really love it. I do like how the Mobi is a lot smaller. I think as a female, it's really nice just wearing things like dresses. You can kind of hide it a little easier. I could definitely see the benefit that during exercise or workout you can unclip it at any time.

Cooper: Can you talk a little about your parents?

Hannah: They did a great job at just kind of normalizing diabetes, and not making a big deal of it. They were doing it for me for the first couple years of my life. I remember just quickly learning how to do it on my own. I don't remember there being any sort of fuss around it.

Cooper: What do your parents do?

Gammon Family L to R: My father Kevin, me, my mother Jennifer and brother Jake — Beaver Creek, CO.

Hannah: My dad owns an advertising agency, and my mom is a substitute teacher at the school that I actually attended.

Cooper: Oh, nice.

Hannah: Yeah, I remember they brought us to diabetes camp as well. We attended the family camp. I was maybe 10 and my brother was 8. I love that they were able to go. It was just a fun kind of family bonding experience and meet other kids with type 1.

Cooper: Have you heard of that nonprofit called You're Just My Type?

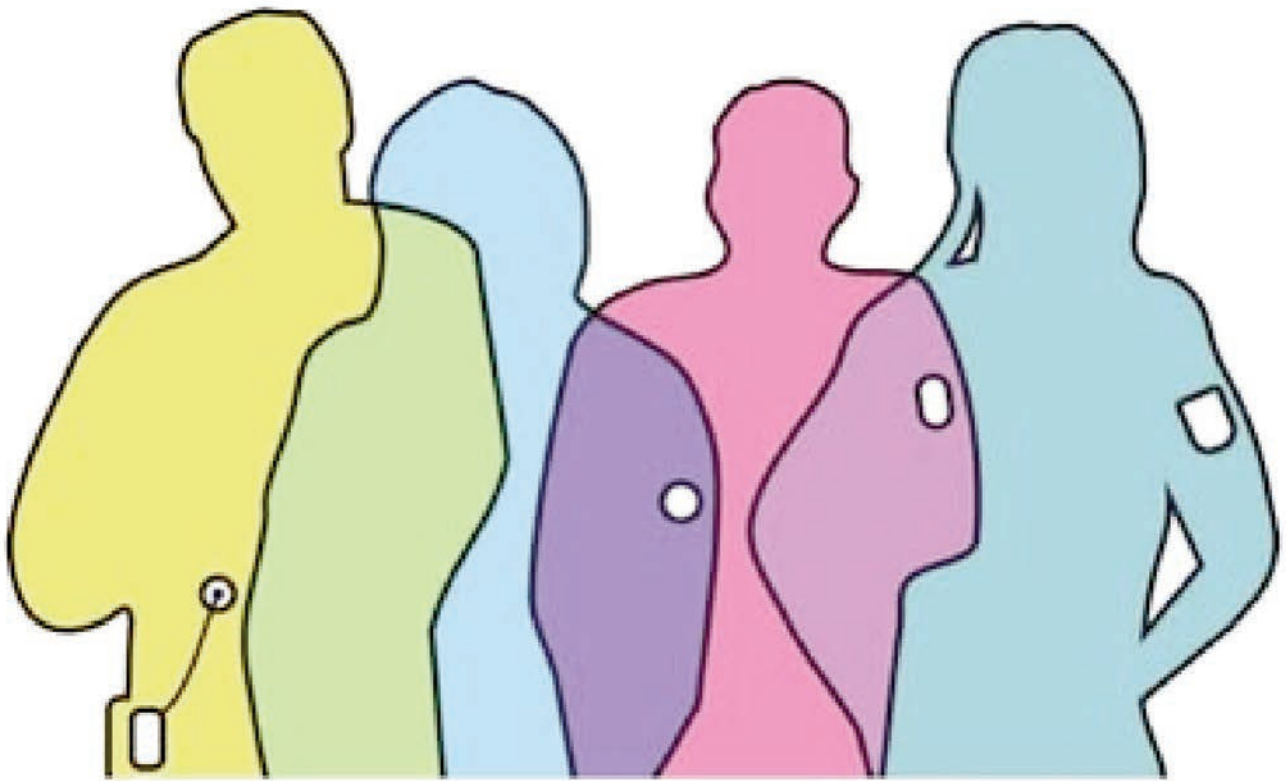
Hannah: Yeah, I know about it.

Cooper: They're kind of like meetup groups for type 1 diabetes in different states, in cities. It's a way of building community and focus on mental health.

Hannah: Right. Community is the biggest thing with type 1. I don't know what I would do without the community that I have. The camp that I went to—I've been a counselor at the camp. I went there as a teenager. I've been really lucky to have had many opportunities to meet other kids my age, teens my age, however old I was with type 1, and I still have those friends to this day as an adult. Having the community is one of the best things that comes from it. ■ **ABILITY**

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YOU'RE JUST MY TYPE

At the age of 17, Laura Pavlakovich took significant risk of education abroad, despite not knowing where or how she could get a re-supply of insulin and test equipment, which were life sustaining for her type 1 diabetes. Her experiences in developing nations motivated her to do something meaningful with her life and lead her to create the nonprofit, You're Just My Type. Drawing from her own needs as a child growing up with type 1, Pavlakovich embarked on a mission to connect and support children, teens, adults and families with type 1 diabetes.

ABILITY Magazine's Chet Cooper met with Pavlakovich over Zoom to talk about her life experience managing type 1 and what lead her to founding You're Just My Type. Pavlakovich discussed the many events and activities for all age groups that her organization holds across the US and UK. She also described how her organization was a catalyst for a large scale, grass-roots diabetes supply and distribution event during the Los Angeles fires of 2024.

Cooper: When did you find out, or you did your parents find out, that you had type 1?

Pavlakovich: My parents found out I was type 1 when I was five years old in 1996. I would walk to school with my mom, and there was a slight hill that we would go up. Suddenly, she noticed that I was getting too weak to walk up this very small hill. And she thought that was very bizarre that I was having a hard time walking up this hill. That was one of the first symptoms that she noticed.

Cooper: Do you remember that?

Pavlakovich: No, I don't remember any of it. So, my mom took me to the pediatrician when I showed the other symptoms. I was wetting the bed. I was very thirsty. She took me to my pediatrician. My pediatrician had her take me home and do a 12-hour fasting so I could come back and do a fasting glucose test the next day. My mom said I was screaming bloody murder for water because I was so thirsty because, as you and I both know, my blood sugar was so high, but we didn't know that was the case then.

She took me back the next morning. They did the blood work, and my pediatrician came out and said, "Your



You're Just My Type fitness event held with a trainer who also has Type 1 diabetes

daughter has type 1 diabetes. Take her straight to Children's Hospital. There's a team of specialists waiting for you". I don't remember that either, but I do remember being at Children's Hospital once we got there and my mom calling my dad to tell him the news. She was just hysterical on the phone. I remember hearing her cry as I was playing with this little Hello Kitty toy. I remember thinking that this is not good. Whatever is happening is not good.

Cooper: So you weren't necessarily in a fog that you remember. I mean, you were still playing, so you still had a decent attitude, except now you're seeing something's happening with the family and your mother.

Pavlakovich: Correct. That's the only memory I have of that time of diagnosis. I don't remember being in the hospital. I was just so young. Or maybe I blocked it out on purpose. I'm not sure.

Cooper: So, what's your first memory of the whole routine as you start that process with the insulin that was required?

Pavlakovich: I have definite flashbacks of being back at the hospital, getting trained for things, and they brought out the orange to my mom to teach her how to give a shot. Life just became really normal with diabetes after that very quickly. I went to this very small private

school. We did not have a school nurse there. My mom would pack my lunch, and she would put Post-it notes on everything I ate with the amount of carbs (carbohydrates). And I had to eat at very certain times during the day. I remember knowing that I was allowed to have a snack at this time and the other kids weren't allowed to. My mom would come to school every day and test my blood sugar at lunch and give me insulin. I was very young, maybe six, when my mom had a feeling that I could probably start giving myself my own insulin and testing my own blood sugar. So, she called the school. She said, I'm going to be right around the corner, but I want you to try something. When Laura comes in to have me test her blood sugar, I want you to tell her that I'm not going to be able to make it today and just see what happens.

I walked to the front desk. I said, "I'm here to see my mom." They said "She's not coming." I grabbed the poker and the meter and I tested my own blood sugar, and I gave myself my own shot. Ever since then, I've been doing things pretty independently with my diabetes.

Cooper: You basically watched your mom doing that day in and day out. You had the mechanism down. You understood what was going on. But did you understand what insulin was doing?



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Pavlakovich: I don't think so. That's such a good question. No one's ever asked me that before. I don't think so. I don't remember. I just knew I had something that made me different. I knew that when there were birthday parties at school, my mom would come and bring me Crystal Light sugar-free popsicles so I could have something sweet when the kids were eating cupcakes and cake. I knew I had to bring a bag with me everywhere I went with my diabetes supplies, and that made me different, too. But I don't think I could grasp, like what, medically speaking, was happening to me.

Cooper: I don't know where you were in terms of the technology and the insulin injections. Were you doing the testing? Each time you ate, you would calculate and then inject, and then one was the long-lasting? Is that the process you were doing?

Pavlakovich: When I was first diagnosed, it was when the pumps were barely coming out, and I was on shots at first. I was on the cloudy insulin and pH, and my mom would roll the insulin. How I started was I would take, I believe, one shot in the morning, and I would have to eat at certain times during the day to make sure everything was working. But then I got put on a pump. I was put on one of the first Medtronic pumps in about first grade. I was on a pump after that. I was on that for a while.

Cooper: You started with Medtronic, and then where did you go from there?

Pavlakovich: I started on the first Medtronic pump, and I stayed on it until high school. I went from this very small private school where everyone knew I was the diabetic kid to this huge public high school where suddenly it drew a lot of attention to me, and I hated it. One time someone grabbed my insulin pump—thinking it was a pager, I'm sure—And it ripped out of me. They didn't know that's what they were doing.

I hated people seeing it on me. And so, I asked my mom to get off of it, and she let me. So, I went back on pens in high school. I got back on a Medtronic pump in my early 20s and got on their first sensor. It was called the InLight, I think. Then I took another break from that. After a few years, I went back on pens. I tried Omnipod last year. I lasted six weeks before I went back on pens. I like getting my multiple daily injections rather than on a pump. Now I have a FreeStyle Libre 3 for my CGM (continuous glucose monitoring), and I'm on pens.

Cooper: Back in the day, you were monitoring your glucose by pricking your finger?

Pavlakovich: Correct. Oh, yeah. I didn't have a CGM until I was probably in my mid-20s for the first time.

Cooper: Oh, my gosh. That's a lot—

Pavlakovich: Every parent I meet of a young type one, they asked, "How did your mom do it?" Things were way different then. She just had to trust. That's when we had logbooks. I would just have to write down my blood sugar in this little logbook and bring it to my doctor. I mean, we could lie back then. I could write anything I wanted. Unless my doctor sat there with my meter and fact-checked every timestamp. But I've talked to a few people in the same boat as me where you could just write down a number, and that's what your doctor would see.

Cooper: Where was that in your timeline where you realized you could use my phone app, or use a monitoring system that checks every five minutes, whatever the case may be?

Pavlakovich: The first CGM I tried was the Medtronic one, and I have to be honest, it was really painful. It was really inaccurate. I had a terrible experience with it. Technology then was not where it is now. So, it left a really bad taste in my mouth. I had already started You're Just My Type when everyone started getting a Dexcom (CGM) for the first time. They would be shocked and would say, "What do you mean you're not on a Dexcom? or "You're not wearing a CGM?"

I was so resistant because I had such a bad experience that I thought, "I'm not putting that thing on me. I don't trust it. I don't want something else on my body." And I finally gave in, "Okay, I'm going to try." This is when Dexcom, even the inserter was almost barbaric. It was this long inserter. I had to call a friend to put the first one in because I was terrified. I was sitting there watching YouTube videos. I had my friend come and do it. I was so nervous. Once I saw how amazing it was, I was never going back. I was like, Oh, my God.

Cooper: Yeah, definitely game-changing. You had been missing out.

Pavlakovich: Oh, yeah.

Cooper: You have this life experience. What was the thought process of creating the nonprofit You're Just My Type?

Pavlakovich: After high school, I went to a photojournalism program. I was always very into photography. This photojournalism program was very unique. It was this art school in Germany, and the focus was on injustice and poverty. We traveled to countries and took photos of very serious topics. We worked in the Red Light district in Thailand. I worked at a government orphanage in China. We were in Paris working with drug addicts. We were in Dubai.

I was 17 when I left (home), and I came from this very

small private school for most of my life. I'm from the South Bay in Southern California. I lived a very, almost sheltered life. And then, suddenly, I was out in the real world at a very young age, and it was obviously a very shocking experience.

Cooper: What did you do in Dubai?

Pavlakovich: We just stayed there for a few weeks while we were traveling back from Egypt to Germany, so we were getting a little experience of the modern Middle East.

I was their only type 1 diabetic student they had ever had. They were very nervous to have me there. The school was this life experience program. It was just about a year long. Before I left, my doctor said, "Well, we can only give you three months at a time. We cannot give you more than that. And that's already a vacation amount of supplies." I was at this age when I wasn't really going to take no for an answer, and there was nothing that was going to stop me from doing this program. So, I left for a year long trip with three months of diabetes supplies on me. And my poor mother, bless her heart, had to help me figure out how I would get the next three months after the first ended, and then the three months after that. We had students from all over the world at this school.

One of the students was from the United States, Colorado. That girl's sister was going to come visit her. So, my mom sent my next three months of supplies to this girl's sister who flew with the supplies to Germany to deliver me.

Cooper: Nice.

Pavlakovich: It was this long process; it was a scary process. By the end of it, I didn't think I was going to get any of my supplies. I had to see a German endocrinologist. They weren't going to give me anything. That alone was hard enough. Then they told us we're going to Egypt, and I had this really low blood sugar. They sat me down and said, "We can't bring you on these trips. This is too much of a liability for us." And I begged and I pleaded. We came up with a compromise where I had to find a cooler that I would keep all of my insulin in before we went to Egypt. So, I found this little cooler that looked like a soccer ball, and I had to carry it with me in Egypt everywhere we went. I'll never forget it.

I learned a lot. I mean, definitely, there were scary times. We were in places where I didn't have everything accessible to me, and I made it work somehow. So, I come home back to Redonda Beach, California and I felt like I have this moral obligation to change the world now after seeing all of these things that I saw.

I wanted to do photography. And all the photographers



LA Adult Mental Health Meetup guided discussion led by a licensed Type 1 diabetes therapist

in Redonna Beach were doing photos of the sunset and dolphins and the ocean, and they're beautiful, but not exactly what I felt called to do. I felt really stuck and really lost. And I got into the service industry, and I was a waitress, and I was nannying. Then I went to a wedding.

I was talking to the photographer of that wedding, and she told me that she had a son who was four years old that was just diagnosed with this thing called type 1 diabetes—I don't think she knew I also had it—She told me her son feels so alone and isolated and cries himself to sleep at night because he thinks he's the only person on this planet with it. Then she said the sentence that really put everything in perspective for me and gave me the idea for the nonprofit. She said, "I can only show him statistics on a computer so many times of how many others are out there like him. He's four years old. He's not going to understand these numbers." And I thought, "Oh, my God." I had this idea. I wanted to photograph as many type 1 diabetics as I could, try to put a face to this invisible disease.

Back then we didn't have our CGM showing, so it was actually invisible back then. And I decided to start photographing as many type 1s as I could. I created this blog. I called it "You're Just My Type," and I just wanted to create a resource for boys like her son and newly diagnosed people. I mean, anyone who had type 1 to see photos of how many others are out there instead of numbers. So, that was the beginning.

Cooper: The idea of showcasing these images was the first phase. In your mind, were you thinking of using a

website or your social media? What were your thoughts at that point?

Pavlovich: Yes. I created a website, a super simple blog; and I created an Instagram account. I called up some friends that I went to diabetes camp with and said, "I want to take your photo." I talked to other type 1 organizations. I reached out and said, "I need type 1 kids to photograph. I need type 1 adults." I started getting families signing up for this opportunity, and I would travel all over Orange County and Los Angeles and drive to people's houses and take photos of them or their children and ask them a few questions. I started collecting all of these photos and information.

The only reason it became a nonprofit is because I was a waitress at this Irish pub. All my customers were like, "We want to help. You should be a nonprofit so we can donate to your cause. This is so cool." So, I thought, "Okay. I'll become a nonprofit." And in 2017, we incorporated and officially became a nonprofit.

Cooper: So, is this your full-time work now? Or are you still serving Guinness?

Pavlovich: It is now. It was just this passion project. We were a nonprofit, but it just stayed this passion project on the sideline while I was doing other work for a very long time.

It wasn't until 2021 that I had this idea. We have all these kids. I've met all of these kids in LA now. And I thought about what I would have needed growing up with type 1. It was in the middle of COVID. People

thought I was crazy because I had this idea to do an in-person event at a time when no one wanted to do anything in-person. But I just felt this need. I thought this was actually when we need something like this. We needed it now more than ever.

I had this idea to do a Type 1 Young Girls event. It was ages 8 to 17 and was basically a mini conference for these young girls with type 1. We had type 1 female volunteers. We had a social worker, a behavioral therapist, a yoga instructor that did a yoga class with the girls, a dietitian that did a carb counting and cooking class with the girls, a Type 1 artist that did arts and crafts with the girls. And it was so beautiful.

We had this amazing turnout. We had a nurse. We did the temperature checks, the COVID masks. It was such a good turnout that after that first event. Everyone was saying, Laura, the adults need this. The boys need this. The young kids need this. You can't just do this for girls.

After that, we did 18 events during those first couple of years. That's when I started running it full-time. We're fully based on donations. We had our first big fundraiser last summer, and we're planning our next one now. But yeah, I'm lucky enough to do this full-time now. And now we're expanding to new cities. We did New York in September, and we go back to New York next month. We have a Miami event coming up in May. We do toddler events in San Diego. We're just trying to do these events in every major city around the world, really. We did London in January as well.

Cooper: You mentioned to me earlier that, while you were in London, the fires were happening in the LA area.

Pavlakovich: Yes. I was in London for about five weeks during the holidays. When I was away, the LA wildfires started—the worst wildfires that we have ever had.

Because of how long we've been around and the beautiful in-person and virtual community we have built, our Instagram account has been used as a way for people in need to find diabetes supplies. That's been going on for years. We get messages that say, "Hey, I live in Austin, Texas. Is there anyone nearby that has extra Humalog?" We know it's not the way things should be done, but, unfortunately, because of our health care system and insurance companies and the price of having type 1, that's what people have to turn to. That was already happening with our account.

I got a message from someone that said, "I just lost my house in the Eaton fire. I need to get diabetes supplies. Can you help me?" And I realized, after that first message, this is not going to be the only message like this that we get. So, I created a flyer that said, "If you've been affected by the fires, just comment below or send us a DM if you need anything, and comment below if

you have extra of anything." I was thinking that one little post would be able to handle this situation. And I was so wrong.

In one night, I woke up to over 100,000 shares of that post. And after one week, it had been shared 500,000 times on social media. And a type 1 diabetic who was in Los Angeles who was just visiting saw the post and messaged me, and she said, "Let me help you run this." And she created this Google form. We were quickly listed on every government website as the Type 1 Diabetes Resource. We were the only type 1 organization that was doing things in this way. We had over 500 people donate supplies. We had to move from a house to a lot, this huge space with all of the supplies and insulin that had been donated. We had people from other countries trying to donate. We delivered to over 65 people who lost their homes in the fire. It's a big story. I don't know how specific you want me to be.

Cooper: I'd love you to keep going into the numbers because I remember seeing your slideshow.

Pavlakovich: In one week, we had over 35 on-site volunteers. We had 400 volunteers who were ready to process supplies, work at the pickup center and drive supplies for deliveries. We had a combination of individuals reaching out from all over Southern California, from other diabetes networks as well. We had over 50 in-person supply donations. Over 150 people just in Southern California responded to donate, over 235 people from across the country and the globe, including Australia, Canada, Germany, who donated supplies. We had over 500 vials of insulin, over 400 CGM supplies, over 1,500 boxes of pump supplies, almost 10,000 syringes, 13,000 pen needles, and almost 20,000 test strips.

Cooper: I'm just thinking of the logistics of all this. You have these different manufacturers and different needs for different individuals. This one person that contacted you and said, I'll help you—she had that background to do the logistics?

Pavlakovich: She didn't have a background in this type of disaster relief, but she had done big group management like this. She was the one that spearheaded this whole thing. So, she was the one that was vetting, reading all of the supply request and going through all of the supply donation forms. A bunch of people wanted to volunteer. So, she had people meeting at this house doing the deliveries. Like you said, it's really specific. We couldn't just take all of these supplies and drop them off at a shelter or take them to a church because every single type 1 diabetic has their own cocktail of medication and treatment and insulin therapy that they use. So, it's not one size fits all, as you know. That was the hardest part, people needing very specific things. We even had volunteers going to Walmart and pharmacies and buying specific supplies that these people needed. We had a lot of Spanish speakers. We had a lot



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of Spanish speaking volunteers that were translating for us. But her name is Liz was the one that really did this. Then we had other volunteers that did have backgrounds in disaster relief and mutual aid that came in and used their expertise in this entire system as well.

Cooper: You had mentioned when you were out of the country, your mother had to figure out how to get supplies to you since you only had three-month supply. Did you think of that when you were starting to see this happen, about your own experience in Germany?

Pavlovich: Well, now that I've traveled a lot more, honestly, it is actually very easy as an American traveling to countries, especially in Europe and Mexico, to just walk into a pharmacy and get to buy the supplies they need.

What this really amplified is how broken the system is in the United States. The system just isn't set up for medical companies. Although I want to say that I'm hopeful they wanted to help, you can't just send supplies to your patients without having your prescription. If your prescription isn't due yet, there's nothing in place for these natural disasters to override all of these rules and guidelines that the United States has in place for something like this.

Cooper: There's a new pump coming out called Twister, I think. Do you know about that?

Pavlovich: No.

Cooper: Apparently, when it comes out, it's going to be sold at pharmacies. You just go in there, get it at the pharmacy. I don't quite understand that whole thing about you have to have a special pharmacist even for the supplies. It's complicated. Not all of them take certain insurance, so you need suppliers to get your supplies.

Pavlovich: And nothing is fast enough. Even if your company says they'll mail you your supplies. It'll be 3-5 days. The thing about having type 1 diabetes is you don't have 3-5 days without your supplies. You need them in the same day that you lost them. So, that's the issue. And that's what having this grassroots community effort of having immediate relief was so valuable and necessary for something like this. I'm sure there are a lot of conditions where it's okay to go a couple of days without my meds, and I'll take them when I get them. But that's not the case with type 1 diabetes. We don't have time to be without.

Cooper: Yeah. I think type 1 diabetes is still not quite understood by the general population.

Pavlakovich: A hundred per cent agree.

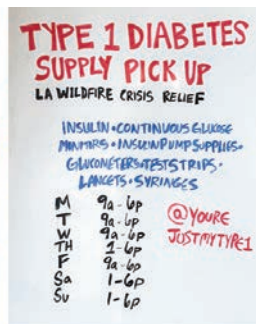
Cooper: So Where are you now? You are opening up new events. Tell us a little bit more about what the events are these days.

Pavlakovich: Every event we put on is a very mental health-forward type 1 diabetic meetup. We have events that are customized for toddlers, ages five and under. We do teenage boy, teenage girl, and adult events. What an adult event would look like is we typically bring in a type 1 licensed therapist or someone that wants to speak about their journey with type 1 diabetes. We do really cool mental health activities like vision boards, share circles, breakout groups. We have this really amazing activity where you write down something you're feeling very vulnerable about or feel a lot of shame around. And I mix up all the papers and I pass them out and people read them out anonymously. So, nobody knows what anyone wrote. And it's the most beautiful activity we've been doing at these events because it really shows how most of us are all feeling the same shame and the same burden that we don't feel comfortable saying out loud, when it's really the shared experience. And at the kids' events, we do rock climbing, the boys do arcades and the girls do self-care days. We always have type 1 volunteers that lead them in guided discussions and chats.

And the toddler events are really for the parents, but the kids are getting old enough now to where they ask their parents, "When can I see my diabetic friends?" I grew up going to diabetes camp, and it was amazing. But it was only once a year, and it was hard to wait those 12 months in between. So, what I want to provide with You're Just My Type is year-round support and events.

Our events are also 100% free to attend, which I think makes us stand out as well. So, our goal is to do events for every age group, every quarter so that if you miss one, you don't have to worry. There's another one in three months coming up. And we have them in different locations every single time. And look, I try to make them really cool and fun. These aren't medical events. You don't leave feeling sad or depressed. Our goal is to give you a really safe space to get to open up, share and vent, but also just make friends in your area who also have type 1, create new connections and just give you a place to feel like you belong because we live in a world where it's easy to feel like it wasn't meant for us, living with a chronic illness like this.

Cooper: So, the people in the audience just stood up and clapped?



Supply collection and distribution during the LA fires

Pavlakovich: Yeah. And I dropped my microphone.

Cooper: Laura has left the building.

(laughs)

Pavlakovich: We actually just came up with this new—not a mission statement—But even me growing up, the social media space or, in general, just the human experience, there are a lot of times in this world where you don't feel like you belong or you're not welcome somewhere or you feel left out. I don't want anyone to feel that when it comes to You're Just My Type. Unfortunately, there are even diabetes orgs and other groups where it's easy to feel like they're very exclusive and that they don't want other people joining. At You're Just My Type, we just created this new branding of your diagnosis is your ticket in, and that's all you need to be 100 % accepted at our events. We wrote this new thing. It says, "The Type 1 community should never feel like an exclusive club because we all know no one chooses this."

But too often, spaces can feel unwelcoming or out of reach, and that's not us. At You're Just My Type, we're all about community and creating safe spaces where Type 1's can show up exactly as they are. No matter your age, race, gender, nationality, or walk of life, you belong here. No barriers, no gatekeeping, just connection, support, and understanding. ■ **ABILITY**

yourejustmytype.com

LAURA san giacomo

Inclusion Matters

Best known for her standout roles in *Sex, Lies, and Videotape*, *Just Shoot Me!*, and *Pretty Woman*, actress Laura San Giacomo has long used her platform for more than entertainment. Off-screen, she is a passionate and vocal advocate for disability inclusion, lending her voice to causes that foster equity, access, and community. A longtime supporter of Inclusion Matters by Shane's Inspiration—a global nonprofit dedicated to creating play, dignity, and social equity for children with disabilities—San Giacomo was honored with the organization's Humanitarian Award and most recently co-hosted its 2025 Heart to Heart Gala.

ABILITY Magazine's Chet Cooper and Jennifer Woodall met with San Giacomo in a virtual interview to discuss her decades of advocacy, the personal experiences that fuel her work, and how inclusion continues to evolve in education, entertainment, and everyday life.

Woodall: Can you talk a little bit about how you became involved with the Inclusion Matters by Shane's inspiration?

San Giacomo: I first heard about it as they were creating the first playground in Griffith Park, and of course I thought it was fantastic. I used to take my son to the park all the time, and I would help him climb the slide, but that was when he was littler and shorter, and I could really control and help him do his climbing, and he would also fit in the swings for very, very young children that have a T-strap, and they're really contained and safer. He was growing out of all of that, but still liked to go to the park,



photo by Ben Copet



Laura San Giacomo Hosting Heart to Heart Gala - photo by Ivy Ninet

and it was becoming extremely difficult and dangerous for us to go. So, this was an amazing thing to have show up in the world. It was so impressive and such a point of common ground for so many families and so many kids. I know that it's had a big influence on a lot of people.

Woodall: Did your son have a favorite thing to play on at the park when you went?

San Giacomo: Well, he loved the slide, and he loved the swing. Those were his two favorite things.

Woodall: Solid choices. On March 21st 2025 you hosted the Heart to Heart Gala for Inclusion Matters. What did you look forward to the most prior to that event?

San Giacomo: Continued spread awareness, continued contributions to build more playgrounds. I think there's 80 right now around the world, so that's pretty great. Obviously, honoring the founders and all of the children that have inspired these playgrounds and all of the companies and governments that have been involved in creating the playgrounds, and of course, honoring the honorees and their contribution that they have made to the community.

Woodall: I'm always interested to know what it's like to prepare for an event that you're hosting. Can you give me a day in the life of what that looks like?

San Giacomo: Well, Scott Williams, who's one of the founders of Inclusion Matters and I co-hosted the event. He, very luckily, is a writer, so he wrote all of the intr-

ductions and I review those and prepare as I would for any other public presentation or job. I do research the people I'll be introducing and go into a deeper dive. I was familiar with some of the honorees just from being in the community for 30 years. Then I try to figure out what to wear. This is basically the biggest problem for all of us. (laughs)

Woodall: Can you tell me about your experience at the event itself?

San Giacomo: Oh, my gosh. It was absolutely amazing. The stories that people told about their connections to each other was just amazing. The stories that people told of the success of the education program were absolutely amazing. They have an education program where someone goes into the classroom and asks "What are your preconceived notions about disability?" along those lines. Then that class of typical kids goes to the playground and has a play date with a group of kids who happen to have disabilities. Then the educator goes back to the classroom afterwards—maybe not immediately afterwards, but sometime afterwards—then asks the student to talk about how their preconceived notions were dispelled by actually playing together. It's absolutely an amazing program. There were lots of stories about that. The change that that's making in younger people—and probably older people as well—it was a really beautiful night. All of these people in the community are so interconnected. It's amazing that in the world of a big city like Los Angeles, we're all so interconnected and have crossed paths in so many different ways. Even one person who's on the board of

Inclusion Matters told the story of how she found out about Inclusion Matters because she was standing behind me and my son on a checkout line at Toys R Us. I turned around and we started talking because I knew that her son had some special needs, and she knew that my son had some special needs. We just started gabbing, and I told her about Inclusion Matters by Shane's Inspiration. She took her son there, and then she ended up on the board, and then she ended up on the Heart to Heart Gala committee. She's been organizing the gala for 10 years. Then she shifted her law practice to be a special education lawyer. It was incredible. It just those kinds of interconnections in the community. I had so many people come up to me and say, "I met you seven years ago." "I met you 15 years ago." because we have all been supporting each other, going to other functions like functions for autism awareness, workshops, seminars, and fundraisers. It was just an amazing night and so warm, and then several people coming up to me and saying, "I raised my children. I had no idea that this was even in need. I had no consciousness that children couldn't play, or we had no exposure to any children who had physical or other kinds of needs or disabilities." They were completely oblivious to this world, which can happen when kids are segregated or people are segregated in separate sites and have just come a little later in life, or even in their 30s or 40s, after they've begun to raise their children. Several people came up and said to me, "I had no idea. I never thought of it before." It was just really moving. It had reverberations, just as Inclusion Matters by Shane's Inspiration has had reverberations.

Woodall: I would love to hear your thoughts on disability inclusion in Hollywood, since that's a landscape that you're familiar with.

San Giacomo: Well, let's see. There's been a little bit of movement, I think. I found it very interesting, actually, during the writers' strike I went to some of the spots where writers were walking the line and found writers who happen to use wheelchairs. It was great to talk to them about their experience and also ask their advice because my son wanted to walk the line and see where it was too dangerous where there wasn't enough room for a wheelchair to actually be on the line or where it was dicey. There was this really great show that I was involved in for a little bit with Joe Mantegna called *As We See It*. It was a couple of years ago, and it was based on another series, I think out of Israel. It was about a father and son, and the son happened to have autism, and he wanted to live independently, and was living independently in an apartment with a couple of other young adults. It was quite amazing and quite well done. Not only in front of the camera, but behind the camera, there were lots of individuals who would maybe not typically be hired, and there was also an advocate on the set. I mean, it was just an amazing situation. Unfortunately, it didn't get picked up, but it was a lovely, blooming community that was happening there, where

lots of points of view were being expressed and played out for people to watch and see and to have some relationship to and understand maybe a little better who might not have that personal experience. I thought that was fantastic. We've had some good examples in the last decade or so, so I think maybe some of these stories are emerging as producers and writers who happen to have family members who have these diverse needs start to tell their stories. Then students' videos and investors have faith and interest. Certainly, *Coda* also opened up that world a little bit.

Woodall: We talked to Joe Mantegna and then also Sue Ann Pien, who played one of the main characters in *As We See It* as well.

San Giacomo: She was great, right? Then she directed a short.

Woodall: Yes! We talked to Bella Zoe from that short, *Once More, Like Rain Man*.

Chet: I got to ask you, who's in the picture behind you?

San Giacomo: That is a painting. Okay, I love this story. This is a painting that my husband did of a selfie that my son took of himself with his iPod, isn't that cool? I asked my husband to paint that as a present to me, and it's quite big, but it's just like the corner of his face, I just thought it was such a striking photo. He really captured it. I've never done anything in front of this painting, and I was like, "Where am I going to go?" The house is so busy today, everybody's home and making noise and stuff so I was like, "I'm going to go in front of the painting."

Cooper: Good choice.

San Giacomo: I'm so glad that you noticed it.

Cooper: It also drew the attention to like, "Okay, who's looking over your shoulder?"

San Giacomo: Exactly. He's looking over my shoulder. That was the metaphor I was going for.

Cooper: What does your son do now?

San Giacomo: Well, right now, he's had some medical stuff going on, so he is just recovering right and doing some of his regular stuff like his workouts and his art and music classes, and just trying to get his body back to good shape.

Woodall: What kind of art does your son like to make?

San Giacomo: Well, he's done needlework, he's done ceramics, he's done painting—he's done a lot of different things. They do a lot of different mediums. He goes to L.A. Goal, and they have quite an established music and



Laura with Allison Cameron Gray, who helped design the first playground and works for Inclusion Matters and Scott Williams, Co-Founder

art program and cooking program. Drama, singing, dance. It's a really comprehensive program. It's really cool.

Cooper: Do you know Habitat for Humanity?

San Giacomo: Yes.

Cooper: Our non-profit ABILITY Corps partnered with Millard Fuller and we created a program called the ABILITY House. Across the country, we started building homes for families with disabilities of low income, but we access volunteers with disabilities to build the homes. We also do something which is called A Brush of Kindness, which is where you're not building the whole home, but you're going to a home that needs some modifications, some paintings, or maybe a ramp built to the home because a family member now needs a ramp. We were doing a brush of kindness at a house in the Greater LA area. I see this young woman in a power chair, fairly severe CP in the sense that to understand her speech, you really have to be with her for a while to really get what she's saying. She had a support person that was with her, and I was watching what was going on with the volunteering, and it was the support person, the caretaker, doing the work. I went and said, "Okay, let's see what we could do here." As we start to learn what she can do, she can grip something. I said, "Okay, here's the idea. We're going to get a power washer because the back of the house needs to be sprayed down with this power washer. We're going to get that and see." Then we got the machine and I said, "Can you hold the handle?" She couldn't. I said, "Okay, hold on."

I tape the handle on the on position and I said, "Okay, can you put your knees together and with two hands hold the wand?" And then we turned it on and I'm looking at the wall, and the wall is being sprayed, but it's going all over the place, and I turned back and she is laughing so hard because she's doing it and she's cracking up, and so we turned off the machine, draped her with a bunch of plastic because she was getting soaking wet, and then we started again. She later wrote a story about it and it turned out, instead of her going to a high school reunion, she came out to this because she heard about the volunteers with disabilities. She had become a writer, and her first published article was about that event. That experience was helping her to actually do something that was meaningful that she saw. It was such a results-oriented experience because the house was so dirty, and when that spray wash hit something, it would turn from really dark gray to white because it was a white house, you just couldn't tell it was.

San Giacomo: That's really something. We all need to recognize in each other the difference that we make. It's beautiful. It's really beautiful.

Cooper: I think volunteering is one of the best ways to actually not just help others, but help yourself. That's why I love the ABILITY House project, because the people being asked to volunteer have never actually volunteered. They've been recipients, but they haven't been able to give back to someone else. It just changes that whole dynamic.

San Giacomo: Yeah, absolutely. That's right, because

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Honoree Chelsie Hill and Paul Barris performing at Heart to Heart Gala - photo by Ivy Ninet

when you help out someone else, you feel really self-confident.

Cooper: Can we talk about your history with CHIME institute?

San Giacomo: I'm not involved in CHIME anymore, but how it started was I had coffee with one of the moms at the preschool. The preschool lab was created by a Department of Education grant that was given to CSUN—California State University, North Ridge—to study full inclusion at the preschool level. So, this other mom and her son was also at the preschool, and she said, “We need to start a school.” because what we were finding is that most of the kids who are in full inclusion are not really being treated as full classmates—full participating classmates. Also, I think there was some issues about being fully included. So, we and some parents and some professors took it to the dean of education. The charter school movement was just blossoming at that time, and the dean was supportive. Then the professors went out into the charter school community, various conferences and such, and people were very negative and thought, “It's not going to fly, Orville.” because it's an extreme extremely expensive model. But they persisted and wrote the charter with the help of some of their friends who were professors in other Cal State universities that had started charter schools, and through I believe a year and a half to two year process, finally the charter was approved. We found a space—a couple of classrooms—at a local church, and we scrubbed the space, and we found tables from the university storage area, and parents sawed off the legs so they would be the right height for the little wee ones, and that's how it started. It was a really exciting and scary time, but it was really exciting. I'll tell you another story that maybe some of the people involved now don't know because they weren't there, but

within the first couple of weeks of school, there was a moment of silence in honor of the persons who were victims of 9/11. It was all around the country at that time. It was a moment of silence, and it happened to be during our pledge of allegiance. In that moment, all the students signed, American Signed Language, the pledge of allegiance. Actually, my son's electronic voice on his AAC was the only voice on the playground as they were all lined up in those first couple of weeks of school. All the kids. Because at that time, there was also a DHH component, a deaf and hard hearing component to the school, and it was extremely moving. The education correspondent for KPCC, Adolfo Guzman-Lopez, did a piece on CHIME at the first 100 days of school. A crew came out to the school to interview the kids and the teachers, and it was very interesting because at the first 100 days, no classmate ever described their friend or classmate, by their disability. They only described them by their favorite food, their favorite superhero, what they had on their backpack, or what they liked to do. Disability was not seen. I know we see that all the time in inclusive education. Kids melt that away, and they're just friends.

■ ABILITY

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Laura next to her son Mason's painting

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jessica **FREW**

Author, Model, Actress, and Advocate

There is power behind the media we consume. What we watch and what we read shape our opinions as we move through the world.

So, what happens when we aren't represented?

Feeling unseen is already a perpetual part of having a disability. The constant self-advocacy can be tedious work; a grating, repetitive motion of explaining yourself and your needs. However, within the barrage of media we are exposed to on a daily basis, lies an opportunity to educate people in the moments when they are most open to listening.

Still, the modeling, film and television industries are, frequently, behind the times when it comes to including people with disabilities in the stories they tell. As a result, there is less awareness and less respect for disability in the world, day-to-day.

Jessica Frew aims to change that.

Frew is an actress, a model, a children's book author and is currently in school at William Patterson University where she is studying criminal justice. Her acting credits include the role of Harmony in the movie *Crispy* as well as Matilda Heptinstall in the TV show *Surviving the Cartel*. Frew, also, has cerebral palsy and communicates using a Tobii eye gaze computer.

Frew's children's book, *The Nonverbal Princess*, was inspired by her personal experience: "People have treated me differently since I was young and thought I wouldn't know anything because I was nonverbal."

The book chronicles the life of a princess with cerebral palsy in the imaginary land of Elesia. A parallel to her own life, the story's princess encounters barriers to gaining the life and confidence she deserves and must learn to overcome them.





Jessica Frew

When discussing what she hoped for her young readers as she wrote the book, Frew stated, “I wanted to teach children worldwide that people with disabilities are humans with emotions, too and they can do anything, like everyone else can, but need to work ten times harder for it.”

In our interview, Frew expressed, “My favorite part of the work I’ve done is being a role model.” The fact is, we need more role models like her.

An overarching theme through Frew’s work is her desire to better the world for people with disabilities. Stepping into each role, she aims to become the representation that is too often missing in media: “I always loved TV shows, movies, runways, and I want to be in TV shows, movies and on runways like the people I saw on TV when I was growing up.”

The notoriously limited representation has led to persistent disrespect and discrimination for people with dis-

abilities, though. For Frew, feeling unseen and dismissed is not new. In our interview, Frew mentioned, “People think I’m just looking into space when they see me for the first time. They talk to me like a two-year-old or they talk about me to someone else in front of my face, like I’m not there. It impacted my mentality for 17 years. I didn’t even have the confidence to communicate in society or stand up for myself.”

If you’ve ever felt devalued, you may understand its impact. “People used to say mean things in front of me without realizing I could understand everything they were saying. It made me feel worthless.”

However, Frew, with supportive family, friends and faith rediscovered her confidence: “You can’t control negative things from happening, but you have control over how it affects your mentality.”

With her love of entertainment, performance and the arts, she discovered she could be the change and the



representation we need more of, “I thought I wasn’t good enough to work in the industry because of my disability until I found the confidence.”

Now, Frew has been able to pursue what she loves. Unfortunately, film and modeling sets aren’t always as accessible as they should be. “The barriers I face in the industries are not wheelchair-accessible sets.”

This is not the first time we’ve heard about accessibility issues in the entertainment industry.

In *ABILITY Magazine*, Jennifer Woodall’s interview with producer Peter Saraf, the need for accessible sets was discussed as an imperative part of filmmaking. When describing the set of *Out of My Mind*, Saraf stated: “[...] we put together what we called our All Access team, which is where we brought together a group of accessibility coordinators to make sure that everybody’s needs were being met on the set of the production [...]”

However, not every production has accessibility coordinators in place which, ultimately, not only limits the cast and crew who may need the support, but it also contributes to the inaccessibility issue in the entertainment industry as a whole.

Jessica Frew has encountered that inaccessibility in film, TV and modeling can show up even in the audition process. Frew mentioned another barrier she’s encountered is, “[...] auditioning for non-disabled roles. It’s okay for non-disabled people to play disabled characters, but not vice versa.”

All is not lost, though. Simply including people with disabilities on more sets can change this cycle. Disability advocacy and inclusivity, one set at a time, will create a better standard in the industry. ■ **ABILITY**

by Olivia Austin

awarenessties.us/the-nonverbal-princess

JUST HANDS

Torsten Gross on Life's Loopholes



By definition, inspiration sparks fresh ideas. But as Torsten Gross has learned through his years in the corporate world and beyond, what people truly need is motivation—practical steps to turn creative thoughts into action. A self-described “multi-hyphenate,” Torsten’s résumé reads like a one-man highlight reel: advertising and marketing executive, competitive race car driver, the world’s only quadriplegic rescue scuba diver, multiple-time marathoner, charity founder, comedian, husband, dog dad, and a person who refuses to accept the limitations placed on those who are C6 quadriplegics like him.

At 15, Torsten dove into the ocean, broke his neck, and was clinically dead for two and a half minutes—an experience he calls one of the most pivotal, and possibly best, days of his life. Ever since, he’s been on a mission to help people uncover the “loopholes” that empower them to rise above any perceived limits. After all, as Torsten says, we all have our own “wheelchairs”—whether it’s depression, PTSD, being on the spectrum, relationship struggles, or something else. On the surface, they may seem to hold us back, but they can also unlock our true superpowers. In this interview, Torsten joined Dr. Ed Timke (Assistant Professor at Michigan State University) and *ABILITY Magazine*’s Brent McMahon (Gold Medal Paralympian) to reflect on everything from life-changing moments to personal reinvention to the drive for real innovation—and, most importantly, the action steps to make it happen.





Formative Years

Ed Timke: How did your early life shape who you are today?

Torsten Gross: I've always described my younger self as something of a rebel. I was never one to follow a straight line. Whether it was in school or sports or general expectations, I had a habit of pushing back. It's tough to say if that was "nature" or "nurture," but looking back, I think I had a strong streak of nonconformity baked into me from the start. Rules—at least the ones that felt arbitrary—never sat well with me.

To be totally honest, I was a difficult kid. Teachers, friends, even my family would tell you I wasn't easy to handle. I had decent intelligence, but for a long time I didn't feel like applying myself in traditional ways. So if the assignment was "Get straight A's," I'd purposely not study. If my parents wanted me to be polite in company, I'd find ways to quietly push boundaries. A lot of that was typical teenage rebellion multiplied by ten.

When I was 15, I sustained a spinal cord injury in a diving accident. That changed my life in many obvious ways, but it also magnified the rebel in me. Suddenly, doctors were telling me all the things I couldn't do, or wouldn't be able to do without significant help. To a kid who had already been testing every limit, that just lit a

new fire. If anything, being confronted by the so-called "can't" made me more determined to say, "Actually, I can." That rebellious nature was channeled toward forging independence as quickly as I could—learning to dress myself, live on my own, and eventually pushing the envelope in areas people said would be off-limits.

For me, that rebellious streak was less about trying to be "bad" and more about insisting there had to be another way. I kept thinking, "If I'm not allowed to do it the 'normal' way, I'll figure out a new way." That impulse shaped who I became, not just physically adapting to life in a wheelchair, but mentally insisting I would never let a standard path define my goals, who I am, and what I do.

Just maybe, ironically, being difficult prepared me to do difficult things.

Work in Advertising & Marketing

Timke: You've had a successful career in the advertising and marketing world. What drew you into that industry?

Gross: My path into marketing and advertising was definitely not linear. After my injury, I couldn't do the usual odd jobs a lot of college students do—things like construction or lifeguarding—so I needed real internships to survive the summers. My father made a few phone calls to people he knew in the ad business, which is how

I got my foot in that door. At first, I thought I wanted to do art direction, but it quickly became clear that my partial color blindness—together with my own restlessness—wasn't the best fit there.

Eventually, I discovered strategic planning, which changed everything. I read John Steele's book *Truth, Lies & Advertising* and got excited by the idea that there is more than one way to solve a problem. Strategy in advertising is about asking "why," peeling back layers of consumer behavior, and ignoring the notion that there's only a single right answer. If something is "impossible," I'll jump at the opportunity to see how else we can approach it.

From there, I learned to flourish in the agency world—some at large, some I started myself. There was a time in my twenties when I jumped around every couple of years, partly because I'd get bored or because I clashed with people who thought I was "too difficult" or "not ready to change." But that eventually became my strength. Being restless meant I uncovered solutions in places few other people even looked. Ad agencies can be hierarchical and, ironically, risk-averse, but if you're willing to be the "rule-breaker," you'll often do work that stands out.

Brent McMahon: That's a great perspective. How did others in the industry perceive you as a professional who also used a wheelchair?

Gross: You'd think there would be blatant discrimination, but most of what I faced was a silent uncertainty. Many people had no idea if someone who used a wheelchair could travel for meetings or presentations. A big chunk of strategy is flying around the world, visiting focus groups, and consulting with clients. Rather than asking me directly, potential employers would just assume I might not manage that, so they wouldn't hire me.

Later, when I'd already established myself, I found out a strategy director had rejected me years before because she worried about my travel. She told me that she felt uneasy even asking me about accessibility—she feared it might be illegal or offensive. That was a big aha moment. I gained an understanding: People are rarely malicious. They're just uninformed and nervous. A straightforward question would have let me clarify that I'm entirely capable of traveling alone. Instead, I lost a job offer.

Thankfully, once you demonstrate success in a high-profile setting, perceptions can shift. The day I started winning pitches, bringing in big clients, or coming up with ideas that generated real buzz, the wheelchair became almost incidental in people's eyes. They saw what I produced, not just how I got around. But if you're just starting out, it's definitely an uphill battle, because there is so much fear around even discussing disability—an anxiety that reveals itself as reluctance to hire.



Work in Sports

McMahon: You haven't just excelled in the marketing world, you're also an avid participant in sports—especially racing. What's your journey in sports?

Gross: I've always believed in taking physical risks. Even before my injury, I pushed my limits in every sport I touched. Afterward, I wondered whether that avenue was completely closed. Initially, I tried the typical adaptive sports—things like wheelchair marathons. That was fun, but I was still searching for the extremes I craved.

I gravitated toward motorsports for several reasons. First, I have always had a penchant for going fast. I won't tell you how many times I have been pulled over. Whatever the number you're thinking, multiply it by at least three times. Second, it became obvious that sitting in a cockpit, hands on the wheel, is an environment where legs matter less than reaction time, technique, and nerve. Yes, I had to figure out custom hand controls and adapt everything to my own body mechanics. But once that was set, I could race wheel-to-wheel against non-disabled drivers. We're on an equal playing field. Either you're fast enough or you're not—that's it.

There's also an adrenaline rush you can't replicate anywhere else. At 150 mph, the last thing on my mind is that I use a wheelchair. I'm fixated on apexes, brake points, and outsmarting the driver in front of me. Racing is simultaneously a physical test—how well can I maneuver the car with my upper body?—and a mental puzzle—when do I brake, when do I accelerate, how do I approach this turn? That combination is addictive.



McMahon: How have other drivers treated you?

Gross: There are two types of people I encounter on the track. Some come up to me, give me a high-five, and say, "Fuck yeah, that was amazing!" They respect the race, the competition, and the skill. Then there are the others—the ones who are absolutely furious that they got beat by a guy in a wheelchair.

There's no middle ground. None. I've had people really pissed off about it, and I could tell you some fun stories. Some are genuinely angry, while others are just baffled and curious. And I love their curiosity. I get it—I'm just as curious about how other drivers set up their cars. Even though we all technically drive with two hands and two feet, everyone has their own preferences for tuning and positioning. I just happen to do it with hand controls.

But the angry ones? They're the best. I can't help myself—I'll mess with them. I'll say, "Bro, you're just a bad driver. That's the real issue here." And if I really want to push buttons, I'll go, "How does it feel getting beat by a cripple? And in a minute, you're about to get passed by a woman and a Black guy too. That's really going to crush your ego, isn't it?"

The Just Hands Foundation

McMahon: You founded the Just Hands Foundation, which focuses on adaptive motorsports. Tell us more about its mission and what sets it apart.

Gross: A lot of people know about adaptive skiing, basketball, marathons, and so on. But very few sports give disabled athletes the chance to compete on equal terms

with able-bodied people, too. That's exactly what we do at Just Hands: we use motorsports to level the playing field, removing the usual barriers so disabled athletes can truly go head-to-head with the rest of the world.

Instead of restricting ourselves to a small circle of adaptive-only competitions, we put disabled drivers on the same track as everyone else. Motorsports has a unique advantage—once you're strapped into a car with the proper controls, the focus shifts to skill, strategy, and nerve. Whether you use a wheelchair or not becomes less important. It's all about how fast you can go, how well you can handle the vehicle.

McMahon: That's fascinating. What does that look like on the ground?

Gross: We organize events that provide track-ready cars with hand controls, so participants can get behind the wheel and learn high-performance driving skills. Some eventually race competitively. Others just fall in love with the thrill of speed and independence. Our guiding principle is that motorsports shouldn't be off-limits to people with disabilities—it should be wide open, with the same opportunities for everyone. We want to see disabled racers on the same grids, competing for the same checkered flags as able-bodied drivers.

As of this year, off the racetrack, we started offering adaptive mountain biking. We have two Bowhead Reach Mountain Bikes which have an e-assist motor. While the motor helps us on flat or uphill, the downhill is where the thrill is. We hit all the same trails, berms and jumps anyone else does. There's a lot of interest in adaptive mountain biking, so the sport is poised for a lot of growth.

Development of SIM Controls

McMahon: I saw on the Just Hands website that you've been working on simulator controls in collaboration with Veigel/Mobility Innovations. Why is that such a big deal?

Gross: A simulator is meant to replicate the experience of driving on an actual track in a real track car. That includes cockpit positioning, wheel feedback, pedal feedback—every tactile element you'd experience when you're doing 120 mph into a turn. But for drivers who use hand controls, most of the existing adaptive solutions just don't feel like the real thing.

So, in partnership with Veigel/Mobility Innovations, we've developed a sim control system that mirrors genuine in-car performance. You can shift gears, activate the pit limiter, enable communications—basically everything you'd do in a race car—using just your fingers. And you don't have to let go of the throttle or brake.



Gross on a panel with John Legend at the Cannes Lions International Festival of Creativity in Cannes, France.

For me, this solves a huge problem: as a race car driver, it was nearly impossible to practice effectively at home. If the sim controls don't match what I use on the track, I'm not really building muscle memory or reflexes. Now, we're offering a solution that lets disabled drivers train in a simulator that feels transferable to a real car, so they can refine their skills and confidence without the logistical hurdles of going to a physical track.

McMahon: That's game-changing, right? Because sim racing has exploded, and now you're ensuring disabled racers aren't left behind.

Gross: Exactly. It's democratizing motorsports even further. Sim racing is already a huge entry point for aspiring drivers, because it's more affordable and safer than jumping straight into a car on a real track. But if adaptive drivers can't find realistic hand-control solutions, they can't develop those skills or measure themselves against the rest of the sim racing community. This new control system changes all that—now you can practice from home, hone your reflexes, and then transfer those skills to an actual race car. It's a big leap toward making motorsports accessible to everyone, which is exactly what Just Hands is all about.

Thoughts on Disability

Timke: You've mentioned people's apprehension about disability. How do you think our society can improve discussions and attitudes about disabilities?

Gross: Step one is simply to be willing to talk about it. We talk openly about race, gender, and sexuality—though we still have plenty of room for improvement—but I feel like disability remains in a gray area. It's an

uncomfortable topic for many. Part of that is, unlike race or gender, disability can happen to anyone at any time. It's a universal possibility that makes people uneasy.

If someone's worried about "saying the wrong thing" or is unsure whether they can ask about accommodations, a chain reaction of silence sets in. They remain uncertain. I remain invisible. It's the worst outcome for everyone. I firmly believe we need to remove that taboo so that direct questions and open conversations can take place. Ask me if I can travel for a job. Ask me how I'll get on stage to give a speech. Ask me if I need assistance. I'd much rather clarify questions than lose an opportunity because you're afraid to ask.

The second part is representation. Businesses and media are slowly recognizing that disability is not niche—over a billion people around the globe live with a disability. Whether we're talking about an ad campaign, product design, or HR policies, understanding disability means you're reaching a huge demographic. More inclusive hiring, more inclusive marketing, and more inclusive everyday thinking isn't just a moral imperative. It's a smart business decision. Yet often disability is an afterthought—someone thinks to add a ramp at the last minute, but they don't plan from the start. That's what we can change.

Timke: You've spoken about "celebrating failure." Can you explain how that idea relates to disability?

Gross: Sure. A lot of us with disabilities have no choice but to fail and keep adapting. At the start, I had to figure out how to dress myself, how to get into a car, how to travel, how to cook. We do a lot of failing and re-failing



before we get it right. That can be frustrating, but it can also be transformative. Once you realize failure is just data—it's telling you what doesn't work—you're free to explore new methods and tools.

I say “celebrate failure” because each stumble is a step toward better outcomes. If you're terrified of messing up, you won't push beyond your comfort zone. With a disability, you have to. When we get comfortable celebrating that, we unlock new opportunities, new technologies, new careers. We stop giving so much weight to the word “impossible.” Sure, we can't do everything the same way as a non-disabled person. But with each attempt, we discover an alternate path that might surprise everyone, including ourselves.

McMahon: You mentioned the need for open conversations, better representation, and new technologies. Where do you think disability inclusion stands today, especially given the current political climate?

Gross: We're at a really important crossroads. In one sense, it feels like disability inclusion has gained momentum—people talk more openly about accessibility, big companies finally introduce inclusive product lines, and we see social media campaigns showcasing adaptive athletes or employees with disabilities. But the political environment is turbulent, and we live in a media environment focused on division and rage.

Changes in policy or shifts in leadership can stall progress if disability rights lose priority. We've seen growing debates over healthcare funding and social services. That directly impacts people with disabilities—everything from in-home caregiving to the costs of durable medical equipment. If a political decision cuts essential programs, it can push us back decades. On the other hand, there's also grassroots energy right now. More people with disabilities are running for office. Non-profits and advocacy groups use online platforms to organize quicker than ever. So we've got this push and pull.

What I hope is that, even if we are in a moment that seems like the lowest things can get in the United States, we keep building pressure from the ground up. Everyday actions—companies setting inclusive hiring policies, schools teaching about disability history, local governments enforcing accessibility standards—those can survive changes in leadership. Plus, I think the more disability is woven into everyday culture, the harder it becomes for people to ignore. We're not a fringe population. We're a massive, diverse group with real power and economic influence. As that reality sinks in, the political environment will have to address us more seriously.

Stand-Up Comedy & Using Humor to Talk About Disability

Timke: Torsten, you've also explored stand-up comedy to address disability. How did you get started? What is your approach to comedy?

Gross: It happened almost organically. I've got a rebel streak and a tendency to say what's on my mind. I got into stand-up after I bantered with comedian Lisa Lampanelli, “The Queen of Mean,” during one of her shows. She asked me, “What's up with the wheelchair?” I fired back with an outrageous reply poking fun at my disability and her weight. That sent the audience from shock to laughter. This was an important interaction because it let the audience know: “Hey, disability is part of my reality, but I'm not fragile. Let's talk about it.” It didn't treat disability as something that's untouchable. It helped people realize that it's just a part of my life, so why not laugh at the absurdities? So when Lampanelli encouraged me to do open mics, I went for it.

My initial material was self-deprecating, poking fun at everyday wheelchair experiences—like calling myself “the ultimate designated driver.” I quickly saw that humor breaks down barriers. Once you make a witty remark about the chair, people realize it's okay to engage, to laugh, to ask questions.

Timke: Lampanelli not only encouraged you to do open mics, but she also helped you write your material. What did you learn from working with her?

Gross: Lisa is famous for her no-holds-barred roasts, and her stage persona can be pretty wild. Watching and talking with her taught me that there's a difference between “punching down” and genuinely bonding with the audience through humor. She could insult somebody's entire existence in a single sentence, but by the end of the show, that same person was hugging her. It was never about cruelty; it was about letting everyone in on the joke.

She fully encouraged me to own my story onstage. Her support gave me permission to lean into material that might seem taboo and trust that, if it's authentic and all-in, the audience will come along, too. People can be too

uptight about humor, so you have to read the room and hope they understand you're coming from a place of disarming people against discomfort they often feel about something like disabilities.

Timke: Do you ever worry about crossing a line or making people uncomfortable?

Gross: Sure, there's always a moment in some crowds where they're like, "Can we laugh at a 'cripple joke'? Are we allowed to?" But that's exactly the tension I want to shatter. If I'm the one cracking the joke, I'm saying it's okay to respond. Laughter builds a sense of shared experience. It also opens the door for real conversations—if they can laugh with me about accessibility challenges, maybe next time they'll think about putting in a ramp or how to make events more inclusive.

Timke: So what's the biggest payoff from stand-up?

Gross: It's freedom. Comedy lets me address disability head-on in a way that's disarming rather than confrontational. I'm showing people I'm not fragile—and neither is the topic of disability. By turning it into humor, we break that aura of taboo. People realize, "Oh, he's cool with this. Maybe I can ask questions." And that's powerful. Because once we're all laughing, having an honest discussion about living with a spinal cord injury or dealing with inaccessible spaces doesn't feel awkward—it feels natural.

Forthcoming Docu-Series

McMahon: We hear you have an exciting project in the works—a docu-series set to premiere on Amazon Prime called *Just Hands: For the Love of Driving*. Can you share some details?

Gross: It's been in development for a while, and I'm thrilled we're finally able to talk about it. The series is all about challenging expectations around disability by focusing on my real, raw story. It features the adaptive racing community, including *Just Hands*. We capture my story of facing countless barriers and how I still show up at the track, determined to compete at full throttle.

The docu-series also gets into the behind-the-scenes development of adaptive technologies being applied differently and how those breakthroughs ripple out into everyday life for folks with disabilities. It's not just about racing cars. It's about opening doors—whether that's in sports, at work, or in personal relationships.

Amazon picked it up because they saw the universal appeal: these aren't just "disability stories," they're human stories. Everyone can connect with facing adversity, seeking community, and discovering new ways to thrive. My hope is that viewers walk away amped to try something they once thought impossible—or to build something that helps someone else achieve it.



We All Have Wheelchairs

Timke: Torsten, throughout this conversation, you've talked about breaking stereotypes, challenging assumptions, and refusing to be put in a box. I heard you once say something powerful—you don't want to be a martyr. You don't want people looking at you and making you a symbol of struggle. Why is that important to you?

Gross: Yeah, I mean, I don't want to be your martyr, and I sure as hell don't want to be your hero. I don't need people looking at me and saying, "Oh wow, look at what he's overcome." That's not the point. I want people to understand that everyone has something they're carrying—their own version of a wheelchair. Maybe it's PTSD, depression, a bad childhood, or something people can't see. The difference is, my wheelchair is just more obvious. And honestly? I'd rather people see my challenge than have one they can't see, because at least this way, people understand when I hit a barrier.

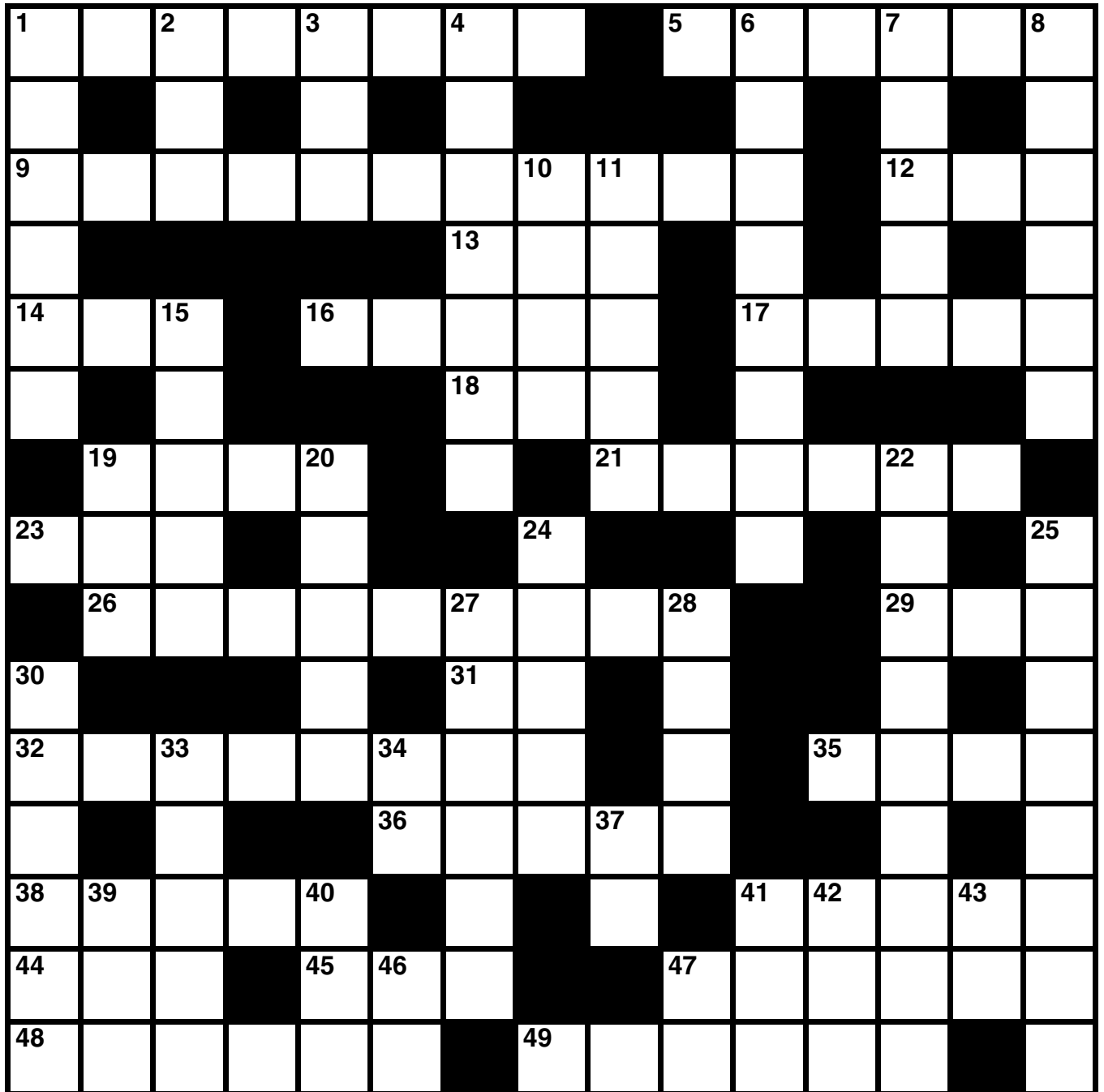
What I want is for people to recognize that they're carrying something, too—and instead of letting it hold them back, they should figure out how to work with it, to push forward, to stop being afraid of it. We spend so much energy hiding the things we think will limit us, when really, those are the things that can make us unstoppable. So if someone looks at me and thinks, "Wow, he's out there racing, starting companies, doing stand-up—I should stop making excuses for myself," great. But don't put me on a pedestal. I'm just doing my thing, finding the loopholes, same as everyone else.

■ ABILITY

torstengross.com



ABILITY'S



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ACROSS

- Actor and environmental activist, Ed _____
- Main character who has cerebral palsy in Peter Saraf's film, "Out of My Mind"
- Founder of Smiles for Speech, helping the disadvantaged gain access to speech and language help, 2 words
- Rock and Roller who sang "Runaway" : ____ Shannon
- Director Jean-____ Godard
- First responders, abbr.
- "The Help" star, ____ Davis
- Workout system, 2 words
- Neighbor of Austria, abbr.
- One of the founders of the Thirst Project, ____ Maxwell
- Viewpoint
- "Levitating" singer ____ Lipa
- ISV Principal Business Development manager at Sales Force whose company has helped her campaign and overcome ALS, 2 words
- "Platoon" setting
- Type of light, abbr
- Canadian-American actress who champions the rights of individuals with Down Syndrome, Caterina _____
- Guitar crosspiece
- Salon job
- Ensures
- ____ Lee Lewis
- The NY Manning
- Just survive
- Holdups
- Approvals
- Six-time Paralympic gold medal and parasurfer, Lisa _____

DOWN

- ____ Seals: organization behind the production of the short film "The Great Cosmic Hoax"
- Author "Disability Pride" ____ Mattlin
- Chap
- Study of the relationship between living things and their environment
- "Walk Like an ____" The Bangles song
- Song that's a blast from the past
- Beatle's submarine color or a Chinese river
- Govern
- Lasting effects of mental or physical wounds
- Asparagus piece
- Hero sandwich
- Basketball
- President and CEO of the United Cerebral Palsy's national office, Armando _____
- Brad Pitt thriller
- Purple gem
- ____ Mary Kennedy Shriver, founder of the Special Olympics
- Prestigious university
- Pro motorcross racer and now a stunt actor, ____ Fiolek
- Desert sanctuary
- On the other hand
- Street, for short
- Pub order
- Understand
- "Along came Polly" star first name
- Large deer
- Railway, abbr.
- Topeka's state
- ____ Vinci

SEE BETTER

AT ANY AGE

AUTHOR

- The Miracle of Pi in Eye
- LASIK in the 21st Century
- Cure for Keratoconus

VOTED BEST

- Newsweek Showcase Top Doctor
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- VC Star Readers
- Consumer Research Council

DOCTOR'S

DOCTOR

- Surgeons & Physicians
- Chiropractors & Dentists

SURGEON

TO STARS

- Actors & Celebrities
- Olympic Athletes

FOR PATIENTS

18-45

- Thin Flap Lasik
- ICL

FOR PATIENTS

45-65

- Superlasik
- Pi in Eye

FOR PATIENTS

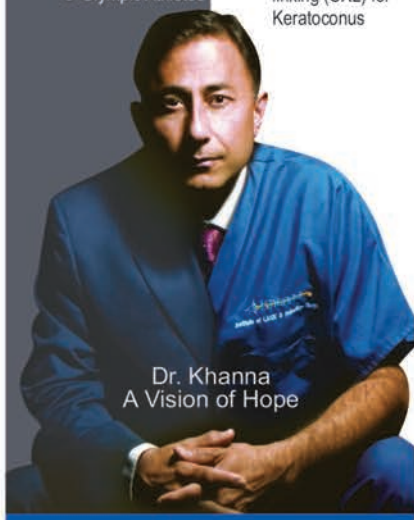
ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

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S R E W S N A
Crossword Puzzle

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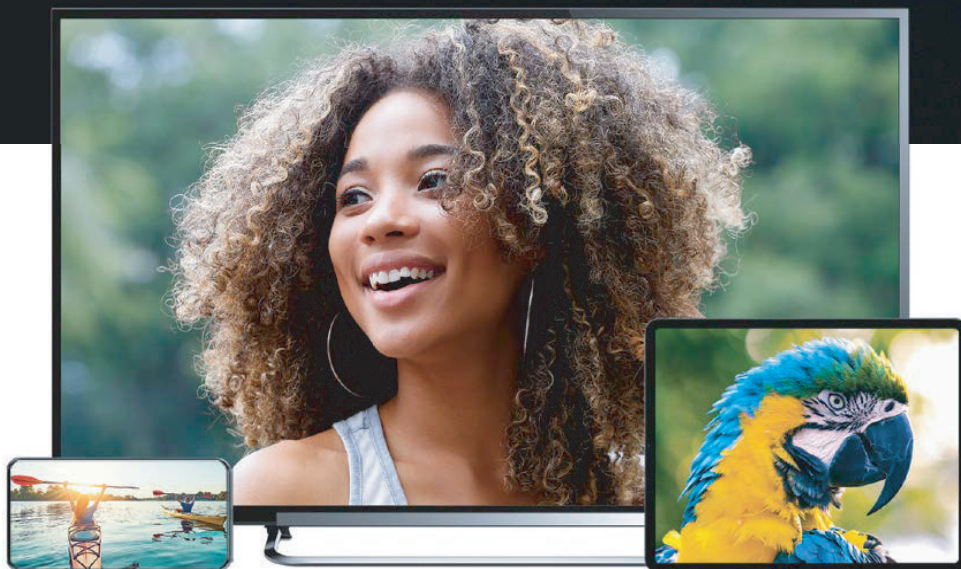
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