LONG HAUL PAUL / MS CURE CROSSWORD PUZZLE ELLA ONYEBE/SIGHTSAVER HUMOR – SQUEAKY WHEEL

ABILITY



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This publication was financially assisted by the California Governor's Office of Emergency Services (Cal OES)

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Ella Onyebe p. 36


John Leguizamo p. 54


Para Surf p. 72


Erik Weihenmayer p. 14

CONTENTS

8 **HUMOR — The Squeaky Wheel: Why I voted**

10 **LONG HAUL PAUL — Picturesque Calendar for MS**

14 **BRAINLINK — Creative Approach to Stroke Therapy**

26 **ERIK WEIHENMAYER — No Barriers**

36 **ELLA ONYEBE — Sightsavers' Untied Nations Mural in Nigeria**

40 **TARYN MACKENZIE WILLIAMS — Employment of PWDs via the DOL**

50 **STAKI SKI — Bringing the Joy of Skiing to All**

54 **JOHN LEGUIZAMO — Interview with Friend and Award Winning Actor**

64 **EPIC PLAYERS — Inclusion Theater Company**

72 **PARA SURF — World ASI Surf Championship**

78 **CROSSWORD — *ABILITY*'s Puzzle**

82 **MARKETPLACE**

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

ABILITY Magazine is published bimonthly
8941 Atlanta Ave. HB, CA 92646 (ISSN 1062-5321) All Rights Reserved

Send address changes to *ABILITY Magazine*, Attention: Subscriptions Manager
PO Box 10878, Costa Mesa, CA 92627; John Leguizamo Issue Dec/Jan 2024-25

Published in USA

DISTRIBUTION
Faxon-RoweCom Library Services
Ebsco - Library Services
Swets Blackwell

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

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

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the SQUEAKY WHEEL



I'm a Disabled SSI Recipient and Medicaid Beneficiary on Food Stamps. Here's Why I Support Donald Trump

Have you noticed how each election season, everyone assumes they know who you support based on your demographics? Christian? Got to be Republican. Queer? Democrat. Ignorant? Republican. Annoying? Democrat.

It's tiresome, and I'm here to publicly reclaim my autonomy in the hopes of inspiring more people to think independently. I, Derrick Deacon, 47, SSDI recipient in poverty and Medicaid/Medicare dual beneficiary, support Donald J. Trump to be the next president of the United States. Here's why.

He'll fix the economy. Of course I agree that gay people should be allowed to get married and that women should be encouraged to get abortions if I'm the father, but ultimately the single issue affecting me most is the empty



space in my wallet. I only receive $800 each month from the government (in addition to my healthcare), and that isn't enough to pay rent or buy groceries.

But with Trump's genius business skills, he will raise the stock market so high that I will have enough stocks to build myself a house of stocks and eat the rest for breakfast, lunch and dinner. Gross domestic product? More like tasty domestic product if you ask me.

You don't need to be friends with your candidate to support them. Do I think Trump is kind? No. Do I want to grab a beer with him? Absolutely not. But we're not picking our wedding party here, we're picking a world leader. Who really wants a president who is nice, or cool, or generous, or able to handle themselves professionally in an even remotely diplomatic manner?

We're losing (sub-minimum wage) disabled jobs. In a disaster for disabled people, 16 states have eliminated or otherwise restricted eligibility for 14(c) certificates. Let's face it: It's not realistic to expect businesses to value disabled workers as much as those who are not disabled — and frankly, why pay 'em more when you can pay 'em less? Trump's free market policies will remove these harmful regulations and reopen the pathway to work: a welcome slave in an otherwise exclusionary labor market. I mean salve, a welcome salve.

He's just as cool with genocide. Sure, Kamala Harris is "working tirelessly" to negotiate a ceasefire, but what better use of my taxpayer dollars than to boost the IDF's bomb collection? They need that money more than I do.

He's just like me, for real. I don't trust career politicians like Crooked Hillary or Sleepy Joe. But you know who I do trust? Billionaires who play golf all day and have weird obsessions with crowd sizes. I know Kamala is a child of immigrants, and Tim Walz is a military veteran and former school teacher, but they just can't relate to me the way an old real estate tycoon with 34 felony convictions can.

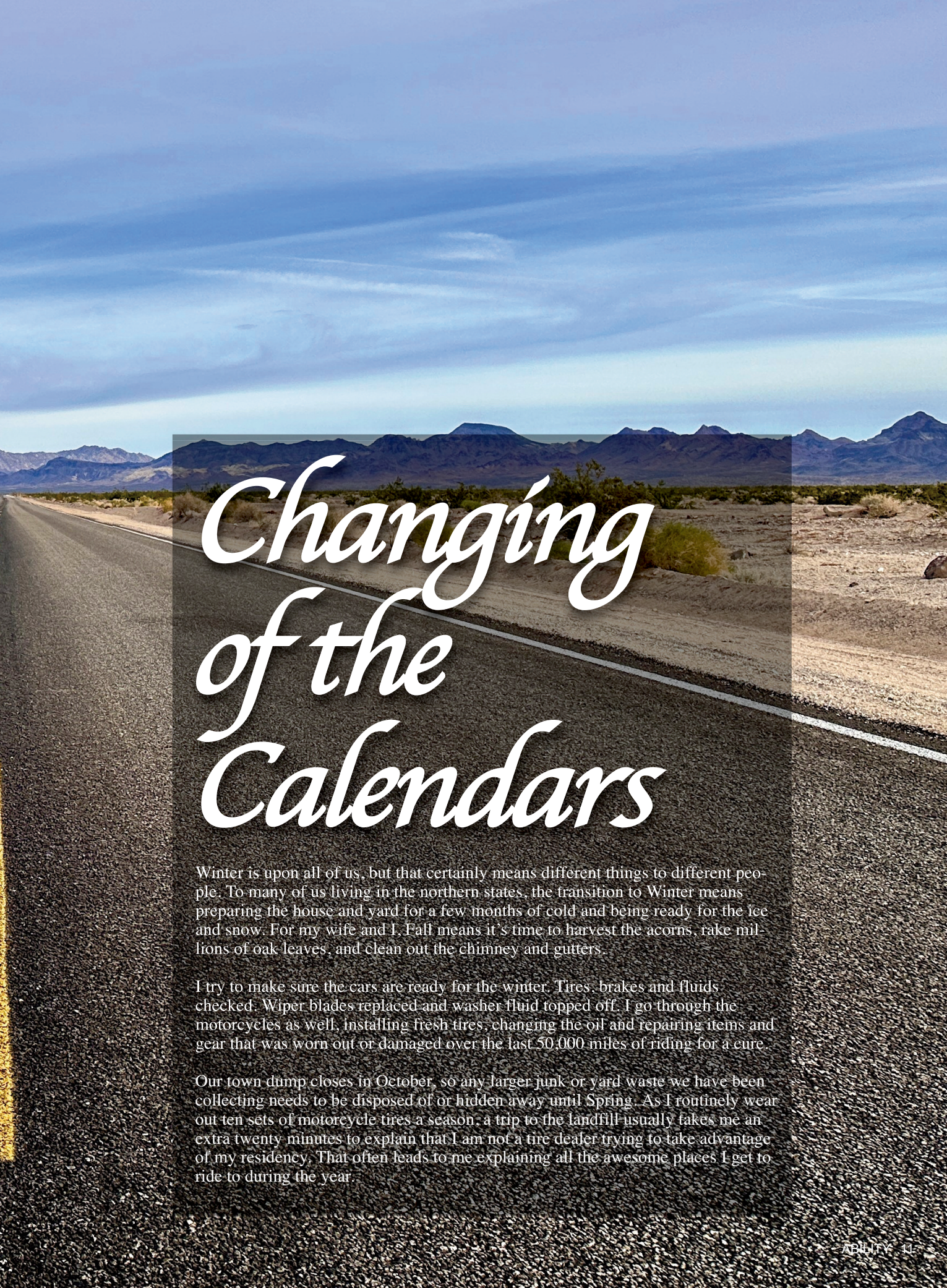
America was once great, then not so great, then great again (2016-2020), and now it's back to not great. It's time to "Make America Great Again" again. ■ ABILITY

by MV Perry
& Steven Verdile

the-squeaky-wheel.com







Changing of the Calendars

Winter is upon all of us, but that certainly means different things to different people. To many of us living in the northern states, the transition to Winter means preparing the house and yard for a few months of cold and being ready for the ice and snow. For my wife and I, Fall means it's time to harvest the acorns, rake millions of oak leaves, and clean out the chimney and gutters.

I try to make sure the cars are ready for the winter. Tires, brakes and fluids checked. Wiper blades replaced and washer fluid topped off. I go through the motorcycles as well, installing fresh tires, changing the oil and repairing items and gear that was worn out or damaged over the last 50,000 miles of riding for a cure.

Our town dump closes in October, so any larger junk or yard waste we have been collecting needs to be disposed of or hidden away until Spring. As I routinely wear out ten sets of motorcycle tires a season, a trip to the landfill usually takes me an extra twenty minutes to explain that I am not a tire dealer trying to take advantage of my residency. That often leads to me explaining all the awesome places I get to ride to during the year.



Winter gives me a chance to look over my events and activities for the coming season and think about planning the year's fundraising activities. One of the projects I look forward to each Fall is gathering 12 of the best photos I collected over the previous year and putting together my annual Chasing the Cure Calendar. It's the only fundraising activity that doesn't benefit the MS charity I work with, and people understand the proceeds from my calendars help offset my motorcycle fuel expenses over the coming year.



I finished designing my calendar in October, and sent the proof off to the printer just as I was leaving for the TouraTexas Rally in Burnet Texas. It was my last event of the year and the 2200 mile trip would be my last ride for a while as I was finally able to reschedule my second corneal transplant for the end of November. As I would need a few months to recover my eyesight, everything seemed to plan out just right.

While I was in Texas, the surgeon called and said they needed to reschedule my surgery. My cornea transplant was then scheduled just five days away, and just 12 hours after I returned from Texas!

I did rush straight home, excited that I might soon be able to see out of my left eye again! As I rode, I realized I would not be able to complete a lot of the Fall chores around the house and yard as I had hoped, because I knew from the last surgery it will be a slow recovery with wonky vision changing daily for a few months until it stabilized.

I made a plan in my head, prioritized the chores and when I got home, I parked the bike and started raking leaves. I climbed the roof and cleaned the gutters and winterized the lawnmower. The rest of the cleanup would need to wait a few weeks.









I was excited to see the UPS driver had delivered 3 heavy boxes of calendars and I was really happy I had them and made sure my website was updated and ready to announce they were available for sale. By the time I made it to bed that evening, I was exhausted, but had very little time to think about the eye surgery merely hours away!

It's now been over a month since receiving my new cornea, and the jury is still out on it's success. My last check up showed vision in that eye was 2/200. My surgeon believes it will improve. Over the last 6 years I have been riding with limited vision in that left eye, constantly dealing with prescription changes for my glasses and the additional complexities of wearing a scleral lens. I do hope this one works, and by hook or by crook (pirate eye patch pun intended), I will be back on the road by March, attempting to ride a million miles while raising awareness and funds for people living with Multiple Sclerosis.

My limited edition calendars are almost sold out! Although I can't really see it very well, I've heard this year's photos are the best yet! ■ ABILITY

longhaulpaul.com/calendar







For eons, neuroscientists, including clinicians such as neurosurgeons and neurologists have striven to remedy maladies of the brain. The uniquely complex anatomy and physiology of the brain compared to other organs of the body have been a general impediment to progress. Of great interest has been failure to recover lost function after injury or damage to the brain like that which occurs with trauma or stroke. Simply put, unlike most other tissues in the body, brain cells lack the ability to regenerate; once destroyed, they are gone forever. This is referred to as a lack of "plasticity."

Brain disorders like those resulting in abnormal movements of the extremities associated with Parkinson's disease are ironically best treated by destroying highly specific small areas in the brain. This to some extent corrects the imbalance between related areas of the brain caused by the disease, thus ameliorating some of the symptoms. This generally requires invasive techniques with associated risks, thus there has long been interest in techniques for modulating communication between areas of the brain without opening the skull (i.e., non-invasive techniques). Focused radiation has a long and successful history in treating brain disease, but mostly for the destruction of brain tumors, and ionizing radiation has some downsides. More recently, innovative practitioners are exploring the use of focused high-intensity ultrasound energy, and even more recently, magnetic energy, to modulate connections in the brain in hopes of remedying certain brain maladies. These energies have essentially no downsides in human tissues.

Since the magnetic energy is passed into the brain through the skin and skull without incisions or bone removal, it is non-invasive and thus called "Transcranial Magnetic Stimulation." Some of the earliest explorations of the use of this technology have involved rather diffuse magnetic fields passed through the brain not focused on any specific brain area in an effort to improve the brain's ability to recover from traumatic injury. The idea is to alter brain cells and their connections to improve plasticity, yielding a better opportunity for repairing damage ("healing"). Recent advances


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Dr. Zucker with patient

in multiple technologies have further honed the potential for magnetic energy to treat certain brain dysfunction due to disease or injury.

A most recent and exciting development is that of the "connectome," which has greatly improved understanding of brain anatomy as it relates to brain function. This is supported by two other technologies: the electron microscope and artificial intelligence. The connectome, coupled with yet two additional modern technological advances allows for the application of transcranial magnetic energy to brain dysfunction. They are "stereotactic focusing" and "Magnetic Resonance Imaging (MRI scans)." Stereotaxy uses concepts identical to those used by global positioning systems (GPS) to precisely identify and target areas of concern in the brain shown on an MRI scan. Coupling the MRI scan with the connectome allows for the identification of specific connection pathways in the brain that have been damaged by a stroke, for example, so that magnetic energy might be focused there in hopes of increasing plasticity and allowing the damaged brain to heal.

Let's "listen in" as Chet and I chat with Dr. Zucker, a neurosurgeon working with a team in Florida under the brand Brainlink to apply these techniques in the treatment of patients recovering from stroke.

Chet Cooper: Can you give a little bit about your medical background?

Dr. Lloyd Zucker: Sure. I did undergrad at Hopkins, did my Medical School at Rutgers, neurosurgical residency at Yukon–finished in '88. Went into private practice, left private practice after a couple of years, did a complex spine fellowship, went back into practice, then decided I wanted to pursue or expand some of the functional neurosurgery I did as a resident, but didn't want to leave practice again, so I found a colleague that was located in Florida and basically every Friday for six months, drove and did DBS (deep brain stimulation) with him, then drove back. So started me down the path of deep brain stimulation, did that for a batch of years. There was a radiologist in our town that bought a focused ultrasound unit from Insightec, and the neurosurgeon that was working with him left, so they came to our program and said, "Would you like to learn how to do focused ultrasound?" so about five years ago, I started into focused ultrasound. Actually, our site was the lead recruiting site for two of the major Parkinson's studies. Now we're doing some low-frequency focused ultrasound. We're opening the blood-brain barrier. Actually, if you've watched 60 Minutes at all in the past year, one of the studies that we're in is the same study that Ali Rezai at West Virginia presented on 60 Minutes. That led me into working with a couple of very interesting companies in brain tractography. The final endpoint is working with a company called Omniscient. A neurosurgeon by the name of Michael Shughrue started that, and it took the human connectome project and mapped it to the

brain and gave us functional connectome. So now we do resting state MRIs, and we see disorders in the brain circuits, and you can take transcranial magnetic stimulation, and you can modulate the circuits. We've started down the road with some interesting things. We do induce neuroplasticity for stroke patients and try and increase their rehab potential or take them if they're plateaued, get them to a better point. I'm starting into some work on concussion patients. This is stuff that our colleagues in China, Australia, Germany are doing. Unfortunately, we're behind in the U.S., and so we made a decision to see what was going on. A lot of our psychiatric colleagues are using TMS for depression, but not mapping the brain. We said patients need access to this technology. We began a clinic. It's unfortunately still off label, but we're staying out of the psychiatric lane. We're not doing any depression or anything like that, but we think it's not taking anything away from the psychiatrist. We think helping rehab stroke patients or concussion patients and trying to see if we can have any effect on Alzheimer's is potentially far more important. So that's what we do.

Dr. Tom Chappell: So, psychiatry Alzheimer's sounds a little more of a diffuse issue, but you're talking about mapping the brain. So are we focusing the electric magnetic radiation in any way?

Zucker: Yes. So whether we use focused ultrasound in the studies or the clinic where we're using TMS, it's exactly that. It is targeted. We are actually finding a site within the brain that–let's use Alzheimer's as an example–there are a few targets within the brain that appear to be majorly affected in the memory circuits, precuneus, a couple of other areas, and we actually stereotypically target. We get a functional MRI. We identify the target, and then we use stereotaxy to actually navigate the TMS to that target.

Chappell: I want to come back to the stereotaxy, but before I do, what are the psychiatrists doing? Are they targeting an area?

Zucker: I guess the best way to say that is some are not. Some are targeting directly. So, they identified the motor strip and they measure forward to the dorsolateral prefrontal cortex, or they use one of the frontal EEG sites. A small handful are starting to truly navigate using specific targets that have been identified, utilizing this new software as being an area that is dysfunctional.

Chappell: That sounds like more superficial sites, but you alluded previously to more deep sites. Are you able to reach those deeper sites with transcranial magnetic?

Zucker: Transcranial magnetic is going to be good from–depending on which one you use–between 2cm and 3 cm. Going much deeper than that, it's either not going to be well-focused or we're going to have to use another energy source, but with the new software that we're using from Omniscient, we're finding that there are a number of cortical targets that are involved in the memory circuits, so they are accessible to TMS.

Chappell: But previously, you alluded to deeper targets for Alzheimer's. Are you reaching those with the magnet?

Zucker: There are two very recent papers that just came out of France that are reaching the deeper targets with TMS.

Chappell: How can they be sure of that?

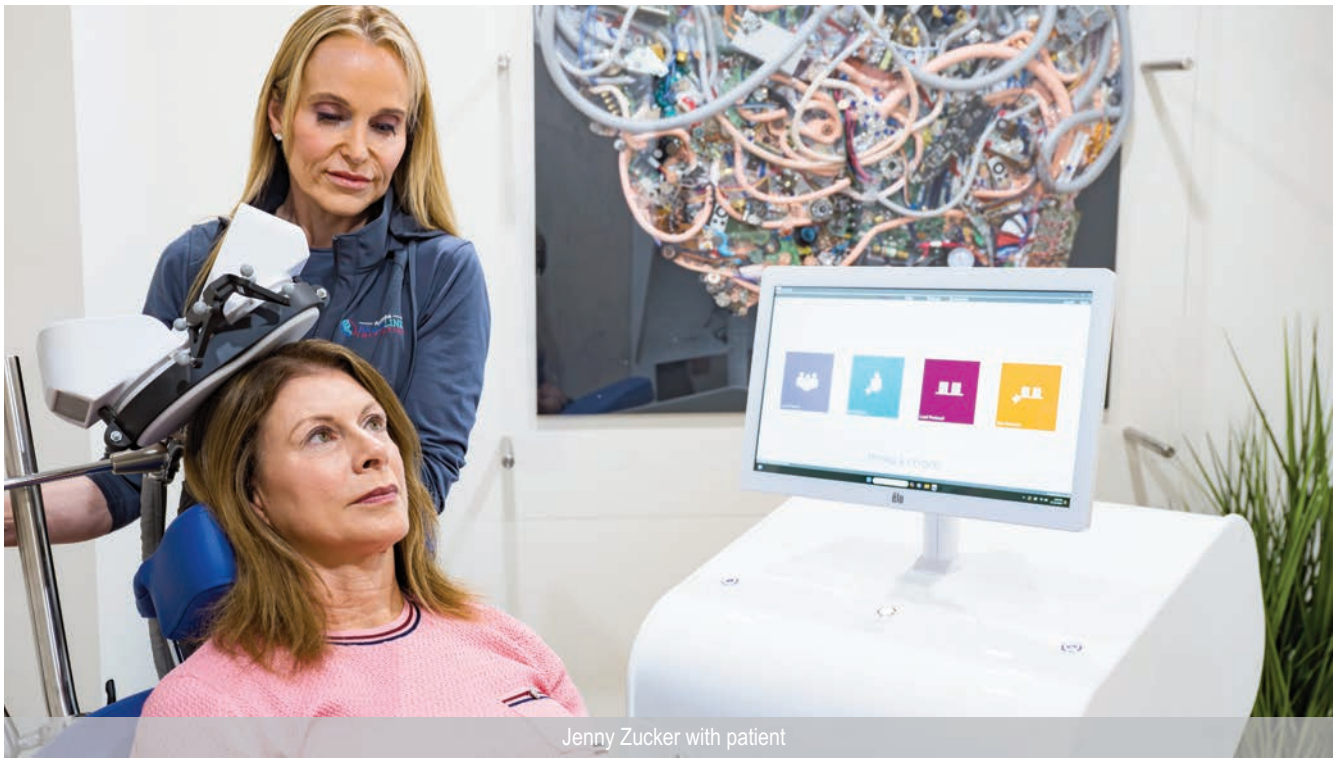
Zucker: Well, they are using an EEG-based system, so they are actually mapping once they stimulate the EEG power and modulating it. I honestly don't have anything other than their recently published paper, as I'm sure you can imagine, they have not let their entire secret sauce out. We're reading a little bit into it, but our software basis and theirs is a little bit different. We're looking at the brain slightly differently than they are. We can look at different nodes or different components of the memory circuit, and some of those are obviously not as deep.

Chappell: Are you able to objectively identify effects of the magnetic radiation? Probably not a good way to call it, the magnetic stimulation.

Zucker: Well, when you say objectively, I mean, to me, objectively in the patient–let's say in an Alzheimer's patient–is going to be the same thing that we're doing in our focused ultrasound studies. An MMSC, an ADAS-COG, basically faded memory analysis because I think not using those when those are obviously the basis of what a lot of other studies had been based on wouldn't make sense.

Chappell: So clinical improvement, but it's not any way to, I don't know, use a functional MRI or PET or SPECT or something to see changes in the brain after this treatment? There's no way to do that.

Zucker: Since we are looking at the brain, we are basically doing a functional MRI, but I think differently than the functional MRI that you and I thought of when we were earlier in our practices. Functional MRI then was a task-based MRI. Basically, tap a finger, look at a picture, do whatever, and look at the bold signal. This is a resting state MRI, and the resting state MRI is looking at the interconnection of all of the different areas. The basic map that it's based on is no longer broadening, it's the human connectome atlas. There's 180 different parcellations in each hemisphere, so 360 total. They've gone ahead and used a machine learning algorithm that basically is looking at all of those areas and can look and figure out. They have a normative group or a nor-



Jenny Zucker with patient

mative atlas that they basically drew from a large group that is in England. They compare to that in any area of the brain that is hypo-connected or hyper-connected, three standard deviations or more outside of the norm is termed anomalous. It can identify how many anomalous connections there are and whether they're hypo or hyper connected. Then that's how we start to develop the targeting because we know what the area is anatomically. Then we get an idea what it is doing physiologically and work to alter it.

Chappell: Those serve as targets, but has anyone or you guys been able to see post-treatment changes in the pre-treatment findings on those studies?

Zucker: Well, the post-treatment changes can be viewed as changes in the network maps that we have gotten pre and post. I guess you'd call it anatomic or physiologic changes as a result of the treatment, but It depends on what you're terming the "physiologic change," because if the resting state MRI has changed, by definition, theres been a physiologic alteration.

Chappell: What stereotaxy technique do you use? How are you focusing this?

Zucker: Well, The stereotaxy outwardly is the same stereotaxy that you and I use in the OR. It's a frameless stereotactic unit. A MRI is taken of the patient–the target that we've identified on the MRI is developed from the patient's own MRI. When the patient is placed in the TMS chair, then the marker is attached to the forehead, just like we would in the OR or somewhere else, so there's a stable point of fixation. The outside of the skull is or skin is traced or identified by an infrared or laser scan. It is co-registered to the MRI. Then you have basically the stereotactic camera. So the head's basically stereotactic space.

Chappell: Yeah, and then you have a magnetic generator of some sort that's able to focus on that.

Zucker: Yeah, it's a figure eight coil, so it's not as finely focused. I do DBS, and I do focused ultrasound. I can tell you the DBS–when I do subthalamic nucleus, obviously, I'm dropping it into something that's 4 millimeters wide and about 7 millimeters deep. The accuracy in the RSC or the spill of the TMS is not quite as good as that, but the energy field itself can be demonstrated. So, you can see where the zone of the highest intensity is and then it drops off like isodose curves on radiation.

Chappell: So you're actually reaching those depths then with the transcranial magnetic device?

Zucker: Again, we're not going for a brainstorm. We're going cortical and just subcortical. To us, the power that you would have to generate to go deep, which is possible, might have deleterious or, let's say, unpredictable effects at that cortical mantle.

Chappell: Just a strange thought here, and I know we want for this to be non-invasive if possible, but would it be of any benefit, do you think, just with your familiarity with magnetic stimulation, to do it through a bur hole?

Zucker: The interesting thing is the degree of absorption

of the skull of the TMS is actually not that bad. Focused ultrasound, the degree of absorption by the skull is actually significant. And since ultrasound in a lot of situations can't be directly transmitted, you need a conductive thing. So, in what we do, the head is actually in a water bath. There are other things. There are certain gels that are being used, and one device, actually, they do a craniectomy and implant the transducer in the place of the bone that's removed. But as you said, you're getting progressively more invasive.

Chappell: I wonder to what extent the Europeans even have been able to do this, but has anybody been able to correlate clinical improvement with any objective change in your mapping?

Zucker: Actually, some of the most in-depth work is coming out of China. Interestingly, I found out through some people that I've been working with in this arena, a two-tier system, even in China, of medicine. There's this medical city that is a whole holistic, but within this is TMS as well, where they pay $80,000. Basically, it's like this holistic Mayo clinic, but they have been doing work in strokes, work in mental health, and they are quantifying outcomes. The group in France with Alzheimer's is quantifying outcomes. You're going to start to see a lot more in the neuromodulation arena, I think, in general, because it's really bursting onto the scene from a neurosurgical point of view. Prior to this, as you know, it was really in the hands of psychiatrists. They were obviously having effects in treatment-resistant depression, but thankfully, they weren't trying to do anything else out of their lane. And it leaves a lot for us to explore.

Chappell: How do you feel about the scientific rigor in some of those settings, such as the Chinese medical city, where you have to pay to get in?

Zucker: Well, I've looked at two of the studies that have come out of there, and at least outwardly, placebo-controlled, randomized, blinded study. So outwardly looks well-designed. Obviously it would need to be scrutinized further, but it wasn't a single arm, it wasn't open label, so they're doing it the right way to certainly try and make data that makes sense. I think you and I both know the next step is it reproducible by groups other than theirs, but they are certainly doing that. The groups in Australia have been a little bit more loosey-goosey about it. The group in Germany is doing it the right way as well. I think you're going to see more and more well-designed studies that are making it into press. The French paper on Alzheimer's last year, I think, was published in Brain. Obviously, if we're getting into peer-reviewed major journals. I think the trick there, I think both of us would agree, is it needs to make it into a peer-reviewed journal.

Chappell: Yeah, that's what I was getting at. Are the studies out of China peer-reviewed in a good journal like that?

Zucker: The ones out of France are peer-reviewed and have been published. Off the top of my head, I cannot tell you where the Chinese study was published.

Chappell: I know I'm beating a dead horse here, but I want to make sure I'm understanding it clearly. Is it possible or has it been shown that there's correlation between clinical improvement and some objective change on your mapping imaging studies?

Zucker: Well, so if you're saying to me, if I took one of my stroke patients that we've treated and seen a clinical improvement in the patient, measurable improvement, and seeing any change in MRI that I do to map out her circuits, pre and post-treatment? The answer to that question is yes.

Chappell: Okay. That would be, obviously, I guess somewhat helpful. One would then ask–and of course, this is where randomized controlled trials come in–just to make sure that those weren't improvements that the patient might have experienced as a natural course of the disease.

Zucker: I think that is an excellent question. The patient that I'm referencing, this patient was near a two years status post-stroke and had a moderate hemiparesis, but had more of a gait initiative variation issue where she almost described it as having to say she had to think, "I want to move my leg." and moved her leg in that fashion. She used an assistive dog at all times for ambulation. Basically, the only demonstrable thing was a small stroke that was basically called basal ganglia. To me, it was a little bit more deep coronary modula. However, she had some very interesting changes on our omniscient side, so on the RMI, the resting state MRI, we did TMS to three separate cortical targets. We were using what's called theta burst. So, the patient would get basically a series of TMS treatment, so five in one day. Each theta burst treatment would be followed by a period of targeted rehab and then about a half hour of rest. They would do that five times, and they did it every other day for two weeks. At the end of two weeks, she was demonstrably better. I know where your mind is going to go, hopefully. I will tell you, I have seen her at one month and at three months, and her improvements are stable and holding.

Chappell: Do you think there's any effect from just more intensive therapy going on there, more intensive physical therapy?

Zucker: I think initially, that was definitely one of my questions. Although she was in fairly regular therapy anyway. I think ours was more intensive than what she was doing. However, in the interim between treatment



BrainLink staff

and now, and the last time I saw her was about a week ago, the level of intensity of any exercise or therapy has basically been back to what she was normally doing. And so whatever gain she got from that two-week period is holding. The interesting thing is both our group and other groups that are doing this are finding out or are seeing that the changes that are induced by neuromodulation are not transient. I think where Dr. Chappell's questions were going, which are very excellent, is, are we able to demonstrate an underlying anatomic or physiologic change in the brain where something is actually obviously going on or else the changes would not remain.

Chappell: I think you'd agree we would need rigorous controlled studies to be confident that some other effect has not taken place in the course of your treatment.

Zucker: I basically would tell you that the ideal–which would be easy to design but hard to do–is what we did for one of our focused ultrasound studies. Patients had the head frame put on, went into the magnet, and the magnet made noise, and they got no energy. So they basically got a sham treatment.

Chappell: Yeah, and then still getting the therapeutic interventions throughout the day, the physical therapy, et cetera, at the same pace and rate. To have it properly controlled, right?

Zucker: Yeah.

Chappell: Two other questions came to mind. Severity of impairment. So, you think you're going to get as much of an effect, an improvement, relatively speaking, with someone with severe deficits versus less severe deficits?

Zucker: My honest opinion would be no. Our experience when talking to Dr. Sughrue, he has basically said, you can't make a tract where there is none. If a stroke has destroyed a majority of the corticospinal tract, then no, you're not going to get something going. However, if there's corticospinal tract remaining and a cortical anomaly can be demonstrated, our experience so far in patients that we've treated is a few of the ones with the more severe deficits. Although I have been able to demonstrate strength improvement to a physical exam, I would have to say the way I feel about them is I don't think that they have functionally improved to a point where the strength improvement has translated into a function benefit for them.

Chappell: Rang bells of my master's thesis many, many years ago–the debate over the mechanisms of recovery of function after brain damage, whether there's plasticity for new pathways in a higher mammal, or rather, our theory was that there were existing pathways that were dormant and were awakened after an injury. This would be theoretical, of course. Do you have an idea as to what you think is going on at the cellular level?

Zucker: I believe that there's got to be something going

on at the cellular level because I have a hard time understanding how some of these improvements remain stable if there hasn't been. I think you would very much enjoy a book that probably now came out about three months ago. It's called Connectomic Medicine. The author is actually Dr. Sughrue. I think a lot of the very astute questions and curiosities that you're asking and have in terms of how they got to this point and what they think the TMS is doing and how they look at the brain, I think it would fit very interestingly with your original thesis. I think it rests somewhere between the two options that you offered. I don't think pathways are dormant. I think that there are multiple nodes. I think in a very severe deficit, you've basically damaged a major node. If there's been minor nodes that have been damaged, you can potentially push messaging over a pathway that not so much was dormant but wasn't as operational in the functional task that you were of the circuit. And by activating or utilizing that circuit, that may help define what plasticity really is.

Chappell: Yeah, that's exactly along the lines of our thesis. This was many, many years ago. A lot of stuff has been done since then. It begs the question as to whether or not there's an actual distinction between what we're saying there. What is plasticity after all. Back then, we thought of it as the pathways were being regenerated, and as you know, we didn't feel like the central nervous system of a mammal could do that. But anyway, maybe we are still talking about a type of plasticity.

Zucker: Well, and the other thing, I mean, part of this software has been a surgical, stereotypic software because what the contention is, is there's really no such thing as non-eloquent brain. And by being able to map out circuits and understand areas that I think, well, I don't know when you finished your training, but many of us were raised in the world of pseudo-architectural brain. And this area was safe and this area is not, and don't work that way.

Chappell: Yeah. No surprise to me, but I came along about the same time you did.

Zucker: I've said to people, and they find it hard to believe when I say, I'm actually in many ways relearning things about the brain, some which I took for granted and others which I've scratched my head. I think you and I have probably both done operations where we've looked when the patient's woken up in recovery and said, "How the hell?" To be able to unlock it a little bit in advance, especially with the intra-axial brain tumors, makes it a very interesting thing to do.

Chappell: Yeah, let's not go down that pathway today. No, not at all. I guess if we're stimulating with magnets only to a depth of a couple of 3 centimeters, theoretically, we feel like that's still modifying pathways that extend deeper into the brain, I suppose.

Zucker: Absolutely. I think truly, if you grab Connectomic Medicine–it's on Amazon–what it will also give you is a slew of reference experiences, but it really begs that very question that you're asking, do some of these subcortical injuries or subcortical pathways have cortical manifestations or attachments? Obviously, the cell body is where? The cortical mantle. There's some part of the loops got to be there, but it begets, I think, the second question that you would ask me, which I'll ask myself is–does modifying at the cortical level modify the entire circuit?

Chappell: Right. I guess you'd have to almost be assured of that if you've got patients who have clinically improved with deeper lesions and have improved clinically with your treatment.

Zucker: Yeah. How should I say this? I'm an optimistic skeptic. I want to continue doing more because I'd like to try and figure out why they get better. Working with some people at Scripps, which we happen to be lucky enough to have in Palm Beach County that are doing some very interesting things on a biochemical level. I've gone to them with what I'm doing and saying, "What do you think?" They're great bench researchers, and they're like, "We'd love to try and figure this out." I might have some more answers for you in the days to come.

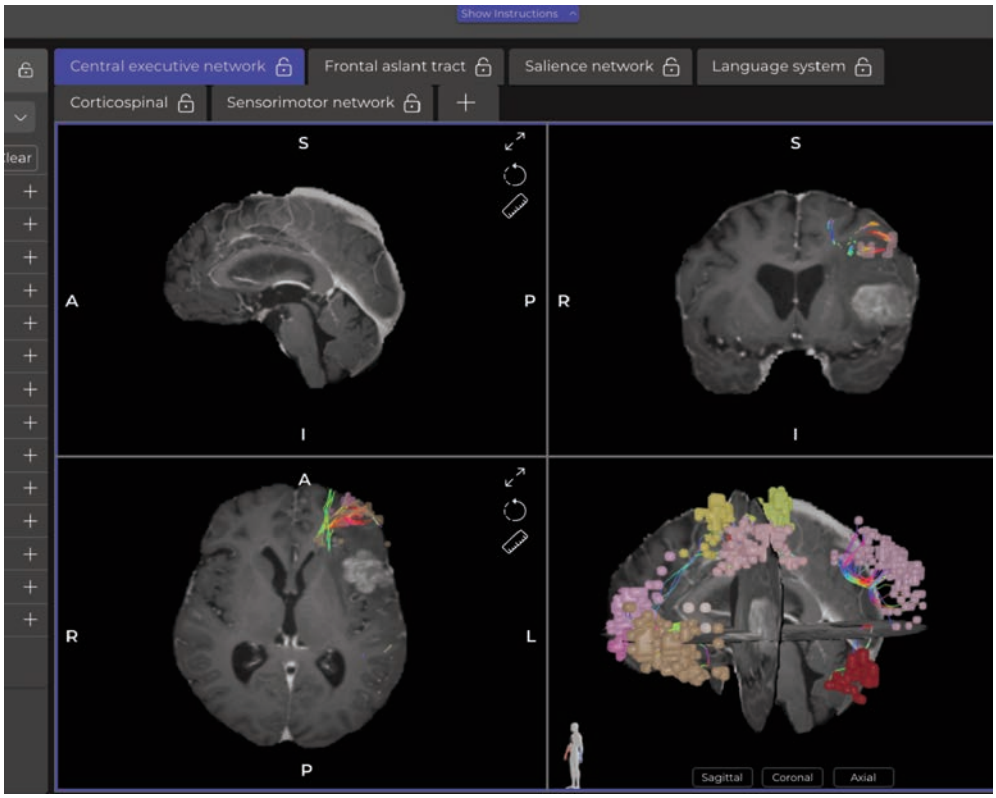
Chappell: Now, that touched on my other question, and that is, is there any role or even possibility for an animal model that would be of some use?

Zucker: After discussions with them, they do have some interesting animal models that I was not aware of, both in lots of arenas, the addiction arena, Parkinson's, you name it. It's one of those things where you get enough people from different arenas in the same room and you start them talking, you can get some very interesting things going. It's a really interesting combination of bench academic research and clinical translation. They're very excited about our willingness to talk to them. Conversely, I'm like, "Wait a second, guys. I'm thrilled that you're willing to talk to us."

Chappell: Look, it's critical, but just occurred to me earlier, what frameless system are you using?

Zucker: The frameless system that we're using with the TMS, it's a company called ANT, but it looks just like what I think you and I would have used in the OR. So it has the camera with three receptors, the adhesive localizer that we put onto the forehead, has three reflectorized balls, just like the Medtronic system. The probe that we use to trace out the calvarium has the three reflectorized balls, so it's literally a slightly smaller but intrinsically the same system that we use on our Medtronic Series 8 in the OR.

Chappell: Also not important, but you may find of some



interest, I was a resident under Bart Guthrie, who, we believe, was the first person to develop a There's some debate about that, but I worked on at least one of the first frameless systems as it was being developed.

Cooper: Let me step in here for a second as a layperson. You work with TMS, but also focused ultrasound. How would you choose what you're doing? Can you say what the difference is for the readers?

Zucker: Two very different modalities. My work in focused ultrasound has been basically two different things. High-frequency focused ultrasound is ablated, so you're actually destroying a small piece of brain. First indication that it was cleared for was unilateral essential tremor. It's now cleared for bilateral essential tremor. Also, we've done work with that for Parkinson's disease, and there's a paper being submitted for publication on an area of the brain called the pallidothalamic tract, which is for Parkinson's disease. Low-frequency focused ultrasound is different. It opens the blood-brain barrier. It has applications in neuro-oncology. It is being looked at at the present point in time for some uses in addiction. There are other areas of brain modulation that are being looked at because the low frequency is not destructive. It just modulates. There's a lot of work going into that. TMS–completely different application. We're looking at it for stroke and concussion, not for movement disorders. And given the work that just came out of France, since we're doing low-frequency focused ultrasound for Alzheimer's, there's a study going on at the present point in time. We may look at some of the applications of TMS in Alzheimer's. So, I have a healthy opinion of what a disability really is…you're allowed to ask why.

Cooper: Well, I actually was trying to avoid that, but go ahead.

Zucker: My dad had polio at age three. He actually ended up with 21 surgeries and a trophic left leg. However, he was ambulatory without braces until he got into his early '70s and had more orthopedic manifestations of his altered gait that became problematic. But he played handball, he played softball. He wasn't mobile like everybody else, but he never let it stand in his way. I learned that for some people, disability is physical, for some people, disability is mental. Or a combination. Not mental as in a disease, but all you had to do is watch the Paralympics, and there were people that had outward physical disabilities that were doing shit that I couldn't even imagine doing.

Cooper: Back to both of the ultrasound and the TMS, they're considered non-invasive, correct?

Zucker: Correct.

Cooper: I had heard you say you were doing something with deep brain stimulation. Isn't that considered always invasive?

Zucker: Yeah, you drill a hole, then you pass something through the brain. So, that falls into the invasive category. In fact, there were people that I saw for essential tremor that when they learned I would be drilling a hole and passing something physically through their brain, they were like "Absolutely not." They have come back and gotten focused ultrasound. And even though I'm passing beams of energy through their brain with the express purpose to destroy a tiny area, the fact that I'm not using a scalpel, not cutting the skin, not drilling a hole, and not leaving something permanently implanted, it is far better received by those patients than the concept of how they define invasiveness.

Cooper: Sure. You talked about MRI and functional MRI. Where does that come from? Is that in your lab? Do you have a facility that actually has that equipment, or is that a hospital nearby that you're working with?

Zucker: Well, I'm at both a freestanding MRI institution and the hospital. These are image sequences that can be done on standard 1.5 and 3 Tesla MRIs. We use a 3 Tesla MRI. Basically, it uses something called fusion tensor imaging, not trying to get too scientific, but it looks at the flow of water through the axons in the brain. There are different ways to interpret that data that allow different levels of what's called tractography or seeing those actual axons within the brain. That's structural. Then you can take it to a functional level, which is what this newest software is doing.

Cooper: So it's measuring water. I always thought it was measuring heat.

Zucker: Actually, no, but when we do focused ultrasound that's ablative, it is generating heat, and the MRI turns into the world's most expensive thermometer.

Chappell: MRI looks at the polar shifts in water molecules?

Zucker: Exactly.

Cooper: I guess maybe because the image is red and all that, they're saying that you can pick up the heat, the slight change.

Chappell: All that colorized stuff you see, that's done with a computer. They tell the computer to colorize certain differences in signal and so forth.

Zucker: That's all artificial. As neurosurgeons, when the MRI era began, we used to joke because everything that was black on a CT, they made white on an MRI and everything. They did this so it would confuse everybody but the radiologists.

Chappell: They played another little trick on us, too. They stood at the foot of the bed and put the right on the left, and we had to stand at the head of the bed and put the right on the right.

Zucker: Yeah. Sorry for all these collegial jokes that are coming out.

Cooper: Now, why the term Brainlink?

Zucker: Well, we were looking for a way to try and explain what we were doing in terms of trying to link brain function and what we were doing together and tried to come up with a host of different names. The one that was the most attractive to all of us was Brainlink.

Cooper: Did you develop the software or did another company develop the software?

Zucker: Actually, a neurosurgeon, Dr. Sughrue. If you go back about 12 or 13 years while he was practicing, and he's still a practicing neurosurgeon, he was working at making what was called the Human Connectome Project, which was really a magnificent endeavor. But once it was finished and we had this connectome map of the brain, nobody was doing anything with it. He's the one that took part of that along with other labs and started linking it to brain function and have developed a much more intricate map of the brain than we ever had before.

Cooper: It was briefly mentioned, but I don't think the question was asked directly. Any thoughts or any work going into creating some clinical trials?

Zucker: Given the fact that a lot of the other things that I do were involved in clinical trials, the answer is yes, we're collecting data prospectively regardless. Clinical trials are usually either investigator initiated or sponsor initiated. The unfortunate part of true IRB (Institutional Review Board) trials is they're expensive, they're hard to design. When you're talking about longitudinal studies, looking at disease that needs to be measured out over a period of time, let's say three or five years, you can see the amount of person power as well as economics tends to be difficult. They're going to get there. It's just taking time.

Cooper: I'm somewhat aware of the challenges of clinical trials. Anything else you would like to add?

Zucker: Well, I appreciated the opportunity to talk. I mean, obviously, this is new and different. We think it has a remarkable potential, and we're only seeing the tip of the iceberg in terms of its applications. We're hopeful that if we can help push the needle and move the science forward, then we've made a contribution.

Cooper: At this point, you're unique in what you're doing in Florida, or are there other facilities similar to what you're doing with the software and the new app application?

Zucker: There is no one else in Florida, to my knowledge, utilizing this software in combination with TMS. There are one or two other sites in Florida that have the software and are using it for surgical navigation, which is the same way we started. That's a hospital-based modality. We're not the only place that has the software, but we are the only place that is applying the software in this fashion.

Cooper: Are the people aware of what you're doing?

Zucker: It's a good question. We intentionally started slowly. We're being very cautious on screening patients and who we take in. The word is certainly getting out, and we're getting more and more inquiries. We're really very–as would be appropriate–result-oriented. We're trying to be very particular in terms of who we choose and how we apply it. You'd love to have the greatest impact

on the most severe limitation outwardly, but that's the best to start I know everyone's different.

Cooper: Knowing that each patient is unique and different, is there a way that you could describe what might be a typical treatment session, number of sessions, amount of time for the treatment, etcetera?

Zucker: I think that the best thing to say that is the treatments are disease-specific. One of my partners is treating tinnitus, and the tinnitus treatments in terms of the length of the treatment and how many treatments different than the stroke treatments. A classical stroke treatment patient is treated for two weeks every other day five sessions each day that they're being treated. The length of the actual physical treatment can range between two and eight minutes. But then with the rehab and the rest period, each one of those is about an hour. Depending on how many targets we treat in the individual patient, they can be in our clinic for 5 to 8 hours on that day.

Chappell: What's he targeting for tinnitus?

Zucker: Well, there's a couple of different ways of looking at it. He's looking at Heschl's gyrus, but there's some other non-directly auditory targets that Dr. Sughrue has developed as well.

Chappell: Any signs of hope there? That's a dilatating condition that I see fairly frequently in my practice now.

Zucker: The hesitation you hear in my voice is that I don't think the direct auditory targeting is going to be the solution, but I don't think there's been enough done in terms of treating the other areas. I can give you some anecdotal successes, but not enough to really say that I think they have the answer. The other thing that I think you may find interesting is one of the targets that's non-auditory is an anxiety target.

Chappell: Very interesting.

Cooper: So, they've mapped some of this in the brain that you can target that specific area?

Zucker: Yeah.

Cooper: Interesting. And what about the psychiatrists? Are they looking and trying this as well? Do they have any outcomes?

Zucker: Most of the psychiatrists are not. They've been doing this for a number of years, and they've been doing it in a way that is not as technology-intensive. I think that's one of the reasons that we didn't march down that road–even though Dr. Sughrue has identified five different targets in terms of between OCD, ADD, major depressive disorder as different sites within the frontal lobe and on a temporal area. The real question that then has to be answered is, does that specificity of targeting translate into better outcomes than what the psychiatrists are already getting? We really didn't want to get into, if you don't mind the vernacular, a pissing contest on whose way of doing it was better because we really didn't want to treat psychiatric disease. There's a whole host of things, especially if you're doing something in a psych patient and they worsen in some way, you really need to be intimately involved with the psychiatric end of things. We felt that there were enough areas like stroke, like tinnitus, like concussion that are woefully underserved that we might be able to have some impact on. So, we didn't go down the psychiatric lane.

Cooper: In concussion, what is it that you map–where the trauma occurred?

Zucker: We're talking about people's convicute and chronic concussion symptoms, that patient where the concussion is not going away. You can show with this software, again, areas of dysfunction. By trying to treat those areas, you can ameliorate some of the "post-concussive symptoms."

Cooper: When you say about the mapping, you're talking about what Dr. Chappell had said earlier about the difference in polar activities?

Zucker: Yeah, basically what an MRI is doing is it's forcing all your protons to align in one direction. Mother nature doesn't like that. They like entropy–disorganization. Then the MRI, basically, you are exposed to a radio wave and all of your protons flip, and as they flip back into a disorganized state–it's simplifying it to a point–but basically, the patient becomes a radio transmitter, and there are receivers that receive that signal and computers that interpret that signal. That's how you get the beautiful pictures that you get because things that are in a crystalline lattice–like bone, it ignores the bone–it sees what's inside. That's how it can peer through, and you get all these remarkable pictures that look like an anatomic atlas.

Cooper: I've always challenged that thought of entropy and chaos. I think it's the opposite. I understand what you're saying about the organization when it's pulled some energies, causing some specific alignment for a period of time for using that energy. But I think it goes back to equilibrium, not to chaos.

Zucker: Well, and I don't disagree you, but the equilibrium can be a balance of organization and disorganization. I don't think it's totally disorganized or totally organized. I don't disagree with you. I think your theory explains my brain a lot better than one of the other polar opposites. ■ ABILITY

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Erik WEIHENMAY

Erik Weihenmayer opens his No Barriers podcast with the declaration that it's easy to discuss the successes, but nobody really talks about the struggles, and it's the struggles that help us break through barriers. As of 2023, roughly 370 people have climbed the Seven Summits,which are the highest peaks on each of the seven continents. Erik Weihenmayer is the only blind person to have performed this remarkable feat. Erik was diagnosed with a rare disorder called juvenile retinoschisis, which caused him his entire visual field by the age of 14.

Having an adventurous spirit, Erik took to testing his limits. He first discovered his gift for scaling heights as a teenager when rock climbing in New Hampshire through a summer program with The Carroll Center for the Blind. This led to mastering the physical and intellectual demands of white water rafting, skiing, paragliding, and mountaineering until his consummate triumph of becoming the first blind person to climb Mount Everest in May 2001. Since then, only 3 other blind people have climbed Chomolungma, the "Goddess Mother of the World."

Now a family man, entrepreneur, and podcaster, Erik's latest mission is to bring his message of limitless vistas through his No Barriers podcast and foundation. *ABILITY Magazin*e's Gina Velasquez and Jennifer Woodall, along with friend of the magazine Jonathan Kratter, joined Weihenmayer in a virtual interview to discuss Erik's No Barriers philosophy of empowering the disability community to reimagine its definition of success. With a rousing call to support each other, dream together, and solve problems together.

Gina Velasquez: Hello Erik. Nice to meet you.

Erik Weihenmayer: Good morning, Nice to meet you guys.


CAMP



7 Summits denali summit

Velasquez: I'm very excited about speaking with you because I'm also blind. I went completely blind about two years ago, but I've had diminishing vision for about 20 years.

Weihenmayer: You just went completely blind a couple years ago. Wow.

Velasquez: As background, Jonathan who is also on this call, just climbed Mount Kilimanjaro, and he's also been my guide. We go for very long walks here in New York City.

Weihenmayer: You walk on the high line?

Jonathan Kratter: No, we don't go on the high line. We live in Queens. We used to take walks across the 59th Street Bridge into Central Park and then walked two loops around the park. Then we walked home. But it's become dangerous getting across the bridge now. There's a lot of electronic bikes and things like that moving at very high speeds. There's very little clearance between the people on the bikes. It's kind of a shared path. I've become uncomfortable going across it, so we go into Brooklyn instead. We walk down to the Brooklyn Navy Yard from queens and back, things like that.

Velasquez: That's how I get my exercise.

Weihenmayer: Well, my exercise is I go out climbing whenever I can get a day off of emails and fundraising for No Barriers and all that stuff. I'm out mostly climbing. I was out climbing at a beautiful canyon yesterday called El Dorado Canyon. It's about 20 minutes north of here and it's about an hour hike uphill. You might climb 400 or 500 feet of different rock faces, and you come back down the mountain by walking down. We actually had to stomp across a creek that was about knee deep, and popped out at the road. We got home about 5 o'clock. I'm climbing all the time–training. I'll be like, "I'm working today, I'm climbing and biking tomorrow with a friend, work, climbing Wednesday, working Thursday and Friday." So usually it's just this combo. Then in the winter I ski and climb frozen waterfalls, so I train for that, and then I do the boring stuff. I have a home gym, actually I have a home rock.

Velasquez: From what I've read about you, you went blind when you were 14, and obviously all of these athletic feats, these successes, that you accomplished all happened afterwards. What was the process of losing all your vision and then having the courage to then go on to climb the seven summits and all the other things you've done?

Weihenmayer: Well, my dad, he was a football player, and when I was a little kid, he had a little football that he was waving in front of my face, and he noticed my eyes weren't really tracking this football. That led to a bunch of doctor visits all around the country. Nobody could diagnose it. Eventually, I went off to Boston to retina associates. They said, "Yes, it's a retinal disease.

It's called juvenile retinoschisis." The way I describe it is there's high pressure in your eyes, and it hemorrhages the retinas away from the retinal walls, so I was losing bits and pieces of my sight, mostly through middle school. They said I would be blind by the time I was an early teenager. There was no cure. I went totally blind about a week before my freshman year in high school. I remember I was in my grandparent's house in Florida, and I thought to myself, "I don't know how I'm gonna get home. How am I going to fly home? I can't see." So, I just hung onto my brother's shirt, and he just allowed me to do that because my family all knew I was going blind. I was the only one kind of half in denial. I was this stubborn kid. I didn't want anything to do with blindness. You know, the typical story.

Velasquez: I think yes, it' was probably partly because you were a kid, but going blind is an incredibly hard thing for anybody to accept at any age, right? The reality that you will never see again is hard to fathom as a concept. Intellectually, the way it affects the psyche is overwhelming.

Weihenmayer: It overwhelms the mind. So, I was just in denial. I would try to ride my bike, and I would run around with friends. I wasn't really supposed to do a lot of physical activity because I had weak retinas. If I got banged on the head, I'd go blind faster, so I wasn't able to do any contact sports. But ironically, once I was blind, the gloves were off. I could do anything. There was nothing else to lose. That's when I joined the wrestling team and those guys–I remember tapping my cane down the hallway towards that stinky, musty wrestling room and signing up and going to tryouts and getting just pummeled. The captain would throw everyone down and pin them in quick succession. I absolutely loved it because they didn't baby me or anything. They slammed my face into the mat like every other freshman. I loved it, and that became my family. I think in a way, that pulled me out of my self-absorption. I was part of a team where the team was more important than me being blind. It was something bigger than me and blindness, and I could contribute. I could put myself forward into that mission. So, yeah, wrestling really was huge, and that helped me find a place for blindness. I'd been really frustrated and angry. I didn't want people to look down on me. I wanted to be part of the group. Middle schoolers are very tribal, and I wanted to be in the group. I wanted to be in the food fights. I wanted to be in the jokes and not on the sidelines, listening to life go by. People not knowing how to deal with me and pitying me was heavy on my mind. I also wanted a life of adventure, and I didn't know how I would ever get that. I just saw a brick wall and couldn't see through it. I didn't know how I would achieve anything I thought I wanted in my life. That was a hard, frustrating time for several years.

Velasquez: So how did you break into the extreme sports, though?

Weihenmayer: Well, I could barely see out of one eye in 8th grade, and I used to still watch tv. I could press my nose right up against the screen and I could see just enough. I was watching this guy on a show called That's incredible. His name was Terry Fox. You know Terry?

Velasquez: No. But I remember the show, That's Incredible. My God, that was years ago.

Weihenmayer: Yeah. Terry Fox was a Canadian who lost a leg to cancer, and out of the hospital, decided to run across Canada. He had watched kids younger than him die of cancer. Instead of allowing that tragedy to crush him and deflate him, he said, "Hey, man, I'm going to run across Canada to raise awareness for cancer research, and childhood cancers." He started running with this old fashioned prosthetic leg. It was before the Internet. So, you know, at first nobody cared, but then somebody called the next village and said, "There's this guy with a prosthetic leg running through town. He'll be there in about a couple hours." And then there'd be five people greeting him, and then by halfway through the run, there were thousands of people lining the roads as he ran by. Unfortunately, cancer came back and killed him, so he wasn't able to finish that run, but he was an incredible hero in Canada. He encouraged and inspired the entire nation to realize that when tough things happen, you don't have to shrink and get smaller and hide in a dark room. You can get bigger. It can give you energy. It can give you a sense of purpose. So I thought that's a cooler way to react to going blind. Instead of sitting in my dark room reading a book on tape. Although I do like audiobooks.

Velasquez: Oh, me too.

Weihenmayer: So that inspired me, and my brothers and dad all being athletes inspired me because I also wanted to be an athlete. I received a newsletter in braille from this organization, the Carroll center for the Blind out of Newton, Massachusetts. They had a recreational program at the time. I don't think they have it anymore, but they had it for a long time. They took us horseback riding, sailing, canoeing and tandem bike riding. One weekend they took us rock climbing in New Hampshire, and I got exposed to rock climbing. I was a wrestler, so I was a skinny little physical kid. I just love problem solving my way up the rock face, feeling and scanning my hands up the rock, my hands and feet as my eyes, trying to figure out how to get from point A to point B to point C. It was just so dynamic and energizing and engaging, you know? So, when I got up to the top about 100 feet up, I sat on this little ledge. I could hear the valley below me. It was fall, and the wind was blowing. The leaves were all scattered and blown across the valley, and I remember there was a chainsaw going way off in the distance, like maybe they were building a hotel or something. I could hear the valley below me and I just thought, "Wow, this is the adventure I thought I'd lost. Maybe I didn't lose it. Maybe I can still do this stuff." It



Erik with Whoopi Goldberg and his dog Uri

was a good lesson for me because I realized that I wasn't going to rock climb like the sighted kid next to me, I was going to feel my way up the face with my hands and feet as my eyes, so I thought maybe I can apply this to other things in life–maybe I should start actually using my cane, and I should start learning braille. I should take it seriously, and I should use a computer with a voice synthesizer so I can type my essays and read them in braille in class. read them out loud. I was still part of the group, part of the crowd. I could read that essay, or that poem in braille in class. I could stand up like everyone else and read out loud, but not with my eyes, but with my fingers. I realized that those skills, those tools of blindness that I thought would make me stand out like a sore thumb, actually brought me back to the world.

Velasquez: This was all in high school still?

Weihenmayer: Yeah.

Velasquez: Wow. I can see how the seeds were sown then for these other things you've done. So, my friend Jonathan is a bit of a climber as well.

Kratter: I don't really do it as much anymore, but in my twenties and thirties I did a lot of rock climbing.

Weihenmayer: Nice. Where would you go? To The Gunks?

Kratter: The Gunks is my primary place, but I did sport climbing on Cayman Brac. I've gone out to the Dakotas. I've gone out to Otter Cliff in Maine, and some other places. I also fell in love with rock climbing, so I have some perspective on the thought of being up at the top of a ledge and sitting down and listening to the valley. I assume you didn't start with lead climbing, but you probably do lead climbing now. Man, putting pieces in the wall and knowing how to trust them is an amazing concept. The thought of not being able to see the route to plan it, but feeling your way as you go is just remarkable to me. I want to add that I've been to base camp up in Everest, and I've looked at the Khumbu Icefall. I was terrified to traverse it because it's such a risky place to be. Even if everything's right, anything still can happen, but to do it climbing over these ladders and vertical ice walls without being able to see where the next step is is just amazing to me.

Weihenmayer: Yeah, the ice fall was treacherous for sure because yeah, you're right–you can do everything right, but it still has a lot of objective danger. There are a lot of seracs collapsing constantly. Not really avalanches coming right down through the Khumbu Icefall, but there are avalanches all around to the left and to the right. Then there's a lot of a blind person's worst nightmare–zigzagging on snow bridges over crevasses the width of your boot, jumping and stepping from ice boulder to ice boulder, and they're rolling and shifting under your feet. But honestly, it's all about time. The way you minimize the risk in the ice fall is you got to get through it quickly. That was hard for me at first as a blind person. My first trip through the Khumbu Icefall took me 13 hours, which was way too long.

Kratter: The thought of going over that amount of space where to your left and right is a long way down, then making sure you clip into the right ropes. All that stuff is at altitude when it's very hard to think, and I imagine very hard to hear. There has to be an incredible amount of concentration to manage that.

Weihenmayer: I was for sure worried about that too. The idea that in the death zone, wherever that starts–I mean, even at 18,000 feet your body can't really heal itself. You'll get a cut on your thumb and it'll ooze and gush for the whole time. It'll never heal. There's not enough oxygen in the air to heal, but when you get up to, say, 26,000 feet, it's the real death zone and you're actually starting to die. You've got to get to the summit and get down as quickly as you can, so I was worried. A lot of people don't realize how much thinking there is in sport climbing. You're constantly thinking, "Am I too cold? Am I too hot? Am I sweating? Am I tired? Am I moving too quickly? Do I need to slow down? Do I need to speed up? What's the weather doing? If I turned around at this point, could I get down? Do I have enough energy to get down?" You're constantly thinking and thinking and thinking, and if I couldn't think, how was I going to be able to be aware and be safe up there? But as it turns out, I was able to think okay, I was fine. I was thinking and I was assessing. I was good. I had a great, strong summit day.

Kratter: You made it across the Hillary Step no problem?

Weihenmayer: Yeah, no problem. And then at the top, you're taking six breaths between each step, so you're moving really slow.

Velasquez: When was it that you summited?

Weihenmayer: 2001. It's ancient history at this point.

Kratter: I just did Kilimanjaro in early October and it's fresh in my memory. The two steps. Four breaths, two steps. It was the hardest thing I ever did. It was much harder than base camp at Everest. There was a point where I didn't think I was gonna make it. I had to find another gear to get up and really take my mind out of the thoughts that were going through my head of getting down. It was really tough for me, this particular climb.

Weihenmayer: Powering uphill is hard.

Kratter: I don't think people understand how much pain there is along the way. Even little things like going to the bathroom. When you're at 15,000 feet just going to the bathroom is exhausting.

Weihenmayer: Yeah. I was on a peak called Cotopaxi, which is an almost 20,000 foot peak in Ecuador. I was on this very steep, snowy peak, and sorry to be gross, but I had to go to the bathroom. You're squatting down in the snow and the wind's hammering down the mountain and you're like, this is not fun.

Velasquez: The thing that I really hooked on was how you open your No Barriers podcast. You open with this statement saying "It's easy to discuss the successes, but nobody really talks about the struggles, and it's the struggles that help us break through barriers." Something along those lines.

Weihenmayer: There's a lot of pain to do this. People think about the fun stuff–the success stuff. They don't think about the pain along the way and the failure. So, that's what I talk about. It's not that I think we should get all myopic and self-absorbed, but people sharing challenges and saying, "Hey, we're part of a club of struggle and it's fine. We're not going to be victims in that struggle, but we can turn that struggle into a narrative that powers and fuels, and to a point where we say, I'm not embarrassed by blindness at all. In fact, I'm proud of it."

Velasquez: Yes, I wholeheartedly agree with you. It took me a while to get there, but thankfully I'm there now.

Weihenmayer: I'm proud of the things I've overcome to live this life as a blind person. It gives me pride and confidence that I survived and flourished despite it all. I think that's a fun club to be in. It's fun to be able to share the experience with people and then talk about the process of going up the mountain metaphorically. How do you go through that uncertain, messy, and murky terrain between base camp and the summit? Let's diagnose what that map looks like so more people can get there.

Velasquez: The thing for me was that I became blind as a much older adult. It started in my 40s. I'm 60 now. What I've been encountering are other older adults who are going blind, and they're still in that hard process of accepting it. Sometimes you want to pass as sighted. It's a mental barrier you have to climb and get out of. Young people, of course, need the mentoring, but I think that older people who lose vision don't have enough support or services.



Erik ice climbing

Weihenmayer: Agreed 100%. I mean, I don't know when's the best time to go blind, but to be honest, I think it does get a lot harder as we get older because we're locked into patterns and habits and things. There are more psychological reasons for you to say, "I once was this, and now I'm not." I have been lucky to not compare notes, to not say, "Hey, that was easy when I could see," because that thinking just brings you to a dead end. Where do you go with that? I prefer to think about the things that can bring you to new places.

Velasquez: I'm thinking particularly of a couple of people I know who are still struggling to get there. I know they will and it's a process, and everyone has their own timeline, but that's what I'm hoping for them, that your message and your podcast helps them see that there's a path out.

Weihenmayer: I heard a speech one time from this blind guy, and I've totally stolen his words, word for word, because he said, and I'm paraphrasing, he said, "I can deal with going blind and not seeing, but the real fear is being shoved to the sidelines into this dark place. To be left there and be forgotten." I've verbatim said that to people because that's exactly how I feel. I could deal with not seeing–although I miss seeing sunsets and beautiful paintings and things like that. I was a very visual person, so I missed that stuff–but the real pain was the idea of missing out in life. So now you're with a disability, and you're shoved into this prison. You partly put yourself there and society's partly put you there, and you don't know how to get out, so a lot of my life's work has been to help people find a way out.

Velasquez: Could you speak about that? I know No Barriers is a podcast, but it's also an organization, and you have all sorts of events and programs.

Weihenmayer: Yeah, we help build a mindset in people. We call it a "No Barriers" mindset. I guess it's kind of a resilience thing. It's like, "Okay, this bad thing happened to me, this tough thing happened to me. I have a disadvantageous or even an invisible barrier in my life. How do I transition into a new identity? How do I adapt into becoming a new person with new goals and so forth, really new habits, new ways of interacting and connecting with the world?" All of this flows from your mindset. So at No Barriers, we've focused on building that mindset. We have all kinds of activities, experiences, and programs that hopefully take people from

one place to another. At the end of the programs, we have people take what I call a “No Barriers pledge.” It's “What are you going to do with this experience now?” It’s really powerful to see people out of the program. It's, “I'm going to run a marathon,” “I'm going to climb Kilimanjaro,” I think was one of them. “I'm going to lose 50 pounds.” “I'm going to walk with my spouse every night.” “I'm going to volunteer at my kid’s school that I didn't think I could do.” “I'm going to ride a horse that I didn't think I could do.” “I'm going to get off painkillers. “I'm going to write a book.” “I'm going to start a nonprofit.” “I'm going to start a business.” It goes on and on. The pledges help people flesh it out. That's been fun. And yes, the podcast is an extension of that organization. It brings in people who exhibit the No Barriers mindset in all shapes and forms. They don't have to be blind. They can be any disability under the sun, or even a scientist, or an able bodied person who's struggling with things like aging. I interviewed Diana Nyad, who in 2013 swam 110 miles from Cuba to the Florida Keys in her sixties. But first she failed maybe five times. I think there's a lot to learn in these stories that can help us break through our own barriers.

Kratter: I was just thinking about when Gina lost her vision completely. How before that we used to take a lot of long walks. We did 20 mile walks and things like that, but then it was just a struggle for her to get going again, and I was thinking about what she overcame just to do these walks. We had to change how we do it. We had to adapt the way we walked. We walk attached to each other now, and there are these hidden signals from my arm, things that I do. We built this mechanism, and then one of the things that I thought about was how we've never gone actually hiking, and I've always felt it's scary and dangerous. I saw you using your poles to see the terrain, and you're using a bell and things like that to follow. I'm thinking there's a way for Gina to do a trail like that. There's a way to do an actual hike.

Weihenmayer: That would be a good place to start, or come out to Colorado. We have a What's Your Everest event with our No Barriers organization where we’ll all hike a mountain together, hundreds of people. There's lots of ways to get started. You want to find some trekking poles. My friends will also jingle a bell in front of me, or I just grab the back of their pack. It's slightly awkward because you want something that separates you a little bit from the other person. But that's okay too. That should be a really fun pursuit.

Kratter: Gina's mentioned doing something like that– going back to Acadia National Park.

Weihenmayer: They have those carriage roads in Acadia. Those are really beautiful.

Velasquez: Oh, it's beautiful there. I've been wanting to go back there, but there's been this concern about whether I’ll manage? But you've inspired me.

Weihenmayer: I know we're digressing here, but that's why I think organizations like the National Federation of the Blind should be doing more to get people out into the world. I mean, yes, they have really wonderful advocacy for different issues, like braille literacy and so forth, but they should be taking groups out on field trips and saying, “Okay, there's a fitness crisis within the disability community. Let's take a field trip to a gym and figure out how to navigate this big ass gym? How is it laid out? How does it organize? What do you do if you get disoriented? How do you find the buttons on the treadmill?” All these things are massive barriers to people getting out there and living fully. Sometimes you need a little kickstart, you need a little catalyst, and I don't think we're focusing on that.

Velasquez: Yes. I've never been into weight training, but I like walking and I like things that are more cardio because I have strong legs. I'm from Ecuador, and so I think it's in my genes.

Woodall: Erik, what's your method for lead climbing and putting anchors in without being able to visually assess? What's your method for trusting that you're putting the anchors in a good place?

Weihenmayer: Usually when I lead something, I will top rope at first, meaning I will climb it with a rope above me and then I'll map out all those places where I want to put gear. It’s always exciting to go up and lead something blind, but it's preferable to take a moment to climb it a time or two. Map it out. Map out what they call the cruxes, find the good gear placements and then go back and lead it. When you lead something that you haven't climbed before, they call it “on sighting.” I call it “non sighting.” I've “non sighted” a lot of stuff, but I prefer to go up a time or two and map it out because I just feel so much safer, it’s more sustainable, you know what I mean?

Kratter: You have to have a very good memory to map all that.

Weihenmayer: You’ve got to be a mapper for sure, but like when I climbed El Capitan, I couldn't get 13 or 15 pitches up to map it, so I had to “non site” a lot of it.

Kratter: You ever have a scary lead fall along the way?

Weihenmayer: Yeah. I was learning to lead climb and I put two pieces in. It was three pieces actually. Then the next one was what they call a fixed piece. It was this piece of gear that was stuck in the crack and it seemed really strong, like it wasn't coming out. So, I clipped into it and leaned on it, and it popped out. Then my next piece ripped out and I took a 30 foot fall. My foot hit the ground, but it was rope stretch, so my foot just tapped the ground with rope stretch. Yeah, that terrified me. That was no good. You’ve got to make sure you place it and it stays. Placing gear is really important to make



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climbing safe. I place it with my fingers. I'll put my hand in there. I'll put my finger in there. I have my harness laid out with small cams to big cams. I try to be super organized so I can get to the right piece as quickly as possible. People thought you could lead climb only by looking at the cracks, I found you could do it by feeling them.

Woodall: Do you have a favorite climb?

Weihenmayer: That's a hard one because It's like asking which is the favorite of your kids? With the seven summits, for instance, obviously with Mount Everest, you get the wonderful culture of the Sherpas. They're in the Khumbu Valley below Everest, so you get to be engulfed in this beautiful traditional culture. Aconcagua, the tallest peak in South America, is this dry, deserty, windy kind of place that's got its own challenges and beauty. And then you have in Antarctica, Mount Vinson, which was 40 below zero when I summited. It was this wild palace of ice and snow. Denali is really cold and really physical. Elbrus, the tallest peak in Europe, was a cool peak because it's kind of a big snowy blob. We actually skied down that mountain for about 10,000 feet from summit to base camp. That was a blast, skiing down the mountain. When I did Kilimanjaro, I helped the first blind African get to the summit. He was blown up in the 1998 US embassy bombing in Nairobi. He wanted to climb Kilimanjaro as a statement that peace can prevail over terror, so we put together a trip and we got him and about eight other blind people to the summit. That was really special and powerful, you know what I mean? Each one takes on its own character and identity. So, I didn't answer your question very well.

There's a peak right behind my house. It's a 12,000 foot peak called Chief Mountain. Both of my kids have hiked it multiple times. I had my daughter in my backpack when she was a baby, and then I adopted my son Arjun from Nepal. When he was five, we hiked the peak together. So that one is really beautiful because it reminds me of my family.

Woodall: I have one last question and it's going to be a weird one.

Weihenmayer: Oh, good. I like the weird ones.

Woodall: I have sensory issues with sense of smell that can be really overwhelming, but one thing that I really love is when I go visit my brother in western North Carolina in the Appalachian Mountains. It smells so sweet and clean and earthy. I haven't done a lot of altitude climbing, but while you're climbing up and adjusting altitudes and things like that, do the smells change? Do you notice changes in smell depending on the height you're at?

Weihenmayer: I'll first start by saying, yeah, the sense of smell is the most powerful thing. Like you, I go down south where my grandparents lived, and there's that beautiful, sulfur-y smell. Then there's all that super flood of vegetation. Rain will also bring out those smells. So, in Colorado when it rains, you're just walking through the forest sniffing away. I probably look like a weirdo.

Woodall: Forests smell so good!

Weihenmayer: So good. It smells so good. A lot of the high mountains are snow, meaning there's not a lot of vegetation. But the way the sun hits actually bakes the snow., and you can smell this baked snow smell. It's cool and smells good. Snow has little pieces of vegetation and little microorganisms–I'm assuming–in it. So, the sun, bakes this stuff and it has this distinct, like rot or vegetation smell, but combined with the snow smell.

Woodall: I lived in Wisconsin for twelve years and I love the smell of snow. That was lowland snow and there aren't a lot of mountains where I lived up in that area was really flat farmlands. The snow had a really metallic smell to it.

Weihenmayer: You know, that's the word I was looking for. That's a good way of describing it. I was struggling to find it. That's the word that describes it. You're right. Metallic. Interesting.

Woodall: Yeah, it's really metallic and it's weird to say, but you can smell how cold it is, right? you can tell the difference when it's a different temperature, and I love that. I have a nostalgic quality attached to the smell of snow. Thanks for answering that, I know it was an oddball question.

Weihenmayer: Sure. By the way, I have a new film. It's called Soundscape, and it's touring throughout Europe right now., It stemmed from a friend of mine that I climbed with. Somebody asked, "If he can't see the mountains, why does he go?" That question stimulated him to create this film. We climbed this huge rock face called the 'Incredible Hulk', and it was a huge day. It was a big five hour hike, a ten hour climb, and maybe a 10 hour descent. It was a 24 hour climb. Anyway, he went into my mind's eye and built all these graphics, all these animations, around, how I see the mountains, and how I put together that map that I was talking about. Piecing together the map through my hands, through my feet, through my ears, through my sense of smell–all the things I use to figure out what I'm doing and the information I need, but also the beauty of the mountains.

Woodall: It's won some awards.

Weihenmayer: Yeah, we put some audio description to it too. Another thing I would add is that I get a lot of attention for doing these crazy things, like kayaking the Grand Canyon, climbing mountains–you know, doing all these things that are really dramatic, and that's good because these wild things I do can help shatter people's perceptions of what's possible so that other people can maybe go forward with more credibility as they think about their own dreams. I just sat in on a book talk and I met this blind guy who was an appellate court judge. I also met a lady who's blind and does all the purchasing for Sam's club. To me those are the people that should be getting more credit–the blind teacher, the blind single mom getting a babysitter for her kids and getting on a bus and going to work every day.

Velasquez: Blind single mom, that was me.

Weihenmayer: Honestly, there needs to be more attention on that because Those are the people I respect. I'm really careful because climbing Mount Everest is one way of celebrating this No Barriers life, but there's a million other ways of celebrating it that are totally different and just as good, or better. I think the world needs no barriers right now. We're so disconnected. Everything's so divisive. I think the world, and especially America right now, needs more communities where people come together. The disability community is a community of people with challenges. We're leaning into each other and saying, "I'm going to lift you up. We're going to support each other. We're going to dream together. We're going to solve problems together. We're not going to be victims. We're not going to sit around waiting for people to plop stuff in our laps. We're going to go out and get it together." I believe in it, and that's what we're trying to do at No Barriers. ■ ABILITY

erikweihenmayer.com

Artist Ella Onyebe
Painting Her Sightsaver/ United Nations Mural

Language comes in many forms. Many may think of it in terms of speech first, then maybe in physicality, but art is a language and an essential part of how we communicate.

In September 2024 the UN and the organization, Sightsavers, revealed four murals in four different cities across the world. They appeared in New York City, USA; Homa Bay, Kenya; Dakar, Senegal and in Abuja, Nigeria. Each mural communicates the importance of supporting youth advocacy in disability rights.

Artist Ella Onyebe designed and painted the mural in Abuja, Nigera. In her eyes, "The mural demands inclusion and global decision making." She stated, "That message from Sightsavers and from young people with disabilities is what I was able to express through the patterns. I love to work with patterns and colors, and I have been able to create a style for myself so that I can speak to the world with my art. With this project, I was able to take my style and combine it with the work that Sightsavers does."

Sightsavers is an organization that works to reduce stoppable vision-related diseases and tropical illnesses in Africa and Asia, but that also aims to build a more inclusive and equitable world for people with disabilities.

With the support of Sightavers, Onyebe created a piece with rich colors and bold designs, despite the obstacles that arose. In describing the process, Onyebe said, "The work started long before the sketch. That took almost two or three months. I started talking about it with the Sightsavers team and they were able to guide me on how to do the work and how to accomplish the message. The painting part took me almost two weeks and there were a lot of challenges. We had water problems because the mural was under a bridge and the water kept dropping onto the work I had done. The water came full force."

Still, Onyebe found it to be an immensely impactful process: "It was a beautiful, beautiful experience. It took a lot, and I was able to show every side of my emotions. There were moments I felt angry, happy, sad and they all came together into this wonderful mural to make young people with disabilities proud."

Onyebe describes being hard-of-hearing: "You want to sit down and communicate with your friends and family, but even if you're talking and they understand what you're saying, how would you feel if you couldn't hear them? I have a hearing aid now, but it was too expensive for me to get one especially with the level it needed to be for my hearing. During that time, I would just be silent. I'm always in my room, even in a big house. My mom knows how I feel when I'm alone and she pulls me back to my family so that they can always be around to make me feel happy. She tries to help lighten the weight of what I'm going through. It helped when I was struggling."





Onyebe found solace through her art. "The very fact I found my way to art makes me cry. I'm where I want to be. It's a therapy for me because I'm able to express myself. I'm always in my happy place when I'm painting."

Art can foster communication and connection, even when it feels difficult. The process alone is a way to communicate because it is, fundamentally, an expression of oneself. Isn't that what language is? The form through which we express our truths and build connection? Onyebe stated, "I work from my instincts. I bring work down from my head to the canvas and sometimes I may not be able to express things in words, so I draw."

For her it has been transformative: "I've been able to heal my depression because I know what to do when I feel down. I try to talk to people and to other artists who are completely deaf and who communicate through writing or who read my lips. Some had hearing before, so they read lips and that's how they listen to you when you're talking. I know a little bit of sign language too and I try to encourage them to do art. I've also had the opportunity to train a few people. I teach them how to paint and I notice they're always excited when they come to learn."



Onyebe also taught art to children with and without disabilities at a carnival event in Abuja. "They got so happy. I love to see that excitement on their faces. They didn't want to leave the venue. According to what a few of the children's sisters told me, they had never seen anything like it before. They said 'Please, do this again.' We invited students from special needs schools and from schools for the deaf. It was an event to celebrate young children. It's something I want to do, maybe; go city to city and train young children to do art. So that we have a network where the kids can grow up to be great artists."

Onyebe stated that: "Young people with disabilities also have dreams they want to achieve through art or whatever means they can. I am hoping that more global leaders will be able to put in more effort concerning young people with disabilities. They need to encourage organizations like Sightsavers and put in more effort in order to get all these young people with disabilities to be active, have jobs and opportunities. There are some people who have multiple disabilities. You can imagine what that child is going through. If world leaders can come together to make it easier for every person with a disability, it will reduce pain, trouble and depression. I encourage the leaders around the world to support and to help."

When there are obstacles to communicating, it is essential to find other ways to allow for connection. Even when we have differences, art can be a profound way to lessen the divide. Giving young people with disabilities the opportunity to express themselves through art creates connection between us all and builds a more inclusive world. Maybe something we can each do on a daily basis is to support the young artists with disabilities around us. ■ ABILITY

by Olivia Austin

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According to a Bureau of Labor Statistics report released on February 22nd, 2024, only 22.5% of people with a disability were employed in 2023. Comparing that to the CDC which reports 1 in 4–or more than 70 million people in the US–identify as having a disability, we as a nation are looking at over a whopping 54 million members of the disability community that are unemployed. The undertaking of increasing employment rates for the disabled community is daunting, sure–but not impossible.

ABILITY Magazine's Jennifer Woodall met with the Department of Labor's Assistant Secretary of Labor for Disability Employment Policy Taryn Mackenzie Williams to discuss the innerworkings of the department, programs in place that offer support to employer and employee alike to foster more accessible and inclusive workplaces for members of the disability community, and how we can strive as a nation to increase employment numbers.

Jennifer Woodall: Hello! Can you give a bit of background on how you came to be Assistant Secretary of Labor for Disability Employment Policy?



Taryn Mackenzie Williams during women's mental health event

Taryn Mackenzie Williams: Sure. Like many, I could say that my career path has not been linear. I got my start in education policy, working for nonprofits in Chicago and in DC, and then had the opportunity, going back almost 15 years ago, to join ODEP, or the Office of Disability Employment Policy, as a policy advisor on the youth team. It was really well aligned with the work that I was doing at my education nonprofit, but it also gave me an opportunity to really focus on the unique needs and also the challenges that youth and young adults with disabilities face when entering post-secondary education and employment. I spent many years at ODEP wearing a variety of hats, getting to know all of our teams and our colleagues here in the agency and across the department. Then, I departed to go work for a nonprofit, focus on poverty issues, including those that impact the disability community, and economic security, or truly, economic insecurity overall in our workforce. Then a couple of years ago, it was tapped to back into this role and was honored to be nominated and hit the ground running in August of 2021.

Woodall: Can you give me a little bit of behind the scenes of what it's like being involved in the Department of Labor–a day in the life?

Williams: Oh, yeah. That is a great question. So, I just shared that I've been with the Department altogether across Boston for 15 years, so I have a pretty comprehensive view of what it's like. I will start by saying that at the US Department of Labor, we are about 15,000 strong. There are a variety of agencies that are located not just here in the National Capital region, but also across the country. We share a mission of wanting to protect and serve America's workforce, including ensuring that job seekers have opportunities for employment, ensuring that employers and employees alike are equipped with the knowledge and the supports they need to go to work and be economically secure and safe on the job and to be able to retire safely. For us as an agency, so much of the work or the behind the scenes is about collaboration; collaborating with the other agencies across the Department whose work– and by work, I mean their investments, their enforcement activities, the technical assistance that they provide, ensuring that people with disabilities, our community– is represented in that work, and that we are not adopting policies or practices that could have the unintended consequence of further entrenching barriers that exist for people with disabilities. So, lots of meetings, to be candid, but also opportunities to get our word out, lots of speaking, being able to liaise with colleagues not only within the Department, but also across the federal

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Taryn Mackenzie Williams

government. You can't talk about disability employment–frankly, you can't talk about America's workforce–without consideration for their health, for transportation–which is critical for accessing the job–for education, and all of the tools that we need in order to be equipped to move into the workforce. I'd say liaising across the Department, but also across a broader federal government, always with the goal of supporting America's workforce and making sure we're looking for opportunities to collaborate and to fill in the gaps that might exist in our programs and systems. No day is the same as the previous one, and I love it.

Woodall: Great. Can you talk about some of the initiatives in place related to disability employment within the Department of Labor?

Williams: Sure. If it's helpful, I'll start by giving a little bit of an overview of ODEP and how we work, because I think that really provides a foundation for understanding what we do and how we approach our work as an agency. ODEP is a small, non-regulatory agency. We were created a little more than 20 years ago by Congress with the goal of working across systems, policies, and agencies with that explicit goal of increasing employment opportunities or increasing workplace inclusion for people with disabilities. Because we are not a regulatory agency, so much of what we do is about collaboration, so much of who we are, frankly, is our subject matter experts that we have on staff who bring a wealth of experience in the policy arenas that intersect with disability employment. Leveraging their skills and their knowledge and their commitment to our mission. That happens in a lot of different ways. We do research. We have statisticians and economists on staff who work closely with statistical agencies to better understand what's happening in the workforce for job seekers and employees with disabilities or workers with disabilities. We provide technical assistance. We do that to individuals that can come in the form of our Job Accommodations Network (JAN), which provides free, confidential, one-on-one assistance to job seekers, employers, or employees about reasonable accommodations. We also provide quite a bit of technical assistance to employers and all levels of government. That is where I think it's important to note, again, that our name ODEP, it's really the policy that we're focused on. What changes in policy can be adopted or what changes would we recommend in order to create an environment where people with disabilities can be successful? We have a lot of priorities, probably more that I could talk about in just this session, but I did want to talk about something that is important to us, not only as an agency, but also as a department, and that is our

work around the Good Jobs Initiative. As a department, we've understood that there are historic investments being made in communities all across the country right now. Many of those investments flow from the legislation that was passed¬–speaking of the Inflation Reduction Act, the IIJA (Infrastructure Investment and Jobs Act)–that's creating jobs in communities everywhere. Our desire is to ensure that the jobs that are being created are good jobs, that individuals are earning family-sustaining wages that allow them to thrive in their communities. In my belief, people should be able to learn, earn, thrive, and be independent in their communities, so when we think about those investments, we want to make sure that it's not just about the new projects, the new construction projects–many of which have gotten started–but in fact, what are the job opportunities that are being created? How do we ensure that those job opportunities go to people with disabilities? We spend a lot of time working with colleagues here within the Department, developing resources for communities, but also working with our partner federal agencies like the Department of Commerce, or the Department of Transportation so as those funds flow out into the communities, they know what they can do to ensure that people with disabilities will have access to those jobs. Right at the end of Disability Pride month, we release something we call our Good Jobs Toolkit, and that's exactly what it is. It's a toolkit meant to provide concrete resources for how people with disabilities and organizations that work to advance disability employment are equipped to tap into those opportunities that are just being created now, but really will help to transform the workforce over years. Infrastructure, as we know, it doesn't just happen in a day. It's not just the awarding, it's all of the jobs that come after that. So that's one example.

Woodall: You mentioned the Job Accommodation Network. Can you go into a little more detail about that and how someone might be able to access that?

Williams: Yeah, that is a great question. A lot of our work is focused on employers, ensuring that they have resources that will help make their workplaces inclusive, that will help them at every part in the life cycle of employment, so what are the tools or practices that they should be advancing when they're recruiting, hiring, retaining, and critically advancing people with disabilities? We know that across all of that life cycle, reasonable accommodations plays a critical role, and it's not just for employers, of course. It's for individuals with disabilities themselves. It's for the job seekers who are applying for jobs. It's for those employees who might acquire a disability on the job, maybe a temporary disability or a permanent disability that leads to a need for reasonable accommodations. That is where our Job Accommodation Network comes in. It is a technical assistance center. It can be accessed at askjan.org–that is the website–but you can call them, you can text them, you can reach them in a number of ways and receive that confidential assistance. As a person with a non-apparent disability, going back maybe a decade ago, I learned that I had acquired a secondary disability of arthritis. I was starting to think through, what would this look like? I thought I knew what it looked like. I thought maybe I would need a different type of chair or I needed to think about my workspace, but as can be the case when someone has acquired a disability, I had a lot of questions and maybe struggled a bit to get to the answers. JAN is a resource that helped me. I know about it because I worked here. I knew about it because I had used it before, and one of the resources that they have is an online searchable database. You can search by a condition. You can search by your understanding of symptoms and/or barriers that you're facing in the workplace, and they'll help you think through what could work in your workplace. They provide scenarios. They also do training for employers. They have, I would say, decades of experience and expertise built from the inquiries that they receive on a daily basis, and that is a service that we provide to the public. I truly–as someone who's used it as an employee, someone who's used it as a manager–I cannot say enough about JAN.

Woodall: In your opinion, where do we succeed as a nation when it comes to disability support in the workforce?

Williams: I would have to go back to the ADA to talk about where we are. We celebrated the 34th anniversary of the ADA, and oftentimes, as I think about it, we have seen a transformation in the physical infrastructure of this country. The ADA quite literally opened doors, created curb cuts, allowed people with disabilities to finally access institutions in the community in a way that they absolutely could not before advocates were successful in getting that passed. I think of disability employment as the unfinished business of the ADA. I know I'm not alone in that. It's a term that is often used when we talk about disability employment. I see positive signs. In the last several months, we started to see a narrowing of the gap that exists between people with disabilities and people without disabilities in the workforce. But even with the narrowing of that gap, there's still a gap that persists, and there are still opportunities for people with disabilities to be more fully included. I think our understanding that people with disabilities are an untapped resource often, and that they can be tapped and bring creativity and innovation into the workforce is an important one to note. As we are represented in the workforce, I started to see and hear a shift from what in the past has been a charity model of disability employment, where we think of it as something we do out of the goodness of heart into something that is much more about the business case for employment, and that is understanding that at a time when employers are seeking talent, that they're leaving an entire community on the table or on the bench if they don't



Taryn Mackenzie Williams being sworn in Assistant Secretary of Labor for Disability Employment

reach out to people with disabilities and create hiring practices and recruitment that ultimately leads to an increase in disability employment. There are, I think, other ways that I would point to as an agency. Every October, we celebrate National Disability Employment Awareness Month, and that is the time for employers in particular to come together to talk about their commitment to an inclusive workforce. And every year we see more of it. We see ownership of disability employment and ownership of that month in a way that is a demonstration that the leaders and HR managers, they're really starting to get it. They understand not only that they should be reaching out to hire more people with disabilities, they also understand that people with disabilities are already in their workforce, and that if they take steps to provide supports best practices, like a reasonable accommodation process, like ERGs or employee resource groups that support people with disabilities, then they're creating an environment that is more welcoming for them. Those are some of the things that I would point to, the data that shows the narrowing, the growth in inclusive practices, the leadership demonstrated by employers as they look to fill their talent gaps with this sometimes hidden workforce.

Woodall: Yeah, absolutely. So then, of course, on the inverse of that, what areas do you think we should focus on to improve disability inclusion in the workplace? Where do you think the effort should be focused?

Williams: Yeah, that's a great question. I will tell you some of the things that we are thinking about right now, and I will focus on two. One is artificial intelligence, and one is mental health. Beginning with mental health, earlier I mentioned the Job Accommodation Network. For us, at times, it is a really strong barometer for what's on the minds of employers and what issues are emerging in the workforce, and for some years, inquiries related to mental health is in the top two topics. I know I don't need to tell you that over the last several years, we've seen an increase in unmet mental health needs. We have a crisis of unmet mental health needs that absolutely has been exacerbated by the pandemic. For us, not only as an agency, but as a broader Department, we have been very focused on bringing all of our resources to bear on the mental health crisis. We want to ensure that employers know that they have a role to play in supporting mental health, in supporting their employees who may have acquired or have mental health conditions. They have a role to play in supporting their employees who may be grappling with mental health in their own families or communities in such a way that impacts their work. We want job seekers and employees who have mental health conditions to know that they can seek resources like JAN, to know that there are resources like those that we make available through our employer-focused technical assistance center, which is called EARN (Employer Assistance and Resource Center on Disability Inclusion), that there are resources available that equip employers with the policies and practices that will make the workplace more inclusive for them. It's clear. It has been a lot of time and I'm fortunate to talk to employers often, to talk to

employers and to talk to policymakers, and it is a constant theme that we need to address the mental health crisis. What are policies that we can advance? What are this and that we should be considering to ensure that individuals stay connected to the workforce? So, I think that is positive. I think it's something that we will continue to focus on. Stigma still exists. I am an optimist and believe that even with the stigma, if we're talking about it more, that gives us opportunity to normalize and to help individuals understand that mental health is health, and workers bring their full selves to work often. We have opportunities to retain and to support our talent if we're being proactive in creating those inclusive workplaces. So mental health is definitely something that we think about quite a bit, that our acting secretary has been very clear that she cares about. We launched a whole new website that brings resources from across the Department.

Then Artificial Intelligence, AI. I am not an expert–full stop, not an expert. We have experts on staff, and they assured me that AI has been around for a long time, but I think we can all agree that the ways in which we think about AI and the conversations around AI have really accelerated in every policy arena. For us, we are focused on AI because we think there are both–I want to call it–there's a promise in peril of artificial intelligence. There are opportunities that workers or job seekers might have in leveraging–and I mean particularly people with disabilities–in leveraging AI as a tool, possibly including in reasonable accommodations to support their work. So that is something that we think about. What are those opportunities and how do we ensure in those test cases that workers and employers are equipped with the knowledge about how AI is being deployed and used and are aware of the risks? The flip side of that is there's peril with AI. Are there are risks in it furthering or advancing the discrimination that already in the workforce? Or I would say the potential for discrimination in the workforce to the extent that tools that perhaps hiring managers use are built on samples that aren't inclusive of people with disabilities. One of the ways that we, as a small policy agency, work on this issue is through another of our technical assistance centers. It's called the Partnership for Employment and Accessible Technology, or PEAT. PEAT, just several years ago, worked on a toolkit. It's like a disability inclusive toolkit meant for hiring managers, intended to help them think through the process of procuring and deploying artificial intelligence. How do we do that in such a way that it doesn't have the unintended consequence or disadvantages job seekers with disabilities? We have also partnered with other agencies over the last several years to ensure that as policy, regulatory, and broader conversations about artificial intelligence continue, that people with disabilities are at the table. That is so critical, and that can be some of role–making sure that the considerations of job seekers and employees and employers with disabilities–making sure that they're considered.

Woodall: So, what does disability inclusion look like in the workplace? If someone wanted to make a more inclusive workplace, what does that look like?

Williams: I think to answer that question, I would start really with the recruitment process. I would start with a job seeker–someone who is considering a role or a company and trying to determine whether or not it's a good fit for them–and that would likely start with going to the Internet, and looking up their website if they have one, and ensuring that that website is accessible. Earlier, we were talking about Section 508 of the Rehab Act Compliance. I would go one step further, depending on the size of the employer and say, "Are people with disabilities represented on that web page? Do I see myself reflected in the work workforce or in the language that an employer uses to describe their work or their products?" Something else I would look for is, is it clear to me as a job seeker or as an applicant, how to request reasonable accommodations for the interview process. Certainly, disability disclosure can be a dynamic process in terms of when it's appropriate or when a person is comfortable with disclosure, but that dynamic process doesn't mean that I should have to search for how to get the accommodations that I need in order to go through that process. My colleagues and I are working towards workplaces where you are included, where there are people with disabilities, individuals who are comfortable with self-disclosure, those who know that they aren't being compelled to disclose, but if it's a part of their identity that they want to share with their colleagues, then there are practices, encouragement resources like affinity groups or ERGs that can support them. Again, I'll highlight the reasonable accommodation process once you're on board, because disability can be dynamic. As we know, what one's accommodation is one day might evolve in a year or two, or one can acquire a disability. I will say two additional pieces. One is a commitment in some way from leadership. Leadership matters. I think about it every day. I see it in my own acting secretary and the way she talks about our commitment to all workers. There is never a doubt who she is focused on and where she wants us as a department to marshal our resources. All means all for her, and as an agency I want our employers everywhere, no matter the size, to be committed to their workforce and to understand that people with disabilities can be a thriving part of their workforce. The last thing I will note is–and this goes back to how I got my start as someone focused on youth and young adults with disabilities–we would talk a lot about expectations and aspirations and how you cultivate aspirations in young people, so they expect more of themselves. So, as the providers, the teachers, their community expects more of them, I want that on the job as well. I am wary of messaging in disability employment that might have the unintended consequence of pigeonholing an individual into a role, right? Of making sure that we get through the recruitment and the hiring and ensuring that we retain them, but not

providing the leadership development opportunities with the access to reasonable accommodations that will allow them to advance. The expectations that are on the job, too. Having leaders with disabilities who disclose, normalizing the fact that people with disabilities don't just get a job, and they're good workers because they show up every day, that's not enough. It is that they have the opportunity to move into leadership roles. They have the accommodations, they have the supports, and there's never any doubt that they are full members of that workforce.

Woodall: So, if someone like a coworker or even a manager, wants to be an advocate–wants to be an ally–do you have any tips for them on where to start with that?

Williams: Yeah. So, this is my disability advocacy hat because there's no one way to be an advocate or an ally. I think it first starts with understanding how best you can provide support in the workplace. It can be just as powerful to grab launch with an employee with a disability as it is to lead the way in the creation of an employee resource group. It is as powerful to speak up in a meeting as it is to sometimes hold back, because perhaps an individual with a not apparent disability needs a little bit more time to communicate their thoughts, or maybe the person with a disability has not been invited to the meeting, so you're holding back because you realize that an opportunity has been taken away. So that's the foundation. There's a lot of different ways that you can advocate in the workplace, seemingly small ways, but also big ways, like adoption of policies and practices. But if you're getting more concrete, I would say that's where we go to the Employer Assistance and Resource Network, or EARN. The reason why I talk about EARN

Is because as a tool, as a technical assistance center, it really meets employers and employees where they are, understanding there's a continuum of knowledge around disability and disability employment and what's best practice. It helps them start to think, "What could I do if I'm a hiring manager?" "What can I do if I am a supervisor and now I have an employee with a disability?" "What can I do if I'm a leader?" It's thinking not only about the process of employment, but also about one's role in the workplace and how you can take steps to be more inclusive in your practices. So that's what I would point to.

Woodall: So you participated in the special Breaking Barriers: Embracing Disabilities in the Workforce. Can you tell me a little bit about what that special was about, and your experience participating in it?

Williams: Yes, that was an amazing opportunity. I was very excited to be able to travel to Atlanta and really engage in a conversation about disability and what it looks like in the workplace. In fact, earlier, as we were talking about artificial intelligence, I was thinking about the extent to which that was a theme in the conversation. It was focused on breaking barriers in the workplace and understanding what barriers persist for people with disabilities being fully included in workplaces. One of the things we discuss is the use of artificial technology andmhow AI can create opportunities for people with disabilities who may have historically been left out of the workforce. We also had a conversation about our need to ensure that policies promulgated by the by the government–but also as employers are thinking about their use of artificial intelligence–that they are considering the needs of people with disabilities. I'll say it again and again, people with disabilities are at the table when they're making those decisions. It's never good when you procure new technology or you come up with a new practice meant to drive up inclusion, and you haven't consulted with people with disabilities from the very start. Those are some of the themes that came up in that conversation. It's been great to see how well received the special is. I know that the producers won awards for the special, and they're really quite proud of the messaging, and I'm excited that they had a focus on a disability employment. I dream of a world where we don't have to have a special focus on disability employment because it's just what we do. But in the absence of that world, the care that they put into developing that show and bringing lived experience from workers and the expertise of the different panelists into the production, it was really an honor to participate.

Woodall: Is there anything that you would like to add that we haven't covered today?

Williams: I would say perhaps one other thing I talked about just a touch. Something I'm particularly excited about and proud of is work that our youth team is doing. I started by saying I started on our youth policy team. It's just something that will always be important to me. We recently launched what we call a Demonstration Project. So, providing funding to states to support them in working across systems and building practices to support youth and young adults with disabilities as they transition to employment. Particularly emerging from the pandemic and all of the headlines that we've had about learning loss, and particularly the mental health crises that have affected young people. It's really important to us that we continue to invest in and support pathways into employment for youth and young adults with disabilities. And when we say employment, we mean competitive, integrated employment and into roles and careers where they can thrive. That project is called our Equitable Transitions Model or ETM. It's meant to support young people, and particularly those from underserved populations. ■ ABILITY

dol.gov/agencies/odep

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New Ski Design for Greater Stability

Ms. Eva has been struggling with multiple sclerosis (MS) for nearly thirty years. It primarily affects the mobility in her right leg. Although her diagnosis is overwhelming, she has been trying to devote herself to sports in her spare time just like she used to a long time ago.

A special model of downhill skis with a stabilizing foot made by a small Prague company in the Czech Republic has been helping her to achieve just that for some time now.

“It’s an amazing thing. I can now do exactly what standard skis wouldn’t allow me to do and perform maneuvers that would otherwise be too demanding. I feel safe on these skis and I am very happy that I am able to come close to how I used to ski before I was diagnosed with MS” says Ms. Eva, whose ability to walk radically started to worsen about ten years ago. Due to these problems, she eventually had to put her dreams of cross-country skiing on hold, and downhill skiing was very difficult and tedious for her for quite a long time.

Ms. Eva, whose neurological illnesses cause extraordinary pain in her joints, can now enjoy a week of skiing in the Tatras on Štrbské Pleso thanks to these special skis.



Skiing with a stabilizing foot, as the name suggests, helps skiers maintain stability, even on uneven terrain. They are equipped with a special alloy tip, which not only prevents the skier from flinging backwards whilst skiing on more difficult terrain, but also naturally returns them to a safe position with the help of inertia.

“It actually works as a rehabilitative aid for me that helps me to stay physically fit. Other than bike riding, I just can’t play any other sports right now and I still have

to rely on support when I go for a walk," explains Ms. Eva, who thought she would never be able to get back into skiing ever again.

Not just your average skis

The special skis used by Ms. Eva were made by a small Prague company called Ski Progress and they bear the name STAKI. The skis were invented in 2008 by athlete and physical education instructor Dušan Peterka, who was inspired by a pair of home-made skis that one of his friends used when skiing in heavy snow. The company that manufactures STAKI skis is now run by David Rubek. Primarily under his leadership, the older and less practical models were gradually replaced with new ones, which work better on the slopes and are visually more aesthetically pleasing.

"Our new models were developed based on our customers' wishes. We already have more than 200 satisfied customers in the Czech Republic. But there is still room for improvement," says David Rubek.

He adds that these special skis were even appreciated by the mountaineering service and sports specialists from Comenius University in Bratislava. According to Rubek, other than skiers with limited mobility and special needs, the skis are also a favorite for beginner skiers and those who have not skied in quite a long time.

"The latest STAKI model was named STAKI Controls. We have upgraded the stabilizing foot so that it is better attached to the ski and it is equipped with a stabilizing binding that is adjustable for size. We would like to expand our assortment with a range of new color designs so that everyone has a pair of skis to choose from according to their own special taste," explains David Rubek.

He adds, however, that although the prototype has now been fully realized, the new STAKI model will go into production this August. So the skis will not be available for skiers until the next ski season. The prototype's development stage lasted for almost two years.

America helped with starting up production

One of the obstacles for the development of these special skis is financing. The development of new skis is extremely costly, and the testing process takes a long time.

For this reason, this year the company decided to ask its potential customers to pre-purchase the new STAKI model through a crowdfunding platform. "Speaking from experience, European customers tend to be skeptical about technological innovation. That's why we tried our luck in the United States on the Kickstarter platform," explains David Rubek.

According to him, the campaign was successful, and even if the money that was raised only covers campaign costs and the first batch of new skis, he is happy. "Nearly seventy people from all over the world showed interest in our skis and we collected more than forty-one thousand US dollars. This definitely tells us that what we are doing is worthwhile," concluded David Rubek.

check this out

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■ ABILITY

stable-ski.com

JOHN Leguizamo

John Leguizamo's breakthrough one-man shows influenced generations of performers of color

to create their own art with authenticity. His characters include "Javier," a wheelchair user, and

his deaf "Uncle Manny," who were based on real life family members. Leguizamo's efforts to bring the stories of disenfranchised populations to light is evident in his stage productions by the casting of authentic talent and covering themes of diversity, inclusion, struggles and perseverance. In his latest work, The Other Americans, Leguizamo explores mental illness and how it's processed in the Latino family at the center of the play–highlighting an underrepresented demographic.

ABILITY Magazine's Chet Cooper, and Leguizamo's childhood friend, Gina Velasquez, joined him to discuss the power of authentic representation in Hollywood, the communal impact of storytelling, and what it means to be an ally.

Gina Velasquez: Hello, John. How are you doing?

John Leguizamo: Hello, Gina. How's it going over in New York and your side of the world?

Velasquez: A couple of fires, but otherwise we're fine. I know you have been very, very busy. You've been telling me about the many projects that you've been a part of. There's a couple of particular interest that I would like to talk about. A couple of months ago–or maybe just a couple of weeks ago–you mentioned to me that you had just finished a film where one of the female leads was a paraplegic. Can you tell me about that?

Leguizamo: Yeah. It's Bob Trevino Likes It–which is winning awards all across the world and one of the highest award winning films this year around the country and around the world, and directed by a LGBTQ+ director and writer. The co-lead is a paraplegic woman, Afro-American, and she's stealing the show. She's so incredible and amazing. In the past, it would have never happened. My Left Foot was played by the amazing Daniel Day-Lewis, but they would have never hired a real paraplegic. When I think of hiring, it was always like, "Oh, an actor can do everything." Yeah, that's great, but it was always only white, abled male actors that got every role and every chance to play everything. While Latinos, we had to endure brown face and being replaced. Obviously, LGBTQ+ also didn't get to play LGBTQ+, and disabled didn't get to play disabled. Al Pacino playing a sight impaired, you know what I mean? It was just the standard practice.





John's and Gina in pink

Velasquez: That's right. What was it? Scent of a Woman?

Leguizamo: Scent of a Woman, yeah, and many, many, many times. They win Oscars for playing disabled characters. That was the other ticket. That if you played disabled roles, you would win a guaranteed Oscar because "what great acting," but they would never think of using a real disabled person or a real LGBTQ+ person or a real Latino. As we witnessed in Argo with Ben Affleck taking a Mexican FBI, incredible Latin story and just dyeing his hair black and growing a mustache and painting it black. It's still going on, but I always tried to include LGBTQ+ in my stories. I try to include the disabled whenever I can. I did in Spic-O-Rama.

Cooper: I had no idea that you did authentic casting. That's really great to hear.

Leguizamo: Yes. I'm writing this musical about transgender women, and we will have real transgender women.

Velasquez: What's the name of that musical?

Leguizamo: SHESUS

Velasquez: One of the characters in Spic-O-Rama, was paraplegic right? Javier, I think?

Leguizamo: Yes.

Velasquez: Oh, my gosh. That was in the '90s. How did I forget all this?

Leguizamo: I'm very sensible to that because of my brother in so many ways. He had osteomyelitis, and then he had spondylitis. In effect, he wanted to be pre-med, and then he couldn't because of his disability.

Velasquez: That's right. That's true. So, this female paraplegic character in Bob Trevino Likes It, what role does she play? What is the film about?

Leguizamo: The film is the true story of the director who had a very terrible relationship with her father. She left home at a young age, but then later on in her 30s, she wanted to reconnect with her dad. She found his name on Facebook and started talking to who she thought was her father, but it ended up being that he wasn't her father. There was somebody who had the same name, but then they met for breakfast, and then they started having a great relationship, better than she had with her father.

Velasquez: So, this lady that we've been alluding to, what does she play?

Leguizamo: She plays the roommate and employer of the young girl playing the director.

Velasquez: And is this based on a real person?

Leguizamo: I'm not sure about that. The director herself was disabled because she was in a terrible car crash.

Velasquez: Oh, wow. That's great. And it's winning a lot of awards.

Leguizamo: Yeah, all over the place. It's insane. The girl's name is Lauren Spencer. She's amazing. Lolo, we call her.

Cooper: We know Lolo.



John Leguizamo and Luna Lauren Velez (Patti) in "The Other Americans"

Leguizamo: No way, that's incredible.

Cooper: Oh, yeah. We actually gave her a cover position because we loved her work so much. That was a few years ago.

Leguizamo: Her work is incredible, man. She's such a beautiful actress. Back in the days, they wouldn't have given her a role. The excuses would have been, "It's too difficult. How are you going to get her out of the trailers?" They would have came up with a million excuses. They still do, I'm sure. I mean, Gina's brought it even more to my attention how difficult it is for disabled people to get employment and how little corporations do reach out. It's incredible. I mean, Gina and I called a lot of theaters, and it was difficult for them to wrap their minds around–and publishers–wrapping their minds around using a sight impaired person to work in their theaters. I'm so glad they're making a musical of Crip Camp. I don't know if you ever saw that.

Velasquez: Yes.

Leguizamo: I mean, that documentary should have won over My Octopus Teacher, I'm sorry. My Octopus Teacher's story was very sad, but these were heroes to change the world, and not to win the Oscars is insane to me. Imagine–to have them come up and receive an Oscar would have been historic and powerful and so inspiring to so many.

Velasquez: What's the name of the director of the Crip Camp musical? Wasn't he the same guy who directed Kiss My Aztec? Tony Taccone?

Leguizamo: Yes.

Velasquez: So, is he bringing it to Broadway?

Leguizamo: Yeah, they're in development. It takes decades to get a musical to Broadway.

Velasquez: And so that will be authentic representation.

Leguizamo: I'm blanking on the name of How to Dance in Ohio, but the full cast was on the spectrum, which is another place that people who are on the spectrum never, rarely ever get to play themselves. Then you have Dustin Hoffman in Rain Man or many, many other versions.

Velasquez: But that, hopefully, is changing. I also wanted to touch on a theme in your current play, The Other Americans. You touch on the topic of mental health, especially for the Latino community. I think it's an important subject that should be discussed more.

Leguizamo: Oh, yeah. The Other Americans. I'm here in DC at the Arena stage, and my play is about mental health, especially in the Latin community. I've had a lot of veterans come in, especially women veterans who have PTSD–Latinas mostly, one of them was white–I thought that play would be triggering, but they felt it was healing to see their plight on stage and to see themselves represented. Then the second-highest-ranking Latino admiral in the Navy said this show is so important because it highlights what happens at home and what happens in the military and in the Navy, that people speak up and they say they're having issues or



John Leguizamo stars as Nelson Castro and Bradley James Tejeda (Eddie) in "The Other Americans"

problems, and everybody says, "toughen up, suck it up." He talks to about 400 sets of parents a year who have dealt with suicide. I was insecure, I was thinking, "Oh, my God, this show is triggering," but it's not. It's having the opposite effect. Many parents have come to me and said, I have a child who suffers from depression, so it was so great to see the show. They feel seen, they feel heard, they don't feel as alone, I guess.

Velasquez: When we went to see it a couple of weeks ago, it was tough. I knew the play pretty well, but I could hear in the audience how they were reacting. It's very powerful.

Cooper: How did you come up with the storyline?

Leguizamo: It's based on an incident that happened in the '90s that shocked me that this was going on, that hate crimes against Latinos were happening in New York City, where we're almost equal to the population of Whites–or we are equal in size, not in status, obviously. It was shocking to me. It was a very shocking event that I needed to put on stage.

Cooper: You were thinking about this for some period of time?

Leguizamo: For years and years, yeah. It seems like the audiences are responding so viscerally. I mean, gasping, weeping, laughing, snapping. I just think it's fascinating. I've never been in a show where people respond so verbally to what's going on onstage, like they're home watching television. I mean, I'm not used to that. One of the viewers said that the responses are because the play likens to Greek tragedies, which was interesting. Subconsciously, in the telling of the story, I hit on some of those archetypical paradigms.

Velasquez: A Greek tragedy about a laundromat owner. It's very modern day, huh?

Leguizamo: Yeah, modern day Greek tragedy.

Velasquez: It's a beautiful play. It really is.

Leguizamo: And getting more beautiful as I find little lines and little moments. Now I'm doing microsurgery.

Velasquez: Well, a lot of it is intimate. These family members are discussing very personal things that usually don't get aired outside of the home, so it's like taking a peek inside what happens in a home when something like this happens.

Leguizamo: Because there's so little Latin representation, we never get to see a real Latin family having real conversations. You just never see that. It's always we're drug dealers or all these tropes.

Velasquez: The cast you have, they're all Hispanic, but just listening to them, I felt like I was at home. It could have been my house or your house and just the way that

parents speak and kids with our Spanglish and things like that.

Leguizamo: I know. A lot of people come and say, "That was my father." I was in shock. And "That was my mother," and "That was my aunt." It's incredible how Latin people feel themselves seen. I mean, obviously, this isn't representative of all Latin families, but just like Death of a Salesman and Eugene O'Neill's Long Day's Journey into Night isn't representative of all white people. Just to see yourself represented in aspects of our culture scene, it has a powerful effect, but everybody has to continue and take up the fight. Able people have to take up the fight for disabled people to help and be allies. It's so important that we become allies and support the fight for equality.

Velasquez: You've been so incredibly supportive of me as I lost vision. You have always been one of my greatest champions. I am grateful for your allyship and your just believing in me. I feel that I noticed as I lost more and more vision that I felt like you had a greater sense of understanding of what it is. Because truthfully, I didn't know what it was like to become disabled. All of this was new to me as well, so with the things that I was going through–which were very frustrating and difficult–I always felt like you went out of your way to understand and to make accommodations for the way I do things. I want to thank you for that.

Leguizamo: It was a pleasure, and it was easy because you're so incredibly talented and gifted. It wasn't difficult. It was a joy to talk to and to work with you. It was easy. To be patient with your use of technology wasn't that difficult. I mean, even able people have such a difficult time with technology. It's not just a disabled person's issue. It's everybody's issue, especially people who are getting older.

Velasquez: Hey, don't go there. Yeah. Thank you, though. It's a pleasure working with you, of course. It's been an incredible, challenging and rewarding ride. You've helped me feel that I can accomplish all these things.

Leguizamo: Oh, I'm so glad because I feel like more able people need to take that cause. Now that you've made me so aware of it, because I just didn't understand the plight of the disabled person and the lack of help from corporations and industries everywhere. I thought the art industry would be much more accommodating, and they're no different than corporations. I think that battle can be won. We need to figure out how to be more vocal and present and put it forward. Corporations need to make an effort and make room and create programs that can help disabled people in every way get into corporations, get into technology, get into banking, get into the arts, because they have lots to offer.

Cooper: Some of the things you're talking about, we've looked at the problem and created some tools for some meaningful solutions. One of them is abilityEntertainment, which is already the largest database of profiles of actors with disabilities in the world. You go to abilityE, casting can put their breakdowns up and search something like "left-handed amputee, a Hispanic between the ages of 18 and 25." We've worked with some of the biggest studios. It all happened because of Netflix coming to us asking for help. They wanted a young girl that authentically used a wheelchair, and they could only find 10 to audition, and we sent them close to 500.

Leguizamo: Wow. Yeah. Oh, my God. That's amazing.

Cooper: Yeah. In 1995, we also created the first online job board for people with disabilities, which is called abilityJOBS. Then more recently, and this is how Gina and I met, is through ABILITY Job Fair, which is the first accessible online career fair. We have clients that range from the Fortune 500 to NGOs to government. We have over 127,000 registered jobseekers with disabilities. We've been working hard to do something around changing the low numbers of people with disabilities working. Then also just the awareness. That's what the magazine's about, is bringing storytelling and awareness around focusing on changing attitudes and the unconscious bias around disability.

Leguizamo: I think it's a laziness. It's people–corporations–not wanting to spend the money. Foolish because they're losing an incredible segment of the population and their incredible abilities and contributions. You're missing out on the next Stephen Hawking. You're missing out on the next Stevie Wonder. You're missing out on so much.

Cooper: Yeah. Missing out on the next Gina.

Velasquez: Yeah. You're missing out on Gina Velasquez. That's right. Those theaters don't know what they've lost.

Cooper: For the general public who might not have seen your plays or one person shows yet, can you briefly describe how you got into acting?

Leguizamo: Yeah, well, I was always the comic, the cut up in my home and in my neighborhood, on my block, in the park, and then in school. Then this math teacher, Mr. Zufa, suggested that I do it professionally instead of disrupting the class. He's passed since now. I was 17, and he put it in my head, and I was like, "Oh, wow." Back then, we had yellow pages. We didn't have Google. That's how old. I went on yellow pages, and I found an acting school, and that was the beginning of my career.

Cooper: On your play, you mentioned a woman. Was that more just for the play–for entertainment?



John's birthday 1979, Gina in white pants

Leguizamo: No, the woman was the acting teacher that I went to, Sylvia Leigh at Showcase Theater.

Cooper: I really enjoyed your play Ghetto Klown.

Leguizamo: I think I was pioneering, if I pat myself on the back. Nobody was doing stories about themselves and their careers. Now everybody's doing their own story. It was like everybody was doing Abraham Lincoln or Mark Twain and I started doing the autobiographical piece. Ghetto Klown was more difficult because it mid career and people were like, "Oh, but he didn't die yet", there was a lot of put-downs, but now everybody–from Alicia Keys to Billy Joel–everybody's doing their life story on Broadway now while they're alive.

Cooper: Yeah, it was really well done. You could tell that you spent a lot of time coming up with how to tell the story in a fun, meaningful way.

Leguizamo: Right. It was very difficult to crack the code on telling your autobiographical story and career in Hollywood. It's very difficult to tell.

Cooper: Yeah. I thought it also showed your acting capability. It wasn't just stand-up, It was this mix.

Leguizamo: Yes, it's my hybrid mix that I created–this blend of acting. It's a play, basically. Obviously, it's very humorous because I love comedy and I love physicality and slapstick and mime. I love all that. I combined this hybrid of stand-up, play, and storytelling and mime.

Cooper: Were you ever a dancer?

Leguizamo: No, but I danced a lot. It's in our culture. We dance at home all the time at every party, and then dance at clubs, We dance at school. We dance everywhere.

Velasquez: We dance on the streets.

Leguizamo: We dance everywhere.

Cooper: You had moves, so that's why I was wondering.

Leguizamo: I dance with it. I love it. I went to all the dance clubs. I spent all my time in the dance club. So, you pick it up and you also experiment at these clubs. That's why they were such a creative and beautiful experience to me. It was such a beautiful place to be artful.

Velasquez: Those are great times. We went to the clubs together. We were teenagers.

Cooper: Tell us about your history between the two of you.

Leguizamo: We grew up in the same neighborhood, but we didn't know each other. We knew each other when we got to high school, Murry Bergtraum in Manhattan. My brother and her sister became incredibly close because we shared so much history that we didn't know. We stayed friends since high school, which is a long, long time ago. I actually stayed close friends to a lot of people from high school, but not from college, which is

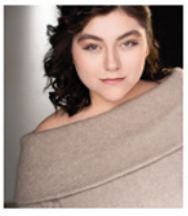
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really interesting because mostly people stay close to people from college.

Velasquez: Right.

Cooper: So you watched the transition of Gina losing her sight.

Leguizamo: Yes. She went from this incredible, brilliant, young, gifted Latina who worked at Bantam Books and was just moving up and killing it. Then she had to retire early in her career before she got a chance to make big moves.

Velasquez: Yeah, but I found my way back in through you. I found my way back in, but then the vision loss really started happening a little bit later than that when I was, what, in my 40s? So, it would have been about 20 years ago. Since then, though, like I said, that's when you and I started being a little bit more collaborative. I lost more vision, but you stayed by me, and I think we've done okay.

Leguizamo: Yeah. Gina has been wonderful. She still has an incredible storytelling sense, which is studied, but innate as well. I love consulting with her on my works because she always gives me great, great insights that are so deep and so profound and so literate, and they're just genius.

Velasquez: Oh, stop. Stop it.

Leguizamo: No, she's underselling herself.

Velasquez: I paid him $10.

Leguizamo: Now you make me look cheap.

Velasquez: You'll do anything for a buck.

Cooper: So, to jump back to "The Other Americans" for a minute, you said you're actually doing micro tweaking of the play right now?

Leguizamo: Yeah. Mostly microsurgery, changing a word here and there that I never got a chance to because it's such a big story. Now, certain words that aren't poetic enough or expressive enough, certain character things that I took out that I was missing, like the wife's backstory a little bit more, I brought it back in, so little tweaks like that I'm doing. I'm going to try out a new line that came to me in my dreams, that when Nelson is running, when his son is running away, and the son and father have a great confrontation, instead of him saying to his possible business opportunity, "Hey, hold on, I'm having a reception problem." now he's going to say, "Forget it! take your deal and shove it up your ass." And then it's done. That's a difference.

Cooper: That's a major difference.



John and Sarah Nina Hayon (Veronica) in "The Other Americans"

Leguizamo: Major, major difference. It doesn't change the course of events, but I'm thinking about the ramifications of that, right?

Cooper: John, it was nice meeting you, and I'm sure we can stay in touch.

Leguizamo: Oh, yeah. I would love to help out as much as I can. I think it's an important cause. I think what you guys are doing is so powerful, so needed. I know I can get a lot of other people to become allies because there's so many people that just don't understand the difficulty. Everybody in America thinks that everything's already fixed for some reason, like racism is over and handicapped people are doing great. Nobody knows. We just have no clue. ■ ABILITY

instagram.com/johnleguizamo





EPIC Players

Inclusive Theater Company

Founded in 2016, EPIC Players theater company was created as a neuro-diverse theater environment dedicated to creating professional performing arts opportunities for neurodivergent and disabled artists. To achieve this goal, EPIC offers inclusive mainstage productions, musical cabarets, original showcases and skills-based classes and career recourses.

ABILITY Magazine's Jennifer Woodall met EPIC performers Josh Cartagena and Mina Cuesta in a remote interview to discuss performing with a neuro-inclusive theater company, navigating the theater industry with a disability and how impactful it is to find a safe space to perform, both as a member of the disability and LGBTQ+ communities.

Jennifer Woodall: Hello. How are you today?

Josh Cartagena: Hello.

Mina Cuesta: We're great. How are you?

Woodall: Good, thank you. Can you both give a bit of your background and how you became involved in the performance arts?

Cuesta: Yes. So, for me, I actually started out studying little classical music, and I had some teachers and I would do a little piano. I actually participated in a city-wide youth opera company when I was 15 and 16, only about two years. And then in high school when I was 15, turning 16, I really got into musical theater. I actually got lucky, when I was 15, I got the role as Cosette because at the time I was really studying classical music–this was at John W. Engeman Theater in Long Island, Northport–so from there on, I went on audition. Sometimes I was successful, sometimes I was not. I had a very detailed, interesting, diverse background. I even performed at Carnegie Hall a few times, once with the New York Pops, with Judith Clurman as a choir director.

Cartagena: So, I have a learning disability, and I have struggled with Tourette's syndrome. About 15 years of my life. Around this time is when I fell in love with music because it felt like my hiding place, you know? I learned about EPIC through a good friend of mine in 2022, and when I started attending, it made me



Charlie Brown Cast: Elizabeth Dicker, Melissa Jennifer Gonzalez, Meghan E Gilson, Gianluca, Andrew Kader, Gideon Piank, Brandon Looney & Travis Burbee

feel accepted. I performed with Billy Porter and Lady Gaga's mother, and it made me feel accepted at that time. I feel more safe performing with EPIC players who are more neurodiverse and being accepted and being queer. Whatever happens, you know, they accept me and they love me for who I am. I got to meet with so many entrepreneurs, like Whitney Houston's mom, Cissy Houston. I got to perform with her at a choir, it was a gospel choir, and I got those opportunities. Then I started moving on to EPIC Players, and I got to perform with Kodi Lee, and Boyz II Men–one of the members–and it was just incredible experience, you know?

Woodall: Can you guys tell me sort of what EPIC Theater is all about, and how it's different from other theaters that people may go to?

Cuesta: So EPIC Productions is a semiprofessional/professional theater company that provides performance opportunities and classes for those who are neurodivergent or those with disabilities. It's the first real, really, really, really legitimate theater production I could find where they had other neurodiverse individuals. It's just like a jewel. It's an oasis in a way, because there aren't a lot of theater companies or let alone places like EPIC.

Cartagena: EPIC is like a neurodiverse nonprofit organization for people with disabilities that enjoy theater and the arts. I feel like it's a safe zone to be who we are, and they accommodate with other people and accommodate with your needs, you know that, because there's times that I struggle a lot and I thank them a lot that I have my advocate, Alexander, who's been there with me, and he always guides me. They have a lot of resources like jobs and performances, and you get paid for these performances. It feels really amazing to have that amount of light pressure. It doesn't feel like it has to be just thrown at you, and they were accommodating to me.

Woodall: So, speaking about the performances, can you guys tell me about some of the shows that EPIC puts on? I would love to hear about your favorite that you were involved in?

Cuesta: Josh and I did sprint Spring Awakening, and it was one of the most heartbreaking productions we did. Spring awakening is about baffling, really complicated feelings. It addresses topics that most Broadway shows–specifically musicals–don't really address. And, because we were a neurodivergent cast, we were performing Spring Awakening through a neurodivergent perspective. It's interesting because anyone could go through this, but neurodivergent people–any marginalized group–are especially impacted by many of the events that happen in Spring Awakening.

Woodall: Can you give me an example of the type of topic that's covered in Spring Awakening?

Cuesta: Well, sexual abuse is a big one. I played Ilse,



Jason Moy the “Tempest”

which was one of the characters, and along with Martha, who, unfortunately, is sexually abused by their own father, someone who’s supposed to support her, but ends up hurting her. I think with people who are neurodivergent, it happens a lot in certain communities. I know this is a heavy topic.

Woodall: Heavy topics are important, especially when we are talking about a group of people, that may not have the ability to advocate for themselves or society is telling them that they can’t advocate for themselves, so they get put in a tough position like that.

Cartagena: I did Spring Awakening, which was my first musical production. I really felt good about it because it opens a world to different priorities, and it feels like me being queer and coming out as who I want to be. It feels different. You’ve got to work hard and study and learn your lines and learn your scenes and the music as well. It’s amazing because I got to play Ernst, who is a queer character. I love it a lot because he tells a story similar to what I go through. I can relate the character of how he feels coming out, you know, and just being you. I’m really thankful a lot to Aubrey and Travis who offered me the role Ernst, because it shows a lot of varieties, a lot of voice dynamics, a lot of processing how to work through trauma and how to be you and take it at your own pace. Love my first performance.

Woodall: So, I grew up in the 90s, and I was on the EPIC website, and I saw a 90s cabaret show, can you tell me about that?

Cuesta: Well, it’s basically different songs from the 1990s, and it’s an entire collage of, like, different themes from the 90s. It could be Sarah McLachlan, it could be Backstreet Boys, it could be The Cranberries. I’m really excited for that theme because the 90s has a lot of angsty music, and I’m so excited to see EPIC interpret that.

Woodall: Yeah, absolutely. Definitely full of angst, that’s for sure.

Cuesta: I’m definitely a very angsty individual.

Cartagena: I think it’s a really good idea because it showcased not only musical theater, but it showcased different levels and styles of singing, and it’s really good. They give opportunities to those who fit the song, you know? I really love that they came with idea. You know, I didn’t get in, but I really appreciate that they took my idea, which is amazing. I did creep from Radiohead.

Cuesta: Love Radiohead.

Woodall: I love Radiohead, too. I got to see Radiohead in 2006. It was really awesome to see them live. Extremely impactful vocals.



Aubrie Therrien and Gianluca Cirafici

Cuesta: This is going to sound very subjective and opinionated, but that's when music was just really, really, really creative and really, really, really collaborative. I miss the early 2000s music genre.

Woodall: I agree. I don't know if it's because I'm biased due to nostalgia or what, but definitely the 90s going into the early 2000s, there was more of a space for experimental music within mainstream than there is now, so you got more diverse things, you know, like Primus, but then also Shania Twain and then also Radiohead. The diversity was a lot more prevalent. I definitely missed that era of music.

Cuesta: A little goth, like a little, Evanescence, My Chemical Romance, and of course, Panic at the Disco, which is a little more pop, but they do implement a lot of angsty music. You don't hear that anymore, now everything is a lot more upbeat. I mean, it was upbeat back then, but everything now is just kind of commercialized. I feel like we definitely need an early 2000s revival.

Cartagena: I actually am opposite. I love songs–a lot of ballads, you know, like, Billie Eilish. I know she has Tourette's and I have something similar, so we have something in common and I feel like I look up to her a lot. Her songs are amazing. Also, Sam Smith or Adele or something that's not overwritten all time and you make it your own, we can make it our own. That's what I like about those.

Cuesta: I completely agree with you, Josh. There's still really amazing music, especially Billie Eilish. I love her metaphorical songs about anxiety. I feel like she does a great job expressing anxiety in ways that aren't really talked about, because anxiety is a big thing with neurodiversity.

Woodall: That's the wonderful thing about music, right? It's a universal language. There are so many different types of music that can speak to different people, and they can relate to it through their personal experiences. It's a wonderful thing. What does a day in the life look like when you are preparing for a show?

Cuesta: So, in theater, you get a script, there's audition and then in a few days, you'll get a call back through an email. You really have to read your emails because sometimes in theater they might let you know when there's a callback, they might not. Then if you get the callback, it's best that you star your email. Then in EPIC, they break it down a little bit. You go to the audition–it's always nerve wracking because EPIC is very professional, so you definitely feel that adrenaline–then, like, it takes maybe, two to six days to receive a callback. Then, whether you get the part, they'll offer you, "Would you like this role?" And if you didn't get in, they will tell you. They'll give you a reason. I think it is very disappointing and saddening when you don't get a place or the role that you really, really, really aspired and worked smart to try to audition, but instead of just leaving you hanging, they will tell you if you did or did not get into a show–specifically in EPIC–which I think is very uplifting, for me, at least. They really see your potential. In most other theater companies, they just don't even bother to tell you, but EPIC will tell you. They're honest when it comes to casting someone in a show and rehearsals and EPIC is prestigious. You're expected to be on time with your materials, with everything. Of course, there are staff there. Sydney Davis, I want to reach out to her, she's helped me through so much. And there's always extra scripts there. You're encouraged to always have your materials with you, but let's say you left your script, there's most likely going to be a script there. Then the first week or two we're kind of just going through the script and breaking everything down, then as maybe a month and a half goes by, we start blocking, and then that's when the action really starts to mold, and you work with your advocate to work on lines and work on character development, too.

Cartagena: So, things I do to prepare for shows. I struggle a lot with memory. I used to have good memory, but I struggle a lot with shows. My biggest thing to prepare for auditions or hows that I'm doing is basically do the song, look at the character. What character fits you the most? Because apparently, it's not about the voice, you know, it's more about who they see in total as a character. You can

have the amazing voice and the amazing gift. But I feel like they mostly look out for who has the whole package. It's not a judgment in place–they love us for who we are–but auditioning in real life, you wouldn't go for a role like, "Oh, I could sing better than him. Let me try this." No, it doesn't work like that. I wanted to do Into the Woods one time, but maybe I was too young for the role. You know, it depends on how it fits you personally. Inside, we can feel like, "Oh, but that's me more. I like this person." but it's not gonna really end up the way you want it to be. It's more about having the voice, having the dance, having the personality, and just presenting it well. I think that's one of them. Also, not to get off topic, but I auditioned for Spring Awakening, and I had to memorize. I didn't want to do the show, but I really thank Aubrey so much for pushing me an amazing way. She encouraged me a lot to do the show. I was not going to audition, and I was like, let me just do it. It could be a chance. Maybe she'll give me a hint, like "You got this. I want you to do it because I know you fit the right role." It all depends on how you put it together and what kind of casting director wants to see you, and they might want to see you under study, and you have to study multiple roles, and that's it. I feel really calm about it sometimes when I get at the middle section.

Woodall: So, it sounds kind of like there has to be a lot of adaptability on your side, where you have to sort of be able to adjust to certain things.

Cartagena: I think I'm more relaxed when the show's about to start, because when it's rehearsals, I feel like I'm memorizing, learning blockings, learning dancing, learning singing, learning acting, and all these amazing abilities, but I think it's more relaxing when it's done rehearsing and just get to the show and show them what you got. Bring it big–big, and strong. I think that's what makes it really happy for me, because I feel like I did it. I give myself pat in the back, and, you know, I did. We all did an amazing job. That's why.

Cuesta: Thank you. Joshua. I know this sounds very subjective, but when I saw you as Ernst, I was like, "Holy moly!" You have something really, really mystical and really, really, really magical. I thought in terms of your vocal abilities, you had such a uniqueness about you. I was almost, like, envious, but in a good way.

Cartagena: You too, Mina. You have an amazing, angelic voice.

Cuesta: Thank you, Joshua. I miss you.

Cartagena: Miss you too.

Woodall: If people or performers want to get involved with EPIC theater, what should they do?

Cuesta: The best thing to do is to talk to someone who knows about EPIC and then maybe get access to the director's email, which is Aubrey, and just email her and kind of give her a description like "Hi, I'm very interested in EPIC productions as a whole." and then just kind of ask her what's the best way to audition and then she'll probably set up a meet. Back in 2021 when I first became a member, there would usually be a meeting, and then they'd offer you some things or some duties that you may have to attend to, like giving tickets during events out. Giving out tickets or checking people's IDs, you know, and then, getting involved, taking some virtual classes. Classes are a big one. It can be nerve wracking to get into a new company and meet new people. I think as long as you work smart and do your best to approach it professionally, you can start somewhere and take baby steps to get even higher and maybe get into a cabaret. But the first thing you do is you take a lot of classes. I remember taking a lot of classes when I was the newbie.

Cartagena: I think the best thing you can do is research. EPIC is really amazing because you get a lot of opportunities, and not only that, they'll reach out to you afterwards. You get into a program. I will say, if you don't have friends who know EPIC Players, I will say search epicplayersnyc.org and you will get a whole website where you get to reach out. It's a really good thing because, you know, it's kind of hard. When I got in, I didn't know about EPIC. I didn't know anybody from EPIC, but my best friend helped me get into EPIC. That was kind of a connection. We have different resources–you can search the website. It's amazing. Then, once you get there, you will start doing commitments, like doing classes, and there's no judgment, no judging others. We are always here for each other. That's what is matters. We get to do opportunities. The more you do classes, that's part of the commitment to earn your way to there, to the opportunities.

Woodall: Do you have any advice or encouraging words for someone who is neurodiverse that may want to get involved with theater but is kind of scared to do that or hasn't ever done that before and may be feeling a little nervous?

Cuesta: Oh, most definitely. What I would do is take baby steps. I think maybe just, like, maybe start off by taking classes or ask as much questions as you want about musical theater. This might sound a little subjective, but I think it's best to start somewhere small but good. For example, taking an acting class through EPIC and learning how to read monologs and developing a little work ethic yourself and developing those soft skills. If you're up for the challenge, then maybe audition for a play, but sometimes that can cause a lot of anxiety or it can make you feel drained, you know? So I would suggest taking those soft skills. Soft skills will give you the foundation. That's what I've always done, and I'm still in the process of those skills. Sometimes it's not always easy to embrace those soft skills, but remember that those soft skills are going to really not only train you for professionalism, but also help you psychologically

through the process. For example, if you take an acting class or an audition ready EPIC class kind of show–which I still do even though that I'm in plays–you know how to audition for a play, so I think the best thing to do is soft skills.

Cartagena: So if people don't have the access to EPIC–which I encourage everyone to have access because EPIC is amazing–have a list of pros and cons, and the pros of what you want to achieve like what's going to happen if you do well. and stuff like that, and the cons will be more of a negative thought, but I wouldn't think of it as negative. I would think of as positive, because anybody can do it. I started singing in 7th grade. I didn't really start when I was small, but I feel like growing up, I got the chance and opportunity to open up my voice, and my singing is my safe zone. It's a safe place for me and I get to sing and perform and dance and act and all these kinds of amazing instruments that I play. Piano–I want to really learn. It's good to take initiative and learn more. Ask questions. Always say, "Hey, how do you do that? I like the way you play that. Can you teach me or stuff like that?" Be confident in yourself, because that's the most important part, is being amazed and telling yourself great things. Never beat yourself up. Always think positive in a way, whatever you want to do, because you can do it, and you will make it great.

Woodall: Do either of you have anything else that you want to mention that we haven't covered today?

Cuesta: Well, I think I want to talk about diversity. I do love where diversity is going with performance. Not only is there EPIC, but there's other theater companies that provide performances and classes for people who are neurodivergent. There are places that we don't know about, like in California, in Florida and many states. However, I think that people have to realize that people with disabilities are not just like a minority group. It's much more general, you know? I think more general theater groups can provide programs specifically for people who are neurodivergent and maybe adopt some of the foundations that EPIC has. We need society–especially education institutions–to do a better job with providing accommodations or creating a space for people with disabilities. I acknowledge that there are accommodations, which is very helpful, but that's not always enough. Yes, I think we've come a long way when it comes to performances, but we're still really behind. I mean, at least through my experiences. This is a little subjective and a little biased, but we're still behind. On a more general note, higher education–specifically in college (through my experiences, at least)–if we can create a space that's similar to EPIC, where the material and the things that are being taught are accustomed to people's individual needs. I unfortunately don't see that or a lot of that in higher education. Even though I see accommodations, I just personally don't think that's enough. I think an adaptive curriculum–which EPIC is very professional, but it's also adaptive all at the same time–I think that's what college should be. Many people would disagree on me on this, saying, like, "Oh, it cost money," and "Oh, it's higher education," but if we're going to provide equitable access, then we're going to have to consider catering things towards people's needs. It's just that higher education is equality but not equity for people who are neurodivergent or autistic, or people with learning differences or disabilities. We really need to do better generally rather than performance opportunities. That is my opinion.

Cartagena: I wish they had more queer LGBTQ+ musicals. I feel like they have Kinky Boots, but we as queer, we don't get a lot of recognition. Even being neurodiverse mixed with a gender/non-gender confirmed, you know? I feel like no matter what happens, to have more opportunities for those who are interested in that field. I'm queer and I'm neurodiverse. I want to be out there more. I want to be comfortable in my spirit. I wish more people did not feel insecure. Everybody's loved for who they are–not everybody's gonna like it, but if nobody likes it, that's their problem, you know? We are who we are, and we should definitely do more musicals. I'm hoping they have a musical on Broadway soon. It'll be amazing to keep the pace going. We had a lot of Tony award winners–Conor Tague, who was part of How to Dance in Ohio, and it really means a lot that he did that. He did an amazing job.

Woodall: Have either of you heard about abilityE?

Cuesta: I think so. Do you mind elaborating a little?

Woodall: Yeah, sure. So, abilityE is part of our nonprofit group that we have, and it is a free platform for people within the entertainment industry that identify as having a disability. You get to put your profile on there, and studios that are looking to hire authentic talent can find you on the platform. I would definitely encourage both of you to make a profile on there because it is free to use, and it's a way for you to be able to get connected with studios that are wanting to hire authentic talent for various types of productions. That's something that we've been doing for a while because we did recognize a need for disability inclusion, particularly within the entertainment industry.

Cartagena: Awesome. If I don't have autism but I have a disability, can I still join?

Woodall: Yes, absolutely. It's open to everybody that identifies as having a disability. You don't have to strictly be neurodiverse. We have a lot of people on there.

Cartagena: That's cool. ■ ABILITY

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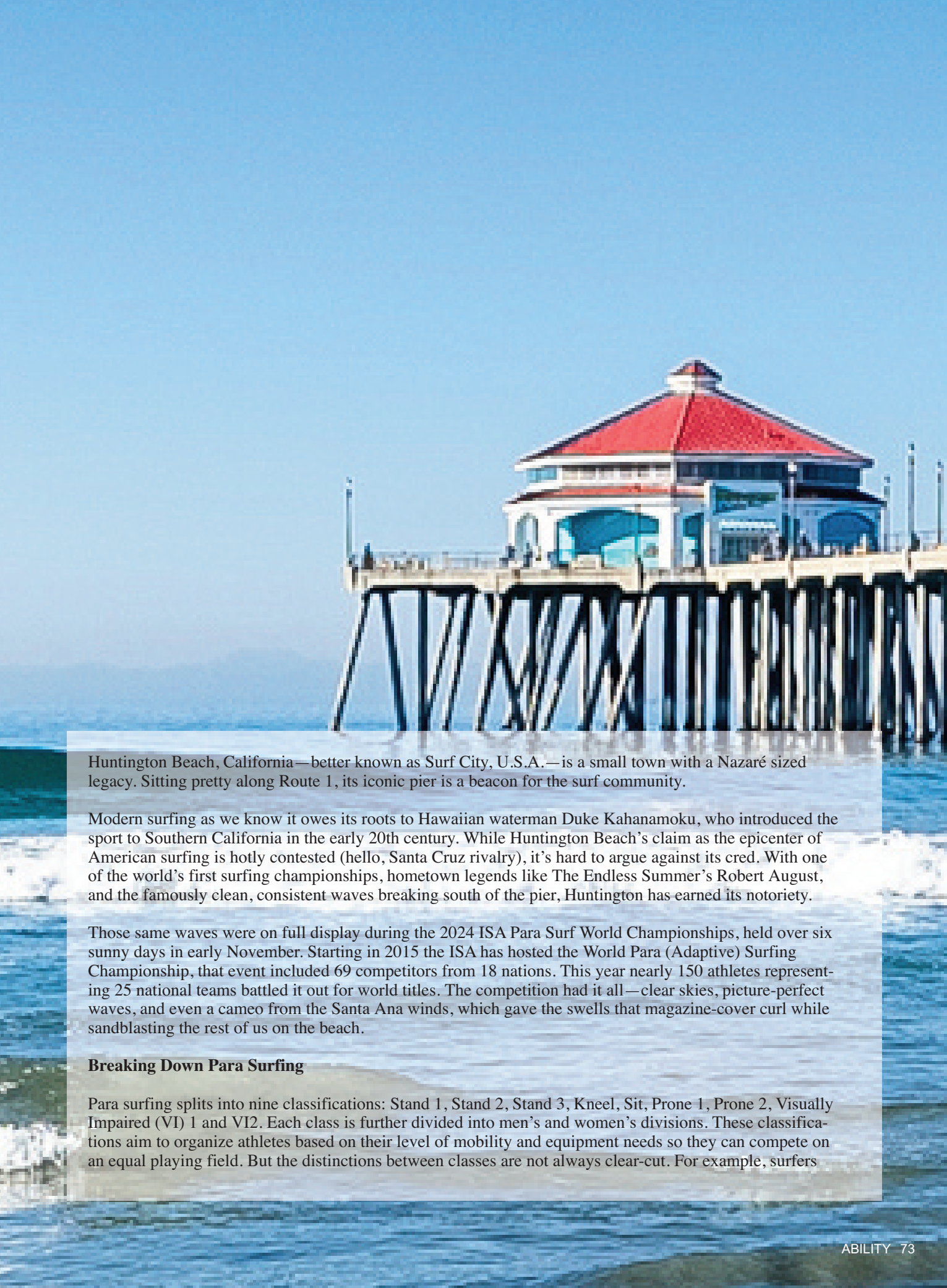
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ISA PARA SURF WORLD CHAMPIONSHIP 2024





Huntington Beach, California—better known as Surf City, U.S.A.—is a small town with a Nazaré sized legacy. Sitting pretty along Route 1, its iconic pier is a beacon for the surf community.

Modern surfing as we know it owes its roots to Hawaiian waterman Duke Kahanamoku, who introduced the sport to Southern California in the early 20th century. While Huntington Beach's claim as the epicenter of American surfing is hotly contested (hello, Santa Cruz rivalry), it's hard to argue against its cred. With one of the world's first surfing championships, hometown legends like The Endless Summer's Robert August, and the famously clean, consistent waves breaking south of the pier, Huntington has earned its notoriety.

Those same waves were on full display during the 2024 ISA Para Surf World Championships, held over six sunny days in early November. Starting in 2015 the ISA has hosted the World Para (Adaptive) Surfing Championship, that event included 69 competitors from 18 nations. This year nearly 150 athletes representing 25 national teams battled it out for world titles. The competition had it all—clear skies, picture-perfect waves, and even a cameo from the Santa Ana winds, which gave the swells that magazine-cover curl while sandblasting the rest of us on the beach.

Breaking Down Para Surfing

Para surfing splits into nine classifications: Stand 1, Stand 2, Stand 3, Kneel, Sit, Prone 1, Prone 2, Visually Impaired (VI) 1 and VI2. Each class is further divided into men's and women's divisions. These classifications aim to organize athletes based on their level of mobility and equipment needs so they can compete on an equal playing field. But the distinctions between classes are not always clear-cut. For example, surfers



Vera Quaresma BRA Kneel

with lower-limb prosthetics might compete in Stand 2 or Stand 3, where standing is required, or in Kneel, where competitors ride in a kneeling position.

Accommodations at para surf events include a wide array of roles from "pushers", fellow teammates who help Prone 2 athletes paddle into waves, to water safety teams, who form a human-net in the water to block surfers from potential hazards, and of course guides, who provide support by paddling side-by-side with their VI teammates. Each role may serve a different function, but they all share the same ultimate goal of ensuring all competitors are free to showcase their skills safely.

The competition itself follows a typical surf comp format: heats of up to four surfers, each scoring their top two waves during a 20-minute window. Longer rides, bigger waves, and stylish maneuvers all contribute to



Davi Teixeira de Aguiar - BRA Prone 2



Zoe Smith - Stand 2 Eng

scores, making each heat a mix of athleticism and strategy.

Women's Prone 2: Jocelyn Neumueller's Golden Moment

Team Australia's Jocelyn Neumueller was the name to watch in Women's Prone 2. After consecutive silver medals in prior years' events, Neumueller came to Huntington Beach gunning for gold. Her strategy could be summed up in one word: patience.

Picking which waves to paddle for is an important component of any surf heat. A bad wave means a short ride, leading to a low score and wasted time. This importance is amplified in the Prone classes.

Athletes who rode or got pulled too close to shore had



Jocelyn Neumueller - Prone 2 Aus

to make a choice. Paddling out with their assistant in the middle of the break, running the risk of taking slams from the white water, or a detour via beach wheelchair to get back out to the channel near the pier. If surfers chose the beach route, a NASCAR pit crew of volunteers and teammates would maneuver competitors into the chair as quickly and safely as possible, doing their best to not get too tangled in the board leash.

Both options take time. Time Neumueller wouldn't want to waste on a mediocre wave.

So, Neumueller would wait for the perfect sets, often earning first priority in the process– priority functions as a right of way if two competitors go for the same wave. Letting the minutes tick by, Neumueller would wait until the last 8 or so minutes of the heat before catching her second or third wave. This tactic left her competitors scrambling to match her scores with little time to react.

In the finals, she caught just two waves—an 8.00 early on that put her in a promising situation. As per her heat strategy, she waited to gain priority in the last quarter of the heat. There was just one problem: no strong waves. Would Neumueller go home with silver again just because she waited too long for a second wave?

In the absolutely nail-biting final minutes, Neumueller snagged a decent wave, scoring 4.67 points. It was Neumueller's second lowest scoring wave of the entire competition, but it pushed her past the reigning champ, Sarah Almagro, securing Neumueller's long-overdue gold.

Women's Kneel: A New Champion Rises

With reigning Women's Kneel champ Victoria Feige sitting out this year for some soul surfing in Nicaragua, the gold was anyone's game. From the start, the battle came down to 2023 silver medalist Vera Quaresma and bronze medalist Audrey Pascual. The competition was fierce, since that previous year the two women were neck and neck for that silver position with just a .1 point difference between their scores.

With an additional 3rd place finish in 2021 and a 4th place in 2022, Pascual arrived in 2024 hungry for the top spot. Quaresma wasn't making it easy though, sitting in the first seat of Round 1 and Round 2 – scoring 10.00 points and 8.83 points respectively. Pascual surfed strong, but at 5.8 points and 8.33 points after the first and second round, it looked like she might be taking home silver.

By the time the Kneel class hit the finals, the energy was electric. Dieters and Quaresma led the pack with matching top scores of 5.4, with Pascual just a breath behind at 5.33. It was looking like anyone's game until Pascual carved a perfect line across the wave, earning a 7.83 and finally clinching that long elusive gold medal.

Women's Stand 2: A Sole Competitor and a Larger Issue

In Women's Stand 2 there was Zoe Smith. And only Zoe Smith. Since she was the only competitor in her class, Smith surfed in the same heats as the Women's Stand 3 class. In contrast, the Men's Stand 2 started with 10 competitors, a glaring example of the gender gap in para surfing. Across all nine classifications, the need for more women competitors is undeniable. This was especially clear in the initial qualifying rounds, where the number of heats for the Men's side of classes would double that of the women's. Women may have made up a third of the athletes at the 2024 competition, but there is clearly still much work to be done.

However, Smith still put on a show, with her strongest rides in the final. Carving out some turns she ended the competition with a solid 9.77 points, proving that she belonged on that gold medal podium.

The Future of Para Surfing: L.A. 2028 and Beyond

As the sun set on the week, there was one shadow over the celebration: para surfing's absence from the 2028 Paralympics in L.A. With the sport's Southern California roots and LA28's theming around diversity, introducing para surfing in the 2028 Paralympics seemed like a no-brainer.

Unfortunately, the International Olympic Committee did not feel the same way.

Surfer Josh Bogle launched a petition to try and start a conversation with organizers, the para surf community ready and willing to compromise and adapt in order to be included in the upcoming games. But even after collecting over 28,000 signatures, they still haven't received an answer.

The Paralympics has its bureaucratic problems, but there's no questioning the fact that bringing para surfing to the Olympic stage would help the sport grow and gain funding. Right now, athletes rely on non-profits, GoFundMes, and their personal savings to travel to events like the World Champs. For now, it seems that athletes will have to wait until Brisbane 2032 for para surfing to compete under those Olympic rings.

Still, as the anthems played at the closing ceremony, it was hard to feel anything but joy. Watching athletes beam as medals hung around their necks—knowing that moment was the culmination of hopes, dreams, and years of hard work —was a reminder of what makes this sport so special. And as the waves kept rolling post competition, you could bet every competitor had the same plan: get back in the water and chase the next one.



Team
Gold – France
Silver – USA
Bronze – Australia
Copper – Spain

Women's Prone 1
Gold – Sarah Bettencourt (USA)
Silver – Paloma Onate (ESP)
Bronze – Jonne Moleman (NED)
Copper – Suzanne Edwards (ENG)

Men's Prone 1
Gold – Kai Colless (AUS)
Silver – Joel Taylor (AUS)
Bronze – Cleuson Araujo (BRA)
Copper – Casey Proud (HAW)

Women's Kneel / Upright
Gold – Audrey Pascual (ESP)
Silver – Vera Quaresma (BRA)
Bronze – Emma Dieters (AUS)
Copper – Erin Koffel (USA)

Men's Kneel / Upright
Gold – Llywelyn 'Sponge' Williams (WAL)
Silver – Dariel Melendez (CRC)
Bronze – Altair Olivares (CHI)
Copper – Mark 'Mono' Stewart (AUS)

Women's Prone 2
Gold – Jocelyn Neumueller (AUS)
Silver – Sarah Almagro (ESP)
Bronze – Georgina Melatini (ARG)
Copper – Beatrice Duran (FRA)

Men's Prone 2
Gold – Freddy Marimon (COL)
Silver – Davi Teixeira (BRA)
Bronze – Cliff Gralton (AUS)
Copper – Jose Martinez (USA)

Women's Stand 3
Gold – Charlotte Banfield (ENG)
Silver – Mireia Cabanes (ESP)
Bronze – Stella Papetti (ITA)
Copper – Ursula Pueyo (ESP)

Men's Stand 3
Gold – Luciano Silveira (BRA)
Silver – Colin Cook (HAW)
Bronze – Eric Dargent (FRA)
Copper – Naomichi Katsukura (JPN)

Women's Stand 2
Gold – Zoe Smith (ENG)

Men's Stand 2
Gold – JP Veaudry (RSA)
Silver – Forrest Weinberg (USA)
Bronze – Nachman Balulu (ISR)
Copper – Philippe Naud (FRA)

Women's VI 1
Gold – Marta Paço (POR)
Silver – Valentine Moskoteoc (FRA)
Bronze – Carmen Lopez (ESP)
Copper – Juliette Mas (FRA)

Men's VI 1
Gold – Elias Ricardo Diel (BRA)
Silver – Thomas Da Silva (FRA)
Bronze – Ben Neumann (GER)
Copper – Kirk Watson (AUS)

Women's VI 2
Gold – Alelí Medina (PUR)
Silver – Ling Pai (CAN)
Bronze – Heloise Lauriol (FRA)
Copper – Lou Mechiche (FRA)

Men's VI 2
Gold – Pierot Gagliano (FRA)
Silver – Roy Calderon (CRC)
Bronze – Luis Medina (CHI)
Copper – Matt Formston (AUS)

■ ABILITY

by Alex Fig

Alex Fig is the founder of Butter Mag, an online magazine that strives to highlight underrepresented athletes in outdoor action sports.

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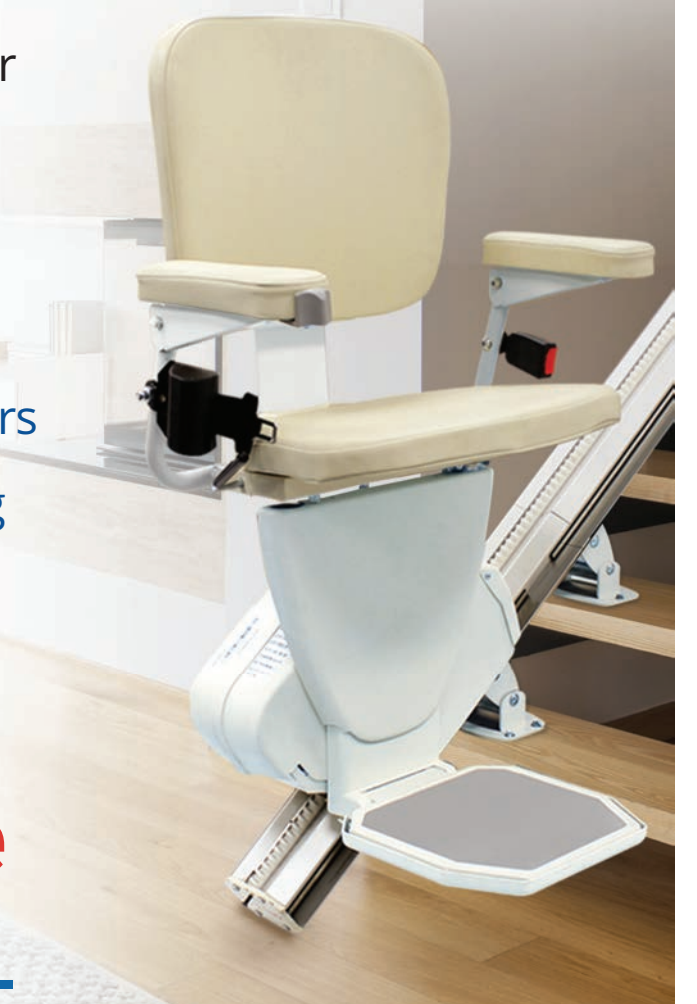
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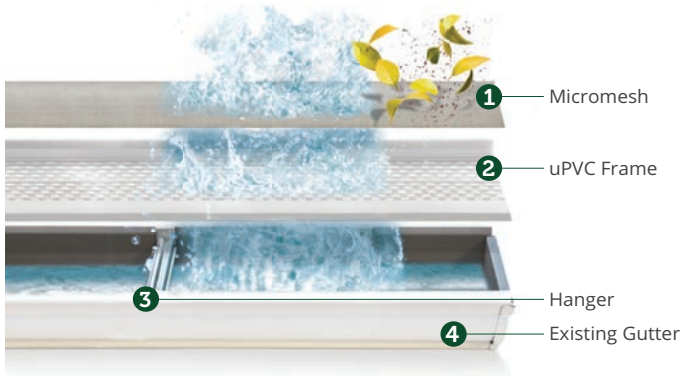
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