

LONG HAUL PAUL SWITCHIFY HUMOR — SQUEAKY WHEEL CROSSWORD PUZZLE CONFERENCE/MARKETPLACE

ABILITY

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DR. MONA

Blind Soccer

Oseas De Leon / Lighthouse

Maayan
access now!

Nat's What I Reckon

Comedy, Music and Cooking

LE MANS

ADAPTIVE RACING BEYOND LIMITS

NYLE DIMARCO



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Le Mans



Nat



Maayan Ziv



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Awkward! Woman with CP Actually Does Know Your Boyfriend's Neighbor's Cousin Who Uses a Wheelchair

NEW YORK — In an inspiring moment that local disability organizations call a “triumph for stereotyping,” local woman Ava Dudley, who has cerebral palsy, made an exciting announcement: She does know your boyfriend’s neighbor’s cousin who uses a wheelchair after all.

Dudley, 32, didn’t think much of it when first asked if she was friends with this wheelchair user because, she mused, “It was the same tired shit. ‘She has one of those chairs too. Blue, I think. Maybe purple. She looks a lot like

you,’ and a photo quickly shoved in my face at the supermarket.”

But soon after that fateful exchange in the produce aisle, Dudley remarked, “Everything clicked.” Your neighbor’s boyfriend’s cousin, identified as 33-year-old Alyssa Ferdinand, boasts a special connection with Dudley. They were traumatized by the same unwelcome clown at the physical rehab hospital thirty years earlier.

“Of course I know Alyssa!” exclaimed Dudley. “She



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didn't look familiar at first, but somewhere in the back of my mind, I remembered."

After spending her afternoon scouring the social media accounts of literally every young disabled person in the Tri-State area, Dudley found Ferdinand's profile, admitting she felt spooked at the mere thought of a peer-aged gimp she didn't at least recognize from a harrowing paratransit ride.

"They say not all disabled people know each other," she said with a sigh, "but the truth is, we kinda do. If we don't go to the same PT clinic, we've likely given each other The Nod at the mall once or twice."

Dudley confessed that she couldn't rest until she explored all possible ways the young women's lives may intersect.

"I started where I always start," she said, beaming. "By combing through people who also follow the Permobil Instagram page. When that didn't yield any results, I looked through the Facebook friend lists of all my comrades from cripp camp. Before I knew what was happening, I was deep in the discussion threads of the Neuro-genic Bladder Babes group, and there she was."

Dudley's epiphany came when flipping through Ferdinand's public Facebook album titled "Childhood Memories." Among the photos was a snapshot featuring a group of disabled toddlers gathered in a hospital playroom with a disturbingly cheery clown. There, cowering beside

then-three-year-old Ferdinand, was then-two-year-old Dudley.

When Dudley noticed the picture, she said, memories hit her like a tidal wave. Mr. Giggles the clown had visited every Wednesday while she was inpatient in 1996. She recalled that she and Ferdinand felt equally terrified of the donor-funded circus demon and spent those afternoons warding off his unsolicited "I Am Special" stickers.

Upon friending each other, the duo discovered their connection doesn't end there.

A bitchy bunkmate from Dudley's childhood cripp camp is the same girl that bullied Ferdinand at adaptive swim lessons, a mutual resentment the reunited pair called "magical." The women, who in fact look nothing alike, plan to meet for lunch soon, and shared that they look forward to being accidentally called by each other's names, a rite of passage for any vaguely associated disabled people. ■ **ABILITY**

by Kathleen Downes



the-squeaky-wheel.com

Founder Steven Verdile



It was cold and drizzling hard as my Yamaha approached the international border crossing. There was no line of vehicles in front of me, in fact, I had not seen other vehicle for the last 20 miles. I picked this particular crossing to get back into Maine because I knew it was never busy. Although I do not mind riding in rain, I hate just sitting idle in a storm because I get twice as wet and my face shield and glasses fog up.

A look at my passport was followed by a few official questions about my citizenship and my motorcycle trip from the Pacific Northwest across almost all of Canada.

“Your license plate reads NOCAR. So you really don’t have a car?”

“Well, to be completely honest, I do have a car, but I don’t use it much.”



Where Are You Going?



“So, your license plate is a deception?”

Because I had to open my visor, it was no longer keeping the rain outside my helmet and drops were rolling down my face, both sides of my glasses and the inside of the plastic face shield. Blinking away the water from my good eye, I couldn’t tell if he was being serious.

I was either getting stripped searched or it was just a real slow day because the US Customs officer stood up and exited his port-a-potty sized guard shack to have a look at me and my well-travelled motorcycle. No longer worried, I recognized his sincere curiosity. I often see it when people realize I just travelled across the entire continent in a short time, alone, on a motorcycle.

However, it was raining and I had hoped his unprotected head getting pelted would clue him in that I was getting wetter by the second and just wanted to get on my way. Out of habit, I kept looking at my right side mirror for approaching vehicles, but there were none in sight. Normally, I enjoy meeting strangers and talking about bikes, but I had been away from my wife and our dog for almost two weeks, and I was hoping to make it home in a few hours for dinner. Did I mention I was getting very wet without the benefit of speed blowing it off my Gore-tex riding suit?

I may have dozed off at one point, but I will swear on a bible after he showed me the pictures of his motorcycle on his phone, he proceeded to show me photos of his grandchildren.

After what seemed like three weeks, a red Toyota Corolla with Maine plates pulled up gently behind me and my Federally employed friend quickly went back into his Fotomat Booth and with a raised arm gesture, waved me into the USA.

He really was a nice guy, and if I really wanted the conversation to continue, I would have liked to explore the real reasons he feels unsafe riding his motorcycle. It makes me sad to hear people giving up something they once enjoyed and are passionate about. It is not an uncommon statement and I hear it from many motorcycle owners all across the country. They feel it’s only a matter of when, so they think they are being safer by riding their motorcycles infrequently, sometimes only a few hundred miles a year.

I would have shared how I just spent ten days on the road covering over 8,000 miles sharing the road with hundreds of thousands of other drivers and not once did I have a close call or even had to hit my horn! This was not unusual for me at all, as I always ride aware that my safety is my responsibility and I ride as if the drivers in the other vehicles not only do not see me, but



Crystal Lake, Gilmanton Ironworks, New Hampshire 10/16/24

August 2025

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Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
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7 National Grandparents Day	8	9	10	11 Patriot Day	12	13
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Bear Butte, Sturgis, South Dakota 8/5/24

October 2025

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Thanksgiving Day

they do not NEED to see me.

“I have a 10 year old Honda. It’s got 3500 miles on it. I only ride it once in a while, because people are always on their cell phones today and as I’m sure you know, every one of them is trying to kill us.”

Had our conversation been in the dry over a cup of coffee or a beer, I might have mentioned the more miles I ride, the safer I am. Learning the skills needed to ride a motorcycle properly and then keeping those skills sharp by riding every day is the best way to not feel so vulnerable on two wheels. I could tell he was in awe of my trip and journey, and my only regret is that I did not spend the time to convince him to get out and spend more time on the motorcycle he clearly loved. I bet it wouldn’t take him long before he felt comfortable enough to enjoy traveling the country the best way possible, on two wheels.

I know how lucky I am, getting to travel across the county on a motorcycle, sharing my story with others who have chronic illness. However, I also hope my travels inspire motorcyclists to dust off their two wheeled machines and go get some saddle time.

■ ABILITY





Maayan ZIV

Access Now!

For Maayan Ziv, access is more than a feature—it's a foundation. What began as a thesis project to crowdsource accessibility information has grown into AccessNow, a global platform that connects users with real-time insights on accessible spaces through a free mobile app and website. With a decade of innovation behind it, the company is now expanding beyond place-based data to influence education, events, and industry partnerships—all with a mission to build a more inclusive world.

In this conversation, *ABILITY Magazine's* Lia Martirosyan and Jennifer Woodall met with Ziv to discuss the journey behind AccessNow, the evolution of her cultural festival AccessFest, and the growing need for platforms that amplify disabled voices. Ziv shares candid reflections on representation, city infrastructure, and her creative roots in photography—illuminating how storytelling and lived experience can drive social change. From launching a grassroots movement to receiving the King Charles III Coronation Medal, Ziv's work offers a compelling blueprint for what accessibility can look like when it's informed by the very people it's meant to serve.

Jennifer Woodall: Can you tell us about AccessNow?

Maayan Ziv: It really started as a thesis project. The idea was maybe we could crowdsource information about the accessibility of places. We could invite people to share information about the places that they know, experiences that they've had—whether they be positive or negative—and get more information about very basic things like entrances and washrooms and



Maayan Ziv created AccessFest via AccessNow to celebrate inclusion and accessibility

all different types of access. So, 10 years later, AccessNow has grown into a company that shares information all around the world. Increasingly so, we've also grown into education and events and expanding that definition of being a go-to resource for accessibility information to being beyond just place-based information to also experience services, and supporting customers and supporting companies that are also looking for information about accessibility.

Woodall: Is AccessNow an App?

Ziv: So AccessNow started as a website and now has a mobile app. It's free to use, and so whether people want to use our browser-based map online or download the AccessNow app, they can search for places in their own neighborhood or around the world. And whether a company, a government, or an individual has shared information, you'd be able to get answers on what types of access you might be expected to find there, and you're always encouraged to contribute yourself. So, if you know something about some form of access, about a space that you've been to, we're always engaging and encouraging communities to contribute. That's how we grow.

Woodall: Can you tell us about AccessFest?

Ziv: Yes. So, AccessFest really was an idea that started very long ago. Over the course of being a founder of an accessibility company, I've had the opportunity to travel all over the world. I've been to many conferences and events, spoken about accessibility and met with great

people. But often we find that accessibility conversations happen behind closed doors. They happen within conversations and communities of people who already care about access, already know about access, and are in the space of creating or improving access. They are typically also a similar format like conferences or trade shows. There aren't that many culture festivals that are dedicated to amplifying the message of inclusion, so AccessFest really is a response to the desire for people with disabilities to be able to show up and be unapologetically ourselves and celebrate the power of inclusion and showcase why accessibility is so important.

Lia Martirosyan: Do you have local talent, international talent — familiar faces?

Ziv: AccessFest is really focused on amplifying disabled talent. That's one of our key focuses. So, everyone who's performing on main stage does identify with disability. We have a series of different performers with different experiences, from Matt Maxey, for example, who is both a deaf interpreter, but then also runs his own ASL workshops. He's also the performer who recently did the ASL interpretation for Kendrick Lamar's Super Bowl performance. We've got folks like Mattmac who is from Winnipeg, I believe, and he's an Indigenous pop trap recording artist. He recently won the CBC Searchlight competition here. We've got folks like Courtney Gilmore. She's a Toronto-based comedian who was on Canada's Got Talent, who is going to be gracing this stage and bringing us some laughs. So, it's really a diverse lineup of different types of artists and performers, as well as we have a speaking series called



Unfiltered, where folks with disabilities are coming together to talk about things like media representation and the next generation of leadership from a youth perspective. We've got one called Designed AF, which is looking at accessibility and design and whether that be digital, physical or experiential. It's really a broad day of programming.

Martirosyan: Did any of the inspiration for creating AccessFest come from your experience of not being able to access festivals in the past?

Ziv: Not really, no. The festival stems from a desire to have something that's ours and owned and dedicated to inclusion. Although, it has come up in conversation definitely with other folks that are expressing that they wish all festivals were this accessible. Our goal is not only to make the festival accessible, but also to celebrate the diverse and dynamic nature of disability within an accessibility conversation. It's very rare that you'll have more than one moment within any type of event dedicated to accessibility. We've decided that that's an entire festival worth celebrating, and that's really what we're focused on.

Woodall: You said this was 10 years in the making, can you talk about the process and the work that you had to put in to get to this point?

Ziv: AccessFest was always something that I longed for. AccessNow has been around for 10 years, and since the very early days, I've always been a guest in the conversation about accessibility. Often, disabled people are

simply that or guests within larger spaces held by other organizations that include access but are not totally or only explicitly focused on that. So, AccessFest really is the 10-year journey to realizing that "Why not us?" Similarly, with the launch of AccessNow app, we've just decided that we want to create a space that's celebratory and unapologetic and broad enough that anyone could see themselves being part of it, disabled or otherwise.

Woodall: What research goes into picking a venue to host something like this?

Ziv: There's a lot of different things that go into it. When we were looking at venues, we were hoping for a location that would be quite central in Toronto, that would be easy to navigate to with public transit, that was also accessible. We looked for a space that was quite barrier free—so not many obstacles, no hallways or issues with elevators or just things that get clunky—especially when you think about the broad and diverse nature of access needs. We wanted a very open space. AccessFest is in partnership with the city of Toronto, so we've been able to take over a public park, which is very open and very central. In the middle of the park, there is an eternal flame that's been there for as long as I can remember, but what many people don't know is that that flame is actually there to symbolize the spark of the resilience of the disability community. So, it felt very fitting for us to be able to host AccessFest right there in that space at David Pecaut Square. AccessFest is in year one of hopefully many years to come, and although AccessFest is based in Toronto, it's an open



invitation for anyone from anywhere who would like to join us.

Woodall: Do you find the infrastructure and cityscapes in Canada accommodating to people with disabilities?

Ziv: I'd say it varies. I mean, similarly to many other places in the world, you can get some great access and some places that still need improvement. I think I'm pretty lucky. I live in the city of Toronto, where I'd say for the majority of the time, I'm able to navigate pretty independently. Like, yes, there is still a need to improve access. Not all of our transportation is 100% accessible. Not every space where business is operating is totally accessible. So, there's still work to be done, but for the most part, having had the opportunity to go many places, I'd say that we are at least pushing in the right direction.

Woodall: You were awarded the King Charles III Coronation Medal. Can you tell me about that?

Ziv: Yeah. It was a really special honor. Here in Canada, folks were awarded this medal for contributions to Canadian society. Mine was in relationship to the work that I've done with accessibility, inclusion, and advocacy. I received my medal from Senator Chantal Petitclerc. She's a very decorated Paralympian, and also now a senator, and having a chance to be received, and to have been acknowledged by another disabled leader, is just that much more meaningful.

Woodall: Do you know Lisa Franks?

Ziv: I do

Woodall: We interviewed her for the magazine. She spends her winters down in California rather than Canada, and we caught her surfing on the beach one day. There was an event going on and a lot of Paralympic surfers were participating, including international athletes like Lisa. Switching gears a bit, can you tell me about your photography?

Ziv: Sure. It feels like a lifetime away now, but I would say I found my voice through photography. When I was in high school, I went on a trip to New York City, and it was supposed to be a theater trip with all of my classmates, and when I arrived, my wheelchair was broken and I could not use it. It had broken in the flight—which is not the first or the last time—and so I didn't get to participate in the regular itinerary. It was about a day later, I received a temporary loaner device from the airline and was able to at least get around, but it was not really comfortable and not really supporting me well. I had to just navigate slowly around the hotel that I was staying at, and just try to get a little taste of New York City. I had a little point and shoot camera and I started just taking pictures of things that I was seeing, and it was the first moment where I realized that I could communicate what I was experiencing without words, and I could invite people to be closer to my perspective. So, I think photography for me became very quickly a vehicle to share my perspective on the world with folks. It really opened a whole new pathway to advocacy without me even knowing it. I've always been a creative. I've always loved the arts and media, and it's still something that I love to do. But I'm not currently working professionally as a photographer. It only comes through in my work when we need a photo. But I always have my own photos.

Woodall: I noticed on your photography website that you got to participate in a project called Kids Who Can. Can you tell me about that?

Ziv: So, the Kids Who Can was a photo journalism project that I did, where a group of about 13 photographers went to different Easterseals camps across the country. I was assigned one of the camps, and I was also the only photographer with a disability who participated. It was an amazing opportunity. It was actually one of, I'd say, the first moments where that passion that I had for storytelling was touching another part of my life. Before Kids Who Can, I was taking pictures of celebrities and then models, but I had never been to an Easterseals camp. I'd never been to camp as a kid with a disability either. So, not only did I get to experience camp for the first time, along with the others that were there for the first time, I got to bring those stories back and be part of a big exhibit, which was great. ■ **ABILITY**

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Meet Oseas De Leon, Senior Technology Specialist at Miami Lighthouse for the Blind and Visually Impaired, and a blind player on the USA Blind Soccer Men's National Team. Also a hopeful for the LA28 Paralympic Games, Oseas' experience as a national player is helping Miami Lighthouse usher in their own blind soccer training initiative for toddlers through high school students. The program will help blind and visually impaired people learn how to play the world's most popular sport - and learn valuable skills in the process.

ABILITY Magazine's Gina Velasquez caught up with the soccer phenom Oseas De Leon and Virginia Jacko, Miami Lighthouse for the Blind and Visually Impaired CEO, to discuss how blind soccer offers blind children the opportunity to get involved in the fast-paced, physical, and technical game.

Gina Velasquez: Hello Oseas and Virginia. Good to speak with you.

Virginia Jacko: Thank you for this opportunity. We're very grateful.

Jacko: Oseas, could you tell us something about your background? When you went through the educational system, was there a special education program for kids who were visually impaired, or did you go through the traditional school system?

Oseas De Leon: I went to a residential school for the blind where I am originally from, which is Guatemala. I'm one out of seven. My six siblings are fully sighted. I went blind when I was three years old, and I learned to play soccer basically when I started walking. At 3, soccer was just kicking and running after the ball, but there was no real soccer training in Guatemala. We would just kick and run after the ball. We had fun, definitely. That was the idea. But we didn't really have good coordination to play with the ball. I didn't really learn how to be skillful with the ball until I was an adult. As

an adult I learned how to dribble, how to avoid opponents, how to score goals, how to kick the ball with different parts of my foot, of my feet in this case.

Velasquez: Did you have soccer balls with the ball bearings in the ball?

De Leon: No. The ones we had were extremely heavy for 5 or 6-year olds. They were not the proper soccer balls. At home what we did was we would poke a little hole in a plastic ball and put some little rocks in the ball to get the sound that I needed. So that way I was able to play with my siblings, not just soccer, but also baseball. It was a bigger ball to be able to hit it. But at the end of the day, I had as much fun as my siblings did.

Velasquez: So in Guatemala, you created these reach-arounds to enable you to play soccer and baseball?

De Leon: Yes. Back then, blind soccer was not a thing. So we didn't use words like voy, voy, voy to avoid contact. We played disorganized, but with a lot of passion for the sport. It was pretty scary. We didn't really play blind soccer. We just played as friends who were also blind. There were no adults, just kids playing around. You could not really call it a sport. It was just basically a recreational activity.

Velasquez: And so how old were you when you came to the States.

De Leon: I moved to the US back in 2000 when I was 21. I became a client at the Miami Lighthouse, and I received orientation and mobility training to learn my way around Dade County. I learned how to get on the busses, how to go to school, how to cross the street, how to use the traffic lights to cross properly. I already had training in Guatemala so I knew how to use my cane. But unfortunately, because the sidewalks in Guatemala are not good, sometimes you would find a drainage open, I had to use the technique where I dragged my cane. Here, my orientation mobility instructor moved me to a two-touch technique where I lift the cane and I'm able to walk faster. That was the very first thing I learned here at Miami Lighthouse for the blind. Then my Braille skills allowed me to learn English, to read it, write it, and speak it. I also received computer training.

Velasquez: That's interesting. You learn to speak English through Braille.

De Leon: Yeah. Basically, I had to take notes to write English properly. It was really tough. Spanish, that's my first language, is a very different language. As an adult, it was hard to really understand the patterns of the words. So writing how the words sounded to me phonetically in braille is how I improved my pronunciation.

Velasquez: I see. Instead of all the weird English spelling, you wrote it fanatically in Braille. How did

you get into soccer as an adult?

De Leon: Well, for over 10 years, I didn't really touch a ball. But then back in 2018, we learned that we had free access to a soccer field. And there was also a gentleman who was trying to put together a group to play soccer. This gentleman gave us some training, and we started meeting with friends every Wednesday to play for a couple of hours. It was a lot of fun to go back to something that I played as a child. It was amazing.

Velasquez: Who was this gentleman?

De Leon: That was a gentleman who was losing his eyesight. He was getting services at the Miami Lighthouse. And this story of soccer and this gentleman reminds me of when I was a child, my mom wanted to make sure that I would continue doing something as a blind child, something that I was doing as a sighted child, something that would make me happy. And that was soccer. So this gentleman also wanted to continue doing something that would give him joy, and for him that was soccer as well.

Velasquez: Can you tell me what the rules are? How do you play?

De Leon: We call it blind soccer, but I think adaptive soccer is good as well. I would say the main rule is that whoever is coming to battle for the ball has to announce it. And that's with the word "voy," which means "coming" in Spanish. So if Virginia is playing against me and she says voy, now I have an auditory cue of where she is as a reference. Then I will try to trick her, try to move to my right, and then come back quickly to my left. So that's how to use voy. We also have three-sided people telling us what to do in the field. We have the goalkeeper who is sided. He will take care of the first third of the field. Whoever is in that third, he will say, "You're going first." And then everyone else Doesn't move, just the person he said will go first. Another of our coaches directs and controls all the traffic in the second third. Whoever moves in that third he is responsible for the directions. If our second player to go for the ball is in that third, he will move that player. The coach will say, "Oseas goes first" or "Virginia, you go," and no one else moves. So again you know whoever you're going to battle for the ball in the other team. If we don't say boy, the referee calls a penalty on us. Then behind the opponent's goalie, there is our third person. If a player is in the third, then this coach who is behind the opponents' keeper will call for that player to move to a specific spot. He will say, "dribble, dribble, dribble," and then he will say, "shot." So that's when we know when to take a shot.

Velasquez: So dribble means to kick the ball forward?

De Leon: Dribble means, "drive, drive, drive," to try to trick our last opponent, as soon as we trick him, he will say, shoot, shoot, shoot. And then we will try to aim quickly at his voice. He will be moving behind the



Oseas De Leon of the Miami Lighthouse for the Blind and Visually Impaired practicing Blind Soccer

opponent's goal, saying, here, here, here, where he finds a spot that the goalie is not covering. Then we aim and shoot really fast and powerfully.

Velasquez: And what about the ball? What is the sound?

De Leon: I brought a ball with me. I'm going to shake it. This is what it sounds like. It has six pockets with rattles.

Velasquez: It's a loud rattling sound.

De Leon: It is loud, but since it's outdoors, you have to have very good hearing skills. The audience is supposed to be really quiet. But even though the audience is quiet, there are a lot of people talking. So you have to have very good hearing skills. What are you hearing? Is it coaches? Is it opponent coaches? Is it the boy, boy, boy, and all that.

Jacko: And we also have side walls that we put up. The sound bounces off the walls.

De Leon: That is correct. I forgot that The whole field is surrounded by these panels, and they are around 60 inches tall. That helps with not losing the ball, but you can also make a path to the wall and receive the ball from the wall. But yes, it's a game that's going on all the time.

Velasquez: So even though the audience must be very quiet so you could hear each other, a lot of people in the stands still speak. Then you have the coaches on your team telling you guys what to do while the other players from your team stand still. But what if, for example, you're going up against Virginia, would Virginia also be

shouting up for instructions, and would her coaches be telling her what to do at the same time?

De Leon: That's correct. Virginia would be saying her "voys" and her coaches will be telling her which way to move. If she's saying "voy," she's going for the ball. So she's coming towards me. I would dribble her. And thinking that I will dribble her, her coach would tell a second player to come for me. Virginia would probably stop battling for the ball. But basically, in the game. I'm going fast. She's already behind me. Even if she wants to come back. It will be hard for her to come back. She's already out of the picture. Now I have to clean the other three players in shifts.

Velasquez: Right. Then her coach would tell another player to go up against you.

De Leon: Right.

Velasquez: So there's a lot of listening. There's a lot of concentration.

Jacko: And this is what's amazing for the one, two, three, four-year-olds, children up to kindergarten. When you have a vision disability, to be able to have the ability for echo localization in terms of sound is a great talent to have. So developing that ability at a very young age is important.

De Leon: And I will tell you, Gina, that those skills translate to being at a corner, crossing a street and listening for traffic. When the parallel traffic stops, I know what to do. I know when to cross the street. I don't really have to know if it's a red or green light. Because of the pattern of the traffic I hear, I am able to decide when

it's a good time for me to cross. And I can tell you that unfortunately, those who have not have the opportunity to play a sport, their orientation is not as good. You can tell me to go any place, as long as there is a sidewalk, I'm able to travel anywhere. I've been to different states here, and I'm not scared of crossing streets because I am confident that I know how to do it properly. I'm not going to cross in the middle of the street. I always look for the corner, and then I'm able to align and make the decision when to cross.

Velasquez: Absolutely. That must be great for confidence building, and that's a great thing to teach little kids.

De Leon: It does build confidence. A lot of times when I was younger, in my teenage years, my self-esteem was low. I would think, "why do my siblings had so many opportunities and I don't." But I'm playing soccer now. This is something that makes me feel proud. Yes, I also play soccer. When they talk about tournaments, I can also talk about tournaments. They talk about wearing a uniform, and I can tell them that my uniform is really nice too. It's a beautiful uniform. I can be very happy because I scored a goal or not as happy because I made a mistake, but I have that. And I can sit down with a friend who's sided and share those experiences. Somebody who has not had that opportunity doesn't have that. I mean, it's just what I think, Gina.

Velasquez: Oh yeah, I completely understand what you mean. I'm blind as well. And I know that when you go blind, you begin to feel left out of things that everyone else is doing.

Jacko: I created a tagline at Miami Lighthouse, and I trademarked it, and it's, A blind person can do anything a sighted person does. They may just need to do it a bit differently. Soccer is an example of that. So the United States Association of Blind Athletes (USABA) did have a Paralympic sport goal. And now, because the games are coming to California, they will have a Paralympic blind soccer team, and we're very, very delighted that Oseias made it to the national team.

Velasquez: You're on the men's national team? That's wonderful. When are the next Paralympics?

De Leon: The Paralympic Games are going to be in 2028 in California. I've already been to San Diego for three camps. That's where the center of training for the men's national team is located. This was my first year. In November, we played England and Japan. So this was our very first tournament. England is among the first top 10 teams out of 100, and Japan is number five. We had never played an international tournament. It was a great experience. And there is a tournament in December of 2025 in Costa Rica where the US is going to be playing Mexico, Central America, and three other countries from South America. Our goal is to be number one

in that tournament so that we can be moved up to the top league where all the hard teams are, the European teams and all that.

Velasquez: Is soccer new to the Paralympics?

De Leon: It is. I believe it started being played in 2016. And the US didn't have a team back then. This is going to be the USA's first time participating in the Paralympics.

Velasquez: The first time in 2028?

Jacko: The first time that the United States will have a national team competing in blind soccer.

Velasquez: That is remarkable, and congratulations.

De Leon: Thank you.

Velasquez: So it's been quite a journey for you to go from a little kid in Guatemala who wasn't able to play with your sighted friends and family members to now being on the USA men's national soccer team.

De Leon: That is correct, Gina. But I can tell you that Miami Lighthouse for the Blind has been a great support for me. And I've been working there for 18 years. I'm 46 years old. I'm not a teenager. But Miami Lighthouse for the Blind has been my second home. And they have supported me in everything that I've done here. I completed a bachelor's and a master's degree, and the Administration and my coworkers have always been supportive of what I do. I never heard someone say, "Oh, you shouldn't do that." Now as a soccer player, nobody has said, "you're too old." On the contrary. We held an exhibition game here in February and we were able to bring close to 200 spectators. Usually the national team has had under 100 spectators in other states. So it was an amazing event. And that's because Miami Lighthouse supports everything that help somebody who's blind to develop any skills that they're working on.

Velasquez: Did you say 200 spectators?

De Leon: Around 200 spectators. A lot of them were clients or former clients. So they learned through that experience that we can also have fun at a higher level, a competitive level. We had a lot of children there. Children were exposed to soccer as well. Children who were blind. So it was an amazing event.

Velasquez: It does sound amazing. You're also a senior technology specialist at the Miami Lighthouse?

De Leon: That is correct. I teach assistive technology and Braille, in English and in Spanish at the Miami Lighthouse for the Blind. I help clients who want to go back to school, either college or university or even graduate school. We also help them go back to work. I work



on a lot of different things with them, such as putting together a resume, learning how to use artificial intelligence, and not just on the computer, but also on mobile devices. I do have a lot of fun. I love my job, and so seeing the impact that we can make on our clients is so rewarding every day.

Velasquez: It's Sounds like a great place to be. Tell us about the blind soccer initiative you have created at the Miami Lighthouse.

Jacko: It's a comprehensive blind soccer program, which has never existed. That is because the age range in Miami Dade schools for a visually impaired teenager goes up to age 22. But the fact that we're starting developing the curriculum for the one, two, three, four-year-olds then all the way through 22-year-olds, That's why I'd like to use the word comprehensive program.

Velasquez: And it's the first of its kind?

Jacko: Yes it is, as a comprehensive blind soccer program. Usually, our kids get relegated to no PE because teachers cannot come up with accessible opportunities for our kids who are blind to be active. And this is an amazing opportunity for the little ones starting from age one to start working on coordination and hearing coordination, as well as hearing-foot coordination. This is key in the sport of blind soccer

It's extremely important to orient ourselves, not just in the soccer field, but in any familiar area.

Velasquez: Who created the initiative at the Miami Lighthouse?

Jacko: I was inspired by Oseas. We have a school for blind children, We serve from blind babies to seniors, and besides our eye care program, there are 26,000 program participants in total each year. So we introduce

blind soccer as part of our strategic plan, Blind soccer required board approval. We made that our strategic plan for this past year. And we wrote a proposal to the Children's Trust. Here in Miami, a very small portion of people's property taxes go to the Children's Trust to support programs for children. They had a solicitation looking for innovative ideas. We were one of only 10 proposals funded for children's programs throughout the whole Miami Dade County. By the way, the Miami Dade school system is the third largest school system in the United States. So it's a huge school system with a lot of children. We occupy an entire block here in Little Havana with what one would normally call a playground. For us, it's an edible garden plus grassy areas. We're converting a significant portion of it now for a mini soccer pitch. So in January 2025, the grass should have been properly seeded and leveled with the drainage so we can have our own mini soccer pitch right here on our campus.

Velasquez: So have you already started the soccer instruction for the children, or is it going to start when the field is ready?

Jacko: The grant began October 1, 2024, and we launched the initiative the week of October 1st when we received the funding.

Velasquez: And how many children did you have at the time?

Jacko: We are committed to having 85 children of all ages involved in our academy. Our academy is a school in collaboration with Miami Dade Schools, and it starts with pre-kindergarten, which means one through four-year-olds, as well as kindergarten, first and second grades. In this coming school year, we are adding third grade. The total number of students in the academy in round numbers is about 50. We will be adding another 35 from our Saturday program, which is a Transition program for Teenagers called STAR program. They are school-age children that are not in our academy from kindergarten through middle school.

Velasquez: So is it a soccer academy you started for the littlest ones, or does the school include academics?

Jacko: For students enrolled in our academy, it's a full time academic school for which blind soccer is part of the curriculum. Youth who attend their community schools attend Miami Lighthouse on Saturdays.

Velasquez: Oh, I see. So the academy is your school?

Jacko: Yes, our school is called Miami Lighthouse Academy.

Velasquez: And Oseias, are you the head coach or instructor?

De Leon: No, my role in the project is as a consultant.

Jacko: He is not an employee of the academy, but He's a project consultant who we go to for everything because he's the smartest person. We collaborated with Barry University in Miami, and the United States Association of Blind Athletes, and now have 12 people, the largest number at one time, become certified blind soccer coaches. These 12 earned certificates as USABA certified blind soccer coaches. Our program is not a USABA program, however, we now have these individuals that know the game of blind soccer and can assist with curriculum and coaching. For us to have 12 credentials under USABA a blind soccer coaches is significant.

Velasquez: What are your long-term soccer goals after the 2028 games, Oseias?

De Leon: That's a great question. Right now, Gina, I'm living this dream year by year, the team selects players every year, so it's not guaranteed my staying with the team until the 2028 games, and that goes not just for me, but the entire team. They are going to make this election for the 2025 team I believe in March or April. I think I'm going to be in the team this year as well. My performance in the last camp was the best of this year. So for sure, I'm going to be in 2025. If I make it to 2028, I can't believe it -- just talking about it, I get goosebumps because Paralympics is a big, big word. Probably that would be my last year because then the next term will be in another four years, and I don't think I would be doing that. But thanks to soccer, I started running. So I think I'm going to continue running and participating maybe in different races and being active. In the end, that's what I want. I want to stay healthy. And then also enjoying coaching blind soccer with children and teenagers at Miami Lighthouse. Maybe helping identify talent here that can be in the national team.

Jacko: And maybe we grow the adults program next. I would like to be able to do that, to begin growing a blind soccer program for adults.

Velasquez: That would be for people over what, 30, 35?

De Leon: Maybe over 22, because our program right now ends at 22. So we would be 22 and up.

Jacko: Exactly. Yes. Confirmed.

Velasquez: Do you have any other thoughts you'd like to share?

Jacko: Just that this all ties in with our motto, that a blind person can't do anything a sighted person does, and we're doing that with blind soccer. ■ **ABILITY**

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DR. MONA

Understanding the Current Science Behind Autism and more...

In today's information-saturated world, even the most complex subjects—like autism—are too often reduced to inflammatory soundbites. When public figures make sweeping claims about “finding the cause of autism,” it not only misrepresents decades of scientific research, but also fuels stigma and misinformation that can deeply affect families and communities.

In this conversation with *ABILITY Magazine's* Lia Martirosyan, Jennifer Woodall and Dr. Mona, a board-certified pediatrician and advocate for evidence-based care, addresses the widespread myths surrounding autism—including the long-debunked vaccine narrative—and explains how increased understanding, awareness, and early intervention are driving rising diagnosis rates, not an underlying epidemic. Drawing from her clinical experience and compassion for the families she works with, Dr. Mona offers clarity on what autism is, what it isn't, and why nuance matters.

This article explores how public misinformation can harm, how science is still unfolding, and why accepting and supporting neurodiversity is key—not just for autistic individuals, but for the broader cultural shift toward empathy and inclusion.

Jennifer Woodall: I would like to talk about the video that you made in response to RFK Jr.'s claim that the government is going to find the cause of autism.

Dr. Mona: So, I think first we have to pull back and say, “How is that possible from a scientific community?” We know that autism is more prevalent than it is years past, but we also have to understand why that is, and I think

that's really important to be clear. So as of today, the recording that we're doing, one out of 31 children in the United States have autism by the age of eight. That was the last time we did this, which was two years ago. When we got the last CDC data, it was one out of 36. That announcement that he made came out right around that same time that the CDC does their every two-year analysis of the prevalence rates. It is something that's been studied for decades. I can say this as a pediatrician, along with things like food allergy rise, autism, we are looking—and when I say we, I'm not doing the research because I'm on the front line—but my colleagues are looking at “What are the reasons? Why are we seeing more of this?” and a lot of the stuff that we see with autism, much like ADHD, which is neurodiverse types, is that there's a higher rate of understanding these conditions. There's a higher rate of clinicians and parents being aware of the characteristics that would make them want to say, “Hey, we need to get my child evaluated.” that makes them get the diagnosis. So, there isn't something that's an external factor, per se, that he's looking at. One thing that really concerns me and a lot of my colleagues is that when any time there's a promise like, “Hey, we're going to have this by the end of September.” for something that's been researched for years, you got to get a little suspicious because if we could do that, we would have already done that, right? That's literally like saying, “Hey, we're going to find the cure for cancer by the end of this time frame.” Now, if there's something in process, let's say there was this really groundbreaking study, and they were just cleaning up the data, and they were going to announce the data in September, that's different, right? You can't start a position and then



say, “Hey, look, we’re going to find the cause by September, and we’re going to now eliminate that cause.” unless there’s a premeditated agenda as to what you think that cause is.

That being said, any evidence-based peer reviewed study will show what we already know: that there’s no external cause for things like autism and ADHD. It is a little suspicious to just throw out deadlines. I’m noticing there’s a lot of things that are being said that’s just meant to stir emotions and get people excited, and then it’s going to come around, I know, and there’s not going to be an answer because they’re going to realize that we can’t have an answer unless they fudge data, which every scientific body in the world will be looking at that data that they present with a fine-tooth comb, right? I mean, this is literally what’s going to happen. So even if we were to come out and say, “Oh, we think it’s this.” We’re going to look at all that data. Every scientific expert in autism, in child development, is going to look at that and see if it makes sense. Is it peer reviewed by people in the field? Because that is very valuable information. Or is it something that has a lot of bias or anything like that? It is a concerning thing. We want to make sure that we are giving science due diligence. I also respect that science is always evolving. We think about autism, and one of the things that I see clinically is that I see that there is a lot of connection between advanced paternal age or advanced maternal age, so is there some mutation happening in the cell lines as women or men age that causes the autism to be more expressed? And let’s say we have a parent who is maybe low intervention autism. Maybe flying under the radar, not really needing a lot of therapies, anything like that. They’re older, they have a child. There may have been a mutation that causes it to be more expressed in their child, but we do see a genetic link, and that is something that I see in my patients through and through. I see there’s nothing about this that makes me worry that there’s something else that’s causing them to express this. I just think it’s internally; sperm can mutate. There can be genetic mutations in cell lines, but to say that there’s something external and that we’re going to have an answer is very audacious, to say the least.

Woodall: Is there actually an increase in autism cases, or is it just that we understand it more so we are able to see how nuanced autism can be?

Dr. Mona: That is exactly it. One of the things that we have to remember is that we are now picking up children who may have flown under the radar. Think about maybe in our generation or our parents’ generation, that quirky uncle that maybe collected a lot of memorabilia and knew every fact about World War II, and would just recite that any opportunity he got. That could be autism. The old terminology was high functioning, low functioning, which is not used as much anymore. There is high intervention and low intervention. So, that could have been a man who had very low intervention autism—

meaning it wasn’t causing him to have any other comorbidity. He was able to live his life, get a job, all that stuff. So, people didn’t really know or do anything about it. But now, because there’s less stigma surrounding autism, there’s more understanding of the various characteristics that parents maybe brushed under a rug for a long time. Our low intervention children are now being diagnosed, meaning kids who may not need a lot of services, may not need a lot of support, compared to our high intervention kids. That is what’s causing that prevalence rate to seem even higher. Because we are picking up those kids. I can attest to that because I’ve been practicing for 10 years. Residencies would add another three years. I am now myself noticing autism in those low intervention children a lot more because of my own understanding of autism. So that kid who’s parent was like, “Yeah, sometimes he’s very antisocial” or “He likes to run away from me.” or “Discipline doesn’t work like it works for my other child.” I’m like, “Okay, is that normal toddler behavior, or is this a neurodiverse child?” Getting more curious about that is what causes us to say, “Okay, could this now be low intervention autism?” and that is what’s causing that rise. Then also from the new data that we have, a lot of autism is now being diagnosed in children of color. Children of color tend to be underrepresented, not that they don’t have autism, but a lot of them ended up not getting the access to clinicians, or maybe they don’t have the follow-up. But now we are catching those children early earlier, which means better outcomes for them.

So, I look at this not as an epidemic—which has been the term that’s been used—because this isn’t a disease. I’m just looking at this as increased prevalence because of the fact that we know better. Like you said, we’re able to notice the characteristics more, and there’s less stigma, so parents are more likely to bring it up versus dismiss it and say, “Oh, it’s nothing. He’s just being a kid.” Parents are now actually in my office saying, “Hey, look, I don’t think this my kid being a kid. I think he really struggles with eating, and he also struggles with behavior, and he also struggles with sleep. I think something’s going on.” and then we dive deeper and we’re like, “Huh, this child has a really hard time with adjustment, has a really hard time with emotional regulation, compared to maybe a peer. Could that just be typical toddler behavior, or could this be neurodiversity?” More times than not, I end up finding out that it’s neurodiversity, and that process can take time. Sometimes I see them, and from the time that I see them and have that little, “Oh, let’s evaluate this.” It can take maybe one, two, three visits to finally get that diagnosis, and the diagnosis helps so that we can provide services for that child, whether it’s in school, preschool, or even at home, so that the family thrives together, so that the family can better support that child, because that’s a huge positive outcome for everyone in that family.

Lia Martirosyan: In the data that you’re pooling together, does it give information about the spectrum? What

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about those children that are at a really high level of autism that have a more difficult time, is there data connected to increase on that end, or is it just data about autism in general?

Dr. Mona: So, the report that came out is done every two years from a subcommittee of the CDC, so it's American data. We don't have international data. It doesn't break down the severity. It did break down overall prevalence in different states. It broke down things like certain parts of California versus certain parts of Texas, boys versus girls, and racial and ethnic backgrounds, but it did not look at the severity of the autism, which I think would be a really good addition to the report that would come out in another two years to look at what's also happening with the high intervention children. I think you brought up a good point because autism, we tend to think it is the banging their head on the wall or the lack of verbal ability. Think about the movies back in the day—Rain Man as an example. It's a very popular movie. That's what depicted autism to a lot of us growing up, and then now we are seeing more shows and movies present autism in a low intervention light. These are children that are in school. These are children that have relationships and friends. They're not sitting there shuffling their fingers, which also goes towards breaking the stigma and stereotypes. That, sure, autism is a spectrum. We know that, but it's not just the

banging head on the wall, violent. That's not it. That is not what we see, and I see in my office. Have I seen that? Yes. But I would say by and large, my autistic population is that low intervention or medium intervention, meaning they get services, they may have some language delay, but they maybe make that up with speech therapy. They may have social quirks, but that is what makes them. That's their autism. They may have some stim behavior, maybe they wringing their fingers or like, twirling their hair. That's very common in neuroatypical children, but we start to see that in all autistic children and I think we'll see that hopefully in maybe another two years. I'm not in charge of the data, but that would be actually very interesting to see how severe it is.

Martirosyan: Where does Asperger's fit in?

Dr. Mona: So, Asperger's used to be a part of the DSM 5 criteria. So, DSM is your diagnostic and statistical manual of mental disorders. It lists autism there, and it used to list Asperger's, but the change was made around 2013 because Asperger's and autism do share a lot of overlapping symptoms. So, rather than having Asperger's be its own thing, now it's just called Autism Spectrum Disorder, and in that autism spectrum, we have this high intervention, low intervention model. It's no longer a thing to call people Asperger's. It was used, but now it's not colloquially language that we use for diagnosing



children or adults. Some people may use it because they were diagnosed with that. For example, if you got diagnosed before 2013 with Asperger's, maybe you've identified with that. Maybe you are Asperger's, and you got that label, and you like it, and that's fine. But now current language is not using that because it's not an official diagnostic criteria or a diagnostic label, if you will.

Woodall: On the topic of autism being a spectrum and how each individual is different, what are your thoughts on how RFK Jr. feels about autistic people never paying taxes, never holding a job, never playing baseball, never writing poems or dating. I would love to hear your thoughts on that as someone who interacts with different autistic people on a regular basis.

Dr. Mona: I love that question, and I think there's two things that we have to think about. One is that is not fair to many of the autistic children and families and adults who do all those things. When we say that, "Oh, autism is this horrible thing that children won't write poems, won't be able to find romantic relationships." I mean, we all know the show called *Love on the Spectrum*, which is a hugely popular show that shows autistic individuals across the spectrum finding love. And I mean, that is an example of that not being true. Now, that being said, we do know that it is a spectrum. So, are there autistic individuals that cannot do those things? Absolutely. Going back to what we were talking about, that, yes, there are some that do need parental or caregiver support for most of their lives, but now that's not the norm in the autism spectrum. That is actually the exception, but that's still a valid reality for those families. I think we have to make sure that we understand that because it's a spectrum, every family who listens to that may say, "No, my kid's not like that," but there

could be a family that's saying, "That is my kid. My kid is one of those kids." The other thing that I think this brings a very powerful point and we need to address is that it also adds to ableism to say that because a human being can't do those things—pay taxes, write a poem, date—that they don't have value in society. So, it's actually very offensive to people with physical disabilities, people with intellectual disabilities, to say that just because they can't do those things, that they don't have value in society. When we say that, it sounds as if, "Well, these are the things that make it part of our life. We pay taxes, and we get jobs, and we have romantic relationships, and that means maybe we'll procreate." That shouldn't be the standard of what we value humans as, right? Everyone has different capabilities. Everyone is on a spectrum in the autism world, but also in general, right? We have individuals that are not autistic who may not ever find romantic relationships. So it goes into that whole stigma that I think is being added and why it's a little painful when I hear that.

We have to be clear that, yes, that is a reality for some families, but it also creates this ableism that is like "I want to tug your heartstrings and say, your kid with autism is not going to be able to do this. And how sad." Well, that is why they struggle, because society thinks that if you cannot contribute, that you don't have value, and that is very hurtful. I, again, take care of a variety of different children from different socioeconomic and neurodiversity backgrounds. I see kids up till 21, so I have autistic children who are 17 so they're young adults, they're larger, they're bigger than their parents, and they are very in need of high intervention. They get upset, and they start lashing out. We've had situations where we had to have people hold down this larger individual to get them calm. That is not easy for a family to

have to navigate, and yes, that child or that young adult may not be able to hold a job or have a romantic relationship, but that person is still a person, and I think that goes down to that. That parent does not want to look at their child as lesser than when they're dealing with what they are, and they want to feel like, "Hey, this is my kid, and that person should also be valued in a society, even if they're not able to hold a job like a top CEO or whatever. It's okay." And this goes into not just autism, but any disability that has to do with physical or intellectual disability, it creates that stigma, that they're not useful, which I think is so harmful.

Woodall: Can we talk about debunking the vaccine-autism connection?

Dr. Mona: I think it's important to remember where it began. So, obviously not to go into too much detail about the Andrew Wakefield study—and he is a name that we will never forget as pediatricians—he was a practicing clinician and lost his license after releasing a now debunked study, a study that was in *The Lancet*, which is a very reputable journal. I mean, this is a journal that should produce evidence-based resources. I don't know how it was able to bypass all the checks and balances, but he released a study saying that there's a link between the MMR vaccine and autism. It was a very small sample size, and it really caused this uproar in the late '90s—about 1997, 1999 that he started this uproar. At that same time, there was a lot of celebrity endorsement of this, meaning we have people like Jenny McCarthy going on news channels talking about her son who has autism, and also how it's because of the vaccines and this and that. So, there was a lot of vocalization of this vaccine-autism connection, and since then, obviously, we've had tons of research coming out, not only in the United States, but Denmark and other countries that show that there is no connection. The thought behind the vaccine-autism connection was mercury. So, in older vaccines, there used to be mercury in the vaccines, and mercury is basically a preservative that helps it last longer and helps it have a better effect. It was thought that maybe having this is what causes these children to end up having autism, and since then, there's been many studies that show that mercury has no impact on development for a child. Even so, with that whole mercury thimerosal connection, because of the public outcry the vaccine community looked at ways of removing it from vaccines and adding different ingredients, and it was removed in the early 2000s. And we still saw autism prevalence rates, because it wasn't the vaccine. It was the fact that there was just more awareness, less stigma, and so that's the story in a nutshell.

Now, of course, there's people who are like, "Well, it's not just the MMR vaccine, it's other vaccines. It used to be just the MMR because of the thimerosal in it, but now it's other vaccines." Now, do we have studies on every single vaccine and its connection with autism? We do not. We only have it really with the MMR vaccine,

which was the one that got all the media attention. That being said, what we see in clinical practice, and I go back to this, is that there is a genetic predisposition to this. I know this because I see it in my office. I see parents, siblings who have it. I see the siblings who have it, whose parents don't know they have it, and once the child is diagnosed, the mom and or dad is like, "Oh, my gosh, I think I have this. I think I actually have autism, and I just never did anything about it or never got the label or diagnosis." And so we see a lot of that. We've just seen an almost 400 % increase in adults being diagnosed with autism because of this, because of the less stigma and more awareness. I will say that it's probably parents of autistic children that are seeing that understanding of, "My kid has this." and then now they're getting diagnosed as well. That diagnosis can feel very liberating. I was speaking to my husband about this because he's like, "Do you think we're just over labeling these children with ADHD and autism, and why do we need to do that?" I said, "I don't think it's over labeling when it gives a person clarity into how their brain works. It's almost like labeling an emotion." If we can label ourselves as frustrated or jealous, then we are more able to handle that feeling. If a child or an adult is able to say, "Wow, I've been dealing with this feeling for so long. I've been feeling frustrated when I go into a social event and I don't want to talk to anyone, and people feel like I should be doing this, now I understand that I don't need to numb myself with alcohol, that I am just different, that I am a different person who's brain works differently." That is so valuable for children and adults to know that they're not crazy, weird, quirky, that they're different, that their brains are wired differently, and that's how I look at ADHD. That's how I look at autism, and giving that child that label in this situation is actually a label of understanding. It's a label of saying, "I have this, and now I'm going to work with it." It's not an excuse. It's not to say, "Well, I'm sorry, I'm not going to do this because I'm autistic," or "I'm not going to do this because I'm ADHD." It's saying, "Hey, I have this. How can I use this to communicate better with my child, with my parent, with my loved one?" If you're an adult with autism or ADHD, and you're now in a romantic relationship, it's saying "How can I use knowing my brain to work with other people and help them understand how to work with me?"

I know we segwayed into why I think it's powerful that we have this diagnosis, but that's that. Autism-vaccine myth is extremely harmful because it makes it seem that this is something that is preventable if you don't get the vaccine, but I do see children who are not vaccinated who have autism, it's a reality, and it makes it seem that autism is this thing to be feared, that you don't want your kid to get this thing, so better not get these vaccines. That creates stigma. So now if we see an autistic child in the community, it's going to be like, "Oh, did you get the shots?" That is what the stigma creates. And if the autism-vaccine myth was true, I can guarantee you every pediatrician in this country would be sounding the



Dr. Mona's family

alarm. If I came into my office and every time I gave a vaccine, the next visit—which people say their lights were dimmed out, that’s the terminology that’s being used—if I saw that ever, that a family came back, and I saw that, I would raise the alarm. That’s what we do in medicine. If we’re seeing a side effect from an antibiotic, if we’re seeing something, our duty is to report. That is what we are assigned up to do. And when people are like, “Well, they’re in it for the money. They’re in it for this.” I’m like, “No, we’re in it because we took an oath to do no harm, and if we saw harm with any medical intervention, including vaccines, we would be sounding the alarm.” So, for someone who gives vaccines very routinely, who vaccinates her own children on schedule without any reservation there. It is not something that I see it from the data. What I see in my office now, there’s no relationship. I think this myth was also created because of just the timing. We know autistic characteristics present themselves more strongly when social and language communication skills are more on demand, which is between the ages of 18 months and two and a half years, so right before that is when we give vaccines. Around the one year mark for the MMR. So, that is honestly the reason why that vaccine got a bad rap is that, “Well, my kid got the MMR. That was the last thing they got before I started noticing the signs.” That doesn’t mean that it’s causal. It is because of the fact that autistic characteristics do present themselves in those toddler years when vaccines are given. That’s not the vaccine, that’s just the development of the child, so that’s something really important for people to understand. I know a lot of adults who have autism or ADHD, and I have a lot of children who have it, and that is their brain working differently and celebrating

that—as hard as it can seem for many people to want to do—the more we can celebrate that, the more we can reduce that stigma.

Woodall: So, just by the nature of media consumption nowadays, anybody can have a platform. Even people in power can have a platform to spread misinformation about things. How does a parent go about processing this information and knowing what to listen to?

Dr. Mona: That is so hard right now, like you said, because there are people with powerful degrees and platforms, and then there’s people who don’t have any educational background. So, the first thing we’ve got to look at is, “Does that person have a medical educational background?” It doesn’t have to be an MD or DO, but does that person have credentials to speak to that niche or topic? Using me as an example, pediatrician/vaccines, pediatrician/child development, pediatrician/anything that deals with child health, development or parenting, right? That is my niche. I’m not going to be talking about OB care because that is not my niche. So, if I start talking about OB care, you’re going to want to raise some flags and be like, “Why is this pediatrician talking about OB? Because she’s not an OB, and she should be sticking to pediatrics.” So, first is, “Does that person have expertise in the niche that they’re speaking about?” Now, within that, you have to understand that there’s people who have decided that they want to go against the grain, and I’m not opposed for people to have critical thinking skills. I have a lot of critical thinking skills. I take something and I listen and I think about my patients, I think about what I’m doing, and I look at the consensus on research. I look at what I think, and I

blend that all together, but there are professionals, let's say, MDs or DOs, that may say, "Hey, vaccines do this, they are harmful." using an example. When you hear that from a medical professional that has the credentials, you now have to say, "This person seems like the lone wolf. Why does this person seem like the lone wolf? Is it because they are trying to sell a book? Is it because they have a supplement company?" Because there's usually some vested interest into why they're the lone wolf. Because when they're the lone wolf, they're more likely to get speaking engagements, which pay money. They're more likely to be able to drive people to book sales. They're more likely to sell things. Everything's a business here, so, you've got to ask yourself, "Does this person have a vested interest into spreading this misinformation? And why are they saying this outlandish thing?" And once you see the outlandish thing, that is pretty good information. Then you've got to take that information to someone that you trust, maybe someone like your pediatrician, maybe someone that's a little bit more balanced, can tell you why that's factual, why that's not. That's what I try to do with my platform. I try to take the good and also the not so good to be like, "Hey, this is actually really valid. Here is where there's limitations," and take that information and then say, "Hey, here's how I'm going to now take that and apply it." Having that person in your network—and it usually should be someone like your pediatrician that you trust, hopefully, to take that information to—is highly valuable. I know some families fall into that misinformation trap because they don't have that person. Maybe their pediatrician was dismissive. Maybe their pediatrician is like, "Oh, you're stupid. Why are you reading stuff online?" And I've heard that. So, I think it's a valuable comment that the consumer, the parent, the person wanting health information needs to understand that expertise matters. And even within the expertise, look at that lone wolf. What are they saying? What are they using to back this up? What is their best interest?

I talk about this a lot. I think the modern health care system, because we don't have a lot of time with our patients, we tend to not have the time for these very detailed conversations like me and you are having. So, what ends up happening is that you push them away because you dismiss them, not because you don't want to talk about it, but because you don't have the time, and that pushes them into misinformation's arms. People who are like, "Hey, you're here. I get it. Let me talk to you about why you should not get this vaccine. Let me talk to you about why you should not feed your child red dye ever. Let me talk to you about this, that, and other." versus, "Let's talk about the balance here. Let's talk about what we need to think about, true benefit, true risk, which is what we know how to do," but many times we don't have the time. And that's a sad reality. That can be very hard as a parent. If you're going to follow any creators online or education online, try to follow the balanced ones. On the flip side, you don't want someone telling you like, "Hey, if you don't

get vaccinated, your kid's going to die," right? Because that is also on the other spectrum, very inflammatory, very, very polarizing. You want someone who's going to say, "Hey, I really want you to consider this. I want you to think about this because X, Y, and Z. It is your choice, but it is something that I highly think is valuable." because I see that happen on both sides. We don't want to ostracize by scaring people, but we also don't want to ostracize people by misinformation. And both of those things can happen on either spectrum.

Martirosyan: Is there research that you know of going on that we're absorbing things like forever chemicals or Teflon, and they get into our own DNA, we have children, and it causing gene mutation that affect things like autism or other issues?

Dr. Mona: So, we don't have anything on that, and that is actually an area that I would think would be very useful. When we talk going back to what RFK Jr. wants to do, I think if we're going to look at that, yes, it's reasonable to look at if there's any impact on environmental factors like that. If they want to include vaccines in that, they can, but the hard reality is because everything is so multifactorial, meaning we don't live in a vacuum, there's so many different variables coming at us at any given time like stress. We know that stress has a huge impact on our genes. If you're chronically stressed, or if you're dealing with stress at a very constant level, that can impact your egg quality and your sperm quality. We know that. I speak to that because as someone who went through infertility, a lot of my peers had to do IVF, and the thought is that in medical school, even if my peers were young, dealing chronic stress, did that have an impact? Again, we know that stress has a huge impact, but it's very hard for us to pull out one thing when we think about the multifactorial impact of genes, right?

Martirosyan: What about gene correlation in families with multiple children?

Dr. Mona: There are twin studies that show that if one identical twin has autism, that the other has a 60% to 90% chance of also having it at some point, meaning I know they're twins, but even if they don't have it at that moment, that they could express it later in their life, too, because of the twin connection. In siblings, we see that there's a one in five prevalence compared to one in 31 prevalence, that if one child has it, the chance of having a sibling with autism is also there, but the thing that we're still trying to pinpoint is that there is multiple genes involved. Genetics is not just autosomal dominant, autosomal recessive, like eye color. That's what we think classically of genetics, or let's say blood type. That is one type of genetics, but we also have different types of genetics, which is chromosomal mutations. You have X-linked inherent inheritance, so that's not your autosomal dominant recessive thing. What it's thought of with autism is that it's polygenetic, meaning there's multiple genes being involved, and it's not inherited in a

simple pattern, not like the autosomal dominant, recessive, or X-linked situation. We do see that there's possibly a single gene mutation or a chromosomal change. We see children who may have like Rett syndrome—I'm just throwing out some names of genetic syndrome—or other syndromes like Angelman syndrome. These are genetic syndromes that have a chromosomal change, but they also have autism as part of that chromosomal change. So, there's a lot of comorbidities between autism and chromosomal things, like Angelman syndrome or Rett syndrome. These are all, again, genetic syndromes that exist, and there's so many of these genetic syndromes that people don't even realize. They can happen in families that don't have any sign of this because these are just genetic syndromes. It's not like you can screen for these, which is hard for many families, but then they end up getting autism with their genetic syndrome. So, is it a chromosomal change? Is it a single gene mutation? But the thought is that it's mixed, that there is not just one marker. We can't just test for the autism gene. It's not as simple as that. If we could get to that, we would be able to tell families like, "Hey, you have autism, and your child may have autism." Maybe it's done in utero, like we do down syndrome, but it's not on a chromosome like that, right? Down syndrome, we're able to do screening in utero, which again is very controversial also because people are like, "Well, why do we need to know?" And that's why I think this could get very tricky, is that with the genetic testing, it's very hard to pinpoint because of all the different factors that go in to it. Then when we think about environmental triggers, how are we going to isolate an environmental trigger?

Martirosyan: You mentioned the CDC broke down the autism rates state by state, so if there's some geo-targeting there, do you see any clusters of areas that are highly toxic?

Dr. Mona: That's a great question. What it did show is that areas that have better resources had more prevalence. So for example, California. California has a really strong early intervention program. What I mean is that when you do screening and also just have access to that, it's affordable, it's subsidized for low income, even high income families if they need the services. So, that area had higher rates of prevalence. We don't know what was going on in that actual city. Your point is valid that is there something in that city? I don't think so, but could it be? Yes, I'm not going to close the door on that. But what we also see is places like Laredo, Texas, a very rural part of Texas with one in 140 prevalence, which is not as high. They don't have as big a population, and they also don't have as much access to early intervention pediatrician visits. Maybe they're not going to well visits as regularly—all things that help us catch the autism early than later. So I understand the environmental aspect, because I'm also very curious about if there is something, but I want to use this example: I practice in Florida. I see so much more autism here than

I did where I was practicing in New York, but I also see a different socioeconomic status. What I see is a lot of parents here who have undiagnosed autism in my communities that are now having kids who then end up having autism. So could it be that we're just seeing a lot of these parents that I work with in a different socioeconomic status that end up being like, "Oh, this person has intellectual disability." don't get the support? Or could it be that they had autism all along? It's very hard to pinpoint what this actually is, but it's also a different socioeconomic status that I see. I think for a long time everything got bumped into school-age kids who weren't paying attention or weren't able to keep up, and they just were labeled as having an intellectual disability where could it have been ADHD, autism, things like that. And then it's like a cycle, because then those adults have children. Their children have the same thing, so it's really come down to, "Are we looking at the whole parent as well?" We should be looking at parent and child when we're looking at this genetic reasoning of autism. And I see it. I see the children come in, and then I see the parent, and then I'm talking to the parent, and I can tell the parent has neurodiversity. It's very obvious for me now because I deal with neurodiversity all day, but they never have the diagnosis. We bring it up, and they end up getting a diagnosis because they're just curious. I think it's important to understand that, sure, can chemicals, can things in our environment to a large degree, like pollution, have an impact on genetic expression? Absolutely. But it's going to happen over generations. That's something called eugenics, like how genes are expressed over generations. So I think it's an area of research, but the question now becomes, how do we pinpoint it? How are we going to isolate what the cause is? I think it's very hard.

Martirosyan: So, if the combination of several genes is what produces the symptoms that then is diagnosed as autism, is there a certain number of genes that needs to be reached?

Dr. Mona: That's an area that we're trying to figure out—again, we are not me because I'm not a genetic researcher—but is it one mutation, a single gene mutation on our whole DNA? Or is it multiple gene mutations? There's no perfect number, and I go back to the example we see that children with certain chromosomal disorders, that it's not just chromosomes that things can be passed down in. It can be different genes that are expressed on our DNA, and so it's not just an addition of, "Okay, you hit 1, 2, 3, 4, 5" and then that's the magic for a characteristics, but what would be so helpful to find out—and I know everyone wants to know—is can we find one mutation on a certain chromosome or on a certain gene that we can say that this is where the mutation is happening, and we're seeing this across the board. We just don't know that yet. That's something that's still being figured out, about where it is. Is it multiple? Is it one? But what we do know is that it could be just a combination of many different things because we see it

in chromosomal changes. We see it in just families who don't have any chromosomal disorders or conditions, and the child just has an autism diagnosis. I have a friend who's both children have the diagnosis, and for her youngest, he's a boy, they're starting treatments because they can't treat all the symptoms. They're saying they're able to treat a couple of the behaviors that he's experiencing.

Martirosyan: Is that legitimate? Is that something that we've reached or something that's actually happening? Or is it just really testing?

Dr. Mona: It depends on what the treatment is. Right now, the gold standard of treatment is not actually anything more than support for the development. So that means OT, occupational therapy, speech therapy, behavioral therapy, physical therapy, if the child has any physical concerns. But besides that, there's a lot of things out there that are not approved or recommended or even thought to actually help and could be harmful for autism. I use the example of a kid in Michigan who was put in a hyperbaric chamber to treat ADHD and sleep apnea—that's not autism, but I'm using this as an example—not a recommended treatment. There is no clinical data in the country or world using that for sleep apnea or for ADHD, and that child died in a hyperbaric chamber when it caught on fire. He was a five-year-old boy, and that's an example of the risk of doing things that are not clinically indicated. Right now, the best support we give is early intervention, speech therapy, occupational therapy, physical therapy, behavioral therapy. And why that helps is that, again, we're not trying to cure the autism out of the child because that's who the child is. You can't remove it. I'm Indian-American, so I joke that It's like trying to take the Indian out of me. I can't take a medication or do something that's going to remove my identity, but what I can do for autism is learn how to communicate. Whether some kids need an assisted communication device that they can touch if they're not as verbal, or if they are verbal, helping them with that. So that is what that means, using the speech so that they can communicate, whether it's spoken language or a device, that they can get the physical therapy if for any reason that it did impact their physical well-being. OT is activities of daily living so that they can try to be self-sufficient. Maybe they have fine motor issues. Maybe potty training is a struggle, so OT can help that. We're trying to help that child for their developmental capability to reach those things. But, to say that there's a treatment plan puts a little bit of red flags or radar for me that I'm curious, what is that treatment segment per se? We want to be clear that we're not doing any things that could have a risk to it, and if a family knows the risks, they want to still proceed, like I said, that is their volition. That is their autonomy. That is their choice to make for their child. But it has to be clearly said what the risk of that procedure is. And a lot of these places don't do that because a lot of these places are not run by medical professionals. They're run by functional medi-



cine doctors who use a lot of pseudoscience, meaning there's no data, there's no safety data, there's nothing. Could they do it? Sure. But they need to be clear on what the risks of these things are, as we would. When we talk about benefit and risks of vaccines, we hand out risks. We obviously talk about the benefit when I'm prescribing an antibiotic. I say, "Hey, look, the benefit is that your child needs this antibiotic. The risk is stomach upset, allergic reaction, etc." Every clinician who is prescribing or doing any intervention should be giving that in verbal and in writing. Sometimes it's not being done and that's very scary to me because that is when we cause a lot of harm, and that can be misplaced fear. When you have stigma and guilt as a parent, you're more likely to seek out these alternative things that can be more harmful than good. I want kids to live their best life for their development. I don't want to live their best life for anyone else's development. Everything is compared against them, meaning I can't predict how their outcome is going to be, but I want them to get the best resources for them, not comparing them to a neurotypical child. I think, the cardinal thing that we want for all of our children, is for them to be accepted for who they are, and for them to feel supported, and we feel like they can help teach them how to communicate and do those activities of daily living. Will it happen for every child? No. Because they may be on the severe spectrum, but we are allowing that from an early age. That is why knowing the signs and characteristics early can really help because it can help them earlier than later to get that diagnosis, get that early intervention, because we do see the earlier we can start services, the better outcomes for children because their brain is moldable.

So, if we're catching an autistic child at 10 years old ver-



sus an autistic child at three or two, we have wiring that we can teach. Okay, how can you communicate instead of melting down into a tantrum? Okay, let's try and get the potty training going so that we can help them, and that helps the entire family. It's such a long, complicated, and very specific process to each family. It's just so much that these families have to deal with on a regular basis, and just watching from the sidelines, and there's nothing you can do besides just be there. I want to be very clear. Every single family that I have that has a child that is autistic, every one of them has cried in my office at one point. I want to be very clear that there is a lot of stress in raising an autistic child. It may not be like that forever because those same families got tied in with the services and are now thriving, meaning they've found their routine, their child has found their routine. The child has gotten older and has learned to really take that autism and work with it in many cases. It's such a nuanced conversation that we're having because on one point, I'm not saying that I want everyone to have autism or that everyone should be neurodiverse. I recognize how hard it is for the families, but I also know that it's not something that we can just snap a finger and say, "Oh, I'm going to remove your autism," or, "Oh, I'm going to prevent it by not giving a vaccine." That is harmful also, because it puts a lot of guilt to a family who's struggling already that they could have prevented this when that's not even the reason. That's why I'm upset. In this situation, there's nothing that you can do or not do that we know of that is going to prevent this from happening. If we did, we would do that, but it's this balance of we want to promote neurodiversity. We obviously want to understand it because it's important to understand. I think having answers is so helpful for families because then they feel like, "Oh, yeah, I get it. There's a genetic mutation. Okay, it happened. That's not my fault. Things happen." It really can provide some clarity to a lot of these families. I

think when we talk about this, it can go either way where some families feel like, "Oh, man, people don't see me. They think it's autism and that we should just celebrate all autism." I want to celebrate our neurodiverse children, but that's not to say that it's not hard, because I think sometimes that can get lost that, "Oh, yeah, neurodiversity, let's celebrate it." But I also know how hard it is. I know how hard that is and how typical parenting methods or getting your child to just eat a dinner is not the same as a neurotypical child. So, celebrating and understanding both of that, I think is really valuable to say, "We have this. It exists," and I want to support our parents. I want them to understand that it is hard in the early years, especially, and that it's not this walk in the park to say "Oh, yeah, my kid has autism. Easy, breezy." That let's recognize that it was a lot of work, a lot of visits, a lot of early intervention, a lot of parenting that had to go on that maybe your neurotypical parent or peer didn't have to do. We can have both of those things and I want to be clear about that because I think it's lost a little bit in this conversation. Both of those groups want to be seen. You know that, hey, neurodiversity is there, but it also can be hard to raise a neurodiverse child. That it's not easy for per se.

Martirosyan: Do you know when or how you found yourself understanding ableism?

Dr. Mona: Thank you so much for this. I think a lot of it happened within the last five years of my practice, and that is when I started to learn more about autism. I'm by no means an autism expert. What I say about that is I know autism, but there are people out there that study this day in, day out more than I do, like developmental pediatricians that are literally doing it day in, day out. What I know about autism is self-learned, meaning I don't have to know all this stuff because there's so many things to know as a general pediatrician, but I'm very fascinated by it. I think it's really important, so I take it on my own to read about these things. I research and all this stuff, but the ableism comment came when I started talking to families about autism, actual families who have autistic children or who are autistic themselves, and asking them about what this means to you and the terminology that we use, person with autism versus autistic person. All these things are what I've learned through my years, especially in the last five years. I had my own child, and this platform of my own education that I do is what prompted me to learn about this so that I can be more sensitive to my patients and also to my community online. I'm still learning every day. If I get feedback that, "Oh, Dr. Mona, that's not what we say for autistic individuals," I take it and I say, "Hey, look, I'm still learning, and I want to learn to be the best communicator on these topics as I can."

Martirosyan: A lot of health care practitioners, I would suggest, are not aware of ableism. When I think about physicians and patients, oftentimes there's a bit of a disconnect. I would like to see more training for doctors when it comes to things like ableism.

Dr. Mona: I don't think you know this, but when my son

was born, we had a lot of gaslighting for my health. Meaning I was telling the staff where I worked that I was feeling sick, that I wasn't feeling good, and they thought it was anxiety. I know this is a different conversation, but in a way, that gaslighting experience now opened my eyes for me, not only about gaslighting that happens in medicine, but also the way we can essentially gaslight for ableism as well. You think about things like making assumptions on what they would want for advanced directive. My husband's an ER doctor, so just say someone comes in with a disability, "Oh, they probably don't want resuscitation." That's an assumption. What is it listed? What do they actually want in their chart? In accessible care—this is something that our office is doing better at, but could be better—is supporting physical and intellectual disabilities. So, interpreters, ASL interpreters, doctors, medical forms, people who are blind. There's so much work that can be done because there's so much diversity out there. It's not just about one or two things. It's something that I think is really important. I think one of the biggest things that we see is that communication of discomfort. Sometimes with my autistic family or children, like I said, who are not as verbal, they may not be able to tell me where the pain is, but I believe them. They're writhing. I look at the mom and I say, "Mom, I also agree, I don't like this. This is not their typical behavior." And even when I educate, it's like, I always try to use that terminology. If they're not verbal, how are we speaking? How are we going to make sure that they understand that we believe them, that there is pain, and not dismiss it. I think it's something that is so important. When I examine autistic individuals in my office—I'm very kind in my exam—but I'm even more gentle with my autistic individuals, meaning I get their attention and I touch their shoulder or I make eye contact even if they don't want it because it shows that I'm connected with them, and then I explain to them what I'm doing, even if they're older. You would expect you don't need to do that for a twelve-year-old, but if I have a 12-year-old autistic patient, I do take a little more time to say, "Hey, now I'm going to look in your ears. Now I'm going to look in your mouth." and it helps them so that they know what expect. To me, these are all things that I've learned just by taking care of autistic children, but also being a mom and having had the experience of being in a system where I felt unseen, unheard, that even though it wasn't a neurodiversity, that it was something with my physical health, I don't want to have that cycle continue.

Martirosyan: *ABILITY* did an interview with Mary and Dick Allen, who, because of their granddaughter, a company called Tandem. In the story, the doctor did not recognize that the young girl had high levels glucose. Why isn't that a standard panel if you're doing blood work?

Dr. Mona: Thank you for understanding that I can't speak to a lot of clinical diagnosis of what happens when I'm not there. So, two things: We usually don't do general screening for bloodwork for children unless there's a concern. So, for example, this child who came in with maybe

extreme weight loss—because that's usually what we can see with type 1 diabetes—maybe some excessive thirst, excessive urination that seems out of the ordinary, there likely should have been a glucose test that's done basically through the finger or the vein, and also maybe a urine study that's looking at if there's glucose being spilled into the urine. That's typical of a child that is coming in with that. Now, that being said, I don't know if maybe in that situation, that clinician, were they not thinking of diabetes? Were they thinking stomach virus? Were they thinking something else? Because that's the only thing that I can envision that maybe they didn't do the workup that was needed. That would have picked that up. But again, I can't speak to what that clinician thought, what they didn't think. If a child is having, for example, diabetic ketoacidosis, like a DKA situation, they should be having high glucose in their body, it should be showing that there's glucose in the urine because basically glucose is coming out of the body everywhere. But it's just hard to say what was happening in that situation.

Martirosyan: So, you could actually test high levels of glucose just with urine?

Dr. Mona: I mean, you definitely should get both because sometimes if it's not high enough, it won't come out in the urine. You should be getting at least a glucose test, which is like a finger stick—that usually suffices. Very rarely do I have to do a venous draw. Then adding on a urine study would be useful as well, but that's in severe cases. How old was the child?

Martirosyan: I think a little over two years.

Dr. Mona: That's another thing, type 1 diabetes in toddlers is much more rare than type 1 diabetes in an 11 or 12-year-old. That is the classic age that we normally do see type 1 diabetes. So, thank you for clarifying that, because a lot of clinicians, maybe even pediatricians, are not thinking type 1 diabetes in a toddler because it is not as common as your older child. So, when it comes to sick visits, it goes down to the clinician thinking about the big picture and looking at, "Okay, what is going on? Do I need to check bloodwork?" but if the child was having a situation of a DKA or high glucose, we would have picked that up in bloodwork, and like I said, bloodwork would be the standard, and then urine would be something else that would be additional—to see if it's starting to go into the urine. But bloodwork includes the glucose test. And depending on the capabilities of the office, usually if it's high and they look clinically unwell, they're probably going to send that kid to the ER, which they'll do further work up. They'll check the metabolic panel to look at the different electrolytes, how those are looking, but in an office setting, it's assessing, triaging, saying, "This doesn't seem right. Let me figure out the why." and then that's where they would go from there. ■ *ABILITY*

Dr. Mona's — [peds•doc•talk](https://pedsdocstalk.com)
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Using his platform for awareness, Australian comedian and content creator Nat, of Nat's What I Reckon, brings mental health conversations to the forefront with his signature blend of humor and raw honesty. Known for his satirical cooking videos and candid takes on life's absurdities, Nat has cultivated a unique space where laughter and vulnerability coexist. Beyond the screen, Nat channels his personal experiences into advocacy, serving as an ambassador for Beyond Blue, one of Australia's leading mental health organizations. Through initiatives like the Big Blue Table—a campaign encouraging open dialogues about mental health over shared meals—he exemplifies how creativity and compassion can break down stigmas and foster genuine connections.

ABILITY Magazine's Jennifer Woodall met with Nat in a virtual interview where he talks about the healing power of comedy, his lifelong relationship with music, how he accidentally became a cooking icon during lockdown and how his long-time partner Jules plays a vital role behind the scenes with her quick wit and vibrant laugh—often heard in the background of his cooking videos. He also speaks candidly about the realities of living with anxiety and depression, the importance of accessible mental health care, and why having a laugh—especially at your own expense—can be one of the most powerful tools for survival.

Woodall: Let's start with music.



Nat and Jules

Nat: I'm obsessed, I love it. It's my happy place. I love being able I create music. I love creating shit, and music is one of the best things ever because it's endless. It's like any art I suppose. I thankfully—as someone who doesn't tend to focus for very long—really got into music at such a young age that I've been playing for over 30 years now. Guitar is my big love. That was my first thing, and then drums shortly after, and bass I ended up playing by default. I'm not going to get into the whole bass politics (laughs), but I play enough bass to get me through. Most days I'm actually down in the studio that I've thrown moving blankets up against the wall of just making as much music as I can. I love it. When I was younger, I went to India with my dad for about a month or something like that. Dad wanted to take me to India, and I've always been into, I suppose what you call “world music” if you were to go to the compact disk shop. I wanted to learn sitar, so I went over and learned a bit of sitar for a while. I've got a sitar there somewhere which I play like shit (laughs) but just any music stuff. I love programming things—I love performing. It's just pure getaway for me. It's just an easy getaway. I don't mind what the instrument is. I'm shit at a lot of them, but the big three, the guitar, drums, and bass, I can hang out and create stuff anytime.

Woodall: You said “world music”. Is that what you like to listen to?

Nat: It's a funny one because I present very much like a metalhead—which I am—but probably most of the music I listen to is either jazz or in quotes, “world music”. I'm big into 70s Nigerian funk at the moment and Ethiopian jazz, like Mulatu Astatke and Ebo Taylor and stuff like that. I like a really old country. I don't mind Hank Williams—old Country. Not huge into modern country stuff. I love fucken pretty much everything, just about everything, but the majority of the music I listen to is the community radio in my bathroom, probably. I have it set to this one station. It's called Eastside FM. Just turn that on and it's just reliable. I love in the background, there's always good tunes going. On community radio, there's heaps of not polished rock and roll all the time, and it's not just jazz, they play all the stuff. I don't mind some pop stuff. I think thanks to my dad who's a massive music fan—and mom, of course—but dad's really into the types of music that I'm into. Dad was in to Nirvana when I was a kid, which is pretty fucken cool, and salt and pepper and hip hop. I just love so much stuff.

Woodall: When did you start to get into the stand-up comedy? Or just comedy in general?

Nat: Well, to comedy in general, I've always been a take the piss kind of guy. It was always a way to lighten the mood a bit. I think that comes for a lot of comedians or people who are into comedy. It's like, well, that's the whole point, right? So, from a young age, I was always



cracking jokes all the time. They're all shit and everyone thought I was very unfunny—some people still do, and that's fair as well—but I think it came, at least in terms of a creative sense, when I started making videos. I started filming bits and pieces of things and turning them into comedy videos, and then the stand-up came from that. I've always wanted to do that shit. I've been on stage a bunch playing music and shit, but comedy is another level. Like doing stand-up is—like you just mentioned—it's incredibly vulnerable. You could watch any footage of someone trying to make someone laugh and it's like someone missing a high five that's not there. It's awkward to watch and everyone feels it. In a live setting, that is enormous because if you bomb or something's not going well, that silence is just fucken the loudest thing you've ever heard. But I wanted to try it, and I had a mate who just was like, “I've got a thing on. You should do it. I really reckon you should get into it.” He's a really lovely artist, and he just booked me for this thing. It was a 15 minute spot and I loved it. All the people were there were really lovely. It was like an art crowd and very supportive so it was great. From there, I fell in love with it. I absolutely love it, but it's hard work. It is really emotionally hard work. I don't think a lot of people quite understand that. Regardless of what level of comedian you are. I boast being a pretty fucken bad one (laughs) because I drift off and I go on all sorts of tangents and shit. Jules has a mic behind the sound desk and runs visual stuff with me. I'm like, “Jules, just

grab the mic and be like, “This bit.”” I'm not the polished type, I'm not like a tidied room kind of comic, but when you do make people laugh, it's just such a nice feeling. You feel like, “Fuck, yeah. That's what I want too. I want us to all just have a laugh and get through this shit a bit.” It's been almost 10 years now I've been doing stand-up, but only really the last five or four seriously. I was more just doing it occasionally at the pub and stuff, and now it's my job. Well, it's a big part of my job.

Woodall: Can you talk about what it's like to prepare for a show?

Nat: I treat it a bit like I treated homework when I was a kid. I just don't do it. (laughs) In the run-ups to shows, if it's a new whole hour, I will run through the hours over and over, for days on end with my partner—who's the best—Jules, who's really into it and she's fucken hilarious. That's my only real prep stuff. More recently, I've stopped relying on preparation too much because I'll get in my head too much stuff, and I think I'm better at being spontaneous. What I used to do, is I used to have a stack of fucken notes on stage that I painstakingly try and hide so that someone couldn't read the note or it wouldn't be out of context. For example, some of the notes I'd have would be these nasty comments that people have left me. I did a thing where I turned a bunch of horrible shit that people said to me or just bizarre things into a song, but those were notes, so there's lyrics that I

tape to a speaker wedge, and I'm like, what if you read those notes and you didn't have the context for that? I get in my head about the person being like, "What a fucken dickhead is this guy?" I would have all this prep done and then just not be able to read any of it. I would spend so much time trying to read this shit that now I'm just like, "Fuck it. I'll just go out on stage and just trust that I'm going to be okay." I know what I want to talk about because you do it so often, you crack these jokes. A lot of them are stories, too, because you have so much shit go on that your life's a bit of a joke. I can speak about so much shit. But yeah, the prep now is really just hang out with Jules backstage and have a beer or something. It's probably not the way you're supposed to do it, but that's the way I do it. I just try and chill out. I'll jump up and down a little bit before I get on stage. My head's trying to jam me out of it. Sometimes I think the hardest times are when you're just fucken crushingly depressed and you have to go and perform, but that's the same for a lot of comics. I think we're all fucken going through it. That's harder to prepare for because you've got to deal with that shit. I do talk about that stuff on stage, too. I talk about mental health stuff heaps on stage, but if you're not feeling like it, you don't have a choice. I mean, you do, you could not go on—I think it's important to be able to have a fucken mental health day boundary on that—but it can be quite catastrophic if there's 600 people there. I know people have gone through that stuff. I think it's important that there is that option, but you've got to push yourself out on the stage sometimes. I still do, but I perform at pubs heaps still, and I actually love that shit.

Woodall: I often use comedy and darker jokes to cope with and help understand the mental health things that I deal with. Do you feel like that that's something that you do as someone who experiences that?

Nat: Yeah. It's almost probably the point of why I do it. I think it's what has brought me here is that, fuck, if you don't laugh, you'll cry, which is also fine. I mean, a cry is fine. On stage, I've done that, too. I've cried on stage. Twice the last year. I mean, what's a day look like without a laugh? Without something making you laugh? What a weird day. There's a lot of people that have that day. They're going through some fucken horrible shit, but I think it's just such a grounding thing to have a laugh. It depends on different things to make different people laugh, like you're saying, dark comedy and stuff. I don't mind a brutal joke if it's punching the right direction, if that makes sense. As long as it's not at the expense of someone or degrading and it's not at someone's expense in an unkind way, but having a laugh about yourself, I think is really healthy to a point. Not dismissing yourself, but it's hugely powerful. It's hugely powerful using comedy. I've said sometimes to mates, everyone loves the blooper reels. I really love bloopers at the end of movies, and there are some shows that I could just go and watch the bloopers. You're just in stitches. It's fucken great. Then for a sec, it gives you

what meditation does, which is just quieting the fucken busy in your brain down a bit and just focus on the one "ha ha" for a minute. It's like, I fucken needed that. It's like a dip in the ocean and you come out and think "I've got a sec. I've got a few more meters ahead of me before I have to deal with whatever it is."

Woodall: Blooper reels are great! I'll watch them every time. You mentioned mediation. Can you talk about what type are you doing?

Nat: Music at the moment. I have done the 'let's go meditate,' and guided meditation stuff is good for me. I don't like the 'sit and just let your mind go' because that fucken scares the shit out of me, but I have done meditation courses and stuff like that. I think the ideal thing for me was to do 10 minutes here or 20 minutes here and then 20 minutes later on in the day. It's great, but like any self-care thing, a lot of people get down on themselves if they don't do it properly. I'm not doing it enough, and it's part of a routine. I'm shit at routine. I think while it's fantastic and incredibly powerful shit, you can very easily give yourself a hard time for not doing it properly or not having the right space. At least that's how I get about it. I just feel like, "Oh, fuck, I'm not meditating right." I remember seeing a sleep psychologist and we're talking about things that are good before bed. The doctor told me to stay away from meditation before bed because that's what I was doing thinking like "Oh, meditation will calm me down before bed." but all it was doing was just me on the stair master in my head going "Don't think about fucken stupid shit. Just go to bed." and it would just stress me out. So, I think it just depends on the person and the place and whatever you're fucken up for. It's like exercise. Great—if you can do it, it's unreal, but you've got to find your way with it, otherwise you'll just end up making it the bad guy.

Woodall: I really enjoy hearing your partner Jules laughing in the background of your cooking videos. I was reading somewhere that she will help design your merch, is that right?

Nat: Yeah, Jules has designed heaps of our merchandise. Earlier on, Jules was doing all the merch. She was designing absolutely everything. Yeah, she designed our old let's say—Ninja Turtles-esque—logo. She was a senior graphic designer, so she's worked for lots of big magazines and some really cool shit. She helps me just make things look very grown up and she's got an amazing eye for where things should go. Jules will do all the thumbnails for the YouTube clips. You may be able to spot in there the ones that I've done because they fucken look shit. (laughs) I think probably the most incredible thing that Jules does in terms of what we're doing is she gets it. She gets what's going on. She gets the mission. She gets the laughs. She's got fucken rock solid politics. She's fucken hilarious. She's just sunshine and fucken takes no shit and kind and fucken just the best and has



my back. She'll help me work a joke out. If I'm like, "Fuck, what am I trying to..." Jules will crack a funnier joke than me so many times. I'm like, "Well fuck, I'll steal your joke if that's right." (laughs) Having that laugh in the background (of the cooking videos) just blows my mind that anyone wouldn't just love it and love her. It's the most generous thing in the world. I feel so lucky to just be around that laugh and that person. We get into it on the YouTube channel sometimes where people will be looking to say shit because they're pricks about Jules, and you just watch it police itself in the comments. There's a bit of a "protect Jules at all costs" thing (in the comments). Why wouldn't you love that? It's the best. I think you develop a nice community online if you put positive shit out there—respectful shit. It translates to moments like that in the comments. I do worry sometimes because it's a really big spot to put yourself—to be online and particularly putting your face to stuff. Sometimes I wish I hadn't, but I do worry how that's going to affect Jules, reading those comments. She goes through mine so often or helps me navigate the comment section sometimes if we need to. She understands just how empty that nonsense is, but it still does affect people, heaps. There's just a point which you do need to turn the comments off in your brain, just don't fucken read them. But yeah, it's just all love for Jules pretty much most of the time.

Woodall: On the topic of cooking videos, how did you get into that?

Nat: It came from necessity in the respect that the content I was making before that, for years before that, was more just trying to give myself the shits and go and wander around events and stuff and just social commen-

tary, I suppose. So pretty much the pandemic thing began to flap its wings a bit, and then it's like, "Shit, we're probably going to be inside for a while." Jules and I went away for the weekend just to an Airbnb somewhere, and people started to do the panic buy thing—like go buy all the fucken toilet roll. That was a big one because toilet roll is delicious and we'll keep you alive, apparently.

Are you just going to wipe your ass until the fucken pandemic is done? What's the plan there? Well, the same shit was happening with all the instant food—which makes at least more sense in some respects, because at least you can fucken consume that—but heaps of it. I went down to this local shop near the place we were staying for the weekend. Of course, dunny roll? Gone. Frozen pizzas—all the frozen shit? Gone. The fucken jar sauce aisle? Looking very fucken sparse. Then I go to the fresh food, and it's like this perfect photo finish of untouched food. What the fuck? We're all going to be stuck inside, let's fucken cook some shit! One of these jars that were left was this fucken basil garlic tomato sauce—pasta sauce. The price of it, I could have fucken made enough for half the supermarket—maybe not quite that much—so we went back to this place we were staying, and I was like, "Fuck, let's just film a thing." I was so pissed off that this fucken stuff was winning, that this jar sauce shit was winning, that I just was like, "Fucken let's take the piss out of it." and then I posted the video and it fucken went bananas. It just went absolutely off its fucken gut. Then things got much more serious. It was lockdown time. I moved into a share house, I was living out of our bags in thinking we're going back to the States, in a friend's bedroom, and then bang! The lockdown hit and I was like, "Fuck, this video is out of



Nat & Teddy Swims

control. I'd be a dickhead not to make another one." I love cooking. It's like my shit. It's one of my fucken big joys is cooking and cooking for people. So, I'm like, "Well, fuck, let's make another one." Then I made a Bolognese video and I fucken put milk in my Bolognese, and then that went even more bananas. Things were hitting over 10 million views. My phone started to ring and I was getting offers to do all sorts of wild shit. People wanting me to sign contracts, exclusivity deals, and I was just always like, "No, I don't want to fucken take money from anywhere," but it got so full on, I was like, "I think I'm a cooking video guy now for a while because this is working." It's not what I thought I'd be doing. I never became a chef or went down that road, but I love doing this. I don't want to turn it into my job, but you can't argue with people who are into it, and that's the point of comedy, if people are laughing and you want to do that, then there you go. Initially, I was like, "I fucken hate this cooking video shit. I just don't want to do it. I'm not a chef. I don't feel like I belong here." but the response was so phenomenal. Jules says this to me all the time that I don't understand what impact it had. Because people thank me and shit all the time. I still have people coming and thanking me at the shop. I understand that I gave you a laugh and maybe helped show you how to make something, but it just was doing this thing that I couldn't quite understand and that I didn't like, but I loved it and I needed it. It's still complicated and I still fucken don't get it. I'm still kind of in a bind of whether I want to do it or do the cooking thing as a performance, but yeah, it's just a phenomenal thing to have happened. I feel very lucky that I found a thing. The cooking thing helped me like it apparently helped some other people. It was just lucky because I've been pushing so much shit out and stuff was working

and it was going pretty good, but now it's my job, it's fucken quite serious. It's my income. It's full-time.

Woodall: I think your video content does a great job.

Nat: Yeah, cool, thanks. I don't have time for fucken all the details and shit, let's just take the nonsense out of it, and the pretension. It's fucken food. It's for everyone. You're lucky to have food, but it doesn't need to be this fucken difficult. These things don't matter. It's such helpful shit. I think it's just like, "Who cares how you cut that shit up? It doesn't matter." Well, that's how I've learned. I've liked the very simple "it's like this, it goes like that." I love Italian food and I love Japanese food, stuff like that, because it's so whole food and simple. It's beautiful because it is, and it's a win. Cooking is a fucken win when you nail it, particularly if you've got people around, you can share that with them. It's like, "Oh, isn't this cool?" Fuck, what a big dose of joy. Self-sustainable joy.

Woodall: What do you think the quintessential kitchen tool is?

Nat: A sharp knife all day. Sharp knife. However, you get there, fucken who cares? But it just fucken makes such the difference, in my opinion. People say shit like a sharp knife's a safer knife and all that. It's true, but whatever. Because you don't want to be forcing a blunt fucken thing and slip. I think that's the point of that one, but it just makes everything so much nicer. Even if the pan's a piece of fucken cooked on shit, you got this knife. Preparing your ingredients with a blunt knife is fucken shit. It sucks. So yeah, that's my pick.

Woodall: Okay, so if you were stranded on a deserted island, you can only bring five ingredients. Salt and pepper and dried herbs don't count as ingredients, but fresh herbs do. What do you bring?

Nat: Oh, garlic. I don't know if there is a ceiling for the amount of garlic you can put in certain things, but I've been trying to find it. Can I stick three whole garlics in this? Yep! Fucken love it. A GPS? (laughs) Chili. I love Chili. I think it has the highest level of vitamin C in it of any fruit. Vitamin C is good to ward off scurvy. There we go. Just fucken Chili. I don't know if it's the need for constant stimulation, but I'll put chili in just about fucken everything. I love it. I fucken love it. Onions because I use them for everything. I love onions, and Jules is a massive fan of onions, and I hope she's on the island with me. Let's pick something weird. Sausages. Sausages and then tomato sauce-ketchup. There we go. So, I can have a sausage sizzled on the island with chili on it. (laughs) What a fucken unsustainable ingredient to bring with you, a bunch of fucken meat.

Woodall: (laughs) Okay, last food question. Do you think a hot dog is a sandwich?

Nat: Well, I suppose I'd call it a roll. Yeah, I suppose it's a sandwich. Fucken hot dogs. My last tour was called Hot Dogs Probably Aren't Real, so I've been thinking about hot dogs. I find them just one of the most trepidatious mysteries ever. What the fuck goes into them? If you ever look in to videos of hot dogs being made in a hot dog processing factory or something, it is one of the fucken most hectic things I've ever seen.

Woodall: You've published books like *Death to Jar Sauce: Rad Recipes for Champions* and *Life: What Nat to Do*. What's your process and inspiration for writing the books?

Nat: Well, I barely read any books, so it felt like it was a bad idea at first. It was part of that thing I was mentioning earlier when my phone just started to fucken ring and I was getting all these offers for stuff, and one of those offers was to write a book. Obviously, cookbook was big on the menu, but I thought that was a really awful idea because I haven't read any books and I'm not very good at reading—I just get lost on a page all the time. I don't know what it was, but I just fucken took a chance on it and started. The first way I was writing was to just talk into my phone and then go home and type it out with one finger on the keyboard. (laughs) Jules would help me. We turned the cookbook into a comic book where the cooking parts are in comic book form because it felt like that makes sense with what I'm doing, but that adds a phenomenal level of work on top of stuff. It's very eye-opening making cookbooks because it's a fucken lot of work, and you have to have people check things, and you can't just put your recipe out there without having people test it. It's an incredible amount of effort, and I've somehow managed to do it in

an incredibly short amount of time—which is probably a good thing—but I think it's called extreme publishing, where the turnaround time is so short. I wrote one of my books in two and a half weeks. That was the *What Nat to Do*. It's like taking the piss out of self-help. It's pretty much just me having a whinge about shit that I think is just stupid advice I've been given or shit advice, whereas the cookbooks are much more meticulous and there's a lot more people involved. It's really fucken intense. Publishing a book is fucken intense. It's a lot of work. It's a lot of to and froing and a lot of tears and a lot of sleepless nights. But yeah, it's wild that I've put a book out at all, let alone four of the fucken things.

Woodall: And award-winning, too.

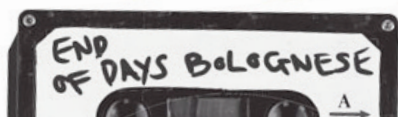
Nat: Yeah. I can't believe that shit. I feel like I had a bit of an unfair advantage in terms of the winning awards stuff because I've got such a fairly prominent social media presence, whereas a lot of authors don't. I'll always find a way to make myself feel shit about it, but it's pretty fucken cool, but not for the faint-hearted.

Woodall: Can you go into a little bit of detail about your advice books?

Nat: So, *Uncook Yourself* was the first book. I had recipes in there that were illustrated, and the rest of it is just me talking about social commentary stuff. It's less advice, and more encouragement to just fucken ignore some shit. My book, *What Nat to Do*, I wanted to call it *Live, Laugh, Meld Down*, but it didn't quite fly. One of the chapters is, “Man Up”—I fucken hate that saying. So, I wrote a chapter about why that's annoyed the shit out of me. I did a chapter about shit sleep advice and all the things I've tried for my sleep which haven't worked. If someone says the word magnesium to me again, I'm going to fucken explode. So, it's more like opinionated waffle on, really. I'm not trying to enter a self-help space at all, although it just accidentally might not be up to me, but it's not like “10 steps to fix your fucken shit.” (laughs) Fuck, don't come to me for that. I'm just here to whinge about it, and hopefully we could relate to it, but that's about it. I'm not trying to fix anyone. I'm just trying to help have a laugh, really.

Woodall: Let's transition to your journey in mental health advocacy, what was that like?

Nat: So, a couple of things. The main thing was that I didn't want all this attention and shit to be about me. I want to do something with it, and I want to help. I want to help in a way that it's manageable and I can speak to. So, I made a video reviewing depression and anxiety while I was in the States, actually, and I posted the video. It was called *Is “It Shit?”* It was the series I was making. I just spoke very frankly about how I felt about those things, and the response was fucken wild. It was really amazing, really touching. So slowly, bit by bit, I



This dish is one of the most classic hits of all time. It can also be a classic bastardised punish if it's jammed with a tonne of stupid shit. God knows the signature bolognese recipe additions I've seen before have been nothing short of fucking bizarre, I've even made a few strange moves myself in the past – everything from barbecue sauce to Vegemite. Now, by all means, put whatever you want in your sauce, but the title of 'bolognese' loses its identity fast when ingredients like zucchini and capsicum enter the room. Made my way – I promise you a classic done right – it's like a good dance move you can rely on without landing on your arse in front of everyone.

SERVES:

6-8*

COOKING TIME:

under an hour

* depending on how sauce heavy you go



HECTOMETER: 4/10

KEY:

Feed the Team | Kiddo Friendly | Low Stress

INGREDIENTS

- 1 ONION
- 2 CARROTS
- 2 STICKS CELERY
- 150-200g PANCETTA (CAN SUBSTITUTE BACON)
- 25-30g BUTTER
- OLIVE OIL
- A BIT OVER 500g EACH OF PORK AND BEEF MINCE
- FRESH ROSEMARY, THYME OR OTHER SAVOURY HERBS (OPTIONAL)
- GLASS OR 2 OF WINE (RED OR WHITE)
- 300g TOMATO PASTE
- 1 CUP MILK
- 1-2 CUPS CHICKEN STOCK
- SALT & PEPPER TO TASTE
- BAY LEAVES (WHO KNOWS IF THEY REALLY DO ANYTHING ANYWAY, SO LET'S PLAY IT SAFE AT 2-3)
- 500-750g PASTA (BUY SOME FUCKEN NICE BRONZE-EXTRUDED SHIT WOULD YA, THE COUPLE OF EXTRA BUCKS GOES A LONG WAY)
- PARMESAN, TO SERVE



57

THE MAIN SHOW

GET THE ONION, CARROT, CELERY AND PANCETTA AND KN BUNG IT IN A BOWL.

HEAT UP A BELT OF BUTTER AND A SPLASH OF OIL IN A BIG POT.

WHEN THE BUTTER HAS MELTED DROP IN THE CONTENTS OF THE BOWL.

KEEPING THE PAN HOT, FRY

ADD BEEF AND PORK MINCE, FRY THE SHIT OUT OF IT UNTIL ALL THE LIQUID HAS EVAPORATED.

HOT TIP: USE A WHISK TO STIR IT, THIS WILL BREAK UP THE MEAT EVENLY.

DON'T WORRY IF IT STICKS TO THE BOTTOM A BIT, AS THE WINE WILL SORT THAT SHIT OUT LATER.

HERE'S WHERE YOU CAN CHOOSE TO ADD SOME ROSEMARY. IF YOU LIKE, GO OUT AND PICK SOME, IT GROWS FUCKEN EVERYWHERE! JUST IN CASE THE WHOLE SPRING INCLUDING THE STALKS YOU DECIDE TO USE ALTERNATIVE HERBS, GO FOR GOLD!

KEEP COOKING THE LIQUID OUT UNTIL THE MEAT MIX IS FRYING. ONCE THE LIQUID IS FRIED OFF, ADD A GLASS OR TWO OF WINE.

THERE IS AN ARGUMENT THAT YOU SHOULD USE WHITE WINE OVER RED WINE BUT I'M NOT GETTING INVOLVED IN THAT ARGUMENT.

AGAIN, WITH THE QUALITY OF THE BOOZE, THAT'S UP TO YOU.

LET THE BOOZE COOK OFF FOR A COUPLE MINUTES THEN DROP IN YOUR TOMATO PASTA.

NEXT - ADD THE MILK.

THE ALMIGHTY CONFUSER

FUCK OFF DICK HEAD - I'M NOT PUTTING MILK IN IT.

I HEAR YOU SAY.

YEAH, IT MIGHT SOUND WEIRD, BUT SO DO A LOT OF THINGS WE DO IN OUR LIVES AND SOMETIMES THEY PAY OFF, SO FUCKEN TRUST ME AND CRANK IT IN!

NOW, IN WITH YOUR STOCK, THE ORDER IS IMPORTANT!

SEASON WITH SALT AND PEPPER, ADD THE BAY LEAVES.

I'M STILL CONVINCED BAY LEAVES ONLY GO IN FOOD TO MAKE IT LOOK LIKE YOU KNOW WHAT YOU'RE DOING.

THEN TURN THE HEAT DOWN

AND COOK IT FOR ALONG AS YA POUND OCCASION LIKE.

PUT THE LID ON

GIVE IT AN OCCASIONAL STIR, AND IF IT STARTS TO LOOK DRY...

ADD A BIT MORE BLOODY

WHEN THE SAUCE IS LOOKING PRETTY MUCH, DOING BRING SOME SALTED WATER TO BOIL AND DING IN YOUR PASTA. IF IT SAYS 11 MINUTES ON THE PACK COOK IT FOR 10...

WHY? 'CAUSE IT'S FUCKEN BETTER!

NO ONE LIKES EATING OVER-COOKED PASTA

THERE ARE A FEW WAYS TO SERVE THIS BUT HERE'S HOW I LIKE IT:

DRAIN THE PASTA AND RETURN IT TO THE POT.

LADLE IN AS MUCH SAUCE AS YOU LIKE AND GIVE IT A BIG ROUND IN THERE. IF YOU SEE THE ROSEMARY STALK OR BAY LEAVES YOU CAN GRAB THEM OUT IF THEY BOTHER YOU, BUT DON'T FRET TOO MUCH, MUSCLES.

USING TONGS, GIVE THE PASTA A LITTLE TWIST AS YOU PLOMCK IT ON THE PLATE, JUST TO BE FANCY.

GRATE A LITTLE (OR A LOT) OF PARMESAN CHEESE ON TOP.

...AND THERE YA HAVE IT!

LEFTOVER SAUCE CAN BE FROZEN IN A SEALED CONTAINER FOR UP TO 3 MONTHS TO SAVE YOU FROM EVER



started to speak about it a little bit more, and it is a bit of an underpinning in my videos anyway, mental health shit. But it got to a point where I wanted to speak about it more often. I made some donations from Nat's What I Reckon. My book won an award here, and I wanted to donate that money to Beyond Blue, which is a mental health foundation here. They're fucken incredible. Then they offered me an ambassadorship with them, not because of the donation, but because I'd expressed some support. A bit of a part of my identity, I suppose—as Nat's What I Reckon, but also as a person—is mental health struggles. It's slowly making sense, but I'm not a mental health professional outside of having it at a professional level going on. (laughs) It feels like the right thing to do. I just think mental health—is it the fucken most important thing on Earth? I don't know. I feel like the fucken meaning of life, really, is not having to suffer every moment of your existence. Some people just suffer, and constantly, and I think that's fucked, and I think that really sucks, and I wonder whether they would suffer so much if they had more support at some stage or now. How many fucken wars would be going on if everyone's mental health was looked after and they felt cared for? I think it's just so, so fucken important. The knock-on effect from people having a fucken hard time is massive, not just for them, but for all of us. Yeah, so that's why I got into it.

Woodall: Can you talk about your personal experiences with mental health?

Nat: It's never been good. I've never been a happy person. I present that way to people, but I just had a really tough growing up. I felt very lonely. I had little pepperings of being bullied a bit. I didn't have heaps of friends when I was younger, and the religion stuff made it a bit hard. So, it got to a point where when I was a teenager, I was in such a fucken bad way and in such bad shape. I was being sent to therapies and trying all sorts of stuff out, but it was like a lot of fucken screaming in the corner and rocking back and forth and just fucken flying off the handle, not knowing what the fuck and I was just so self-destructive. I just didn't want to be around. It was the worst. People were trying to support me, too, but I think I just have mental health problems, and I need to talk about it. Sometimes it takes some time to get through that shit and it's still every day. I have to get up, I have to take my fucken medication, and I get on with it. But I talk about it, and I'm lucky because I can afford to see a therapist, so that's massive. I'm lucky, but some people can't. But it's every day. It's fucken every day. It's every night. It's nonstop. I suffer all the time. Even in our chat now, I'm anxious. I'm really fucken anxious. I'm so used to it and meds help and stuff, but I never really, truly feel at ease. I feel like I'm in a space where I have a choice of what I want to do with that, and I've tried the other thing, which is just fuck myself up and just see where that goes, and it doesn't end well, or I can try. I can try to keep it up every day. I can try and fucken get better and do it for Jules and do it for

people that love me if I can't do it for myself. It sounds a bit black and white thinking, but that's what I want. I want to get better. I know I'll never be “better,” whatever that means. I'll never be happy happy, but that's all relative. Happiness is a health halo thing that's sold to people a lot of the time anyway. If you're eternally happy all the time, that sounds fucken annoying as well, to be honest. The comedy would be shit. (laughs) But yeah, that's it. I'm just on a constant hum of going through it, so I can relate to people struggling from that angle. There's levels of it far worse than what I'm going through.

Woodall: For such a long time, there's been—and there still is—a stigma against mental health where it's equated to weakness.

Nat: It fucken baffles me that it's seen as a type of weakness. Like you're saying, it's not at all. How hard it is to get through a day when you're fucken just begging not to have to get out of bed. You don't want to see anyone, you don't want to do anything, you don't want to fucken shower. I don't want to eat. I just want to cry and hide in a fucken doona. A real blokey thing that I can speak to is that men have this like “you can shut up and put up” kind of attitude or the messages that some of these fucken dickheads online telling you “You have to be aggressive and strong and alpha and all this showing emotion is vulnerability and therefore it's weak. You leave yourself vulnerable to attack.” My God, that's just such a fucken toxic way of thinking. Everyone's got some shit going on. Not being able to relate to each other on that level seems like a fucken endless bummer to me. We all know someone or are the person with fucken mental health struggles. We can all talk about it. Fucken why not? Why does it have to be a stigma on something? It's because people are told it's wrong or you're not heading the right direction if you give in to it or if you're crying. It's like some military movie or something. It's not war. Well, it is in some respects in your head, but I find it so frustrating. I just see people just ignore it and I know people that are like “No, no, I don't need to talk to someone. I'll be alright.” Fuck, yes, you do. Yes, you do. We all deserve that. Even people that have fucked up and might be in jail or whatever need support. Everyone deserves support. Otherwise, we can't get better. To make that seem like a “don't talk about it” zone is so fucken dangerous. I do worry about the way the world's going in that respect, too. I'm seeing a lot of that fucken alpha bro shit, and it's crushing to see people squashing people's need for support. ■ **ABILITY**

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Nat's What I Reckon
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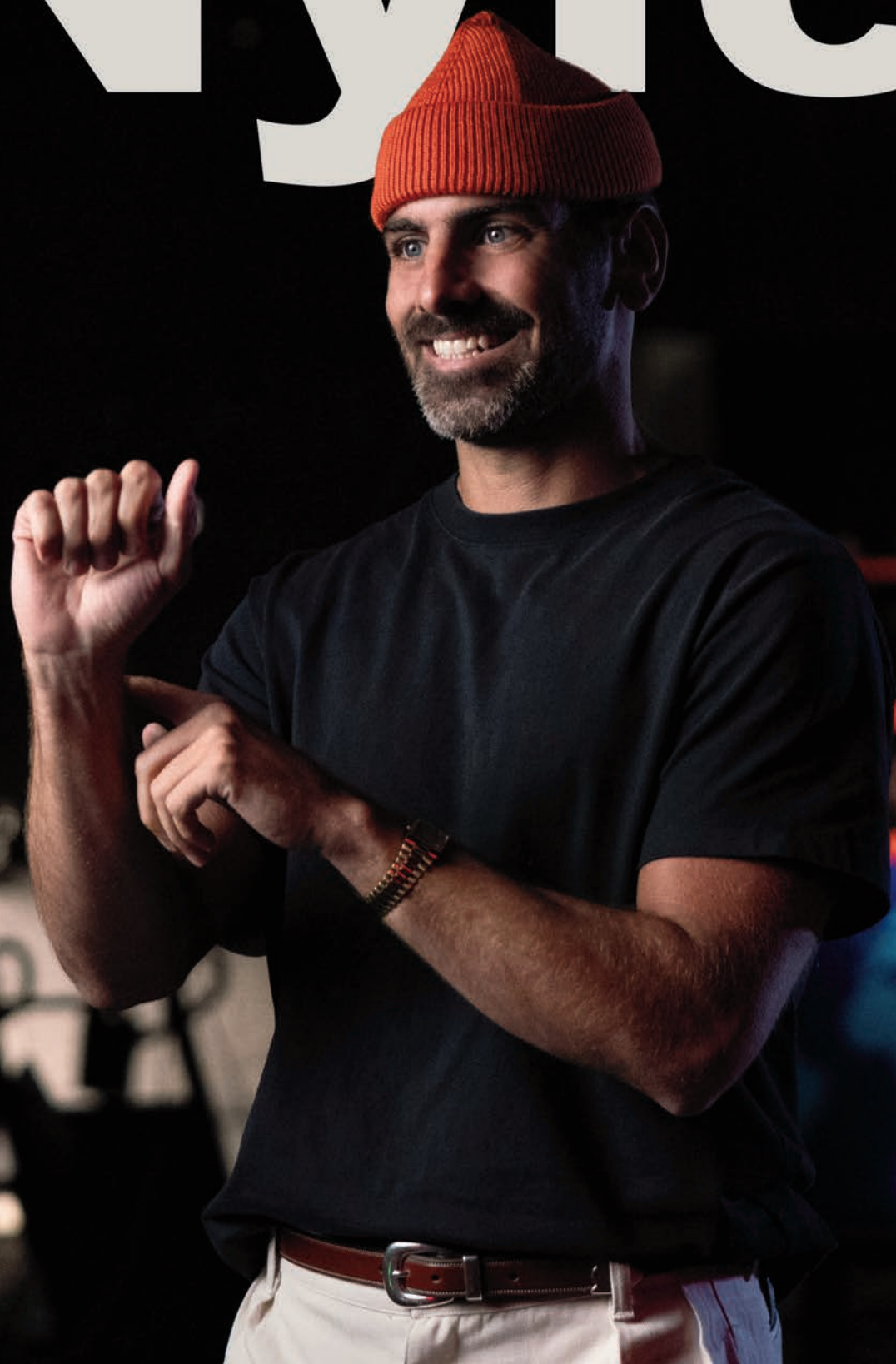
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Nyle



DiMarco

Nyle on Deaf History, Inclusion and Justice

American filmmaker, model, actor and Deaf activist, Nyle DiMarco has consistently used his platform to advocate for the Deaf community and broader disability rights. After gaining national recognition by winning America's Next Top Model in 2015 and *Dancing with the Stars* in 2016, DiMarco has focused on projects that amplify Deaf culture and stories. In 2020, as an executive producer, he launched the reality series *Deaf U* on Netflix that followed a group of Deaf and hard of hearing students at Gallaudet University, the world's first university for Deaf and hard of hearing people. He was an executive producer of the 2021 Oscar-nominated documentary short *Audible* on the Maryland School for the Deaf, of which he is an alumnus. His 2022 memoir, *Deaf Utopia: A Memoir—And a Love Letter to a Way of Life*, celebrates Deaf culture and American Sign Language through personal stories about his upbringing and family. His latest endeavor, co-directing the documentary *Deaf President Now!* with Davis Guggenheim, brings to light the pivotal 1988 student protest at Gallaudet.

The documentary, which premiered on Apple TV+, revisits the eight-day protest sparked by the university board's decision to appoint a hearing president over qualified Deaf candidates. Led by students Bridgetta Bourne-Firl, Jerry Covell, Greg Hlibok, and Tim Rarus, the movement culminated in the appointment of Dr. I. King Jordan as Gallaudet's first Deaf president, a landmark moment in Deaf civil rights history. The film employs innovative storytelling techniques, including immersive sound design and a Deaf Point of View, which uses the sensory and linguistic perspectives of Deaf people to convey the experiences and emotions of the protesters.

DiMarco sat down with Dr. Ed Timke (Assistant Professor, Department of Advertising + Public Relations at MSU) and *ABILITY Magazine*'s Jennifer Woodall and Chet Cooper to talk about his journey, what it meant to making and co-direct a film about one of the most defining moments in Deaf history, and how his work continues to shape conversations in media and society about access and inclusion.



Tim Rarus, Bridgetta Bourne Firl, Greg Hlibok and Jerry Covell

DiMarco's Background and Its Connection to *Deaf President Now!*

Ed Timke: Can you talk about making *Deaf President Now!* and how it connects to your personal journey, career, and advocacy?

Nyle DiMarco: I come from an entirely Deaf family. I'm the fourth generation—my parents, grandparents, great-grandparents, and brothers, including my twin, are all Deaf. They also went to Deaf schools. My parents went to Gallaudet, and I did too. I graduated in 2007. That kind of legacy is rare, and I've seen what my parents and grandparents went through. Those generational experiences impact how we think.

So much of what's in the film reflects that—small things like light doorbells, or how visual noise works in our lives. For example, if someone bangs on a door, you don't hear it—you see it rattle. Those details shaped the world I grew up in, and they shaped this film too.

Jennifer Woodall: What was your educational experiences before Gallaudet?

DiMarco: In my younger years I went to a school that was more oral-focused. That means it emphasized speech over signing. I knew what that looked like and how that environment could be limiting. I wanted to bring that perspective into the film as well to show that Deaf people thrive when we're allowed to fully be ourselves, in our own language.

Timke: I was born with profound hearing loss and have implantable hearing devices. Growing up, I never saw people like myself in the media. What was your experience?

DiMarco: Growing up, anytime that there was a Deaf representation or Deaf storylines in TV or in film, Deaf and hard-of-hearing people were always portrayed as one-dimensional without nuance or depth. While perhaps that wasn't necessarily wrong, it just wasn't accurate or reflective of my experience or perhaps other Deaf or hard-of-hearing people's experiences. That was one of the biggest reasons why I made *Deaf U* and *Audible*, and now *Deaf President Now!* It was really to show a range in a spectrum of the Deaf experience, especially with Dr. I. King Jordan, who went Deaf much later in life, but is still very much considered a part of the Deaf community. I think that's really beautiful. I want to show the entertainment industry as a whole just how much color we have within the Deaf community.

Timke: What can people learn about what it means to be Deaf or hard of hearing through your film?

DiMarco: Deaf people are not a monolith. Too often people assume that all of our experiences are the same. You and I, while we're both Deaf, have completely different experiences. But at the end of the day, we're both Deaf. I would hope that people really start to understand that.

Timke: The film's story is already well-known in the Deaf community, right?



Nyle DiMarco on set with Davis Guggenheim

DiMarco: Oh, absolutely. It's one of the first stories you learn when you enter the community. But what's ironic is that it's still virtually unknown in the hearing world. That's something we hope this film changes.

Producing *Deaf President Now!*

Woodall: Let's talk more about the film's production. I noticed you used voiceovers instead of subtitles for some interviews. Why?

DiMarco: It was a stylistic choice. The film is fast-paced, packed with archive footage and visuals. It was a very unique challenge as a director to decide how we would have a hearing audience perceive things from a Deaf perspective and understand everything that we were throwing at them. We also wanted them to follow the story as comfortably as possible. Forcing hearing folks to read captions felt like we weren't giving people enough time to absorb what we showed them. They could also miss out on some of the incredible visuals.

Woodall: The sound design was also really striking, especially in the emotional moments where it went totally silent. As a hearing person, I felt like it was very impactful.

DiMarco: Thank you. That was very intentional. My co-director Nguyen Davis and I wanted to draw hearing people in and out of a Deaf perspective. Silence isn't empty to us. It's an essential part of how we experience the world. We tried to use it in ways that would resonate emotionally and also help people reflect.

Timke: You had a large Deaf crew to bring a Deaf Point of View behind the scenes, too. What was that like?

DiMarco: We had 40 deaf folks working on set across departments. I believe that's the most that's been done in Hollywood to date. We're very, very proud of that. It's been a passion of mine working in this industry to hire as many Deaf people as possible. Many of them have worked in this industry for longer than I have and have not been able to find the opportunity to land good jobs. So it's great to be able to provide more experience to them and help shore up their resumes. My goal is to ready them to be able to tell their own stories and make their own content in the future. That's the dream.

Timke: How do you think that impacts the story that you told in the end?

DiMarco: It's so interesting because I think it's so important to have at least one person from the community behind the camera. I hired Wayne Betz Jr., a very good friend of mine who's an incredibly talented deaf filmmaker. He really started in the wrong era, unfortunately. He started making films 20 years before my time, and ended up, because of a lack of opportunity, working the regular 9-to-5. Having him on set was so great to be able to have another set of eyes to be a sounding board. I think it really heightened the film and allowed us to assume more and push limits more. Having more Deaf folks on set is a really unique environment. It created space for the kinds of informal interactions—like socializing and problem-solving—that hearing crews often rely on to drive a movie forward.



Greg Hlibok giving a speech during a protest

We wanted to make sure our set had that same dynamic and sense of connection for everyone.

Advocacy and Reflections on Deaf History

Woodall: In the documentary, I saw how some hearing people have this “let me help you” type of mentality. Do you still feel like that is prevalent within the Deaf experience today?

DiMarco: All the time. It happens everywhere, every day. I don’t think it’s to the extent that you see in the film, but many hearing people really believe that they know what’s best for us. They may have great intentions, but good intentions can oftentimes do the most damage. There’s still so much work that needs to be done. I think we would hope that this film would re-inspire folks to not be complicit in thinking that way.

Woodall: What can allies do to be supportive?

DiMarco: Follow Deaf people on social media. So many of us are out there working to educate the public. Share our work. Amplifying the voices of the Deaf community is so important. Include us in conversations, especially when decisions will have an impact on us. Being more inclusive makes the world a better place.

Woodall: The film shows that even within the Deaf community, some people once doubted a Deaf person could lead. Do you think that mindset still lingers?

DiMarco: In some ways, yes. Back then, internalized

oppression was strong. Today, it’s more about complacency. In Indiana right now, Deaf schools are being defunded, but we don’t really see Deaf people talking about it. It’s easy to forget how hard we had to fight to pass laws, and laws can be regressed quite easily. While the Gallaudet protest was about the appointment of a Deaf president, it also helped the passage of the ADA. I really hope that this film will re-inspire our community to fight for one another, and also just to make the statement that the fight truly is never over.

Chet Cooper: Did you get to spend time with I. King Jordan?

DiMarco: Yeah, it was great. We had a chance to go out to dinner prior to the interviews, and we got to obviously shoot with him a lot. It was really nice.

Cooper: Did you speak to him after the final cut to see what he thought about how everything came together?

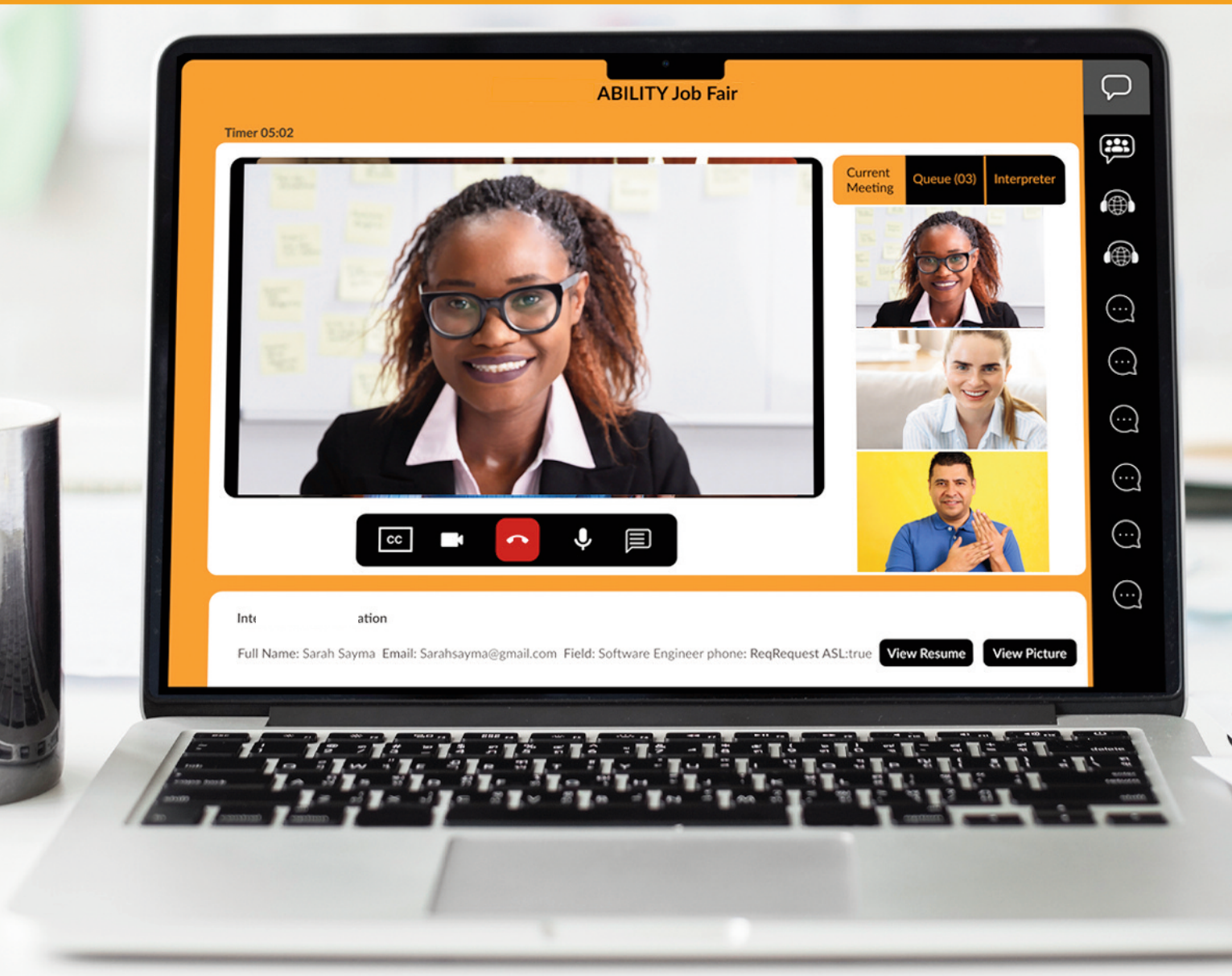
DiMarco: Yeah, actually, we watched the film together. We were really hoping that he would like it, and at the end, he said what many people said, that it’s an amazing film and he felt that it really captured essentially the essence of present now and of the deaf experience within it. So that was a great relief to know that we got his stamp of approval.

Timke: What do you think the film offers to people with other disabilities?

DiMarco: I hope it inspires them to take back their



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power and own their agency. A lot of us don't realize it's up to us to stand up and be empowered. I hope this film shows the power of collective action and what we can do together to fight exclusion.

Timke: The film makes me think about the Independent Living Movement in Berkeley in the 1970s. When I've taught about this, people are blown away by what happened there and the impact it had.

DiMarco: That's one of my favorite stories too. So powerful. Movements like that and Deaf President Now are part of a broader legacy of disability justice.

Timke: Why are schools and universities that serve historically excluded people so important, such as Gal-

laudet for Deaf and hard-of-hearing people, and HBCUs for Black communities?

DiMarco: I think we all need to feel at home. We all want a place where we can go and get our education in the most comfortable and conducive environment. That's so critical, and that's what we need to be talking about. It's one of the biggest reasons why I didn't want to go to a hearing school, because I knew that I wouldn't be able to maximize my potential, and I wouldn't be really immersed the way that I would be within my own community. Gallaudet is such an ideal place. And university in general is where we find our identity, where we build our sense of self-worth in many ways, and really is where we set ourselves up for a successful future.

Right now is a very interesting time. There are many Deaf schools out there that are very vulnerable. They're in a position where they're facing budget cuts. If you look at Indiana, they're cutting things significantly while other public school budgets are being increased. They've decided that services for the Deaf don't really need to be shored up. That's really dangerous.

From my experience, a lot of hearing people in the United States have good intentions and believe that mainstreaming might be better for Deaf folks, but that's not always the case. For so many Deaf kids, they really thrive in an ASL environment. Like myself, I fully thrive in ASL rather than English. While I'm fluent in both, I'm very much more comfortable in my native language. I would hope that people would continue to work to, after seeing this film, to bring in Deaf folks to advocate for a better quality education, which essentially is why the Deaf President Now protest happened in the first place.

Timke: I'm a historian and find your film important because it brings Deaf history to a broader audience. At a time when diversifying historical perspectives is attacked, why do you think history matters? And do you see yourself as a historian now that you've made this documentary?

DiMarco: Honestly, I was never really a history person, but it's interesting now that I am a filmmaker. I find myself reading a lot more Deaf history and really diving into it. I think I'm much more knowledgeable now in terms of our culture than I was before. But history is so important because we need to know where we come from in order to get where we're going. And I also think we need to know how far we've come. So much of our Deaf history really shaped not only the United States, but the world. And I think it's important that we reflect on that because we are, in fact, equal citizens, and there's incredible value in remembering that. ■ **ABILITY**

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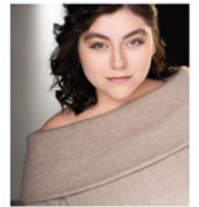
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LE MANS

ADAPTIVE RACING BEYOND LIMITS



Elena Rosberg's directorial debut, "Le Mans, Racing Beyond Limits," is a riveting documentary that explores the world of adaptive motorcycle racing. Set against the backdrop of the prestigious Le Mans European Motorcycle Championship, this film showcases the determination and spirit of riders with disabilities. Filmed between April 18th and 20th, 2024, in Le Mans, France, Rosberg's documentary highlights the excitement of the races and its extraordinary athletes. "Le Mans, Racing Beyond Limits" promotes participation in the sport for people with physical disabilities and encourages viewers to overcome their own limitations and pursue their dreams. To share her motivation for

this film, Rosberg met with Legendary long-distance motorcyclist and ABILITY Magazine columnist, Paul Pelland along with motorcycle enthusiast and publisher, Chet Cooper.

Rosberg, an Austrian entrepreneur, model and film maker, is married to former motorcycle racer Martin Hejduk. They have five children and 4 grandchildren, including European kart champion Niki Kresse and actress, singer Valentina Waldner.

Paul Pelland: I watched your movie. Pretty awesome.



Being transferred to the bike

Elena Rosberg: Thank you very much. So, you're in Los Angeles or where are you now?

Pelland: I'm actually in New Hampshire in New England. I write a column for ABILITY Magazine. I travel the country on a motorcycle. So, that's why we thought that it'd be fun to have me as part of the interview. My goal is to ride a million miles for multiple sclerosis.

Rosberg: Really.

Pelland: I do patient advocacy. I do patient presentations, but I also do a lot of motorcycle travel seminars and things like that.

Rosberg: Have you've been to Austria?

Pelland: Not yet.

Rosberg: But to Europe?

Pelland: I was in Madrid for a day, and then we went to Morocco.

Rosberg: Madrid and then Morocco.

Pelland: Right. It was for a motorcycle event put on by Bridgestone Tires.

Rosberg: Okay.

Pelland: They sponsored me, and they invited me to go, so I couldn't say no. But mostly, I travel all over the United States, and Canada. On a motorcycle. Everywhere I go is on a motorcycle.

Rosberg: Nice. Last year, I got married in Las Vegas. And we flew to Los Angeles and we rented some Harley's. We went from Los Angeles to Las Vegas.

Pelland: Very cool.

Rosberg: Actually, exactly one year ago.

Pelland: Well, congratulations on your anniversary.

Rosberg: Yeah, June first.

Pelland: And you're still married?

Rosberg: (laughs) So far, so good. Yeah, it was nice a nice trip, a great experience.

Pelland: It's a nice area. Let's see, we're in May. So, the weather, it wasn't too hot. It can get pretty hot in Vegas in the summer. I think I was just looking at a video I did a few years ago when I was there. It was 115 degrees Fahrenheit, which I'm not sure what that is in



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Celsius, but- Yeah, it About 45, 45 or so.

Rosberg: It's bad. It's really bad.

Pelland: Hot enough that your shoes melt on the pavement.

Rosberg: But Las Vegas is crazy. The wedding was great, and with Elvis, of course. Las Vegas is crazy.

Cooper: What got you involved into the motorcycle space?

Rosberg: My husband. I met my husband two years ago, and he used to be a motorcycle racer. So, of course, he told me a lot of things about it, and that's why I wanted to understand him. Why does somebody race motorcycle race? And he's still involved in the sport. He's an official at the FIM (International Motorcycling Federation). And that's why two years ago, I went to Croatia, to Krupnik, just to watch a motorcycle race. It was really just to understand him, what he did.

That was the very first motorcycle race I ever witnessed. And there was also the European Handy Bridgestone Cup for disabled riders. And that's where I saw those riders for the first time.

Cooper: Does your husband use adaptive equipment?

Rosberg: No. He was a racer when he was young. We are now in our 60s, so we are old. (laughs) No, he has nothing to do with disabled racing.

Cooper: Oh, I see. So, you happened to notice disabled riders.

Rosberg: Exactly. I was at the race track, and there were a couple of races. I saw this guy racing as well. I was shocked and fascinated at the same time. I didn't even know that something like that existed in motorcycle racing. What fascinated me was this difference in the preparation, this arduous preparation, getting dressed, and then the race starts, and then bang. I mean, then it's a normal race. It's a motorcycle race. So, this difference—Once the race starts, all these differences and it disappears. That was so fascinating for me. And also, they were so cool. They're one of the most joyful. They're cool. They have fun. I mean, it was fascinating.

Cooper: And then you started to make connections with some of the riders, and you thought — I should share their story?

Rosberg: I mean, these guys are unbelievable. I started following some of them on Instagram, and then Jacob Lawrence, the young Austrian, who won in the 600 CC class. I followed him on Instagram. And he was 23 at the time.

Cooper: I think that's called stalking.

Rosberg: (laughs) No. Lawrence has been using a wheelchair since he was 18. He films himself. It was his first season and he was already winning everything. In his films he says, "Hey, guys, these are the happiest, happiest weeks of my life". And you could see it in his eyes. It was true. So, for me, I didn't want to make a film about disability because I do not understand enough.

For me, it's like people who are living their dream. No matter what, they just do what they love. I thought "I would like to film this, to make a film about that." Just one day of a race and show people who do what they loved since childhood. I mean, they all say, "I was two or three years old, I got my first motorcycle." They had a dream like we all have a dream, but often these dreams were destroyed. And these guys, they do what they dreamed of, no matter what.

Cooper: Did you ask why they ride?

Rosberg: Yeah, they all said it started in childhood. I asked if it wasn't motorcycles, would you do something else? And they all said, "What? I don't understand the question." If you didn't ride a motorcycle, what other sport do you think you would have chosen? And they were like, "What is she talking about?"

Cooper: One of the things I continually hear what people, myself included, think about bikes is the concept of freedom. There's something about feeling free when you're on a motorcycle. And yes, usually it starts when one is young, but people that are older also get it.

Paul, would you use the word freedom?

Rosberg: Yes, I do understand.

Pelland: Yeah, absolutely. Something about getting on the bike and freedom from everything because your mind and your body takes part in the act of riding a motorcycle. You need to focus and all your body parts need to be working in the right order. So, it keeps your mind free, a moto mindfulness. It takes all your concentration, and so that everything else fades away. And you are free. You're free from all the things that are bothering you in life, and the ability to lean, and to look where you want to go, and the motorcycle just follows. And there's a bit of excitement, there's a bit of speed. There's a little bit of an outlaw feel when you get on a motorcycle. It's thrilling, and it's exciting. And I, obviously, enjoy riding motorcycles a lot more than anything else. And again, I've never played golf. There's nothing else I do. It's all I know and all I enjoy. I think that you see that in these racers that, sure, they have more things to overcome, but they're still out there doing what they love. I think that's pretty cool.

Cooper: Does your husband still ride?

Rosberg: Yeah, he has a lot of motorcycles.

Cooper: Do you ride?

Rosberg: When I was young.

Cooper: Did you race?

Rosberg: I rode a long, long time ago. No, I never raced. Once I had kids, I stopped. However, as I mentioned when we got married, we rode Harleys from Los Angeles to Las Vegas.

Cooper: Paul, actually was able to get a doctor to write a prescription called moto-medicine. And a well-known psychiatrist believes there is a mental health benefit for those people that ride.

Rosberg: This intense focus helps you forget everything. If people may traumatize or everything always comes. If you have to focus so intensely, it all falls away.

Cooper: Yeah, it's odd because sometimes you actually stop focusing. You become one with the bike and your surroundings and time are altered.

Rosberg: It is a phenomenon. I think people who have been traumatized, for example, in childhood, often seek dangerous things because with dangerous things you have to focus. You have to concentrate so much because then everything else falls away. And that makes people happy in this flow state.

Cooper: Paul, do you get this? You look back and go, "Wait, I'm in another city. How or when did I get here?"

Pelland: Oh, yeah. Some of the days that I'm on the bike, it's long. It could be 14, 16 hours and going through multiple areas of the country, even. And before I know it, I'm at my hotel, and I've just driven a thousand miles or 1,200 miles, and I don't really remember much of it, other than I was just enjoying myself and being on the bike and in the wind. So, yeah, it clears my head. I mean, sometimes I get to where I'm going and I forget that I'm who I am or what I've done. And I have a family at home? (laughs) But, yeah, I get in that groove, where nothing matters. Just enjoying myself.

Cooper: What do you do on a day-to-day basis other than documentaries? Or is that what you do?

Rosberg: I start working on my next film.

Cooper: Where do you live now?

Rosberg: In Vienna, in Austria.



Jakob Lorenz

Cooper: The film awareness building for the documentary? Or is there something beyond that?

Rosberg: Well, when I made it, I didn't know what will be of this film. But now, it's on Amazon, Apple TV, and Google TV, which I'm very happy and thankful. As I mentioned, we had this dream, and so often these dreams are destroyed. It's like a topic for me. So, I think if somebody watches this and somebody has given up on their dreams for a long time and says, "Hey, wait a second, if this guy can do it, maybe I sign up for this class or I go to a sports thing or I do one move closer to my dream..." Then I would be very happy. Also the film is in a couple of festivals. It's been nominated for a couple of festivals, maybe it will win.

Cooper: Maybe somebody watches your film and decides, I'm going to ride a million miles. (Paul laughs) Is there anything else you would like to share about this?

Rosberg: This whole International Bridgestone Handy Race is really the work of Di.Di. Diversamente Disabili, this Italian nonprofit, together with Stéphane Paulus—He's French rider. They started it all. And they, Di.Di. and Paulus, started this Cup that's every year. It started in 2017. So, it's thanks to them that such a thing exists. I don't know in the United States if there's such a thing, but that this exists in Europe. And Di.Di. is very interesting. I think thousands of disabled riders—They do seminars. They have Di.Di. Day. So many young people come. People think they would never get on the bike, and they bring them back on the

bike. It's a very emotional thing. So, it's thanks to Di.Di. and Emiliano (Malagoli)—He's also in the film.—and Stéphane. They started it together. And it's thanks to them that such a thing exists.

Cooper: Have you been to their location?

Rosberg: Unfortunately, no. But I want to. And I would like also to film maybe all this Di.Di. Day, as I said, when they bring people back on their bike for the first time, they're on the bike again.

Cooper: Do you happen to know what bikes they're using?

Rosberg: No, I don't know. I don't know exactly. I mean, in my film, they show the adaptation.

Cooper: Yes. Those are the racer. Yeah, the racing bikes. But do you know if Edi does other types of bikes? Is it all street? I don't know.

Rosberg: I don't know.

Cooper: Paul have you haven't heard of them? Paul, you're in a different world when it comes to these bikes, right?

Pelland: Yeah. It's funny. Everybody I meet thinks I know all Yamaha's corporate-sponsored racers and street riders, street racers, track racers and off-road — I don't. I know a lot about motorcycles. A lot about riding, but I've never really been one to race. I go fast enough on the street. Plus, with my cognitive decline, I



Alex Innocenti

would need a GPS to go around in circles. I'd be the guy that left my left blinker on.

I think when people see a film like this, they realize that the issues that they think that is keeping them from doing what they want to do are very minor compared to what other people have as far as physical issues. And they're still out there doing it and doing what they love. And I think that inspires people to do anything, whether it's take a ballroom dancing or whatever. It's... Yeah, it's exciting. It's great. My life isn't so bad if they're able to... They can't walk, and yet they racing a motorcycle at warped speed and doing what they love. I think it's inspiring. It's inspiring no matter what you do in life or whether you like motorcycles or not. It's still that they're able to see the inspiration and the thrill and excitement that people can have. Just because you have a disability doesn't mean you can't still get out there and enjoy your life.

Rosberg: Yeah. Some people—Mental limitation can be even worse, obviously, than physical limitation.

Pelland: Absolutely.

Rosberg: If you have something you're afraid or something like that, you have this limitation. It can be much worse sometimes. For me, it was also inspiring.

Pelland: Yeah. It is. Plus, there's all that leather and gasoline and all that fun stuff.

Rosberg: And Le Mans, it's really a nice track.

Chet: Yes.

Rosberg: And the race was right before the 24-hour race started. So, there were already lots of people there—and normally, I don't think so many—But lots of people came already. And there was this atmosphere because their race was right before the motorcycle 24-hour, Le Mans started.

Cooper: Have you heard of an organization called Motodempion, it supports adaptive motocross riders. Maybe your next documentary?

Rosberg: (laughs) I haven't heard of this. I'll look them up. Thank you both this was really great. ■ **ABILITY**

tv.apple.com/us/movie/le-mans-racing-beyond-limits/umc.cmc.15a7rr5h0337ebmh3p67vy4xp



Elena Rosberg



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Switchify – Open Source Overcoming Accessibility Barriers for Various Adaptive Switches

As Owen McGirr navigates the digital world, he makes his own way and shares that way on the Google App Store. McGirr, founder of Switchify, brings his skill and experience to the app that makes Android phones more accessible for users with physical and limited movement disabilities. McGirr, a software developer with cerebral palsy, works to close the gaps in existing assistive technology to promote ease of use and independence when using the latest smartphone technology. Switchify app is a customizable smart phone interface for use with various adaptive switches.

In a virtual interview with *ABILITY Magazine's* Gina Velasquez, McGirr discusses his motivation to develop Switchify and its purpose of technological empowerment for people with a wide array of physical disabilities. He also provides a detailed description of the app's features, how it works and how users who are blind and have physical disabilities can use it.

Gina Velasquez: Could you tell me a little bit about yourself?

Owen McGirr: I'm a software developer from Donegal, Ireland. I was born with cerebral palsy, which has shaped not only my daily life, but also my professional journey. From a young age, I understood the barriers that people with disabilities face and the importance of assistive technology in breaking them down.

In secondary school, I began to experience just how transformative assistive technology could be. I relied on AAC, augmentative and alternative communication, tools to express myself using software that converted my typed messages into spoken words. While this was empowering, I also encountered the limitations of available technology. Many tools were either difficult to use, overly expensive, or not tailored to my specific needs. These experiences planted the seed for what would become my passion for creating accessible user-focused technology.

After secondary school, I attended Atlantic Technological University (ATU) where I studied software development. My time at ATU was both challenging and rewarding. While many aspects of university life required me to adapt, my passion for coding and problem solving kept me motivated. It was here that I began

to see how my skills as a developer could intersect with my experiences as a person with a disability. I realized that I could not only use technology to help myself but also create tools to help others.

One of my early projects was Sayit!, an AAC app designed to provide a simple and effective voice output for nonverbal users looking for an accessible, easy-to-use solution. It aimed at addressing affordability and simplicity, making it a good fit for those who didn't need complex systems. Although I've since discontinued its development, it marked an important milestone in my career. It showed me the impact that well-designed assistive technology could have and inspired me to keep pushing forward.

Velasquez: How did creating Sayit! Show you its impact on non-verbal users?

McGirr: SayIt! taught me how essential usability is in assistive tech, and that lesson directly influenced the work I do today.

Velasquez: Why did you discontinue developing it?

McGirr: I discontinued development because I wanted to focus on projects that would have a broader impact. Today, my focus is on Switchify, an open-source Android app that improves Switch access functionality. My personal journey from navigating school with AAC tools to fighting to overcome accessibility barriers in daily life has been the driving force behind my work. I believe that no one should have to struggle to access technology, and I'm committed to creating tools that empower people to live more independently and with dignity.

Velasquez: Back to your time at ATU, I'm curious about your experience getting through the traditional system, if that was something that was difficult.

McGirr: I was very lucky, I would say. For exams, I was given extra time, and the social aspect wasn't really that different. I was always included. I got in trouble like anyone else. Yes, I'm very lucky.

Velasquez: So, you were in the traditional educational environment?



McGirr: Yeah.

Velasquez: And the technology was there for you as you were growing up?

McGirr: Yeah. Well, it has come a long way since.

Velasquez: I see. But there was enough for you when you went through school. I mean, you graduated from university with a degree in computer science.

McGirr: It was enough to get by.

Velasquez: You mentioned that you're now focusing on Switchify, the app that you created. Can you tell me more about that and describe how it works?

McGirr: Switch access is a way to control a device without using a touch screen, mouse, or keyboard. Instead, it uses something called a Switch. A Switch can be a button, a pedal, or even a head sensor, something that can be pressed or activated by a simple movement. Think of it like this.

Imagine you can't use your hands to touch a screen or type on a keyboard. The switch lets you interact with the device by doing something simple, like pressing a button with your head or foot. The way it works is through something called scanning.

Picture a box moving across the screen. It highlights different things, like apps or letters on a keyboard. When the box reaches what you want, you press the switch to choose it. For example, if you want to open an app, the box moves from one app to the next. When it highlights the right one, you press the switch and the app opens.

Switch access also works for typing.

Imagine a keyboard on the screen. The box moves through each row of letters. When it reaches the right row, you press the switch. Then it scans through each letter in that row, and you press the switch again when it highlights the one you want. This system allows people with limited movement to use devices like phones or tablets, even though it takes a little longer. It gives them the ability to do things like browse the Internet, send messages, or make phone calls using just a single switch in simple movements.

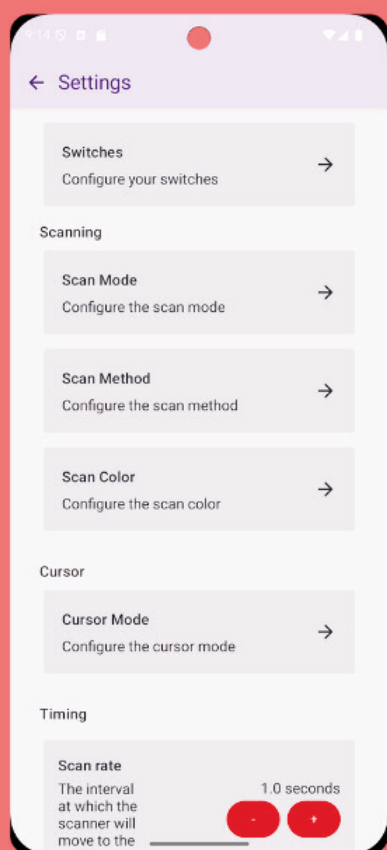
Switchify takes this system and makes it better. It allows people to customize how the scanning works, use advanced gestures, and interact with their devices in ways that are faster and more flexible than standard options.

Velasquez: What kind of switch is normally used with a cell phone?

McGirr: A common switch used with cell phones is a simple button switch, such as the Jelly Bean or Buddy Button, which connects via Bluetooth or through a specialized interface like AbleNet's Blue2.

Velasquez: Does a phone switch incorporate a stenography notation type system for ease of conversation and to avoid overtaxing users? For comparison, there's contracted Braille, which is a notation system to indicate larger patterned words for ease of reading. How do you operate a cell phone switch?

McGirr: Switches are operated by small movements—pressing a button, tilting the head, or even blinking.



Customisable scan settings

They don't use a stenography-style notation system. Instead, scanning interfaces highlight options sequentially, and the user activates the switch when their desired choice is highlighted. The simplicity of scanning systems prevents overtaxing AAC users, as it eliminates the need for rapid or complex input while still enabling full control over the device.

Velasquez: Is Switchify software alone, or is it software plus a hardware device,

McGirr: It is an app, and you do need Switches, which you can buy from people like AbleNet.

Velasquez: What is AbleNet? I am not familiar with them.

McGirr: AbleNet is a company that specializes in assistive technology for people with disabilities. They offer devices like switches, mounts, and communication systems designed to make technology more accessible to those with limited mobility or communication challenges. These tools are particularly helpful for Android

and iPhone users who need alternative access solutions.

Velasquez: So you need switches, and then you attach them to your Android device?

McGirr: Yeah.

Velasquez: And then your Switchify app is free, correct?

McGirr: Yes.

Velasquez: Is Switchify Android-based only, or is it also available for iPhones or Apple devices?

McGirr: It's just Android, simply because it is the platform that the tools were the least developed for, and I wanted to change that.

Velasquez: Right, and was this because there was no motor accessibility or little motor accessibility for Android devices?

McGirr: Exactly.

Velasquez: From the perspective of being blind, I was listening to your description of how the Switchify technology works with the box moving around, and that's how you know when to touch a button or switch to select something. I was thinking that a blind person would not be able to use either Switchify or something similar if they're also not able to type.

McGirr: Switchify was primarily designed for individuals with physical disabilities, but I'm actively working on expanding its usability to benefit people with visual impairments as well. This means ensuring the app not only functions well for Switch users, but also integrates accessibility features that make navigating the interface easier for those who rely on auditory feedback.

One of the major updates I've developed is to include the ability for Switchify to read out the elements on the screen as they are scanned. For example, as the scanning box moves across buttons, apps, or menu items, the app will announce what each element is, allowing visually impaired users to know exactly what they're selecting. This will provide a regulatory cue, making the experience intuitive and functional for those who can't rely on visual input.

This enhancement bridges the gap between Switch Access and screen reading technologies. By combining the two, Switchify can become more inclusive, ensuring that individuals with both physical and visual disabilities can benefit from its functionality. It's a challenging but exciting development, and I believe it will open up even more opportunities for people to interact with their devices independently. Ultimately, my goal is to make Switchify accessible to as many people as possible. Everyone deserves tools that empower them to interact with technology on their own terms, and

adding features for visual impairments is a step closer to that vision.

Velasquez: Absolutely. And what has been the response to the Switchify updates for people with visual impairments.

McGirr: The update for users with visual impairments has been received positively. I've had feedback from some users testing the new screen reader compatibility. And while there's always room for improvement, I'm encouraged by the progress. Expanding accessibility features is an ongoing priority for me, and hearing directly from users helps guide my work.

Velasquez: Is this a hard system to learn? Being a JAWS (screen reader for blind and visually impaired people) user, I know it takes a while to learn all the basic commands. You need a bit of an education to become proficient. Where do switches stand on that spectrum of ease of learning to use?

McGirr: This is a good question. I've been a Switch user since day one, and I'd say it takes a lot to learn. Unfortunately, I'm not the best person to ask because to me, it's like second nature.

Velasquez: I realize I'm likening Switchify to the computer screen reader I use, JAWS. I think Switchify is more like Voiceover (screen reader) for the Apple products. Is that correct?

McGirr: Yes.

Velasquez: And Apple's Voiceover, app for the blind and visually impaired, as you know, is all gesture related. You hear something like text content or the element that has focus, and then with your fingers you flip to the left or to the right to select an action. You navigate entirely with gestures. With Switchify, you watch the movements of something switching to the left or to the right, and then you select a choice when the focus lands where you want it. So, I feel like that's a sort of way to describe the similarity. Is that correct?

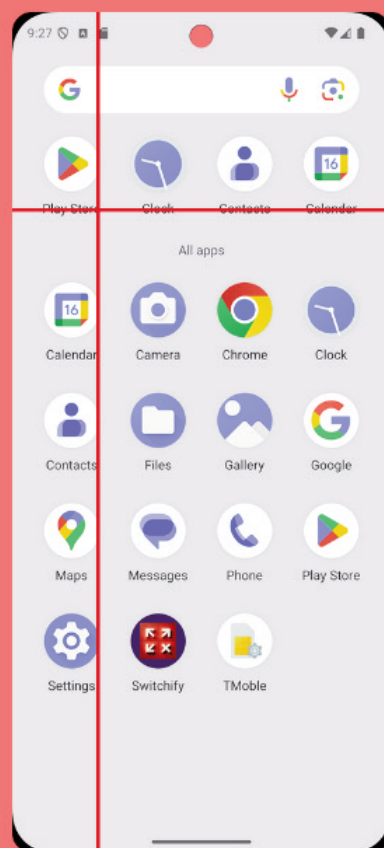
McGirr: Yeah. A long time ago, we used to have to hack Voiceover to use with switches.

Velasquez: Can you tell me more about that?

McGirr: A long time ago, to use switches on iPhones, we had to create workarounds (or hacks) to make Apple's VoiceOver screen reader compatible with switches. This was because switch support wasn't natively available on iPhones then.

Velasquez: So, this was the only way for you to use iPhones back then? With hacks? How long ago was this?

McGirr: Yes, hacking VoiceOver was essentially the



**Use your device via switches
with the onscreen cursor**

only way for people with mobility disabilities to use iPhones with switches back then. Thankfully, accessibility has come a long way since. This was about 10–15 years ago.

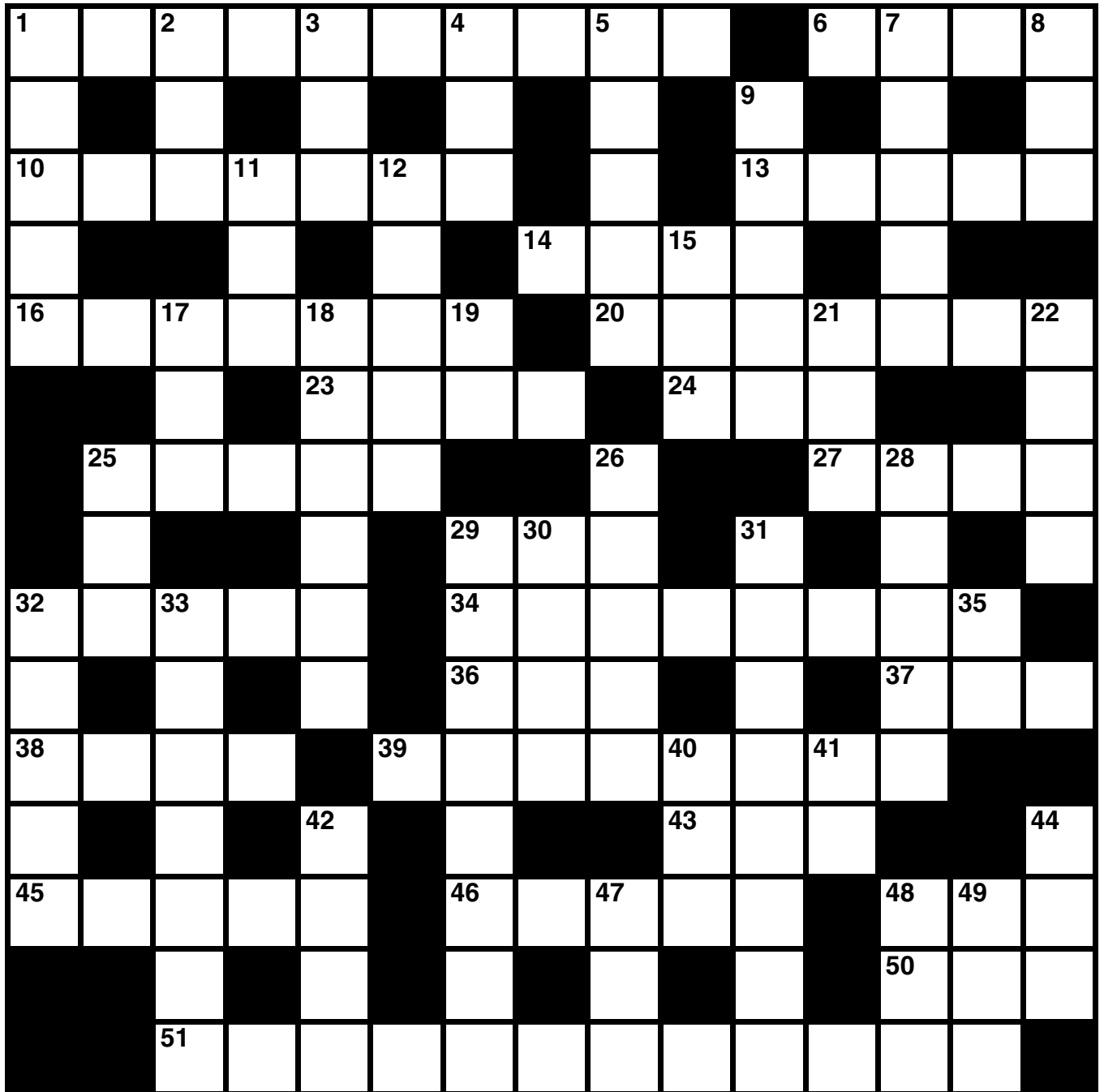
Velasquez: Is there anything you want to add about the Switchify app?

McGirr: I'd like to add that funding is really important for me to keep improving Switchify and making it more accessible for everyone. I'm working hard to add new features and support users, but this requires ongoing resources. If anyone would like to get involved or support the project, they can reach out to me directly or contribute through the Indiegogo campaign. Any support goes a long way in helping me continue developing the app and making technology more inclusive.

Thanks again for having me. ■ ABILITY

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ABILITY'S



Crossword Puzzle



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ACROSS

1. "Pretty Woman" star supports Cerebral Palsy and Inclusion Matters by Shane's Inspiration, Laura ____, 2 words
6. Accessible
10. Salesforce trailblazer who is deaf but has pioneered with events catering to people with special needs, 2 words
13. Couple who helped their young daughter who had diabetes and then founded a Center for care of Diabetes patients, Mary & Dick ____
14. Machu Picchu's location
16. John Lennon's dream song
20. The world's only quadriplegic rescue scuba diver, ____ Gross
23. Biological unit
24. Consume food
25. "Game of Thrones" star ____ Dinklage, a role model for little people
27. Having difficulty walking
29. Financial professional, abbr.
32. Wheelchair user who played a key role in the Hulu thriller, "Run", ____ Allen
34. Broadway musical about a founding father
36. Land of the brave and free
37. It's mightier than the sword
38. Actress and model with roles in the movie "Crispy" and the TV show "Surviving the Cartel" campaigning for access for disabled actors, Jessica ____
39. Loyal, reliable supporter
43. Rock containing valuable minerals
45. Uplift
46. Mountain tops
48. Environmental prefix
50. Period, in web addresses
51. Dedicated bike rider logging miles in his campaign for a cure for MS, 3 words

DOWN

1. Czech company created skis for people with limited mobility
2. Negative vote
3. Chapel vow, 2 words
4. North Atlantic food fish
5. French painter, Claude ____
7. Tom Cruise's profession in "Top Gun"
8. A Bobbsey twin
9. Started "Just My Type" Diabetes meetings, ____ Pavlakovich
11. Humorous person
12. Dog tag datum
15. Fish eggs
17. Top race car driver
18. Frozen covering at the Earth's poles, 2 words
19. Chicago transit system
21. Letters on a Cardinal's cap, abbr.
22. Requirement
25. Paranormal ability, abbr.
26. "Slum Dog Millionaire" star, ____ Malik
28. Raise an orphaned child
29. Audacious
30. Spanish word for "happens" as in "Que ____?"
31. Resolves, 2 words
32. Fermented milk drink
33. Civil Rights lawyer who fights for the rights of disabled people, enforcing the ADA regulations, 2 words
35. Compass point, abbr.
40. Chinese cooking pan
41. About, in memo headings
42. Academic administrator
44. Software program that performs automated tasks
47. ____ Dhabi
48. Domain for educational institutions, abbr.
49. Military rank abbreviation

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- Pi in Eye

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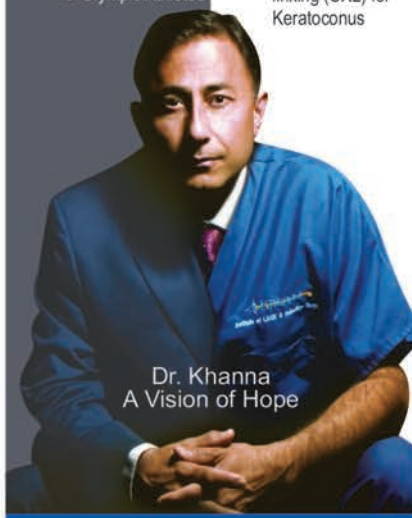
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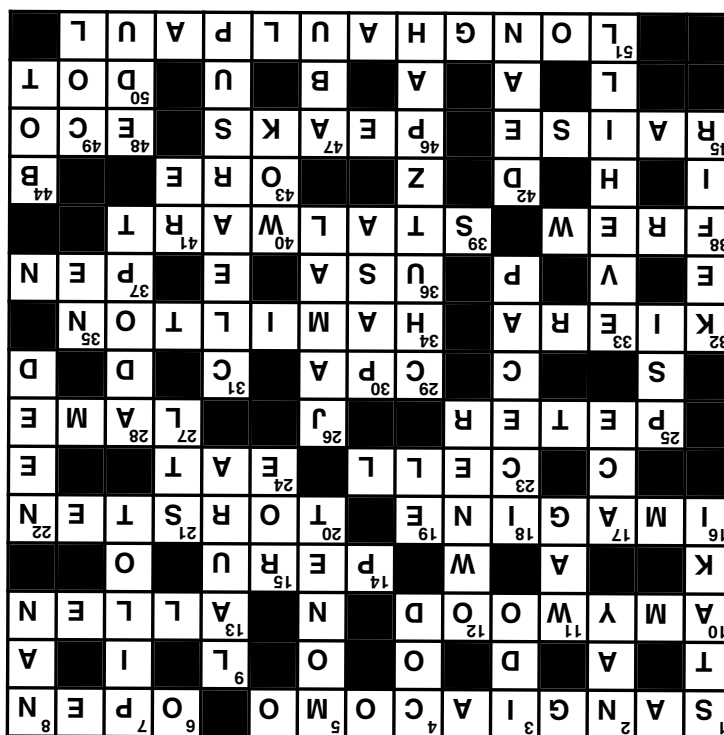
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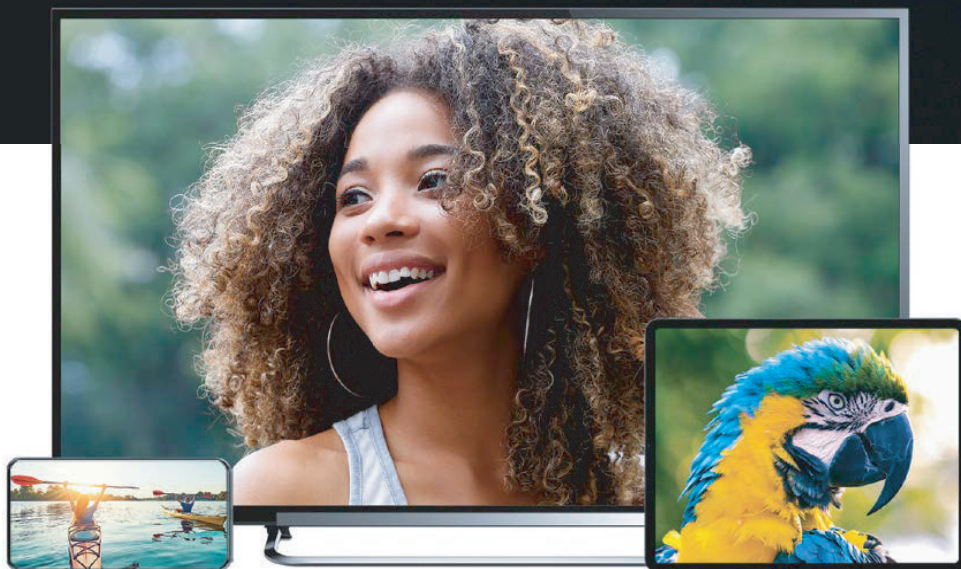
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*Based on sales, profits, assets, and market value as of March 31, 2021.

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- **DiversityInc** magazine has ranked Wells Fargo No. 7 on the list of the 2021 Top Companies for People with Disabilities. **DiversityInc** also ranked Wells Fargo No. 25 on the Top 50 Companies for Diversity, No. 17 on the list of Top Companies for Employee Resource Groups, and named among the Top Companies for LGBT employees.
- For the tenth consecutive year, readers of **CAREERS & the disABLED** magazine recognized Wells Fargo as one of 2021's Top 50 Employers of people with disabilities.
- **Equal Opportunity** magazine ranks Wells Fargo No. 15 on the 30th Annual Top 50 Employers 2021 list.

Accommodations and accessibility assistance for team members and job seekers:
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Accessibility at Wells Fargo: wellsfargo.com/about/diversity/accessibility

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