

ABILITY

Leigh Koechner
NO MUNDANE MOMENTS

Nic Novicki
THE FILM CHALLENGE

**Syrian Refugees
War on Disabilities**



**Photography by
Darrell Gulin**

Charlotte
A RAE OF SUNSHINE
PART TWO



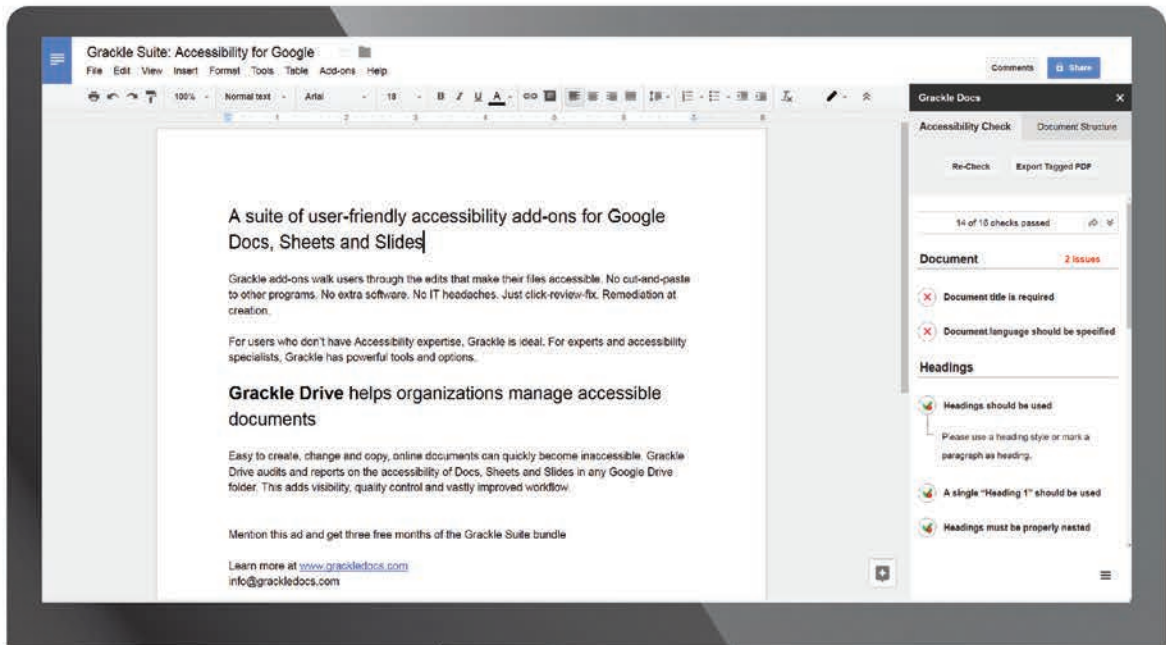


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VOICEYE

For iOS & Android



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Since I am the ambassador for Husqvarna I am always involved when they do special events for women, and as I have mentioned in the past they put on quite a few of these which are always amazing!



Recently we did a Babes Ride out day, it was April 27-29th in Gorman California, it is for girls who really love to ride and camp too! A bunch of my friends went that live out in California and I also met a lot of new people too. My friend, Natalie, flew in from TN to help with interpreting for me. It has been really hot here in Florida so I was frozen on my first day there when I went there it was so cold, brrrrrr!, luckily the second day warmed up a bit. Husky brought a bunch of motorcycles for the girls to try out and ride, I was responsible for the girls that wanted to do this and I would take little groups out on trail rides it was a lot of fun. We camped out and hung out at night time, if you are ever interested in these ride out days you should take the time to sign up it is always a good time and everyone has fun. They are usually promoted by social media and in the dirt bike and road bike magazines.

It's the summer time and I packed up my tiny house and left it behind for a month and a half, I'm headed out to do some AF67 MX classes. I can't wait it is going to be so much fun! My first stop is Texas for a two day class, I also have classes in Illinois and Colorado and then back to Texas! I get to do a couple of private lessons with some of my regular students.



It's going to be a busy summer, in addition to bringing my dirt bike I'm also bringing my mountain bike and I am stopping off with some friend in Telluride, CO to do some biking. Maybe you will see me out there on my road trip.... ■ **ABILITY**

Ashley Fiolek

Women's MX Riding Coach



Ashley Fiolek is a 4x Women's Pro National Motocross Champion, 2x X Games-Super X Gold Medalist. She was the first female to earn the first factory ride. She won Championships on a National level as an Amateur, a Privateer, and a Factory rider.

Ashley is retired from motocross racing, but still rides for the love of it. Through her MX Coaching she is looking to share her love of riding, pass along her tips for proper riding technique, and help other females build skills in her a better rider. For Ashley the key to great riding is having fun!

Check out some videos of Ashley riding

GENERAL INFORMATION SHEET

Coaching available to Female Riders Beginner to Intermediate, at all ages

Location
Southern California: Pacific Coast, Orange, Anaheim, Fullerton, Buena Vista, etc. or anywhere with a riding track, training facility, or private track.

Typical schedule

- Meet up with Ashley and an instructor at 8:00am
- Warm up Ride
- Riding and Training Skills and Technique
- Work on improving skills and technique such as riding form, braking, throttle control, jumping, and line selection.
- Practice on selected
- Complete a 10min
- Lunch on location. We suggest water in the day because tracks are usually in better condition in the morning.

Fees

- Private One on One Lessons - \$150.00 per day (does not include individual track practice fees)
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Grinding to the American Dream PART I

The passenger ship pulled into Ellis Island on a hot summer day. The newly arrived Italian immigrants poured off the ship with hopes of finding a better life. Among them was Ugolini, an older man in his sixties, who was short with well-toned, aged muscles that were covered by bushels of curly hair. He walked with a slight limp as a result of slipping on a banana peel on his kitchen floor. The hunched man carried a ragged leather suitcase in one hand and the paw of a chimpanzee, who wore a tiny red bell hop cap, in the other, as they strolled towards the check-in station to begin a new life.

For the last twelve years, Ugolini had scraped out a meager living by traveling the southern cities of Italy, churning a hand-cranked organ and singing operatic songs in a scratchy, off-key baritone voice. Eventually, he acquired a perky monkey to dart around with a tin cup and collect coins from amused on-lookers, while he concentrated on getting his song lyrics right. The monkey's name was "Chimps," and he was rescued from a traveling circus that mistreated their animals (Chimps was required to perform six shows a day as a trapeze act while dressed in a puffy tutu with a few drunk clowns). The name "Chimps" was a misnomer; Chimps was not a chimpanzee, but a larger than normal chubby spider monkey.

In the old country, times were lean. Ugolini would often

grapple with his monkey sidekick over a stale roll that a deli owner would supply for free, if Ugolini promised to play his barrel organ on the next block down. Ugolini made the decision to try his luck in America, the land that promised wealth and riches to anyone willing to work hard.

Ugolini's sister, Rosa, had moved to America seven years earlier and had found residence in Little Italy, on Mulberry Street, in Manhattan, New York. She bore a strong resemblance to her brother, except that his moustache was a tad more bushy. She was well known in the neighborhood for her uncanny ability to give spot-on fortunes by reading the lumps off various vegetables that her clients would set in front of her. Zucchini readings were her bread and butter, and her predictions were spot on. She once warned a woman of an impending horse cart accident just by feeling the bumps on the elongated, tubular green plant. Sadly, the client was a skeptic, refusing to believe anything about the black arts. Coincidentally, the following day said client was trampled by a team of spooked horses pulling a vegetable cart. After that, the lady went on a strict meat diet.

Rosa was excited to see her brother and get the news from the old country. The two united with hugs and kisses outside of Ellis Island, while the monkey scampered in circles, stretching his legs out from the long cruise.



“Wella, I seea youa stilla gotta thatta furry thing?” Rosa stated.

“Heya, thisa monkey isa mya ticket to thea American dream,” Ugolini responded. “Everyonea lovesa the monkey.”

“He’s a noa good. Whena you gonna getta a reala joba likea streeta cleaner, huh?” the sister clamored. “You’ra back is stronga enougha to a lifta the horsea pooh piles.”

“Shuta your mouth,” the old man barked. “Wherea youa live? Thea monkey. Hea needsa nap.”

Ugolini settled into his sister’s small, two room, apartment and quickly learned his way around. It was a bustling neighborhood – a prime area to make some money. A man-monkey musical team usually operated on downtown streets. The organ grinder would set up on a street corner, wearing his instrument on a strap over his shoulder, and then support its weight with a stick while he played. Meanwhile, the monkey, tethered to a leash, would scamper around with a tin cup, collecting change. Audiences were dependable, and enjoyed the herdy gerdy songs like: “Dixie and “Funiculi, Funicula.” Sometimes the monkey would tumble, flip, or do a playful jig to the amused people. Then, he’d stick his tin cup in front of their faces, coaxing the dupes out of spare change. Chimps had the routine down pat. After ten to twelve hours on the street, the pair would arrive back home and dump the loot on the bed to count their day’s wages. On a good day, they could make up to three dollars, but that was a rarity.

The old street performer would pour the coins into a cigar box that he had found in a back alley outside a seedy brothel. Deep down, it bothered him that the prostitutes could smoke better cigars than he could afford, but he was at least grateful that he didn’t have syphilis. Chimps watched Ugolini stuff the box under the cheap bed mattress. It would be nice to have some of that loot to make him feel important, he thought.

“Nowa youa getta to beda, sleepy head,” Ugolini said as he shoved the monkey under the covers. Then he took off the little pet’s hat and patted him on the head, “I don’ta wanta youa alla grouchy tomorrow ina fronta alla the paying customers.”

Ugolini began to walk out of the room then spun around to catch the monkey flipping him off with his stubby middle finger. “A littlea wisea guy, huh?” he huffed. The old man flew off the handle and grabbed the little runt from under the covers and put him over his knee and began swatting its behind, hoping to teach him some respect. Ugolini was never proud after he whacked the monkey’s bum, but it had to be done to ensure discipline and it happened all too often. The neighbors knew it too. Every night, they could hear old Ugolini spanking the monkey.

Ugolini sat at the kitchen table staring at an almost empty bottle of wine. “Whatta are youa looking at?” he slurred at the red vino. Since he arrived, he had put in long days on the street and money was barely trickling in. He was disillusioned that he hadn’t yet achieved the American dream. They were just scraping by. Every day was the same, grinding his organ while the monkey got all the attention. Sometimes, the little beast would scamper off for hours leaving Ugolini to track him down, only to find him flirting with giddy dames enamored with his monkey tricks. Time was money and he wasn’t making any when his furry partner wasn’t waving that tin cup.

One day, while out pedaling, Ugolini’s eyes fell upon a shy apple peddler. Her name was Becky and she was beautiful in her own homely way. It was love at first sight. Ugolini stood there frozen, contemplating how to approach the vision of beauty. Suddenly, she looked up and with a big smile she beamed, “You are soooo cute.”

Ugolini, playing coy, bashfully bowed his head as he nervously circled his foot in the dirt. The excited girl raced towards him. He perked up and smiled. She ran up to him, then right past him, and picked up the monkey who was standing behind him. As she twirled the furry mammal around, the monkey stared at the old man while sporting a devious smirk. To add some fuel to the fire, the monkey winked as he snickered. Ugolini’s face turned as red as Roma tomato, as he boiled in anger.

That night, Ugolini made a six course meal for the monkey. He placed a Caesar salad, a loaf of garlic bread, a bowl of Pasta Fazool, Baked Rigatoni with sausage and cheese, and a slab of tiramisu cake in front of his little partner. As he tied the napkin around the Chimp’s neck the old man gently stroked the back of the monkey’s head as he nicely asked, “Maybe tomorrow you introducea the pretty apple lady to old Ugolini.” The monkey shrugged rolling his eyes then began digging into the food.

Later in the evening as the man was tucking the monkey into bed he repeated his earlier statement, “Yeah, nowa youa bea the good littlea monkey and say somea nice things to thata fruita girl abouta me. Thatsa whata friendsa do. Youa anda Ia, we alwaysa being good friends.” The monkey ignored him as he reclined on his back and lifted his legs up to his stomach. “Oh, youa wanna a littlea belly rubsa? Sure. Why not? Whatsa friendsa for?” The monkey snuggled in for his gentle stomach massage and would later demand a bedtime story.

Ugolini sat on a barrel excited over an introduction. His heart was beating fast, knowing he would soon meet the girl of his dreams. An hour passed, and then another. Frustrated, Ugolini went to find the problem. In the street, he found a vacant push cart with no monkey or apple lady in sight. He roamed the city for hours in





search of the pair until darkness set in. Distraught over his predicament, he was about to head to the police station to file a missing animal report when he heard some loud music rippling from the corner pub.

He made his way over and peered through the window, there sat the backstabbing monkey with the love of his life. They were enjoying dinner as they giggled and laughed, sipping on a glass of red wine. The Italian man watched in disbelief while the monkey led the girl onto the dance floor. His wrinkled face dropping in disgust. With his enraged heart pounding, he seethed as he watched the couple Lindy Hop across the floor. It was a cold slap in the face to the Italian peddler. His mind raced, but deep down, there was no denying it; the monkey had game, and he was just a little man who used an animal to do his begging.

As Ugolini lay awake in bed, he heard the monkey stagger in. A flower vase crashed to the floor and soft slurring monkey noises could be heard emanating from the front room. An angry, restless, Ugolini turned on the light to find the drunken animal swaying in the hallway with lipstick on his fur and wreaking of expensive booze as a cigarette dangled from his lips.

“You’rea sada sight fora the sore eyes,” Ugolini huffed.

The glazed-eyed monkey looked at his master as if to say something, but then just vomited on the floor. His head bobbed as he smirked then fell face down.

The next morning Ugolini was dressing the monkey for work. “I’m putting a leasha ona you,” snapped Ugolini. “Thatta way I know exactly whereasa you are and whatsa you’rea upa to.”

Chimps murmured a hungover groan. “Shuta youra little monkey moutha,” the old man chirped. “Ugolini, he knowsa whatsa best for you.”

One hot, sweltering day, things reached a tipping point. The daily take had been poor and to top it off, Chimps had wiggled out of his leash and tied it to the tail of a bulldog. Ugolini eventually figured it out when he felt the dog relieving itself on the old man’s leg. Ugolini spent half the afternoon searching for his monkey, only to find the little thing snuggled on Becky’s lap as she fondly petted him. Ugolini flew into a rage. He walked up and grabbed the monkey and brought him out to the street.

“We’ve been out here alla morning and afternoon anda alla you gotta a show isa twoa pennies anda onea nick-el.” The monkey shrugged as if he could care less. “Heys you a littlea monster, you better getta youra heada in the game or I’m a gonea finda newa partner.”

The monkey threw down his hat and squared off to the feisty old man. The little furry beast began circling his dukes as he eyed up his master. “Oh, youa wanna piece of Ugolini?” the old man huffed as he set down his Hurdy-gurdy. Ugolini hunched over like a bareknuckle prizefighter and threw a couple of air punches followed by a quick shuffle of the feet. Unflappable, the monkey squared up to him as a street crowd gathered around. In no time, the monkey scurried up the front of the old man and wrapped his arm around his fat wrinkled head then shrieked as he bit his nose. Ugolini was able flip the beast over his shoulder and onto the ground. The two began to roll about, changing positions of dominance. At one point, they were able to get to their feet; with their arms wrapped around each other’s neck and touching foreheads, they circled each pawing the other for the upper hand. And, within seconds, they were back to rolling around in the dirt.

Becky ran out and got between the two and stopped the fight. “You two oughta be ashamed of yourselves,” she shrieked.

“Wella thata littlea bugger started it,” Ugolini responded.



"I don't care who started it. You two have worked together for a long time," she pleaded. "There's a lot of love here. Now both of you two to try and get along."

She was right. The pair settled down. They got up and dusted themselves off. Ugolini picked up the monkey's hat and tin cup, which was overflowing with coins. The crowd had obviously enjoyed the fight. The three of them all went out for lunch, but much to the old man's chagrin, Becky's attention was on Chimps, as usual.

That night, Ugolini begged the monkey to put in a good word for him with Becky. Chimps just sat there with his arms folded. The Italian man grabbed his satchel of money and poured it on the table. He pushed half the pile over to the furry animal. "Thatsa for a you. We fifty-fifty partners." Hey, come on. I do anything for a my pal." The monkey was no fool. He knew Ugolini was now kissing up to him. He wanted the girl and the monkey was the only one who could open that door, but the old man was going to have to earn it.

The next day, the two were back on the street, but things had drastically changed. The monkey was now in control and running the show. The sound of the organ reverberated through the busy Five Points neighborhood. Churning the handheld organ was none other than Chimps, while Ugolini, wearing the small red cap, scampered around on his all fours waving a tin cup in front of surprised spectators. It was embarrassing. Humiliating. And that's the way the monkey liked it.

While Ugolini did a clumsy somersault in front of the on lookers, he looked up and noticed Becky watching from the crowd. Ugolini had never been so embarrassed in his life – except the time when his mother made him balance a meatball on his nose at a family gathering. The monkey had made a monkey out of him and knew it. On the upside, they made more dough then they ever had before.

"I'ma through witha you!" Ugolini yelled as he threw down his tiny hat. "You'rea nothing buta disrespectfula little scamp, treating your Ugolini likea you have."

That day, the act split up. The monkey moved to a flop house and soon found gainful employment running numbers for a Five Point's gang known as the Bum Rum Boys. He was making good cabbage too. While in the mob, he climbed the ladder and started making illegal booze runs. And it wasn't long before Chimps was strutting around town in a nice tailored suit, smoking a cigar, and flashing green backs... ■ **ABILITY**

Continued in next issue...

by Jeff Charlebois

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In looking at the world today, I recognize that it's not the same world that my parents experienced, or even the one I remember growing up.

Too many people lack compassion for those who are different—be it another ethnicity, race, religion, disability, sexual orientation, or class.

In some ways these prejudices have always existed, but in the last three decades there seemed to be more tolerance for diversity as a whole. Or perhaps the bigotry was simply more hidden or glossed over. However, from the 2016 election on, there's almost been a tacit support of people expressing their prejudices, and with no apology for doing so.

From the 80's through 2012, Fortune 500 companies—as well as government agencies—invested in diversity and sensitivity training to create a more inclusive work environment. Not to say that these measures aren't still being taken, but it seems that far fewer strides are being made to uphold these values than in previous decades.

Meanwhile tolerance, in some cases, has devolved into resentment. Truthfully, I have always felt that “tolerance” is thinly veiled resentment in some ways. I mean, I've been tolerated many times in my life, and believe me, I can feel the difference between that and truly being accepted as equal.

So in understanding that we have become a less tolerant world, what can I do to help change it, and make it more loving, respectful and kinder to all?

Without going into politics, I would rather tackle our own individual worlds within the bigger world: What I can do is make a small contribution daily towards promoting positive energy, which creates a ripple effect throughout the world.

The number one rule is to not allow ourselves to become bitter and angry. Even when things seem negative, we must focus on the silver lining surrounding the situation.

For example, the other night I got all dressed up, put on makeup, gassed up my car, and drove to Beverly Hills to meet up with friends for a fun evening. I ended up waiting for almost an hour in the wrong location as I'd taken the address down incorrectly. Later I drove home, removed my makeup, and put my jammies on, feeling very depressed.

My roommate Alex came in and was curious why I was back so soon. Instead of counting the night as a total loss, he looked on the bright side: “Well, you got dressed up, got out, and that excited you. Since your sister Gloria passed away, you've been grieving, and haven't been motivated to go out and have fun, so tonight was a good start!!!”

I took what he said to heart, and he was right: I needed to focus on the good that came out of it, not the pain and frustration of what felt like a wasted effort. Before I went to bed, I glanced at Gloria's framed photo on my dresser, and felt like something in her eyes affirmed that Alex was right, and to keep moving forward, knowing that she would be with me always.

“Remember, I always loved to laugh, and passionately embraced life,” Gloria seemed to be saying. “And I can still do that through you. Buck up and don't lose your smile or passion for each and every day!”

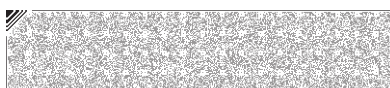
As we contend with the issues of the day, we have to monitor our mental sandbox lest it become a litter box.

■ ABILITY

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by Geri Jewell



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As I stood watching the celebrities parade down the carpet, I thought it might be fun to pretend I was one of them, and after repeated rejections, I finally found a willing accomplice to escort through all the flashing bulbs and microphone pokes of the paparazzi.

“Do you want to walk the carpet?” I asked.

“Oh, I’m not a celebrity, I’m here because I have multiple sclerosis (MS),” replied my brand new friend Caroline.

“Me too! And that’s why we deserve to walk too. Grab my arm, let’s do this.”

I will never be a Hollywood celebrity, but by being invited to attend the 24th Annual Race to Erase MS Gala at The Beverly Hilton in Beverly Hills, I sure felt like one. The decision to head out to the West Coast for this event was not an easy one for me. Eight days away from home and 6500 miles on the road was going to be expensive, especially considering this was not an event I was paid to speak at. After leaving my steady employment in October of last year, requests for me to speak have unexpectedly slowed down, and I have struggled with finding new opportunities to cover my expenses. Without a fiscal sponsor, my quest to chase the cure for MS has been tough on the pocketbook.

I decided to take the chance, however, draining my savings further with the hope of meeting people who could help propel my story and mission to cure MS with additional exposure. I also wanted to meet fellow MS advocate Nancy Davis to discuss the possibilities of working together on fundraising in the near future. Davis has raised over 36 million dollars for her Center Without Walls, a collaborative of top MS centers across the country. This year brought out Hollywood’s A-list and raised 1.6 million dollars!

I made the decision to attend just two days before I would need to leave New England for the three-day long trip to the West Coast. One of the biggest problems I never thought I would ever have was finding something to wear to a celebrity gala. One look in my closet and I realized I had no clue. Thanks to FaceTime and my daughter Ayla, who pays attention to fashion and entertainment, I was able to get some threads that would be acceptable in Beverly Hills. I carefully rolled my formal wear and packed it gingerly into the Yamaha’s left saddlebag.

I prayed it would unroll after 3000 miles and 45 hours with limited creases!

I replaced my tires with new ones, changed the oil and left for my first star-studded event two hours before daybreak. I was excited! I rode from New Hampshire to Joliet, Illinois where I stayed purposefully at a place





Paul and Quincy Jones

called the Hollywood Casino Hotel so I could tease my Facebook fans that I had arrived in California in one day. No one fell for it! Another early morning departure and a long day's ride lie ahead to Vail, Colorado. As exhausted as I was, I should have tried to go further, because it was below freezing when I awoke six hours later and headed through the mountains to complete the third day and final leg to Los Angeles.

I spent a night with my good friend, Kevin Nixon, the motorcycle marketing genius, who lives in Long Beach. Having spoken to hundreds of groups of people living with MS, bikers and corporate executives, it was odd that I was actually nervous about attending a party where my only job was to mingle and not get salad dressing on my new tie.

I arrived early, watched a crew set up the red carpet, *actually orange* for MS, checked in and quickly went to my room to check on the contents of my bag I had bought on clearance at Macy's. The suit did survive, the shirt was ruffled more than I had thought possible, but I figured if I got the front to look decent and never took off my jacket, no one would ever know — well, *nobody until now*.

I really had no clue how these fancy shindigs worked. I ventured out to the lobby about an hour before the silent auction started. I shot a couple of selfies with the

big-ticket item, a DB11 Coupe donated by Aston Martin of Beverly Hills. The car was later auctioned live during dinner and fetched \$290,000!

The stars began to arrive as a mariachi band played by the water fountain outside the foyer. The 50 or 60 people from the national and international media were already signed in and had staked claims along the edge of the carpet, apparently lined up according to their Nielsen ratings.

I got my invisible wrist stamp and headed over to where everyone else was watching the carpet parade. A group of fans had been gathering and ropes were being tightened to keep the spectators away from the guests.

It was a special night at The Beverly Hilton, hundreds of celebrities were joining forces and emptying their wallets to fund research to find a cure. They all waited patiently in line to get their pictures taken and be interviewed. The pictures would be circulated with half-truths and gossip for a week or so, bringing attention to the celebrity but also the fundraiser. Some of them loved the fuss, and some of them did not. I suppose that's show business!

I felt special knowing these famous people cared about others and myself and took time out of their busy lives to help find a way to stop our disease from





progressing. I shared my story with David Osmond, who along with his father Alan Osmond, had been diagnosed with MS. David is an advocate with an amazing positive attitude as well as a gifted voice, carrying forward the great Osmond legacy. He seemed interested in my million mile journey and promised to check out my website.

Later, in the same ballroom where the Golden Globes are held each year, we watched a moving tribute to this year's honored guest, actress Jamie-Lynn Sigler, who brought her fight with MS into the public eye last year. Grammy award-winner Siedah Garrett sang, *Man in The Mirror*, the song she wrote for Michael Jackson, and a new single, *Carry On*, which was written for this event. Siedah Garrett also announced for the first time that she, too, had been diagnosed with MS, a disease that strikes regardless of age, race or economic class.

The iconic band Chicago delivered an amazing set, and in a Copperfield flash, it was all over. The stars were whisked away in their Bentleys and Rolls, probably to some after party way above the authority of my hand stamp.

It was amazing and exciting, and an honor to be invited. I hope next year I will be able to participate more as an advocate and join forces with the Race to Erase MS organization that is clearly on the same path as I am, *Chasing the Cure*.

Although meeting Quincy Jones, David Osmond, Robert Herjavec, Randy Jackson, Paris Hilton and Cathy Griffin were quite memorable, it was the *Access Hollywood* interview on that magic carpet ride that had me smiling the entire 3,000-mile ride home.

"Forgive me, what are your names?"

"This is Caroline and my name is Paul."

"And what was it that you were in again?..."

"You may have seen us in that show, *Before They Were Stars*."

"Sure, sure, and what else?"

"Nothing else."

(Dropped the Mic) ■ ABILITY

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Darrell Gulin

EXPLORER OF LIGHT

Darrell Gulin has a profession most of us can only dream about. He travels the globe, from Antarctica and Africa to Asia and Europe, capturing rare and exquisite moments in nature, whether its baby leopards gamboling in Kenya, polar bears leaping off ice floes or acres of blooming bluebonnets in Texas. A full-time nature/travel photographer, he's also one of Canon's 'Explorer of Light' photographers, a title given to a select group of world class photographers and cinematographers who are chosen to share their expertise with eager audiences.

A steady hand is a prerequisite for most professional photographers, but Gulin developed an essential tremor in his hands that in earlier times might have ended his career. He shared with *ABILITY*'s Lia Martirosyan and Chet Cooper how he compensates and beautifully manages to snap crisp, breathtaking photos.

Darrell Gulin: I've developed this hand tremor over the last decade. I travel the world constantly, five, six months out of the year. What happened is, we did an interview with Canon in Hollywood just a few months ago. We started developing this idea knowing that as an 'Explorer of Light', I'm still able to function doing photography even with the tremor. So we wanted to start letting more people know.

Chet Cooper: Why are you here?

Gulin: Because I wanted to be!

(laughter)

Lia Martirosyan: Is the tremor triggered by something?

Gulin: It's called an essential tremor, which means they really can't figure it out. It just happens as some of us age and inherit it. My grandfather on my dad's side had it.

Cooper: It's not Parkinson's or Parkinson's-related?

Gulin: *(pause)* It's a tremor. What happens is, you don't lose balance or cognitive abilities, except I can't sign my signature now. There's lot of things that I used to be able to do. You just reinvent it. Like right now, I



can double-click on a mouse faster than anybody. I can transfer files to places unknown.

Cooper: Whether you like it or not.

(laughter)

Martirosyan: When you're holding the camera, do you still have the tremor?

Gulin: Oh, I've got the tremor.

Martirosyan: So the camera's that good?

Gulin: We used to have 50 and 100 speed film, and that was about as fast as we could go. The shutter speeds weren't very fast. So a tremor couldn't be balanced out. What I've got now is image stabilization, which stabilizes after three to four shots and helps counterbalance any shaking. The ISO (International Standards Organization) allows us to have a faster-speed film. In ISO, I can go up higher and not have any of the grainy problems of the past. So my shutter speeds are faster. I can handhold a bigger lens at 1/1000th of the second, where before, during the film era, maybe I was at 1/60th of a second, and everything

would have been blurry. I don't know if that makes sense, but all these things now —

Cooper: It's a little blurry to me.

Gulin: *(laughs)* It's still a little blurry.

Martirosyan: I don't know if you mentioned it, but were you taking photographs prior to the start of your tremor?

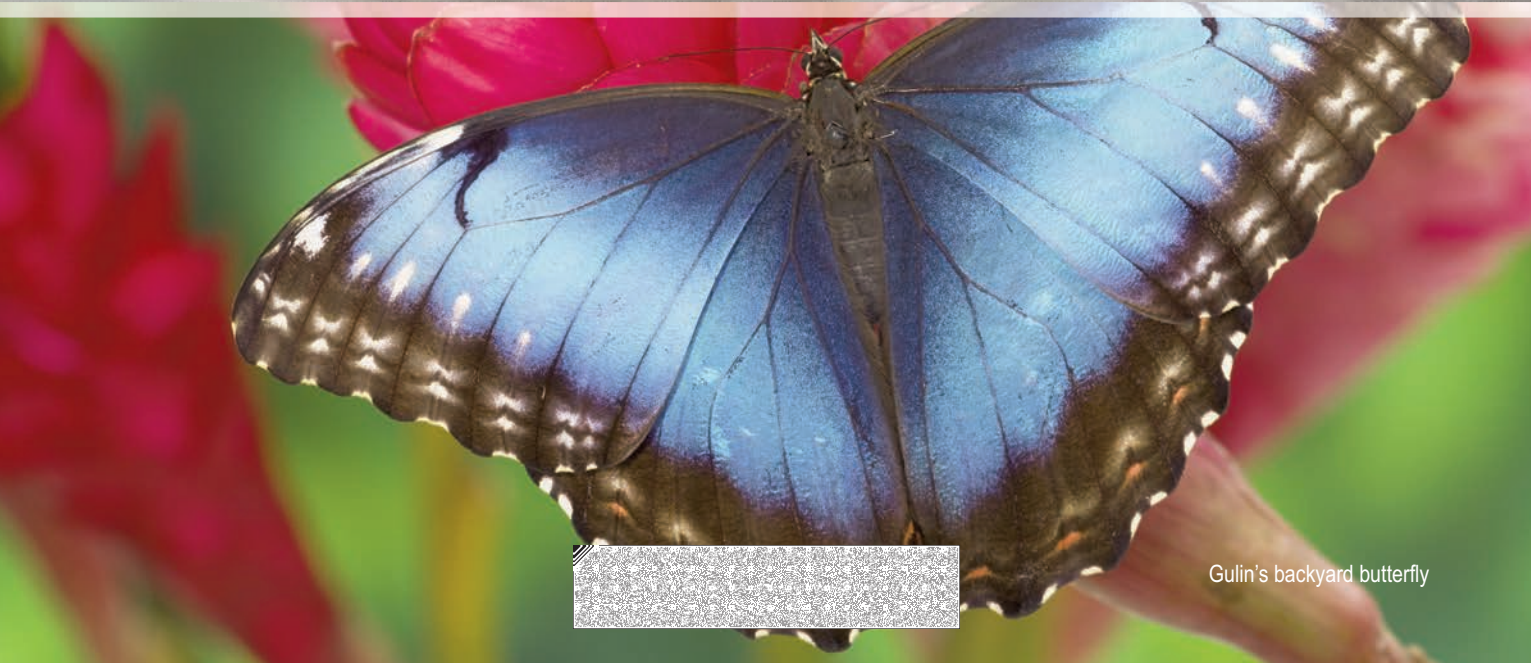
Gulin: Yes. And have I noticed a difference? Technique-wise, I have to be really good. I have to be cognizant of my shutter speeds. I have to be cognizant of the subject. When I can be on a tripod, I'll be on a tripod.

Cooper: What about the camera?

Gulin: *(laughs)* I'll put the camera on the tripod. He's a smarty-pants. How long have you worked with him?

Martirosyan: Several years now.

Gulin: Oh, good! Yeah, I don't go on the tripod, but the camera goes on the tripod, and that works also, with shutter cable releases, etc.



Gulin's backyard butterfly



Cooper: You have this great photo of a polar bear leaping in the air. How did you get it?

Gulin: What happened is, the polar bear is in the middle of the air, believe or not, with the tremor. I'm using a big 500mm lens, which weighs about five or six pounds, and I'm hand-holding it because I'm on board a ship moving around. I see this polar bear on one ice floe and then there's not an ice floe and you know the polar bear's got to jump. What I'm doing is, I'm anticipating where that polar bear's going to jump, and by having a fast shutter speed, I'm able to capture it in mid-air. I'll show you the picture. Of course, somebody asked, "Did he make it to the other floe?" And he did.

(laughter)

Martirosyan: What is your favorite subject?

Gulin: This might sound silly, but my favorite subject is what's in front of my lens. I was a bird photographer. I love birds. But then I left a really good six-figure-paying job, and I went full-time at this. Now I've been married 50 years this September, and my wife's looking at me, "What are you doing?" I had to say to myself, "Do I want to be famous, or do I want to make a living at

this?" And I chose to make a living. Birds were just not the thing.

Now one of my biggest-selling things—I travel the world. I've been to all seven continents. I just got back this last week from Venice. I'm in Africa, Japan, China—all over the world. But 40 percent of my sales dollar-wise come from things I take in my backyard or in my house. Butterflies, rocks, feathers and other details, etc.

Cooper: That's in your house?

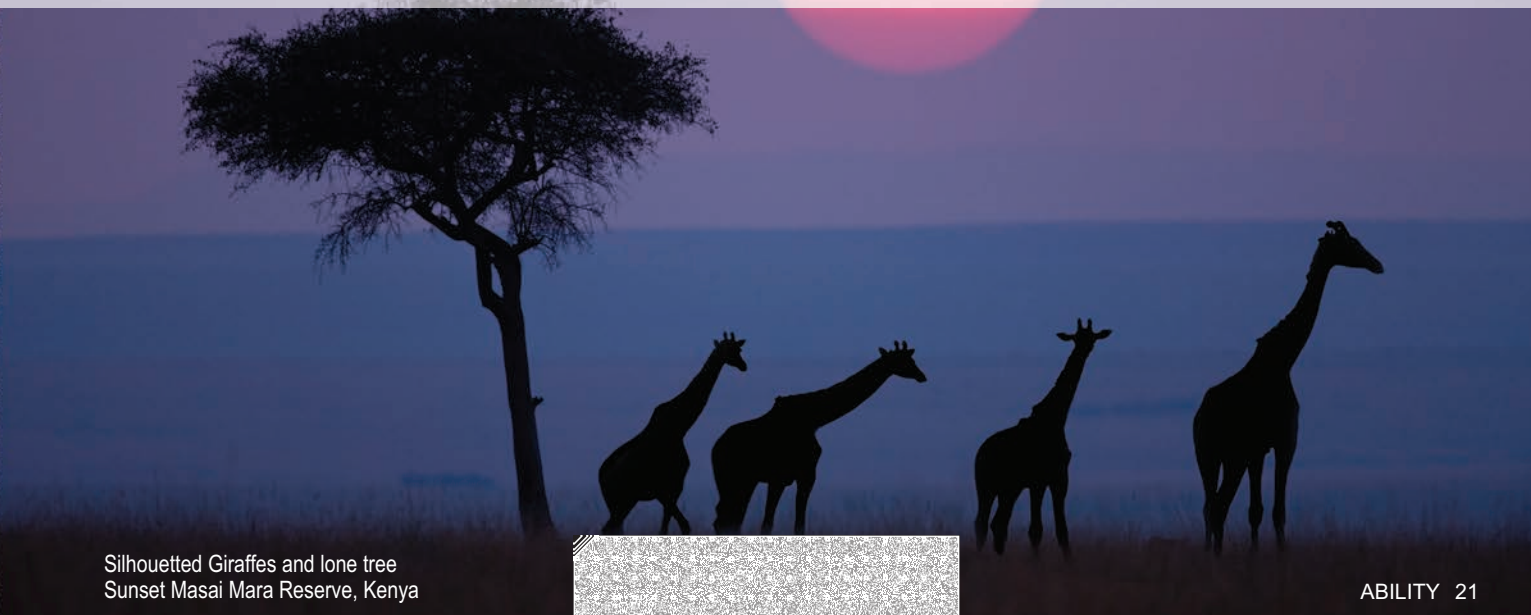
Gulin: It's in the house. I've had in the past USDA permits to raise tropical butterflies, and my grandkids would come over on Thanksgiving and butterflies were flying in the kitchen, trying to go into the turkey gravy.

(laughter)

Our friends would come by. They're called atlas moths. I raised them, and they were up on the ceilings and all over.

Cooper: Do they come from the rain forests in South America?

Gulin: Yes. Some of them come from the rain forests,



Silhouetted Giraffes and lone tree
Sunset Masai Mara Reserve, Kenya

some from Asia. What I found is, I have all these different passions. So I'm sorry, I don't have a favorite subject. I love wildlife, just because of the interaction that you get with it.

Martirosyan: You don't have to have one, I was just asking if you do.

Gulin: I know.

Cooper: But wait a minute. He does. It's you.

Gulin: *(laughs)* See—Not too bad.

(laughter)

Another question that I get is, what are my favorite places on the ground? They are wildlife areas. One is East Africa on the plains of Kenya with the Maasai and a million wildebeests coming across the river. The next place is south Georgia, not Russia, but south Georgia. There is an island down near Antarctica. I'll show you pictures of the king penguins. And the third place is my backyard, because I have developed our garden over the last 30 years to be photographed.

Cooper: I heard that people will hire you to take a photo adventure.

Gulin: I teach photo workshops and conduct my own tours now. I've done them for over 30 years. People then pay me to travel the world to teach them how to photograph. Isn't that a great gig?

Martirosyan: That's not bad at all!

Gulin: So I go to Venice. It costs clients \$6,000-\$7,000, and I get to photograph alongside them and have the nice Italian meals. I love working with people. Teaching teaches the teacher. I'm always learning.

Martirosyan: I like that.

Cooper: You mentioned something about horses earlier. Were you talking about the Calgary area?

Gulin: I've been doing cowboy and cowgirl horse drives at different ranches around the West. But where I've been doing it lately is in Shell, Wyoming. I just came back from one last month. It was eight below zero.

Cooper: You're shaking because you're still cold!

(laughter)

Gulin: I was so cold, people there didn't know if I had a tremor or if it was just cold. But we have almost 90 head of horse that we run en masse. It's exciting.

Martirosyan: Where do you stand when they're running?

Gulin: Sometimes they run right to me.

Martirosyan: Oh, my gosh!

Gulin: One time a cowboy was running his horse and broke the rein. The lady didn't move. She got hit. I swear, she flew five feet in the air and landed on the ground. We were out in the middle of nowhere. We had no cell service. So we had to have one of the cowboys



ride to the next house, which was a mile away. The emergency vehicle followed the cowboy through the fields by horseback.

Cooper: Was she OK?

Gulin: That night she went to the hospital, and the next morning she was out photographing again. I think I would have been slow and in bed.

Martirosyan: You have great stories!

Gulin: Well, I've been charged by bull elk. I've been stalked by polar bears. I've been charged by grizzly bears. I've been growled at by mountain lions. I'm still here.

Cooper: And 50 years with your wife!

Gulin: That's been—if this goes into the magazine—really smooth sailing!

(laughter)

I'll be in Austin next month for the bluebonnets.

Cooper: Is that jazz?

Martirosyan: Aren't they birds?

Gulin: No, the bluebonnets are little lupine.

Cooper: Oh, flowers!

Gulin: I can teach you guys. The bluebonnet is the state of Texas wildflower.

Cooper: Those jets.

Gulin: What are the Blue Angels?

Cooper: That's what I was thinking of.

Gulin: No, I'm not going to do the Blue Angels or bluebirds. I'm doing bluebonnets, paintbrush, and all these others, where there are acres and acres of seas of blue.

Cooper: That's happening in Death Valley right now apparently.

Gulin: Oh, right now. We've had so much rain here in California, but the same thing's happening in Texas. Right around April is the time to be down there for the bluebonnets. I fly into Austin, with my wife, and we're going to go chase wildflowers.

Martirosyan: Beautiful! Are you based in California?





Gulin: I'm based out of Seattle, Washington. But I get down to California quite a bit.

Martirosyan: *How do you maintain a garden? Doesn't it rain a lot?*

Gulin: Seattle does not get a lot of rain. They get a lot of cloudy, misty days, which are really good for gardens—they're almost like English gardens. We get a little bit of snow, about 35 to 37 inches of rain per year, which is not that much.

Cooper: *How did you get connected with Canon? Apparently you've been using Canon products for a long time.*

Gulin: I got connected with Canon when I started working with them 32 or 33 years ago.

Cooper: *So it's a new relationship.*

Gulin: A new relationship. To be successful in photography, you need three things. One, you'd better be a great photographer. It doesn't mean the best, but a great photographer. You need to be really good with business, and you need interpersonal skills. Trust me, when I meet with people, I love talking and interrelat-

ing with them. George Lepp, who is one of the Explorers of Light, has been a friend since '88. I got him into the stock agencies, such as Getty Images, and he helped me develop a relationship with Canon.

And then the instant success took 20-some years before I became an Explorer of Light, which is probably, along with being the president of North American Nature Photography, the biggest highlight of my career.

Cooper: *What happens with the Explorer of Light program?*

Gulin: With the Explorer of Light program, they've got 40 or 41 of us in North America right now who are Explorers of Light in all fields, from Sports Illustrated photographers to the top wedding photographers, like Bob Davis out of Chicago, and we've got four or five in the nature and wildlife field. Fortunately, I've been one of those. We're under contract on a yearly basis. We go and speak around the US representing Canon. I do printer work with them, so we go to different events to speak for them. For example, I'll be at the Professional Photographers of America conference in Wisconsin this Saturday.

Cooper: *And then you're off to Austin?*





Gulin: And then I'm off to Austin on my own. I have to fund some fun for myself.

Martirosyan: It sounds like a lot of traveling.

Gulin: People ask me, because I am 70, "When are you going to retire?" Well, I'm not going to. It's interesting that it takes years to develop some of these skill sets. It's good to share them with people.

This is not a job. When I was the executive VP for a beer, wine, and hard liquor distributor, it was work when I'd have to negotiate with the Teamsters in Alaska. Going to the Venice carnival is not work. I'll be doing the cowboy horse drive shortly, and I'll be in some ghost towns in Montana in May.

Cooper: Where? We only know Whitefish. Is it near there?

Gulin: No. These are more down by Dillon and Missoula. We'll base ourselves out of Missoula, and then I'm in Africa again in June.

Cooper: Can you invite us to go to Africa with you?

Gulin: Sure. We're sold out this year, but the following

year it only will cost you about nine grand.

Martirosyan: You can get a photo of the lion chasing me.

Gulin: We don't want that.

Martirosyan: It'll be quick, though. You've got to be fast.

Gulin: I'll tell you, lions concern me, but leopards more so. They'll consider you more prey. But probably the most dangerous animal I deal with is the polar bear. I was onboard a ship holding 45 to 50 passengers. It's not a huge ship, but it's a good size. A polar bear can reach over 12 feet high and one reached up onto the third deck, shimmied up, put its head through the drainage area, and grabbed one of my clients's legs and tore his pants as we pulled him away. Now, if it would've gotten his ankle, his leg would be gone, because the polar bear weighs about 1200 pounds.

Cooper: This is why I don't buy skinny jeans.

Gulin: *(laughs)* I wouldn't either. ■ **ABILITY**

gulinphoto.com
learn.usa.canon.com/explorers_of_light/eol_home.shtml





Nic Novicki

THE CHALLENGE

For Nic Novicki, there's no task too great. Whether in front of the camera, where he's acted on *The Sopranos*, *Boardwalk Empire* and *Private Practice* or behind the scenes writing, directing and producing short films, web series, or independent feature films, the guy is adept at just about any role he finds himself in.

But the actor, comedian and producer knows better than anyone about the trials and tribulations of finding steady work in the entertainment industry. At three feet, 10 inches tall, he knows it's an even steeper climb for people with disabilities.

To help counter this underrepresentation and foster greater inclusion, Novicki created the Disability Film Challenge four years ago to boost the profile and opportunities in film for those with disabilities. Since its inception, he's received more than 150 entries from aspiring filmmakers, and the list of sponsors keeps growing. This year, he joined forces with Easterseals to expand the Challenge, now called the Easterseals Disability Film Challenge. The contest is straightforward enough: write a script, shoot the scenes and edit a three to five minute film in a single weekend. Winners are awarded mentorships with industry luminaries and an invitation to submit their film to the HollyShorts Film Festival.

During a conversation with *ABILITY*'s Chet Cooper, Lia Martirsyan and actress Christina Cannarella, Novicki spoke passionately about this year's Film Challenge, his origins in the entertainment industry, and why we don't see more people with disabilities in films.





Chet Cooper: When did the Film Challenge come about?

Nic Novicki: I'm a comedian, an actor and a producer, I've always been doing my own stuff. Rather than just do stand-up or go on a couple of auditions a year, I've produced my own films—my own shorts. About four years ago, I was directing, writing, and starring in a short called "A Little Broke," and it was such an amazing moment where I was like, "God, I love what I'm doing with this!" And I thought to myself, "There's not enough people with disabilities doing this. I bet I'm the only person right now who's doing all aspects of a short—writing, producing, directing, and acting." And I thought, "We need to come up with an incentive for people who don't have disabilities to want to work with people who do have disabilities." Because work gets more work. I was on *The Sopranos* and that led to me being on *Boardwalk Empire*.

The problem is people with disabilities were not getting that first job. A lot of times, it's us waiting: "I hope I'm going to get that job." So the Film Challenge gives incentives to people who don't have disabilities to enter the contest, because each film has to have an actor, writer, director, or producer with a disability, someone either in front of or behind the camera. So I was making my short, thought of this idea, and was like, "I'm going to come up with this crazy Film Challenge." Met someone at Dell computers right away, and I came up with a

deck on how the Challenge would work. I got mentors on board, and we had our first Film Challenge. People made these awesome films. They loved it. It was a great experience. The winners' films screened at the Chinese Theatre during HollyShorts Film Festival, and I myself had directed a couple of shorts that were in there. A lot of it was just using people I had already worked with initially and asking, "Would you mind being a mentor? Would you mind letting us screen in your festival?"

The second year I got actor Peter Farley to be a mentor, which is a bigger mentor, and then I got more people to sign up and enter, so it became more of a thing in New York, Los Angeles and in the Midwest. The third year was even bigger. And then this last year I partnered with Easterseals, which has been our biggest Film Challenge by far. It's everywhere now. I know a lot of people on Facebook who are kind of related to it, but when I go on Facebook, that's all I'd see—people trying to promote their awareness campaign or talking about how they were excited about the Challenge.

Christina Cannarella: What year did this all start?

Novicki: I came up with the idea in 2013, and the first Film Challenge was in the spring of 2014. Just last weekend was our fourth Challenge. It's crazy how much it's grown.



It's opened me up so much to learn about other disabilities. I'm a little person, so I know little people stuff. I go to little people conventions. My wife is a little person as are a lot of our friends. It's a weekend film competition where you must have someone with a disability in front of or behind the camera. But now I know so much about all these other disabilities from doing the Challenge and talking to people and figuring out accessibility concerns. It's interesting, and I'm proud of all the filmmakers. Great stories came out of it.

Lia Martirosyan: How many entries did you have?

Novicki: We had around 60, out of that, 35 made it, which was more than ever before. Participants have certain requirements to follow. They have to do the whole thing—write, shoot, edit—over the course of a weekend, it has to follow the genre and certain elements. Some weren't able to complete their film over the weekend.

Martirosyan: Who comes up with the genre?

Novicki: I usually come up with it. This year I worked with my partners on finalizing the genre, and it was good for everyone else. Usually, I come up with one genre and the themes, and I'll ask people I trust—mentors and judges—"What do you think of this?" Just so they're all on board, and it's something everyone's excited about.

Cooper: This year you decided it had to be inside an airplane, and people had to jump out as part of the challenge?

(laughter)

Novicki: Yeah, exactly! I said, "Everyone needs to jump out of an airplane if you want to be in the Challenge. Parachutes are optional."

Cooper: That's why only 35 people made it!

Novicki: *(laughs)* Yeah. I usually keep it vague about how many films we went through. As crazy as it is, we have a significant portion of the films made with disability content each year. For the last four years, the films made represent a vast majority of content that deals with people with disabilities in a scripted narrative. There's just a lack.

Cannarella: Why do you think that is?

Novicki: It all goes back to why there are not enough incentives. Studios, networks, producers are thinking about, "How can I sell the show? How can I get viewers?" And there is a huge population of people with disabilities, but they're not showing them. They're not coming out and saying, "We need content." They kind of are, I guess, since *Speechless*, because that's been a huge hit. There's a lot of different disabilities, and I think sometimes that can be tough, too. People won't think some-

body has an invisible disability, that that person has a disability.

This year there was a significant growth in our films. We had way more people enter the Challenge and more films were finished. Part of that was because of our new sponsors with SAG-AFTRA and CBS Entertainment Diversity. Dell has sponsored every year of the Challenge. But also having Easterseals Southern California partnering with me, we renamed it Easterseals Disability Film Challenge, but having them as the largest disability services organization in the nation helped to give it out to all other chapters, all affiliates of Easterseals found out about the Challenge and spread the word. It's been a great year. I'm excited about everything.

I traveled a bunch, too. I went to the ReelAbilities Film Festival in Cincinnati as a celebrity VIP. I got people to sign up from there. I did a lot of shout-out videos with actor RJ Mitte. I did a shout-out video in which RJ and I did a Facebook live, where we talked to all of his followers, which was amazing. I was like, "Hey, if you want RJ's number, if you're into RJ, sign up for the Challenge." We were talking about all the exciting mentors and opportunities for participating in the Challenge. It was cool.

I did a workshop at SAG-AFTRA in New York, which was amazing, a lot of people come out. We did a workshop at Performing Arts Studio West, where there were 100 plus people attending. I find sometimes when I talk about the Challenge in email or it's sent out in an email blast to a school, it doesn't necessarily translate into submissions. But when I go into a school and tell people, "Look, I've been an actor and a comedian and a producer for 16 years. I've been in 40 TV shows and movies. I've gotten Martin Scorsese attached to projects and shot my own pilots. You have to create your own content. You have to produce your own stuff. No one's going to just give you things. My Film Challenge," I will say, "offers better incentives than any other—even if you get your film into Sundance, it's amazing, as that's the pinnacle of all festivals. Once you're at Sundance, it doesn't guarantee that you'll get a mentor meeting. You won't necessarily be in front of an executive. You do get that amazing screening opportunity and the experience of being there, but we also offer the experience of screening at the Chinese Theatre and being at HollyShorts Film Festival and attending all the events." We make it cost-effective for people to enter the Challenge, and we have a special agreement with SAG-AFTRA, so participants can use Leonardo DiCaprio, if they can get him, in their film. If they want him to be in a Film Challenge and he agrees to do it, he could be in a short and they don't have to pay him.

Martirosyan: What's your background in entertainment?

Novicki: I started doing stand-up when I was 18. The best thing about stand-up is that you don't need a film





Nic on Sunset Boulevard



crew. With acting, you're still at the mercy of a play or a movie. With stand-up, you can just go out and do stand-up, which I've been doing for years. That was the same mentality I had when I entered the film and TV business; I've got to just do it, even if it's not great. I always tell people, "Look, your first film's not going to be *Titanic*. You can't think about it like, 'I'm going to win the Academy Award.'" The first short I directed was so bad; it was terrible, I apologized to all the actors and everyone. "Look, I'm sorry." At the end I was like, "We're not submitting this anywhere. I was 100 percent honest." But my next short was a lot better. That got into festivals. The short after that, I sold to HD and streamed online. You just learn the more you do these things. You learn how to be better with the crew and the cast, and I found that not only does work get you work, but the people who get you work are the people who are on your team. If you're in a short film together, you're going to want to work with them again. Even though this short was done with no budget, you get ten grand from a producer or from a client to do a commercial. Wouldn't you rather hire the people you're already comfortable with than the people you're not comfortable with?

Martirosyan: But where do you think people with disabilities are making the greatest inroads in film?

I think it's the independent film movement and specifically for people with disabilities, it's driven more by us. Yes, the studios and the networks need to be more involved and give us more opportunities. As an actor who's 3 foot 10 inches, I'll be honest, sometimes it can be really frustrating to not get a certain amount of auditions, especially

when I already have a large body of work. But ultimately, I can't wait for someone else. For people with disabilities, the numbers show that we can't wait. We, as a community, have to be more proactive. I think the studios and the networks can be more inclusive and try to help us get into more mentoring programs. There's a lot of writing, producing and directing programs. I think they need to give a little bit more training. Maybe if outside companies offer more training for people with disabilities, they can get into these showcases and diversity programs.

Cooper: If I did film mentoring, I'd use the Titanic as well, except I'd say, "Your film will sink."

Novicki: *(laughs)* That's the thing. Most films do end up sinking like the Titanic. But if you're lucky enough to get the lady who drops the necklace in, you're in good shape. It's hard, though. But that's the beauty of doing shorts versus doing a feature film. When you do a feature film, you're investing a lot of money, whether you're lucky enough to raise money from people you don't know personally. You're only going to get one shot from people like that. Or, if you're getting money from your friends and family for this feature, there's a lot of pressure that this feature has got to be amazing. You've got to know what you're doing, learn through trial and error, web series, doing other shorts, just playing around.

That's the thing with iPhones now. You can do so much. They look great. If you light an iPhone and get the proper lenses, it's amazing. I have a friend who was in the movie *Tangerine*, (filmed using three iPhones), and it was exhibited in 700 feature film screens.



Cooper: *You did a good job.*

Novicki: Thanks. It's crazy. Some of it just fell into place. I was a writer for CBS' Diversity Showcase, so they knew about the Film Challenge from me talking about it, and they became a sponsor.

Cooper: *Was the Diversity Showcase years ago?*

Novicki: They have one every year. It's the biggest diversity showcase each year around the country. It's where Kate McKinnon and Randall Park got discovered. I was the only person out of 200 or something with a disability.

Cannarella: *It's not just disabilities but diversity in general?*

Novicki: No, it's pretty much anti-disability. *(laughs)* I happened to be on camera.

You have to be able to write at least one sketch every day for the Showcase. And it's performed in front of 100-something people.

Cooper: *Oh, this is new information.*

Novicki: You have to have a certain level of comedy experience, which a lot of people, unfortunately within the disability world, don't have.

Cooper: *This event at CBS is humor-based?*

Novicki: Yes. It's a sketch comedy showcase. They've done it for almost 15 years. It's a big showcase.

Martirosyan: *What are the requirements?*

Novicki: You have to submit a writer packet. It's bigger for the actors. That's where a lot of people get development deals.

Cooper: *Do you know Jeff Charlebois?*

Novicki: Maybe.

Cooper: *He's been writing for us for years. He does stand-up comedy. He's known as Ham on a Roll, and he's funny. How many days are you on the road doing stand-up?*

Novicki: It varies. This year I've focused solely on the Challenge. Running it, coming up with ways to get more people to sign up, and promoting it. I was all over the country promoting the Challenge, and I filmed a pilot in Tupelo, Mississippi. I talked to a kid at Ole Miss while I was there, and the community college in Tupelo, Mississippi. I was in New York a couple times. Every time I go to those places, I'm like, "I've got to get up and do stand-up some time." My stand-up is sort of like a drug. You want to do it. You're looking for places to get up on stage. But I've done Tours for the Troops; I've performed in the Middle East, in Africa, and in Europe. I'm performing quite

a few places. But on the road, it varies. I was just on the road this last weekend. I'll be doing stand-up every day this week. It kind of changes based on what gigs are out there.

Cooper: *It sounds like you've been to some interesting places around the world. Have you ever thought—maybe it's too dangerous? Have you ever thought of going to New Jersey?*

Novicki: *(laughs)* I've been to a lot of dangerous and crazy places. But once I went to New Jersey, actually I was just in Atlantic City two weeks ago.

Cooper: *Where? What venue?*

Novicki: I wasn't at a venue. I was there for a bachelor party.

Cannarella: *Ooh! Tell us about that!*

Novicki: It was a good time. Atlantic City was fun. The last time I was in Atlantic City, it was technically a sound stage. It was fun to go back there. I went to college in Philadelphia, and when I was there, we used to go to Atlantic City sometimes.

Cooper: *Drexel University?*

Novicki: I went to Temple University.

Cannarella: *What did you study?*

Novicki: Business. I double-majored in marketing and entrepreneurship, and then I went to the American Academy of Dramatic Arts. I was doing stand-up the whole time, and when I got out of school, it was one of those things where I had a crazy job working for Citigroup. I did the private show for all Harvard MBAs. These guys were high up in the finance world. And they all loved me. And the CFO of Citigroup wanted to hire me. He was like, "I want you to work for me." And I decided not to and to just do stand-up. So I went from that job opportunity to living with four comedians in a two-bedroom apartment.

Cooper: *I saw that show.*

Novicki: *(laughs)* Yeah!

Cannarella: *What do you like better, doing stand-up or acting...?* ■ ABILITY

Continued in next issue...

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nicnovicki.com
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SYRIANS LEARN FIRST HAND WAR IS HELL!



One hundred fifty three years ago, Union General William Tecumseh Sherman issued his definitive statement on war: “War is Hell.”

In 2013, Syrian Christians and Damascus residents 14-year-old Mariamma (Mary) and her 16-old brother Outha (Joseph) were caught in the middle of a battle between rebels and government forces. They decided to split up. While running to a building, Outha took a bullet from a rifle that nearly tore his right arm off. He was taken to Tishreen Military Hospital in Damascus where a team of doctors worked valiantly to save his life. They did. Orthopedic surgeon Dr. Tommy Taylor was one of the doctors who operated on him. Outha spent six weeks in the hospital recuperating. He was given training on how to use the arm. Before leaving the hospital, Dr. Taylor fitted Outha with a newer and better prosthetic arm.

The prosthetic arm made him nervous. It drew attention to him that he did not want, and the hook had a menacing look and feel.

The family’s woes did not end with Outha’s tragedy.

During that same battle, Mariamma was running along a street in Damascus when an IED (improvised explosive device) exploded. She was taken to a hospital, and

due to her injuries she lost the use of her left leg and has scars on the left side of her body and her face. In addition she has recurring nightmares of the incident.

Mariamma’s mother, Amira, found Mariamma three days after she sustained her injuries. Four days later, Amira took her daughter home. Although Amira did not know where Outha was, she had enough faith to believe he was not dead. Six weeks later when he returned home, Amira was overwhelmed with emotion. She says, “I nearly fainted when I saw he only had one arm.”

Being disabled made Mariamma and Outha look more humanely at the thousands of people in their community physically scarred by the war. They saw people armless, visionless, hard-of-hearing or deaf, speechless, multi-scarred, cognitively challenged, nearly skeletons and others with multiple injuries. All of these people were homeless, hungry and destitute.

The brother and sister knew they would have to be strong and resilient to survive. They were witnessing firsthand the utter, human destructive carnage of war. The war infuriated them. Their bitterness towards their government could not be measured.

Shortly after Mariamma and Outha’s near death experiences, government forces arrested their father, Hassan.





Hassan was a critic of Syria's president Bashar al-Assad. The government seized their property and forced them from their home. Leaving their home was a crushing blow. Six generations of their family had lived there. Their father and grandfather were lawyers. Since the war started in 2011, 15 members of their family had died from indiscriminate bombing. The dead included grandparents, aunts, uncles, cousins and nephews. Taking with them only what they could carry, the family fled to Turkey. The more than 600-mile walk to Turkey was long and hard on Mariamma's left leg and equally hard on Amira. They became refugees. How does the world define a refugee?

Every month, 30,000 people are injured in Syria in conflict related violence. The International NGO Safety Organization (INSO) reports that between September 26, 2016 and December 28, 2016, there were 8656 attacks using explosive weapons in Syria, which accounted for 72% of the reported attacks and an average of 94 bombings daily.

Who Are Refugees?

Following World War II and in response to the large numbers of people fleeing Eastern Europe, the United Nations 1951 Refugee Convention adopted, in Article 1(A)(2), the following definition of "refugee" to apply

to any person who "owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it."

The Syrian Crisis

The numbers tell the bleak story of the toll the Syrian crisis has had on its citizens. Twelve million Syrians affected: 6.3+ million internally displaced people in Syria, 4.9 million Syrian refugees registered with the United Nations High Commissioner for Refugees (UNHCR), 3.1 million internally displaced people in Iraq and 2.9+ million Syrian refugees in Turkey.

Upon arriving at the camp, Mariamma, Outha and Amira were surprised to see international organizations providing a range of services to the refugees. They saw doctors, physical therapists, social workers and psychologists.

A report issued in February 2017 by an international NGO working to help Syrians impacted by the crisis in





Syria, Lebanon, Jordan and Iraq contains the following description of humanitarian services to refugees:

The NGO provides support to hospitals, clinics, and specialized care centers in Syria, Iraq, Jordan, and Lebanon, providing post-operative physical and functional rehabilitation. Our staff fits individuals with orthopedic devices (artificial limbs and braces), distributes mobility aids (wheelchairs, walkers, etc.) and special equipment (toilet chairs, anti-sore mattresses, etc.). We work to ensure people recover as much of their mobility as possible and can take part in day-to-day life. Psychosocial support is also provided for the families of people with disabilities. This work is intended to help families offer long-term support to loved ones who are in disabling situations. Community support groups offer families the opportunity to share their experiences and to identify practical solutions to help them cope. These services are essential for, patients who have lost all or some of their mobility and need to perform exercises to avoid developing permanent disabilities, and patients who have permanently lost some of their mobility and need rehabilitation care to avoid medical complications, enhance their comfort and, in many cases, move around autonomously again.

“We walk the camps, informing vulnerable people about available services, and offering access to very specific types of care. Staff then follows up with these people. Handicap International also helps other organizations

ensure that the most vulnerable are included in the actions they implement.”

Once the family was settled in the camp, Mariamma was given a walker and counseling. Outha was given a new prosthetic arm and counseling. Having lost her home and husband, nearly losing both children and the long trip to the camp, Amira was lost. She needed psychosocial support.

The camp was depressing. Many of the people there had lost everything. Their situations mirror Amin’s story.

Amin, 60 years old, Amman (Jordan), January 2017

“We left everything behind”

Amin is from Homs, Syria. In 2014, he fled Syria to take refuge in Jordan. Due to a lack of adequate care, his diabetes has taken a serious turn for the worse in the last few years, and in June 2016, he had his left leg amputated. He was fitted with prosthesis and received physiotherapy and occupational therapy.

“In Syria, I was a butcher. I loved my job and happily spent most of my day working,” recounts Amin when he recalls his life before the war. “We lived a normal life, everything was fine. I had a car and we lived in a big





house.” Whilst his grandchildren play at his feet in the living room of the small apartment he now lives in, he continues to talk about how everything changed.

“We left Syria just over two years ago. Life had become a real struggle in Homs. We first took refuge in a school in the suburbs of Damascus with other families. We stayed there for six months, but the school was bombed and we had to move again. A year later, the bombing reached the town we were living in, where we thought we would be safe. That’s when we decided to flee to Jordan, leaving everything behind.”

Amin’s diabetes got worse when he arrived in Amman. “I had a wound which would not heal. I consulted several doctors, but I didn’t have the means to pay for treatment. My condition worsened and, one day they told me I had to have an amputation.” After the surgery, one of his close friends advised him to contact Handicap International. The organisation fitted him with prosthesis and provided him with physiotherapy and occupational therapy sessions. “I can get around again and that has really changed my life here,” concludes Amin with a smile.

How are Syrian Refugees relocated to the U.S.?

The process begins with a referral from the UNHCR registers refugee’s worldwide and provides aid and

assistance until they are resettled abroad or (more likely) returned home once conditions ease. The registration process includes in-depth refugee interviews, home country reference checks and biological screenings, such as iris scans. Military combatants are expunged.

Every refugee goes through an intensive vetting process, but the precautions are increased for Syrians. Multiple law enforcement, intelligence and security agencies perform “the most rigorous screening of any traveler to the U.S.,” says a senior administration official. Among the agencies involved are the State Department, the FBI’s Terrorist Screening Center, the Department of Defense and the Department of Homeland Security. A Department of Homeland Security (DHS) officer conducts in-person interviews with every applicant. Biometric information, such as fingerprints, are collected and matched against criminal databases. Biographical information, like past visa applications, are scrutinized to ensure the applicant’s story is genuine.

Amira says, “One interview led to another and then to another and another and another.”

Refugees will not be admitted into the U.S. if they are a security risk, have connections to known bad characters or have outstanding warrants or criminal violations.





Lawyer Jason Ward specializes in assisting immigrants entering this country. He scoffs at the Trump administration's efforts to slow down people from Syria, Turkey, Iraq, Iran, Lebanon and Jordan.

"Refugees coming into America from Syria, Jordan and Iraq have been well vetted. They pose no more threats to the U.S. than Vice President Pence," Ward says.

Mariamamma and Outha adjusted to the camp fairly easily. A school was set up, and they went. Soccer was played daily. Outha and Mariamma were fascinated by the programs set up to help people with disabilities. They offered their assistance by visiting people who needed help.

Outha developed a passion for backgammon and won many games. Meanwhile, Amira and her two children anxiously waited to hear about their refugee status.

Two years elapsed from the time the UNHCR started the referral process until Amira and her children learned they were going to the United States. It was a happy but sad occasion. Amira and the children knew they would never return to their beloved Syria.

"Syria was our home. Syria is in our blood. Arabic is our native language, not English. Our foods, culture,

clothes and religion are different," Outha has stated.

According to the Migration Policy Institute, although Syrian refugees represent a new flow to the United States, the broader Syrian immigrant community, while quite small in size, has had a U.S. presence since the late 19th century. As of 2015, approximately 83,000 people born in Syria resided in the United States, accounting for less than 0.2 percent of the overall foreign-born population of 43.3 million. It is also well integrated, with Syrian immigrants having higher levels of education and English proficiency than the overall foreign-born population.

Amira, Mariamma and Outha arrived in New York in November 2015, and they were met by relatives. It was a tearful reunion. Mariamma and Outha had never met their American cousins. Since their arrival, Amira found a job working for a travel agency with offices in the Middle East. She misses Syria, and she misses her dead husband.

Amira had visited New York 25 years ago before her marriage. She spent the summer working for her relatives who owned a restaurant and a bookstore. She was happy to be in a place where there was no war. She had personally experienced too much war. She was with her family, and that was enough for her to be content.





Mariamamma was awed by her first Christmas in New York City. She had never seen so many decorations and so many Santa Clauses. Her first Christmas in the U.S. was, “the best Christmas in my life” she said. She will finish high school next year, and she has a Syrian boyfriend. When her left leg bothers her, she uses a wheelchair. She feels more comfortable using a wheelchair here than she did in Syria. She marvels at the laws and technology available in America to advance opportunities for disabled people. She joined an advocacy group working on behalf of people with disabilities, and she believes Syria will never have laws benefiting disabled people. She intends to go to college and major in Middle Eastern history and teach here. She works at a movie theatre on weekends. She believes she has more career options here than she had in the Middle East. Despite it all, she is still troubled by nightmares involving the incident in which she was the victim of an IED.

Outha is a college freshman. When he started college, a disabled student introduced Outha to a variety of assistive technology products. Outha was attracted to voice recognition immediately. “It’s a powerful tool. I can do anything I want with it,” he says. He uses it for his writing and other tasks. He is dating an American girl, and he works 30 hours a week stacking books, ordering books and ringing out customers at the international

bookstore owned by his relatives. He is becoming accustomed to people staring at his prosthetic arm. He has a new prosthetic with a hand, which looks more natural than the hook. He is aware of the many laws passed in the United States prohibiting discrimination against people with disabilities, and he is amazed at the yearly salaries people here earn.

Outha and Mariamma still think of Syria. They doubt they will ever return. They have seen hell. They have lived through hell. They do not want to be reminded of hell.

Outha and Mariamma share a common goal. After they have been in American for five years, they intend to become American citizens. ■ **ABILITY**

by John M. Williams

Writer’s note: Fearing retribution by the government towards their friends in Syria, Amira, Mariamma and Outha agreed to be interviewed on the condition I did not use their last names, I could not take photographs of them or give physical descriptions of them.

unhcr.org
handicap-international.us
atechnews.com



WAR ON DISABILITIES



Since the beginning of the war in Syria, thousands of refugees with disabilities have tried to escape to Europe, facing scarcity, death, and war, without the proper assistance and protection to meet their basic needs.

Reports show that approximately 30% of crisis migrants from Syria have special needs due to physical, sensory, or intellectual impairment, chronic disease, or injury.

The Asylum Procedures Directive requires that Member States of the EU protect vulnerable groups that include minors, refugees with disabilities, the LGBT community, and pregnant women. This is also in accordance with the UN Convention on the Rights of Persons with Disabilities.

However, in the case of refugees with disabilities, they are being overlooked and are falling through the cracks, according to Human Rights Watch researcher Emina Ćerimović.

This occurs both as refugees flee and as they arrive in and work to integrate into a new society. It is not easy for anyone to escape war and leave their country, but individuals with disabilities face unique challenges.

Ćerimović also pointed out that even making the decision to flee is a major difficulty for people with certain

types of disabilities, as some may not recognize the hazards they face.

“The first struggle is just being able to flee; the second is, you might have intellectual disabilities and not understand the danger,” she said. “I interviewed a 24-year-old man I met in Greece. He is deaf and back in Aleppo, in Syria, just because he’s deaf, he could not hear raids; he could not hear air strikes.”

Ćerimović reported that this young man’s parents would not let him go out, confining and isolating him for three years before he was able to flee. They feared his deafness would prevent him from seeking shelter in the case of an attack.

This is why the role of family members can be crucial. In some cases, families decide to stay together and face the cruelties of war to avoid leaving someone behind. Similarly, Ćerimović said that in all her time in refugee camps, she has never met a person with a disability who was not accompanied and assisted by relatives.

“Although a disability may seem like a hindrance to escaping a conflict zone, for others it is in fact the reason to flee,” said Gesa Müller from Lebenshilfe Hamburg in Germany who provides lifestyle support for individuals with disabilities.



This was the case for 19-year-old Karan, a Syrian teen who has severe intellectual and physical disabilities. His mother decided to flee Aleppo when lack of access to medical care became a grave concern.

“Because of bombs, deaths and weapons, my son’s condition became worse. He started having crises, and it affected us very much,” she said. “He used to take medications, but now there is nothing.”

Karan’s mother explained that because they had to cross rough, uneven terrain without any mobility aids, the journey was slow and difficult. “The journey was really so tough for my son. I did this journey for my son. If it was not for him, I could have stayed back,” she said.

For those who make the decision to flee, one of the most common routes to enter Europe is by land from Syria through Jordan and into Turkey, where they travel by sea into Greece.

Because this sea crossing is typically done on over-filled dinghy boats, any personal items seen as unnecessary, including wheelchairs, are generally not permitted. Other devices, such as hearing aids, are likely to be damaged.

Once they arrive in Greece, refugees stay in camps sometimes for just a night, but in other instances, bottlenecks and changing laws force them to stay in one place for months at a time. However, many of the camps are provisional and as such, have not been equipped to accommodate individuals with special needs.

According to Ćerimović and her team, individuals with mobility issues may have difficulty meeting basic necessities, such as gaining access to shelter and water. This is because these facilities are often built far away from each other, on higher ground and uneven terrain.

Sanitation accommodations are generally not wheelchair accessible; she described stories of individuals descending from their wheelchairs and crawling across unhygienic floors just to get to the bathroom.

A 28-year-old Syrian refugee, who was physically wounded and in a wheelchair after a rocket struck his home in Damascus, described his experience in an immigration detention center in Hungary on the Serbian border.

“Every two or three days all the others are taken out to the courtyard to get some fresh air, for 15 or 20 minutes. I haven’t been out for 42 days because of the stairs,” he said.

There is very little to do in the camps, so those who are unable to leave face boredom and sometimes feelings of uselessness. The poor conditions in the camps and lack of psychosocial support can lead to mental health issues, in which trauma may be compounded.

“While working in the camps I have observed emotional, mental and social problems including depression, anxiety, PTSD, hypervigilance, anger, despair and social withdrawal,” explained Michelle J. Wong, director of World Media Advocacy.

He explained that confinement can cause a loss of the will to live, lack of sleep and appetite, drastic weight loss and a tormented mind, due to feeling out of contact with the outside world.

Ćerimović reported meeting people who had attempted suicide because of the conditions in the camps. According to psychologist Amer Omar of the Woman and Health Alliance International, providing crisis migrants with some counseling services is not enough because in order for a person to fight against depression, s/he needs to change his/her environment and have access to food and shelter.

Although a few NGOs such as World Media Advocacy, Save the Children, and Doctors Without Borders do enter the camps to identify and assist individuals with special needs, there are not enough resources to go around. People with disabilities that are not visually identifiable tend to go unnoticed and unaided.

Most refugees in the Greek camps eventually manage to move on, and many aim to head to Germany or Scandinavian countries. Those areas are known to have some of the best social support systems for asylum seekers in Europe, although conditions even there may be far from ideal.

Müller outlined some of the main struggles a refugee with disabilities confronts once arriving in Germany. Again there is a problem with identification in reception centers and camps, since special needs are not a topic in the entrance interviews.

Identification is left to social workers or volunteers, despite a lack of intersectional training. Their experience is either in working with people with disabilities or with refugees but not both.

Müller said most individuals with disabilities self-identify or have family members who contact social workers, but because of cultural differences and stigmatization, many fail to reach out.

In Germany, approximately 10 percent of citizens receive benefits for a severe disability, in contrast to 5 percent of people with a migration background. This shows that individuals with severe disabilities and a migration history are significantly less likely to be identified.

Completing the paperwork for an application for asylum, requesting an identification card, finding a physician and gaining access to rehabilitation services or medical devices is a discouraging process that can take months or even years.





The experience of Mohammed Reda is just one of many examples. Reda is unable to walk due to injuries from an airstrike in Syria, and, after being in Germany for eight months, he still had not been issued a wheelchair.

He reported he had not been outside his apartment in over a month, since there is no one who is willing to carry him. Although he was able to reach Germany, he has not been able to begin his new life due to inefficiencies in the bureaucracy.

Stories such as this point to the fact that the process of identifying and aiding refugees with disabilities should begin sooner upon their arrival and should be expedited.

For those who make it through the identification process, there are still struggles ahead. For example, in Germany's biggest cities, Berlin and Hamburg, it is extremely difficult to find barrier-free living; while others may need to travel hundreds of miles to attend language classes that are specific to their needs. This is required in order to receive financial support from the State and is a first step toward assimilation and integration.

However, Müller added that it ultimately might be easier for a refugee with a disability to integrate, because there is little fear of those with disabilities or injuries, the elderly and children.

This sentiment was echoed by Nujeen Mustafa, a young woman with cerebral palsy who, at the age of 16, fled from Syria to Germany.

As she described the change in attitudes of Europeans towards refugees after the 2015 terrorist attacks in Paris, she said, "But generally the Germans were still open and friendly, as they had been ever since we arrived. Maybe it's easier for me being in a wheelchair as I look benign."

Although it may have been comparatively simple for Mustafa to find a place in German society, things were much harder for her along the way.

When she and her family were still in their Aleppo apartment, she was unable to navigate down the stairs to the relative safety of the basement, so they all stayed on the fifth floor as the building shook during the raids.

She recalled feeling like a burden to her family numerous times, such as when she and her sister hid in a bathroom during a regime bombing against the Free Syrian Army in Manbij.

"We were in that bathroom for four hours. If we were all going to die, I wanted it to be me," she said. "The rest of my family each had a definite use, but I couldn't see I had a use for anybody."





Eventually, the younger members of Mustafa's family were able to flee and, despite the challenges faced along the way, she and her sister reached Germany, where she was immediately impressed by the opportunities available to her.

"At the station we were amazed by the lifts and everything designed to make life easier for disabled people. As [my sister] says, 'everything is different in Germany,'" she stated.

Although according to Ćerimović and Müller, there is still much to be done to improve the lives of refugees with disabilities in Germany and other European countries. Simply being allowed to reside in a place with this type of infrastructure is a life-changing opportunity for many.

Mustafa explained, "The first day I ever went to school, I was just one month shy of my 17th birthday. I was nervous but also happy, for finally I could say I have done something normal in my life."

Her experiences in school have also given her a new hope for the future. "The point of this school is to train us to be as independent as possible, and when we finish here at 18, we do training in what they call vocational work. We have no facilities like this in Syria, and I know I am very lucky," she said. "Even some people in

Germany think special schools like this are too costly and that disabled people should go to school with everyone else. Maybe one day I will."

A similar optimism is held by Anas al-Hakim, a 25-year-old Syrian who was paralyzed as a teenager during a surgery related to craniofacial fibrous dysplasia.

Al-Hakim arrived in Germany in 2014 to pursue higher education. He states, "Living in Germany is like a dream. I can go wherever I want with the transportation system, and there are wheelchair accessible ramps in most buildings."

According to the World Health Organization, physical barriers to basic mobility often prevent individuals from fully participating in society.

This was true for al-Hakim, as he explained, "I prefer everything in Berlin to Damascus. My family is there, but here I can move freely with my wheelchair. It comes down to the freedom of movement."

When talking about living in Damascus with special needs, he put it simply: "You don't see someone with a disability very often. It's strange even for [Syrians] to see someone in a wheelchair. They don't mean to stare or look, but they tend to."

This perception was shared by Mustafa who has said, "I didn't confront my disability in Syria because I didn't go out, and I avoided people looking at me. The teachers here think I need to be realistic and accept how I am and get on with it, learn to eat by myself and move my chair, not keep talking about being an astronaut or walking."

In both of these instances, life in Germany has afforded individuals with mobility issues a chance at a life that never would have been possible in Syria.

This is certainly the case for Fatima Albakour, who was just 7-months-old when shelling left her with burns over 60% of her body. A physician at the hospital in Idlib, Syria suggested giving her a lethal injection because her injuries were so severe they would result in the lifelong inability to walk or talk.

However, Dr. Marita Eisenmann-Klein helped bring Albakour and her family to Germany for surgery. Although Albakour is still in pain and has a long road to recovery in front of her, doctors believe the first operation was a success, and there is now a team in place to help her as she prepares for her new life.

It is clear that fleeing a conflict-affected region is difficult for anyone, and individuals with disabilities face particular challenges during flight and resettlement. Many stories also show that individuals with disabilities who are able to escape to a country like Germany are afforded chances at a life that may never have been possible.





Despite this improved quality of life, governments and programs continue to overlook and underserve refugees with disabilities.

Since 2015, Greece has received more than €125 million in refugee aide and an additional €370 million has been raised for humanitarian agencies; however, Čerimović said that refugees with disabilities are still not getting the services they need. Furthermore, the UK declared in February 2017 that their flagship program to resettle the most vulnerable victims from the Middle East and North Africa has been put to a halt. Due to a lack of suitable infrastructure and social support, children with disabilities will be forced to remain in refugee camps.

A significant number of crisis migrants with disabilities are seeking identification and asylum, and we have an ethical obligation to improve the refugee processing system to ensure all claims are considered seriously and efficiently.

Thus, it is more pertinent now than ever before that governments, aide organizations and individuals come together to assist refugees with disabilities during flight, in the camps, and as they seek to build their lives in a new society. ■ **ABILITY**

by Kelsey D. White, PhD
photos by Michelle J. Wong

Kelsey D. White, PhD is a German instructor at the University of California in Santa Barbara. Her current research focuses on the documentation of stories of crisis migrants with disabilities, injuries, or chronic illnesses, particularly as they settle in Western countries.

Michelle J. Wong is a photographer, journalist, writer, and founder of the non-profit organization World Media Advocacy. The goal of his recent work is to increase awareness for the needs of individuals with disabilities, to fight for their rights, and to help alleviate the devastation of individuals fleeing from conflict-affected areas.

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NO MUNDANE MOMENTS

LEIGH KOECHNER

By nature, Leigh Koechner is openly raw and honest but also blessed with a lightness of being. She's funny and quirky, too. A mother of five—with husband actor David Koechner—she does stand up, creates a variety of videos, and is the parenting expert for Jiyo, a personal well-being app. *ABILITY*'s Chet Cooper and Lia Martirosyan joined the Kansas-native at her family home in Los Angeles, where she discussed her mission in life, the miraculous birth of her youngest, and how she's choosing to share her gifts with the world.

Chet Cooper: Your routine is funny. Is it true you had a head trauma?

Leigh Koechner: I did—I fell off a cliff when I was 13 years old. We were mountain climbing and rappelling down a mountain at a summer camp, and as we came back down the mountain, the trail was thin, and I kept grabbing daddy long-leg spiders and throwing them at my girlfriend's back, because she hated them and we teased her constantly. I turned back around the other way and literally slipped off the side by goofballin' it. I fell 10 feet and landed on my head. There was a 250-foot drop after that, so it was great I landed there. But the way I hit my head knocked me unconscious. They had to rappel down to me, run three miles to get a board to put me on and bring me down. I guess when you have head trauma you throw up quite a bit. I wasn't aware of it, but I was throwing up and screaming and saying wild things, and then I'd black out.

I woke up about 48 hours later in Boone County, Arkansas, in intensive care. I remember I couldn't move my head. I had no idea where I was. There was some really drunk man chained to his bed, like handcuffed, who had been in an accident, screaming. I was like, "Where am I?" And then I looked, and I saw the owner of the camp and he said, "Hey, darlin'! You're injured. You banged your head up pretty good." I didn't cry or anything, I was 13, and just lying there. But the second I heard my dad's voice—they put the phone to my ear—and I said, "Daaaad!" He said, "I'm on my way, baby!" He was a doctor. He took a LifeFlight from Kansas City to come and get me. I was in intensive care for a little bit, and then in a room for about a week.





WILD & FREE



Leigh and husband David Koechner

What we have found is that it jarred my short-term memory. How I describe it is, I have a little staircase in my brain. When you say, “How was last night?” I run up and look, and it’s blank. And somebody will say, “Remember? We were at Marion’s.” And I say, “Oh, my gosh, it was a blast!” There’s a little prompting that has to be done.

Lia Martirosyan: Creative illustration.

Koechner: Yeah! When I was trying to decide how to describe it, people were like, “Were you drunk last night?” I used to be a pretty big partier, and I would say, “Yes.” Sometimes I thought it was because I was drinking, and I had one drink too many. And then when I quit drinking for a while, it was still happening. That’s how we found out. It got a little bounced around up there.

Martirosyan: Daddy long-legs.

Koechner: It was the daddy long-legs’ fault.

Cooper: How do you feel about them now?

Koechner: I just enjoy them. I have a collection of them in my bedroom.

Cooper: What kind of a physician was your dad?

Koechner: He was a plastic and reconstructive surgeon in Kansas City. Here it would be considered more plastic, but there it’s more reconstructive. When people got in car accidents, he’d put their faces back together or remove cancers.

Martirosyan: So you grew up in a medical environment?

Koechner: Yes. I used to go to the emergency room with my father. He would let me put on gloves and hand him stuff. I went to the operating room and got to observe, and I loved it. I thought I would do pre-med until I got into college, but I liked partying and cocktailing way more than studying, so I went from pre-med to recreation and leisure.

Martirosyan: You have that smile.

Koechner: It’s so funny. That’s really what I majored in. In college, I was in a sorority, and I was doing the mail, that was my job that day. I was putting the mail in the mail slots. My dad had just called me and said, “What is your major? You’re a junior. You have to pick your major, because you have to get all those classes in.” I was like, “Whatever, Dad.” He said, “Pick one. I’m only paying for four years.” I said, “OK.” In the mail I saw a picture of a beach, so I flipped it over to see where to put it, and it said, “I miss you, sisters. I love you all. I’m having a blast at my internship.” I was like, “Who knows Kim Anderson? What is her major?” They said, “Rec and leisure.” I said, “That’s what I’m signing up for.” I ran and signed up that day and called my dad and he belly-laughed, because he’s a super-smart guy. He said, “Fine. Just graduate in four years.”

I have to say, most people do not use their college degrees. It’s less than five percent or something like that. I actually used mine. I went to work at resorts around the world and set up activity programs and had some fun. I was at Club Med teaching scuba diving.

Cooper: Did you go to graduate school?

Koechner: Recently. From Club Med I ended up just moving to California—“just?” I love it here! I got a job



in post-production and bounced around, then I got married, started being more creative, having the freedom to be creative, I wasn't stuck in a job where I felt like I was suffocating and not filling my heart with joy.

I recently went back to school and got my master's in Spiritual Psychology, because I almost sold a reality TV show. I remember somebody pitched it, I was excited and wanted to do one, and then we almost sold it. I remember right before we found out I thought, "I don't feel connected to this at all. This isn't who I am. This isn't what I'm about." They passed on it, and I was so glad. I thought, "I'm not going to move forward in this until I know who I am, what I'm about and why I'm here." Some serendipitous things happened. Somebody said, "You need to go to this school." It lit me up. I started five days later. I found out the two things that I wanted to know: who I really am and why I'm on the planet. I found those things out, and now I only move in line with things that support that.

Cooper: And what are those two things?

Koechner: That I am a soul, temporarily in this earth-suit, the gift I've been given is that I'm filled with joy, and I have a bright light. When I share these gifts with other people, I've found that it makes a difference in a very positive way to myself and to the people I touch. That's exciting, because now it's so clear I'm here to shine my light and to be all of me. Those are two things I know how to do with grace and ease. When we're lined up with what we're supposed to be doing, it's with grace and ease we move through the world!

Martirosyan: Is that something you have to remind yourself of every day? It's a big thing to realize, but it's also a big thing to maintain.

Koechner: No! I think when we get really clear about what specific gifts we have been blessed with and we're using those gifts to be of service, it's easy. It feels good. It's healing to me and to whomever I'm working with or talking to.

Cooper: You mean helping others?

Koechner: Yeah!

Cooper: That's totally selfish.

Koechner: It's really selfish. I only help others to feel good. (laughs)

Cooper: It's the most selfish thing you do, and people don't realize it.

Koechner: Being of service is the best way to be happy and to feel good and be filled with joy and a sense of purpose.

Cooper: It says in the Bible that it's better to give than to receive, probably almost every religion has something like that, yet people wait to go to church and tithe or they do certain things, they're not truly giving unconditionally, but it's so beneficial to one's soul. We do it all the time. I think what Lia's question was is that you get caught up in the world's activities, watching the news, hearing people do things that harm others and the planet, that's when it's difficult to say, "Am I still doing good?"

Koechner: It's interesting because if everything on this planet were perfect and rosy and beautiful, and we all thought the same and skipped around, we wouldn't be learning a whole hell of a lot.

Cooper: I'd be surfing more though.

Koechner: You would probably be surfing more. Without the darkness you can't have light. I think without the things we perceive as bad or horrible, you can't have people who can be of service to help. There has to be the —

Martirosyan: —balance?

Koechner: Yes, because I think we are here to be human—we're here to miss the mark, to get covered up and unravel, and to get back to our greatness. Although I don't think it's beautiful when horrible things happen to people, but from the horrible experiences we rise, and we take care of each other, we stand up taller and get the meat of who we are.

I don't watch CNN, because it's just yammering on and on about how bad things are. That doesn't interest me. It interests my husband, but I've set limits. I told him, "If you're going to do five minutes in front of the TV, do five minutes of meditation. If you're going to do 15 minutes of ranting about Donald Trump, do 15 minutes of playing catch with your son. You've got to balance it out. I'm not going to watch you fill up with negative energy. It's not welcome."

Cooper: I would say 15 bad, 30 good.

Koechner: If you choose to wring your hands, stare at the TV, and bring your blood pressure up, it's a waste of energy. If you know you're in alignment with bringing light in and then sharing that, you're doing your part for the world.

Cooper: Tell us about your parenting videos. Is that part of your mission?

Koechner: Yes! As I told you, I found out who I am and what my gifts are.

Cooper: Oh, by the way, do you have children?





Koechner: A couple.

Hi. My name's Leigh Koechner.

(laughter)

I'm a mother of five kids, and I'm married to actor David Koechner.

Cooper: OK, so you are married and have five kids.

Koechner: Five kids who are very different and who are insanely perfect at showing me how much work I still have to do. Because I will talk about stuff like, "You know, when you're a kid, just take a step back and take a breath." I'll teach my staff. And then when I come home, I'm shouting, "What did you say?" And then I giggle. It's like I'm observing this crazy person.

Cooper: I think back to what Lia was saying about how you stay on the path of your being, because of the realities of life. The children are a perfect example.

Koechner: Perfect. My biggest triggers are my children. Something I learned when I, in what I call "spirit school," was compassionate self-forgiveness. We beat ourselves up. We all are our biggest critic and our biggest bully. We are to ourselves more than anybody else will ever be. The thoughts from our childhoods still run through our heads. And most people still take those childhood thoughts, like, "I'm not good enough." Everyone has a story they created when they were little—something happened. For example, my mother was mentally ill and locked behind her bedroom door. We didn't have access to her. So how I perceived that in my

seven-year-old little girl mind was, "I'm not even good enough for my own mother to get out of bed for."

I was unworthy. Nothing mattered. I acted that way. I was a wild ass in school. I did whatever I wanted. I drank. I did drugs. I made out with a lot of people. I was trying anywhere to connect and find out who I was. But I thought nothing mattered because I wasn't even good enough for my own mom. Who would love me if she doesn't love me? Come on! And that's from a thought I had at seven. We put those thoughts in our heads, and we live our whole lives under this teeny pebble from when we were a kid in these adult bodies! That's why you see parents overreact when something happens to their kids, because they have a huge bag of—if I can say it—crap on their backs that they're carrying from their childhoods, because they haven't worked through it. They haven't cleared it out.

Parents get so wrapped up in their kids because they're working out their own stuff on them, as opposed to going, "Well, my bag's really floppin' around right now. I'm going to set it down. I'm going to look at my kid, and I'm going to listen and keep my mouth shut." That's really hard for me, listening and keeping my mouth shut. That's why they are constantly showing me, "This is what you need to work on. This is what I need from you." And when I don't do it, they show me by how they react to me. Whether it's a door slam or an eye roll or a shutdown, they're saying, "You're not showing up in a way that is supporting me. I can't talk to you." I'm like, "Come on, I'm sorry I interrupted. Tell me!" "Too late! Get away from me!"

So these new videos I'm doing touch my heart, because



I've been doing all this work on myself, and then I was thinking outside myself, "Who am I going to partner with? I have all this information. I have a friend who is friends with Oprah Winfrey. Can she introduce me?" No, it became very clear it was not going to be through that channel. And then there was something else. "Is this going to be it?" No. And then right before New Year's Eve we went to San Diego for Christmas break. It had been raining, and it was sunny one day. I got up, and everyone was still asleep, and I said, "I'm going for a fast walk on the beach, and then I'm going to meditate, and then I'll be so excited!" I went to Audible, and it said, "You have a free book." It was a book by Gabrielle Bernstein. She does spiritual books like *Spirit Junkie* or *The Universe Has Your Back*. I don't like her, because she's doing what I think I should be doing, and she makes me mad because she's really skinny. I'm like, "I'm not listening to her."

She kept popping back up, and I said, "Forget it. I'm going to go get something else." So I closed that app and got something else. She popped up there, too. I believe signs like that are not an accident.

Martirosyan: They're based on your searches!

Koechner: *(laughs)* She came up on something that I hadn't used before, and then another one came up. I said, "I'll listen to her." I heard her say, "Are you done with holding yourself back? Are you done not being? Are you ready to—?" I said, "Yeah, I am ready! Yes, I am done! I am ready to step into my greatness." I'm fast-walking and it ends, and I do a Facebook live. I had met this guy at a conference in Aspen called "Lead With Love," which my friend started. I was one of the speakers. They had dinners every night. There was a group going that I didn't know well. I went up to grab a drink and an appetizer, and this man sat next to me, and we had a conversation. We were laughing a lot. He got my business card and wanted to keep in touch, so he reached out to me. He said, "Hey, I'm doing this app. Check it out." He sent me the app, and I got on and I didn't get that deep into it because my kids were probably yelling at me or I was yelling at them.

And then he emailed me and said, "Would you be interested in being the parenting expert for this app?" His name is Poonacha Machaiah. He partnered with Deepak Chopra to create a global well-being app called Jiyo, and it's amazing. He asked me to be the parenting expert. He had reached out to me, and I kept blowing his emails off. I don't know why. I guess I still had a fear inside of my body. That day on the beach when I did my Facebook live and I declared, "I'm no longer holding myself back," and I did all these things, I thought, "I'm texting that guy back." I texted and said, "I'm ready to work." He said, "Great! Let's talk Tuesday." And I started working with them. I shot a bunch of videos for their parenting portion. My videos are there and now I'm creating an online parenting course for them to promote with me.

Cooper: And you have kids, too!

Koechner: And I have kids! That's what he said to me: "We had, like, a hundred parenting experts come to us. We had authors, speakers, all of these people, but I don't find very many people who are actually living what they're teaching. You're living it. You're doing the work, and you're in it." So when you said, "How do you decipher between getting caught up and being human and trying to stay on track with your gifts?" It is allowing both of them to exist and honoring both of them and realizing, "I'm only here to be human, because this is never changing. This is going back where it came from, but I am here to be all of this. I'm here to be vulnerable. I'm here to mess up. I'm here to fly and succeed. I'm here to be happy, to be full and to shed all the old stories and thoughts that were my blocks before, my little ball and chain that I snipped, in order to do what I'm supposed to do."

Cooper: Good stuff.

Martirosyan: Are you going to continue with stand-up?

Koechner: Yes. I started the stand-up about six months ago. I went to see my husband perform in Burbank. I went into the greenroom, and he wasn't there, so I started talking to the two women who were in there. And one of them asked, "Do you do stand-up?" And she said, "You should." And I said, "Yes, I should!" And she said, "If you ever do, you have a spot here." I didn't know who she was, but I found out she was the owner. She sat near me during the show, and a woman opened for my husband, and she was so funny. I said, "That girl's so funny." She said, "She teaches a class. You should take it." So I signed up and started taking that class, and then I started writing stand-up. I went out to the first place. You had to do an open mic between each class. I went to the first one, and they said, "Hey, would you come back and do a show?" I was like, "Sure." The next one, "Would you come back and do a show?" "Sure." And my teacher said, "Make sure you don't do any shows until you're done with the class." I was like, "Too late!"

(laughter)

I love it. I feel at home. I love being on stage. I love telling the jokes. The only thing is—

Cooper: —nobody's laughing?

(laughter)

Koechner: That's the hitch. I love that everyone has to sit and listen to me. Here, in my house, everyone runs. There they can't move. They paid for it. They're actually listening.

Martirosyan: And they have to get a two-drink minimum.





Koechner: Yes! They've got a buzz, and they're stuck, and they've paid. I love it.

Cooper: Your backyard looks like a playground.

Koechner: Doesn't it? I have little kidville. My heart shifted when I got involved with Shane's Inspiration and their accessible playgrounds. My fifth child, we had frozen embryos —

Cooper: Oh, we already had lunch, thanks!

Koechner: *(laughs)* My fifth child was frozen for 10 years. We thawed out the four frozen embryos. One survived, and we put that child into a surrogate. They said during the pregnancy that something was wrong with her, that she had an infectious disease. We went to an infectious disease doctor who said, "She does have an infectious disease, but you need to see a heart doctor. Her heart's messed up." So we go to a heart doctor, and he said, "This is wrong, and this is wrong, but that's the least of your problems. You need to go to a skeletal doctor." The skeletal doctor said, "You have a child — ." It kept getting worse. The doctor said, "Your baby's brain had stopped growing. The head is basically a balloon, and it grows around the brain. If your baby survives, she'll be in a wheelchair. She'll have to have open-heart surgery. She'll atrophy, and you'll have to move her limbs." This was the picture they were painting.

I chose my surrogate eight years prior because she was the only surrogate who would never terminate under any circumstance. In our contract, we didn't put anything in it about terminating, because I wouldn't either. So we get to this thing, and all of the doctors are saying, "The

biggest gift you can give this child is termination, instead of making her struggle and all the pain she's going to go through and you can't even comfort her." And I remember coming to my husband, and I had a pastor over to pray about it, and he said, "The technology is a gift in so many ways. To have all of this information." Basically he was saying, "Go for it." My nanny at the time, who was married to Jesus, said, "Why would you do that to her? Let her go?" I remember thinking my whole life, "I would never under any circumstance consider abortion." And they were saying things like, "This isn't about you. This is about all of your children and what you already have."

We ended up, of course, not terminating, and we made the decision not to. We were just moving forward. The doctor was like, "Wait a second, your baby's brain is at two percent. It's never been at anything." And then the next time she said, "Her fingers are — the exogamic bowel's gone." Everything that was wrong was starting to disappear, and she was born healthy.

The doctor said, "This has been obsessing, because I'm the one who writes the medical journals. All I can say is that your baby had that infectious disease so badly that she shut down and waited for it to pass, and now she's catching back up. That's the only medical explanation I can find. I found a case 50 years ago, and that child was born blind." I said, "She's not going to be born blind." As soon as I heard about my baby, and as soon as we decided to go through with it, I started reaching out to people to find doctors and specialists. We had a great wheelchair. I wanted to find the things that would help. Somebody introduced me to Marci and said, "You need to talk to her, she has great resources." So I talked to



her, and she said, “I’ll put you in touch with great doctors.” All of a sudden I had a community, and it was doable. It went from heartache and devastation to, “People will rally around me and help me. I can do it with whatever we’re given.”

My gift from her was that she was born healthy. She was not blind. She’s a little rambunctious and out of control, but other than that, my gift was to release my judgment on abortion. I released all these judgments that I was raised with and that my dad had said about people and things. I released all of them except that thought. He brought me to my knees by realizing that it was a viable option for us. This allowed me to shed the judgment and to know that everyone is doing the best they can with where they are. My way is not the right way.

Martirosyan: Wow! What a wonderful outcome.

Koechner: Yeah! I’ll take it! And we pause every once in a while, and my husband and I will lock eyes and look at Eve and remember. It’s the present of gratitude.

Cooper: But how cool that you were prepping her for life and planning to integrate her into society, which is not always so open and accessible. But you were getting her prepped for the best she could—

Koechner: —prepped for success, that’s right.

Cooper: That was so cool to think, “We’re going to get her the best wheelchair.”

Koechner: I remember the moment we decided not to terminate, and we were bawling, because it was all so emotional. My husband said, “Her name’s Eve.” I said, “That’s never been on any of our lists. What are you talking about?” He said [*near tears*], “That was the first from God, the first woman. This is our first.” I was like, “Eve’s going to have the best damn wheelchair. It’s going to be over there. It’s gonna be bedazzled!” And from that moment, it shifted. I went from devastation and heartache to f#cking—excuse me!—”Let’s go!”

Cooper: Put a dollar into the jar.

Koechner: I didn’t say that, he did. (*laughs*) Would you quit throwing me cuss words? It was sweet. And then one time I remember I was in the car with Charlie and Margo, six or seven years ago, and they were in the back seat, and I was driving, and I said, “Hey, guys, I want to tell you something about Eve. She might be in a wheelchair.” [*near tears*] And my son said, “That’s going to be really hard for her.” And my daughter said, “Oh, I can’t wait to help her!” And I was just like, “It’s going to be OK! It’s going to be what it is.”

Martirosyan: Yeah.

Koechner: I put mascara on too.

Cooper: Me too.

Koechner: I’m going to grab a Kleenex for her because she’s all blubbery. I just think life gives us such wonderful obstacles and heartaches and struggles to liberate us and to learn from. ■ **ABILITY**

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Charlotte RAE

Part II

On a beautiful Los Angeles afternoon in a high-rise overlooking the city, contributing writers Geri Jewell and David Zimmerman had a wonderful visit with the legendary actress Charlotte Rae. Both Jewell and Rae starred in the 80s sitcom *The Facts of Life*. They were joined by publicist and friend, B. Harlan Boll, for a loving get-together of memories with a woman who became a light for any kid that was alone and who needed a mom.

Zimmerman: You did the film, Ricki and the Flash, with Meryl Streep. Did you enjoy that?

Rae: Oh, yes. She was very kind to me. I was very nervous. I felt so comfortable, because she made you feel comfortable. I said, "You know, I'm scared shitless because I have this little scene with you, just you and me." And she said, "Oh, I know how you feel, because I was in a movie that this actor directed, and he asked me to do this last little bit in the last scene of the picture, and everybody knew everybody. And I was coming in at



the last minute, and I made a mistake, and I could see them all looking at each other, and that made me feel worse. And then he did it again, and I made another mistake. So I know exactly how you feel.” She couldn’t have been warmer or more adorable. That made me feel completely relaxed.

Zimmerman: When I mention Carl Reiner...

Rae: I love Carl. He used to come over for dinner with Estelle, all the time. And what a wonderful raconteur. And then she died, and he used to come a couple of times. But now he doesn’t want to go out very much. He had an apartment in New York. I think he doesn’t go any more. But the thing that keeps him alive is writing. He writes one book after another book after another book.

Boll: He just finished one. He and Mel Brooks have become kind of a couple. It’s very funny to watch.

Rae: I saw Annie Reiner sing. She’s wonderful. I went to see her at the Catalina Bar and Grill. She’s a psychoanalyst and a writer, but she sings and loves singing. She sings Leonard Cohen and all sorts of songs. She really enjoys it. All of her father and mother’s friends, Mel Brooks and everybody, they all show up.

Zimmerman: Yes.

Rae: The opera singer.

Zimmerman: Oh, I loved that! And then right after that I saw the clip of you in Hair, dancing on the table!

Rae: I worked the Village Vanguard and the Blue Angel, like Orson Bean did, and I would do a takeoff on the Milwaukee Garden Club ladies. I would do songs that Sheldon Harnick wrote. Sheldon went to Northwestern, and he wrote a little number that I sang in the musical there. When I went to New York, I kept looking for people to write special music, you know. And they weren’t half as good as he was. I went to the Broadway musicals, and I called him and said, “You really should come to New York.” He was playing the fiddle. He was from music school. He had written this wonderful number. It was during the war. I was a factory worker in the defense plant. It was called, “I’ve Got This Gotta Go Home Alone Tonight Blues.” Wearing overalls and everything. I said, “Come on, why don’t you come to New York? You’re more talented than most of the people here.” He said, “No, I’ll just stay here and play my fiddle.”

And then I saw *Finian’s Rainbow*, and said, “Oh, my God, I’m going to send this album to him.” I said, “You’re made of the same stuff. Come to New York.” He listened to it, and said, “That’s what I want to do with my life!” He finally came to New York. And still to this day he mentions that I sent him the album that focused him on what he wanted to do with his life. So there you are.



Rae with Meryl Streep and Kevin Kline during filming of *Ricki and the Flash*

Jewell: You know what surprises me, and I didn't know this until I did the TV Land Awards with you, was your relationship with Cloris Leachman and the fact that you were roommates.

She took your place on *The Facts of Life*. I'm not religious, but I'm very, very spiritual, and I don't believe in any accidents. I believe that things happen for a reason. And I found it fascinating that you had this history with her. How do you feel about that, that you were connected in some way?

Rae: It was just amazing, because I was busy, busy, busy. We were roommates, and we had a great time together, but then we—

Jewell: —drifted apart?

Rae: Yeah. I wasn't busy thinking of who would replace me. And she was not part of my life at that time. But we had a mutual friend, Jan McCrady, and Jan kept connected to me and very connected to Cloris. I told her I was leaving the show, so Jan told her, and Cloris got her agent on it, and got cast.

Zimmerman: When I was listening to the book, one of my favorite stories was when you were—

Jewell: No! (laughs)

Zimmerman: It was when you were—is that OK? (laughs) I just loved it, about the orgasm. I couldn't stop laughing.

Rae: I thought it was kind of sweet to share.

Zimmerman: It was such a human story, and that's what I loved about your book. I identified with so much of it, like I said before, too, about the Jewish side of it, for me. It's a story for everyone. You were so open with it. I got something, and since you had that little sweet story, I have a little sweet something for you.

Rae: My goodness, the flowers are enough!

Zimmerman: I have one for you and one for Geri! It's a fun little gift. I hope it's OK! (laughs) Geri said you'd like it.

Rae: Oh, thank you, thank you!

Zimmerman: You're welcome!

Jewell: Oh, it's a chocolate woman! A chocolate diva! Cute, David.

Rae: And the perfect chocolate man! (laughs) I like it. I like it.

Jewell: I'd like to ask you about the fact that you overcame cancer. I think we need to talk about that, because this is ABILITY Magazine, and you are a survivor. You're amazing.

Rae: I'm not amazing. I'm just so incredibly grateful. It's a miracle they discovered it in time, because they find pancreatic cancer when it's stage four or worse, and then it's inoperable. My mother, my older sister Beverly, and my uncle all died of pancreatic cancer—it is genetic. In fact, just recently we lost the wonderful actor, John Hurt, who played *The Elephant Man*.



Zimmerman: And Patrick Swayze.

Rae: And because I was a celebrity in my hometown, Milwaukee, this doctor, who had taken care of my sister and my mother, asked, “Would you come to Milwaukee and talk to people about getting a checkup if they have this history in their family?” And I said, “Sure, I’ll be glad to.” After doing radio, television and other PSAs, I asked, “Could I get a checkup myself? And he said, “Sure.” And I said, “What about my younger sister Mimi? Could you do her?” “Yes, we’ll do her.” We had to pay, of course, with our Medicare, but it was the test that saved my life!

Zimmerman: Did they put a tube down your throat?

Rae: Yes, down to my pancreas, and they did find something—they were cysts. So the next day, they did it again, and they said, “No, it’s not cancer. It’s benign. Just get it checked in six months in LA, and we’ll give you a place to go.” Then six months later in LA, I went to this doctor and I didn’t like him because he kept saying, “Mrs. Garrett,” and I thought, “I don’t like him.” Stupid, stupid. So I thought I’d wait six months—

Zimmerman: You mean another six months?

Rae: Yes, and go back to Milwaukee a year later. When I got there, they checked it, and they kept me hanging around for hours and hours. Everyone was leaving their offices, and I was still there, and I had pancreatic cancer, either third or fourth stage. They talked to me and said, “Do you want to have it taken care of here or in LA?” And this is very important for people to know. I want to give the exact name of the organization: Pancreatic Cancer Action Network (PCAN). I have been in touch with this organization, and they were very, very helpful. I said, “I need to do some research. I have to find a surgeon and determine the best course of action. I called PCAN, and they said, “We won’t recommend a doctor, but we’ll give you the name of doctors we know who have done the most surgery.”

Zimmerman: Did you have symptoms?

Rae: None. That’s the problem. So anyway, I called and did research. I guess I auditioned them for the part. I went to St. John’s and I met a wonderful doctor there, and he asked for the résumé of what went on in Milwaukee. They sent it to him, and he said, “You’re operable.” With that, I went to UCLA, and I met Dr. Howard Albert Reber. They did the surgery right away. It was not the head of the cancer, it was the tail of advanced cancer. They cut it off and they took out the spleen, and I had six months of chemo.

Anyway, a friend of mine who is a survivor of esophageal cancer, she and her husband supported me. I had a positive attitude. I’d heard that Marilyn Horne, the opera singer, was a survivor of pancreatic cancer, so I

asked Tyne Daly, who’s a friend of mine, if Marilyn would speak to me. And Tyne connected me with her. I said, “I’m scared about the operation.” She said, “Of course you are. Why don’t you do what I did? I went to a wonderful hypnotist, Cheryl O’Neil, and she helped me imagine good stuff.”

Jewell: Oh, I love that!

Rae: So I went to Cheryl, and she made some recordings. By the time I went in, I was in such good shape. I was ready for the operation. I came out of it saying, “I’m still alive!” They were wonderful. I did the chemo, and I kept imaging all sorts of things they were getting rid of, bad cells and all that, and I’m here today. It’s a miracle.

Zimmerman: The power of the mind is so important.

Rae: And spirituality.

Jewell: Yes, absolutely. Let go of all negativity from our consciousness.

Rae: And it’s so important anyway, because life is tough. Let’s face it. But it’s also beautiful. We all have to deal with it one day at a time. With our political division at hand and stuff like that, we have to constantly reaffirm our positivity. We take action when we can, but in the meantime, we must savor the day, absolutely savor the day, and be grateful for our lives.

Jewell: I think I know a good friend of yours, Rosemary Forsyth. We’ve become very close.

Rae: Oh, I love Rosemary! She’s a lovely lady!

Jewell: Indeed, she is! I’m so blessed to have become friends with her. She’s a wonderful human being. She always speaks so highly of you.

Rae: That’s nice. I saw her at somebody’s birthday party last Friday. She picked me up, and we went.

Jewell: What a small world! I want to share something with you. I think it was three years ago that someone contacted me on Facebook and said, “I have a scrapbook that belongs to you, and I’d like to return it.” I wrote him back, “No, you don’t. I never had a scrapbook.” “Yes, you did, and it’s yours,” the person wrote. “Well, then, upload photos,” I said. He uploaded cards that I had saved from you, greeting cards and Christmas cards and notes and a telegram from Brandon Tartikoff, from Norman Lear, my first episode of Facts, TV Guide, and I said, “How in the world—?” Because I had mentally blocked that I had ever even had a scrapbook. And I said, “How did you get it into your hands?” He was in a celebrity memorabilia shop that he ran in Las Vegas, and he said about 30 years ago, a woman came in with several things, and that’s one of the things she gave him. It was stolen from someone who was in my





life. The reason I'm sharing this with you is because I saved every note you ever wrote to me. I was looking through it like a little kid. "Oh, my God! Oh, my God!" I had gone through so much pain later in the '80s that I mentally blocked so much of the good, so much of the joy, and it was handed to me 30 years later. I wanted you to know that.

Rae: Oh!

Jewell: I saved everything!

Zimmerman: I have to say, she talks about you a lot and about the joy you have brought her.

Rae: I'm just in awe of her. I don't know how you do it.

Jewell: Same as you do. I think you and I believe in God, believe in a higher power, in the Spirit, and that's what keeps me going. I try not to get into the earthly stuff. I know that's a part of it, but my heart and soul and spirit are so far from that, and that's what allowed me to be a survivor. And I'm a survivor, and you know that.

Rae: Oh, for sure! Let's have a grape. What's that famous thing that May West said? "Peel me a grape."
Boll: I thought it was, "Come up and see me some time."

Zimmerman: So you can come up and peel me a grape. You can do both!

Jewell: "Never give a sucker an even break?"

(laughter)

Rae: Once I forgot—I was pregnant, and the director had rehearsed us and rehearsed us. Joe Papp was the assistant director at the time. He was not the producer of "Shakespeare in the Park" and all that, but this was in New York. We kept running through this thing called Appointment with adventure so many times, and I thought we were finished, and I was going to go home and take a nap. I said goodbye to everybody, including Joe, and gave everyone a hug, and went out of the studio on to Fifth Avenue near Harlem. I hailed a cab and was just about to get in the cab, when Joe Papp said, "There's one more scene." So they rushed me in, ripped off my clothes, threw something on me, and poor Sheila Bond, she was in the room looking for me. She didn't know what to—she was looking in closets and drawers. Finally, I came in and we finished. And then Bea Lillie and Reginald Gardiner—they were on *The Ed Sullivan Show*. I'll never forget this. They did this sketch, and he had to go behind the screen to change his clothes and come out again, and he came out again, and his fly was open.

Jewell: (laughs) Oh, my God!

Rae: It was before they taped shows. And all of a sudden they saw this arm go out and zip him up!

(laughter)

And Milton Berle, he used to get very nervous. I remember when we were in Florida with *The Jackie Gleason Show*. I was so nervous about doing the show early on that I got psoriasis from nerves. They flew me down to Florida, and he didn't rehearse. He came on and did it



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live without rehearsing. That's the way he felt comfortable. But Milton Berle was nervous, and he had to do this thing with the diners on the show, they had to lift him and do something. He was very nervous and was screaming and telling them how to do it, and finally they said, "Look, if you're gonna keep doing this, we ain't lifting you. You better shape up, 'cause we're not gonna do it. We don't like the way you're talkin' to us." He had to behave. He got so nervous. But lots of television was not taped. Steve Allen was so wonderful.

Jewell: Oh, I love Steve!

Rae: I was a big fan. He gave me about 12 books he wrote.

Jewell: I remember I became very close to Steve Allen, Jr. We were in Canada and Steve, Sr. was there, and he invited us to dinner. We ate at a Chinese restaurant. All of a sudden, Steve started laughing and nobody could understand what the joke was. And Steve, Jr., said, "Dad, what's so funny?" And he said, "I just realized something. If Geri was born in China, she'd be anorexic! She can't use chopsticks!" And he couldn't stop laughing.

Rae: Steve Allen?

Jewell: Yes! How does someone eat in China with cerebral palsy?

Zimmerman: It would fly into somebody else's mouth.

(laughter)

Boll: There's a generation out there that doesn't think of you as Mrs. Garrett as much as they think of you as Molly, the Mail Carrier, from *Sesame Street*.

Rae: That was early television. What an honor, to be on that show, informing kids about learning and about music and everything. I loved it. It was a hard time for me, though. That was when I was with my older son, and we were having trouble trying to figure out what to do to make him better. We finally found out that he was autistic, schizophrenic and also developmentally disabled. It was a very hard time.

Zimmerman: I did love your story about when they first told you...

Rae: Yes, I was pregnant with Larry. John and I went to this doctor for a diagnosis of Andy, because I felt something was wrong, but I didn't know what. And he was doing things with him, and he said, "Come back after you have your baby." So I came back after Larry was born. I think John was at work. And he told me that he was autistic, and I thought, "Oh, thank God!" I almost got down on my knees.

(laughter)

Rae: "He's artistic! That's all! That's the only thing that's the matter with him! He's just very creative!" And





Rae swinging on a tire as Molly the Mail Carrier on *Sesame Street*



Rae on *Lil Abner*

he said, “No, I said autistic. He has autism.” I never had heard that word in my life. Now you hear it all the time.

Jewell: I went to school with maybe one or two kids who had autism. But that was then. It’s not like it is today. I’m surprised he was diagnosed. He was my age, wasn’t he?

Rae: Yeah.

Jewell: That must have been in the ‘50s or early ‘60s?

Rae: My older boy is 58, and he’s three years younger than Andy would have been. Andy was three years older. He’d be 61.

They told me to wait another year or so, and if by the time he’s six, if he doesn’t improve, institutionalize him. I said, “What? I’m not gonna put my child in an institution.” That was the beginning of our searching, trying, and we did. We tried. We did the best we could. We really did. He got into a school at one point that a minister found on 12th Street and Fifth Avenue, and we paid \$2,000 a year, which was a lot of money in those days. But transport was a problem. I went to a town hall meeting with the mayor, which was televised. I’d given up work because I wanted to do everything for Andy and for Larry. We made posters, and we marched in front of the building about transport for our kids.

Jewell: Such commitment and love!

Rae: I went into the meeting and said, “I am the mother

of a handicapped child who is developmentally disabled.” And I explained all that we would want, and that we would pay for the education, because there were no opportunities in the schools at that time. No classes then.

Jewell: Especially on the East Coast, believe it or not. The East Coast was way behind the West Coast.

Rae: So I said, “We need transport so we can get our kids to and from school.” And Mayor Wagner said, “Aren’t you Charlotte Rae?” I said yes. He said, “I’ve seen you on *Car 54*. Yes, we will look into that, we certainly will.” And I thought, “Here I am, trying not to work. I’m just devoting myself to Andy, and because they know and have seen me on television, they’re helping us.” And his therapist, whom we found later on, said, “You should by all means work. It’ll be better for him and better for you to be part of something you love.”

Jewell: She was right. And I’m so glad you did.

Rae: Yeah, me, too.

Zimmerman: Thank you so much Charlotte. What a wonderful afternoon.

Rae: Thank you for my flowers and the candy! ■ **ABILITY**

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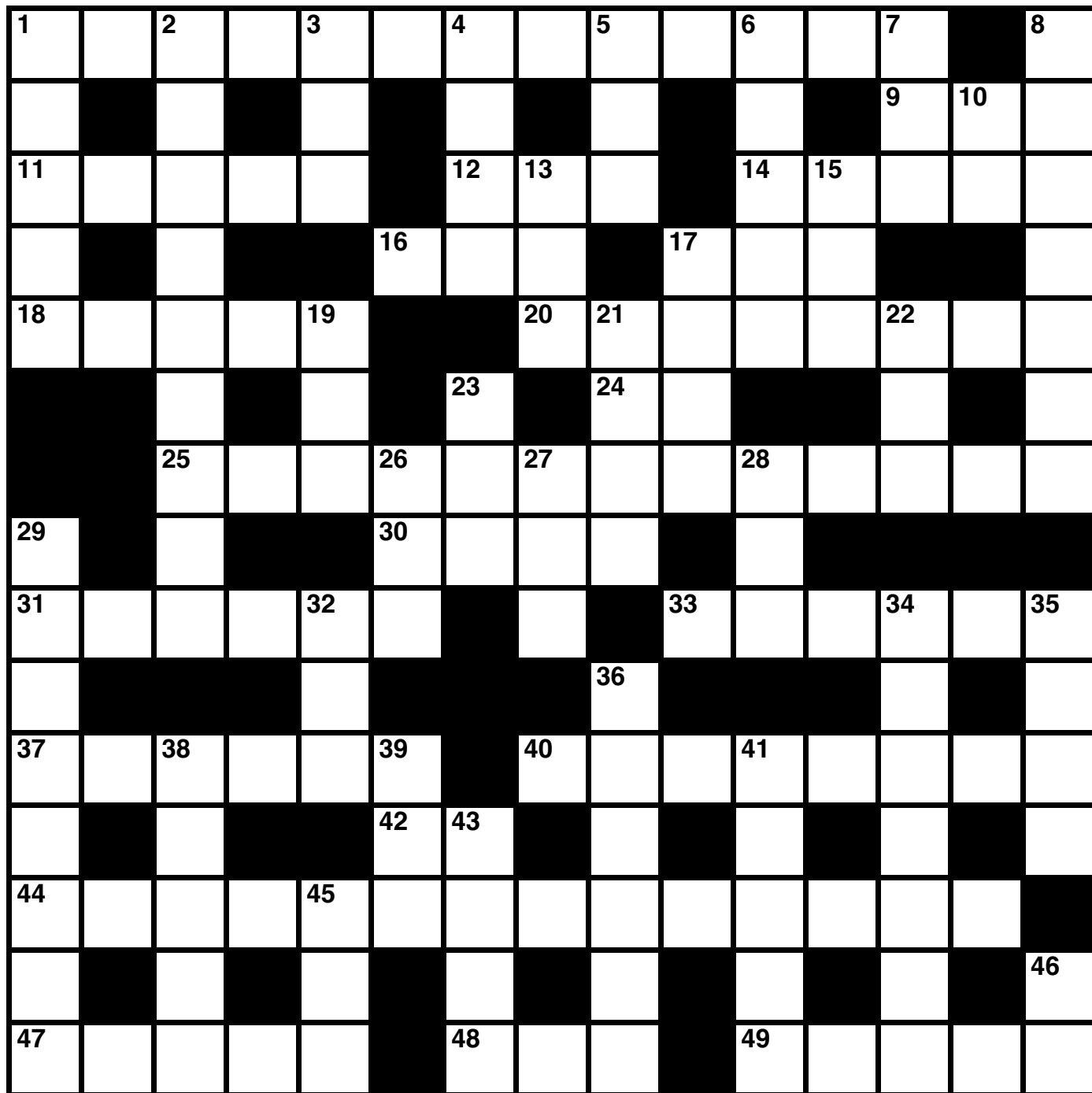
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ACROSS

1. "The Office" star who works with Shane's Inspiration, 2 words
9. "___ Day Now" (Bob Dylan hit)
11. TV series " Fargo" star who has cerebral palsy, ___ Dobrescu
12. Michele of "Glee"
14. Opinions
16. Chinese food no-no
17. Tom Harkin's position for many years, abbr.
18. ___ Hirsch, star of "The Girl Next Door," supporter of the UNHCR, a charity for protecting refugees
20. Gospel protest song, "We Shall ___"
24. ___ Capitan
25. Actress in a wheelchair who starred in "The Glass Menagerie"
30. Seagoing, abbr.
31. Writer of "The Executioner's song"- ___ Mailer
33. Has faith in
37. Longs for
40. "Two and a Half Men" star who takes kids to Shane's Inspiration, 2 words
42. Big name in the Indy 500, ___ Foyt
44. Actions to meet special needs for people with autism at their jobs
47. Discover
48. Actor Tommy ___ Jones
49. Range-roaming ruminant

DOWN

1. Canadian rapper supports THORN, campaign to abolish slavery
2. Star "At First Sight" about blind boy who regains sight, 2 words
3. Actor Aykroyd
4. Painter's medium
5. Career with numbers, abbr.
6. "When hell freezes over!"
7. "Facts of Life" actress Pancreatic Cancer Network, Charlotte
8. Dish sometimes served "on the half-shell"
10. Compass point
13. "I" problem
15. Corp. abbreviation
17. Narcissist's love
19. Conclude
21. Rant and rave
22. Row boat propeller
23. Old Glory's country
26. Rustic lodging
27. No longer "with-it"
28. Corn serving
29. Actor in a leg brace Broadway's "Groundhog Day," 2 words
32. Columnist Landers
34. "Never give up" and "Shovel your today's challenges to tomorrow's freedom" for example
35. "You betcha!"
36. Comfort
38. Ghana's capital
39. "The Big Smooth", first name
41. "___ Every Mountain" from "The Sound of Music"
43. "Glass Houses" singer, Billy
45. "___ in Black" comedy film
46. Fashionable

answers on page 62

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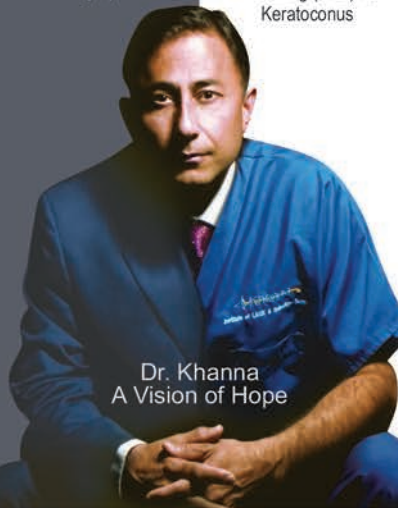
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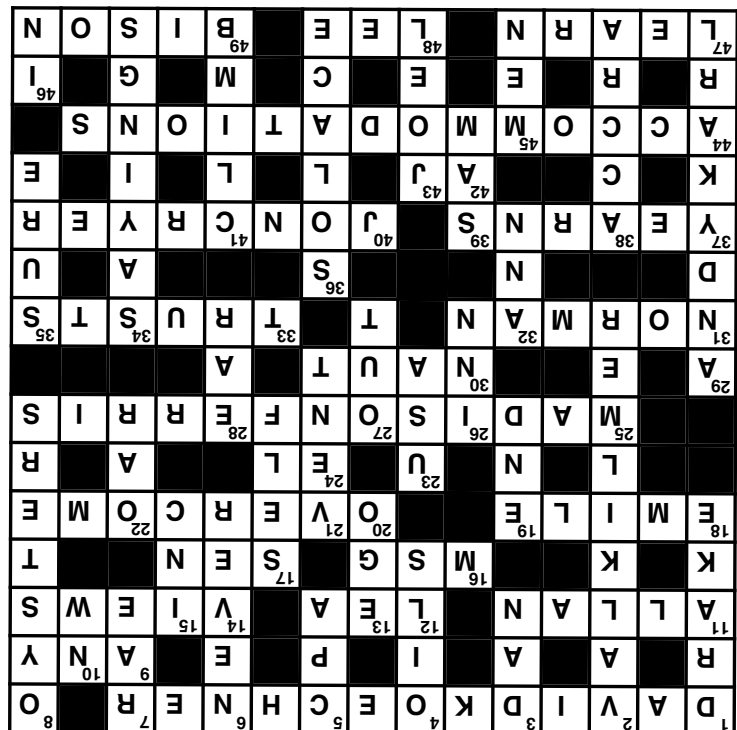
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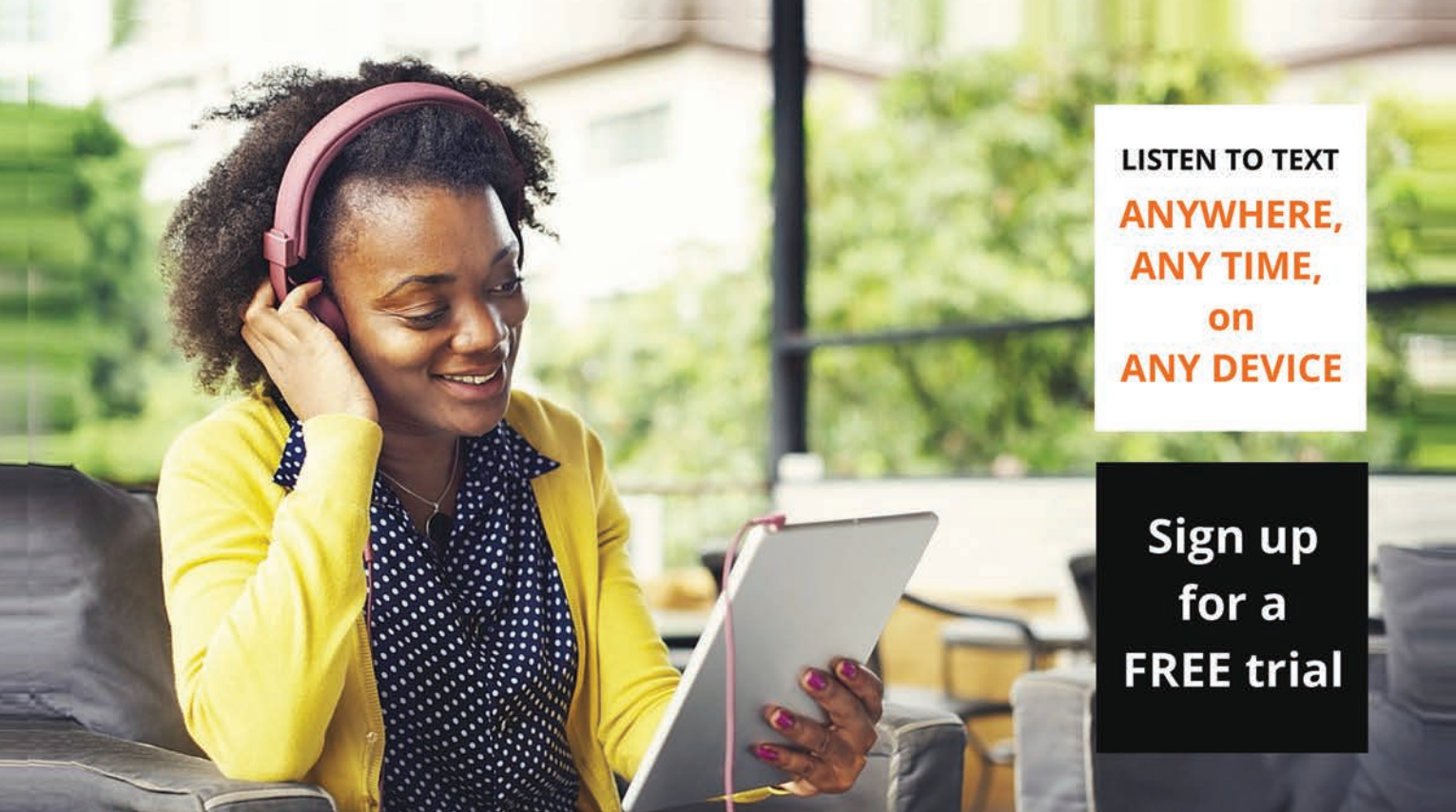
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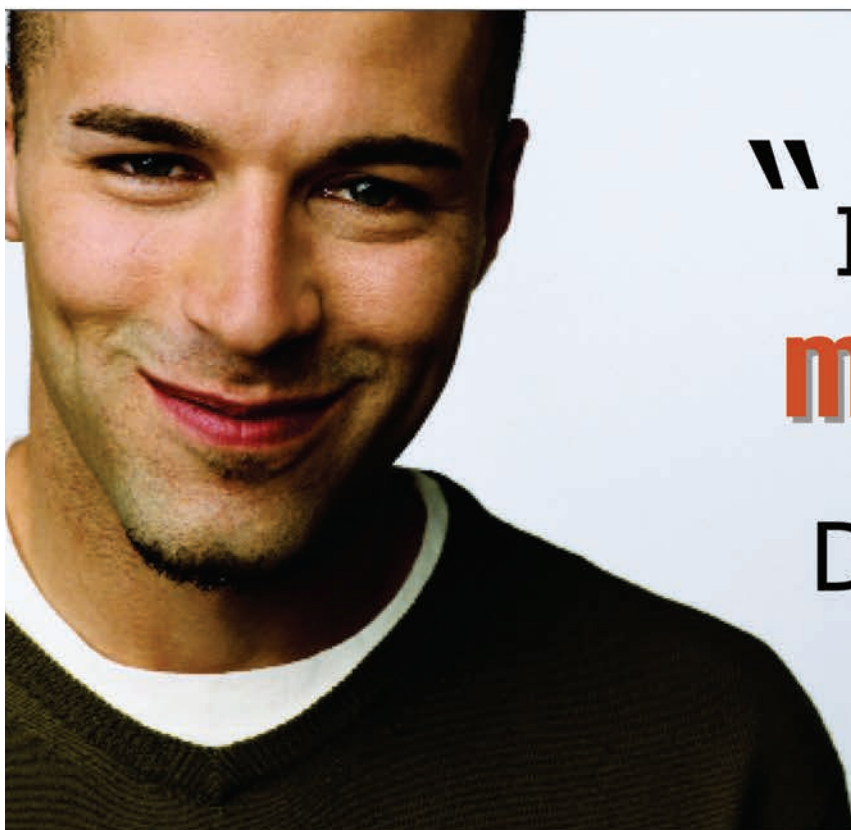
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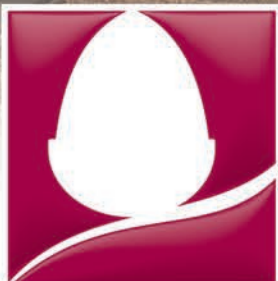
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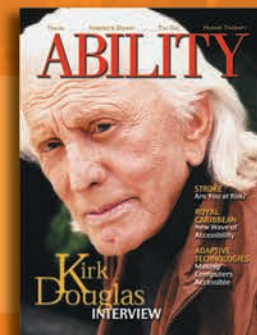
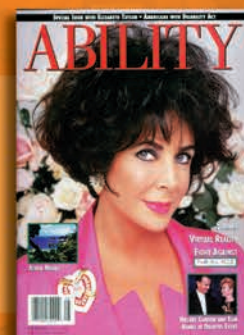
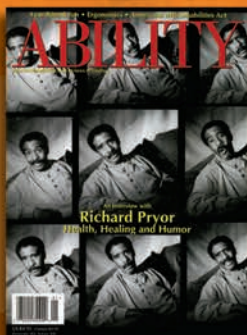
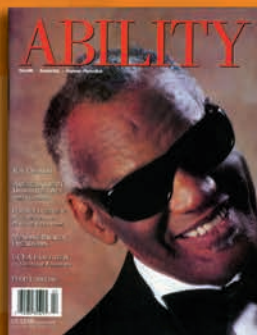
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