GERI JEWELL ASHLEY FIOLEK LONG HAUL PAUL JEFF CHARLEBOIS: HUMOR THERAPY BOOK EXCERPT: EXPECT A MIRACLE CROSSWORD/ EVENTS/CONFERENCES

ABILITY



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THIRST PROJECT



HALF MAN
STINKY TOFU

+

OrCam See It Now
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Editorial pages have VOICEYE codes for a new level of content access - *Enjoy*

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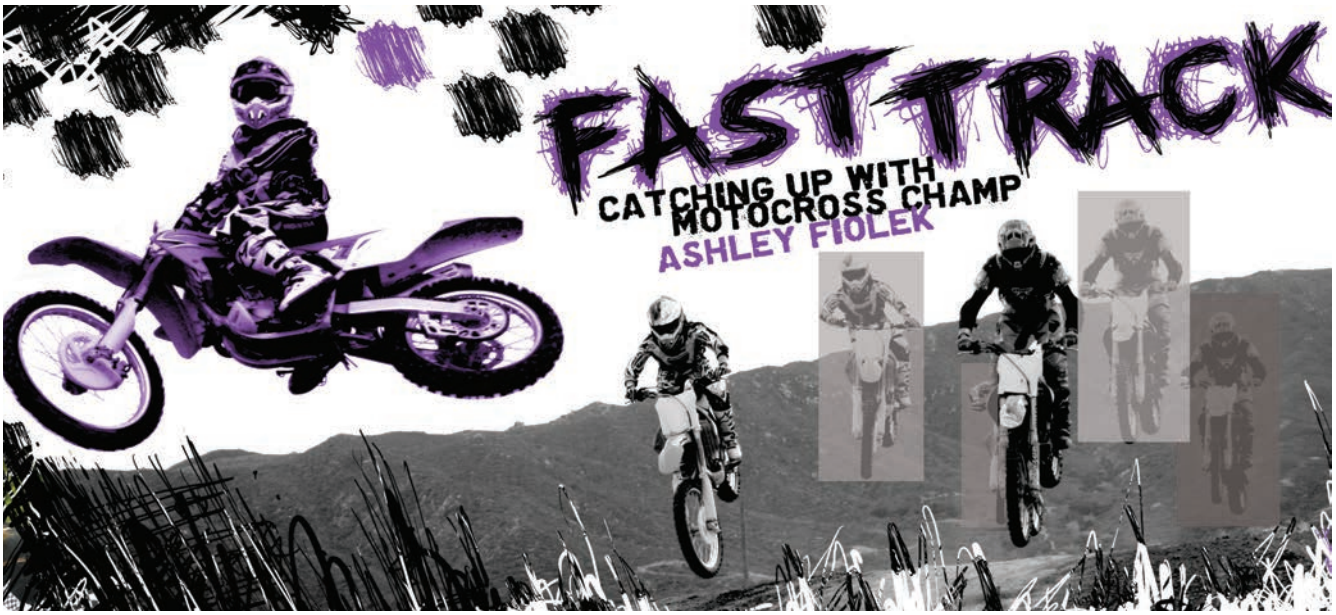
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- For High Contrast modes, under the "Setting" selection, press the button with four colored squares.
- To access the 58 Language Translator, press your phone's "Option" button, and select "Translate". To translate into another language, select the language button to the right, choose your language of preference, then hit the "Translate" button to the right of the selected language.





This one's for the girls.

In recent months, I've had a fun time teaching at AFMX schools in Georgia and Florida, which has kept me flying back and forth. Then my really awesome sponsors invited me to two different women's ride days!

A huge thanks to the people at Fox for their "Babe's Ride Out 2" event. It was incredible and only ladies that ride moto could join. We had a great adventure on a bunch of different trails in Gorman, CA, northwest of Los Angeles. It was a good experience because it was just a bunch of girls who wanted to have fun.

I got to ride with some of my friends, as well as with some girls that I met at the event. We camped there, too. There were raffles, pit-bike races, delicious BBQ, and karaoke. Lucky for everyone there, I did *not* sing!

The weather was super windy but no one seemed to mind, we were all having too good of a time, enjoying everyone's company, and basking in the love of dirt bikes.



Recently, I got back from the second cool event, which took place in the Pacific Northwest. It was sponsored by Husqvarna, which threw a girls' ride event in Washougal, WA—30 minutes west of Portland, OR. During my racing days, Washougal had one of my favorite tracks, so I was really pumped to go there. My best friend, Ash, was my plus one, and my agent, Miki, drove up to meet us as she only lives four hours away. We all made a number of new friends.



As you might imagine by the name, it was for women riders only, which also included newbies who wanted to learn how to ride. It was amazing to me to see all the girls and how motivated they were. They were riding great, ripping up those trails in the woods.

Husqvarna is thinking of throwing a similar event in Colorado in the next few months. I will definitely be going again and, if any girls out there reading this want to join us, make sure you sign up when you see it advertised! It's great to see people in the industry sponsoring girls-only events. ■ ABILITY



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The year was 1948. I had been a cop most of my life until I was asked to turn in my badge. They just didn't like the way that I did things… which way? My way. Good cops would spend hours, or days, following the rules to get vital information on crimes. Me, I'd slap someone around for a good ten minutes and have all the information that I needed to make an arrest. It wasn't right, but in my eyes, it wasn't wrong. It was the way that I rolled. The way I bounced. The way I got things done. They didn't like it, and I didn't much like them, so I opted out of the blue uniform and went out on my own to become a private dick. Which was not so smart, I barely made enough money for a Dagwood sandwich and a bottle of gin.

continued from Chris Wood issue

The next morning, Kitty raced into my office. She seemed upset, unsettled, frazzled, ruffled, and disturbed. She had received an anonymous phone call, sometime in the night and it was from our old friend, the perv, wanting to return the pictures to her. The only caveat was that she pays him five thousand dollars. I guess nothing in this world is free. She said that if she didn't meet with him tonight, with the money, that he would send the pictures all over town. She'd be destroyed, humiliated, disgraced, and embarrassed. I couldn't let that happen. She had grown on me, like a wart, and I wasn't about to get her burned off.

I stopped in at the bank to see an old fling. Bitsy was a banker who I could bank on. A teller that wouldn't tell anything if asked any questions. She'd back me by fronting the money that I need for the night. Why not? I'd been good to her. She was part of my past, but we never had a future, only good times. She was a chubby, big, thing with a body shaped like Dodger Stadium—but that's just a ballpark figure. Back in the day, I used to stop by, after closing hours, to see her and make a deposit—sometimes I even had some money on me. We would often slink away into the backroom and have a tryst in one of the vaults. She believed in safe sex. I got the overnight loan from her I was looking for and she threw in a smile.

It was close to midnight as I stood in the park. I was cautious, on guard, and maybe a little scared. Rhythmic footsteps approached me from behind. I spun around and there he was. No one said a word. We slowly exchanged envelopes and while still watching each other, we both took a quick gander at the contents of our envelopes. "Hey, what's the big idea?" he questioned. "These aren't Kitty's pictures." Before I could answer, a shot rang out and the poor sap collapsed in front of me. I dove behind a tree as more shots rang out, each one with my name on it. I never liked chitchat, so I wasn't about to wait around to ask the many questions that were swimming in my mind.

I scurried away like a raccoon caught in a dumpster, and sunk into the darkness.

I needed some time to think, so I meandered into my favorite watering hole, The Tipsy Turnip. I cozied up to the bar. I was feeling low, so I ordered a Highball. I just handed some lug in the park five grand, just to have him hand me five grand. The whole thing stank like a three-day-old halibut, rotting in a musty sewer. That guy wasn't looking for dough. He was looking for the same thing I was, Kitty's pictures. They were a hot item and the trail had just gone cold, and I wasn't warming up to the fact that someone had set us up. While the unlucky John had gone down, I tried to remain up, but nothing made sense.

The next day the newspapers identified the body as one Frankie Deluchee. Who the hell was this park fella? I needed information about this dead slug. Tommy "Two Thumbs" Malone, was a shifty con artist who worked the east side. He got his name because he had one thumb up his butt and one in his mouth, playing switch. His hustles were small time (things like corner shell games, pick pockets and running numbers… mostly prime ones). He liked to gamble too. I went over to the race track to see the man who had his nose in everything on the streets. He knew everyone, and if you covered a few of his bets, his belly would spill like vomit. I could get information straight from the horse's mouth, or should I say, the horse better's mouth.

"Two-Bit Bum" hit in the second, which put Tommy in a good mood. "So what do you know about a Frankie Deluchee?" I asked.

"He was a pilot for TWA and then they canned him for flying with his pants off," Tommy spilled. "The poor sap fell on hard times. Lost his license, and then started hitting the bottle and gambling a lot. I saw him one night in a card game... even had a dame on his arm. The girl could bet. I mean heavy. Two grand a hand."

"You know the dame?" I asked.

"I never seen her before," he pondered. "But, she went by some animal name… Poochie, Possum, Birdie… Kitty, that was it."

I stood frozen with my jaw resting on the floor. I flipped Tommy a buck and told him to take "Secret Surprise" to win in the fifth.

I hit Kitty in the kisser with the information I had. She seemed unfazed. "Yeah, I knew him," she off-handedly remarked. "We had a few dates, but there was nothing to it. He was a loser who liked the hooch more than me. I haven't seen him in a long time."

"Well, you won't see him again. He's dead," I stated.

"Frankie!" she bellowed as she broke down and cried. The news seemed to hit her hard for someone she barely knew. Were they real tears, or the crocodile ones that turn and bite you when you least expect it? I didn't know if I could trust her. I decided to keep her gambling hobby to myself. I may need to play that hand later.

I started to dig into the life of this drunk pilot. He flew high, living beyond his means. I spoke with a baggage handler down at the airport (I busted him once for tap dancing while juggling carry-ons for quarters). You want to play in my town, then get a street performing permit. Yeah, he had heard of the raucous pilot. The talk was that he had stewardess in every city, every room, and every other bed. The sky playboy liked the party life. When he got canned from his job, things went belly up for him. With his income dried up, quieted wild nights, he went on to booze bashes or "pin-the-tail on the hussy" games. The ape had a reputation and this case was driving me bananas. Is that why Kitty stopped seeing him? There's only one thing a dame likes more than her man, and that's his money. And without cabbage, the coleslaw tastes a lot different.

I changed my thinking. Instead of looking at the players that traveled in Kitty's circle, I'd take a look at the main character in this murder mystery play. I'd been playing the understudy all week and, now, dress rehearsal was over. It was time for my performance. Who was Kitty Brunswick? I wondered about her and why she had my head spinning like a milkshake blender at the corner drugstore. It was time to find out a little more on the leading lady.

As I drove around, I kept telling myself, "Yeah, so what?" She cozied up with a pilot and took a few flights on his bank roll. It doesn't make her a bad person; it just makes her a republican. A lot of girls want a man who can give them the finer things in life, but it just didn't sit well with me. My insides were crawling like a beetle on a rose petal in a summer garden. I headed south on Henderson, then turned down Mulberry, and pulled up to the county library. I was working on a hunch that maybe Kitty had something in her past. Something that would jump out at me. Something that wasn't pretty.

I once dated a librarian. Her name was Shirley Feldman. She read my mind and I read her body. I used the braille method. The relationship didn't last long. You might say it was a short story. It ended in a fight where she threw the book at me. She was feisty; I learned that you could never judge a book by its cover, but that was just a long ago chapter in my life and I've turned the page. Shirley was the cat's meow and had the memory of a baby elephant, and a nose to match. She recollected the name Kitty Brunswick. After an hour of digging, she pulled up an old article that mentioned Kitty. It was more about her husband, Johnny Tortellini. He had owned several Italian delis and appeared to have done quite well for himself. Unfortunately, the poor rogue had died in an odd manner. Poison accident. Coincidentally, Kitty had been married to him at the time.



I felt bad for Kitty to lose a husband, that is until I had my old banker gal pal look up some of Kitty's old records. What I found hit me liked a baby delivery doctor slapping a baby's bum and welcoming him into the cold world. I'm sure that the fifty thousand dollars that was deposited into her account right after her husband's death dampened her grieving. I'd never make that much dough in my life. I tracked down where the money came from. It was large insurance company. The timing was uncanny, coincidentally and suspiciously, because she took out a death policy a week before her husband's death. I wondered why she didn't use her psychic abilities for her gambling hobby.

"Sure I was married before. Is that so wrong?" Kitty stated. "He was a good man and I loved him." "Kind of a strange death, wasn't it?" I threw out.

"I don't think so," she fired back. "A lot people die from accidental rat poisoning. It wasn't his fault." She began pacing with an intense look. "Those rats were all over Johnny's meat. Every morning he'd come into that deli and there were half-eaten meatballs and mild sausages strewn on the floor. Those dirty rats didn't like the hot sausages. Mild, that's all those rodents wanted. Johnny had had it. Those big mice were driving his business into the ground. One day, Johnny came in and noticed one of the rats slumped in a corner with his tiny paws resting on his fat plump belly. He had been feasting all night on Johnny's profits. That little monster looked up at my Johnny, with pasta sauce all over his whiskers and he… he smirked. Johnny flew into a rage. There was craziness in his eyes. I'd never seen him like that before. He vowed that he was going to kill the rascals. I pleaded with him. 'Johnny don't. Don't Johnny. Think about us and our dreams.' It was too late. Johnny had gone off the deep end. He raced out the door to the hardware store and bought the rat poison. I tried to warn him. I begged and pleaded but they were too smart for him. That night the furry scoundrels got into the poison. They didn't eat it. No, those good-for-nothings mixed it in with the powdered sugar and then my Johnny made himself a cannoli, and he dropped like a bowling ball in the Hudson river. Filthy lousy rats. I hate them. I hate 'em all."

I had heard stories like that, but it wasn't that unusual. After all, I once ate a shoe thinking it was potato. I still had my doubts though. "His death made you a rich woman," I pried.

"I don't care about the insurance money," she shrugged. "I'd take my husband back any day of the week, even if it's my hair salon day," she said breaking out in tears. "Johnny did the lawn work and I could sure use some weeds pulled."

I never had a green thumb, but I just hoped she wasn't pulling my weed. Money's a crazy thing. It can make



you kiss the devil without a breath mint. “Come on, let’s go out to a fancy place,” she said cuddling up to me. “I’ll let you buy me dinner.”

After dinner, Kitty didn’t invite me back to her place. It was odd, but maybe she just wanted to be alone. Her excuse was she had to get to bed early, because she’d be spending the next day helping out at the soup kitchen. She had a big heart. People like her gave bums the chance to flash grateful toothless smile. It was just what I needed to have a little quiet time checking out her place.

I had no trouble jimmying the lock. It was easy. I had a cousin named Jimmy who used jimmy locks and put jimmies on his ice cream. He did things quickly and didn’t jimmy-jack around. I learned quickly from him. The only hang up I had with him was that he liked to wear dresses.

The inside of Kitty’s place was well decorated: plush carpet, velvet couches, and few paintings that could possibly dot a museum wall. I noticed some mail on a desk. I shuffled through the stack like a deck of cards. Neiman Marcus, Tiffany’s, Montgomery Ward. This gal was hocked up to her plucked eyebrows in bills. Another envelope peeked my interest. I opened it and noticed an insurance policy in Frankie Deluchee’s name. Once again, Kitty had stumbled into a pile of money. I guess lightning could strike twice.

She walked in the door with a handful of shopping bags, overflowing with blouses and dresses. She was startled to see me sitting in her chair sipping on a stiff vodka martini. “How did you get in here?” she huffed.

“I’m a detective,” I answered. “That’s what we do.”

She ignored me and set her new clothes on the couch then fished around in a furniture drawer for a cigarette.

“Soup kitchen have a sale today?” I sarcastically remarked.

Without missing a beat, she responded, “They closed early. It was a slow hobo day.”

“Word on the street is you like to dabble in the poodle action,” I knowingly inquired.

“Sure I’ve dabbled. What’s it to ya’?” she sassed back. “It was just a way to deal with my Johnny’s death.”

“You ran up quite a hefty tab with Ming a Ling Ling,” I fired back.

“Yeah, well, my mind wasn’t right then,” she retorted.

I was tired of the runaround. I was getting as dizzy as a school girl jumping rope in a tornado. Yeah, I said it. I

decided to come clean and put it all on the table. "The night in the park. You set it all up?"

"Don't be stupid," she retorted. "I just wanted those photos back."

"The only problem is, you have the photos," I continued. "I figured maybe your half-witted boyfriend thought he was buying the pictures from me since he had the same amount of money in his hands as I brought."

"I don't know what you're talking about, you dumb baboon," she huffed.

"Don't you?" I calmly replied, waving Deluchee's insurance policy in front of her.

"What the hell's that?" she clamored.

"An insurance policy in case Frankie died. It even covers murder," I continued. "Something tells me that you didn't think he'd be around too long."

"He lived a reckless lifestyle," she shot back. "Why not cover the bases? And if I make some money on that rum-filled bum for doing something stupid, well, that's just playing it smart. Besides, I deserve it for all the lying and cheating the louse put me through." She lit a cigarette and poured herself a drink.

"I tracked down your dead husband's sister, Sledge. She said that her brother despised cannolis. Wouldn't touch 'em. Said they made his face blow up like a Macy's Day Parade balloon."

"You leave Macy's out of this," she blurted out. "They have a lousy three-day exchange policy and I don't know if I'm still gonna like a dress in a week. Who does?"

"My cousin Jimmy does. You had a fat policy on your husband," I pushed. "Took it out a week before his death. No wonder ya' like the gambling. You must be a lucky broad."

"What are you driving at?" she questioned.

"You're good with policies, but you want it all, don't ya' doll face?" I snickered. "Well, life's not a pretty little package that's dressed up in colorful wrapping paper, where ya' spend your days trying to figure out how to tie a bow."

"What does that mean?" she questioned.

"It means don't pull your red wagon with one hand, so don't play coy with me, pumpkin," I shot back, not understanding a word I've said. "I know your type. One day you're big, and the next day you're small. You take long walks outside hoping it doesn't rain. And when you're home all by yourself, ya' pour a glass of wine and stare at the shadows on the wall, humming Ethel Merman songs, and wearing fluffy slippers. Do I got it right, chicken?"

"Yeah, I like fluffy slippers. What's it to ya'? You're some smart detective," she cynically remarked. "You think it's easy flying in those planes, listening to babies cry, people demanding blankets, and serving drinks and meals like some cheap diner waitress? To hell with all the people who want a little pillow. I'm done making nickels. That life's over. And every guy I've ever met has never been able to give me the good things. Things I deserve."

"Who shot Deluchee that night in the park?" I pressed.

"Alright, smart guy, you wanna know the score? Well I'll tell ya'. I was in the hole to Ming for ten G's and if I didn't pay him he was gonna have me… work it off. I think you can figure that out. So, I told Ming he'd get his cash if he got one of his henchmen to rub out Frankie. I told him the money would be sitting in his cold dead hand."

"That's only half the grub you owed him. What about the other, half?" My words dribbled out like a slow dripping leaky toilet. The GE bulb went off in my head. She stared coldly at me.

"I guess the other half of the lettuce was in my hand," I surmised.

"That's right," she smirked. "Like I said, I always pay my debts… one way or another."

"You got it all figured out, doll kitten baby. What's to stop me from walking out that door and singing like a jaybird to the cops?" I asked.

"They wouldn't believe the lyrics," she cracked wise. "Besides, I'm willing to share my dough. You keep your trap shut and we can both be on the beach of Playa del Carmen by tomorrow afternoon."

"I don't fly that way," I chirped. "I travel by right and wrong, sister."

"Well that's a one-way trip to the poor house," she laughed. Kitty walked over to her desk and picked up a piece of paper. "My big pay day has yet to come."

She handed it to me. I looked it over. I could feel my heart pound like my head after a two-day bender. Clever. It was quite an expensive insurance policy; I was holding a cool half million. The only snag was, it had my name on it. When I looked up, Kitty was holding a gun, gripping it like a baby would a rattle. Well, this baby wasn't about to wet his pants and cry. I only do that alone.

"Where do ya' want it?" the cold-hearted woman asked.



"How about Chicago?" I tried.

"It's got a lousy airport," she hit back.

"Toledo?" I suggested.

"They don't have an airport," she snipped.

She was right and I never liked Toledo anyway. I was out of answers. My brain froze like an Eskimo's cup of water in a… an igloo freezer. I couldn't think of any other places. "Maybe we can talk this out over a Gimlet," I squirmed.

"Gimlet's are for chumps and talk is cheap," she said raising the gun.

"Maybe," I responded. "But a Gimlet at Chili's bar is pretty expensive."

We were in two completely different camps. She was looking to kill me and I was looking to live. I quickly thought, remembering my old days on the force. In a split second, I stooped down and began clucking like a chicken while flapping my arms. It was a distraction I had learned from Brooklyn Billy who pulled that shenanigan every time I tried to arrest him. My hope was that it would buy me time. I was wrong, she shot me in the arm. Flapping time was over.

I cowered against the wall as she raised the gun to my head.

Suddenly, as if sent by a Mexican angel, Jose, the gardener, popped his head in the door, "Ah jess Miss Kitty. I finished the weeds and I do the bushes real nice for jou. Jou want me to…"

"Get out, you nosey burrito!" she screamed.

"Jess boss, I come back for a later time," the little frightened guy murmured, as he scurried out like a jumping bean on a blazing skillet. But, that was all I needed. With speed and agility, I kicked Kitty's legs out and she hit the ground like a meteorite from Planet X. I rolled on top of her, fighting for the gun. I had to admit she smelled good, like a jelly doughnut in a fresh bakery on a Sunday morning, if it were open. We were two alley cats, scratching and clawing at one another, each trying to get the upper paw. A shot rang out.

The bullet had lodged in poor Jose's right buttock cheek. He should've minded his own business and not lingered around, listening at the door.

They found my car at the bottom of a ravine and my charred body inside. Coincidentally, I was on the beach in Playa del Carmen, lying in the sun with Kitty, and drinking a Gimlet. There's right and there's wrong, and then, sometimes, there's just plain common sense. They figured it was my charred body in the burnt wreckage of my car. Poor Ming a Ling Ling. What can I say? I like poodles, almost as much as money. ■ ABILITY

by Jeff Charlebois





Born in 1958 in Hunan Province, Shuilin Peng suffered severe injuries in a road accident in 2004 in Buji, Shenzhen. His body was amputated in half, and today he is China's rarest truncation survivor.

Peng is less than three feet tall and walks on his two arms. He lost his lower body when a freight truck struck him on a road and left his torso sliced in half. Since his lower torso and legs were beyond repair, doctors sewed him up. At the time of the accident, a television reporter caught the tragedy on tape, and Peng's story was beamed all over China, as were his many subsequent operations. He is considered nothing short of a medical miracle.

Shuilin Peng

HALF MAN SPECIAL TOFU







Peng hopes his story is an inspiration to people with disabilities. Although many feel sorry for him, his son admires his father: "One person who is disabled became famous for climbing Tai Mountain. My daddy can climb the tallest building in Changsha city!" And to do so Shuilin Peng holds his upper body very straight while using two wooden blocks to move around. Each step makes a big sound.

But his health remains unstable. "No one knows how long my daddy will live since his medical situation is a rare case," explains his son. "There is no precedent in the medical field for his condition."

To maintain his bodily functions, he has an artificial urinary tract and anus. His monthly medical bills—about $333—include the frequent replacement of catheters and urine and drainage bags. To reduce medical costs and avoid long lines at the hospital, his wife learned to change his catheters and drainage bags at home.

GRATITUDE FOR A FULL LIFE

On the day of our interview, I walked with Peng the fifteen minutes to his home. He started to take off his body case as perspiration had soaked his shirt. His wife brought him a bucket of water to clean himself and explained, "We can help him around the house, but we like to let him do things for himself. He feels good when he can do work around the house."

Although Peng sometimes uses a wheelchair, he is active. His son told us his father learned to do tricks with his wheelchair in only three months. "I admire him! He has fun with that wheelchair." In Peng's spare time, he plays card games with neighbors, lifts weights, practices calligraphy and plays music on his Hulusi, a Chinese folk instrument.

His son says his father doesn't shy away from speaking to people, especially the homeless, whom he often tells, "You're able persons! You should not beg. Even I can get work as a disabled person." These moments make his son feel proud.

On the day of our interview, it was Peng's 57th birthday. In his honor, a local chairman from the Hunan Xiangxiang's Disabled Association came to his home, where a birthday celebration was underway. While everyone chatted, his wife gave a toast, saying cheerfully, "Lao Peng, congratulations to your 11-year-old reborn self!" I couldn't help but stare at this elderly married couple that seemed to defy the odds. Peng smiled at his wife and drank some water. She cut the birthday cake and served

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the first bite to her husband. He blushed when he realized all the guests were watching him.

Without question, Peng has lived a challenging life since the accident. Although a decade has passed, he has yet to receive any compensation from the local courts. "I have to live no matter what," he says. "When I am strong enough, I will fight in court for other people who are disabled."

What sustains this Chinese man is his deep love of family. Despite the loss of his lower body, Peng knows he hasn't lost everything. "I still have my upper body and the rest of my life to live. I still have my wife and my son." He loves practicing calligraphy and playing the Hulusi. Peng uses two customized wooden blocks to walk around. He is able to stand with the help of a customized egg-shaped case created by the China's Rehabilitation Research Center. His wife has become a "home nurse," which she's done for 11 years.

HIS SUPERMARKET DREAM REALIZED

In 2008, with the help of a certificate from the Human Disabled Person's Federation, Peng's dream of opening his own convenience store was realized. But with 38 convenience stores in the area, competition is stiff. His monthly net income of $333 is just enough to cover medical expenses. Although he opened a second store in Changsha last year, it is currently closed for remodeling. He pays rent and salary for one employee, but his net income barely covers all of his expenses.

To help make ends meet, he decided to sell his homemade tofu snack, called Stinky Tofu in China, in front of his convenience store. He branded his special recipe the "Half Man Special Tofu." The name recognition, says his son, has a competitive advantage. "My father is indeed a half man. Other people can't copy him. Our family has a special recipe and people love to eat it for a snack."

Although his special fermented tofu snack is tasty, few customers have sat and sampled his product thus far, which worries the grocer, who paid $1500 to establish the snack stand. His son, however, offers reassurance, suggesting his father be patient. The tofu, he says, is delicious, and customers will come someday. But Peng knows what he must do: "I need to keep busy every day. I don't want to sit all the time. I have lost my lower body, but I can't waste my upper body. ■ ABILITY

by staff reporter Ying Li
photography by Heyong Zhang

This story is part of a series of articles published as an exclusive editorial exchange between *China Press for People with Disabilities & Spring Breeze* and *ABILITY Magazine*.


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TALES FROM THE CRYP71C M3553G3

A cryptic remark has a hidden meaning and is understood only by those for whom it is meant. A cryptic code is a language system understood only by those who are familiar with the code. A cryptic reply is a very brief response conveying little and not plainly understood. And a cryptic message on Facebook, Twitter, or Instagram, is usually intended to send a specific message to one person, yet at the same time broadcast it to everyone.

If truth be known, I am probably the princess—if not the queen—of cryptic messages, although I do not believe I always was. As a kid, I basically took everything at face value. My first time around the rodeo, I never questioned if there was a hidden message or agenda behind what I perceived. It wasn't until high school that I began to detect that sometimes there were layers to messages, and began to wonder what someone or something *really meant* beyond what was being communicated. That being said, I can safely say that being able to add layers of meaning is a form of intellect acquired with maturity. Although some people don't "get it" and never will.

Something that can mean more than one thing requires a way of thinking that challenges our perceptions and forces us to look beyond the obvious. Babies do not come into the world and question their surroundings, like "Hmm, I wonder why my pacifier is pink. What does this *really* mean?" We're born trusting completely and this, in my opinion, is the hallmark of cryptic messages. In order to develop the skill, one must first experience lack of trust. The more we do not trust something or someone, the more we look for what may be hidden.

I personally developed trust issues in high school and began to question more as a result, rather than blindly believe everything and everyone. This can be a good quality to have, if not taken to the extreme, where we destroy a sense of trust in all things.

Now let's jump to the use of social media and cryptic messages. Remember, this is a new medium and has the potential to reach hundreds, thousands, and even millions of people quickly. So this communication of sorts should be used with care, caution, and responsibility. The problem is we cannot always control what people put out there. Truthfully we can only control what we put "out there" ourselves, and how we respond to what other people choose to post.

Basically we are all using social media to communicate something. Recently I posted on Facebook, "I am not going to write any sort of cryptic message here. Goodnight." The next morning there were several responses like, "Hmm, I wonder what she really meant by that," and one specific one, "I understand—we'll talk tomorrow. Goodnight." To which I replied: "No, you don't understand because this post has nothing to do with you… lol, have a beautiful day!"

True, my post had nothing to do with the friend who thought it did. However, it was a cryptic message to another friend, who had posted a cryptic message, which I assumed was directed at me. Instead of responding directly to the original message, I just wrote something cryptic on my own timeline suggesting that I wasn't going to engage with the friend. But I still don't know if the original cryptic message was intended for me, or whether this friend has even acknowledged my cryptic message. The only thing that we achieved was to passive aggressively validate our feelings.

So what is the harm? In this particular case, there was none. However if we are using social media to communicate a grievance with someone intimately, then we are doing harm to ourselves by bringing everyone into something that should be private. We therefore are using social media to validate or empower "our side of things" and passive aggressively expect our friends, colleagues, acquaintances (and sometimes even those we don't even know) to become allies, witnesses or therapists.

This kind of communication is not really as harmless as we may think. Let's say a friend of yours RSVP'd but did not show up to your party and, instead of calling the friend, you write on Facebook, "There's always a party pooper or someone who found a better party to attend, but was a no-show at yours." The danger with these cryptic messages involves making assumptions. First, the assumption is that we've been wronged, and second that others will think this message has something to do with them.

Even something as innocent as posting a quote like: "I usually give people more chances than they deserve, but once I'm done, I'm done." If there is an unresolved issue with a friend, and they read that message, the issue may never get resolved. Better to wait to post something like this way down the line, long after any personal issues have been resolved.

We need to stop using social media as "the couch" because all we are really doing is communicating passive aggressively, when there are qualified doctors, counselors, ministers, and close friends we can turn to privately. We can still write cryptic messages, but without the hurt feelings that can result from them. And yes, this cryptic column was about you...lol! ■ ABILITY

by Geri Jewell

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WE ARE ALL MADE OF STARS

Agency Reps Actors of All Abilities

Gail always busy in her sun-kissed office

The way top actors get jobs is through an agent. The way top actors with disabilities get jobs is through dedicated folks like Gail Williamson and Mark Measures of Kazarian/Measures/Ruskin & Associates (KMR). Williamson has placed talent on *Glee*, *American Horror Story* and *Shameless*, among others, while Measures is a 25-year industry veteran, whose clients include Jane Lynch, Elizabeth Perkins and Angela Kinsey. The two recently spoke with *ABILITY*'s Lia Martirosyan and Chet Cooper at KMR's offices in Studio City, CA.

Gail Williamson: I started out at KMR by hanging out on Cindy (Kazarian's) couch, working on my laptop. The very first year they paid me four times as much as I brought in, and yet they said: "Great, let's have a second year."

Chet Cooper: They started you off with a trial period just to see what would happen?

Williamson: Yeah, and even after it cost them the first year, they still believed in me. I think we made a profit the second year. The other day Cindy said to me, "I had no idea it would move this fast." But you know how many years we've been doing the work with actors who have disabilities. And now I've had five clients on Broadway, four of whom are deaf and the first woman to work on stage in a wheelchair in *Spring Awakening*. That was a big deal.

I recently booked JLouis Mills as a series regular on NBC's show *Heartbeat*. He's a big guy who's blind in one eye; he had cataract surgery that went wrong and it blew out his cornea, so now one of his eyes is milky colored. The show wanted a character who could obviously have been injured in the war. They were originally looking for someone who was an arm amputee, but I said, "Let me show you everybody I've got!" (*laughs*) And now we have casting directors who call us directly. They'll say, "We've put out something for somebody in a wheelchair," and they'll get, like, 2,000 submissions, and they know those people aren't all in wheelchairs. So they'll call me directly.

Lia Martirosyan: You've done a lot of work with actors who have Down syndrome—

Williamson: I put a whole classroom together with kids who have Down syndrome on *Switched at Birth*. I get calls for actors with Down syndrome because my son has it. *Switched* never put a thing in the breakdown. They just called me, and I put it together for them, so my clients had the opportunity to be in it that other people didn't. But ultimately, I want this department to go away because there won't be a need for it. I want every agency to include talent of all abilities.

For now, though, there's still a need for the work we do, and also for the advocacy that this department does. I'm also real clear with my clients that, if along the way they find somebody who wants to invest in them, they have to consider leaving to try that opportunity. And if that agency can't do what we do here, they're welcome to come back. But they have to test the waters constantly.

Cooper: We were recently in NY at ReelAbilities Film Festival. Did you hear what happened with the movie, Margarita, With a Straw*, which they screened?*

Williamson: No.

Cooper: There are three characters with disabilities

in the film: one has cerebral palsy (CP), one uses a wheelchair and one who's blind. Lia and I had just come from a long day at the United Nations, so we left missing the Q&A where somebody asked, "Does the lead woman really have CP?" The writer-director said, "No." And there was an uproar. She tried to defend that choice. If the director had come to your agency, looking to cast that part, would you have been able to find a female actor with CP?

Williamson: It would depend on the age, ethnicity and involvement.

Martirosyan: They would have needed to be 20- to 30-years old, and somewhat attractive. Definitely had to have some appeal.

Cooper: Appealing enough that she had at least three sexual encounters in the movie, so that other people would find her attractive.

Williamson (*shows a picture*): This is who I have in NY.

Cooper: She could have worked.

Williamson: Did they audition for the part?

Cooper: That was the big question: Had they really looked for an actor with CP?

Williamson: And if they had, they would have found my agency, so if I haven't heard from them, they haven't looked around. That's how I feel nowadays. If anyone starts looking online for disability and hiring actors, they end up here eventually.

Ali Stroker could have been amazing. She's a paraplegic from an accident when she was two, but she can do anything. But if you offer it to Ali, is it union? What does it pay? She's at a different level.

Martirosyan: It probably wasn't union.

Cooper: The whole thing was probably low budget. But it was a lead in a film.

Martirosyan: But once you're union, you don't take those kinds of roles, right?

Williamson: Union actors can do ultra low-budget projects where they're just paid $100 a day. But they still have to do the paperwork, and they have to pay some fees. So it's not impossible. Back when she and I were working together in the beginning, it was impossible to do a union job unless you wanted to pay big bucks for everything. They've got all these new moderate/low-budget/ultra-low-budget projects that you can do now. But do you want to put in 15 days at $100 a day? It's creative, and it's a business; it's always both. But did they try? The one scenario that always comes back is *Glee* with "Artie" in the wheelchair. They tried; they auditioned people. In fact, I've seen an interview with casting director Robert Ulrich saying he would look harder in the future.

Martirosyan: What were you saying about Nina Genatossio?

Williamson: Our equity agent found her. I first met her in a department store where she was working at the time. Nina came and interned for a while for no pay, and then started assisting different people and when my department got ready, they said, "Do you want to hire Nina?" I said, "Yes!" I had been impressed with her since she was an intern. Back then I had her type up reviews from movies I screened at the film festival for the National Down Syndrome Congress. She'd say, "Can I see this movie?" And she'd take it home. "Can I see this one now?" And I thought: "She's invited herself into my world!" (*laughs*)

Cooper: We just met two people like that in NY; they're millennials, aren't they? They have an "I want to help the world" attitude, which is so nice!

(*laughter*)

Williamson: Yes. Every now and then, I'll look at one of Nina's e-mails and she's like, "Hi, hope you're having a nice day," and I think, "I've got to be nicer in my e-mails." Nina also does musical theater; she was in NY auditioning for *The Phantom of the Opera*.

Martirosyan: Lovely, so she sings?

Williamson: Beautifully. In fact, the Lyric Theater of Oklahoma is doing *Fiddler on the Roof*, and they decided that two characters, Hodel and Perchik, would be deaf. Nina sang the song that Hodel sings. I recorded her, and we sent it to Sandra Frank to practice. Now we're doing a Skype audition in our office with Oklahoma, and Nina is reading with Sandra as the father, and here she's telling her father goodbye, and then goes into this song. It goes from them having this touching moment to Nina and Sandra singing. It was this amazing moment, where the two women were so connected as one voice, and we were all just weeping.

Martirosyan: That's sweet.

Williamson: And, of course, Sandra has a lot of experience because someone has been her voice in *Spring Awakening* for the last five or six months on Broadway. She just clicked right in with Nina, and there was an amazing moment.

Martirosyan: So Sandra's mouthing the words and somebody else is singing?

Williamson: She's signing, not even mouthing. She's signing while someone else is singing. They're not quite sure



Mark Measures making things happen and telling Lia about it

how they're going to do it. *Spring Awakening* is going to tour next year. Do see it. It's pretty amazing. At times Sandra is looking in a "mirror," and the person who's voicing her is on the other side as she signs. And sometimes when she's signing, the person is clear off-stage talking, saying what Sandra is signing. Sometimes it's done as a part of the staging in the scene when they're in school, where the words suddenly appear on a chalkboard. It's very cool.

So they're going to work on how to do this in Oklahoma. And they picked Hodel because here's a woman who's leaving her family, and wouldn't she be even more interested in leaving her family if she could find a soul mate who shared her deafness, someone she could communicate with? That would make her more set on going to Siberia to be with this man. I thought it was a unique way of seeing it. They're going to try it. That wouldn't have happened 20 years ago. Things are getting interesting.

Martirosyan: They are! I have fun memories playing Hodel in junior high.

Williamson: That's a great role.

Martirosyan: And a good story.

Williamson: Do you act now?

Martirosyan: Not as often as I'd like. I'm focused on my music. If I had good representation, I'd do more acting.
Williamson: Send me your headshot, résumé, and links to you singing, acting—whatever you've done!

Martirosyan: How many people are seen for a role?

Williamson: Every role in a breakdown gets 3,000 to 5,000 submissions. So if I'm going to pitch something outside the box, I've got to have enough stuff to pitch them with before I can consider taking them on. We did that with the MTV show *Faking It*. Two girls are in high school and not very popular, until a rumor gets out that they're lesbians. They don't stop the rumor because they like being popular. The show needed another girl to be the campaign manager for one of the fake lesbians who's running for school office, so we submitted Ali Stroker, using her tape from *Glee*. Casting sent it to the producers, who sent it to the network, and they called me and hired her within about four hours. She didn't even have to audition. They liked her uniqueness.

Martirosyan: Nice. Don't people need representation to get points to get into the unions?

Williamson: Yes, and that's why we look for the disability roles. We look for the specific roles that you would be right for.

Cooper: How many points do you need in SAG?

Williamson: You need a SAG job. One of my clients just had an audition, and he was the only guy there in a wheelchair, but he's a SAG member and had a good tape, so I could submit him, and he happened to have met this casting director before. And that's the other thing, when people tell me they've gone to workshops, they've met this casting director or they know this person, I try to look for opportunities for them to get in with people they already know. That makes it easier.

Cooper: So joining SAG is also a networking opportunity?

Williamson: It is.

[*As Gail dashes off to an appointment, Mark Measures joins the conversation*.]

Cooper: Tell me how your commitment to diversity grew?

Mark Measures: I guess, technically, I started in '89 or '90 with actor Otto Felix. Do you remember him? He did a thing called HAPPI at the time. It was an organization for performers with disabilities, for want of a better term. I was at another agency at the time, and we started something very similar to what Gail is doing by funneling people to this agency. Otto was finding work for actors with disabilities and calling us as the agency of record, because they didn't have an agency to represent them.

And then, over the years, I knew Cindy had the department here, which was always a part of the business, but it did not have the kind of focus and push we gave it once we were able to get Gail here.

At one point, though, Cindy tried to close the division. This was seven or eight years ago. They were saying, "You're discriminating against people with disabilities if you close the division." She wasn't going to *not* represent performers with disabilities; she was going to funnel them into other departments. The problem we find very often, and Gail can tell you this: there are a lot of people who say they want to do this work, but they don't want to really make the commitment to it. They don't want to get their pictures, they don't want to get their stuff online, they don't want to be coached, and they don't want to put their tapes together; they don't want to do what anybody else has to do to make it in this business. It's no different whether you're differently abled or not. You have to do what you have to do to work, just like any actor does. So anyway, she reopened the division to avoid being sued by the union, and it limped along until we were able to—

Cooper: Limped along?

(*laughter*)

Measures: No pun intended!

Cooper: I'm surprised that somebody balked at them for trying to close it.

Measures: And it's sad, because Cindy was always an advocate. So Gail kept sending people our way, and when the state let Gail go, we tried to find a place for her, because she's unbelievable.

Cooper: I don't know anyone who has a more solid background than she does in this area. You've got the right person.

Measures: The right person 100%. And ultimately, our goal is to eliminate her.

Cooper: I'd get rid of her tomorrow.

(*laughter*)

Measures: It's just that we don't want there to be a separate division. We've shamed much of the New York community with Ali Stroker who said, "It's been 200 years of Broadway, and you're just now getting a performer in a wheelchair?" And the response we got from casting in New York was, "Well, if more people represented these actors, we would—" We were like, "You're so full of it. You have to make the decision to bring in actors who are differently abled."



Cooper: Why don't other agencies do this?

Measures: Because agents, for the most part, are lazy. And it takes work to get appointments for differently-abled actors.

Cooper: It takes work to make that money?

Measures: Yes. It's work just to sell the talent. Everything we do takes work. It takes work to convince a casting director that there's no reason you can't use someone who's an amputee or whatever—unless it's part of the story. We go to producers and say, "Hey, we have actors who've had two legs amputated, and you wouldn't know it unless you saw the prosthetics. Write it into *Chicago Fire*. Write it into a show where you've got an able-bodied fireman who gets his leg crushed, and show how he makes that transition afterwards." You have to educate producers. The main character in *House* was supposed to be in a wheelchair, but the network said, "No."

Martirosyan: I didn't know that.

Measures: So they gave him a limp. Last year, ABC gave us all their pilots and said, "Where can we use differently-abled actors?" Gail was able to show them where. We look at every breakdown and think: is there any reason this character can't be an actor in a wheelchair? Is there any reason this can't be an actor with a missing appendage? Is there any reason this can't be a blind actor? So, for us, it's educating the community.

Cooper: That's really good.

Measures: That's what we have to do every day. A lot of agencies don't want to educate. They just want to have somebody say, "Well, you see so-and-so." "Oh, sure." And not, "You see so-and-so. They're in a wheelchair. Maybe it's a good idea." Gail tells the story of being at some event where there was a producer talking about a McDonald's commercial and how he wanted to cast everybody. Gail said, "Okay, so if you were doing a McDonald's commercial and you need a brown-haired, brown-eyed boy of 12, would you cast my son, who has Down syndrome?" And he went, "No, I wouldn't do that." She was like, "Why?" He said, "Well, because people would wonder why he was there." And Gail went, "He's there because he's hungry!"

We run into that all the time. There were two incidents last year, one was *Justified* and the other was the Clint Eastwood movie, *American Sniper*. In *Justified*, they used an actor who jumped out of a chair, climbed out a window and down a pole, but they used an able-bodied actor and computer-generated imagery to eliminate his leg. That makes us crazy. We have actors who can do that. We have Paralympians. And why did Clint Eastwood use actor Jonathan Groff as a leg amputee instead of an actor who is a real amputee?

Cooper: Do you ask them?

Measures: We try. In that instance, though, he used two other actors later in the piece who were vets who had been injured in the war. We tell them, just call us. At least bring in our talent. If they can't do the job, we don't want you to hire them just because they can climb out of a chair and climb down a pole. We want you to hire them because they're the best actor for the job. Cindy and I both feel this is one of the most important things we do on a daily basis. The rest of it is selling soap.

Cooper: You're always cleaning up when you sell soap.

Measures: You're cleaning up if you sell enough soap.

Cooper: When we talked to Safeway about selling the magazine. The manager said, "It's an interesting magazine, but do you really think a magazine dealing with disabilities belongs in a food store?"

Measures: As if people with disabilities don't eat?

Cooper: Right, and that's what I thought of when you told the McDonald's story.

Measures: I guarantee you every single person with a disability needs to eat.

Martirosyan: At KMR, is your concentration in one area?

Measures: I run the agency, but I work specifically in the voiceover and equity department.

You may be in a chair and completely unable to walk, and you can be a voiceover actor in a video game.

Cooper: Did you do voiceover? You've got a good voice.

Measures: No, I've been an agent for over 30 years. We have a booth for voiceovers. Now you do it by the ad agencies. The casting people send us the copy, and we bring in actors who are right for the roles. So in the voiceover area, we're both a full-scale casting facility and agency. That's how it works now. They get their copy read for them, as opposed to having to listen to random reels and figure out which voice fits. So that's good for us.

Lia, I read in the magazine that you're an opera singer. Musicians, for the most part, are good at voiceover. They have rhythm and tone and pace—all that you learn in singing a song. It translates really well. Robby Robertson of The Band does tons of voiceovers. We could send some copy your way. ■ ABILITY

kmrtalent.com
springawakeningthemusical.com
nbc.com/heartbeat



SECOND SET OF EYES

From perusing junk mail to researching art history, an assessable device is helping people with low vision discern what's on the page when they want to read. *ABILITY* caught up with optometrist Bryan Wolynski, O.D., one of the team members behind OrCam. He is well-versed on the OrCam MyEye assistive technology device. When we met with Bryan, he spoke about the technology behind OrCam as well as gave us a personal demonstration of the device. He emphsasizes the importantance of the device, and lives it has changed. One of those lives belongs to Cindy Coons, who we also chatted with.

Bryan Wolynski: The OrCam has three different features. It takes a picture to read books, magazines and newspapers—anything that's text. It won't read handwritten text, but it can read any printed text. It also has some product recognition, such as Band-Aid, Coca-Cola or Entenmann's, which are written in script but is also a logo. It has to memorize the product. That's part of the machine learning aspect of the software. The other computer vision part of the software is facial recognition. It can help people who've lost their sight, as well as many people with macular degeneration, who can't see facial features and don't know who's in front of them.

Cooper: You mentioned meeting with young students and someone who is 100 years old.

Wolynski: I've trained dozens of individuals around the New York City area. One gentleman happened to be 100, and he used the OrCam successfully. He used OrCam's MyReader. The other version is called MyEye. MyReader just has software for reading, which was his specific interest, to be able to read his mail and the newspaper. He didn't want his wife reading the mail to him. He was a lawyer, and actually is still working two days a week. I trained him to use the MyReader, and I'm going to work with him a little bit more. He needs more TLC. But it's amazing, and he's so happy that he's reading on his own, feeling independent. That's what this is about, creating independence so someone can do his/her thing.

The youngest person I taught is 25 years old and is an art history researcher. She needs the OrCam to read and look things up. Without this, she couldn't do her work. It's great to see this from both perspectives, one using it in retirement, and another using it at work. I have so many other stories of people using it in many different ways. Most people who use technology, and are comfortable with it, say it's freeing, because they're currently relegated to either their basement or a room on the side of the house—their "low-vision" room, where they have all their tools and desktop stuff and screen readers, which are not portable. One gentleman told me it was great he could sit in the kitchen with his kids and wife and is able to read and do all the chores he wants.

Cooper: The 100-year-old man, he's studying for the bar with this?

(*laughter*)

Cooper: I needed to get the joke in.

Wolynski: Exactly! It's giving the bar out.

Cooper: This sounds great, but what if you're not able to point.

Wolynski: There's three ways OrCam can trigger the camera to take a picture. The whole device itself is intuitive and portable, with a smart camera that takes visual images and converts them into audio. In order to trigger it to take a picture, you can use a button, like on an old-fashioned camera. In Israel they call that the trigger button. You trigger it to take a picture.

If someone can't push a button, possibly due to neuropathy from diabetes, you can point, and it recognizes your finger in an upward gesture, and then it will take a picture. If you cannot point or push a button, you can tap on the device, and it can take a picture that way as well. So there are many different ways OrCam can be used by many different individuals. OrCam has tried to come up with enough solutions for each person's situation.

Cooper: Is the text reading component OCR (optical character recognition)?

Wolynski: The text reading is optical character recognition. It only can do print. I'm an optometrist who trains people to use OrCam, and I work with my patients and clients to use it. I consult with them on that, as well as read up on some studies that are going on. One specifically was just completed at Wills Eye Institute in Philadelphia with glaucoma patients from 44 to 88 years old. It was a small, independent study to start. I was a liaison between the company and the patients, who had 20/200 vision or worse, which meant legally blind status. With OrCam, they had increased reading speed, which also has been shown to contribute to increased reading comprehension and increased quality of life and satisfaction.

Cooper: I remember the company that was the first to create what we know today as OCR.

Wolynski: Right. And those reading machines went for something like $40,000 back in the '70s.

Cooper: So this is different?

Wolynski: Yes. It's a proprietary algorithm that's used.

Cooper: Does it record the information anywhere?

Wolynski: No. It is not saving the information. It has a mini-USB port on this side. It's capable of hooking up to a computer.

Cooper: But it could be a Bluetooth that's uploading on a regular basis, if we wanted?

Wolynski: It could. It is not at this moment. They are seeing Bluetooth working with Bluetooth hearing aids, so for people who have Bluetooth hearing aids, they would be able to use OrCam more easily. Right now it's a closed system. It's not searching the web, not searching the cloud. There's no programming you would have to do.

Cooper: It's the immediate environment?

Wolynski: It's not even the immediate environment. It's just the speed of it picking up that OCR; it's instantaneous as you read. That's why it's able to work quickly, because it's not uploading anything. Other instruments are slower because they have to upload, which takes time. This one is able to do it on the fly, right away.

Cooper: You can hear the text right away?

Wolynski: You can also increase or decrease the rate of speed, change it from a male to a female voice. There's a lot of personalization you can do with the device that we haven't done.

Cooper: Can it read other languages?

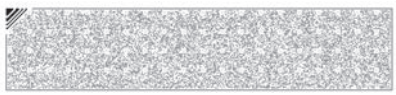
Wolynski: Right now it's only in English and Hebrew in Israel. They're looking at other languages, but we're not doing that at this time. It's been a great experience working with the company. It's an amazing technology, and very bright people work for the company. They've really gone out of their way for a lot of individuals. During the pre-launch, they had people signing up. The first 100 people to get an OrCam device got a personal visit. It was all over the US. They sent me to Albany. They sent somebody else to Maine. I went to Florida.

Cooper: Who else went to Florida?

Wolynski: Only me. It was good. I worked there for quite some time at the Miami Lighthouse for the Blind and Visually Impaired, so I had some connections down there. It was interesting going down there for that. Not every technology will be good for everyone. Reese, who's an occupational therapist, came up with an evaluation form. That way we could determine if somebody was a good candidate. I went to a woman's home. She was not a good candidate. She kept pointing the instrument, kept talking into it, thinking it was going to talk back to her. She wasn't the right fit. I had a nice cup of tea with her though.

Cooper: She was a congresswoman?

(*laughter*)





Wolynski: No, but with me being a low-vision optometrist, I was able to talk with her about her other options. That's one thing OrCam has done, hired people who are trainers around the country who are certified low-vision specialists or occupational therapists. They're all people who work in the field and have the best interest of the user, client or patient in mind. If someone buys an OrCam, they get an in-home training session of up to three hours from a certified OrCam trainer.

Cooper: Will insurance pay for it yet?

Wolynski: We're looking into it. At this point, we are working with the VA. Just recently we found out OrCam was accepted on the list for the Department of Rehabilitation here in California. It's an accepted unit now. That's exciting.

Hopefully it'll get to some people who can use it on the job. I've seen that. There was another lawyer whom I worked with who's using it. He was on a CNN interview. Another woman who's a math teacher is using it. There are many people using it in their careers. A retired doctor just wanted to be able to read the journals sitting on his couch, instead of being at the computer with a screen reader. It's more comfortable.

Cooper: It's helping a lot of people. ■

For Cindy Coons, this little gizmo has transformed her life. Legally blind since 1987, Coon's doctor in Indiana recommended the 55-year old mother try the OrCam MyEye. Now, she wouldn't dream of a day without it. Paula Fitzgerald spoke with Coons about her experience with this pioneering technology and her new grip on independence.

Fitzgerald: How has the OrCam MyEye changed your life?

Coons: (*laughs*) Oh, my! It's changed it tremendously! I can go to the store now. I can read menus at restaurants, and I can read street signs now. I can read my email. And if I want, I can read a book with it, and I can read my recipes and a lot of my cooking.

Fitzgerald: Wow! That's revolutionary.

Coons: Yeah, tremendous change! (*laughs*)

Fitzgerald: How long have you been using it?

Coons: About two months.

Fitzgerald: It looks like it attaches to the frame of your eyeglasses.

Coons: Yes, it sits on the right earpiece of my glasses.



Fitzgerald: Is it heavy or uncomfortable to wear?

Coons: No. It goes along the length of the earpiece of your eyeglasses, and it acts like the pupil of your eye, and the speaker is right by your ear.

Fitzgerald: Tell me how it works exactly?

Coons: It takes a picture of whatever you're looking at. For example, if you want to read, it takes a picture of the text—the printed material—and reads it back to you.

Fitzgerald: Do you have to tilt your head or hold the text a certain way so the camera can see the text?

Coons: No. You just sit wherever you're sitting, and you point, and it will take the picture. If you're holding a product you want to read, you point your finger, and the camera will pick up your fingernail. And it tells you if it can't pick it up, and if it can't, it says, "Turn your head to the left" or "Turn your head to the right."

Fitzgerald: So it reads the text back to you immediately?

Coons: Yeah, once it takes a picture, it will automatically program it and read the information back to you immediately.

Fitzgerald: That's amazing!

Coons: Yeah, it really is!

Fitzgerald: What about people? Can it capture faces?

Coons: Yes, it will identify people, too. In other words, if someone's standing in front of you, it will take their picture, and you can then put their name on it.

Fitzgerald: So it's like a contact list that stores a person's name and photo?

Coons: Right. If you're in a room with someone, and you look at that person, it will automatically tell you who that person is. There's a trigger button on a small square box that I wear on my pant's pocket. It's attached to the earpiece device by a thin wire. If you want to take a picture of the person in front of you, you'd push the button, hold it for two seconds, and it will tell you there's a person in front of you. If you click it again, it will say the person's name. Then it will ask you to confirm the name, so you push the trigger button again. There's also a volume button.

Fitzgerald: How many photos can it store?

Coons: It stores up to 20.

Fitzgerald: Has it ever confused anyone?

Coons: Nope. When they first told me about it, I was like, "Are you serious? That just sounds too easy!"

Fitzgerald: Have you ever freaked anybody out?

Coons: Yes, a few. (*laughs*) People sometimes think I'm recording them. I was at a home show one day, and they asked me if I was recording anything. Of course, I said no because I wasn't.

Fitzgerald: It sounds like you use it every day.

Coons: I absolutely do.

Fitzgerald: Do you have to plug it in each night or does it use batteries?

Coons: You do have to recharge it, which takes about an hour, maybe.

Fitzgerald: That's reasonable. Has it ever lost its charge when you're out and about?



Coons: No.

Fitzgerald: And the voice… is it male or female?

Coons: Mine is female. But you can change it if you want.

Fitzgerald: What about accents?

Coons: There is one voice on there that does have an accent, but I'm not sure what it is.

Fitzgerald: What surprised you the most about it?

Coons: That it could do so much! (*laughs*)

Fitzgerald: I bet! If you go into a movie theater and watch a film with subtitles, are you able to know what's going on in the movie?

Coons: I don't know if it would work in there or not. I haven't tried that yet. What I have tried and does work is at the church I attend. The song lyrics are displayed on a screen, and the device can read the words.

Fitzgerald: So it allows you to participate so much more. Is there anything you wish it could do but can't?

Coons: There are a few things. It doesn't read coins, as in quarters and dimes, but it reads dollar bills. But I can generally tell which coin it is by the size and feel. And the other thing I wish it could do and that my husband would like me to be able to do is read cursive writing, especially on Christmas cards. It's the cursive or fancy writing that it doesn't read.

Fitzgerald: I get that. How long did it take you to get used to the device?

Coons: Not very long really. I only had one day of training with it. They showed me how it worked, and then I started using it immediately.

Fitzgerald: Anything else you wish it could do?

Coons: Stoplights! It won't read the stoplight to tell you whether it's red, green or yellow. But whomever I spoke with yesterday said that it used to do that, but it's a liability thing, just in case it would read wrong (*laughs*).

Fitzgerald: Yes, that would indeed be a problem! Did insurance cover the cost of the OrCam MyEye?

Coons: No.

Fitzgerald: How much did it cost you?

Coons: Mine was $3,900. I'm on a two-year payment plan and make a $150 payment each month. So it makes it affordable.

Fitzgerald: Yeah, sounds like a deal. I am so excited that you have this new technology.

Coons: Yes, me too! ■ ABILITY

orcam.com



Oriol and Haiti's Disability Movement Continue Despite Political Uncertainty

Since October 2011 James English has served as an advisor to Gérald Oriol, Jr., Haiti's Secretary of State for the Integration of Persons with Disabilities. *ABILITY Magazine* has followed Oriol's five-year tenure in office with feature stories in 2012 and 2014. This article is the third in the series and coincides with Oriol's final year in office as Haiti's highest ranking government official working on behalf of an estimated one million persons with disabilities. Oriol, who has spinal muscular atrophy, is believed to be the most severely disabled high-ranking government official in the world today.

Friday – April 1, 2016

On the 6:25 a.m. flight from Miami to Port-au-Prince, I reread the text messages I received the previous night from Secretary Oriol about Vanessa Previl, Monique Vincent and Jesula Gelin, three women from Lévèque who were deaf and recently murdered near the Haitian community of Cabaret. The three apparently had traveled to Port-au-Prince to purchase supplies for their small businesses and were unable to return home early in the day due to a traffic jam caused by the collapse of a bridge. The women left their minibus and set out on foot with the hope of finding a place to sleep for the night. Sadly, they encountered a gang of criminals who are accused of torturing and eventually killing all three women. The story took an unusual twist when one of the suspects said some gang members of the community believed the women, who could not speak and communicated using sign language, were *lougarou*, a Creole term for werewolves. While persons with disabilities may have had to cope with stigmatizations due to superstitions within Haitian culture, Oriol urged restraint in order to avoid making premature conclusions, as it was possible the lougarou story was not the culprits' beliefs, but rather an attempt by the accused to divert attention and blame away from themselves by evoking negative stereotypes of persons with disabilities.

As media speculation about the murders increased, Oriol sought to reinforce collaboration between the community—especially friends, neighbors and family members of the victims—and the authorities involved in the investigation, not only to ensure justice prevails but also to have a thorough understanding of the context in which the crime occurred. According to Oriol, "If the crime is not carefully documented, this will be a two-headed tragedy: the judicial system will fail to give justice to these three women, and Haitian society will lose an opportunity, even if tragic, to get a better understanding of the dynamics between culture and disability in the country and how to address these subjects collectively for the betterment of Haiti."

In response to the brutal murders, the disabled community organized a demonstration scheduled for the morning of my arrival. The group planned to convene at St. Vincent's





Protestors march through the capital of Haiti demanding justice



Secretary Oriol entering the historic Vodou waterfall, Saut d'Eau


A reporter from Radio France Internationale interviews Secretary Oriol at a march honoring three deaf women recently murdered

School for Children with Disabilities in Port-au-Prince and from there, they would march to the Ministry of Justice to honor the victims and demand culpability for the perpetrators of these horrible crimes. Secretary Oriol joined the march to show solidarity with the victims' families and friends and to bring greater awareness to the rights of persons with disabilities in Haiti.

I asked the Secretary if I could join him at the demonstration. "Yes, you can. Wear a white shirt if possible," he texted back.

After quickly passing through the Toussaint L'Ouverture International Airport, Oriol's driver, Jackie, met us at the curb and drove us into the capital. We arrived at St. Vincent's just as Secretary Oriol and approximately 300 other persons with and without disabilities began their march.

In October 2011, President Michel Martelly appointed Oriol as Secretary of State with the disability portfolio. Martelly completed his five-year term in February 2016. A disputed first round of the Presidential election resulted in a delayed second round, which necessitated the selection of an Interim President, Jocelerme Privert, to take office when Martelly stepped down. The Parliament subsequently approved Privert's second nomination for Interim Prime Minister, Enex Jean-Charles, as well as 15 members of his Ministerial Cabinet. The various secretaries of state who were appointed by former President Michel Martelly, including Oriol, were likely to be changed soon.

"Welcome back to Haiti," Secretary Oriol said as he passed by me in his wheelchair. At least for another day, Oriol remained the country's highest-ranking government official working on behalf of the nation's persons with disabilities. Despite the ongoing political uncertainty and the possibility that his tenure in office would end soon, Oriol was determined to spend every day in office advancing the disability agenda in Haiti.

During the march, I had the good fortune of finally meeting one of my heroes: Joseph Jean Paul, aka "JoJo," a well-known Haitian artist with disabilities. JoJo paints beautifully despite having no arms or legs. He is also on the staff at St. Vincent's School for Handicapped Children and invited us to visit him later in the day.

At the conclusion of the march, Oriol and I headed straight to a meeting at Digicel headquarters in Port-au-Prince. Digicel Foundation, the non-profit arm of Haiti's largest telecommunications company, provided funding support to Oriol's agency for several initiatives related to disabilities, including a pilot financial empowerment program for 30 persons with disabilities in the Central Plateau. The pilot, which was a collaboration between the secretary's agency Bureau du



Saut D'Eau, historic Vodou waterfall



Secrétaire d'Etat à l'Intégration des Personnes Handicapées (BSEIPH), Association des Handicapés pour l'Avancement de l'Arrondissement de Lascahobas (ASHALAS), Fonkoze Foundation, Texas Christian University (TCU) and the Digicel Foundation, had reached the end of its original 12-month duration. At the meeting, the Fonkoze Foundation announced they planned to continue working with the pilot participants for another six months. Even more impressive was the foundation's decision to mainstream disability throughout its Chemen Lavi Miyò (CLM) program, which is an 18-month graduation program that offers a pathway out of ultra-poverty for Haitian women and now, Haitians with disabilities. In addition to these significant outcomes, the partners discussed the possibility of creating a second, larger pilot program that would serve approximately 100 people with disabilities. The expanded pilot program would provide participants with two income-generating activities, as well as access to healthcare, home accessibility upgrades, financial literacy training and regular visits from a case manager, at a cost of approximately $200,000. The partners agreed to begin searching for potential funding sources for the expanded program.

After the meeting at Digicel, Secretary Oriol and I devoted Friday afternoon to a special project. During Oriol's tenure in office, we frequently talked about creating a children's book on disability in Haiti. Now, as he approached the end of his appointment, our dream had become a reality. Panther City Press, the non-profit arm of TCU Press, had just released the Creole version of *Galia's Dad is in a Wheelchair*, a children's book about Oriol's relationship with his daughter and disability in Haiti. I authored the book, which has beautiful illustrations by Teddy Keser Mombrun, a political cartoonist for Haiti's largest newspaper, *Le Nouvelliste*. Oriol provided the Creole translation of the book with some assistance from our good friend, Dr. Michel DeGraff, a Haitian professor of linguistics at the Massachusetts Institute of Technology. Now, we had the privilege of distributing hundreds of free copies of the book to schools and libraries throughout the country.

Following book deliveries to FOKAL, a cultural organization with 19 libraries in Haiti, and to the Akademi Kreyòl Ayisyen, an organization promoting the use of Creole throughout Haitian society, we ended our workday back at St. Vincent's. We distributed dozens of copies of the book to students with disabilities and visited with JoJo, who showed us a selection of his most recent paintings.

At dinner that evening, Secretary Oriol and I reminisced about some of the more memorable moments from his nearly five years in office. We also discussed some unfinished business: two important pieces of legislation that were making their way through the Haitian government. The first was a bill that would establish a National Solidarity Fund for the Integration of Persons with Disabilities. The bill, which had already passed the lower house and was now awaiting senate approval, would use government revenues, budget allocations and donations to help persons with disabilities undertake



JoJo (L), a well-known Haitian artist, with James English (R)

income-generating activities, attend school and procure adaptive materials. The other pending legislation was a draft bill on accessibility norms for the built environment in Haiti, and it was currently sitting in the Prime Minister's office, awaiting executive approval.

Although Haiti still lacked the enforcement capacity to ensure new laws such as these would be fully upheld, Oriol and his colleagues were looking over the horizon in their attempts to create a legislative framework that would ultimately serve as a foundation for the rights of persons with disabilities in Haiti.

Saturday – April 2, 2016

On Saturday morning, we drove into the mountains northeast of the capital to Lascahobas, a small town in the eastern reaches of Haiti's Central Plateau, where 27 persons with disabilities from the financial empowerment pilot program were waiting to receive completion certificates in the presence of their families, the pilot sponsors and Secretary Oriol. Two of the pilot participants did not complete the program for a good reason: they'd found permanent employment. One pilot participant was unable to finish due to health reasons.

According to Oriol, the financial empowerment program designed by the Fonkoze Foundation's CLM team and Dr. Dawn Elliott, a professor of economics from TCU, "is significant for two reasons. First, in a country like Haiti, which is prone to natural disasters and political crisis, it is imperative the most vulnerable populations have some means to survive difficult times. But also, financial independence creates within Haitian society a new perception of persons with disabilities as important contributors to the development of families, communities and our country."

Following the three-hour ceremony, our group stopped at the historic Haitian Vodou waterfall, Saut d'Eau. In his position as secretary of state, Oriol has always promoted tolerance and understanding. Although he is not a practitioner of Vodou, he certainly respects the role it plays in Haitian society.

The waterfall at Saut d'Eau is not exactly handicap accessible. The secretary had to be lifted in his wheelchair above the turnstiles and then carried approximately 300 yards down a series of staircases to the water. Two Haitian men held me by the arms and led me over slippery rocks to the base of the waterfall for some memorable iPhone photos.

At the end of the day, as the sun was beginning to set over the Central Plateau, we visited *l'Ecole Mixte Nouvelle Jérusalem pour les Sourds*, a small school near Mirebalais for children who are deaf. The secretary's agency recently provided a small grant to the school to help build its dormitory, which is home to 45 children with hearing impairments. We distributed copies of the children's book and visited with the principal and teachers at the school.

At dinner that evening, we talked about what Secretary Oriol might do after leaving office. Amazingly, Oriol had not taken a single vacation during his five years in office. In addition to spending more time with his family and traveling, Oriol planned to pursue his social work through Fondation J'Aime Haïti, the Haitian non-profit he co-founded to champion the rights of persons with disabilities and disadvantaged youths in Haiti.

Before saying our goodbyes, I asked the secretary for a formal statement on his tenure in office.

According to Oriol, "It has been an honor to serve my country at the highest levels within the public sector. Since my appointment in October 2011, I have worked non-stop to improve the living conditions of persons with disabilities. Although much remains to be done, we have been able to help move the disability agenda forward in Haiti. Today, BSEIPH is present in seven out of 10 departments in the country, a new law has been voted by the parliament and promulgated by former President Martelly and efforts are underway to mainstream disability across the public agenda with the creation of an inter-ministerial committee on disability. I am confident that if efforts are maintained in the long-term, persons with disabilities will be able to fully exercise their rights as citizens and achieve their full potential, and, in the process help Haiti shine greater." ■ ABILITY

James English works at Texas Christian University.

Nancy Villere - CrushPhotoStudios.com

Chyler Leigh

MODERN ICON

You may know Chyler Leigh for her portrayals in *Not Another Teen Movie*, *Grey's Anatomy* and *Supergirl*. She and musician-husband Nathan West also run a company that's a go-to source to learn, in part, about the altruism of people in the entertainment industry, Charity Pulse. Leigh states that "As a founding member of Charity Pulse, I'm thrilled to take part in offering a fresh spin on the world of entertainment to help redefine what it means to be a modern day icon." Leigh and West, who worked together on the TV series *7th Heaven*, have three children, and are big supporters of the Thirst Project, a non-profit organization that brings safe drinking water to communities around the world. *ABILITY* recently spoke with Leigh about all of her projects.





Chyler Leigh in *Supergirl* — Plays Alex, serving as a top secret agent in the clandestine Department of Extranormal Operations (D.E.O.)



Nancy Villere: Can you talk about your latest project?

Chyler Leigh: Sure. My husband and I started a company called Charity Pulse. We're just in the very beginning stages, but what we're trying to do is to be a go-to source to learn about people in the industry, whether they're musicians, actors or athletes—anybody who is given a significant position of influence. It's taking what we do by trade and viewing it through a more altruistic lens. When you see somebody come up, any particular celebrity, and something comes out about them that might become negative, we're trying with our website to go in between as a buffer and say, "Yes, okay, this might be one thing, but did you know this person also supports such-and-such? Here's a little bit more information about whatever charity they're working with." We're trying to open the eyes of people who might perceive celebrities as narcissistic. We're trying to show the connection between people in the entertainment field and charity work, and bring it all together to let people know.

Villere: Do you have a website yet?

Leigh: We're in the beginning phase of it. Our website is going to a second-phase launch this week. My part is a section called "10 for 10." The website has three segments that will talk about people who are ordinary citizens and those who want to find something to be passionate about, so our website is a place to learn about local charities. People can find something that they're into, and then we'll put a spotlight on ordinary citizens who are doing something really amazing. We also have a segment about modern icons—in other words, finding well-known people in the entertainment business. I wrote a piece about David Bowie and his effects—

Chet Cooper: Before or after?

Leigh: After. I talked about his charity work. A lot of people didn't know how involved he was with local charities and with the AIDS Foundation. I didn't know a lot of those things either. Looking back, I was very humbled by it, thinking, "My gosh, if only I had known those things, and not found out in the aftermath." So I have a segment called "10 for 10," which is about finding people in the industry and asking 10 questions in 10 minutes to find out what the altruistic motivation is behind what they're doing and what they're involved with. I ask them some fun questions, but also deeper questions, to learn more about them, so people have more than just the gossip side of someone's life. They can understand a little bit more about that person's heart, what they're working towards and what they're passionate about.

Cooper: And then you'll put the 10 for 10 interview up on your website?

Leigh: Yes. I did my first 10 for 10. I'm on the show



Supergirl, and one of my coworkers is David Harewood. He's an amazing man. He was my first 10 for 10, which will be up on CharityPulse.org this week. It'll be a podcast version of our interview, but I also wrote a piece about him. He's done incredible work with the Anthony Nolan Foundation.

Cooper: So the website will have three segments: a podcast-type 10 for 10 segment, the everyday citizens doing good work, and the third part?

Leigh: That'll offer information on local charities. The everyday citizens are those people who are real stand outs in their communities.

Cooper: Which segment is about doing good work?

Leigh: That's called "Modern Citizen." And then the "Pulse" is where you come to understand the charities we're highlighting and also asking people to help us be aware of them as well. So if you know of a foundation that you're excited about, submit it to us. If you want to piece this and this, eventually that'll be part of what we're doing, too—being able to provide people with something like a questionnaire to help them narrow down what it is that they're passionate about based upon their likes and dislikes or something they want to learn more about. And then we can couple them with another charity, so they're running in their own lane and are able to be more hands-on.

Cooper: Interesting. We should try to work together. We've been publishing for 25 years. We've interviewed so many celebrities and influential people. We never did a 10 for 10, but we could tie things in together so we could do—"And now for Charity Pulse, we're going to ask you 10 for 10," and then feed that back.

Leigh: Great! I would love that. Since we're in the beginning stages, we're just getting everything down to put up on the website, so everyone can understand it.

Cooper: So you're a writer as well?

Leigh: Yeah. My husband's a musician. We do music together. He's in the middle of recording a five-song EP and he'll put that out pretty quickly, too.

Cooper: What kind of music?

Leigh: It's his band. It's a band that's hard to categorize. It would be more like Indie pop culture.

Cooper: Will he be promoting Charity Pulse as part of his awareness when he's on tour?

Leigh: Yeah. That's where his hands are right now. Besides the music, he is getting the website established



Chyler Leigh and Melissa Benoist as *Supergirl*

and running. I've been working on the show, but that's where I can use my influence and my position to find people to interview and ask them these questions. It's simple and it's fun, and at the same time it helps people tie those things together.

Cooper: You've got several people here you should do that with right now.

Leigh: Well, yeah, I need to know them and know what I'm talking about so when I ask them—

Cooper: Oh, I thought the 10 for 10 interviews are about asking standard questions?

Leigh: No. I want to be able to tailor the questions. Many will be the same questions, but I don't want just a surface interview but more, "Help me understand what is the hardest thing you've had to deal with in your life? How did you overcome it? How did it influence you to be the person you are?"

Villere: It might be more than 10 minutes.

Leigh: You'd be surprised. Some of the questions are like, "If you could only have one meal for the rest of your life, what would it be?" That's a quick one, and it leaves room for those moments when people have longer answers. That's the goal, the 10 minutes, but I'm not going to be like, "Oh, no, sorry!" We're doing it fresh in order to bring an altruistic lens to the entertainment industry. ■

continued on page 42

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Thirst PROJECT



At 19, Seth Maxwell learned people around the world were drinking from swamps, mud puddles and earth dams. He also discovered waterborne diseases kill scores of children every year. When his pastor began preaching about missions to provide safe water globally, Maxwell and six of his friends founded the Thirst Project in 2008, for which they've raised more then $8 million to fund clean-water projects for more than a quarter of a million people. *ABILITY* recently spoke with Maxwell along with friend and supporter Chyler Leigh about living on purpose.

Cooper: How did you get started with the Thirst Project?

Seth Maxwell: I had a friend, a photojournalist for National Geographic, who was the first person to expose me to the global water crisis, and I learned that 1.1 billion people didn't have access to safe, clean water. Today it's about 663 million people around the world.

Cooper: How many years has that been?

Maxwell: That was eight years ago.

Cooper: So it's gotten better?

Maxwell: Yes, measurably, for sure, but what it practically means is that in developing communities around the world, women or children literally walk for about three and a half miles from their homes to whatever standing water sources are available, so rivers, swamps, mud puddles. And then, as a result of drinking from these unsafe water sources, will contract easily preventable waterborne diseases, such as diarrhea or dysentery, which actually kill more kids under the age of five than AIDS, malaria, or all world violence combined, including war. We build fresh-water wells in developing nations and impoverished communities to give people clean water.

Cooper: How did you two get to know each other?

Maxwell: At church, actually.

Chyler Leigh: Yeah, many, many moons ago, like seven years.

Maxwell: Seven or eight years, yeah.

Cooper: Let's count the moons. How many moons would that be?

Maxwell: About eight years.

Leigh: Yeah.

Cooper: Eight times 365—

(laughter)

Leigh: Oh, that's a lot of math!

Maxwell: I don't do math.

Leigh: I don't do math, either. We just smile and look pretty. That's about it.

Cooper: So you met at church—

Leigh: Mm-hmm.

Cooper: —and you both sing?

Maxwell: (*laughs*) No!

Leigh: (*laughs*) No! Well, you know.

Maxwell: (*laughs*) In the shower.

Leigh: Yeah, exactly.

Maxwell: In the car.

Leigh: (*laughs*) That was right at the infancy of the Thirst Project. That was when he really just came up with the idea of taking bottled water out into the streets and giving it away and talking to people about the water crisis, as well as what we can do to help and empower the youth.

Cooper: I noticed earlier you were drinking water. When you drink water, do you think of the work that's being done around the world?

Leigh: Yes. (*laughs*) You know, I have kids, and we're very, very strict about water use in the house and obviously turning faucets off, and the kids always get bothered by it. But we've been working together many years, and we've funded wells for the Thirst Project. One year, they actually put together a video from the community where they'd developed a well, and it was a big thank you to our family. And the kids saw it and were so affected by it, just the fact that whatever little thing we could do, we created a life-giving source out there. It hit home with them. So we remind them all the time about being good and responsible with our drinking water.

Cooper: There was a little bit water left in the cup.

Leigh: I chugged it! I wasn't going to toss that away. That would be terrible. I would be a horrible person to be here with the Thirst Project and just toss water away. It would be awful.

Cooper: Over the edge.

Maxwell: Put it on a plant.

Cooper: Have you traveled at all with the project?

Leigh: I have not had the honor to do so, but Seth does.

Maxwell: Yeah. I'm leaving tomorrow at 9:30 for Swaziland in South Africa.

Cooper: Doesn't that sound like an amusement park?

Leigh: In theory. I'm sure if you go to Swaziland it wouldn't be quite as amusing.

Maxwell: It's not like Disneyland.

Cooper: Have you been there before?

Maxwell: Yeah, this will be my 29th time to Swaziland.

Cooper: Wow! There are no direct flights? It probably takes a while to get there.

Maxwell: Yeah. It's from LA to Atlanta, Atlanta to Johannesburg, and Johannesburg to Swaziland.

Cooper: And once you're there, what do you actually do?

Maxwell: I will either take donors or volunteers to see the impact of their work or lead teams that'll do builds or meet with people who want to contribute to building a water project. They'll spend two or three days at a different site or at a single site, going in after the hole's been drilled, and they'll do everything from mixing cement to digging a trench, laying pipe and fixing the hand pump, so that when it's done, they can see the impact of their work on the water projects.

Cooper: Nice! How long does it take to build a well, from start it to finish?

Maxwell: The actual construction process takes about four days, which is really fast. But the process from identifying a site to doing the hydrology and groundwater surveys, to determining where in the community we should build, to the four days of construction, to the pump test to assess the quality and yield and getting those results back, and then training the community on maintenance, repair, sanitation and hygiene, is a six- to nine-month process, depending on which community we're working in.









Cooper: Do you have filters in place after the well is produced, or do you just take it straight from the well?

Maxwell: Almost always, which is why we do a pump test for water quality. We'll assess for high levels of fluoride, or if there's a trace element of arsenic. If there is, we'll make sure we modify or provide a filter. But we're digging 200 to 300 feet deep, tapping into existing and well-protected water tables and aquifers, so nine times out of 10 the communities just take it out of the ground.

*Cooper: [*turning to Chyler*] You have a shovel in your garage?*

Leigh: (*laughs*) I do. It would take me six to nine years to get to the middle down there.

Maxwell: Three hundred feet.

Cooper: So you have equipment in place that can drill?

Maxwell: Yeah, we drill. It's not, like, by hand. The drilling process takes maybe a day and a half to drill the hole.

Cooper: And do the volunteers create a safe environment so things don't fall into the well, including people?

Maxwell: The boreholes are probably a foot around. People aren't at risk.

Cooper: A mole could fall into the hole.

Maxwell: We put casings down. The casings could be PVC or cement. They prevent it from collapsing into itself. Then we'll cement around the casings and let that rest for a few days. At that point the volunteers come in. They'll dig a foundation and mix the cement for the foundation, fix the hand pump, install the gravel pack and sanitary seals and all those kind of things. This is all done under our team's direction.

Cooper: So it's all hand-pumped? There's no electricity needed?

Maxwell: For a number of reasons, we almost never do electric pumps. The communities we work with are extraordinarily rural. Sometimes it takes two, three or four hours from the nearest city to drive to these places. You're on roads that are only roads because you're driving on them.

Since there are no grids to tap into, electricity is not an option, or if you were to install a fuel-powered generator, the community can't always maintain the cost of the fuel, so you'd spend all this money building this project, and then if the community can't maintain the fuel costs, it would be rendered inoperable. There are



Seth Maxwell is the water angel in Swaziland

reasons we don't use solar power that often either. Again, not if but when you have to replace a solar panel, there's not a local Ace Hardware where you can buy it.

Cooper: What about wind pumps? You know the ones you see all over farmlands?

Leigh: Wind power?

Maxwell: Yeah.

Cooper: What are they actually actually doing?

Maxwell: They are doing power. I would say that's used primarily in the developed world. You wouldn't see that used as much in less developed countries.

Cooper: No, I mean the old wooden rickety object. Is that pumping water to the fields? Keeping the well—?

Maxwell: I don't know. I'd have to see the exact—

Leigh: Windmills?

Cooper: Yeah, it's an old windmill.

Maxwell: Oh, that's what you're talking about! I don't know.

Cooper: I was just thinking wind power.

Maxwell: Absolutely.

Cooper: Did you learn anything listening to what Seth said?

Leigh: I always learn things from Seth. He's like this beautiful angel—

Cooper: It just flows out of him.

Leigh: The water man. He's just a wonderful human being who has worked incredibly hard and done an incredible job. Empowering youth is the most important part of what he's been doing. He's teaching kids to love—to find something they're passionate about—and when they do, to go at it without abandon. How many projects have you done?

Maxwell: 1,832 projects.

Cooper: That's incredible.

Leigh: And how many youths have been involved, would you say?

Maxwell: We've had in our history probably about 400,000 students do some kind of fundraiser, like a dance, a video game tournament, a walk or a cut-a-thon.





Nancy Villere - CrushPhotoStudios.com

Seth pondering a world of clean water

Cooper: Do the winners of the fundraiser get to go to any of the sites?

Maxwell: Yeah. Every year we take the top 10 students who raise the most money within our school programs to see projects and sites. And then there are other people who just want to come, so they'll say, "I'm going to fundraise. I'm going to pay the cost to go to the field."

*Cooper: There are some people who have never gone and who just stay home. [*Looking at Chyler*]*

Leigh: I'm one of them, unfortunately!

Maxwell: I think it's even more impressive when someone doesn't have to go to the field and says, "I see and recognize how important it is. I want to get involved without having to have that experience."

Leigh: My husband and I both work with Seth, but it's a little bit harder in our circumstance. We have three little kids, so with work and whatnot, for us to get out there and do that, it literally pulls at me. I want to go so badly, especially to see what we've done, to just be a part of it, to just be affected by it. It's one thing to see it on TV, it's another thing to see it in photos, but it's a whole different experience when you're there, and you're seeing it and you're living it in those moments. That's something I'm very passionate about being able to do, but the work schedule has been very difficult.

Cooper: Habitat for Humanity—probably others do this, too—but they have programs where they charge, so instead of going on vacation, you go to a work site somewhere in the world. The whole family goes, and they use that as a common playcation. Have you thought about trying to do something like that?

Maxwell: We have people who will pay to go. We don't make money off of it, but we have them cover the cost of their trip. It's already pretty costly to fly. If you're going from somewhere like LA or Atlanta to Swaziland, depending on when we book, we've seen ticket prices as low as $1,200 and up to $2,900 once. Usually the whole trip, including ground transportation, bed and breakfast, food and whatever else is needed to put people up, is about $4,000 per person for a two-week trip. It's not cheap. Not everyone can necessarily afford to do it.

Cooper: Those people who are doing this with Habitat can afford it. It's not for everyone, that's for sure.

Maxwell: Absolutely. ■ ABILITY

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NAME DROPPING

By the spring of 2005, I was bothered by tingling, weakness and loss of dexterity in my hands. But it was my failing memory that scared me enough to seek answers. For two years, I had been secretly struggling with cognitive issues — fuzzy thinking, trouble making decisions, multitasking and short-term memory issues. My kids laughed when I tried to order a pizza, and I couldn't remember our own address. I laughed too, but deep inside I was scared. Something had changed in my brain, and I was becoming forgetful, confused and had even gotten lost driving on what should have been familiar roads. At times, I was unable to answer even simple questions. I got frustrated and angry at others and myself, fearing I was going insane. I tried to mask and hide it all. Having recently been awarded sole custody of my kids, I feared losing my mind would certainly lead to losing my children.

Cognitive issues in multiple sclerosis (MS) patients are common, and most of the time they remain minor and manageable. However, when it is your brain that goes to mush at the most inopportune time, it really sucks! I spent the first seven years after my diagnosis hiding my memory deficits. I struggled with multitasking, retaining information and names. My cognitive issues caused me collateral damage in the form of anxiety and extreme exhaustion, and I was pretty sure they would cause me to lose my ability to support my family.

Today, as I travel the country sharing my story, I explain my cognitive difficulties freely with my audiences, family and friends. I try to make light of my symptoms and have a funny quip always on hand for when I get caught in a brain fog. I don't fear losing my job or my kids who have grown up and moved out. I have learned ways to work around my poor memory by using a smart phone, planning my days better and exercising. The exhaustion caused by worry has been reduced, and I have come to terms with my limitations, but there are still times when my disease-ridden brain writes checks even *my* witty humor can't cash.

Such was the case at a recent motorcycle convention in Orlando, where I was unfortunately reminded of how much damage my immune system has caused by chewing away my brain and leaving gaping potholes.

It was exciting to be invited to display my motorcycle inside the convention center with the big dogs and share my story and quest to ride a million miles on my Yamaha. I would have the opportunity to see and meet racing



legends and representatives from all the major motorcycle product manufacturers and retailers. It was another opportunity to find and secure new sponsors, as well as thank the ones already supporting me.

I spoke at a dinner, sponsored by a pharmaceutical company, for people living with MS the night before the convention, and coincidentally would be delivering a talk in the same city on my return a few days later. It was a decent crowd, and the doctor who spoke was energetic and personable, so we chatted a bit afterwards about my adventures.

After a leisurely ride to my hotel the following day, I began my preparation routine for the convention, looked at a street map to make sure I knew how to get to the center and copied the venue's floor plan into my phone. My bike was ready with brochure holders in place. I had snacks and drinks in my backpack, and I set my clothes and medications out for each of the three days. I knew I would be tired each night and getting these things done now would save me from having to endure a game of indecisive mental ping-pong later.

I arrived at the convention center but somehow entered on the opposite side from where the event was and walked at least 50 miles throughout the building to get to the right place. I then had to retrieve my motorcycle and get it to the proper loading area. I was tired and hot, and the convention had not even started yet!

After settling in, I noted where my booth was in relation to the entrance and went to find a restroom. After leaving the restroom, I couldn't remember what I had just made a mental note of and proceeded to get lost while trying to find my way back to my bike. It is hard to explain, but looking up and around in a noisy, crowded environment, I could see all the banners, booths and people, which appeared to be familiar and yet unfamiliar to me, *all at the same time*.

It wasn't until the third day of the convention that I was finally able to find my way back to my booth without the help of someone else. It wasn't that I didn't remember I was located three rows back from the middle of the front entrance, I just couldn't trust myself as to find the front entrance. I would walk halfway there and stop, think I recognized another path and switch directions. If I had been wearing my SPOT Personal tracker device, I would have created quite a bit of entertainment for my followers!

I slipped away from my booth to visit Tex Mawby, the president of Gerbing Heated Clothing (now Gydes Supply Company). Gerbing has been making heated motorcycle jackets and gloves for decades and is the brand all others compare themselves to. Without heated gear, I would never be able to ride comfortably in the winter







season when temperatures can go below zero. It is so important to me that I carry a spare set of heated gloves and a jacket liner in my saddlebags from December through April.

I thanked Tex for donating gear as prizes for my fundraisers, and we talked about my journey and the history of heated gear. He showed me a few new products, asked me my opinion and gave me one of their new wireless controllers to test out. "Promise me, if you write a review of my stuff, you must be completely honest. No BS, tell it like it is. I want to know the truth," he said. I agreed, and we shook hands.

The day ended in an auditorium with a keynote delivered by the CEO of True Value Hardware Stores. It was a long hour, but also interesting and an opportunity to collect pointers to improve my own presentations.

The next day I arrived early to find the doors were not yet open, so I sat outside drinking an overpriced cup of coffee. The man who had delivered the keynote the night before sat down across from me, and I gave him a short wave. A minute later I decided to sit next to him and engage him in conversation. I expressed my gratitude for his talk, admiration of his speaking abilities, and relayed an experience I had at his company. I then went into detail about who I was and what I was attempting to do. I gave him my card and then we discussed touring motorcycles. After about 10 minutes, the doors opened, and we went our separate ways.

About 2 p.m., a chill ran throughout my body. I was telling someone about my chance meeting with the CEO when suddenly I had doubts about who it was I had actually been speaking with that morning. In a dreadful, *Dear God* fumble for my cell phone, I googled the CEO and felt my stomach climb into my throat as his profile appeared. The man whom I praised for his great speech and whom I'd shared my entire story with that morning looked nothing like the picture staring at me from my phone. To my horror, I realized I had made a terrible mistake and had introduced myself to TEX MAWBY, from Gerbing. *The man I had spent 30 minutes talking with the day before*.

I knew this was a doozy of a screw up. An extremely rare moment, I was seriously embarrassed. I finally got up the courage to walk over to the Gerbing booth and wait patiently in a line of customers to eat crow. The look Tex shot me when it was my turn at the counter was a cross between quizzical and condemning.

"That was you in the lobby this morning, wasn't it?" I asked.

"Yeah."







Photo: Tobie Stevens

"And I thought you were someone else?" I added.

"Ah, yeah. That was a bit weird. Didn't know what the hell you were talking about, and then you gave me your card again."

"Well, I am here to apologize. I am quite embarrassed and blame MS and its effects on my memory." I apologized over and over. Not sure he understood until later that evening when I spotted him at a restaurant bar and he smirked and waved at me with a solitary finger. Only then did I start to feel a little better. His gesture was meant for my disease of course, not for me.

On the final day of the convention I had been asked to do an interview. A noise in the background caused me to completely lose my concentration, so I was unable to answer simple questions. I couldn't even recite the saying that is on my brochure and on the back of my business cards. The interviewer had memorized it and fed it to me word for word.

I once heard a cure for MS was a million miles away, so I thought I would just go get it and bring it back.

Clearly I need to ride faster, because days like these are becoming more frequent.

Of course, the week of my memory faux pas would not be complete until I arrived at the MS dinner on my way home after the convention. I was stopped short while trying to introduce myself to the physician. "Paul, we did a talk together last Thursday, remember?"

"Of course I do!"

No, I did not.

As he presented the slide deck, talking about MS symptoms, I desperately wished I could remember, but I'd swear I was hearing him for the very first time.

I often joke my memoirs will be titled, *No Recollection*, but sometimes it isn't so funny.

For all the family, friends and acquaintances I have hurt by not remembering things we did together, thoughtful conversations we had, your name or even who you are, please do not take it personally: *I have a doctor's note*. My inability to remember doesn't mean you are not important to me; you really are. Although I *may look so good*, hidden symptoms of MS like fatigue, chronic pain, bladder dysfunction and cognitive decline can be real pains in the ass to live with, but they fuel my drive to keep *Chasing the Cure*. ■ ABILITY

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Deputy Secretary Christopher P. Lu manages the US Department of Labor's (DOL) 17,000 employees who seek to expand work opportunities for all Americans. He co-edited the book, *Triumphs and Tragedies of the Modern Congress: Case Studies in Legislative Leadership* and spoke with *ABILITY*'s Chet Cooper and Lia Matirosyan at the recent CSUN conference in Northridge, CA, also known as the Annual International Technology and Persons with Disabilities Conference. DOL consultant Josh Christianson joined in to discuss a new DOL app that helps streamline the job application process.

Lia Martirosyan: Deputy Secretary, is this a new position for you?

Deputy Secretary Christopher Lu: I've been on the job since April 2014.

Martirosyan : Did you take over from Kathy Martinez?

Lu: No. There's the secretary, the deputy secretary—which is me, the number two person—and then we have about 10 assistant secretaries, and Kathy was one of those. She was in charge of the Office of Disability and Employment Policy.

Cooper: Is there anybody in her place now?

Lu: We have an acting assistant secretary, a wonderful woman named Jennifer Sheehy.

Cooper: Oh, I know Jennifer!

Lu: She's fantastic.

Cooper: So why is she acting? It's not a bad profession, but—

(*laughter*)

Lu: It's a Senate-confirmed job, and in this climate getting anybody confirmed is very challenging. Literally no one is getting confirmed at this point, so she'll stay in the acting role, where she seems perfectly happy.

Cooper: After Jennifer's installed, maybe we can get a Supreme Court justice nominated.

(*laughter*)

Lu: Believe me, I feel incredibly lucky! I got confirmed two years ago, before the door closed.

Cooper: But even then it was tough.

Lu: It was. But I spent a good chunk of my career working on Capitol Hill, so I did establish several relationships.

Cooper: On both sides of the aisle?

Lu: Yes. But at this point it's not about the merits of any one person. It's one of the things I think is most troubling about our political system right now. It's become so divisive, and it shouldn't be. The vast majority of issues we work on as a department aren't partisan at all. Our employees have a variety of functions. I divide up our work in two ways: (1) We train people for jobs and help them find jobs. (2) We work to protect people. We obviously have OSHA (Occupational Safety and Health Administration), and we've got the Wage and Hour Division (WHD). We enforce workplace laws, including some of the anti-discrimination laws that protect people with disabilities. We often think of the Department of Labor as the department of opportunity. Our job is to provide economic opportunity for people, and the best way you can do that is by giving them access to good, quality jobs, which allows people to have good, middle-class lives.

One of the reasons why I'm here is to ensure that everybody has the opportunity to succeed, whether it's people with disabilities, veterans, women, disadvantaged young people… There are far too many people who have not shared in the broad-based prosperity that we've had in this country. When you look at people with disabilities, the unemployment rate is about double what it is for people without disabilities. But, even worse, I think the labor force participation of non-disabled people is 2/3, 60 percent, and with people with disabilities it's about 18 percent or 20 percent. People aren't even getting a chance to participate in the workforce. These are issues that we confront.

Martirosyan: That is so frustrating.

Lu: In the 21st century, it's a global competition with other companies, and in this competition we need to feel the full pain, and we're not feeling the full pain. There are a substantial number of people who are left on the sidelines, and a large percentage of them are people with disabilities. It's important for me to come to conferences like this to show our commitment, but also, frankly, to learn. In this job I've certainly had an awareness of the challenges within this community, and now I have an increased awareness of those challenges, but I'm excited about how technology can help address a lot of those issues. In my CSUN talk, I laid out a lot about how technology is so ingrained in everyone's life. It's not only your work life, it's your personal life. It allows you to engage with more people and more information than ever before. But if it's not accessible, you're being shut out of a huge part of what is in our workplace and in our society. So I'm excited to come here to learn, to try out all kinds of technology, and to see how we can better support these efforts.

Cooper: It's really good that you're here, especially for the Department of Labor to come out to this one event in particular. The hands-on experience really opens your eyes.

Lu: We have a lot that we can do. We've got grant money that we can give out to foster best practices on disability employment. We've got regulations we've put out that incentivize the hiring of people with disabilities. I think one of the best tools we have is our bully pulpit, coming to venues like this and saying, "We're the federal government. We care about these issues. We want to support your efforts." When we go around and try on technologies and people take photos of me trying the technology, that's a good thing. A lot of this technology is not only great for people with disabilities, it's great for people without disabilities. I'm excited about what this means for everyone.

Cooper: Have you seen any new technology?

Lu: I tried out Sesame Enable, using the movement of my head to click on things. Can you imagine what this could mean for a multitasker? I can shift my eyes or move to one side and that moves a [computer] mouse. The amount by which it could increase my productivity! We were also talking about the Dragon technology (Dragon Speech Recognition Software) that allows you to transcribe words. That has huge implications for people with disabilities. If I ever do another a book, I'm just going to speak the whole thing and use Dragon to transcribe it.

Cooper: Some people lack finger dexterity. I often see people talk to their phones to transcribe emails.

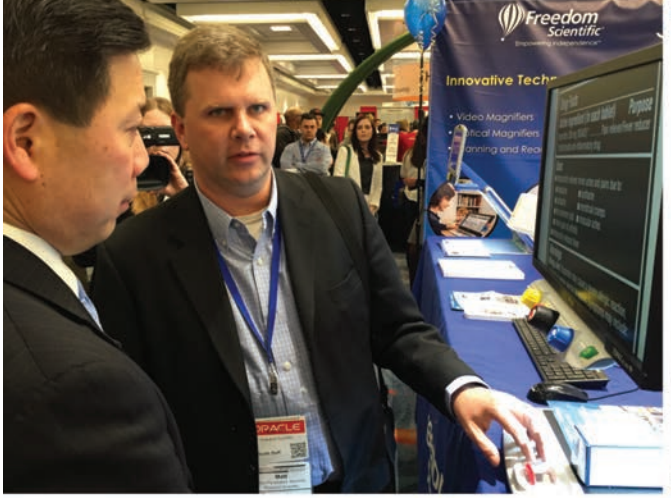
Lu: And I think that's a lot of what we need to do to commercialize some of this technology, and to show the implications for people without disabilities. I'm really intrigued by the driverless car, because I have been taught by Kathy Martinez that one of the greatest challenges for people with disabilities is transportation. If you could figure out a car that drives itself and can help people who are blind get to work, that would be phenomenal. But more important than that, the technology that goes into the driverless car can produce safety features for all cars, because it can evaluate the distance between cars and adjust your speed. If you put that into existing cars, it has the ability to reduce accidents, even if we're driving those cars. I think that's one of the keys here, to show how that technology can help everybody.

Martirosyan: And for multitaskers, can you imagine going to work with all this extra time?

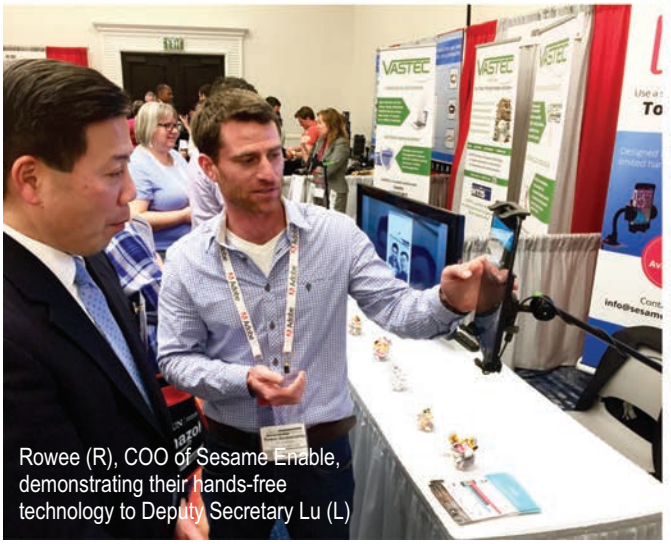
Lu: If I'm using my Sesame while I'm in my driverless car, with my Dragon, talking, moving my head at the same time—

Cooper: —eating breakfast—

(*laughter*)







Rowee (R), COO of Sesame Enable, demonstrating their hands-free technology to Deputy Secretary Lu (L)



Lu: —eating breakfast, shaving, (*laughs*) it'd be pretty phenomenal.

Cooper: Showering, what the heck? I think of that all the time, the benefits of having a driver, but if the car was the driver, it's really—

(laughter)

Martirosyan: Those extra hours of the day that we're always looking for.

Cooper: Yeah, we're all overworked. Is this your first technology conference?

Lu: It's my first CSUN. But it's not going to be my last. This is a lot of fun.

Cooper: Did I read that your team is about to launch something?

Lu: TalentWorks. It's a really exciting initiative. We were looking at expanding the recruitment and hiring of people with disabilities and realized that one of the greatest impediments is inaccessibility of online hiring. We did a survey and found that 56 percent of people with disabilities had found out about a job and applied for it by using a mobile device. But many of the features they were using were inaccessible to them. In that same survey, 46 percent of people with disabilities said that their last experience of applying for a job online was "difficult to impossible." So we realized that technology provides a wonderful virtual tool to interview people, to assess them, to post jobs and to apply for them, but if those tools aren't accessible, you've narrowed the pool of people you're trying to attract.

TalentWorks is an online portal that provides best practices for employers who want to improve the way they recruit and hire online. It's meant to be constantly updated and include an online community where people share ideas about how we can improve. We hope that it allows greater access, because people just aren't applying for jobs through their Sunday newspaper classifieds anymore.

Cooper: They're not circling ads.

Lu: They're not taking their résumé, folding it in thirds and mailing it off. They're applying online. And to ensure that all of those different avenues are as successful as possible, we launched TalentWorks. It's live now. We want to hear from employers, advocates, etc., whether it helps or not, and what improvements are needed. It's meant to be a compendium of best practices for employers.

Cooper: Who put it together?



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ABILITY CORPS





DOL Deputy Secretary Lu trying on the OrCam MyEye device *(see pg 27 for more)*

Lu: Josh can tell you more about that part.

Josh Christianson: We were trying to look at the biggest obstacles for people with disabilities in the workplace. We were talking to researchers and vendors and asking them what the problems were, and it quickly became clear that it was online job applications. We decided to go to the source and put out a survey.

Cooper: What do you mean by the "source"?

Christianson: To people identified as people with disabilities who had applied for a job online within the last year.

Cooper: How did you find them?

Christianson: We used a lot of advocacy organizations we partner with to say, "Can you spread the word?" We had people take a survey, and through that we were able to identify some of the main pain points people report when they're dealing with online job applications. Those issues were what we addressed in most of the resources we put out. Then we went to developers and employers who said, "What are the best practices for how to get around them?" So everything from initial social media and outreach for improvement, to video interviewing, to ways to make the process accessible in order to bring a new employee on board.

We hope to have this move on to the employment life cycle, where once you're hired and in the job, that your workplace technology is accessible so workers can do their job appropriately. We heard that e-recruiting is an issue. We put out a survey so we could hear from users specifically, and that really drove the work we did regarding solutions.

Cooper: I saw the brief this morning, and you have only one job board on there.

Christianson: We're not promoting that job board. They do have an accessible platform. They were one of the many collaboratives we had to inform about what we do. But we talked to lots of people who have different platforms.

We did a blog with them where they kind of gave us their best user experiences. But they're a pool of employers themselves. We talked to their customers on why it's important to reach accessible talent. If you look at our webinar list, we have lots of different organizations that promote accessible job seeking. We do talk with lots of different folks.

Martirosyan: Is this government funded?

Christianson: Our company is not the government. This project is actually funded by a grant. So we have a little more flexibility in what we can do. But a lot of it comes down to who collaborates with us. We put a wide net out, and we're always happy to talk with folks and get thought leaders to share their ideas. They had done a survey with users as well, and that was our first connection point. The site is meant to change and evolve. We want to get more voices and ideas represented.

Lu: Government can be a powerful agent for driving change. But we can't solve these problems. We don't have the resources. This ultimately has to be a collaboration with private business, nonprofits and advocates. We come into this without a monopoly of good ideas. I want to hear from other people. If somebody tells me a great way to do something, that's wonderful.

It's part of the flexibility in the grant. We bring together all kinds of people: public, private. We work with state agencies and other federal agencies.

Cooper: What about New Jersey?

(*laughter*)

Lu: Sure, why not? ■ ABILITY

dol.gov
peatworks.org/talentworks/resources/infographic
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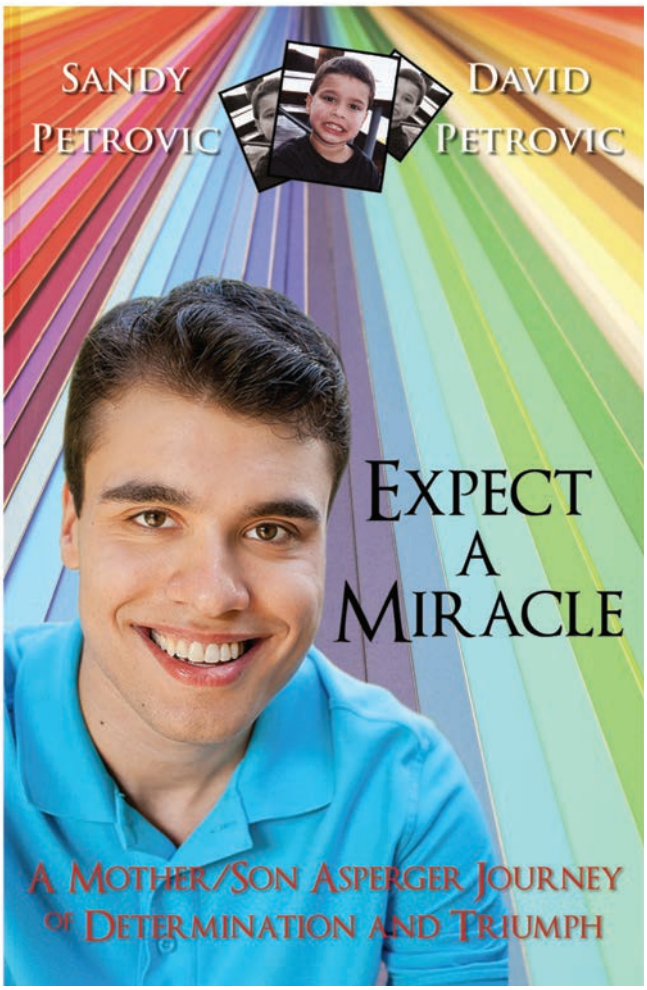
Qualified? Capable? Anxious to prove things to an employer? We've got plenty of job listings from dynamic companies, non-profits and government who want to hire. We're warning you though, they might be a little biased. After all, since many already employed people with disabilities, their expectations might be a bit higher than average.

abilityJOBS.com

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AN EXCERPT FROM



David Petrovic is much older than his 22 biological years. A person with autism and Tourette's, he battled many social, communication, learning, and sensorimotor challenges. Supported by an ever-evolving team, Dave transformed from a struggling and insecure tween to a fulfilled and equipped young man. Once feeling like a misfit without purpose, he journeyed to a place of peace, joy, self-acceptance, and achievement. David learned to self-accommodate and self-advocate. He loves who he is, including his autism, and he's determined to help others by sharing his life-changing realizations.

Dreams, grit, and support empowered David to graduate cum laude in Middle Childhood Education. He now aspires to teach and mentor students in the developmental stage of life that he found most daunting. Using his strengths and experiences, he strives to prevent bullying, foster an understanding and acceptance of differences, and inspire teens to maximize their potentials. Dave's autism has become an asset to keenly perceive what's important in life. He impacts others and demonstrates how "hardship has great purpose." I should know: I'm the mom who journeyed with him these past two decades.

Seeking to reach a broader audience, we have taken to print and podium. We have co-authored *Expect a Miracle: A Mother/Son Asperger Journey of Determination and Triumph* and are avid public speakers on many platforms. Solo, Dave has gone beyond by speaking to hundreds of adolescents on important teen issues, such as the effects of bullying. He educates on autism and differences and is breaking down barriers and stereotypes. He lives his motto: "Embrace a difference…and MAKE a difference!" And he proves my motto: "Not DISability, but DIFability."

To learn more about us and our book, visit www.aspergermiracles.com. But meanwhile, catch a preview of Expect a Miracle through the following:

EXCERPTS (©2014)

Back Book Cover Synopsis

"Co-authored from the separate viewpoints of both a twenty-year-old young man with Asperger's Syndrome and his mother, this work makes it possible to experience life from the perspective of a person with Asperger's, thus enabling its intricate understanding. A unique case study, the book chronicles David's life from birth until successful and fulfilled college living. It reveals every challenge confronted (including bullying), every solution employed, and practical lessons learned along the way. Inspiring hope and ideas, this book would be of interest to those with Asperger's/Autism Spectrum Disorder, their parents and loved ones, and professionals who teach and counsel them."

Chapter One: Why?

(pp. 1-9)

"We are not scientists, psychologists, or education specialists. We are simply a devoted mother/son team who embraced this "trial and error" journey years ago with a relentless determination and tenacity that has not waned. Simultaneous with the realization that David had differences and special needs, I began my search for knowledge, for resources, and mostly—for hope. I was desperate for a guaranteed pathway of intervention and the assurance that my little boy would fulfill his potential and find happiness.

There was no such recipe or absolute promise.

What we did discover along the way, however, were countless guardian angels, both lay and professional, who added their support and special gifts to the therapies, programs, and resources we utilized. This combination, along with dedication and hard work, resulted in a truly miraculous and inspirational outcome. Challenges still exist, as they do for everyone, but David has exceeded every dream I dared to dream—and continues to amaze us daily with his steadfast determination to

achieve his own dreams.

The intentions and motivation for this book are numerous. First and foremost, we would like to provide the hope for others that we sought ourselves. Congruent with the claims of experts, our personal testimonials will exemplify that many skills and behaviors deficient in persons with Asperger's Syndrome CAN be learned. We will show that self-fulfillment and happiness CAN be obtained . . .

. . . Everyone has strengths, and everyone has weaknesses. It must be remembered that even typicals** have social skills flaws—no one is perfect, and everyone has gifts to contribute to the good of all. In addition, it might not be realized that not all the characteristics of AS [Asperger's Syndrome] are negative: there are some commendable and amazing features that are, in fact, coveted and treasured.

The previous statement provides me with the perfect segue to another purpose we have in writing this book. Different does not equal inferior. We hope to stimulate an epiphany of understanding and tolerance for those who are perhaps unknowingly prejudiced towards individuals with differences, with AS being one of them. We implore these parties to rethink their assumption of superiority and to give relationships a chance! Go beyond superficial Asperger idiosyncrasies to explore and connect with the person within—you may never experience more talent, sincerity, loyalty, or unconditional love. So much has been written about individuals with AS having problems with understanding the ways and perspectives of the mainstream. This is my attempt to address the reverse. We aim to educate and inspire the "typical" world's understanding, appreciation, and acceptance of those with AS. . .

**Simply for ease in writing, I occasionally refer to individuals without AS as "typicals," shortened from "neurotypical," as frequently seen in other works. I intend no offense with this categorization and hope none is taken. . .

by Sandy Petrovic

Hello! My name is David Petrovic. Now, like my mother said, we are not any kind of Ph.D. experts, but we do have some insight based on our experiences. I am writing this book because I want it to be a beacon of hope for typicals, families, and exceptionals alike. There are three principles that I've learned in my life that I want to get across in this book:

1) Don't settle for a life that people expect you to live because you have a disability. Go for the life that you "want" and don't let anyone or anything get in the way of you living that life; I didn't.

2) I am a person with an exceptionality (key word: PERSON). People with disabilities aren't mutants or other



worldly species; we're just what we are: people! The one rule I've used in my life is the Golden Rule: Treat others the way you want to be treated. Simply, you're nice to someone, you get it back, and vice versa. At school, the office, and social events, don't be too quick to judge someone based on what you see on the outside. Take a chance to actually have a conversation starter. You may be surprised by what you learn.

3) Everything happens for a reason! It is my ULTIMATE belief that everything we go through in life has a certain purpose. Whether positive or negative, the experiences that life has to offer make up who we are as people.

Throughout this book, you will be getting the perspectives of both the mother and the son. My mom's views will be in regular print and mine will follow in italics."

Chapter Eleven
(David: pp. 259-60)

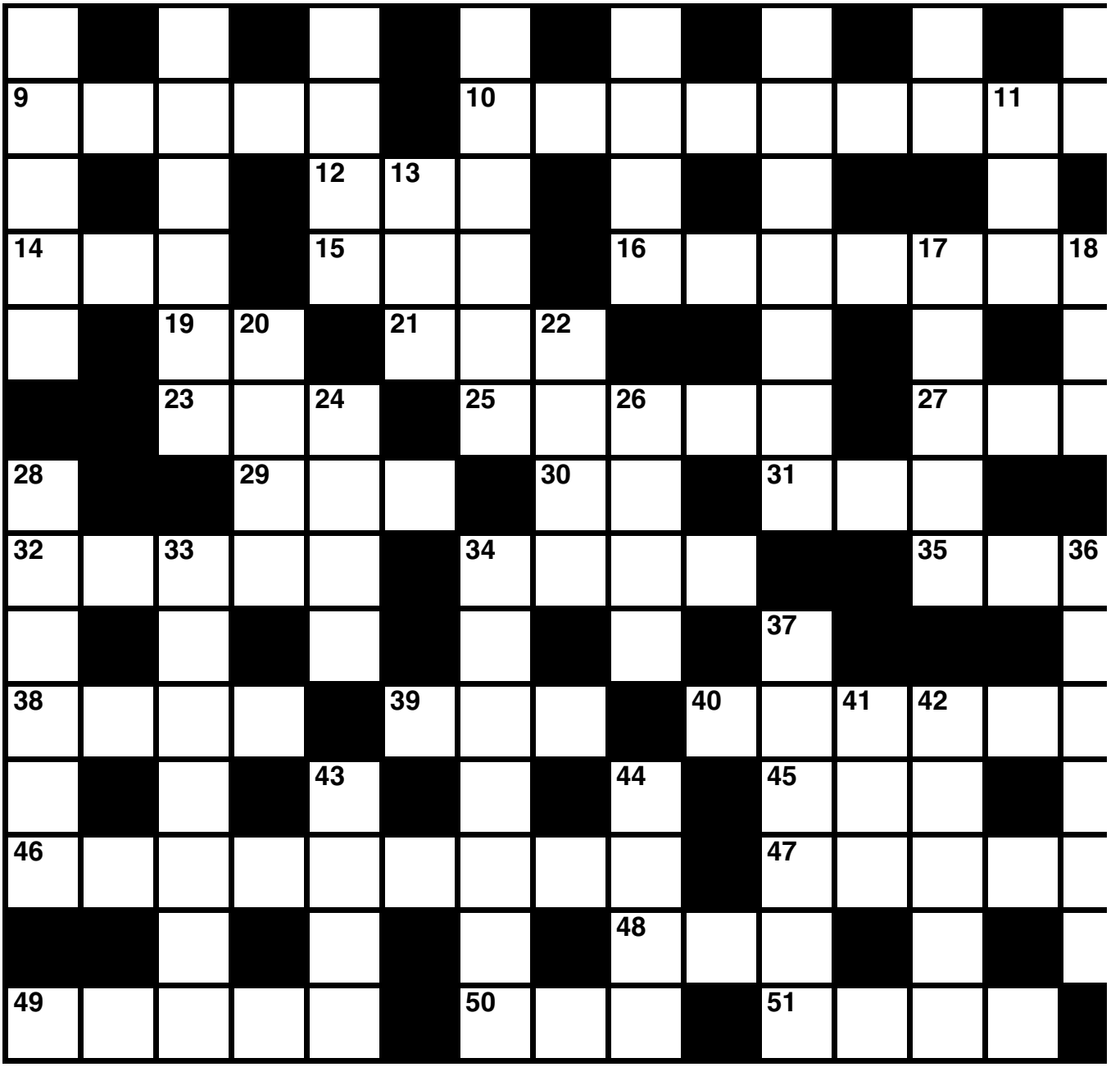
". . . Starting high school as a young, challenged freshman, I always ran out of the school like a crazy person because I was so desperate to get out of there. I had no friends, no social life, and no hope. And I always asked the question, "Why Me?!" But look at what happened in four years . . . Now, it doesn't mean the struggles are over—because they're not. I'm always going to have struggles, but with hard work, determination, and the support of others (as well as faith), instead of having a life I have no control over, I can have the life I've always dreamed of!"

Chapter Fourteen
(David: p. 333-4)

". . . Throughout my life, I've had people look at me in a weird way: you know, kind of like, "Well that kid is sort of –odd!" But like I said, I am who I am, and I love it. And if some people don't, well then, I'll still be polite, but I won't try for more. I'll admit, it's not always easy being me, but I wouldn't have it any other way. . . In my opinion, a world where everyone is the same is a boring world. To summarize, be confident in who you are, own it, and love it!" ■ ABILITY

by David Petrovic

ABILITY's



Crossword Puzzle



ACROSS

1. App that enables you to hear printed text
5. Dog that's trained to assist people with a disability
9. Perfectly clear
10. Played Dr. Albert Robbins in CSI, Robert ___ ___, 2 words
12. Loneliest number
14. 16th US President
15. Retorts are his forte
16. Pined
19. Tie breaker, for short
21. Tom Hanks film about a boy with a dream
23. Irish comedy film' "Waking ___ Devine"
25. Name of a Barbarian and a late night host
27. Drink for pirates
29. Purpose
30. Old form of you
31. Nighmare tree?
32. "American Hustle" star, last name
34. Animated cartoon character or San Francisco rail system
35. Stand in
38. "Construction" company produced its first wheelchair mini figurine
39. "Chicago" lyricist
40. 70s band who sang the David Bowie song "All the Young Dudes" Mott the ____
45. French for street
46. Showing a lot affection for
47. Actor with cerebral palsy, who played Walter White Jr in "Breaking Bad"
48. "Back to the Future" actress Thompson
49. Mentor
50. Frisbee, for example
51. "Not too late" singer, Jones
52. ___ caching

DOWN

1. Spock, e.g.
2. Strategy to "make the right real" for people with disabilities in Asia and the Pacific
3. Bequeath
4. Photographic, as memory
5. Smart
6. Portrayer of Stephen Hawking in "A Theory of Everything"
7. Long-term fund
8. Conger is one
11. Peggy or Spike
13. Ink mover
17. Society's "averages"
18. River barrier
20. Kind of spirit
22. "Naked Maja" painter who opposed Fascism
24. Word with satellite or side
26. Bill Gates, originally
28. Actress who had a breakthrough role in "Children of a Lesser God" (first name)
33. "Don't know much about _____," one of Sam Cooke's lyrics
34. Raymond's last name in "Rain Man"
36. Prominent actress with Down syndrome who plays in "Ameri can Horror Story" Jaimie ____
37. Crazy "Psycho" character, first name
41. Parisian's agreement
42. Disabled actor in "Game of Thrones," ____ Dinklage
43. Noted fugue composer
44. "____ Betty" show

Crossword Puzzle

answers on page 62

Crossword Puzzle

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www.mylifewithoutlimits.org



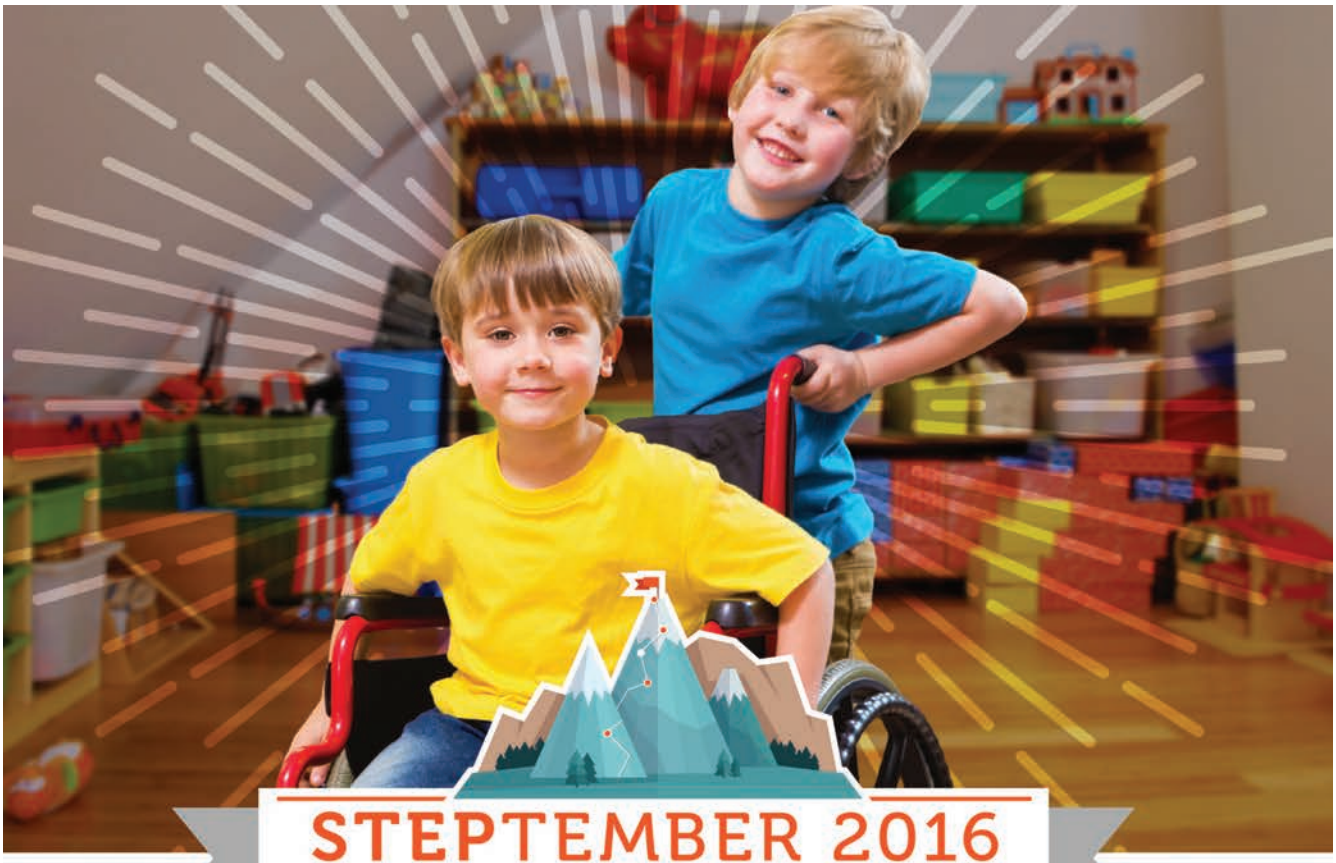
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INTERNATIONAL FEDERATION OF HARD OF HEARING PEOPLE

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WASHINGTON HILTON
WASHINGTON, DC

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- Opening night **Get Acquainted Party**
- Two off-site events to choose from: **Scavenger Hunt in Dupont Circle** or **Monuments by Night,** Friday, June 24
- *Capital* banquet on Saturday, June 25
- **Awards Breakfast and Ceremony** on Sunday, June 26
- First-timer registration discounts
- **Complimentary registration for veterans with hearing loss who have not attended an HLAA Convention in the past**

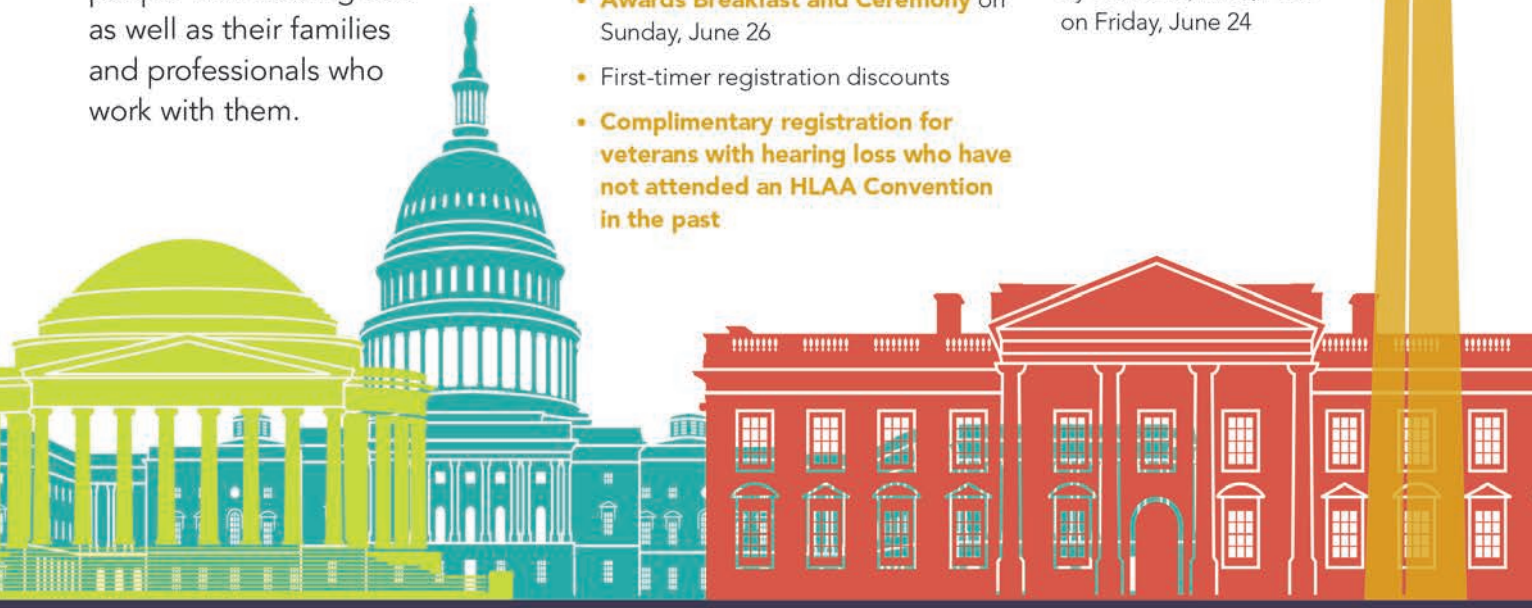
SPEAKERS



Jenny Lay-Flurrie, Chief Accessibility Officer and Chair of the Disability Employee Resource Group of Microsoft will deliver the Opening Session keynote address *Disability as a Strength* on Thursday, June 23



Research Symposium: *Novel Approaches toward Addressing Hearing Loss—Ideas on the Cutting Edge* moderated by Frank Lin, M.D., Ph.D on Friday, June 24



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A
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T
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American Stroke Association
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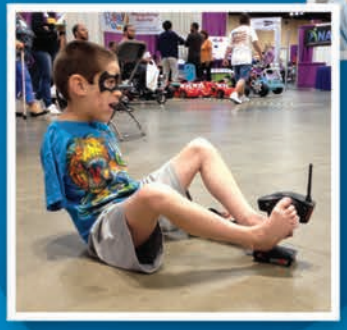












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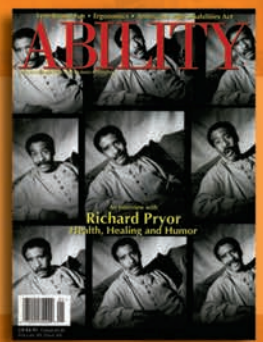
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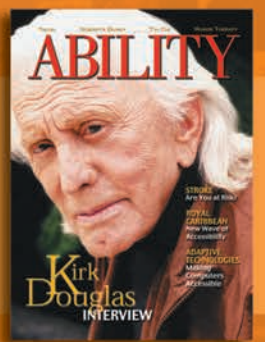
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