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Vernal Equinox



It's that time of year again, the vernal equinox, when night and day are nearly the same length. In Latin, *ver* means "spring" and *equinox* means "equal night." And while there's a fall equinox, only in spring does the sun cross the equator moving northward, on the up, you might say.

This time of year means different things to different people. For example, college students, who spend the week between terms partying, call it Spring Break; while Christians think more along the lines of the resurrection of Christ. Jews celebrate Passover, while florists rejoice at the sudden surge of flower sales.

Of course, children become obsessed with candy-filled Easter baskets, colored eggs and a mystical bunny that hides eggs for them to hunt; while those with hay fever are basket cases, thinking only of Claritin and Benadryl.

All versions of spring are valid, including spring cleaning and spring fever. The former may mean cleaning your home top to bottom, getting your taxes done or re-evaluating your Facebook friend list, and deleting those people you can't remember "friending" in the first place.

Spring fever may show up as listlessness, restlessness, loss of appetite, intense nervous excitement and insomnia. But those could just be symptoms of wanting desperately for summer to arrive.

Regardless of what vernal equinox means to each of us, one constant is that winter is its prelude. In spring, we temporarily say goodbye to cold weather and watch the snowmen melt, their carrot noses nibbled by rabbits that may or may not be related to the mystical egg-hiding bunny.

In every season, we should greet the day with a spring in our step, springing forward with optimism and hope.

We should spring into action when help is needed, and use each day as a springboard to launch us closer to our dreams. Remember, an attitude of gratitude goes a long way in winter, spring, summer and fall.

If your mattress springs poke you, turn it over to see if it feels any better. If not, chuck the thing. Same with your life: See what might be poking you and causing discomfort, and let it go, like the soft petals of a dandelion head in a March wind.

Happy spring everyone! ■ ABILITY

by Geri Jewell



gerijewell.com



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My big move.

I just started a new adventure. I moved from my home in St. Augustine, Florida, to California. I travel back and forth so much because most of the motocross industry is in Southern California and most of my friends are here, too, so I decided it was time to head west.

Off and on, I've been looking for a house in Cali, but every time I came for a visit nothing really caught my eye. In November, my friend Jeff told me about this one house that sounded too good to be true. I saw lots of pics and videos of it and had several different people check it out for me. Then I decided to just go ahead and buy it. I made the right choice; the house is beautiful and I love it!

I was kind of nervous leaving the comforts of St. Augustine, where my family was right down the road, but I decided to follow my dream of living in California. One of my roommates from Florida moved back to California with me, and since then I've found two more roommates. It's definitely not boring or lonely at my new place.



Ashley packing up to move from Florida to California.

I bought the house in November, but had a couple more trips to do and some speeches to give before I could move in. Then my family wanted me to be home for Christmas, so I didn't relocate until the end of January. That's when I packed everything I own into boxes.

Wow, I didn't realize how much stuff I had until I had to move it all. It was never-ending. My roommate, Brittany, was already in California, but flew back to drive out with me. My dad and my grandpa also came; they drove the moving van, and Britt and I followed in my truck. We were loaded down.

When we arrived, my dad and grandpa decided to stay an extra week to help me set everything up and get my utilities turned on. We were all really busy that week, trying to accomplish as much as we could and we got a lot done. I was very proud of my new place.

My family really misses me, and I miss them, too. Lucky for me this is a wonderful time for deaf people. My parents and I text every day and have a virtual face-to-face Skype call at least once a week, So I get to see them, and they can see me, and it makes being far away not lonely at all.

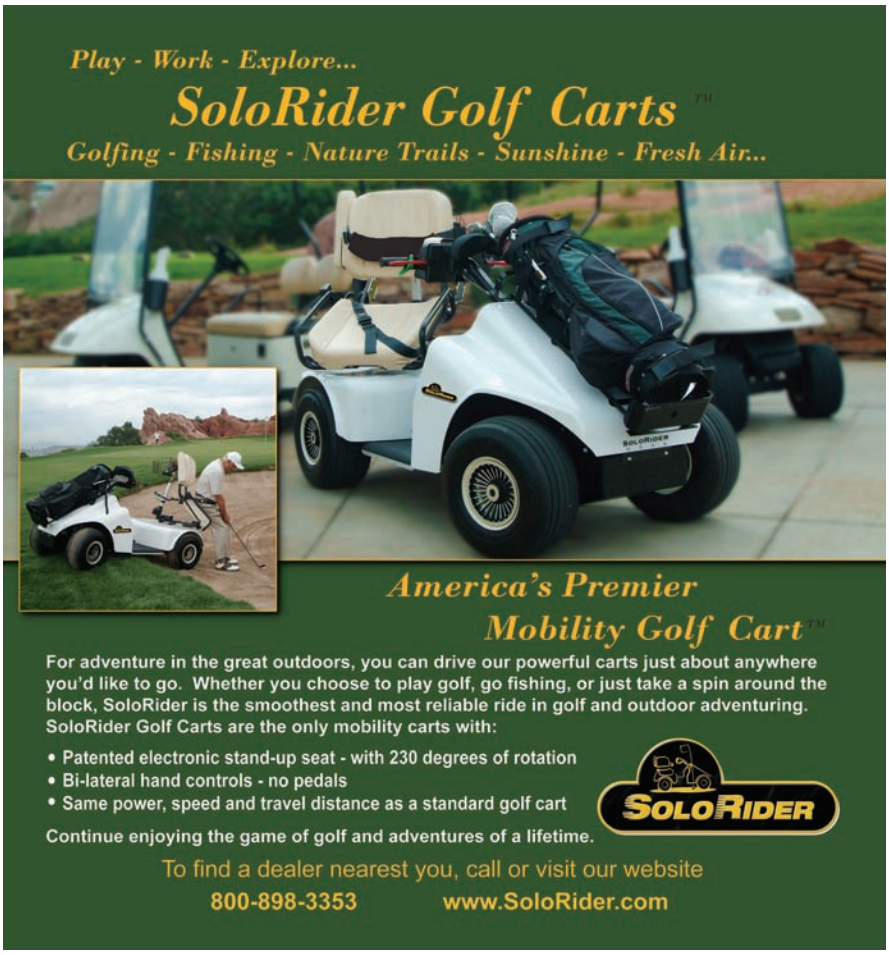
About a month after I moved, my mom received an email from Red Bull of Tampa asking me to give a motivational speech to Walgreens' managers in Tampa, Florida. She quickly sent me an e-mail, asking if I wanted to come home and do the speech, in part so that we could all see each other.

Red Bull let me come in a day early and my mom, dad, brother and grandpa all drove over to pick me up from the airport and we got to hang out. Mom stayed with me so I could practice my speech; she helped by interpreting. My dad and my brother stayed in a "dog friendly" hotel because they brought along the new puppy I had gotten them for Christmas. We even got to go to a dog beach to hang out.

I recently flew back from Tampa, and all went well. The Walgreens team was very welcoming and friendly. I felt a little awkward at first because there was no Audio Visual equipment available and I was worried when I couldn't show a video of what I do. But my talk still seemed to have an impact on everyone.

The whole trip was a lot of funz and I can't wait to see what's in store for me next! ■ ABILITY

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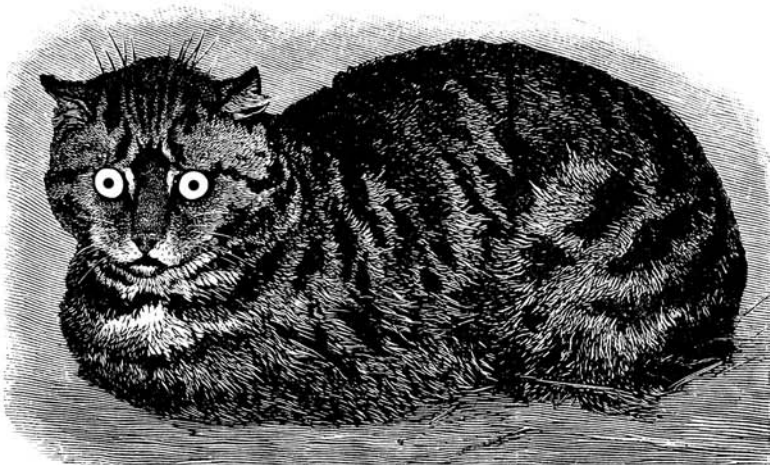




L to R: Walgreens conference, Davin Joseph Tampa Bay Buccaneers Man of the Year and Ashley giving here speech to a reseptive audience.

The Greek GEEK

(Part One; A Catastrophic Tail)



The year was 492 BC and Zotikus had just arrived in Athens to study under the astute philosopher Euripides, so named because as a ticket-handler, theatergoers handed him their tickets and said, "you rip a these." While Plato and Aristotle had stressed the mind and the body, individuality and happiness, Euripides was less conventional. He found thinking too much about anything was time consuming and stressful. Socrates felt it important to lead a questioned life; Euripides, on the other hand, felt that the less one knew the more one could get away with. He surmised that claiming ignorance was noble.

When an inquisitive student asked Euripides if man was meant to suffer, the philosopher paused for a few seconds, winked with both eyes, shrugged his shoulders and slowly nodded with a "maybe." He felt by being non-committal he had less of a chance of being wrong. Students became disillusioned with the teacher, Zotikus even asked for his money back. After refusing to return the student's funds, the irate prodigy snippily asked the charlatan if he had ever read any accounts on ethics by Socrates. He slowly nodded then simply replied, "and Socrates is?"

Zotikus grew older and developed a love for the arts. One night, the young man went to a musical play written by Homer and Hammerstein, about an illustrious affair between Zeus and a peasant flower girl. It was called "Gods and Dolls." The plot line was Zeus teaching an earthly simpleton to portray herself as a societal goddess. Throughout the second act he would attempt to teach her proper English but, it was all Greek to her. The show stopping number was called "I've Grown Accustomed to Your Pomegranates."

While at the play he met a beautiful actress named Kaliope, who played a cypress tree and was enamored by way she gracefully swayed her branches. This talented artist was actually the king's daughter and had gotten the part as a result of the casting agent, Nepotism. The couple fell head over gladiator sandals for each other and it wasn't long before they began discussing the M-word, which was obviously money. Prior to reciting their nuptials, Zotikus wanted to know the status of the dowry.

Before King Vasilis would allow this Greek geek to marry his daughter he wanted to ensure that the fellow was worthy. Zotikus would be given a simple task of going to the island of Crete and picking up a bottle of perfume for the king to give to his wife, Queen Gagaga. Their anniversary was just around the corner. Lately, she had been on a new fad of dabbing sheep urine behind her ears, all the rage—but the ruler lacked the guts to tell her she smelt bhaaaaaad.

"Can't you get anyone else?" Zotikus questioned. "I'm the lead in a new play called "The Odyssey" and it opens next week."

"You'll be back by then," the king shrugged.

"I hope so. It's a once-in-a-lifetime role," Zotikus responded.

"So is marrying my daughter," the king sternly replied.

"Let's hope so, I signed a pre-nup," he retorted.

The king had some serious reservations about his daughter marrying an actor. "They don't make any money," he stated. "Plus, they're always saying 'Look what I can do.'" Down deep, he was hoping the wannabe thespian would get lost at sea or, better yet, get a job.

That night, Zotikus met up with Kaliope to say his goodbyes before departing on his journey the next day. She was worried. Kaliope gave him an emerald bronzed fibula. This was a safety pin to help keep his toga closed. She did not want him hanging out in faraway lands.

"It was my grandmothers," she smiled.

"A knife or a sword might be handier," he remarked.

"You have my love," she assuredly responded.

"Love doesn't kill Titans. You don't have a bow and arrow, at least a shield?" he suggested.

"Don't be silly," she laughed. "You're just grabbing a bottle of perfume."

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They stared into each other's eyes for almost an hour, gazing lovingly at one another. Suddenly Zotikus jumped up and shouted, "You blinked! I win!" and he punched her arm. Then he kissed her like he had practiced on the Venus statue, except this time it didn't taste of city grime. He patted her head then vanished into the darkness.

Before departing, he swung by Mount Parnassus to have his fortune read. There was a flame rising from a crack in the rock, the hot spot for people in the know or at least wanting to be. Most likely, a lightning strike ignited the natural gas, but to the Greeks, like their yogurt, it was sacred. They believed the flame to be of divine origin and built a temple around it. This housed a priestess who was known as the Oracle of Delphi, giving out prophecies she claimed were inspired by the flickering flame. Zotikus was curious of what fate awaited him, and he wondered about the two lotto tickets he bought a week earlier.

In the dingy cave, he put coin in a clay vessel then sat on a small boulder, waiting for the show to begin. Through the eerie smoke, the Oracle appeared. Gracefully dancing and twirling "a perilous journey awaits you," she murmured. "You will go through many trials in many lands. You will be weak at times and strong at other times. Some days you will be dirty and some days you will be clean. You will find love, lose love and, who knows, maybe find love again. But, and this is very important, no matter how you slice and dice it, it ain't gonna be easy."

"Will I make it back home alive?" he anxiously inquired.

The Oracle's pupils grew big as her eyes penetrated him like a toothpick in one of those tiny wiener dog houre d'oerves. "You will, you will, you will…. I'm sorry your time's up," the woman snapped.

Zotikus leaped up, frantically checking his pockets for loose change to throw in the vessel. The Oracle slowly moved back into the thick smoke.

"No! No!" he screamed as she vanished. "What about the lotto tickets?!" he cried.

Zotikus had gathered a group a guys to go with him. He brought his best friend Maximus, a well-known playboy who hated Trojans. Also with him were a group of his artsy clan; Atropos the juggler, Funicius the comedian and Efimia the mime. Basically, they were all out of work and were looking for something different in life. Kicking a clay pot in the street was getting old. "Why not get away for the weekend?" they agreed.

They boarded a ship called Halkyone. Nobody knew that it was a Persian name that meant "Water Leaker." The gang seemed to be lackadaisical regarding the

voyage and tended to look at it as more of a toga party cruise. They set sail. The fellas awoke with their ship lodged on a sandbar. They jumped in the water and, after a quick game of Marco polo, they swam to shore. Everything was quiet at first then from the green forest came the sound of a million meows. The crew had found Catlypto, the lost island of kitties. A rumbling noise was soon heard growing louder and louder. They picked up the brown rocks on the beach to have something to throw at any would-be-attackers. It was useless. The beach was actually a humongous litter box and they weren't holding rocks.

Suddenly, a herd of kitties appeared from out of the jungle and were charging full speed. Zotikus, thinking quickly, pushed the juggler in front him and jumped on the shoulder of Maximus. Closing in, the kitties were in a full gallop. The men cowered down as they prepared for the worst. However, the kitties stopped dead in their tracks then, lovingly, began circling, rubbing their furry cheeks on their furry legs.

The kitties led them into the multi level cat condo that was about the size of the Acropolis. It had obviously taken years to build the feline nest. Sitting on a throne and nibbling ironically on cat fish were the leaders Andromeda and Pussywillow. He and she were an adjoined Siamese cat with two different gendered heads and one fat, fluffy gray body. Together they were both one powerful Peloponnesian pussy.

The kitties had made the boys slaves. They were ordered to bathe the cats once a week. After the fellows were through licking the cat's body they would cough up fur balls for several hours. The cats were ruthless. For three months the outsiders were subjected to catch fish, fill kitty bowls, carve scratching posts, make small decorative squeaky toys and provide round-the-clock belly rubs. The men knew that their own survival depended upon escaping.

Zotikus approached the rulers one day and told him her that he and his colleagues would like to thank all the island kitties for their hospitality and wished to make them a great feast.

"What would be on the menu?" Andromeda inquired.

"The main dish would be fish gumbo stew served with sardine appetizers, a few gyros, a little baklava, and some lobster tail."

"I'm allergic to shellfish," Pussywillow interrupted.

"Then I'll make you a seaweed feta salad and some keftedakia?" Zotikus shrugged.

"May we also have a side of spinach phyllos dipped in a cucumber sauce?" Andromeda excitedly asked.

"I don't see why not," Zotikus slyly remarked. "After all, you are the king and queen kitty."

"That we are, you petty, worthless stinking Greek," Pussywillow belittled. "That you are. Now get your hairy backside a cooking. We feast by five."

The kitties taunted and hissed at the slave boys as they slinked off to prepare the meal.

Unbeknownst to the kitties, Zotikus had loaded the meal up with cat nip. The kitty's bellies were full and extremely satisfied, as evident by the purring choir floating in the air. But now, they were hungry for entertainment. The cat nip was kicking in and the kitties were becoming restless and playful. To settle them down, Atropos the juggler, stood before the cats tossing up coconuts and conch shells. The little animals were bored off their tails. The magician got up and made a mouse appear from his hat. A cat pounced on him and ate the mouse then he claimed he was a better magician cause he made the rodent disappear.

Zotikus launched into an akward Zorba the Greek-like dance. As he squatted and kicked his hairy legs up, the kitties rolled around, roaring with meowed laughter at the clumsy clown. They were now peaking on the cat nip and primed for the planned escape.

Zotikus pulled out a small pan flute he had whittled out of a piece of drift wood. He began playing. The kitties became quiet, cocking their head in amazement. He continued to play the sweet song as he marched into the jungle. The cats, mesmerized, followed behind him in a straight line.

Leading them up the mountain, he brought them into a cave he had discovered while looking for coconut milk for a litter of kittens. The moonlight seeped through the opening as the sound echoed beautifully off the walls. The kitties, in awe, sat and listened.

Zotikus stopped playing and said, "whoever plays this will have the strength of Zeus and the agility of Mercury." He then threw it in the middle of the cat clan causing an all out kitty brawl as they scratched and clawed each other for the musical toy. A few moments later, the cave was pitch dark. Zotikus had ducked out during the melee and his men had rolled a boulder in front of the cave, sealing the felines in. The men doggy-paddled off the kitty island to their ship.

As they sailed away, faint, rhythmic, high-pitched cries could be heard. Later on, the island would be known as "The Land of a Thousands Meows With A Pan Flute Melody." Safely on board, the weary adventurers settled in for a long cat nap. ■ ABILITY

by Jeff Charlebois

to be continued...



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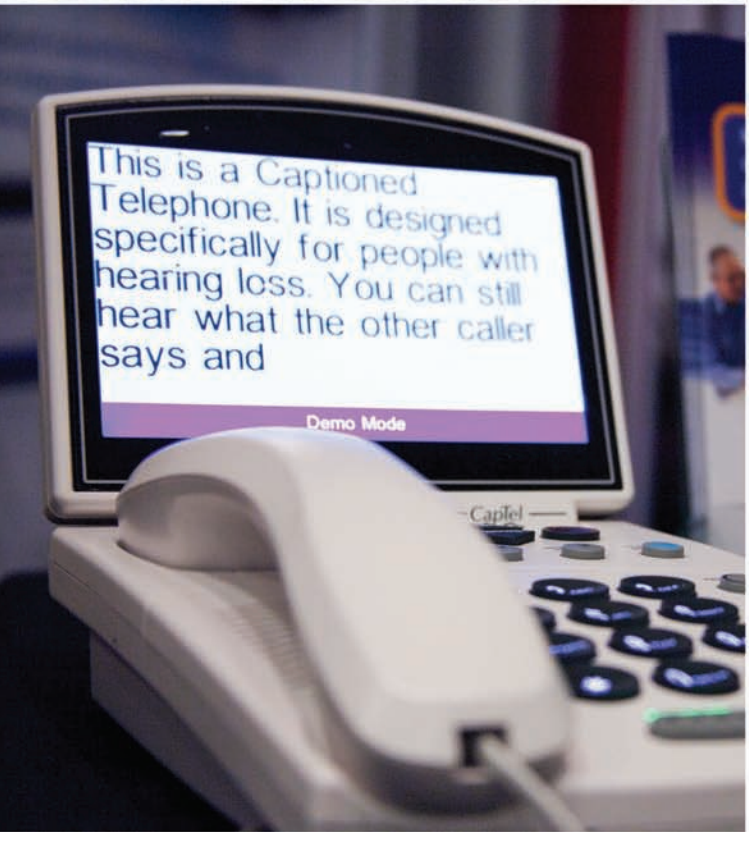
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Beam Me Up CSUN!

Brand new to ABILITY Jobs, I was honored and excited—okay shaken—to be invited to my first California State University, Northridge (CSUN) Conference in San Diego. It was also my first major crowd scene since my sensorineural hearing loss about seven years ago.

With a scant two days' notice, I got pulled into the deep end of the assistive technology pool by ABILITY. Wide-eyed and a bit red-eyed from my flight from Washington, DC, to San Diego, I walked gingerly into the 28th Annual International Technology and Persons with Disabilities Conference, commonly called CSUN. There, I found an abundance of inspiration.

Diverse groups of people with a range of abilities and disabilities teamed with excitement. We came from around the world, using whatever we needed, from service dogs, to assistive devices, to canes and electronics, in order to stay at the top of our game. We shared our experiences and visions for advancement.

Corporate accessibility leaders from such companies such as Adobe, Comcast, Oracle and State Farm, demonstrated their latest innovations throughout the weeklong event. We were all invited to the groundbreaking of a new association dedicated to enhancing the accessibility profession; it aims to provide an international structure of support, which also includes collaboration and education. Ultimately, the aim is to increase opportunities for people with disabilities.

From the presenters, to the participants, to the person just breezing by—everyone had a story that was their gift to share.

Lily Bandak, a captivating woman who presented her vibrant view of the Arab world through photography, left a lasting impression. She captured the cultural essence, architecture and landscape from Bahrain to Egypt. She snaps her pictures as she rolls along in her wheelchair, doing what she loves and besting the effects of multiple sclerosis (MS).

Attendee Ray Grott, director of Rehabilitation Engineering and Assistive Technology Project at San Francisco State University, has been attending CSUN for more than 20 years. His passions include developing assistive technologies to help people with disabilities adapt to work and life environments. He spoke movingly of his

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clients, including some with Usher syndrome, a disorder that affects both hearing and vision.

Microsoft, JP Morgan Chase, IBM and Bank of America, to name a few, told similar corporate narratives about their commitment to employing people with disabilities.

Microsoft, for example, actively searches for talent for entry-level Internet technology (IT) positions as well as to test new technologies, says Cynthia Shelly, senior technology strategist. Kurt Mattes, a vice president at JP Morgan Chase, and Phill Jenkins, a representative on IBM's US Access Board, were clearly driven to encourage people with disabilities to enter and grow in the field of IT.

Mattes pointed out that one of his top Web programmers "who can build a mobile app from the programming language code up" is blind. So is IBM's Matt King, an IT engineer who beamed about his passion as a champion tandem cyclist, and how some people get nervous when he gets close to the edge of the track.

ABILITY Awareness brought international flavor to CSUN by displaying samplings of its future art exhibit, "From China, With Love." The delicate poetry, painting and photography illustrate the immense talents of Chinese artists with various disabilities. The main 85-piece exhibition and auction will take place, for the first time in the US, later this year. This historic creative exchange will extend into 2014 when an exhibition featuring US artists with disabilities presents in China.

On a personal note, Mitchell Levy's presentation for Hamilton CapTel (Captioned Telephone) was most memorable and useful to me. I was so enthralled to learn about this cell-phone captioning technology that I didn't notice Levy had a sign-language interpreter assisting him until the Q&A session. CapTel technology was developed by Raketu Communications to create an easier phone experience by captioning complete phone conversations, both incoming and outgoing voices, on CapTel-equipped phones, computers and many smartphones. Devices and free services are also available through Sprint CapTel.

I'm eager to use these services as I take ABILITY Jobs to the next level, connecting abundant talent with fantastic companies.

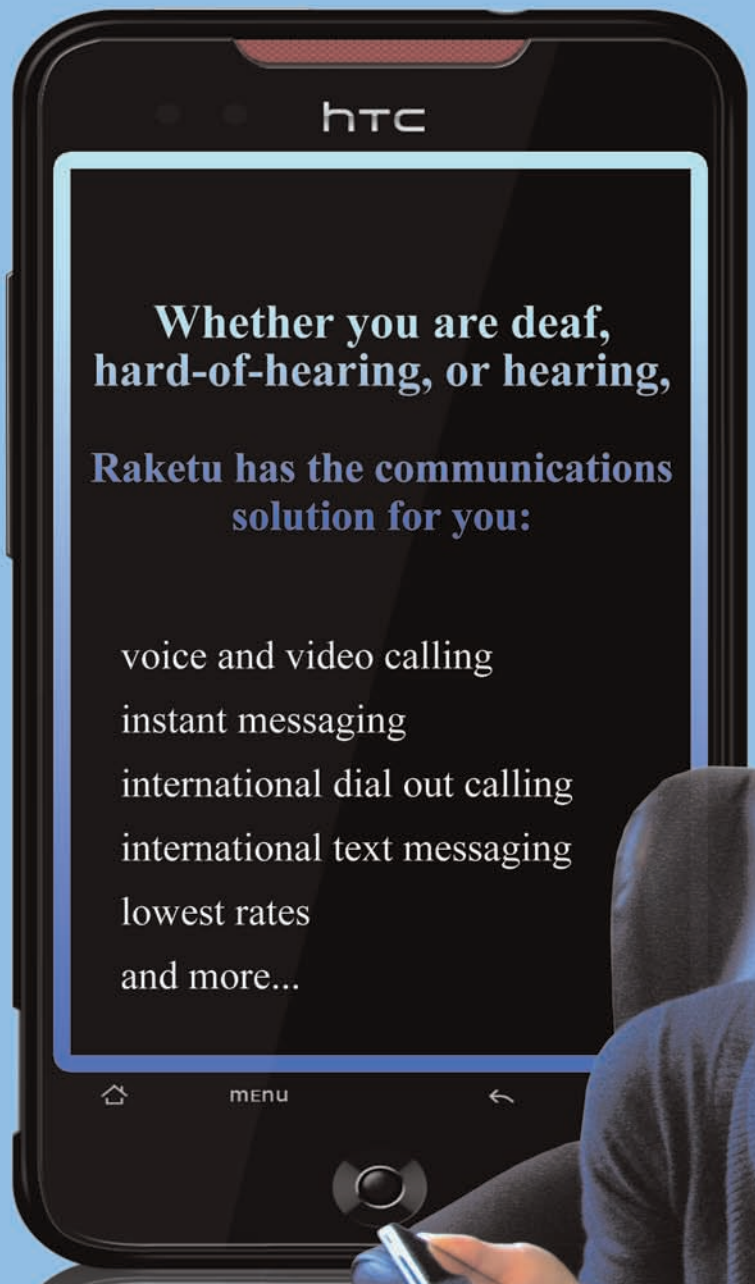
After CSUN, I couldn't be more excited to help job seekers with disabilities move to their highest professional opportunities, while supporting companies as they meet their goals to employ the wealth of qualified individuals within this arena. ■ ABILITY

by Marge Plasmier

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IF LIFE WERE EASY, EVERYONE WOULD GET ONE

I never claimed to take the easier, shorter, or most traveled road. As a matter of fact, I usually take the path where everyone warns me, "You can't get there from here!"

Pursuing uncharted paths can be rewarding, but it can also whack you in the knees, throw you down and steal your breath away. I don't know about you, but when I do manage to scramble to my feet again, I'm more determined than ever, and I'm not just talking about bouncing back from the uncertainties of living with Multiple Sclerosis.

In 2001, I rode in what is called "The World's Toughest Motorcycle Competition." The bike was a Russian Ural with tubed tires, drum brakes, and no electronic ignition. Even the bike's manufacturer warned me that I had no chance of finishing an 11-day, 11,000-mile event riding their motorcycle.

Because of my reputation as a prankster, many felt I'd foolishly squandered a coveted entry spot in the race. However, all kidding ended when, 250 miles into the ride, I blew the first of three engines. If I had quit then—a thought I briefly entertained—the next 10 years of my life would've turned out differently. But I got up and pressed on.

Eight hours and three or four more breakdowns later, the steering blew, and deposited me face down on an Arkansas interstate, where I slid about 50 feet on my belly. I was ready to quit after that. But with the help of a kind state trooper, who called his wife to bring me some oil to replace what had spilled during the fall, I rose from the ashes, so to speak, and forged ahead.

By then I had made it three quarters of the way around the country on the world's biggest piece of junk, with no intention of doing anything more than dragging it across the finish line. But suddenly a broken engine pushrod stood between me and my goal. Over the phone, a Russian mechanic empowered me: "Just find metal and make pushrod," he suggested. So I limped into a Rawlings, WY, hardware store, and cobbled together enough items to fabricate the needed engine parts. Once more, I got up, powered forward and finally finished the rally.

Later, when I could laugh about it all—sort of—I put together a slide show presentation: "Having MS is Like Riding a Russian Ural in The Iron Butt Rally." It recounts the painfully humorous and uncanny similarities between entering an endurance competition on an antiquated Russian motorcycle, and every day life with MS. Finding and harnessing my inner strength helps me persevere through seemingly overwhelming challenges and carve out my own destiny.

The past few months have been kicking the hell out of me worse than that Russian Ural, including a recent 100-day headache.

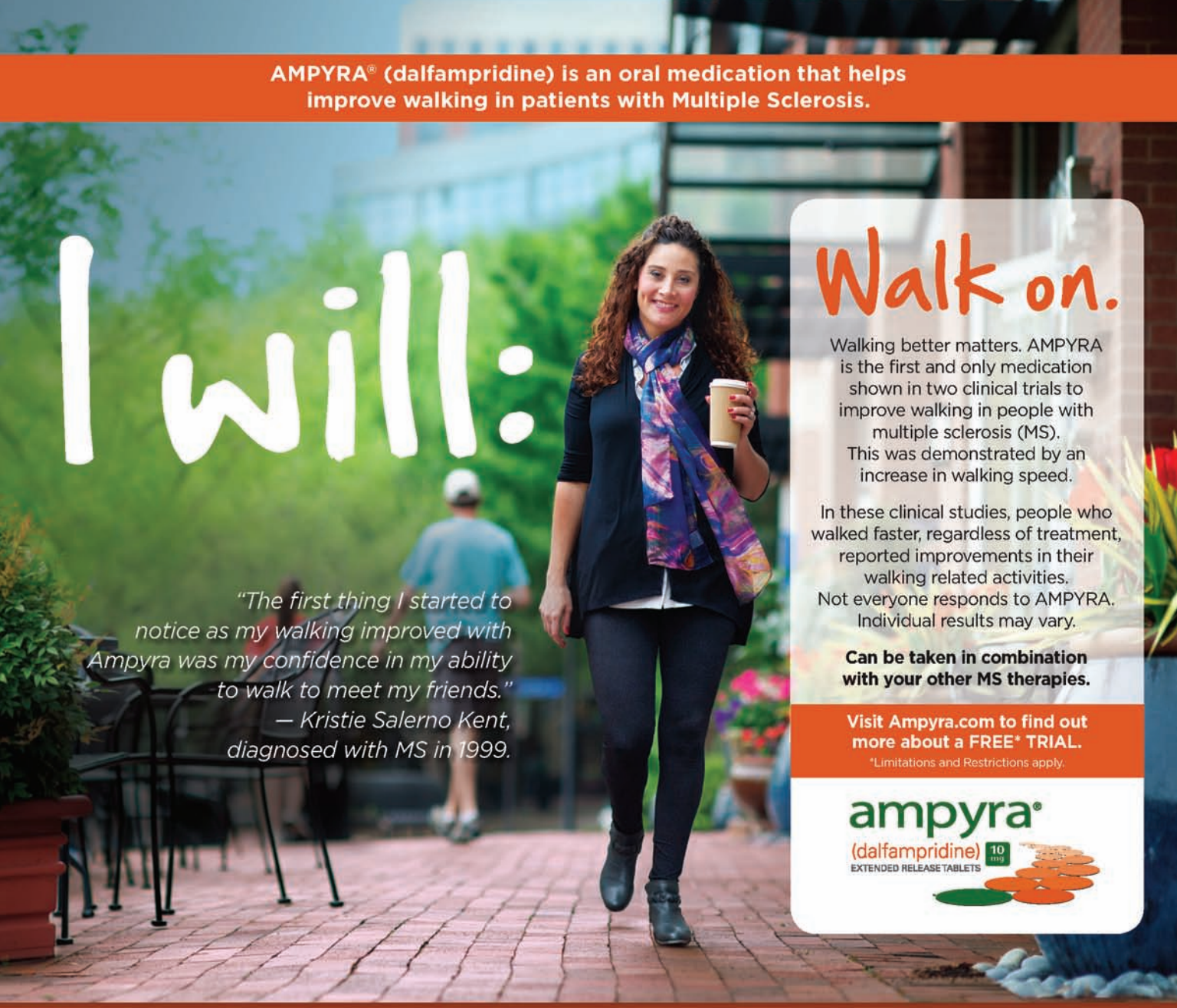
It came on last fall, and was the kind you get when someone switches your coffee to decaf and doesn't bother to mention it—multiplied by 10. The pain continued the next day, the day after that, and on and on without ceasing. For the first time in my life, I left work early for several days, and even used up some sick time.

We wondered if it might be a new MS attack, although an MRI scan showed no new lesions on my brain. However, there were signs of significant stenosis on my spinal cord. Around Christmas, I got a steroid epidural, but the headaches would not go away. As a precaution, I was prescribed Acthar Gel, an alternative to steroid infusions for MS relapses.

I recently started physical therapy, and between the gel and cervical traction, I've finally gained some relief. It was not until February—three-and-a-half months later—that I had my first full day without a pounding headache. Apparently all the years of riding with a helmet, coupled with bad posture, put too much pressure on my vertebrae. Now I focus on sitting up straight, and stretch daily to keep the headaches and any future surgeries at bay. It took me a while, but finally I was able to get up and at 'em once again.

Just as I was celebrating my first headache-free week in 100 days, life kicked me in the kidney: I first experienced a sharp pain in my abdomen and lower back on the right side as I stepped out of the shower one day.

AMPYRA® (dalfampridine) is an oral medication that helps improve walking in patients with Multiple Sclerosis.



Walk on.

Walking better matters. AMPYRA is the first and only medication shown in two clinical trials to improve walking in people with multiple sclerosis (MS). This was demonstrated by an increase in walking speed.

In these clinical studies, people who walked faster, regardless of treatment, reported improvements in their walking related activities. Not everyone responds to AMPYRA. Individual results may vary.

Can be taken in combination with your other MS therapies.

Visit Ampyra.com to find out more about a FREE* TRIAL.

*Limitations and Restrictions apply.

ampyra®
(dalfampridine) 10 mg
EXTENDED RELEASE TABLETS

Talk to your doctor to see if AMPYRA may be right for you.

In two pivotal trials 35% and 43% of patients taking AMPYRA responded to treatment vs. 8% and 9% of patients taking placebo.

IMPORTANT NEW SAFETY INFORMATION
Do not take AMPYRA if you are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA.

IMPORTANT SAFETY INFORMATION
Do not take AMPYRA if you have ever had a seizure, or have certain types of kidney problems, or are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA.

Take AMPYRA exactly as prescribed by your doctor.

You could have a seizure even if you never had a seizure before. Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.

Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.

AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same.

AMPYRA may cause serious allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have shortness of breath or trouble breathing, swelling of your throat or tongue, or hives.

Please see the full Patient Medication Guide on the following page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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MEDICATION GUIDE FOR AMPYRA® (am-PEER-ah) (dalfampridine) Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is the most important information I should know about AMPYRA?
AMPYRA can cause seizures.
- You could have a seizure even if you never had a seizure before.
- Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.
- Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See "How should I take AMPYRA?"

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

What is AMPYRA?
AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

Who should not take AMPYRA?
Do not take AMPYRA if you:
- have ever had a seizure
- have certain types of kidney problems
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA

What should I tell my doctor before taking AMPYRA?
Before you take AMPYRA, tell your doctor if you:
- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant.
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements.

Know the medicines you take. Keep a list of them and show it to your doctor and pharmacist when you get a new medicine.

How should I take AMPYRA?
- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- **Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.**
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine).

What are the possible side effects of AMPYRA?
AMPYRA may cause serious side effects, including:
- serious allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have:
  - shortness of breath or trouble breathing
  - swelling of your throat or tongue
  - hives
- kidney or bladder infections

See "What is the most important information I should know about AMPYRA?"

The most common side effects of AMPYRA include:
- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store AMPYRA?
- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

Keep AMPYRA and all medicines out of the reach of children.

General Information about the safe and effective use of AMPYRA
Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

For more information, go to www.AMPYRA.com or call 1-800-367-5109.

What are the ingredients in AMPYRA?
Active ingredient: dalfampridine (previously called fampridine)
Inactive ingredients: colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

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Ardsley, NY 10502

Issued 01/2013

This Medication Guide has been approved by the U.S. Food and Drug Administration.

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ACØRDA®
THERAPEUTICS

Within minutes I was doubled over in pain. As one who usually just reaches for a needle and thread to patch myself back together, my wife was quite concerned when I told her that I needed to go to the hospital. I knew it had to be my appendix, a kidney stone or—given the severity of the pain—the impending birth of a child.

It turned out that an "asteroid" had decided to pass from my kidney, getting stuck on the way to my bladder. Writing this column, I was in excruciating pain, and had been for days. If the stone didn't pass by a certain time, I was told: "We're going to jam a laser up there and blast it to smithereens." Fortunately, the bugger eventually passed before they had to go in there after it.

Sure, I've been slowed down by some rough patches, but I'm still determined to raise both awareness and funds for MS by setting more motorcycle endurance records. People laughed at me when I said I was going to ride 1,000 miles on 100 different motorcycles in less than 24 hours. And yet with the help of a dealership and some friends, I not only pulled it off, but also raised $4,000 while setting a new world record.

Since then, I've been talking about a much more serious and difficult feat: breaking the current endurance record of 31,000 miles in 31 days. For my best shot at success, I know that I need to secure sponsorships from a motorcycle manufacturer and a pharmaceutical company. I chose April Fools' Day 2013 for obvious reasons, and figured 10 months would give me plenty of time to prepare. I believed I could convince a motorcycle manufacturer of my ability to ride, and of the great publicity such an event could generate for them.

Unfortunately, I have not yet found a manufacturer who is willing to lend me a couple of bikes to set a world record for MS. I suppose they may be worried the bikes may not make it, or that the feat sounds too dangerous. (Although some of these guys sponsor every type of road race, motocross and around-the-world adventure in other countries.)

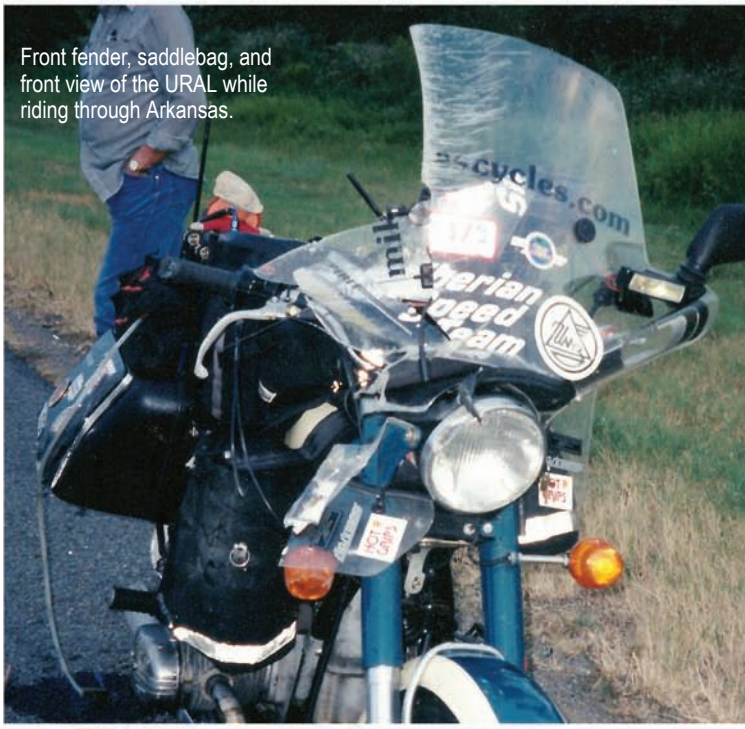
I continue to ride to many MS events, sharing with patients my story and the lessons I've learned about living with this condition. So far, however, I have not been successful in booking a formal talk or presentation.

Though my spring world record bid had to be postponed, when the time does come, plenty of friends have promised to help, and some companies that make tires, gear and accessories have stepped up to be sponsors. Use of the bikes, servicing them, gassing them up, and the personal loss of income during the trip would cost me around $30,000, and I just cannot take that financial hit on my own.

Without corporate sponsorship or speaking opportunities, I have to get more creative. But I will find a way to break the record riding at least 32,000 miles in 32 days.



Like clockwork, the Ural broke down just about every four hours!



Front fender, saddlebag, and front view of the URAL while riding through Arkansas.



The Bike slid down the highway in front of me, creating rich colorful sparks.

Putting the pieces in place may take longer, but will make the resulting story all the more interesting.

September sounds like a better month for breaking a world record, anyway! ■ ABILITY

by Paul Pelland

Longhaulpaul.com

Flash Forward

TRIATHLETE WINS WITH CLUBFOOT



Tony Spineto's body pulsated with pain. He only had 100 more yards to go in the final stretch of the Ironman Arizona competition, but it felt like 100 miles. He gave it everything he had because after five months of training, there was no way he could come up short.

"As I turned into the finisher's chute," he recalls, "I was greeted with a large cheering crowd and bright blinding lights... I reached deep down inside myself and disregarded all pains and fears."

Racing his final steps, he stretched his arms out, reaching for volunteers to catch his weakened body. He had done it, despite earlier claims from doctors that he would be in a wheelchair by the time he was 20, hobbled by bilateral clubfoot and arthritis.

'I'm an Ironman!' Spineto thought, but his next thought was of his feet, which ached horribly.

At birth, his feet looked as if they'd been rotated inwardly at the ankle. Without treatment, a person with clubfoot may appear to walk on his ankles or the sides of his feet, but Spineto underwent surgery in 1975 for a cosmetic correction of his condition, which occurs in one out of every 1,000 children born. Though surgery improved his feet and ankles' appearance, physicians advised him to limit his physical activity.

"My doctors told me not to run," suggesting it would cause more harm than good, he recalls. "So I led a really unhealthy lifestyle for many years."

When his daughter was born, his wife, Erin, a sailor and triathlete herself, challenged her husband to run to lose weight. At the time, he was around 260 pounds. So he started jogging in 2006, ultimately dropping about 100 pounds.

Once it was established that he could run, his wife challenged Spineto to tackle a sprint triathlon, which starts off with a quarter-mile swim, moves on to a nine-mile bike segment and concludes with a two-mile run. Spineto took the challenge on and bested it late last year.

But it wasn't until the couple's son, Eli, was conceived that Spineto fully dedicated himself to an active lifestyle. During the pregnancy, he and Erin went to weekly sonograms because she is a type-1 diabetic. During a routine visit, the doctor showed the couple their baby's heart, lungs and, well, boy parts on the screen.

"We asked if he could check out the feet, and the doctor was like, 'Uh, okay.' We looked at the feet and then at each other, and knew right away," Spineto recalls. "The doctor had this blank look on his face; [he got] very quiet. He wrapped up everything and said, 'When you're all cleaned up, come into my office and we'll have a discussion.' We knew what it was going to be about."

The image showed that the couple's unborn son had bilateral clubfoot, just like his father.

Spineto said the doctor redirected the conversation toward "options."

"We were like, what do you mean options?" Spineto said. "He said, 'You have the option of having an abortion.' We looked at each other, and man, it was hard."

The difficulty of comprehending what the doctor had just told them wasn't about a political ideology. It wasn't about the medical diagnosis of their future as parents.

"When the doctor asked us that question, it hit me that the world doesn't see my son as worthy of living because he has some limitations. Just because a person has a disability doesn't mean that they don't deserve life," Spineto says. "At that moment, my racing took on a different cause. My son is why I race."

Spineto left the doctor's office on a mission. He knew the difficulties that he had faced with clubfoot were being overcome through physical activity. That day, he decided to take on more triathlons in order to educate as many people as possible about clubfoot and its possibilities, not its imperfections.

"I wanted to begin to raise awareness… and I wanted to do something to set an example for Eli," Spineto says.

He began competing in Olympic-distance triathlons, which are twice as long as sprint triathlons. Then he moved up to half-Ironman competitions. Then, last November, he crossed the last threshold: becoming an Ironman.

As he began to lose weight, he overhauled his diet, and now follows a vegan regimen. He begins training for triathlons six months in advance, spending 20-30 hours a week performing two workouts a day, including a run, bike and swim. And every step he takes is riddled with difficulty.

"Over the years of racing, I've accepted that it's going to be painful and a challenge," he says. "It's something you deal with while you're out on the course. It's expected. I don't know how I do it, but I have the drive to do it. I have a purpose. When you have a drive and a purpose, they override your weaker moments.

"Ever since I was a kid, I've been in pain. All I know is chronic pain. When you're out on the course, it's more intense because you're pushing your body to the limit. It's something I accept."

The ironic thing about Spineto performing through the pain is that his bike and swim times are equivalent with those of top triathletes. His run times, however, are very poor. He's accepted that, and knows he's not competing





Spineto with son, Eli

to win gold medals, but to win acceptance for others with his condition.

"I'm playing with the cards I've been dealt, and at that point it becomes an individual sport," Spineto says.

He takes no medication—even when he competes—despite the fact that his feet, legs, hips and back all hurt. He participates in 11 races per season, and aims to throw his name in the hat for the USA Paratriathlon National Championship Event, as well as the world championship in London this September.

His sponsorships outfit him with clothing and nutrition; they also cover entry fees for larger competitions, which offers him a bigger platform from which to share his story. Though his backers know that he's not likely to win events, they have partnered with him because they believe in his cause.

After he'd tried countless brand name athletic shoes to alleviate pain during his training, he began reaching out to shoe companies that specialized in triathlons, and an email to Hoka One One landed at just the right moment:

Spineto told them about his mission and asked to try out the company's product. One of the owners responded because his friend had just had a baby born with clubfoot. Hoka One One sent Spineto 10 pairs of running shoes, and soon after signed a deal to sponsor him.

"It's not really about the weight or living a healthy lifestyle right now," he says. "It's about racing for my son and raising awareness for kids with clubfoot. When my son was born, they gave my wife and me little hope about his physical outcome. So far he's completed three triathlons at age 7." Kids' triathlon events go in reverse order, with a half-mile run, 2-mile bike and 25-yard swim.

Spineto's message is to "get up and get moving." Parents contact him all the time through his blog or Facebook page, praising him for the example he sets.

The athlete also works with the nonprofit organization MiracleFeet, which treats a million children with clubfoot worldwide, so they can run, play and attend school like everybody else. He helps train the company's doctors, who have worked with children in East Africa and Mexico, correcting the condition through a nonsurgical procedure, called the Ponseti method, which helped Spineto's son.

The method involves manipulating the ligaments, joint capsules and tendons, and then using a plaster cast after each manipulation to lock the degree of correction, and soften the ligaments. The process takes a couple of months.

"The nice thing about the Ponseti method is that it's cheaper than surgery and the outcomes are better," Spineto said.

Using his own personal experiences, Spineto helps put an end to misconceptions and stereotypes, says Lauren Wall, program manager for MiracleFeet, who adds: "Through Tony's example, parents see that clubfoot won't hold their child back."

Spineto finds that having Eli run alongside him in a marathon is a powerful way of educating people about the benefits of physical activity for people with clubfoot. It also gives the father-son pair an amazing bond. "The quality of my son's life is far greater now than if he was 'normal.'"

And so is Spineto's. ■ ABILITY

by Josh Pate

clubfootathlete.com
miraclefeet.org

Idea Power.®

New and fresh thinking requires new and fresh thinkers. The energy industry is always changing. As one of the largest energy providers in the United States, Southern Company is committed to being at the forefront of technology, research and innovation. That's why we're always looking to grow and develop a diverse, smart and talented workforce that will bring groundbreaking ideas to our company. And we support suppliers and partners of all backgrounds to better serve communities throughout the Southeast. For more information on our commitment to diversity, visit southerncompany.com.

Photos of actual Southern Company employees.

SOUTHERN COMPANY

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WELLNESS PROGRAMS:
Better for your Health? Worse for your Wallet?

From First Lady Michelle Obama's *Let's Move!* campaign, to personalized medicine research, to workplace wellness programs, there is a growing trend in our society to focus on preventing illness.

In fact, in 2011, the Surgeon General issued the nation's first National Prevention and Health Promotion Strategy. The Patient Protection and Affordable Care Act (PPACA), also known as Obamacare, which goes into effect in January 2014, also includes many prevention provisions.

One major aspect of the PPACA alters the way employers can run workplace wellness programs. While these programs have the potential to create better health results for many, they also have the potential to unfairly burden individuals with disabilities.

Employers are encouraged to use various incentives, including cheaper health insurance premiums, to engage employees in a wellness program. Providing equal access to all ensures that individuals with disabilities or chronic disease do not end up paying even more for health care than they currently do. Protections under the Americans with Disabilities Act (ADA) and the PPACA mandate that employers provide equal access, and design programs in which people with disabilities can participate fully.

These protections, written into the PPACA and the ADA, can help those with disabilities navigate wellness programs without facing discrimination. Under these rules, employers are required to provide alternatives so that individuals with disabilities or medical conditions can participate in the programs to the best of their ability—or get waivers if they are unable to participate at all. Individuals must know their rights in this area and be proactive with their employers to ensure equal access to the benefits provided by these programs.

EMPLOYER WELLNESS PROGRAMS

Employers across the country increasingly use wellness programs to encourage healthy behavior amongst employees. The 2021 Kaiser Family Foundation and Health Research and Educational Trust annual survey of employer health benefits found that 63 percent of small companies offered health benefits, including at least one wellness program, while 94 percent of large companies (200 or more employees) offered such programs.

These numbers are expected to continue to increase as health care costs rise. A report by the Georgetown University Health Policy Institute notes that, "[S]tudies estimate the return on investment for workplace wellness programs is between $3 to $6 in savings for every $1 invested… These savings result from lower use of health care services, reduced absenteeism and reduced workers' compensation and disability claims." Given these incentives, more employers are starting wellness programs.

They range from offering free flu shots or gym memberships to providing incentives for meeting exercise or health goals. The latter model—giving a reward for meeting a health target, or alternatively a penalty for failing to meet one—can greatly impact employees with disabilities. Individuals with disabilities or chronic diseases may not be able to meet a health goal due to their condition.

For example, an employee with a mobility disability may not be able to fulfill exercise goals or meet a certain Body Mass Index (BMI) target due to an impairment. Both the PPACA and the ADA offer protections against discrimination for individuals with disabilities. However, recent changes under health care reform have raised concerns among disability advocates. Disability Rights Legal Center (DRLC) and other advocates are monitoring these changes, and educating individuals with disabilities about their rights in order to ensure that the system works fairly for everyone.

PPACA CHANGES TO WELLNESS PROGRAMS

Under the PPACA and other laws, there are two types of wellness programs: participatory and health-contingent.



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---making essential medical discoveries that improve health and save lives.

Chief Officer for Scientific Workforce Diversity
Office of the Director, National Institutes of Health
Department of Health and Human Services

Are you a top-level Scientific Researcher or Scientific Administrator seeking a career at one of the preeminent biomedical research institutes in the nation and the world? This position offers a unique and exciting opportunity for a leader to develop and implement initiatives enhancing diversity and promoting equity in the biomedical research enterprise, including NIH and other health and medical research entities. This position is expected, through the development of new programs, policies and practices and through cultural change, and shared responsibilities, to positively impact both the government and nongovernment workforces. The Chief Officer for Scientific Workforce Diversity serves as a member of the NIH Director's senior leadership team and will also serve as the co-chair to two newly formed Committees.

We are looking for applicants with a commitment to scientific excellence and the energy, enthusiasm, and innovative thinking necessary to lead within a dynamic and diverse organization. Applicants must possess an M.D., Ph.D., or equivalent doctoral degree in a scientific field related to biomedical research, plus expert stature in their discipline as demonstrated through their publication history and other contributions to their field. The strong candidate will have evidence of managerial, administrative, and mentoring ability. The full list of qualifications required can be found on the vacancy announcement located at http://www.jobs.nih.gov/vacancies/executive.htm.

The successful candidate for this position will be appointed at a salary commensurate with experience and accomplishments, and full Federal benefits, including leave, health and life insurance, retirement and savings plan (401K equivalent) will be provided.

If you are ready for an exciting leadership opportunity, please see the detailed vacancy announcement at
http://www.jobs.nih.gov/vacancies/executive.htm
Applications are due by 11:59 p.m. on Tuesday, April 30, 2013.
Please contact Lynnita Jacobs at 301-402-4077 for questions and/or additional information.
DHHS AND NIH ARE EQUAL OPPORTUNITY EMPLOYERS

NIH

Participatory wellness programs offer no reward or do not require an individual to meet a certain goal in order to receive the reward. An example of a participatory wellness program is an employer who offers a free nutrition class, or who pays for a gym membership, regardless of whether the employee goes to the gym or loses weight.

Health contingent wellness programs are ones in which an employee must meet a health-related standard or goal in order to receive a reward. For example, employees pay lower health insurance premiums if they participate in a smoking cessation program or reach a target cholesterol goal.

The PPACA alters the rules for health-contingent wellness programs by increasing the maximum permissible reward. Now, employers may offer a reward of up to 30 percent of the premium cost of health coverage. Prior to the PPACA, this cap was 20 percent. The maximum reward can be as high as 50 percent for smoking cessation programs and other tobacco-reduction programs.

In these situations an employee who fails to meet the goals set by the wellness program may pay 50 percent more in premiums than his or her counterparts. The concern is that it may be more difficult for individuals with disabilities to reach the standards set by wellness programs without taking into consideration necessary accommodations.

Individuals with disabilities must know what alternatives are available such as waivers or modified requirements as an accommodation, so that they can successfully navigate these requests and not end up paying more than their coworkers for health insurance.

WELLNESS REGULATIONS

While the PPACA laid out the increased reward allowances from 20 percent to 30 percent of premiums, the details of the practical aspects of the law are left to regulations, which are developed by the federal agency, in this case the US Department of Labor (DOL), which is charged with implementation of the law. Public comment is also required.

The DOL laid out proposed rules in November 2012 on how wellness programs will work in practice. Many disability rights advocacy groups, including the DRLC, submitted comments and feedback on the proposed wellness regulations.

Under the proposed new rules, employers must give employees a reasonable alternative standard to the wellness program goal, if it is "unreasonably difficult" for an individual to complete the advertised wellness program because of a medical condition. An employer also must give an alternative if it is medically inadvisable for the employee to participate.

For example, imagine an employer who offers a 30 percent premium reduction for employees who complete a wellness program, which includes a standard of running seven miles a week. For someone like Betsy, an employee who recently went through cancer treatments, running is not medically advisable. As a reasonable alternative, the employer should still give Betsy a 30 percent premium reduction if she walks four miles a week—a goal that her doctor may feel better suits her.

It might also be the case that Betsy's doctor would advise against any physical activity in the months following her treatment. In this scenario, the employer should give Betsy a waiver, along with the 30 percent premium reduction because it would be medically inadvisable for her to participate.

How would someone know that his or her employer is required to provide a reasonable alternative or a waiver? All employers are required to let their employees know that these options are available in any materials that describe a wellness program. However, individuals may have to be proactive in requesting an alternative and negotiating what will count as a reasonable alternative.

Employees might only be able to sign up for employer wellness programs once a year. Individuals with disabilities must read the fine print of materials describing a wellness program, and speak up to inquire how to take advantage of a program that is available within the company, or to find out how to avoid being penalized or having a higher premium charged.

Individuals with disabilities or chronic conditions already pay higher out-of-pocket costs for medical care than healthy individuals. If such individuals do not get reasonable alternative standards that account for their medical situation, they may be charged higher premium rates as well.

While the regulations make clear that an employer can require a doctor's note to show that an individual needs a reasonable alternative standard, the regulations do not go into detail about who would set and monitor the new standard. During the public comment period, disability rights advocates are raising concerns that privacy rights of employees and their dependents will be threatened if employers are able to monitor the standards.

For example, Charles' employer has a wellness program that asks employees to reach a certain BMI through exercise. However, due to a disability that has left his muscles too weak to fully support him, Charles is unable to exercise enough to achieve that goal. A reasonable alternative may be for him to take cholesterol-lowering medication, if it does not have adverse side effects. However, if his employer is allowed to monitor Charles' progress by having access to his medical records, his privacy rights may be violated. Encouraging participation in wellness programs should not come at the expense of an employee's medical privacy or overall health.

THE EXTENT OF ADA PROTECTIONS

Although the final rules of the PPACA regulations are in the works, employees should remember that the protections of the ADA still apply. For over 20 years, the ADA has protected employees by prohibiting discrimination based on disability with regard to employee benefits, such as wellness programs, and it will continue to do so. Moreover, the ADA prevents employers from screening potential employees to see whether they might have a disability, so that the employer could avoid providing a reasonable alternative to a wellness program.

Under the ADA, an employer is not allowed to ask a current employee whether he or she has a disability. Additionally, any medical records or information that an employer does collect during the program must be kept in a confidential file separate from the employee's general HR file. If any of these rules are violated during the course of the wellness program, employees can file a complaint with the Equal Employment Opportunity Commission (EEOC).

Similarly, the Genetic Information Nondiscrimination Act (GINA) also has specific rules regarding wellness programs. Under GINA, an employer is only allowed to collect genetic information, including family medical history, in a completely voluntary wellness program. Therefore, if a reward or penalty is imposed within that program, then any questions in a health survey regarding genetic information must be voluntary. The form must clearly state this to the employees.

The good news is that the protections under the ADA are still in effect, and wellness programs might help move employers and employees alike to develop a health care system that focuses more on prevention. On the flip side, there needs to be further clarification regarding implementation of the rules governing wellness programs as they expand to make sure that they are in alignment with the ADA and continue to offer protections to people with disabilities. The EEOC, which enforces the ADA, and state agencies must take an active role in overseeing employer wellness programs in practice. While individuals with disabilities and chronic conditions benefit from a well-designed employer wellness program, employers must ensure that all employees have equal access to lower health insurance premiums. ■ ABILITY

by Anya Prince, Esq. and Laura Riley, Esq.

Prince and Riley are staff attorneys at the DRLC's Cancer Legal Resource Center.

disabilityrightslegalcenter.org
dol.gov/ebsa/healthreform



NAMI

The Nation's Voice on Mental Illness

www.nami.org

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NAMI—the National Alliance on Mental Illness—adds something new to its Web site. Whether it's the latest on science and research, opportunities for education and support, resources for recovery, or tools for advocacy, I turn to NAMI.org to keep me informed, inspired and involved.

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Kendall
ON ICE

Kendall Hollinger is a triple threat: ice skater, singer and spiritual warrior. At 16 she glides across the ice with a winning smile and plenty of tricks up her sleeves—all honed over the 11 years she's made the rink her second home. Neither a broken bone, nor a rump-chilling fall fazes this California girl, a top skater in her region. Even the fact that she's allergic to more than 95 percent of foods and many airborne allergens doesn't slow her roll. *ABILITY*'s Lia Martirosyan caught up with the rising star.

Lia Martirosyan: What's a typical day in the life of Kendall Hollinger?

Kendall Hollinger: I get up, take my nutritional formula and medicine, and then eat via a feeding tube. After that I go to the rink and skate for a few hours. I'm home-hospital schooled in the afternoons; I might also have a vocal lesson at my church and then I do lots of homework.

Martirosyan: Have you ever attended a conventional school?

Hollinger: No, the day I went to get my school photos taken in kindergarten, I broke out in hives walking through the hall. So my doctors said that, at that time, my going to school was not safe and that maybe I could try again once I got to middle or high school. So when I turned 11, my allergic reactions were still so severe and numerous that my allergist didn't think it would be a good idea.

By then, I wanted to stick with the education I was getting, because it would have been hard to say goodbye to the teachers I'd had for so long. After another three years passed, we considered school a third time; we even looked into my getting a peanut-allergy-sniffing dog, because they have those now. But again, it didn't work out. I think I'll definitely go to college.

Martirosyan: Physically attending school is overrated; as long as you're self-motivated, you'll get that degree! Have you been diagnosed?

Hollinger: When I was two days old, I stopped breathing. My mom and dad panicked; they didn't know what happened. Doctors didn't know either. But I had really, really bad acid reflux from my allergic reaction to my mom's breast milk. I continued to have allergic reactions to food and when I was about two years old, they finally did blood and food testing, and found out that I had an anaphylactic reaction to 95 percent of all food. And then when I was three and a half, I got my feeding tube placed, because I "failed to thrive"-weighing about 25 pounds at that point. I was really skinny and I wasn't getting my nutrition, because I couldn't eat anything.

Martirosyan: Are on a liquid diet?

Hollinger: I can eat some things now and that's why I got the feeding tube, because they put formulas into that, which helped me grow and kept me alive. I can eat the 5 percent of foods that I'm not allergic to: chicken, rice, potatoes, turkey and beef. I can have a good amount of food. My favorite thing is potatoes. I put them in everything. And the only allergies I ever outgrew were milk and dairy, so I can have, like, chocolate; that's my favorite. It's my little treat. When everyone else, like, at birthday parties is eating cake, I'll be in the corner with my Hershey's bar. And they always want my stuff, and I'm like, "But you can have the cake!" The grass always looks greener on the other side.

Martirosyan: So what keeps you going?

Hollinger: My faith in God, my family and the support of my friends. I have two mottos. The first is: believe fearlessly. Never give up on a dream because it can happen. I was six when I stepped out on that ice, and I never would have thought that it would turn into this dream that I love so much. I don't know how it happened, but I'm so happy and blessed to have this sport. My other motto is: You don't live to eat; you eat to live. Any way that you can get your nutrition is good.

I've met other kids with food allergies and they've taught me a lot about handling everyday things. They inspire me.

Martirosyan: Do you follow a set schedule for nourishment?

Hollinger: When I was little, I had a feeding pump, so I was on the formula 24/7. As I got older, it became harder, because I didn't want to have a pump on my back when I skated. That's when I started doing gravity feed, where I hook my tube up and pour formula down into my stomach. I do that about four times a day. So this goes on throughout the day, like breakfast, lunch and dinner. I'll normally need extra formula before school because I'm so exhausted from skating. But afterwards, I definitely have more energy; it's just like after eating a big meal.

I have a sweet tooth. Mainly I eat Hershey's bars. Hershey's actually built a wall in their facility to separate nut products from milk products, so thank goodness they did that because now I can have chocolate bars. (*laughs*)

Martirosyan: How did your allergies reveal themselves?

Hollinger: My doctors have done a lot of studies and they're still researching food allergies, because it's a growing problem. I think there are about 15 million Americans with food allergies. It's funny because I tend not to have allergies to the things that I eat a lot, but then one day I can wake up, eat one of them and be allergic. Like, I used to have tomato all the time. I





would eat tomato sauce on my spaghetti or ketchup on French fries. And then one day I was eating a cheese pizza, and I had a really bad reaction. Ever since, my lips swell whenever I eat tomato. We had blood testing done, and sure enough I was allergic to tomato.

Martirosyan: Do you have a variety of reactions?

Hollinger: I have different reactions to different things, I'm deathly, deathly allergic to any type of nut or seed, eggs, soy and pork. When it comes to nuts, even breathing them or touching them makes my face swell up, the worst part is that my throat swells up and I stop breathing. I've almost lost my life eight times, which was terrifying.

I'm really careful about not ever eating something I'm allergic to; I check labels and ask chefs what's in a dish to be sure. One of my worst reactions happened at the rink when I came for a skating lesson with my coach; all of a sudden I started feeling like I was going to pass out. I can only guess that what happened was I touched the music player and then wiped my eye and one of the other girls, who had eaten a brownie with nuts, touched the music player before I did. A few minutes later I was on the ground and the paramedics were working on me.

My mom gave me my EpiPen—a shot of epinephrine—to revive me. It was hard because the rink has always been my safe zone. So when all of a sudden it wasn't, that took a lot to get over, but I came back the next day and was like, "This is not going to be ruined. This is my happy place!" Now, before I touch the music player or the wall, I wipe it down with a wet wipe, so I don't come in contact with any food or nut residue that could be on it.

Martirosyan: Bacteria doesn't thrive as well in cold environments, do you think this is why the ice works for you?

Hollinger: Yeah, that's what we thought when I started skating at six. I had convinced my mom to take me to an ice skating class. My dad was skeptical. "I think she should try it, but let's be careful," he said. He was really worried that I was going to fall on my stomach and hurt my tube or something. And the doctors were just like, "No, never. You're not doing that." I was like, "Why?" I wanted to skate so badly. I watched Michelle Kwan and Sasha Cohen on TV during the 2003 world competition, and I remember giving my mom a look like: "I want to do that." And then one day I did. (*laughs*)

Martirosyan: Michelle and Sasha are your idols in the figure skating world?

Hollinger: For sure. And Joannie Rochette, she skates for Canada, she really inspired me too, because her mom passed away right before she went to the Olympics and she had to skate through that, it was the most inspiring thing I'd ever seen. She had tears coming down her face during her performance and she conquered that. It showed me that no matter what you're going through, no matter what your trial is, you can overcome it. The ice is such a good place to get it all out of you.

Martirosyan: How far do you plan on taking this?

Hollinger: I'm currently third in my region after competing last September in Arizona. I trained all season and landed my double jumps and I was so happy. It was fun to fly there with three of my best friends and though we compete against each other, we're still so supportive of each other. I think this sport can be really difficult because we're a bunch of girls the same age, going for the same titles, in the same competitions. I try to stay away from those thoughts, though. Now, my goal is to get more double jumps, work on my double axels, and then maybe some day to go to nationals and the Olympics.



Kendall with new service dog, Lola

Martirosyan: What else do you enjoy?

Hollinger: I'm a singer and I love performing in my church.

Martirosyan: How long have you been singing?

Hollinger: My whole life, but I didn't actually start taking vocal training or vocal lessons until a year and a half ago. My grandpa sang opera and my grandma's a concert pianist, so I've grown up around music. My grandpa's actually in charge of all the music for Calvary Chapel in Costa Mesa. He transitioned from opera to gospel, bringing the opera into gospel. My grandma plays and my grandpa sings, and they have recorded a few CDs. Sometimes I get to sing with them in church.

Martirosyan: Do you ever think about taking part in singing competitions?

Hollinger: Yeah. I actually auditioned for *The Voice* a year ago. It was hard, because I went in and I guess they had viewed a video of me singing before. They said, "You're going through. They just need to review your audition." So I came in, had my cowboy boots on and gave it all I had. They said that they really loved my voice and my style of music, but it wasn't what they were looking for for the show.

Fortunately, it wasn't one of those cattle calls, where it's like, "Number 205," and you just start singing. I'd heard that's what some shows are like. *The Voice* was actually a good experience, because I'd never auditioned for singing before, the producer was really nice, and everyone in the room clapped for everyone else. ■ ABILITY

community.kidswithfoodallergies.org
foodallergy.org
nlm.nih.gov/medlineplus/druginfo/meds/a603002.html
en.wikipedia.org/wiki/Epinephrine

Anaphylaxis or Anaphylactic Shock...

is a type of allergic reaction where the immune system has a severe, potentially fatal reaction to otherwise harmless substances from the environment. The reaction begins within minutes or even seconds of exposure, can quickly lead to airway constriction, skin and intestinal irritation, and a change in heart rhythm. In severe cases, it can result in total airway obstruction, shock and death.

As with other allergies, anaphylaxis is caused by the release of histamine and other chemicals from mast cells. They are a kind of white blood cell found in large numbers in the tissues that regulate exchange with the environment: the airways, digestive system and skin. On the surface, mast cells display antibodies called IgE (immunoglobulin type E), which are designed to detect environmental substances to which the immune system is sensitive.

A substance from a known threatening source, such as bacteria or a virus, is called an antigen. A substance that most people tolerate well, but to which others have an allergic response, is called an allergen. When IgE antibodies bind with allergens, they cause the mast cell to release histamine and other chemicals, which spill out onto other nearby cells.

When these chemicals interact with receptors on the surface of blood vessels, it causes them to leak fluid into surrounding tissues, where fluid accumulates, and the area becomes red and swells. The smooth muscle cells of the airways and digestive system constrict, while nerve endings cause itching.

In anaphylaxis, the response is due both to hypersensitivity to the allergen and the fact that it gets distributed through one's system. Exposure by ingestion, inhalation, or skin contact can cause anaphylaxis. In some cases, it may develop from less severe allergies.

Anaphylaxis is most often caused by allergies to foods, drugs and insect venom. Specific causes include:

- Fish, shellfish and mollusks
- Nuts and seeds
- Stings of bees, wasps or hornets
- Ingredients in meat tenderizers
- Vaccines, including flu and measles vaccines
- Penicillin
- Cephalosporins
- Streptomycin
- Gamma globulin
- Insulin
- Hormones (ACTH, thyroid-stimulating hormone)
- Aspirin and other NSAIDs
- Latex (from exam gloves or condoms, for example)

Exposure to cold or exercise can trigger anaphylaxis in some individuals. Symptoms may include:

- Hives
- Swelling and irritation of the tongue, throat or mouth
- Swelling of the sinuses
- Difficulty breathing
- Wheezing
- Cramping, vomiting or diarrhea
- Anxiety or confusion
- Strong, very rapid heartbeat
- Loss of consciousness



YOUR BRAIN ON JAZZ

Charles Limb is a medical doctor whose lifelong love of music inspired his career choice. He plays dual roles as associate professor of otolaryngology—head & neck surgery—at John Hopkins and is also a faculty member of the Peabody Conservatory of Music. A talented saxophonist, he interweaves music and medicine through his innovative research into how creativity affects the brain. Here he speaks with *ABILITY*'s Chet Cooper.

Chet Cooper: What kind of surgery did you do this morning?

Dr. Charles Limb: They call it an encephalocele, where brain tissue herniates down into the temporal bone, above the ear. I had to go in behind the ear to try to elevate and reduce the brain tissue, and reconstitute the bony division.

Cooper: So all went well for the patient?

Limb: Really well. As a temporal bone surgeon, everything I do is related to the ear. It's a field I enjoy, it suits my interests and skill set nicely. I feel pretty lucky.

Cooper: Did your love of music lead you to become an ear doctor?

Limb: I was a musician who loved music my whole life. I'm just crazy about it. I not only like to listen to it, but to think about it and study it, read about it and explore it. I want to understand it better. It always mattered to me, well before I settled on a career, or had an inkling that I could combine music and science.

Cooper: So you had an epiphany that you could connect the two?

Limb: It was a process. At some point, every musician grapples with whether they're going to pursue it as a profession, or do something else to make a living. Some musicians absolutely feel that there's no other road for them. And then there are other people, like me, who could have gone into music, but I didn't feel like I deserved to. And what I mean by that is I wasn't willing to suffer for my art. You have to have the conviction, that you can ride out the lows, to be a really successful musician.

In the meantime, I was good at scientific things. I loved music because it was about life captured in all its essence, all of its beauty and all of its pain. To me, medicine was similar. It captures life at its most profound and its most mundane. Maybe, in a philosophical sense, I felt very comfortable deciding to pursue a career in medicine. My motivation may have been linked to music in some internal way, but the reality of it was that I was going to medical school to become a doctor. During those years, I thought to myself: You know what? I can study hearing. And then, several years later, I thought: I can study music; this could literally be the focus of what I do.

Cooper: Do you pipe in music when you perform surgery?

Limb: Whenever I can, because it enhances the aural environment in which I work. Soft music allows me to enter a state of concentration that's different from when the ambient sound is noisy or unpleasing, given the sounds of the drill and other operating room equipment.

When I was growing up, I always preferred to work with music playing; it allowed me to sit at a desk and work for hours, whereas without music the silence was a distraction.

Cooper: Can your patients hear the music playing in the background during their operation?

Limb: No, typically they're asleep.

Cooper: So you don't do local anesthesia?

Limb: Every once in a while I do; in those situations I ask the patient if they would like to hear soft music or not. It's up to them. But most of my patients don't hear well, which is why I'm doing surgery on them.

Cooper: Do you place cochlear implants?

Limb: Exactly. That's my area.

Cooper: So you get to speak to patients who may be hearing for the very first time?

Limb: Yeah, it's a pretty neat thing. Now, there are many different kinds of hearing loss and many people get implants who did hear before their surgery. A lot of them are people who haven't heard in a long time. So if you or I lost our hearing today, we'd become a cochlear implant candidate. When the implant is activated, it wouldn't be the first time we were hearing, but it would be a whole new way of hearing.

Cooper: Do you know Kathy Buckley?

Limb: I do not.

Cooper: She's a stand-up comedienne and probably the most notable stand-up comedienne who is deaf. Kathy was an advocate against implants for a long time, as are many people within the deaf culture; they don't feel there is anything wrong with being deaf. But Kathy went on to get a cochlear implant some years ago and afterwards we interviewed her. She talked about how, before the surgery, she used to feel the vibration from the audience's laughter and watch them participating. After the surgery, when she first heard the actual laughter, she was so moved that she broke down crying.

Limb: Yeah, there are so many things we take for granted



in this world and one of them is to hear the sounds in it. Yet, what's interesting to me is that whenever I talk to patients after they've had cochlear implants activated, their first observations tend to be pretty mundane. For example, many patients say, "I didn't know the toilet was so noisy."

(laughter)

Limb: Or, "I didn't know that when the dryer stops, it makes a loud, obnoxious beep." What a funny way to encapsulate the world of sound after your hearing's been activated.

Cooper: I saw your TEDx talk about your study of improvisation on YouTube. (See page 37)

Limb: Actually, I did two TED talks. The other one deals with music perception in patients with cochlear implants.

Cooper: I saw the one about the different studies around jazz and rap. You spoke about different activities within the brain and I noticed the part where you said that when jazz is really happening, the brain suppresses self-awareness. This makes me think about those moments when singers close their eyes and go into their own space, as if they don't realize they're in front of millions of people watching on TV or thousands in a live audience. Do you think that's what's happening with them?

Limb: Yeah, and without being too sweeping in my generalizations about creativity, I think that what most forms of art share in common is that their creator is in a different mode of thinking, if you will, than when they're doing something that's not creative. What I'm getting at is that I think creativity, neurologically speaking, is a very different state of mind, where you're generating lots of ideas with some facility and some sense of reward or pleasure is achieved in this process. I think that humans are hardwired to create. It's not arbitrary that we do this kind of thing. I suspect that it's part of our very basic biology.

Now, to try to establish how that breaks down into different art forms, for example, jazz vs. poetry vs. architecture—that's where it starts getting much harder for scientists to connect the dots.

Cooper: Some say, to be creative, you have to turn off your brain.

Limb: That is what my studies of jazz imply; there's a certain component of conscious self-monitoring that one has to let go of, to an extent.

Cooper: Because it's too restrictive.

Limb: Correct. You overthink. Trying too hard to execute something impedes your ability to do so.
Cooper: I was talking to some athletes about being in the zone and I feel like there's something similar to what you're talking about.

Limb: Definitely.

Cooper: I ride motocross and there's a different space, a zone. It's hard to get into it and sometimes you just can't. But when you do, everything flows with such ease.

Limb: That's right. Your conscious perception of reality is altered and you're able to do things by letting your subconscious neuromechanisms flow, which you can't do if you're consciously trying to force them.

Cooper: Do you have goals for your studies around improvisation and creativity?

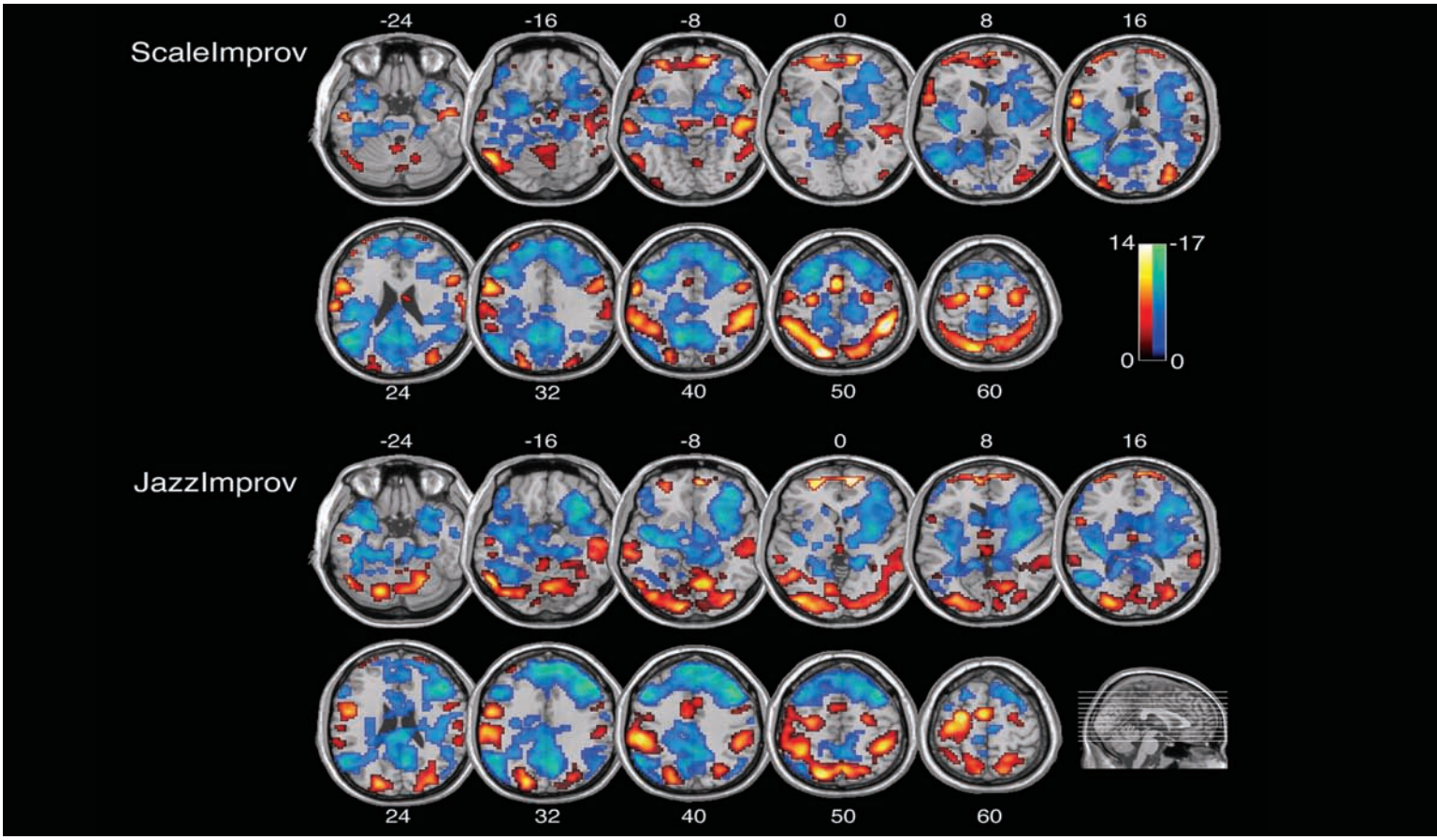
Limb: These studies are in their infancy. We're just beginning to understand how creativity occurs in the brain. These are the questions of a lifetime and I don't believe that they'll be answered quickly. I have far too much respect for music and the arts to think that a couple of scientific studies are enough to explain the whole thing. Yet it's possible that in a cleverly designed science experiment, you could get closer to the truth.

My goal is to come up with a series of well-designed experiments, so we can start to describe some of the fundamental neurobiology of art and creativity. These studies of multiple art disciplines would be ongoing and use different scientific techniques. The challenge is that it's very costly. It requires grants and this is not an area where there are a lot of clear funding sources. It's been difficult for me to get the backing to continue these experiments, despite the fact that they've been well received and have generated so much interest in the media and the public. The NIH [National Institutes of Health], for example, doesn't feel that understanding creativity is a part of its mission.

Cooper: Perhaps you'll have to be more creative in the way you write up your study, so that it fits in with something that they can understand is a part of their mission.

Limb: Yes. I may have to be a little more strategic. ■

ted.com/talks/charles_limb_your_brain_on_improv.html
ted.com/talks/charles_limb_building_the_musical_muscle.html



YOUR BRAIN ON IMPROV

This is an excerpt from Limb's 2010 TEDx Talk:

I'm going to start off by playing a video of Keith Jarrett performing; he's a well-known jazz pianist and an iconic example of someone who takes improvisation to a high level. He'll improvise entire concerts off the top of his head, and never play it that exact same way again.

How can the brain generate that much information, that much music, spontaneously? I set out with this scientific concept that artistic creativity is magical, but it's not magic.

Is it truly possible to study creativity scientifically? It may be. In my lab, I ask what is this brain doing to enable us to be creative?

The main method that I use to take pictures of active areas of the brain is functional Magnetic Resonance Imaging (fMRI). When you're in an fMRI scanner, you're in a big magnet that's aligning your molecules in certain areas. When a neural area is active, it shunts blood flow to that area, causing an increase in local blood with a deoxyhemoglobin (hemoglobin not combined with oxygen) change in concentration in that area. Deoxyhemoglobin can be detected by an MRI, whereas oxyhemoglobin (hemoglobin and oxygen combined) can't. So through this method of inference, where we measure blood flow instead of neural activity, we say that an area of the brain that's getting more blood is active during a particular task.

Using the fMRI [during a creative activity], an area that's thought to be involved in self-monitoring is turned off and this area that's thought to be autobiographical or self-expressive is turned on. And we think, at least in this one study, which could be wrong, that to be creative, you have to have this weird dissociation in your frontal lobe. One area turns on, and a big area shuts off, so that you're not inhibited. You're willing to make mistakes and not constantly shut down all these new generative impulses.

When I think about improvisation and language, what's next? Rap, of course and specifically, freestyle. I've always been fascinated by it. There are a lot of similarities between what takes place in freestyle rap and what happens in jazz. So how do you study rap scientifically? You have a freestyle artist come in and memorize a rap that you wrote for them, and then you give them key words and have them freestyle.

Limb raps:

Thump of the beat in a known repeat
Rhythm and rhyme make me complete
The climb is sublime when I'm on the mic
Spittin' rhymes that hit you like lightning strike
I search for the truth in this eternal quest
My passion's not fashion you can see how I'm dressed
Psychopathic words in my head appear
Whisper these lyrics only I can hear
The art of discoverin' that which is hoverin'
Inside the mind of those unconfined
All these words keep pouring out like rain
I need a mad scientist to check my brain

(*applause*)

So the freestyler gets cued different words. He doesn't know what's coming, but hears something off the cuff. And when we put him in the fMRI scanner and have him freestyle, then we look at what gets activated.

With the rapper's brain, we saw language areas lighting up, but with the freestyler, we saw major visual areas light up. There's major cerebellar activity, which is involved in motor coordination. This research is very preliminary, but kind of cool.

I think that over the next 10, 20 or 30 years, a real science of creativity is going to flourish, because we now have new methods to take a complex process, such as jazz improvisation and freestyling, and study it. For now, we ask far more questions than we can answer. ■ ABILITY



Photos by Zhang Lijie

Despite Difficulties, There's Dad

In a family photograph, four people affectionately hold each other. The eldest man, Zhu Bangyue, needs the support of a cane as he stands behind three people with disabilities. To look better in the photo, he wears new clothes. He smiles wearily, while the other faces are expressionless. This picture only hints at the tragedy endured by the people within it.

Zhu Bangyue's wife, Zhu Lingmei, and his two adopted sons, Gu Zhonghua and Zhu Shaohua, are not just family, they are basically his "patients." Each suffers from progressive muscular dystrophy (MD). Over the years, they lost control of their facial muscles when the tissue of their lower eyelid muscles weakened, making them sag outwards. The condition, known as eyelid ectropion, leaves the eyes exposed and vulnerable to the elements; in a cold wind, their eyes tear up and become bloodshot.

The slightest injury can cause the family members serious harm. Zhu Shaohua's lower lip hangs from a simple fall in 1996, when his jaw hit a piece of rock. He lost six teeth, and had to get 10 stitches to close up the gash. Over more than three decades, his body has confronted new challenges daily.

Dinner again. One by one, old Zhu Bangyue, who has a wooden leg, drags the three pulley-drawn wooden chairs from different corners to the dining room.

His wife and elder son are in even more serious condition than he. Their legs are bandaged to prevent hip pain. Gu Zhonghua's once tall and strong body practically falls off his wheelchair; his two legs drag on the floor, leaving a zigzag pattern as Zhu gets him to the table for dinner. He can't support the weight of his own head, which rolls backwards uncontrollably, unless supported by a board.

Zhu Lingmei's face has changed; her hair is falling out. Gu Zhonghua's hands, at one point muscular and powerful, are now swollen and bruised. Zhu Shaohua's former nickname "Bamboo," for his height and build, is no longer appropriate. He now wears clothes too large for his deteriorating body.

Last year, more than 30 volunteers from the Loving Care Commune in Shaowu City, Fujian Province, rounded up the family for an outing. They were elated. "We haven't been to town for 20 some years. How everything has changed!" Zhu Shaohua wrote in his blog, using his left ring finger, the only one still usable.

Joy is hard won for this family. Neighborhood kids call them "robots" and the "living dead."

In 1964, doctors confirmed that Zhu Lingmei had MD. They also told her the disease could be genetic. Unable to resist family pressure to have children, she gave birth to two sons. At first, all were happy for her and her seemingly healthy children. Then life took a sudden turn.

In 1971, her son Zhu Shaohua was a cute and lively four-year-old. But then something went amiss: whenever he spoke, his eyelids began to turn upward and his eyes didn't fully close. Classmates pointed at him saying, "Don't look at us like that! It's frightening!"

Both children began to lose control of their face and shoulder muscles. While they were small, their natural growth spurts covered up the severity of their symptoms; but over time, muscles and internal organs deteriorated. Few with the condition survive past age eighteen.


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Seeing the change in her sons' physiques, Zhu Lingmei's heart broke. By 1990, Gu Zhonghua couldn't walk. By 1995, he couldn't sit up. In 1998, Zhu Shaohua became disabled. After their high school graduation, one brother was rejected for a job, and the other couldn't pass the physical exam to attend a university. The challenge of supporting the family landed on Zhu Bangyue, a loving soul who came along later in their lives and accepted the children as his own.

Zhu Lingmei was filled with guilt: "I owed God, I owed my children, and I owed my husband Zhu." She thought about divorce. She even thought about taking the lives of her two children and herself to spare her husband the hardship. She wondered at times if sacrificing her own life would lead to happiness for the rest of her family: "If that could be done, I would have done it," she says.

To provide sustenance for the family, Zhu Bangyue hiked over mountains and into the countryside. He saved up cloth- and grain-ration coupons to exchange for pork. He heard ginseng was healthy, so he gave it to his sons as a snack.

When the family needed to move, some landlords worried that the wheelchairs would damage the floor; others believed people with disabilities brought bad luck, and wouldn't rent to them. Eventually, they found a place to call home.

These days, Zhu Bangyue does everything from grocery shopping, to cooking, to serving meals daily, to bathing his family. His day starts at 5:30 a.m., and doesn't end until he tucks everyone in at the end of the night. The most difficult task is bathroom duties. Zhu Bangyue built a wooden frame that sits above a bucket. He carries each of the three patients to the frame so they can go; occasionally someone falls, which makes for a mess.

"The night I swallowed the poison, father stayed up all night and didn't leave my side," one son recalls. "Frustrated and angry, father said that as long as I'm alive, he'd do anything for me. He hugged me after I came to consciousness, crying and saying that if we go, we go together."

In 1986, Zhu Bangyue fractured his left leg in a car accident. To save money, he used the least expensive antibiotics and painkillers, and tried saline-soaked cotton balls to clean his wounds. Zhu Lingmei argued with him because she wanted Zhu Bangyue to treat himself better. "Those sleepless, painful nights were difficult," she says. "To be alive meant greater suffering than being dead."

Zhu Bangyue planted different flowers in the front yard: roses, dandelions and peonies. In fine weather, he wheeled mother and sons outdoors. Once the flowers bloomed, Zhu Bangyue showed his wife the splendor. "They will wilt soon," she said, to which he replied, "They will wilt, but they will bloom again next year." When someone advised him to institutionalize his wife and children, the normally good-tempered Zhu Bangyue grew angry and replied, "As long as I'm here, this family will never be separated."

In 2006, Zhu Bangyue suffered three failed skin graft operations on his leg. Eventually, it had to be amputated. The local Shaowu City Office raised funds to fit him with an artificial leg to replace the leg that tortured him for more than 20 years. But last year he fainted after being brought to the hospital. The doctors diagnosed him with a stroke and other conditions, such as atherosclerosis. Zhu Bangyue worries about his declining health. Who will take care of his family if he cannot?

Last Mother's Day, Zhu Lingmei fell twice and suffered multiple fractures. But she couldn't undergo surgery due to a weak heart and weak bones: her body couldn't take the anesthesia. Instead, she went home and rested.

"As long as I can move, our family will stay together," her husband says. These days, mealtimes are the family's happiest moments of day.

"We approach life without fearing death. We cherish our time together," Zhu Shaohua wrote in his blog. Recently, he completed a novel, while Zhu Lingmei has became more diligent in prayer.

Zhu Bangyue is 70 now. His two sons have lived past age 40, beating the odds. Last year, with the help of the neighborhood community and coal miners, the family applied to be organ donors at the provincial Red Cross. When they go, their hope is that their organs will save the lives of others. ■ ABILITY

by Lu Feifei

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

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A Real Education

I'm a few months away from attaining the highest degree in academia, the culmination of an 11-year journey. I've spent six years earning a bachelor's in psychology; two pursuing a master's in social work; and another three getting a PhD in international psychology, which focuses on multicultural research and practice. That time doesn't include the two and a half years I spent working towards a license to practice psychotherapy in California.

As I approach graduation, one part of me wants to display my diplomas on the wall in beautiful frames and leave it at that, while the other part of me wants to flaunt my achievements to all the educators who gave up on me along the way. I want them to know how wrong they were about the child they once wrote off as learning disabled.

During my elementary, middle and high school years in Fresno, CA, I was assessed three times by different psychologists, who all emphasized the fact that I had poor visual memory. Although a couple of teachers showed compassion by putting in extra time to help me complete assignments, for the most part I was encouraged to pursue the manual arts, such as carpentry or mechanics. Some even nudged me towards the military, suggesting that I would be a poor fit for college.

I had only scored 80 on my IQ test, which was considered low. In 11th grade, I wrote at a 5th grade level. In 12th grade, 97 percent of my class scored higher than I did on the SAT, the standardized test for college admission. My poor performance got me placed in special education.

There, everyone had a learning disorder and none of us came from families with the resources to hire tutors or get the extra support we needed. Up until then, my entire world had revolved around school. So when I was tagged with this disempowering label, removed from my classes and escorted across a football field to a bungalow as the "normal kids" watched, I felt a deep sense of shame.

My 'special ed' classmates' resentment of their situation got channeled into angry outbursts, while my frustration was turned inward.

I felt that something was broken inside of my head. If I lost my keys, it was because I was flawed; if I received a good grade, it was because the teacher liked my personality and not because I deserved it. A little voice inside told me that I was no good, that I was not smart enough, that I was weird and weak.

To avoid that painful walk across the football field, I finally dropped out, which also meant I gave up my right to a free college education. At the time it didn't matter because I didn't think I would ever go to college anyway. I mean, I barely made it out of high school.

After that, I was rejected by the military because I had asthma. I ended up at a fast food restaurant, working as a bun toaster and dishwasher. At the time, my manager suggested that I could get free money if I signed up for classes at the city college, which I did. But to get up to the level that allowed me to enroll in general education classes, I had to take two semesters of reading and writing.



At that point in my life, learning to type without looking at the keys was my biggest accomplishment. It engaged my tactile memory and brought my spelling abilities up to college level within a year's time. Previously a word's letter patterns eluded me, but when I had to type a word that I didn't know how to spell, I began to rely upon my fingers as I typed each letter. Acquiring this new skill had a huge impact on the way I viewed myself. If I wasn't stupid and incapable of learning, as I'd been told, maybe I could experience the world in a different, more affirming way.

I'll admit, early on that I had an odd way of looking at things. As a kid, I was fascinated with serial killers, not because I admired them or entertained heinous thoughts as they did, but because I wanted to know how they came to hurt people. What life experiences brought them to the point of committing such unspeakable acts of violence?

Of course this fascination scared the crap out of my mother and teachers, so I stopped talking about it, but my curiosity remained. At the time, I needed a mentor to help me learn more about what it meant to be human; I needed someone to feed me knowledge around my interest in human behavior, but I didn't have anyone who could guide me.

My father was an alcoholic, and I began to follow in his footsteps. Drinking seemed to be the only way to quench my thirst and to get to know myself and others on a deeper, more feeling level, because when I drank I became more open to emotions. That's how it felt on the inside, anyway. On the outside, I began to get into trouble.

When I was 19, I was the passenger in what the cops said should have been a fatal car accident; it was alcohol related. Around that same time, I caved to the pressures of helping some older guys in the neighborhood break into a couple of houses. At 20, I witnessed my best friend being stabbed, and at 21, I woke up in jail, having been arrested the night before for a DUI. Thank God I didn't hurt anyone. This was my lowest point, when the voices, telling me I was unworthy, grew louder than ever.

A month later, when I showed up at my court hearing, I apparently hadn't learned a thing: I arrived drunk out of my mind because the night before I went out with some friends and ended up drinking until 7 a.m., knowing that my hearing was just two hours later at 9.

My attorney quickly pulled me into the bathroom and gave me a verbal lashing. He looked deep into my eyes and said, "Tell me you didn't @%&*ing drive here?" I lied and told him that I was dropped off. He gave me a piece of gum and warned me to shut up and let him do all the talking. He told me not to look at the judge.

I can still remember the disgust in his eyes when my lawyer said that he hated his job because of clients like me. Here I was drunk at the very hearing in which he was trying to convince the judge to go easy on me because I had "learned my lesson."







Clockwise from lower left: The author with friends on the island of Shikoku, Japan; among the Masai in East Africa, learning from a Quechua woman in Ecuador; with a Mexican man just released from prison; a festival in Ecuador, and with a Maori Healer in New Zealand

I felt as disappointed with myself as my lawyer did: I didn't have any work skills, I had a criminal record and my life was adrift.

One morning, I woke up early with the crazy notion to walk across Fresno, the city in which I was born, raised and had spent most of my years. It took me eight hours. While I still don't know why I did it, I can tell you this: the journey momentarily silenced my inner critic. The most memorable part of that day was eating lunch with a group of homeless men downtown.

They told me stories about how they landed where they were. Many gave me advice on how I should live my life. Although what they said wasn't profound, this encounter surrounded me with friendly faces and interesting stories of adversity, which helped replace the negative schemas that I had developed about homeless people. At the same time, the experience sparked something else inside. For the first time, I began to feel a sense of direction and I longed to explore how we human beings are all connected.

From there, I got financial backers for a three-day bike ride from Fresno to San Francisco; I intended to raise money to leave the United States to study in Japan. Along the bike route, my mother followed behind me in her car, determined to support me, even though she wasn't clear about what I was trying to do with my life.

After spending a year in Japan learning about religion, I went to South Korea and then continued onward, because every mile I crossed, every story I heard expanded my world view, muting my inner critic until it was completely silent. That's when a small voice began to whisper that I was, in fact, good and getting better.

After a year I returned to the States, but still had the travel bug, so during a break in my schooling I jumped on a bus from Los Angeles to Mexico. There I encountered a man who told me that he was just released from prison the day before. He had spent 30 years behind bars for two murders he'd committed during a drug deal gone bad. As we talked, I envisioned a baby being born inside this man's aging body; newly free, he was excited about everything. I felt deep compassion for him.

As I passed through Guatemala, I arrived at Lago De Atitlan (Lake Atitlan), where people from all over the world go to escape the problems of society. The lake is surrounded by many villages, in which Mayan culture is still evident.

It was there that I met other people like me who felt and thought at deeper levels. Their ideas about society and their frustration with the "normal life" resonated with me. I considered hanging out for a couple of years with the vagabonds that I met there, but I had bigger visions of what I wanted to do with my life. I had a beautiful girlfriend back home, whom I'd met through a college friend. She provided me with the support that I needed and had never felt before, even though she—like my mother—couldn't understand why I needed to travel alone to sort out my inner world. And just like my mother, she believed in me. I wanted to eventually create a life with her, but I first needed to follow the inner voice that whispered to me that I should circle the globe.

As I continued my schooling, I continued to fantasize about travel, because that's how I learned about my inner and outer worlds. During my master's program, I wrote a grant for a trip to Tanzania to help women living with HIV/AIDS use their skills to generate income and be less dependent on outside funding. During my three months in East Africa, I encountered the Masai tribe. They continue







to wear their traditional clothing and fiercely guard their culture, even as the globalized world surrounds them, because they feel such pride in their heritage. I could feel the honor they took in being Masai. It hit me that I have never felt such pride in myself and my culture; they set a powerful example for me.

During the second year of my PhD program, I visited the Maori in New Zealand. A healer there, named Hinewingari, told me to take off my shoes and stand on the earth, so I could feel "her" breathe, and I did. She said, "When you feel 'her,' she will be with you forever."

While in New Zealand, I met organizers of an international psychology conference in Australia, who invited me to visit to come and make a presentation on international psychology. There I learned about Aboriginal healing practices and indigenous communities' struggles to overcome stereotypes placed on their Culture. During my time there, I realized that I related more to Aboriginal peoples than I did to the academic researchers from the most prestigious schools around the world.

For my PhD dissertation, I worked with the Quechua tribe in Ecuador, trying to understand their healing practice of *ayahuasca* (pronounced aja' waska), which is a psychoactive substance that when drunk, summons spiritual experiences. The effect *ayahuasca* had on me was to give me a better appreciation of the complexity of life beyond labels, science and religion, where there is peace and a strong spiritual existence connecting us all.

During this trip to Amazonian Ecuador, I experienced a drumbeat at the core of who I am. It resonated throughout my being, and further affirmed the sense that I am good. It was here that I released the guilt I'd been carrying about my father's death, and the animosity I felt towards him for leaving my mother, brother and me many years earlier. I'd felt guilty because when I was 19 he'd tried to re-enter my life, but shortly thereafter was burned in a fire. I'd stood in the corner of his room, angrily watching as he took his last breaths, never saying a word, even though the nurse told me that he could have heard my voice. A part of me blamed him for my broken brain.

Moving beyond the pain associated with my dad, I began to feel that I could be a good father and that I could raise a child who would be intelligent and make a contribution to the world. I ended up marrying my girlfriend and a year after my trip to the jungle she gave birth to our beautiful son, Waska. The name comes from the Quechua word of ayahuasca and means vine, or vine of the soul.

I found peace when I stopped trying to fit into the molds created by others and began listening to my own voice. I also started to help others move through their pain by helping them see themselves from a broader perspective. Ironically, not feeling like I was good at anything helped me to become good at identifying other's strengths, particularly those whom society deems as rejects.

Next year I will take my son and wife down to South America, so they can experience the various ways that people live. I will make sure my son finds a mentor to guide him in whatever direction his inner voice takes him. ■ ABILITY

by Scotty Enyart

The author is a psychotherapist who enjoys working in multicultural settings where he can use his skills to develop culturally sensitive projects and provide direct services. He loves to travel and meet new people.

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AMYpalooza!

AMY BRENNEMAN

Amy Brenneman is best known for her TV roles on *Private Practice*, *NYPD Blue* and *Judging Amy*, which was based on her real life mother, who was a state superior court judge in Connecticut. As the wife and mom of two, daughter, Charlotte, and son, Bodhi, Brenneman is heavily involved in her children's school, CHIME. She favors its unique approach to education by blending together typical kids, like Bodhi, and kids with disabilities, like daughter, Charlotte, who has cognitive challenges. In recent years, the actress has hosted, along with actor Benjamin Bratt, the fundraiser CHIMEapalooza, and has traveled as an ambassador for CARE, the humanitarian organization devoted to fighting poverty. Brenneman recently spoke with *ABILITY*'s Chet Cooper and Lia Martirosyan.

Chet Cooper: We had a meeting recently with the confernce producers of ABILITIESme happening in the United Arab Emirates. They are working with their department of education to better intergrate children with disabilities—and I mentioned CHIME.

Amy Brenneman: We actually just got a grant to develop a three-day curriculum so that people from other schools can come; one day they'll observe a classroom, and the next day there'll be seminars. The whole thing will give professional support to people who want to be inclusive, but don't know how. It's going to happen in the spring and, hopefully by the fall, we'll have people come through four or five times a year. Erin Studer, CHIME's executive director and principal, got me involved. I think I was one of the only parents to be in on the planning; it was mostly educators asking, "If you had to boil down inclusion into three two-hour seminars, what would it look like?" It was a super-cool process.

Lia Martirosyan: How did you connect with CHIME?

Brenneman: My daughter has cognitive academic special needs. I got an Individualized Educational Program (IEP) for her when she was three. Back then we were in another school for a couple years, waiting to see if it was going to do it, and it immediately became clear that it was the wrong fit. But there were very few options. I actually heard about CHIME around that time, because one of the first grade teacher's kids went to the same preschool as Charlotte. So CHIME had been on my mind. And then I saw it and immediately knew that it would be a great fit for my daughter. We've been there for four years. So she's in fifth grade, and my son is in second.

Cooper: It's great that both your kids can attend the same school. What grade level does CHIME go up to?

Brenneman: Eighth. There's a big push to start a high school.

Cooper: How's that campaign coming along?

Brenneman: I'm sure it will happen. Erin is very committed to it. High schools have some different, yet similar requirements. It'll be the same sort of philosophy of project-based, accessible curriculums. A lot of the mechanics would be the same, scaffolding the academics…

Martirosyan: How does "scaffolding" work?

Brenneman: I believe scaffolding is the word they use to mean: How is this particular learner going to access this particular curriculum? The concept is to make the lessons accessible to kids with different abilities. Like right now, in fifth grade, they're doing the Revolutionary War, and the class is reading *Johnny Tremain*. My daughter has an adapted version of the novel that's better—so she can access the plot and participate in class discussions; the language is more simplified.

Cooper: I like the term "scaffolding"; it conjures up images of building around a certain issue, and then assuring everyone access to it. How did you get involved in TASH [an advocacy organization that promotes full inclusion of people with significant disabilities into their communities]?

Brenneman: Through Amy Hanreddy, who is on the California-TASH board. When we first came to CHIME, Amy was the assistant principal, and she's an enormously important person to me. She asks me to do things and I do them, because they always turn out well.

Cooper: I was surprised to see you do that song-and-dance number at the TASH event in November.

(*laughter*)

Brenneman: Because of that conference, I got to meet Eva Sweeney, who is now a rock star to me. [Sweeney is a gender-studies scholar with cerebral palsy.] I feel like I meet so many amazing people. Comedian Allison Cameron Gray, a buddy of mine, is going to be part of the next CHIMEapalooza.

Cooper: Are you going to bring in those Pittsburgh tap dancers; the ones who do that Riverdance-style performance?

Brenneman: I know—it's like Irish step dance.

Cooper: Isn't that Riverdance troupe an Irish group?

Brenneman: Isn't tap dancing like Fred Astaire?

Martirosyan: Jazzy.

Brenneman: Yeah. Riverdance is that weird, straight-arm, step-dancing thing.

Cooper: And there are three rivers in Pittsburgh, so maybe that's where they picked up the name.

(*laughter*)

Tell me about your recent CHIMEapalooza event?

Brenneman: It was for the CHIME Institute, not just for the elementary school. Lots of people in our elementary school would say, "What is the institute?" because they didn't come up through the infant-toddler or pre-school levels. CHIME Institute oversees infant-toddler, preschool and teacher training. So part of why I took over the fundraiser is I thought: I want to connect the charter school to this bigger mission. If you get there and your kid doesn't have an IEP, and you just know it's a great school, you wouldn't even know how cool the school really is. Although everybody senses there's



Amy Brenneman playing Violet Turner on the ABC drama *Private Practice*



something really special about this place, and about the care that the teachers take. When you dig deeper you realize why. It has to do with seeing each kid as an individual, and individualizing the curriculum.

Before CHIMEapalooza, Benjamin and I did this small fundraiser, and I kept thinking, This does not feel like our community. Our community is funky and wild and eclectic. So I had this vision for a night that was funky and wild and eclectic. It was a great success last year, both in terms of money raised, inclusivity and how fun it was. It's not politically correct, "Those poor kids." It's really, "This is why this community feels so great."

Cooper: So the second one was at CSUN (California State University, Northridge).

Brenneman: Benjamin and I wrote it and we included my friend Tim Daly and Lorraine Toussaint—and some performers with disabilities into it. Allison Cameron Gray did some of her stand-up; she's amazing.

Cooper: CHIME is affiliated with CSUN; do you attend the CSUN technology conference?

Brenneman: No.

Cooper: Do you know about it?

Brenneman: I do.

Cooper: Then you probably know that it deals with different issues relating to accessibility and technology. Some of the products demonstrated during the conference are life-changing.

Brenneman: How cool.

Martirosyan: Aside from your TV show and your fundraiser, what else have you been up to?

Brenneman: In December, I went to this little town in Peru with CARE; I've started to do some traveling for them. The program I was looking at had to do with nutrition for pregnant moms and kids. I was with this really wonderful man who's a pediatrician in Lima, works with CARE and was my translator.

I was really struck by this one kid there. His mom came up to me; she spoke a Peruvian language and she said to this doctor, "Can you help me? My son is six years old and he doesn't speak." My little ears just perked right up. I said, "Tell her my daughter didn't really talk till she was four." And I thought, wow, what are the chances of this kid getting what he needs? But at the same time this boy is part of a town of 123 people, where he's loved and belongs.

Cooper: Did he sign?

Brenneman: No. I think there was something 'spectrum-y' about him, but he wasn't totally shut down. I thought, okay, my daughter didn't speak at two and they said, "Get her into speech therapy," the next day she was in speech therapy. In LA, though, we have resources. When you do international developmental work, you realize that first you need clean water and sanitation and then, if a person has a special concern on top of that, you try to deal with it.

Cooper: Was this CARE part of the woman empowerment portion of the program?



Brenneman: It was basically—I want to go. I brought my kids. They wanted to send us to Africa and I thought, I don't know if I want to go all the way to Africa. But logistically, Peru is a very easy trip. It was a program called *Windows of Opportunity*, which is mostly nutrition for these villages that are pretty remote. It involves a well-baby checkup; everything we would do at a pediatrician's office.

Cooper: It's good that they're doing that. One challenge is follow-up. Often times there's such a need, we've done stories on the Mercy Ships, where people literally walk for days to be seen by a doctor. The lines are so long sometimes they can't be seen. Then they have to go back home and the ship doesn't return for another year, if it comes back at all.

Brenneman: That's right. But I think what CARE really wants to do is train local people. That's the only way it's going to have any legs to stand on.

Cooper: The Mercy Ships are looking to do that, too. They do try to bring other local health care facilitators onto the ship to learn, but the equipment can present challenges.

Brenneman: I'm sure.

Martirosyan: What are you working on creatively, these days?

Brenneman: I pitched a movie to Showtime the other day. My friend, Rodrigo Garcia and I had an idea about a year ago about a mother of a pretty seriously disabled kid. And whenever I pitch the script, it's sort of like we have to pretend there's no CHIME. We're making the kid about five, so they're sort of coming out of that cocoon of adjusting and meeting the Eva Sweeneys of the world. People might think, who would want a disability? Nobody, right? And then, okay, but what is this CHIME-like community? And look at how vibrant and life affirming it is for everybody. Because it's about authenticity, acceptance and communication—all this stuff that's interesting.

We were talking about casting. So Gail Williamson, of Down Syndrome in Arts & Media and Rodrigo knew each other from somewhere else. It was interesting, because Rodrigo is just an amazing storyteller, but he doesn't know of this disability world at all, so I've been sort of leading him along and we had this great meeting with Amy Hanreddy. And at the end she said, "What's really cool is, you could cast a doctor with a disability." Rodrigo got really nervous. I was like, "It's okay!"

(*laughter*)

We talked about it later, and we're not there yet, but I said, "Hypothetically, what is it about that idea that

makes you nervous?" And he said, "I have to direct." It just is a new thing for him.

There's this parallel to this in the piece that I put together for CHIMEapalooza 2013. It's a piece about *Brown v. Board of Education*, which integrated the nation's schools in 1955, and the Individuals with Disabilities Education Act (IDEA) in 1975. They said, "It'll never work, it'll be disruptive." And then it actually worked out.

Cooper: But sometimes when you look at history, it doesn't work so well, like giving women the right to vote.

(*laughter*)

Brenneman: That's right; it was a terrible idea!

Martirosyan: That's why I love watching Jon Stewart. He grabs a lot of footage from things people have said in the past and then uses it to comment on current events to show how hypocritical they are.

Brenneman: I said to my husband the other day, "Who else does this?" He was doing a segment on the head of the NRA, and he was saying, "We can't make any changes," and then Jon Stewart said, "The basic idea that's gaining traction is a much better ID system," and then they found that same guy 15 years ago saying, "Well, basically, if there's a better ID system…" He literally said that. It's on film.

Martirosyan: I always think of how incredible Stewart's team is. They find all this archival stuff, and sometimes within very tight time windows. I don't know why politicians don't do it. Are you politically involved?

Brenneman: I am and recently I got really involved with Prop 30 [which increased some taxes that were allocated to education], too, because I thought, man, CHIME is going to go down the tubes. I went down to this empowerment center in Inglewood and made phone calls. I was so freaked out.

Cooper: Have you become more of an advocate since becoming a mom, or have you always been that way?

Brenneman: I've always spouted off. (*laughs*) I'm obviously very opinionated. The vast majority of my friends in the circles that I run in send their kids to private schools. And I would have, too. But I grew up in the public school system and then you have a kid with an IEP, and actually by law the public schools should service kids with IEPs. Now we find ourselves in this public school that we dearly love. The fact that California is 47th out of 50 states in what we spend per pupil is sick. It's really sick—how about putting some money in to it?

I had the radio on this morning and heard, "The Pentagon may have a couple more furlough days because of these trigger cuts," and I thought, "Good." (*laughs*) I mean, I feel bad for those people, but they've had it pretty good for a long time, so okay, a furlough day or two.

Martirosyan: How did you first get into acting?

Brenneman: I started doing plays when I was in seventh grade and I never stopped.

Cooper: Spouting off?

(*laughter*)

Brenneman: Spouting off. CHIME had a wonderful woman who's still a good friend of mine who ran this theater program in Connecticut, the town I grew up in. It was very, you know, 70s, so it was all about self-expression. I vaguely knew there was this profession called acting, although every time I'd bring it up to my parents, they were like, "No. That doesn't exist." So there wasn't anything pre-professional about it, but it was all about self-expression and community. I just loved it. But when I went to college, I didn't major in acting, I majored in religion.

Cooper: Where did you go to school?

Brenneman: Harvard.

Cooper: Where's that?

Brenneman: (*laughs*) Cambridge, Ma. I was into Hindu stuff. Then I lived in Kathmandu and ended up getting into Tibetan stuff. But then, while we were there, we started a company.

Martirosyan: You started a theater company in Kathmandu?

Brenneman: No, sorry! (*laughs*) That would have been awesome! Right out of college we started a theater company that was community-based and we would create theater around our concerns. I'm always circling the same bunch of interests.

Cooper: And what are your major interests? It wasn't disability back then.

Brenneman: It's really community-based theater, self-expression. What I did for CHIMEapalooza is put out a call for people to submit stories to the CHIME community on the subject of school or inclusivity. My favorite thing is when people offer their stories. Then, as a theater artist, I shape them into an experience for an audience. It's all about the stories.

Martirosyan: CHIME is a great story. How many students does it accept? Is there a limit?

Brenneman: Yeah, there's a waiting list. People drive in from 40 zip codes. It's crazy. There's nothing like it,

really. There's a school called WISH in Santa Monica; it's sort of a sister school. CHIME has a methodology for doing this thing. You can have inclusivity if you happen to have a really cool principal who's interested in it. But back to your point: There are usually about four applicants for every slot. And then CHIMEapalooza was such a success and Ben and I did publicity around it. Then it jumped up to eight applicants for every slot! It's not like we have any more space!

So I said to the principal, "I feel really bad!"

Cooper: Oh, no! Unintended consequences.

Brenneman: Right.

Cooper: You're really a mean person!

Brenneman: (*laughs*) I'm a terrible person. But you know, really what we hope to do and I think professional development will help, is it to make it look better. Our campus is just so ghetto.

Cooper: It looks like a public school.

Brenneman: It just looks like crap and I became beautification queen, I asked, "What's our budget?" And it was nothing. We have no money.

Martirosyan: And yet you have a waiting list.

Brenneman: (*laughs*) The school looks a little better now. But also, where we put our resources is in staff. First of all, there are about 20 kids per class and in that classroom is a general education teacher, a special ed teacher, who usually has three different classes, but they're present, and then up to two or three paraprofessionals for kids who may need support in different areas. That's a lot. That makes the model appeal to everybody, because who doesn't want to have small classrooms and more teachers? So our field looks like crap, but we have really happy kids.

(*laughter*)

Cooper: I've been there twice. It doesn't look like a private school. But it's a good feel.

Brenneman: Yes. People walk around and there are these mini-classrooms especially for younger kids, and outside the classrooms will be a little trampoline. It's for kids who have a hard time sitting. "Okay, she needs to jump." There are accommodations. I teach a class there; I'm going to teach this afternoon.

Cooper: What are you teaching?

Brenneman: It's called playmaking. It's basically generating material for theater. There's a guy who does traditional plays with the kids, like *The Wizard of Oz* or whatever. The stuff that I love is creating characters and all the different elements of a performance. So we do movement, physical stuff and I'm teaching them vocal warm-up.

Last week was really wonderful. They wrote more autobiographically, which they were shy about at first. We were doing a warm-up, we're on the floor—and we have two nonverbal kids, so they do the warm-up in their own way. But there was this one kid that I didn't really identify with any particular disability and he was walking around, eating snacks. I thought, okay, can you sit down and do the warm-up? That's when I realized that I didn't know what his diagnosis was. Maybe he's got a diffcult time sitting down. My heart just kind of opened up. As long as you're not being disruptive, which he wasn't, I think CHIME just gives you a little bit more slack, especially with an after-school program where they're coming off of a big full day.

Cooper: Did the kid engage eventually?

Brenneman: Oh, yeah. He's a fantastic kid. With nonverbal kids it's always awesome to figure out how they can communicate. One kid I know very well, so I know when he's engaged. One kid I don't know as well.

Cooper: Do they have augmented devices to speak with?

Brenneman: They do. One of them has a really wonderful aide, Sonya, who has really become part of the class; and the other, his aides come and go, so he hasn't been quite as consistent. I love it, because I love self-expression. First of all, it's a jewel. Something gets offered up.

I've wanted to teach this class for a while. I love creating a safe space for the kids. Last week, they started talking about bullying.

Cooper: What are their views on bullying?

Brenneman: As an example, this girl said there were some girls on the playground who wouldn't play with her. Honestly, between you and me, I feel like kids use the term "bullying" as sort of a catch-all.

Martirosyan: What does a parent have to do to get their child an IEP?

Brenneman: If there are any concerns that the child might need special accommodations, state law dictates that the school has to provide speech and occupational therapy. As well as adapt the curriculums to the students. There are these goals that my daughter has—we sign off on it and it's a government document.

Cooper: I often hear from parents about the struggle they have with different schools to update and evaluate. Have you experienced anything like this?

Brenneman: When my daughter was three, we got her

an IEP in the brave new world of special ed. I was so ill-equipped and there were two different days of evaluations. The first day she was miserable and had this epic tantrum, it was so embarrassing. And then the second time she was evaluated, she was delightful. A friend of mine said: "You want the kid to freak out on evaluation day, because then you get more services. You get behavioral, you get this, you get that." My friend went on: "I deprive my kids of naps and food before their IEP." (*laughs*)

CHIME has a wonderful speech therapist. By law, your child is going to get an hour a week, but it's just not enough. Right now, Charlotte's terrible with her sense of time. She'll say something's going to happen tomorrow, even if it's any time in the future; it could be a month from now or next year. So that's been a goal: drill down on her language. Her speech person knows that; her teachers know that. Honestly, though, it does come down to the parent. I can't even tell you how many times we're like: "Where's the person who's supposed to be running this show? Oh, it's me!" (*laughs*) I'm the mother.

Martirosyan: It's really tough on parents.

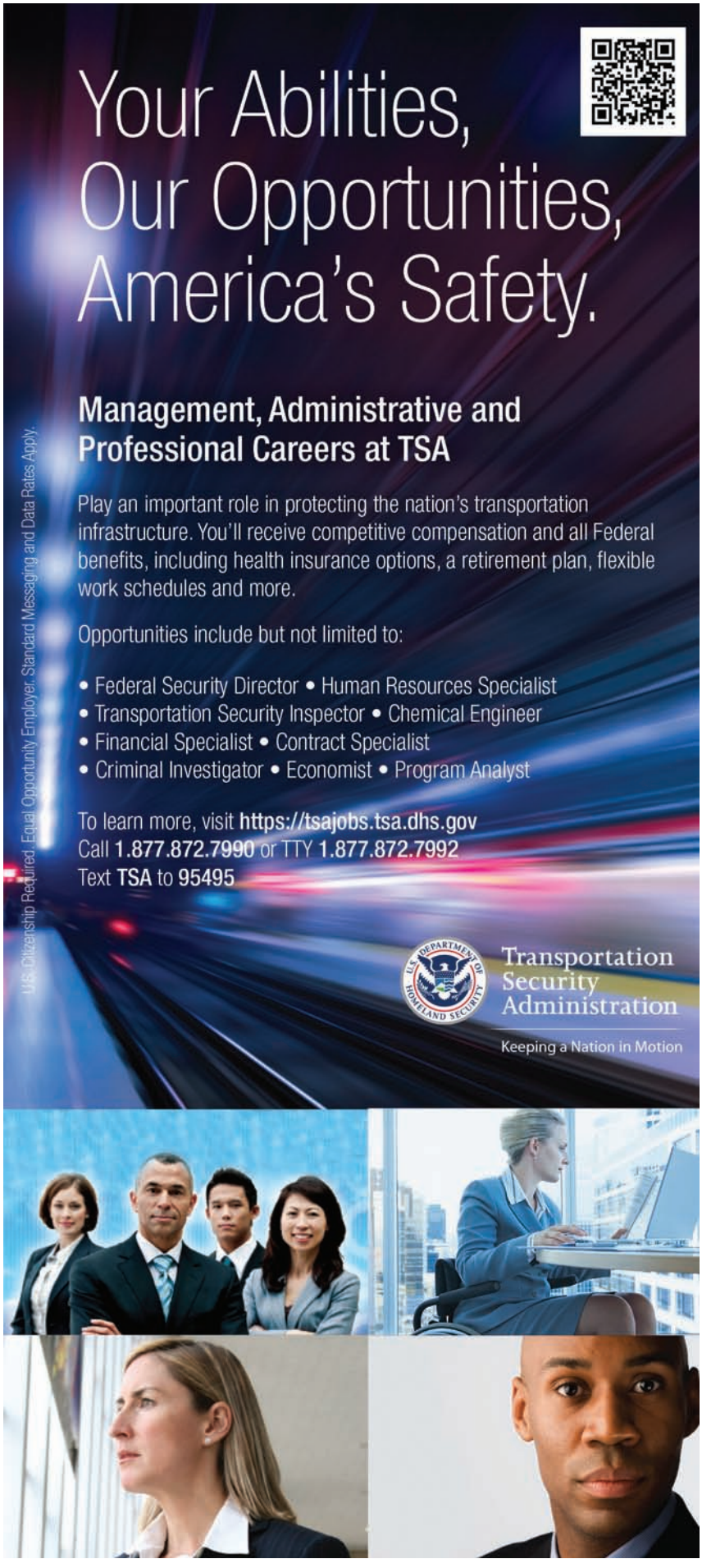
Brenneman: One of our founders has a son with a pretty severe disability; she wrote something called, *IEPs for All*.

Martirosyan: At the end of your class at CHIME, will there be a performance?

Brenneman: A small one. The co-teacher and I love this process. The kids ask, "Are we going to do a play?" I say, "No, we're not going to do a play! Everybody does plays!" And at the end I looked at the co-teacher and said, "They really want a performance." (*laughs*) So I think we'll show parents, or whoever wants to come, the kinds of things we do. It's really important for us, especially in this product-goal-oriented moment we find ourselves in, to go, "We're not going to have costumes, but we're going to do something." I'm actually going to look through their writing and start crafting a little production. You should come.

■ ABILITY

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EXPANDING AUTISM AWARENESS
In the Middle East

As the United Arab Emirates (UAE) gear up for a big 2013 conference on disability, His Excellency Fahed Bin Al Shaikh of Dubai works to raise awareness about autism in his part of the world. He and *ABILITY*'s Chet Cooper recently spoke via Skype.

Chet Cooper: How did you start working within the autism community?

HE Fahed Bin Al Shaikh: I watched advertisements about autism, and then I called friends to ask them about it because it's something that hadn't really been explored in my country. Some people wondered whether autism was a disorder, a disease or a sickness. They tended to think of it as a disease because, growing up, we thought of disability in terms of someone being deaf or not being able to walk, or that a disability was something that occurred after someone was in an accident.

Before the term "autism" was used, people would mention something about a person's social communication; they would say the child didn't interact with a lot of people. The difficulty that I am facing now in my center—and that others are facing in a lot of centers—is that people still don't perceive autism as a disability, but in fact the disability laws should be protecting those who have it, too. Lacking the ability to engage socially can be a disability.

Now, I'm trying, with the help of ABILITIESme in Dubai, to speak with the government about this matter. We need to include autism in our laws. Some might just say, "Well, the person is mentally ill, closed off, doesn't look you into the eye…" This is what autism looks like. It needs to be diagnosed. I have tried to sort out things and said: Why don't we use the term "autistic," instead of putting all disabilities under one umbrella?

Cooper: What would the benefit be of writing that into the law?

Bin Al Shaikh: The benefit would be that the law would specifically cover the child or adult with autism.

Cooper: So there is a need to better define the condition?

Bin Al Shaikh: Yes, because if you have a child with autism, you may not get support for that child, whereas if he were deaf or blind—a more recognized disability—you might get more help.

Cooper: We have the same problem in the States. Most parents can't afford the $10,000 to $15,000 a year, or whatever the exact cost is, for the different services that are needed. I think many people around the world struggle with that.

Bin Al Shaikh: If someone earns, for example, a $5,000 per month salary and then you have house payments, utilities, transportation, schools, clothing, food and everything else—and here comes a child with autism. How much do you think his care is going to cost? Then if the government says, "Your kid doesn't have a disability," that makes it worse. People who are blind, who are deaf or who can't walk have laws to protect them. It's only right to protect those with autism.

Cooper: How does the government pay for those services through your system? Is there universal healthcare?

Bin Al Shaikh: We have eight autism centers in the United Arab Emirates that I know about. Disability is not covered by the federal government. Let's take Dubai, for example. It has its own police, but there is also the federal police. It has its own schools, but they are under federal law. In every Emirate, there is one Ministry of Social Affairs, but the Emirates all belong to one federal department.

Cooper: That's how it is in the States, too: We have state law and federal law. Federal law typically is higher than state law, but there's often fighting between the two. Some states are more aggressive than others.

Bin Al Shaikh: We also have regulation challenges. For example, we have something called the Silicon Oasis. It's an independent government on its own. It regulates

and licenses companies under its jurisdiction. You also have the Media City and the Knowledge Village, for instance.

Cooper: I didn't know about those.

Bin Al Shaikh: If you want to come and start a magazine in Dubai, you can either go to the Economic Department, where you would pay the fees and get your license, or you can go to the Media City and get licensed. The difference between them is if you go to the Economic Department they will tell you you need to go to the federal department to start a magazine. They need to see what subjects you intend to cover and the actual kinds of stories that will go into the magazine. But if you go to Media City, they can easily issue you a trading license. They don't complicate matters. Why? Because it's a small state. We have federal law, then we have state laws, and there are another three or four or five states that are being subsidized.

Now, we have Healthcare Authority—one department, one government entity. We have Silicon Oasis, one government entity. We have Enterprise Free Zone, that's an entity. We have Jumeirah Lakes Towers, that's an entity. There're around seven to eight in Dubai. The problem that I see is that if you say you want to open an autism center, it's very easy to do so. They will give you the certificate, and you can easily bring in people and start working. What I am trying to do with the new venture, called ABILITIESme, is to expand the definition of our disability law and to talk with the government about creating a regulatory board. The board would only issue licenses to autism centers that are working together, under one umbrella and under the same regulatory board that would certify therapists. It'll be better than having everything scattered around. That will be a big topic at our upcoming ABILITIESme conference in Abu Dhabi this coming December.

Cooper: So the regulatory board would be administered at the federal level?

Bin Al Shaikh: Yes, because if you are trying to implement a law, you cannot do it from the bottom up. You need to go to the upper division of the law—to the federal level—discuss it and say, "X, Y, Z is going on. The government should do X, Y, Z for their people. The people should know the rights for their autistic children." Over here, when you have a child with autism, you are lost. They'll say, "No, he does not have a disability. He can walk. He can do a lot of things." But they don't understand that autism is something else.

There are a lot of people in the world with autism who have been treated and who have reached their individual potential. There is hope. There is only an issue if you have a child with an autism diagnosis and you walk away saying, "I can't do anything. The government needs to do this for me." This is wrong. If you stand up and you face the issue, you can get the support. The support is there, but it has to be sought out.

Cooper: When the government does step in and support children with disabilities, do they pay whatever is needed up to 100 percent? Is it a sliding scale according to the family's income?

Bin Al Shaikh: The Community Developing Authority in Dubai has an annual budget. If you are a UAE national living in the UAE, and suddenly you have financial issues and are unable to pay rent, you would bring in your documents and explain what financial problems you are having. They would verify that you have an issue and say, "Okay, we are going to support you by paying for your housing accommodation."

If you have a child with a disability, for example, with hospital or school expenses and with more expenses coming, the government of Dubai would step in and say, "Okay, how much does schooling cost?" They would pay it for you. When you have a child with autism—which is very expensive to treat—some small state governments, like Dubai, would pay X amount and then advise you to take the autistic person to their center. But there are a lack of therapists and a lack of qualified people in the UAE. If the university would train occupational therapists, speech therapists and behavior therapists over the next 10 to 15 years, we would have more experts on board rather than appointing people from outside the country.

It would be good if we had people graduating from the UAE with special therapist qualifications. Everybody would love that. But we don't see a lot of people inside the universities asking for these courses. If nobody takes the classes, nobody will teach them and nobody will graduate or be qualified to offer these services. There is a lack of awareness in that area, too. That's how I see it.

Cooper: There's a saying from a popular movie: "If you build it, they will come." So if some of the universities there build a training center around disability, or autism specifically, I think the students would come. You can't wait for people to ask if they have the coursework. You have to offer it and interest will grow.

Bin Al Shaikh: Emirates University is launching a new speech therapy department. I think it takes a student four to six years to graduate with a bachelor's degree. With this new program, maybe interest will grow in that subject. But if we do approach the government and say, "We have a lack of occupational therapists and a lack of speech therapists," perhaps they can implement this coursework into the universities. They could look at it and say, "Okay, let's have a degree to certify speech therapists, behavior therapists, occupational therapists, psychologists and clinical psychologists." We have to start somewhere.


Dubai skyline

Cooper: When we last spoke, I mentioned that I was on the campus of California State University, Northridge. They support a school called CHIME, where a small but significant percentage of the kids have disabilities and autism is definitely part of that integration.

Bin Al Shaikh: I was reading an article about that.

Cooper: The university has a lab with two-way mirrors in the classroom, so as the kids and student teachers interact, the parents and other faculty can watch—it's a learning environment. Every day after school, if there's a problem with one of the students, they sit down and say, "Paul wasn't really reacting today. What can we do differently?" They continually review the curriculum, pay attention to how the children are behaving and explore how they can get the results.

It's a wonderful, evidence-based program, and it's creating real-time research on enhancing the lives of kids with different disabilities. Kids with autism often present the most difficult behavioral issues, like you said, and the research is still relatively new. The number of new cases is staggering.

Bin Al Shaikh: When I listened to the news of the school shootings in the US a few months ago, they said of the gunman, "Oh, he was autistic; he had Asperger's." As you know, they are so quick to label someone. People get scared when news that like that comes out.

Cooper: When there is a mass shooting people often assign mental health issues to the suspect, which is a challenge for those dealing with advocacy in those areas. It puts the fear in you that anybody labeled as having bipolar or schizophrenia or some other mental illness is on the brink of snapping.

Bin Al Shaikh: When the parents in my country heard that a kid with autism was involved in that mass shooting, some said, "Oh, no, if there's a classroom with an autistic child, I'm not going to let my child go there." There is no awareness about it. A child with autism should have exactly the same rights as a typical child. He has the right to be taught. He has the right to be treated. He has the right to everything any other child has.

Cooper: What is happening around Attention Deficit Hyperactivity Disorder (ADHD) or dyslexia?

Bin Al Shaikh: These are important issues, as well. ADHD, dyslexia—I know that there are a lot of dyslexic people in my country, but again, you need to be able to get a proper diagnosis. Sometimes at schools, they will say, "The child is not listening properly, he's always failing, he's not being good in class, he doesn't look at the board, he's always naughty, he's a mischievous child, he doesn't pass his class." Why do we always have to blame the child? Maybe there's more to it. Why don't we diagnose the child and see if he or she is dyslexic?

Cooper: Or has ADHD?

Bin Al Shaikh: Yes. It's not that difficult, but people don't always know about it. How can we come up with something to raise awareness and get people treatment? It needs to start from somewhere. If your son fails in class, does it mean he's naughty and not studying? Maybe the child is too scared to say, "I can't see properly. I have an issue with my eyes." I suggest that each school, when they think that the child is not performing well, have the kid diagnosed for dyslexia, dyscalculia, ADHD—anything.

Cooper: Your country signed and ratified the Convention on the Rights of Persons with Disabilities.

Bin Al Shaikh: Yes, but it takes a long time to implement laws. It doesn't happen the next day. It's not easy anywhere in the world.

Cooper: When was the law written?

Bin Al Shaikh: Some laws were done in 1971, implemented in '82, amended in '92 and then amended again in 2002. Additional laws were over the last decade.

Cooper: So you need an amendment to include autism.

Bin Al Shaikh: Yes. If we don't come to the government and tell them, "We have an issue. We are facing a lot of difficulties," how would they know to expand the law? What do we really require? We need a regulatory board that licenses autism centers from one department. It shouldn't be under a lot of different entities. This is what we are working on. The government is very open to having something like that.

Cooper: That's good to hear. ■

autismtrustfoundation.com

Leveling the UAE Playing Field



About 20 percent of United Arab Emirates (UAE) nationals living in Dubai report having disabilities and more women are affected than men by about five percent, according to a 2012 study by the Dubai Health Authority.

The UAE is a country made up of seven emirates (including Dubai and Abu Dhabi, its capital) and is located on the Arabian Peninsula in the Persian Gulf. Populated by nearly five million people, the UAE is bordered by several Middle Eastern nations, including Qatar, Saudi Arabia and Iran.

To raise awareness of disability issues in the region and beyond, an ABILITIESme Congress was planned for late spring 2013 with governmental meetings, conferences and workshops to address policy regarding inclusive social development, as well as local, regional and international partnerships between governments and their constituents.

The initial meeting was intended to set the stage for the coming ABILITIESme December 2013 confab, where attendees will define priorities for stakeholders in the global disabilities sector. They will map out the responsibilities for government agencies in the arenas of economic, social, education and professional empowerment of all people with disabilities.

While the UAE's special education programs and services have been developing since 1979, eight years after it won independence from Britain, it was in 2006 that His Highness Sheikh Khalifa bin Zayed Al Nahyan, president of the UAE, issued a federal bill ensuring equal care, rights and opportunities for people with disabilities in education, health, training and rehabilitation.

The law includes hiring goals for people with disabilities in the public and private sectors and focuses on increasing accessibility to public buildings and residences. The bill also emphasizes integrating this population into public and private schools and allowing those with disabilities to retire earlier than typical coworkers—and with full benefits.

The UAE and Gulf Cooperation Council countries are involved in a global resolution through the World Health Organization, to advocate equal opportunities, rights and dignity for people with disabilities, especially those who are poor. In 2008, the UAE also became a signatory of the Convention on the Rights of Persons with Disabilities, the UN global campaign to recognize the inherent worth and rights of all members of the human family—including people with disabilities—as the foundation of freedom, justice and equity everywhere.

ABILITIESme will be held from December 9–11, 2013, at the Abu Dhabi National Exhibition Centre, United Arab Emirates. It is sponsored by dmg :: events (formerly known as dmg world media), a subsidiary of the Daily Mail and General Trust in the United Kingdom. ■ ABILITY

dmgt.co.uk



BECOMING WHOLE



When I was a little girl, I don't remember having a firm concept of God, specifically. Yet I do remember having a very clear idea of what heaven would be like. I believed that heaven would be just this: a place where I could talk freely with my brother.

It would be a place without the limits of autism on his part or lack of knowledge on mine, a place where I could ask him a question and receive a complete answer. I remember wanting to ask him about the details of our life; I wanted to know if Cheerios were really his favorite cereal or if he ate them simply because that's what Mom bought. I wanted then what I want now: a window into his mind and heart.

Yet maybe, just maybe, I can only see in part because to see fully would be too much beauty to bear.

For me, heeding this wisdom means that, even as I hope for heaven, I look for those sudden windows into my brother's mind and heart now.

I remember a time one such 'window' opened: during the long-ago era when my brother was obsessed with *Snow White and the Seven Dwarves*. He had (still has) all seven stuffed dwarves, and he loved to line them up. He referred to himself as 'Grumpy' or 'Happy' depending on his mood. I realize now that the film was probably an excellent way for him to learn about identifying emotion, since each dwarf is typecast and consistent in facial expression throughout the story.

One day, my parents asked him, "Willie, if you're Happy, who is Mommy?" For reasons inexplicable, Willie replied, "Mommy is Bashful!" Mommy is not bashful. However, Bashful is a thoughtful, kind dwarf, so perhaps these qualities were behind his choice.

My mom then asked, "And who is Daddy?" Willie said, "Daddy is Doc!" This choice seems a bit more logical. My father wears glasses and has a calm, direct way of expressing himself. He has a quirky sense of humor, and he's a natural leader.

Finally, my mom asked, "And who is your sister Caroline?" With no hesitation, Willie said, "Caroline is Snow White!"

So there you have it. To my brother, I am a Disney princess. He may not be able to say things like, "Caroline, I look up to you," or, "Caroline, I'm glad you're my sister," but he can cast me in a starring role in the movie of his mind.

I may not be able to see all I'd like to see of my brother's mind and heart, but what I can see is astonishing. He's creative, hilarious and generous with his casting.

• • •

One day, as I was walking home in Washington, DC, I passed a family on the sidewalk. Mom, dad, grandma, teenage guy, walking and smiling. As I passed, I noticed that the teenager had some form of physical (and perhaps intellectual) disability.

In that moment, I felt such a strong combination of feelings: happiness that this family was out on the town together; sadness for the experiences of ostracism and prejudice that this teenager and his family have undoubtedly faced because of his disability; grief at the way that they're not supported by society as a whole, because the rest of society sees themselves as 'whole'—

and then a bittersweet joy, because I can only imagine the kinds of amazing gifts this guy has to share.

I was almost in tears—simply from seeing a stranger's face. And that illustrates my passion perfectly: to seek out the treasures in each person and illumine those treasures through story.

To write and fight and work and strive for a world in which we celebrate people not just for what they can and can't do, but for who they are and how much they are able to love.

And that's what *Love's Subversive Stance* is about: assuming the subversive stance of loving people—including ourselves—for exactly who we are.

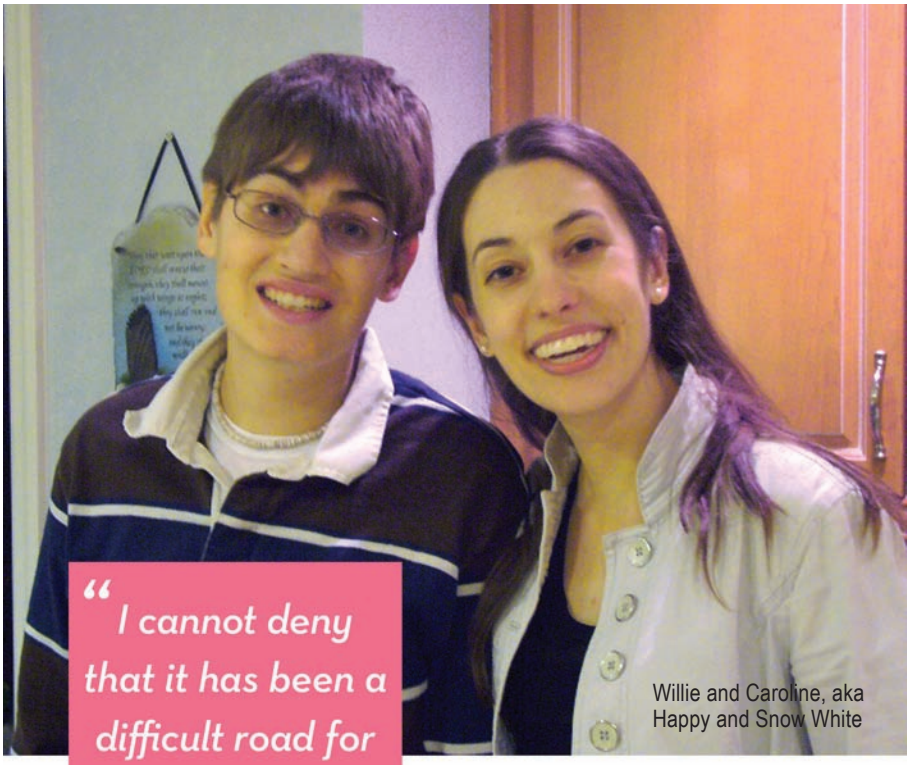
Such acceptance is radical; such relationships are rare. Yet I know that it is possible to love without agenda. It is possible to say to someone simply, "I love you and I celebrate you. I will walk alongside you as you grow and change, but I won't put pressure on you."

• • •

At times I wonder what my life would have been like had I not been Willie's sister. I know my parents have wondered the same thing: what would life have been like for us, for him, if he had not been born with autism? I cannot deny that it has been a difficult road for us. Yet I cannot bring myself to wish for a different path. It does no good for me to speculate and compare my brother to imaginary, non-autistic brothers I 'might' have had.

What can I do? I can accept our life as it has been and celebrate what holds us together. In doing so, I'm learning to reject comparisons and embrace what is. And what is, is downright puzzling. It calls into question all my old assumptions.

At times I wonder how much of the pain of my brother's disability has come from autism itself and how much has stemmed from the distance I have felt between him, and the rest of the world. As a society, we don't believe that people with disabilities have incomparable gifts to offer us. We don't believe that people with disabilities can teach us about overcoming adversity and what it means to be whole in the midst of brokenness. And this is our loss.



Willie and Caroline, aka Happy and Snow White

"I cannot deny that it has been a difficult road for us. Yet I cannot bring myself to wish for a different path."

At times I feel like my brother's defender, as though I was meant to be his protector against the prejudice of the world. And it's true—this is a way of loving him and advocating for him. Sometimes, that may mean standing up for him. It may mean asking a dear friend not to use the word 'retarded.' It may mean speaking at budget hearings and advocating on his behalf and that of others like him.

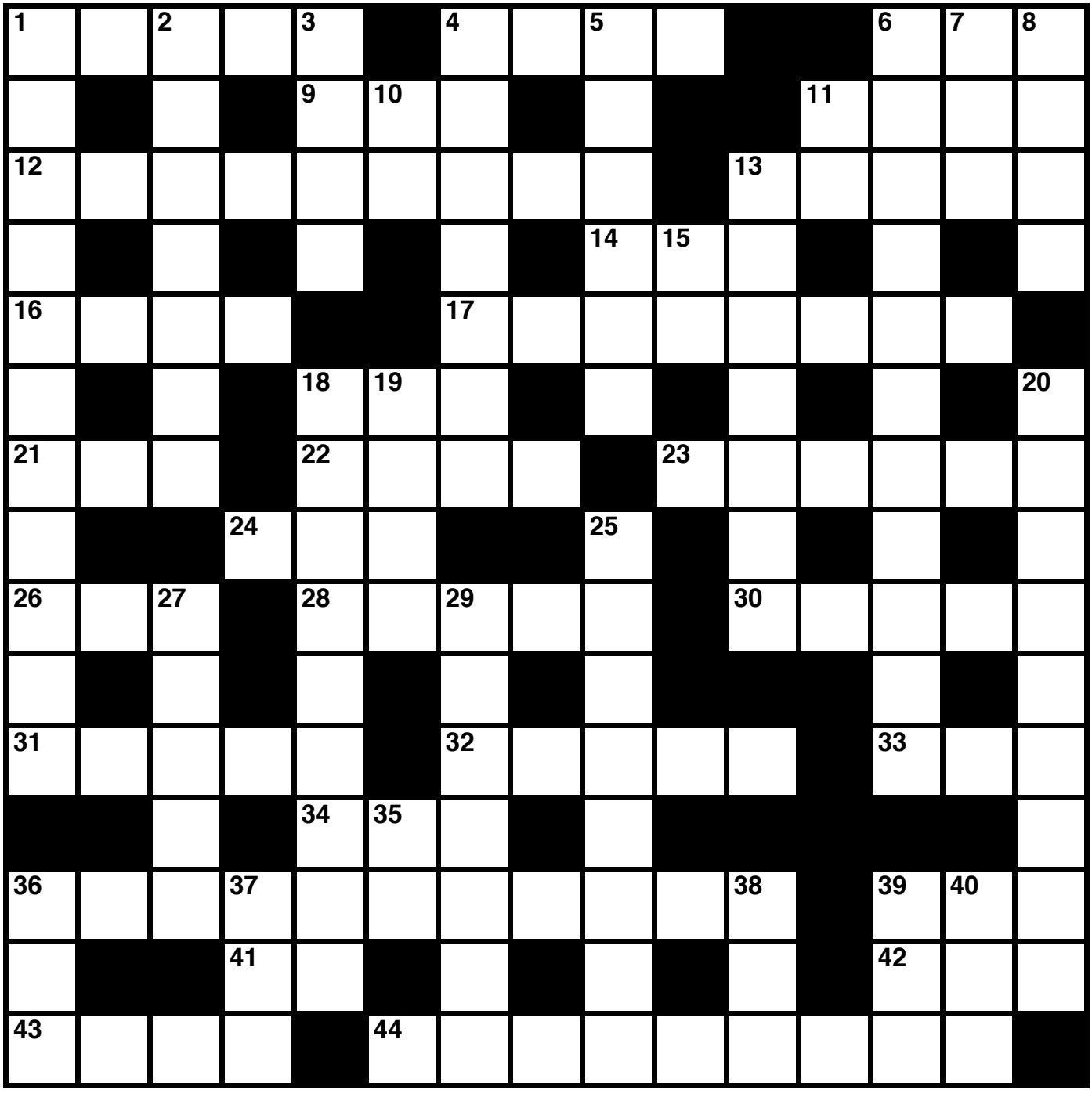
Yet most often, keeping the faith means simply being there for him in the day-to-day matters, in the ordinariness of life. For example, I've committed myself to calling him weekly, to being a part of his routine. The most important testament of my love for my brother isn't in my words. It's in how I relate to him. It's in a willingness to do things that benefit him. It's picking up his medications for him or calling him or attending his piano lesson when I'm home, to see him shine.

Standing in solidarity with Willie is the boldest statement I can make. I'm saying: not only is my brother worthy of love and belonging, not only is he uniquely gifted—he's akin to me and he's my friend. ■ ABILITY

by Caroline McGraw

Caroline McGraw is a would-be childhood paleontologist who digs for treasure in people with autism and intellectual disabilities at A Wish Come Clear (awishcomeclear.com), and empowers caregivers to do the same. This post is an excerpt from her recently-released book, *Love's Subversive Stance: Ground Yourself & Grow In Relationship*

ABILITY's



Crossword Puzzle

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ACROSS

1. Advocate for inclusive global travel, Scott ____
4. Chapman University president who overcame speech problems as a kid and wrote a book about it, James L. _____
6. Think outside the ____
9. Rowing equipment
11. Co-ed dwelling area
12. Help out freely
13. Diving gear
14. Little mischief-maker
16. Melody
17. Independent minded person who thinks for himself or herself
18. Connect
21. Part of L.A.
22. Chances
23. All together in a choir, in ____
24. French for soul
26. Spiritual path
28. Short Japanese poem
30. "When it is dark enough, you can see the ____" Ralph Waldo Emerson
31. Enjoy the taste of
32. Bagel choice
33. South Korean car maker
34. Relations
36. "The Sessions" actor (2 words)
39. The redwoods at Yosemite will bring this emotion
41. Well-liked
42. Great NBA coach who drafted the first African American player into the NBA, ____ Auerbach
43. Jewel in a park or a garden
44. Educates

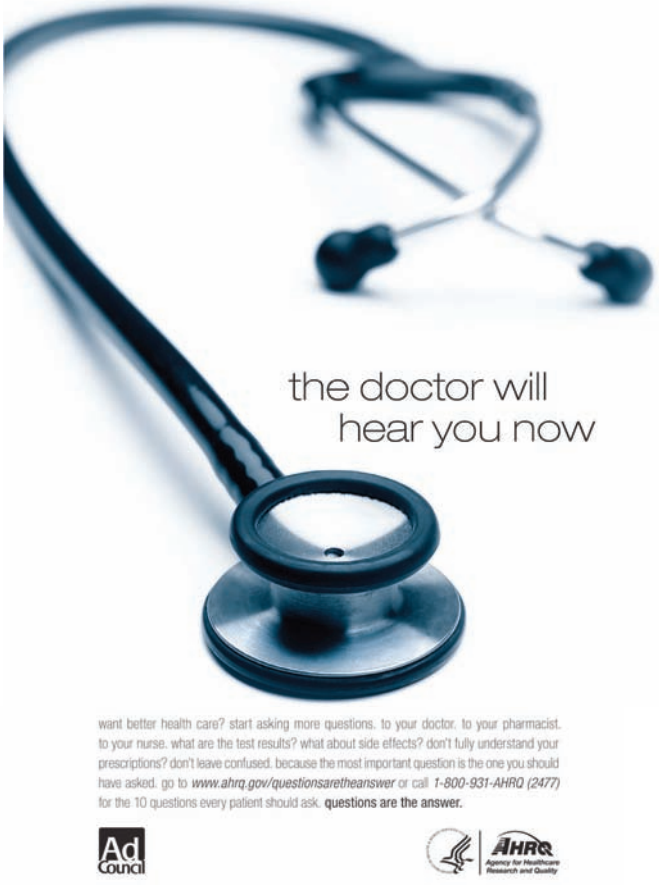
DOWN

1. .Brings back to life
2. They are surrounded by sea
3. "I'm just a man, not a hero. Just a boy who wants to sing this ___" Gerard Way
4. Imagined a great future
5. Flourish
6. Gets off the floor and smiles and carries on..... (2 words)
7. Venus or Mars, for example
8. Reindeer exercise time
10. Where it's ___
11. Site of the National Gallery
13. Fountains
15. "___, myself and I" Beyonce
18. Senator who has introduced legislation to prohibit the use of seclusion in locked or unattended rooms at schools (2 words)
19. "College isn't the place to go for ___s" Helen Keller
20. Willing to be what one is with no fear
25. Very very happy!
27. Philosophers have contemplated it for a long time
29. Triathlete
35. Des Moines state
36. Humor
37. Take a rest
38. "Because being with ___ makes perfect sense" Tim Mcgraw
39. Creative creation
40. Montgomery of jazz

Crossword Puzzle

answers on page 62


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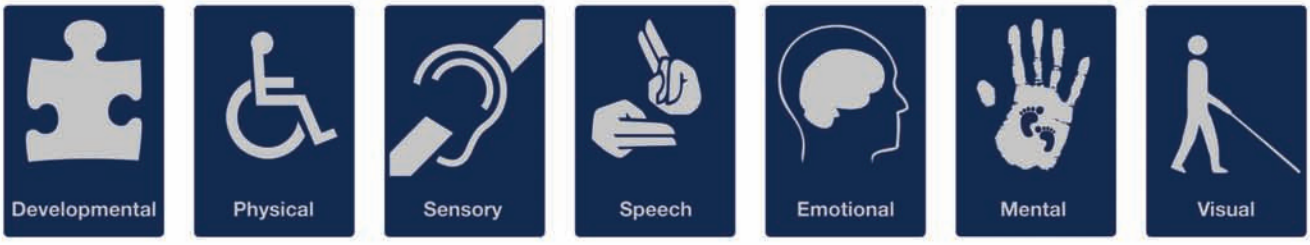
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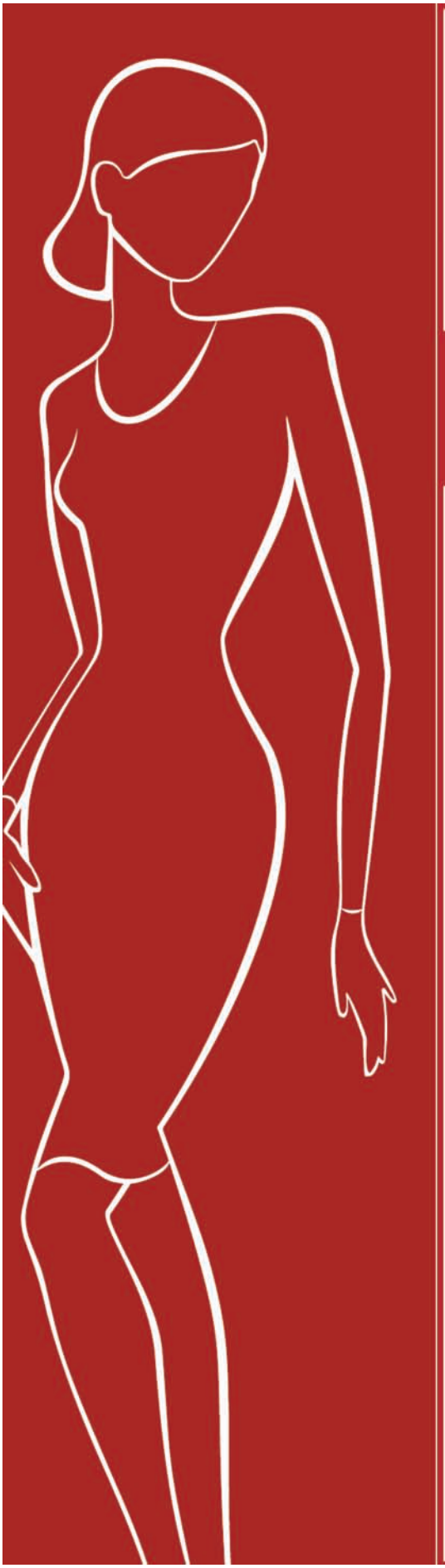
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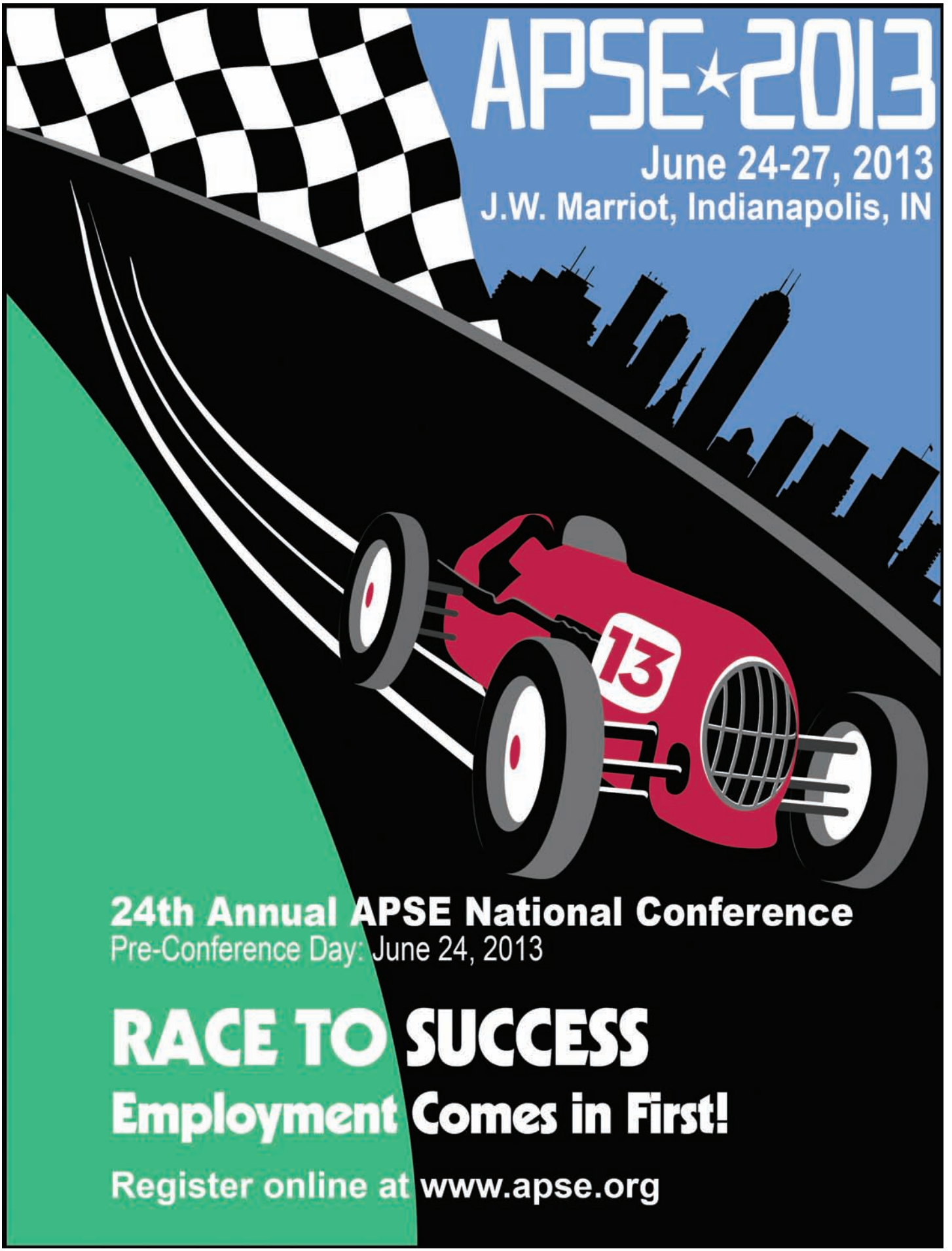
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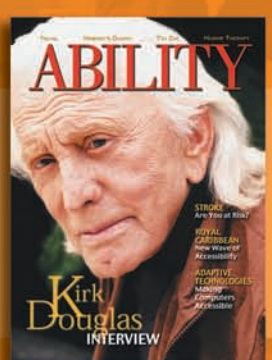
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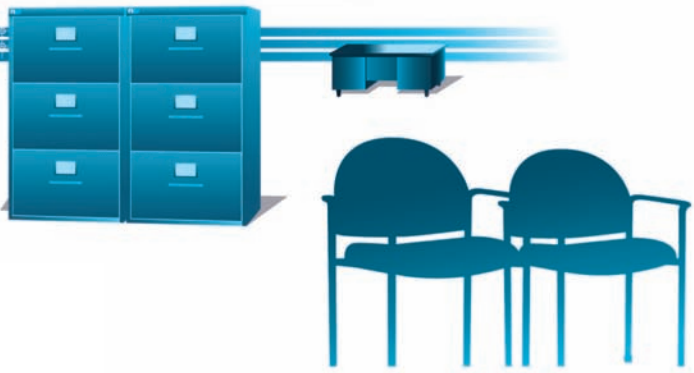
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