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The collage consists of three images. The top-left image shows the dome of St. Paul's Cathedral and the Millennium Bridge. The top-right image is a close-up of the bridge's steel truss structure. The bottom image shows the bridge's towers reflected in the water at night.

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Once again, it's the off-season. I love it, but it is super busy, too! My friends never seem to understand. They think, well, you are done racing, so you must be really bored. That is not the case. From February through May, I usually train and get ready for the season, and then in May, I start racing, which lasts until September. If sponsorship and benefit requests are asked of me, I normally try to see if they can be scheduled after racing season. Ok...well my mom is really the one who handles all my scheduling. There were so many things to do that I actually had to start keeping a calendar on my phone of when and where I needed to be. Maybe this is because I am 22 now, and with as many concussions as I have had, I would forget everything.

So as soon as I finished in September, there were a couple of red carpet events for the TV show, *Switched at Birth*, and those were just fun to do and I got to hang out with everyone. I had a short break and then I was off to New York for the Women's Sports Foundation (WSF) benefit dinner. They have a dinner every year to help raise money to support all of their wonderful programs for young girls, which includes helping them get involved in sports. It is also a time for all of us female athletes to get together and have a great time, and to appreciate what everyone does in her respective sport. I really look forward to this event. It was a little sad this year because we lost a great female athlete, freestyle skier Sarah Burke, who was a wonderful person and who always wore a bright smile at every WSF event. She had a bad fall while practicing for the Winter Olympics. We talked about all the good memories we had of Sarah; she will definitely be missed!

After WSF, the next big thing on my agenda was to

head to Las Vegas for SEMA, the automotive specialty products trade show. I was there to do some autographs for my sponsor, Traxxas., which, by the way, is company that makes wicked-fast remote control cars. I had never been to the show before, but I had a good time in Vegas. It was a whirlwind because it was right before Halloween and I wanted to be back home, in Florida, to go trick or treating with my little brother. I wouldn't miss that tradition for anything. My roommates and I and all of Kicker's friends dress up and go trick or treating, and then we come back home for pizza. It's always tons of fun.

The following weekend my mom and I headed up to Atlanta for the International Motorcycle Show. We had to be there at 5am on a Thursday to shoot a little video commercial for the show. I worked with Ricky



Ashley with fan Ashley

Carmichael and Colin Edwards. We had to work past 2 am, but we had a really fun time, just laughing so hard, even though we were all tired. The next two days we came back for autographs and had fun hanging out. I met one girl, Ashley, who did a report on me for her American Sign Language class. It was really cool. I had sent her some gear so she could dress up like me for her report and do some autograph signing. Her mom brought pictures and we got to talk and hang out during the autograph session. It was really nice to meet her and hear all about her speech.

Right now, I am in California and just finished going to the DRLC (Disability Rights Legal Center) benefit dinner. It was definitely a rad event. I was lucky to have this opportunity to go and receive the DRLC sports award. It was cool to meet many so people like Kurt Yaeger, Paula Pearlman and Micky, along with other guests of the evening. There were other deaf people as well, and they all thought it was great that we were all together at the event. I also got to catch up with some of the people from *ABILITY Magazine* whom I had not seen in a long time, so that made the night even better.

After this event, I head back home, and then my mom and I will go to Greece for a TedX event. They hold conferences around the globe for “ideas worth spreading.” I was asked to give a presentation. I’m a little nervous about speaking in front of everyone, but I am thrilled to have the honor of being invited. It will also be

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my first time in Greece, so it should be very exciting. Then, I am off to Indiana for the “Women in the Winner’s Circle” awards presented by Lyn St. James, the Indy racecar driver. I see her every year at the Women’s Sports Foundation event and I am really looking forward to this event....fast driving. That’s what it’s about! As you can see, when my “season is done,” it is not really done. And there is still so much to do! ■**ABILITY**

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Ashley and the man behind the scenes—her dad



# THE ELECTION IS OVER, BUT LIFE GOES ON

**N**ever in my life have I seen such a polarized and volatile presidential election as the one that just ended. But it reminded me of the 1976 campaign, when Carter won over Ford, and polarization and volatility broke out at our kitchen table. It was the first time I was old enough to vote, and when I told my family that I backed Carter at dinner that night, my father was furious. He asked me what possessed me to register as a Democrat. I told him that after Nixon, I couldn't support the Republican Party.

In my naive youth, I expected my Mom to take my side. But she wouldn't back either of us. She told my Dad that I had the right to register with any party, and that she would not allow politics to divide our family. Then, when I asked her whom she had voted for, she balked. "There is no law that says I have to reveal who I voted for, and no one should be intimidated for exercising that freedom, period!"

Regardless of whom Mom and Dad voted for over the course of their lives, neither of them lived long enough to experience the presidential election of 2012. They did not face the glut of information on the Internet, nor the dozens of daily e-mails from both parties, asking for money. Yes, my parents read the paper and watched television ads for the candidates, but they did not have Twitter or Facebook, and they did not lose friendships over a tweet or a post.

The 2012 and 1976 presidential elections were very different from one another—from the candidates to the controversial issues that followed them. In 1976, for example, the Peace and Freedom Party's presidential candidate was activist Margaret Wright with running mate Benjamin Spock, MD. In 2012, their candidates were comedian Roseanne Barr and activist Cindy Sheehan, whose son was killed fighting in the Iraq War. Roseanne Barr? Well, being a comedian myself, and having known Rosanne in the late 70s and early 80s from the Comedy Store, has inspired me to run in 2016. Just kidding. Scared you, didn't I?

And the controversies, oh my!! In 1976, *Playboy Magazine* published a controversial interview with Carter, where he admitted to having "lusted in my heart" for women other than his wife, which cut into his support

among the evangelical Christians. Now in 2012, Obama's support of Gay Marriage cut into his support among the evangelical Christians.

In the 70s and 80s, political jokes could even get a chuckle out of the party being made fun of, but no more. These days, even a joke about Big Bird ruffles feathers, and an empty chair joke implies an empty conscience.

I do not mind losing some friends on Facebook or Twitter, but I do mind being shamed for exercising the most fundamental cornerstone of being an American: freedom of speech. You can block me, unfriend me, unfollow me, even undress me in your mind (although I can't imagine why you'd do that), but you cannot undo my presence as a citizen. During all the volatility before the election I knew that, no matter who actually won, I still would be the same "me" I always was.

For better or worse, richer or poorer, in sickness or in health, liberal or conservative, we as American citizens are still in this together, and we need to move forward together. Remember, no one likes cocky, arrogant winners or angry, bitter losers. As Mom would say, "Knock it off!" It should not take a Hurricane Sandy to remind us of what is really important in life—but in a way, maybe it did take that for all of us to witness true bipartisanship, watching people from all walks of life come together for a single cause: helping one another in a time of need. Let's take that spirit with us even in our differences. And remember these wise words...

*You take the good, you take the bad  
You take them both and there you have  
The facts of life, the facts of life.  
There's a time you got to go and show  
You're growin' now you know about  
The facts of life, the facts of life.  
When the world never seems  
To be livin' up to your dreams,  
And suddenly you're finding out  
The facts of life are all about you, you.*

So from me to you—whatever your political persuasion—have a nice day! ■ **ABILITY**



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by Geri Jewell



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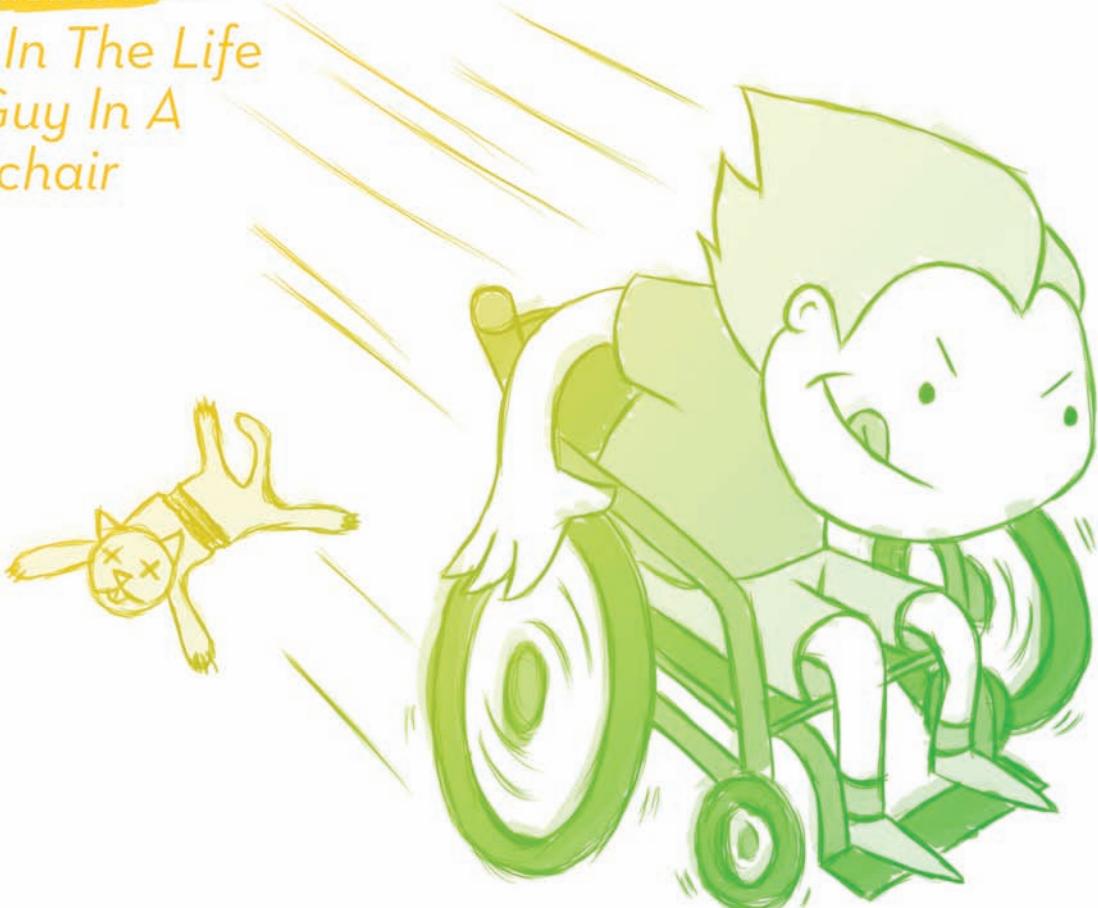
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## A Day In The Life Of A Guy In A Wheelchair



had a few places to go today. I tend to save all of my errands up for one day in the week. It's just a royal pain, leaving the house, getting in the van... and that putting on my pants... forget about it. But my survival depends on it, so it was out into the cold world to take care of business.

My first stop is at an office on the third floor of a building. I had to get a paper notarized. This paper basically states that I really am who I've been claiming to be my whole life... except when a bill collector calls, then I am Juanita the cleaning lady. Anyway, it cost me ten bucks to sign a statement that tells "whoever" that Jeffrey is really Jeff.

When I come out of the building there's a ramp that wraps around the side and had like eight turns in it, which was good because if it went straight down it would've look like an Olympic ski jump runway and I'm not looking to break any records or legs. So I begin to make my decent down the ramp and I notice I'm starting to pick up speed... a lot of speed. The next thing I know I'm whipping around each turn; one minute I'm up on two wheels then down on four. Up on two and down on four, praying I don't flip. As I'm uncontrollably hauling ass, the wind is whipping through my hair like I'm eating a York Peppermint Patty, getting that cool sensation. I must be quite a spectacle because as I near the bottom a crowd has gathered

around and are now cheering me on yelling "Hell on Wheels!" and pouring Gatorade on my head. I want to look cool and control so I'm smiling and laughing while bugs are getting caught in my teeth. I have no idea how I'm going to stop but know that God has a plan for everything. As I race to the bottom of the ramp and into the parking lot, white-knuckling my knees, I am fortunate enough to run square into some big fellow's huge butt. I'm not injured at all because it's like a big air bag went off, so I'm fine... although I total my wheelchair and have to call Cripple A.

After I am able to get a rent-a-chair, I have to go to the bank. As soon as I get in the door, several bank employees rush me wanting to know how my day's been going. They have now surpassed car dealership salesman as most annoying salesman. The good thing is the banks aren't stupid, they hire a lot of hot babes. Many of them can't use a calculator but your damn right you're going to open a line of credit. She's a babe! A babe who won't tell you she has a boyfriend until you sign up for their high interest rate credit card. It's so hard to impress a girl who has access to your balances. My mind wanders and I wish I could sneak into the vault with her and just make love. At least it would be "safe sex." I digress.

They always want me to use the teller window that's been lowered for peeps like me in a wheelchair. Someone has to shut their window then come over to help me.

I tell them they don't have to go through all that trouble, I can use the adult window. Oh well, it is convenient. I like when there's more money in your account than you thought. I remember when that happened to me in 1992. Sometimes it sucks being paralyzed but not this day. When I'm in the bank someone busts in wearing a ski mask and waving a gun. He yells, "Nobody move a muscle!" and I'm like "Cool, I'm good to go."

Next, I have to run over to the mall and pick up a little gift for my girlfriend, just her, I had already got my wife something last week. So I'm about to come out of this store and there is another guy in a wheelchair about to come in so he gives me the go ahead sign to come out, which I do. Well I have a lot on my mind and I neglected to give him a "thank you" wave. You know, that little wave of your hand when a car lets you pull out in front of them. Well that must've pissed the guy off. The dude starts chasing through the mall. He's got an electric wheelchair, probably four-wheel drive. The only thing I have are my two arms and a life. To top it off, the disabled cat talks with one of those voice boxes. So he's following me through the mall, hot on my ass, screaming, "I want my thank you wave." I'm like, "Come on man, I got things to do." I don't have time to play cops and robbers with this loony freak. So I'm ducking in and out of stores hoping to shake this guy off my tail cause he's on me like stink on pooh. If I break left, he breaks left. "Where's my thank you wave?" that voice box reverberates. My mind is racing, searching for any relief. I'm in panic mode on how I'm going to lose this man on a mission. Up ahead, I see a Victoria Secret store and I'm thinking if I can lure the guy in there maybe he'll get distracted, stop, look around, maybe smell the underwear or something... and I could lose him. No dice. Dude is hell-bent on getting his thank you wave. Well this chase goes on for another 20 minutes and right before I get to the food court the son-of-a-bitch tags me with a pit maneuver, causing me to spin out and into a sunglass kiosk. I lay in a mangled heap on the sticky mall floor. As my vision comes back into focus, and wearing some new Ray Ban knock offs, I can make out the smirking face of the disabled tyrant hovering over me. Then, I hear that annoying voice box, "Looks like checkmate to me." Whatever. I buckle and give him his thank you wave.

I need to get some gas in my van. I know this seems like a simple task but it's just not that easy when you're in a wheelchair. By law, one of the employees at the station is supposed to come out and pump the gas for you. What usually happens is the Middle Eastern guy in the glass booth just blankly stares at me as I shoot him a flurry of hand gestures trying to convey that I'm disabled. I frantically point to my placard dangling from the rearview mirror mouthing the word "wheelchair." He pretends to stock candy bars. Maybe they don't have wheelchairs in Pakistan. After awhile, I wrangle an unsuspecting customer to go in and tell Achbar I'm disabled and, whether he likes it or not, he needs to pump

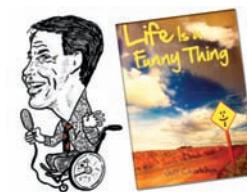
my gas. I ain't a bad guy. Finally, he comes out and starts with the "I am sorry, my friend. I did not know" routine. I say, "You need to get your head in the game, champ." He says his name isn't "Champ" and wants to know what game I'm talking about. I tell him, "That's okay, I didn't really need that last hour of my life anyway and that I enjoy "waiting for things." It helps me grow as a person. Foreigners, especially third world foreigners, are amazed that I can drive. They will just stand there with their mouth open as I pull away wondering how can this be. This is America, baby! We can thaw meat in a microwave in four minutes.

Speaking of meat, my last stop is always the grocery store. This is true for several reasons; one is the frozen items which puts you on a clock; and secondly, my mind gets lost in there and I just diddle-daddle. Something about a grocery store... I just lose myself. I meander up and down aisles not knowing what I'm looking for and I don't care. It's like a mental escape. I can't use a cart; pushing myself around is hard enough, so I put a basket on my lap. This means I must chose very carefully what I'm bringing home. I only have so much room but, I must admit, my stacking ability is top notch. Not many people in the world can balance bananas on a V-8 bottle. Some people, like that foreigner at the gas station, marvel at my abilities. I'm grabbing some chips and this lady says, "You are so courageous." I tell her I'm just getting chips; maybe if it were a box of tampons I could understand.

I get to the checkout line and, like a Jenga game, start unloading my basket. Credit card works. I remember my pin number. It's all good. The bag boy helps me out and carries my stuff to my van. I give him a tip; I tell him to take "Dancing Fool" in the sixth race. I kid, but I did say something stupid. As I'm leaving he says "Drive carefully," and without thinking I say, "You too." Then I catch myself, realizing this guy isn't going anywhere. So I try to cover up and I'm like... "Yeah, you too... you... drive those carts carefully. Don't run into any.... stacks of... canned peaches... or jars of... pickles so... drive carefully." The bag boy looks at me like buffoon. Now I have to shop somewhere else until he quits or gets fired.

Life in a wheelchair is crazy, but I'm alive... and I got a full tank of gas. ■ **ABILITY**

by Jeff Charlebois



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# **One, Two, Three, Four...**

## *swimming against the odds*

In the frigid waters of the Bering Strait, while dodging floating ice, Philippe Croizon relied on his 18 months of training to keep himself focused. "One... two... three... four..." Croizon repeated in his head as the rough waters crashed around his shoulders and face. Croizon had trained his mind to shift away from emotional thoughts and to stick strictly to mechanics.

Croizon, who is a French athlete and quadruple amputee, recently completed one of the most impressive accomplishments in water thanks to that steely mind-set: he connected five continents with four swims. Croizon partnered with able-bodied athlete Arnaud Chassery for their international challenge, beginning back in May 2012 and completing the task in August. The duo completed four swims in four months:



- The first swim began in Oceania, concluded in Asia.
- The second swim began in Africa, concluded in Asia.
- The third swim began in Africa, concluded in Europe.
- The fourth & final swim spanned from America to Asia.

Croizon and Chassery swam nearly 53 total miles and spent 45 total hours in the water. The first question that comes to mind regarding Croizon's accomplishment is: what was he thinking?

"I tried to avoid thinking in general!" said Croizon, who used prosthetic flippers at the end of his legs. "I completed sessions of Sophrology—mental and physical exercises—for several months to learn to manage emotion, particularly while swimming."

According to the International Sophrology Federation, Sophrology consists of mental and physical exercises that lead to a healthy, relaxed body and alert mind. Croizon said he used the exercises to ensure that his emotions didn't overcome his body.

"I listen to my body to see if everything is going well," Croizon said. "I think about my two boys and my partner in life, Suzana. When I feel my emotions are taking over, I begin to count my movements, 'One, two, three, four,' then I look at the boat and repeat, 'One, two, three, four.'"

Resorting back to the counting of movements kept Croizon calm and focused on his task. And his task was a hefty one.

Croizon's pathway to the water began March 5, 1994. His arms and legs were amputated following an electrical accident, and he struggled facing such a new life. During his recovery, Croizon watched a documentary about a woman who swam the English Channel. That's when Croizon decided he could do that, too.

Croizon admits he was a "couch potato" prior to his accident, mostly watching sports on TV rather than participating in them. But the documentary changed him.

"Two and a half months after my accident, I truly woke



Left to Right: Swimmer Philippe Croizon and Arnaud Chassery map out the 4 crossings:  
#1 Oceania - Asia; # 2 Africa - Asia; # 3 Europe - Africa; and crossing # 4: USA - Russia

up and decided to live,” Croizon said. “I did this for my two sons, who need a father to guide them through life.

“A few days after this realization, I was watching television and saw a 17-year-old girl who had successfully completed her second swim across the English Channel. At that moment, it was as if I had forgotten that I had lost both my arms and legs, as I envisioned overcoming everything. I said to myself, ‘Why can’t I do that one day?’ without truly understanding what this statement and decision would represent.”

The first step to his new lease on life was more like a major jump.

“Getting up and off the couch, my first big challenge was to go skydiving. We jumped out of a plane at almost 16,000 feet,” Croizon said. “A journalist asked me what my next challenge would be, and without hesitation I replied, ‘Crossing the English Channel.’”

Croizon began a rigorous training schedule of swimming

five hours a day in open waters with the French marine police, also known as the Maritime Gendarmerie. Following two years of dedication, hard work, and water training—in addition to support from several French political leaders—the 42-year-old Croizon crossed the 21-mile English Channel on Sept. 18, 2010, more than 16 years after his accident. His time was slightly under 14 hours.

Shortly afterward, he decided to target his international challenge of connecting five continents with four swims along with swimming partner Chassery. The preparation, however, was far greater than anything Croizon had ever endured.

“Getting ready for this challenge required [a] strong will and commitment,” Croizon explained. “I swam between three and five hours per day, and followed that with an hour of strength training. Arnaud Chassery and I trained in Brittany (France) in the fall and spring to experience conditions similar to the ones we would encounter in our four swims: cold water, with strong



Crossing #4 was the most dangerous: swimming to the island of Great Diomede (Russia) to the island of Little Diomede (US), in the middle of the Bering Strait—water temperature does not exceed 3 °C

currents. We also went to Toulon (France) to meet with divers from the French Navy and learn from their experience in very cold water. Finally, we worked with doctors to mimic the physical effects that we would be up against. And, we went to a lake in Font-Romeu-Odeillo-Via (France), which is at an altitude of 6,500 feet, to load our red blood cells. Basically, it was 18 months of very intensive training.”

In April 2012, Croizon announced the international challenge. A month later, he and Chassery completed their first 12-mile swim from Australia to Asia. In June, the duo finished the second leg of the feat, swimming 12 miles across the Red Sea. In July, they swam nine miles across the Strait of Gibraltar. Poor weather delayed the final piece of the puzzle by four days, but Croizon and Chassery completed their challenge on Aug. 17th when they swam across the Bering Strait’s 39-degree waters.

Croizon credits his wife, Suzana, for her support, and said he never considered stopping the challenge. His motivation was far greater than swimming the open waters.

“I want to demonstrate that a disability is not the end of oneself and that a person who has a handicap can accept this and be happy,” Croizon said. “People with disabilities participate in sports because they enjoy it, not because they are seeking recognition. They are doing their best to be part of our community and society. Achieving your personal best is usually the goal for any athlete, able-bodied or otherwise.”

Chassery concurred. “Everyone has to surpass themselves in their own way, with their own means,” he

added. “You need to know how to listen to your heart; the energy that resides there is common to all humans.”

While Croizon is reaping many of the benefits and collecting recognition for the international challenge, he is quick to mention his swimming partner Chassery. In fact, Croizon said, the fact that the duo completed the task together epitomizes Croizon’s message to the world.

“While symbolically linking five continents, Arnaud Chassery and I put forth the universal messages of courage, equal opportunity, and international peace and solidarity,” Croizon said. “If two people, one with a disability and the other able-bodied, are capable of bridging five continents, we are not that different, are we?” ■ **ABILITY**

by Josh Pate

[nageraudeladesfrontieres.com](http://nageraudeladesfrontieres.com)  
[BBC News Video](#)  
[bbc.co.uk/news/world-europe-19306814](http://bbc.co.uk/news/world-europe-19306814)



First crossings: ten hours of swimming along the coast to the village of Mabo, Indonesia, on the Asian continent.



# LONG HAUL PAUL PART TWO

**O**n a recent rainy morning in Pembroke, NH, endurance motorcycle rider "Long Haul Paul" Pelland set a world record by riding 100 different bikes 1,000 miles in 24 hours. The 100 SADDLES-Sore 1000 event raised \$4,000 for the National Multiple Sclerosis Society. The achievement represents the first world record for Pelland, who was diagnosed with Multiple Sclerosis in 2005.

No stranger to extreme riding, Pelland is a card-holding member of the Iron Butt Association, an organization that attracts the best motorcycle endurance riders in the world to compete in extreme long-distance contests—such as the

Iron Butt Rally in which entrants try to log 11,000 miles across the continental United States in 11 days.

Pelland is determined to rage against his disease long enough to set a few more motorcycle endurance records and ride one million miles over the next 10 years, or until a cure is found for MS. Whichever comes first. It's a quest he calls his Endless Road Tour.

Part II of *ABILITY*'s Christopher JB interview:

*JB: You said earlier that, while going through an ugly divorce, you began endurance riding because it made*

*your problems go away while you were on the bike. I'm guessing that it's also your way of achieving mindfulness on a regular basis, the way others might use yoga or meditation.*

Paul Pelland: Right. Even the ride down to Florida this past winter, I rode probably 2,800 miles the whole trip. When I get to a hotel and I take off my gear and unload, I say, "I've got to call my wife." Then I hang up from her and I'm back into that whole [mindfulness] mode. For the whole ride down, all 16 or 18 hours of it, if somebody were to stop me at a gas station and say, "What are you doing?" I would have to stop and think and remember that I'm married, I have a dog, I have a house, I have two kids, and I have a granddaughter. All those things are not in my thoughts the whole time I'm riding. It really is just a clear head. I'm focused on the road, not intensely, it's just a pleasure. It hits some sense in my brain that just allows me to be one with the universe, I guess.

*JB: Before you began endurance riding in 1998, you said you were more of a weekend motorcyclist, which didn't give you that one-with-the-universe feeling, right?*

Pelland: Yeah. I think I started riding in '89. I was just your typical rider. You go out on a Sunday morning when it's sunny and bright and the weather's warm. I didn't use it to commute. It was only a pleasure vehicle. My first couple of bikes probably went 2,000 or 3,000, maybe 4,000, miles a year. We have long winters here, when the bikes get put away.

*JB: What do you do for a living?*

Pelland: Hopefully I'm going to ride motorcycles for a living, one way or another, by next spring. Right now, I work at a nonprofit. I'm a program administrator for a program where we refurbish durable medical equipment. We take in donated equipment that people no longer need, like power wheelchairs, scooters, patient lift equipment, bath equipment, that type of stuff. We have technicians go through it and basically put it back to factory specs, and then we sell it back to people who don't have insurance, who don't have the means to purchase new equipment at 50 to 80 percent off what it would cost new.

*JB: Everything you do, whether it's riding motorcycles or your daily work, seems altruistic.*

Pelland: It is. This is a new career for me. I started after my diagnosis. It was something that I felt was important. I was actually hired as one of the technicians who did all the modifications and customization of equipment for people with severe disabilities. We'd help somebody who has very limited use of maybe one finger be able to drive a power chair and run their computer with just a small amount of motion. Or build customized armrests, headrests, leg supports or things

that the wheelchair manufacturer does not create or have. I still do that at my organization, but it's separate from the used market. It's on new chairs that I do customization.

*JB: It sounds like you're making a real difference for people with disabilities.*

Pelland: It's very rewarding. We see a lot of kids, so every day I see kids that get a piece of equipment and, when it's set up right, how much of a difference it makes in their lives or their parents' or caregivers' lives. I do enjoy it.

*JB: You're fortunate to have such an effect on the lives of others. Now let me turn back to your recent record-setting accomplishment. Can you talk about this event?*

Pelland: Sure. We spoke about what a SaddleSore1000 is, and everybody that's in the Iron Butt Association has done one. It's not easy to do, but it's not a hard ride. My [record-setting] ride is called 100 Saddles-Sore 1000. I rode a SaddleSore1000, which is 1,000 miles in under 24 hours, and I did it riding 100 different bikes.

*JB: All that bike-switching definitely makes it unique.*

Pelland: I had to stop and swap bikes 99 times. This event was sponsored by National Powersports Distributors, a motorcycle dealership here in New Hampshire. They're actually one of the largest used motorcycle dealers on eBay. Great company. I've bought six or seven bikes from them myself. They have a huge selection of every type of bike, from choppers to side cars to sports bikes. They held their open house on September 29, 2012, so I finished the race at a big barbecue at their open house, and 100 percent of all the donations went to the National MS Society.

*JB: Riding conditions were far from ideal that day. Describe some of your challenges.*

Pelland: I began the ride [from the dealership] with a signed witness form and a gas receipt, and rode off into the drizzly Friday afternoon. At the first gas stop I couldn't get my cold damp hands back into my gloves. I almost took a fit... The extreme fog and drizzle lasted five hours throughout the night. The temperature ranged from 42 degrees to about 50 degrees for the entire 24 hours. It never dried out. I was a wrinkled wet noodle, and I was unable to follow my planned fuel stops because I was getting such poor mileage due to the rain. I had to push hard to keep to my planned route and times.

*JB: So you had a set 10-mile loop that you kept to with each bike and you would come back to the dealership, hand off one bike and jump on another that someone had warmed up for you? And you did this 99 times, in 21 hours, with only three hours rest?*

Pelland: Right.

*JB: Pretty crazy. What kind of bikes did you end up riding?*

Pelland: I rode cruisers, customs, touring bikes, classics and even a Guzzi! Straight pipes, stock pipes... I rode two or three bikes that had really long forward controls that were so far away I had to sit on the tank to reach them. I would stab in the dark on the left for the shift lever, then roll the throttle into the night. I had no idea what bike I was on or what amount of power it had or how the brakes worked. I just took off and did my measured loop. I had to peer over my fogged glasses and under the fogged face-shield just to see at all. At one point, I just took off my glasses and did the best I could. It was a miracle I did not wipe out or drop any of the bikes.

*JB: So this hodge-podge of bikes really made it more difficult, because the typical endurance ride requires a tour bike, right?*

Pelland: Yeah. Most of the long-distance rally stuff is done on major touring bikes, sport touring or touring bikes, like BMWs or a Honda Gold Wing, Honda FT1100, Kawasaki Concours, or a Yamaha FJR—bikes with luggage and amenities you need in order to spend time in the saddle.

*JB: Your Endless Road Tour is already underway, and your next record attempt is on April 1<sup>st</sup> of next year. This time, instead of setting a world record, you're going to try to break an existing one, correct?*

Pelland: Right. The attempt will be to ride 50,000 miles in 50 days. That will be one of the major achievements of the tour, with the hopes of getting more people to donate to my cause. The money donated will go to the MS Society or to an organization for people with disabilities.

*JB: What's on the agenda between now and then?*

Pelland: I might do what are called extreme rides in between. I might do a Bun Burner Gold, which is 1,500 miles in 24 hours. There's also SaddleSore 2000. There's a ride that I've never done that I'd love to do which is a coast-to-coast in 50 hours or less. I might do one or two of those before the end of the year. I'm hoping in the meantime that one of the pharmaceutical companies or MS nonprofit organizations will allow me to come and speak at their events. If that happens, then I could be traveling all over the country during the middle of all of this. That's my goal.

*JB: What's the underlying goal of your million-mile journey?*

Pelland: This is a new quote from me that's now on my





website; "I once was told a cure for multiple sclerosis was a million miles away, so I figured I would just go get it and bring it back."

*JB: Has anyone ever ridden a million miles on a bike, let alone someone with MS?*

Pelland: Actually, there are people who have documented riding a million miles in their lifetime. I've probably ridden 250,000 to 300,000 undocumented miles over the past whatever years. But I never sat down and really documented each bike and each time I traded the bike and all that stuff that's needed. So I decided to start this Endless Road Tour with MS, for MS, on July 6<sup>th</sup>, 2012, which was my son's 18th birthday. I had threatened that I'd come back to long-distance riding when my kids were grown, so I felt like that was a significant day to start. And so began my journey. So I am now riding the Endless Road Tour. I'm looking to turn it into a non-profit, and hopefully becoming an ambassador for one of the pharmaceutical companies, because I think there's a place for me, and I think that I could do a lot of good and help a lot of people.

*JB: I think so, too. What if there comes a point where, God forbid, you can't ride anymore?*

Pelland: When I had to stop riding after I got custody of the kids, I said, "You know, I just rode in two Iron Butt rallies. I've done things that people dream about doing, and I did it twice." So I think that I'll be OK when I won't be able to do it again. I felt that way then and I think I feel the same way now. I love motorcycles, but if the day comes when I can't hold up a bike any more, there are other things I can do. I'm sure I'll find some way to ride. I think the Endless Road Tour is going to turn into motorcycle-related events, and probably my own long-distance rally. I have some very good friends here that want to be part of this and want to make this an organization. We can do fundraisers. If I have to show up on the back of somebody's bike at the beginning of an event or ride as a passenger or something during one of these events, I think I'd be fine with that. I think the Endless Road Tour, whether I make the million miles or not, will continue with others helping me out along the way.

*JB: Sounds like a doable plan. Have you heard of a drug called Ampyra, which has helped a lot of people.*

Pelland: No, I'm not on it. That's the one that helps with the weakness in the leg?

*JB: Yes. It's supposed to improve walking for people with MS. It's supposed to work by strengthening the signals sent by the brain through nerves that have been damaged by MS.*

Pelland: When I go to patient events, there are experts who talk about all the different stuff that's out there.

There are three basic disease-modifying drugs that have been out for 10 years, I think. I'm on one of them. It's an injectable—I inject myself every morning. It basically is a decoy. MS is an autoimmune disease. My immune system is attacking the fatty tissue on my nerves and in my brain. This stuff is a decoy so that the immune system attacks it instead of the fatty tissue. It allows the progression of the disease to slow. It doesn't cure anything and it doesn't stop it, but it makes it slow down. So instead of having an attack every year, I'm probably having an attack every five years.

*JB: Do you know what your prognosis is for your MS?*

Pelland: What's funny about MS is, everybody is completely different. There are some symptoms that are similar, but because it attacks only the brain and spinal cord, which connects every single thing in your body, somebody could have problems with their bladder, somebody else could have problems with their feet. There are more muscles and nerves in your feet and legs, so that's why a lot of people tend to have issues with their legs. It's just because there's more nerves in your head that go to your feet. That's basically it. And there are a lot of nerves that go to your eyes, so a lot of people have issues with their eyes. It could affect any part of your body, wherever it decides to attack. So mine has attacked the area that controls my short-term memory.

*JB: Are you still doing rallies at that IBA level, where they send you through places like Death Valley in 125-degree temps, and then up a muddy mountain peak in Colorado in freezing cold, or are you backing away from such extremes?*

Pelland: I did a rally this year called the Mason-Dixon 20-20. It's a 36-hour rally out of Maryland. It's the first rally I've done since the '03 Iron Butt. I entered it basically just to see what I could do and how limited I would be with my cognitive issues. I finished the rally, maybe 44th or something, but I did finish. I learned that I could still spend the time in the saddle, but I also learned that I was useless as far as trying to do the planning during the rally. My brain just couldn't—I didn't have the skills to plan the route. I struggled with a lot of the multitasking stuff, and I made a lot of dumb mistakes. And that's the MS. I really couldn't do the right thing when I got to a bonus. And I know the right thing, and if you asked me today or the day before, I would have told you exactly what I needed to do, but when I got there I couldn't figure out what I needed to do, just because of the fatigue and the tiredness and the heat.

*JB: Combined with the MS...*

Pelland: Yeah. So I realized that I probably can't do a rally again, unless it was something I could plan two weeks before, and then I could do it. But I need clear defined things. I just need a destination, basic stuff. I

can't do multitasking when I'm pushing my body to its limits. I can ride, I can get in the saddle, I can be at your office in two days, no problem. (*laughs*) But if you asked me to try to figure out some map problems along the way, I wouldn't be able to do it. So I figured out that I probably won't be able to enter any of these events, but I'll definitely be showing up at them and trying to raise money while I'm there. But these other rides that I'm saying I'm doing, these are all ones that you do on your own. So I could plan it two weeks in advance and have it all set up, and then I'll just follow my plan. With a couple little things thrown in, it's fine.

*JB: So this Endless Road Tour is really your own rally...*

Pelland: I guess you could say that, and if I can pick up a bonus at each one of the places I talk, that would be great. (*laughs*) In a sense, it's a rally. And maybe I'm racing against a cure. So it's either a million miles, or they find a cure. Whichever comes first, I'd be happy with that.

*JB: Let's hope you don't have to ride a million miles before they find a cure. What kind of assistive technology do you use on the bike now, given your MS?*

Pelland: One of the main problems I have is controlling my body temperature. I wear a full protective suit made by Aerostich, the top of the line riding gear, heavy-duty and waterproof. It does get hot. A full-face helmet, gloves, boots—I wear the whole thing every time I ride. So a big problem is the heat. They do make cooling vests and cooling systems. The problem with those is, it's great if you're going to go on a Sunday afternoon ride, you can soak it in ice or put ice in it and have a couple of hours where it's nice and cool. But when you're riding 14, 15, 16 hours a day, having to stop every two hours or three hours to get ice and put it in a system, it just doesn't work for me. So I actually have a company that built a system called CoolShirt. They've offered to give me some of their products. Some of their systems will last six hours and some will last even longer. So I've used one of their systems this summer, and I'm going to be getting another system from them in the spring. They build systems for race cars and things like that. So I can't wait to see it and certainly use it, and one of the things my website's going to do is have lots of information about equipment like this.

*JB: So when you're chillin' on your bike, you're literally chillin'...*

Pelland: Right. The other thing that I can't ride without is a GPS. A GPS for a motorcycle, for whatever reasons, is ten times the price of the ones they sell for cars. (*laughs*) They're waterproof and they allow planning and that type of thing. I like to have at least two of them on me, and also I have apps on my phone which I use all the time. One of them is a GPS app, but I also use the voice recorder constantly while I'm riding. I just press a



# I will:

*"The first thing I started to notice as my walking improved with Ampyra was my confidence in my ability to walk to meet my friends."*  
— Kristie Salerno Kent,  
*diagnosed with MS in 1999.*

AMPYRA<sup>®</sup> (dalfampridine) is indicated as a treatment to improve walking in patients with multiple sclerosis (MS). This was demonstrated by an increase in walking speed.

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#### New Safety Information

Ampyra may cause serious allergic reactions, including rare occurrences of anaphylaxis.

#### Important Safety Information

Do not take AMPYRA if you have ever had a seizure or have certain types of kidney problems. 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.



# Walk on.

Walking better matters. AMPYRA® (dalfampridine) is the first and only medication shown in two clinical trials to improve walking in people with multiple sclerosis (MS).

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

**Can be taken in combination with your other MS therapies.**

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EXTENDED RELEASE TABLETS



Talk to your doctor to see if prescription AMPYRA is 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.

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.

**For more information, please see the complete Medication Guide on the next page. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://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

### **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:**

- Kidney or bladder infections
  - Serious allergic reactions, including anaphylactic reactions
- 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](http://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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Paul Pelland at the finish of the 100 SADDLES-Sore 1000 event—a fundraiser for the National Multiple Sclerosis Society. Paul set a world record by riding 100 different bikes 1,000 miles in 24 hours.

button and I can record my thoughts or things that I need to do when I stop for the night or even at the next gas stop. That way I'm not constantly stopping to fix things. I just make a note of what I need to do; otherwise, I would not remember it. With my short-term memory, I will often jump on the bike, take off, and forget that I left my earplugs on the side of the gas pump. I won't stop to put them back in. That three, four, or five minutes to pull over, get off the highway, find them and get them back on, especially if you're trying to make time, I don't like to do.

So I make a note to myself to put the earplugs in the next time I stop. As long as I have a routine, I make sure everything gets done. You pump the gas, you reset the odometer, and you check your notes. That's what long-distance riding really is about anyway. When you get tired is when you really need to have a good system. Everything in my pockets is in the same place. Everything on my bike is in the same place. I know where every tool is. I know if I get a flat in the middle of the night, I know where my headlight is, my camp light is, my toolkit to fix the flat. You practice fixing a flat in the dark, things like that. This all comes in handy when you're on the road. You're not always going to have cell service, you're not always going to get a tow truck to come out and fix a motorcycle flat. In fact, they won't. So you need to have a system so you remember where things are and in case something happens, you know what to do or who to call.

*JB: Do you have a favorite iTunes playlist?*

Pelland: What's really cool about having a short-term memory is, I can listen to the same 20 songs for hours on end, and I don't remember that I listened to it two hours earlier! (*laughs*)

*JB: That is an advantage, and it's cheaper too because you don't have to buy as many songs.*

Pelland: There are days when I don't listen to music at all. Those are the days when I'm just deep in no thought whatsoever, and the noise in my helmet from the music kind of disrupts it a bit, so it's just the silence of the road.

*JB: Just you and the road.*

Pelland: Yeah. It's the smell, it's the feel. If I move my leg a little bit the bike changes direction. I can look one way and the bike goes that way. It's being one with the bike—they say it's the closest thing to flying an airplane. I've never flown an airplane, but I certainly have ridden a lot of motorcycles. I do love it. ■ **ABILITY**

[longhaulpaul.com](http://longhaulpaul.com)





# STICKS & STONES

## Rick Howland



ick Howland picked a fine time to visit the east coast: The Canadian actor arrived shortly before Hurricane Sandy devastated the Atlantic seaboard in late October, and was still drying off when we spoke to him. Howland co-stars as Trick on the SyFy TV network show, *Lost Girl*, a supernatural crime drama about a Fae—the Middle English word for fairy—who is trying to fit in a world of humans. At 4 foot 7, Howland who has osteogenesis imperfecta (brittle bones) has tried, mostly successfully, to fit into the acting world without getting crushed. *ABILITY*'s Chet Cooper caught up with him recently.



Cast of *Lost Girl*, left to right: Rick Howland; K.C. Collins; Kris Holden-Ried; Anna Silk; Ksenia Solo; and Zoie Palmer

*Chet Cooper: Were you affected by Sandy?*

Rick Howland: We got quite a bit of rain. Nothing really bad happened here, though; no major portions of the city knocked out or anything.

*Cooper: Nothing really bad happened—until this phone call.*

Howland: (laughs) Yeah!

*Cooper: Where do you film *Lost Girl*?*

Howland: In Toronto, on the west end of town.

*Cooper: Does most of the cast members fly in, or are most of them Canadian, as well?*

Howland: The majority of us are Canadian and live and work in Toronto. Anna Silk, who plays Bo, the lead character, and one of the other actresses were [living] in LA before the series. Anna flies up and stays for the year while we're in production, and then goes back after we're done.

*Cooper: A lot of productions shoot in Canada because it's often less expensive with the currency exchange rate.*

Howland: Yes. Canada also gives tax credits within certain provinces.

*Cooper: Tell me about your character on the show.*

Howland: Trick is 2,000-year-old bartender. He runs the Dal Riata, which is a bar but also a way station. All Fae who come into that part of the world have to check in with him, whether they're Light Fae or Dark Fae—meaning good or bad. It's a way of keeping track of everybody. Also, Dal is neutral ground, so when they're in the bar they can't fight. They have to get along. In season 2two, we find out that Trick is Bo's grandfather.

Trick used to be the Blood King a long time ago, and he still is a Blood Fae, which means that what he writes in his own blood becomes true, so he can manipulate the future. But there's always a karmic kickback. At the end of season 1one, he uses his blood to change the future and help Bo, and it inadvertently awakens the Garuda, an even more evil presence than any Dark Fae we've ever come across, so we end up having a battle at the end of the second season.

*Cooper: I saw some images of you on the show, and you don't look a day over 1,500.*

Howland: (laughs) Thank you! I'm aging well. I guess it's the Blood Fae part of it.

*Cooper: Was the show adapted from a book?*

Howland: No. Apparently the stunt guys had an idea for a show that was based on a succubus. [In medieval folklore, a succubus is a female demon who appears in dreams, and takes the form of a woman who seduces men, usually through sex.] Their idea was *Lost Girl*, but darker and even more sexy. I think they approached Jay Firestone, the main producer, with the idea, and he got Michelle Lovretta, the lead writer for the first season, and she put the thing to a fine point, bringing *Lost Girl* to life.

*Cooper: And she wrote it in blood and changed the future.*

Howland: (laughs) Somebody did.

*Cooper: Now that they've revealed that your character is related to the lead, does that secure your role for a few seasons?*

Howland: I think so. The show's going to go on forever, I hope. I'm really enjoying it. It allows me to do a lot of different things, so I don't get bored. We've done three seasons so far. Season three comes out in January. They're promoting it on Showcase.ca. For season 2 two we did a pre-show, and we're doing that again for season 3 three. Soon we'll hear back about whether there'll be a season 4 four. I have high hopes.

*Cooper: When you did the last Showcase, what question did fans ask you?*

Howland: I often get asked, "Who do I love working with the most?" The truth is I love working with everybody. I enjoy all my scenes with all the other actors, because they all have different elements. With the girls, I get to be a protector and father figure. While with Kris Holden-Ried, who plays Dyson, I get to have these kinds of warrior/soldier-after-the-battle drinks in my lair, and plan what to do next.

*Cooper: What I heard you say is that you don't like working with anyone, and none of the scenes are all that interesting. (laughs)*

Howland: Hey Chet, don't turn this around on me; I've got to come out sounding like a nice guy!

*Cooper: Do you play Trick as a moderate guy or do you play him as a fellow who's holding back a temper?*

Howland: He's not mean, but you don't want to upset him. At the same time, if you need help, he's going to be there for you. He's a very open, considerate person. Somebody who's been around for 2,000 years either shuts down and knows no one, or learns to accept people for who they are. I think Trick's done that.

Bo, the main character played by Anna Silk, always comes to Trick for information about the Fae world and

to get advice. He's a father figure, and an encyclopedia. At one point the character Kenzi calls Trick "Trickopedia," because he has all the information.

*Cooper: (laughs) Does Trickopedia have a wife?*

Howland: He was married a long, long, long time ago, and his wife was a warrior who died in battle. You see a bit of her in episodes 13 and 22, where the Garuda has gotten hold of me and takes me through these flashbacks, trying to convince me that the choices I made back then weren't the right ones. He shows Trick to himself, now and then, with his wife. We had a daughter and then our daughter gave birth to Bo, who gets raised by humans, discovers that she's not human and starts trying to figure things out, which is how the series begins.

*Cooper: Is your daughter, /Bo's mother, alive?*

Howland: Yup. And you come across her eventually. She's played beautifully by Inga Cadranel. She's in episode 13 also, which is one of my favorites. In it I end up having to buy this drug to see into the future, and I go to this drug dealer who has lost her vision, and it turns out that she and my character were lovers a long time ago, which she mentions.

*Cooper: So she was your "blind" date?*

(laughers)

Howland: That's a pretty bad. But she wasn't blind when he first met her. I think she went blind later. She's also a truth-seer; she knows when people are lying. She can flick her long fingernails and make [people] tell her the truth. It's a cool trait; she'd be a great person to have around.

*Cooper: What's your acting background?*

Howland: I started acting in high school because I needed an art credit, and I was terrible at drawing. My very first class, I was bitten. And then I just started doing shows in school and went on to a university for a year, and then to another university for another year, and then I just went out and started acting.

Being short and having a disability, it's been a battle to break down barriers, but I've found directors, writers and producers who like casting outside the box. I get roles that are anybody kind of roles that are written with depth, and they're also for people who look different. That's great.

When I was very young, I spent a lot of time in and out of plaster casts. I have osteogenesis imperfecta—brittle bones—over 80 broken bones since I was born. I've also had surgery a bunch of times. So I spent a lot of time watching television and I thought to myself at



photos by New World Media

1. *A Little Off The Top*
2. *Four Strombones Comedy Troupe*
3. *To Catch A Yeti*
4. *Short Tongue Freddy*

some point, ‘If I want to make a difference in this world, if I want to not feel like I’m so different when I’m in a wheelchair or on my crutches, I’ve got to get used to people staring and pointing or making a comment to the person next to them.’ It’s hard to be pointed out like that, but then on TV you see these people who are getting pointed out, and it’s out of respect, because they’ve got this body of work. So I decided at some point—and I’m not sure when—that that would be what I needed to do in order to make it maybe slightly better for the next little kid who comes along and looks different.

*Cooper: And I’m trying not to make a joke about “body of work.”*

Howland: You should write down your jokes and try stand-up.

*Cooper: I joke a lot—and some of it is funny. But you have to be a good actor to make it in stand-up, and I’m not an actor. Every comedian in the club has great jokes, and it sounds like they ad lib, but that’s an act. That’s why you see so many TV shows coming out of the stand-up arena.*

Howland: Yes.

*Cooper: I used to publish a magazine that dealt with humor.*

Howland: *Mad* magazine?

*Cooper:* National Lampoon.

Howland: I was close.

*Cooper: I had a lot of writers around me, and I’d go to open mic with them, and they’d have great material, but they couldn’t make it work onstage. I’ve talked to Robin Williams several times, and when he’s not on, he’s not funny. But then he hits the stage and bam!*

Howland: Improv is more like acting than stand-up. I’ve done both. But you’re right: There’s an art form to stand-up, and you need to find what works for you. I know comedians who’ll be going along in their usual routine, find that it’s not working, and switch to another set of jokes, because they’ve been performing them for years. I look at Jerry Seinfeld, a brilliant stand-up comedian, and his wickedly funny show... Or Larry David’s genius [on *Curb Your Enthusiasm*], but if you look at his cast, they’re all comic actors. Robin Williams can actually do drama, too. When you talk to him, he doesn’t have to be in joke mode, he can be in regular-guy mode. He can access that darker, dirtier, emotional place where human beings go.

I like doing it all. I can do stand-up, improv or a sketch show. Drop my pants in front of an audience, no prob-

lem. Make sure I'm wearing some colorful funny-looking boxer shorts. But to do stand-up—or what I find even harder in the performance vein is playing guitar and singing—I have to fight those nerves, push them down. Nervous energy can be really useful for an actor, because it can get you into the scene. But with music, it can get in your way.

*Cooper: Do play an instrument?*

Howland: I play guitar and a tiny bit of mandolin—I'm teaching myself that. I play harmonica a little bit. I've got two albums on iTunes. They're kind of my own homegrown albums. I've sold a couple this year; thank you fans out there! I've been writing songs since I was 16 or 17. It's one of those things I've always done to get the bad energy out: Beat up a guitar instead of myself.

*Cooper: Many years ago I interviewed a drummer who also has brittle bone. He's only broken his arm a couple of times, and the doctor's like, "You can't do this. It's way too risky," but he just kept going. He's been able to sit in with some really big bands over the years. I cannot remember his name. He had fairly long arms, and it was interesting to see him just beating the heck out of those drums.*

Howland: My arms are quite long, too, and if you have a lot of breaks in the longer bones, they can shorten and your spine kind of gets shorter, which also then makes your arms look longer. I know that for sure. But I'd have to agree with the doctors in terms of that particular guy because drums are impact, but if he's in control of it and he's doing it and he's developing it well, he's actually strengthening those bones by doing light impact.

*Cooper: I think their concern was him hitting his wrists on the metal rims.*

Howland: Oh, right.

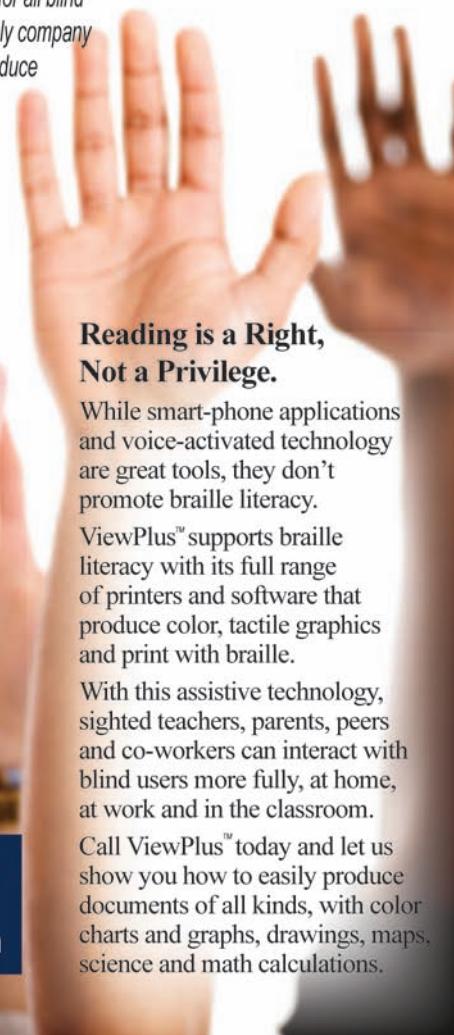
*Cooper: Apparently it only happened once or twice. Eventually he got so good that he didn't feel like it was that much of a risk.*

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Howland: Because he's in control. [Did you know that] in a fight scene, the victim is actually in control? So if you and I were having a fight scene on stage and you were going to be choking me, you would put your hands up toward my neck, I would grab your wrists with my hands, and I would control the look and how much weight was going on me from you.

*Cooper: I did not know that. That's interesting.*

Howland: So then the person who's the underdog actually has the power. Hopefully, anyway. If somebody loses their balance and falls on you, that's something you can't avoid. But for the most part, that's the way it works. The only time I've ever hurt myself on stage was when a guy in my comedy troupe lost his balance and



Howland as "Harry Buttman," commissioner of the NHL in the film *Bon Cop, Bad Cop*

fell on me, and I blew up my ACL. I didn't do comedy for quite a while after that. It's fascinating. I like hearing [stories like the one about the drummer], especially with another person with my condition.

The disease isn't going to keep us down. Doctors are going to say, "You've got to be careful." Your parents are going to say, "You've got to be careful." And you're like, "Yeah, but I'm still going to do it." I'm still a human being. I still have that brain. I still have the intention, as everybody else does, to go out and do what I want to do.

*Cooper:* (laughs) Loved ones are inclined not to let the child fall, but having a child fall sometimes is not a bad thing.

Howland: Exactly. My parents were great for that. I'm really thankful to them for not making me cautious to the point where it kind of bled into the rest of my life, like, "Oh, I can't do that. I'm not going to go outside. I'm not going to do that!" And then suddenly I'm not doing anything. They actually did the opposite. "Go do it. Don't hurt yourself. Be careful, but go and do it." They were like, "You're going to be an actor? Really? Don't you want to do something else?" "No, not at all."

*Cooper:* "You don't want to be a wrestler?"

Howland: I played one once. It was in *The Jesse Ventu-*

*ra Story* on NBC. I had a tiny part in it as a wrestler, and I actually wrestled Chris K Canyon from World Championship Wrestling. It was even more set up than wrestling might be choreographed. I don't want to step on anybody's toes. I don't know if you grew up with wrestling, but I grew up with George "The Animal" Steele and [Jimmy] "Superfly" Snuka and stuff like that. George "The Animal" Steele always had the claw maneuver. I loved that. He'd grab somebody's head and squeeze it, they would fall to the ground and he'd win.

*Cooper:* My girlfriend does that.

Howland: (laughs) So you're familiar. I said to Chris, "Okay, if we're going to wrestle, we've got to be really careful here. No picking me up, no body slams, nothing like that, but I'd really love to put the claw on you." He was like, "Oh, that's awesome!" So he does this running around, jumps, bounces off, flips around me, does all this acrobatic stuff, makes it look fantastic, and then falls right into my hands. And I squeeze his head and he falls to the ground and I win.

They had, like, I don't know, 400 or 800 extras in there, and background people as the audience for the wrestling, and they were loving it, because they like Chris K Canyon. He's actually a star. They're were cheering and everything. So when I put him down and the guy does the three count, the audience went crazy. It was exhilarating.

*Cooper: The fans weren't mad at you?*

Howland: They were happy I won.

*Cooper: I thought maybe they were so diehard that they might come after you.*

Howland: They had to do whatever the director told them to.

*Cooper: Oh, this was for a scene—and not reality?*

Howland: It was a scene. I would never actually get into a wrestling ring, ever, unless I was, like, the guy with the bullhorn.

*Cooper: So they set the scene where there is already a live audience in place?*

Howland: Yeah, we were shooting a show.

*Cooper: What other roles have you played?*

Howland: In Canada, I was in a movie called *Bon Cop, Bad Cop*. It was co-written by a guy named Patrick Huard, who is actually the comedian of Quebec. It's a story about a French cop and an English cop, and there's been a murder on the border between Ontario and Quebec—one being English and the other French.

So the English cop arrives from the English side, the French cop arrives from the French side, and they each try to push the crime off on the other. But their captains tell them that they have to solve the crime together: There's a serial killer killing hockey players in the NHL.

*Cooper: And you're the killer?*

Howland: No, I play Harry Buttman, who is a spoof on Gary Bettman, the commissioner of the National Hockey League. I wear a blond wig and a flashy suit. You probably don't know this, but in the '70s in Quebec, politicians were being killed and disposed of in the trunks of cars. So [Huard] thought it was funny to make that a running joke in the movie, and my character spends most of the movie in the trunk of a car.

*Cooper: Who was doing the killing in real life?*

Howland: I don't know; I don't even want to say that it might have been mob-related, but—

*Cooper: It sounds like organized-crime.*

Howland: There is or was a strong organized-crime thing in Quebec, but I'm not sure if it was related.

*Cooper: Do you speak French?*

Howland: No, unfortunately. I was supposed to. But I

was in and out of school so much with broken bones that by the time I got to high school, they were like, "You don't know French?" I was like, "I know, you didn't teach me." And they were like, "Well, you don't have to take it anymore." And I was like, "Okay, thank you." And I stopped taking it. I regret that now. I got tutored at home when I couldn't go in to school for English and science and math. If they'd given me a tutor for French, I'd be completely bilingual by now, which would have been great, because that would have given me another province to make money in as an actor.

*Cooper: I love the fact that you say bilingual and in your mind it's immediately English and French. Here, if you say bilingual, everyone would think it's English and Spanish.*

Howland: Canada is multilingual; I think there are more people in the country who speak Chinese. It is the second-most-spoken language in Canada. French may be even lower down than Ukrainian.

Remember those cartoons when we were kids growing up about "How a Bill Becomes a Law"? There was the one about how America was a melting pot. You all got in the same pot and kind of stewed together. I always liked the idea of that everyone who comes to America gets to be a part of the American dream. But Canada is more of a tossed salad...

*Cooper: (laughs)*

Howland: ... The different people come in, but they don't blend together and get stewed down. They keep their separate crispiness, but they're all in the same bowl that is Canada.

*Cooper: It is interesting how different communities start to gravitate to geographic areas because of people they know who have moved there, so they keep growing into that particular area. California is a melting pot, too. We've got a lot of people from all over the world who come here.*

Howland: People say that no one's actually from Toronto, and that everyone comes to make a living and go to the big city. But people do grow up in Toronto; at the same time a lot of people do come here, and I would expect that California is similar.

*Cooper: The people who are originally from here brag about it. Have you been to the States a lot?*

Howland: I was down for New York Comic Con a couple weeks ago. Thankfully it wasn't the same weekend as the storm. Otherwise there would have been a lot of superheroes washed away. ■ **ABILITY**

with people and folks to get Solo-Dx tracks into theaters soon.

*Fitzgerald: Are you in discussion with potential distributors?*

Warren-Lane: We've had some promising meetings with distributors. They have some caution, which is totally justifiable and understandable, because they don't know what the potential is for basically making an audiofile available on the World Wide Web before the film has debuted on the big screen. There are some great reasons that that shouldn't be a point of fear, namely all the spoiler alert sites are already out there, and graphic novels and hardcover versions of movies and kids' books versions of movies are all made available months before a movie comes out. So we don't ultimately see a huge obstacle. It's just a matter of getting people familiar and acquainted with the idea of something before they'll necessarily jump in. That's just human nature.

*Fitzgerald: If I were blind and I wanted to see a film in which Solo-Dx was not available, are there services out there that I can get?*

Warren-Lane: There are a number of service providers of [audio] description out there now, and they have varying relationships with the distributors. And then, of course, they're either limited or not limited by whatever platforms those distributors are using to get description out there.

*Fitzgerald: Can you speak more about the impulse behind Solo-Dx? For example, what motivated you, how long did it take to develop, and what was that process like?*

Warren-Lane: We opened our doors in March of this year. From then till now, it's been a steady incline in terms of its occurrence and recurrence to us. It's like when you get an idea and it tickles at first and then it doesn't go away, so you reconsider it and it still doesn't go away, so then you reconsider it again. So I would say since March, it's been one of those things where we've had our meeting of our four heads together about different strategies and who we want to approach, and all different kinds of places for description, let alone means of delivering it, and when it kept re-presenting as a really compelling option, we said, "OK, we really need to dive into this."

*Rosenberg: Can you walk her through the process of how we make a Solo-Dx?*

Warren-Lane: Once we choose a title, we have software that allows us to watch digitally. Between two lines of dialogue, we can time out how long it goes by. For example, it could be five seconds; it could be five minutes. And once we have that interval, we are then free to fill that interval of time with the fluid narrative of

what's going on, depending upon how the story's going. From that, we output a screen, which is literally entry after entry after entry of those time intervals from start to finish of the film or a section of the film, and then we take it into our mix bay and we have our voice-over talent come in. They don't get any time to read the script in advance, because generally Hollywood's timeline will be our timeline in the future, so they've got to be able to do a cold read right away. So our engineer sits there, our narrator gets into our booth, we sit outside the booth with the engineer with our little talk box, and the movie is called up on screen and they voice the script. We're careful when we choose our narrators, too. The beauty of that element adds a whole new dimension to the quality, because we tell our narrators to imagine that they are sitting next to a blind loved one. It could be a sibling, spouse, girlfriend, boyfriend, or child. Whoever it is, they're sitting next to a blind loved one and they are the portals to the description.

The idea is that we don't want it to be too wooden and robotic. They're an audience member, so if what's happening on-screen is happy, we should hear happiness. You should hear the smile in the voice. And if it's suspenseful or if it's action-packed, it should be the same thing. You experience that in your gut, and it should come out in your read. But at the same time, we want our narrators not to ham it up. They can let the material lead them. They don't have to lead the material. That's actually usually the biggest challenge for some of the voice-over talent we bring on, because they're used to being full-on actors. But we actually need kind of a halfway point between a radio journalist, like when you listen to NPR, and a storyteller. It's that sweet spot of emotional investment with clarity of delivery. Then we record it and output a file; then our engineer goes back in, cleans it up, and makes sure that it syncs properly. Then it's just about us uploading it to the World Wide Web.

*Fitzgerald: How did you decide on "The Hunger Games" and "Raiders of the Lost Ark?"*

Warren-Lane: Our thoughts immediately turned to, "What project, what titles do we do?" We naturally went with something that was very logical, which is that most blind and low-vision entertainment enthusiasts mirror their sighted peers. So we looked at the best-loved movies of all time and what was coming up currently that was going to have an incredible following. We thought that was the natural place to go. The whole idea is that Solo-Dx evolved out of troubleshooting what the current circumstances were for a blind viewer.

*Fitzgerald: Do you folks also write the scripts?*

Warren-Lane: Correct. We write in sections and then we kind of hand the script to the person to the right and then we all edit each other. We also do continuity viewings, where after a project is completed in sec-



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tions, we will review it together just to make sure that a final running through of the tome shows that everything is consistent and lining up and things have been named the same thing continuously, and we've developed as the movie has developed its content, that we're following that.

*Fitzgerald: Your company opened its doors in March, and after just several months of beta testing, you brought Solo-Dx to market?*

Warren-Lane: Yes. The four of us, we've actually been collectively writing, editing, and producing description for 40 years. We came from a place that actually pretty much pioneered description. It began with live theater in New England, and then it was a big question, why can't they supply it for TV and movies? And we all had our start through this PBS company and then realized, "You know what? We think we have a lot more to give, and we want to do it." So we took the plunge.

*Fitzgerald: I noticed your backgrounds in theater, writing and audio description. You've all been very productive in such a short amount of time.*

Warren-Lane: I think it's a cross between eagerness and determination. We really like what we do. And actually the climate right now is so great, because with the FCC having done what it just did for broadcast, and there are English-speaking countries other than the U.S. and states within the U.S. that are all beginning to legislate access to movie theaters. It's a really exciting time—one of those watershed moments. There was a point at which captioning got to the top of the hill and started downhill, and now everyone knows what captioning is. Description is at this really great moment of that kind of arrival on the scene.

*Fitzgerald: Can you elaborate on the FCC's ruling?*

Warren-Lane: It's called the Twenty-First Century Communications and Video Accessibility Act of 2010, I believe. It incorporates, among other things, a requirement that CBS, ABC, NBC, Fox, TNT, TBS, Nickelodeon, and the Disney Channel all offer 200 hours per year or 50 hours per quarter of described programming. There are details about where they have to do it, like markets based on population density. I frankly don't understand how they do the math. But it's basically 200 hours per year for each of those nine entities. That kicked off on July 1<sup>st</sup> of this year, and come July of 2016, the FCC will have the power to say, "OK, we're going to ratchet it up by as much as 75 percent, and it will now be 350 hours per year."

*Fitzgerald: You currently have audio description complete for two movies. What's next?*

Warren-Lane: I'm happy to tell you that we plan to make the first four episodes of *The Walking Dead*, sea-

son 1, available some time next week (October). We've begun work on *The Princess Bride* and the first *Harry Potter*.

Rosenberg: They don't sleep!

(laughter)

*Fitzgerald: Apparently not. But you primarily focus on film and television?*

Warren-Lane: Right now, yes. But I've got to tell you, the culture of the brand that we're developing is actually—anything where a description can be delivered by means of digital audio, we're happy to provide it and we will provide it. That includes zoos and museums and aquariums and to some extent theme parks.

Rosenberg: A lot of people are asking us, why isn't the description just in the movie itself? And what we really like to stress is that having the description as an accessory to the movie really allows blind and visually impaired people to finally see a movie with their sighted friends. It really is just something new and something different, and there are a lot of pros to having them separate. For \$1.99 it's a steal! (laughs)

*Fitzgerald: But if the description were embedded in the film, would they be able to watch together?*

Warren-Lane: They could, and this is totally fair, but some sighted people actually find description to be a little obtrusive. Once again, this is part of what made Solo-Dx be born, and that was, how do we create something where you can have your description experience in the company of someone who's sharing the same simultaneous experience but without the descriptions? So if you put in a DVD and you're sighted and you go ahead and navigate your way through the screen menus and you turn on the audio description, then everyone in the room is going to be listening to the description with the movie.

*Fitzgerald: Which was challenging for me, I must say.*

Rosenberg: It's tough, because it's a lot of information that you're getting hit with at the same time.

*Fitzgerald: My struggle was getting it synchronized to the film. I would imagine that's probably a common challenge.*

Warren-Lane: It is. It's a little bit like being familiar with cracking an egg. The more you do it, the easier it gets. Certainly no one shies away from the fact that they have to crack an egg. (laughs) You warm up to it, and once you have that, it gets to the point where it's second nature. You're not going to think about it any more. ■

# GOING SOLO

With popcorn, drinks, and the help of an unobtrusive MP3 file, Jeff Thompson and his family could finally enjoy a movie together, at home, just like most people do. "The neat part is, I had an earphone in and I was doing it all on my own," says Thompson, who is blind. "I didn't interrupt anybody else." The Minneapolis-based blogger, who writes on IT and the blind world, is optimistic about the recent arrival on the market of a new audio description MP3 file called Solo-Dx.

In the past, Thompson either watched movies while having to infer the visuals, or he watched them with audio description, which is an extra narration track embedded into a film to describe the visuals for blind and low-vision users. Neither option offered the best of both worlds for Thompson and his wife and daughter, who are not blind. Embedded audio description plays along with the film, aloud, which meant his wife and daughter had to hear it as well. It also requires some assistance to navigate the DVD player, so Thompson had to rely on others.

"I was impacting them by having it on, so they were subjected to me," he says. "Obviously they don't make films so you have to hear that [audio description]; they make films perfectly normal and then the audio description enhances my experience. But I don't have to enhance everybody else's, which is usually not enhancing theirs."

But Solo-Dx is poised to change the viewing experience of the blind and those around them. Created by Hollywood Access Services, LLC, Solo-Dx can be downloaded to any standard media player. It's convenient, affordable (.99 on Amazon and \$1.99 on iTunes), and perhaps best of all, fosters greater independence for blind and low vision entertainment users. "I did not have to worry about adjusting my TV, reconfiguring the DVD, or anything like that," explains Thompson, who downloaded the file to his iPhone. "It was a seamless experience. I just had to sync it up, listen to the countdown to a certain point, and then hit play and adjust the volume."

As someone who is neither blind nor tech savvy, and new to audio description, my own experience with the technology was refreshingly straightforward. I downloaded the Solo-Dx MP3 file of *The Hunger Games* to iTunes on my MAC, and plugged in my earphones to listen to instructions, which were concise and clear. A

beep told me when to pause and a guitar strum signaled when to proceed. With *The Hunger Games* ready to go in my DVD player, I held the DVD remote in one hand and my computer on my lap. My only challenge once the film began was synchronizing the audio description track to the film, which took me a few tries.

As the movie played and the description began, only then did I fully grasp the revolutionary impact of Solo-Dx. To watch the screen while listening simultaneously to both the film's audio and the audio description track was an exercise in sensory overload. My head spun; it was a lot of information to process at one time. I now understood the significance of having a supplemental track for blind users who want to enjoy movie night without impacting sighted viewers. For a while, I closed my eyes and just listened, and the experience reminded me of Reader's Theater in which actors read a script with great inflection and theatrical flare, except in the audio, a singular female voice narrates throughout.

The quality of Solo-Dx's description in *The Hunger Games* is vivid, dramatic, and well written. The narration is well paced, an important feature Thompson notes. "I've listened to films [with audio description] in movie theaters a couple of times and people critique how they over-talk and describe too much. Solo-Dx's track was a good balance; they didn't squeeze too much in there, so you're playing ping-pong in your head."

The descriptive narration is also precise, including characters' facial expressions, dress, and actions. For example, in *The Hunger Games*, when the main character, Katniss, finds her friend, Rue, mortally wounded, the narrator says:

*"In a clearing, Rue writhes on the ground, trapped in a net tied between two trees. (pause) Catness cuts the net's rope with her knife, freeing her. Rue embraces her tightly. Marvel appears and he uses his spear. Catness fires an arrow into his torso, dropping him, then turns around and gapes. Rue stares down numbly at the spear tip embedded in her own chest. She slowly withdraws it. She falls backward into her friend's arms."*

The implications of the Solo-Dx technology appear far-reaching and could potentially be applied to wherever digitized audio description is needed. According to Mathayu Warren-Lane, one of Solo-Dx's creators, the company is currently working on a trial with Universal Studios Hollywood. What the company eventually hopes, however, is that their technology finds its way into movie theaters, which is what Thompson wants too. "If I knew we were going to a movie theater, if it was that far ahead of the DVD, I would sneak it in," he says. "I know they say turn off all equipment, but I could have it in my pocket and have my earphones in and listen perfectly...if that's where it goes." ■

ABILITY by Paula Fitzgerald



# *The Sessions...*

How A 38 Year Old Virgin Lost It



# W

riter/director Ben Lewin was scouring the internet for material to create a sitcom around sex and disability, when the polio survivor stumbled upon an article that deeply moved him.

“I felt that if I could achieve on film what the author had done to me with his writing, then I could potentially deliver something powerful,” he said. The man was the late Mark O’Brien, a writer who used an iron lung, and who was determined to lose his virginity at the tender age of 38.

Lewin shot that film, and Fox Searchlight affirmed that he did indeed deliver something powerful by purchasing the movie, made for \$650,000, for a cool \$6 million.

O’Brien, played masterfully by John Hawkes, enlists the guidance of a Catholic priest (William H Macy) and later the help of sex surrogate (Helen Hunt) to help him



Left: Writer/director Ben Lewin on the set of *The Sessions* with William H Macy.

Right page; Mark O'Brien in his iron lung; crew on the set; and sex surrogate Dr Cheryl Cohen Greene.

experience the kind of human contact he can, up to that time, only imagine.

Recently the Media Access Awards, an annual event honoring people in film and TV who advance the portrayals and employment of people with disabilities, recognized not only Lewin, but also the film's casting director Ronnie Yeskel and the film's star, Hawkes.

While Hawkes does not have a disability, Lewin and Yeskel made every effort to cast the starring role with an actor who has a disability, but none of the ones who read for the part "felt quite right."

Hawkes ultimately won the part after a two-hour lunch meeting with the director. He says he was drawn to the role for several reasons, including Lewin's experience as a polio survivor. Hawkes read every article and poem written by O'Brien, and credits the 1996 Oscar-winning documentary by Jessica Yu, *Breathing Lessons*, as incredible reference material:

"It's 25 minutes of Mark O'Brien speaking frankly and often emotionally about his life... It was just invaluable."

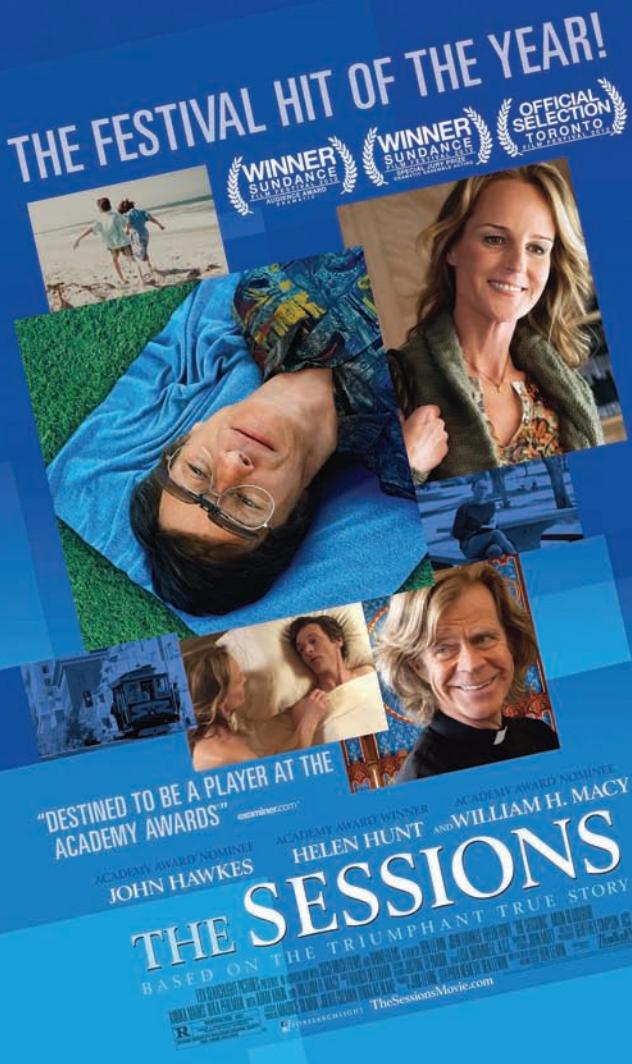
To simulate O'Brien's horizontal posture, Hawkes used a soccer-ball-sized piece of foam, which he laid onto the left side of his back to curve his spine. He spent hour

upon hour in this position, to the point that some of his organs began to migrate. He was even told by his chiropractor that his spine had become stiff from lack of movement. But Hawkes brushed it off, saying it was "a minute amount of pain compared to what many people face minute-to-minute."

Very early on in the process, before Hawkes was cast, Lewin got the rights to O'Brien's article, "On Seeing a Sex Surrogate," from the late writer's partner Susan Fernbach, who is now keeper of his estate. The 1990 article was written after his four encounters with sex surrogate Dr Cheryl Cohen Greene.

Lewin's next call was to Greene. She recalls their conversation: "Ben told me he had gotten the rights to the article, which I had read years ago. I knew my feeling about Mark was, would he be able to transfer what we did to a relationship with another person? And it didn't happen for quite a while (his relationship with Fernbach didn't develop until eight years after his sessions with Greene). So I think it came from a frustrating place, describing his emotional state at the time. The tone of the article was "Did I make a mistake? Did I do the wrong thing? I hired Cheryl, I had my experiences, but what have I done with it?"

Lewin told Greene he intended to make a movie, and



wanted to know her side of the story. She was used to curious strangers calling to try to get a look at a surrogate partner. She had no idea who Lewin was so she started googling him while they were on the phone, quickly realizing that he was a legitimate director developing a feature film project. That's when she agreed to meet with him.

Lewin arrived at her house with his long-time friend and chief financial backer, Jules Coleman. The filmmaker, who has known Coleman since they were teens, trusted his judgment and sought him out as a sounding board. In addition to Coleman's support, a number of friends and families invested in the project and a budget was cobbled together with small individual investments and loans.

During the visit with Greene, Lewin explored the difference between a typical sex worker and a sex surrogate. Who does this kind of work, he and Coleman wondered. And what is the work exactly? There were a lot of questions. Their conversation took place at Greene's kitchen table.

"At one point I said, 'Would you mind if I go over and get my notes? Because I don't remember,'" Greene asked. The meeting with Lewin and Coleman took place in 2007, and Greene's sessions with O'Brien dated back to 1986. "Ben and Jules both looked at each other with surprise and went, 'Notes?! I can't believe it! This is



amazing! This person is serious about her profession." The notes formed the basis for all of the scenes between Greene and O'Brien in *The Sessions*.

O'Brien had already written about Greene publicly, so she felt no need to keep their work together confidential. Based on Greene's notes, O'Brien's article and Fernbach's insights, they formed the basis for the film.

"When they left, they walked down my stairs," Greene recalls, "talking immediately about making it a different kind of movie." Indeed, the dramatic thrust of the story is about an awakening beyond sex, and the consciousness of love as a journey.

O'Brien's story evolved from there. The shooting script became an amalgamation of the frustration expressed in his original article, "On Seeing a Sex Surrogate," his sexual desires, his reaching out, his being rejected, his persevering, his attachment to Green, the pain of detaching from her and then, jumping ahead many years, to his time with Fernbach. It showed how, despite the challenges, O'Brien ultimately experienced love in a full and robust way.

O'Brien and Greene both came from a similar religious background. "I was raised Catholic and always had questions about sexuality," says Greene. "I wondered

why people have sexual urges if it is supposed to be sinful. I never got direct answers and I never got good answers." Like O'Brien, she grew-up feeling guilty about her sexuality.

After she discovered masturbation, she was embarrassed by the urge to do it, but masturbated anyway. "I had a lot of problems with sleep because of anxiety around school." She had dyslexia, which caused a host of problems, yet went undiagnosed. "Pleasuring myself really helped me fall asleep at night." Her first husband didn't feel a lot of guilt and shame about his sexuality. "He told me that I was a wonderful person and that what the church had been telling me was total bullshit; and anyway, how could I believe in a God that was less compassionate than I was? So that made sense to me."

She sought therapy. She'd also heard about the work Masters and Johnson were doing with people around sexuality, and thought, "Wow, that's fascinating!" In Boston at the time, she and her husband moved to California in 1968, where their marriage opened up to include other partners. "People were exploring with other people. It's kind of a scary idea but also a fascinating, intriguing one."

A friend of Greene gave her a book called *Surrogate Wife*, in which a woman tells the story of how she worked at Masters and Johnson. Later Greene talked to Dr Bill Masters about how one becomes a surrogate. Shortly after that, she attended sex-information workshops in San Francisco.

The environment offered a positive approach to exploring and fulfilling one's sexuality. The topics were discussed in a frank open forum. "They showed me two different movies: Each of them had women masturbating... I found the films mind-blowing, because I'd never seen erotica or porn or anything like that." Greene began to realize that she could shape her own ideas about her sexual self. Good, bad, positive, negative, or indifferent, it was all up to her. She made a promise to herself to get over being ashamed about masturbation. She recalls thinking, "I want to be able to talk like these people do about sexuality."

The workshop was made up of small groups with each person sharing their attitudes about themselves and their sexuality. Some people cried and there was a feeling of a weight being lifted. Greene learned that one of the women featured in the films was a sex surrogate. Greene got her phone number and called her. "She connected me with a couple of the therapists she worked with, and they confirmed for me that I was on the right path. They said that if you were going to be a surrogate, you had to have compassion, empathy and life experience. By then I was 29, had two children, and was a great believer in therapy as a tool to get out of stuck places and move yourself forward." Greene became a professional sex surrogate and wrote the book *An Intimate Life: Love, Sex, and My Journey as a Surrogate Partner*.

In 1986, O'Brien came into her life. "He was the first quadriplegic male, the first person who was that profoundly disabled. He couldn't sit upright because it would stop his breathing. He could be tilted up slightly to one side, but he couldn't move a whole lot. He could move a finger and that was basically it."

Lewin and his team captured the truth and essence of what happened to the lives of these people meeting at that juncture, people who helped O'Brien realize his desire to explore something that, up until that time, he felt was forbidden to him.

As depicted in *The Sessions*, O'Brien asked his therapist to find him a sex surrogate. The therapist did some research and connected with Greene. Later, during their first phone conversation, the writer described his feelings as if he were on the outside of a wonderful restaurant peering through big windows seeing everyone on the other side having a delicious feast—one in which he would never partake. Greene encouraged him, "You deserve a seat at that table," she told him, determined to help him.

Unlike many people in similar situations, O'Brien was especially adept at expressing himself both through his writing and verbally. Greene remembers, "He was very good at communicating. In the film, O'Brien's character has a line saying that he wants to experience a woman before his 'use by' date expires. That's an example of his wit. He was one of the most articulate men I've met, disabled or not."

There's a point in the middle of the movie when O'Brien mails a poem he wrote to Greene's home, which is not exactly how it happened in real life. She recalls, "I didn't see the poem like they have it in the movie. I saw it a year later, when he gave me a pamphlet of poems that he had written. The 'Love Poem to No One in Particular' was the first poem. And when I read it, for a moment, I wondered if he had written this beautiful thing to me? It was gorgeous, and when you hear it finally in the movie, the effect is amazing. And then I caught myself, 'No, he has written this for the woman in the future. He has written it for a relationship I helped him prepare for.' And that's what I still believe. He called me the day he met her and told me over the phone, 'I was able to tell her I'm not a virgin.' And he was happy about that."

Says Greene, "I've worked with a lot of disabled people since Mark. Some were seriously disabled like he was. There were some who were quadriplegics, paraplegics, a few who had cerebral palsy, and one with spina bifida, all these different kinds of conditions that prevented them from voicing what they really wanted or truly felt. Mark had his intellect and his poetry. Thank God his partner, Susan Fernbach has formed the Lemonade Factory Press so that all of his work will be available for future generations." ■

# Excerpts from Mark O'Brian's article “On Seeing a Sex Surrogate”

## POEMS BY MARK O'BRIAN

### August

The month of Elizabeth.

Of suddenly famous me  
getting phonecalls from

John Callahan, 20/20, NPR,

a new computer

and no time to write.

But mostly Elizabeth —

her 2 hour phone calls,  
letters, gifts, sweet names,  
of being in love,  
utterly gone,

bonkers for Elizabeth.

Liz, Liz, lovable Liz,

of all the women who could be or is,  
none is more luscious  
than loverly Liz.

• • • • •

### Free Man Liberates Paris

I feel her hands, they're kitten soft  
her love is tiger fierce.  
with quiet skill she weaves  
a universe composed of fun --  
bubbles, websites, food.

she treats me like a hero, as tho

I've liberated Paris  
or something big like that,  
when all I've really done is  
kiss her soft, lovely mouth, kiss  
her lips, her nose, kiss  
her nimble, witty tongue.

In 1983, I wrote an article about sex and disabled people. In interviewing sexually active men and women, I felt removed, as though I were an anthropologist interviewing headhunters while endeavoring to maintain the value-neutral stance of a social scientist. Being disabled myself, but also being a virgin, I envied these people ferociously. It took me years to discover that what separated me from them was fear—fear of others, fear of making decisions, fear of my own sexuality, and a surpassing dread of my parents. Even though I no longer lived with them, I continued to live with a sense of their unrelenting presence, and their disapproval of sexuality in general, mine in particular. In my imagination, they seemed to have an uncanny ability to know what I was thinking, and were eager to punish me for any malfeasance.

Whenever I had sexual feelings or thoughts, I felt accused and guilty. No one in my family had ever discussed sex around me. The attitude I absorbed was not so much that—polite people never thought about sex, but that no one did. I didn't know anyone outside my family, so this code affected me strongly, convincing me that people should emulate the wholesome asexuality of Barbie and Ken, that we should behave as though we had no “down there's” down there.

As a man in my thirties, I still felt embarrassed by my sexuality. It seemed to be utterly without purpose in my life, except to mortify me when I became aroused during bed baths. I would not talk to my attendants about the orgasms I had then, or the profound shame I felt. I imagined they, too, hated me for becoming so excited.

I wanted to be loved. I wanted to be held, caressed, and valued. But my self-hatred and fear were too intense.

I doubted I deserved to be loved. My frustrated sexual feelings seemed to be just another curse inflicted upon me by a cruel God.

I had fallen in love with several people, female and male, and waited for them to ask me out or seduce me. Most of the disabled people I knew in Berkeley were sexually active, including disabled people as deformed as I. But nothing ever happened. Nothing was working for me in the passive way that I wanted it to, the way it works in the movies.

Now that I had decided to actually see a surrogate, I had another problem: where would I meet her? I didn't have a bed, just an iron lung with a mattress barely wide enough for me. When Cheryl called back, she asked if I could come to her office, which is up a flight of stairs. I told her that would be difficult. Finally, we agreed to meet at the home of one of my friends.

I was terribly nervous when I asked Marie whether I could use her place. I had visited her often in her spacious living room, which contains a double bed. Marie, who uses a wheelchair, had made the cottage she and her lover share completely accessible. It was also within walking distance (or wheelchair-pushing distance). When I told her about Cheryl, she readily agreed.

As the day approached, I became increasingly apprehensive. What if Cheryl took one look at me disabled, skinny, and deformed—and changed her mind? I imagined her sadly shaking her head and saying, “Oh no, I'm sorry, I didn't know....” She would be polite, but she would flee from me.

On the phone, Cheryl had explained that she would interview me for the first hour of the session; then, if I agreed, we would do “body awareness exercises.” I was too scared to ask what this meant, but said I would give it a go.

When March 17 arrived, I felt unbearably nervous. I had to remind myself repeatedly that we were just going to talk about sex; in the second hour, we would do those “body awareness exercises,” whatever they were, but only if I wanted to do them.

Vera, one of my morning attendants, dressed me, put me in my wheelchair, and pushed me to Marie's cottage. Vera tried to reassure me, but it didn't help. I felt as though I were going to my own execution. ■ **ABILITY**





WRITING HIS OWN SCRIPT

# KURT YAEGGER

A ctor, director and professional athlete Kurt Yaeger is best known for his recurring role as Greg "the Peg" on the FX series, *Sons of Anarchy*. A motorcyclist since he was four, he grew up to be an avid BMX aficionado, and even had his exceptional riding talent incorporated into the popular Nickelodeon cartoon, *Rocket Power*.

After a motorcycle accident, Yaeger became a below-the-knee amputee. But he's kept it moving, teaming up with business partner Josh Gillick to create the production company ArtistFilm, which has produced a number of projects and has an extensive slate of productions on tap. *ABILITY*'s Chet Cooper and John D McMahon recently met up with Yaeger at his manager's Los Angeles home near the famed Hollywood sign.

*John D McMahon: I read that when you were a child in a play about the birth of Christ, you sat on your hands and wouldn't budge.*

Kurt Yaeger: That's right. I was seven, and I was a stubborn little brat who was afraid to go on.

*McMahon: That article made it sound like it was a hop, skip and jump from acting classes to getting your role. Was it that easy?*

Yaeger: There's nothing easy about this industry; acting is probably one of the hardest things I've ever done in my life.

*McMahon: What was your first break?*

Yaeger: I'm still waitin' for it! (*laughs*)

*McMahon: Did you start getting feedback right away?*

Yaeger: Yes. I went out and started auditioning at places and booking roles. I don't know why, but I took classes then, and I still take them. You never stop learning, because you're always trying to figure out new roles, new characters, new things. I don't really ever feel like I have a problem when I'm on set.

A lot of people are like, "Oh, that's Ron Perlman, you've got to act against him." I'm like, "Okay, just give it to me and I'll do fine." My biggest problem is memorizing material for an audition, because when I walk into the room there's all this stimuli. Let's say it's your office: You've got pictures of your family and your friends, little doodads, a penguin—and all these thoughts are going through my mind right at the moment that I need to focus on what I'm doing. So now I get on set early, on my own time, and just sit in the space and get used to it. For me, working is easier than auditioning.

*McMahon: Did you have a fear of auditions?*

Yaeger: Originally I had a fear of rejection, which is a lack of self-confidence ultimately. But that's partially why I had to do this. Now I have a production company and I've done a feature film and a bunch of shorts, and we have a bunch more projects in the works. And when you can look behind the scenes at the casting process, you know it's not about rejection. It might have been the most amazing performance ever, but if the person is too tall, too short, too brown, too white, has blond hair or whatever it is—maybe the person looks too much like the casting director's ex—then not getting the gig may have nothing to do with the performance. You have to learn to treat auditioning as matter-of-factly as drinking a glass of water.

*McMahon: What do you like the most, being in front of or behind the camera?*

Yaeger: I don't have a preference. Acting for me is liberating. It's almost like therapy, because I grew up in a blue-collar environment where you're not supposed to have feelings. So it's freeing to be in a safe place like a TV or film set where you discover feelings, and where you're supposed to be open and honest with everybody while exposing the weakest parts of you. That's really interesting. And then when people congratulate you on revealing the weakest part of who you are, then you start realizing that that might not be weakness. It might be a different kind of strength.

Being behind the camera, on the other hand, you have control; you have the ability to make decisions for characters, for where the story line's going to go, how you want to put it out there, how you want to edit it. Acting is like where you paint on the—

*Cooper: Canvas.*

Yaeger: Thank you. Acting is like being the canvas, and being behind the camera is like being either the paint or the paintbrush. They're both a part of the creative process, it's just that they have two different functions.

*McMahon: As an actor, do you search for the character's weaknesses first?*

Yaeger: I try to discover the character's primary motivation. In a screenplay, you can make up a hundred different variables of a character. Is he there for love or respect, or is he there out of fear? What's he doing? Why is he doing it? Then I can build on the intricacies. Does he pick his fingernails? Does he always do this when he's lying? All the little things that come with it. But it's also like, if you're doing a caricature and you're like, "I want to do a blue-collar guy from Jersey," you have to go and do the research on the region, the who, what and why.

If it's a period piece, what they would be saying and how they would be saying it? You have to have enough knowledge as an actor to be able to throw out some improv if the scene just goes to a different place, for some reason. You have to be that character even outside the words on the page. Or else all you'll be is the words on the page, and that usually falls flat.

*Cooper: Talk about Sons of Anarchy.*

Yaeger: It has been a great experience. To wake up in the morning, put jeans and a t-shirt on, ride my motorcycle to the set, get into wardrobe and put on a different pair of jeans and t-shirt, and get out and ride a different motorcycle is a pretty good gig. My character, Greg "the Peg," is a new nomad that comes in and causes trouble inside the club. I wanted to give Greg a little more heart than some of the other new characters that come in. I don't want to just play a guy who's a murderer. That's basic. I want to explore what's different about this guy.



Kurt Yaeger on the set of *Sons of Anarchy*

He seems to be the only character that has a conscience. I wanted to play that out in the words he says.

*Cooper: Did you get to choose the bike?*

Yaeger: We all ride Harleys, but we can choose which one we want to ride. So I chose the Fat Bob with the dual headlights.

*Cooper: Do you like the dual headlights because they afford better depth perception?*

Yaeger: Yes. I don't want to get run over on set by the camera truck.

*McMahon: What's it like to work with Ron Perlman?*

Yaeger: That guy's a character, man. He tells the funniest trash jokes you can imagine, and then the director says, "Okay, we're ready, and action!" And Ron sits down and goes, [in a serious voice] "Now listen, guys..." And you're thinking, 'Wait a minute, you were just telling a joke a minute ago.' I love it.

*McMahon: So he can really switch?*

Yaeger: Absolutely. He's a pro.

*Cooper: Can you remember one of the jokes?*

Yaeger: No, I don't remember any.

*Cooper: It would be cool if you could.*

Yaeger: It would be really cool, but I've had 11 concussions, so that doesn't help.

*Cooper: Have you really had 11, or 12, concussions?*

Yaeger: (laughs) Yeah. I don't know if you can tell, but my jaw's been broken. It's a little crooked. I've broken my scapula. Never broke my clavicle, which is really weird, because that's the one part that should've popped.

*Cooper: What happened with your motorcycle accident?*

Yaeger: In 2006 I hit a pole and went over a 40-foot embankment, crashing on the side of the freeway. I don't know how long I was there, maybe 10 minutes, and when I woke up, I could move one leg, but not the other, and my pelvis was broken. I pulled out my cell phone and called 911 to come get me.

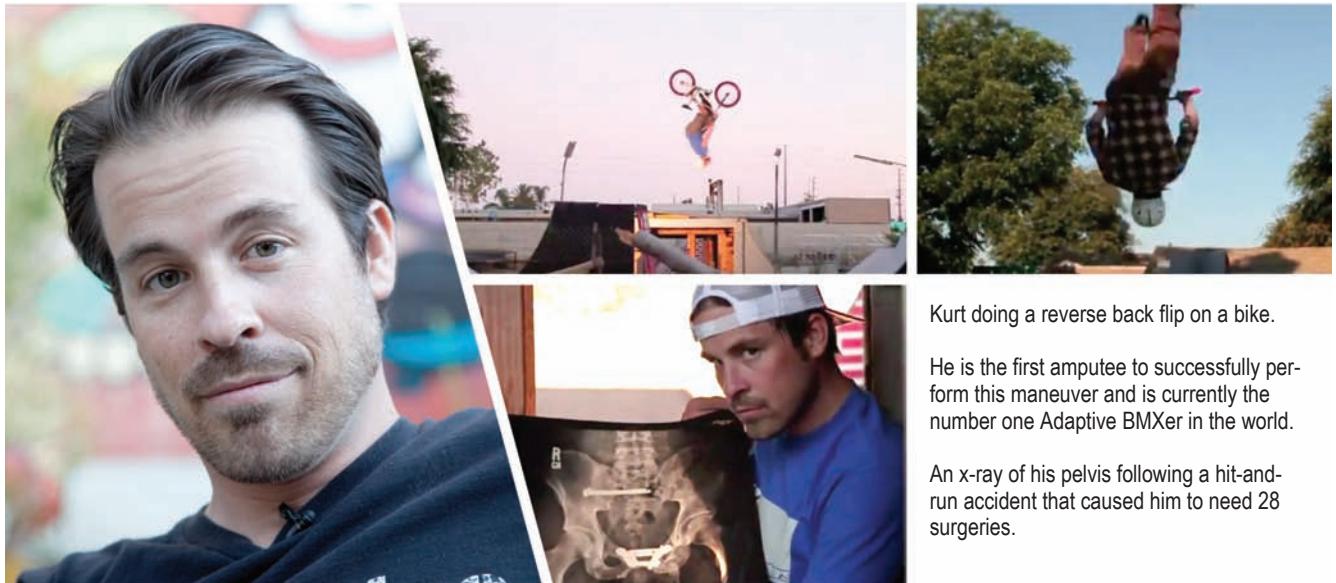
*Cooper: How did the accident happen?*

Yaeger: A car ran me off the road; we've never found the individual.

*Cooper: I want to say, sorry about that; I spilled some coffee on my lap and...*

Yaeger: It's okay; I'm perfectly fine now, but you do owe me quite a bit of money. (laughs)

*Cooper: Where did this happen?*



Kurt doing a reverse back flip on a bike.

He is the first amputee to successfully perform this maneuver and is currently the number one Adaptive BMXer in the world.

An x-ray of his pelvis following a hit-and-run accident that caused him to need 28 surgeries.

**Yaeger:** In San Francisco. I'd been riding motorcycles since I was four years old, so it's not really a matter of something I did wrong. Anyone who knows motorcycle riding knows that there's only two types of riders: the ones who've already crashed and the ones who will down the road.

**Cooper:** What kind of bike was it?

**Yaeger:** A Ducati Monster 1000 SI. I ripped the baffles out and cut the pipes down, which makes it noisy because loud bikes save lives. When someone revs the engine [on a noisy bike], it's them saying: "I'm over here, in your blind spot."

**Cooper:** I know that you lost your leg; can you talk about your rehab?

**Yaeger:** I spent three and a half months in the hospital. My pelvis was broken in half, my bladder was torn in half, my ACL was torn, the MCL in my right leg... I had seven broken vertebrae, collapsed lungs, broken ribs on my right side, deep vein thrombosis in my lower limb. They removed my left leg below the knee. There were a lot of problems. A lot of the recovery in the beginning centered around moving slightly, or having body parts moved for me, to keep some circulation going. But mostly it was about resting and not doing anything that was going to injure me any further.

I did that rehab all on my own for about six months, because when I went to the facility it was more like geriatrics: "Here's a band. Stretch it." So I just did it on my own. Up in San Francisco, Lake Merced has a seven-mile loop around it. I would go out there when I couldn't even walk, and grab a wheelchair, put it on my shoulder, go down each step with one leg to get to my car, crawl to my car, put the wheelchair inside, drive to the lake, and then get out and push myself around the lake. Seven miles. That's just the stuff that I would do to recover.

When I got my prosthetic leg I thought, "I'm off to the races." I put that thing on and took one step and I was like, "Aaagh! This hurts!" It probably was another two months of me walking and trying to do everything I could, and then I went back to my prosthetist and he said, "Why aren't you moving forward?" My leg was a bloody mess. He said, "You need to see the doctor." So I went to the doctor, and they were like, "We need some x-rays." I got x-rays, and then they said, "We need MRIs," and I knew there was something wrong. So when we got the results of the MRI, they said to me, "We don't know how to tell you this, but they cut your leg off wrong; we're going to have to do it again."

**Cooper:** But it was the correct leg?

**Yaeger:** Yes.

**Cooper:** Oftentimes they will prepare the leg knowing the prosthetic's coming. Odd they overlooked that.

**Yaeger:** They had so much other stuff to deal with to put me back together, and the leg wasn't a life-saving thing.

**Cooper:** You were still in survivor mode.

**Yaeger:** Yeah. They were like, "Look, we've got to rebuild his internal systems." So they saved my life in first, but because I had compartment syndrome, if this was my leg, they had to keep cutting it back. So at some point they were like, "We're just going to keep cutting and not worry about fitting the prosthetic foot later on. He might lose his knee, so what's the difference if we make this really pretty and perfect?" And then it finally stopped. I started to heal. At that point, I was able to have a leg that wasn't going to have to get cut from the knee up.

**Cooper:** So you had another surgery?

Yaeger: I had about 28 surgeries when I was in the hospital. I think I'm up to 56 surgeries now.

*Cooper: So when you go to the hospital, they all yell, "Kurt!"*

Yaeger: Yeah, I have my own parking spot and they wave me right in. I get to inject myself. They're like, "Oh, he knows what he's doing." I'm like, "Oh, the occipital arch on that bone doesn't look very good, Doc." He's like, "Oh, you see that, too?"

*Cooper: But you learned a lot about medicine in the process.*

Yaeger: Oh, yeah. I have anatomy books at home so I could learn about different parts and bones, and what they do and why they do it so I could fix them in my mind, and make it work for my body. A doctor can only tell you from the outside what your body's doing. He can give you a best guesstimate, but only you really know what's going on inside. Because of my high tolerance for pain, there've been plenty of times when I've walked into the hospital and said: "I need to get x-rays." And they go, "I'm sure you're fine, young man."

And then I show them my broken knuckles snapped and my twisted wrist, and they're like back: "Oh, my gosh! You need pain medicine." And I'm like, "No, I need you to yank this back into place and put a splint on this, because I can't do it." It's that kind of pain tolerance. So only you know what's going on in your body, and it's your responsibility to learn as much as you can in order to give them the best information you can about yourself. If the doctor doesn't have the information from you, he's making a wild guess. Probably a good guess, but you make the best assessment of your own body.

*McMahon: Would you say you're kind of like Evel Knievel?*

Yaeger: I could not compare myself to Evel. He was the man. He was doing stuff before anybody even thought it was cool. He didn't have any suspension. He was just a daredevil. But the thing is, you noticed from his character that he was calm and took calculated risks.

*McMahon: Are you a bit of a daredevil as well?*

Yaeger: I don't consider myself a daredevil, but I do take risks.

*Cooper: Calculated risks.*

Yaeger: Yes, but I don't like being afraid of something. If someone dared me to do something that I thought was a poor decision, I wouldn't do it, no matter what they said. But if I thought I could do it and they dared me, I'd ask how much and at least put some money on it. I just looked up right here and there's a tall roof and a lit-

tle roof, and I wonder, can you make this distance? Two story down to one story? I bet you could.

*(laughter)*

*Cooper: So tell me about this rider named Darius Glover.*

Yaeger: I met him through a friend of mine. He lost the use of his legs in a motorcycle accident, I believe, along with spinal injuries. He's probably the fastest kid I've ever seen on a motorcycle. At Milestone he was jumping the big tabletops, the back 100-foot one, with only a cage around his legs.

*Cooper: So he was riding a lot?*

Yaeger: As a kid, he rode a lot, trying to get sponsors, and then got hurt.

*Cooper: What does he ride? KTM has done a really good job supporting riders. Where as Honda can't see itself—*

Yaeger: They probably don't want to mark it that someone can get hurt riding this very dangerous thing.  
*(laughs)*

*Cooper: Tell us about your BMX riding.*

Yaeger: I've been on the BMX since I was a kid. I've been on motorcycles since I was four. My dad had a cabin up in Paradise Pines, which is north of Chico, and we'd ride motorcycles all the time. It was so much fun that I would ride BMX every day that I was not at the cabin. We had a field behind our house where I built jumps. They were one mound, which turned into doubles, which turned into bigger doubles, stretching out further and further. Then I was doing 40-foot-plus jumps.

*Cooper: You sent me a video of you. Are you the first person to—*

Yaeger: Yeah. I'm the first amputee to pull a back flip in history—that I know of. No one else has come to claim it, so I'm assuming it's true. And then I'm the top adaptive BMX in the world right now. I went to the X Games. I can do tailers, back flips, 360s, bar spins, every trick. But it was a long process of relearning to ride. It's not just pedaling the bike, it's weight distribution, it's pressure distribution, it's the fact that I have less muscle on the left lower half of my body than I do on the ride side, so not only do I have less power, but I physically have less weight on one side now.

*Cooper: So is it easier to whip your bike in the air because of that?*

Yaeger: No, it's just difficult all the way around. Riding bikes is just so much harder with one leg.



Kurt during the DRLC gala meets the ladies from *Push Girls* Auti, Angela, Mia and Tiphany. Kurt presents Ashley Fiolek with her DRLC award.

*Cooper: You really feel the difference?*

Yaeger: You really don't feel the difference. That's the problem. You don't know if your foot's on the pedal or not. You have no idea. When you land the trick is when you know you pulled the trick. Because that's where you're like, "Oh, my foot's on the pedal." That's only when you know it, when you actually roll away and go, "Oh, it was on the pedal." And there've been times that I haven't rolled away and been like, "I guess I didn't get on the pedal." (laughs)

*Cooper: Then you're thinking, 'I guess that nurse is going to see me again.'*

Yaeger: Yeah. I've gone back in a couple times since then.

*Cooper: At the X Games do you do motocross as well?*

Yaeger: I don't ride motocross. I don't like it that much. I go to the tracks and keep up with people, but it's more like camping: Drinking beer and hanging out around the fire afterwards.

*Cooper: Have you met Ricky James?*

Yaeger: I have not. Only Darius Glover. I think it would be interesting, because you know Ricky who's really fast, and I know Darius, who's a very fast rider as well, and they're both paralyzed and both rip on bikes and I was like, "I wonder how funny it'd be if they raced." And when we were talking earlier you said, "I'd put money on it." And I said, "I've got a hundred on Darius," and you said, "Okay." And I said, "What if we made them race and had a bunch of people put money on one or the other or both and gave all the proceeds to a nonprofit such as the Christopher Reeve Foundation?"

*Cooper: And ABILITY Awareness. (laughs)*

Yaeger: And ABILITY Awareness. How awesome

would it be to be able to have contests like that?

*Cooper: It'd be like a mini-X Games. I've thought of doing something like that. Get everybody to compete in wheelchairs or monoskis and watch their awareness grow. It would also be entertaining.*

Yaeger: I'd love to see that.

*Cooper: Like wheelchair basketball. I think a lot of people could compete for fun and build more awareness. How would you do something with a prosthetic? I guess you could splint something.*

Yaeger: Oh, just hack someone's leg off if they want to compete with me. It's not that bad. (laughs)

*Cooper: There you go. "It's going to cost you an arm or a leg to get in this race."*

Yaeger: Just a leg.

*McMahon: What was the mental adjustment you made when you went from two legs to one?*

Yaeger: You work through a new physical identity; you're like, "This is now my body," and you have to go through stages of grief: "This didn't happen to me, isn't happening. Everything's fine, hahaha." And then you go through the real pain of dealing with the situation. But I don't know if it's what we were talking about earlier, where it's the two brains, that I like the physical work and the mental abstract. I put those together to figure out what's going on. I think that there's a physical sense to it, like you have to push yourself through a certain type of pain in order to advance. It's just like stretching, how stretching really hurts sometimes, but it's not bad pain, it's the right kind of pain. You have to realize that there's good pain and you should fight through that kind of pain.

If today you walked a mile, in three days walk two miles, even if it hurts. Bring a cane just in case, so you can get off it a little bit. But push your limits so that you become stronger and faster. The other part of what I had to do is figure out how to make the equipment work for me. In the beginning I tried to make my prosthetic leg work like my real leg, which I found out after a week was complete folly, because it's never, ever going to function that way. But my good leg can behave identically to my prosthetic leg. So I made my real leg function like the prosthetic leg, and now when I walk, I have no gait, no limp, no movement, no difference between my steps because I made my real leg function the same way. It masks that I have a prosthetic leg. I focused a lot of time on trying to figure out things like that.

*McMahon: Your experience hasn't scared you off your bike?*

Yaeger: I was afraid to get back on my bike, but I knew getting on it would get rid of the fear, and I don't want to be afraid of something. I was afraid of spiders for a long time, and I worked up to letting a tarantula crawl on me. Do I still get on a motorcycle and ride it as carefree as I once did? No, but I'm not afraid of it.

*Cooper: Did you go to college?*

Yaeger: Yeah, I was working towards my master's in hydrogeology.

*Cooper: "Pot"ology?*

Yaeger: Hydrogeology not hydroponics! (laughs)

*Cooper: Energy issues?*

Yaeger: Groundwater subsurface and aquifer-based contaminants.

*Cooper: Environmental issues.*

Yaeger: Yes, but also dealing with cleanup or storage of water filtration systems or removal of old dams. Fifty years ago, 100 years ago, we were a dam-building society.

*Cooper: Dam right we were!*

Yaeger: And they used quicksilver or mercury to strip out the gold from the other materials, and then that [contaminated material] would form sediment behind a dam, and my job was to remove it. I would come in and figure out flow rates of the materials so that they wouldn't go downstream and destroy salmon beds, while at the same time trying to clean up the heavy metals. I liked it so much because it was the right mixture of white collar and blue collar work. You could go outside and get your hands dirty, and then go use your mind to figure out the bigger problem.

*Cooper: Never heard anybody talk about that mixture before.*

Yaeger: One of my first jobs was as a plumber's assistant: "Dig that hole, level, 18-inches deep, 6-inches wide, 400-feet long." And you're making this perfect thing. And after four months of that, you're like, "I need a little stimulus upstairs." And then you just do brain work and you're like, "Man, I want to get outside and do something physical." Hydrogeology was the right combination.

*McMahon: What made you transition from hydrogeology back to acting?*

Yaeger: It took almost a year and a half for me to walk under my own power without a crutch or a cane, and by that time I'd forgotten most of the applied calculus that I used to do the hydrologic processes. So I would've had to go back and relearn all that, and the idea of it was daunting. It took the steam out of me. I was like: I want to do something else completely.

perfect.



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*Cooper: Dam calculus.*

Yaeger: I know. I love working on problems and figuring out the solutions, but there was just something that I've always loved about film and TV. I know something about most major films like where they shot it. I'll see scenes, like the first *Indiana Jones*, and see the problems. In fact, there's one scene inside the snake pit, where they shake the big statue of a snake and it smacks into a wall and breaks out just enough so they can push a huge heavy boulder out and get out into the sunlight. Well, if you look in the shadows, when he pushes the boulder, the shadow of the rock goes bouncing away. So you're like, "Yeah, that's styrofoam." You just catch all these little things.

*Cooper: I thought you were going to see the lunch truck in the background.*

Yaeger: Yeah. There's a lot of things you could see. Like, they're supposed to be out in the desert and a truck is passing by, a plane's flying by with a contrail.

*Cooper: During a cowboy scene.*

Yaeger: I've always had a huge interest in film, but I don't have any family in the business, no cousins or buddies, no friends. I'm just another Caucasian guy with the least amount of skill. That's what I figured. And it's only those people that are going to get it. But at some point during the recovery, I said, 'You know what? I can do this. I can figure this out.' I think it was a matter of facing death in that kind of way where you just say: "I'm going to do what I want to do, no matter what the consequences are."

*McMahon: I notice, too, that you're getting pretty involved with United Cerebral Palsy. Is there a reason you chose that particular nonprofit?*

Yaeger: I do work with the UCP of New York City. I don't know what specifically brought me to them except the fact that I was blown away by little things, like how they use the iPad to help little kids and adults speak. They're eloquent; they just can't get the words out. Their minds are functioning at high capacity. So for 500 bucks, which is not a lot of money, you can give them a voice. So to support a good organization that does supply those technological advancements seems to be a no-brainer.

*McMahon: So what's in store for you down the road, Kurt?*

Yaeger: Over the next year I'm raising money for a four-film package, and developing a show with a disability theme. As an actor, I have a few projects coming up that I've talked to a couple different production companies about, and maybe I'll do one or two TV shows as well. But that's all tentative. Everything in Hollywood is

tentative until you're doing it and the check has cleared. There's another show that I'm working on right now that's in development, which is about extreme sports—the behind the scenes of everything. Building that out is probably the number one thing right now.

*Cooper: The show related to disabilities—was that inspired by the injury?*

Yaeger: Absolutely. People in my family also dealt with some disabilities. My dad had polio as a kid, so he has skinnier legs. My grandfather died of AIDS from being injected with the HIV virus, before they did major screening of blood. So that's why I do the AIDS walks, to raise money for awareness and prevention and research. When I lost my leg, I was thrust into a new world. I was completely blown away by what I saw.

One thing I'll never forget, I was doing a scene with a lovely girl named Allison who has CP. Her disability was pretty involved. She didn't speak very well. She had a hard time getting the words out, and it was hard to understand her. The scene was probably three or four pages, and we were going to perform it in front of 300 people. We did a couple practice runs on it and then she asked me in her way, "Can I—can I—write you about the scene?" And I'm like, "Sure!" This is how I talked to her the whole time. "Absolutely, Honey! Anything you need, Allison, anything you need." I treated her like a little kid. When she wrote me the email, I didn't know that she was working on her second degree; she was more eloquent than I am and smarter. She just had a hard time getting it out. So I felt like a complete jackass.

*Cooper: Are you involved with the Media Access office?*

Yaeger: If they need help finding someone, or if someone is looking for amputees, they generally give me a call. Although my representation usually handles that now. I do leave myself open to getting a job or getting noticed any way I can. I don't limit myself. Because if someone looks up your website and your information and they see my stuff, they may not have gone to Media Access, or vice versa. Or they may look in one magazine and see me, but not see me in your magazine, just because they flipped through that one extra page. I don't think you can be in too many places.

You have to keep things fresh. And it's a pain. But 80 percent of acting is getting work. Preparing the auditions, going to auditions, working on your head shots, doing your reel, putting together this information, calling those people, waking up and paying it forward and going to these events—that's all a pain in the ass. But when you've got the gig and you're on set that's the fun part. ■ **ABILITY**



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# From China With Love

# 从中国与愛



Usually when we hear about China, the stories focus on factories and goods, jobs shipped overseas and other news items that make the country sound uninviting. But when *ABILITY Magazine*'s Chet Cooper traveled there to meet some of his counterparts in publishing, he found himself forming lasting friendships.

During that time, *ABILITY Magazine* (AM) and *China Press for People with Disabilities* (CP)—including their sister publication *Spring Breeze*, announced their intention to exchange editorial content that would be published in both China and the US. And over the months, they followed through with their editorial exchange, including articles on autism, art therapy, rare diseases, and teaching with a disability. The stories have been of a human interest nature—exploring common experiences, as well as the differences, that people with health conditions and disabilities face in both countries.

Another agreement between CP and AM is the first ever art exhibition in the US, featuring the works of Chinese



Ni Lin presenting a gift of appreciation to Paula Pearlman



L to R: Chet Cooper, Ni Lin and Wei Mengxin

artists with disabilities. And the following year, CP will, in return, host an art exhibition showcasing the works of American artists with disabilities in China.

Recently, Ni Lin, publisher of CP, and Wei Mengxin, China's United Nations delegate, and several of their colleagues who had hosted Cooper in Beijing, paid AM a visit. They spent several days in Southern California, meeting some of the AM team, watching the surfers from the Huntington Pier, seeing highlights of Los Angeles and enjoying an evening at the annual Disability Rights Legal Center (DRLC) gala.

As a special portion of the gala, Ni and the delegation presented a beautiful framed carving to DRLC Executive Director Paula Pearlman, for allowing the CP and AM to promote the forthcoming art exchange project. Eight of the art pieces were unveiled during the event. More than 80 pieces will be part of the coming exhibition.

The gala, also known as the Franklin D. Roosevelt dinner, is dedicated to America's 32nd president. FDR had polio and—behind the scenes—got around the White House in a wheelchair. This year, the FDR dinner noted positive portrayals of disability in distinguished network television programming. Kurt Yaeger, a co-star of *Sons of Anarchy* hosted. (see page 44)

Also on the bill for the evening were the Sundance cable network stars—and our past cover subjects—*The Push Girls*, who navigate the world in wheelchairs, along with Ashley Fiolek, our longtime columnist. (see page 6) The DRLC's mission is to champion the rights of people with disabilities through education, advocacy and litigation, while *ABILITY Magazine*, along with its Chinese counterparts, seeks to provide new insights and awareness into our individual levels of ability. ■ **ABILITY**

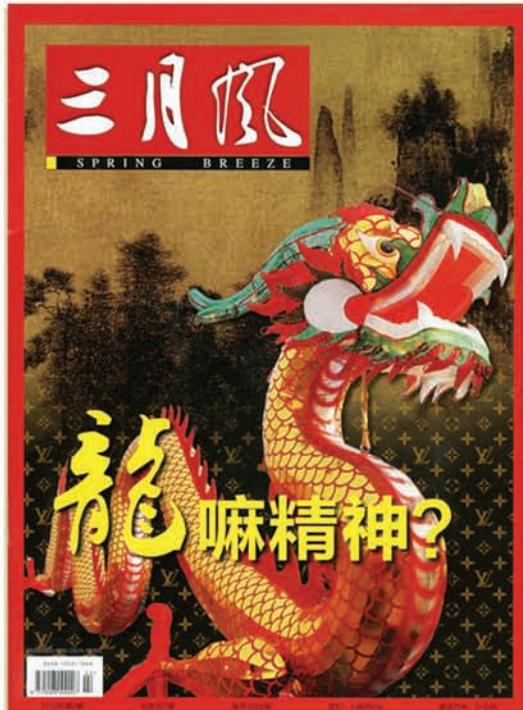
DRLC Honorees



L to R: Patti Carr, 90210 Co-Executive Producer, Victor J. Gold, Dean of Loyola Law School (LLS), Barbara Ullman Schwerin, Esq., Founding Director of DRLC's Cancer Legal Resource Center, Paula Pearlman, Esq., DRLC Executive Director, Ashley Fiolek, and Bob Cooney, former Associate Dean of Business Affairs at LLS

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## 茅于燕 我们在教书，不是收容

### Beyond Sheltering: Teaching Children with Disabilities in China

If you pass the Xinyun Institute for Children with Mental Retardation, you will see Mao Yu-yan's name in the building's window. Although she's the founder of the institute, her contribution to the research and education of children with developmental disabilities isn't often spoken about.

At 86, no one believes that she still works. But she can often be found traveling alone by bus from her home in Sanlihe, to the facility in Beijing where she serves as a consultant. She refuses to use a driver: "Each way takes two hours. It's a waste of time for him." When others tried to persuade her otherwise, she became angry. Finally, a compromise was reached: At the end of the day, a driver takes her a short way to a station

where she rides the bus the 20 stops back home.

Born in 1926, Mao Yu-yan is the daughter of Mao Yisheng, China's leading expert on bridge construction. She's a researcher on the psychological health of infants at the Chinese Academy of Sciences. In 2000, she was awarded the China Naito International Award for Child Education for extensive research in early training of children with developmental disabilities.

#### AN ALARMING RATE: ONE IN 100

It was in 1975 that a doctor from a hospital in Beijing was asked to test the IQ of children with developmental disabilities. At the time, strange new therapies were



being used to treat them, such as having them eat pig brains, or injecting the children's brains with various animals' fluids, and other such concoctions. Mao's job as a researcher was to work with the doctors.

The pig brains, supplied by the Beijing Meatpacking Plant, were processed into drugs to treat 160 children with developmental disabilities. Soon, however, researchers discovered not only was there no value in these treatments, but they also led to serious side effects, such as high cholesterol and obesity. The experiments were soon interrupted by the devastating Tangshan Earthquake in 1976.

After things settled down again, Mao continued her

work. She volunteered to go to a local Beijing clinic to explain the difference between dementia and psychosis to the nurses and doctors there. She received a list of 788 people with developmental disabilities, which accounted for about 3.4 percent of the total numbers she surveyed. "I was astonished by the high ratio! Three people in 1000 are have a mental disability," she said. Because the samples did not include the so-called underachievers and children under three years of age, she began to wonder if the ratio might be higher. After she conducted further research, she came up with a new ratio of 1.07%, which was widely accepted. But the news didn't lead to widespread concern, because most people thought there was no hope for these children. Mao insisted that they had a lot of untapped potential.

"I kept appealing to the public to recognize that the early training of pre-school age children with developmental disabilities is very important. If they are over six years old and miss that window for training, their IQ is unlikely to improve," she says.

Mao befriends the children's parents. They often have heart-to-heart talks, even sharing details of their personal lives. More and more people know her name, and she receives a lot of mail from distant places. "Some of their questions are hard to reply to, so I give them common sense advice, and comfort them again and again, often remaining awake all night," she says.

When asked if her famous father influenced her career choice, Mao says "no." In her memoir, she recalls that her father was so kind-hearted that every payday, he would first send money to someone else in need, and then budget for the family's expenses. Following her father's personal example, she sends money to a family member with a developmental disability just as she has every month for the last 40 years.

In 1980, as a visiting scholar, Mao studied at Cornell University for six months. When she returned to Beijing, she initiated a program for educating children with developmental disabilities, and then promoted the early form of special education schools in Beijing. At the time, some of her colleagues at the Chinese Academy of Sciences chose to research gifted children, which was low cost and rewarding, while Mao devoted herself to the research of children with developmental disabilities.

## A NEW, LONG MARCH

From 1980 to 1986, Mao researched the psychological development of roughly 1000 infants and young children, focusing on a close study of 29 children from birth to age three. Based on this research, she designed the first diagnostic scale to provide the foundation for diagnosis and treatment. While in her sixties, she spent a great deal of time traveling to clinics to conduct inquiries.



86-year old Mao Yu-yan travels 2 hours on her own each way to volunteer to help the children.

At the same time, she began writing training manuals, but could not get access to outside resources for more information, except from brochures. Drawing from her own experiences, as well as what she read in brochures, she classified and analyzed her data, and finally completed *The Early Intervention Program for Mentally Retarded Children*, which is the predecessor to *The Early Education Manual for Mentally Retarded Children*.

The manual was published in five colors: sea blue, pink, yellow, beige and light blue, which correspond to specific areas of training, which include physical movement, fine motor skills, language, cognitive capability, and social behavior. "The manual is very thick," says Mao, "covering everything, so that therapists don't need to use other books."

Still, her full vision has yet to be realized due to a lack of support. Some doctors and therapists at large hospitals didn't believe children with developmental disabilities can learn vocabulary beyond the word "Mom."

Undeterred, Mao headed to the library to look for other ways to achieve her goals. One summer morning, she found her inspiration in a foreign book. She learned that parents in the United States were instrumental in getting laws passed to prevent prejudice, and to ensure the education of children with developmental disabilities. "It was a beacon calling me forth," she would later say. She realized it was possible to organize the parents of these children to help build a special school.

In 1985, 16 like-minded strangers gathered in the meet-

ing room of a mental institute to discuss how best to establish a school for these children. A preparatory committee was formed. She named the school Xinyun, which means that it could offer a new destiny to unlucky children.

## FINDING DIGNITY IN CLEANING TABLES

Though its establishment attracted wide attention, and especially won the support of many celebrities and experts, the Xinyun Institute has still had to relocate a number of times. It began in Zizhuyuan, with two rooms, three retired women, two children with developmental disabilities, and an old organ.

"What are you doing here?" curious passersby would sometimes ask.

"We are training these children," teachers would reply.

"Is it necessary to train them? It sounds interesting," they would say.

Over time, the children's numbers grew: From two to four, and then to 20. The school had to be relocated as rents rose and spaces grew too small. Despite the poor conditions, the teaching remained rigorous and precise. Mao divided the children into three classes according to their ages, providing group teaching, activities and individual training. Each child received an individualized program.

"When I wrote the manual, I had no idea if it would be productive," Mao recalls. At the time, her manual was



the only guidebook available, so it was difficult to find comparable education methods. Fortunately, the 20 children she trained improved and eventually entered special education schools or conventional primary schools. Since 1985, 500 children have received education and training at Xinyun.

"In the beginning, I was too naive. I thought they could learn easily," Mao recalls. "But that is far from the truth. I have recorded that one needs to teach a severe child 800 times to remember a word. Language is very difficult for them," she says.

"Though learning such tasks as how to use a toilet requires extreme patience and effort, the children still make great progress," explains Mao. "If a child learns and has the capability to clean the table, it is a marvelous advance. In other countries, for a severe child, no matter how small the progress, he or she receives a graduation certificate. We agree with that, too. If a child can clean the table, it is also a way to show his dignity."



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*.

# An Interview with Mao Yu-yan

*Li Ying: Children here are all moderate or severe. What is considered to be an accomplishment for them?*

Mao: If a child learns to speak or walk while they are here, that is an accomplishment.

*Li: For more than 20 years, what do you think is your greatest achievement?*

Mao: To see that these children are teachable. If you make up your mind and insist on training them, they can make amazing progress and show their dignity, too.

*Li: It usually takes a long time to see a child make that kind of progress. Before that, how does a teacher deal with her own frustrations and remain encouraged?*

Mao: I encourage them. When a new teacher comes, I tell her, "You are so excellent, and you are not just working; you are donating time and labor to a great cause. We don't just feed the children and send them home." One of my wishes is to show the whole society that we are teaching beyond sheltering.

*Li: Did you ever think about giving up?*

Mao: In the beginning, I was full of confidence. The biggest challenge happened in recent years. When the lease expires, it often requires a great deal of time and energy to find a new place. The old teachers are aged, while few new teachers can be found. At the same time, the leaders are old, too. We are aging quickly beyond what we expected.

*Li: Is it easy to find young teachers?*

Mao: Few young teachers want to come here. The wages are low, and they are not allowed to charge for individual training. I can't ask parents to pay more. All the families with a child who has a disability have been burdened enough. Though with few followers, I have no regrets at all. Even if I can only save one or two children, it is still worthwhile. ■ABILITY

by Li Ying

chinadp.net.cn

# PRIVATE Enforcement OF THE LAW WILL INCREASE Accessibility

**T**here is an impression that most Americans with Disabilities Act (ADA) Title III cases (against private businesses and commercial facilities) are unmeritorious and are just a way to line the pockets of greedy attorneys who are more interested in money than accessibility. Rather, Congress developed a thoughtful statutory scheme with built-in safeguards that promote individual enforcement of anti-discrimination laws, which means lawsuits by and for private individuals. The ADA is unique among federal anti-discrimination laws because it provides a means to restructure the physical environment of places of public accommodation – that is, mandatory injunctive relief, which requires actual physical changes. This statutory remedy is the backbone of Title III of the ADA, and the driving force behind private enforcement.

The Disability Legal Rights Center (DRLC) is committed to enforcing the ADA through litigation, education and advocacy. We believe that there are sufficient safeguards and policing mechanisms in place (through state bars complaint procedures and court rules regarding vexatious litigants) to ensure that unscrupulous attorneys and litigants do not undermine the important function of private enforcement.

**CONGRESS INTENDED PRIVATE ENFORCEMENT**  
Congress enacted the ADA in 1990 upon finding, among other things, that “society has tended to isolate and segregate individuals with disabilities” and that such forms of discrimination continue to be a “serious and pervasive social problem.” This discrimination, exemplified in exclusion, segregation, physical and communication barriers, and relegation to lesser services, was found to have placed individuals with disabilities at a disadvantage and inferior status in society. In fact, Kessler Foundation and National Organization on Disability recently found that people with disabilities spend less time socializing and going to restaurants than do people without disabilities, suggesting that

“significant barriers [including physical obstacles] still exist that prevent people with disabilities from going outside the home.”

Congress explicitly stated that the purpose of the ADA is to provide “a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” and “clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.”

Under Title III of the ADA, which prohibits discrimination by owners and operators of places of public accommodation, someone who has encountered the barrier is entitled to an order of injunctive relief—including barrier removal and policy modification—upon showing violation of the Title’s accessibility provisions. Unlike the other two major titles of the ADA, individuals have no private damage remedy for Title III violations, making its injunctive relief provision that much more essential.

The injunctive relief provision of Title III of the ADA was the result of months of thoughtful deliberation by Congress. As ultimately passed, Title III reflects the Congressional commitment to vigorous, privately enforceable non-discrimination standards, comparable to the legislative commitment reflected in other major federal civil rights laws.

## INJUNCTIVE RELIEF IS MANDATORY

The plain language of dictates that violations of Title III are subject to mandatory injunctive relief. “Injunctive relief shall include an order to alter facilities to make such facilities readily accessible to and usable by individuals with disabilities to the extent required by this subchapter [and where] appropriate, injunctive relief shall also include . . . modification of a policy . . .” Courts have held that there are no exceptions for substantial compliance.

Compliance with the ADA’s physical accessibility standards requires business owners to take proactive steps and, often, to incur costs. Unfortunately, the threat of injunctive relief is generally not going to be sufficient to guarantee voluntary compliance. Business owners may erroneously assume that barrier removal is more expensive than it is, or may underestimate the amount of new patronage that would result from making their businesses accessible. Additionally, the owner’s assessment of the costs and benefits of accessibility may be skewed by prejudice against or stereotyping of people with disabilities, even if the prejudice or stereotyping is unconscious. Enforcement that is guaranteed to result in timely injunctive relief is therefore essential to realize the equal access goals contemplated by the ADA.

Congress chose to make private enforcement “the primary method of obtaining compliance with the [ADA].” Yet, more than fifteen years after the enactment of the ADA, violations of the statute’s public accommodations

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title remain, by all accounts, widespread. It is estimated that ninety-eight percent of buildings are not compliant with the ADA. Testimony from advocates across the country affirms that many if not most businesses remain inaccessible, even in circumstances where it would be easy to remove barriers. Government alone cannot be counted on to fill the gap. If the ADA does indeed regulate “more than 600,000 businesses, 5 million places of public accommodation, and 80,000 units of state and local government”, the Department of Justice clearly does not have the resources to take on each and every accessibility violation. Actions brought by defenders of civil rights serve a crucial function in enforcement and “advance the time when public accommodations will be compliant with the ADA.”

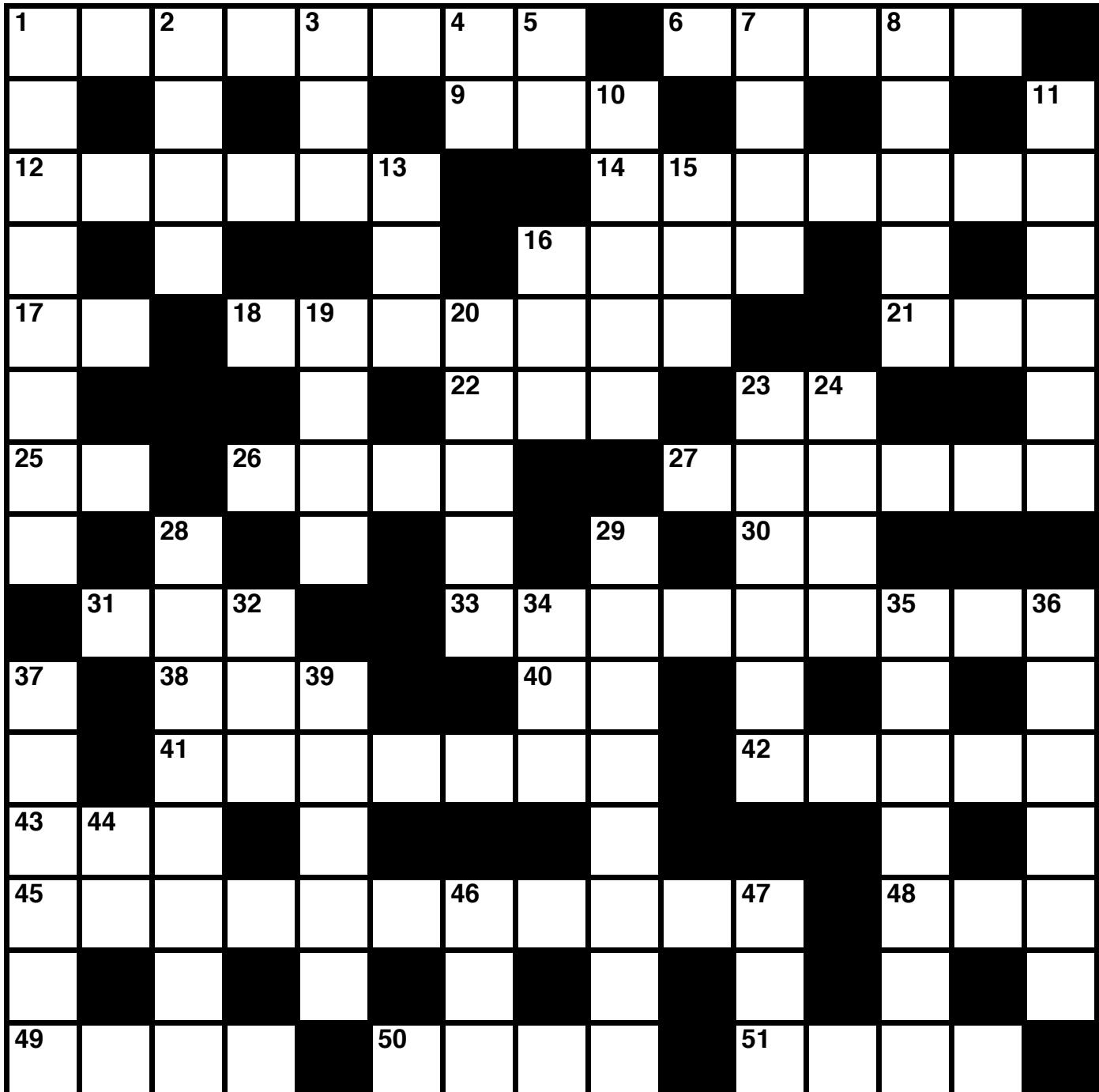
Despite clear Congressional intent to the contrary, ADA access cases against privately owned places of accommodations under Title III are becoming inherently more risky and difficult for the private bar to bring. In addition to the statutory framework of looking to future changes, there is a 2011 Ninth Circuit decision that imposes higher pleading standards on ADA plaintiffs challenging architectural barriers and a risk related to the ability to recover attorneys' fees. A plaintiff must show that there is a risk of the harm happening to her again. Her ability to bring a lawsuit is also tied to her disability, meaning that a wheelchair user suing a restaurant can only obtain an injunction with

respect to the barriers affecting her specific disability, and cannot—for example—seek relief for individuals with vision impairments.

Now some people may believe that these limitations are a good result, but we believe they would be mistaken. The DRLC recently filed an amicus brief—friend of the court brief—in the Moeller v. Taco Bell Corp. case that is being litigated by the firm Fox & Robertson and others in the Northern District of California, and is now on appeal at the United States Court of Appeals for the Ninth Circuit. We are very concerned about the chilling effect of these types of court decisions and narrowing interpretations of what is an ADA violation that requires injunctive relief. As a result of all these risks and hurdles Title III of the ADA is fast becoming a chronically under-enforced statute. As litigation is extensive and costly, most private plaintiffs are not willing to stick-out the litigation process with mere hope for a favorable ruling. If the courts are permitted to further reduce or weaken the strong incentives that do exist—like the promise of mandatory injunctive relief upon establishment of violations of Title III—the result will inevitably be less private enforcement of the ADA, which ultimately means less accessibility. ■ **ABILITY**

by Michelle Uzeta and Paula Pearlman  
[disabilityrightslegalcenter.org](http://disabilityrightslegalcenter.org)

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# Crossword Puzzle

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## ACROSS

- 1 President's wife who supports numerous charitable causes
- 6 Turkish journalist and MP, honoree at the 2012 International Women of Courage Awards, Safak \_\_\_\_\_
- 9 Spots
- 12 The birthplace of pizza
- 14 President who supports 50 charities including his own
- 16 Rita's profession in the Beatles song
- 17 Emotional intelligence, for short
- 18 First licensed driver with diabetes in the history of IndyCar racing, Charlie \_\_\_\_\_
21. \_\_\_\_'easter
22. King Kong, e.g.
23. Fourth \_\_\_\_\_
25. Dr \_\_\_\_\_
26. Top singer who supports the Keep a Child Alive charity providing AIDS treatment in India and Africa, Alicia \_\_\_\_\_
27. Take That singer and X Factor judge who works with many UK charities, Gary \_\_\_\_\_
30. It's repeated three times in a One Direction song title
31. Airport posting, abbr.
33. Children's charity that celebrated 21 years at 10 Downing Street in 2012 (2 words)
38. Fall back
40. Calvin Johnson's position in the NFL, for short
41. He's battled MS but has ridden a million miles as an "Iron Butt" bike rider, Paul \_\_\_\_\_
42. Accept (2 words)
43. Exclamation of impatience
45. Movie starring William Macy and Helen Hunt about a sex surrogate (2 words)
48. The girl from Ipanema came from here
49. Former Sun, now Laker
50. Actress and singer host of [loveyourflawz.com](http://loveyourflawz.com), \_\_\_\_ Larson
51. Buddy in the UK

## DOWN

- 1 "Hair" actor whose daughter is autistic and who raises funds to help autistic children, Joe \_\_\_\_\_
- 2 Abbreviation for UN convention concerning the rights of people with disabilities
- 3 New Year's \_\_\_\_\_
- 4 Hollywood's home
- 5 Mr. \_\_\_\_ (horse)
- 7 Type of rock
- 8 "Rocketman" singer (first name) who supports 45 charities and his own
10. Climb
11. "Phantom of the Opera" composer, \_\_\_\_ Lloyd-Webber
13. "Casablanca" pianist
15. Count Basie's "\_\_\_\_ Darlin"
16. Shows where to go
19. Rapper on "Law and Order"
20. More contemptible
23. Beach footwear
24. Type of jazz
28. Special Olympics athlete and global messenger, John Franklin \_\_\_\_\_
29. Intensely loyal
32. Anti slavery President
34. Have
35. French term for raw art (2 words)
36. Singer and UN Goodwill Ambassador fighting HIV and AIDS, Annie \_\_\_\_\_
37. Ohio city
39. \_\_\_\_ Brothers
44. Surprised expression
46. "To \_\_\_\_, with love" movie
47. "The \_\_\_\_ of all fears"

answers on page 64

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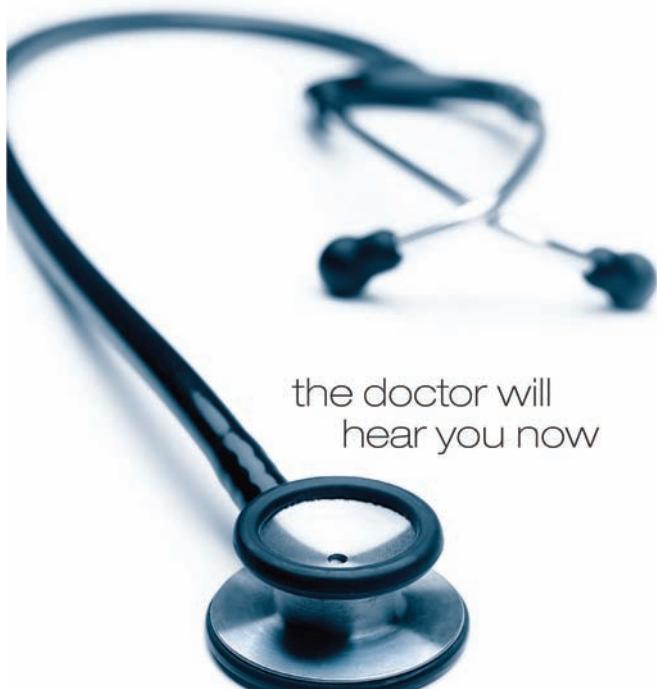
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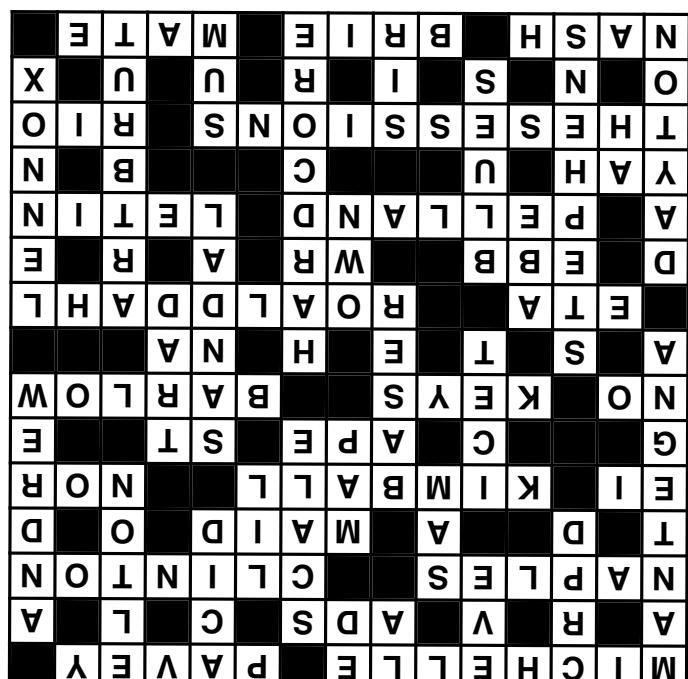


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## Crossword Puzzles



**SUMMARY NOTICE OF CLASS ACTION AND PROPOSED SETTLEMENT**

TO: ALL PERSONS WHO (A) HAVE AN AMBULATORY DISABILITY FOR WHICH THEY USE WHEELCHAIRS OR SCOOTERS, AND (B) BETWEEN THE DATES OF MARCH 15, 2009 AND THE DATE OF ENTRY OF THE FINAL APPROVAL ORDER AND JUDGMENT WERE OR WOULD HAVE BEEN UNABLE TO OBTAIN EYE EXAMINATION SERVICES AND CARE AT AN AMERICA'S BEST STORE DUE TO A REASON RELATED TO THEIR DISABILITY OR WHO WERE OTHERWISE TREATED ADVERSELY DUE TO A REASON RELATED TO THEIR DISABILITY.

You may be affected by the settlement of a class action lawsuit captioned *Luna et al v. America's Best Contacts & Eyeglass, Inc.*, Case No. 11-CV-01783 (the "Action") that is currently pending in the U.S. District Court for the Northern District of Illinois (the "Court"). The purpose of this Notice is to inform you of a hearing on a proposed settlement to be held by the Court at the Everett McKinley Dirksen United States Courthouse, Room 2503, Chicago, Illinois 60604, on February 6, 2013, at 11:00 a.m. (the "Final Settlement Hearing"). This Notice only includes a summary of various terms of the proposed settlement and does not purport to be a comprehensive description of the terms of the settlement agreement (the "Agreement"). The Agreement is available for review at <http://www.rsplaw.com/civil-rights/>.

**IF YOU ARE A SETTLEMENT CLASS MEMBER, YOUR LEGAL RIGHTS ARE AFFECTED  
WHETHER YOU ACT OR NOT. READ THIS NOTICE CAREFULLY.**

The Action alleges that America's Best Contacts & Eyeglasses ("America's Best") violated the Americans with Disabilities Act in its provision of eye examination services and care to persons using wheelchairs or scooters. America's Best has denied and continues to deny any liability or wrongdoing with respect to the facts or causes of action asserted in the Action. However, to avoid additional expense and eliminate uncertainty and risks from continued litigation, America's Best has agreed to settle the Action by entering into a settlement, as provided for in the Agreement.

As part of the settlement, America's Best has agreed to (a) install Chair Glides or Chair Movers in its Stores; (b) implement a procedure to survey its Stores to determine whether any potential issues exist related to the accessibility for individuals who use wheelchairs and scooters, and then remediate its stores accordingly; and (c) adopt policies and provide trainings related to serving customers and patients with ambulatory disabilities.

On October 4, 2012, the Court entered a Preliminary Approval Order preliminarily determining, for settlement purposes only, that the Action may be maintained as a class action on behalf of a class consisting of all persons who (a) have an ambulatory disability for which they use wheelchairs or scooters, and (b) between the dates of March 15, 2009 and the date of entry of the Final Approval Order and Judgment were or would have been unable to obtain eye examination services and care at an America's Best Store due to a reason related to their disability or who were otherwise treated adversely due to a reason related to their disability (the "Settlement Class"). The Court approved and appointed the law firm Robbins, Salomon & Patt, Ltd. to represent all class members ("Class Counsel"). Class Counsel will seek up to \$234,600 in attorneys' fees and expenses for work performed through final approval of the Settlement and will be entitled to additional reasonable attorneys' fees and expenses subject to a total cap of \$97,250 for work performed after the effective date of the Settlement.

The purpose of the Final Settlement Hearing is to, among other things, (a) determine whether the Settlement of the Action on the terms and conditions provided for in the Agreement is fair, reasonable, and adequate to the Settlement Class; (b) consider Class Counsel's petition for attorneys' fees and expenses; and (c) consider any objections of any affected persons as to the Settlement or Class Counsel's petition for attorneys' fees and expenses.

**YOU ARE NOT REQUIRED TO RESPOND TO THIS NOTICE UNLESS YOU WISH TO FILE OBJECTIONS  
OR BE HEARD AT THE HEARING.**

Any member of the Settlement Class who objects to the settlement or Class Counsel's petition for attorneys' fees and expenses may file a written objection in person or through counsel at the Final Settlement Hearing. For details on how to file a written objection, please see the Settlement Notice at <http://www.rsplaw.com/civil-rights/>. Written objections must be received by January 9, 2013.

If you properly serve a timely written objection, you may appear at the Final Settlement Hearing, either in person or through personal counsel hired at your expense, to present your objection in person. To do so, you must serve a written notice of intent to appear to the Court as provided for in the Settlement Notice at <http://www.rsplaw.com/civil-rights/>.

If you have filed a timely written objection, the Court will consider it even if you do not appear in person at the Final Settlement Hearing.

If the settlement is approved, Settlement Class Members will be barred from suing America's Best as well as other Released Parties, including National Vision, Inc., Consolidated Vision Group, Inc., Independent Professional Corporations (as defined in the Settlement Notice), and others, for any type of relief, with the exception of claims for monetary damages, regarding the claims in the Action (referred to as "Released Claims" and defined below). If the settlement is approved, all of the Court's decisions regarding the settlement will bind Settlement Class Members.

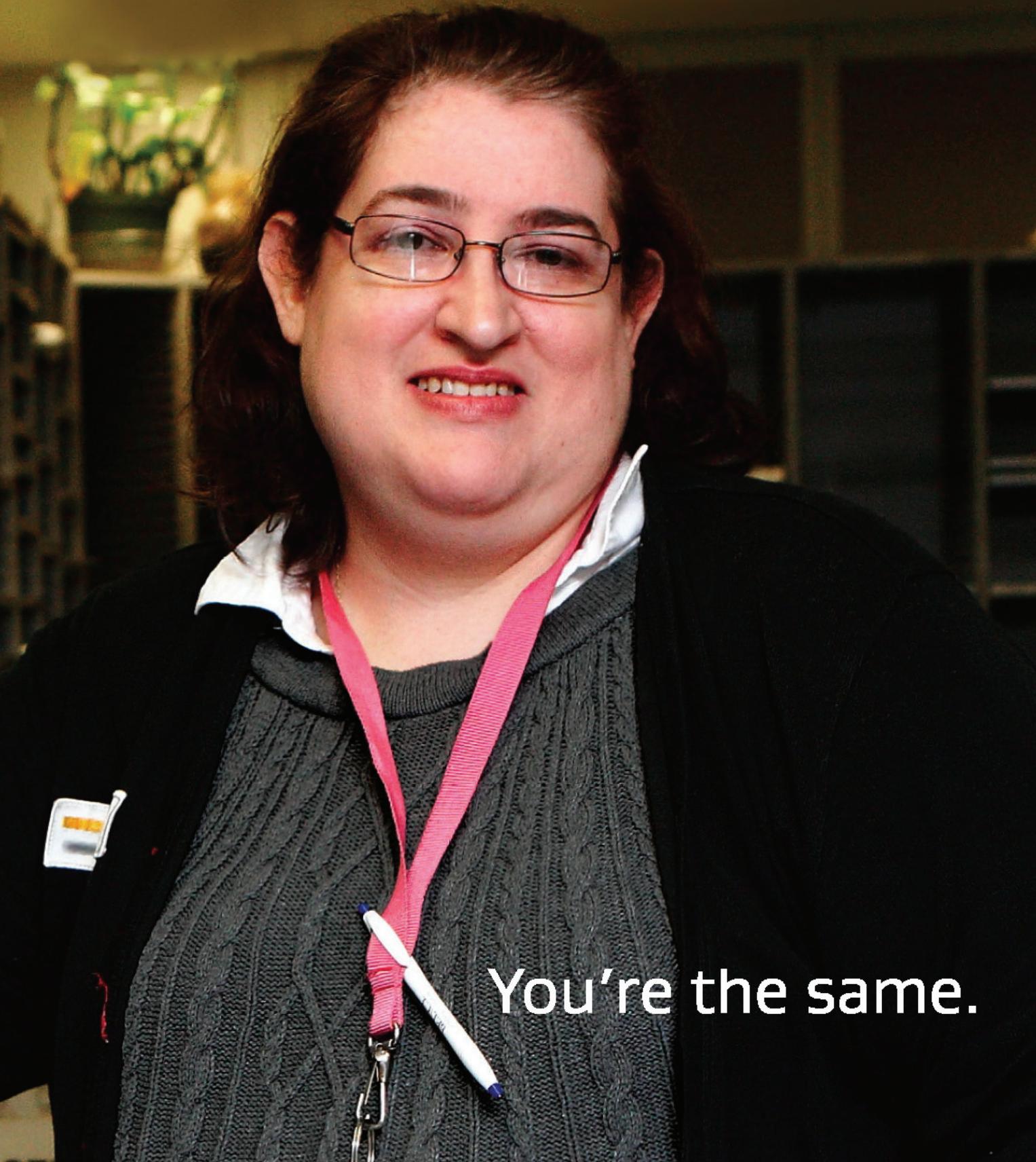
Released Claims include any claims for declaratory or injunctive relief, regardless of whether such claims arise out of state, local, foreign, federal, statutory, regulatory, common or other law or rule, which are based upon, arise out of, relate in any way to, or involve, directly or indirectly, (i) a denial of access to facilities, goods, services, or accommodations at the Stores; (ii) discrimination or harassment in the full and equal access to and/or enjoyment of facilities, goods, services, or accommodations at the Stores on the basis of the Settlement Class Member's ambulatory disability; (iii) claims for fees, expenses or costs incurred in prosecuting or settling the Action, or in connection with any claim for benefits conferred on the Class. Released Claims do not include the right to enforce the Agreement or claims for monetary damages.

More information, including the Settlement Notice, can be found at <http://www.rsplaw.com/civil-rights/>. For further information, you may contact Class Counsel at:

Andrés J. Gallegos  
Robbins, Salomon & Patt, Ltd.  
180 N. LaSalle St., Suite 3300  
Chicago, Illinois 60601  
Telephone: (312) 782-9000  
Facsimile: (312) 782-6690

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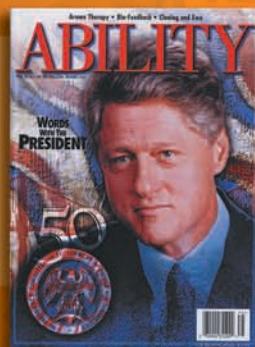
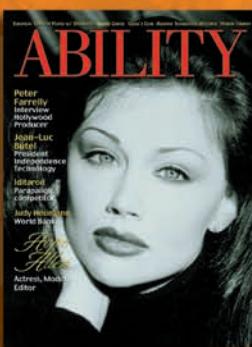
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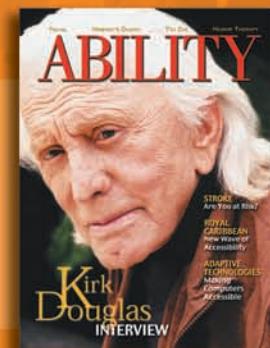
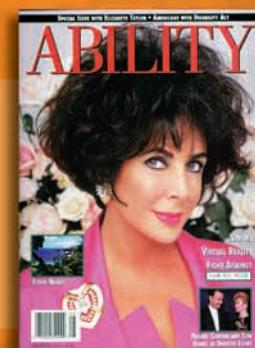
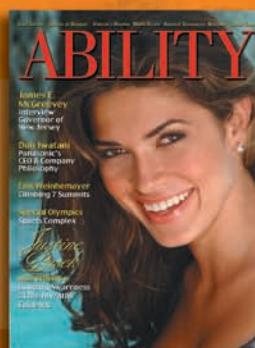
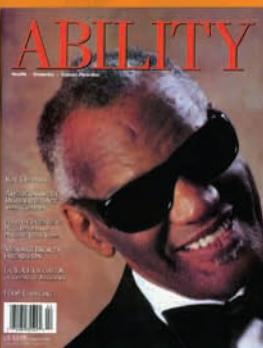
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