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WE'RE ALL IN THIS TOGETHER

Dear *ABILITY* readers,

In my three decades in the Congress, I have learned that the creation of a budget for our government is more than just an exercise in accounting. A budget is a document that reflects the author's vision of America: it establishes priorities and defines what kind of a society we want to have. That is why I am so deeply troubled by the budget introduced by Paul Ryan, the House Budget Committee chairman and Republican nominee for Vice President, which House Republicans have passed twice. The vision they have outlined for our country's future is truly frightening: a society in which our fellow Americans are left to fend for themselves, as programs that underpin our social contract are gutted while millionaires would receive a $265,000 annual tax break, on top of the $129,000 break they would enjoy through the extension of all of the Bush tax cuts. Of course, these giant tax breaks would not be fully paid for.

Meanwhile, the Paul Ryan budget would ensure that the people who need help the most would be hit the hardest. To partially offset these tax cuts for millionaires, the Ryan budget includes deep, draconian cuts to programs that strengthen the middle class, and the ladder of opportunity that allows Americans to work their way into it. Education, Medicare, financial aid for college, law enforcement, environmental and food safety, medical research, investments in our infrastructure—all of these are piggy banks that the Ryan budget would crack open for the wealthy. But that's not enough. The nonpartisan Tax Policy Center estimates that, under the Republican plan, middle-class families with children would see their taxes go up, on average, by more than $2,000.

For Americans with disabilities and their families, the outlook is even bleaker. The Ryan budget would turn Medicaid into a block grant, cut federal investment by $810 billion over the next ten years, and foist the entire program onto already-strapped state governments. Nearly half of Americans with disabilities rely on Medicaid for access to health services and supports that span from hospital to home. These services are vital, and allow our citizens with disabilities to live with dignity in their communities, and reduce healthcare costs by keeping nearly three million seniors and people with disabilities out of nursing home care and in their own homes. The impact of the Ryan budget cuts to Medicaid would mean more people with disabilities would be forced into institutional care, which is fiscally untenable, morally wrong and violates the spirit of the historic Olmstead ruling.

The Medicaid program is also a lifeline to hundreds of thousands of middle-class American families who have children with lifelong disabilities like Down syndrome and autism. Half of Medicaid recipients are children, many of whom have a disability, and these cuts would put the care they need out of reach. The future under Paul Ryan's plan is truly a place where families who need medical or respite care for their children will be on their own.

The country depicted in the Paul Ryan budget is not the America I know. The America I know is a place where we ensure that everyone has the opportunity to live up to their full potential. It is a society where we lift each other up, rather than tear each other down for our own gain. It is a country where we do not relegate people with disabilities to second-class citizenship. These are the stakes. We must choose the right path forward.

Sincerely,

Senator Tom Harkin

Senator Tom Harkin (D-IA) is Chairman of the
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I just wrapped up my last season racing the WMX (Women's Motocross) Outdoor National series. We had eight rounds of racing and our last race of the season was held at a track in Lake Elsinore, CA. At the beginning of the year, I announced that this would be my last season racing in this particular series, so I wanted to go out with a bang.

The first couple of rounds were going well. I wasn't leading in the points, but I was very close to my toughest competitor, Jessica Patterson. We had gone back and forth in the first races and she was now just a mere three points ahead of me. At the beginning of a series, this is not a bad place to be.

Previously, at round three in Colorado, things had gotten a little "rough" for me. I was riding well and having a good time, but in the second moto, the track was sketched out. I was coming over a big jump and I'm not exactly sure what happened, but everyone told me I "cross rutted" [when each wheel of the bike is in a different rut in the track, putting the bike in an awkward and askew position] when I came down and I was thrown to the ground, hard. I have had a few concussions since last year and when I crashed it seems I had another one. I don't even remember what happened; I was dazed, but I got up and continued to ride. Everyone noticed that I was not myself, but I kept powering on. I wound up finishing in an overall position of sixth place, but I don't even know how that happened. I was still down 16 points in the series, and things were not looking good for me.

I was taken to the medic and I was out of it. I hurt all over and I couldn't remember where I was or what had happened. They gave me oxygen and did tests on me. After that I went back to my hotel, but later in the evening I was brought to the hospital because it seemed as though I was getting worse. I had to delay my flight home for one day because the doctors did not want me to fly.

Round four was to be held in Mount Morris, PA, at a track called High Point Raceway, but before I could get back into the race, I had to take another concussion test. Before the season starts, each rider takes a pre-concussion test, which is basically a baseline so doctors know at what level your brain is functioning. There are no right or wrong answers; they just want to know if something is wrong after you've had a bad crash or a concussion. So I had to retake my test to see if I was ready to race again, but I kept failing. I was so upset that I couldn't ride or work out or do anything until I passed this test.

On the Friday before the race, I took the test again. I was feeling better and my memory was coming back, so I assumed all would be well. I took the test in the morning and then flew out to the track. On Saturday morning, the medics and doctors looked at my results and said that I would not be allowed to ride. I couldn't believe this was happening! It was to be my last year, and I wanted to win this championship one more time, but my chances didn't look good. Instead, I had to sit on the sidelines and watch my fellow racers take off from the start. I was so angry, so upset with myself and with everyone. After leaving High Point, I was halfway through the series, in fifth place over all, and 63 points behind Jessica Patterson. The championship was slipping through my fingers.

Before the doctors would even consider letting me race, I had more medical tests ahead of me. I had to see two different neurologists who ordered more complex tests than the ones I had already taken. Since I was in such a rush to get back to the race, and prepare for the X Games, I decided to test for over six hours in one day. I also had to do some physical testing. My results were good, but my symptoms were lingering; I still couldn't remember a lot of things. I was also nauseous and I couldn't eat. The doctors told me I would have to miss the X Games. So far, 2012 had been a very disappointing year for me.

The next race of the outdoor series was to be held in Red Bud, MI, at one of my fave tracks in my home state of Michigan. I look forward to this event every year, but would I be able to race? I was nervous about passing the pre-concussion test. On a Friday, the medics tested me

again and told me I was cleared to ride. Finally, the week before the race started, I was on my bike again. My practice mechanic, Brian, drove my bike up to Michigan where I practiced on some of my favorite local tracks. I was so happy. I showed up to race on Saturday morning and it looked as though Jessica was a bit off in practice, riding slower than normal and not doing all of the jumps. I heard from someone that she was riding with a broken hand. I wound up winning both motos at Red Bud and now I was back in the game. I moved up to third place, which left me only 26 points behind first place.

My next race was in Washougal, WA. I knew Jessica was doing better since she'd had a plate put in her hand. Jessica, Tarah and I all battled, but I was riding well and feeing good. I again won both motos. The championship was within sight once again—all was not lost. I was now 11 points away from first place.

Round seven was held in Southwick, MA, at Moto-X 338, a track that always worries me. It is sandy, rough and rutted. This track would make or break the week for me. I needed to win both motos, which was something I had never done before at this track. My good friends, Travis and Lyn-z Pastrana, came to help cheer me on. I was so glad to have them there because they helped to calm me down. I was nervous, but I knew that I would try my best and give it my all. When the racing was over on Saturday night, I walked out of Southwick with two more wins. I was now in second place, with only five points between Jessica and I.

Travis Pastrana showing support for Ashley

Heading into the last round at Lake Elsinore, CA, I didn't try to figure out ahead of time the point situation, I just knew I wanted to win both motos. Jessica, Tarah and I were all within five points of each other and we each had a shot at the championship. We were each going for it.

That day, practice felt good and I jumped this huge, 110-foot double, so I was pumped. I had the fastest qualifying time, so I was ready to race. I got the holeshot [the rider who is the first one through the first turn] and was off in the first moto. The world champion from Italy was there and she won the moto, while I

Ashley clearing a 110 foot jump during the Nationals at Lake Elsinore

came in second. I knew her points would not affect ours because she hadn't raced here before, and I didn't want to make a stupid mistake so I happily took second place. Jessica had hurt her ankle earlier in the week, so she held on to fourth place. Everyone rushed up to me after the moto and told me I was only one point behind. Oh my, to be 63 points down at one time and now be only one point behind—I could do this! If I finished in front of Jessica, I would win the 2012 WMX championship.

I was nervous on the second moto, but I also wanted to be done. It had been a long season and it was time to wrap it up. I got the holeshot again and then the Italian girl passed me. I was riding cautiously, because I knew how important this race was. I stayed in second place for most of the race, and then my mechanic wrote on the pit board that Jessica had pulled off the track. She'd landed hard on one of the jumps and tweaked her sore ankle, so she couldn't finish the race. I couldn't believe it. I was down to one lap. I let third place pass me and I was just taking it slow. I knew it was over.

At the finish line, I threw my bike down and went to hug one of my fellow riders. I then rode over to the podium slowly, and my dad and little brother ran over to hug me. I saw my mom and all of my friends and fans. What a great ending to a crazy season! ■ ABILITY

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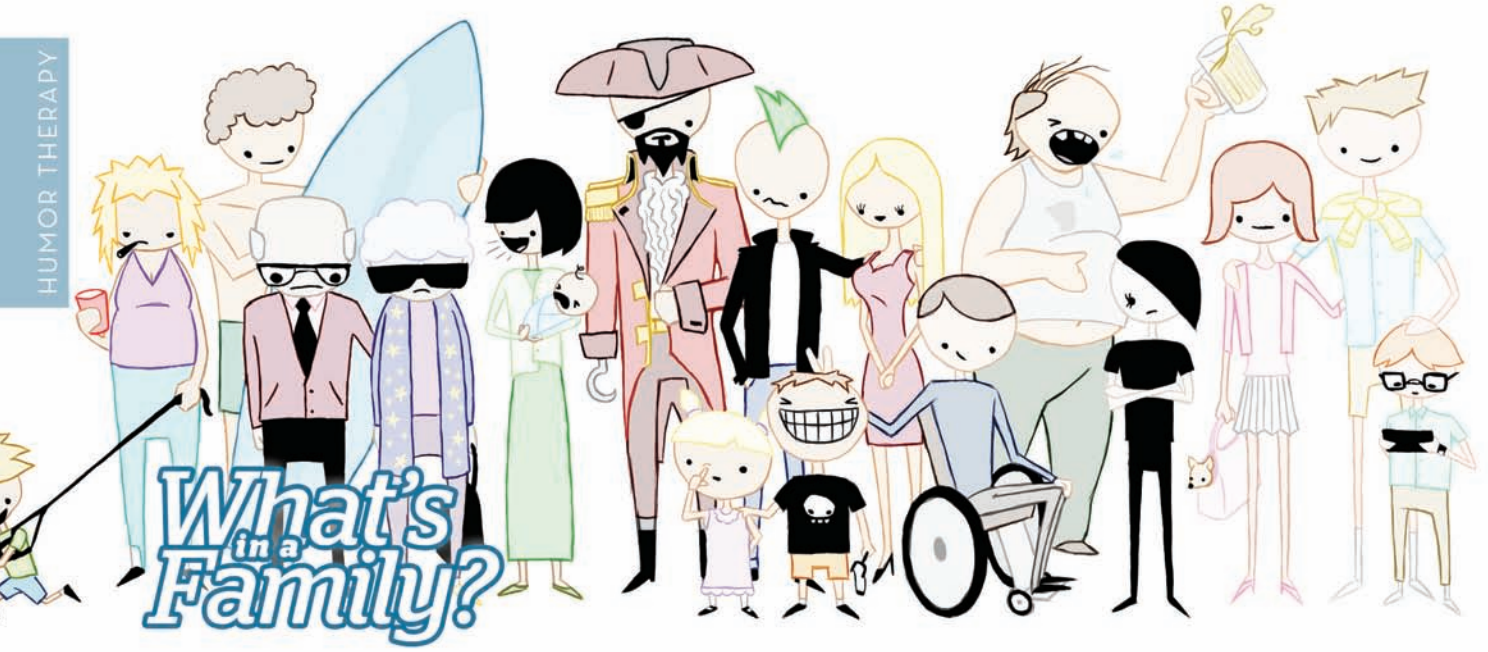

Every five years or so something happens in the family that brings all the relatives together. It's usually a wedding, funeral or holiday meal. Recently, my cousin got married so that put everyone together for a weekend.

Some of these folks I hadn't seen in ages. I attended many of their weddings years ago and now some were with a totally different spouse. I always remember their giddy faces at their ceremony when they couldn't keep their hands off one another. The groom would stumble over to me and drunkenly slur, "She's the only one in the world for me." And here he is with someone else and actually was married to someone else before that. So maybe, there are only three girls in the world for him.

The weddings themselves have become boring. It's like watching the same movie over again with a different lead. These days, marriages have a short shelf life. In all honesty, it would probably be more exciting to be invited to the divorce. Have the ole bride and groom get up and share a few words about one another...

HUSBAND: My grandfather used to tell me about living through the great Depression. (*LOOKS UP*) Grandpa, I was married to this… monster for six years. So I guess you can say I lived through my own great depression. People become doctors in six years. You'd think in six years she'd learn how to fry an egg. I gave her a diamond ring and she gave me herpes. I could never kiss my wife either. The wine bottle was always in the way.

WIFE: My turn. I never know when he's through talking because I finished listening to him the day after the honeymoon. What a fun time that was. The seal at Sea World performed better than he did. He would snore sweet nothings in my ear. But he was a good provider. Whenever I looked at our bank account it provided me with an excuse to end this lousy marriage.

Back to the wedding, I've noticed people can change a lot in five years. Thick hair becomes thin. Thin becomes gray. Then gray becomes bald. Smooth skin turns wrinkly. Wrinkly turns hairy. Muscles become flab. Flab becomes fat. Fat becomes "who cares?" It's strange how I haven't changed… he says wishfully.

Sadly, I don't even like to be around people to begin with. Throw in some crazy family members and I would opt to be lost at sea… probably less sharks there. I know, every family has their fair share of loony birds but why do they have to always sit by me at these functions? I just want to eat my chicken in peace.

You always run into that one relative who you didn't really know very well but you have one story you rehash every time you see them. "Remember when we were ten years old and we went into your mom's closet and put on her dresses and we were dancing around the house to the *Saturday Night Fever* soundtrack?" he says. "Yeah, that was… something," you say. Then you pretend that another family member is calling you over and you're like, "Hold that thought. I'll be right back. Aunt Selma wants to tell me something." Then you spend the rest of the evening avoiding that guy because he'll keep adding to the story. "… And then we were jumping on the bed in our underwear…" That one freakin' story is rehashed every time you see him. That's all he's got.

One cousin is the gossiper. All family information must go through her and be dispensed by her. She's the family filter and dispenser. She's always so nice and caring as you spill your guts to her. Then she passes out your guts to everyone. Then people come up and say, "I'm sorry, I heard about your guts." Then you get pissed because your guts were a private thing. Crazy. Some people have a lot of guts. On the flip side, whenever you want to know about someone's family business, she's the go-to girl. It always starts out, "You didn't hear this from me but…"

Every family has a drunk or two. They can be touch-and-go depending on what stage you catch them in. The fun, happy stage isn't so bad. Sentences get repeated a lot, but it's tolerable.

"I'm serious, you're my favorite one of everybody here. You hear me, you're good people," he slurs.

"Yes, I know Uncle Jack, you've said that a few times already," you sigh, looking for an escape.

"I'm serious," he responds fighting to keep his head still as he leans over and hugs your neck, his hot booze breath panting on your cheek. "Of everybody here, dammit, you're the best-est of everybody… here."

The other stage isn't so fun. The angry, slurry blurbs like, "You think you're better than me?" or the, "What are you looking at?" and, my favorite, "The hell I'm drunk!"

I've witnessed it and it's not pretty. A family without a drunk is like a bowling alley without shoes. I don't even know what that means.

"So what have you been up to?" gets thrown out a lot at these events. I've never had a good answer to that question. I always fall back on "Same old stuff." Besides, doesn't my Facebook page cover my news. The worst part is catching up on what their kids are doing. A lot of it usually centers on how well they're doing in college or on their new job. Later on I would find out (from the gossiping cousin) the kid's living at home because he just got out of rehab.

I'm not good with the small talk. My strong point is I'm a good listener and nodder of the head. I usually throw in a couple pithy phrases like "that's crazy" and "damn" just to assure them I'm listening to their boring babble. I'm very resourceful. Hey, whatever gets you by.

There's always that extremely insecure relative who was born to be a liar. Ever since you've known him, he's always been the king of bullsh**. The unbelievable thing is that he actually believes it. Whatever you say he's got a story to top it. If you told him you went to the baseball game the other night he would say he's best friends with the pitcher. If you told him you just bought a TV he'd tell you about the movie theatre he just purchased. He can't imagine that people can like him just for who he is. He's probably right. I must admit, I do enjoy some of his stories as he's such a creative chap. Where the hell is he when I need writing ideas?

Then there's always that guy, usually a cousin or an uncle, whose got his hands in some new money-making venture. And, it always seems shady. Every time you run into this dude he says he's raking in the dough. You can always count on a stock tip from him. The funny thing is that he usually drives a 15-year-old car with a couple dents in it. By the end of your conversation Uncle Ponsi is willing to bring you in on his "can't miss" business, but you can't tell anybody. All you need to do is break out your checkbook.

My favorite relative is the one who has always been in trouble since he was a kid. And I don't mean little things like throwing a baseball through a neighbor's window. I mean throwing a baseball through a neighbor's window, then climbing in and robbing them. And burning the house down. While growing up, every other month one of my parents would blurt out at the dinner table, "Your cousin Victor's back in jail." The only thing you could do is shoot your brother that half-snickered look because you've hung around with that cat and you know what he's capable of. Whenever you run into the hoodlum you size up his attire, wondering which items have been stolen. From day one this rebel was trouble… "ba ba ba bad to the bone." If he made a family event, it was because he was out on parole. The sad thing is his mom is really nice but you can just see the lines on her face from every traumatic delinquent ordeal her menacing kid put her through.

There are always one or two sluts in the extended family. Every function you meet them and you have to memorize a new guy's name. I'm not judging, I'm just saying. Of course, there's always the gay one, the fat uncle, the trashy aunt, the overly religious one, the nerdy oddball, all of whom I happen to love dearly. I usually stay in touch with the nerd in case something happens to my computer. One of my aunt's is big into kissing. Every time you see her WHAM you're blindsided by a wet, sloppy kiss. The worst part is her moustache tickles and she has that nasty cigar breath.

All and all, nothing crazy happened at the big wedding reunion. Sometimes at one of these events there's something to talk about. Something like, "I can't believe Judy slept with that hairy dude in the band," or "I can't believe Victor puked on the wedding cake." Nothing good like that. Maybe the next one. Sadly, everyone behaved.

Did I have a terrible time? No, it's always good to see familiar faces… even from the family. Anyone who once annoyed you, you can deal with it because you know you won't see them again for another five years. Then there are the ones you've lost touch with and you promise to call them more often. Hopefully, they won't wait by the phone.

Anyway, I'm alive. I survived another family reunion. I'll be at the next one. There's just something about being around the people you love when there's an open bar. ■ ABILITY

"Ham on a Roll"

by Jeff Charlebois

In this fast-paced technological world, Devis Inc. is making notable inroads. The female-owned company has won awards for its "Access Jobs" application, which is among the first of its kind to offer users accessible job-search tools across multiple platforms.

Recently, Devis' CEO Cristina Mossi and Project Manager Stephanie McLeod, spoke with *ABILITY Magazine*'s Chet Cooper about their new app.

Cooper: What motivated you to start Devis?

Mossi: Eighteen years ago I started with the company as a programmer, worked my way through the ranks, and then ran out of jobs, so I decided to buy the company about four years ago.

Cooper: So it was an internal buyout?

Mossi: Yep. *(laughs)*

Cooper: I looked at your website. It seems like your focus is government work.

Mossi: Yes. We focus mostly on federal work. When we started the company, we worked with the Agency for International Development, so we were very much international development focused, trying to leverage IT in that environment. It just naturally led to other populations that could use our help and that could use IT, which includes people with disabilities. Somehow it all seems related—in my head. *(laughs)*

McLeod: Plus, working internationally, we also have to think about usability and making things with open source, so it'll be a little cheaper. This really lends itself to working in the area of accessibility.

Cooper: I heard through the Department of Labor that you won the Innovation Award for Access Jobs.

Mossi: That's correct.

Cooper: Can you tell me a little bit about that?

Mossi: It's technically a widget, which is a little piece of an application. It's a mini-application that can live within other people's websites. The point of it is to collect information about jobs that you're trying to search for. It knows how to communicate with a custom Google search engine in the back that has spidered the web for jobs that are tagged in a particular way.

The innovative part of it is that the widget is lightweight, movable, and uses other technologies. It currently posts jobs, so you don't need a separate database. People don't have to register on our site to post their jobs. If they're already posted on their website or on an existing job bank, then Google will find them and bring

them to us, and then our widget has that API that can connect to it and bring them forward. And also present them in an accessible format, which was one of the key elements of the competition.

Cooper: Is the idea that the widget could be put on someone else's website?

Mossi: The idea is that it could be on the Department of Labor's website or the website of anybody who wants to offer a way of finding jobs for people with disabilities.

Cooper: Let's say we put the widget on ABILITY Magazine*'s website in an effort to hire people with disabilities; how does the widget facilitate that?*

McLeod: You would post your job the same as usual. You would have to give us your domain name, such as abilitymagazine.com. We then add your domain name to a list that the Google search engine will try to find. So you don't have to do anything—you don't have to post the job in the widget. You post the job wherever you would normally post it, and then you add a little bit of markup to it so the Google search engine knows that it is a job that you want to appear on the widget.

Cooper: So if you're posting a job on a job board—

McLeod: That job bank would need to be on the whitelist, which is the only caveat. USAJobs is one that's on the whitelist right now.

Cooper: So when you get on this whitelist, which is the opposite of the blacklist, I guess—

Mossi: Yes. *(laugh)*

Cooper: Then your widget has been configured in such a way that—

Mossi: It can find those job postings.

McLeod: So if you think about how a Google search engine normally works, it's looking for everything on the World Wide Web. With this, you enter your keywords into your search and it will only look for things that are on the whitelist.

Cooper: So it's looking through a specific filtered list, being your whitelist?

McLeod: Exactly.

Mossi: So your search results are going to be custom. They're not including everything out there, but a very specific list so that you don't have to search through nonsense, basically.

Cooper: So if you're a company looking to hire people with disabilities, and you're going to disability-specific job boards, is this also where you put the

Far right: Stephanie McLeod and Ben Wetzel of Devis, with other winning teams at the FCC Developing with Accessibility award ceremony.

tag? Or do you put the tag on all your jobs?

McLeod: If you were to go to a disability-specific job board and search for a reporter in Arlington, VA, for example, you would get a subset of information about all those jobs. It tells you the name of the position, the name of the hiring organization, the location of the position and all that sort of information. That's the information that needs to be tagged appropriately, so that the widget knows how to pull it up. Once the domain is on the whitelist, then any job posted to that website could get pulled up as a search result. The tagging is to allow the correct information to be brought forward to the user within this widget.

Cooper: So it's helpful to jobseekers with disabilities because it broadens their search capabilities?

Mossi: I think it not only broadens, but it also simplifies it in the sense that they're not going to get garbage from the generic Google search or a generic search and Dice. These would be jobs in which the employer has actually put some thought into it and said, 'Hey, we would like to hire somebody with disabilities,' and they have gone through the effort of putting their name on the whitelist.

Cooper: Is there a cost for the widget?

Mossi: No.

Cooper: So in a sense you're going to be competing against job boards that are helping people with disabilities find employment?

Mossi: No, because our idea is that we would promote those job boards and job banks. We have no problem with them being part of our whitelist. We're actually marketing to them, as if to say, 'Hey, put your name on here. If you're on our whitelist, then your jobs will be showing up in other places as well.'

The employers still have to post on those job boards and pay whatever fees. Job boards aren't free for the employer. But they will be free for the jobseeker. And if their board is on the whitelist, then they're going to have a broader distribution of those jobs for the seekers, so they'll get more visibility. And if they're trying to reach a particular population, and they're looking through our widget, then they're going to get a faster hit. That's how we view it. So there's no cost to us or to the jobseeker. And the employers are still using their same mechanisms. So if they like to use Dice, for example, then Dice puts their name on the whitelist at no cost to them, and it's basically just another marketing angle to have those jobs out there.

Cooper: I think I get it, except Dice is not disability-centric.

Mossi: No. So if the jobs in Dice have these tags, here's where the employer can say, 'Well, if I'm trying to target this audience, I'm going to go that extra step of putting it on the whitelist and put in these tags.'

McLeod: Right. If they don't have these tags, it's not going to get pulled up by our search engine. The search engine would find it just because it's on the whitelist, but it won't find any information to pull up to the user, so it won't be displayed.

Mossi: The ones that are tagged are the ones that are going to get filtered into the search. That way you can sort of filter through the ones that are tagged and not tagged, and the ones that are tagged really come to the front.

Cooper: And the name of the widget is Access Jobs, and you'd get the widget from that site? Or do people have to go there or use a code to get the widget on their site, and have it link to the page that you have up now?

McLeod: Actually, the widget is designed to fit inside an iframe, so that the widget will be hosted at a website. For people who want to have the widget on their web page, all they have to do is create an icon on their page and link it in a hyperlink to the live site. Does that make sense?

Cooper: I think so.

McLeod: You don't need code. Anybody can go in and link to it.

Cooper: And will job boards specific to disabilities need that?

Mossi: No.

McLeod: They probably won't want to put this on their site because that would be redundant. The bigger issue

is that they would want to be on the whitelist, and then organizations, such as the Department of Labor, could use the widget, one-stops that have a website could use the widget, or other sites that are trying to help people find jobs could use it.

Cooper: Who came up with this idea?

McLeod: We did something very similar for a veterans' job bank. It's part of the National Research Directory. It uses the same concept in which employers have to get on the whitelist and mark up their code if they specifically want veterans to apply for these jobs. But we added another layer: Aside from changing it to be for employers who are looking to hire people with disabilities, we incorporated some responsive design aspects, which increases the acceptability of it by allowing the site itself to display appropriately, no matter where you're viewing it. If it's a widget on somebody else's web page, iPad, phone or in Firefox, IE, or Chrome, for example, the page is going to look the same.

Cooper: That's the accessibility component that you're talking about, then?

Mossi: That is part of it, to try to make sure that it's device-aware so that it basically shows up correctly, depending on the device it's on. So it is responsive, and tries to figure out what you are using, what size screen you have, and then adjusts itself so that it looks the best it can on that device.

Cooper: What about for voice activation? Is it set up so that someone using Jaws can navigate through it?

McLeod: Absolutely. It allows users with a keyboard, mouse or voice to navigate through the website. It'll work with a variety of technologies.

Cooper: Do you find that the larger social platforms, such as Facebook and Twitter, are as accessible as they can be?

McLeod: No.

Mossi: No. *(laughs)*

Cooper: Have you thought about building a widget that helps social media become more accessible?

Mossi: Yes, we've actually played with YouTube already, trying to make it more accessible. We did a prototype of it a year ago, mostly because some of the controls were not really keyboard-accessible, and they weren't tagged very well, so we put a little layer on top of it to make sure that it was compliant. So it would be a great idea to investigate other social media tools and see what we could do with them. ■ ABILITY

自闭症原生艺术家：天真者的像

THE INNOCENT: ARTISTS WITH AUTISM

They are a group of artists with autism, and their art could almost be classified as *art brut*, a French term meaning “raw or rough art.”

Art brut was a label coined by artist Jean Dubuffet in 1945 after visiting mental hospitals in Switzerland,

where he was deeply moved by the patients' paintings and sculptures. He considered their work, created outside the boundaries of mainstream culture, representative of a more magical side of art.

China acknowledged a form of *art brut* in 2008 when the United Nations established April 2 as "World Autism Awareness Day," highlighting the need to improve the lives of those with the condition.

The country recently held its first autistic children's art exhibition in a remote gallery in Beijing's 798 art district. The event lasted only a day. Viewers expressed delight with the imaginative artwork, and more impressed that the artists were children with autism.

Autism is a developmental disorder that makes communication and social interaction difficult. It affects about 8 to 15 people in 10,000, and there is an upward trend, according to international statistics. There are more than one million autistic children in China today. While boys are three to four times more likely to develop the

condition than girls, no one yet knows what causes it.

Children with autism develop differently, and show their value in distinctive ways. For instance, works by autistic artists are full of raw, creative energy; they're innocent and direct, which comes from a pure heart. The style seems to suggest that we can return to our own innocence. Although their purity and creativity surprises us, it also reminds us of our shame: For too long mainstream society has trapped, ignored and misunderstood the talents of those with autism.

As Picasso once wisely observed: "It took me four years to paint like Rafael, but a lifetime to paint like a child."

■ ABILITY

by Zhang Li-jie

SPRING BREEZE

chinadp.net.cn

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*.

Because I was on a sitcom called *The Facts of Life*, and because I know the actress Lisa Whelchel, I have received tons of e-mails asking me if I am aware that Lisa will be on upcoming episodes of the CBS reality series, *Survivor*. Well, of course, I was aware of it, and I support Lisa 100 percent. On another note though, I have been asked if I would consider doing Survivor as well. Truthfully, I thought of doing it quite a while back, and there are many directions we could go in.

For example, the show could feature only people with cerebral palsy—among others, RJ Mitte, Josh Blue and Tom Ritter. Again, we could broaden the spectrum and have the competition include all people with disabilities, although the athletes would have an unfair edge against those like myself. So, how could Survivor embrace people with disabilities and be totally fair?

Well, why not have six people with "real" disabilities compete against celebrities who have to simulate a disability and not sway from the disability that they have been assigned. For example, Heather McDonald would have to do her impression of "Cousin Geri"; Rush Limbaugh would have to have electrical tape across his mouth and one arm taped to his torso; Charlie Sheen would have to be blindfolded; Simon Cowell could only speak with a talking board and with one finger on each hand tapped down; Kris Jenner must wear a 200-pound fat suit and have no access to Botox; and Tom Cruise must be a wheelchair user and have no access to the Church of Scientology. Who would be the winner here? Probably Charlie Sheen, because even if he lost, he would no doubt spin it into a profitable self-marketing blitz.

Truthfully, those of us with real disabilities could easily out-survive these celebrities on an island any day, because the real winners in life are those of us who have always been survivors and are recognized for our abilities and not our disabilities. Those of us who are the real survivors in life include among many others: Michael J. Fox, Josh Blue, Marlee Matlin, John W. Quinn, The Push Girls, Stevie Wonder and Gabrielle Giffords.

All in all, winners in life do not see themselves as victims and know deep down that their greatest attribute is maintaining a positive attitude. The real disabilities in life are not the human conditions that challenge us, but the learned conditions that can destroy us: hatred, prejudice, abuse, deception, greed, hypocrisy, false pride and despair.

To survive in life, we must also keep strong in spirit. We cannot give up in the face of hardship. We must have compassion and empathy for others, as well as a good sense of humor. Because if we cannot laugh at ourselves and see the humor in any given situation, then we will become bitter. "Occupying bitterness" takes a lot of wasted energy; "occupying happiness" takes courage and perseverance! ■ ABILITY

by Geri Jewell

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Golfer Matt Lees

Golf has been a progressive experience for Matt Lees, just as it is for most people who play the game. There was no ah-ha moment for Lees when his scores dropped dramatically. But the patience he has shown—and consistent improvement—since he was 11 years old has him now playing at a professional level.

This year, Lees spent spring and summer as the assistant golf pro at Pala Mesa Resort, just north of San Diego, CA. His daily job includes giving private golf lessons and working on his game. He is on staff with Cleveland Golf as well, so he uses the company's clubs and attends demonstrations to other golfers.

Bottom line: Lees plays a lot of golf, and gets paid to do it. He's living his dream, but it hasn't always been par for the course.

"It's definitely been a very big test of patience," Lees said. "It's hard for me to explain to people how straining it is on the mind sometimes, just with controlling my emotions in times of patience and having the mental fortitude to keep going. But at the same time, I have plenty of drive to want to do it."

Lees was drawn to golf because of the sport's difficulty. It's an individual game, and Lees knew that if he could succeed at golf people would have less reason to question his physical abilities. Lees was born without a left hand and faced his share of difficult times as a kid growing up in Philadelphia, where his peers often poked fun. Golf, however, allowed him to seclude himself, away from the questions, stares and remarks.

"The reason I got into golf is still kind of the reason I keep doing it right now," said Lees, who also played Little League baseball and soccer but always went back to golf. "When I was a young kid growing up, sometimes people would give me a hard time about it. I was a pretty good athlete. Golf caught my interest because it was the hardest sport. I thought if I can beat somebody in golf, then that was satisfaction in itself, and that was one of the things that drove me to it."

Lees swung a club with his right hand only and mastered the technique. As he grew older, he began trying to create a sleeve and prosthetic hand to add greater power to his swing. After about seven different setups, he partnered with Dudas Diving Duds, a scuba-diving shop in West Chester, PA, near his home. The final product was created with fabric similar to a scuba-diving wetsuit. The hand area was a round metal slot below the wrist where the golf club grip was inserted. Velcro strips held the sleeve in place.

Once Lees got adjusted to the new sleeve, he began booming the golf ball. He increased his drives from 120 yards to 185 yards. Frustration, however, set in. "Actually, it made me a little angry because when I finally got a device that worked and started playing with it, when I hit the ball it upset me more," Lees said. "I could hit it well and see how I could hit the ball with that prosthetic, but I would think about what I would have been able to do with two hands."

Lees' father, Jim Lees, said he can see that his son still wrestles with his disability at times.

Performing has been a natural talent for Lees. He used to deliver inspirational talks as a teenager, and one even spoke to the PGA. Golf also gave him confidence in his abilities. He said he didn't mind it when people stared at his prosthetic hand because it gave him a platform to promote what he could do rather than what he couldn't.

Lees decided his platform needed to be larger, so he packed his bags and moved west to attend the Professional Golfers Career College near San Diego. The program serves a dual role by helping students improve their game to a professional level while also educating them on working in all areas of golf course management. The finished product is a degree in professional golf course management, which gives students the credentials to work in all positions at a golf course from course maintenance to lessons to the business side of running the pro shop.

During his time at the school, Lees decided to abandon his prosthetic and go back to swinging a club with one arm.

"One, the prosthetic never felt like a natural part of my body. Two, it was a lot of hassle when I was playing," Lees said. "The materials would make me sweat a lot and putting it on and off all the time was a hassle for me. I put it aside and worked at the driving range."

"With that device, I can bomb it with anybody out there, probably 300 yards," Lees said. "The way I'm golfing now, I swing one-handed and it's a little bit easier for me. I feel like I can play just as good or better one-handed as I did when I had the device.

"When I first started without it, my scoring average playing with the device and playing without it was a difference of four of five strokes. The device definitely helped me hit the ball further, but it didn't necessarily help me get the ball in the hole with less strokes, which is the name of the game."

Lees shoots in the mid-70s now with a 4-handicap.

"I play as a right-handed golfer, so it's like a forehand if you're playing tennis," Lees explained. "Actually, just the dynamics of the swing and the technique that I use, really what brings the club down to the ball is centrifugal force. I swing really slow. My swing comes down to the smoothness and the tempo and the timing of getting the club into position at the right time. You'd be amazed to see how easy you can swing with the right technique and how far you can hit the ball."

Lees aims to play golf for an audience, whether that's on a national or regional tour or hosting exhibitions while representing a golf company.

"People are amazed he can hit the ball close to 300 yards and consistently," Jim Lees said of his son. "He has a lot to offer, and hopefully he'll get his satisfaction out of helping other people play the game of golf."

Jim Lees said he and his wife, Laurie, will continue to support their youngest son's dreams. They know he wants to play competitively. In fact, Matt Lees is in the beginning stages of the three-year process to obtain a PGA Tour Card.

"I want to have an audience that will watch me hit golf balls and get some kind of motivation or inspiration out of it," Lees said. "I get a lot of satisfaction out of watching people's reaction to what I can do. I also know that I am leaving something in those people's minds—a little inspiration or something. They're going to take something away from that day and see what is possible."

Lees has come full circle from gravitating toward golf in order to get away from other people to now striving to play golf so others can watch him—and be inspired. His aim is that others will see him play and know their dreams are reachable, too. ■ ABILITY

by Josh Pate

palamesa.com/golf
View interview: lees.abilitymagazine.com

ONE MAN WITH MS ONE MILLION MILES

LONG HAUL PAUL

When the call rang into the bluetooth in Paul Pelland's helmet, he was in the middle of the infamous 2003 Iron Butt Rally with some of the best endurance riders in the world. The rally spans the continental United States, and challenges the 100 chosen entrants to ride 11,000 miles in 11 days.

The competition tests a rider's capacity to stay in the saddle hour after hour, fighting severe sleep deprivation, extreme heat and cold. The Iron Butt Association, aka "rally bastards," sadistically plan a route that takes riders through places like the Mojave Desert at high noon, and then sends them up a muddy 14,000-foot road to frigid Pike's Peak in Colorado.

But Pelland was feeling good. For the moment, he was in first place, and then the call brought even more good news: He'd been awarded custody of his two young sons. But the legal work on that would take several more weeks, enabling him to finish out his ride without worry.

But as Pelland continued on the third leg of his rally through Florida, he noticed a persistent numbness in his hands. The sense of being one with his bike—a mindful bliss that he so cherished—disintegrated. Then he came across a downed rider who turned out to be a friend whom Pelland knew well. But as he looked down at his fallen friend's face, he could not remember the man's name.

In Part I of a two-part interview, Pelland tells *ABILITY Magazine*'s contributing editor Christopher J.B. how an unexpected diagnosis changed the course of his life.

Christopher JB: Can you talk about the Iron Butt Association?

Pelland: The organization started out small and is getting bigger. They have an annual conference and do certified rides all across the world. It's a club that anyone can get into, by documenting what's called the SaddleSore 1000. Basically you have to document where you went in a 24-hour period, and you have to have done 1,000 miles or better. You submit all that information with an entry fee of $25 or something like that, and they put the information into their computers and can tell if you're fudging. Actualy there are lots of other organizations who run these kinds of long-distance rallies as well. There are probably 50 different rides across the country. Most are 24-hour rallies, benefiting different charities.

If all your information is proven to be correct, you'll receive a certificate and a little license plate bracket that says, "Iron Butt Association: World's Toughest Riders." Then you're a member. And once you're a member, you can enter any of these other events. I've done a lot of them; in fact, my first rally was called the Butt Light.

JB: (laughs)

Pelland: It was a long, seven-day, 7,000-mile rally. And when they say 7,000 miles, that's just to give somebody an idea of what the average rider will do. You don't have to do the 7,000. You might be able to do the rally and end it in 5,000 miles. The winner might do it in 9,000. It's just to give people an idea that you're not riding 50 miles a day and having cocktails at night. This is really different. These are people who push the bike and themselves to the limits. And it's all for a plastic trophy. There are no cash prizes for any of these events, other than a trophy for some of the bigger rallies. But that's it. It's a camaraderie of the top long-distance riders in the world.

JB: According to the Iron Butt website, there are only 53,000 members, yet only 100 are chosen to compete in the Iron Butt Rally. Why are so few selected?

Pelland: It's a lot to manage. It takes them two years to actually plan each one of these rallies because of the logistics: If you have 100 riders doing 10,000 or 11,000 miles, that's a million miles of riding and a lot of things can happen. Most of these bikes will need tires at least once. Some people start the rally, and then drive by their home, stop for a rest and never finish because they can't get out of bed. People rarely ride together or even see each other except at the mandatory checkpoints.

JB: Do you ever partner up or do you prefer to go it alone?

Pelland: It's really hard to ride with somebody else because you're trying to make the best use of time; maybe your bike needs gas at 300 miles and theirs can go to 350. If they have to stop every time to accommodate you, they've stopped 50 miles sooner than they needed to, cutting their chances of covering a greater distance and getting, maybe, one more bonus that day than you. There's nothing worse than being late. And you're always late on a rally. You have to stop if somebody else needs toothpaste or something. I can't do it. The people that do it, all credit to them, but it is difficult to ride with another person.

JB: The goal is to stay in the saddle as long as you can, while managing your sleep, diet and navigation strategy better than anybody else manages theirs. That's how you win, isn't it?

Pelland: Right. There's no way that anybody could ride at warp speed for days on end. It's impossible. First of all, your bike's fuel mileage is going to drop by almost 50 percent, and the alertness that you need riding at a high speed wears you out so much quicker. It's just impossible. You know, if the rally was an hour or four hours long, maybe somebody could ride at top speed, but it's just impossible to do that for long periods of time.

The other thing that these rallies do is make sure people ride safely. They're usually mandatory sleep bonuses, which means you basically have to document that you've stopped somewhere for four hours without putting any miles on your bike. That could be having a witness and having a receipt at a gas station that shows one time and then getting another receipt at the same gas station four hours later to prove that you didn't move. They usually make those bonuses either mandatory, or so high in points that if you don't get them, you won't be in the top 10.

JB: How do you get bonuses?

Pelland: A lot of them require taking a photograph. When I used to do the rallies, it was back when you had a Polaroid, so you'd have to take a Polaroid of whatever the item is. The bonus may say, 'Go to such-and-such a street, and on the left-hand side of the street there's a plaque. The plaque lists a person who was in World War II. Take a picture of the plaque and take a picture of the year he passed away.' So you ride 600 miles to this one bonus destination, and you take out your flag. Everybody has a rally flag given to them the day of the rally, and it has a specific picture on it that no one else has, and then it has your number. So there's no way to fake the picture. So you put your flag next to the sign and take the picture. Then you write down in the rally book the time, the date, the mileage, and the answer to the question. You make sure your picture's good, and that you can see the item and the flag, and then that bonus is good, and you head to get your next one.

Right after jumping across a washed out road near Bull Frog Marina Utah, after riding the famed Burr Trail

When you get to the checkpoint, you hand in your digital card —I used to hand in my photographs—and your rally book, and they'll go through it and score you at the table. A lot of people either forget to put their flag in the picture, don't put down the date, include the wrong sign. And that's how tons of bonus points get lost at the table.

JB: Such simple mistakes are probably owing to sleep deprivation and road fatigue, because the endurance part of this rally sounds no less challenging than, say, competing in a triathlon, which clearly doesn't have the same danger quotient.

Pelland: There are all kinds of safety meetings. It is dangerous. Riding a motorcycle is dangerous, and pushing yourself and the bike to its limits is dangerous. You need to know your body. You need to know your skills. You need to know when it's time to pull over and take a break.

JB: So let's go back to that summer of 2003, when you're in the middle of an Iron Butt Rally and you received news that, after a bitter divorce and years of a child custody battle, you've finally been awarded custody.

Pelland: The last court hearing was right before I left for the 2003 Iron Butt Rally. It just so happened that we had the court hearing in June or July, and it always takes them six or eight weeks to come out with a ruling. So by then, I was in the third leg of the rally in Baton Rouge, LA, when I received the phone call from my attorney. I started crying. I couldn't see. I know at that point I definitely pulled over, and I was just an emotional ball of nerves and everything started going through my head. OK, now what? I never thought it was going to happen.

JB: And then, on the heels of that elation, and being in first place in the rally, something was going wrong with your body. Talk about your emerging symptoms.

Pelland: I don't remember a lot of that day. I showed up in Florida. I don't remember the exact checkpoint, but at that point in the rally, I was actually in first place. I had collected the most bonuses up to that checkpoint. But when I arrived, I was quite confused. I had all kinds of cognitive issues as far as remembering the day before.

JB: There's so much planning and thinking involved with these rallies, which must have really made it doubly scary for you when the problems started.

Pelland: I knew I was supposed to get tires there. I didn't remember if I got my bike to the dealership or not. The organizer and rally master of the event, Lisa

Landry, said, 'Paul, you look like crap. You need to go to your room right now.' I had a room reserved at each of the checkpoints. She said, "Don't even bother coming to the riders' meeting." The riders' meeting is a mandatory meeting where you get the bonus packets and any information about the last leg, along with your point standings. All this is given out at each one of these checkpoints during the 11 days. She said, 'Don't even come. Do not come. You go right to bed.' So I did, and I don't remember when I ventured out, but I was then told that I was in the lead.

I don't remember much of that day. I had shared a room at the hotel with a fellow rider from New Hampshire, because that's what you do: You split a room with somebody else, since you're usually only in there for three or four hours at most anyway. I had seen him in the room, I remember that. It was Lake City, FL, I just remembered the checkpoint.

JB: And even after a decent rest, the problem didn't go away. You still felt as if your brain was being attacked by something.

Pelland: I slept late and left a few hours after everybody else had gone, because they had all received their bonus packets and had done their mapping and figured out where they were going for the last leg. I got my rally book and I looked at it, and I really couldn't understand it. I couldn't plan the next leg. So I basically did the simplest thing. I picked the biggest bonus, and just headed toward it in Key West, FL. It was kind of a sucker's bonus, but it was the only thing I could do. I literally could not figure out where to go.

So I got my bike and there was something wrong with the bike. I knew I had hit a big pothole in Death Valley a couple of days earlier and bent the rim, but I had the tires put on, and I stopped at the side of the highway, which is not really safe. I felt like the tires were on backwards or something. My hands were vibrating and tingling. It was hot, and I thought I was rally-fried, which is a fatigue you get from being in the saddle 20 hours a day for five, six, eight days straight.

I thought my feelings were due to the rally, and to the fact that I knew it would be my last one, given that I had won custody of my boys. Besides the fact that competing is dangerous, I wouldn't have the time or the money to be away from them.. So all these things combined added to my stress.

I came across a motorcycle accident. The bike was upside-down in the ditch, and the rider was on the ground. It didn't look fatal, but part of the rules of the rally are, if you come across an accident, you have to stop, and if it is a rider from the rally, you have to stay with them until help comes. You also have to report it to the rally master to make sure they can get people out there, and make sure the family's notified. So I stopped, and I looked down at this rider, and I knew who he was, and [the rescue crew] asked, "Do you know who this is?" And I said, "Yes, his name is—" and I couldn't remember his name. I'm looking at him and he's looking up at me. I think he had a split lip, but other than that, his face was crystal clear, and he said, "Paul, it's me!" And I'm looking, and I had to actually walk away, because I was embarrassed, and I didn't know his name. And then I came back and I remembered that we all have nametags on our chest and I grabbed it off his jacket.

I then called into headquarters and I said, "So-and-so is down, rider number X." And the person at the other end of the phone said, "Oh, that's Bob." So I turned back to the scene and I said, "His name's Bob," and then I remembered his last name. He was the guy that I had actually shared a hotel room with the night before. So I left there, and I was just floored that

AMPYRA® (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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- constipation
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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).

Aux lights, gps, laptop, cellphone, radar, music, custom bars risers, seats, all add for better long distance travel.

I was looking straight at this man that I know very well and couldn't recall his first name. That haunted me the whole rest of the rally.

I got down to Key West and then from there it was up the Blue Ridge Parkway to Maine. At the next checkpoint, my hands were shaking, numb and tingly, so much so that I couldn't even sign in my score. Somebody had to help me with my points. By then, I had dropped quite a bit in the point standings because I didn't pick a good route.

From that point, I ended up talking to a few riders and picking a better plan for the next stretch. We headed up to Nova Scotia and did a bunch of bonuses up there, and then we all took the ferry back across to the States and continued down I-95. But at one point, I was riding with a rider, and he had an accident on the highway, and this time I ended up staying with him. We went to the hospital and spent a long period of time there, and then I got a cab and we ended up getting a hotel room. I picked up his bike and brought it back to the hotel. He had a broken toe. In the morning he was going to head home, and I convinced him to at least try to finish the rally. He ended up finishing.

I knew at this point that I wasn't competing to be the top rider. I just wanted to finish and then go on with what the plans were for the rest of my life. I was also having trouble concentrating and the confusion and the problems with my hands. I ended up coming in ninth place at the finish.

JB: That seems great with all the stops you made and the problems you had.

Pelland: It was good. I was pleased. But again, my hands had no strength at all. It was months after the rally and I couldn't squeeze nail clippers. I worked in a trade, with my hands and tools, and it really bothered me. Like any other guy, you know, you don't go to the doctor until something's bloody or has fallen off.

JB: That's a man thing, for sure.

Pelland: It was two years later when I was diagnosed, but up until then I had started to really get scared. I thought I maybe had dementia, Alzheimer's or something, because I couldn't remember people. I'd see somebody in the morning at my shop and somebody would come in in the afternoon and I wouldn't recognize that they were the person that was there in the morning.

JB: So it was more than just forgetting names, you were forgetting faces too.

Pelland: I was forgetting the whole event, that they were there, and that they had dropped off something to be repaired. And when they said, "Remember I did this?" I would fake it, but I really had no recollection. I had other issues where I'd call to order a pizza, and they'd say, "OK, what's your phone number and address?" And I could not recall my own phone number. I had it written down in my pocket, and it's a phone number I'd had for six years. I would order things and fill out the form online and have it shipped, and it would end up at a house I was at five, six years ago. And then every time I'd write my address I'd second-guess it … It's the short-term memory stuff.

I used to travel around the country, I've been in all of the lower 48 states, but if you give me directions that have more than two lefts and rights, I will not be able to get there. I will get lost. I write it down. I use a GPS everywhere I go. I use a GPS every day on my way to work. I can look up in my daily travels and just look around and not know exactly where I am. I know

that I'm on my way to work, but it looks like a place I've never been before, and I see it every day. It's a scary thing.

JB: Very scary.

Pelland: So those were the things that brought me to the doctor—actually, there was one event. I had just gotten engaged in the spring of 2005. I was in a Staples department store with my fiancée, and I saw a woman I knew from when my son was in Cub Scouts. I knew I wasn't going to remember her first name, but I couldn't avoid her. She saw me and she came over and said, "How're you doing? How's everything going? How's your son?" I said, "Well, great. I'd like to introduce you to my fiancée. This is—" And I'm looking right at her, and I could not recall my fiancée's name. What do you do at that point? I was horrified. Of course my fiancée put her hand out and gave her name, and I turned away and thought, 'Oh, my God.'

That's when I decided to see my primary care physician. He didn't think there was anything wrong, but he said, "I'm going to send you to a couple of specialists to rule out any kind of crazy stuff. It's just the stress. You're a single dad now and you've got all this stress going on. That's what's causing it." He thought I might have had carpal tunnel with the problems with my hands.

JB: So when were you able to get an accurate diagnosis?

Pelland: I was diagnosed with Multiple Sclerosis (MS) in 2005. At first the doctor told me, "I think maybe you have ADD or something like that, but I want to do an MRI, just to rule out anything else. I see some things, but for the most part you just seem distracted." We did the MRI, and of course he gave me a call and said, "Well, there's some stuff on there that's not good." He told me there was a possibility it was MS or a series of strokes that I had had. Either one didn't sound too great to me. He said, "We'll have to do a spinal tap to confirm it."

The day of the spinal tap, I sold my rally bike. I was driving my kids everywhere, so there was no time or place for a motorcycle. And I was OK with that, because I knew what I had to do. But the day that I went for the spinal tap, I was looking online and I found a motorcycle for sale, a touring bike. With my fiancée's blessing, I said, "You know what? If I'm going to have MS, I've got to get back on a bike and ride every single day while I still can." So when I left the spinal tap, I called my buddy up and said, "Look, there's a bike down by your house. If you think it's half as good as I think it is, then buy it and I'll come down and pick it up and give you the money for it this weekend." He picked up the bike for me and I start riding again, just commuting and that type of thing. But I really felt that my time was limited and I need to ride as much as I could.

JB: So you received your diagnosis, bought another bike, and from there your mission evolved. You vowed to ride one million miles with MS, a one-man journey, which is definitely endurance riding. What, exactly, does endurance riding give to you that nothing else can?

Pelland: It's funny. It always stems from the same thing. I started long-distance riding probably in 1998 or '99, after being in the middle of a horrible marriage. I would come home after working 8-, 10-, 12-hour days, and I would jump on the bike and just ride until the tank was empty and come home and everybody was asleep, and I'd leave in the morning and go to work. I found myself riding hours and hours just to make things go away. And it worked. It allowed me to survive mentally. That's how I really

The box is a 5 gallon aux fuel cell, allowing better range. Gives peace of mind in the middle of the night, and less stops each day.

started long-distance riding.

So let's go forward to 2011. My oldest son has graduated college with a master's degree. My youngest is just finishing his senior year in high school, when he starts to have some issues.

JB: Never a break, huh?

Pelland: *(laughs)* I started to go through a lot of stress, and at one point I asked my wife if she minded if I went to Florida for what's called the Iron Butt Association Annual Pizza Party. Basically, it's the once-a-year gathering at Daytona Bike Week of all the long-distance riders in the country. I had not been to any motorcycle events or anything relating to long-distance riding in a long while, because I knew how much I loved it but I had to stay away. With the problems at home with my son, I told my wife, "I don't know if I can do it, I don't know if my body can do it, but I just want to do this."

So I jumped on my bike in the middle of March and rode down to Florida. I took the long way, and it took me the better part of two days. It's 1,400 or 1,500 miles. I enjoyed the party down there. On the ride home, I rode from Jacksonville up to my brother's place in Virginia Beach and spent the night with him. He's a good 10 years younger than me. He used to always admire my riding. He asked, "Why don't you start doing it?" And I just thought about it and said, "You know, for the past few years, because of the MS and because of my issues with fatigue, I thought I couldn't do it. But I just rode 800 miles straight and I wasn't really that tired." By the time I rode home, I started to formulate this plan that maybe I still could enter these events, do endurance riding, and find a way to do what I love, and put it together with what I have, the MS, and do something to help other people.

By the time I got home, I had all these ideas. My first thought was to try to break a world record, and if I got notoriety, I could probably go to these events and speak to people about MS. When you have MS, there are things you can do and all sorts of things to help you. I used a lot of assistive technology and different types of things riding long distances even before I had MS, but with MS, there are things that I need to do as I'm riding to make sure I stay safe and focused. So that's kind of how it got born.

I was first going to do one big ride, and then some people said, "Why don't you turn it into a 10-year plan or some kind of mission?" It took a couple of months to figure out, but I finally nailed it, and the response has been overwhelming from people with MS, old colleagues, motorcycle riders, people in the MS Society, and different groups that have all shown that they're very much behind me.

JB: Is the inaugural leg of this million-mile journey still April Fools' Day of 2013?

Pelland: Yes. My original plan was to ride 100,000 miles in 100 days, but I've been talked out of that by almost everybody. So my thought now is to do what I call a 50k in 50 days, and that will be to ride 50,000 miles in under 50 days.

JB: Will that break a record?

Pelland: It will. The record as it stands right now is 31,000 miles in 31 days. The Iron Butt Association certifies these records. Guinness no longer will certify any records that involve anything on public streets, or anything that has to do with time or distance. The Iron Butt Association does have a certified ride that's called a 30-day or a perfect month, which is riding 1,000-mile days for 30 days straight, and I think two or three people have received that recognition. And then one rider decided to do a month that had 31 days, so he actually holds the record for 31,000 miles in 31 days. These are all documented.

JB: How is it documented exactly?

Pelland: With witnesses at the start and at the beginning, and a ride like this will also require witnesses throughout certain parts of the ride. Also I will need every gas receipt with the date, time, and location. And I have to report my mileage at each stop. I have to have a record of where I went each day showing the stops, and the gas receipts will all have to coincide. A ride of

this magnitude will require them to see my credit card receipts of repairs, maintenance, tires, oil changes, all those things will have to be certified by a receipt from the shop that did the work and also have the mechanic or the shop foreman sign another sheet saying, "Yes, Paul was here, this is the bike, this is the mileage at this time," to prove that it was done.

JB: There will be no doubting your accomplishment.

Pelland: Right.

JB: You said that your time frame for the million miles is about 10 years?

Pelland: The rough estimate is 10 years, 100,000-miles a year. There are a lot of people who have done that, and there's actually an award for it. There is somebody who did 100,000 miles in six months, so that is also a record, which at some point I may come close to breaking. But the whole key to doing this type of record is planning. If you can ride 1,000 miles within the legal speed limits and do it within 16 hours, then that leaves eight hours of sleep.

The problem comes in when bikes need service, get a flat tire, or break down. It's 50 days, seven weeks and a day. A lot of things happen. It's proper planning and having support at home with people who can look up traffic or give me weather information so that I might change my route, if needed. I'm going to stay at home every night, or plan to. That way I'm in the same bed and I have the same routine every single day. I'll get up and have probably four or five different routes that I do, I'll switch them up, but this way, the spare bike that I need will be at the house, and also I'll never be more than maybe 300 or 400 miles in a straight line away from my home, or local help, if break down.

JB: And you are going to make speaking appearances along the way?

Pelland: Right. One thing about having MS, there are a lot of great support groups. There are a lot of great pharmaceutical companies and nonprofits that hold different patient events. Here in New England, there's probably something every single night of the week, where I could have a free dinner and listen to a specialist or patient advocate's talk. That's usually somebody who has MS, but they're doing something in their life that they want to do, and they give a little pep talk about ways to help. It's great for people who are newly diagnosed or people who just give up on the things that they used to love to do. So these events go on all over the country. Some nights there are five or six within 100 miles of my house.

My goal is to talk about what I'm doing, but also to help people realize that there are ways they can do the things that they used to do. Maybe it's technology, maybe it's just reevaluating how they do it, or maybe it's finding something they really have a passion for, as I do for riding motorcycles. I feel unbelievable when I'm on the bike. I don't know how to explain it except, I asked my wife, who's been going to yoga classes and taking classes on mindfulness and everything, "What is this mindfulness stuff?" And she explained it to me in about 20 minutes and I looked at her and said, "You mean it's like riding motorcycles!" *(laughs)*

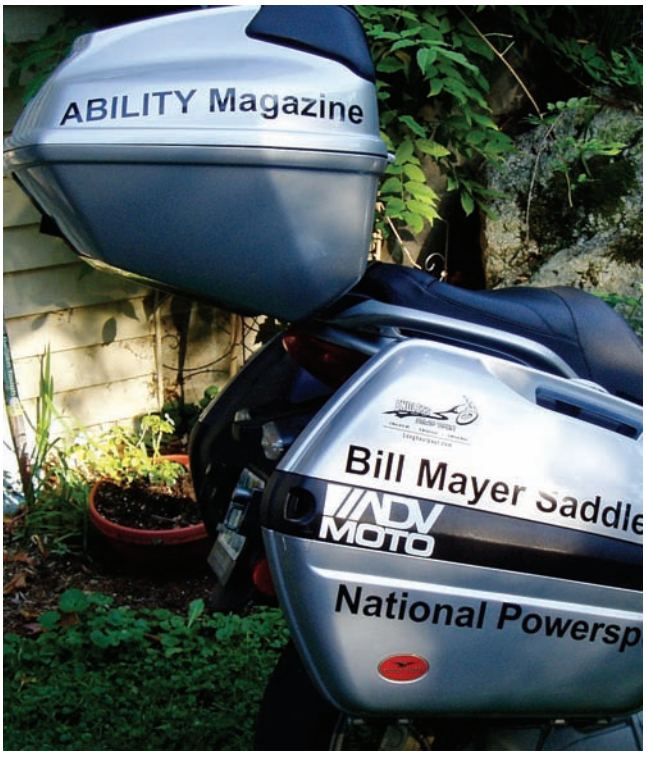
JB: Finding mindfulness at all is the hard part.

Pelland: I guess that's what it is: my mindfulness. I can get on a motorcycle, like I did yesterday. I had a phone call that wasn't pretty and I wasn't having a great day, and I just looked at my wife and said, "I need to go for a ride." And she says, "Yeah, good, go." I took off and I had no destination. I literally just pointed to a random place on my GPS and said, "Get me there in the shortest distance," which is kind of fun, because that always sends me through all kinds of back roads and dirt roads and gravel and cow paths. I just went out somewhere for about an hour and a half, and then I decided, "All right, I'm doing pretty good," and I turned around and took a different way home, and by the time I got home, my head was clear. I didn't think about what had happened earlier in the day one bit. My mind was blank and I was just me, one with the bike, on the road.

■ ABILITY

by Christopher JB

End of Part One. Join us next issue for Part Two of Long Haul Paul's Endless Road odyssey.
longhaulpaul.com



FULL SPEED AHEAD

Charlie Kimball runs laps around diabetes

Security is tight and a veil of secrecy permeates throughout the caravans of massive, 18-wheelers at the Long Beach Grand Prix. What's at stake is the protection of each team's coveted racing technology, for one change in the engineering can alter the outcome of a race. But secrecy aside, on this particular day, members of Team Kimball, including the successful race car driver Charlie Kimball, his father Gordon, and his public relations manager, Tip Nunn, met up with Team *ABILITY*, including human relations manager Donna Mize, medical editor E. Thomas Chappell, MD, photographer Nancy Villere and editor-in-chief Chet Cooper.

Five years ago, Kimball, then 22, was diagnosed with type 1 diabetes and was forced to abandon his racing program midseason. Undeterred, he climbed back into the cockpit the following year and claimed a podium finish in his first race after returning. Traveling more than 200 miles per hour, he's the force behind car No. 83 for Novo Nordisk Chip Ganassi Racing. He is also the first licensed driver with diabetes in the history of IndyCar racing.

While Mize and the others waited for Kimball, who was in a meeting, Nunn shared interesting stories about the young racer's upbringing: Charlie and his parents, for example, struck a deal while he was growing up. His mom always said, "B's don't race. You've got to get A's if you want to keep racing."

Kimball was later accepted into Stanford, but deferred entry for two years in an arrangement with his parents. His mother advised, "You can give this racing thing a try, but if it doesn't work out in two years, get your butt into Stanford."

Cooper: What's his likely major?

Tip Nunn: Possibly engineering. You know, I wanted to mention something about the way Charlie found out he had diabetes when he was in the UK. He went to the doctor for one thing, and the doctor asked, "Is anything else bothering you?" That's when Charlie said, "Yeah, I'm really thirsty." So he looked at him and said, "Have you lost any weight?" He said, "Yeah, like, 20, 25 pounds." It's not unusual for a driver to lose a lot of weight. When they weigh in for their physical in February, they want to be the heaviest they can be, because the weight of the car is based on that weigh-in, and they know they're going to drop weight during the season. But they diagnosed him almost immediately. It was an interesting situation which he just happened to be at the right place at the right time.

In the UK, they have diabetes centers. Charlie was immediately put on the FlexPen (a pre-filled, dial-a-dose insulin pen). He was never given a vial and syringe, never given a pump. Novo helped create a sponsorship opportunity.

A lot of teams will let their whole staff go at the end of the season on September 15th, and one of the great things about Charlie's team is that everyone stays year-round. You have that camaraderie and teamwork. You end up getting the best guys. Also, I love seeing more women involved in racing. J.R. Hildebrand, on the National Guard Panther team, has a woman who works in a key position on their crew. Years ago, women weren't allowed in the pits.

[Charlie's dad, Gordon Kimball arrives.]

Nunn: I was telling them about how Charlie first got diagnosed.

Gordon Kimball: My wife claims credit for connecting Charlie with Dr. Anne Peters. We went on the Internet and started looking for "diabetes" and "sports," and because she had worked with Gary Hall, the Olympic swimmer who won a gold medal and was diagnosed with type 1, we sought her out. But when we called to see if she would take Charlie as a patient, the woman at the desk said, "Yeah, but it's about a two or three month waiting list for a first appointment." I said, "Okay, do you mind if I bring some information down?" She said, "No, that's fine." So I took one of his racing brochures down and a couple pictures, because I thought, if she got a kick out of helping Gary Hall, she'll enjoy working with Charlie.

After I dropped the material off, she called the next day and said, "How about three weeks from now?" She found a spot for him. Charlie was on his way to New Zealand to do a race at the time, so he went to the appointment on the way to the airport. She sat and talked to him for half an hour and they made a connection.

Cooper: Did Charlie get the racing bug from you?

Kimball: Yeah, it's my fault.

(laughter)

Cooper: I heard you've been in the business for a while now.

Kimball: My father brought home a soap box derby rule book when I was 10 or 11, and I discovered racing. That's what I wanted to do. I got a degree in mechanical engineering and started begging for jobs in racing. I was fortunate enough to work in IndyCar and Formula 1.

Cooper: Were you successful? Feel free to brag about yourself!

(laughter)

Kimball: I designed two cars that won at Indianapolis in the 80s, and then went to Europe and worked on a Formula 1 for McLaren, which was the premier team. So, yeah, I had some success.

Cooper: How do you think your experience influenced your son? You were in racing and engineering. He races and is likely to study engineering in college…

Kimball: When I was growing up I had a fun go-cart that I drove around, and after we'd moved back from England, my younger brothers had left it in severe disrepair, so I gave it to Charlie for Christmas as a project to rebuild. We straightened it all out, fixed it all up. My mistake was that I said, "It doesn't have a seat. Let's go see if we can find a seat for it." So we went to a go-cart shop in Van Nuys, and they had a race car for sale. We got the seat and went home, but Charlie just kept bugging me about buying the race car. I thought, "That's something that I can at least help him with." So that's probably how he got started.

We did go-carts together, and that was a great father-son thing. We had an awesome time. I fully expected that when the time came, he'd go away to college and that'd be the end of it. Then I made a second mistake, which was, for his 16th birthday, I gave him a test in a Formula 4. He did six or eight laps and came back and said, "That's the most fun I've had in my whole life." And that's how it started. And he just loves it.

Cooper: And I assume he was fast, and you kept supporting him because of that?

Kimball: He was good. We went to an institute that evaluates that sort of thing, because I thought inevitably we needed to find out before we spent a lot of money that he had what it takes talentwise. He ranked right up with some of the best Formula 1 drivers. So I thought, "OK, he's got the talent."

[Charlie Kimball emerges from his meeting to join us.]

Cooper: A career as a race car driver is demanding enough without a health condition. How do you deal with the complications of diabetes while staying competitive?

Charlie Kimball: The big difference for me is the adjustments we've made—for instance, my glucose monitor literally mounts on the steering wheel. So when I'm driving, I can check my speed, my lap time, my gears, the revolutions-per-minute lights, and my blood sugars all on one monitor.

We're currently working on integrating it into the car's telemetry so it'll come up on the dash as miles per hour, miles per gallon, and a blood-glucose number. And once it's in the car's telemetry—the car's data system-we can transmit it live back to the pit lane so my engineers will be able to keep an eye on it and track the lows or highs, even at different points during the race—lap 20 is this number; lap 50 is that number...

Dr. E. Thomas Chappell: Most people don't monitor their blood glucose quite that tightly.

Kimball shows off the complex gear he uses to keep his diabetes under control behind the wheel.

Kimball: True, but most people don't drive an Indy car at 220 miles per hour, either.

Cooper: You haven't seen Tom [Dr. Chappell] *drive.*

(laughter)

Chappell: I have a Tesla!

Kimball: Nice. With me, monitoring closely is a necessary evil.

Chappell: You don't want to take any chance of a lapse in concentration, much less a lapse of consciousness, obviously.

Kimball: Exactly.

Cooper: I imagine that having this equipment is a condition of having a license to race and staying on the circuit.

Kimball: That's right. Because I monitor my condition constantly, they have the confidence to give me a license to compete. With that comes the responsibility of treating myself or stopping if the numbers aren't what they're supposed to be because it's not safe. I can't put other drivers at risk on account of me.

Cooper: That device (large patch, pictured) goes into your arm?

Kimball: It's essentially a sensor.

Cooper: So it's just external?

Kimball: No, there's a subcutaneous wire that monitors my glucose levels. It's an injectable device. One of the keys to monitoring is having a backup plan that gives me the confidence that I can always keep track of what's happening. So, if I've done my job before I get in the race car, it's literally just a backup plan, and additional reassurance for myself, for the team, for my competitors.

Cooper: Do you have the sensor on all the time?

Kimball: A sensor lasts seven days, so I change it out every week. I wear it every time I'm in the race car, and sometimes when I'm struggling with managing my condition in everyday life, and things aren't going quite the way I'd like them to. It keeps track of what's happening.

Cooper: But you can put it on and take it off easily?

Kimball: No, once you take the unit out, it goes in the trash, so you have to put in a new sensor. But I do shower with it, swim with it, work out with it. Obviously in the race car—as much as we sweat, as gross as that is—

Kimball all suited up and ready to get in the zone.

it's not unlike a shower, and it's not uncommon for drivers to lose 10 or 15 pounds just through sweat. When you think about it, we wear long-sleeved fireproof underwear—tops and bottoms—and then our race suits are three fireproof layers, with gloves, fireproof socks, race boots and a helmet. We may get a bit of a breeze, but there's no air conditioning, no cool suit, and it's not uncommon for cockpit temperatures to reach triple digits.

Cooper: No air conditioning?

Kimball: It's just the air over the car. My helmet has ventilation designed into it to move air through my head to keep me cool, but there's no designed air conditioning unit, because it's an open-top race car.

Cooper: Note to self: Invent air conditioning...

Kimball: Every pound in a race car has a purpose, and an air conditioning pump and unit are unnecessary weight. It's not worth it. The other adjustment is actually here in the cockpit. I'll go around the other side. If you guys want to step in here, I'll show you.

Cooper: Oh, nice. So you've got water and juice down here, and under there Mai Tais and cocktails.

Kimball: *(laughs)* Most racing drivers have a drink bottle in the car, because we lose weight through perspiration. I fill my drink bottle with ice water so I can stay hydrated throughout the race. I also have a second drink bottle, and both are usually mounted in the bodywork on the side of the car. My second drink bottle has orange juice in it with sugar mixed in, so it's about 30 grams of carbs per four fluid ounces. If the monitor shows my blood glucose is low because of the physicality of driving the car, then I've got the orange juice to bring my blood sugar up, and I don't have to stop.

Cooper: Why is the bottle itself orange?

Kimball: That's the color of my sponsor, Novo Nordisk's brand. Different insulin brands have different brand colors. Levemir, which is the longer-acting insulin, has a green label and a green button and a green cartridge, while the NovoLog is orange. The nice thing about my car this year is that the drink tube plugs into a connection in the side of the car.

Cooper: And you're sure that's not the fuel line?

Kimball: *(laughs)* That's definitely not the fuel line. The tube comes out of the bottle and runs right into my helmet. While I'm driving, I can reach down. I know forward is for juice and back's for water. And Brad, my mechanic, always puts the bags in the right way so it matches the labels. The tubing runs through different compartments in the side of the car.

Team Kimball hits the track.

Cooper: Because of the heat, you put it in with ice and let the ice melt?

Kimball: Yeah, the idea is that we pack the bag, and the bag's insulated with ice water, and then the orange juice with the sugar mixed in is made up a couple of days ahead of time, and we freeze ice cubes of that mixture, so when it melts, it doesn't dilute the carbohydrate ratio.

Being in the side pods, close to the radiators, which cool the engines, the bottles tend to get hot. Logically, I might need the orange juice towards the end of the race, after my blood sugar has had time to burn off, so we try to keep the bottles as cool as possible for as long as possible. It's a very high-tech race car, but the drink bag itself is simply a camel bag that mountain bikers and runners use. That way, even if the fluid is swashing around because of the high G loads while I'm driving, it's not introducing any extra air, so I don't have to suck a bunch of air to get the fluid. It works well. And fortunately, I've never needed the sugar water to keep driving. It's a backup plan to a backup plan to a backup plan—safety nets all the way through.

Cooper: But you could drink the sugar water if you feel like you want something sweet rather than the water, or does that compromise your system?

Kimball: It would affect my blood sugars, and I like to stay within a certain range. I start the race within a range that burns off to safe, healthy numbers. And I don't want my blood sugar to be too high, because of focus or vision issues. So if I'm thirsty during the race, I hydrate with water. That's how diabetes management works in the cockpit of an Indy car.

Cooper: That seat looks like a tight fit.

Kimball: It's comfortable for me. But it would be hugely uncomfortable for you—

Cooper: Because my biceps are so big?

Kimball: *(laughs)* And because it's custom-molded for my body out of one piece of polystyrene, it has uniform energy absorption all the way around, so any direction of impact in a potential crash, I'm safe and protected. The seatbelts are doubled up; one belt lays flat on my chest, the second belt goes over a HANS [head and neck support] device. It's a carbon-fiber yoke that attaches to the back of my helmet.

When we go in the lounge, I'll show you all the safety equipment. The first belt holds my body and the second belt holds the HANS, which is better protection in the event of a crash. It's not just for comfort, but also for the way the load reacts in a crash. So those are the differences in my cockpit—my race car versus any other driver's.

Cooper: Do you have a certain diet before a race?

Kimball: Definitely. Not just on race morning, but the whole weekend leading up to the race I stay away from rich, heavy or fatty foods and eat lean proteins and carbohydrates, including a lot of wheat pastas, rice and complex carbs. Race morning, my pre-race meal consists of about a cup and a half of cooked pasta without any sauce, maybe a little olive oil in it, a grilled chicken breast and a little salad.

Cooper: That's your breakfast?

Kimball: No, that's lunch, pre-race lunch.

Cooper: What do you eat for breakfast?

Kimball: Breakfast is usually a couple of eggs for protein, a little bit of wheat toast, a cup of coffee, and a glass of water. I have a pretty good idea of how my body's going to react blood-glucose-wise before I eat, so I know how to judge and adjust for it ahead of time. And then pre-race lunch, after the pasta, the chicken, the salad, a little bit of fruit, and depending on what I'm shooting for blood-sugar-range-wise, I may have a white roll or two—a simple carb factored in to help me maintain that blood glucose for longer so that it's more stable and not up and down. Ideally, I get in the car within 20 points of when I get out of the car.

Chappell: Which is about what range?

Kimball: Usually I aim for between 160 and 180 to start, which is higher than I'd normally be on any given day, but it gives me a margin in both directions, high or low, before I'm having any physiological adverse effects. At a recent race, I started at 187 and got out at 163, so that's a 24-point swing in a two-hour, 200-mile race. That's right in the range of what I'm shooting for: healthy numbers all the way through. With racing, diabetes management is personalized for the individual.

Chappell: Most people just don't control themselves that tightly. Some of them don't control themselves as tightly as they should, even for doing nothing, much less racing a car.

Kimball: Exactly. I feel very lucky that I have racing; it's a great incentive and a great carrot. Pardon the food reference—

Cooper: Continuing with the orange theme…

(laughter)

Kimball: Yeah, it's an orange theme. What I meant is that racing is a great incentive for me to focus on managing my health, like getting my eyes tested or getting my teeth cleaned. Anytime I feel off physically, I go to the doctor and figure out what's wrong. I need to stay healthy to stay strong. And the amount of exercise that I do to stay in shape as an athlete really helps with managing my health.

Cooper: So when you're in tip-top shape and don't have to focus so much on your body, do you find that you go into this place that some people describe as "the zone"?

Kimball: Absolutely.

Cooper: I get in the zone every so often when I ride motocross. Can you tell me what happens for you when you go there?

Kimball: Ideally, I work towards being in the zone every time I put on my helmet, and I think most drivers reach some semblance of the zone every time they're in the cockpit, at least at the professional level. The difference becomes how intense that zone is. I can see individual rocks on the racetrack, individual pebbles on the side of the track, individual blades of grass, and yet still feel like I'm seeing the race from a helicopter's perspective. Does that make sense?

Cooper: It does. What do you think accounts for this different level of awareness?

Kimball: I think it's that moment where your subconscious mind and your muscle memory take over. All the years of experience and practice come together to create that time where you are simply reacting to everything that's gone before, except as the moment happens.

Cooper: In those moments, does time feel different?

Kimball: I get out of the race car and put my watch back on and I don't know where two and a half hours have gone. And then there are times when the first 20 laps fly by, while the next 20 laps take eons *(laughs)*, and then the last five laps fly by again. And it's not necessarily relevant to anything that's happening on the track except the mindset and the focus and the concentration and the adrenaline.

For me, entering the zone starts with a very specific routine: I get into the cockpit, put my earplugs in, put my helmet on, hand my monitor to my mechanic to put it on the steering wheel, put my gloves on, step in from the left side of the car, put my right foot to the right side of the car, get in, pull the belt up, have the mechanic tighten me down, the radio check...

Donna Mize: It's a ritual.

Kimball: Exactly, and it prepares me to focus and achieve the mental concentration to compete. I love it. There's no place I'd rather be than in the race car, any time of day or night.

Cooper: Somebody was talking to me about my love of motocross and surfing, and they said, "Oh, you're an adrenaline junkie." And I said, "No, it's not really adrenaline. It's something different. It's actually peaceful when you're in that space."

Kimball: Exactly.

Chappell: Some athletes get to a point where they're not getting a lot of adrenaline, depending on what they're doing.

Kimball: I don't usually.

Chappell: You don't get jazzed, you don't feel pumped. You get a big surge before the race, but once you're going—

Kimball: Yes, and I used to get out of the race car and have to eat to buffer that adrenaline drain, to have something in my stomach or else I'd feel nauseous. But, now, I get out and I'm fine; physically, I feel like I could go run 5 or 10 miles, but, mentally, I'm exhausted.

One of the questions I get a lot when I'm talking to families with diabetes is, "How do you handle the adrenaline spike? Doesn't that make your blood sugars go up?" I say, "I think that actually I am very relaxed because [the cockpit] is home. It's where I'm most comfortable and best prepared. As a result, I don't spike, I don't get that blood-sugar effect."

Cooper: The stress is before the race, not the race itself.

Kimball: Right. Last year I raced the Indianapolis 500 for the first time. Single biggest one-day sporting event in the world. A mecca, as far as I'm concerned. Before the race, my sugars were 20 to 30 points higher than I'd expected, simply because of the excitement. It was my first time seeing those 400,000 people, the first time doing driver intros to the whole wall of spectators for a race I grew up idolizing. I'm not surprised that I had a stress response. But during the race, my sugars reacted normally.

Cooper: Just before our interview you probably spiked from the stress, right?

(laughter)

Kimball: A little bit. I looked out and thought, "Now that guy, he looks like he's going to be trouble." (*laughter*) Let's go inside so the boys can finish.

[Everyone climbs the stairs into Charlie's truck trailer and enters the hospitality area. Charlie brings out his helmet.]

Kimball: This year it's a whole new car and engine package. [*points*] That's the HANS device I was talking about. Belts go underneath and over the top. The device clips onto the side of my helmet there, so the cockpit surround does a really good job of protecting me from behind. The HANS device then protects the forward motion. In fact, the basal scull fracture is the injury it's designed to prevent.

Cooper: Tom [Chappell] *is a neurosurgeon and our medical editor.*

Kimball: So then you know what I'm talking about. Here is the place that the drink tube comes through, runs down the seat belt, and plugs into the fitting in the side of the car. And then the tube's right in front of my mouth and I can grab it and sip on it whenever I need to.

Cooper: And you don't need to look; you just know where it is?

Kimball: Right. Here's the microphone for the radio so I can talk to the team.

Cooper: So if they hear you go [slurping sound], they know what you're doing?

(laughter)

Kimball: I try not to key up the radio when I'm drinking, but I did once because the bite valve wasn't sealing, so when I'd go through the corners, it'd spit water into my face. So I keyed up the mic, and I said, "Hey, guys—this was during practice—we've got to work on the drink system."

They said, "Yeah, you sounded like you were underwater." I said, "I was."

(laughter)

Cooper: I notice you have bugs on your helmet. I forgot you're head is above the windshield.

Kimball: We tested up in Sonoma, CA, at Sears Point, a few days ago, and then we came straight down here for the race, so I haven't had an opportunity to clean it off.

Cooper: When the truck delivers your equipment to different places are your people in the back of the truck?

Kimball: No, the cars go on top. The equipment's in the middle, and the mechanics fly in and meet up with it.

Cooper: There's nobody in the back?

Kimball: No, unlike *Days of Thunder* back in the day [*laughter*], the guys don't actually ride to races in the truck.

Cooper: Beyond traveling from race to race, you go around doing outreach for kids with diabetes...

Kimball: I do that often. In fact, recently in Long Beach, CA, I went to Miller Children's Hospital, and there was an event with families and kids with type 1 diabetes, healthcare professionals, and four endocrinologists. I told my story and gave a presentation, and I spent about 30 or 40 minutes doing a Q&A session. They asked how I manage my condition and turn lemons into lemonade.

In fact, it was really poignant, because one guy put his hand up and said, "Look, I'm a college football player. What would be your advice?" I said, "You'll still be able to play. In fact, I've met a Super Bowl winner who has diabetes. If you give me your e-mail, I'll put you in touch with him. You can ask him how he does it." He proceeded to tell me that he'd just been diagnosed the day before. And I thought, "Man, if I'd been able to meet a professional athlete facing the same challenges as me the day after I was diagnosed, it would have made my load lighter."

I gave myself two weeks to grieve after my diagnosis, and my friends gave me four days. They didn't let me off the hook. It forced me to focus and figure out what I had to do to get back in the car.

Mize: When you get that kind of diagnosis, people often tell you what you can't do, rather than what you can.

Kimball: Right. A couple of weeks ago at the screening of the film, *The Barber of Birmingham*, we had about eight young boys with type 1 from the Juvenile Diabetes Research Foundation [JDRF] who came with their families. I showed them around the car, showed them my helmet, brought them into the truck, and had lunch with them in the team's hospitality suite.

I saw one of the mothers at the autograph session a couple of hours later and I said, "Did they have fun? Are they enjoying themselves? Are you enjoying yourself? Are you going to come back to the race?" And she said, "It's great," and then she got a little choked up, and I didn't understand why at first. She said, "When my son got diagnosed six months ago, he'd been playing baseball.

But after he learned that he had diabetes, he said, 'I don't want to play baseball anymore. It's not worth it.'" After meeting me and talking with me about racing, her son asked if they could stop by the sports store on the way home and pick up a glove and a ball so he could play baseball again.

Mize: Oh, that's great!

Kimball: I can't think of anything better in life than my ability to make a difference, while still getting to race. I get to live my dream. I don't see why having diabetes should stop anybody from living their dream. Any bump in the road, any unexpected circumstance, you can learn from it and figure out how to make it work for you rather than against you. I have a great team. Not just here in the pit crew. The guys at Chip Ganassi Racing are some of the best in the business, if not the best in the business. So that side of things is covered. And my healthcare team—Dr. Peters, her diabetes educator, her nutritionist—they're three women. I call them Charlie's Angels *(laughter)* because they keep me safe in the race car. They're always there to give me advice, help and support.

Cooper: Have you met Mary Tyler Moore?

Kimball: I have not, but I think what she's done for the JDRF is incredible. The diabetes community as a whole is spectacular. It's one of the strongest support systems out there. You know you're never alone, and you can always reach out and get help when you need it. That makes a huge difference. I've met some great people along the way: Will Cross, who climbed Mount Everest and has been to both poles; Kendall Simmons, the Super Bowl champion I was talking about; Jay Hewett, who's done the Ironman 14 times. The Ironman is 12 hours. I feel very lucky to have met people that I never would have otherwise. And I do think I'm a better athlete and a better driver because of diabetes rather than despite it.

Chappell: Because of the focus you were talking about?

Kimball: Exactly. Don't get me wrong; if I could give diabetes back, I would, for sure. I think if you asked anybody if they could give it back, they would.

Cooper: But it's changed your life in a positive and strange way...

Kimball: Absolutely! I never expected to hear a doctor say, "I think you have diabetes." But I've figured out how to make it work. Isn't that how anyone is successful in life: take the downs and turn them into ups? Plus, I get to race in the Indianapolis 500, which is every boy's dream. ■

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the lowdown on DIABETES

Diabetes is a defect in the body's ability to convert glucose—sugar—to energy. We get sugar from the carbohydrates we consume, such as bread, rice, pasta, potatoes, corn, fruit and milk products, which give us our fuel. We also get it from less savory sources such as soft drinks, candy, cakes and other desserts.

Too much sugar, which can turn to fat in the body, overwhelms the ability of our pancreas to create a sufficient amount of insulin to process all the sugars we consume. Sometimes the problem is that the body is resistant to insulin, or it may be that the body is dealing with both a dearth of insulin and resistance to it at the same time.

Two major types of diabetes are common in our society. Type 2, the better known of the pair, accounts for 90 to 95 percent of all diabetes. It primarily affects adults and is closely associated with inactivity and obesity. For reasons still largely unknown, type 1 diabetes occurs most frequently in children and young adults but can appear at any age. Type 1 accounts for 5 to 10 percent of all cases in the United States. It develops because the body makes too little insulin and appears to have a genetic component that has yet to be identified. (Something called gestational diabetes can affect pregnant women, but is much less of a problem and ends when the baby is delivered.)

Too much sugar in the blood is detrimental to all of our organs, but the ones that are most affected are the kidneys, which can fail; the heart, which can go into cardiac arrest; and the brain, which is at risk for stroke.

If you have more than one of the following symptoms, ask your doctor to test you for diabetes:
- blurred vision
- slow-healing cuts
- erectile dysfunction
- unusual thirst
- frequent urination
- inexplicable exhaustion
- rapid weight loss (usually associated with type 1)
- numbness or tingling in hands or feet

For those who have diabetes, the amount of sugar in the blood varies widely throughout the day, requiring them to take extraordinary measures at times to keep the levels within an acceptable range. Often, they must rely upon a device that punctures the skin to extract a small amount of blood, from which the sugar level is analyzed. That allows them to determine how much additional insulin they need. Typically it is delivered through a self-administered injection. Though not yet widely available in the US, an insulin pen is now in use in Europe. It resembles an ink pen and allows less painful, more convenient injections.

As diabetes often affects those who are overweight, diet and exercise can play a major role in reversing the affects of the disease. In fact, recent scientific findings show that weight-loss surgeries, such as the Lap-Band, which makes the stomach smaller and can result in substantial weight reduction, can be an effective treatment for type 2 diabetes in many patients. However, not all overweight persons are good candidates for the procedure. Even for those who are, it is risky and controversial, so make a careful decision before agreeing to it.

Diabetes can seriously impair your health and even be fatal. So if you or a family member is dealing with the disease, take every measure to lessen its impact on your health. ■ ABILITY

by E. Thomas Chappel, MD

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JOE MANTEGNA

ACTOR, ADVOCATE, FAMILY MAN

Joe Mantegna isn't so much a movie star as a character actor. Since his debut in the 1969 Broadway production of *Hair*, he's diligently perfected his craft. Over the years, he's added writer, producer and director to his credits, along with his roles as husband to wife, Arlene, and father of grown daughters, Mia and Gia.

Mia, his oldest, is autistic, high functioning and well aware of her condition. She also has a wealth of support in her family who ensure that she's involved in the world as much as possible. Her father's career as an actor has played a part in her development, as well.

"Show business is such a public profession," Mantegna says, "and there are not many shrinking violets. So you're talking about people with a lot of personality and energy and putting that energy out there. It's probably a positive thing for my daughter Mia, because it's a

L to R: Joe Mantegna, AJ Cook and Shemar Moore on the set of *Criminal Minds*

dynamic environment where there's a lot of stimulus and interaction."

"It's an in-your-face kind of stimulus. She hasn't existed in a closed society where she's hidden behind the curtain and it's like, 'We'll deal with this privately,'" he continues. "It's always been our intent as parents to get her out in the world, so she can learn to cope. We know there are obstacles to overcome, but at the end of the day, she'll be better prepared to continue on in her life probably for many years, well beyond when either her mother or I will be around to help. So, it's important that we give her all the tools and help we can now."

Long one of the busiest actors around, with a resume that ranges from *The Godfather: Part III* to *The Simpsons*, Mantegna tries to impart the wisdom of his years to his daughters.

"You can list a myriad of diseases and things that can go wrong with a human being," he says, "but you find accommodations can be made. You have to adapt to the world as it is and find modifications whenever possible to make life a little easier."

When he was first starting out as an actor, however, Mantegna refused to take the career path that seemed easiest.

"I didn't have a plan B," he says. "I knew I wanted to be an actor starting at the age of 16. It was all or nothing."

That's been his approach as a parent of an autistic child as well—no fallback position, full commitment. And that in part explains why he recently hosted ACT (Autism Care and Treatment) Today!'s annual Charity Golf Classic Tournament in Westlake, CA, where he helped raise funds for military children with autism.

"My feeling is, if it helps put a face on these kinds of organizations, why wouldn't I [support it]?" Mantegna explains. "There are a lot of people less fortunate than I am. I have the means and the capability to take care of my daughter. Many people have it a lot tougher. So when I'm asked by these organizations to devote some time and energy to helping them reach some of their goals, I'm glad to do it," he says. The military angle was a bonus for Mantegna, whose uncle served in General Patton's 3rd Army during World War II. The actor is a staunch supporter of the U.S. Armed Forces, and co-hosts an annual Memorial Day concert with fellow actor Gary Sinise.

Autism affects the rich and the poor, the obscure and the well known, including Sylvester Stallone, Jenny McCarthy, Holly Robinson Peete, and Aidan Quinn. More children will be diagnosed with autism this year than with AIDS, diabetes and cancer combined.

Mantegna, 65, was born in Chicago and studied acting at DePaul University. He married Arlene Vrhel in 1975. Eleven years later their daughter Mia was born after an emergency C-section performed to save the child's life. At birth, she weighed one pound and 13 ounces, and spent her first few months in intensive care. A few years later, the Mantegnas noticed that her ability to speak was as limited as her attention span. After having her evaluated by a neurologist, they received the diagnosis.

Even though it was 22 years ago, Mantegna remembers it distinctly. "When they tell you your child has autism, it's devastating. It feels like somebody shot a cannonball into your chest." He remembers listening to the doctor and feeling the hopes and dreams he had for his daughter begin to be replaced by worry and concern that she'd never have a fulfilling life.

Mantegna pauses, the memory clearly visceral for him. "But, you know, you have a couple of choices during a moment like that. One choice is to surrender and whine, 'Woe is me,' and see the glass as half empty. Or you pull yourself together and see the glass as half full. And you ask yourself, 'How do we try to maybe fill it up a little more?'"

Mantegna and his wife resolved to face it as a family. His film career was full swing, requiring him to spend months on location all over the world. Yet, he made

certain his wife wasn't going to have to deal with parenting on her own. "I would have to do movies in Russia, Canada, or Australia. Do I say, ' Honey, you're here with our daughter. Good luck. I'll be gone for a month or two. I wish you the best?' Or do I make accommodations?"

For the actor, it wasn't a difficult question to answer. He chose to stand his ground when negotiating with producers. "Okay, we're going to Russia for three weeks? Then [my family is] all going," he would tell a producer. "'Really?' the producer would ask. 'Yeah, really. We're all going or I'm not going. Get another actor.'" Mantegna's resolve paid off, and his family benefited.

As a result, Mia and Gia have traveled the world, attending schools in different countries, and Mia has been exposed to a variety of therapies. As the girls got older, however, world travel got less appealing. "They didn't want to move so much, understandably," Mantegna recalls. "They had friends, and their social life evolved around school. I realized I had to look at what I could do to change my lifestyle. Rather than traveling the world making movies, what else could I do professionally?" Mantegna has been a regular on the TV show, *Criminal Minds*, for six years, which has enabled him to come home every night and lead a more balanced life.

One trait he possesses that allows him to roll with the hard knocks is his sense of gratitude. "I don't care how successful you are, who you are, or what walk of life you come from, everyone has their own story of problems and challenges. If having a child with a disability is the worst thing that has happened to me in my life, then so be it. I've been lucky in many respects," Mantegna reflects.

He is aware of the contrast between his life and some of those around him on the golf course in Westlake. "Talking about military families—they don't have the luxury, as I do, to be with their families while they work. I played golf with these men today. One of them is in the Navy and works on a submarine. He gets on a submarine and goes away for six months on tour. He can't take his wife and kid with him—autism or not. They don't give you an extra bunk on the sub."

Mantegna tends to see things that way, from a practical point of view, from an Everyman perspective, sometimes looking in, sometimes looking out. He thinks back, for instance, to when Mia was first born and he and Arlene had a sense that their life was going to change but didn't know exactly how: "I didn't know what it was like not to have a child with autism. It had its challenges, without question. And sure, if I could summon a genie who could grant me one wish in this life, I would say, 'Let's fix that! Let's make that go away!' But that's not going to happen. So it's something my whole family deals with, and we just do the best we can. A lot of people are dealing with things far worse. It's like the old proverb: I lamented over the fact that I had one shoe until I saw a man who had no feet.

"I think in some ways you're strengthened by these kinds of challenges in life. If you can't totally overcome them, just make the best of the situation."

Mia's autism has not only strengthened her mom and dad but enabled her sister, Gia—born two and half years later—to learn empathy and compassion at an early age. Having a second child gave the Mantegnas a broader perspective on both parenting and child development. He says, "If you just have that one child"—one diagnosed with a disability—"you never will understand the normal kind of developmental stages that a child should go through to reach maturity." With Gia, the Mantegnas were able to discover which behaviors could be attributed to autism and which were just a part of growing up. Some things were similar and some were different. "In many ways my younger

The Mantegna family L to R: daughters Gia and Mia; mother Arlene and father Joe

daughter has to be the older sister because you have one child who develops up to a certain point, where the other child bypasses her in many areas. But Gia benefits from that in many ways."

The pride is Mantegna's eyes is clear as he talks about the relationship between his daughters. "At a very young age, Gia understood that her older sister was a lot different than the other kids," he says. Gia sensed that she had to take the reins and grow up a little faster. She's become Mia's protector, her guardian and even her teacher."

Mantegna has seen firsthand the difference between those who don't have empathy for Gia and those who do. One of the latter, a teacher in Chicago, was instrumental in helping the family realize they didn't have to always protect Mia from the rest of the world, and that she could learn with the other students and adjust to changing environments. That teacher convinced them it was all right to put Mia in a regular first-grade classroom as long as the other children, and the adults who interacted with her understood more about her condition. Not surprisingly, that teacher had a sister with autism.

"It was the first time a teacher, or any one else, said, 'Don't worry about it' and included her in a regular class," Mantegna recalls. "Up to that time, my daughter was in special education."

The actor and his wife sat in the back of the classroom and observed as this caring instructor took Mia by the hand and led her to the front of the class. She introduced the child by saying: "Here's Mia. She has autism. She's going to be a little different than the rest of you. She's going to probably talk to herself. She may just walk up to the blackboard and start drawing. She may sing. She may say strange things, but we're all going to help her, right?" The Mantegnas became teary-eyed as they watched a room full of 6 year olds respond enthusiastically: "Yeah, OK!"

That teacher had a tremendous impact on how the family viewed their situation. They moved from necessity thinking to possibility thinking. As parents, the Mantegnas would never again buy into the idea that their daughter had to be in special education and forever live in a sheltered environment.

"When we came back to Los Angeles, that experience changed our whole outlook on how our daughter should be educated—what we should expect from the schools, what we should expect from life in general, in terms of inclusion," Mantegna says.

Mia attended regular classes from fifth grade through high school. She also attended an 11-week socialization program at the Help Group in Los Angeles, which enabled her to speak more comfortably and confidently on the phone. The Mantegnas used the Chicago school teacher's strategy of just letting the kids know. "Once you include the other students, they become part of the process, and they become accommodating," the actor observes. "Passing the information to others makes all the difference."

Today, Mia works one day a week as a bookkeeper in the family restaurant, 'Taste of Chicago', in Burbank, CA. She is good with numbers and adept with computers. The rest of the time, she works as a makeup artist for Inclusion Films, a production company that offers a series of practical workshops for adults with developmental disabilities, run by former special-education teacher, Joey Travolta, the brother of actor John Travolta.

When you listen to Mantegna talk about Mia, it's obvious that she has taught him and the rest of his family how to understand and accommodate autism on an intimate, loving level. And because the family has chosen to expose her to many different social environments rather than keeping her hidden behind the curtains, maybe those of us she touches along the way will also learn how to better adapt to autism, as Mia has learned to better adapt to the world. ■ ABILITY

by John D. McMahon

View interview: mantegna.abilitymagazine.com

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Nancy Alspaugh-Jackson

Crusader for Autism Treatment

When former television producer Nancy Alspaugh-Jackson took her adopted son, Wyatt, to the pediatrician for a checkup in 2004, she pointed out that the two-year-old had abruptly stopped talking and had begun to throw violent tantrums.

"My pediatrician knew virtually nothing about autism," Alspaugh-Jackson says. "He'd dismiss it by saying, 'Oh, boys, they're late talkers.'"

Shortly before her son's third birthday, however, a next-door neighbor noticed his behavior and said, "I think Wyatt is showing signs of autism." Alspaugh-Jackson called her pediatrician and reported what the neighbor had said, to which the doctor responded, "Since when did plastic surgeons' wives start diagnosing autism?"

After Alspaugh-Jackson raised the possibility of autism with her son's pediatrician a second time, he said Wyatt was due for his third-year checkup anyway, so she should bring him in. Afterwards, the doctor noted that Wyatt "was at least a year delayed," but still didn't diagnose autism.

"Then it was this wild goose chase for the diagnosis," the mother recalls, "which took another six months. At the end of the whole process, I remember a particularly bad day when Wyatt threw a horrible tantrum for about an hour. He broke things. He scratched me. He bit me, and finally I was able to get ahold of him in my arms and rock him. I just prayed to God: 'If you can help me, if you help me figure this out, how to help my son, I'll do anything. I'll help other families.'"

Finally, Wyatt began receiving a form of therapy called Applied Behavioral Analysis, or ABA, which should be initiated within an autistic child's first two years. Wyatt was already four when his mother enrolled him. It started with an in-depth assessment. Once that is completed, behavioral-modification techniques are used to improve the child's skills in deficient areas. The lessons change as the child masters a given topic. For example, it may take one month for the child to understand labels, and another month to grasp concepts such as size or color. Wyatt's challenges were more related to interactions with other children: he got locked into repetitive behaviors that kept him from socializing. He wouldn't make eye contact, and his language skills atrophied.

Alspaugh-Jackson says, "It's almost as if you're taking somebody back and returning the brain. You're opening up those neuro-pathways. It makes every individual with autism better, and it recovers many. We're sold this myth that autism is incurable, and

while we don't [say] that it can be cured, autism can be 'recovered' from."

Since psychiatrist Leo Kanner introduced the term "early infantile autism" in 1943, awareness of the condition has grown slowly. But over the past two decades in particular, the increase in the number of reported cases can be attributed to changes in diagnostic practices, referral patterns, availability of services, age at diagnosis, as well as public awareness.

For many years, autism was considered a psychological disorder, but experts now know that it's a neurological condition. They also know that the incidence of autism in a child is greater when the father is older than with the mother is older. One potential explanation is the known increase in mutation in older sperm.

Recent studies point to another possible explanation for autism: Compromised immune systems in those who develop the condition. So there may be a genetic piece to the puzzle, but it appears to be smaller than previously believed, which raises hope for the benefits of treatment.

In the past, many autistic children were considered hopeless, condemned to spend their lives in diapers, unable to brush their own teeth or dress themselves. Some autistic children have begun to make truly remarkable progress after just a few months of ABA treatment. For Nancy and Wyatt, the therapy has proved life changing.

In 1987, ABA's creator, Ole Ivar Lovaas, PhD, published a study indicating that, with his methods, autistic children could make a full recovery. Subsequent research has yet to reproduce his results. Lovass served as a mentor to Doreen Granpeesheh, PhD, when she was a graduate student at UCLA; she went on to become a supervisor at his facility, the UCLA Clinic for the Behavioral Treatment of Children, which remains committed to Lovaas's findings. Granpeesheh says she believes autistic children recover through ABA, because she has witnessed it time and time again.

"ABA depends on two things," Granpeesheh says. "One is good ABA. This means good therapy technique. What techniques do I use to shape a child who's nonverbal [until he or she can have the] completely normal conversation of a five-year-old? That's a lot of steps. If you know those techniques well, you can be a good behavioral analyst. The other side of effective ABA is knowing context. It's one thing to teach a child labels or colors; it's a little different level of complexity when you're teaching a child… about not being bullied, being assertive enough or having an appropriate conversation.

Joe Mantegna and Nancy Alspaugh-Jackson

"For example, if I teach a two-year-old child how to vocalize their needs and describe things in the environment, by the time that same child is five, I would have to teach them conversational skills. Conversational skills would be broken down into 'who am I talking to?' because there's a difference between talking with a friend, an adult, or teachers. Is it formal or informal? What is my setting—school, home, casual, or in a supermarket? Is it one person or many? Am I listening to this person or am I just talking on about my own topic? Is my topic boring this person, based on their body language? There are 20 different aspects of conversation that would have to be taught."

The higher levels of the ABA curriculum address social nuances that many of us could benefit from reviewing.

Many parents who take their children to the Tarzana, CA–based Center for Autism and Related Disorders (CARD) agree that ABA is life-changing. In fact, the US government recognizes ABA as the single most effective method of intervention for autism. Currently 31 states fund the treatment through health insurance.

The ABA program is both intensive and expensive: it requires children devote 40 hours a week to it, and costs about $40,000 a year per child. To help families meet these demands, Granpeesheh formed a nonprofit called ACT Today! which stands for Autism, Care, and Treatment Today. Many of the beneficiaries lack insurance coverage, so the board—many of whose members are parents and experts in the field—helps review applications and gives out grants directly to service providers.

Alspaugh-Jackson was so grateful for what CARD did for Wyatt that she wanted to give back in a big way. Now that Wyatt is on solid ground, Alspaugh-Jackson is honoring the promise she made to God to help others when she was so desperate for help herself. When she found out about ACT Today!, she immediately volunteered to help raise funds to support the organization. Drawing on her experience as a television producer, she organized events, set fundraising goals and managed logistics. She also leveraged her industry network, asking Leeza Gibbons of *Entertainment Tonight* and *Dancing With the Stars*' Tom Bergeron to serve as hosts. She enlisted neighbors to donate items for auctioning. Before she knew it, she had orchestrated a successful backyard fundraiser in which tens of thousands of dollars were raised. Eventually, Alspaugh-Jackson was invited to join the board and today is executive director of the organization.

"In life, a lot of us have callings we never thought we would have," Alspaugh-Jackson says. "I often say that I didn't choose this path, it chose me." She says she's grateful to be able to contribute to such an important need, but is humbled by the scope of the problem. She recalls, for instance, a family in Uganda that ACT Today! assisted: "We helped bring a child here who was being tortured in his village; he was literally being beaten for having autism." Alspaugh-Jackson worked through her church to obtain a visa for the boy so that he could come to the US for treatment. The child's aunt told Alspaugh-Jackson that her nephew would've likely been killed had he not gotten out.

More and more, the community organizer recognizes how much there is that still needs to be done, but ACT Today!'s triumphs and the acknowledgements she gets from other parents keep her going. A smile spreads across her face as she explains: "I'll get a letter from a therapist who works with a child and says, 'This child has progressed more in the last six months with ABA therapy than in the last three years I've worked with him.'" ■ ABILITY

by John D. McMahon

act-today.org


Dr. Doreen Granpeesheh

The "It's Only Another Beer" Black and Tan

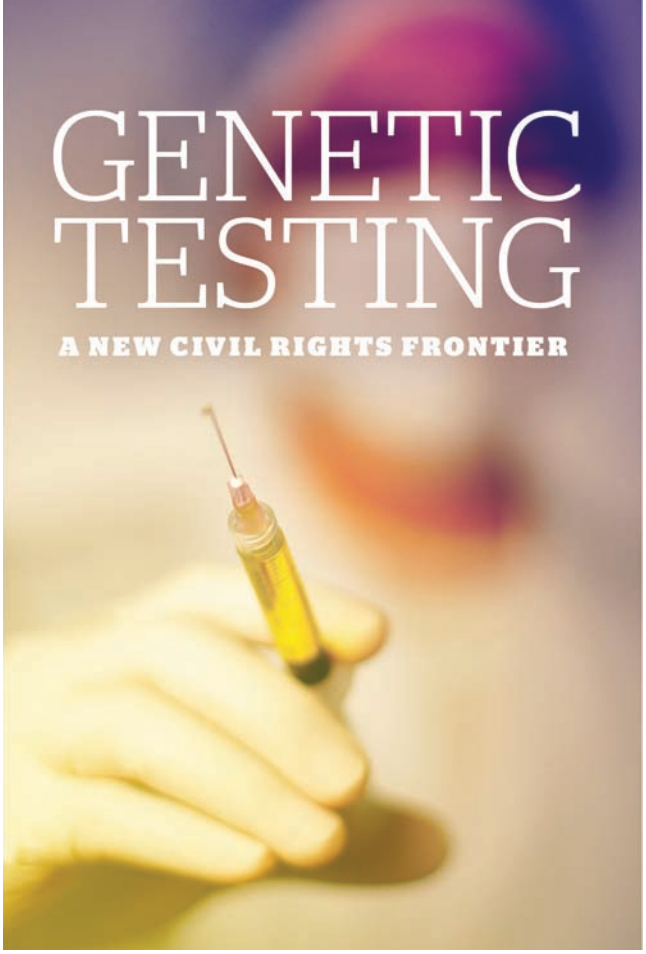
8 oz. pilsner lager
8 oz. stout lager
1 frosty mug
1 icy road
1 pick-up truck
1 10-hour day
1 tired worker
A few rounds with the guys

Mix ingredients.
Add 1 totalled vehicle.

Never underestimate 'just a few.'
Buzzed driving is drunk driving.

AdCouncil.org

U.S. Department of Transportation



I get the call often at work: "I'm thinking about taking a genetic test. Should I do it?" Seems like a good topic of discussion for a doctor and a patient, but that's just the thing. I'm not a doctor; I'm an attorney. For most people, the decision of whether or not to take a medical test does not involve speaking to an attorney. However, for those with family histories of cancer, certain cases of hereditary deafness, or other genetic conditions, the decision to take a genetic test can raise a host of legal concerns about what happens to the results and how they may be used.

As the science of genetics advances, doctors, researchers and clinicians will increasingly use genetic testing and information from family history to help guide treatment and prevention options. Scientists are beginning to better understand the hereditary nature of many diseases and disabling conditions. For example, much progress has been made in understanding the familial nature of chronic conditions such as Alzheimer's disease, heart conditions and diabetes, as well as familial causes of many disabling conditions, such as certain birth defects, deafness and blindness. While information about the genetic causes of a disease can be beneficial medically, the increased use of this information raises legal concerns.

For example, many individuals contemplating genetic testing are concerned that results could be used to deny insurance coverage or to discriminate at work. Genetic discrimination occurs when an employer or health insurance company uses genetic information or family medical history to make an adverse decision. For example, if an employer refuses to hire an individual because they have a family history of Huntington's Disease, this would be genetic discrimination. Additionally, if an insurance company raises premiums for an individual based on the fact that they are a carrier for Tay-Sachs, this would be discrimination.

The Genetic Information Nondiscrimination Act (GINA) is a federal law that prohibits employers and health insurers from using and collecting genetic information to make decisions. Additionally, the Americans with Disabilities Act (ADA) protects individuals from discrimination in the workplace based on a current disability, but also based on a perceived disability. For example, if an individual has a hereditary form of muscular dystrophy that has not yet affected their muscles enough to create a disability, their employer would violate the ADA if the employer regarded the employee as having a disability prior to symptoms. But, while GINA and the ADA provide many important protections, it is risky to see these laws as the panacea.

Unfortunately, some are laying to rest all fears of genetic discrimination in the wake of GINA. I mentioned to a genetic counselor that I am a genetics attorney. She looked at me inquisitively and basically said, "But genetic discrimination doesn't exist anymore… They passed a law." While this is a completely understandable position for the medical community to take, without further information and safeguards it may not be the safest course legally for their patients and the community for two reasons.

First, not everyone follows the law. Second, legislators don't always foresee all possible gaps in the law before passing it. There are tangible steps patients can take to avoid genetic discrimination.

By no means am I trying to be a naysayer about genetic testing. It is exactly because genetic testing can provide such important personal and public health benefits that I caution about legal concerns; however, I do not want to discourage testing or discourage full disclosure to your doctor or other health care professionals. So, here are a few legal items that every individual who is taking a genetic test should consider.

How am I going to control my genetic information?
One of the greatest protections of GINA is that it bans health insurers and employers from collecting genetic information about an individual, except in limited circumstances. This is invaluable given that it is often difficult, not to mention expensive and time-consuming, to prove a case of discrimination. If a patient can ensure that genetic information doesn't get to the decision makers, they can take away the very means of discrimination from the start. Under GINA, an individual does not have to tell an employer about their genetic information or disclose this information to a health insurer. Genetic information is defined broadly to

include the results of a genetic test, but also use of genetic counseling, participation in genetic research, and family medical history of any disease or condition.

Why is genetic information in my medical records anyway? While an individual can fill out health insurance applications without genetic information or can shield information from an employer, this will do little good if the information gets there in other ways. The treasure trove of genetic information is most likely in medical records. Under GINA, all medical records requests must contain a note that genetic information should not be included. The onus is then on healthcare professionals to remove genetic information. Unfortunately, there is little evidence that this is happening. Therefore, the patient must be proactive and request a copy of their medical records to see what is contained and to speak to their doctors about the desire to have the information properly redacted.

What other insurances might I need? While GINA covers health insurance and employment, there are other insurances that are important, if not essential, especially to individuals with genetic predispositions. Most notably, these are life, long-term care and disability insurances. The use of genetic information in these fields is regulated at the state level. Therefore, individuals should check to see what the rules are in their state and perhaps in the states of their family members. Usually, a state's department of insurance has these rules and regulations.

GINA only protects genetic information, not manifested diseases. Once an individual is experiencing symptoms of a genetic condition, GINA becomes less relevant. In these cases, the individual must turn to the ADA and health insurance protections. The protections in health insurance are also rapidly expanding. Most notably, under the Patient Protection and Affordable Care Act (PPACA), otherwise known as healthcare reform, insurance companies will no longer be able to deny coverage to adults with pre-existing conditions. Due to healthcare reform, children with pre-existing conditions already cannot be denied based on manifested symptoms.

Despite these expanding protections, those individuals getting genetic testing today are in many ways the legal guinea pigs for a new civil rights frontier. The science of genetics is much more advanced than the law, so legislators and courts are trying to catch up. There still remain unanswered questions about how the law will be interpreted. While genetic testing is a personal, familial and medical decision, it is essential to remember that it has legal implications as well and that it may be worth calling an attorney—not just your family doctor—when considering getting tested. ■ ABILITY

by Anya Prince, Esq.

disabilityrightslegalcenter.org

Connecting the Dots

PHOTOS BY TOM OLIN

A puzzle of nine symmetrical dots connect. Fine-toothed gears knit together in a well-oiled machine. An A team works towards a common goal: Every part is necessary to the whole in order to reach the desired outcome. Efforts to create social change are no different.

While the disability movement has many parts—developmental disabilities, physical disabilities, learning disabilities, etc.,—we are all parts of a whole. And history shows that when we work together as a single voice, then we are a force to be reckoned with. Consider the legislation passed, amended or dramatically overhauled, which could not have occurred had we remained divided.

As a community, we have historically set aside our individualized sub-community priorities to throw our weight behind the Civil Rights Act of 1964; the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Some may say we came together during these times because the prize was so big that we had to. At those crucial moments, our sub-community priorities were secondary to the common goal of our united community. So what is our excuse now? Why does it seem that we have lost some of this ability to work together to protect our rights, which have come under attack during these difficult financial times and opposing political forces?

For example, Medicaid swings in the balance. As a result, we could see waves of individuals having to leave their homes—some for the second time-because the services they need will only be available to them if they are living in an institution. By a one vote margin, the Supreme Court handed down a decision on health-care reform that upholds the Patient Protection and Affordable Care Act (PPACA) of 2009, benefitting all those with pre-existing conditions. However, inclusive education policies are being upended by a new crop of segregated disability—specific charter schools. They are popular because, unlike public schools, they are perceived to "get it."

These examples deeply concern me because they apply to the lives of people in my immediate social circle. But when I step outside my own realm of experience, I am struck by the realization that there are thousands of other scenarios happening every single day denying people their rights with little or no recourse available. This brings to mind several questions: What are we, as a movement, going to do? What are we doing to influence policymakers and the public not only to listen, but also

to act? It depends on how we, as a group, connect the dots, and come together as a team rather than as individual players.

So, what can we do to remain united, despite our differences?

"Some people don't like to ripple the tides," commented Tom Olin, a disability rights pioneer and renowned photojournalist responsible for capturing in print much of the disability rights community's history in the making. "That's why we have organizations like ADAPT, people who chain themselves to fences and risk going to jail, but we have to remember, their role is only one piece of the puzzle. There's a lot more that needs to happen to really get stuff done."

Admittedly, I am one who may not resort to direct action as a first response. At the same time, I recognize and value its necessity. A Latin adage states: *Si vis pacem, para bellum*, which translates as, "If you want peace, prepare for war." It seems as though we are approaching a time when the world is warning us that we need to do this very thing, as a collective community, to claim a common ground and a universal goal. Those who blockade the entry to a public building need to work with those who sit behind desks in cubicles writing legislation. Those who negotiate with government appointees need to exchange information firsthand with teens with disabilities in public schools.

Social and political climates are such that we must work together because we no longer have a choice. What we do have a choice about is making sure that we take the time to pull together, prepare and strategize. Much has changed since the passage of the ADA, which, in my opinion, was the last time we functioned as a collective.

Yoshiko Dart, a disability rights activist and wife of the late Justin Dart, Jr., who helped draft the ADA, once described the disability community as an orchestra. "We all play different instruments in the melodies of social change," she said. "There are times when some of our instruments play with vibrant force, while others are silent, but that does not mean that any of them are less important than the others."

But it seems we may need a reminder today that this 1990 victory was not the end of our quest. We are not finished with what we have to do, together. While the ADA strove to encapsulate opportunity and accessibility for all, many breathed a sigh of relief and wiped their brows, mistakenly assuming the victory was won. Granted "life was made livable" by this law, and many of those born after the passage of the ADA admit that they are without a full understanding of what the struggles were like before it was enacted. In a sense, the ADA provided us with a means of justice and social order.

(*Previous Page*) Pre-ADA, ADAPT members crawl up US Capitol steps to protest lack of accessibility for citizens with disabilities.

(*Below*) They object to inaccessible city buses prior to ADA passage.

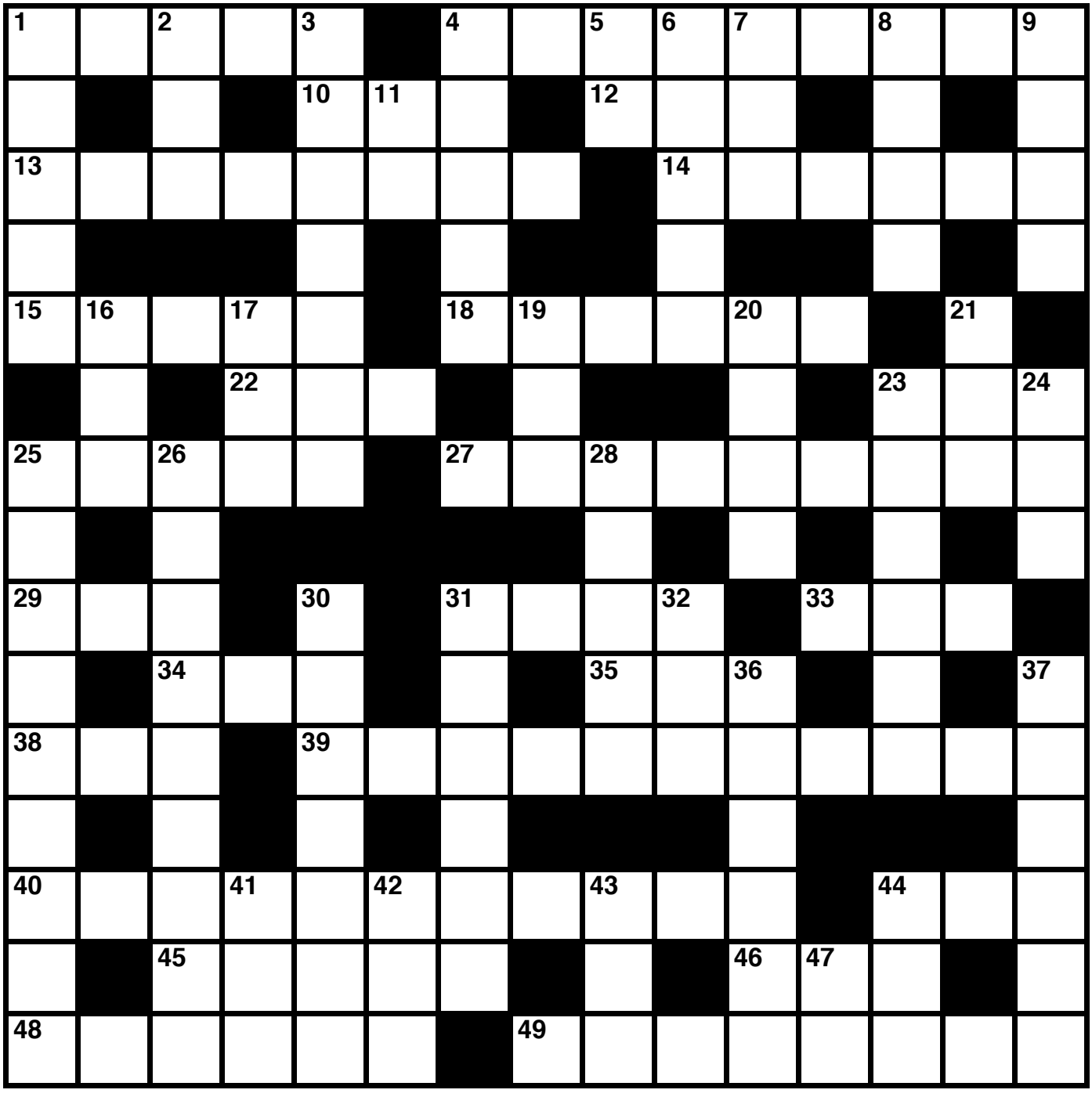
However, as Wislawa Szymborska, a Polish poet and Nobel laureate once wrote: "I prefer chaos to the hell of order." In the poem from which this is taken, she suggests that we should not be swayed by feelings that we are fully protected by the laws as they stand today because, as example shows, many in our society continue to be denied our rights, and even laws that put certain rights in place are being challenged every day. So, as Szymborska suggests, we may have to raise some hell to protect what should be rightfully ours.

Without question, I am grateful for the rights and liberties to which I am entitled. I am thankful for the freedom to choose specific initiatives toward which I devote my time. My realization, however, is that there is an increasing need to fulfill responsibilities on behalf of the greater community, for without it, our rights as individuals are all the more in peril. ■ ABILITY

by Betsy Valnes

Betsy is an active member of the disability rights movement both in the United States and abroad.

ABILITY's



Crossword Puzzle

ACROSS

1 First deaf person to be interviewed on Conan O'Brien's show, Ashley ____
4 Senator campaigning to help more people with disabilities get into the workforce (2 words)
10 Wedding promise (2 words)
12 Hang out on the couch
13 "We shall _____" protest song
14 "Imagine" singer
15 "Fly like an ____" Steve Miller Band song
18 Told a big fish story
22 Noah's boat
23 Spelling movie: Akeelah and the ___
25 Has fun
27 Sundance Channel's new hot show about "chicks in chairs" (2 words)
29 Mellow jazz instrument
31 Clean
33 "We're number ___!"
34 Promise of a payback
35 Reporter's question
38 Wife of 14 across
39 Push aside as unimportant, often of minority groups
40 Encouraging creativeness and energy
44 Station that is running the show "Different is the New Normal"
45 Sheets and stuff
46 Night before
48 Most bashful
49 He had a terrible stutter from a young age and eventually became a famous speech therapist, Charles ____ (2 words)

DOWN

1 Couldn't move!
2 Stretch out
3 NFL players
4 The "deaf, dumb and blind kid" in the Who song
5 Motor vessel, for short
6 Champion for blind people, ____ Keller
7 Life measurement
8 Tennis great who supports the Womens Sports Foundation and the Elton John AIDS Foundation, Billie Jean _____
9 Supreme Court count
11 Manage
16 Nelly Furtado's "___ Good Things"
17 Put down
19 Aladdin's monkey
20 Innovative
21 Make sense
23 South-east Asian country
24 Second sight, abbr.
25 Aka "Bladerunner," Oscar ____
26 Nervously
28 Japanese food
30 US poet who wrote against discrimination and emphasized the essential self, EE _____
31 American Idol rocker who was diagnosed with Tourettes when he was a boy, James ____
32 Huge amount
36 German classical composer
37 Movie preview
41 Cobbler
42 No longer working, abbr. .
43 "Beautiful Mind" actor, middle name
44 Energy
47 Roman 6

Crossword Puzzle

answers on page 62

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted in December 2006 at the United Nations Headquarters in New York, and was opened for signature in March 2007. There were 82 country signatories to the Convention. This is the highest number of signatories in history to a UN Convention on its opening day. It is the first comprehensive human rights treaty of the 21st century. The Convention entered into force in May 2008.

The Convention follows decades of work by the UN to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

To date, about one billion people live with some form of disability. Persons with disabilities tend to be acutely vulnerable to exclusion and are disproportionately poor.. Furthermore, there are an estimated 150 million children in the world with disabilities, of which about four-fifths of them live in developing countries, and millions more live with parents or relatives with disabilities. No society can ignore such a massive number of people nor leave them on their own.

The CRPD is also a response to the fact that the potential of persons with disabilities was not being tapped. Persons with disabilities who continued to be denied their human rights were kept on the margins of society in all parts of the world. In addition, they felt that they had very little to say in plans and programs that were supposedly created for their welfare, and for the improvement of their conditions. The CRPD sets out the legal obligations of countries to promote and protect the rights of persons with disabilities.

Since it was officially enacted the CRPD has continued to maintain its momentum to attract agreement and support. This is due in no small measure to the innovativeness that it promotes the interdependence of all human rights. As of July 2012, there were 153 country signatories, and 117 country ratifications.

INFORMATION AND COMMUNICATION

Virtually all aspects of society are affected by the pervasive usage of information and communication technologies (ICT), including mobile communications, television, computers, digital interfaces and the Internet.

To know how much progress is actually being made by countries in ICT accessibility a second edition of the CRPD Progress Report on Accessibility in Information and Communication Technologies has been published. It reviews and rates the status of ICT accessibility and assistive technologies regarding CRPD implementations in 52 ratifying countries, which represents 77 percent of the world population.

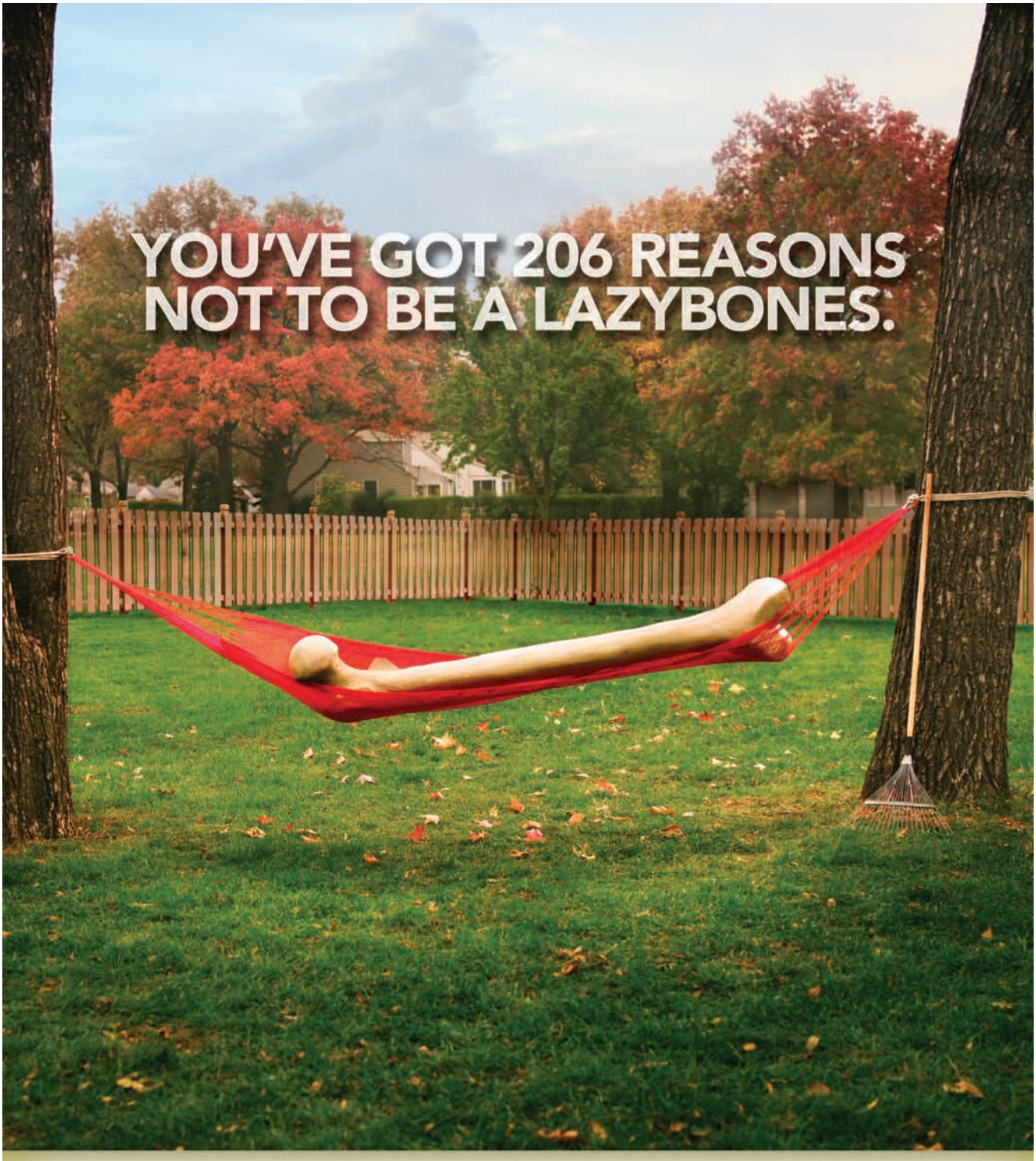
This comprehensive report offers disability advocates, governments, civil society and international organizations monitoring the progress of the implementation of the CRPD a unique benchmarking tool with data on country laws, policies and programs pertaining to accessible and assistive ICT around the globe.

The Progress Report is produced by G3ict (a Global Initiative for Inclusive Information and Communication Technologies—an Advocacy Initiative of the the United Nations Global Alliance for ICT) in cooperation with Disabled Peoples' International (DPI) and various disability centric organizations and experts in countries where DPI correspondents were not available.

Implementing ICT accessibility policies and programs is a complex endeavor involving multiple sectors of society and the economy, and requires the active engagement of a variety of participants. It's an essential step for all stakeholders in order to address gaps and opportunities in their own countries.

g3ict.org

View interviews from the 5th States CRPD: crpd.abilitymagazine.com



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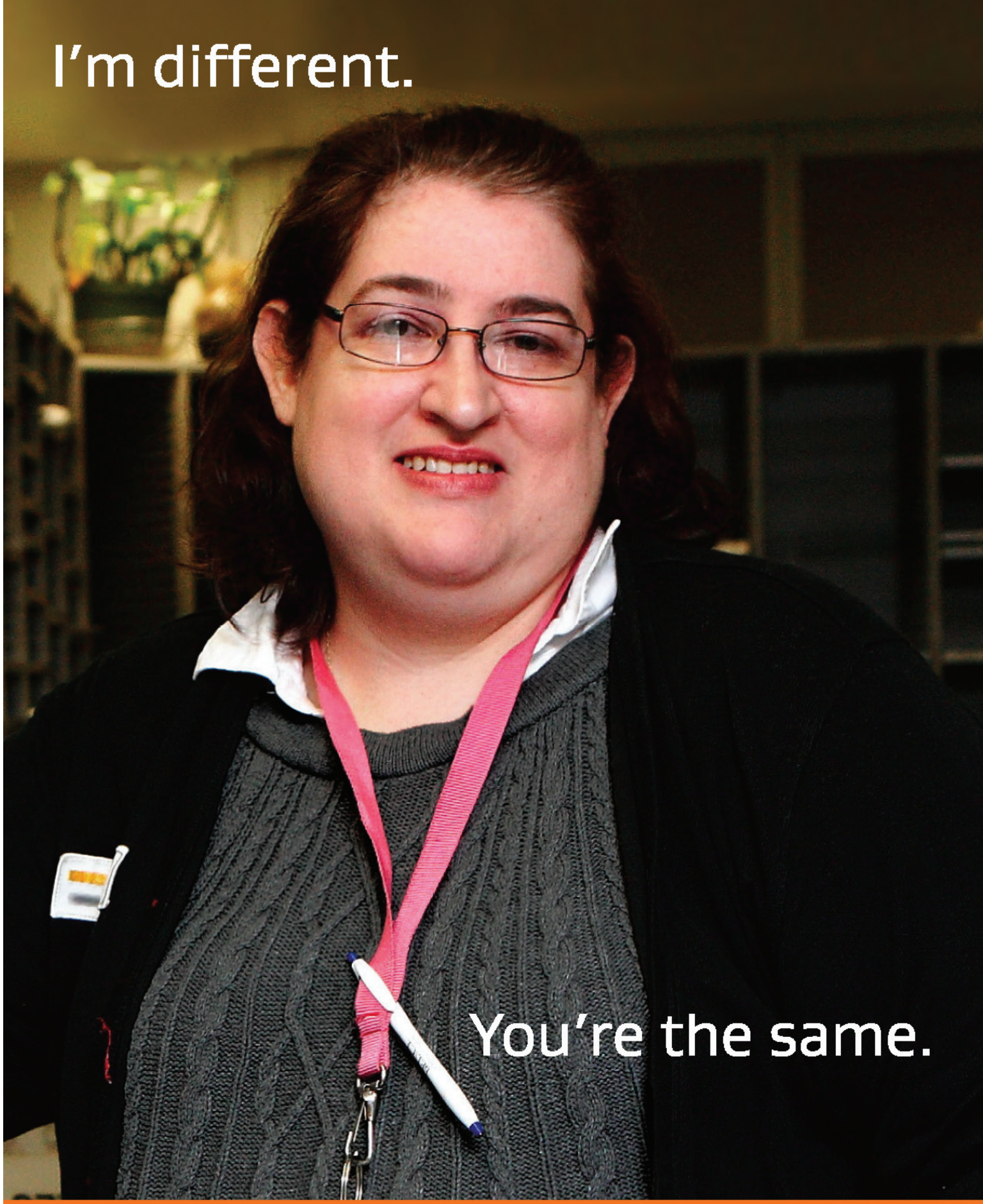

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So Many Answers Left Unquestioned ...

The 2012 TASH Conference is coming to Long Beach, Calif., November 28-December1! Attendees from around the world will come to learn about emerging practices and the latest research, network with others in the field of significant disabilities, and stake their claim in a movement to include people with disabilities in all aspects of life.

This year we are reminded there are *So Many Answers Left Unquestioned*, a theme inspired by a poem from Megan Jones, a self-advocate in North Carolina. It challenges us to think deliberately about the way systems work, programs are funded and people are supported. We will revisit long-held beliefs about "disability," and pose questions to many of the "answers" that have limited the ability of people to access inclusive education, integrated employment and lives in the community.

Expert Panel on Inclusion
November 28, 2012

What have we accomplished in advancing inclusion? Why haven't we done more? What can we do to ensure progress is made? We can learn a lot about the future of inclusion by understanding the challenges of yesterday and today. Join us during the 2012 TASH Conference as an expert panel on inclusion tackles these important questions.

Featuring

Madeleine Will (Moderator)
Director, National Down Syndrome Society

Norman Kunc
Disability Rights Activist, Author and Speaker

Charlie Lakin
Director, National Institute on Disability and Rehabilitation Research

Barbara Ransom
Attorney

Wayne Sailor
Professor, University of Kansas; Founding TASH Member

Keynote Amy Brenneman
December 1, 2012

Amy Brenneman, a parent, actress, producer, and advocate, received her degree in Comparative Religion from Harvard University and was a founding member of the award-winning Cornerstone Theater Company. Most recently, she has played the role of Violet in the ABC series, *Private Practice*. As the parent of two children who attend a fully inclusive school, Brenneman has worked to promote the importance of transitioning from segregated models of education toward innovative and fully inclusive schools where children with and without disabilities learn together.

2012 TASH Conference
Long Beach, California
November 28 - December 1, 2012
www.tash.org/2012tash

- More than 200 concurrent and poster sessions
- Short-course workshops with leading experts in the field, included as part of registration
- Full-day skills-building post-conference workshops*
- Town halls, forums, film screenings and special events
- Exhibit hall

* Additional registration required for post-conference workshops

TASH CONFERENCE

So Many Answers Left Unquestioned

LONG BEACH / CA / NOV 28 - DEC 1, 2012

Equity, Opportunity and Inclusion for People with Significant Disabilities Since 1975
Learn more at www.tash.org or www.tash.org/2012tash

My Child Without Limits.org

UCP United Cerebral Palsy™

Life without limits for people with disabilities™

BraveKids

My Child Without Limits is an authoritative early intervention, online resource and community for families of children ages 0-5 with developmental delays or disabilities, and professionals looking for a single, trusted, aggregate source of information that relates to their needs and interests.

mychildwithoutlimits.org

* en Español

Brave Kids serves children with disabilities and chronic/life-threatening illnesses and their families by providing a support community, information and resources about numerous medical conditions such as genetic diseases, autism, cancer, cerebral palsy, ADD and many more.

bravekids.org

PUBLIC EDUCATION & OUTREACH

UCP's knowledge of disability issues has been accruing for more than 60 years. Connecting individuals and families with the resources and services they need helps fulfill UCP's mission of advancing the independence, productivity and full citizenship of people with a spectrum of disabilities.

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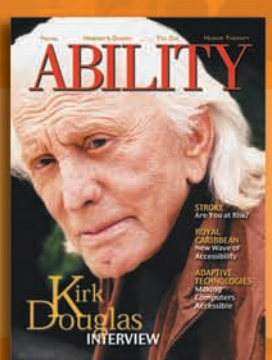

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Photos of actual Southern Company employees.

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