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Editorial pages have VOICEYE codes for a new level of content access - Enjoy

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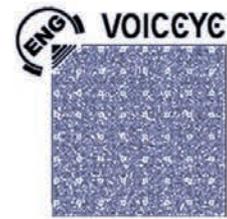
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VOICEYE

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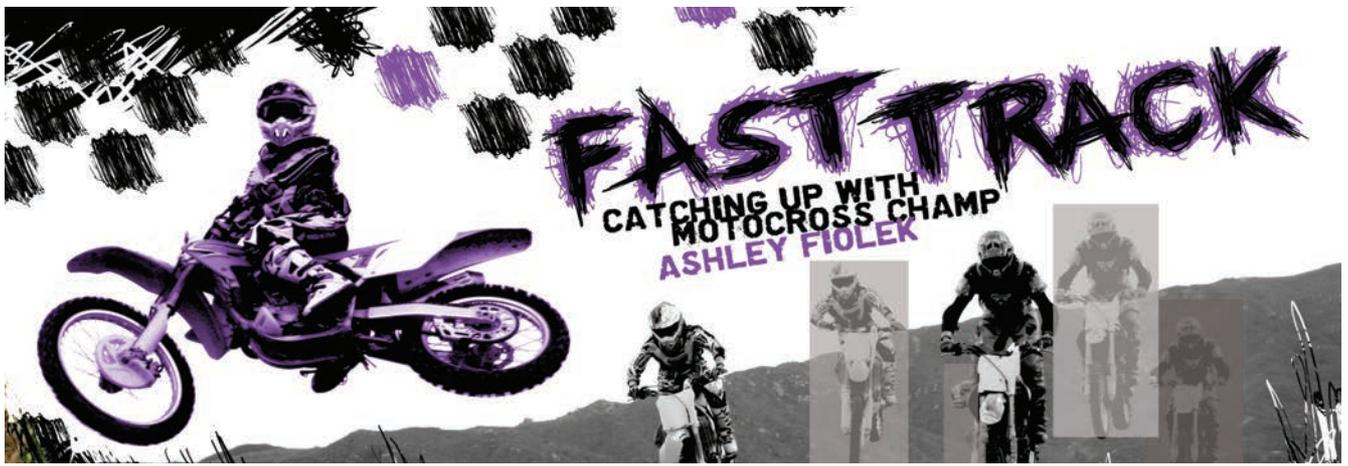
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Android

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





My family and I took a trip back up to Michigan for Christmas and New Years. We had a really good time but it was so darn cold! When it's minus 12, you can't really enjoy much.

We flew into Grand Rapids, MI, and as we got closer, the pilot made an announcement: We were entering the runway under low visibility, so it might seem like we were landing, *but* we might actually pull back up and land in Indianapolis, instead!

My mom was freaking out. "Are you kidding me?" she said, because then we would have to drive all the way back to Michigan, and the roads were not good.

As we approached the landing, everyone prayed we'd be able to land. Finally we touched down and everyone cheered.

It was still sketchy after we got into our rental car Christmas night, and there was hardly anyone on the roads. That was a good thing, since they roads were covered in snow and ice!

We were all very hungry because it was 7 p.m. by the time we got to the hotel room, but everything was closed down, partly because of Christmas, and partly because of the passing storm.

We were going to settle for the chicken sticks and granola we already had, but luckily we had driven by an open McDonald's, and once we got settled in, Dad went back out for us. Whoo hoo! Go Dad!

After Michigan, I was off to an MX class in Texas for two days, and then to a private lesson with one of my riders. So I packed up my truck with a trailer and bikes and headed to Houston.

My mom was going to fly out on Sunday to interpret for the Monday and Tuesday classes. She wasn't feeling well, so she stayed behind! While I was on my way out there, I heard the Monday class would probably be canceled because it was raining so much that the track would likely be flooded.

I was disappointed because I was looking forward to riding that track. We got into Houston, and my mom was supposed to fly out Sunday morning, but the day before she woke up with blood coming out of her ear, and her eyes were super red.

She went to the clinic, and apparently she had a sinus infection that gave her conjunctivitis in both eyes and ruptured her eardrum!! So, no flying for mom!

My agent contacted all the girls and asked if it would be ok if I just wrote on a pit board, and then demo'ed on my bike what to do. They all said they were fine with it.

Since Monday's class was canceled, we had until Tuesday to relax. I woke up that Monday morning, headed to my truck to get something out of it, and something didn't seem right.

I looked down. I had a flat tire and then, when I walked around to the other side, there were two flats!! When I looked closer, my tires had been slashed! Ugh...not the way to start out a Monday morning! We got tires at Walmart, and since I didn't have my jack or any tools with me, AAA came and put the tires on for me.

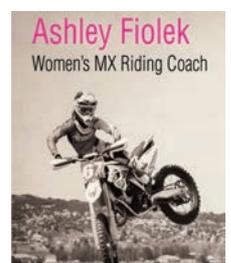
Later on in the day I found out that my private lessons had to be canceled because the girl I work with had lost her grandmother. So my big riding week turned out to be just one class!

The class went really well, though, even though my mom wasn't there to interpret. The girls seemed to really enjoy just riding with me, and reading my instructions off of the pit board.

I wound up having a great time and meeting some wonderful people. After class we started the long trip home! Now I am back in Florida and I must say it is not as cold as Michigan, but it still could stand to warm up here, too, brrrrr! Stay warm everyone :-)

■ ABILITY

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THIS IS YOUR FUTURE

The future is coming and there's no way to stop it. For close to 10,000 years the horse was the main mode of transportation, until we hit the 20th century, then, the horse was demoted to just a gambling vehicle. Within a hundred years we went from the horse and buggy to the automobile to flying in the skies. Technology is attacking us from every direction. Some good and some bad.

I remember going to the library (that's a big building with lots of books in it) and leafing through encyclopedias to look up information like... what does a spider monkey eat or how does an elephant sleep? Now days, you just sit on the couch and call out to Alexa for answers to mindless questions. "Alexa, how many miles is it from here to Moscow?" With things like Alexa, soon nobody will need to read. You can lounge around and ask Alexa to tell you what the book *The Old Man and the Sea* was about. "Oh my God, there's a whale in it, Alexa. Does it eat a lot of people... like the old man?" you eagerly ask. Bingo, you just saved yourself two or three weeks of reading a book. Now you can act cool in front of your friends by throwing out Hemingway references. I'm not worried about the kids learning to read though. They need Facebook.

Technology is moving at the speed of light. You go out and buy the latest toaster that's able to send a message to your cell phone letting you know your bread is now toasted. Then, in no time, it becomes out dated and you feel you've been ripped off. If you just waited another day you could've bought a toaster that butters your toast, then walks it over to the table.

Just when you think there's nothing else left to invent something comes out and blows your mind. I recently saw a mechanical bed that can sense when one is snoring then it will raise or lower you until you stop the sleep snorting. How many marriages might this save? I'm going to wait for the next version. That one that changes the sheets laced with your snoring drool and then makes the bed.

If you have an invention that doesn't work by cell phone, shelf it. It's worthless. Some new cell phones, coming out in the next few years, have a function where you breath into them and they will detect up to fifty-four diseases. That's crazy. Could you imagine after a bad day where the wife has left you, you've been fired, and you totaled your car then you huff into your phone and it tells you that you have Typhoid. Or, how about you're having a great day where you won the lottery then you breath into your phone and it reads, "Congratulations, you have been diagnosed with Ebola!" That could very well dampen your day. What if you're in the midst of a phone conversation wishing your mom "Happy Mother's Day" and your cell informs you that you of some disease. "I gotta go, ma. I think I have Meningitis." Your mother responds, "Well, have some chicken soup and a glass of ginger ale." You inform her "Mom, my phone says I only have twelve hours to live." On the Brightside, they'll be less doctor bills. I can see me sitting in front of my phone, sweating, trying to build up the courage to get tested, I finally exhale into the Samsung and I get a text that reads, "Halitosis. Damn, does your breath stink!" I'll take it. Beats Cholera.

There is already an app called "moodies" which can tell

which mood you're in. Do we really need this? Come on, it's common knowledge that everyone's always in a bad mood. Hopefully the app will be able to send someone else's mood to you. "You know Bob, I think I will have that beer with you after work. My wife's mood was just sent to me and "grumpy and pissed" is not something I should be rushing home to." What's next? An app that tells you how hungry you are? How tired you are? How frisky you are? "No sweetie, the app says it's cuddle time?" Or, "Honey the app says you need to put on the eye mask and spank me with crop stick." Soon, we won't ever have to feel or think. They'll be an app for that.

Artificial intelligence is gaining a lot of momentum now. Watson, the IBM computer, already helps nurses diagnosing cancer, 4 times more accurately than humans. Yeah, but can Watson give you a sponge bath? If the A.I. makes the "finger in the butt" check-up routine obsolete, I say bring it on. Many of these high-tech computers are beating chess grand masters at their own game. Sounds like us humans are in "checkmate." When one of these computers can win an argument against a woman, I'll believe in their power.

In 2018 the first self-driving cars will appear for the public and, in the next five years, you won't need a car. You'll just need to punch a button on our phone and, voila, a driverless car pulls up in your driveway to take you to your destination. You won't want to own a car anymore. No more wasting time filling up with gas, taking it to the mechanics or searching for a parking spot or looking for ketchup packets between the seats. The big question is who controls the radio in the car? If you're stuck listening to All Talk Radio station maybe the car payments are worth it.

Uber has pretty much put the taxi service out of business. Thank God, nodding and pretending like you understood what the cab driver just said gets old quickly. So does him constantly saying "my friend." And, so does that wet body odor smell that's permeated into the upholstery. Those driverless cars better not have that filthy stench. I can't see them lasting long. When people don't own things, they abuse the living hell out of it. Those vehicles are going to be like a cheap motel on wheels. The good thing about a world of driverless cars is they'll be no more stress teaching your kid to drive or waiting for that phone call that starts out with "Dad, don't worry, I'm okay, but you know the car you let me use tonight..." Without owning a vehicle, insurance companies will have massive trouble because without accidents, automobile insurance will become 100 times less expensive. Their car insurance business model will disappear and, hopefully, there won't be so many commercials with Flo holding back on giving Jamie a name-your-price tool.

Electric cars will become mainstream about 2020. Cities will be less noisy because all new cars will run

on electricity. You'll now be able to hear the gun shots ring out. Electricity will become incredibly cheap and clean: Solar production is really becoming ubiquitous. With cheap electricity will come cheap and abundant water. Desalination of salt water now only needs 2kwh per cubic meter (@ 0.25 cents). We don't have scarce water in most places, we only have scarce drinking water. Imagine what will be possible if anyone can have as much clean water as he or she wants, and for nearly no cost. Smelly people may finally decide to take showers. Now we just need the cost of brewing beer to come down.

On every street corner, building and probably bathroom, there will be cameras. Our lives will be on video. You come home an hour late from work, your wife asks you, "Where you've been?" and you tell her, the bank then to Starbucks. Next thing you know, she puts your ID number into the computer and a video pops up of what you were doing throughout your day. Sure enough, you went to the bank and Starbucks, but then it shows you walking out of a massage parlor, with a devious smirk on your face. Smile, you're on candid camera, you sneaky little dog. We got you, Joe! Blame it on your Mood app that claimed you were "extremely horny."

Drones will dot the skies. These things will be bringing goods to our houses like groceries, prescriptions, packages, etc. Going out to do errands will become a thing of the past. You'll have that extra time to work-out. Who we fooling? If we're too lazy to go get our milk is exercising really in the cards? Well..., you'll have more time for Netflix. We won't be concerned of bird's pooping in our hair, the big fear will be a drone smashing into your head. Who knows, instead of a jetliner being brought down by a flock of seagulls that flew into the engine we'll hear the tragedy was caused by some twelve-year-old punk's drone sent up to spy on the neighbor girl laying out by the pool.

This is just a glimpse into the future and it's right around the corner. Thanks to technology we will all be living longer. An average of 100 years is not out of the question. Do we really want that creepy uncle living that long? Does this mean you'll have to work longer for your Bitcoin savings retirement? Maybe..., if you're lucky enough to have a job that hasn't been given to a robot. And, on a side note, will advocate groups be fighting for the right to marry a robot? It is an ideal partner. It can be programmed to cook, clean and won't put on any weight. I wonder if it gets half the community property if there's a divorce. I don't know if I like the future. Privacy will certainly become obsolete. There will be a footprint of everything you've done throughout the day; where you've been, who you've talked to and how many times you checked yourself out in the mirror. The past always seems much better. I was younger and everything just moved slower. ■ ABILITY



by Jeff Charlebois



Should I Change My Latitude?

The New Hampshire winter started off pretty darn cold. December's temperature never went above freezing, and the first snowfall is still on the ground, way at the bottom. Living in New England makes riding a motorcycle year-round a slightly unintelligent choice for transportation.

Last year I found myself on one of New Hampshire's scenic byways right before a freak snowstorm hit. I survived to tell about it, and even better, I had the GoPro running. You think I would've learned my lesson.

A few weeks ago I got a call from a magazine wanting to run a feature story on my million-mile journey. The editor wanted to set up a date for me to meet with a local photographer on my side of the country. The plan was to take photos in a Vermont studio for half a day, and then spend a few hours riding down the road, in my element, followed by a van of photographers with cameras. A ten-page story was a big deal and was sure to bring me much needed exposure.

We settled on a Wednesday shoot as I was leaving the

following day to ride down to Orlando for a presentation. I watched the weather carefully, and besides the temperature being in the teens, the meteorologists never made any mention of snow. Which was great, because motorcycles are not supposed to be ridden in the snow.

It has become frightfully clear to me that all the data we are storing in the Cloud these days is wreaking havoc on our weather forecasters. On the day of the shoot, just a few hours into my ride to Burlington, it started to snow. It was freezing cold, and now it was slippery. I tried to get off the highway at one point, but the bike just slid sideways and somehow managed to stay upright. I decided to try making it off the next available ramp. The next exit was partially clear, so I turned off the ramp and made a slow right turn directly into a gas station. I parked under the fuel pump awning and cried Uncle. I phoned the photographer and asked if he could drive the remaining 10 miles or so to come pick me up. There was quite a bit of ice, so it took three of us to walk my bike to a parking space in front of the Dunkin Donuts. I grabbed my gear off the bike and abandoned it until later in the day.



DEI BEST PLACES TO WORK 2017SM
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The photo shoot was laid-back, no hair or makeup artist, and I didn't even check myself in the mirror before we started. We did a video for the website, talked about my mission to ride a million miles for multiple sclerosis (MS) and my journey so far. By the time we stopped for lunch and went back to retrieve my bike, the temperature had risen to 25 degrees, the sun was out and the salted roads were starting to dissolve the ice.

I rode over a few miles of winding roads, with the camera crew in tow. We continually stopped and turned around to do it all again. Take one, take two, take three. By mid-afternoon we had finished all the road shots, shook hands, and I headed south to Orlando to speak at an MS patient event.

Although I try to stay away from snow and ice, I often find myself having to ride in extreme cold. Having the proper gear makes all the difference! When the temperature is only 15 degrees, and you are moving at 70 mph, it can feel more like 20 below. Warm but thin base layers are important, and I also rely on a heated jacket liner and heated gloves to keep me warm all year. My outer jacket is from a company called Aerostich and is made

from high-quality waxed cotton to keep it waterproof.

I have a pair of leather Gore-Tex gloves that were customized by Ken Phenix of Phenix Flaming Hot Heated Motorcycle Gear. He can take any gloves and add carbon wiring to make the glove heated. My new HJC helmet has a special shield insert that prevents the frost and fog from blocking my view. A neck warmer, thick wool socks and long underwear are always worn underneath anytime the temperatures are expected to be chilly.

Having the right cold weather riding gear is not just for comfort, but it will save me from getting frostbite, or worse, freezing to death!

When I think about moving south, I remember how bad the heat affects my MS symptoms and soon realize I'd much rather keep dealing with the cold winters!

Is it spring yet? ■ ABILITY

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HOPE and GLORY

I am among millions of people who was thrilled to see 2017 go bye bye. It was not a year that I will ever look back on and think, “Gee, I wish I could live that over again!”

Yet, even knowing this, I still find myself from time to time going back anyway: in my dreams, subconscious thoughts, or just through visceral blooms of pain, disappointment, and heartbreak.

However, it has occurred to me recently that every time I think of the struggle of those 12, soul-crushing months, I do go back and live it again, even though I claim it’s the last thing I want to do.

So, how do we really recover and move forward from a bad year? I think the key is to become fully aware of what we focus on. By being in the now, we can stop ourselves in our muddy tracks, and shift internally to a positive, fresh path that changes our brain’s patterning, allowing us to breathe more deeply and access natural joy.

For instance, if I am reliving the memory of losing my sister Gloria, who died of lung cancer in 2017, then reviewing that mental “snapshot” creates sorrow, detonating unhappiness, exploding into more unhappiness. Thus 2017 trails behind every step I take, even as I try to slip away from it.

Politics and other horrific events of 2017 have affected us all, challenged our faith, stirred our anger, and threatened our connection to positivity.

However, it’s possible to catch ourselves in those thought processes and say, “No, I will not drag this negativity into today!”

I understand that many of us struggle with depression. For some, it’s a biochemical reality deep inside our bodies. Fortunately, there are therapeutic measures to help us cope. And on top of that we have the power to stay aware, replacing difficult thoughts with affirming ones.

Many examples come to mind: A close friend watched her parents’ brand new home burn to the ground one Christmas eve. The entire family stood across the street

watching the house and everything in it, including newly purchased Christmas gifts, succumb to raging flames.

The trauma felt unbearable, until my friend’s 4-year-old niece yanked on her dress and said, “Aunt Kelli, I know it’s sad that grandma and grandpa lost their home, and all the presents are burned, but isn’t it exciting though!”

The whole family laughed at her childlike innocence and later huddled together in a motel, celebrating that they’d all gotten out alive, where they upwrapped the real Christmas gift of life: They still had each other.

For me, my sister’s death in 2017 was without a doubt the most painful thing I have ever experienced. And I have gone through the stages of grief, anger and despair. But as I move forward into the new year, I make a daily effort to reach for the sweet memories of having Gloria as my sister, so they can take the place of any pain that tries to rise up.

I still laugh when I think of the day I was looking for an outfit in Macy’s. I was hurting physically, and there were no benches or chairs to sit on, so I sprawled in the middle of the floor in women’s formal dresses.

My phone rang in my purse, and it was Gloria. My hearing aides are synced with my iPhone, so as we chatted, it looked like I was talking to myself. She was telling me something excitedly, and I was sharing in her excitement and laughing.

Then a security guard came over and said, “Ma’am, you cannot sit in the middle of the floor. You have to get up, right now.”

Gloria could hear him, but he couldn’t hear her because her voice went directly into my hearing aids. She said, “Tell him to go f**k himself. You don’t have to move anywhere!”

I said, “Gloria, I can’t say that to him!”

He interrupts, “Ma’am, you have to get up. You cannot sit here!”

I said, “Gloria said I don’t have to move.”

He then thought I was talking to an imaginary friend, and replied, “Okay, you and Gloria can stay here, it’s okay.”

After that, Gloria and I couldn’t stop laughing!

So as we continue to move away from 2017, remember not to take the agony of the old year into your new beginning. Make an effort to remember the good things and more will manifest. For me, 2018 will be one of magical hope and glory. ■ ABILITY







CRISPR

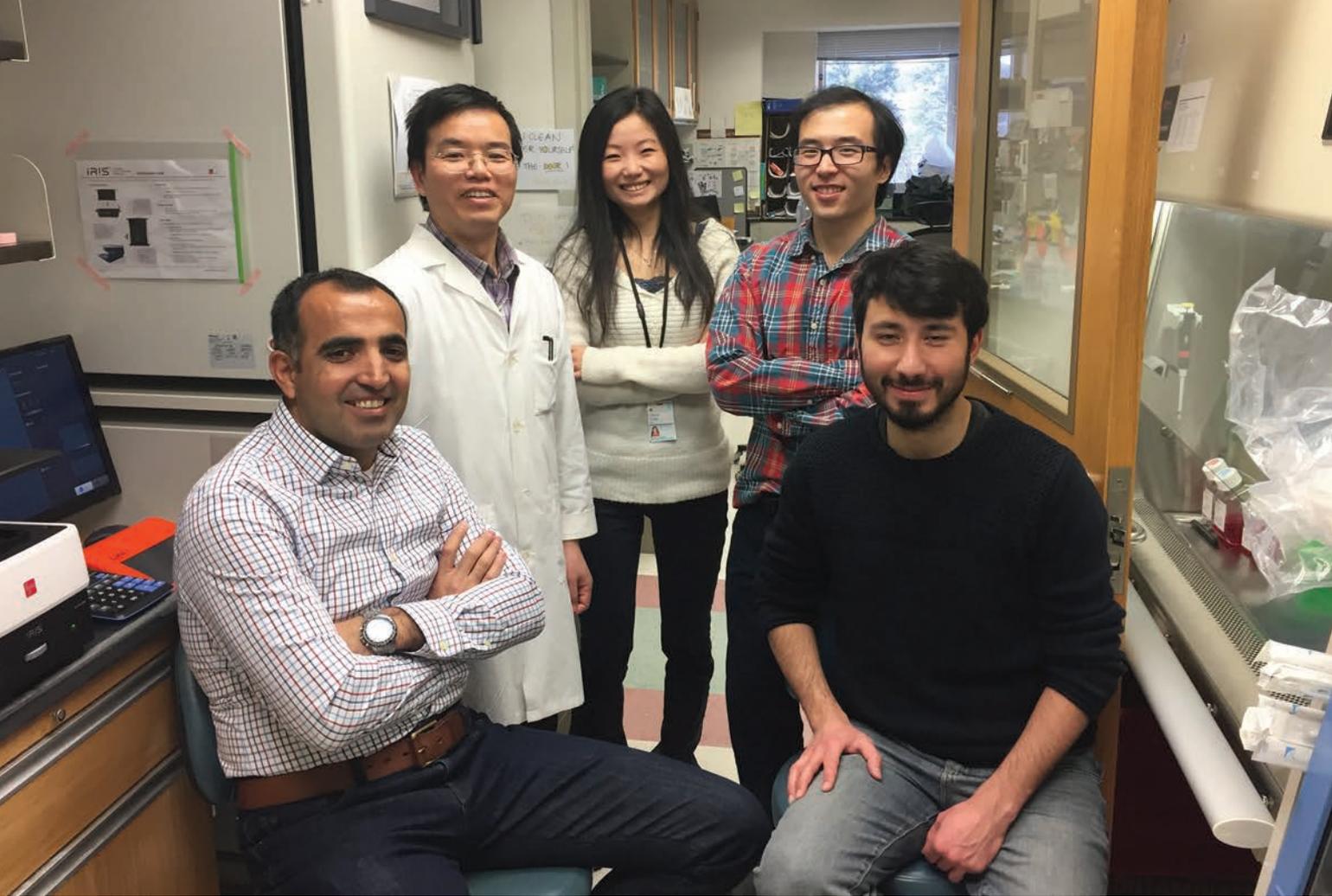
a unique way **Stop**
to silence genes

CRISPR—no, it’s not a new cutting-edge kitchen gadget for low fat diets, rather it was first recognized by Osaka University researcher Yushizumi Ishino in 1987, who found sequences of interrupted repeats in microbes was unusual because repeated sequences are typically arranged consecutively along DNA. Evidence then came that CRISPR is an adaptive immune system. When a microbe is invaded by a virus, the first stage of the immune response is to capture viral DNA and insert it into a CRISPR locus in the form of a spacer. These spacers can be cut out, but damages the DNA.

Mazhar Adli, PhD, and his team have developed a technique to prevent genes from carrying out their function without causing the extensive DNA damage the current approach requires. This is important because silencing genes allows scientists to understand what individual genes do and identify the ones that cause disease. Gene silencing also may one day let doctors better treat and even cure genetic diseases with abnormal gene activity.

Our genes – the blueprints for life – are segments of the long double strands of DNA in our cells. To silence genes using the current approach, the CRISPR system cuts both strands. Doing this too often causes the cells to die — a major limitation for CRISPR. Even cuts that are not fatal to cells can have unintended effects that result from the body’s efforts to repair the broken DNA.

Adli’s approach, on the other hand, avoids cutting the DNA altogether. Instead, it takes advantage of the fact that DNA is made of four main building blocks: cytosine, adenine, guanine and thymine. Adli’s method lets scientists use CRISPR to convert one building block into another to artificially create what are called stop codons – the “off” switches that naturally occur at the end of genes. Turn cytosine into thymine, for example, and the whole gene is silenced, meaning there is no protein production from that gene.



ABILITY caught up with Dr. Adli to dig deeper into this innovative system that is revolutionizing the new era of science.

Carol Brown: Can you tell us the quick background on CRISPR [pronounced “krisper”]?

Mazhar Adli: About 30 years ago, Japanese scientists discovered this weird sequence in bacteria, and they called them “Clustered Regularly Interspaced Short Palindromic Repeats”. So CRISPR.

Brown: Makes me think of food.

Adli: (*laughs*) Thirty years ago we didn’t know anything about it, and in 2005 people started to realize that some of these genetic sequences in between those palindromic sequences actually doesn’t belong to bacteria, it belongs to some viruses. That of course immediately sparked an idea that somehow the bacteria is able to store a portion of virus genetic information into its own genome. And if the bacteria is doing this, evolutionarily it has to provide some sort of advantage to bacteria. One of the ideas is that somehow, maybe this is an immune system. In a way, you are carrying a photograph of your enemy in your own pocket. If you encounter that enemy again, you can protect yourself better. People started to work on it. How does bacteria use the CRISPR system as an immunity against viruses?

In 2012 the first major paper was published describing that bacteria actually use this—in this CRISPR, there’s a protein called a Cas9 protein, and it uses short RNA. Part of its short RNA belongs to the virus, so it’s kind of a complementary sequence to the virus DNA. And this is how bacteria recognizes a virus. As soon as it recognizes this short RNA, it can cleave the DNA from the virus. This gives greater protection to the bacteria, so they can survive better with the viruses.

This sparked the idea that, what if you put this protein and this short RNA in mammalian cells? Can this be used so we can go and cleave specific regions in the mammalian genome? And they showed it also works in the mammalian system. Since you have an enzyme now and RNA, a very short, RNA molecule, you can custom-design it. This gives you the ability to send this protein to anywhere you want in the genome to create these breaks or double-stem breaks in the DNA.

Brown: You’re talking about cleaving. That’s not your approach?

Adli: Right, this is not what we are doing. This is how traditional CRISPR works. Basically, it goes and cleaves the DNA. After it cleaves the DNA, the cell has to repair this DNA, and when it makes the repair, it makes some random mutations. In a way, it’s kind of genetic scars that are left behind. Some of these scars

cause mutations and cause what we call knock-out. Basically, the gene cannot produce a protein because of these random mutations. This is how the traditional CRISPR works. When people say “CRISPR-mediated gene silencing,” this is what they mean, the silencing as a result of these DNA breaks and due to these random mutations left behind from the breaks.

What we are doing is completely different. First of all, the traditional CRISPR works very efficiently with the DNA double-strand breaks and with the scars, but the problem is two-fold. One, we cannot predict what’s going to happen to that DNA. It’s a completely random insertion and deletion at those sites. Second, in our genome, we usually have more than one copy of a gene. In normal cells we have at least two copies. But in the research environment, in cancers and other situations, we have multiple copies of a gene, and when there is a DNA the cell thinks something catastrophic is happening, that the cell is dying and is undergoing what we call apoptosis. It’s a programmed cell death.

So it’s not because we silence the gene or because the gene is no longer present, it just due to excessive DNA damage due to the activity of CRISPR. So we wanted to overcome this challenge. We are not making any double-strand breaks, we are changing the genetic code. Do you have any biology background?

Brown: You said the word “biology”? What does that mean? (laughter) My undergrad is in biology, but that doesn’t mean I know much today.

Adli: I don’t know how simple I should go?

Brown: Good point. I’d guess the simpler the better.

Adli: We found around 17,000 genes we can target this way, and, as you know, we have roughly 20,000 genes. The way the genetic information is being tracked or translated, we have this strip of codes. This is how the genes code for proteins, with this strip of codes. Some of this strip of codes code for nothing, basically, we call them “stop.” When the gene comes toward the end of a gene, we have these stop codons. We are changing one base, one nucleotide, into another one directly. This allows us to create these stop codons early on in the genes, so there are no strand breaks. By creating these stop codons, when the gene is being translated, the gene is being cut right at the beginning of it. There’s no protein production from there on.

This way the cell does not realize there is a strand break because there is no strand break, and since there is no DNA damage, there’s cell viability, and the cell’s survival returns to normal. In the other case, if you create a strand break, the cell undergoes stress, and in certain cases it doesn’t survive; it’s undergoing cell death, or it reduces its overall viability. You’re kind of making the cell sick when you make a double-strand break,

when you cleave the DNA. But in our case, we are converting one genetic code directly into another one, and by editing these genetic codons, we are stopping the protein expression.

Brown: Can you give us an example of what that allows potentially to happen?

Adli: For a lot of diseases, including cancer, sometimes we have an apparently active gene. We just want to silence that gene: to inactivate that gene. Our way allows us to directly do this. The second thing is, research-wise, we can now apply this method and understand the function of genes. We can do this one gene at a time. We can also screen many, many genes, thousands and thousands of genes. In the screening scenarios, for example, we can delete, in genetic terms, we can say “gene deletion” or “knock-out.” We can silence: we can inactivate genes. Instead of inactivating one gene at a time, we can inactivate thousands of genes in a population of cells, and then we can let these cells, for example, form a tumor and see which gene is the most important in terms of tumor formation, or which gene is most important in terms of responding to a drug.

So the method we are using is called “base editor,” rather than just CRISPR, because the conventional CRISPR, as I just said, goes through the DNA double-strand breaks. But this base editor is converting one base into another one, and it’s much more precise genetic editing. The major advantage of this approach is that it’s much more precise. Let’s say one cell out of a thousand undergoes the mutation or the genetic editing you desire. With our approach, it’s 60% of the cells, or in certain cases an even higher percentage of the cells have the desired genetic editing.

Let’s say you want to edit the word “c-o-n-t-r-o-l.” With CRISPR, it will randomly shuffle some letters in that region. We are saying that, if the word is “c-o-n-t-r-o-l,” we just want to replace “n” and “t,” we can do this with this new method. It’s a much more precise way of genetic editing. And more importantly, it is safer, because the cell is not sensing DNA damage because we don’t make any strand breaks, any DNA breaks.

Brown: Are there plans for clinical trials?

Adli: At the moment it’s not at clinical trials, but we are hoping that we can apply that base editing technology to certain diseases, cystic fibrosis is one of them, and potentially, hemophilia is another one. Hopefully we can make these precise genetic changes in these diseases. Of course, we have to first show in the resource environment, in the research lab, that this is working in the human cell lines, and then show in the animal models that it is working. Then it will come to the clinical trials. Right now it’s not at the clinical trial level yet.

Brown: Have you tried animals yet?

Adli: We can make these editings in animals, yes. We've tried them in animals, and it works *in vivo* as well. Right now we're trying to see what is the best disease model to apply this to, because we need to pick a disease model where we can deliver this systematically to the patient. For example, a muscle disease, let's say muscular dystrophy, we probably will not be able to use this method because of the delivery issue. We can correct genetic mutations in human cell lines, but the bottleneck is the delivery of this system to the whole body. Locally, for example, you can inject it, and locally you may do some corrections. If you inject it into the muscles of the arm, you correct those muscles, but the other muscles in the body will not be corrected.

However, certain genetic diseases, let's say blood malignancies, when there's something wrong with the blood cells, you can correct the blood stem cell. Once you do that, you can introduce that stem cell to the patient, and it will repopulate the entire blood system. Every cell in the blood system can be corrected in this way. That's why blood malignancies are probably the early diseases where this will be applicable.

The second disease setting is cystic fibrosis-type diseases, where the lungs are the area affected. You can have the patient inhale the virus carrying this agent, and this genetic mutation will be corrected in some of the cells. The good thing is that you don't need to correct 100% of the cells in the lungs to get rid of the disease symptoms. If you correct only 10% of the cells, you eliminate 90% of the disease symptoms. This is another disease where this will be applicable early on. We are excited and trying to work in these directions to identify a disease where we can apply this more efficiently.

Brown: Are you the only ones working in this? Are other labs around the world working this way?

Adli: While CRIPSR is relatively new, a lot of people are working on this technology and improving it further, refining and perfecting it. Ours is one of the labs developing CRIPSR-based tools. Companies also are investing heavily in this research. Everyone is picking his/her own niche. Some are using the traditional CRIPSR. Usually the research labs are invested in perfecting the technology and some big companies are using the existing technology and trying to go to the clinic as soon as possible.

Brown: The way you're approaching it, is that unique?

Adli: Yes. What we call the CRIPSR stop, changing these genetic codons to silence genes, is a technique we came up with and first published on. Other labs have worked on the CRIPSR base-editing technology,

but we invented the CRIPSR stop: stopping the protein expression by using base editing.

Brown: Now that you've invented this, will that be knowledge other universities and labs around the world can use?

Adli: We are making all the reagents, everything, open-source. I am a big fan of open-source. We've already published all our findings. We've put all our plasmids and all our reagents out. Everything we've found is out there right now. We want other people to try it and further improve the technology. We are also improving it. We patented it, but for research purposes, it's freely available to everyone who wants to use it in the research environment. We are hoping other people will use it and show that it's efficient and safe, most importantly.

Brown: Are you looking for the best disease to work on?

Adli: Yes, I am reading a lot about genetic diseases. I am talking to the clinical people about these genetic diseases. As a research lab in academia, I'm trying to pick the best disease model to apply this technology to for a couple of reasons. One is that there are certain diseases a lot of companies are invested in it because there is a large volume of patients, and they can make money off of it. But for me, there are some rare diseases, and this could be directly applicable, and a company may not invest in it because there is not a large number of patients. You know how the pharmaceutical industry works. If they see there are enough patients, then they invest in these kinds of diseases.

I as a scientist whose research is funded by taxpayers' money, I am also interested in the diseases where a company may not wish to invest in it, but I can make some contribution to that area.

Brown: When you say "rare," you couldn't work with undiagnosed genetic diseases?

Adli: If it's undiagnosed, of course we don't know what it is. But the rare diseases, let's say you have one in 5,000 people, one in 10,000, pharmaceutical companies are most likely not going to invest anything in it. Sometimes we call them an "orphan disease," very rare genetic diseases. Usually in these situations, foundations or research labs are trying to find a cure for those kinds of diseases.

Brown: If legs are atrophying, you'd be able to inject modified cells in the areas where the muscles are having issues?

Adli: That is the current way some labs are invested in using CRIPSR for muscular dystrophies. There is good success in local areas. In cell lines, we can definitely cure many genetic diseases. The bottleneck is how to

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deliver this systematically to patients. You can inject in local areas, but in the long term, this is not seen as a cure, because you have to inject many, many times, and if that muscle cell dies, your cure is gone. But if you could find a stem cell where you can make this correction and give that adult stem cell to the patient, in theory you would eliminate the disease for the rest of the patient’s life.

Brown: Even if you didn’t, wouldn’t you be at least slowing down progression?

Adli: Yes. With those local injections it should slow down the progression. But for some muscles, for example, the diaphragm or internal muscles, cardio muscles, there the problem is how to deliver to those kinds of muscles.

If the diagnosis is done, injections will definitely be one way to slow it down. Researchers are exploring different avenues in this approach. One school of thought says we should find the genetic reason, try to correct the genetic code, make this correction, and this will be a cure. Other people say that for a lot of these diseases, we may not be able to identify the genetic cause or make the correction, but we can identify the major driver of this genetic abnormality. For example, in some muscle dystrophies, there is not a genetic mutation, but there is an independent accumulation of certain metabo-

lites in the cells. They say that if we can neutralize the metabolites, we would get rid of the symptoms they cause. Those approaches say you can give certain drugs that will hopefully systematically reduce the overall accumulation of those metabolites.

All these approaches are equally viable. Hopefully in the near future we’ll have drug-based things that will eliminate some of the metabolites and help stop this progression.

Brown: What do you think your timeline is for human trials?

Adli: That honestly depends on the funding situation. When the diseases are rare and the risk is higher, getting funding gets tighter. The early things for which we can easily get funding is to say we’re going to apply this to cancer or other diseases that affect many, many people. For rare diseases, I am currently preparing an application for private foundations. Those are the ones where we can hopefully get some funding to start to do this kind of research. Unfortunately, to be able to do any kind of research, I need to hire a post-doc-level person, pay his/her salary and pay for the reagents. For this one, I am currently writing funding grants hoping to get some pilot projects going. ■ **ABILITY**

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Please Take a Seat

INTERNATIONAL TOILET TOURISM AWARDS





We may be on the verge of a renaissance when it comes to toilets and the spaces they inhabit. Travel and tourism researchers Carolyn Childs and Bronwyn White conducted focus groups and quantitative research on the impact of public toilets in tourism destinations. And guess what? The quality of a restroom matters ... *a lot!* Their research revealed that well-designed bathrooms—not the perfunctory standard stall types, but colorful, truly accessible, even entertaining loos—are revenue boosters for surrounding businesses. Thoughtfully designed bathrooms can even become destinations in their own right, encouraging repeat visits.

To spotlight their findings, the enterprising duo, whose company is MyTravelResearch.com, established the 2017 International Toilet Tourism Awards. With 30 entries from Australia, New Zealand, Canada and the US, six winners were chosen. *ABILITY*'s Chet Cooper and Lia Martirosyan caught up with Carolyn Childs to chat about “how they do their business,” the awards and tourism trends.

Chet Cooper: What is your core business about?

Carolyn Childs: Our core business is about filling a gap that we saw in the market, which is that the tourism industry is composed of a very large number of small-to-medium enterprises. They either are not well informed about research or don't have very large budgets to spend on research and good evidence-based approaches to marketing. Bronwyn (White), through her time both at Qantas and then at Destination New South Wales, one of the state DMOs (destination marketing organizations) here in Australia, and I, as a commercial research practitioner, found was when we took research out and talked about it in the right way, people found it a powerful tool. But their perception was that they often didn't know how to use it, and they didn't feel they could afford research.

In the Internet age, there's an absolute mass of information out there. First, there's a filtering job to look at it all and ask, “Which of this information is good?” Because there's a lot of self-interested research published now. Some of that can still be great research because it stacks up. But second, to then bring it down and package it in a way that's affordable. So the core of what we do involves our membership site. It's a very similar model to Skift but slightly lower cost, and we're both research practitioners of many years' experience. So whereas Skift has broadened out to be more of a general news hub with a core of research on tourism, we're still sitting in the heart of researching marketing and consulting. This is what we do. With a monthly membership fee, people can go in and use the content. So really what we do is, we'll take themes, issues, topics, and we'll pull together the research and put it together in very practical and user-friendly ways to say, “Here's what this research is telling you, and just as importantly, here are the practical things you can apply to your business to get better results.”



We've also launched evidence-based products to help small-to-medium enterprises and smaller destinations with their marketing. We've created an off-the-shelf marketing plan where 80 percent of the work is done for you, so the framework is there, and then we coach you to do the rest of it. But we still found there were some businesses for whom even that was too much. So we've just created something where we've said, "Look, if you do these five things, your digital marketing will work better." That's the heart of what we do.

As I'd mentioned to Lia, we also create research products where we see a gap in the market. Again, it's about finding and exploiting gaps in the market, so we syndicate research on topics. We've looked at things like senior travelers. Senior travelers have suddenly become fashionable, but when we did that research back in 2012, people still tended to look at them as wrinkly, old, conservative, grumpy, and with no money. We've demonstrated that's actually not the case. Other research topics have been things like visiting friends and relatives. The final thing we do is take on customized research for clients like any other research agency, but we tend to focus on things where—we've got better and better at saying, "Look, we're working with people who know us and know what we can bring, and we're working on topics we think fit nicely with our business." I mentioned that one of them was around the issue of accessible and inclusive tourism. We're

doing a project for the federal government here in Australia in two of Australia's states on that topic. That's us in a nutshell.

Cooper: That was not a nutshell.

Chids: I know it might have been a bit too long. We're still trying to work out how to do the one-line version of that. *(laughter)*

Cooper: That's going to take a little time.

Chids: If you have any ideas, let us know.

Cooper: I understand you have a membership and certain things are available to members. Can you give me an example of a typical member, if there is such a thing?

Chids: When we think of our customer personas, there are probably two core types of members. One would be smaller destinations, such as local government areas. You might talk about counties or smaller towns. That would be one of our core audiences. And what you tend to find are people who are in the tourism area who haven't always been in tourism. Last week they might have been looking for schools and recycling and suddenly they're put into this tourism. Or even if they're in tourism, they're probably trying to do everything on a very small budget. So that's one type of member.

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The second type of member is comprised of small-to-medium enterprises. They're people who like research, but again they either can't afford it or they don't have time to work their way through it. Those are our two core personas.

Cooper: So one might be a tourism department within the city government or state, and that's whom you'd target as your client?

Childs: Yes.

Cooper: You mentioned having a new product that takes it off the shelf. What would a coming-off-the-shelf product look like?

Childs: To understand the marketing plan blueprint, here's an example: let's put this person in who last week was running recycling and this week has moved into the tourism role, and they've been told, "OK, you're in tourism now, you have to create a marketing plan." First, you're new to tourism, and second, there aren't a lot of marketing plans in recycling. And this is based on a real person. *(laughs)* When we met this person, we were like, "She's so our persona!" Since it's an online product, the client has a microsite. They log in, and there are steps involved.

The first thing we do is "on-board" them. There's a series

of on-boarding webinars where we introduce clients to all of the elements. Then all of the elements are there for them as PowerPoint documents with recordings of coaching calls. For example, we'll do a coaching call on what's a brand and how to populate your brand framework. We'll do a coaching call on how to create customer personas of the type I've just talked about for our business and coaching calls on how to apply macro-trends to your business. We've got a data file that we created for 50 macro-trends that impact their businesses. But then, obviously again, there's a filtering job there. We have a coaching call on how to figure out which trends they should be giving priority to in a plan. That's how the product works.

Cooper: How do the coaching calls work?

Childs: They're group coaching calls to make it cost-effective. We run them on a cycle, twice a year so far, but we're ramping that up to be three times a year. So basically, the client has a series of webinars, and they can click in and join at any time. That product is \$1,500 for members, but it's for the lifetime of the company. As long as we're around, and we're offering the product, those calls will be there.

Cooper: What's your health like? Just joking, it was a lifetime joke.

Childs: *(laughs)* My health's pretty good. I plan long-

term! We talk about being 2.25 people, but we don't want to be a big company, but rather a big network. We have what we call a neural network of people we work with who are experts on particular topics. Having run a number of small companies, I've always got a succession plan for what I call the "bus theory." There's your good health, but there's also the what-if-you're-hit-by-a-bus theory. (laughs) So basically it's a lifetime product. You can click in and you can listen. The plan's been going for a couple of years, so clients have been asked to update it, and they'll click in again. We also have a day once a year in Sydney where we put all of those things together, and this is free for clients. Obviously you have to get yourself to Sydney, so at the moment that benefit's primarily for our Australian and New Zealand subscribers. In all those coaching calls we do a kind of immersion in marketing for a day. That's usually lots of fun. We call it the Tourism Marketing Rock Star Day. Last year Bronwyn was dressed as Amy Winehouse, and I was dressed as Adam and the Ant. We try to make it fun for people, because small businesses and small cities can get a bit freaked out by marketing, so we try to make it fun.

Cooper: That's what Sylvia and Lia are wearing right now, what they're outfitted as. (laughter)

Childs: I wanted to do Abba, but neither of us wanted to wear the one-piece white suit. I wanted to do it the way it's done in Muriel's Wedding, but neither of us quite had the courage. (laughter)

Lia Martirosyan: My hair's too curly for all of those costumes.

Childs: Bron had a wig on. (laughs). We're doing it in September this year, so if any of you are around at that time and want to be part of it. It's September 14th.

Cooper: We have to be in China, but I think it's the 21st.

Childs: We'll send you the invite.

Cooper: Not that China's close.

Childs: Oh, it is. It's only eight hours away.

Cooper: Oh, that's better.

Childs: Sorry. Since I moved to Australia from the UK, I've gotten into that mindset of anywhere that's less than 10 hours is close.

Cooper: (laughs) I know! Whenever I travel internationally, especially to places like the Middle East or China, I always think, "Oh, might as well stop over at so-and-so." I still haven't been to Australia. So tell me about how the Toilet Tourism Awards came about?

Childs: OK. Well, Bron and I have a history of creating things where we keep telling people they should do it and

no one listens, so we get fed up and go off and do it. So what happened was through years of doing research, we kept talking to people about what influenced them to visit particular destinations, particularly on—and this would be very relevant in the US as well—long driving trips, or what made them enjoy a destination or stay longer in it. One of the things that consistently came up was the importance of toilets, knowing there's somewhere to stop.

For example, there's a big northern migration that happens in Australia during the peak of our summer for Christmas and New Years where people would drive from Melbourne or Sydney up to Queensland. That's a long drive. From Melbourne, it's a day and a half of driving. So you do have to stop places. We found people would stop somewhere for a toilet, and if the toilet was good, they would stay and have a coffee there and maybe even have lunch. If it was the right place in the trip, and it was a nice town, and they could see there were places to stay, they might do an overnight stop on the way up. Gradually we saw that as bringing money into small regional communities.

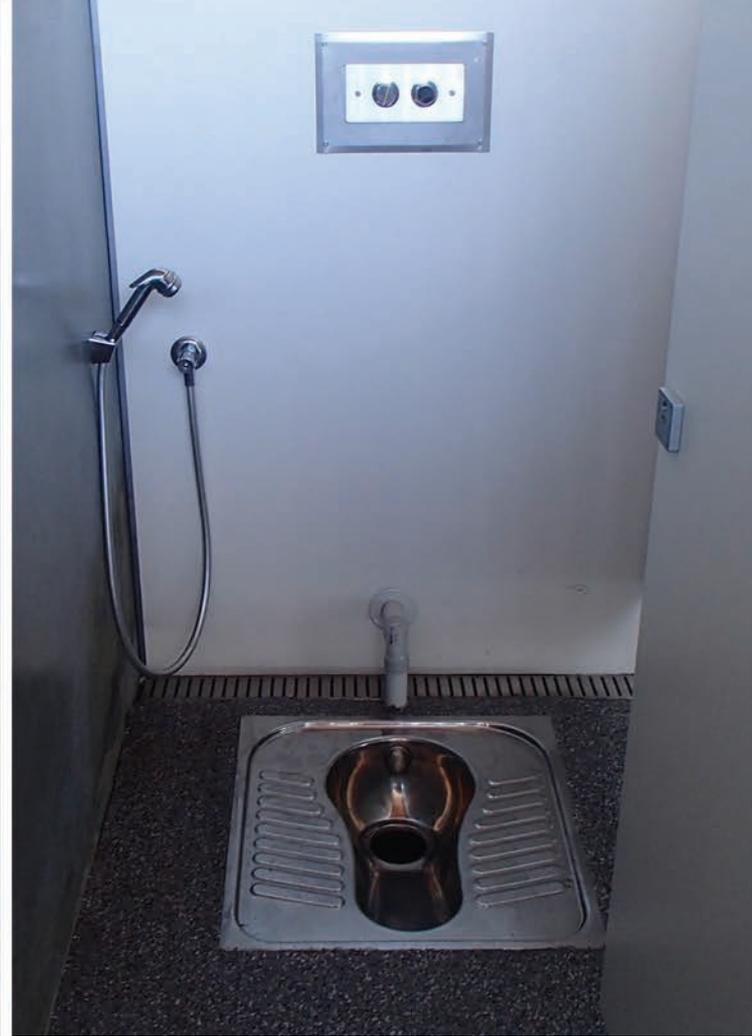
Similarly, I was back in the UK, and when I'm traveling over there I'm traveling with my mother, who's a type 2 diabetic. That means she's not really relaxing and enjoying anywhere if she doesn't feel like when she needs to go to the toilet, she needs to go. What we saw all the time was that the key to people getting the most out of destinations, and we know that people who get the most out of destinations spend more money, was toilets. And we kept talking to the various tourism bodies that give out awards and said, "We think there should be a toilet tourism award." Everyone laughed, but no one ever did it.

So we had a sponsorship we were doing that came to an end. We were looking at whether to renew that sponsorship or do something different. We said, "Look, no one else has done this. Why don't we just do it?" Because we think, to be honest, it's quite interesting. I've had a few people from other awards contact us since this award came out, because we think that once we've got this going, other people will pick it up. The selfish business part of my brain says, "I want to keep this all for ourselves." But we think the more people are talking about this issue and the more people are seeing there is a reward for having great or interesting toilets, the more that will raise the industry's game on this issue.

Cooper: So it came to an end?

Childs: We were sponsoring an award for young tourism professionals here, and that contract came up for renewal. The direction they wanted to go in and we wanted to go in were different, so we said, "It's time we created this tourism award from scratch." So this is our property. We own this asset.

Cooper: But the pun was, it did come to an end. Never mind. Sorry.



Childs: *(laughs)* Oh, sorry! I haven't had enough coffee for jokes like that yet! *(laughs)*

Cooper: *(laughs)*

Childs: It's almost impossible not to use puns when we start talking toilet tourism. The puns seem to—

Cooper: *They just keep coming out!*

Childs: Yeah, it's completely incontinent.

Cooper: *It's gonna hit the fan for sure.*

Childs: *(laughs)* Yes!

Cooper: *I noticed you had an award specifically for accessibility.*

Childs: Yes.

Cooper: *Tell us how you got people to submit. How did you make it all happen?*

Childs: That was through our networks and our PR agency. One of the things we advise businesses to do through our database is to pay attention to PR. We're a freemium model. There's a paywall where most of the content is located, but we try to make sure that the

reason people pay for that is because the content we offer, such as our newsletters, is lots of fun. So we've been building networks through that. So we put it out through our networks and through partners. We're members of PATA, the Pacific Asian Travel Association, and we're members of the Travel and Tourism Research Association, which I mentioned earlier. I am currently the chapter president of Asian Pacific, so we put it out through their networks. We put it out through our own databases. Although we no longer sponsor the Young Tourism Professional award, we put it out through their networks. We did a global PR campaign in conjunction with our PR agencies in Asia.

Cooper: *Where did most of your first submissions come from?*

Childs: It was quite interesting. Our first submissions all came from outside Australia. We assumed as an Australian-based business that would be where most of the applications would be, because that's where we're currently strongest. But initially we had applications come in from the US and New Zealand. But what we've learned is that all these were last-minute types, so suddenly on the last day the submissions were due back in June—we had about 10 or 15 beforehand, and very few from Australia, and then overnight we had another 25. *(laughs)* All from Australia overnight.

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Cooper: Nice!

Childs: So that's how it came about and how we put the word out. The accessible part came around in two ways. As an issue, this is dialing up in importance for all sorts of good reasons, and I probably don't need to tell you what most of those reasons are.

Cooper: I love the fact that you're tying commerce and fun into this. Our nonprofit has been trying to promote accessible toilets globally. As you know, when you travel in certain parts of the world, they don't have sit-downs. It's a huge problem for people who are trying to travel beyond the way they're supported in their homes. It's really, really difficult for someone who can't use that facility.

Childs: And that's what we wanted to do, to inspire people. There is a good side to this as well. Instead of giving people money as a prize, we're donating it to UN World Toilet Day so the prize is that everyone gets membership in all of our products. Each of the winners of the categories will all get that, so there's a commercial angle for us. And we're making a \$2,000 donation in Australian dollars, probably about \$1,600 or \$1,700 in US dollars, that goes into promoting good, accessible toilets. That's something we're passionate about.

I think partly this arose from our point of view as some-

times fun and doing the right thing, but also a really good business opportunity. We're seeing a movement of conscious capitalism. To me, this is an underexploited opportunity, and that's why we tendered for and won this big project in Australia. We said, "We need to move people—." Because even in economies where there are facilities for people with disabilities, we find that it's very often seen as a clients' mindset. It's important we have that, because of the basic human rights of people with disabilities, but we also see a massive opportunity for businesses that prepare to go above and beyond and shift from a compliance mindset to a more commercial and lasting mindset.

Cooper: Are you familiar with the conference that was held in Montreal? It was considered the first world conference on accessible tourism.

Childs: We're familiar with it. Unfortunately, we weren't able to go, but it's very much on our radar. We're working with a partner who specializes in accessible tourism gear. I'm almost certain you'll know him, for he quotes you and your magazine quite a lot: Bill Forrester from Travelability. Do you know Bill?

Cooper: I get a lot of bills, but I'm not sure if I— (laughter). I'm not sure if I know him.

Childs: He's a very widely admired spokesperson on accessible and inclusive tourism here in Australia. He



runs a specialist travel agency for people with disabilities. He's also very much about leading best practices and building the rest the inventory and working with people to develop products that meet the needs. We've partnered with him on the research. We met Bill at a conference here, and we've been talking to him and starting to raise awareness of this issue here. But yes, you're right. It's a huge problem internationally. So we're familiar with the conference but have been focused initially more on working for it here.

For example, I spoke at a conference put on by the government of New South Wales that was not just about tourism, but work-play-live. It was about making sure people with a disabilities have full access, because what's been driving that here is a change in the way we perceive people with disabilities. Our national disability insurance scheme has moved from a kind of expert provision model to a person-centered provision model. It looks at who you are as an individual and asks, "What are your needs?" And within the budget constraints, which I think will get more onerous, it tries to say, "Rather than you having to do it this way."

For example, an occupational therapist I met said, "In the old days, if you had cerebral palsy, you went to the Cerebral Palsy Alliance, and they said, "Here are our providers. Here's what we think you should do. You go and do it." Whereas now you'll have somebody who

looks at your child with cerebral palsy and says, "OK, your specific needs are this, this, and this." Anyone can register to be on that list, and as long as you're on their list of providers, if you want to go to a particular provider, you get a budget to spend on that provider.

Cooper: It's being driven by commerce, which you were saying is the key issue. The other thing they're tying together is not only supporting some stats, but there are dollars behind travelers who happen to have disabilities, plus the tie-in with aging.

Childs: Yes.

Cooper: You tie in the fact that more and more people will acquire more and more mobility issues as they age, and it makes more sense to have areas that have accessibility built in. And again, not just because it's something required by certain local laws, but if it's driving commerce, people will do it. If they're going to make money on having more of an accessible bathroom, and if they could see that as a legitimate reason for putting some monies into it, they'll do that. That's why I was excited when I saw what you're doing. You're having fun. You're putting it out there, and hopefully you tie it in with some statistics. You're saying just in toilets alone, but if you could tie in some stats that say accessible toilets, accessibility in general moves the trust industry, that's really impor-

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tant and close to what we're trying to do.

Childs: At the moment, we're in the process of developing a study that will look at the opportunities and where they are in Australia. As part of this, we are doing desk research. My favorite number from this, and it came from the UK, and I'm desperately trying to remember the source, they talk about the walk-away pound, which is money you don't see, which is something I'm quite passionate about. People say they don't see an opportunity, and I say, "You don't see what walks away." I'm drawn to technology. It came to me, an organization here called Ideas put it in front of me, a number from the UK. It's 1.8 billion pounds a month.

Cooper: *That is interesting. I've never heard of that concept. What an interesting concept to dangle in front of businesses to say, "Look at the walk-away!" I like that!*

Childs: It gets people to think beyond where they are. One of the interesting things they're saying—I'm not allowed to talk in too much detail about the research I'm doing for the government, because it's embargoed until the tourism industry signs it off—

Cooper: *Sure.*

Childs: —but one of the things I'm hearing, and I'm sure you hear it all the time from the hotels, is, "There's never any real demand for accessible rooms. We have to have them, but we can't sell them for the same rate

because there's no interest in them." I'm guessing you hear that.

Cooper: *No, actually, we don't hear much of that. We sometimes hear the opposite that the rooms have been taken. When we travel, we often ask for accessible rooms, and oftentimes they're just not available. And there's another issue, of course, if they're not truly accessible. It's amazing how so many of these hotels have been scammed into what they think is accessible. They stick these little wheelchair signs on all kinds of areas that aren't accessible. There are bathrooms that have the little accessible sign, and you can't even open the door because it's too weighted.*

Childs: Yeah. Interestingly, being a consultant and in places where people tend to view that you can't sell the accessible room, very, very often I get put in the accessible room anyway. My father, when he was alive, was in a wheelchair, so I was at the Pacific Asia Travel Association (PATA) conference in Guam, and I was in this room the hotel claimed was an accessible room. I'm sitting there saying, "You could get into this room. You could get into the bed, you could get into the bathroom and have a shower, but mostly you would have to be in a wheelchair to use the shower, because the floor was slippery because it didn't drain. There wasn't even the slightest slope to drain the water. But, secondly, there was no way you'd have been able to watch the television in the room and certainly no way you'd have been

able to get onto the balcony in a wheelchair to enjoy the beautiful view, which ___the point of being in a hotel in Guam rather than in your own home where everything's adapted for you.

But that's one thing we very frequently hear from the hotel industry in this part of the world, that there's no money in it, and it's something they have to do, and other people don't like staying in those rooms. But one of the things that seems to be emerging from what we've seen is, who's ever promoted those rooms? Who's ever targeted people with a disability and said, "We have these rooms"? How do you know no one's buying them? People don't buy them because they don't know you've got them. That's why I liked the idea of the walk-away pound. And the interesting thing is, it's not all travelers with disabilities. Some of it's obviously from the people who travel with them who don't want to be helping them in a situation where it's more difficult than it has to be, but some of it's also a reputation and brand issue.

Over the years, one thing I've discovered is that even the most affluent and apparently self-centered of people—premium business travelers—judge your genuine commitment to things by how you treat people who need a bit more help. That tells people what's really important to you. Even if we're giving people lots of dollars, we want to be loved for more than our dollars as a customer. One of the things the walk-away pound talks about is the business lost when people with disabilities find it's not for them, and they tell other people who then don't stay. Again, there's still that, "Does he take sugar?" point of view, that people with disabilities don't have friends, don't have relatives who are passionately engaged on their behalf. Even from a brand and reputation point of view, it is really dumb not to do this thing well.

Cooper: And there's this other area of people who might not be using a wheelchair but they definitely need grab bars in the bathroom, and some hotels don't see that as a value. It always boggles my mind. You would think they'd have some slips and falls occurring more than normal, because they're doing the least amount to help people, whether it's aging or just the fact that you can't bend your knee the way you used to, for whatever reason. There are certain levels of accessibility I think should be built into all areas, not just into the hotels.

Childs: I think that's coming. The other thing is, you might have rooms that are better for somebody, where it's not so many steps. If you're somebody who is not in a wheelchair but struggles to walk a certain distance, putting that person in a room at the end of the corridor, when you could give them a room that's three steps from the lift, those kinds of things. It's an emerging topic our microtrends picked up. One of our business propositions is built around the idea of—and I'm never sure if I should be quoting George W. Bush, but there

you go—"misunderestimated" opportunities. We think that's one of the reasons this came to us. We think it's a underestimated opportunity.

We can show there's an advantage and give some PR and credit to people, like the winner of the Most Accessible Toilet at Arthurs Seat Park in Victoria, Australia. ___It's all part of the larger tourism development. They have a chairlift that's fully accessible. It's quite a steep slope to hike up in that part of the peninsula. They've a fully-accessible tourism experience. What we really loved about them was they've integrated it into that, and they've also made it so it's not just for us. This is so the whole region can have an asset to offer. We love that, which is why they were our winner, because they really put it together. It's a fantastic example of a facility that they've invested social capital in, but it's also part of the experience, which is fabulous for people with disabilities.

Cooper: It's such an important topic. We recently published an article on grad student Mei-Li Hey from UCSD who went to Uganda and created a portable accessible toilet seat for people who would need to use local latrines, which is basically a hole. Many people do not have the ability to squat over an open pit. So they designed a portable toilet seat that was made with materials local to the community.

When we travel, we've experienced it ourselves. In some places in the world you can't find accessible restrooms. The first experience was in China, where we thought, "OK, we'll go to a McDonald's, Burger King, KFC, an international brand, and there will be at least a sit-down toilet there." Nothing. You have to really search if you're looking for a sit-down toilet in certain parts of the world. That's just not good for tourism—and of course it's not good for the local people.

There are a lot of parts of the world that are wonderful and thrive on tourism, but I don't think they're thinking about the accessibility portion of toilets.

Childs: Probably not, although we had someone in India contact us who did not submit for the award in the end, and it's not so much about accessibility, but it's a very interesting idea and a great story.

He has one of those hotels you rent by the hour. He spotted an opportunity in the market. He's targeting foreign tourists with the opportunity to have a room where, as he said, it's clean, and it's got its own bathroom with a toilet, so that you can pay for the room by the hour, and because it's India, it's not cheap, but even if you're somebody who doesn't have a disability, access to a clean toilet in India is a pretty valuable thing. And because it's so hot, people can refresh and wash. He spotted a new market opportunity.

He dealt with Bron rather than me, and she's traveling at



just the accessible area. And the other thing, talking to people here, there are apps to tell you where toilets are.

Cooper: I was going to ask you if you knew about toilet apps.

Childs: Yeah. We've come across those. I've a picture on my phone of the app on someone's phone. I've seen a number of people with a disability who travel, and that's the number one app they upload. It's logical. No one is going to have a good time if they know they need to go to the toilet, and they can't. That's kind of a core human need, pretty low down on the hierarchy of needs for human beings. Not for everyone, for there are people who don't mind going behind a bush, but I don't think that's most people. That's what we're trying to do.

I suppose one of our inspirations for doing this is the Ig Nobel Prize. These are science awards that first make you laugh and then make you think. It's sticky in marketing terms because it makes you think. These awards are done around the same time as the true Nobel Prize awards. They're sponsored by the scientific community. They do it for projects they think will get people in the ordinary community talking about science. I personally love the Ig Nobel awards. If it's fun and there's money in it, it will get us a lot further. There's a group of people you'll

the moment and not on the call. But we'd be happy to put you in touch with him. I don't know if his toilets are fully accessible.

Cooper: So his idea is that if you want to come in, use the restroom and take a quick shower, there's a market for that.

Childs: Over and above adulterous Indian couples, there is a market for foreign tourists. And because it's all very discreet, you wouldn't necessarily meet anyone else who'd have any problem with it. You'd just come in, use the room and be there for an hour or for as long as you wanted it. We thought that was a good piece of lateral thinking. And again, fun. It's a quirky story. It'll stick in people's minds. Interesting, even though most of our entries tended to be from more advanced economies like Australia, New Zealand, Canada and the US, the pick-up for this has been very wide. We had press clippings last night picked up in Papua New Guinea, in the Pan-Asian press, and the Gulf news and the United Arab Emirates picked it up and did a big piece on it. Obviously they're looking at the broad tourism area rather than

convince with the worthy moral argument, and that remains vital because we're talking about people's human rights. We should never lose sight of that. But that's not incompatible with saying, "If you've got really wacky, crazy toilets that are a fun place to visit, that will help." I'm sure that will be a major boost to the economy, having accessible toilets, having the accessible tourism attractions.

Cooper: There was a company that was presenting in Montreal at the conference that had a self-cleaning, accessible public restroom. Quite expensive, but the whole thing would clean itself. You'd buy a unit and plop it down wherever, let's say it's in a park or wherever you might place it. I don't know how the company's doing, but the engineering was incredible. I don't know if you've ever heard of anything like that.

Childs: It's ringing bells. It was interesting, because at the conference I spoke at here for New South Wales, a lot of the focus at the moment tends to be on doing this affordable rather than best practice, but I think something like that again becomes a destination. It's one of

the things where people will go to see it.

Cooper: (laughs) Yeah!

Childs: And that's the case that we've had every time. We've done a few pieces on the subject of toilets in the past where we've talked about this. In fact, we got invited to UNESCO and had a brand partnership around the broader issue of toilets. They've made it a human rights issue for women, which is very interesting.

Cooper: Nice.

Childs: It's not about accessibility, but it's on that angle. And they've created a see-through toilet. They put it down on Bondi Beach here in Australia and invited a few of us who have written. Brom was due to go but couldn't, so I went in her place. There's a blog piece on our website about it. It was very interesting. It's a great brand partnership. Unilever, who's one of the big corporations who are really thinking about conscious capitalism—not perfect, of course, but thinking in that space—picked this connection between Domestos, the bleach product, and this connection to toilets. They're sponsoring creating public toilets in places like schools and towns, because apparently it's a reason why women aren't allowed out of the home, because there's nowhere for them to go to the toilet, and there's a huge risk of sexual assault. They created this pop-up loo. It's a fabulous, fabulous thing. It's interesting, because they pop it up, and you get to go and sit in there. They ask you not to use it, of course. It's a strange feeling. No one can see in, but you can see out. You can see people coming up and looking at you.

When they interviewed me about it, I made it into their Facebook commercial on the topic. There are all sorts of people coming up to me and saying, "I saw you in the pop-up loo!" It's genuinely an issue that gets talkability.

Cooper: How could they see you? How did they know you were in there?

Childs: They've got a big display up of this toilet with mirrors telling people what it is. People are walking up to it, and you can see fully around, because it's a one-way mirror. People are asking, "What is this? I wonder if you can really see it?" They press their faces against the glass. It really did give you a good sense of the invasiveness of not having access to a private space to go to the toilet. It was a great partnership because they used it to talk about a lot of the issues. They had a thing where you could spend a penny. I don't know if that's a term you use in North America, but in the old days there were slot toilets, and almost anywhere they used to use pounds as a currency, which includes Australia. We talk about spending a penny, meaning that's money that you put in the slot to use the toilet. They had pennies, and you cast them in the vote for which you thought was the most motivating message about what was going on,

whether it was about access to education or freedom from sexual violence. They had a whole series of topics, and they used that to recruit their message. It was a very, very smart piece of PR.

Cooper: Can you remember if the toilet had grab bars?

Childs: No, it didn't. It would have been quite difficult, because it was slightly up on a pod. I've made a note of the Kenya example, that the toilet you can take with you so you can sit anywhere, I think that's a really nice, practical solution to this issue.

Cooper: It's one solution. If the problem is the people who are designing things aren't thinking universal per se, they're thinking what has been, not going beyond what can be.

Childs: Yes.

Cooper: It's getting to those designers and showing that it doesn't have to cost any more if you design it properly, to build in something you can hold onto as you're lowering yourself to the toilet. It's a different model to think of. I've seen that box before with the mirrors, and you could see out but not in. I didn't quite know what they were doing with it; I've just seen images of it. So it was all a marketing concept for the issues you just brought up?

Childs: Yeah, we were working on a list of key things the tourism industry could do that doesn't cost a lot of money but would incredibly increase your idea. It's the idea that it doesn't always have to be expensive infrastructure. I'd be stealing the credit for this idea, because it was Bill's. He said, "In the average tour company, what's wrong with having a fridge on the bus, and if you've got a fridge on the bus, promoting it so people who have medication that needs to be kept cold, for example, such as injections, diabetics can know their medications are safe on your tour bus?" That's a few hundred bucks. It's a major benefit. It vastly increases your number of people. And to be honest, even a tour guide who's got a bunch of sweets in his/her pocket. Relating it to a personal example, my mother has been a diabetic for a few years, and at first she was absolutely terrible in making sure she had something with her if her insulin level started to shift. Suddenly she'd say, "I need to eat something now," if you just had something there. Or even relatively simple thing like a guide's wearing a microphone with an induction loop hearing on them, so even if you're somewhere where you've got no hard infrastructure, I think those costs would be under \$100. These are some of the ideas we're coming up with. That might be something to think about in the future when we've got the report together. We know people love lists editorially. ■ ABILITY



YOGABILITY

The YogAbility Institute in Santa Monica, CA, offers a therapeutic approach to yoga for people with disabilities and special needs. Its founder, Bea Ammidown, is a certified yoga therapist and former journalist who wrote for *Life Magazine* and the *LA Times* before a head-on collision in 1985 changed the course of her life. Through four years of rehabilitation, yoga proved instrumental to her healing, so Ammidown embraced yoga therapy as her life's work.

A highly personalized approach, yoga therapy is based on an assessment of an individual's physical, mental, emotional, and psychological state. A therapist develops an individualized plan so a student can practice yoga tailored to his or her specific needs and that, over time, alleviates pain and enhances well being.

Nearly 80 years young and nimble, Ammidown teaches classes around town and in her home studio, six days a week. A mother of three and a grandmother of six, she shows no signs of slowing down. She's done numerous videos, including a DVD, *Special Needs Yoga*. Being a senior, she says, helps her relate to her students, especially those with special needs. "I'm very pleased to say how old I am, which sounds younger every year." On a recent, warm fall day, we chatted by phone about her mission, her approach to teaching, and where she gets her indefatigable energy.

Paula Fitzgerald: Tell me about your journey to yoga. What hooked you?

Bea Ammidown: (*laughs*) Well, I was born with loose joints, as they say. My physical therapist says I'm "bendy" rather than flexible. So as a little girl, being kind of double-jointed, I loved doing backbends and splits and dancing, which is what yoga is about—being connected to one's body. That always gave me great pleasure.

Then, after I'd moved to California, I found a book on yoga by Richard Hittleman. That was in 1962. I thought, "Oh, that looks good. Let me do a little something at home." By the early '70s, I learned about yoga classes and good teachers. One was through UCLA Extension, so I became a student there. Many years later, I was in a very serious accident, having done yoga for years, and recuperated after surgeries and various procedures, and I thought, "Well, whatever I have been able to do for myself, I'd love to share a lot of that with others with special needs, and I'd love to put together programs and classes."

I trained at YogaWorks in Santa Monica, which involved years of study. I stopped doing journalism and started giving little classes and then more classes followed. I loved what I was experiencing personally, which also helped my writing, so I taught yoga and writing for years. I continue to do that in special classes and workshops.

Fitzgerald: And when did you start the YogAbility Institute?

Ammidown: In 1999. We are a nonprofit organization that was started on the coattails of my first nonprofit called HumoRx-Laugh Wagons, a program inspired by Norman Cousins' book, *Anatomy of an Illness*, and our friendship. He called it psychoneuroimmunology. He showed himself funny movies and said, "Take less pain medication, because with affirmative emotions we truly assist the immune system."

Fitzgerald: Scientists have proven that, haven't they?

Ammidown: Oh, they certainly have. They continue to prove it with blood tests and other kinds of tests.

Fitzgerald: Is the institute primarily for people with a range of different disabilities and special needs as well as people who can do regular yoga classes?

Ammidown: Yes! I do point out that everybody has sensibilities and special needs and areas where they want more attention. That's what a yoga therapist, who must have the right kind of training, offers. It requires thousands of hours of training. So it sounds very daunting and impressive, but I never stop learning how to approach a student, how to approach myself, and how to be present with my practice.

Fitzgerald: I watched some of your videos, and you have such a nurturing style and a lovely way of relating to students.

Ammidown: Well, thank you!

Fitzgerald: In one video, I noticed a young woman doing yoga in a wheelchair.

Ammidown: Yes, she's been coming for almost 20 years, and she was here this morning. She's now 35. I started working with her when she was 18. It's amazing.

Fitzgerald: What are her particular challenges and how does yoga therapy help her?

Ammidown: She has cerebral palsy. Her mother wrote a testimonial about what she observed the experience was like for her daughter. In 2007, she wrote this: "After four and a half years of weekly YogAbility classes, my daughter has developed better balance, body positioning, awareness and concentration, confidence, community-building, interactions, social graces, and her skills are enhanced. She is so proud and delighted with her accomplishments."

And just today, I came across a 2007 issue of the *International Journal of Yoga Therapy*, and in one of the abstracts, I found this: "The delights and benefits of yoga for cerebral palsy: a case history."

Ever since she began with me, I've said, "Whatever



you're learning, you can share with other people. I'd like you to realize that you are in a special education yoga teachers' training course." So every year I give her a little exam and have her teach some part of the regular class that I give. She just loves doing this.

Fitzgerald: I bet! So tell me, how does a yoga therapy class differ from a studio yoga class?

Ammidown: Well, studio classes, the ones at gyms, for example, are usually filled with students, and the teacher usually does not ask about specifics. I always ask very specific questions. They can tell me if they have any sensitivities, any issues, and any areas of the body I should be aware of. I also always ask whether they like being adjusted or even touched. Some people don't want to be. I feel that's a very important and respectful way of giving a class. In a regular yoga class, you get a set routine. There's often music, sometimes too loud, and not pleasing to some people. One could say it's quite impersonal. Or the very, very hot power ones where people are sweating all over the place—that cannot be very pleasant. But then you've got classes led by instructors who are aware, conscious, and respectful of people.

Yoga studios are on every corner, like Starbuck's. It's important to be very mindful of who you're practicing and studying with and ask the people at the studio, "Tell me about the instructors." There is a newly-owned yoga

studio where I'm now teaching called Mandala Center in Santa Monica. I teach a class there once a week for seniors and those with special needs of all ages, as well as at the YMCA, the cancer center, and in my own home studio. But at Mandala, they're so aware and conscious of who they hire as teachers. You can click the name and read a complete résumé on each one.

In my studio classes, I want to sit with someone, but not for too long, because my classes aren't more than an hour long. At the YMCA they're only 45 minutes, and it's chair yoga, which I also offer at my studio.

Fitzgerald: It sounds like your classes are extremely customized.

Ammidown: Exactly! That's what viniyoga is, in the vernacular. It means adapted for the person. If you have a bunch of people in the class, how can that be given? I could say that's a challenge, certainly for anyone new, but, fortunately, I've taught for quite a few years, and I do look around and observe and then support students in doing what is appropriate and safe.

Fitzgerald: Is there a particular type of yoga that's more suitable to someone with special needs?

Ammidown: It depends on the special needs, doesn't it? I've had students with severe autism. One young man used



to sometimes come with two caregivers. He wore braces and was screaming and hitting himself. And after a class with the right music and the right words, the right environment, the right support, including the caregiver and me, he was calmer. I always like to include the caregiver to see how they can take in what I'm offering and doing.

Fitzgerald: So the caregiver gets to do yoga, too?

Ammidown: A bit, yes. It depends on the caregiver. I've had many, many who participated.

Fitzgerald: With children who have severe autism, what kinds of changes do you see in them over time or even from just one class?

Ammidown: From one class, I couldn't say, but for instance, one boy, who was maybe 16 or 17 when he started, was able to relax and even smile; he no longer yelled and hit. His braces were taken off. It became a very soothing, supportive time for stretching and feeling his accomplishment. We used some of the differently sized balls for him to roll around on—it was just lovely. And there are some pictures of us together. I've written about him as a case history.

And then there are the children with Down syndrome who I've just loved being with. I've worked with one family since their son was three years old. He wasn't

really ill, but they needed someone to help him go down a slide and different things like that. He's now in his twenties and he's a soccer champion.

Fitzgerald: That's wonderful!

Ammidown: He even takes yoga classes now. So his story is a beautiful one. His parents are terrific. I would go to his home, and I would ask his siblings or a parent to participate, if they were available. It became a community event.

Fitzgerald: So you make house calls, too?

Ammidown: Yes. I did then. I make fewer now.

Fitzgerald: When you teach, do you incorporate different modalities, such as music?

Ammidown: Yes. If I don't know the people, I'll ask if they like soft music. In private classes, I ask, and I absolutely respect and honor their wishes. But it also depends on my own mood. Sometimes I want the silence as well. And I like them to hear their own breath. That can be very effective and relaxing and a game to bring the awareness. At the YMCA, I always play some music, but it's very soft.

Fitzgerald: Do you ever do yoga in the water?



Ammidown: Yes. I've taught in a friend's pool through the years. It's a very shallow pool and it's warm, and to do yoga in a pool is just heaven. My other regular student who has cerebral palsy—she drives and lives with her boyfriend and has a job and everything—had me come to her pool at a gym and give her appropriate exercises to do in the pool. That was marvelous, doing yoga in a pool.

Fitzgerald: *I'm curious how you tailor yoga poses for people in wheelchairs or those who have extremely limited mobility.*

Ammidown: I've had quite a few students who are paraplegics. The bridge pose is a really good one. If their legs are down or their legs are out, there are ways of tightening the glutes and imagining you're lifting your pelvis, that is if they have awareness in that area.

Those that can, I have them hold their arms out to the side making circles using weights. I have weights of all sizes and some that go around their ankles and wrists to help build strength. And then there's just being able to lean forward with the right kind of back support. That can be very nice. You can put five or 10 pound weights on top of the thighs or knees, or sitting down with their legs out straight, as straight as they can have them. I have bolsters of all sizes and shapes that are utilized for the right kind of support for the right kind of condition.

Breathing is *the* most important. That's where it begins. Of course, we know that's how it ends. I've practiced for years at different assisted living places and have had 10 to 20 men and women, and if all they're doing is breathing and being present, they're doing yoga.

Fitzgerald: *Can you gauge healing in somebody with special needs?*

Ammidown: I can't, but they can. (*laughs*) It depends on what they're healing. With broken bones or bad shoulders, that's one thing. Mental and emotional healing, we know that's different, but we also know yoga means "connection," that's how we connect our body's talking and feeling to the mind and to the heart, to the spirit. Having been through that really serious accident in 1985, I came back to the US and had 15 different surgeries and a leg shortened. I had to learn to walk and talk again.

Fitzgerald: *And your yoga practice helped you through the surgeries and recovery?*

Ammidown: Yes, fortunately, I'd done yoga for years, and I had support from people. I'd decided to move forward and began swimming as often as I could in my neighbor's pool. Someone had to carry me to and from the pool. I also worked out on a stationary bike to build my muscles, and I saw I was going to come back to my regular self. I had to have a leg shortened. I didn't want



to wear a built-up shoe anymore, because I like to dance and walk and hike, so I saw that what I could do for myself I might be able to share with others.

And then two years ago, I fell off a curb on my way to take a computer training class. I was carrying things that were too heavy, and my eyesight had been also very badly damaged in the accident. I fell off a curb, and I broke both my arms and wrists.

Fitzgerald: Oh, that's awful!

Ammidown: It was terrible. For two months, I had both arms in a cast up to my armpits. I had to be taken care of. I had to be washed and fed. But I taught yoga probably the next day.

Fitzgerald: You're kidding?

Ammidown: I'm not kidding.

Fitzgerald: How were you able to do that?

Ammidown: I sat in a chair. I'm telling you, when I am doing my own practice, let's say I even had a bad cold—of course, if I had a fever I wouldn't do it—but if I had a bad cold, and I'm not sniffing, I do my yoga, and I feel all right. And then I'll go back to bed and be sick. Sometimes that happens.

Fitzgerald: How do you see your mission as a yoga instructor?

Ammidown: My mission is to be able to give back from the abundance and wealth that I have.

It's to be able to reach the right people at the right time to share, instruct, educate, and inspire them through my on-going training about how they can use their bodies to

feel better, think better, do better, and make a difference in the world.

Fitzgerald: Do you have a favorite pose?

Ammidown: I do. It's the shoulder stand. That was a favorite when I was pregnant with my daughter in '62. I just love being in this inverted position. But nowadays, because of different reasons, I use a block so I can get my legs up, and it's just marvelous. But then, I also love down dog. I did so much of that already today. I've given two classes and taken one class already today.

Fitzgerald: You do yoga with such enthusiasm and joy. How do you keep your energy up?

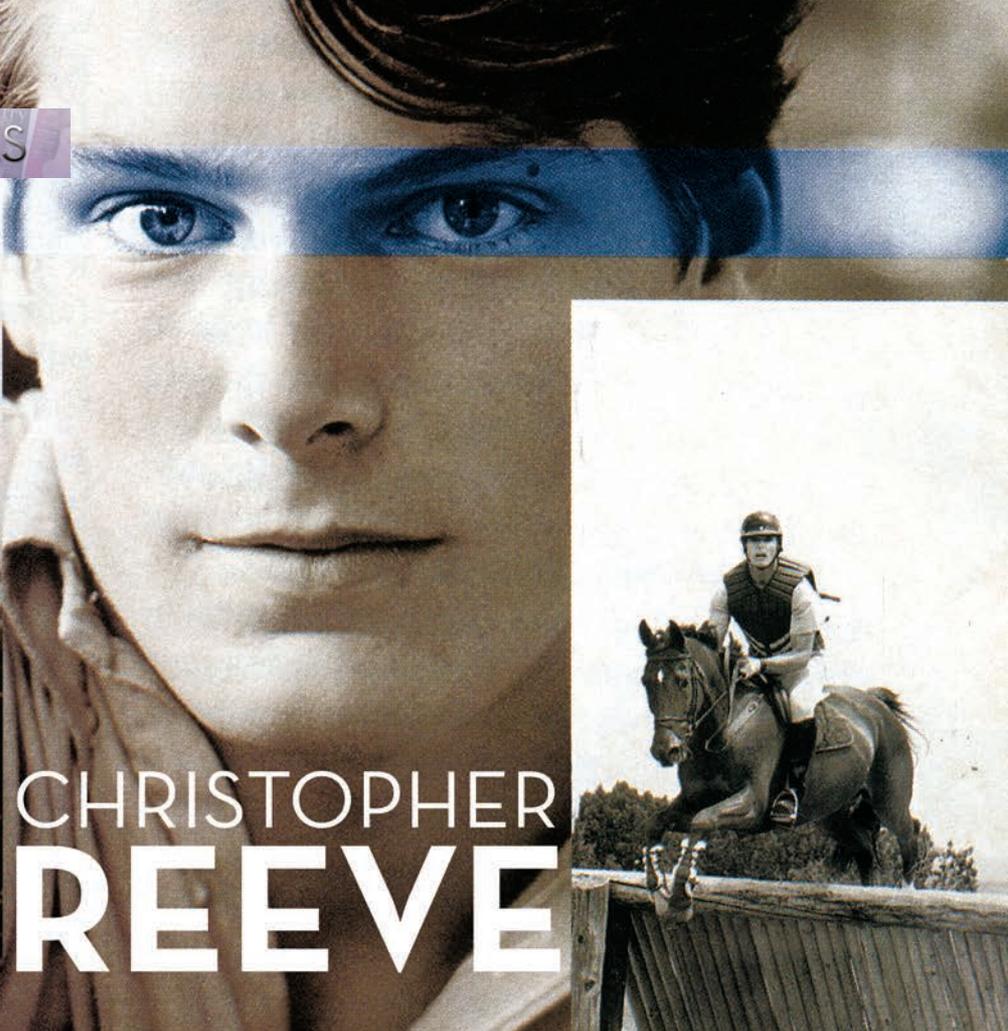
Ammidown: I do. Of course, we know about the importance of nutrition. And I still drink coffee and have ice cream. *(laughs)*

Fitzgerald: That's good. You've got to make time for the little joys.

Ammidown: Yeah! In addition to nutrition, it's also connection to spirit and to my higher power. My spiritual world and life is present. I pray to grow more effectively each day. It's knowing how to give back and be open to receive, too.

Fitzgerald: A lot of people scale back in their 60s and 70s, but you seem revved up, ready to go.

Ammidown: Yes, I would say now more than ever. Being around the right people is really important. Not turning on the news at night. Having the right literature, the right sounds, the right silence. That's how. ■ **ABILITY**



CHRISTOPHER REEVE

As we gather the articles and scan the interviews we see Christopher Reeve does change into his role of Superman and leaps tall buildings. These interviews do not address Dana—keep your eye out as we continue our Archive Series

We, at *ABILITY*, were delighted by the invitation to interview Christopher Reeve. We were anxious to know about his personal progress. He has been consulting with distinguished physicians worldwide, and we knew of his full agenda working on behalf of cures for diseases of the central nervous system—a great many speaking engagements, television appearances and the establishment of a foundation to support this work.

We also knew Christopher has been thrust into the role of spokesperson for the national disabilities community, and we are aware that this doesn't appear to be going especially well. We concluded it would be informative to talk to him, discuss recent developments and issues about the disabilities movement, and to gain Christopher's view of the controversies about his role in these various activities.

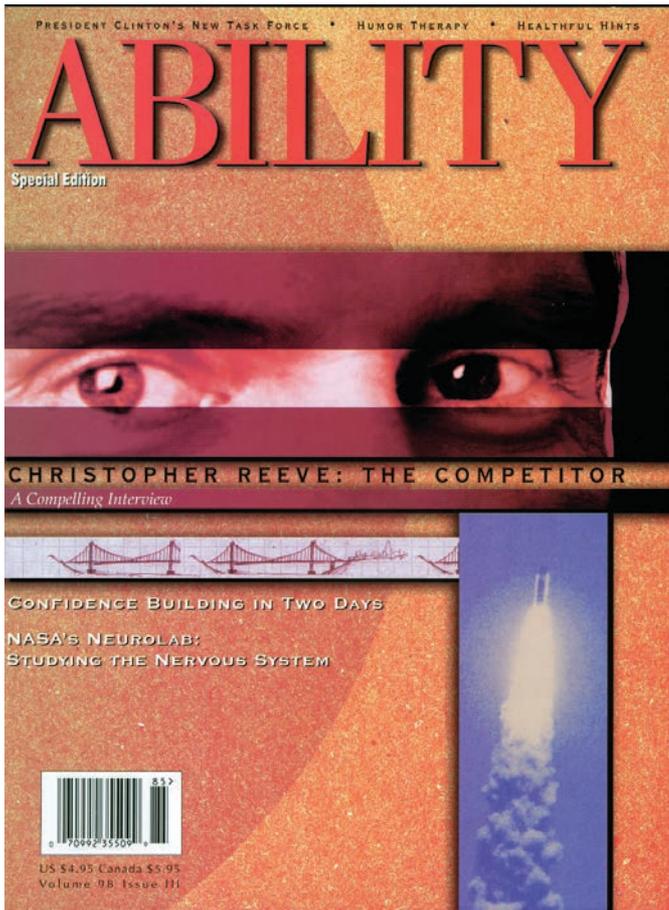
Our plan for the interview included facilitating a telephone link between Christopher and disability activist, Dr. Frederick Fay. We met with Christopher and his

wife, Dana, at their spacious home in New York, in the woods—a reasonable commuting distance north of New York City.

Our collective first impression was that we were in a house designed for a large man. Generous rooms, big chairs, not a lot of furniture, sort of rough and ready—a place for people who want to experience and make the most of every season. On closer examination, it seemed that the fundamental sensibility at work was accommodation to a person using a wheelchair. Hardwood floors, not many rugs, a very operational space. It is not a house appointed by an interior decorator; instead, it is the home of a family whose overriding design scheme is to choose things that are personally meaningful—objects were selected because the people who there like them.

As the day advanced, we didn't change our minds about our early impressions—only the primary intelligence at work. It became obvious that the most important thing going on in this house is the thoughtful, considerate and supportive rearing of the children. It's a kid's house. It is a place for children to gain greater confidence and self-esteem. There are children's drawings and paintings everywhere, on the walls and, of course, the fridge and cabinets. Evidence of developing awareness, special visions, further insights, and a loving family.

It is a lush, rural area, with a watercolor-esque pond visible



through the window, not far from the house. Looking very much like Walden, it seemed an immense bottomless pond. That house was also a marvelous place for a conversation, a telephone link between Christopher Reeve and Dr. Fred Fay. And as a conversation between these men developed—ripened—it appeared bigger; a large place where large people gather to talk about large things; matters of being and of not being, individual responsibilities, heady social agendas, ultimate goals, final issues and what it means to be a person.

Not far into the conversation, it became clear that, whatever their differences, here were two men who liked—respected—each other. As time passed, a piercing light from the overhead window moved across Christopher's pillow toward his face. "Would you like for us to close the curtain? The sun will soon be directly in your eyes."

"No, it comes in every day at this time, it feels wonderful."

The sun did fall across his face; it was hot, and Christopher perspired. It was a very personal, highly sensory experience—the kind of thing essential to feeling completely alive.

Background

When John Wayne first met Christopher Reeve at the 1979 Academy Awards, he turned to Cary Grant and said, "This is our new man. He's taking over." Fresh

from starring in the hit movie *Superman*, Reeve was a hot property. Unfortunately, it was this very role which made it so difficult for Reeve to fulfill the promise Wayne and others had seen in him. Not because he didn't have the skills, but because he had played the part of Superman so well.

Reeve would soon learn, like many actors before him, who once you've played the American icon and hero, that it's tough to just drop the cape and tights for another role. Even a Julliard trained actor and Cornell University graduate who had played so many of the classics on and off Broadway had to come to terms with the fact that he was now typecast as a comic book hero. The image persists today, even after his 1995 accident. A soon to be released biography by Chris Nickson, entitled *Super Hero*, begins with the following passage:

"Christopher Reeve might have portrayed Superman in the movies, but no one thought he might really be a superman himself. Until May 1995, when he was thrown by his horse and left paralyzed. For many people, that would have been the end. They'd have simply given up. For Reeve, it was a new beginning, an accident that really did transform him into a superman. To many Americans—indeed, to people around the world—he's become as symbolic in his wheelchair as he ever was in a cape."

The story has been almost too compelling not to make the allusion to his most memorable role. Yet, as we continue to know and recall him as the Man of Steel, we fail to notice that there has always been so much more to Christopher Reeve than the comic book hero.

In many ways, Reeve's heritage reads more like an epic novel than a dime story picture book. He has traced his own lineage to the thirteenth century and the French aristocracy under the name D'Olier. During the French Revolution, several members of this family lost their lives. His great-great-great-grandfather, William D'Olier escaped to Ireland and then moved to Philadelphia during the Great Famine. Between William and Chris, the men in the family include a president of Prudential Insurance, a founder and commander of the American Legion and a celebrated literary academic. Christopher had a lot to live up to before he ever heard the name Superman.

As a child it didn't look like he would fulfill many of these expectations. He was sickly and shy. When his parents divorced, he became ever more so, almost entirely drawing himself inward. Serious and often awkward, Reeve tended to gravitate toward solitary activities. He felt most comfortable honing his cycling, fencing, sailing, skiing and horse riding skills. His stepfather did not allow television in the home, so Christopher turned to reading and academia, much like his natural father, a professor at Yale and Wesleyan. Eventually, he found his life's calling—the theater.

Between the ages of eight and 16, Reeve worked in a



number of plays at the Princeton Day School, Princeton's McCarter Theatre and, during summers, at the Williamstown Theatre in Massachusetts. At 16, he had an agent and was aspiring to attend Cornell University. In the heat of the early seventies, with Vietnam and Watergate boiling over on college campuses, Christopher ignored the activism and turmoil. Instead, he concentrated on acting, and it eventually paid off with an invitation to New York's esteemed Julliard School for Drama. Here he met William Hurt, Kevin Kline, Mandy Patinkin and ended up rooming with none other than Robin Williams. The courses allowed him to polish his skills and complete his degree at Cornell.

Yet, before he could finish his time at Julliard, he was drawn away by his first acting job outside of theater. His role as Ben Harper on the Soap Opera, *Love of Life*, allowed Christopher to get a good apartment in New York City and eventually buy a small plane. He flew around the country like a barnstormer, often landing in a field and sleeping under the stars. One night in Chicago, the next night in New Orleans; all during the era of free love and a rising fame. While the temptations were enormous, Reeve stayed focused and landed a prime role on Broadway opposite Katherine Hepburn. His work there eventually led to the casting call for the role—*Superman*. A casting agent picked his photo out of a Screen Actors Guild file and saw he had the dramatic background to play the part.

Now, most actors would have been thrilled, but Christopher was never fond of comic books. In fact, he had no real childhood memories of the character. But, it was work, and it was a big budget movie. People often think Christopher won the part because he looked so good in the suit, but that was not exactly the case. Instead, it was his Clark Kent, glasses and all, that left the producer and director convinced. He had the ability to look and act like a nerd one moment and a super hero the next. There was little argument over his casting and he was sent on his way to Pinewood Studios in London to begin filming.

The producers had thought that Robert Redford, Paul Newman, Warren Beatty, Clint Eastwood, Ryan O'Neil or maybe even Bruce Jenner would play the part—but they got Christopher Reeve. Who was that again? The producers were so worried that Reeve wouldn't draw an audience that they gave Marlon Brando the highest salary in Hollywood history, \$3.7 million for twelve days work and a few minutes on film to play Superman's father Jor-El. Reeve got \$250,000.

Christopher had to look good in a suit, so he immediately started on a new diet and weight lifting regiment with David Prowse, the actor who played the physical part of Darth Vader in *Star Wars*. He increased his weight by thirty pounds and added four inches to his chest and three inches to his biceps. His bench press went from a measly 100 pounds to 350.

While getting lunch one day in his Superman costume at the commissary of Pinewood Studios, he stepped on the toes of a modeling executive names Gae Exton. He pursued her relentlessly and eventually got her to go on a date with him. When *Superman* was screened for the Queen of England, he took her along and introduced her to Her Majesty. Now, how could a woman not fall for a man in a Superman suit who takes her to parties with royalty? They became a couple and eventually had two children before separating in the late 1980s.

After a long and troublesome shooting schedule, with Reeve doing all his own stunts, *Superman* made its American premiere at a Special Olympics benefit attended by Jimmy Carter, Barbara Walters and Henry Kissinger, in Washington DC. In the first week of release, Hollywood realized it had discovered something special. When Reeve was asked how it felt to be a movie star, he remarked, "I don't know. This is only the third day I've been one. Come back in a year and I'll tell you." The reviews were in and the writers loved him. One reviewer called him "ridiculously good-looking" and another "the living equivalent of comic-strip art." The public loved it, as well, and the film became one of the highest grossing holiday season releases ever, eventually taking in over \$300 million. When the Oscars came around, the film received four nominations and took home one award. While Chris was not nominated, he had arrived, and everyone waited to see what he'd do next.

He was being offered a very big script in Hollywood. He turned down *Urban Cowboy*, *American Gigolo* and *Body Heat*. When asked why, he remarked, "I found the idea of a man servicing older women for money quite distasteful... [And] I didn't think I'd be convincing as a seedy lawyer." Instead, Chris opted for a \$500,000 role as the male lead in the romantic classic *Somewhere in Time*. Reeve justified taking the part of Jack Collier by reasoning "I like the character—a man who's incomplete. He has all the material things he needs, all the comforts, but he's missing a passionate commitment to something other than himself and goes in search of it." Perhaps this role was not that far off of Reeve himself. During the filming the location, a small island in Michigan, was so inundated by fans, Reeve eventually made a deal with the crowds. He had to promise to tour the state and sign autographs after the shooting was done to get the production back on schedule.

When the movie was released, it seemed much of America, and certainly the critics, weren't quite ready for Superman to play a romantic role in a fantasy period piece. But Christopher had already agreed to do *Superman II*, and for many of his fans they couldn't wait. When it was released, the critics gave the film positive reviews and the box office reception was very strong.

Yet, Christopher fought hard, perhaps too much so, to distance himself from the image of Superman. In a string of films in the eighties, he chose roles in smaller

budget films that would force him to be everything the Man of Steel wasn't. In *Deathtrap*, a murder mystery with Michael Caine, he played a gay psychopath. While his acting got some good reviews, people were clearly not ready to see Reeve kiss Caine on the lips. In his next film, *Monsignor*, he played a Roman Catholic priest who befriends Mafia members and seduces a nun!

His fans and the critics did not receive these efforts kindly and only reiterated their support for his career when he once again donned the tights and cape for *Superman III* with Richard Pryor. This time around, the film didn't sit as well with critics, but was still a substantial draw at the box office. With this effort, Reeve seemed to be ready to please with his audience to let him leave the role behind him. In an interview, he remarked, "Look: I've flown, become evil, stopped and turned the world backward. I've faced my peers, rescued cars from trees. What is there left for Superman to do that hasn't already been done?"

His next two films were indicative of the non-Superman roles and projects he had chosen in the past. Both were period pieces, the first was called *The Bostonians* and the second *The Aviator*. The latter was so bad that Reeve tried to convince the producers not to release it. He followed these two pieces up with yet another historical role in the CBS TV movie *Anna Karenina*. None of these efforts seemed to play up his strong point and did little to advance his career. Once again, Reeve had to pull out the cape for one last go at the super hero.

For *Superman IV*, Christopher received \$4 million and got the producers to agree to support his own project, called *Street Smart*, as well. Both productions were troubled by money, and *Superman IV* was released with some creative editing before it was even done. Even so, a rough cut of Reeve in his most famous role did better than any of his other projects could.

Reeve was trapped, and he knew it. No matter how hard he worked for roles that would be the antithesis of Superman, his fans and Hollywood producers were not going to let him break away. When one understands the very nature of this entrapment, it becomes easy to understand why Reeve often cringes, even today, when people allude to him as a super hero.

With his career in question, and his personal relationship with Gae falling apart, Christopher seemed to be losing direction. He did what he knew best. He went back home and worked in the theater as much as he could. One evening, while taking a break, Reeve went to cabaret and became enamored with one of the performers on stage. Her name was Dana Morosini and, like Gae, he had some convincing to do to get her to go out with him. In the end, he won her over. Reeve was in love again and it revitalized him.

He began to become more involved with politics,



campaigning to clean up the Hudson River and even risking his life by leading a rally in Peru against Pinochet government. Whispers and rumors circulated that perhaps Christopher might want to run for office. Yet, he never really took them seriously. He knew what he was—an actor, and he still had a strong desire to show it on the big screen—without the super hero costume.

He took a role in a moderate success called *Switching Channels*, which actually called for him to bleach his hair blond. But, this film didn't turn his career around. He had lost the "hot" label and wasn't getting any scripts. Without Dana Reeve, he may have fallen apart. But, his love for her and his continued work on the small stage and television kept him going. At 37, Reeve found that if he wasn't doing films, he needed to fill in the gaps with something that was really important and could make a difference. He turned to the environmental movement and became a committed activist. He began narrating historical and journalistic documentaries and fought to preserve federal funding for the Arts. As he said himself, "Real life hit me in the face in the eighties."

And in the early nineties, things began to look up again. He and Dana decided to marry and had a son of their own. After being virtually invisible on the Hollywood movie scene, producers started coming back. He worked on two well-received films back to back called,

Morning Glory and *The Remains of the Day*. These roles were followed by his part in *Speechless* which also brought him good reviews. One critic wrote, "Mr. Reeve has quietly evolved into a versatile character actor... It's only a matter of time before he is 'officially' rediscovered and celebrated, like John Travolta."

Just as he seemed to be escaping the label of Superman and reviving his film career, a freak accident while competing in a cross-country horse competition left him paralyzed below his neck. Reeve thought of suicide as he woke in the hospital. With Dana at his side, he asked her if she would just "let him go." As he recalls it, "Without missing a beat, she looked me right in the eye and said, 'But you're still you and I love you.'" From that moment, Reeve has committed himself to one day walking again. His work since the accident has been entirely indicative of this cause. He was the host of the 1996 Paralympics and gave a speech at the 1996 Democratic National Convention. He has kept busy with over fifty speaking engagements a year and worked as a director on a HBO movie called *In the Gloaming*. His political work has turned to reforming healthcare and increasing research money for the study of the spinal cord and central nervous system.

Ironically, his accident has only served to resurface the super hero allusions. One can almost see his discomfort on the inside when people bring it up. Of the 36 photos

in his soon to be released autobiography, only one is of him in the famed Superman suit.

Christopher seems like a natural spokesperson for the disability community and the media has all but anointed him as such. People with disabilities have long been America's largest minority group. Yet, for the most part, they have remained faceless in the public perspective. After the shock of the accident and relief for Reeve, people began to see a real opportunity to put a "face" on the disability civil rights movement. In fact, he seemed ideal for the job of spokesperson—an actor and political activist with enormous charm and a Hollywood smile.

This left Christopher Reeve staring at a fork in the road. From one direction, there was the potential that he could publicly lead an emerging civil rights movement for people with disabilities. From the other direction, there was the prospect that he could work for a cure—a get out of disability free card—which would not only allow many people with spinal-cord injuries to walk again, but also lead to therapies for other neurological disorders. The dilemma? It would be difficult for any one person to advance both causes at the same time. The need for a cure is best advanced by highlighting a normative need for people to be able-bodied. On the other hand, promoting civil rights for people with disabilities would involve encouraging people with disabilities just as they are.

The Interview

Chet Cooper: Christopher, are you aware that there has been controversy about you being considered a spokesperson for people with disabilities?

Christopher Reeve: I have heard of sporadic incidents. I think at one or two of my speaking engagements, there were people who wanted to meet me and talk about it. But, I don't have any idea of the scope or the scale of the dissatisfaction.

CC: The concept, in general, is that you have been launched into position as a spokesperson for people with disabilities.

CR: I wouldn't define myself in that way.

CC: But, that seems to be the perception in the country. With the media's intense focus on your story, you are, in a sense, considered an advocate.

CR: I can't speak for all people with disabilities because I have very limited knowledge of all disabilities. I am mostly aware of spinal cord injuries, Multiple Sclerosis, Parkinson's Disease, stroke and Alzheimer's—all the diseases that affect the central nervous system and the brain. I talk to researchers and mostly focus on those conditions. There are so many other things and I can't take on the mantle of responsibility for everybody and all conditions.

But, I'm doing what I can to raise awareness. That was the purpose of the television special on ABC a couple of weeks ago. I mean, to get two hours of primetime on national television during the ratings sweeps was to not only highlight spinal cord injuries, but to also show at least three disabled performers, two comedians and a dancer, was frankly unheard of. Also, in my foundation, 30 percent of the money we raise goes to quality of life issues for people with disabilities. My personal vision and focus is on research, therapies, interventions and cures.

I feel I have the right to put my energies where I want them, as does any other individual with a disability. If some person with a disability says, "This is hopeless" or "This is a waste of time" and that I shouldn't be doing that, then that is their opinion. It's almost like any public figure, there are going to be people who think that Bill Clinton is the best thing that has ever happened to America, and there will be other people who think that he is lying and that he should run out of the office. There will always be differences of opinion about things when you are a public figure. I realize that's part of the deal.

CC: So you, in a sense, have been launched as a spokesperson for an organization that you don't want to be a permanent member of? What would you say to the person who had never been able to walk and never will, regardless of what happens with your research? Their belief is they don't need to walk to be a whole human being. They are able to live a fully functional life, independent of walking.

CR: But, I've never said that they are less of a person. In my condition, I would prefer to walk rather than not walk. That's where I am coming from, and if there are other people to whom that is not important, then that's their choice and, you know, so be it. I am not judging anyone's particular beliefs or value system. All I am saying that there are a lot of people out there in the same condition as myself that would rather not be in a wheelchair. We were not born meant to be living in wheelchairs. We were meant to be walking upright with all of our body systems fully functional, and I'd like to have that back. I was not elected, nor was I appointed. I never went out and said I would take on the mantle of representing all people with disabilities. I can't do that. No one individual can.

One individual may be able to represent AIDS because it's a very specific condition, but I don't think there is anyone with AIDS who keeps wanting to have AIDS. The recognition after Rock Hudson's death and Elizabeth Glazer's child, the work that has been done by Elizabeth Taylor or by Betty Ford on substance abuse, have all happened because of a human face that people recognize and attach to the condition. And a lot of forward progress has been made. To ask me to represent all people with disabilities is unfair, and impossible.



CC: There are so many issues surrounding people with disabilities.

CR: And that's why I can't represent them all. I am not the spokesperson for people with disabilities.

CC: But, because of your marquee value, you are the most prominent person that I know of to have a severe disability. You are already changing the perceptions. The fact that you have a limited mobility but have remained as productive and active as you are, really shows the world some significant things about people with disabilities. Let's get Dr. Fay to interject in this conversation.

Dr. Fred Fay (via teleconference): I've been following you in the world wide web.

CR: Is someone running a web site that chronicles what I am up to?

FF: Yes, there are actually several with a whole lot of information on the various TV shows and movies you've involved in and a detailed history of your recovery and lifestyle. I'm wondering how accurate they are? Now, I see that you've been very busy and successful in focusing public and media attention on spinal cord issues. What is your sense on how long it might take to find a cure?

[Dr. Fred Fay: psychologist, community organizer, and political activist. Dr. Fay co-founded over a

dozen organizations. He currently chairs the Democratic National Disability Advisory Committee and chaired the disability constituency for the Clinton/Gore campaign. He is also a founding board member of Justice For All, an organization formed to defend and advance disability rights in Congress. Fred Fay has a Ph.D. in Psychology. Paralyzed at the age of 16, years later he was diagnosed with a spinal cord cyst, which prohibits sitting upright. In 1987, he developed his "power wheel-bed." It gets him around his house and acts as his communication center to the world. Fred Fay was interviewed in Vol. 98 Issue 1 of *ABILITY Magazine*.]

CR: Well, I think it will be a combination of approaches. They are working on gene therapy, nerve cell transplants and regeneration. It seems they believe regeneration is the best answer. You don't have to regrow the whole new spinal cord. In effect, you just need to bridge the gap. This was proven to me the other day when I was at UCLA and I was put on the treadmill. Just like you'd find in any gym. I was suspended in a parachute harness with my full body weight on the treadmill. As the treadmill moved, my right leg went back and my flexor muscles in my hip picked up my leg and transferred the weight to the other one and I moved forward and walked with a practically normal gait without any information coming from the brain. It almost seems like the spinal cord has a memory of what to do. For people who say you need to bridge the gap, which for my case

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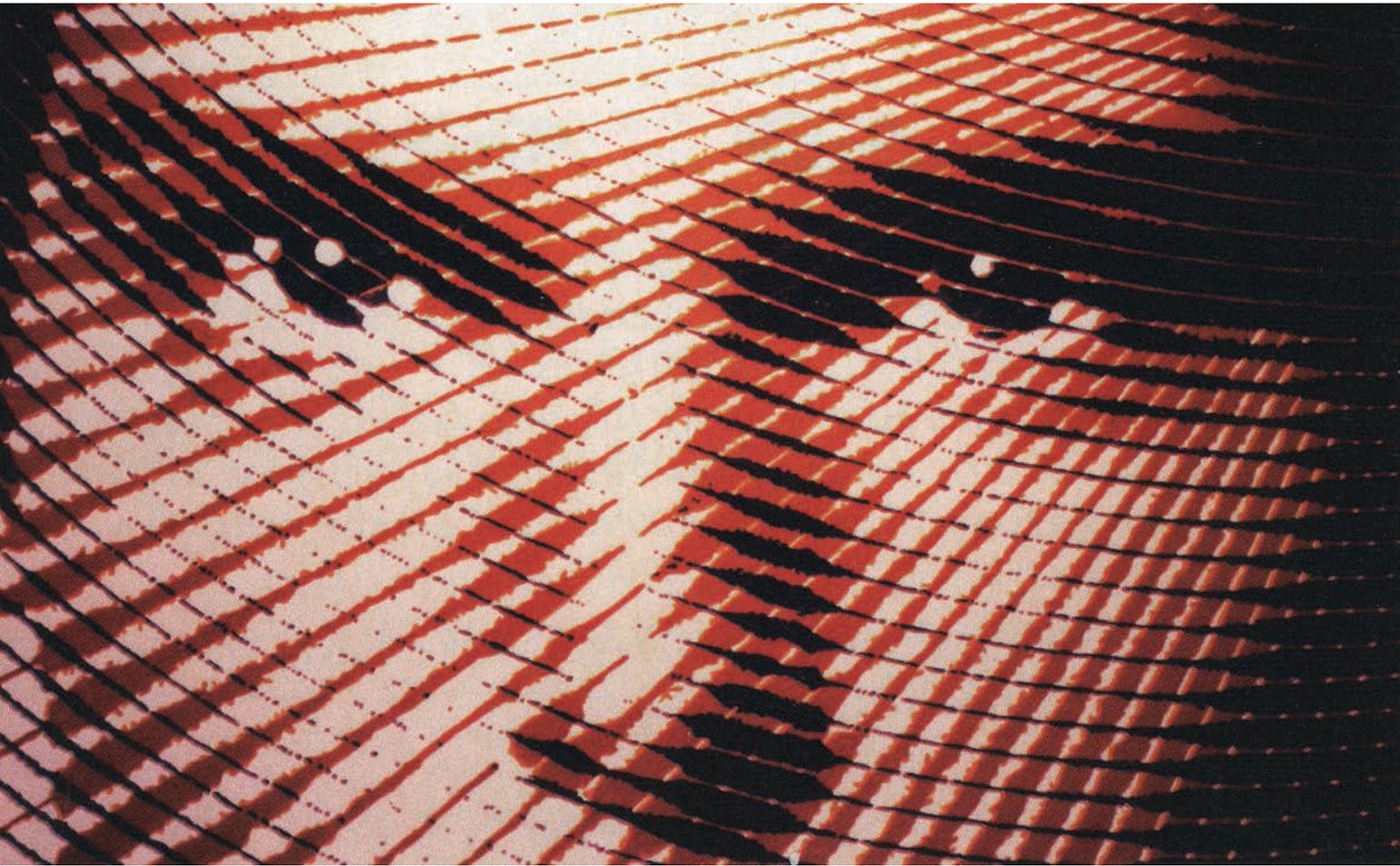
is only 20 millimeters, that seems to be very probable to me. Of the leading researchers in the world, I regard the number one man as Dr. Martin Schwab in Zurich. He has achieved a full recovery in rats who have had their spinal cords transected. On a scale of 0 to 14, where zero is no movement and fourteen is normal, the rats are now walking at about a level of 12.5 and to the untrained eye you wouldn't know anything was wrong with them. The next step is to humanize the antibody to this protein that inhibits regeneration. My understanding is that if all goes well that he will be ready for human trials within a year.

FF: Justin Dart, who I believe you met at the Paralympics, has just received the Presidential Medal of Freedom, and said the other day that, "The Disability Rights Movement has lacked a great communicator. If Christopher Reeve were to champion civil rights for people with disabilities, then he would have the opportunity to become the front-page advocate that our movement has lacked." Do you think down the road that you could find yourself fighting for the rights of people who are blind or deaf or developmentally disabled – an altogether broader coalition of people with disabilities?

CR: Well, I don't think that I would be able to be a spokesperson for people with all disabilities because it's such a widely diverse group and there are so many attitudes that people have about disabilities. I was just say-

ing a minute ago here that pretty much everyone who has AIDS would want to be cured, they would rather not have AIDS. In the Civil Rights Movement of the 1960s, everyone involved wanted equal and fair treatment so there was unity behind the movement. But, there are some people who have been in chairs for a very long time who say, "there is nothing wrong with me." They don't believe that a cure is possible and that it is a waste of time or maybe they are just in a mindset where they think research is irrelevant. So, it is very hard to represent the entire disability community. I am doing what I can, based on my own beliefs. I think that is all an individual can do. I am trying to share the effort on behalf of others. I am primarily concerned with diseases of the central nervous system and the brain. My focus is on cures. I think they're possible. Just as possible as when Kennedy said in 1961, that by the end of the decade we'd put a man on the Moon. For me to take on the entire disability community would be impossible. No one individual can do it. But, I am certainly putting my efforts behind what I believe in and that's the most truthful thing I can do.

FF: You alluded to the fact that some people with disabilities are happy to remain as they are—living perfectly productive lives. Others feel what they see is a pity approach of fundraising that can fuel negative stereotypes about disabilities. How do we go about promoting research without devaluing people with disabilities?



CR: I'm not sure. There is a problem that needs to be addressed and you know I think that the fight is reasonable. I look at the positive side of what can be accomplished.

FF: To able-bodied people, if you are quadriplegic and you're alive, you are automatically courageous. If you can talk, you are an inspiration and if you actually do something, anything, you're a saint. Are you ever tired of those labels?

CR: Well, I sometimes joke with my assistants and the nurses about getting a T-shirt that says, "I'm not your inspiration—get a life." But, I don't really mean that. It's hard sometimes, with the way people gush. They mean well, and the main thing is that if I can do positive things that are helpful to others, then I'm not concerned with what they call me.

FF: I've been involved with the Democratic Party and I was impressed by your speech at the Democratic Convention. Do you think that down the road you might even consider running for office?

CR: Well, I've been asked that many times in the past. But no, I don't think so. I think that the difficulty of raising money and having to deal with special interests groups and having to make too many compromises would really bother me, I'd rather be an advocate for something I really believe in than finesse the issues in

order to stay in office. No, I think right now, most politicians have a hard time being true to themselves and true to their beliefs because they are fighting for their survival, and I wouldn't want to be in that position.

FF: There are far too many of our brothers and sisters with disabilities who are stuck in nursing homes simply for a lack of help with the activities of daily living. There is a piece of legislation that would enable people with disabilities to get the personal assistance services that they need to live independently in their own community. I was wondering if you are family with this bill or support it?

CR: No, I hadn't heard of that particular piece of legislation. I believe that if we can hasten the pace of research up with interventions, therapies and cures then it will get people up and out of difficult situations. This way, we won't go broke just maintaining them on Medicare or parking them in nursing homes, where they receive minimal care. I take the long view, which is that these are problems that can be solved if the money flows. That is why I am trying to double the budget of the NIH [National Institutes of Health]. We should send a very strong message to Congress to help them realize that as America gets older that we are going to have more and more people with disabilities and we need to fix them, not just park them someplace.

FF: I know other people who have had disastrous expe-

riences with the medical system and managed care. With your experience, what thought do you have about American health care policy?

CR: First of all, insurance caps should be raised. Insurance companies should be forced to pay out the benefits that the patient is entitled to. The problem is when you have the patient request something, the insurance company immediately denies and the reason they do that is only 30 percent of patients fight back. All of this while there are certain CEOs of insurance companies taking home \$300 million a year in personal income. That is outrageous. We need to make insurance companies provide the benefits they are supposed to, and we shouldn't have to fight for necessities, whether it's a back-up ventilator or a shower chair or physical therapy. For example, I'm not allowed to have physical therapist do anything below the level of my shoulders because they say it is irrelevant.

FF: Perhaps the most controversial issue in the past few years in the disability community has been the work of Dr. Kevorkian. Where do you stand on issues of euthanasia?

CR: I think it is a matter of individual choice. I think people should have the freedom to make their own decisions. Personally speaking, if I were at a certain level—let's say my brain stem would have been injured and I couldn't move my face, swallow or talk—I would say that is below the line of acceptability. I think if somebody, after a great deal of thought and having exhausted all other options, wants to make that decision then they should have the freedom to do so. For all of us it is our life, and each of us has a different threshold as to what they can stand. I don't think there is any benefit to keep people alive who are in horrible pain or suffering or a vegetative state. So, in theory, I am not opposed to it.

FF: I think what concerns most people with disabilities is, who makes the decision. I think you would agree that it is up to the individual. If doctors are deciding it for people, that is extremely distributing.

CR: Right. It has got to be the patient.

FF: Frequently, people who do make that choice haven't had peer counseling or other support. It is important that people really get a chance to look at the options.

CR: Absolutely, and that is why I say that it would only be an absolute last resort.

FF: I was so moved by your interview a couple years ago when you told us about when you saw your wife for the first time after the accident. You said, "Maybe this isn't worth it, and I should just check out," and she was crying and said, "But you're still you and I love you." That just changed my life it was so beautiful.

CR: Yeah, that's what happened and that's actually the title of my book, *Still Me*, which comes from what she said to me.

FF: I think a lot of people right after the injury feel like they are half a person.

CR: Yeah, it's hard to see after the injury. If you are lucky, before long, you find there are good reasons to carry on. And I think now we are out of the dark ages, in terms of the research. As little as five or seven years ago, people would have thought a cure for spinal cord injuries were impossible. In the mid-1980s, a cure for AIDS was thought impossible, because it takes time, commitment and money and grass roots effort to support it. There is virtually no problem that we can't overcome. So, here we are, talking about regeneration trials in human beings, possibly by the end of 1998. That's incredible. You don't want to throw in the towel, because there's always something amazing just over the horizon.

Who knows why an accident happens? The key is what do you do afterwards. There is a period of shock and then grieving with confusion and loss. After that, you have two choices. One is to stare out the window and gradually disintegrate. And the other is to mobilize and use all your resources, whatever they may be, to do something positive. That is the road I have taken. It comes naturally to me. I am a competitive person and right now I am competing against decay. I don't want osteoporosis or muscle atrophy or depression to beat me.

CC: What is the concept of your new book?

CR: Well, it's more than just an autobiography. It's the outline of my life story, but it also gets into politics of medicine, into research, and into insurance and various other issues.

CC: What prompted you to write it now?

CR: Back in late 1995, I was approached by a number of publishers and, at first, I resisted because I didn't know what I would write about. In 1996, it became clear that a book could be helpful. I also need to make a living. I didn't know what my future would be. You know my career as an actor is over. There was a time where I didn't know if I'd be able to make the transition to directing. Writing a book was the first concrete job that I was offered, and I thought it would be a way to raise awareness. I don't pull any punches in the book. I let people know what it's like to live with a spinal cord injury. I think it's something that most people know very little about.

CC: Will there be surprises in the book?

CR: I think it will be very informative. I think most people think you just end up sitting in a chair. They don't understand all the physical issues of bowel, bladder and



sexual function, skin breakdowns, osteoporosis, muscle atrophy, circulation problems and everything that can come up that I fight every day.

CC: Are you producing or directing at this time?

CR: My recent TV special I produced with Don Misher, who is really the premier producer of events in Hollywood. He did the Oscars, the Kennedy Center Honors, the Emmys and he ended up deferring a lot to me because me didn't know much about spinal cord injuries. I helped him design the program. ABC wanted it to be about me and I said no, use my name but let's tell a story of ordinary people, and that's why we did the profile on Travis Roy and the story of the couple who got married and they are both in chairs. So, one is a very sad story of a man who at 18 had an injury, and the more uplifting story about this couple. I also wanted to have performers who had disabilities, like a comedian with cerebral palsy. I wanted to put him out there on primetime where people would feel uncomfortable and then just relax because he's so funny. I was very happy that we were able to get that on the air.

CC: Do you have any other projects that you're currently producing?

CR: No—not so much producing but directing. There are a couple of things that I am considering for the fall. They are movies... dramas.

CC: How do you travel now? I know you used to have a pilot's license.

CR: I had a license for 20 years. We travel on private planes now. The issue with the airplanes is the room it takes for the oxygen tanks, because sometimes I need to be on oxygen when I'm traveling. The other problem is the seating. Even in first class, they don't recline. For example, I couldn't sit doubled over like I sometimes need to do. I have very sensitive skin and I've fought off one infection and I'm fighting off another now. The airline would actually compromise my condition. I've been fortunate so far in being able to take advantage of companies donating flights. There is always some nice CEO that will donate a flight, so I can go speak at the rehab center or whatever or to Jacksonville to the chapter on MC. So far, we haven't been able to go commercial, but someday I hope to do that. But, I think it will be after I get off the ventilator.

CC: You used to work with a lot of environmental causes, is that still the case?

CR: Well, a lot of my political activity before the accident revolved largely around environmental issues and campaign finance reform, the National Endowment for the Arts and a group I was involved with for many years, the Creative Coalition. We fought to get recycling started in New York. We worked to stop a huge coal burning power plant from being built near

Albany. We worked to protect New York's water. We managed to get the state to spend a billion dollars to buy land to protect the reservoirs. I worked on that issue for more than a year and a half with Robert Kennedy and John Cronin.

Those used to be the issues I was working on. Since the time of the injury, I have shifted my emphasis on issues of the disabled on a number of fronts. For example, I am working with Senator Rockefeller in trying to pass legislation that would raise the cap on insurance policies from one million dollars to ten million, because if you have a catastrophic situation, you can go through a million dollars in a few years. I am also working on trying to double the budget of the National Institutes of Health, so that the pace of research can pick up. Now, only 22 percent of grants applied are funded and that's not enough. If they had more money, they could fund more research. We are on the cusp of some real breakthroughs. Consider what's happened in AIDS research in the last 10 years. In 1984, the government spent no money on AIDS, now they spend \$1.3 billion. As a result, the progress has been absolutely extraordinary. Per person, the NIH spends \$1,100 per year on AIDS research, but they only spend \$30 for research on Parkinson's, but a cure for Parkinson's, doctors say, could be accomplished with adequate funding. This would all carry over to spinal cord issues, as well. WE really need the NIH to lead the way. So, we're working on that, and also on legislation that would require every insurance company to take one-penny of health premiums and give it to the NIH. That would raise \$24 billion a year. The insurance companies think this is an unfair tax and they are not willing to let go of that one penny, and they say they'd have to pass the costs along to the consumer.

CC: Has anyone come up with a formula that would show how much they'd save by reducing the amount they spend on these health situations?

CR: Yes. But, only look at the short-term profits. We've told them that if they spend more on research, then they'll have to pay out less in benefits. It's been very, very difficult.

CC: How are things progressing at the Reeve-Irvine Center at the University of California Irvine?

CR: In my opinion, things have gone way too slowly. They should have named a direction and been up and running by now. I am disappointed in the amount of time it is taking. We asked the Dean of the Medical School to find the right person and get him or her in the building, but that hasn't happened. This has been going on for almost three years now. I am frustrated by it.

FF: Beyond all this work you have told us about, how

do you find time to have fun, and what do you most enjoy doing?

CR: Well, I get a great deal of pleasure out watching my younger son, Will, who is five, do his various activities from hockey to soccer to learning to ride his bike without training wheels. He has a great emotional effect on me. He is a source of pride and joy as well as amusement. Spending time with him is almost always an uplifting experience.

My wife and I go to the city to go to the theater, we go to our country place in Massachusetts. I don't have the fun of competing with my horse or sailing, but we find other ways. As you know, this whole thing is about adaptability and finding pleasure in ways that you might not have thought possible before.

Recently, I went sailing in Rhode Island. It was actually blowing 35 [knots]. It was the tail end of hurricane Bertha. I went out in one of the 12 meters, and old one from the 1930s. We went out and raced and had a good time. But, I have to say that just to be out on the water and to be in a boat is so frustrating for me. I've been a sailor all my life, and to not run the boat and be the captain—to just be there sitting strapped in—is actually more depressing than uplifting. Maybe someday that will change, but I've found it difficult emotionally, 'cause I've never been cargo or baggage before. Since my earliest days on the Jersey shore, I was on the match racing team for my yachting club. You know, I've sailed in all kinds of boats. They have been a huge part of my life. At night I dream about sailing.

CC: Really. What are you like in your dreams?

CR: In three years, I've never had a dream where I'm in a wheelchair. In the mornings, when I wake up, it always takes a while to adjust, and then I remember I can't move my arms or I can't move my legs. It sometimes takes five or ten minutes to come back to reality. In my dreams, I do all the things I used to do. I'll be sailing or riding or traveling or acting on stage. My mind is hanging on to the memories of when I was upright.

It's left me in a position to where I hold on to a realistic hope, not just based on optimism, but on hard data from scientists. They have been upfront and honest about what is coming, and what is possible. Now that regeneration is possible, and the antibody to the protein has been discovered, it just needs to be humanized. I do regard this realistically as a temporary situation, and that is reaffirmed in my mind and in my dreams.

I am a competitive person and right now, I am competing against decay. ■

Introduction by Bruce Barton
Story by Mark Gray





ABILITY had a chance to speak with Christopher Reeve on the set of the TV show *The Practice*.

*Chet Cooper: Over the past few years, you have been progressively making the transition to disability advocate. How does participating in an episode of *The Practice* correlate with your goals?*

Christopher Reeve: My overall aim as a disability advocate is to reach out in various ways whether that means promoting legislation in Washington, working with the media or conducting interviews to reach a wider audience. Within the framework of a TV drama, which of course has to have twists and turns in the plot, you can subtly introduce these issues.

*CC: What prompted you to choose *The Practice*?*

CR: I thought that it was the most logical show because it's very contained; it mostly takes place in the courtroom, the witness room and the judge's chambers. The audience is forced to focus on the words. I've also been following the show for a while and I think they do good job. I wrote a story treatment and gave it to David Kelley and he called and said he liked it very much.

CC: Will you be credited as a co-writer of the episode?

CR: No, I collaborated with David Kelley on writing the story. Then he wrote the teleplay based on the story that the two of us came up with.

CC: Briefly describe the story line of this episode and the role you will be playing as an actor.

CR: In this episode, I have a very wealthy older brother whose 16 year-old son, Justin, was in the car with me practicing for his driver's test. We got into an accident and he was killed and I became a quadriplegic. My brother, Derek, has never forgiven me for that—he thinks it is my responsibility and my fault. After being estranged for a year Derek has been killed and my wife is on trial and that's where the episode begins. My wife admits that she killed him but is pleading temporary insanity due to "caregiver burnout;" she's been depressed, she's been having blackouts, completely blanking out on what happened during an entire day. There is a record of phone calls, emails and meetings where she had begged Derek for money and he refused to help. The issue is whether the jury is going to recognize caregiver burnout as a legitimate medical condition, something that would warrant a release on temporary insanity. I am trying my hardest to support her in this.

CC: What exactly is caregiver burnout and how are you addressing the issue?

PractiCo

CR: In this episode, my wife, played by Carolyn McCormick, is handling my case by herself. That means dressing, feeding, cleaning up...it takes over her life. People who are put in that position often end up feeling very depressed and hopeless. Worst case scenario: Caregiver burnout usually happens when people living with disabilities reach the limit on the lifetime cap of their health insurance policy—which is usually a million dollars. While it sounds like a lot, if you have a severe disability you can run through that amount in only a few years. After that you may have to sell your house or borrow from relatives...anything to raise enough money. Ultimately it comes back to the relatives or the caregivers and that can become a tremendous strain on them.

I'm trying to demonstrate to insurance companies that it would actually be profitable to provide proactive care, therapy and service for people with disabilities.

CC: How do you convince the insurance companies there's a benefit?

CR: If the insurance companies can pay for a treadmill, for example, to be installed in private homes it's not a large investment and there are many benefits. People who have control of their upper body often walk again in a couple of months. Virtually all of them are able to walk on their own—using a cane. They're not cured, but they are rehabilitated. They're out of their wheelchairs.

I've had the opportunity to exercise since October 1995. The benefit is my muscles have not atrophied. Pulmonary condition and osteoporosis are huge issues which cost insurance companies a lot of money when patients need treatment or hospitalization. I haven't—knock on wood—needed to be hospitalized in more than five years.

CC: When we last met you had a pretty serious decubitus.

CR: I'm doing much better. In fact, I was able to withstand a 13 hour flight from Los Angeles to Sydney. I don't need to be turned at night and I can sit up in the chair for longer...all that is important.

CC: Your recovery has actually made unprecedented progress in some areas.

CR: In September 2000 when I found I was able to

move my index finger on my left hand they began a study conducted by Dr. John McDonald of Washington University in St. Louis. Results from the study were made public last September both in the *Journal of Neurosurgery* and in the *Proceedings of the Academy of Science*. It showed that I have been reclassified from ASIA A all the way down to ASIA C and that I have some sensation now on approximately 70% of my body.

In regards to the functional recovery of my legs and arms...most of the movement I can do can't be done in a chair...because of gravity. By lying in bed or floating in a pool you take the gravity away and gain quite a lot of movement back. I've been fortunate to have the best possible care but this care and the equipment should be made affordable to everyone. For example, an FES Exercise Bicycle right now costs about \$15,000.00 retail. I know a manufacturer who says they can be made for \$1,500.00. It is just going to be a combination of small companies who are willing to manufacture equipment for a lower price...but they will only be able to do it if they get the support of healthcare plans, insurance companies and rehab centers. I really think that if the whole community works together and doesn't look at each other as adversaries, we could absolutely revolutionize rehabilitation.

CC: How has the Christopher Reeve Paralysis Foundation changed over the past few years and what significant achievements has it experienced?

CR: The foundation originated as the American Paralysis Association by Henry Stifel of Springfield, New Jersey. Mr. Stifel founded it in 1982 after his son, at the age of 17, was in a car accident which resulted in a spinal cord injury. The foundation had a few people working and was able to raise a modest amount of money. It grew over the years and in its course developed relationships with the best scientists in the world.

I came on board in 1996 and the name was changed to The Christopher Reeve Paralysis Foundation in 1999. Since that time we have quadrupled the money raised for our research and quality of life programs. And now there is also the Christopher and Dana Reeve Paralysis Resource Center — just down the road from our main office in Springfield. It's funded through a cooperative agreement with the Centers for Disease Control and Prevention. The first of its kind, the Paralysis Resource Center is a clearing house of information for people



who are newly injured or people who have been living with paralysis for more than a couple of years. There they can find referrals to whatever they need.

CC: Even before the merger though, you were already branching into quality of life issues.

CR: I was. In 1997 I became the Vice Chairman of the National Organization of Disability, which fights for accessibility, job opportunities and recognition of the rights of people with disabilities. I wear two hats as they are both equally important.

CC: A few years back, you and I talked about the manner in which people were automatically elevating you to a spokesperson for disability. At that time you were going through a transition in your life, and probably a little more focused on finding a cure than advocating for quality of life issues. How would you say things have changed?

CR: Right...I think perhaps it is understandable when you are newly injured that you think life's not worth living. Once you get past that phase—hopefully with the help of family, friends and professionals—then you move on to asking, “What kind of a life can I build?”

Then you become quite interested in the state of research: Is there something out there? Is there a chance to get out of this situation? I've generally found depending on how long people have been injured, their state of mind there differs. Some people don't even want to hear about a cure, don't even want to think about it. Some people even say, “Well if you invent a cure are you suggesting there is something wrong with having this disability?” And I say, “Well, if there was a cure available tomorrow, which would enable me, or anybody else to get up and walk again my vote would be, ‘Yes please.’” If someone else were to vote, “No, I like myself the way I am,” it's a free country but I think that it is about choices. We should not conceal the possibility of being able to change the situation and to be able to recover function. I can't see why that is unreasonable. What if we had never bothered to try to cure tuberculosis, polio, smallpox, the flu... what if we were still using the surgical techniques from the 19th century? What if we were not able to do heart transplants...it doesn't make any sense.

CC: You obviously feel strongly about this now.

CR: When you put yourself in a position of leadership or advocacy, when you take a point of view then you



Chris and Chet on the set of *The Practice*

have to be able to be strong. You have to say, “This is our goal, this is what we are trying to do...we want scientists to conduct practical research that will lead to human trials that will lead to therapy.” You can’t do that half-heartedly so yes, I am very aggressive about it, particularly because money is tight. We want to get the most out of every research dollar that we can. And yes, we are at the point now where we are pushing the scientists. We want them to go faster, we want them to feel a sense of urgency, we want them to think about the millions of people and consider that they themselves, or their loved ones, could suddenly suffer a debilitating injury or come down with an incurable disease. Would that make them feel any differently?

CC: Do you find the same works within the realm of politics?

CR: I’ve found working politically that the officials who get it are those that have a personal or emotional connection to the issue. For example: Nancy Reagan. Now that her husband doesn’t even recognize her, now that it hurts, she’s speaking out. My question is, “Why couldn’t she have spoken out before?” I think back to the question of whether or not the Federal government would fund AIDS research and remember President

Reagan was against it. In fact, he implied that AIDS was God’s revenge against people who lived certain lifestyles. Today women and children, thousands and hundreds of thousands of people are dying not only here but world-wide. Now the federal budget for AIDS research is 1.8 billion —in the early 1980s, it was zero. Why did it take so long? Because the climate has been changed. And the people have demanded it and I think we can learn a lesson from that. I do believe that people have the power.

CC: Do you foresee the same wave of acceptance happening for stem cell research as eventually happened with funding for AIDS and HIV research?

I feel particularly because stem cells hold such promise to cure so many diseases that there is a basis for a new grass-roots movement. I also think the federal government is going to remain deadlocked because of social and religious conservatives. What we are doing now is moving on to the state initiatives to pass the legislation that should be passed by the federal government. California was the first to pass the bill last September which allows scientists there to conduct research on stem cells derived from any source. Similar initiatives are also under way in New Jersey, New York, Massachusetts, Ohio and Wisconsin. I feel that because it’s the right thing to do, because there is very strong popular support, because it is a major opportunity for the research community as well as the pharmaceutical industry, I think that legislation will pass that the federal government won’t be able to overturn. Scientists in England are allowed to do all kinds of stem cell research and they are funded by the government to the tune of 40 million pounds which is about \$75 million. Other countries such as Israel, Sweden, Finland, Switzerland, China and Singapore are also doing cutting edge stem cell research.

CC: Are you able to work with them at all?

CR: Yes actually. I am in touch with a scientist that used to be at the University of California San Francisco, Roger Pederson. He left a few years ago because of the restrictions in the United States and is now heading the stem cell team over at Cambridge in the UK.

CC: I saw a documentary about your recovery.

CR: It’s called “Courageous Steps” and was made by my son Matthew.

CC: Any other projects you have been working on?

CR: I’m trying to do three things at once. I’ve enjoyed my path as an actor—but I’m also trying to get the message out for our foundation and specifically for people living with disabilities. ■





Chris and Dana

CHRISTOPHER REEVE

Tribute to a Real Life Action Hero

Please, let's forget about calling him Superman just this once.

More appropriate labels would be pioneer, warrior, father and husband. But the actor-turned-activist, who died from heart failure October 10 at the age of 52, will forever be remembered as the man who portrayed the title role in the 1978 film *Superman* and its three sequels. Leaping tall buildings in a single bound made him famous. Fighting for research to find a cure for paralysis made him legendary.

"SO MANY OF OUR DREAMS AT FIRST SEEM IMPOSSIBLE, THEN THEY SEEM IMPROBABLE, AND THEN, WHEN WE SUMMON THE WILL, THEY SOON BECOME INEVITABLE."

Born September 25, 1952, in New York City to Barbara Johnson and Franklin Reeve, young Christopher was immediately thrust into a life surrounded by larger-than-life figures. His father, a novelist, poet and professor, often hosted fellow writers like Robert Frost at their home. After his parents divorced when Reeve was four, he fell in love with a different kind of storytelling. He landed parts in school plays, and acting became his top priority as a young teen. He worked during the summer at the Williamstown Theater Festival in Massachusetts when he was 15. His time and success on the stage demanded that he hire an agent the following year.

Reeve attended Cornell University and majored in music theory and English, but he continued acting professionally. Work took him to Britain, to France and all across the United States. But he returned back home just before his senior year at Cornell, when he, along with Robin Williams, was selected to attend the Juilliard School of Performing Arts in New York. They were the only applicants selected that year for advanced placement at Juilliard, and they went on to become roommates and close friends.

His work spilled over onto the silver screen with appearances on a television series and soap operas. In 1976, he earned a role in the Broadway play *A Matter of Gravity*, starring Katharine Hepburn. This chance of a lifetime cost him another chance of a lifetime—his time

constraints with the play forced him to drop out of Juilliard. But the experience of working with Hepburn was something Reeve later said was well worth passing on graduation from the prestigious school.

"DON'T GIVE UP. DON'T LOSE HOPE. DON'T SELL OUT."

Two years after starring beside Hepburn, Reeve broke through as his own star when he was cast in the role that, for many, defined his career. He turned a comic-book drawing that had a cult-like following into a life-like character in *Superman*. His six-foot-four muscular frame was perfect for the role of the tough yet loving action hero who disguised himself as reporter Clark Kent when not fighting evil. During the filming of the movie, he met Gae Exton. The couple later had two children, Matthew and Alexandra.

In addition to the three *Superman* sequels, Reeve was seen in romantic films like *Somewhere in Time*, *Speechless*, *Deathtrap*, *The Bostonians*, *Street Smart*, *Noises Off*, *Above Suspicion* and *The Remains of the Day*. But he never left the stage, continuing to work in plays between his movie obligations. Those roles included *The Marriage of Figaro*, *Fifth of July*, *My Life*, *Summer and Smoke*, *Love Letters* and *The Aspern Papers*.

Away from Hollywood, Reeve split with Exton and shared custody of their two children. He then met and married Dana Morosini in 1992, and the two had a son, Will.

Reeve continued to seek parts beyond the mold of the comic-book character, but nothing brought him out of the blue tights of Superman. He became synonymous with the action hero no matter how hard he worked to drop the cape. He had brought the character to life, performing his own stunts to make man's never-ending fantasy of flying through the air under his own power seem possible. The suit fit him perfectly. The S on his chest might as well have been engraved.

"YOU PLAY THE HAND YOU'RE DEALT. I THINK THE GAME'S WORTHWHILE."

Reeve was passionate about outdoor sports. He flew

planes and gliders, sailed, skied and enjoyed scuba diving. But horses sparked the fire of his competitive nature as he entered his early 40s. He rode them in competition and did well, as he did in everything else.

Eastern Express was the horse Reeve was riding during an equestrian jumping competition in Culpeper, Virginia, on May 27, 1995. Approaching a three-foot-tall, man-made jump, Eastern Express stopped and bucked, propelling Reeve forward. His hands caught in the bridle, his head hit the ground first, and the force of the fall fractured his neck at the second cervical vertebra. The man known to many for fighting fictitious evil villains immediately entered a battle with quadriplegia. The man who put a face on a comic-book character now put a face on spinal cord injury.

Approximately 250,000 Americans, 82 percent of whom are male, currently live with spinal cord injuries. When the nerve cells of the spinal cord are damaged, they can't divide and multiply to repair themselves. The injury prevents communication between the brain above and the body below, leaving the functioning of limbs severely limited or nonexistent. Because scientists can't reconstruct the delicate web, the loss of function becomes permanent.

Reeve didn't quit, though.

"EITHER YOU DECIDE TO STAY IN THE SHALLOW END OF THE POOL OR YOU GO OUT IN THE OCEAN."

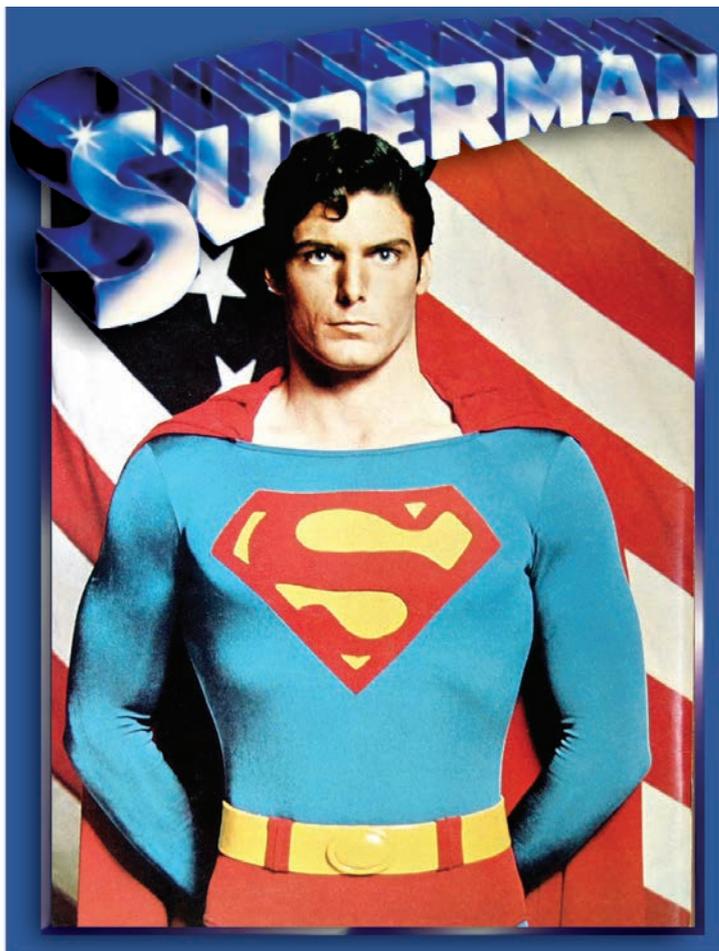
Reeve's actions revolutionized the way the world views people living with spinal cord injuries. From his motorized wheelchair, which he controlled by breathing into a straw, Reeve stood up for those who couldn't. His wife,

meanwhile, stood right by him. Dana cared for her husband after his six-month hospital stay and arranged their New York home to accommodate their new lifestyle. She also assisted in his newfound mission—to fight for an answer to spinal cord injuries. He and Dana started the Christopher Reeve Foundation, and the organization merged with the American Paralysis Association in 1999 to form the Christopher Reeve Paralysis Foundation. The foundation focuses on funding research for the development of new treatments and cures for paralysis.

It also provides a platform to improve the lives of people with a range of disabilities, such as Parkinson's disease, Alzheimer's disease, multiple sclerosis, amyotrophic lateral sclerosis, strokes and spinal cord injuries. Reeve helped establish the Reeve-Irvine Research Center at the University of California-Irvine College of Medicine, which supports study of trauma to the spinal cord and diseases affecting it. The foundation has also given 617 Quality of Life grants, totaling 5.6 million dollars, to nonprofit organizations providing services that directly improve the daily lives of people with disabilities. *ABILITY Magazine's* sister program, the nonprofit *ABILITY Awareness*, was fortunate to receive a Quality of Life grant to help support its hallmark program, the *ABILITY House*.

As the years passed by, Reeve's condition didn't diminish his drive to be on the stage. Demonstrating that people with severe disabilities are still employable, he starred in a television remake of Alfred Hitchcock's *Rear Window*, an episode of the TV drama *The Practice*, and other projects. He also welcomed chances to direct and produce, with award-winning success. His final project, A&E's *The Brook Ellison Story*, was based on the memoirs of an accomplished woman with spinal cord injury and aired shortly after his death.

Reeve traveled coast-to-coast for interviews, public appearances and speaking engagements. He appeared



The following leaders have shared their thoughts on the passing of Christopher Reeve with ABILITY Magazine:

“Mr. Reeve was an example of personal courage, optimism and self determination. He was brave in the face of adversity and was greatly admired by millions of Americans. He will be remembered as an accomplished actor and for his dedicated advocacy for those with physical disabilities....”

—President George W. Bush

“Christopher Reeve was introduced to many of us through one of his first major roles—Superman....The fact that Christopher also devoted so much of his time, energy and passion to spinal cord injury research and to improving the lives of others with his condition shows very clearly the great inner strength he possessed. He was a leader and an American treasure, and his passing leaves a void in the hearts of everyone who knew him, and many whom he never met.”

—California Governor Arnold Schwarzenegger

“We all got to know [Christopher Reeve] through his heroic acts on the big screen, but we came to admire him because of the heroism he showed in real life. In the

face of personal tragedy, he found the hope, determination and will to live....Christopher Reeve will remain an inspiration for spinal cord patients, a motivation for doctors and scientists and a hero to us all.”

—Senator Hillary Clinton

“Today, we lost a man who was truly America's hero—Christopher Reeve....He was an inspiration to all of us and gave hope to millions of Americans who are counting on the life-saving cures that science and research can provide. He met every challenge with a courage and character that broke new ground in this struggle.... Because he had the strength to carry this cause, I know one day that we will realize that inevitable dream.”

—Senator John Kerry

“Since his accident, Christopher dedicated his life to medical research, particularly embryonic stem cell research, which scientists think could lead to cures for spinal cord injuries, Parkinson's, juvenile diabetes and many other conditions....Christopher's legacy as a leader and fighter for stem cell research and disability rights will live on and continue to inspire us to keep up the fight.”

—Senator Tom Harkin

In the last week of this year's legislative session, the Research Review Act, already ratified by the House of Representatives, passed unanimously in the U.S. Senate. The first-ever piece of legislation approved in the U.S. that directly addresses spinal cord injury and paralysis research, the act promotes greater collaboration within the scientific community. It incorporates many of the main provisions of the broader Christopher Reeve Paralysis Act, which did not reach the floor of the Senate this year but is expected to be reviewed again in the next legislative session.

The act was introduced with bipartisan support by congressional sponsors Michael Bilirakis (R-FL) and Sherrod Brown (D-OH). The Christopher Reeve Paralysis Foundation (CRPF) worked closely with the National Institutes of Health (NIH), the Crohn's and Colitis Foundation and the congressional sponsors in helping to craft the legislation.

The Research Review Act calls on NIH to prepare a report, to be released by early next year, delineating the agency's specific steps to promote multidisciplinary research teams to advance treatments, develop new therapies and collaborate on clinical trials concerning spinal cord injury and paralysis research. It operationalizes the key goals of NIH and the scientific community to encourage collaboration and limit research redundancy. Disability advocates have lauded the act's passage.

CRPF's senior vice president Michael Manganiello expressed disappointment that Reeve did not live to see the legislation enacted: “Christopher Reeve was extremely proud of the Research Review Act and understood the importance of shining a bright congressional light on the work being funded by the NIH and his foundation.”

In speaking of CRPF's goals for the future, Manganiello continued, “Christopher's loss was a shock to all of us, but he was such a big presence that we all feel him around us, which is very comforting and makes us aware of his enormous legacy. He did so much in the past ten years, but there was much more that he still wanted to address—not only research, but quality of life, rights of the disabled, caregiver support. There are so many things that we need to keep doing, both on a federal and a private level.”

Manganiello concluded with an expression of thanks to the public and the disability community for their hard work over the past three years in letter-writing and visits to their senators and representatives, and he asked that they also thank the congressional chairs and sponsors for their efforts to enact this historic legislation.

The full Christopher Reeve Paralysis Act would expand upon the work of the Research Review Act by encouraging interventions to improve the quality of life and long-term health status of people with physical disabilities, and to more widely disseminate information and clinical findings.



In Loving Memory of Chris and Dana Reeve

The Christopher and Dana Reeve Paralysis Act (CDRPA) was first introduced in Congress in 2007 and signed by President Obama on March 20, 2009. The Act was named for the late Christopher Reeve and his wife Dana, whose courage and grace in the face of adversity, coupled with their extraordinary activism, were an inspiration to millions around the world.

The CDRPA has three components that support and enhance paralysis research, rehabilitation, and quality of life programs.

TITLE I. PARALYSIS RESEARCH

CDRPA expands research on paralysis at the National Institutes of Health (NIH) by establishing the Christopher Reeve Paralysis Consortia.

This style of research promotes collaboration – connecting scientists doing similar work in multiple fields to enrich understanding and speed discovery of better treatments and cures.

TITLE II. PARALYSIS REHABILITATION & CARE

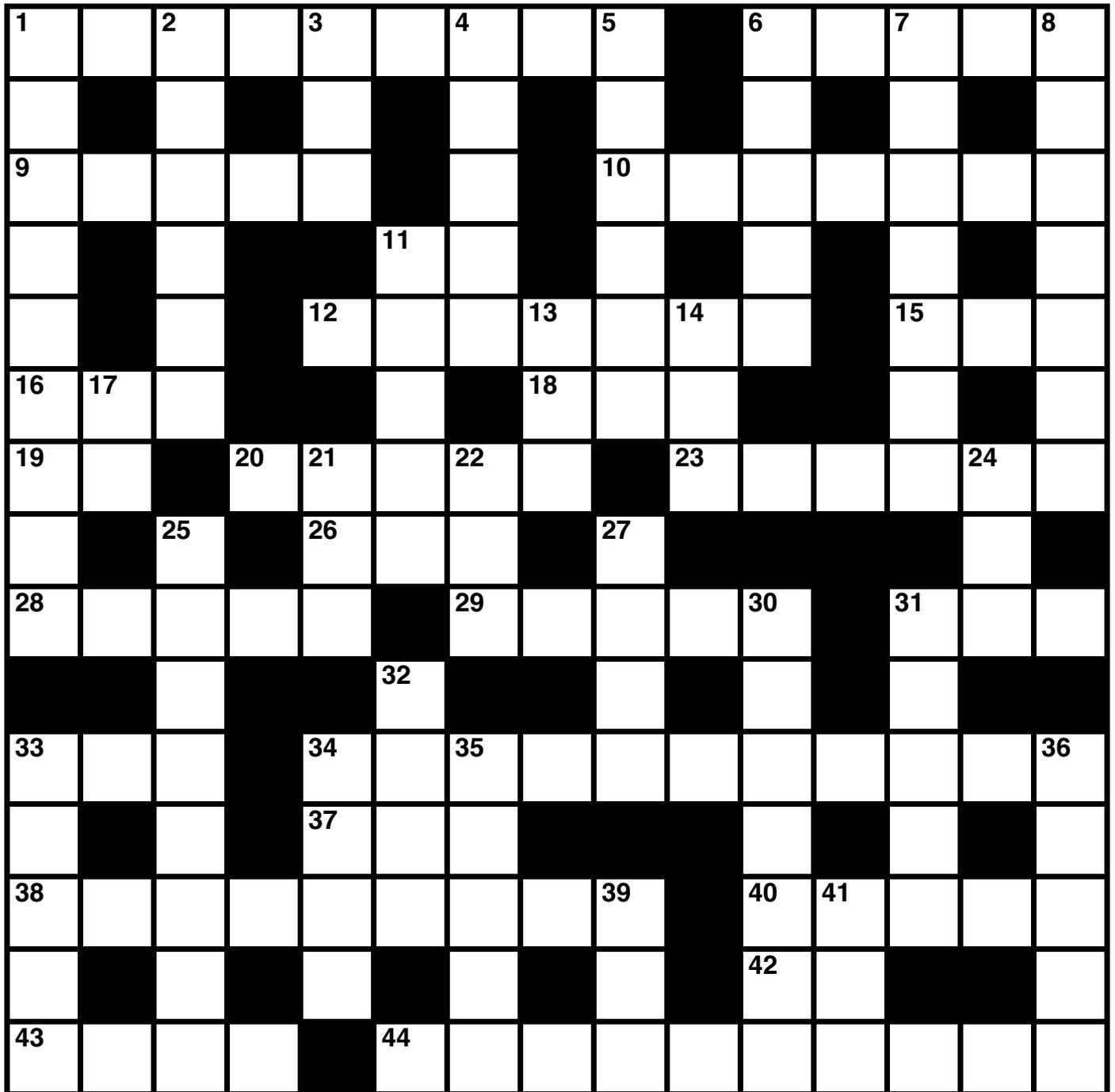
The law calls for rehabilitation research to advance daily function for people with paralysis. This includes intensive, activity-based research to measure the effectiveness of certain rehabilitative tactics that aim to improve mobility, prevent secondary complications, and develop improved assistive technology.

TITLE III. IMPROVING QUALITY OF LIFE

CDRPA will develop unique programs at the US Department of Health and Human Services to better the quality of life and long-term health status of persons with paralysis and other physical disabilities.

Programs include providing grants to nonprofit health and disability organizations to educate the public about paralysis, improve access to services, and integrate life with paralysis into society, as well as coordinate services within each state to assist persons living with paralysis. ■ **ABILITY**

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Crossword Puzzle



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ACROSS

- Letting others in
- ___ George, Diversity Advocate on SAG
- Canadian hero who ran a marathon a day for 143 days with one leg, ___ Fox
- "We have lifetime after lifetime to evolve, but what happens between the times of each incarnation?" Marsha _____
- Copper symbol
- Oscar winning film about standing up to racism starring Viola Davis, 2 words
- "___ Duke" by Stevie Wonder
- Theater duration
- Neighbor of WA
- Popular
- Bring fresh life to
- There's always light at the end of it
- Actress ___ Dawn Chong of "The Color Purple"
- Really want, with "for"
- Chinese senior paraglider who is disabled, ___ Flyer
- Nelson Mandela's org.
- Wonder
- Top level sports contest for people with disabilities
- ___ date, 2 words
- What you are capable of
- Actress who supports the Hear the World charity, Lindsay ___
- Magazine manager, for short
- Rainbow whapes
- Charity in China training runners who are blind for long distance events, 3 words

DOWN

- Staying true to one's beliefs
- Comedian with the "7 dirty words" routine, George ____
- 180° turn, slangily
- Inspire, as with ideas
- Karaoke selection
- Bourbon-and-mint drink
- Singer supporting Operation Smile, Jessica ____
- Free of artificiality
- ___ Press for People with Disabilities
- One-word question
- Ping-pong net skim
- All nations org.
- Ending for west and east
- Ending for election or auction
- Many, many years
- Like the Grand Canyon
- Devil's doing
- One who walks a lot
- He pledged a \$1 million Genesis Prize to go to refugee causes, ___ Kapoor
- Desire
- Head of the pack
- "On Golden ___" starring Katherine Hepburn and Henry Fonda
- Increase
- Musical numbers
- Zodiac sign
- Keats' composition

answers on page 64

SEE BETTER

AT ANY AGE

AUTHOR

- The Miracle of Pi in Eye
 - LASIK in the 21st Century
 - Cure for Keratoconus

VOTED BEST

- Newsweek Showcase Top Doctor
- LA Daily News Readers
 - VC Star Readers
 - Consumer Research Council

DOCTOR'S DOCTOR

- Surgeons & Physicians
 - Chiropractors & Dentists

SURGEON TO STARS

- Actors & Celebrities
 - Olympic Athletes

FOR PATIENTS

18-45

- Thin Flap Lasik
- ICL

FOR PATIENTS

45-65

- Superlasik
- Pi in Eye

FOR PATIENTS

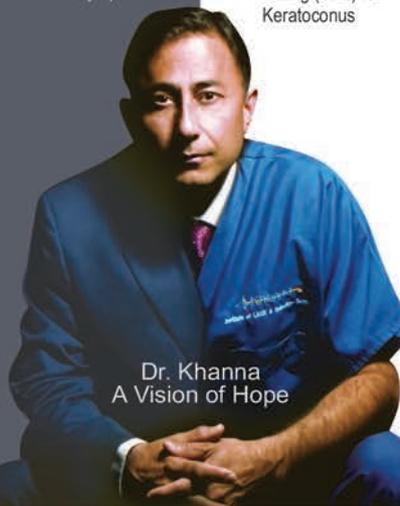
ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

OTHER THAN

LASIK

- Pterygium
- Intacs & Cross-linking (CXL) for Keratoconus



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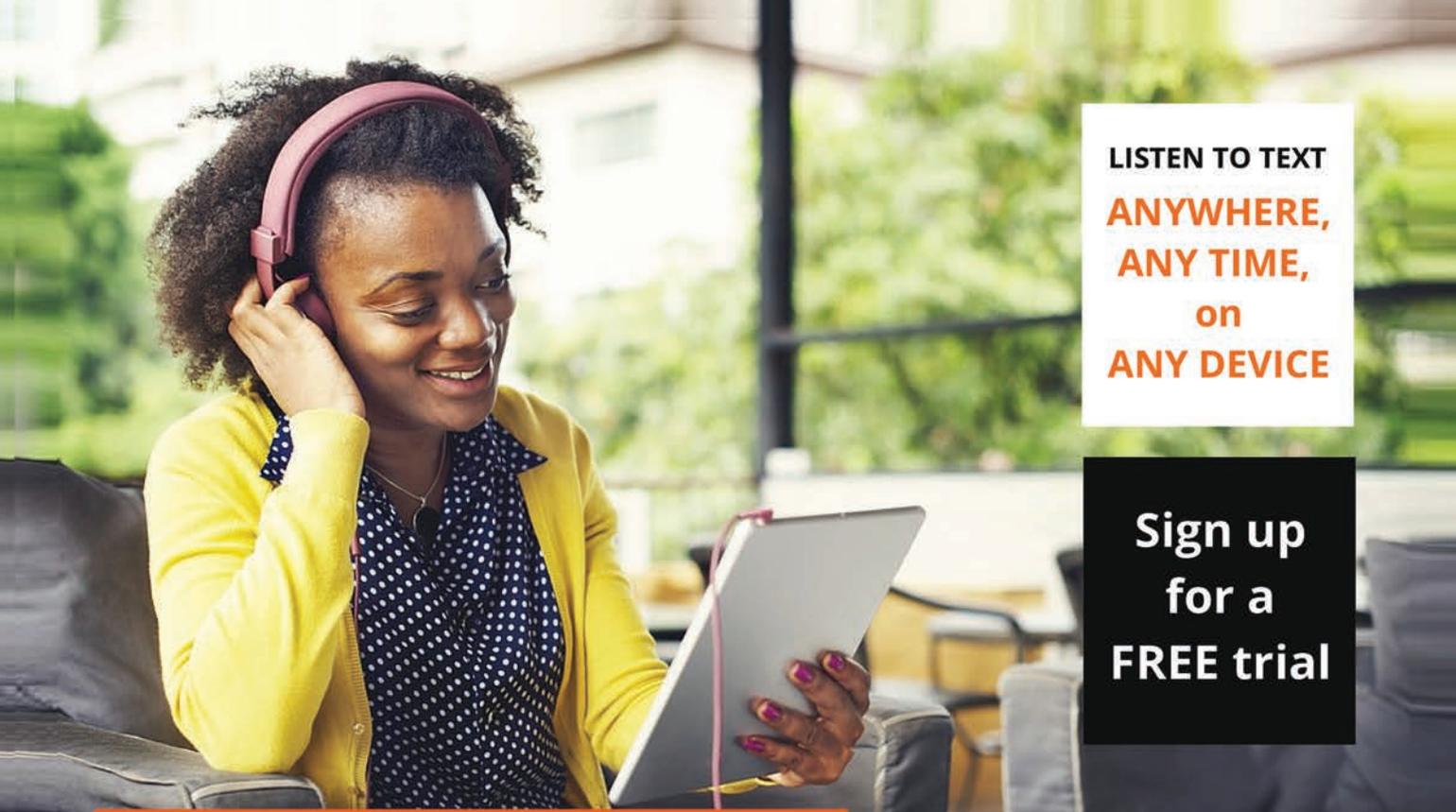


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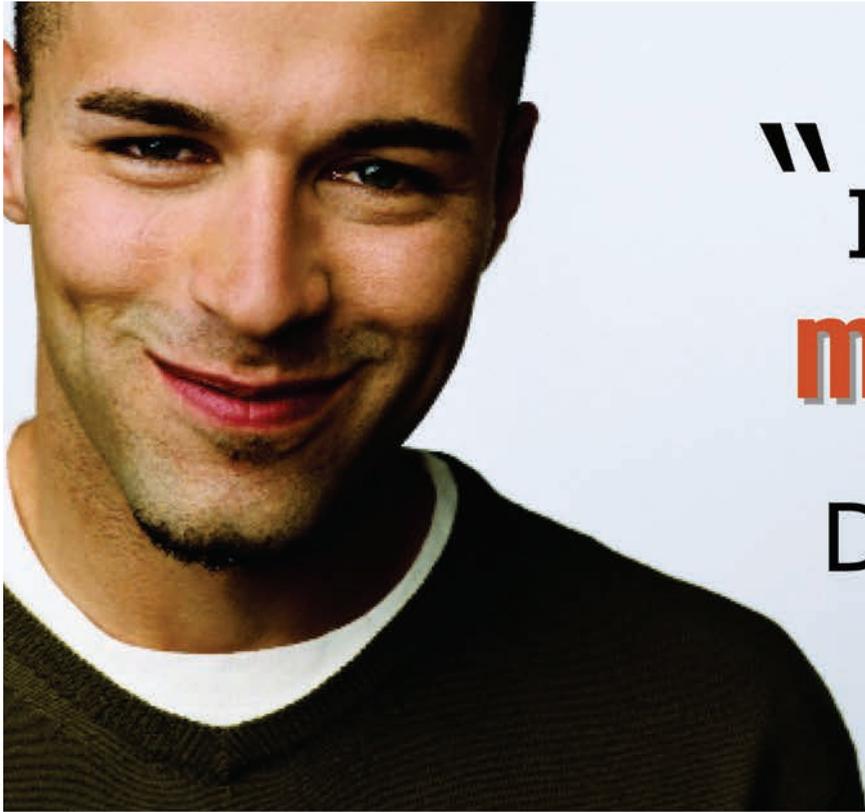


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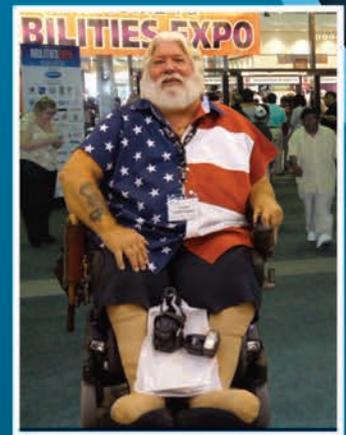


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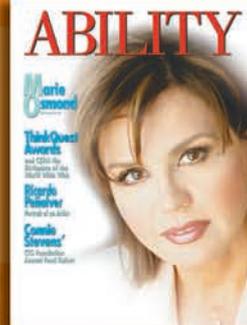
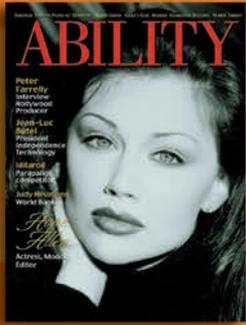


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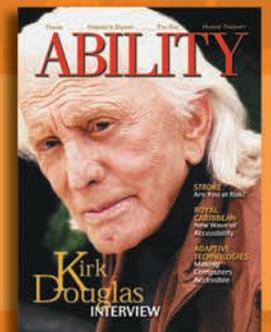
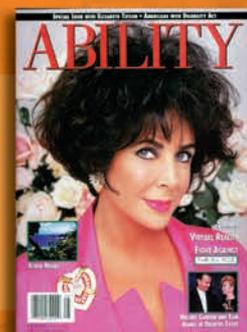
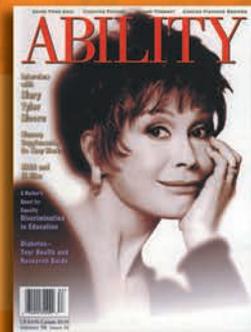
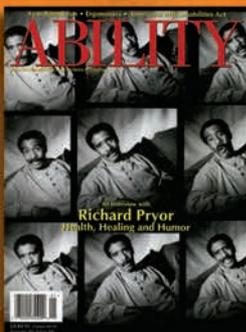
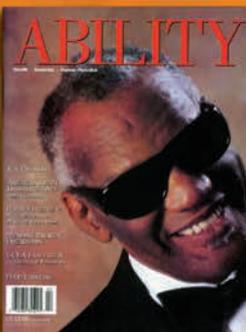
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